UNIVERSITY OF KWAZULU-NATAL

THE RELATIONSHIP BETWEEN PSYCHOSOCIAL FACTORS AND POOR
NEUROCOGNITIVE AND SOCIO-EMOTIONAL DEVELOPMENT IN CHILDREN
PERINATALLY INFECTED WITH HIV IN SOUTH AFRICA

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Submitted in fulfilment of the degree of

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Howard College

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DECLARATION

I certify that this dissertation titled "**The relationship between psychosocial factors and poor neurocognitive and socio-emotional development in children perinatally infected with HIV in South Africa**" is my own work. It is being submitted in fulfilment of the degree Doctor of Philosophy (Psychology) at the University of KwaZulu Natal. This research work has not previously been submitted for a degree nor has it been submitted as part of the requirements for a degree or examination to any other university or institution other than the University of KwaZulu-Natal.

I also certify that the dissertation is an original piece of research and it has been written by me. Any help and assistance that I have received in my research work and the preparation of the dissertation itself have been appropriately acknowledged.

In addition, I certify that all information sources and literature used have been duly acknowledged.

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Antonio G. Lentoor (Student ID- 207524466)

Date: ….th November, 2015

DEDICATION

This work is dedicated;

To my late grandmother, Katie Catherine Overmeyer, for being my pillar of strength; my parents and siblings; this is our achievement.

and;

To the children and families who battle with the effects of HIV/AIDS on a daily basis and those individuals whose aim it is to continue to fight the scourge of the pandemic.

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ABSTRACT

Background: Survival among perinatally HIV infected children has increased over the last few years in South Africa, mainly due to the availability and accessibility of combination antiretroviral therapy (cARTs). These children, however, remain a vulnerable group with respect to heightened behavioural and socio-emotional problems as well as neurocognitive deficits. The majority of HIV-positive children live in an environment of multiple deprivations; i.e. poverty, parental death or ill health, stress associated with daily living and poor stimulation in the home environment. Early childhood is known to be a sensitive period for brain development, especially in forming neural circuits underlying behaviours and higher cognitive functions. Injury or insult and environmental deprivation (impoverishment, nutritional deficits and lack of nurturance) have the potential to create vulnerability which can negatively impact on the life trajectory of the child. With this in mind, the aim of this study was to investigate the impact of key psychosocial factors, namely, socio-economic status, caregiver depression, quality of home environment and nutritional status, on the neurocognitive and socio-emotional functioning of perinatally acquired HIV-positive children living in semi-rural Eastern Cape, South Africa.

Method: A cross-sectional, convergent mixed method design using non-probability sampling was employed. Quantitative data was collected on 152 dyads of perinatally infected HIV positive children on cARTs (mean age = 63.13 months) and their caregivers. The Wechsler Preschool and Primary Scale of Intelligence-III (WPPSI-III) was administered to assess the neurocognitive functioning of the children, while the Strengths and Difficulties Questionnaire (SDQ) (caregiver report version) was administered to assess the children's socio-emotional function. Anthropometric data was obtained from the HIV-positive children through the WHO-anthro-programme to assess nutritional status. The Home Screening Stimulation Questionnaire (HSQ) was administered to assess the quality of home environment the

children were living in. The Beck Depression Inventory, 2nd edition (BDI-II) was used to assess caregiver depression among the 152 (mean age = 45 years) caregivers. Qualitative data was obtained through a series of semi-structured in-depth interviews with a sub-set of 44 caregivers of the HIV-positive children who were conveniently recruited from the quantitative sample. A series of one-way ANOVAs, independent t-tests, chi-square and correlation analyses was performed on the quantitative data. The qualitative data was analysed using interpretive phenomenological analysis.

Results: The converging quantitative and qualitative results in this doctoral study provides evidence that various psychosocial factors differentially impact neurocognitive and socio-emotional development of perinatally HIV-infected children. Older HIV-positive boys who lived in suboptimal, poor quality homes and who demonstrated stunting, wasting and /or were underweight (indicators of nutritional status) were worse off neurocognitively when compared to younger boys and girls infected with HIV from similar environmental deprivation context. Socio-emotional adjustment was also generally poor, with caregiver depression strongly associated with poor socio-emotional functioning among HIV-positive children. This relationship existed whether or not the child was raised by a biological or non-biological caregiver and was greater in younger children. The children's overall psychosocial difficulties mean score was 16.9 (SD = 5.05), with indications of the significant presence of psychological and behavioural symptoms. Hyperactivity problems was reported in 40.1 % (M = 5.27, SD = 1.72) of the children, emotional problems in 29.6 % (M = 4.31, SD = 2.34), conduct problems in 41.4 % (M = 3.13, SD = 2.18) and peer related problems in 51.3 % (M = 3.49, SD = 1.46).

 The qualitative data indicated, *inter alia*, that stigma negatively impacts on caregivers' mental health and deters them from seeking social support. This in turn, exacerbates caregivers' poor mental health and capacity to adequately meet the needs of their HIV-

positive children, ultimately leading to negative child outcomes. This finding highlights the importance of Bronfenbrenner's micro- and meso-system variables, such as the importance of quality parent/child interaction, adequate language stimulation through dialogue, and availability of tools within the home and school environment that could act as a buffer against the negative effects of HIV on the infected child's developing brain. The children's neurocognitive, psychological and behavioural development is influenced by their ecological context.

Conclusion: This is the first study in South Africa investigating the impact of psychosocial factors associated with poor neurocognitive and socio-emotional functioning in perinatally HIV-infected children. The findings highlight that it is not enough to just focus attention on the medical management of paediatric HIV. Despite having access to cART's, HIV-positive children are vulnerable to developing neurocognitive deficits and socio-emotional and behavioural problems. These problems can impact negatively on their ability to learn and thrive academically, establish pro-social relationships with peers, and importantly, adhere to their treatment regimes. The need for integrative interventions including the identification and treatment of caregiver depression as well as nutritional supplementation, early parenting skills training and psychosocial stimulation to improve overall health and future quality of life of this population is recommended.

DEFINITION OF TERMS

AIDS -acquired immunodeficiency syndrome: Is a chronic, life-threatening condition caused by the human immunodeficiency virus (HIV). It damages an infected person's immune system and impedes on the body's ability to fight organisms that causes disease.

Attachment: Is a process that involves an emotional bond between the infant and his/her caregiver and it normally develops over the first year of life; and it lays down the foundation for the child's socio-emotional development.

Human immunodeficiency virus (HIV): Is a sexually transmitted infection that is contained mainly in bodily fluids such as blood, semen, vaginal fluid and breast milk. HIV is considered to be slow progressive virus that exposes individuals vulnerable to a host of opportunistic infection and illness which will eventually results in AIDS.

Low-and middle-income countries: Are collectively referred to as developing countries of which South Africa is part of.

Neurocognitive functioning: Involves the central nervous system and cognitive abilities, such as; complex attention, executive function, learning, memory, language, perceptual-motor or social cognition.

Neurocognitive deficit: Refers to any shift in abilities and functioning of these cognitive faculties which causes interferences in a person's everyday independence and learning ability. Evidence normally on neuropsychological testing will indicate significant decline from previous level of performance in one or more of the cognitive domains; such as, complex attentional ability; executive function; learning and memory; perceptual-motor; and social cognition.

Primary caregiver: Refers to women who assumed the primary caregiving role of the HIV+ child. These women could be the biological mothers or a non-biological women such as relatives, i.e. grannies, aunts etc. who falls between the age of 18 and upwards.

Socio-emotional development/functioning: Is a term that broadly encapsulates social functions such as peer relationships, pro- and anti-social behavior, emotional dispositions, as well as psychological problems such as externalizing and internalizing behavior problems; and temperamental characteristics of a child.

Vertical transmission or perinatal transmission/infection: This involves the passage of human immunodeficiency virus (HIV) from mother to baby at any of the three major time periods; in utero (across placenta) during pregnancy, around the time of birth, and postpartum as a result of breastfeeding (mothers milk).

Anthropometric measures of nutrional status: Measurements of stunting, wasting and underweight are commonly used in research as as indicators of nutritional status as cited in the thesis. It is important to acknowledge that anthropometrics is by definition an outcome of numerous influences and not just nutrition.

ACRONYMS

ADHD- Attention Deficit Hyperactive Disorder

AIDS- Acquired Immunodeficiency Syndrome

ANOVA- Analysis Of Variance between groups

ART- Antiretroviral therapy

AT- Attachment Theory

BBB- Blood Brain Barrier

BDI-II- Beck Depression Inventory-II

BSID- Bayley Scales of Infant Development

cART- combination antiretroviral therapy

CD- Caregiver Depression

CD4- Cluster of differentiation 4

CDC- Centre for Disease Control

CDCHU- Center on the Developing Child at Harvard University

CFS- Cerebral Spinal Fluid

CI- Confidence Interval

CNS- Central Nervous System

DOH- Department of Health

DV's- Dependent Variables

EST- Bronfenbrenner Ecological Systems Theory

FR- Fluid Reasoning

FSIQ- Full (Global) Scale Intelligence Quotient

GLC- General Language Composite

HAART-Highly Active Antiretroviral Therapy

HAZ- height for age z-scores

HIV- Human Immunodeficiency Virus

HIV- (HIV negative)

HIV+ (HIV positive)

HE- Home Environment

HOME- Home Observation for Measurement of the Environment

HPE- HIV related Progressive Encephalopathy

HSSQ- Home Screening Stimulation Questionnaire

IV's- Independent Variables

IQ- Intelligence Quotient

IPA- Interpretive Phenomenological Analysis

INP- Integrated Nutrition Programme

LMICs- Low and middle-income countries

MGRS- Multicenter Growth Reference Study

MDI- Mental Developmental Index

PDI- Psychomotor Developmental Index

PHIV- Paediatric HIV

PIQ- Performance Intelligence Quotient

PLWHIV- People Living With HIV

PSQ- Processing Speed Quotient

PMTCT- Prevention of mother-to-child transmission

NASHPS- National Antenatal Sentinel HIV Prevalence Survey

NGO- Non-Government Organisation

NRF- National Research Foundation

NS- Nutritional Status

NFCS-FB- National Food Consumption Survey-Fortification Baseline

SA- South Africa

SADQ- Strengths and Difficulties Questionnaire

SAGARPR- South Africa's Global AIDS Response Progress Report

SES- Socio-Economic Status

SD- Standard Deviation

SPSS- Statistical Package for the Social Sciences

UK- United Kingdom

US- Unites States

UNAIDS- Joint United Nations Programme on Acquired Immune Deficiency Syndrome

UNICEF- United Nations Children's Fund

UNGASS- United Nations General Assembly Special Session

USA- United States of America

VIQ- Verbal Intelligence Quotient

WPPSI-III- Wechsler Preschool and Primary Scales of Intelligence-Third Edition

WAZ- weight for age z-scores

WHO- World Health Organisation

WHZ- weight for height z-scores

WHO/NCHS- World Health Organisation/ National Center for Health Statistics

WISC-III- Wechsler Intelligence Scale for Children- Third Edition

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BACKGROUND

Introduction

The Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) continue to pose a global health threat (Klatt, 2013), with the AIDS pandemic having claimed millions of lives the world over since its discovery in the early 1980s (Klatt, 2013; WHO/UNAIDS/UNICEF, 2013). HIV is transmitted mainly through bodily fluids containing the virus, such as blood, semen, vaginal fluid, and breast milk. HIV is considered a slowly progressing virus that renders infected individuals vulnerable to a host of opportunistic infections and illnesses which will eventually result in AIDS over time (Klatt, 2013). To date it remains an incurable disease and millions continue to suffer and even die from it annually, particularly in low resource settings (Bekker, Venter, Cohen, Van Cutsem, Boulle, & Wood, 2014). Heterosexual intercourse is considered the main way in which HIV infection spreads, but is definitely not the only way of transmission (Klatt, 2013). The main transmission route for the HIV virus in children occurs prenatally, at birth, and during breastfeeding from mother-to-child infection (Klatt, 2013; WHO/UNAIDS/UNICEF, 2013). The economically most productive sector of society (*i.e.* ages 15 to 35) continues to be the group most affected by the pandemic, which results in a loss to the South African economy (Klatt, 2013). This includes predominately HIV+ women of childbearing age who are typically needed in the workforce but who are unemployed.

The devastating impact of HIV/AIDS on children, adolescents, caregivers, and families remains a major challenge, as HIV/AIDS presents numerous unique and complex medical, financial, and psychosocial challenges to families (Klatt, 2013). Globally, women of childbearing age are disproportionately the worst affected by AIDS, and a consequence of

this, is that a significant number of children are in turn infected with HIV perinatally (WHO/UNAIDS/UNICEF, 2013; Klatt, 2013; Bachanas et al., 2001b). Women are often confronted with the double burden of being infected and having the responsibility of caring for their HIV-positive children (Huges & Caliandro, 1996).

Locally, South African woman of childbearing age and children from resource-limited backgrounds remain at high risk of HIV infection (WHO/UNAIDS/UNICEF, 2013) despite the availability of combination antiretroviral therapy (cART). According to the WHO/UNAIDS/UNICEF (2013) report, South Africa remains one of the countries with the largest number of pregnant women living with HIV. According to another WHO/UNAIDS/UNICEF report released in 2010, South Africa was able to reach the target rate set by the United Nations General Assembly Special Session (UNGASS) of providing antiretroviral therapy to at least 80% of pregnant women in need of them between 2008-2009, which reduced the risk of mother-to-child transmission (MTCT) of HIV. Owing to considerable effort by the South African government to eliminate new infection among children by 2015 as part of a global initiative, a reduction in newly-infected HIV children of up to 43% was achieved between 2003 and 2011 according to the South Africa's Global AIDS Response Progress Report-SAGARPR (UNAIDS, 2012). What remains alarming is the fact that Africa is estimated to account for more than 90% of all pregnant woman living with HIV and new HIV-infection among children ranging between the ages of 0 and 15 years (WHO/UNAIDS/UNICEF, 2013).

According to the 2012 National Antenatal Sentinel HIV Prevalence Survey (NASHPS) conducted in South Africa, the prevalence of HIV among the country's adult population aged between 15 and 49 was estimated at 29.5% (DOH, 2013). However, women 15 years and

older constituted 3.4million of the total number of adults living with HIV in 2012, while new HIV infections among children (–zero to 14 years) was estimated at around 21000 (95% CI: 19000 - 32000) in 2012 (DOH, 2013). Furthermore, an estimated 370000 (95% CI: 340000 – 420000) new infections were reported in 2012 (DOH, 2013). According to the report an estimated 2.5 million people were still in need of anti-retroviral treatment (ART) in 2012, despite the fact that South Africa had the largest antiretroviral programme worldwide (DOH, 2013).

Among the 22 Sub-Saharan African countries covered by the Global Plan (South Africa included), a total of about 1 550 000 children are estimated to be in need of antiretroviral therapy, of which only 33% had access to treatment by the end of 2012, compared to 63% of HIV infected adults (WHO/UNAIDS/UNICEF, 2013). While it is encouraging to note that the number of children younger than 15 years receiving cART rose from 566 000 in 2011 to 630 000 in 2012, the percentage increase remained evidently smaller than for adults (11% versus 21%) (WHO/UNAIDS/UNICEF, 2013). Despite continuing challenges to the AIDS response, South Africa has made tremendous progress over the past 5 years that has led to millions of children and adults living with HIV being saved by effectively managing infections and preventing new infections, largely because of the roll out of ART (Simelela & Venter, 2014). South Africa has intensified efforts to eliminate HIV and AIDS by implementing new policies supporting universal access to free antiretroviral therapy (ART) for all people infected (UNAIDS, 2012), with children and pregnant women enjoying priority. Currently South Africa has the largest number of people living with HIV (PLHIV) on antiretroviral therapy (ART) in the world, with an estimated 2, 5 million people already started on ART while 376, 000 people were started on ART in 2012 alone (Bekker et al., 2014; Simelela & Venter, 2014). Since January 2015 all persons in South Africa with a CD4

less or equal to 500 cells/µl started receiving antiretroviral treatment (Meintjies, 2015). The adoption of this decision allows access to all adults, irrespective of clinical stage, as well as immediate access to treatment for all children, life long treatment to pregnant women regardless of CD4 status and all persons with TB who are co-infected with HIV (Meintjies, 2015). This change reflects the shift in SA policy between 2012- 2013 that aligns with the WHO 2013 guidelines. This resulted in earlier identification of children and more rapid treatment and better treatment regimens for all PLHIV (Bekker et al., 2014). It is important however, to acknowledge that this changing landscape will likely reflect age differences as younger HIV+ children would have had access to optimal timeous treatment in the past five years unlike our older age group (e.g. early and late adolescence and adult groups), as observed in studies from the developing countries (Smith & Wilkins, 2015). In the course of HIV management it means fewer children will be diagnosed with early onset of AIDS defining illnesses such as HIV encephalopathy, and fewer premature deaths incidences will be reported, unlike prior to universal access to optimal cART drugs during the early 90's (Smith et al., 2012). This is an important change in South African paediatric management as MTCT is reducing, so it will soon become an adolescent epidemic as is the case in the US and Europe where paediatric HIV has been considered largely an adolescent and young adult epidemic for at least the past decade (Smith & Wilkins, 2014).

With advances in treatment of HIV leading to prolonged life expectancy of those infected (Bekker et al., 2014), paediatric HIV is now viewed as a chronic illness with periods of acute symptomatic illness (Bachanas, 2001b). However, associated psychopathology, neuropathology, and psychosocial complications nevertheless remain serious challenges (Lentoor, 2006; Antinori et al., 2007). Neurocognitive impairments due to HIV infection of the CNS are detectable across all disease stages in people infected with HIV in both

developed and African countries (Joska et al., 2012; Ruel et al., 2012). Despite the availability of combination antiretroviral therapy (cART) drugs neurocognitive impairments are known to persist (Boyede, Lesi, Ezeaka, & Umeh, 2013) in more than 40% of people infected with HIV (Betrand et al., 2014; Sing et al., 2010; Joska et al., 2010). As access to HIV treatment expands throughout South Africa and Africa, an increasing number of pre-school and school age HIV+ children are being identified with neurocognitive impairments (Ruel et al., 2012; Boyede et al., 2013). Neurocognitive deficits can be global, however executive functions, speed and information processing, attention and working memory, language and sensory perception, and psychomotor skills are most commonly affected by HIV infection (Smith & Wilkins, 2015; Ruel et al., 2012; Boyede et al., 2013; Joska et al., 2012, & Vally, 2011). Deficits in these various neurocognitive domains have major implications for daily functioning and adaptive psychosocial behaviour of the person living with HIV. Executive dysfunction has been associated with impaired daily functioning in areas including problem solving and prosocial behaviour (Smith & Wilkins, 2014); while problems in the domain of memory has been shown to affect one's ability to successfully execute future intentions, independent functioning and decision making. Research has also shown the cognitive dysfunction; especially in areas of executive function, memory and attention, and learning, is a strong predictor of treatment non-adherence in HIV+ people (Smith & Wilkins, 2015; Vally, 2011). Language and psychomotor deficits seems to present more frequently in infants and young children; especially expressive language and vocabulary, which translate into problems with learning, skills needed for reading, development and independent functioning (Brackis-Cott et al., 2009a; Ruel et al., 2012). Consequently, research found that HIV affected approximately 40% of perinatally HIV positive children's (PHIV+) verbal ability (e.g. verbal fluency) (Joska et al., 2010; Vally, 2011). Abubakar et al. (2008) in a review on paediatric HIV neurocognitive deficits in sub-

Saharan Africa (SSA) concluded that HIV has been shown to affect psychomotor function much earlier in the stages of infection and appears to persist across age groups.

While the maternal experience of caring for a child with chronic illness is well researched in high resourced countries (for example: Aldrige, 2006; Spalding & Mckeever, 1998; Hauenstein, 1990; Wigert et al., 2006; Otsuki et al., 2010), very little attention is given to the experience of caring for a child maternally infected with HIV in South Africa and other low resourced countries (New, Lee, & Elliott, 2006; Abubakar, Van Baar, Van de Vijver, Holding, & Newton, 2008). Childhood chronic illness has been shown to have a significant impact on the family system. High rates of maternal depression, anxiety, parenting stress, poor child development outcomes, and sibling adjustment problems are some of the negative consequences identified through research (Otsuki et al., 2010; Bachanas et al., 2001a; Cluver & Gardner, 2007; Nyirenda, Chatterji, Rochat, Mutevedzi, & Newell, 2013; Abubakar et al., 2008). The HIV/AIDS pandemic poses a unique challenge as most mothers of HIV-infected children are HIV-infected and have either died or are battling with their own illness, while still having to carry the responsibility of caring for an infected child (Kullgren, Morris, Bachanas, & Jones, 2004). The mother's HIV-infection and health status can affect her child's well-being and survival in many ways. For a caregiver especially, any illness already compromises caregiver-child relationships through reduced availability, energy, and resources, but HIV may add additional challenges. HIV could be considered an additional stressor in an environment that is already considered stress vulnerable (Cloete, Strebel, Simbayi, van Wyk, Henda, & Nqeketo, 2010). Consequently, many HIV-positive mothers may not be available to care for their children. On the positive side, an illness can also sometimes intensify relationships, leading to a strengthening of relationships and

commitment. Some mothers are able to make selfless decisions where the children's needs are made a priority, despite the continuing challenges they may be confronted with.

In the case of perinatally HIV (PHIV) infected children from poor resource African countries whose biological parents have died, grandmothers and aunts have, in the main, assumed a caregiver role for HIV+ children (Akintola, 2008a; Cluver & Gardner, 2007; Puthanakit et al., 2010). In a 2004 General Household Survey by Statistics South Africa, it was found that more than 35 % of all South African children were living with a grandmother, and in an estimated one-third of these households, neither parents were present, often making the grandmother the primary caregiver (UNAIDS, 2004). It has been shown that South Africa has more than sixty percent of double orphans being raised by a grandmother or relative other than the biological parent (StatsSA, 2004). These children and caregivers are also often living in poverty which poses additional challenges. It is argued that poverty exposes PHIV-positive children to various psychosocial risk factors, which often co-occur and impact negatively on the child's neurocognitive development, thereby contributing to poor health, lack of readiness for school, poor academic performance, and psycho-emotional problems (Kiernan & Mesah, 2008).

The largest burden of the HIV pandemic, combined with poverty remains in low- and middle income countries and results in various social and economic challenges for the poor and already vulnerable (Ivers, Cullen, Freedberg, Block, Coates, & Webb, 2009). A bi-directional relationship exists between HIV/AIDS and poverty, where "…HIV/AIDS is at the same time a cause and an outcome of poverty and poverty is both a cause and an outcome of HIV/AIDS" (ILOAIDS, 2005, p.1). Individuals and families living with HIV do not only confront the reality of sickness but also loss of productivity, loss of income when the ill

person is no longer able to work, often leading to food insecurity (Ivers et al., 2009). This traps people in a cycle of poverty and ill-health. Inadequate quality and quantity of food compromises healthy immune functioning and medication adherence. This is mainly due to the fact that poverty can lead to the consumption of inadequate diet suffient for healthy immune boosting and treatment support (Ivers et al., 2009).

Poverty and HIV also create vulnerability to nutritional disorders, such as malnutrition among HIV-positive children, which has its own adverse effects on child developmental outcomes. The complex interaction between poverty, nutrition and HIV presents a major challenge, at least still in low-income contexts, and threatens the targets and goals of the Millennium Development Goals set out by the United Nations for fighting undernutrition and HIV (Ivers et al., 2009). Moreover, HIV-positive mothers from low resource countries have a higher risk for premature birth or low birth-weight infants, which put them at an even greater risk of stunting and wasting (Kimani-Murage, Norris, Pettifor, et al., 2011) compared to those confronting the epidemic in high resource countries where a steady decline in premature and low weight births have been observed due to early access to treatment and better socioeconomic conditions (Schulte, Dominguez, Sukalac, Bohannon, Fowler, 2007; Lawn, Cousens, Zupan, 2005). In a systematic review, premature births disproportionately affected newborns in resource-constrained countries; comprising 7.5% and 11.9% of births in developed countries and in Africa, respectively (Beck et al., 2010). In a study conducted among a cohort of 927 HIV positive women from Tanzania, Zack et al. (2014) found that premature birth rates for infants were twice as high as those observed in previous studies of HIV-infected populations from sub-Saharan countries; 24% versus 11.9%. This is also much higher than that of premature infants born to HIV-infected mothers in the US (Schulte et al., 2005; Martin et al., 1997). This observed difference is likely due, in part, to many low

resource countries still struggling with ongoing poverty and poor healthcare, unlike in the US where improvement in nutrition provision, maternal health and access to better healthcare is a reality (Zack et al., 2014; Schulte et al., 2005).

The psychosocial, economic, and health vulnerabilities accompanying the pandemic in low resource countries create an urgent need to strengthen efforts to curb the spread of the disease. However, in the absence of a cure, attention must be directed to better understanding and dealing with the associated health, developmental and, psychosocial consequences of the pandemic. The effects of paediatric HIV infection is widespread and remains a major concern, especially in relation to child developmental outcomes and the fact that in low- and middle-income countries (LMICs) not much attention has been given to the associative developmental consequences of the disease compared to developed countries. For this very reason the importance of addressing maternal and child HIV infection cannot be stressed enough.

The main goal of this doctoral research is to identify the psycho-social determinants of poor neurocognitive and socio-emotional development outcomes in HIV positive children from low socio-economic backgrounds in South Africa. International literature suggests that these include: poor socio-economic status, poor quality of home environment, nutritional status, and caregiver depression (Nachman, Chernoff, Williams, et al., 2012; Coscia et al., 2001; Kiernan & Mesah, 2008; Gagliardi & Honigfeld, 2008; Sayre et al., 2001; Ramchandani et al., 2005; Puthanakit et al., 2010; Iversen, du Plessis, Marais, et al., 2011). In the context of sparse local empirical evidence examining these factors in low-resource contexts, this doctoral study aims to contribute to the limited knowledge on the impact of these factors on neurocognitive development and socio-emotional functioning of HIV-positive children in

South Africa. The information generated from this study has the potential to inform tailored health and psychosocial interventions within a resource-limited setting such as South Africa.

Research problem statement

HIV/AIDS predominantly affects women and children from communities that are characterised by a lack of financial and social resources (Brackis-Cott, Kang, Dolezal, et al., 2009a; Brandt, Dawes, & Bray, 2006; Petersen, Bhana, Myeza, et al., 2010a). As a result, HIV/AIDS presents rather unique and often complex medical, financial, and psychosocial challenges to families afflicted by the pandemic (Brown, & Lourie, 2000; Petersen et al., 2010a). As already mentioned, while there is a fair amount of international literature on the maternal experience of caring for a child with chronic illness, very little attention has been given to the experience of caring for a maternally infected child with HIV in South Africa. Chronic childhood illness has been shown to have a significant impact on the family system. High rates of maternal depression, anxiety, parenting stress, poor child development outcomes, and sibling adjustment problems are some of the negative consequences identified through research (Forsyth, 2003a,b; Puthanakit et al., 2010; Bachanas et al., 2001a). The HIV/AIDS pandemic poses a unique challenge as many mothers are HIV-infected and battling with their own illness, often in secrecy as a result of HIV stigma, while still having to carry the responsibility of caring for their infected child (Brandt et al., 2006). Furthermore, with the increased number of HIV-infected orphans we see a disruption in family structures where grandmothers and aunts often assume a caretaking role for the children (Petersen et al., 2010a). The children and caregivers are also very often living in poverty which poses additional challenges (Brant et al., 2006).

The overwhelming burden of HIV/AIDS on children and their caregivers remain amplified with adverse effects on their health and quality of life. Therefore, interventions that promote caregiver-child well-being, should be prioritised. The need for this becomes apparent as many children are surviving and thriving into school age and adolescence, despite at times having lost both parents as a result of the pandemic. They are also at increased risk of experiencing emotional, behavioural, and educational challenges. While it is encouraging to note that with the advent of cART both mother-child transmissions can be reduced and longevity improved, the protective and preservation mechanism of cART on neurocognitive and socioemotional development remains questionable. Several studies have shown that neurocognitive functioning among children does not improve after receiving antiretroviral therapy (Puthanakit et al., 2010; Smith et al., 2008). A recent review conducted by Smith & Wilkins (2015) of studies on ART's and neurocognitive function among PHIV youth in high resource countries showed that despite access to optimal cART, and viral suppression, these youth may still experience neurocognitive problems. This continuing risk of cognitive deficits has been linked to early diagnosis and severe disease progression (i.e. AIDS diagnosis) (Smith et al., 2012; Wood et al., 2009; Nachman et al., 2012). The risk was even greatest amongst those PHIV youth who experienced early HIV-encephalopathy. It has been argued that these surviving youth were exposed to suboptimal treatment in the earlier years before the advent of cART; leaving the developing brain of the PHIV youth vulnerable to the worse effects of the virus (i.e. HIV encephalopathy) (Smith et al., 2012). However, it is clear from evidence that the availability and accessibility to cART has resulted in fewer premature deaths to date due to its positive impact on the progression and incidences of reported early and severe neurological diseases amongst the PHIV population. Given this, it can be argued that the issue may be that many perinatally infected children have other reasons they may perform poorly on neurocognitive assessments-i.e. poverty, low birth weight, prematurity,

psychosocial factors, etc. If this is the case, then it is important to explore these contextual factors, as the effects of ART's cannot remedy the negative consequences of these concomitant contextual factors. It is therefore important to explore the psycho-social context in which these children are raised to try and trace any relationship that may exist between context, neurocognitive status, and psychological adjustment of the HIV-infected child. Previous studies have shown that improvement in parenting skills, a reduction in parental stress, and more stimulating responsive parenting may circumvent the risks and effects of poverty and illness on children's neurodevelopmental outcome. As a result, caregiver-child interaction becomes vital given the association between parental stimulation and child neurodevelopmental outcomes. Furthermore, this highlights the importance of conducting research that can shed light on and inform interventions aimed at improving neurodevelopmental outcomes in children infected with HIV. Adequate parental skills and stimulating home environments among caregivers of HIV+ children can both promote caregiver-child interaction, which in turn can also fight the adverse effects associated with poverty within this population.

Research aim

The research aim was to understand the psycho-social factors associated with the poorer neurocognitive and socio-emotional developmental status of perinatally (vertically) HIV-infected children in South Africa.

Research objectives

The objectives of this study were as follow:

1. a) To examine the characteristics of caregivers of HIV-positive children in relation to socio-demographics and depression; and b) of HIV positive children in relation to

neurocognitive functioning, socio-emotional functioning, nutritional status, and home environment.

2. To examine the relationship among each of the following factors on neurocognitive and socio-emotional functioning in a sample of South African HIV-infected children: home environment, SES, caregiver depressive symptoms, and nutritional status.

3. To determine which factors are most strongly associated with neurocognitive and socio-emotional functioning in the sample.

4. To understand the challenges confronting caregivers of HIV-positive children.

Research questions

1. What are the characteristics of caregivers and the HIV-positive children in the study?

   a. What are the socio-demographic characteristics of caregivers and their HIV-positive children?

   b. What is the emotional state of caregivers of HIV-positive children?

   c. What is the nutritional status of HIV-positive children?

   d. What is the quality of the home environment that HIV-positive children are raised in?

2. a) What is the relationship among each of the following factors: home environment, caregiver/child connectedness, SES, caregiver depressive symptoms, and nutritional status; and b) what is the relationship between these factors and neurocognitive and socio-emotional functioning of a sample of South African HIV-infected children (3-7 years of age)?

3. Which factor(s) is/are most strongly associated with poor neurocognitive and socio-emotional functioning in a sample of South African HIV-infected children (3-7 years of age)?

4. What are the challenges confronted by caregivers of HIV-positive children aged 3-7 years old?

The age range of 3 – 7 years was chosen given that while many children in this age range would have access to cART, many HIV+ children in South Africa come from low socio-economic backgrounds and are likely to be exposed to a number of risk factors for poor neurocognitive and socio-emotional outcomes which may be compounded by their HIV+ status. Identifying risk influences for this vulnerable population would be important to inform contextually relevant mental health promotion interventions that could be delivered during these formative years, so as to promote optimal neurocognitive and socio-emotional development to aid the prevention of mental health problems and high risk behaviour during adolescence and young adulthood (which is the focus in developed countries such as the US and Europe) (Smith & Wilkins, 2015). This is especially important as research indicates that 50% of mental disorders in adults have their onset before the age of 15 years (Kessler, Berglund, Demler, Jin, Merikangas, & Walters, 2005).

Significance of this study

The results of this study have the potential to enhance our understanding of the factors that differentially impact the neurocognitive and socio-emotional outcomes in HIV-infected children in South Africa. Additionally, the results from this study could potentially help inform strategic interventions in both clinical and family settings that serve to promote quality of life for both the child infected with HIV and the caregiver. Lastly, the study could contribute to shaping the roles of psychologists' responses to the HIV/AIDS pandemic, thus ensuring the needs of families infected and affected by the pandemic are met in a holistic manner.

Structure of thesis

This thesis comprises of eight chapters, and is structured as follows:

Chapter one – Introduction

This chapter presents the background for the study, the problem, the objectives of the study, and the research questions that guided the study.

Chapter two – Literature review

Chapter two discusses related literature and previous research on paediatric HIV with references to neurocognitive functioning, socioemotional adjustment, and caregiving. This chapter draws on both international and local literature (albeit limited) to provide a broad perspective of the topic, but also highlights gaps in the existing research. In so doing, it focuses on consolidating the literature and research already focused on examining similar dynamics. The emphasis is primarily on using existing literature to shape the location and relevance of the present study, specifically in South Africa.

Chapter three – Theoretical framework

In this chapter the principal theory in which the study is grounded is discussed. At this point reference is briefly made to the application of Bronfenbrenner's theoretical framework with regards to the neurodevelopmental and psychosocial aspects of perinatally acquired paediatric HIV and caregiving. Ecological Systems Theory by Urie Bronfenbrenner (1979; 2005) guided this research and is thus presented with John Bowlby's (1969) Attachment Theory incorporated at the relevant ecological levels.

Chapter four – Methodology

In this chapter the methodological framework is presented in terms of the research design, the study setting, sample and sampling techniques, instruments for data collection, data collection procedure, and the analysis of quantitative and qualitative data. The chapter ends by

explicating measures of credibility employed during the present study which serve to authenticate the findings.

Chapter five – Quantitative findings

Chapter five presents the results from the cross-sectional quantitative aspects of the study.

Chapter six – Qualitative findings

Chapter six of this thesis presents the findings of the study in alignment with the qualitative paradigm informed by Interpretive Phenomenological Analysis (IPA) (Smith & Osborn, 2007). Interviewed caregivers' narratives are incorporated into this chapter, which allows their voices to be heard and attempts to produce a richly contextualised body of data around the practice of caregiving within the context of HIV.

Chapter seven – Discussion of quantitative and qualitative findings

A discussion of the findings takes place in chapter seven, where the focus is on integrating the quantitative and qualitative results within the conceptual and theoretical frameworks adopted by the study. The chapter ends by providing a summary of findings obtained in this doctoral study, illustrating the points of convergence and divergence of the quantitative and qualitative data.

Chapter eight – Contribution to knowledge and future research; Limitations, implications, and recommendations; and Conclusion,

In concluding, chapter eight draws on the preceding chapters, and attempts to illustrate the importance of the findings from this doctoral study within the broader HIV/AIDS pandemic. Discussions regarding contributions to current knowledge and suggestions for further research are provided. The chapter also provides a discussion of the challenges experienced in conducting this doctoral study and some of its inherent limitations. It ends by providing recommendations emanating from the findings of this doctoral research.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter provides an overview of existing literature on paediatric HIV. The discussion focuses specifically on the associated consequences of the disease on the developmental outcome of a child's neurocognitive and socio-emotional functioning. Furthermore, reference to the impact of caring for an HIV-positive child within the context of concomitant structural and financial resource limitations are also explored in relation to the HIV-positive child's developmental outcome.

Paediatric HIV and neurocognitive functioning

Pre- HAART and Neurocognitive function

Over the decades we have come to learn that HIV is a known neurotropic virus that targets the brain by crossing the blood–brain barrier soon after infection, resulting in the structural and functional pathology observed in HIV+ children and adults (Bertrand et al., 2014; Davis et al., 1992). This, combined with less than optimal treatment to curb the effects of this transmission or penetration of the virus across the blood-brain barrier (Mocchetti, Campbell, Harry, & Avdoshina, 2013), provides the optimal condition for the replication of the virus. Replication of the virus ultimately leads to immune suppression (i.e., the body's natural response to fight off disease and illness is compromised) and increased viral load of the cerebrospinal fluid (CFS). This in turn leaves the body susceptible to HIV-related infection and neuropathology, such as HIV-related progressive encephalopathy (Bertrand et al., 2014). Research has come to show that the brain has even become a protective reservoir that acts as a sanctuary where the virus can fester (Bertrand et al., 2014; Mocchetti et al., 2013). As such

in the era prior to the advent of highly active antiretroviral therapy (HAART), high rates of HIV-related progressive encephalopathy (HPE), the most severe manifestation of central nervous system (CNS) HIV was frequently observed. HPE caused the infection of HIV which affects the functioning of the brain and is manifested by a variety of cognitive, motor and behavioural abnormalities. It results in a failure to attain, or loss of prior achieved developmental milestones, or loss of intellectual ability, brain dysfunction and motor deficits. It has been cited that progressive encephalopathy was usually the first AIDS-defining illness in HIV+ children as a consequence of early CNS damage, at the time when many HIV+ children went untreated or received suboptimal ART treatment (Cooper et al., 1998). Children infected with HIV prior to ART, in the late 1990's were treated with suboptimal antiretroviral therapy drugs which resulted in viral resistance to many ART's (Smith & Wilkins, 2015). This predisposed HIV+ children to the risk of long-term neurological impairments. Consequently, HIV+ children with growth retardation (stunting) was commonly observed, while thousands of HIV+ positive children succumbed to premature death (Schulte et al., 2007). Past studies conducted in the early days of ART availability, where the use of single agents was the standard to treating HIV, confirmed that HIV effects on the CNS was observed in a wide array of neurodevelopmental problems ranging from gross deficits in global intelligence, receptive and general cognition, visual spatial integration and gross motor functioning (Tardeui et al., 1995; Wolters, 1997; Chase et al., 1995). The relationship between neurocognitive deficits and HIV in children was postulated to be directly related to the effects of HIV on the central nervous system or to the effects of central nervous system infections on neoplasms secondary to immune compromise (Budka, 1993). Data from a study conducted by DeCarli, Civitello, Brouwers, & Pizzo (1993) showed that children with symptomatic HIV-1 infections had a higher incidence of structural brain abnormality, especially cortical atrophy, white matter abnormalities, and calcifications.

Furthermore, in their studies these researchers found that children with white matter abnormalities were more cognitively impaired. Researchers at the time found, when compared to non-infected children, the HIV infected children had significant deficits (Louthrenoo et al., 2004). Similar results was echoed in studies conducted in the low-resource sub-Saharan countries of Rwanda and Tanzania (McGrath et al., 2006; Msellati et al., 1993), where financial resources was limiting availability and accessibility of ARTs. In a large prospective cohort study from Rwanda, Msellati et al. (1993) found a progressive decline in the HIV infected infant's neurodevelopment. The results reported that these infants presented with greater gross motor deficits during the first 24 months of life, which was attributed to the AIDS stage of the infection. As indicated by Msellati et al. (1993, p. 848) "...delay was either a reflection of the chronicity of the HIV-1 disease or a direct expression of the central nervous system involvement or both".

Advent of cART and Neurocognitive function

With the global availability of cART to perinatally infected children we witness a decline in premature death and more HIV+ children now had a greater chance of aging into school-age, adolescence, and even adulthood (Small et al., 2104; Crowell et al., 2015; Mellins & Malee, 2013). With this it is clear that cARTs altered the face of the epidemic tremendously, and made a huge difference in preventing encephalopathy which was the AIDS-defining condition which most perinatally infected infant and children had early on in the epidemic and that often led to premature death of HIV+ children (Smith & Wilkins, 2015). Not only did cARTs have a definitive effect on the progression of the disease but also significantly decreased incidences of early severe central nervous system disease (*e.g.* encephalitis) as fewer children are now diagnosed with the disease (Mocchetti et al., 2013). Research showed that the development of early treatment using combination antiretroviral therapy, along with

prophylaxis for opportunistic infections, has gradually resulted in a reduced concern about acute, life-threatening complications, and greater concern over the chronic and long-term functional impact of the disease (Vally, 2011). However, even with the medical advances in managing HIV, the central nervous system remains a key target of HIV infection (Rausch & Stover, 2001; Vally, 2011; Sadock & Sadock, 2003). Studies conducted on HIV+ school-age children were now able to find noticeable neurocognitive difficulties in these cohorts. Studies exploring this phenomenon were able to conclude that, while HIV disease shifted from being a fatal to a chronic illness with the availability of cART; neurocognitive and behavioural functioning of HIV-infected children has become a major concern (Mocchetti et al., 2013; Joska et al., 2010; Smith & Wilkins, 2015).

It could be that while the blood brain barrier (BBB) is robust in nature to protect the brain (cells, and neurons etc), it may also block the effective penetration of the ARVs (Mocchetti et al., 2013; Smith & Wilkins, 2015; Ances, Letendre, Alexander, Ellis, 2008; Joska et al., 2012) and perhaps this is why neurocognitive deficits continue to persist (Smith & Wilkins, 2015). It has been argued that while the BBB is protective in nature it can also have an adverse function in relation to HIV and antiretroviral drugs (Mocchetti et al., 2013). Some researchers have even suggested that the BBB may even reject the medication used for treating HIV infection (Smith & Wilkins, 2015). On the other hand, while anti-retroviral drugs are able to successfully and effectively supress peripheral viral load, it does not prevent the ongoing reproduction of HIV-1 neurotoxic proteins once the proviral DNA is integrated into the brain (Bertrand et al., 2014). Research has shown while cART drugs are able to manage the replication of the HI-virus, it has minimal effect on the viral protein formation upon arrival in the central nervous system (Mocchetti et al., 2013). The underlying mechanisms involved in this process are not simple and would reflect the complexities

associated with understanding this phenomenon (Bertrand et al., 2014). Research over the years has come to show that genetic factors and a complex relationship with virological factors combined are associated with the continuing neuropathological vulnerability (Smith & Wilkins, 2015; Joska et al., 2010). Either way, it has been suggested that the central nervous system can become a reservoir for the HIV and as such the ARV's effective capacity to be protective against the negative effects of the human immunodeficiency virus on neurocognitive functioning can be limited (Ances et al., 2008; Mocchetti et al., 2013). Perhaps also an important link to the argument of persistent neurocognitive deficits is the role of HIV subtypes, commonly referred to as clades in the era of cART (Joska et al., 2010; 2012; Singh et al., 2010). South Africa and Southern Africa is known to be the regions where HIV-1 Clade C is prevalent (Singh et al., 2010). However, most research is conducted in areas where Clade B is predominant (Joska et al., 2012). It has been argued that Clade C is less neurovirulant; meaning presenting with less severe forms of neurocognitive deficits (Joska et al., 2010). However, various studies have come to show that neurocognitive impairments occur at similar rates and with equally deleterious effects as the others clades, as the viral proteins are considered equally neurotoxic (Joska 2012; Singh et al., 2010). In addition, the role of delayed or late–initiation of cART is also an important factor to consider in understanding the persistent manifestation of neurocognitive deficits. As cART only became readily available in South Africa in the public sector around 2004, many children and adults were vulnerable to the effects of HIV (Sing et al., 2010). It goes without saying that phenomenal strides have been made over the past decade with regards to the ART rollout in South Africa with over 2 million people now on antiretroviral therapy which is now being initiated at primary health care (PHC) clinics that should be accessible to all (Simelela & Venter, 2014). However, still to date, many struggle to access cART due to poverty and lack of resources that prevent people from accessing PHC facilities; and this is important in

contextualising the neurocognitive vulnerability of HIV+ children in resource-limited settings (Simelela & Venter, 2014). The age at which antiretroviral therapy is commenced is a crucial predictor for neurocognitive outcomes (Rice, Correira, Schutte, 2014). The challenge that South Africa confronts is that the PHIV+ children infected pre- 2004 are now adolescents and as a result of delayed initiations of cART were vulnerable to opportunistic infections, low CD4+ count, elevated viral loads and at greater risk for neurocognitive dysfunction (Joska et al., 2012). HIV clearly targets the brain and results in adverse CNS effects, and while antiretroviral drugs supress active replication of the HIV it has shown to have minimal effect on viral protein formation once in the CNS (Mocchetti et al., 2013). To date no treatment has shown to be restorative. Perhaps while we continue to observe neurocognitive impairments the availability of cART now at least prevents the worsening of the function. Nevertheless, research shows that neurocognitive improvement is associated with the effective peripheral viral load suppression, with early cART initiation, where cART effectively penetrates the CNS (Smith & Wilkins, 2015). On the other hand the limited protective effect on the neurocognitive function has been associated with significant chronic aspects of HIV; particularly in children perinatally infected, especially as it impacted on the growth and development, the central nervous system and resulted in related negative neurobehavioral manifestations (Joska et al., 2010; Ances et al., 2008; Nozyce et al., 2006; Smith et al., 2004a; Coscia et al., 2001; Smith et al., 2010). Common consequences of HIV infection in PHIV+ children range from delays in cognitive and language abilities, motor development and visuospatial skills, visio-motor and visio-perceptual proficiency, to impaired concentration and attention (Joska et al., 2011). Furthermore, impaired verbal memory, mental slowing, and neurobehavioral deficiencies, such as apathy, depression/pseudo dementia, anxiety/agitation, sleep disturbances, irritability, social withdrawal, personality

changes, and ADHD have also been observed (Brackis-Cott et al., 2009a,b; Ruel et al., 2012; Puthanakit et al., 2010, 2013).

Most studies conducted in developed countries comment on the neurodevelopmental delays in PHIV+ children. Smith and colleagues (2006), in their study examining the effects of perinatal HIV infection among children, revealed that a strong relationship exists between the stages of illness and neurocognitive functioning. Smith et al. (2006) report that HIV infection puts children at an increased risk of poor neurocognitive functioning when there is a past Centres for Disease Control Prevention AIDS-defining illness (CDC-Class C), early severe illness. Moreover, HIV-infected children with an early AIDS-defining illness and HIV encephalopathy, also tend to develop and grow at a slower rate than expected, when compared to HIV positive peers without an early severe illness. The evidence from this study is in keeping with previous studies, especially those done prior to the advent of cART (Epstein et al., 1988; Epstein, & Gendelman, 1993; Mellins et al., 1994).

Other studies from the United States (US) on children who commenced treatment later report similar findings. Jeremy et al. (2005) conducted a study to determine the effectiveness of protease inhibitor combination therapy on the neuropsychological functioning of HIV-infected children. These children showed poor neurocognitive functioning after 12 months of protease inhibitor based antiretroviral therapy when compared to normative data available for similar age group peers. The research found that an undetectable viral load in stable antiretroviral therapy was experienced by HIV-infected children, but no improvement in the overall neuropsychological functioning of the HIV-infected children. While it is encouraging to note the efficacy of antiretroviral therapy in reducing viral load, its effectiveness in remediating neuropsychological functioning in HIV-infected children, at least within 12 months of treatment, was poor. Similarly, in a study exploring the impact of perinatal HIV

infection on scholars' receptive language and word recognition (which are both important domains of cognitive functioning), the HIV-infected cohort showed more deficits in these cognitive domains as compared to uninfected controls, and were also functioning at a subnormal cognitive level (Brackis-Cott et al., 2009a) despite being on treatment. Another study by Brackis-Cott et al. (2009b) found that HIV-infected children between the ages of nine and 15 scored poorly on measures of language functioning when tested on a widely used US test of verbal ability (the Peabody Picture Vocabulary Test [PPVT]) and a reading measure (the Reading Subtest of the Wide Range Achievement Test [WRAT3]). Of these, 54% scored <25th percentile on the PPVT and 40% scored <25th percentile on the WRAT3. Additionally, more than half of these participants were academically retained or in a remedial class. It has been argued that language dysfunction is the most commonly identified deficit amongst PHIV+ children due to the association found in the calcification of the basal ganglia and white cortical matter infections (Joska et al., 2011). This is significant given that both these CNS components are associated with higher brain functions such as language, praxis and socioemotional behavioural regulation (Joska et al., 2011). Vally (2011) found that about 40% of PHIV+ children struggle with verbal fluency. Children with language deficits are also more likely to present with subnormal cognitive functioning and experience difficulties in learning which is indicative of compromised cognitive skills (Brackis-Cott et al., 2009a). It was speculated that children and adolescents perinatally infected with HIV would present far more learning problems impeding their ability to perform optimally in school settings, as compared to their non-infected peers (Brackis-Cott et al., 2009a). PHIV+ children who are verbally compromised may also lack the basic skills for learning and reading which in turn can be highly problematic because poor language skills may limit their understanding of illness; and as adolescents, compromise sexual inhibitions, negotiation for safe sexual

practices, as well as adherence to treatment regimens (Smith & Wilkins, 2015; Vally, 2011; Brackis-Cott et al., 2009a).

A recent study was conducted amongst 396 school-age children with perinatally-acquired HIV infection (PHIV+) in the USA, as part of multisite prospective cohort studies, to trace the neurodevelopmental outcomes in PHIV+ children after period of effective cART exposure (Crowell et al., 2015). The research found that effective virologic suppression during infancy and early childhood had a positive impact on neurocognitive functioning in later school-aged PHIV+ children. However, the findings were not clinically significant and the improvement was only seen on global neurocognitive functioning (FSIQ). Nevertheless, the study was significant in that it adds to existing findings that confirms effective role cART has in virologic suppression and immune reconstitution (Wood et al., 2012; Smith & Wilkins, 2015).

Accordingly, studies from developing countries also show that with the advancement and availability of cART, the rate of HIV encephalopathy declined remarkably, albeit with some residual neurological, cognitive, and developmental delays (Chiriboga et al., 2005). The implication of this is the need for early identification and treatment of HIV+ children, which should see infants surviving far beyond what was initially expected and progressing into adolescence and adulthood (Jeremy et al., 2005). For many HIV+ positive children in low-middle income countries accessing early treatment or getting optimal treatment is complicated by the continuing devastating effects of poverty, which result in most of these children still struggling to access health related resources and as a consequence presents as a major factor for poor compliance to HIV medical care (Small et al., 2014).

To date only a few studies investigating the impact of HIV on neurocognitive functions have been conducted in developing countries (e.g., Puthanakit et al., 2010; Martin et al., 2006;

Coscia et al., 2001; Bisiacchi et al., 2000). Some emerging studies from Asia have demonstrated neurocognitive deficits in HIV-positive preschool and school age children. Thailand, albeit in its infancy phase, has begun to shift their research focus from HIV-infected infant studies to include children of school age living with the virus in an attempt to understand the impact the disease has on these children's schooling and overall learning experiences (Brackis-Cott et al., 2009a; Puthanakit et al., 2010).

A study from Thailand using the Wechsler Intelligence Scale for Children-III (WISC-III) to assess cognitive functioning in school-age HIV-infected children demonstrated that infected children, when compared to HIV-affected (exposed to HIV through mothers HIV status but not infected) and normal (not exposed to HIV) children, had higher levels of cognitive deficits (Puthanakit et al., 2010). Worthwhile to report from this prospective long-term follow-up study was that even after the children received antiretroviral therapy for an average of three years, no marked improvements in their cognitive functioning were reported. Furthermore, these children had an undetectable viral load and normal CD4 cell count (Puthanakit et al., 2010). Nevertheless, this is not a unique finding as other studies investigating cognitive functioning of HIV-infected children reveal similar data.

Additionally, in a study conducted in South Africa, Smith et al. (2008) explored neurological and neurocognitive deficits in a sample of HIV-positive children living in resource-constrained settings in Cape Town, and assessed the responses of these children after six months on HAART. The researchers concluded that children who commenced antiretroviral therapy had shown no improvement on cognitive functioning after 24 weeks of treatment, and evidenced the greatest deficits in the receptive and expressive language domain. This result is significant in that language development is part of the developmental domain of higher cognitive functioning, which has far-reaching consequences for learning outcomes (Smith et

al., 2008). A limitation of the study was that there was no control over confounding variables, such as socioeconomic and cultural factors that could also have contributed to the outcome of the study. The researchers concluded that timing, when rolling out HAART in children, is a critical determining factor in predicting the neurocognitive and neurological outcome in HIV positive children (Smith et al., 2008), which is in keeping with the findings from developed countries.

Studies emerging from other low-income African countries also provided similar findings (Ruel et al., 2012; Van Rie, Mupuala, & Dow, 2008). Ruel et al. found significant cognitive and motor deficits in their cohort of HIV-infected Ugandan school-age children when they were compared with HIV-infected control children (2012). In contrast, a study conducted among Congolese infants and children indicated improvement in cognitive functioning in their HIV-infected cohort (Van Rie et al., 2008). However, it emerged that improvements were only noticeable in children >30 months old and the researchers argued the early ART initiation, soon after infection, may prevent irreversible impairment in the critical stages of infant development.

Current research with Paediatric HIV (PHIV) youth in the developing countries and cognitive function

Despite declining incidence of severe central nervous system complications such as HIV encephalopathy that is associated with severe AIDS-illness, paediatric HIV (PHIV) is still associated with neuropathogenic sequelae resulting in a wide range of neurocognitive problems in youth with PHIV, despite having access to optimal cART (Smith, et al., 2012; Wood, Shah, Steenhoff, & Rustein, 2009; Nachman et al., 2012; Smith & Wilkins, 2015).

In a study Wood et al. (2009) followed a group of eighty-one youth living with HIV since birth to explore the relationship between early severe HIV disease diagnosis and long-term neurocognitive outcomes. Their findings suggest that youth with early class C disease (CDC-C) progression, despite current optimal cART, viral suppression, and immune recovery from early AIDS diagnosis, continue to exhibit neurocognitive deficits into adolescence. Similar findings was echoed by Smith et al. (2012) that showed HIV+ youth with a prior CDC-Class C diagnosis leads to persistent neurocognitive deficits, especially more so when there was a previous diagnosis of encephalopathy. However, Wood et al. (2009) suggest that even in the absence of confirmed prior encephalopathy, HIV+ youth remain to be at high risk of having neurocognitive deficits, as long as an early severe HIV disease were present. Nachman et al. (2012) in their large study of 319 youth with PHIV even found that a more severe prior CDC-Class C diagnosis predisposed the HIV+ youth to significantly worse neurodevelopmental delay, irrespective of virologic suppression. These findings show that early brain pathology significantly increases the risk of long term neuropsychological deficits in children.

Encephalopathy in early stages of development was not only associated with global cognitive dysfunction of the PHIV youth but also with domain specific impairments. Smith et al. found that early diagnosis of encephalopathy significantly increased the risk for dysfunction in the cognitive subdomains of perceptual reasoning and processing of speed, in the long-term (2012). In addition, paediatric HIV+ youth, even in the absence of diagnosed encephalopathy but a CDC-C event, was at greater risk for processing speed impairments and working memory deficits when compared to their healthier or uninfected peers (Smith et al., 2012). While in another study the researchers found that receptive language and word recognition, which form part of verbal domain of cognitive functioning, are affected in PHIV youth, irrespective of their virologic suppression (Nachman et al., 2012). Subsequently, similar

results were found in a study conducted amongst PHIV youth up to the age of eighteen years in Amsterdam, while being clinically stable on cART (Cohen et al., 2015). The verbal neurocognitive domain amongst PHIV youth was poorer when compared to a healthy matched group. These findings have been attributed to an early CDC-C disease which is argued to be a possible risk factor for neurotoxicity secondary to high level viral replication that predispose the child to long term CNS dysfunction (Wood et al., 2009).

While the studies discussed above clearly demonstrate neurocognitive impairments amongst PHIV youth, a couple of studies in the USA and Europe were able to show some minimal improvements in motor and cognitive functioning following HAART (Jeremy et al., 2005; Koekkoek et al., 2008). In a study conducted in the Netherlands on neurocognitive functioning PHIV youth after initiation of HAART, the researchers found that the global neurocognitive function of the cohort was comparable to established norms for their age (Koekkoek et al., 2008). In other words, their neurocognitive functioning was found to be within the average range of cognitive development. However, important to note is that the researchers only relied on one of the subtest of cognitive functioning. Furthermore, performances on specific subdomains were found to be significantly impaired when compared to age-appropriate norms. The findings suggest that executive dysfunction and processing of speed impairment was significantly related to HIV disease (Koekkoek et al., 2008).   Another study that showed modest improvement was conducted by Jeremy et al. in the USA, where four-hundred and eighty nine HIV-infected youth up to age 17 years were assessed neuropsychologically (2005). The results from the study showed that after 48 weeks of protease inhibitor (PI)-containing regimen, improvement was only observed in the domain of vocabulary in spite of viral suppression and immunologic reconstitution. While this

finding is encouraging, the cohort demonstrated persistent neurocognitive impairment in the other neurocognitive domains in comparison to age-appropriate norms (Jeremy et al. 2005).

A common trend that emerged from these studies and that is encouraging to note is the fact that the availability and accessibility of cART made a tremendous difference in the lives of infected children and adolescents. The lack of consistent response of neurocognitive functioning to the effects of cART, on the other hand, perhaps signifies the importance of early diagnosis and treatment for preventing progress of the HIV disease in children and the development of potentially irreversible neuropathological complications of the HI-virus. Consistently, despite observable neurocognitive deficits, no differences were observed between those infected with and without CDC-C diagnosis with respect to clinical markers in any of the studies. This suggests that long-term viral suppression, immunological recovery from an early and severe AIDS diagnosable illness and preservation of immune functioning after initiation of cART is possible. The aforementioned findings are therefore promising given the reality that many people from poor resources communities, in need of ART, still only gain access to treatment late in the progression of the HIV disease, long after diagnosis.

Psychosocial factors and Neurocognitive function

Notwithstanding, the results of the abovementioned studies, which suggest that delays in ART initiation may compromise neurocognitive functioning in HIV-infected children, psychosocial factors may also play a role (Puthanakit et al., 2013; Brookes-Gunn et al., 1996; Bradley et al., 1989, 1980; Ruel et al., 2012). Perhaps this premise could explain the continuing neurocognitive vulnerability that HIV-infected children may exhibit, despite access to antiretroviral treatment. It is well known that exposure to HIV among children often occurs in the context of environmental factors that pose equal, if not greater risk to the child's development (Bennett, Schott, Krutikova, & Behrman, 2015; Smith & Wilkins, 2015). Smith

and Wilkins (2015) state that "understanding cognitive …outcome PHIV [children] and youth is complicated by the individual; contributions and complex interactions of several potentially deleterious psychosocial factors concomitant with HIV infection and its treatment" (p. 244). Concomitant environmental risk factors, such as a mother's own HIV positive status, poverty, substance abuse, maternal instability, poor household intellectual stimulation, and limited caregiver education are all factors associated with paediatric HIV-infection (Bennett et al., 2015; Bradley & Caldwell, 1980; Bradley et al., 1993). Similarly, a caregiver's emotional status, as a result of his/her own physical and psychological well-being and that of caring for an HIV-positive child, may itself impact negatively on a child's neurocognitive development (Bennet et al., 2015; Knitzer et al., 2008). Caregiver health has been associated high levels of stress that has the potential to impact negatively on the nurturing relationship between the caregiver and child (Hackl, Somlai, & Kalichman, 1997). Sick caregivers are less likely to work due to their health constraints or that of their children which increases their vulnerability for stress (Potterton et al., 2007). Caregivers who are stressed and depressed are more likely to experience parenting as a burdensome activity that can prevent them from engagining in parenting behaviour that could promote neurocognitive and emotional development of their children (Lachman, Cluver, Boyes, Kuo, & Casale, 2014).

Literature focusing on other child related chronic illnesses documents the significant impact that home-environmental factors, such as parenting style, parental/caregiver stress, psychological functioning, socioeconomic status (SES), and poverty have on children's cognitive functioning (Bradley et al., 1989; Bradley & Corwyn, 2002; Yeates et al., 1997). In a study exploring the relationship between home environment and cognitive development in the first three years of infant lives, Bradley et al. (1989) found that higher intellectual

functioning was positively associated with responsive parenting in the home environment. Moreover, Yeates et al. (1997) in their study on brain-injury subjects found that the pre-injury home environment was a determinant of recovery and cognitive functioning amongst school-aged children with traumatic brain injury. Similarly, a positive correlation was found in a study exploring the association between maternal IQ, home environmental factors, and child IQ in low birth–weight, premature children (Bradley et al., 1993).

The strength and association between contextual factors and central nervous system factors may also explain some of the varied aspects of neurocognitive functioning in children infected with the HI-virus. Perhaps, like in other chronic illnesses where children suffer, the home environment can mediate the association between socioeconomic status and the outcome of HIV-infection on the child's neurocognitive and socio-emotional development. The psychosocial environmental context is one of the most prominent influences on cognitive function among children living with HIV. Chilren living with HIV are often at a higher risk of being exposed to living in an environment characterised by poverty (UNAIDS, 2012). Poverty creates the vulnerability for increased exposure to stressful life events; including violence, psychological stress, family disintergration, instability and suboptimal rearing social contexts (Mellins & Malee, 2013). Poverty and stressful life pose a great risk to the child's development outcome (Foster & Williamson, 2000). This is an important association as poverty remains a reality for many families living with HIV in South African (Potterton et al., 2007).

In a cross-sectional study (n=43) exploring the effects of environmental factors on the cognitive functioning of HIV-positive children, home environment was associated with neurocognitive functioning among HIV-infected children (Coscia et al., 2001). Noteworthy from this study is the fact that home environment in the context of HIV/AIDS can operate as

a protective factor against the negative effects of poverty on neurocognitive development or vice versa. Therefore, the results from this study suggest that children infected with HIV and living in poverty are at greater risk of neurocognitive-developmental deficits, as they may be more likely to live in less stimulating and supportive home environments. These children are also more likely to present with psychological and behavioural problems. In the same study, Coscia et al. (2001) found that the association between home environment and an HIV infected child's neurocognitive functioning varied as a function of the health status of the child, while children with a more severe disease progression exhibited an increased vulnerability to a negative home environment. Thus, children with greater central-nervous-system impairments may also be at greater risk of more negative neurocognitive outcomes, secondary to a less stimulating environment (Coscia et al., 2001).

Conclusion

In summary, while cART promotes normal growth, development, and quality of life for this population, the effects of the virus on the neurocognitive functioning of infected children and adolescents in low- and middle income countries requires more exploration. Most research on neurocognitive functioning among HIV infected pre- and school-age children has been conducted in the United States and Europe where children have access to treatment earlier than children in resource-limited settings. For this very reason the picture of neurocognitive impairment among HIV-infected children in resource-limited areas might be worse.

These literature suggests HIV-related neurocognitive deficits among HIV-infected children which may be mediated by the timing of cART as well as home-environment and socio-economic status. However, as most of the aforementioned research was conducted in the United States, the outcomes of these studies are not directly comparable to those few studies that have been conducted in developing countries, because children in the United States have

access to treatment earlier than children in low-to-middle-income contexts. In addition, the outcomes of these studies suggest that in a high-income context, antiretroviral therapy seems to assist in preventing neurocognitive impairments in the absence of an early AIDS-defining illness. However, in low-to-middle income contexts research seems to indicate that HIV-positive children present with poor neurocognitive functioning and are likely to become more prevalent, especially given the problems of timeously accessing cART due to the continuing complications as a result of associated poverty which impacts of resource availability, compliance and pose a threat to further scale-up of ART care for children infected with HIV due to problems in the function of health care services (Simelela & Venter, 2014 . Thus, while antiretroviral therapy has a dramatic virologic impact on HIV-infected children, its effects on the neurocognitive outcomes of HIV-infected children from developing contexts are likely to be less dramatic.

Moreover, what remains unclear and still requires exploration are the extent to which cART can disrupt or reverse the neuropathological effects of HIV in children infected. It does appear that the CNS may be less prone to recover, especially if early AIDs-disease occurred prior to age of five years, the critical periods of development, as this is when the infected child's vulnerability for poor neurocognitive functioning with long term developmental outcomes increases. Moreover, the pathogenesis of neuropsychological deficits in HIV positive children and PHV youth may differ between LMIC and developed countries such as the USA and Europe, given the different viral strains. Currently it is known that subtype B predominates in the USA and Europe, while HIV subtypes A, D, and C predominate in Africa (Joska et al., 2012). Research indicates the slightest genetic variation can alter neurotoxic potential, especially as the various subtypes are associated with different rates of HIV-associated neurocognitive deficits (Joska et al., 2010). In addition, in developed countries

there are factors other than HIV that can impact neurodevelopment of PHIV+ children that is comparably different from South African and many other African countries; for example, prenatal drug exposure remains a problem in developed countries. Thus, the pathogenesis of neuropsychological deficits may not only be related to the early neurotropic effects of the HI-virus but also the direct effects of toxins due to in utero drug-exposure, as is the case of many children and youth living with HIV in the USA and many other developed countries (Smith & Wilkins, 2015). While, on the other hand South Africa has factors like poverty, poor nutrition, change in caregivers, low maternal education, and poor home environments that can potentially can also make a difference to the neurocognitive function of the PHIV-infected child, and may not only be due to the pathophysiologic effect of the HIV infection. As such the extent and severity of neurocognitive deficits observed may be different and this has implications for interventions tailored for PHIV children and youth from LMICs. Also the long-term neurotoxicity associated with prolonged used of cART on youth can also potentially create vulnerabilities to poor neurocognitive outcome (Wood et al., 2009). However, literature remains limited on this dynamic and requires further exploration. In conclusion, this neurodevelopmental observations stimulated research focusing on the relation between HIV-infection and neurocognitive development, where the risk for global neurodevelopmental deficits among HIV infected children has been established (Puthanakit et al., 2010; Coscia et al., 2001; Willen, 2006; Louthrenoo et al., 2004; McGrath et al., 2006).

Socio-emotional development and paediatric HIV

From a psychosocial perspective it has been argued that exposure to chronic and acute stressors, and frequent negative life events can have a direct adverse impact on emotional experiences and social adjustment of children (Pappin et al., 2015; Denham, Bassett, & Wyatt, 2007). Research identifies three sets of factors as having a continued influence on the

modelling and shaping of social behaviour and the emotional developmental outcome of children, namely: the individual, the immediate family, and the community (Bohlin & Hagekull, 2009). This influence has been well researched and theoretical models of temperament, attachment, and social learning provides unwavering support therefore (Bohlin & Hagekull, 2009). As Bohlin & Hagekull (2009) stated, early temperament traits in combination with attachment and social factors is imperative to the development of social and emotional functioning. It is also argued that healthy social and emotional adjustment from infancy to adulthood is imperative, as it is associated with mental and physical health, academic performance, and in later life, work performance (Denham, Wyatt, Baseett, Echeverria & Knox, 2009).

According to some researchers, socio-emotional development is impacted upon by the relationship that is established and exists between the individual and his/her environment (Bohlin & Hagekull, 2009; Suwalsky, Hendricks & Bornstein, 2008). Furthermore, this coexisting relationship is argued to have both positive and negative social and emotional features that impact on the individual's adjustment (Denham et al., 2009 and Bohlin & Hagekull, 2009; Bornstein, Suwalsky, & Breakstone, 2012). Moreover, research identified five constructs associated with optimal and non-optimal outcomes for children and adults. These aspects pertain to social competence, attachment, emotional competence, perceived competence, and temperament/personality, and are considered important for the socio-emotional functioning outcome in children (Denham et al., 2009). Crucial to this relationship is the interactive dynamic of parenting. It is argued that despite the importance of these five constructs, socio-emotional development does not occur in isolation, but is significantly influenced by a child's rearing context, *i.e.* socio-cultural community. Parenting practices and caregiver-child interaction is therefore important, as the emotional and behavioural

repertoires of a caregiver and child are considered predictive of child-development and adjustment outcomes (Bohlin & Hagekull, 2009; Van Agt, Verhoeven, Van Den Brink, & Koning, 2011). A caregiver who engages with a child in a range of developmentally appropriate social and emotional interactions will establish a secure caregiver-child bond; a predisposing aspect that will allow the child to explore his/her external environment and enable him or her to regulate and adjust emotionally, in addition to being socially well integrated (Everett, Weinfield, & Hamilton, 2000). Failure to develop a secure bond with the child may result in disintegrated developmental outcomes in the child, thus creating a vulnerability that could expose the child to behavioural and psychological problems, which could have serious negative implications into adolescence and adulthood (Bohlin & Hagekull, 2009).

The construct of *social competence* as part of socio-emotional development is defined as the effective functioning in social contexts, the ability to initiate prosocial interaction, and demonstrate social compliance (Denham et al., 2009). Social interaction begins in infancy, e.g. interaction between caregiver and infant, or their interest in and curiosity for attention from other people and children their own age (Mavroveli, Petrides, Sangareau, & Furnham, 2009). In toddlerhood it is often marked with peer relationships, e.g. the ability to establish playmates and participate in prosocial group play. Preschool age often marks the beginning of more complex social and emotional facets, where peer interaction gains greater importance, but the connection with the caregiver remains intact. This is also when prosocial capability is developed, allowing the child to regulate and manage emotional arousal through peer interaction.

Attachment as a construct, on the other hand, is another crucial aspect of socio-emotional development in children, and refers to the bond that develops between an infant and caregiver

during the first several years of life (Zimmermann, 1999; Bowlby, 2005; Ainsworth, 1989). These emerging attachment styles form the foundation that determines whether an infant will develop close relationships with others as he or she progresses through infancy to adulthood (Meyer & Pilkonis, 2001). For example, an infant whose caregiver is sensitively attuned to his or her signals and responds to the infant's cues with accuracy is more likely to develop a "secure base" from which he or she can explore the world (Bowlby, 2005). On the other hand, a caregiver who is less attuned with sensitivity to the infant's signals and cues and who is a slightly rejecting figure will foster an "insecure-avoidant base" in the infant, rendering such infants more likely to respond timorously. On the flip side a caregiver who is over-involved, intrusive, or who responds inconsistently to an infant's signals and cues fosters an "insecure-ambivalent" attachment with the infant. Thus, the internal working model from which such an infant will explore his/her view of self and others would evidence apprehensiveness and hesitation, with the infant progressing into adulthood lacking self-confidence (Holmes, 1993).

Emotional competence is another aspect of socio-emotional development (Denham et al., 2009). Children are capable of experiencing and expressing emotions, such as happiness, sadness, anger, and fear as early as infancy (Denham et al., 2007). By the end of toddlerhood and pre-school age they should be able to express social emotions like guilt, shame, and empathy. Thus, the ability to experience, express, and regulate emotions, and which is defined as emotional competence, is crucial for optimal and healthy functioning. This ability is dependent on both the interpersonal and intrapersonal dynamics of the child. During infancy much modelling and direction is required as the infant differentially reacts to his/her caregiver's emotions. By preschool and through kindergarten, the child is able to understand

basic "good" and "bad" emotions and takes on a more independent role in emotional regulation, but is still supported by the caregiver (Denham et al., 2007).

From as early as infancy, another aspect of social and emotional development is rooted, namely *self-perceived competence*. This is the ability to self-motivate, self-direct, and to successfully perform and master tasks that are developmentally age-appropriate (Denham, 2006). Infancy and toddlerhood, for example, mark the period for expression of ownership and possession. This is evident in the successful negotiation of developmental milestones, such as in toy-play with the self and others, as well as in the relationship with the primary caregiver. As the child develops into pre-school and grade-school age a more differentiated self-perception becomes evident (Trentacosta & Shaw, 2009). The child is able to be more self-aware and peer/teacher evaluations become influential as it impacts on the child's self-evaluation, which is associated with self-perceived competence. Likewise, self-perception is crucial as it influences the child's motivation and performance, and the child ultimately displays an increased awareness of differentiated physical, cognitive, and social abilities which influences the child's self-perception and competence (Trentacosta & Shaw, 2009).

Temperament is another construct associated with social and emotional development. According to Bohlin and Hagekull (2009), temperament consists of an amalgam of biological traits evident from early infancy, and which forms the unique characteristics of an individual. These characteristics are believed to be biological in nature but interaction with the socio-environment allows for individual behavioural patterns to be moulded, which in turn forms stability and consistency in character (Bohlin & Hagekull, 2009). However, it has been argued that stressful, life-altering events and early caregiving practices can bring about permanent changes to temperament and personality formation (Bohlin & Hagekull, 2009). This highlights the interactive, bio-psychosocial dynamic of development.

Given the foundational aspects of social and emotional development as described above, it is clear that there are important social and psychological implications for HIV-positive children and their caregivers, as a direct consequence of changes brought about by the HIV pandemic. Bohlin & Hagekull (2009, p. 596) argues that "…child stress experiences in connections with negative life events could be a risk factor for negative development both directly and in interaction with temperament". Not only does HIV have an adverse effect on a child's physical health, but it can be argued to challenge the healthy social and emotional development of infants and young children infected with and affected by HIV too. The resulting consequence of this adverse effect on socio-emotional development can manifest in poor social relationships or behavioural problems.

Furthermore, one could argue that children infected with and affected by HIV confront extraordinary challenges to their mental health, which can impact on their adjustment in both home and school environments. Given the fact that HIV/AIDS remains a highly stigmatised disease, infant and young children are likely to experience stress in indirect ways, mediated by parenting, family, and social-environmental systems. This is reflected in Bronfenbrenner's ecological model, which posits that "…children's development is embedded within micro contexts such as family, school, and peers, which interact to influence well-being and development, and are themselves embedded within and influenced by broader meso-and macro systems such as societal and social factors" (Tudge, Mokrova, Hatfield, & Karnik, 2009, p.4).

Research has reported that children living with an HIV-positive caregiver are at increased risk for a wide range of mental health problems that impact negatively on their emotional and behavioural adjustment (Forsyth et al., 1996; Forehand et al., 2002; Wild, 2001; Bauman, Silver, Draimin & Hudis, 2007). Studies from developed countries have reported

neurobehavioral impairments in HIV-positive children which include internalising (e.g. depression, anxiety) and externalising (e.g. oppositional deviant or conduct problems, attention deficit hyperactive disorder) symptoms (Brackis-Cott et al., 2009a; Smith et al., 2004; Puthanakit et al., 2010, 2012; Mintz & Epstein, 1992; Bauman et al., 2007). In a study exploring the effects of parental HIV infection on uninfected children, it was found that HIV-exposed children were at high risk of psychological disturbance (Forsyth et al., 1996). Bauman et al. (2007) in their study reported that HIV-exposed children are highly vulnerable and display higher rates of psychological symptoms that could be associated with factors like caregiver illness (e.g. hospitalisation), lack of social support, and socio-economic problems. Similar results were echoed in a study conducted by Lee, Gortmaker, McIntosh et al. (2005) where infected children displayed worse psychological functioning when compared to uninfected children.

Up until recently, studies have started to shift focus onto youth living with HIV since birth. This has resulted in more studies being conducted to trace the long term emotional and psychological trajectory of PHIV+ children, especially given that this cohort would have been exposed to optimal cART therapy over the past decade or two, at least in the US and Europe (Mellins & Malee, 2013). While most of these studies have been conducted in high-resource countries, it has relevance to South Africa and other LMIC where cART are becoming more and more easily available, despite continuing challenges with accessibility. With the widespread availability of treatment most of the PHIV+ children even in LMIC are maturing into adolescence and adulthood, and as such the implementation of evidence lead intervention programmes should become a priority (Mellins & Mallee, 2013), especially given the contextual differences. In their review of studies focusing on the mental health of PHIV+ youth, Mellins and Malee found that the research indicated that this cohort has a high

vulnerability to developing mental health problems (2013). However, the health and HIV status of the PHIV+ youth were found not to be always associated with their mental health outcome, in both developed and low resource countries. It emerged that contextual psychosocial factors such as parental physical and psychological health, stress, associated cognitive deficits and age had the strongest predictive outcome on the mental health status of the PHIV+ youth (Mellins & Malee, 2013). While, on the other hand, better mental health functioning among PHIV+ youth was found to be associated with caregiver-child interaction and social support.

In one of the few longitudinal studies, the Child and Adolescent Self Awareness and Health (CASAH) study, recruited youth up to age 16 years from four hospitals in the New York City, USA, to establish the rate of mental and emotional disorders in PHIV+ adolescents (Mellins, 2012). Using the Diagnostic Interview Schedule for Children (DISC-IV) the research established a prevalence rate of 61% of psychiatric disorders among PHIV+ youth (Mellins, 2009). Over time there was an increase in the percentage, with the prevalence for a mental disorder reaching up to 69% among both PHIV+ and comparative PHEU cohort (Mellins, 2012). Substance use disorders were found to be low in both PHIV+ and perinatally HIV-exposed but uninfected (PHEU) youth. Compared to the PHEU youth, the PHIV+ youth had more mental health services at 18 months follow-up. Furthermore, at 18 months follow up the prevalence of any disorder also decreased substantially to 44 % in PHIV+ youth, while for PHEU youth no significant change was observed (55%). Moreover, a significant increase in the prevalence of mood disorder in PHEU was observed (Mellins, 2012).

Similar to CASAH study, both PHIV+ and PHEU youth were found to display psychiatric disorders in the International Maternal Pediatric Adolescent AIDS Clinical Trial Group

(IMPAACT) longitudinal study that comprised of 1055 PHIV+ youth, PHEU, and HIV-youth with an HIV+ family member (HIV-A) up to the age of 17 years across 29 USA sites (Gadow, 2012). Furthermore, they displayed higher rates of psychiatric disorders when compared to the general population. Most commonly identified mental disorders were ADHD, depression, anxiety and disruptive behaviour (Nachman, 2012). The severity of the disorder was not related to any specific ART regimen used. A large cohort, Pediatric HIV/AIDS Cohort Study (PHACS) with youth up to age 16 years from across 15 sites in USA and Puerto Rico, found that among PHIV+ youth a detectable viral load and being raised by a biological mother, increased the risk for mental health problems and poor adherence to ART therapy (Mellins, 2011). PHIV+ youth were also at greater risk for mental health issues, sexual risk behaviour and substance use when compared to PHEU youth. The Longitudinal Epidemiologic Study to Gain Insight into HIV/AIDS Children and Youth (LEGACY) study conducted across 22 USA sites with youth up to age 24 years, found that 55% of 197 PHIV+ youth was engaging in at least one risky behaviour (i.e. ART non adherence, substance use, sex) and the risk was associated with having a comorbid psychiatric diagnosis of either mood disorder, disruptive behaviour disorder, and ADHD (Kapetanovic, 2011).

Studies on the mental and psychological health among HIV+ youth from LMIC, albeit limited, have also found that PHIV+ youth from low resource countries are at greater risk for emotional and behavioural problems when compared to the general population. A cohort study of PHIV+ youth up to the age of 15 conducted in Zambia showed that the youth displayed significant mental health problems when compared to a normative matched group using the Strengths and Difficulties Questionnaire (SDQ) (Menon, Glazebrook, Campain, & Ngoma, 2007). The PHIV+ youth displayed significantly more emotional symptoms, peer

related problems and total difficulties. Similarly Lowenthal and colleagues found that just over 17 % of the PHIV+ youth up to age 17 years met criteria for emotional and behavioural problems on the Pediatric Symptoms Checklist (PSC) in a cohort of PHIV+ youth from clinics across South Africa and Botswana (2012). The findings also strongly suggested that depression, symptoms of attention deficit disorder and executive dysfunction in the PHIV+ youth was more commonly associated with virologic failure.

Evidence of behavioural and emotional problems among PHIV-infected children and youth reinforces the need for more studies to be conducted in LMIC, where HIV continues to be a problem and HIV+ people continue to struggle with access to cART; due to lack of available resources as a consequence of poverty. This is especially important, given that both poverty and mental illness adversely impact on child development (Costello, Compton, Keeler, & Angold, 2003) as it exposes children to various vulnerabilities (i.e. nutritional security, ART non-adherence, accessibility problems, risk behaviours (sexual or substance related), etc.).

Caregiving in context of HIV/AIDS and Poverty

The role of caregiving for a child in many cultures is the primary responsibility of the mother. Young children especially, are more dependent on their caregivers and as a result vulnerable to declines in the quality of caregiving (Murphy & Marelich, 2008).   Given the multigenerational nature of HIV-infection it is worthwhile, from a research perspective, to explore what impact the disease is having on this role; more so given the fact that 98% of children infected with HIV results from mother-to-child transmission (WHO/UNAIDS/UNICEF, 2010). Furthermore, with more and more perinatally infected infants progressing into childhood and adolescence, the need for empirical data to demonstrate the impact this pandemic is having on the surviving children and their family structures is underscored. This is especially so given that some surviving children are raised

by mothers infected with HIV, as well as many being orphans living in abject poverty (Coscia et al., 2001; Petersen et al., 2010a).

Parental Health

Until recently most research focused exclusively on parenting interactions with healthy children and those children confronting chronic illness and disabilities, (Sayre et al., 2001; Treyvuad et al., 2009a,b). While there is a growing number of studies on the plight of caregivers infected and affected by HIV/AIDS in developed countries, there are still very few from developing countries (Murphy & Mareleich, 2008). Not only do HIV-positive mothers have to battle their own illness and witness the deaths of others in the same predicament, they also have to deal with the knowledge that their children are infected with the disease and still raise them (Huges & Caliandro, 1996; Hackle et al., 1997). As a result they are often burdened with the inability to confront their own mortality as well as that of their children. It is documented that childhood chronic illness brings about significant strain on the family system, including high rates of maternal depression and anxiety, marital distress, and adjustment problems (Bachanas et al., 2001a,b; Treyvaud et al., 2009, 2010). Likewise, parental illness has been shown to impact on caregiving capacity and increases the risk of psychological problems in affected children (Patcher et al., 2006; Forsyth, 2003a, b).

The caregiving behaviour of a parent and the quality of the early parent-child relationship are two factors that have been identified as influencing and promoting development outcomes in children (Sayre et al., 2001; Richter, 2004; Richter & Grieve, 1991; Anderson, Doyle, & Victorian Infant Collaborative Study Group, 2003). As stated by Sameroff et al. (2010, p. 101), "…development, particularly in the earlier years, is a function of ongoing cycles of child-caregiver transaction that weave together the fabric of psychological functions, including the mental health of the young child". Based on this premise, the caregiver's health

and overall well-being is thus of critical importance in relation to exploring the child's health and wellbeing. Mothers infected with HIV commonly live as single parents in economically disadvantaged environments with not much social support and their children may therefore be at risk of ill-health (Brandt et al., 2006). When a caregiver confronts a chronic illness, the children usually suffer as the caregiver's capacity to care for them becomes interrupted (Richter, 2004). The consequences of such a disruption can have multiple adverse effects on the psychological functioning, neurodevelopment, physical health, and wellbeing of the affected children (Richter et al., 2009; Richter & Grieve, 1991). In addition to this, poor child-health adds even greater demands to a caregiver's already strained load (Richter, 2004). Consequently, in situations where a caregiver is infected with HIV, she is now confronted by the dual challenge of being a patient and a caregiver (Hackle et al., 1997).

The multiple stressors associated with being HIV-positive and caring for HIV-positive children are most likely to place these women at an increased risk of mental health problems, which in turn will exacerbate the stress associated with parenting. This may result in a vicious cycle impacting the caregiver-child dyad negatively. Positive caregivers may be unable to cope with the stressful reality of their HIV illness and may also be overburdened by carrying the sole responsibility of caring for their infected children (Brandt et al., 2006). Being HIV positive is also associated with the increased risk of having mental disorders (see Brandt, 2009 for review). For example, one of the most commonly associated mental illnesses is depression, which is rooted in life circumstance, illness, poor support networking structures, and daily life stress (Brandt, 2009). Literature on research investigating the impact of maternal depression is in consensus, in that it has been associated with adverse outcomes on both parenting and childhood neurocognitive and socio-emotional development (see Kiernan & Huerta, 2008; Gagliardi & Honigfeld, 2008; Knitzer, Theberge & Johnson, 2008). With

regards to the impact of parental depression on the parenting role, research suggests that there is a breakdown in attachment between the caregiver and child, and as a result the caregiver-child relationship suffers. Furthermore, due to the debilitating nature of parental depression, parents are less likely to carry out their functioning role as parents and as a result are less likely to engage in behaviour repertoires consistent with enhancing a child's neurocognitive, social and emotional development, and well-being (Knitzer et al., 2008; Gagliardi & Honigfeld, 2008).

Caring for a child is a time-consuming and emotionally-taxing activity that becomes exponentially more burdensome if the caregiver is ill and has a child suffering from a chronic illness. Hence their increased vulnerability to developing depression, especially in the absence of poor social and financial support structures (Tompkins, Henker, Whalen et al., 1999). The caregiver may be overwhelmed with constant concerns over the child's health and worries about the future, and as a result may be flooded with feelings of inadequacy. These concerns may create heightened levels of distress and in turn these caregivers may experience a lack of confidence in their ability to parent as they are unable to meet their children's needs. In a study conducted by McLearn, Minkovitz, Strobino, Marks & Hou (2006) the parenting practices of depressed mothers were investigated and the researchers concluded that depressed mothers engaged in parenting practices most likely to impact negatively on the children's overall development. Parenting practices showed no clear structure and routine; and parents were less likely to engage in play behaviour with the child, breastfeed, talk to, read books to, or respond to the child's nonverbal cues (McLearn et al., 2006). The consequent effect on the child's developmental outcome can be devastating and may even have long-lasting implications for the child. As indicated by Knitzer et al. (2008), depressed caregivers are more likely to expose their children to health risks and less likely to

adhere to health advice for themselves and their children. Depressed caregivers will also find it more difficult to respond to and manage chronic illness in their children (Knitzer et al., 2008). As a result, children parented by depressed caregivers are known to display a spectrum of cognitive and socio-emotional problems (Gagliardi & Honigfeld, 2008), including strong associated behavioural problems, such as attention-deficit/hyperactivity disorder, conduct problems, anger and violent behaviour, depression, and anxiety (Kiernan & Mensah, 2009; Knitzer et al., 2008). Moreover, cognitive deficits observed in children who are exposed to depressed caregivers have shown to negatively affect school readiness and the success of these children (Knitzer et al., 2008), and they have even exhibited deficits in social competencies (Kiernan & Huerta, 2008). Consequently, these children who have a greater tendency to engage in negative social behaviours, are at greater risk of peer pressure, and have a low social concept. Finally, children parented by depressed caregivers have a high risk for developing antisocial behaviour (Gagliardi & Honigfeld, 2008).

Parental Stress

The maternal experience of caring for a child with a chronic illness or disabilities is well documented. Parents of these children experience heightened levels of psychological stress associated with their situation (Drotar et al., 1997; Wiener, Theut, Steinberg, & Riekert, 1994) and a study conducted by Drotar et al. (1997) exploring the correlates of psychological distress among mothers of children and adolescents with haemophilia and HIV infection found that these parents experienced increased levels of psychological stress. Wiener and colleagues (1994; 1995) found in their studies that parental psychological adjustment to children with an HIV diagnosis was associated with high levels of distress and an increased risk for psychiatric illnesses, such as depression and anxiety. This co-morbidity is associated not only with the burden of caring for an HIV-infected child, but is also fuelled by feelings of

guilt, anxiety concerning their health, impending fear of dying, and the uncertain future of both themselves and their children (Wiener et al., 1994, 1995; Hughes & Caliandro, 1996). In a study exploring the predictors of psychological adjustment in school age children infected with HIV, Bachanas et al. (2001) concluded that caregivers' psychological distress was found to be a significant predictor of a child's psychological adjustment.

As increased stress is placed on the mother as the primary caregiver, so does parenting stress rise. The emotional toll of parenting can be high, partly because parents are relatively socially isolated and do not always get support from the community and their extended family (Brandt et al., 2006). Many HIV-positive mothers must deal with their illness in isolation owing to the stigma associated with the disease, as well as prevalence for HIV-related discrimination remaining rife in communities, and their fear of rejection and abandonment by relatives and close associates (Ingram, & Hutchinson, 1999; 2000). These experiences further compound the stress experienced by mothers as caregivers, thus complicating the problems inherent in parenting. As indicated by Forsyth (2003a), children born to mothers infected with HIV have shown to present more psycho-developmental problems, which is likely to be a consequence of the disruption in the parenting and caring capacity of the mother as a result of the HIV infection.

Parental Interaction

The strain of caring for a sick child while managing one's own illness and bearing responsibility for children is a tremendous burden on many mothers infected with HIV (Bachanas et al., 2001a). As is the case of rearing children with other chronic illnesses, maternally HIV-infected children tend to make unique and often greater demands on their caregivers. Therefore, it is plausible to assume parenting for caregivers of children infected with HIV is marked by increased worry, emotional pain, and other concerns when compared

to caregivers of children without illness (Button, Pianta, & Marvin, 2001). Coscia et al. (2001) in their study exploring the relationship between home environment and HIV-infected children's cognitive functioning found an association between parental interaction and disease severity. As the child's disease progressed, the caregiver's interaction became less stimulating and supportive, thus creating a higher vulnerability for poor cognitive development and socio-emotional functioning. These researchers suggest that as the HIV-positive child becomes more ill, perhaps the caregivers' relationship with the child weakens. One hypothesis is that the HIV-positive caregiver does not expect the HIV-infected child to survive beyond early childhood and this influences the caregiver's capacity to bond with the child. Another hypothesis is that the sheer burden of caring for a chronically ill child, particularly under harsh conditions, may cause resentment. Equally, HIV can be argued to cause a breakdown in the quality and quantity of the critical early relationship between caregiver and child. Poor bonding, for example, may in turn impact on developmental outcomes. As shown in studies of pre-term babies; environmental factors, such as effective parenting characterised by warmth, sensitivity, consistency, and connectedness, have a positive relationship with cognitive and social-emotional competence (Treyvuad et al., 2009a; Smith et al., 2000).

Effective parenting has been shown to facilitate healthy caregiver-child dyads and is associated with greater optimal development outcomes in children (Richter, 2004). This premise is located within the theoretical perspective of secure attachment coined by John Bowlby (Bretherton, 1992). Bowlby was the first of many theorists who described the importance of caregiver-child relationships and their effect on children's development outcomes (Bretherton, 1992; Richter, 2004). According to Bowlby (1982), securely attached children have an internal representation of the caregiver as stable, responsive, and caring that

serves to provide the child with a secure basis from which they can explore their environment, grow, and develop (Bretherton, 1992). Subsequent research related to parenting has successfully demonstrated the relevance of attachment models. Treyvaud (2009a) and colleagues in a study of pre-term infants, found a positive relationship between cognitive development and sensitive caregiving. Therefore, children whose caregivers interacted with them in a warm and positive manner showed particularly positive outcomes in cognitive development (Treyvaud et al., 2009a). Similar results were echoed in a study conducted by Richter and Grieve (1991) where the relationships between home environment and cognitive functioning were explored amongst a sample of South Africans. Consensus from these studies was that facilitative, warm, positive, and sensitive caregiving contributed to positive cognitive development and healthy psychological functioning in these ill-health children. Thus, the results illustrate that the quality of a caregiver's interactions and his/her ability to create an environment conducive of learning and development is positively associated with cognitive development in children, and operates as a protective factor against the adverse effects of poverty. Richter (2004) recommended that such effective parenting is important and should be encouraged, as it can mediate the effects of poverty and promote development in children. Consequently, the findings of these particular studies are encouraging as they demonstrate the importance of enhancing caregiver-child interaction, which in turn can promote optimal outcomes in children.

Research has shown that parental illness impacts negatively on positive parenting, as it increases parental stress and disrupts the parent-child relationship. This has, stimulated interventions that can enhance positive parenting in HIV+ caregivers in low-and middle income countries. While maternal illness is considered a risk for poor outcome in their children, evidence also suggest where HIV+ mothers were given the opportunity to enhance

their capacity to deal with their illness and to strengthen parent-child relationship, the outcomes proved to benefit both the mental health of the caregiver and the child (Mavhu et al., 2013; Murphy & Marelich, 2008). A few studies that emerged have started looking at the resilience in young children whose mothers are living with HIV in an attempt to improve developmental and psychosocial outcome for both the HIV-infected mother and child (Mahvu et al., 2013; Ellof et al., 2014; Murphy & Marelich, 2008; Visser et al., 2012; Richter et al., 2009). In the study with HIV+ mothers from South Africa, there were also HIV+ mothers who were able to express their own desires to live positively, for themselves and their children; they were also able to recognise how their own behaviour was affecting their children; and this had a positive impact on their ability to parent and communicate effectively with their children (Visser et al., 2012). This suggests that there are caregivers who show resilience and work very hard to care for their children. Interventions directed at mother-child relationship were able to further enhance HIV+ mothers' capacity to cope better with their own illness and as result able to build psychological resilience in their children (Visser et al., 2012). It is well demonstrated that resiliency has the capacity to affect the long-term trajectory of a child's emotional, cognitive and adaptive functioning. In another large study conducted in Tswane, South Africa among 390 mother-child pairs, an intervention that focused on mother-child dyads was not only able to enhance the parent-child relationship, but it also resulted in significant reduction in children's externalising behaviours, while improving on the children's adaptive functioning (Eloff et al., 2014), for at least a year following the intervention. Evidently, also in the study was a significant reduction in depression among children. Importantly, benefits were not only noticeable for the children but also for the HIV+ caregivers who engaged in less frequent avoidant coping behaviour (Eloff et al., 2014). Similar finding was found in Murphey & Marelich, who established that HIV-positive mothers in their study were able to better cope, and this translated into better

adaptive potential in their children (2008). The benefit of interventions focusing on caregiver-child dyads has the potential to have a long-lasting resilient effect on both children and their HIV+ caregivers. Recently, the first large study that examined the relationship between HIV/AIDS and positive parenting, using a sample of 2,477 caregiver-child dyads was conducted in KwaZulu-Natal (Lachman, Cluver, Boyes, Kuo, & Casale, 2014). Findings from the study indicated that HIV+ caregivers and those caring for AIDS-orphaned children engaged in less positive parenting in comparison to non-affected families. However, non-HIV sick caregivers or those caring for orphans of other chronic illness were not associated with any positive parenting. The findings were mediated by psychosocial risk factors, such as poverty, caregiver depression, etc. However, the study does suggest that a parenting programme that is aim at improving caregiver psychological health and encouraging positive parenting has the potential to safeguard against risks of poor child psychological and physical health outcomes in HIV affected families living in poverty. This finding is promising that HIV-exposed caregivers have the ability to engage positively with their children, albeit the finding suggests that the effect size was small (Lachman et al., 2014). This nevertheless suggests, if adequately tailored interventions are implemented to look at strengthening child-caregiver relationship, that it can ameliorate the children's response to the exposed adversities. This, in turn, has the potential to have a lasting impact on children's developmental and psychological outcome. The findings from these studies is promising as it indicates that while many children are at risk for various negative psychosocial outcomes, that mothers living with HIV and those caring for AIDS-orphans can be resilient and are able to take adequate care of their children, despite the challenges.

Extended Relatives

On the other hand, the increasing HIV pandemic in South Africa poses a substantial threat with a detrimental impact on the provision of care for children. As biological parents become ill or even die and are unable to care for their children, the responsibility of caring for these children is often transferred to grandmothers, aunts, and other children and relatives (Akintola, 2008a; Petersen et al., 2010a,b; Cluver & Gardner, 2007a; Cluver & Gardner, 2007b; Bauman et al., 2006). As a consequence of the impact of HIV the family structure may change. Due to the incapacitating nature of HIV/AIDS or even deaths of parents, the need to provide some form of guardianship for the affected and infected children must be prioritised (Cluver & Gardner, 2007c). As indicated by Richter et al. (2004b) it is not uncommon in the African context for relatives to assume a caretaking role of HIV orphans. However, the assumption of caretaking responsibility often occurs in the context of other factors, such as having to raise other grandchildren and cousins. These relatives are often still in the process of grieving for multiple family members who died of HIV and are even confronted with continued stigmatisation from the community (Petersen et al., 2010a; Akintola, 2008a,b). This often places additional stress on relatives caring for HIV-infected children.

Furthermore, the abovementioned caregivers may experience heightened levels of psychological distress as a result of the increased stress associated with their situation, and may require social and health support too (Petersen et al., 2010b; Asante, 2012). Literature, on grandparents as caregivers of HIV-infected orphans shows, for example, that caregivers' personal ill health may prevent them from adequately responding to the needs of the child (Musile, 1998). In the context of limited capacity, foster caregivers, particularly grandparents, may prioritise the physical wellbeing of children over the learning, intellectual, and emotional

needs of said children. Correspondingly, the coexistence of HIV with poverty further limits caring capacity, as caregivers frequently have difficulty accessing health services, they have to deal with complex medical treatment, and struggle to acquire financial assistance to meet the health and nutritional needs of the children (Cluver & Gardner, 2007a; McLoyd, 1990,1998; McLeod & Shanahan, 1993,1996).

In a study conducted in four districts of Thailand, researchers found that children reared by their grandparents presented with poorer cognitive functioning and were at higher risk of developmental delays when compared to children reared by their biological parents (Nanthamongkolchai et al., 2009). The biological parents, when compared to non-parents as caregivers, promoted holistic development of the child's emotional, physical, and intellectual capacity. In another study conducted among Thai children by Puthanakit et al. (2010), 75% of HIV-infected children were cared for and raised by their grandparents and other relatives, while 73% of HIV-affected and normal controls lived with their biological parents. Emerging from this study, the HIV-infected children were at higher risk of poor neurocognitive functioning when compared to the controls, despite adjustments to accommodate socioeconomic status and family structure.

Poverty

Despite the shift in South Africa's political dispensation from apartheid to democracy, it should be noted that a large number of South African citizens still live in abject poverty (Stats SA, 2012). It is estimated that the South African child population account for approximately 18.7 million, with 2.3 million of them still being forced to live in shacks or some form of informal dwelling (Iversen et al., 2011). Moreover, from this population approximately 30% under the age of five live in over-crowded conditions. In a study conducted in 2007 by the Housing Development Agency, it was found that approximately 6000 households are still

headed by children under the age of eighteen years (National Department of Human Settlement, 2013).

Living conditions for a large number of people are still characterised by a lack of access to quality basic services, including adequate housing, electricity, safe and clean running water, toilet facilities, and refuse removal services (Statistics South Africa-StatsSA, 2007). In 2008 Iversen et al. (2011) found that nearly 7 million children in the country still do not have access to clean, safe, drinkable water in their households.   According to StatsSA (2007), about 25.2% of households in the Eastern Cape had no access to flush toilets as compared to the Western Cape which had more than 50% accessibility. In terms of access to piped-water the Eastern Cape is considered the worst off, remaining below the national average (StatsSA, 2007). While it can be argued that some improvement did occur since the new political dispensation assumed power, a large number of children are still exposed to harsh socioeconomic living conditions (StatsSA, 2007; National Department of Human Settlement, 2013; Iversen et al., 2011). These conditions create an environment that fuels vulnerability to mental and physical illness, and easily spreading diseases.

The high levels of stress and co-morbid psychiatric conditions, such as depression, associated with caring for chronically ill children have been shown to have a negative impact on parenting (Colletti et al., 2009; Costello et al., 2003; Cooper & Murray, 1998; Ramchandani et al., 2005). The capacity to care for children usually suffers, as the impaired mental state of a parent living with a primary chronic life-threatening illness like HIV, does not only disrupt parenting ability, but also adversely influences the attachment between parent and child (Knitzer, 2008). The disruption is further exacerbated by the fact that HIV often co-exists with poverty, which means the infected mother and child will probably live in socio-

economically disadvantaged contexts that pose additional challenges (Hochhauser et al., 2008; Cluver et al., 2009; Engle & Black, 2008). Research has established a link between the negative effects of poverty on parental roles and child development (Costello et al., 2003; McLeod & Shanahan 1993, 1996; McLoyd, 1990, 1998; Hashima & Amato, 1994). Poverty has also been associated with negative parental health, which independently and jointly impact on the child's cognitive and social-emotional well-being in an adverse manner (Coscia et al. 2001; Sayre et al., 2001). Furthermore, economic deprivation creates a catalyst for psychological stress and vulnerability amongst caregivers, which further predisposes them to depression (Kiernan & Huerta, 2008). Hence, a caregiver confronting impoverishment on a daily basis is more likely to be stressed, which in turn may impede the quality and quantity of their parenting (Brandt et al., 2006; Lachman et al., 2014). The implication of this dynamic has an overwhelmingly negative effect on the child's developmental outcome.

Puthanakit et al. (2010), in their study of HIV-infected children aged 6 to twelve years, found for example that family structure, low caregiver education, and low family income were highly associated with the risk of poor cognitive functioning in the sample. Low socio-economic status (SES) has also proven to be associated with a variety of obstacles hindering effective rearing, such as inadequate nutritional provision, lack of time for cognitively stimulating activities in the parent-child dyad, and poor parent-child relationships owing to associated stress (Hochhauser et al., 2008). The association between SES and home environment therefore suggests that children infected with HIV and who are living in poverty, also live in less stimulating and less supportive home environments. This is certainly plausible given the reciprocal nature of the child-parent dyad and their environment. Additionally, maternal infection may affect the quality of caregiving which, when combined with poverty, may further frustrate the attachment relationship, resulting in poor child-

development outcomes (Coscia et al. 2001; Knitzer et al., 2008). Studies focusing on healthy, preterm, disabled, and chronically ill children also support the premise that poverty serves as a risk factor for poor cognitive and socio-emotional functioning outcomes (Sayre et al., 2001).

Some researchers argue that poverty is the single factor most associated with HIV/AIDS vulnerability, physical and mental ill-health, impaired parent-child dyads, and child development outcomes (Coscia et al., 2001; Gagliardi & Honigfeld, 2008; Kiernan & Mensah, 2008; Kiernan & Huerta, 2008). In a large-scale cohort study (N=13, 877 children) in the United Kingdom (UK), Kiernan & Huerta (2008) explored the impact of economic circumstances and maternal depression on children's cognitive and behavioural problems at three years of age. The researchers found that poverty had a stronger association with poor cognitive and behavioural outcome in children, whereas depression was strongly associated with behavioural outcome. Furthermore, poverty not only directly impacted negatively on a child's outcome, but was also associated with poor maternal wellbeing, which indirectly impacted negatively on a child's outcome. In other words, caregivers who were depressed were also living in impoverished circumstances, lacking the resources (physical, mental, and material) to engage with their children (Kiernan & Huerta, 2008).

Similar results emerged from a longitudinal study conducted in the UK where poverty, maternal well-being, and family status was examined to see what impact it had on children's cognitive and behavioural development in early childhood (Kiernan & Mensah, 2008). Children exposed to depression and poverty had significantly negative cognitive and behavioural outcomes. Moreover, poverty still remains the strongest predictor of poor cognitive and behavioural outcomes, even in the presence of caregiver depression (Kiernan & Mensah, 2008). From the above mentioned research on poverty the catastrophic effects it has

on quality of caregiver-child relationship, child-development outcome, and the caregiver's quality of life becomes evident.

In a longitudinal study, researchers studied the association between poverty and child mental health, through a naturalistic experimental approach, by looking at three groups of families; families who moved out of poverty (ex-poor), those who remained poor despite receiving an intervention (persistently-poor), and those who were never-poor (Costello et al., 2003). Children who moved out of poverty displayed a decrease in the frequency of psychiatric symptoms. This association had a lasting impact on the child's psychological well-being; and their symptoms levels were virtually comparative to those who were never exposed to poverty by the fourth year.   Moreover, the strongest effect was observed in the children who moved out of poverty as they displayed reduction in behavioural symptoms such as conduct and oppositional disorders. Children who were poor more commonly displayed anxiety and depression, with very little change to it when they moved out of poverty. Interestingly, parental supervision emerged as the only mediating effects of poverty and behavioural symptoms but decreased in adolescence, albeit more so for the persistent-poor group. The children's behavioural symptoms was affected by the fact that persistently poor parents did not have the time available to devote to supervision as they had to increase their working time due to financial constraints. These findings suggest that interventions targeted at strengthening caregiver-child relationship can benefit from additional attention to the impact of poverty and the mental health of the caregiver-child dyad, even within our families affected by HIV/AIDS. While generalisation to children living with HIV must be cautioned, the finding from this study nevertheless holds promise to low-middle income country such as South Africa where poverty coexists with HIV/AIDS and mental illness.

Nutritional Status

Children from low-income families are particularly vulnerable to nutritional deprivation and are at increased risk of various medical and developmental deficits. Malnutrition not only affects the physical health (i.e. immunological resistance creating vulnerability for disease and illness) of children, but also jeopardises neurodevelopment through its adverse effects on brain development, poor neurocognitive development, growth, and failure to thrive academically (Engle, Grantham-McGregor, Black, Walker, & Wachs, 2009; Engle, Black, Behrman, Cabral de Mello, Gertler, Kapiriri, Martorell, Young, & the International Child Development Steering Group, 2007a; Morley et al., 1999, Morley, 1998; Morley & Lucas, 1994). Moreover, in low-income countries where there is the burden of an already super-imposed medical condition such as HIV/AIDS, the chances and adverse implications of malnutrition worsens, particularly more so as these communities are often also battling with the adverse effects of poverty (Iversen, du Plessis, Marais, Moreseth, Hoisaether, & Herselman, 2011). Despite the fact that South Africa is almost 20 years into democracy, the majority of its people are still living in poor socioeconomic conditions, with high rates of poorly educated individuals and unemployment a reality for many (Iversen et al., 2011). Malnutrition therefore has its roots in poverty and sociocultural inequalities in South Africa, as is the case elsewhere in the world (Iversen et al., 2011; Lozoff, Jimenez, & Smith, 2006).

Childhood malnutrition can be classified clinically based on three indicators: stunting, wasting, and underweight, which are derived from the anthropometric data of the child. These indices are internationally accepted and expressed using the following indices: *low* height for age (stunting), *low* weight for height (wasting), and *low* weight for age (underweight) (Gribble, Murray, & Menotti, 2009; Alderman, Hoogeveen, & Rossi, 2006, 2009; Labadarios, Steyn, Maunder et al., 2005). Stunting is reported to be the most common

nutritional disorder affecting South African children's physical growth and cognitive development (Berry, Hall, & Hendricks, 2009, 2010), and is also considered the strongest predictor of mortality in children below five years of age (Berry et al., 2010). In the South African National Food Consumption Survey, stunting was found to be the highest ranked nutritional disorder affecting children in South Africa (Kruger, Swart, Labadarios et al., 2007). Furthermore, according to the South African National Food Consumption Survey-Fortification Baseline conducted nationwide in 2005, it was reported that in the cohort of children ages 1 to 9 years of age, 20% were stunted while 10% were under weight (Labadarios et al., 2007). Additionally, the highest rates of malnutrition occurred predominantly in rural and semi-rural settings, such as your farms and informal settlements. (Labadarios et al., 2007; Labadarios et al., 2005a,b; Iversen, 2011).

Additionally, research literature estimates that 50.6 million children under the age of five years are malnourished in developing countries, with malnutrition accounting for 60% of all deaths occurring among this age cohort (Faruque et al, 2008). Bourne, Hendricks, Marais, & Eley (2007) in their study "*Addressing malnutrition in young children in South Africa*" posit that despite major advancements made to improve the malnutrition status in South Africa over the past 10 years and more, improving child health remains a top priority as a continued deterioration in child health still persists. One of the reasons attributed to this alarming picture is the HIV/AIDS pandemic and the challenges it poses to the overall health of the child. Poor nutrition (inclusive of micronutrient deficiencies), growth failure, and weight loss have all been linked to HIV/AIDS infected children in South Africa (Steenkamp, von der Marwitz, & Giovanelli, 2004). In a study of HIV-positive pre-school children it was observed that more than 60% of the HIV-infected children had multiple micronutrient deficiencies, while >30% of them were underweight and >50% were reported to be stunted (Steenkamp et

al., 2004). In a later study conducted in Manguang amongst antiretroviral-naive-HIV-positive children, it was reported that 41% were underweight, while more than 80% were stunted and three percent wasted (Steenkamp et al., 2009). The results from this study are significant in that it was able to demonstrate that HIV not only compromises the nutritional status of HIV-positive children, but also the improvement thereof, even though they had access to a daily balanced meal (Steenkamp et al., 2009). The study also reported a relationship between growth failure and high HIV-1 viral load, and a compromised immune system in these children (Steenkamp et al., 2009). Additionally, it has been shown that HIV-positive infants with growth failure and a compromised immune system are at increased risk of premature death (Steenkamp et al., 2009). However, the results need to be interpreted with caution as it cannot be denied that there are other factors that contribute to the HIV-infected child's compromised health (Steenkamp et al., 2009). These results perhaps speak to the importance of not only healthy nutrition, but also early access to ART in children infected with HIV (Steenkamp et al., 2009).

Bourne et al. (2007, p 231) argue that HIV/AIDS has provided its own challenges by "…giving rise to multiple nutritional-related diseases". Malnutrition is argued to be one of the main causes of illness and death in children. As it weakens the child's body, it creates physical vulnerability, such as a weak immune system which disenables them to fight off any opportunistic infections caused by HIV/AIDS (WHO, 2007). According to the 2003 National burden study conducted by the Medical Research Council (MRC) in South Africa, the infant mortality rate increased by 60% in the year 2000, despite various nutritional and health-related mechanisms being in place (Bourne et al., 2007). Of all these deaths, 30% was attributed to micronutrient malnutrition, diarrhoea, low birth weight, and other infections

(Bourne et al., 2007). Consequently, HIV/AIDS was said to remain the highest contributor to the prevalence in and increased severity of malnutrition in children (Bourne et al., 2007).

However, the situation is said to have improved since, owing to the roll-out of PMTCT. An evaluation of the PMTCT on a national representative sample reported greater uptake of the programme, with evidence of a decline in the transmission of HIV from mother to child (Nannan, Dorrington, Laubscher, et al., 2012). This finding may be indicative of an expected decline in the under-5-mortality rate. The introduction of exclusive breastfeeding among HIV-positive mothers and the uptake of mother and/or infant antiretroviral treatment prophylaxis are believed to contribute significantly to the decline in the under-5-mortality rate (Nannan, et al., 2012). Moreover, an estimated eight percent increase of nevirapine prophylaxis uptake among HIV-infected pregnant women from 2004 (22%) to 2005 (30%) has been reported by the United Nations (Nannan, et al., 2012).

Furthermore, the response to the nutritional status of HIV-infected children is currently incorporated in the Integrated Nutrition Programme (INP) of South Africa (Bourne et al., 2007), while micronutrient supplementation and food fortification initiatives have been implemented country wide. The uptake of vitamin A, iron, and iodine supplementation is rolled out nationally for children under the age of six years and for women within the first three weeks post-partum (Bourne et al., 2007). HIV-positive children also receive food supplementation as part of their antiretroviral treatment from local treatment centres. However, despite the observed pattern of change in child mortality and the efforts to bring about improvements with regards to the health and nutritional status of South African children, the challenge of malnutrition remains constant for HIV-infected children with

adverse health implications and premature mortality (Kimani-Murage, Norris, Pettifor, et al., 2011).

Globally, nutritional status is used as an appropriate measurement for gauging the well-being of children, and in particular to identify those children who are at risk of disease vulnerability and developmental deficits (Faruque et al., 2008; Engle, Grantham-McGregor, Black, Walker, & Wachs, 2009). There is a considerable amount of evidence confirming that nutrition influences cognitive performance and socio-emotional development in children (Morley, 1998; Black, Dubowitz, Hutcheson, Beren-Howard, & Starr, 1995; Engle et al., 2007; Engle et al., 2009). Likewise, research on child development has consistently demonstrated that a child's school readiness, as well as their academic and employment success, is dependent on both cognitive and social emotional functioning (Blair, 2002). Stunted children have also been found to lack social and emotional competency skills, ranging from apathy, insecure attachment, and less playfulness, to shyness and withdrawal in addition to negatively affecting their cognitive faculties (Engle et al., 2009).

Various studies found that when there is nutritional deficiency in children, their development is more likely to be compromised (Grantham-McGregor et al., 2007; Walker et al., 2007; Engle et al., 2007; Walker et al, 2011, 2000, 1991). Grantham-McGregor et al. (2007), for example, demonstrated that early childhood stunting, combined with poverty, places children at risk of developmental delays, thus curbing their potential to excel in their school learning career. This echoes the results that emerged from Walker et al.'s (2007) study, which indicates that impaired cognitive ability has adverse implications on a child's school readiness, socio-emotional functioning, and sensorimotor development.

Certain deficiencies, such as iodine deficiency, can result in irreversible mental retardation in children, which means the child's potential for future productivity is compromised (Engle et al., 2009; Grantham-McGregor et al., 2007; Grantham-McGregor et al., 1999a; b). Also, as suggested by some intervention studies, the provision of nutritional supplementation alone or in combination with cognitive and psychosocial stimulation to malnourished children, not only resulted in improved cognitive functioning, but also enhanced sensorimotor development (Engle et al., 2007).

In a prospective, cohort study conducted in Jamaica the effects of childhood psychosocial stimulation and milk-based formula supplementation on the cognitive and academic functioning of stunted children was evaluated (Walker et al., 2005). Results from this study provide evidence that psychosocial stimulation in early childhood has positive benefits for cognitive and educational outcomes in stunted children (Walker et al., 2005). Additionally, learning deficits such as reading and mathematics problems were more evident in the stunted children who did not received stimulation when compared to those who did (Walker et al., 2005). They also presented with global cognitive deficits as measured on the standardised intellectual assessment WAIS, with deficits in working memory, non-verbal reasoning, and language (Walker et al., 2005). The Jamaican study showed that in relation to long term outcomes, stimulation resulted in better cognitive outcomes as compared to supplementation alone (Walker et al., 2005).

A study conducted by Faber, Kvalsvig, Lombard, & Benade (2005) in South Africa assessed the impact of iron and other micronutrient supplementation, in the form of fortified porridge, on infant development in a randomised control trial. The research results concurred with most other studies, as children not only showed significant improvement in their iron status and a reduction in anaemia, but also presented improved sensorimotor and cognitive development

after 6 months of daily fortified porridge consumption, especially when compared to those in the non-fortified group.

Morley (1998) echoed similar results in a prospective randomised nutritional outcome study. The research demonstrated that early nutritional provision during infancy improves overall neurocognitive outcomes in children, with the evidence of these nutritional provisions during infancy persisting well into childhood (Morley, 1998). The effects of early nutritional provision demonstrated advantageous indicators to adaptive, language, socio-emotional, and personal development as measured on standardised mental, cognitive, and social scales (Walker et al., 2011; Morley, 1998). Adversely, children who do not have access to optimal nutritional provision proved to be at an increased risk of delays in intellectual development, which has far–reaching, detrimental outcomes on future performance for academic and vocational success (Nyaradi, Hickling, Foster, & Oddy, 2013; Engle et al., 2007; Morley, 1998). For example, longitudinal outcomes of stunting has shown to be associated with a lack of formal employment at ages 20 to 22 amongst Filipinos, while the benefits of nutritional supplementation in the first two years of development in Guatemalan boys were associated with better wage-earnings as young adult men (Walker et al., 2011).

Furthermore, the benefits of improving the supplementary intake of iron and folate in pregnant women have correspondingly proven beneficial to the unborn child. Not only can it prevent stunting, but it is also important for young children's cognitive, sensorimotor, and mental development. Li et al. (2009) in their study conducted among women (N=58282) in China, provide supporting evidence of the benefits maternal multi-micronutrient supplementation has on child development. In this double-blind, randomized control trial the participants were provided with multi-micronutrients (five minerals plus 10 vitamins); folic acid and iron; or folic acid during pregnancy at levels equivalent to the approximate

recommended daily allowance. Children (N=1305) were assessed at three, six, and 12 months respectively using the Bayley Scale of Infant Development (Li et al., 2009). The evidence from this study strongly supports the benefits of multi-micronutrient supplementation for pregnant women, as it proved beneficial to child developmental outcomes (Li et al, 2009). In another study conducted in Nepal the benefits of maternal iron and folate supplementation during pregnancy revealed positive effects on intelligence quotients (IQ), executive functioning, and sensorimotor development in young children (Christian, Murray-Kolb, Khatry, et al., 2010). Resultantly, the outcomes of these studies are in keeping with other studies showing the overall benefits of multi-micronutrient supplementation of pregnant mothers on the mental, sensorimotor, and cognitive development of their children as measured on standardised developmental scales (Li et al., 2009; Engle et al., 2007).

As is evident from the literature reviewed, malnutrition remains a world-wide threat that undermines the affected children's overall development, thereby adversely affecting our future economy, as these children are unable to reach their full potential. Children who are malnourished are more likely to be developmentally compromised, thus jeopardising their school readiness, which in turn has long-term implications for academic and vocational success. Moreover, these children are vulnerable to being trapped in a lifestyle of poverty, which renders them unable to actively participate in the economy at large and fuels the vicious cycle of inequality. Despite the aforementioned observations regarding the positive effects of existing poverty and malnutrition programmes, greater effort is required to alleviate this scourge by evaluating, strengthening, and improving existing plans.

Conclusion

In summary, while paediatric HIV infection itself impacts negatively on the central nervous system, contextual factors such as home environment, poverty, and maternal/caregiver factors

may also contribute to the negative neurocognitive and socio-emotional outcomes observed in this population. It can be argued that caregiver HIV-infection introduces additional challenges to parenting which may interfere with the caregiver-child attachment relationship, and result in a lack of psychosocial stimulation for the child. Poor maternal responsiveness, for example, is associated with maternal ill-health such as HIV and depression, which impacts negatively on a range of child outcomes. Therefore, the infant-caregiver relationship
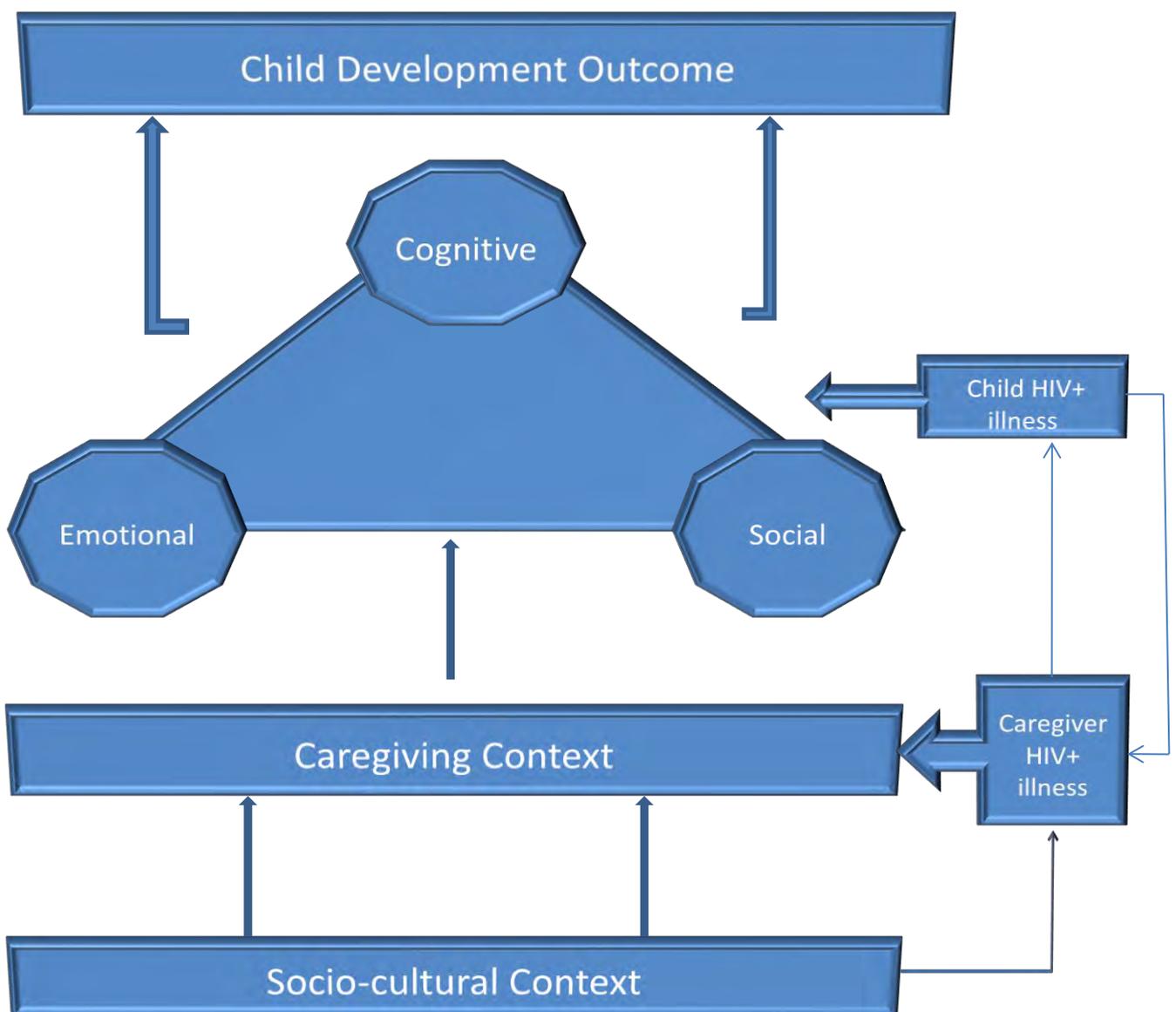
Model 1: Child Development Model: The model is based on the above mentioned literature on child development outcomes. Illustrated in the model are the dynamic association among

socio-cultural, home-environment (caregiving context), parental and child HIV ill health pathways predicting the cognitive, emotional and social development of an HIV positive child.

depends heavily on the quality and availability of the caregiver. Similarly, disruptions in family structure as a result of HIV deaths leads to orphans being cared for and raised by relatives, in particular grandparents, which in turn has implications for the developmental outcomes of these children, particularly under conditions of poverty and poor support services. On the other hand, emerging studies that started to focus on enhancing resilience in children whose caregiver is HIV positive, holds promise to the fact that adequate interventions can have long lasting benefits on the developmental and psychological trajectory of children and their HIV positive caregivers. Consequently, the link between poverty, HIV/AIDS, and malnutrition has been established, and its impact on perinatal, infancy, and early-childhood development outcomes is clearly documented. In conclusion, no study investigating the psychosocial factors that impact on perinatally-infected HIV children's neurocognitive and socio-emotional functioning has been conducted in South Africa to date. Given the association with emotional deficits observed in the literature, this reinforces the need to include socio-emotional development, psychological distress, and socioeconomic factors as key variable in this study, all of which should be measured in addition to neurocognitive function.

CHAPTER THREE

THEORETICAL FRAMEWORK

Introduction to theory

This chapter discusses the Ecological Systems Theory of Urie Bronfenbrenner (1979; 2005), which is the theoretical framework that informed this study. The aim of this chapter is to anchor research in a solid theoretical paradigm, while simultaneously demonstrating how it informs the chosen independent variables (e.g. maternal depression, nutrition, home environment, and socio-economic status) that are measured in this doctoral study. Firstly, the chapter provides an overall discussion of Bronfenbrenner's Ecological Systems Theory to conceptualise the overall influence and pertinent role of context on human developmental outcomes, as well as the relevance of conducting psychosocial research within the paediatric HIV population using the abovementioned model as a guide. Secondly, and simultaneously, Attachment theory (Bowlby, 1969; Ainsworth, 1978) is incorporated into the microsystem as a means of illustrating the importance of early proximal experiences and to help gain insight into the complex nature and influences of caregiver-child interaction. Additionally, it also provides a better understanding of how these relational processes have a direct impact on the child's development trajectory throughout life. Thirdly, while this study predominantly examines factors that impact on the microsystem (*i.e.* maternal depression and nutrition), and exosystemic variables (*i.e.* socioeconomic status and community context) that form pertinent parts of the HIV-positive child ecology, for the purpose of providing an overall understanding of Ecological Systems Theory, a discussion of all ecological levels will be provided to clarify its relevance to psychosocial research.

Bronfenbrenner's Ecological Systems Theory

Ecological Systems Theory (EST) was devised by Urie Bronfenbrenner (1979-2005), a well-known psychologist whose work in development and systems theory provides a useful construct for understanding contextual and lifespan developmental influences on child developmental outcomes. A further adaptation of Bronfenbrenner's EST which incorporated a child's individual biological characteristics led to the reformulation of the model as the Bioecological Systems Theory (Tudge, Mokrova, Hatfield, & Karnik, 2009; Paquette & Ryan, 2001).

Bronfenbrenner's theory posits a dynamic perspective on *what, when,* and *how* a child's development is influenced (Tudge et al., 2009). According to this theory the child is central to the context and it is theorised that the child *affects* and is *affected* by the environment in which he/she is born and raised, depending on his/her exposed developmental vulnerability (Lerner, 2004; Paquette & Ryan, 2001).

The theory postulates that a child's family environment is important, as this is the primary space where he/she spends most of his/her time and where emotional influences occur (Bronfenbrenner, 1986). In other words, this space is where the primary sources of nurturance and learning should occur. Other occupied spaces, such as the extended family, day care, neighbourhood, school, and society at large, also play an important role in influencing a child's developmental outcomes (Bronfenbrenner, 1986; Bronfenbrenner & Morris, 2006).

In studying children within their environmental contexts, Bronfenbrenner was able to observe how a child's unique characteristics were interrelated with his/her surroundings (Derksen, 2010). As a result he was able to theorise that child development is part of an interactive and dynamic process where the child engages in and is influenced by an ever–changing, multilevel environment, both in and across systems (Paquette & Ryan, 2001). The theory

argues that child development does not occur in a vacuum, but within a context of multiple influences (Smith, 2011). Bronfenbrenner's Ecological Systems Theory thus provides a framework for understanding the aforementioned influences on child developmental outcomes.

EST proposes several interlocking spheres/levels/systems of influences, namely *micro, meso, exo, macro,* and *chrono* (Paquette & Ryan, 2001) (Model 3)*.* EST further postulates that there is an interplay between the individual and these systems that results in bi-directional relationships with various developmental impacts and outcomes across the individual's lifespan (Smith, 2011). Based on ecological systems models it can therefore be argued that various intra-individual, familial, and contextual factors can influence the psychosocial and neurodevelopmental outcomes of children infected with HIV. Consequently, Bronfenbrenner provides a useful framework with which the researcher of this doctoral study aimed to explore the psychosocial and neurodevelopmental outcomes of children infected with HIV within their ecological contexts.

Microsystem

With the child at the epicentre of Bronfenbrenner's EST, the microsystem is the first level of influence on development (Bronfenbrenner, 1979). The microsystem is also argued to be the innermost of all the levels and involves the immediate environment in which the child is. Bronfenbrenner's *microsystem* essentially refers to the child's immediate relationships with caregivers, family members, and friends/peers, in other words interpersonal relationships.
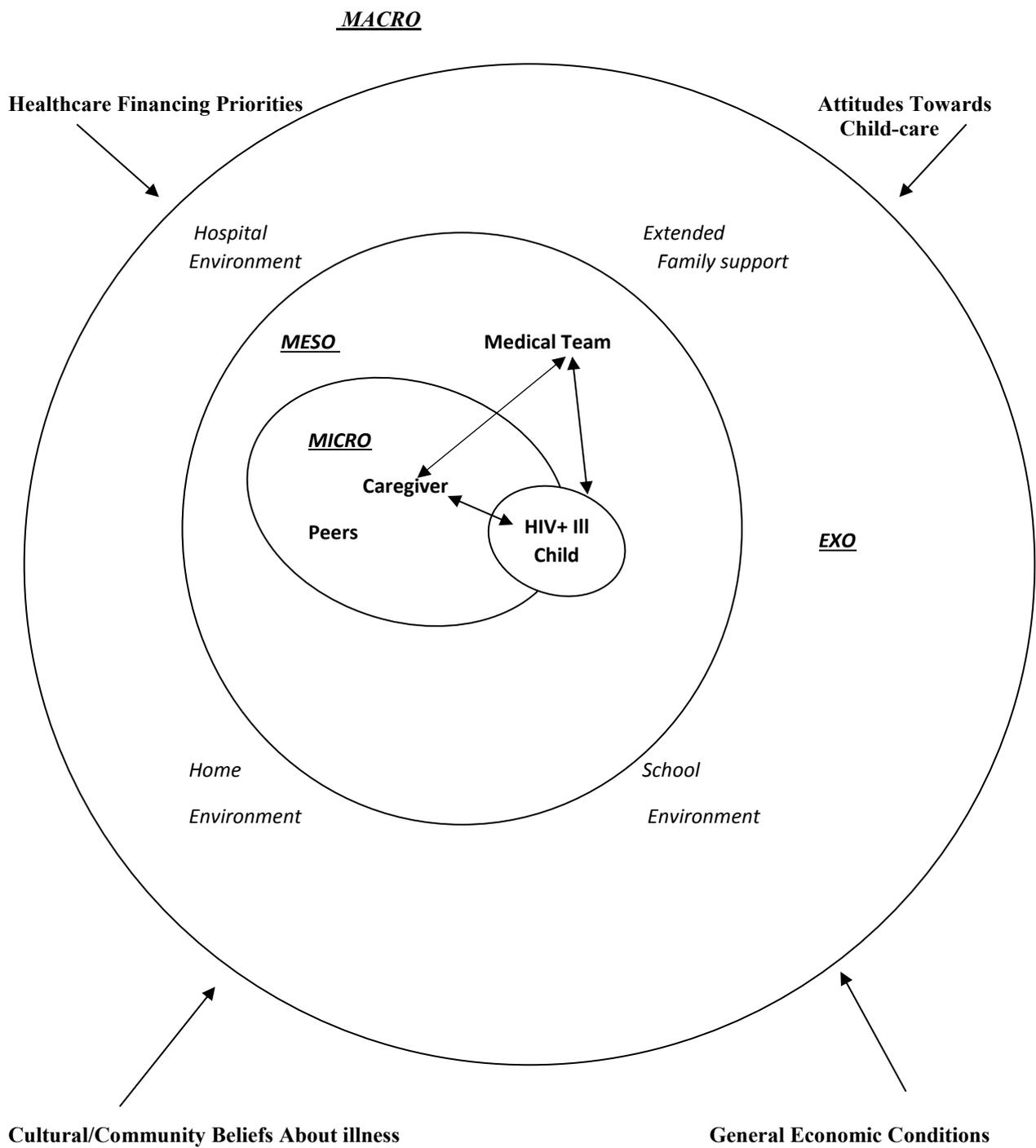
Model 2: Socioecological model based on the principles of Bronfenbrenner's ecological systems theory applied to HIV+ ill child (adapted from Steele *et al*., 2007, p 59).

A child's developmental outcome is dependent on his/her interpersonal or proximal involvement with these social and interpersonal environments (Smith, 2011), as the microsystem is where the child's immediate and most intimate/personal relationships occur (Paquette & Ryan, 2001) and reflects the primary *attachment* experiences of the said child (Broberg, 2000). Relationships categorized at this level are, for example, parent/child, family, peer, and teacher/student relationships, among others. As a result it is argued that the interactive experiences in this system are reciprocal in nature (Tudge et al., 2009; Smith, 2011), which supports the premise that the more *nurturing* the relationship between the *child* and the *primary caregiver*, the better the *developmental outcomes of the child* (Drury, Sanchez, & Gonzalez, 2015; Smith, 2011). The use of ecological theory in this study to better understand the influence of HIV on a child's neurodevelopmental outcomes stands to prove invaluable, as much research elsewhere has been conducted to identify specific factors that impact the outcome of children's neurocognitive and socioemotional development. Notable amongst these are the impact of poverty in relation to nutrition and neglect, parent-related physical health and its impact on attachment and child-bonding, as well as cognitive, socio-emotional developmental outcomes, and the mental health of the child (Sherwin & Boland, 1994; Blanchette et al., 2002; Coscia et al.,2001; Drotar et al., 1995; Petersen, Swartz, Bhana, & Flisher, 2010b; Engle, Grantham-McGregor, Black, Walker, & Wachs, 2009). Because some of these studies have focused primarily on the association between proximal factors (e.g. parental ill health exposure) and the child, they typically fall within the child's *microsystem* (Forehand et al., 2002; Steele & Grauer, 2003). Therefore, the impact on the child's developmental outcomes is evident from the very beginning, and research has, for example, established a link between an expectant mother's health and well-being and developmental outcomes of her unborn child (Bordeax et al., 2003). Hence, establishing a

healthy attachment with a primary caregiver is paramount to a child's socio-emotional and brain development outcome (Drury et al., 2015).

Attachment Theory (AT) is inherent to the microsystem of a child and has provided ample evidence supporting the dynamic of sensitive and warm interactive parenting in relation to the long-term benefits it holds for children's cognitive and socio-emotional development due to the proximal nature of interaction (Bowlby, 1969). Children who experience secure attachment and bonding are more likely to achieve academically and progress vocationally, compared to those children who have had a break-down in their primary attachment relationship and bonding (Brooker & Woodhead, 2010). Bowlby argues that, based on AT, the child's early experience with their caregiver will determine the quality of bonding in the child-caregiver dyad (Bowlby, 1988). Furthermore, the theory postulates that the established bond will determine what Bowlby refers to as the "internal working model" of the child, which is argued to be critical to the said child's developmental outcomes (1988). Bowlby emphasizes that the internal working model forms during the first few months of life, in response to the caregiver's interaction with the child. The theory claims that the internal working model is what the child internalises as the expected response and behaviours of *attachment figures* in any given situation (Bowlby, 1988). This internal working model is derived from the quality of the bond established between child and caregiver. More so, the theory asserts that contact (closeness) and comfort, together with trust, are essential for the development of attachment in the child-caregiver dyad. Thus, a caregiver who responds sensitively, responsively, consistently, and timeously to a child's signals and needs will help lay the foundation for a positive bonding experience with that child, which in turn is the recipe for establishing a positive internal working model associated with secure attachment-figure relationships (Drury et al., 2015). Therefore, the abovementioned could be considered

the formula for *positive proximal interaction* resulting in a *healthy microsystem,* which tends to enable *positive developmental outcomes* in a child, thus providing an enriching ecology in which the child can grow (Paquette & Ryan, 2001).

The role of the primary caregiver cannot be overstated. Attachment, which is broadly defined as the web of emotional bonds that develop between a child and primary caregiver, usually emerges during the first several months of life (Bowlby, 1988). However, evidence generally shows that children become attached to familiar individuals who respond to their need for physical care and stimulation within the first six months of life. Contrary to what was initially argued by some scientists in the area of child development, attachment is now said to be influenced by an amalgam of intrapersonal factors of the *child and interpersonal factors* of the *caregivers* and *environment* (Shaffer & Emerson, 1964). Initially they believed that feeding was the basis for attachment, but Bowlby rejected this notion with subsequent research on attachment and child development reinforcing the rejection of the premise that attachment is a function of feeding. The opposite is argued, which extrapolates how the nature and quality of a primary early relationship with a child is an essential aspect of attachment development. For example, in a study conducted by Shaffer & Emerson (1964) it was found that feeding had no impact on attachment. Instead the child evidenced attachment towards other members of the family such as fathers, siblings, and grandparents, thus positing the conclusion that attachment with these caregivers was a function of consistent responsive interaction with the said child (Shaffer & Emerson, 1964). The significance of this premise has important implications for children who are raised in households where the extended family is heavily relied upon; a common occurrence within the majority of South African families. This is important, as one is able to see various microsystems emerging (e.g. mother-

child, granny-child, aunt-child, etc.) that are all equally important to the outcome of the child's ecology and which influences the child's development.

The quality of a child's microsystem is also directly influenced by what Mary Ainsworth (1978) terms a 'secure base'. The development of appropriate attachment allows the child to use the caregiver as a secure base from which to explore the external environment. Ainsworth extended Bowlby's work through her contribution of the secure base, and jointly strengthened the argument of attachment as crucial to the early cognitive, emotional, and behavioural developmental outcomes of the child (Ainsworth, 1978). Starting in the early months of life, the child develops an internal working model for the attachment figure who interacts with the child, which provides the base from which the child will discover their surrounding environment. Ainsworth (1978) coined three major attachment styles as the foundation of child-caregiver attachment. She postulated that this foundation would determine whether the attachment dyad is "…secure, insecure-avoidant, [or] insecure-ambivalent" (Zeanah & Gleason, 2015; Ainsworth, 1978; Meyer & Pilkonis, 2001). For example, a child whose caregiver is sensitively attuned to his or her signals and accurately responds to their cues, is more likely to develop a "secure base" from which they can explore the world. Thus Ainsworth would deem such a child securely attached. On the other hand, a caregiver who is less sensitive to a child's signals and cues would be slightly rejected by the child and this would foster an "insecure-avoidant base". Such children are less likely to be under distress upon caregiver separation and also less likely to approach the caregiver instantaneously upon return. A caregiver who is over-involved, intrusive, or who responds inconsistently to the child's signals and cues would foster an "insecure-ambivalent" attachment with the child. Such children are more likely to be clingy towards the caregiver and anxious upon separation. The internal working model from which the child will explore

his/her view of self and others would be evidenced by apprehensiveness and hesitation, with such children progressing into adulthood lacking security in the self. Such children would also be more at risk of developing psychiatric conditions such as reactive attachment disorder (RAD) and disinhibited social engagement disorder (Zeanah & Gleason, 2015) given the lack of a secure attachment formation.

The importance of the *quality of the early child-caregiver relationship* is thus crucial to child developmental outcomes. Since the development of this theory, much interest has gone into research exploring the impact of caregiving in early life on the developmental trajectory into adulthood (Zeanah & Gleason, 2015). Child development research has consistently provided support for the view that the early bonding and attachment process have enduring psychological and neurophysiological implications for the child (Keller & Otto, 2009). Similarly, cross-cultural research has provided evidence of the universal importance of attachment in early childhood (Tamminen, 2006; Keller & Otto, 2009; Richman, Miller, & Levine, 1992). Emerging from these studies is the notion that development is a universal process when attachment becomes central, as it lays down the foundation that allows learning and growth (Brooker & Woodhead, 2010). The importance of this is likewise indicated in neuroscience research which asserts that healthy brain development is dependent on the quality of the earlier relationship a child is exposed to by his or her caregiver (Center on the Developing Child at Harvard University (CDCHU), 2009; Keller & Otto, 2009; Knitzer et al., 2008). Development refers broadly to the growth and changes an individual undergoes in his or her physical, mental, and social functioning and is rooted and shaped in an ecological context (Keller & Otto, 2009). This view encapsulates the importance of the mutual interaction between the mental and the sociocultural context in which a child is located. A lack of mutual responsiveness between the child and caregiver can result in a weakened bond

in later life which could adversely impact the developmental outcome of the child (CDCHU, 2009).

Model 3: Attachment Dynamic in relation to the ecology of a child and his/her health and developmental outcomes.

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│                                                                           │
│                      ┌──────────────────────┐        ┌─────────────────┐  │
│                      │ High caregiver       │ ──────>│ More positive   │  │
│                      │ responsiveness to    │        │ interaction     │  │
│                      │ child's cues         │ ──────>│                 │  │
│                      │ communicating needs  │        │ More            │  │
│                      │ for food, comfort,   │        │ psychosocial    │  │
│  ┌─────────────────┐ │ stimulation, warmth, │ ──────>│ stimulation     │  │
│  │ Physically close,│ │ etc.                 │        │                 │  │
│  │ attentive,       │ └──────────────────────┘        │ More sensitive  │  │
│  │ reciprocally     │ ───>                     ──────>│ to basic needs  │  │
│  │ stimulating,     │                                 │ e.g.  food &    │  │
│  │ mutually         │                                 │ security        │  │
│  │ pleasurable M-C  │                                 └─────────────────┘  │
│  │ interaction      │ ┌──────────────────────┐                 │          │
│  │                  │ │ Child's positive     │                 v          │
│  │ e.g. caregiver   │ │ affect directly      │        ┌─────────────────┐  │
│  │ (HIV + or        │ │ stimulates growth,   │        │ Better growth   │  │
│  │ negative)        │>│ immune functioning,  │        │ and             │  │
│  └─────────────────┘ │ exploratory &        │        │ neurocognitive  │  │
│                      │ prosocial behaviour, │        │ and             │  │
│                      │ etc.                 │        │ socioemotional  │  │
│                      │                      │ ──────>│ development     │  │
│                      └──────────────────────┘        │ outcome of the  │  │
│                                                       │ HIV+ child      │  │
│                                                       └─────────────────┘  │
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Adapted from Zeitlin et al., 1990.

To date, literature that is rooted in attachment theory on the whole acknowledges an investment that needs to be made from the start of life in order for the outcome to have enduring cognitive, emotional, social, and behaviour benefits (Oates, 2010). There has been a

wealth of research on the impact of maternal depression on child developmental outcomes, as it threatens the formation of a healthy caregiver-child microsystem.

Gagliardi & Honigfeld (2008) reviewed studies measuring the impact of depression on attachment and found that depression presented as a major obstacle to the development of sound attachments between a child and primary caregiver. Reportedly, in the studies that compared depressed and non-depressed caregivers, depressed caregivers exhibited insensitivity, inconsistency, and an inability to respond appropriately to their child's cues and needs. The context in which these children were reared was characterised as non-nurturing and un-protective environments. These children also showed greater impairment in psychosocial functioning, as well as more behavioural problems, such as anger, anxiety, and inattentiveness (Cooper et al., 2009). Depression in HIV-positive children of depressed mothers also held true for HIV-positive children in developed countries (Bachanas et al., 2001; Havens et al., 1994; Drotar et al., 1995; Martin et al., 2004). The link between attachment and child competence is also evident in the research. Thus, emerging from this review of studies is the consensus that children who have experienced poor attachment present with cognitive-developmental delays which is a risk factor for school readiness and relates to poor scholastic achievement (Cooper et al., 2009). Moreover, children who lacked a positive attachment relationship with their caregiver evidenced deficits in their regulatory functioning, greater anxiety, and were prone to low personal and social competence. Child-rearing practices utilised by these parents evidenced inconsistent parenting routines, was lacking in stimulating play activities such as singing and cuddling with the infant, and showed parents who were unresponsive and insensitive to the needs of their children. Ainsworth argues that sensitive and responsive parenting is essential to healthy child development, especially with regard to affect regulation and modulation (1978). However, a

depressed caregiver interacts less positively with the child and responds with a more negative emotional repertoire. In turn, the child exposed to this type of interaction reacts with greater passivity towards their caregiver.

Based on the literature we understand how critical caregiver responsiveness is to the child as it is a function of the attachment relationship in the child-caregiver dyad and lays the foundation for healthy microsystem which predicts the subsequent cognitive, emotional, social and behaviour outcomes of the child (Zeanah & Gleason, 2015). That is, a caregiver who is able to sensitively identifies, cares, and responsively meet the child's need.

Yet, caregiving does not occur in a vacuum and is rooted in economic and sociocultural contexts that are argued to have a major impact on the nature of the caregiving relationship (Richman et al., 1992; Tamminen, 2006) and ultimately on the child's development (Brooker & Woodhead, 2010). Caregiving can become a stressful, overwhelming experience for caregivers, especially when familial, economic, and sociocultural factors interfere with the function of caregiving. In this regard, the role of the other systems (meso-,exo-, and macrosystems) highlight the importance of an ecological approach where *early life interaction* interacts with the *environment* to influence child developmental outcomes.

Exploring the impact of psychosocial variables from the microsystem through to the macrosystem on HIV-positive children's neurodevelopmental and socio-emotional outcomes in this doctoral study is an attempt to strengthen the understanding of these influences on children with perinatally acquired HIV.

Caregiver depression, nutritional status, and quality of home environment (quality of stimulation) are all incorporated in this study, with perinatally HIV infected children as microsystem and mesosystem variables and demographic characteristics, particularly socio-demographic and neighbourhood characteristics, as exosystem variables. Against the

backdrop of the aforementioned theoretical understandings, I argue that at a microsystemic level, caregiver depression has the potential to negatively impact the HIV-positive child's socio-emotional and neurodevelopmental outcomes as depression can make it difficult to meet a child's needs (See model 3) in the following ways: i) through a caregiver-child relationship characterised by a lack of warmth, supportive, and stimulating interaction as a result of a disruption in the attachment relationship between caregiver and child; ii) by impeding the caregiver's capacity to adequately meet the HIV-positive child's nutritional needs, leaving the child vulnerable to nutritional deprivation which has a further negative impacts on neurocognitive and socioemotional development (see Model 3); and iii) through promoting an impoverished home environment where there is a lack of emotional and physical stimulation (See Corscia et al., 2001). A weakened microsystem as a result of caregiver depression thus has the potential to have a profound deleterious impact on an HIV-positive child's care, adjustment, and socio-emotional and neurodevelopmental outcomes (See Model 3) (Bronfenbrenner & Morris, 2006). It also has implications for adherence to medication for the child living with HIV. For example, a caregiver that is not emotionally and physically attuned and available to meet the needs of the ill-child has negative implications for the child's health and developmental benefits. In other words, the HIV-positive child's health and developmental status is dependent on the quality of the caregiver-child relationship, with early provision of treatment of the HIV-positive child primarily being the responsibility of the primary caregiver. Accordingly, the role of the caregiver is very important, especially in ensuring the child's *adherence* to medication (Steele & Grauner, 2003). If a caregiver is not responsive to his/her child's medical/health needs, this could result in major negative medical and neurodevelopmental outcomes in the HIV positive child (Steele & Grauner, 2003). Consequently, poor adherence to antiretroviral treatment in children living with HIV have been associated with caregiver factors, such as high caregiver

distress, lower caregiver reported quality of life, poor treatment regimen knowledge, as well as poor caregiver-child communication and social support from immediate and extended family (Steele & Grauner, 2003).   Young children will not generally know their status until it is disclosed to them which is generally at around nine years of age (Paxton, 2002).   Until such a time the health and developmental benefits of the child will be completely dependent on the caregiver, the relationship the caregiver develops with his/her child, and the health system that provides treatment to the child. For a caregiver to be fully aware of the child's health demands he/she is required to be emotionally attuned and to spend quality time with the child.

Mesosystem

The mesosystem of Bronfenbrenner's EST reflects the importance of strong integrated support networks and the implication thereof on the developmental outcome of a child (Bronfenbrenner, 1979). The mesosystem demonstrates how different parts of *multiple microsystems* come together, either to operate synergistically in order to benefit the child or incompatibly with negative outcomes for the child's development. The quality and quantity (time spent) of the proximal experiences between the different multiple microsystems will determine whether developmental outcomes are enhanced (Paquette & Ryan, 2001). For example, teacher/caregiver expectations will determine the expected potential and expectation of a child's academic progress. If there is effective communication between a caregiver and teacher, the child is more likely to know what is expected of him/her academically, and is thus more likely to show progress.

With reference to this doctoral study some evidence already exists in relation to mesosystemic variables (Coscia et al., 2001). Following on Bronfenbrenner, quality of the

home environment as a mesosystem variable would be influenced by other microsystems operating within the home environment and may buffer a negative caregiver child-relationship. The quality of the doctor/caregiver microsystem will also influence the mesosystemic level of the child either positively or negatively (Smith, 2011). Factors to consider include: i) whether the caregiver has a clear sense of his/her child's medical/health needs; ii) whether he/she demonstrates the capacity to actively translate this in his/her interaction with his/her ill-child and the necessary stakeholders, such as the nurses and doctors who have to help him/her meet the child's demands; iii) whether the caregiver and medical team have the same goals for the HIV-ill child; iv) whether their expectations are clearly communicated to one another; v) whether caregiver's needs are expressed to the medical team in order to aid him/her and the child, etc. (Model 3). Furthermore, the degree to which each of the microsystems are interacting and engaging with each other may dramatically affect the HIV-positive child's health status, emotional adjustment, and neurocognitive outcome (Steele & Grauner, 2003). For this reason it is argued that the provision of a safe, nurturing, and stimulating environment serves as the foundation for optimal child development, hence the importance of multiple positive, interactive microsystems to ensure a progressive mesosystemic effect. Consequently, *quality of home environment* was included as a mesosystemic variable in this doctoral study based on the assumption that other microsystems, besides the caregiver child dyad, operating in home environment may serve to create a more stimulating and nurturing environment that could possibly offset a positive caregiver-child microsystem. However, it should be noted that the study did not measure the impact of the relationship of other multiple microsystems directly (e.g., doctor-caregiver-child), except through exploration in the qualitative phase of factors impacting on caregiving.

Exosystem

According to Bronfenbrenner, the exosystem refers to socio-environmental contexts that can affect a child's development indirectly (Bronfenbrenner, 1979). The exosystem indirectly affects the child's developmental outcomes by influencing the micro-and the mesosystems in a particular way (Paquette & Ryan, 2001; Lerner, 2004). Socio-economic status (SES) was included as an exosystemic variable in this doctoral study based on the understanding that SES can affect childcare and development (Elliot-DeSorbo et al., 2009; Kiernan & Mensah, 2009). Living in poverty is a reality for many HIV-positive children in South Africa (Brant, 2009; Richter, 2004; Cooper et al., 2009; Petersen et al, 2010) and economic deprivation generally exacerbates the possibility of poor cognitive, emotional, social, and behavioural developmental outcomes in children (Brooker & Woodhead, 2010; Costello et al.,2003). Effects can be direct, such as through a lack of basic access to food, clean water, decent sanitation, and easy, readily accessible health services (Penn, 2010), as well as indirect. With respect to the latter, caregivers under financial stress are likely to experience greater overall stress that places them at greater risk for depression (Gagliardi & Honigfeld, 2008), which in turn impacts negatively on attachment as previously discussed. Thus, it can be argued that poverty indirectly promotes contexts that foster a breakdown in the attachment relationship between infant and caregiver (Brooker & Woodhead, 2010).

Poverty can also lead to lack of other psychosocial resources such as lack of child care. It results in economic constraints on caregivers that affects their ability to devote scarce time and resources to child care (Costello et al., 2003). This is especially so, where the primary caregiver who most of the time is the mother, also has to be the head of the household (Richter & Rama, 2006). Additionally, grandparents and other relatives who assumed primary caregiving roles (i.e. including assuming financial responsibility), reported high

levels of fatigue associated with financial concern and caring for HIV-ill child, especially in the absence of social support (Caliandro & Huges, 1998). Their own health care needs can have a negative impact on the quality of care they are able to provide to the HIV-ill children. Caregiver burdens are also heightened where the caregivers' own health prevents her from adequately meeting the needs of her HIV+ child (Burgos, Hernandez-Reif, Mendoza, Castillo, & Shor-Posner, 2007). HIV as well as poverty may make is more difficult for caregivers to access optimal care for their children. The economic deprivation that most HIV+ women confront in low-resourced context limits them to choose the type of lives they would like to live (Kane, 2009). Most of the time they have to struggle to even meet the basic needs of their children; not having access to proper sanitation, clean water that pose as an additional threat to child health, and often having to live in overcrowded homes or shacks, where the safety is compromised (Kane, 2009). Kane in her study among black HIV+ women in Khayalitha, South Africa found that women expressed the need for supportive services that has the potential to mitigate the negative effects of poverty, enabling them to care for their ill children better (2009). She argues that this has the potential to relieve mothers confronting HIV from the burden of care.

In a study conducted by Elliot-DeSorbo et al. (2009) which included vertically infected HIV positive children from across America, financial stress was found to be highly correlated with weak immunity in the HIV positive children and their caregivers. The researchers found that the HIV-positive children had lower CD4+ absolute counts, and were more frequently hospitalised than children who did not come from financially constrained homes. They also reported that the homes of caregivers looking after children with HIV and who were under financial stress, were more disorganised and chaotic, with the caregivers being less vigilant and concerned about adherence to medication (Elliot-DeSorbo et al., 2009).

Furthermore, a lack of access to mental health services by most people living in poverty or financial constraint is another factor in the exosystem that may directly and indirectly impact negatively on a child's health outcomes; directly through poor access to services, and indirectly through an unresponsive/depressed caregiver, who is less likely to seek out health services that may support a child's healthcare needs.

Additionally, fear of HIV stigma and discrimination are two further exosystemic issues that may impact negatively on care and access to health care services (Ingram & Hutchinson, 1999; Hackle et al., 1997; Sandelowski & Barroso, 2003). Most often, additional stressors such as fear of stigma (Klunklin & Harrigan, 2002); discrimination and isolation limits caregivers from accessing assistance from families and formal organisations (Potterton, Stewart, & Cooper, 2007), even when it is available. Caregivers may not disclose the child's status to family and friends and as a result struggle to cope in silence (Ingram & Hutchinson, 1999; Hackl et al., 1997). Moreover, this discrimination of children infected or affected through HIV by extended families and the community could also indirectly impact negatively on their emotional, cognitive, and academic functioning (Corcia et al., 2001). Thus, while not measured quantitatively, the impact of stigma on caregiving was explored qualitatively.

Macrosystem

The fourth level of Bronfenbrenner's EST is known as the macrosystem, which is remote or distal, but still influences children's developmental outcomes (Bronfenbrenner, 1979) through the micro, meso, and exosystems. The macrosystem includes cultural norms and values, as well as the laws and/or policies of the broader society in which the child is raised (Tudge et al., 2009). For example, South Africa inherited a legacy of inequality from Apartheid policies that contributed to the majority of its population living in poverty, and

having unequal access to education, health, and social infrastructure (Petersen et al., 2010b). Although much effort has been made to alleviate poverty, the country is still faced with high rates of poverty and unemployment. This picture is further exacerbated by the confounding HIV/AIDS pandemic which adds its unique health, social, psychological, and economic burdens to an already strained society and economy. The macrosystem is where policies that promote or reduce inequalities are located and operates through the exosystem, mesosystem, and microsystem to impact indirectly on child-developmental outcomes (Paquette & Ryan, 2001). Therefore, this is the level on which policies facilitating access to treatment and social grants, such as the child support grant and foster care grants are located. However, these variables are not measured in this doctoral study and merely mentioned to provide greater context and understanding of the effects the macrosystem can have on children living with HIV. Consequently, future studies may want to consider including this variable.

Chronosystem

According to Bronfenbrenner's EST, passage of time as it relates to the child's maturational processes also has an effect on the ecological outcomes of human development (Derksen, 2010; Paquette & Ryan, 2001). The child will undergo change due the maturational processes, but these changes will also be influenced by his/her environment, which may in turn indirectly shape his/her development and health indirectly. The chronosystem acknowledges that different stages of child development are accompanied by particular vulnerabilities, thus allowing certain risk influences within the micro-, meso-, and macro-systems to have a greater impact on child outcomes, depending on the child's particular developmental stage. This level is reflected in the intergenerational transmission of poverty and the added burden of HIV that has left many children orphaned. A child who did not receive adequate stimulation (emotional or cognitive) is also more likely to access poor

schooling, thus reducing his or her chances for academic achievement and thereby forcing them to settle for a low-income job. This then has the potential of being transmitted into the next generation and in so doing sustaining the cycle of economic deprivation and/or poverty (Grantham McGregor et al., 2007). Apart from the economic deprivation that results from the intergenerational cycle of poverty, it also contributes to food insecurity (nutritional deprivation), inadequate social and living infrastructure, and has an association with various psychosocial and medical problems, including HIV/AIDS (Petersen et al., 2010a; Gratham & McGregor et al., 2007; Engle et al., 2009; Bourn et al., 2008). With particular reference to the research target group (HIV-infected children), well documented research exists about the link between the predisposing vulnerabilities of the HIV/AIDS infected child, poverty, malnutrition, poor mental health, poor maternal responsiveness, and the impact this has on the pre-,peri-, and post-natal development of the HIV-infected child (Abubakar, 2014; Engle et al., 2007; Bourne et al., 2007; Iversen et al., 2011; Petersen et al., 2010a). HIV-infected infants are at greater risk of sensorimotor, neurocognitive, and socio-emotional developmental delays owing to the HIV virus's prenatal attack on a foetus's developing brain (Laughton et al., 2013). Furthermore, the developing brain is also affected by the environment in which HIV-infected infants and children are born and reared. Post-natally, these infants and children are often raised by primary caregivers who are ill as a result of HIV infection (physically or psychologically), or in the case of orphans, by extended family relatives (WHO/UNAIDS, 2006). Their rearing is usually characterised by a lack of psychosocial stimulation and food insecurity, resulting in nutritional disorders such as malnutrition (*i.e.* Vitamin A and iodine deficiencies in HIV positive children has been linked to compromised immunity and irreversible mental retardation, respectively). Both combined and individually, these factors can impact negatively on a child during various stages of development, impeding optimal cognitive, social, and emotional development. Research

comparing HIV-infected and HIV-uninfected children found that HIV-infected children are more likely to have learning problems that negatively impact on their school performance (Ruel et al. 2012). Moreover, HIV-infected children and adolescents are more likely to be psychologically and emotionally vulnerable to developing depression and behavioural problems. Due to a failure in learning, they are also at greater risk of not qualifying for high-income jobs and more likely to be unemployed or dependent on the grant system, which may in turn put them at greater risk for economic deprivation as adults (Abubakar, 2014). Thus, in looking at the risks associated with HIV through the chronosystem one is able to better understand how the different levels of influence on development (micro, meso, exo and macro systems) may negatively impact a child's growth as a result of particular vulnerabilities.

In conclusion, a child who is raised in a supportive socio-cultural network with positive proximal experiences will have a good foundation for positive development. Bronfenbrenner's Ecological Systems Theory is able to capture the interactive reciprocal and dynamic interplay between the child and his or her ecological levels to provide an understanding of the impact that each layer of system has on the child's developmental outcomes. The child serves as an active participant in the process, which reinforces the importance and relevance of the evolutionary approach to what is also now known interchangeably as Bioecological Systems Theory. Recent developments in neuroscience research provides ample evidence of the reciprocal relationship between nature and nurture in development, and is captured in the progressive reformulation of Bronfenbrenner's theory (Petersen, Bhana, Lund, & Herrman, 2014).The individual is understood to embody genetic, physical, psychological, and behavioural characteristics, all of which interact with their socio-cultural environment through a reciprocal process (Bronfenbrenner & Morris, 2006). This

dynamic process is observed in the HIV-infected child who is at risk of being born with various neurocognitive vulnerabilities into a socioeconomic deprived ecology. Together, through dynamic reciprocal processes, these vulnerabilities arguably impact on the developmental outcomes of the HIV-infected child. Consequently, for a study of this nature to be conducted in South Africa, in an environment characterised by socioeconomic and health vulnerabilities, this theory provides a useful framework for better understanding the complex factors that interplay and influence the health and developmental status of the study population. Finally, the importance of this conceptual framework hinges on the fact that it supports the inclusion of the aforementioned ecological variables, all of which are said to be associated with neurodevelopmental outcomes in children living with HIV.

CHAPTER FOUR

RESEARCH METHODOLOGY

Introduction

This chapter discusses the methodology that was used in undertaking the study. It commences by reiterating the aims and objectives of the study and providing details of the site where the research was conducted, followed by a description of the research design, sampling, research procedure, and a discussion of the ethical process followed to obtain approval for this doctoral research study. The second part of this chapter provides a detailed discussion of the quantitative methodology used to collect data and also provides a description of the analysis. This is followed by a detailed discussion of the qualitative methodology employed for the study, and the chapter concludes with a section on how the data will be stored.

Research aim

To reiterate, the research aim was to understand the psycho-social factors associated with the poorer neurocognitive and socio-emotional developmental status of perinatally (vertically) HIV-infected children in South Africa (See Figure 1 below).

Research objectives

The objectives of this study were as follow:

a. To examine the characteristics of caregivers of HIV-positive children in relation to socio-demographics and depression; and of HIV positive children in relation to neurocognitive functioning, socio-emotional functioning, nutritional status, and home environment.

b. To examine the relationship among each of the following factors on neurocognitive and socio-emotional functioning in a sample of South African

HIV-infected children: home environment, SES, caregiver depressive symptoms, and nutritional status.

c. To determine which factors are most strongly associated with neurocognitive and socio-emotional functioning in the sample.

d. To understand the challenges confronting caregivers of HIV-positive children.
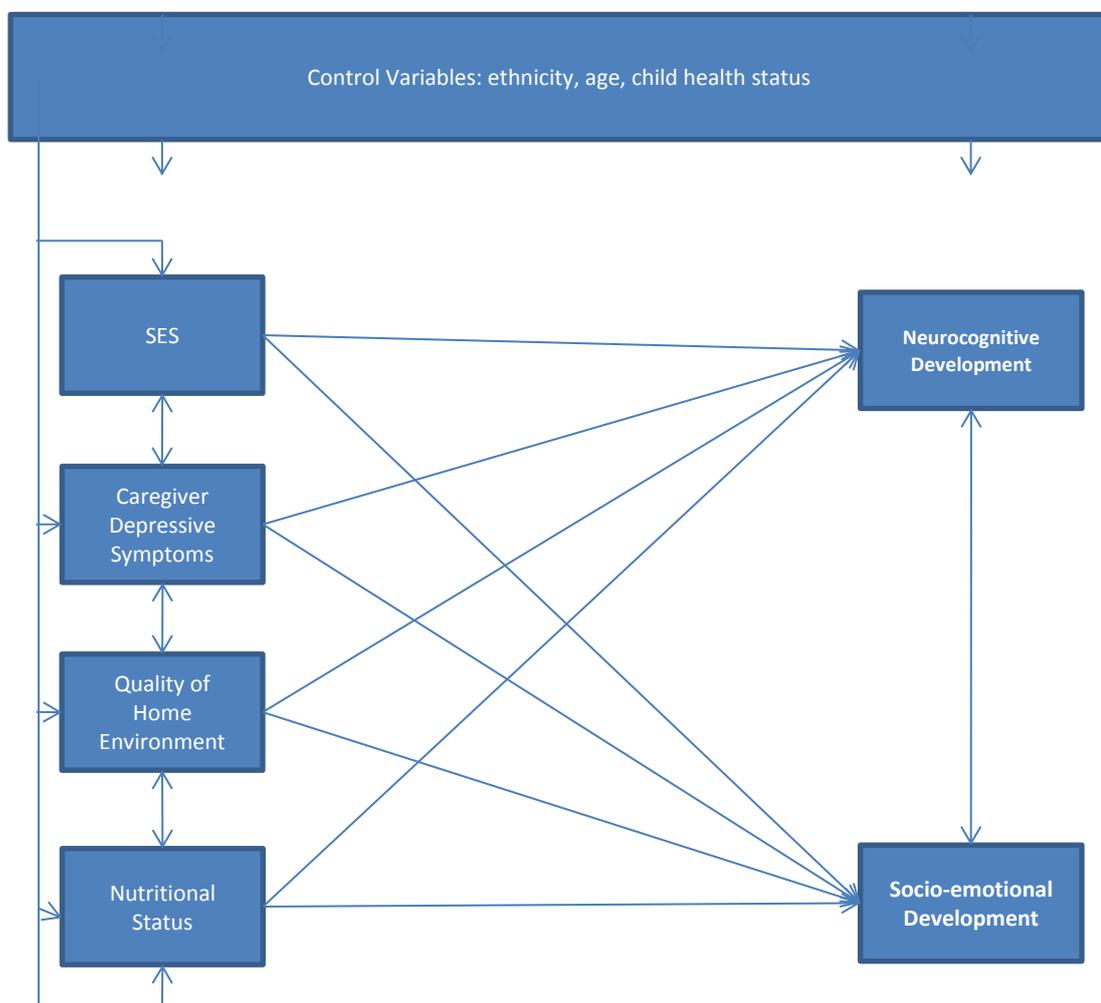
Figure 1: *Model of associative pathways:* The model depicts Independent Variables (IV's) as SES, Caregiver depression, Quality of Home environment, Nutritional Status; and Dependent Variables (DV's) as Neurocognitive development/functioning and Socio-emotional development/functioning.

Research site: Background to the research site (Buffalo City Metropolitan Municipality)

The research was conducted within the Buffalo City Metropolitan Municipality District in the Eastern Cape (Figure 2B).

Demographics

The Buffalo City Metropolitan Municipality (Figure 2 B) forms part of the Amatola District of South Africa, and is situated in the central part of the Eastern Cape (Figure 2 A & B). The Amatola District is made up of urban, peri-urban, and rural areas (Englin, 2007; Hamann & Tuinder, 2012) and the Eastern Cape is the second largest province in the country of South Africa, with the third largest population of South Africa's nine provinces tallying at approximately 6.4 million people (Stats, 2011). The Eastern Cape is also one of the poorest provinces, with high levels of under development and unemployment (Stats, 2012a). The Buffalo City Metropolitan Municipality is one of the urban metropolitan areas within the Province and accounts for 42% of the district's population. At present the population estimate for the Buffalo City Metropolitan Municipality is around 724 306 people, with an estimated growth projection that is likely to decline owing to the impact of HIV/AIDS on its inhabitants (DOH, 2013). The demographic profile suggests that 41% of the population is aged 19 and below, whilst 52% of the population is between 20 and 59 years of age. As a result the Buffalo City Metropolitan Municipality remains a hub for employment–seeking individuals, despite having an estimated unemployment rate of approximately 24,3%. Furthermore, youths below the age of 29 reportedly account for 65% of the Buffalo City Metropolitan Municipality's unemployed population, with a mere 1.2% in possession of university degrees, and a staggering 16,2% lacking any formal schooling. Finally, the municipality's population breakdown (according to race) is as follows: Black, 616 833; Coloured, 52 212; White, 53 311; and Indian, 1950 (Englin, 2007). It is reported that HIV continues to pose a threat

Figure 2: A-(Above) Map of South Africa showing location of Eastern Cape; B-(Bellow) Local municipalities of Amathole District depicting Buffalo City.
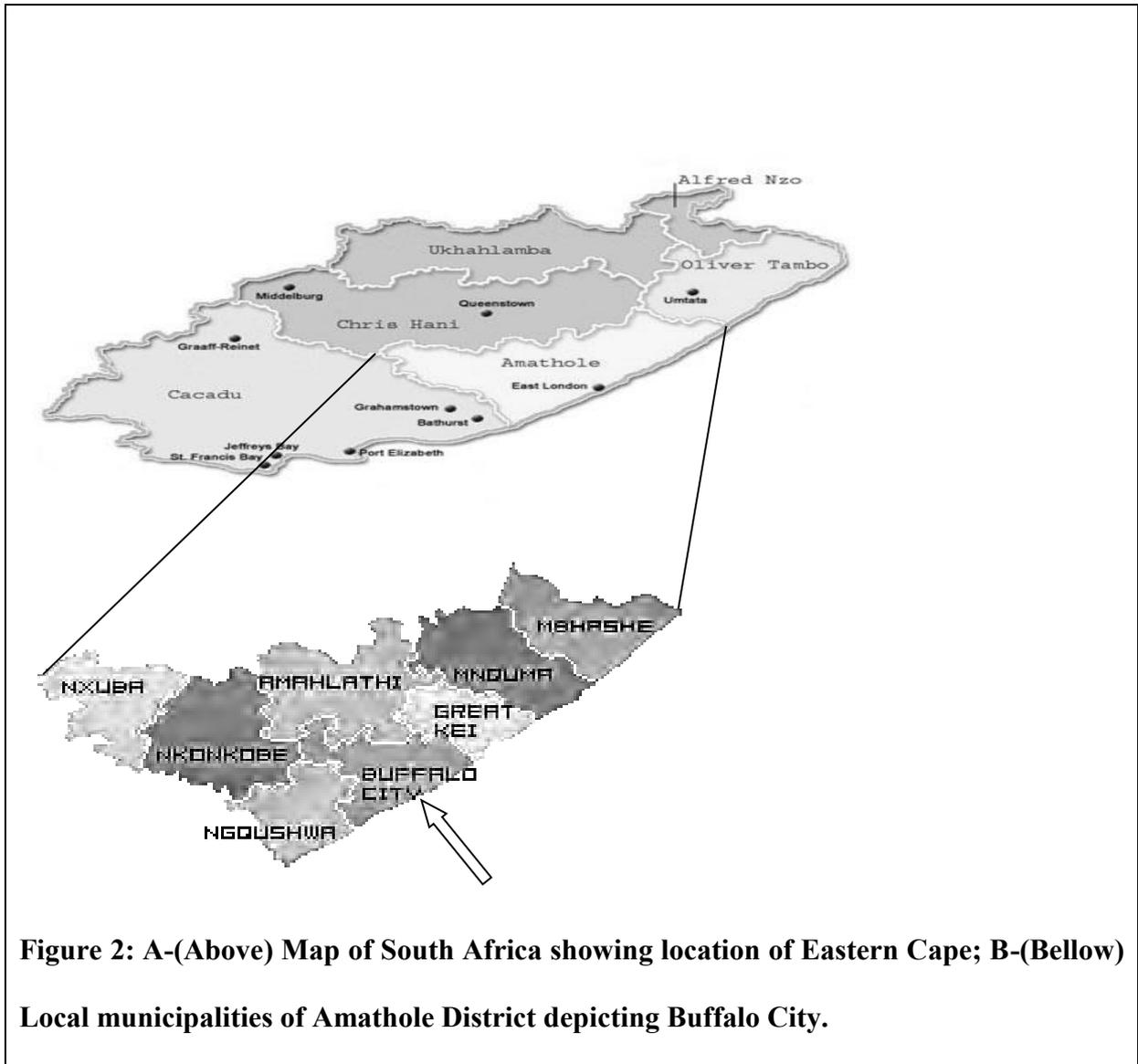
within the Buffalo City Metropolitan Municipality, especially with regards to social and economic development. This is exacerbated by the co-existing abject poverty in the municipality and the province as a whole. It is reported that many people within the Eastern Cape are still in need of Antiretroviral Treatment (ART) (DOH, 2013). The National Growth and Development Summit report released in 2007 estimated that 28% of HIV infections rates were found in the fourteen major metropolitan areas of the Eastern Cape (Englin, 2007).

HIV prevalence

Locally, the Eastern Cape was found to have a recorded HIV prevalence of between 20% and 30%, with the highest infection rate reported amongst black Africans. Women remain disproportionally affected as they are reported to have a higher prevalence rate than men while the pandemic continue to grow among the economically productive sector age 15-25 years (DOH, 2013). Furthermore, young black woman are also disproportionally more vulnerable to HIV infection, and research shows that informal and formal urban settlements are hardest hit by the impact of HIV/AIDS, with a reported rate of 30.3% and 29.5% respectively (DOH, 2013).

Reportedly, The East London Hospital Complex (ELHC) comprises of two hospitals, Cecilia Makiwana (research site) & Frere located in the Buffalo City District which had the second highest HIV prevalence rate (34.4%) in the Eastern Cape province (EC), coming in close second to the Joe Gqabi District which had 35.2% in 2012 (DOH, 2013). According to antenatal prevalence rates for 2012, these two districts had an overall prevalence rate higher than that of the average for the Eastern Cape, which was estimated to be 29.1%, as well as the national prevalence for the country, which was estimated at 29.5% (Carty et al., 2014; DOH, 2013). This placed the Eastern Cape among the four provinces with the highest HIV prevalence nationally (DOH, 2013). It is estimated that more than >100 000 patients are registered for antiretroviral treatment in the EC province, while paediatric ART uptake is relatively unknown (Carty et al., 2014). In a recent retrospective audit of paediatric HIV outpatient subspeciality clinics at the ELHC it was found that 2484 positive patients between the age of $0 - 25$ have been registered to date of which 14.01% are 0 -5 years and 41.95% are $5 - 10$ years (Carty et al., 2014).

Research design

Based on the overall aims, research questions, and objectives of this study, a Cross Sectional Study design was deemed appropriate (Graziano & Raulin, 2004). The study employed a combined methodological approach utilising both quantitative and qualitative procedures, also known as the *mixed method research approach*. As indicated by Johnson & Onwuegbuzie, mixed method research is a "…class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts, or language into a single study" (2004, p. 17). It has been argued that the mixed method approach is able to strengthen and avoid the shortcomings entrenched in single research approaches (Johnson & Onwuegbuzie, 2004; Onwuegbuzie & Johnson, 2004). For this very reason, the mixed method research approach has received much credibility as a research methodology across various single research studies (e.g. See Cresswell, 2008, 2009, 2012; 2013, Biggerstaff & Thompson, 2008; Johnson & Onwuegbuszie, 2004; Johnson & Onwuegbuszie, 2012).
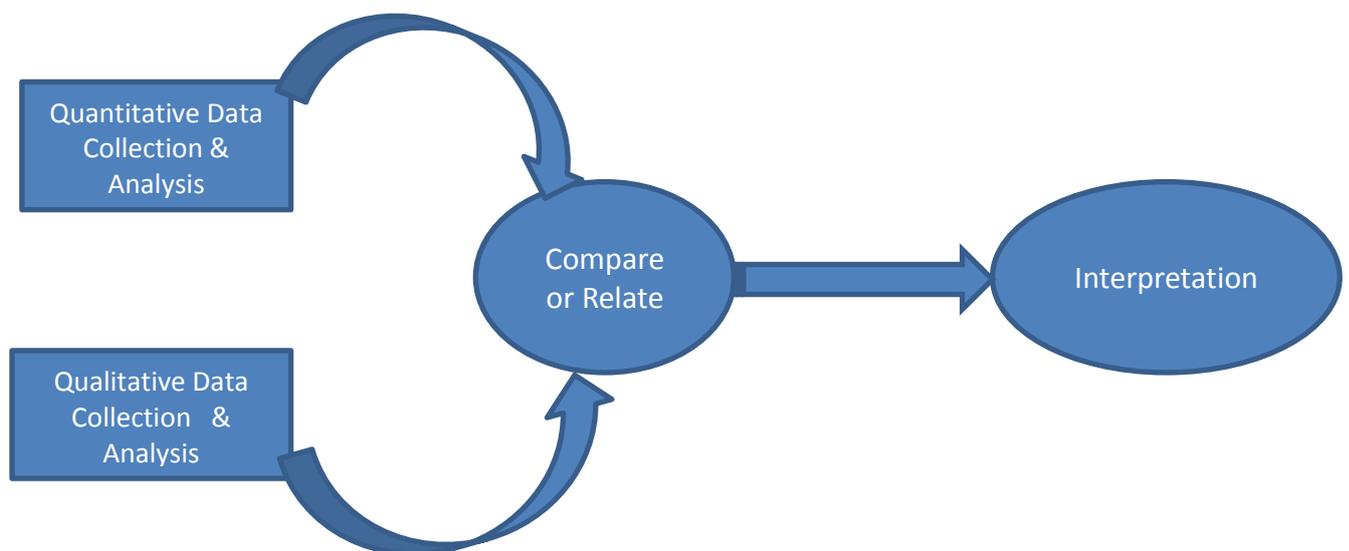
Figure 3: The Convergent Parallel Mixed Method Design: Adapted from Fischler, A.S. (2012)

The Convergent Parallel Mixed Method Research Approach (Fig.3) was deemed most appropriate in undertaking this study (Johnson & Onwuegbuzie, 2004), as it allows for the concurrent collection of both quantitative and qualitative data (Onwuegbuzie & Leech, 2005). Furthermore, it allows the two sets of data in the analytical phase to be analysed separately while tolerating the option of merging said data during the interpretive phase of the study. It should be noted that at times data is incorporated during the analysis phase, but only when deemed necessary for the adding of value and understanding to the data set. The mixed method approach should also be selected carefully with respect to the entrenched underlying research question(s) (Johnson & Onwuegbuzie, 2004; Onwuegbuzie & Leech, 2006; Onwuegbuzie & Leech, 2005). For the purpose of this study the convergent parallel mixed method approach was selected to help meet the objectives of the study. Based on the methodological literature, the convergent parallel mixed method approach has the potential of meeting the entrenched research objectives, as both types of data collection (quantitative and qualitative) add equal value for understanding of the research question (Johnson & Onwuegbuzie, 2004).

Rationale for using the Mixed Method Design

The methodology employed via mixed method design places the current study in a good position to better understand the research subject, as the goal of this study is not merely to demonstrate associative relationships between psychosocial context variables and child neurodevelopmental outcomes. The use of a mixed method design thus served as a means of exploring the prevalence of neurocognitive and socio-emotional dysfunction amongst HIV-positive children, while also providing qualitative data on the psychosocial context in which the caregiving of these children is performed.

One of the major advantages of the mixed method design is that it provides an opportunity to explore the inter-relationship between variables in a single design study, *i.e.* child HIV illness, caregiving role, and other contextual factors that serve to impact negatively on the child's neurodevelopmental outcome (Johnson, & Collins, 2009). Moreover, another advantage of utilising the mixed-method approach is that it allows an opportunity for method triangulation through combining quantitative and qualitative methods in a single study. As such, the researcher is able to verify the quantitative findings against the qualitative findings and vice versa (Onwuegbuzie & Leech, 2005), as well as contribute to a more comprehensive empirical understanding of the data. Therefore, triangulation increases the credibility and validity of the results of the study (Onwuegbuzie & Johnson, 2006; Reid, Flowers, & Larkin, 2005; Bryman, 2004, 2006). As indicated by Bryman (2004), triangulation is one of many rationales for multi-method research as it offers the prospects of enhancing the validity of the findings in the study by cross-checking, comparing, or relating one method to another. Any research is required to be conducted at the highest level of scientific standard that will enable it to be considered credible (Babbie & Mouton, 2002; Graziano & Raulin, 2004) and the mixed method ensured that this scientific requirement was met throughout this doctoral study (Onwuegbuzie & Johnson, 2007).

Given the aforementioned advantages, the mixed methods design was best suited for this doctoral study because it enabled the researcher to understand the extent of HIV's effect on the neurodevelopmental outcomes of children living with HIV, while also providing an understanding of the psychosocial context and its relationship to the observed neurodevelopmental outcomes. It enabled the researcher to capture caregivers' responses to dealing with the reality of having to care for a child with HIV, thus providing him with a very useful, detailed understanding of not only issues related to the child's health and

development, but also the experiences of caregivers responsible for dealing with a child living with a life-threatening or chronic illness.

Generally, the mixed method has the potential of enriching the body of research on the experiences of caregivers and children where the child is perinatally infected with HIV, and as such offers an in-depth understanding of the research while also contributing to the limited local empirical data on the subject.

Research sampling

Sampling method

The study made use of a convenience sample (Graziano & Raulin, 2004; Babbie & Mouton, 2002) which was selected from local paediatric hospitals within the Buffalo City Municipality. Convenience sampling forms part of non-probability sampling techniques and allows for the selection of participants based on the fact that they are conveniently accessible to the researcher (Castillo, 2009; Babbie & Mouton, 2002). This sampling method has been deemed appropriate and feasible for the current study, given the selective nature of the sample, *i.e.* a clinical sample of perinatally HIV-infected children using ARVs and their caregivers attending hospital.

Furthermore, given the sensitivity, ethical considerations, and the personal nature of the diagnosis of these samples it would have been very difficult to locate and recruit the participants needed for this study otherwise. Despite the given convenient accessibility of these participants, the highest ethical standards were adhered to as participants' participation was on a voluntary basis. They were invited to be part of the study without duress and only those who responded to the invitation were included in the study; following informed consent

procedures and depending on whether they met the appropriate inclusion criteria (these will be discussed later).

While some of the major advantages of this sampling technique lie in the fact that it is a quick, inexpensive, and easy means of recruiting participants, especially due to their availability, there are nevertheless also disadvantages to consider (Babbie & Mouton 2002; Castillo, 2009; Graziano & Raulin, 2004). One of the major disadvantages associated with convenience sampling is the issue around generalization as the selected sample would not necessarily be representative of the entire population and may be criticized for sampling bias (Graziano & Raulin, 2004). This limitation is likewise amplified by the use of a volunteer recruited sample, as was used in this study (Castillo, 2009).

Research procedure

Following the approval of the study by the University of KwaZulu Natal's Biomedical Research Ethics Committee (BREC) reference number BE252/11 and the Ethics Committee of the East London Hospital Complex (Refer to Appendix 1), permission was obtained from the Head of the Paediatric Department who introduced the researcher to staff and requested their cooperation for the duration of the study. During this introduction the researcher provided a detailed presentation of the nature and purpose of the study.

This was followed by introducing the study to the caregivers who attended the paediatric HIV clinic operating in the Paediatric Department. The study was explained to the caregivers and they were invited to participate in the research project. Using the process of informed consent, the caregivers who met eligibility criteria signed informed consent and were included to participate in the study. The process of informed consent was explained to

participants in their mother tongue, *i.e.* in isiXhosa by an isiXhosa research assistant who was a qualified clinical social worker (Refer to copy of informed consent in Appendix 2).

Both quantitative (caregiver and child outcome measures) and qualitative (individual interview with caregiver) data were collected for the study. Caregivers completed a series of quantitative questions on family demographics, child emotional development, and home environment in which the children were raised. A depression scale was administered by the researcher and 60 minute individual interviews were also conducted. With the children, a neurocognitive assessment was administered in their caregivers' presence, and the researcher also obtained each participating child's age, weight, and height. All the measures were administered in the hospital, except for the home environment measure which was administered at participants' homes. The researcher had previous training in the administration of each of the measures.

Ethical consideration

Ethical clearance was granted separately by the University of KwaZulu Natal's Biomedical Research Ethics Committee (BREC), and the Ethics Committee of the East London Hospital Complex (Refer to Appendix 1).

Participants of the study were approached in the Paediatric Department after formal access was granted by the Head of the Department and written informed consent was obtained from the children's caregivers, while assent was directly requested from the child. The research was explained to the caregivers in English and isiXhosa by a clinical psychologist and an isiXhosa–speaking clinical social worker who had prior experience of working with HIV/AIDS-infected children and parents. Each caregiver was provided with a detailed

information sheet (Refer to Appendix 2) containing contact details for the researcher and his supervisor. Only after the caregiver fully understood the content and nature of the study, as was indicated on the information sheet, were they allowed to give informed consent and voluntarily participate in the study. It was emphasized to the caregiver that they were under no obligation to take part in the study and whether or not they wanted to participate in the study, would not affect their child's treatment or quality of care at the health facility. They were also informed that all the information collected would be treated with the strictest confidentiality. The limits of confidentiality, as reflected in the information sheet, was also discussed and explained to participants in their mother-tongue. In addition to the parents giving consent on behalf of the children, the child was verbally informed of the study and asked whether they want to be part of the study in a child friendly and age appropriate language and given the option of refusing participation. Each child was made aware of the freedom to decline participation even though the parents consented on their behalf to participate. The children were further informed that they will not be punished if they so choose not to participate in the study. However, none of the children declined participation. Further, all caregivers were informed of the option to receive clinical feedback on the children's assessments. Those caregivers who wanted feedback were offered feedback session by the researcher. However, only 5 caregivers requested feedback. A feedback session of approximately 30 to 45 minutes was arranged individually with each respective caregiver. A possible reason that only five caregivers requested feedback on the neuropsychological testing could perhaps be explained by the fact that neuropsychological testing is not widely accessible to our people and especially among our poor black communities (Cockroft & Laher, 2013). Currently, neuropsychological testing is not part of the routine management of PHIV+ children in the Paediatric department in the hospital and broader Buffalo City Municipality.   One of the important rationales for doing this study is to

promote routine neuropsychological evaluation of pre- and school-aged HIV-infected children. Early detection of neurocognitive deficits can assist in planning of specifically tailored interventions for HIV+ children that can ameliorate the loss of developmental potential (Engle et al., 2007). Finally, participants were informed of the availability of counselling and social-welfare services should the need for these arise.

Quantitative methodology

Quantitative sample recruitment

The study conveniently recruited 152 child/caregiver dyads as part of the quantitative component of this cross-sectional doctoral study. The sample was recruited by inviting both biological and non-biological caregivers of perinatally-infected children with HIV and who were treated with ARVs through the Paediatrics Department from the local hospital that serves low-income, peri-urban, rural communities. The perinatally HIV-infected children on treatment consisted of both boys (n=65) and girls (n=87). The sample of caregivers 18 years and older (*M*=45 years), whose children were HIV positive and were in the age range of 31.38 and 92.78 months (*M*= 63.13) were included in the study. All of the caregivers were from socio-economically disadvantaged backgrounds, with the hospital predominantly accessed by people with a low socioeconomic status.

Inclusion and exclusion criteria

The sample of participants had to meet certain criteria to be included in the study. Child participants were selected for inclusion on the basis that they had a current diagnosis of HIV, were perinatally infected, were on treatment, had a stable CD4 cell count, and had had no new symptoms of HIV infection that were considered severe and indicative of serious bacterial infections, encephalopathy, lymphomas, or pneumocystis carinii pneumonia (as

defined by the Centres for Disease Control and Prevention as a clinical category C diagnosis) in the 12 months preceding the study (Schneider et al., 2008). The sample was heterogeneous with regards to gender, while participants' race was homogenous, given that the facility from where the sample was drawn is predominantly accessed by South Africa's Black African population group. Finally, caregiver participants had to be the primary caregiver of the HIV positive child.

Participants were not excluded based on the use of language. Although the population accessing the health facility is predominantly isiXhosa speaking, many of them have English as a second language or at least at conversational level. In the case of non-English speaking participants a translator, who was a clinical social worker, was utilized.

Furthermore, individuals who were not able to volunteer or who decided to be part of study but were unable to give informed consent were excluded from the study (*i.e.* individuals that accompanied the child to hospital for treatment on behalf of the primary caregiver). Moreover, children and their caregivers were only included in the study if the caregiver or legal guardian provided written informed consent and the child assented to participation, following a detailed explanation of the purpose of the study.

Description of quantitative measures

For the *quantitative phase* a series of quantitative measures used in previous studies were utilised, including The Beck Depression Inventory, 2nd edition (BDI-II) (used to measure caregiver depression), the Home Screening Stimulation Questionnaire (HSQ) (used to measure home environment quality), the Wechsler Preschool and Primary Scale of Intelligence- III (WPPSI-III) (used to measure dependent variable neurocognitive

development), the Strengths and Difficulties Questionnaire (SDQ) (for measuring dependent variable socioemotional development), and the Demographics and Anthropometric data test (for the assessing nutritional status of HIV-positive children [Refer to figure 4]).

Furthermore, the reliability of the quantitative measures was based on Cronbach's alpha which is the most commonly used measure of reliability of a scale and usually ranges between zero and one. The closer the Cronbach's alpha is to 1.0 the greater the internal consistency of the items in the scale (George & Mallery, 2003). It is widely recommended that a Cronbach's alpha coefficient of above 0.7 to 0.8 is an acceptable value representative of good reliability (DeVellis in Pallant, 2010). However, some have argued that when dealing with psychological constructs a value below 0.7 can be realistically expected owing to the diversity of the constructs that are measured (Kline in Field, 2006). The reliability of the Cronbach's alpha coefficients calculated for the quantitative analysis measures used in this doctoral study are presented in Table 2 in chapter 5 (quantitative findings). Overall, all the measures used for quantitative data collection were reliable.
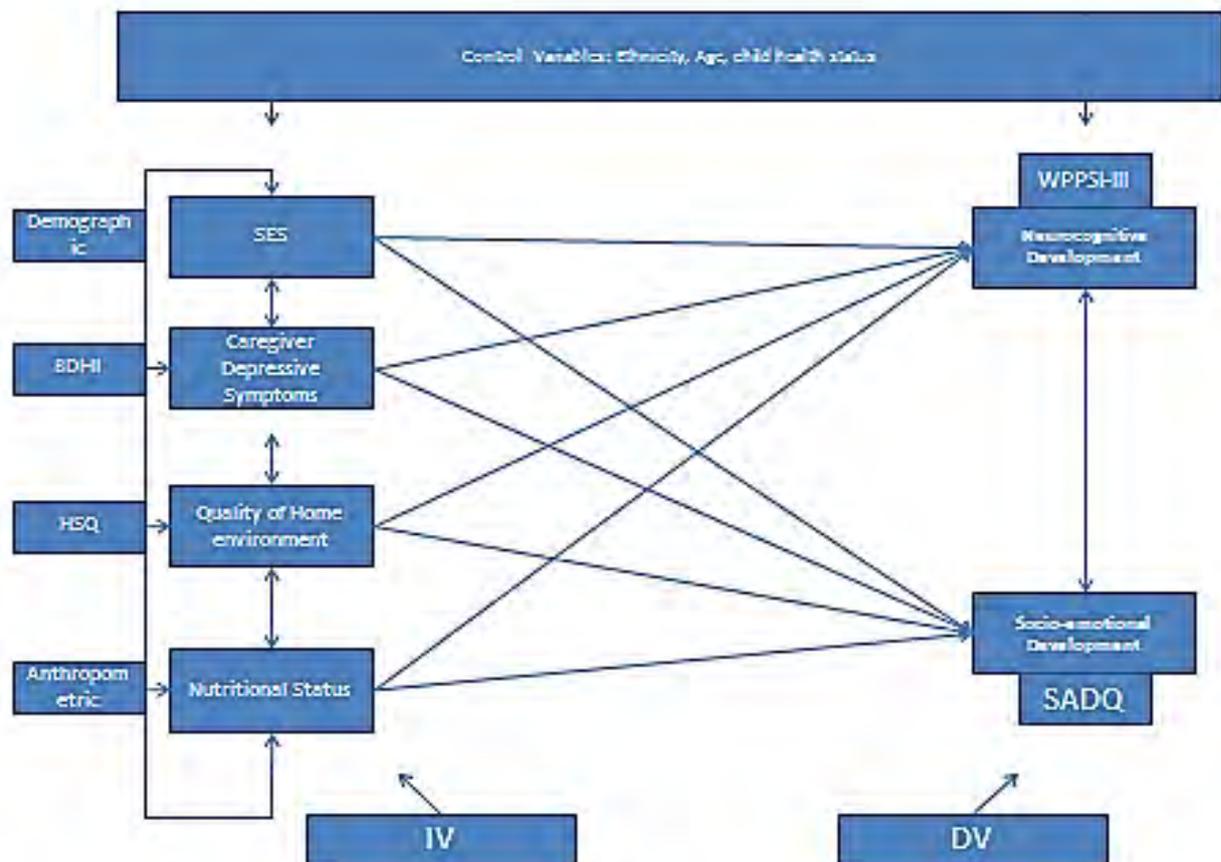
Figure 4: Measures depicting pathways between the Independent Variable (IV) and Dependent Variable (DV) with their corresponding measures used in the quantitative phase.

The Beck Depression Inventory, 2ⁿᵈ Edition (BDI-II)

The Beck Depression Inventory (BDI-II) (Beck et al., 1961) consists of 21self-reported items that assess the presence and severity of depression among psychiatric and normal populations across cognitive, affective, somatic, neurovegitative, and endogenous domains of depression. The self-report assessment is rated on a four-point scale with varying degrees of symptom severity, ranging from zero (no symptom) to three (severe symptoms). The 21 symptoms and attitudes assessed by the BDI-II include: 1) Mood, 2) Pessimism, 3) Sense of failure, 4) Self-dissatisfaction, 5) Guilt, 6) Punishment, 7) Self-dislike, 8) Self-accusation, 9) Suicidal ideas,

10) Crying, 11) Irritability, 12) Social withdrawal, 13) Indecisiveness, 14) Body image change, 15) Work difficulty, 16) Insomnia, 17) Fatigability, 18) Loss of appetite, 19) Weight loss, 20) Somatic preoccupation, and 21) Loss of libido. Thus, the ratings given by a participant for each of the 21 items range from zero to 63 and is normally divided into four categories. A score of zero to 10 was considered within the normal range or asymptomatic, with scores of 11 to 16 indicating mood disturbances, scores of 17 to 20 indicating borderline clinical depression, 21 to 30 moderate depression, 31 to 40 being indicative of severe depression, and 40+ indicating extreme severe depression (Beck, Steer, & Garbin, 1988a). The questionnaire is easily administered and takes about 5-10 minutes to complete. The BDI-II is well utilised in both clinical and research settings.

The Beck Depression Inventory was used as the measure of depression amongst the caregivers in this study (Beck, Steer, & Garbin, 1988a). This 21-item self–report measure has been used extensively in research internationally and locally (Kagee, 2008). The BDI-II has consistently demonstrated excellent reliability and validity amongst samples of patients with chronic illnesses (α=0.85), patients living with HIV (α=0.85), and community based samples of adolescents living in South Africa (α=0.86) (Kagee & Martin, 2010; Kagee, 2008; Ward, Flisher, Zissis et al., 2003). In the present doctoral study the reliability coefficient of this instrument as measured by Cronbach's alpha was 0.9, which is indicative of an excellent internal consistency measure (Gliem & Gliem, 2003). The BDI-II was deemed to be a reliable measure of depression among the sample of caregivers caring for HIV-infected children.

Home Screening Questionnaire (HSQ)

The HSQ is a self-administered, 34-measure questionnaire based on the Home Measurement of the Environment (HOME) Inventory (Bradley & Caldwell, 1978; Coons, 1981). It is an

interview version of the Home Observation for Measurement of the Environment (HOME) (Caldwell & Bradley, 1984) and provides a score representative of the overall quality of the home environment in which a child is reared. It includes a wide range of characteristics such as activities around language stimulation, family activities, play, organisation, and discipline, and also includes a toy-checklist to find out about the availability of toys in the home. A home environment characterised by a lack of stimulating quality would likely have few written and reading materials or children's toys available, and adult caregivers in these homes are likely to engage in very limited stimulating activities with the child. As such, a home environment lacking in stimulating quality for a child would be categorised as "suspect" (a score of 41 or below on the HSQ), while a "non-suspect" home (a score of 42 and above on the HSQ) is characterised by a higher stimulating quality. The use of the HSQ in this doctoral study used the same cut-off score to categorise home environment to reflect lower (lack) or higher (sufficient) stimulating quality. It is reported that the HOME is the most widely used observation measure in child developmental research and is used to investigate the intellectual abilities of children (Bradley et al., 1988; Bradley & Caldwell, 1980, 1984, 1978).

The successful use of the Home Screening Questionnaire in South Africa has been demonstrated in a number of studies. In a study conducted among black infants in Soweto researchers administered the HSQ and found a significant correlation between the home environment and cognitive development in the sample (Richter, 1989). Similar results were obtained in another study conducted in the 1990s among another group of black South African infants, where the researchers concluded that the factor structure of The Home Screening Questionnaire significantly corresponded to the HOME scale among Western samples (Grieve & Richter, 1990). The Home Screening Questionnaire's ability to predict the relationship between home environment and cognitive function was also confirmed in a

large study conducted around large industrialised sites in Durban, Pietermaritzburg, Johannesburg, and Pretoria (Richter & Griesel, 1991). Apart from the South African context, the HSQ has significantly predicted the effect of home environment of healthy developing and disabled children in Turkey (Kesiktas, Sucuogglu, Keceli-Kaysili, Akalin, Gul, & Yildirim, 2009), and unhealthy children in Portugal and United States (Cocsia et al., 2001).

The Home Screening Questionnaire was used as a measure of stimulation quality in the home environment (Caldwell & Bradley, 1984; Bairrao, 2003). It is a quick and practical tool that identifies home environments likely to be suboptimal for child development. Although the HSQ is not validated for the South African context, it has nevertheless been widely used as a measure of home–environment quality in a development context (Richter & Grieve, 1991; Nair et al., 2009; Frankenburg & Coons, 1986). The measure has been validated amongst thousands of parents of low–income families and is readily used by both researchers and healthcare providers who work with low-income families (Frankenburg & Coon, 1986). A study of poor home environments conducted in India suggests that one can confidently apply the HSQ in development research and for clinical use in low-income settings (Nair et al., 2009). In this doctoral study the HSQ had an internal consistency reliability of 0.61 on the Cronbach's alpha index. The HSQ was found to have acceptable reliability (George & Mallery, 2003) and thus proved a useful measure of the proximal home environment and the effect of stimulation on the developmental outcome in the sample of HIV-positive children.

Wechsler Preschool and Primary Scale of Intelligence-III- (WPPSI-III) (Wechsler, 1989)
The Wechsler Preschool and Primary Scale of Intelligence-III (WPPSI-III) was originally designed by David Wechsler as an intelligence test for children (Wechsler, 1989). The test is used to assess neurocognitive functioning in young children of pre- and primary school age,

and has been revised to the current version (WPPSI-III) which accommodates an expanded age range and is suitable for children between the ages of two and a half years and seven years and three months.

This version saw a new subtest (object assembly) included and other subtests (matrix reasoning, picture concepts, and word reasoning) were designed to enhance the measurement of *fluid reasoning*. Fluid reasoning (FR), also known as fluid intelligence, is the ability to reason abstractly, think logically, and solve problems in novel situations, independent of prior learning or education (Cattell, 1987). Examples involving fluid reasoning may include tasks such as solving puzzles, building blocks, or any other task involving problem-solving schemes (Ferrer et al., 2009). It is a pertinent component of neurocognitive development in children as it lays the foundation for children to acquire other abilities (Blair, 2006). It has been argued that FR emerges early in life, after the development of general, perceptual, attentional, and motoric capabilities, and is utilised by the child during any information retrieval process (Ferrer et al., 2009). It has also been found to accurately predict future school and cognitive demanding occupation performance in children. Thus, FR plays an essential role in the way children learn tasks that require complex spatial, numerical, or conceptual relations for current and future orientated performances (Gottfredson, 1997; Ferrer & McArdle, 2004). Through research FR has been linked to important cognitive abilities, such as working memory, executive functioning (Engle et al 1999), secondary memory (Mogle et al ., 2008), short term memory, and the processing of speed (McArdle et al., 2000).

The WPPSI-III consists of 14 subtests, including: 1) block design, 2) information, 3) matrix reasoning, 4) vocabulary, 5) picture concepts, 6) symbol search, 7) word reasoning, 8)

coding, 9) comprehension, 10) picture completion, 11) similarities, 12) receptive vocabulary, 13) object assembly, and 14) picture naming. Coding and Symbol search was taken from the WISC-II and incorporated and adapted to measure *processing speed*. The WPPS-III provides subtests and composite scores that represent functioning in a wide range of neurocognitive domains, as well as providing a composite score that represents a child's general intellectual ability (i.e. Full Scale IQ), and consists of two age-bands (two years and six months to three years and 11 months, as well as four years to seven years and three months). This was done in recognition of the substantial changes in cognitive development that occur during early childhood. The WPPSI–III provides Verbal and Performance IQ scores in addition to a Full Scale IQ score. Furthermore, a processing-speed quotient and a general language composite can be determined for children in both age bands (two years and six months to three years and 11 months, as well as four years to seven years and three months). Children in the two years and six months to three years and 11 months age band are required to do only five of the subtests: Receptive Vocabulary, Block Design, Information, Object Assembly, and Picture Naming. It should be noted that Quotient and Composite scores have a mean of 100 and a standard deviation of 15, while subtest scaled scores have a mean of 10 and a standard deviation of 3. Consequently, Quotient and composite scores can be expressed as any of the following: below 70 (extremely low), 70-79 (borderline), 80-89 (low average), 90-109 (average), 110-119 (high average), 120- 129 (superior), and 130 and above (very superior) (Wechsler, 2002).

Two main broad factors of the WPPSI-III are assessed, namely performance and verbal skills. It has been argued that the Performance factor (also known as non-verbal scale) can easily be administered across a diverse linguistic terrain as it does not need a child that can write or talk to the clinician, and as such it may also be less sensitive to cultural bias in terms of

contextual diversity (Povey, 2008). The verbal test consists of questions that are orally given by the examiner with no time limits. The WPPSI-III as a measure of cognitive function has been applied to HIV research in children from low income backgrounds and is representative of the larger population of children living with HIV in the developing world (Fishkin et al., 2000). Although the WPSSI-III is not validated for the South African cultural context, it is used in this doctoral study based on the fact that the measure correlates well with WISC and WAIS, both of which are normed for South Africa (Shuttleworth-Edwards et al., 2013). Secondly, WPPSI-III has been widely used on a global scale, including in places like Mexico, Pakistan, Brazil, and Iran, as well as in South Africa (Fernald et al., 2009). Also, in a report released by the World Bank Organisation on early child development in low income countries, the WPPSI-III was recommended as a reliable tool for assessing childhood neurodevelopment in Africa (Fernald et al., 2009).

Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997)

This tool is a useful screen of children's emotional and behavioural development problems (Goodman, Meltzer & Bailey, 1998). The questionnaires consist of 25 items that refer to different emotions or behaviours that assess the level of psychological symptomatology in children (Smith, Fawzi, Eustache, Oswald, Surkan, et al., 2010). The scale takes about 10 minutes to complete. For each item a respondent marks one of three boxes to indicate whether the item is ***not*** *true*, ***somewhat*** *true*, or ***certainly*** *true* for the child in question (Goodman et al., 1998). Each item is scored zero, one, or two, where somewhat true is always scored one, but whether Not true and Certainly true are scored zero or two depends on whether the item is framed as a strength or difficulty. The scoring sheet explains which item contributes to which subscales and subscales point to the likelihood of a significant disorder, and/or a disorder of a particular type. On the back of each questionnaire are questions that

aim to address severity by scoring the duration of the difficulties and their impact on the child or others. The Strengths and Difficulties Questionnaire covers ages four to 16, and there is an additional scale for children aged between three and four (Goodman et al., 1998). The scales can be scored to produce an overall score indicating whether the child/young person is likely to have a significant psychological problem, while the total difficulty can be classified as mild/low (zero to 13), moderate/borderline (14-16), or significant/abnormal (17-40) for the total scale. Selected items could also be used to form subscales for Pro-Social Behaviour, Hyperactivity, Emotional Symptoms, Conduct, and Peer Problems (Goodman, 1997). These, in turn, can give an indication of whether a child/young person is likely to have a significant emotional or behavioural problem/disorder, and what type of disorder it is (Goodman, 1999). The SDQ has been found suitable for use in resource-limited settings and has shown to sufficiently discriminate between emotional disorders, conduct disorders, and hyperactivity disorders in children (Mullick and Goodman, 2001; Goodman et al., 2000).

 The SDQ has been used extensively in Africa, including in Ghana (Doku, 2009; 2010; 2012), Kinshasa (Kashala et al., 2005), and South Africa (Cluver & Gardner, 2006) in HIV infected and affected samples. Internationally the SDQ is recognised as a valid scale that corresponds well with child psychiatric diagnoses and have proven a useful tool for assessing at-risk children in low income contexts (Doku, 2009). In a study conducted in Bangladesh, the SDQ was able to significantly discriminate between the psychological symptomatology of both clinical and community samples of children with an estimated receiver-operating-characteristics (ROC) curve ranging from 0.84 to 0.89 (Mullick and Goodman, 2001). Thus, the SDQ readily lends itself to use in both clinical and research settings as a tool that is quick to administer, relatively inexpensive, and practical in identifying children's psychological health. Govender and colleagues evaluated the concurrent validity of the SDQ in a sample of

AIDS-affected children from poor home environments in South Africa (2013), and the results of their study showed that the SDQ had an internal consistency reliability of 0.71 on the Cronbach's alpha index. Their study implied that the SDQ could be confidently applied in assessments of children's psychological health. Psychometric analyses showed that the SDQ in this doctoral study had a Cronbach's alpha reliability coefficient of 0.73, suggesting that the SDQ was a reliable tool in assessing the psychological functioning of the sample of HIV-positive children who took part in the study.

Nutritional status

The anthropometric data and age of the child are used to provide three measures of nutritional status, namely length-for-age, weight-for-age, and weight-for-length (WHO MGRSG, 2006; WHO Anthro, 2005). These anthropometric measures of nutritional status were obtained in accordance with WHO standard procedures. The WHO child growth standards were informed through the results of a WHO Multicentre Growth Reference Study (MGRS) conducted between 1997 and 2003 in six international countries (Brazil, Ghana, Norway, Oman, and the USA). This study allowed for the development of an international standard of growth and development measure for infants, children, and adolescents, using a sample of healthy breastfed children that were raised in a supportive environment which enhanced growth potential over time (de Onis et al., 2004). All obtained anthropometric data was transferred into a software programme called the WHO Anthro programme for ages (zero to five years), Beta Version, and the WHO AthroPlus programme for ages (five to 19 years), which are informed by the WHO standard growth 2006 and reference 2007 respectively. The WHO Anthro software generates height for age z-scores (HAZ), weight for age z-scores (WAZ), and weight for height z-scores (WHZ). The WHO AnthroPlus (five to 19 years) mirrors the functionalities of the WHO Anthro for zero to five years, with the exception that this software

derives nutritional status indicators only for the following indicators: weight-for-age, height-for-age, and BMI-for-age with their respective individual z-scores. The WAZ, WHZ, and HAZ are expressed as a *z*-score <-2SD of the median of a reference population, as calculated according to statistical standards methods recommended by the World Health Organisation/National Centre for Health Statistics (WHO/NCHS) (de Onis et al., 2006). Finally, the results from this analysis are classified as stunting, under-weight, and wasting, respectively.

In keeping with the protocol of ensuring the collection of reliable anthropometric data in this doctoral study, the standardised protocol set out by the WHO Multicentre Growth Reference Group was followed (detailed protocol can be accessed by visiting this website: http://www.who.int/childgrowth/training/en). The WHO growth standard and the WHO reference 2007 came about from a sample of six countries (Brazil, Ghana, India, Norway, Oman, and the USA), in an attempt to set a true international standard by which the growth and development of children could be measured (de Onis et al., 2004). Some argue that children grow similarly when their health and care needs are met (WHO MGRSG, 2006; WHO Anthro, 2005).   Therefore, to ensure the collection of accurate and reliable anthropometric data for this doctoral study, the following standardised measurement procedures was adhered to in collecting the data:

- The equipment used was correctly calibrated on a regular basis.
- Training was conducted based on the recommended measurement protocols, in addition to standardisation sessions with the research assistant on data collection.
- The child's date of birth was taken from the hospital records (folder) where available. Alternatively, the caregiver was asked for both the child's date of birth and age on the day of measurement, to avoid an incorrect reporting of information. Where birthdates

had not been recorded or were unknown, caregivers were probed for the approximate date of birth based on the calendar.

- The standing height was measured for children two years and older.

- Information was entered as recumbent or standing height, depending on which one was measured.

- Children who were able to stand up were measured while standing, whereas children who were unable to stand or who were too weak to do so were measured in a recumbent position.

- It was always indicated whether a child had oedema or not.

- After the age, sex, weight, and length/height information had been entered, the results were checked by using a graphing option to view single and multiple measurements, following each entry.

- Those child records that appeared to have extreme values beyond the flag boundaries were re-investigated and correctly recorded.

Socio-economic status

The demographicinformation regarding age, ethnicity, level of education, employment status, income, and marital status was obtained. This section also gleans information on housing, access to water, sanitation, electricity, appliances (e.g. fridge, washing machine, etc.), and food security.

Quantitative data collection

To clarify, despite the fact that measures such as the Beck Depression Inventory (BDI-II), the Home Screening Stimulation Questionnaire (HSQ), and the Strengths and Difficulties

Questionnaire (SDQ) were used in the study, all of which are paper-and-pencil questionnaires designed to be completed by the caregiver, a structured interview format was preferred during data collection to avoid any reading difficulties, misunderstandings, and the by-passing of certain items by participants (Refer to Appendix 3). The interviews were conducted predominantly in English by me; however where the participant showed lack of understanding, a bilingual clinical social worker was used to translate into isiXhosa. This is acknowledged as a possible limitation as we can never be sure of the accuracy of the questions administered. However, the translator is a trained clinician who was provided with training in every instrument used in the study.

Caregiver outcome measures

Caregiver's emotional functioning

The Beck Depression Inventory (BDI-II) (Beck et al., 1961; 1988a) was completed by participating caregivers to assess affective, cognitive, motivational, and physiological symptoms of depression. Impairment in any of these functioning domains may impair a caregiver's ability to adequately respond to his/her own needs and that of their ill child. BDI-II is a widely used standardized measure of depressive and anxiety symptoms (Beck et al., 1988b). This data was collected to measure the emotional function of caregivers (HIV-positive or negative) involved in assuming the role of parenting a HIV-positive child, with the assessment taking an average of 30 minutes to be completed.

Child outcome measures

Neurocognitive functioning

The neurocognitive development level of the HIV-positive children in the study was measured by the Wechsler Preschool and Primary Scales of intelligence-III (WPPSI-III) with

their caregivers present and after informed consent had been given. The caregiver had little interaction with the child during the assessment on request from the researcher and sat quietly on a chair in the corner of the testing room. The decision to allow the caregiver into the room was due to the fact that most of the children found it difficult to separate from their caregivers. This measure was administered in the Paediatrics Department of the hospital in a private consultation room. This decision was taken to prevent any major disruption in the child's hospital routine. All assessments were conducted behind a closed door, with a "*do not disturb*" sign in place, so as to prevent any disruptions during the assessment process. The process of administration was explained to each child participant in an age-appropriate manner. The assessment was conducted within one consultation with an average of two hours in duration. However, in cases where children were known to have short concentration spans, the testing was split over two appointments which were conducted at least a week apart.

Socio-emotional functioning

The Strengths and Difficulties Questionnaire (SDQ) was used to collect data on the child's emotional and behavioural development and is considered a useful measure with which to screen and establish whether a child has significant socio-emotional problems or difficulties. The measure was explained to the each caregiver and was given to each participating child's caregiver to complete. Thereafter, the measure was completed by the caregiver with the assistance of an isiXhosa translator who went through each item on the scale with the caregiver. It took approximately 15 to 20 minutes to complete the measure.

Nutritional status

Anthropometric measures of child nutritional status were collected from all the HIV-positive children participants in the study. Child nutritional status is commonly assessed with three

indicators, namely stunting (low height for age), underweight (low weight for age), and wasting (low weight for height). The anthropometric measures were all taken in accordance with the WHO child growth standard procedures (de Onis et al., 2004, 2006; WHO Anthro, 2005). Each child's weight was measured in kilograms (kg) to one decimal, using a mechanical bathroom scale accurate to 120kg. The height of each child was then collected by measuring their length with an inelastic tape measure in a vertical position by having them stand barefoot on a flat surface against a wall. Their birth dates were taken from their hospital folders and was confirmed by asking caregivers the age of their child. Finally, their nutritional status (using the indicators stunting, underweight, and wasting) were expressed as z- scores of <-2 or more, standard deviations below the norm respectively, using the World Health Organization (WHO) child growth standards 2006 and WHO Reference 2007 Anthro software (Schwarz et al., 2008; de Onis, 2006).

Home environment

Home screening stimulation

The caregivers were asked to report on the home environment in which the HIV-positive child was being raised. This was measured through the Home Screening Questionnaire (HSQ), which took about 30 minutes in total to be completed by the caregiver with the assistance of an isiXhosa translator who went through each item on the scale with the caregiver. This assessment scale was administered at the caregiver's home, as it allowed the researcher an opportunity to observe the living conditions in which each child was being raised. Caregivers were contacted telephonically (in cases where caregivers had phones/cell phones) two to three days prior to the visit and were informed that a home visit would be conducted shortly, but the exact date and time was not specified.

Demographic status

Caregivers were asked to report on basic demographic information, including age, race/ethnicity, relationship status, employment status, and education level. Additionally, they were asked to report on access to basic services such as electricity, flush toilets, and running tap water. Finally they were asked to report on the type of dwelling they resided in, and whether they had a fridge, microwave, and/or vegetable garden.

Quantitative Statistical Analysis

All data collected for the quantitative part of this study was captured into the statistical programme IBM Statistical Package for the Social Sciences (SPSS), version 21.0, following the appropriate scoring and coding of each measure. The level of significance for all the statistical tests conducted was maintained at p-value <0.05 (two-tailed) (Statistics, 2012).

 Following the capturing of the data into the IBM SPSS software, the first step was to cross-tabulate the data, which required said data to be manipulated. The Shapiro-Wilk test was conducted to explore the data and to observe the assumptions of normality in the data. No systematic or random errors were noted and missing data was found not to be a problem in the dataset. Finally, the Levene's test was used to assess assumptions of equality or homogeneity of variance in the variables.

In the second step, descriptive statistics were calculated for all the independent and dependent measures, namely WPPSI-III, SDQ, HSQ, BDI=II, Nutritional status, and socio-demographics to provide comprehensive descriptive statistics of the sample. Univariate statistical analyses included means, standard deviations, frequencies, ranges, and percentages for socio-demographic characteristics, prevalence of psychological symptoms among

caregivers, psychosocial symptoms, and neurocognitive deficits among the children on whom the research was conducted. In order to establish the reliability of psychometric measures used in the study, the Cronbach's alpha was run to determine the internal consistency for the BDI-II, HSQ, and SDQ.

In the third step, bivariate analyses were performed to measure the association between all the predictor and outcome variables to establish whether any significant association existed among the variables. Correlation analysis was conducted for the sample as a whole and for groups (caregiver–biological and non-biological, as well as age-group of caregivers 18 to 35 years of age, and 36 years of age and above).

To see if any significant differences existed between children raised by biological or non-biological caregivers and by a younger or older caregiver, an analysis of variance (ANOVA) was conducted. One-way ANOVA for three level age groups (three to four years, five years, and six years and above) was conducted to find out if any differences existed among the children's ages and the various dependent and independent variables.

The independent t-test was conducted according to caregiver type (biological or non-biological), age of caregivers (younger [18 to 35 years old] versus older (36 years old and above]), and the gender of the children in the sample to determine whether any differences on measures existed.

Lastly, regression analysis were conducted using the independent variables caregiver depression, home environment, socioeconomic status, and anthropometric data with the dependent variables neurocognitive and socioemotional functioning.

Coding and re-coding of variables

For the socio-demographic variable coding was done as follows: gender was coded as 1=male and 2=female; age for both children and caregivers was entered in its original form, but was re-coded for the purpose of analysis as 1=31.38 to 47.99 months, and 2=48.00 to 92.79 months for the children; and for the caregivers it was coded as 1=18 to 35 years, 2=36 to 59 years, and 3=60 years and above. Moreover, type of dwelling was coded in the following manner: 1=brick/concrete house, 2=traditional hut, 3=sink shack, 4=wooden house, and 5=other. The number of people living in the house were categorised into number of persons and coded as follows: 1=zero to two, 2=three to four, 3=six to seven, and 4=more than seven. The same was done for the number of persons per bedroom, *i.e.* 1=zero to two, 2=three to four, and 3=more than four. Furthermore, categories for water accessibility were coded as: 1=own tap, 2=communal tap, 3=river/dam, 4=borehole, and 5=other, while types of toilet was coded as: 1=flush toilet inside the house, 2=flush toilet outside the house, 3=pit, 4=bucket/pot, and 5=communal toilet. With reference to household apparatuses available in the home, items such as fridges, microwaves, telephones, and/or televisions were all coded as either 1=yes, or 2=no. The category for type of fuel the household used was categorised as follows: 1=electricity, 2=gas, 3=paraffin, 4=wood, and 5=open fire. Moreover, the highest level of education of the participants were categorised in the following way: 1=no education, 2=grades one to seven, 3= grades eight to ten, 4=grades eleven and twelve, 5=tertiary level education, and 6=do not know. Likewise, the categories for caregiver employment were as follows: 1= housewife, 2=unemployed, 3=casual/piece jobs, 4=child support grant, 5=disability/old age pension, 6=do not know, and 7=self-employed. Finally, the type of food availability was based on the availability of a vegetable garden and was coded as 1=yes and 2=no.

Home environment stimulation was assessed through the HSQ. Initially data was entered in its original form, but was it was subsequently re-coded to ascertain the children's vulnerability to a lack of stimulation in the home environment. All the questions were recoded into dichotomous variables with one as "Yes" (indicating availability of resources) and zero as "No" (indicating non-availability of resources). A total of 41 and bellow was labelled as vulnerable or suspect, which meant the child lacked adequate stimulation at home, while a total of 42 and above was deemed not vulnerable and meant the child received adequate stimulation in the home environment.

The participating children's psychological functioning was assessed through the Strengths and Difficulties Questionnaire which was coded as 1=low/mild difficulty, 2=some/moderate difficulty, and 3=high/severe difficulty. Initial responses on each item was coded as 0=not true, 1=somewhat true, and 2=certainly true. Re-coding to questions seven, 11, 14, 21, and 25 was made as they were reverse scored items. In turn, caregivers' depressive symptoms were categorised as a score of 0=no symptoms, 1=low/mild symptoms (one to 16), 2=moderate symptoms (17 to 30), and 3=severe/significant (31 to 40>).

The WPPSI-III responses to determine level of cognitive functioning was categorised and coded as 1=extremely low (<69), 2=borderline (70 to 79), 3=low average (80 to 89), 4=average (90 to 109), 5=high average (110 to 119), 6=superior (120 to 129), and 7=very superior (>130). Similarly, the anthropometric measures for nutritional outcomes (WAZ, HAZ, WHZ) was code as 1=normal (-2.0 <), 2=moderate (-3.0 <-2), and 3=severe (<-3).

Moreover, density was used to assess whether the HIV-positive children were living in overcrowded home environments, and question 26 was re-coded as follows: 0=overcrowded

(more than two persons per bedroom), and 1=not overcrowded (less than two persons per bedroom). Finally, the type of caregiver was codes as 1=father, 2=mother, 3=siblings, 4=grandfather, 5=grandmother, 6=aunt, 7=uncle, 8=cousin, 9=friend, and 10=other. For the purpose of analysis these were re-coded as 0=biological caregiver (mother) and 2=non-biological caregiver, which included three to 10, with exception of the male figures listed as numbers one, four, and seven (*i.e.* father, grandfather, and uncle) to maintain the homogeneity of the sample.

Qualitative Methodology

Description of Interpretative Phenomenological Analysis (IPA)

The qualitative component was informed by Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2007) to gain a better understanding and explicate the experiences of participants as they are encountered and lived (Fade, 2004). IPA denotes the way in which participants perceive an experience, and is reflected directly through the way they talk about, and behave in relation to the lived event (Fade, 2004). Consequently, the way in which participants make sense of their experiences forms the basis of IPA (Cooper et al., 2012; Fade, 2004).

The key underlying theory of IPA is phenomenological, interpretive, and idiographic (Fade, 2004; Smith & Osborn, 2007; Reid et al., 2005). Thus, "IPA is phenomenological in that it seeks an insider perspective on the lived experiences of individual[s]" (Fade, 2004, p. 648), it is interpretative as far as participants construct and give meaning to their own reality, while the researcher guards against his/her own preconceived knowledge, beliefs, and judgment, and in so doing the participant's subjective information/data is presented (Reid et al., 2005; Fade, 2004). IPA acknowledges the researcher's personal beliefs and viewpoints, and

embraces the premise that understanding requires interpretation. It is ideographic in that it allows research to be focused at a particular level (what is distinct), while attempting to balance this against commonalities shared by various participants (Reid et al., 2005; Fade, 2004). Moreover, IPA proves useful not only to look at an individual's experience of a health condition, but is also able to explore the experiences and meanings ascribed by families and extended families in confronting the phenomenon.

Firstly, IPA is phenomenological as it is concerned with a participants' perception of an event, which (in relation to this study) includes the participants' shared experiences in managing/caring for a child with a chronic illness. Secondly, is interpretative, as gaining access to an individual's world depends on, and is complicated by, the researcher's own preconceived ideas. Thirdly, IPA acknowledges accessing the subjective world of the participants. Subsequently, the researcher has to become an active interpreter in the process of making sense of the participant's world through a process of active interpretations (Fade, 2004). As indicated by Brocki & Wearden (2006), interpretative activity is needed as part of making sense of and understanding the participant's world. This is achieved while the researcher tries to make sense of the participants, who in turn are trying to make sense of their own personal worlds. As such, IPA attempts, as far as possible, to gain an insider perspective of the phenomenon under study, while acknowledging the researcher's role as primary analytical instrument (Fade, 2004, p. 648).

The utilisation of semi-structured interviews in collecting data is *one* such design in which this process is achieved with IPA. In this way participants are encouraged to 'tell their story' and the researcher is able to facilitate the process (Fade, 2004; Reid et al., 2005). Central to IPA is the researcher's engagement in an interpretive relationship with the scripts that emerge

from these interviews, thus allowing him/her to enter into the participants' 'world', enabling

him/her to make meaning of the text (Fade, 2004).

According to IPA, engaging with a text is not only about categorizing it into chunks of data

units, as the researcher(s) has to identify meaning in the participants' experiences as reflected

through the text, in addition to identifying commonalities, differences, and contradictions

across participants experiencing the same phenomenon, all of which requires close interaction

between the researcher and the text (Fade, 2004; Reid et al., 2005). By engaging in this

process the researcher is able to enter into an interpretative relationship with the text, thus

allowing him/her to access the participant's 'world' and come to understand their

world/reality (Fade, 2004). Moreover, findings from IPA research are highly nuanced and

can complement and provide meaning to quantitative research on the specific phenomenon

that is explored.

Justification for using Interpretative Phenomenological Analysis (IPA)

Although IPA found popularity predominantly within the field of health psychology,

published studies also exist in the fields of applied social and clinical psychology (Reid et al.,

2005). It has been argued that this popularity perhaps is attributed to IPA's ability to

contribute to the biopsychosocial perspectives (Reid et al., 2005), in other words, the

recognition that health professionals are becoming increasingly more aware that the way in

which patients interpret their health experiences and assign meanings to those experiences are

central to them, similar to receiving a diagnosis and subsequent treatment for an illness (Reid

et al., 2005). As such, IPA as a methodology provides one the opportunity to gain a greater

understanding and insight into a patient's perception of their health status, which is not

limited to some quantifiable measures (e.g. scales and questionnaires) that do not fully allow

one to appreciate the 'live experience' coupled with an illness diagnosis. Consequently, IPA patients/participants have the opportunity "to express their views about strengths, wellness, and quality of life" (Reid et al., 2005, p. 21), which are often lost on, and sometimes even immeasurable, on quantitative scales.

Therefore, IPA provides one the opportunity to focus on the experiences of multiple patients/participants who are confronting the same disease or illness (Fade, 2004), and is achieved within the contextual and cultural frame of the participants. In this way IPA proves useful in providing a detailed understanding of how individuals confront, respond to, and deal with chronic illness/disease, as well as its effects on the contextual reality in which these experiences are lived out (Reid et al., 2005).

In research where there is less concern for aspects of cause and effect and greater interest on being explorative and gaining subjective insights to experiences, IPA could prove invaluable. Like most qualitative paradigms, IPA as a methodology has the potential to enrich understandings of health and psychosocial research (Fade, 2004). Moreover, given the fact that health experiences are not limit to a single period in time but rather occur over extended timeframes (e.g. living with a chronic illness), IPA is ideally suited to capture these ever-changing narratives.

As part of phenomenological psychology the goal of the qualitative component of this doctoral study was to: i) generate and collect data regarding the experiences of caregivers caring for HIV-positive children; ii) identify key themes from caregivers' experiences with respect to caring for an HIV-positive child; and iii) describe the lived shared experiences of caregivers living with HIV-positive children. Additionally, the following experiences were

explored: the experience of being the caregiver to a child living with HIV (a child who has to attend various hospital appointments for treatment); how, as caregivers, these individuals make sense of their experiences and the meanings they ascribe to it; caregivers' perceptions of issues relating to the support of their children while balancing their own needs against the needs of said children, as well as those of the rest of their family; and issues around social response to their children's illness and the perception and meaning they attribute to this. As Reid et al. (2005) stated, the role of an IPA researcher is to uphold the responsibility of making inferences cautiously, and with awareness of the contextual and cultural background against which data (interview transcripts) are generated. Therefore, as the researcher I attempted to understand and interpret the experiences of these caregivers in the collaborative and impartial nature reflected by IPA (Fade, 2004; Reid et al., 2005). As part of interpretative phenomenological research each participants' perception and understanding of what is important in relation to caring for a child with HIV was studied in the hope of providing an in-depth narrative account of shared common experiences.

Qualitative Sample recruitment

Forty-four (N= 44) caregivers of the 152 caregiver/HIV-positive child dyads recruited for the quantitative study were conveniently chosen for the qualitative study from the following three groups of caregivers: HIV-infected biological mothers; HIV affected caregivers, including caregivers of maternally orphaned HIV-positive children; and caregivers of maternally non-orphaned children whose biological mothers are absent (incapacitated by illness or are working). Thus the sample of caregivers for this qualitative investigation is a sub-set of the 152 caregiver/child dyads sampled for the quantitative study. The inclusion criteria for these caregivers required them to be female and aged 18 years or older. A caregiver is defined as the person who assumes the primary caregiving role of the HIV-positive child (this can

include the biological mother or extended relatives such as an aunt or grandmother). The gender of the caregivers was kept homogeneous, as children in the area are predominantly raised by women. The qualitative sample of caregivers comprised of 52.3 % of HIV-caregivers and 47.7% HIV+ caregivers.

Semi-structured Interview Schedule

The choice of using a semi-structured interview schedule to guide the individual interviews is informed through the theoretical underpinnings of IPA (Smith & Osborn, 2007). In using a semi-structured interview schedule the researcher aimed to explore and gain a better understanding of the experiences encountered by participants of a particular psycho-social and health phenomenon.

According to Babbie & Mouton (2002) one of the main limitations of closed-ended questions lay in the researcher's inability to capture some important details due to its rigid structure. Hence the rationale for using a semi-structured interview schedule in guiding the individual interview as captured. Like Smith & Osborn (2007, p. 59) say, "...the advantage of the semi-structured interview [is that] it facilitates rapport/empathy, allows a greater flexibility of coverage and allows the interview to go into novel areas, and it tends to produce richer data".

The semi-structured interview is one of the IPA tools used to collect data about participants, and as such allows participants to tell their story in their own way, which is a central/core component of IPA (Fade, 2004). Consistent with IPA, an open-ended and non-directive style of interviewing allows participants to make sense of their personal world/reality, thus enabling them to bring this reality across to the researcher. In this way participants allow the researcher access to his/her psychological and social world and guides the researcher in

his/her probe of emerging areas with less emphasis on questioning order. Therefore, "[t]he interviewer is understood to work with the respondent in flexible collaboration, [in order] to identify and interpret the relevant meanings that are used to make sense of the topic" (Reid et al., 2005, p. 22). This approach allows participants to discuss matters that they would often find difficult to talk about and as such permits the researcher to explore and guide participants through the process of bringing sensitive material to the surface that might not under different circumstances have come to the fore. In this way, semi-structured interviews are particularly suitable for research involving issues of a personal and complex nature.

Consequently, the current doctoral study made use of semi-structured interviews as part of the qualitative data collection process. A semi-structured interview schedule was constructed in guiding individual interviews of approximately 60 minutes long, with the interview serving as the primary source of information gathering for the qualitative component of this study. In keeping with the aim of IPA it was used as a guide to generate further discussions on what participants revealed of their psychological and social worlds, which meant that participants controlled the direction the interview took and were able to discussed areas important to them. Given that the research area explored in this doctoral study is of an extremely sensitive nature (*i.e.* HIV which is a chronic and life-threatening illness that presents with various health and psychosocial complications), the use of semi-structured interviews to collect data was the most appropriate qualitative tool to employ.

As a result, participants enjoyed flexibility during the interview and were at ease to discuss their personal experiences in whatever way they deemed necessary, which is seldom possible when using quantitative surveying measures. Moreover, this approach also allowed participants to discuss their personal experiences with respect to caring for a child living with

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HIV in a non-threatening and comfortable manner that is consistent with the phenomenological approach, where the emphasis is on trying to understand the psychological perceptions of the participant.

Constructing the interview schedule (Refer to Appendix 4)

Constructing the interview schedule is a preliminary step in the qualitative research process with the purpose of generating ideas or hypotheses (Babbie & Mouton, 2002). Creating effective research questions for the interview process is one of the most crucial components to the interview schedule. Thus the importance of developing an interview schedule lies in the fact that it allows the researcher to have a broader perspective of what needs to be covered during the interview (Prescott, 2001). Thus, the structure of the interview schedule has to do primarily with the extent to which the questions to be asked of the participant are developed prior to the interview.

As the information sought for this study was complex and sensitive, involving a topic about which much was not known in local scientific literature, an in-depth semi-structured format using an interview schedule prepared in advance was deemed necessary (Smith & Osborn, 2007). As such, the researcher adhered to the following process to construct the interview schedule used for this study:

- Initially, the process involved reviewing local and international literature relating to HIV in children, families living with HIV, and child development. This process informed the development of the interview schedule and the form and breadth it was to take-on. It is unlikely for any researcher to embark upon research without having any knowledge of the current literature of the topic under study;

- The researcher determined the general area of interest that had to be explored via the interview. This entailed exploring and clarifying the lived experience of having to care for a child with a chronic illness such as HIV from the caregivers' perspective. As such, the researcher had to identify areas that needed to be covered in the interview schedule. For example, the nature of caregiving and the context in which it takes place, as well as focusing on caregivers' experience with the health system/healthcare team, their experiences relating to support, and the difficulties associated with having to provide care to an ill-child in the face of other psychosocial challenges.

- After determining the general areas that had to be explored, the next step involved the sequencing of questions in a logical order, while still keeping in mind the entrenched level of sensitivity. The aim here was to structure the questions in an order that would initially allow a rapport to be established with a participant, then leading into questions with greater sensitivity towards the middle of the interview process, and questions that would allow for the probing of the issues under exploration (*i.e.* providing care to a child with a chronic illness such as HIV), while allowing participants to narrate their ideographic experiences, and in keeping with the underpinnings of IPA (Reid et al., 2005; Fade, 2004). The questions were open-ended and designed to reveal what is important to understand about the phenomenon under study. This would allow clear differences and similarities to emerge among participants, thus eliciting common experiences, but would also be flexible enough to accommodate further probing through the use of appropriate prompts of interesting points or areas where information was difficult to elicit (Smith & Osborn Reid, 2007).

Qualitative Data Collection

Apart from the quantitative measures of data collection, the research also allowed qualitative data to be collected as part of the study exploring psychosocial factors impacting on the neurocognitive and socioemotional development of HIV-infected children. Data were collected on a voluntary basis using a semi-structured interview schedule (See Appendix 3) to foster in-depth discussions, in keeping with the principles of IPA (Reid et al., 2005). This method was utilised as the researcher felt it would assist in generating rich data of the subject under study. With permission of the caregiver participants, the individual interviews were audiotaped. After agreement to participate, a brief description of the research was presented to each caregiver before committing herself to take part. The researcher explained to the caregivers (as written on each participant's information sheet) what they were committing themselves to in order to enhance clarification.

The semi-structured interview schedule was prepared in English and translated into isiXhosa, thus allowing each individual interview to be conducted in isiXhosa with the assistance of a Xhosa-speaking assistant or in English, whichever language the caregiver felt comfortable with to express herself in. Each individual interview was conducted in the hospital in a secure and private environment, *i.e.* a consulting room, and lasted about one to one and a half hours. The interviews, albeit guided by an interview schedule, were open-ended and discovery orientated, in keeping the focus on phenomenology and the lived experience of the particular phenomenon (Fade, 2004). As Babbie and Mouton (2002) indicates, "…the chief short coming of closed ended questions lies in the researcher's structuring of responses…[which] could be overlooking some important responses"(p. 233). A space was created where the caregiver could feel safe, speak openly, and engage freely with issues of parenting, HIV/AIDS, and the accompanying difficulty aspects within the pandemic. Thus, the individual interviews form the primary data source for the qualitative part of the study, as it

allowed the researcher to capture the in-depth caregiver experiences of raising an HIV-infected child. Furthermore, through the process of clarifying, probing, and minimal verbal response, the researcher enhanced the openness and willingness of the caregiver. Although initial anxiety and discomfort was observed as a result of talking to a stranger when the interview commenced, the researcher worked to eliminate this possible threat, by reassuring participants of security and confidentiality, which resulted in noticeable comfort emerging as the interview progressed.

During the interview process the researcher was able to repeat certain questions, through paraphrasing and reflection, which assisted or facilitated the researcher's understanding of the participants' points of view. This also ensured that the researcher's interpretation of what participants had said were verified and clarified on the spot by the participants themselves. It should be noted that both researcher and assistant are trained at conducting interviews as a result of their clinician training, which ensured adequate probing, paraphrasing, and reflection during the interview process.

Qualitative Analysis

In light of the exploratory nature and aims of this study interpretative phenomenological analysis (IPA) was used to analyse the data from the interviews (Reid, Flowers, & Larkin, 2005; Fade, 2004). The researcher strived to find a balance between the ideographic experiences of the interviewed person, while also trying to focus on what experiences were common across contributors (Reid et al., 2005).

Research assistants translated and transcribed all the audio-taped interviews form isiXhosa to English verbatim. Thereafter, I as the primary researcher read and re-read all the transcripts to

immerse myself in the data. Data analysis was approached as an inductive process, in which all the respondents' narratives were allowed to emerge, as is consistent with IPA (Reid et al., 2005). Thus, by applying this approach I allowed the respondents' voices to emerge from the data, adding to the richness of qualitative research and in keeping with IPA (Reid et al., 2005). The following steps were taken to analyse the data in a manner consistent with IPA:

In the first level of analysis the transcripts of all the interviews were examined independently and subjected to open coding by means of making notes describing striking issues emerging from the narratives. Preliminarily a line-by-line review of each transcript was done and augmented by notes depicting pivotal ideas in the data, which in turn were noted in the margins of the transcript. This first level analysis was carried out for each transcript consecutively, which allowed the researcher to study each transcript distinctly, in addition to comparing and contrasting varying responses as they emerged from each transcript. Once a general understanding of the transcript as a whole was achieved, the researcher could construct a list of key concepts running throughout the transcript. At this level considerable interaction with the data is a necessity so as to maintain the rigour inherent to IPA, that is, the data should reflect the context of the respondent's reality (Fade, 2004).

Following the above, each key concept that emerged was broken into categories to provide meaning to the different aspects of a respondent's experience of the phenomena under research (e.g. caregiving in context of HIV). Each category of meaning was given a code that described the emergent meaning as reflected in the respondent's words, such as associated health challenges. Each code was then colour coded throughout the entire transcript, and codes representing dimensions of an overriding category were grouped together. Once the entire transcript had been coded in this way, themes were extracted and listed. At this point comparing data across categories, as well as across and between individual respondent

transcripts were facilitated to validate core categories and enhance the reliability of the data. Moreover, a single transcript was completed before moving on to another and the process was repeated for each transcript until the analysis of all interviews was completed.

Following the above, the researcher looked for connections between and among themes in order to cluster them in a meaningful way. It is important to note at this point that the researcher was already engaging in the interpretive process, as he tried to make sense of the respondents' experiences as reflected in their narratives (Cooper, Fleischer, & Cotton, 2012). As a result the researcher was able to identify umbrella, or super-ordinate, themes by linking all the sub-themes (made up of a cluster of themes) that emerged, and then extracted them across all transcripts. All codes were clustered into sub-themes, which were than grouped under super-ordinate themes to not only reflect respondents' words and thoughts, but also capture the researcher's interpretations (Fade, 2004; Cooper et al., 2012). At this point an independent investigator (supervisor) was consulted to review sub-themes and superordinate themes, with the identified themes being further saturated to improve validity. This process saw the supervisor independently assist with the verification and confirmation of themes. The process proved invaluable and pertinent, as the supervisor utilised it to subject the transcript to scrutiny and to observe the quality of the data collected. As indicated by Reid et al. (2005), an independent audit of analysis was not only acceptable, but pivotal to the cross-validation of data.

In the end the qualitative results corresponded with the themes that emerged from the analysis, and all quotations were drawn from individual respondents' interviews/transcripts, thus grounding the data. The researcher found the process of re-reading and immersing oneself in the transcripts in order to co-construct and extract themes, as well as to explicate

emerging data as a method for making meaning of the data, a labour intensive practise. Overall, the data analysis followed an inductive and iterative process consistent with IPA (Reid et al., 2005).

Trustworthiness and Credibility of Qualitative Research

According to the interpretative and phenomenological nature of the study, the quality of the study was measured against the principles informed by Lincoln and Guba (1985). They suggest that the principle of trustworthiness is a more applicable concept to be used when evaluating the quality and scientific standard of qualitative research. In ensuring the study maintained good practice, a few guiding principles were observed to achieve trustworthiness: 1) credibility, 2) transferability, 3) dependability, 4) conformability, 5) transparency, and 6) reflexivity (Babbie & Mouton, 2002; Reid et al., 2005; Elliot et al., 1999).

Credibility refers to having confidence in the truth of the findings. According to Glaser and Strauss (1967), credibility of qualitative research rests on the overall assessment of how the researchers derived their conclusions. In evaluating the credibility of research findings, an evaluator should ask whether the subjects are appropriate informants for exploration, and whether the data they offer are true representations of the topic of concern. In the case of this study, participants are considered reliable owing to the very fact that they are narrating their own narratives as caregivers of HIV-infected children. It should therefore be accepted as an accurate representation of their living realities. Furthermore, by means of a process of clarification used throughout each interview the researcher was able to validate his perceptions and interpretations of respondents' narratives on the spot and with the participants.

<u>Transferability</u> entails verifying to what extent the results are context bound. As the sample consisted of boys and girls, as well as their maternal caregivers, they were recruited through convenience sampling from a local hospital that predominantly served individuals from low-socioeconomic backgrounds (Babbie & Mouton, 2002).

<u>Dependability</u>, according to Lincoln and Guba (1985), refers to the reliability of the conclusions drawn from the research study. In this case reliability was enhanced as the results were independently analysed (Lincoln & Guba, 1985), while the reliability of the researcher's interpretations and data coding were subjected to discussions with an independent supervisor, which assisted the further development of a tree of themes. Moreover, reliability was also enhanced by the method used to obtain the body of information from the participants. Consequently, the face-to-face in-depth interviews when compared to the quantitative scales were deemed an appropriate tool to strengthen the reliability (trustworthiness) of the qualitative enquiry (Morrow, 2005).

In addition to the above, this doctoral research protocol and all its measures and interview schedules were submitted for review and were granted approval by two independent ethics review boards, which speaks to the fourth component of enhancing the study's trustworthiness; a process Licoln and Guba (1985) refers to as <u>conformability</u>. This process allowed for the various research procedures to be formally audited and reviewed independently, thus ensuring the reliability and validity of all conclusions drawn. As Babbie & Mouton (2002) stated, "[it] is the degree to which the findings are the product of the focus of the inquiry and not the biases of the researcher" (p. 278).

Moreover, and inherent to IPA, a degree of <u>transparency</u> is based on the level of relationship

the researcher and participant has entered into, and allows for a contextually rich exchange and sharing of experiences. Thus, the process is authentic, clearly defined, and open for interrogation from both the researcher and participant's point of view (Reid et al., 2005; Elliot et al., 1999). Verbatim accounts of participants' lived experiences were captured and redistributed by means of verbatim quotes. These are all factors inherent to IPA that allows for *flexibility* and *credibility* (Reid et al., 2005; Elliot et al., 1999). Likewise, credibility was also enhanced through cross-evaluation, cooperative inquiry, independent auditing (supervision), and cross transcript review (Reid et al., 2005).

Finally there is reflexivity, which refers to a researcher's awareness of being a co-constructer of meaning and interpretation (Smith & Osborn, 2007). Fade (2004) argues that in IPA the researcher becomes an analytical instrument; a necessity for making sense of participants' experiences. In this context a researcher cannot be considered as biased unless the researcher loses tract of their self-reflexive position (Reid et al., 2005; Elliot et al., 1999). Subsequently, and as a means of ensuring that scientific credibility is adhered to, I (as the researcher) was always wary of my own beliefs and assumptions when engaging with the data. Thus, understanding my role as researcher is both interpretive and collaborative, and is one of the core characteristic of IPA (Reid et al., 2005).

Storage of data

To reiterate, all the interviews conducted for the qualitative phase of this study were audiotaped and transcribed verbatim with participants' permission. Audiotaped files were then transferred from the digital tape recorder onto a laptop that was keyword protected. These recordings were then transferred onto a memory-disk, where it will remain safely

stored away in the supervisor's office at the University of KwaZulu-Natal for at least five years. Thereafter, the files will be deleted.

The paper measures (e.g. questionnaires) were sealed and stored in appropriate office storage boxes, and will also be kept safe and secure in the supervisor's office at the University of KwaZulu-Natal for five years. All the electronic versions of the quantitative data are safely and securely stored on the researcher's personal laptop and is password protected, thus restricting access to anyone other than the researcher.

Conclusion

In conclusion, this chapter provided a detailed discussion of the methodology used during both the quantitative and the qualitative aspects of this doctoral study, and ends off with a discussion of how credibility was achieved and the data stored.

CHAPTER 5

QUANTITATIVE RESULTS

Introduction

In this chapter the results emerging from the study will be presented and briefly commented on. There are two components to the results in this doctoral dissertation, namely quantitative and qualitative results. This chapter presents the quantitative results in addition to all the analyses conducted, output figures, and tables. The quantitative results account for a major component of the study, exploring the relationship between psychosocial factors (*i.e.* socioeconomic status, caregiver depression, quality of stimulation in home environment, and anthropometrics as a measure of nutritional status), which arguably influence the neurocognitive and socioemotional developmental outcomes of HIV-positive children. The chapter that follows will in turn present the qualitative results.

Characteristics of HIV+ children and their caregivers

Socio-demographics characteristics

Table 1 shows the characteristics of the HIV-positive children and their caregivers. A total of 152 black African, first language Xhosa speaking caregiver/child dyads were enrolled in the study. The child characteristics show that over half of the participants were girls (57.2%, n = 87) compared to boys (42.8%, n = 65), with an age range of 31.38 to 92.78 months (*M* = 63.13). Over a third (33%) of all the children werw in grade R (n = 46).

Table 1: Participants' Socio-demographics   (N=152 caregiver/child dyad)

Child Variables	*N*	*(%)*
Total participants	152	(100)
Male	65	(42.8)
Female	87	(57.2)
Age in months		
Mean age	63.13	
Age range	31.38 - 92.78	
Current school grade		
N/A	46	(30.3)
Crèche	13	(8.6)
Grade R	46	(30.3)
Grade 1	33	(21.7)
Grade 2	12	(7.9)
Grade 3	2	(1.3)
Primary Caregiver Variables		
Caregiver (*N*=152) Relationship to the child		
Biological mother	56	(36.8)
Grandmother	72	(47.4)
Aunt	20	(13.2)
Sibling	3	(2.0)
Other/Foster parent	1	(0.7)
Age in years of primary caregiver		
Mean age	45	
Age range	18 - 79	
Education of primary caregiver		
None	2	(1.3)
Primary	45	(29.6)
Standard 6 - 8	47	(30.9)
Standard 9 - 10	52	(34.2)
Tertiary level	3	(2.0)
Don't know	3	(2.0)
Socio-economic variables		
Caregivers' employment status		
Housewife by choice	2	(1.3)
Unemployed	3	(2.0)
Employed (piece jobs/minimal skills)	11	(7.2)
Grant (child support grant)	113	(74.3)

Disability/old age pension grant	22	(14.5)
Self-employed	1	(0.7)

Type of living dwelling

Brick concrete house	119	(78.3)
Traditional mud/hut	5	(3.3)
Tin/shack	28	(18.4)

Number of people in dwelling

0-2 persons	4	(2.6)
3-4 persons	46	(30.3)
5-6 persons	49	(32.2)
More than 7 persons	53	(34.9)

Number of rooms excluding bathrooms, kitchen, toilets

0 - 2 rooms	124	(81.6)
3 - 4 rooms	26	(17.1)
More than 4 rooms	2	(1.3)

Accessibility to drinkable water

Own tap	115	(75.7)
Communal tap	36	(23.7)
Other	1	(0.7)

Type of toilet

Flush inside dwelling	73	(48.0)
Flush outside dwelling	47	(30.9)
Communal toilet	32	(21.1)

*Utilities

Access to electricity	150	(98.7)
Working fridge	130	(85.5)
Television/radio	150	(98.7)
Working stove	147	(96.7)
Working microwave	86	(56.6)

* multiple responses, hence they do not add up to 100%

All the children (N = 152) were HIV-infected and on ARVs, and over 63% (n= 96) of these

children were living under the care of an adult relative or extended family member, such as a

grandmother, aunt, or non-related adult Furthermore, the average age of the caregivers was

45 years, with at least 65% of all the caregivers having completed high school. Moreover, the majority of caregivers surveyed reported that they were unemployed, with their main source of income sourced from a government social grant (88.8%, n = 135). The majority of the children were living in brick and concrete houses (78.3%, n = 119), while 18.4% (n = 28) were being raised in shacks. Approximately 68% of the children in the study were raised in a dense home environment, 52% (n = 79) had to use an outside toilet (75.7%, n = 115) had access to drinkable water through their own tap.

Neurocognitive functioning characteristics of HIV-positive children

The HIV-positive children's neurocognitive functioning was assessed using the WPPSI-III.

The global (FSIQ), verbal (VIQ), performance (PIQ), processing speed (PSQ), and general language (GLC) components was one standard deviation below the mean of the normative standardised sample (See Table 3). The scores ranged from extremely low/mentally deficient (IQ: 69 and below) to high average neurocognitive functioning (IQ: 110-119).

Moreover, more than half (73%) the sample of children tested using the WPPSI-III fell below the average (M=100), with the mean full scale IQ of the sample being M=81.47, SD 12.81, indicating an overall performance below the standardised norm. Only 1.3% of the overall sample had a performance that fell in the high average range (IQ: 110-119) while 32.2% performed in the borderline range (IQ: 70-79) (See Figure 5).

On the VIQ the HIV-positive children had a below-average performance ($M = 77.66$, $SD = 11.24$) indicative of substandard cognitive and intellectual functioning with scores falling in the range of 16 to 104. Approximately 43% of the sample fell in the borderline cognitive

functioning range (IQ: 70-79), as compared to only 13.8% of the children performing in the average range (IQ: 90-109) (See figure 5).

The sample's overall mean for the PIQ was 89.60(SD = 16.98) with children's scores falling within the range of 31 to 127. Of the total PIQ, 56.5% of the children scored below the average norm, with 8.6% of the children's scores being at least one standard deviation above the normative mean. Only 7.9% of the children in the study scored were 2 standard deviations below the normative mean on the PIQ, compared to the VIQ's (15.1%). Additionally, when matched to the VIQ (13.8%), more children scored within the normative range on PIQ (29.6%) (See figure 5).

The results further showed that over 40% of the children in the study performed in the extremely low cognitive and intellectual range with respective to both PSQ (M=72.38, SD=16.93; and GLC (M=67.54, SD=17.74). Only 4.6% and 16.7% of children in the study performed within the normative mean range on the GLC and the PSQ respectively.

The mean subtest scores on the WPPSI-III for the HIV-positive children in this study showed that the children scored consistently low on all the subtests. The mean subtest scores of the HIV-positive children in this doctoral study was at least one to two standard deviations below the international reference group of children recruited from a variety of educational and clinical backgrounds. The reference group were based on a sample of children who have been exposed to environmental and biological risk factors that place them at risk of developmental delays (Wechsler, 2002). Some of these commonly identifiable risk factors included "low birth weight, chromosomal abnormalities, perinatal respiratory distress, congenital infection, nutritional deprivation, abuse and neglect, prenatal drug or alcohol exposure, hypoxia, and

brain haemorrhage"(Wechsler, 2002, p. 114). The WPPSI-III can validly be applied to provide estimates of cognitive ability in children who fall within the "…at risk groups" (Wechsler, 2002). However, it is advisable that the data from this sample should not to be considered for representative diagnostic purposes and should not be used as sole criteria in categorizing children according to their cognitive abilities due to the fact that the WPPSI-III has not been validated for the the South African context (Wechsler, 2002).

Figure 5: Neurocognitive profile of HIV-positive children. Figures below are percentages of children in the different ranges

	Extremely low	Borderline	Low average	Average	High average	Superior	Very Superior
General Language	44.1	24.3	27	4.6	0	0	0
Processing Speed	43.9	17.5	21.1	16.7	0	0.9	0
Performance IQ	7.9	19.7	28.9	29.6	8.6	5.3	0
Verbal IQ	15.1	43.4	27.6	13.8	0	0	0
Full Scale IQ	13.8	32.2	27	25.7	1.3	0	0
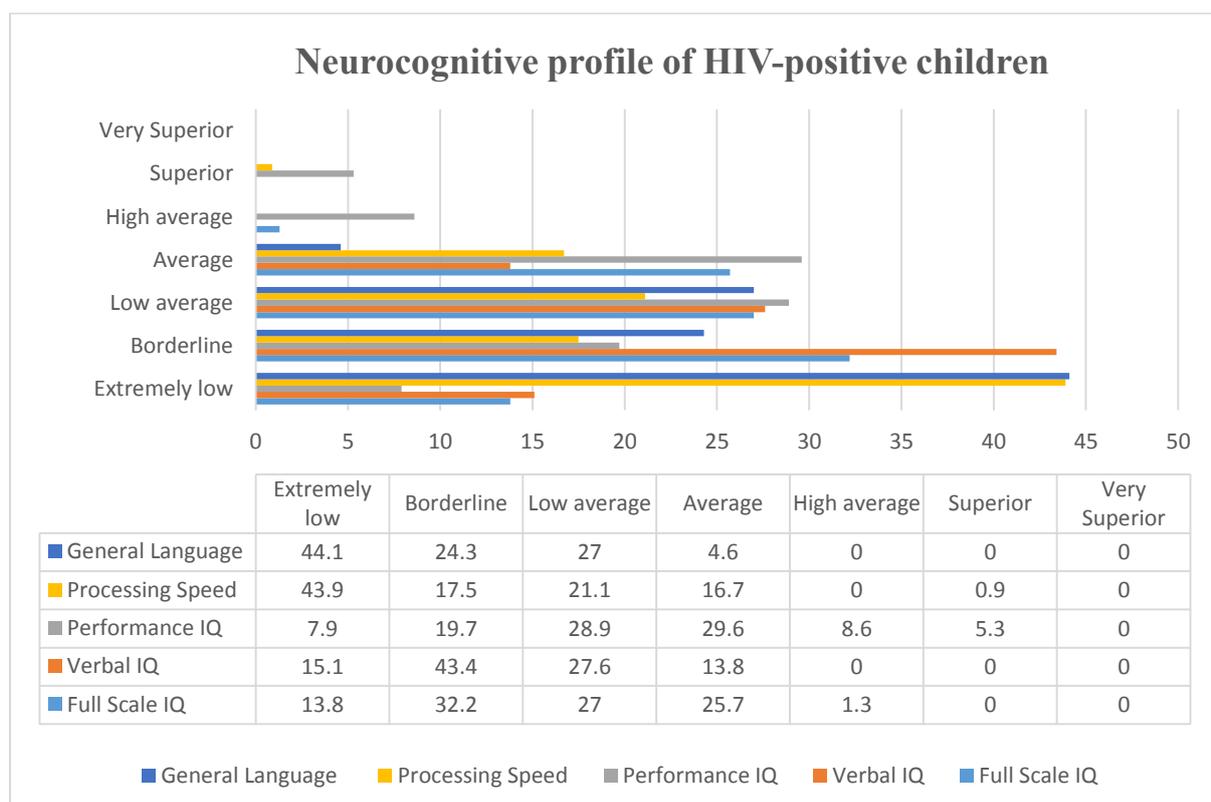
Socio-emotional functioning of HIV-positive children

The children's level of psychosocial functioning was assessed using the Strengths and Difficulties Questionnaire (SDQ). The SDQ demonstrated good reliability, reflecting an internal consistency reliability coefficient of 0.73 (See Table 2) on the Cronbach alpha index,

which in turn suggests that the measure can adequately discriminate and assesses the psychological and emotional problems of the children in this study. The children in the sample obtained an overall psychosocial difficulty mean score of 16.9 with a standard deviation of 5.05, and scores ranged from mild psychological difficulties to markedly high, indicating significant presence of psychological symptoms (range 5 to 30) (See Table 4). This suggests that the HIV-positive children displayed a range of socioemotional dysfunction.

Table 2: Descriptive statistics for measures used

Variables	Measure	N	Items	Scale Range	Mean	SD	α
Depressive symptoms	Beck Depression Inventory–II (BDI-II)	152	21	0 - 38	4.41	6.688	.896
Home environment	Home Screening Questionnaire (HSQ)	152	34	7 – 35	14.69	3.215	.608
Socio-emotional functioning	Strengths and Difficulties Questionnaire (SDQ)	152	25	11 – 36	24.42	6.757	.727

Table 3: Descriptive statistics for the WPPSI-III Measure

Percentage in each WPPSI-III category

Category	Mean	SD	Range	Extremely Low (69 and below)	Borderline (70-79)	Low Average (80-89)	Average (90-109)	High Average (110-119)	Superior (120-129)	Very Superior (130 and above)
Full Scale IQ	81.47[a]	12.81	42-110	13.8	32.2	27.0	25.7	1.3	-	-
Verbal IQ	77.66[a]	11.24	16-104	15.1	43.4	27.6	13.8	-	-	-
Performance IQ	89.60[a]	16.98	31-127	7.9	19.7	28.9	29.6	8.6	5.3	-
Processing Speed	72.38[a]	16.93	7-122	43.9	17.5	21.1	16.7	-	.9	-
General Language	67.54[a]	17.74	6-104	44.1	24.3	27.0	4.6	-	-	-

[a] more than one SD below the normative sample mean (*M* = 100, *SD* =15)

Overall, 49.3% of the children in this study demonstrated moderate to severe levels of psychosocial difficulties (*M* = 16.9, *SD* = 5.05), with 50.7% of them exhibiting at least mild psychosocial difficulties (See Figure 6).

Figure 6: *Total psychological difficulty for HIV-positive children in the study.*
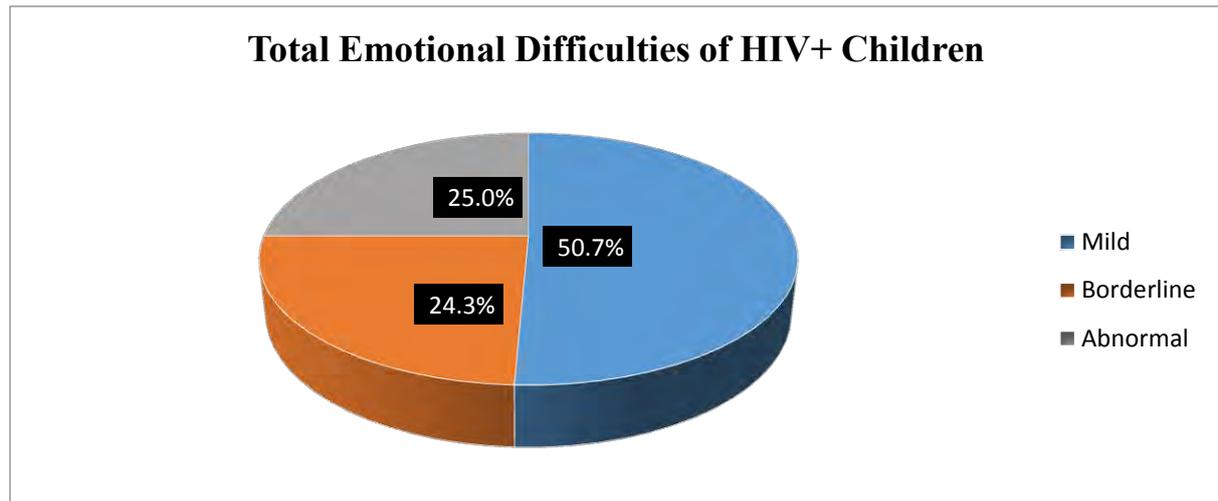
According to the caregivers' reports, their children demonstrated hyperactivity problems (*M* = 5.27, *SD* = 1.72), emotional problems (*M* = 4.31, *SD* = 2.34), as well as conduct (*M* = 3.13, *SD* = 2.18) and peer-related problems (*M* = 3.49, *SD* = 1.46) (See Table 4).

Table 4: Descriptive statistics for the SDQ (Strengths and Difficulties) measure

				Percentage in each SDQ category		
Category	**Mean**	**SD**	**Range**	**Mild**	**Moderate**	**Severe**
Total Difficulty	16.9	5.049	5-30	50.7	24.3	25.0
Conduct Problems	3.13	2.182	0-10	58.6	15.8	25.6
Hyperactivity	5.27	1.719	0-10	59.9	15.8	24.3
Emotional	4.31	2.342	0-10	70.4	9.2	20.4
Peer Problems	3.49	1.456	0-7	48.7	43.4	7.9
*Pro-social	6.65	1.842	1-10	71.7	17.8	10.5

*Pro-social category not calculated in the overall difficulty percentage.

Looking specifically at the symptomatology presentation of the children, as reported by the caregivers, the most prevalent psychological symptoms were distractibility (87.5%), nervousness and clinginess (76.3%), restlessness, and being overactive (75%) (See figure 7). Figure 7 also shows that fears (70.4%) and worries (70.4%) were the most common anxiety symptoms, whilst anger - "often temper tantrums"(59.2%), unhappiness and tearfulness (53.3%), somatic symptoms – "often complains of headaches and illness" - (41.5%), and isolation "rather solitary" (50.7%) were found to be the most prevalent depressive symptoms. The prevalent externalising behavioural symptoms in children, as reported by the caregivers were "lying and cheating" (44.7%); while 29.6% reported instances of "fighting with others".

Figure 7: *Frequently reported psychological symptoms of HIV-positive children.*
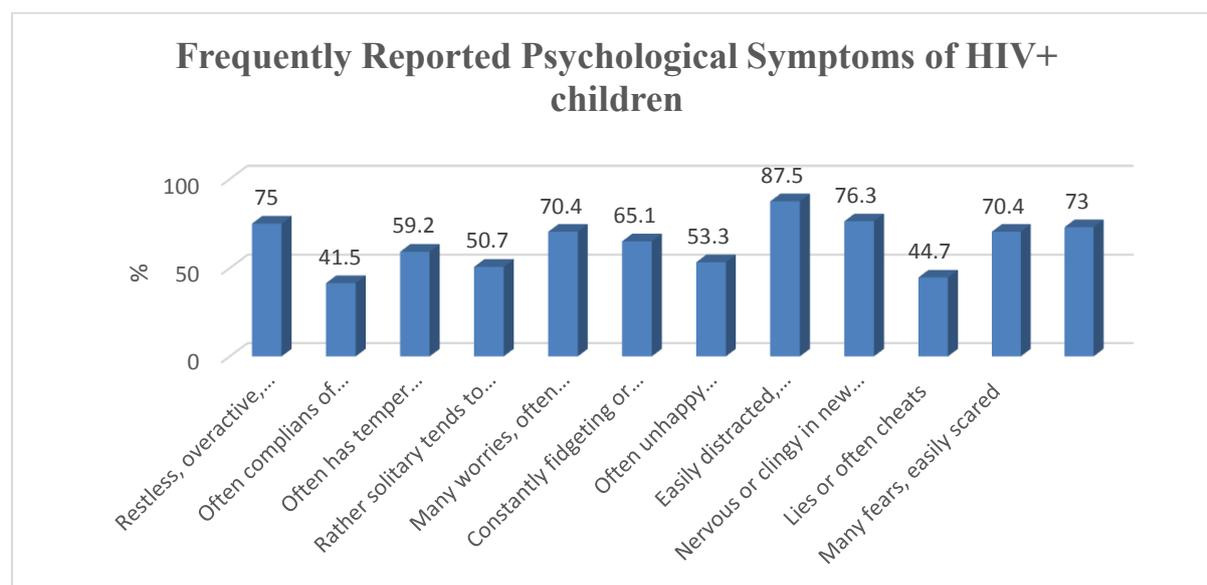
Nutritional status of HIV-positive children

Anthropometric measures of the nutritional status of HIV-positive children are reported based on the height- and weight-for-age, as well as weight for height z-scores, the HIV-positive children's nutritional status was determined in line with the WHO standards (z scores <-2 respectively). Of the 152 HIV-positive children in the study, 36.2% were stunted (n = 55),

while the prevalence of underweight children was 12%, and those with wasting was 2.7% (n = 4). These finding suggest that more than half the sample of HIV-positive children in this doctoral study exhibited indicators of nutritional deficits.

Quality of home environment of HIV-positive children

Based on the Home Screening Stimulation Questionnaire (HSQ) all of the children in the study lived in unfavourable home environments (n = 152, 100%). The psychometric analysis conducted on the HSQ results reflects an acceptable internal consistency reliability coefficient of 0.61 on the Cronbach alpha index, suggesting the measure can be considered reliable in assessing the quality of the home environment in which the children in this study are raised (See Table 2). The overall mean for the HSQ ($M = 14.69$, $SD = 3.22$) suggests that all of the HSQ scores fell below 42 placing them in the category of "suspect", meaning the quality of the home environment lacks the appropriate physical, emotional, and psychosocial stimuli needed for a child's optimal growth and development (Pessanha & Bairräo, 2003).

Characteristics of caregiver psychological functioning

Among the caregivers of the HIV-positive children in this study, the Beck Depression Inventory-II (BDI-II) demonstrated an adequate internal consistency reliability coefficient of 0.89 on the Cronbach alpha index (See Table 2). This demonstrates that the BDI-II, as measure of depressive symptomatology amongst the sample of caregivers, was reliable.

The overall mean of the sample of caregivers on the BDI-II was 4.41 (SD=6.69) with scores ranging from "no symptoms" to "severe symptoms" (range: 0-38). Forty-eight percent (n=73) of the caregivers (both HIV-positive and negative, as well as biological and non-biological) presented with some depressive symptoms, while 52% (n=79) reported having no symptoms of depression. From the overall sample of 152 caregivers in the study, 40.8% of caregivers reported mild depressive symptoms, while 6.5% reported moderate depression and 0.7% were severely depressed (see Figure 8).

Figure 8: *Overall Caregiver Depressive Profile*
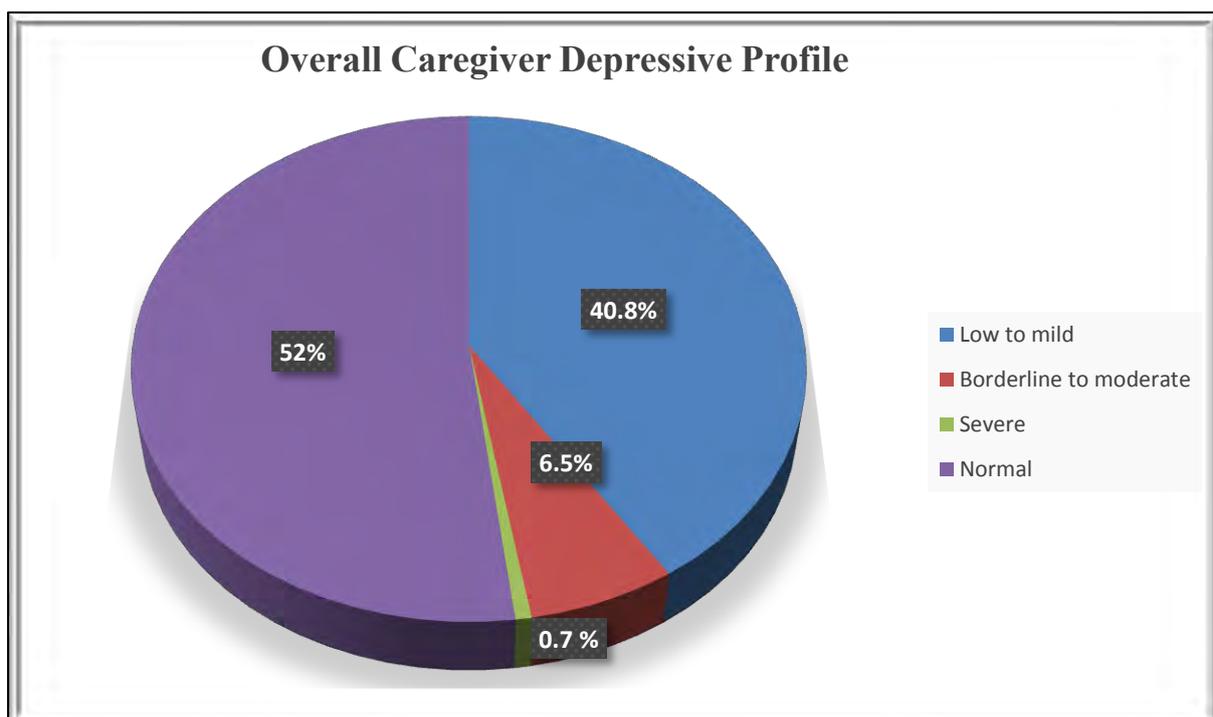
As indicated in Table 5, biological caregivers in the study scored worse on the BDI-II (*M* = 5.00, *SD*=6.88) compared to their non-biological counterparts (*M* = 4.10, *SD* = 6.60). Mild depressive symptoms were reported in 38.6% of biological caregivers compared to 42.6% in non-biological caregivers (See Figure 9). However, biological caregivers reported a higher

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percentage (10.5%) of moderate depression, compared to only 4.2% of the non-biological caregivers. These results may suggest that biological caregivers are worse affected by depression, may perhaps due to the personal nature of their own illness and not being able to access support systems.

Figure 9: *Biological & non-biological caregivers' depressive profiles. Figures in the table are percentages.*

Biological & non-biological Caregivers' Depressive Profiles

	Low-Mild depressive symptoms	Moderate depressive symptoms	Severe depressive symptoms
Biological Caregivers	38.6	10.5	0
Non-Biological caregivers	42.6	4.2	1.1
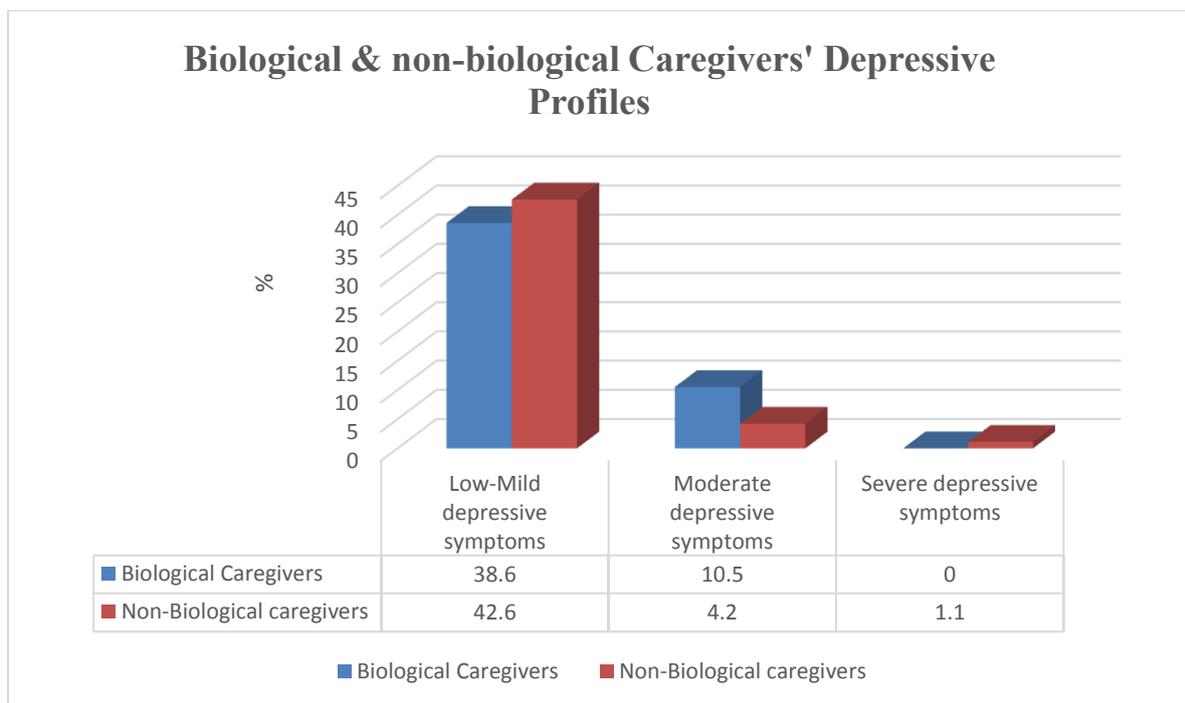
Table 5: Descriptive statistics split by biological and non-biological depressive symptoms

BDI-II		N	Mean	SD	Normal No Symptoms 0	Low Mild 1-16	Moderate Borderline 17-20	Moderate 21-30	Significant Severe 31-40	Extreme > 40
Caregivers	Biological	57	5.00	6.879	50.9	38.6	7.0	3.5	0.0	0.0
	Non-biological	94	4.10	6.604	52.1	42.6	2.1	2.1	1.1	0.0

Percentage in each BDI-II category

Relationship between the predictors and neurocognitive outcome variables in the sample of HIV-positive children

A Pearson product moment correlation coefficient was used to determine if any significant relationships existed between all the variables in the model (FSIQ, VIQ, PIQ, PSQ, GLC, SDQ, BDI-III, HSQ, Weight for age z-scores, Height for age z-scores, weight for height/BMI for age z-scores, Toys availability [physical stimulation], Reading material, Density, Caregivers age, Caregivers education level and Type of caregiver [biological/non-biological]). The correlations are presented in Table 6, and it should be noted that PIQ, CGL, and caregivers' age had no significant relationship with any of the variables.

Relationship to neurocognitive functioning

To investigate the factors associated with the neurocognitive function of HIV-positive children in this doctoral study, a series of correlation analyses were conducted. In the study, the variable of global neurocognitive functioning (FSIQ) was positively associated with both underweight ($r = 0.17$, $p < 0.05$) and stunting ($r = 0.16$, $p < 0.05$), suggesting HIV-infected children with global neurocognitive dysfunction are also more likely to have growth retardation. Furthermore, global neurocognitive functioning (FSIQ) was also negatively associated with HIV-positive children's socioemotional functioning (SDQ) ($r = -.17$, $p < 0.05$), suggesting that HIV-positive children with compromised global neurocognitive functioning are at greater risk of having severe emotional problems. Interestingly, while no significant relationship was established between global neurocognitive functioning and the quality of home environment, the results still suggest that the amount of stimulation a child is exposed to in the home environment as measured on the HSQ, significantly influences the sub-neurocognitive domain of verbal neurocognitive development (VIQ) as indicated in their negative association ($r = -0.18$, p<0.05). Moreover, the availability of physical stimulation

Table 6: Correlation Matrix depicting association between the **predictor and outcome variables for the sample**

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1	Full IQ	-	.736**	.871**	.711**	.428**	-.165*	-.022	.094	.171*	.160*	.017	.134	-.112	.011	.016	-.011	-.049
2	Verbal IQ		-	.521**	.476**	.534**	-.148	-.061	-.184*	.092	.111	.007	-.049	-.169*	-.016	.003	.059	.020
3	Performance IQ			-	.459**	.265**	-.116	.038	.127	.127	.077	.050	.099	-.042	.083	-.017	-.047	.079
4	Processing				-	.360**	-.125	.006	.102	.224*	.152	.122	.247*	-.141	.021	-.054	.069	-.085
5	GLC					-	.011	.053	-.041	-.011	.086	-.097	.037	-.090	-.040	.132	-.008	.076
6	SDQ						-	.314**	-.033	-.048	-.127	.085	-.082	.073	.056	-.061	-.008	.034
7	BDI-II							-	-.021	-.010	.002	-.011	-.105	.090	.131	-.011	-.013	-.105
8	HSQ								-	.236**	.184*	.054	.586**	.328**	.189*	.112	.049	.198
9	Weight for Age									-	.653**	.457**	.095	.068	.066	.116	-.049	-.003
10	Height for Age										-	-.369**	-.019	.016	.016	.054	.004	-.007
11	Weight for height											-	.143	.075	.051	.091	-.075	.016
12	Toys availability												-	.173*	.071	-.113	.231**	-.020
13	Reading material													-	.211**	.032	.078	.067
14	Density														-	-.055	.007	.064
15	Age of Caregiver															-	-.337**	-.445**
16	Education Caregiver																-	-.154
17	Caregiver Type																	-

Significance level, *p <0.05; **p <0.01

(with regards to availability of toys) in the home was found not to be associated with sub-verbal neurocognitive functioning (VIQ) ($r = .002$, $p < 0.01$) and weight for age ($r = 0.22$, $p < 0.05$). Verbal neurocognitive functioning was also negatively associated with lack of language stimulation in the form of reading material availability in the home ($r = -0.17$, $p < 0.05$).

Factors associated with the neurocognitive functioning of HIV-positive children in relation to primary caregiver

Caregiver type: The results from this study showed that there were no significant associations found between the dependent variables and global neurocognitive functioning of HIV-positive children raised by a non-biological or biological caregiver, suggesting that the global neurocognitive functioning of HIV-positive children was not related to quality of home environment, socio-demographics, anthropometric indices, or caregiver depression. This was found to be irrespective of the HIV-positive child's relationship to the primary caregiver. However, the results (see Table 7) showed that verbal neurocognitive functioning correlates significantly negatively with both reading stimulation ($r = -0.24$, $p < 0.05$) and quality of home environment stimulation (HSQ) ($r = -0.21$, $p < 0.05$) for HIV-positive children raised by non-biological caregivers. A significant relationship was observed between childrens verbal IQ and the availability of reading materials in the home of older caregivers ($r = -.221$, $p < 0.05$).

Caregiver's age: For younger caregivers, the socioemotional functioning (SDQ) of the HIV-positive children was negatively associated with both global ($r = -0.29$, $p < 0.05$) and verbal neurocognitive functioning ($r = -0.39$, $p < 0.01$), while verbal neurocognitive functioning had a much stronger association (See Table 8), suggesting that HIV-positive children in this study

who are neurocognitively compromised are also likely to experience emotional difficulties. This suggest that there may be less regular and clear verbal exchanges or verbal stimulation between adult caregivers and children, which also could potentially be having an impact on these children's emotional development; as this requires interaction between child and caregiver. Similarly, the verbal domain of neurocognitive functioning was negatively associated with the children's home environments (r = -0.27, p < 0.05), suggesting that an unfavourable home environment with a lack of appropriate stimulation compromises the healthy cognitive development of these children. It may be that younger caregivers engage less frequently with their HIV-positive children and do not expose them to reading and reading tools in the home owing to the unavailability of sufficient stimulating resources.

On the other hand, in relation to older caregivers, children's global neurocognitive functioning showed a significant positive relationship with both underweight (r = 0.22, p< 0.05) and availability of physical stimulation in terms of toys (r = 0.27, p < 0.01), which indicates the lack of adequate nutritional provision and insufficient resources available in these homes to meet the basic needs of the children.

Table 7: Comparative Correlation Matrix: **Split by Caregiver Type**

		1	2	3	4	5	6	7	8	9	10	11	12
1	Full IQ	-	.746**	.871**	-.193	.133	.012	-.013	-.037	-.154	.136	.215	.086
2	Verbal IQ	.736**	-	.474**	-.074	.012	-.131	-.015	.066	-.248	.085	.105	-.117
3	Performance IQ	.871**	.547**	-	-.212	.181	.027	.003	.026	-.041	.069	.174	.101
4	SDQ	-.154	-.176	-.075	-	.410**	-.074	-.108	.057	.085	-.178	-.210	-.236
5	BDI-II	-.093	-.101	-.035	.271**	-	-.169	.036	.173	.014	-.182	-.195	-.220
6	Toys	.196	-.011	.134	-.087	-.062	-	.200	.009	.702**	.398**	.164	.640**
7	Reading Material	-.167	-.237*	-.072	.159	.131	.155	-	.313*	.276	.092	.032	.291*
8	Density	.040	-.059	.121	.056	.096	.144	.156	-	.342	.146	.111	.220
9	Weight for height	-.137	-.195	-.098	-.042	-.083	.080	-.257	.245	-	.634**	-.074	.515*
10	Weight for age	.186	.100	.151	.011	.101	-.079	.047	.027	-.026	-	.653**	423**
11	Height for age	.135	.113	.034	-.094	.105	-.110	.008	-.034	-700**	.656**	-	.345**
12	HSQ	.091	-.207*	.124	.049	.109	.572**	.341**	.206*	-.075	.129	.122	-

Significance level, $^*p <0.05$; $^{**}p <0.01$
Values above diagonal are for *biological caregivers* and values below diagonal are for *non-biological caregives*.

Table 8: Comparative Correlation Matrix: **Split by Caregivers' Age**

		1	2	3	4	5	6	7	8	9	10	11	12
1	Full IQ	-	**784****	**.849****	**-.286***	-.165	.060	.077	.054	-.090	-.028	-.125	-.044
2	Verbal IQ	**.713****	-	**479****	**-.381****	-.203	.092	-.033	-.108	**-.274***	-.063	-.163	-.067
3	Performance IQ	**.882****	**.540****	-	-.150	-.079	.039	.091	.148	.023	.060	-.067	-.026
4	SDQ	-.117	-.056	-.103	-	-.040	**-.291***	-.169	**.299***	-.176	-.100	-.140	.029
5	Weight for height	-.134	-.229	-.094	.129	-	**.686****	.007	-.005	**.583****	.025	**.613****	.302
6	Weight for age	**.219***	.091	.166	.047	-.033	-	**.613****	-.165	**.311***	.134	.147	.191
7	Height for age	.191	.167	.072	-.113	**-.690****	**.669****	-	.166	.264	.167	.042	.145
8	BDI-II	-.059	-.036	-.016	**.325****	-.063	.075	.078	-	**-.289***	-.050	-.148	.074
9	HSQ	.184	-.141	.175	.025	-.156	**.202***	.153	.121	-	**.369****	**.610****	.186
10	Reading Material	-.152	**-.221***	-.091	.147	-.004	.040	-.046	.166	**.307****	-	**.283***	**.283***
11	Toys	**.270****	.010	.180	-.058	.178	.074	-.043	-.084	**.574****	.111	-	.001
12	Density	.049	.013	.139	.069	.243	.015	-.036	.158	.191	.164	.106	-

Significance level **$p<0.01$, *$p<0.05$

Values <u>above</u> diagonal are for caregivers aged 18 years to 35 years and values <u>below</u> diagonal are for caregivers aged 36 years and above.

Factors impacting on neurocognitive functioning of HIV-positive children

To investigate if the neurocognitive functioning of HIV-positive children in the study would be influenced by the type of caregivers, an independent t-test was conducted (See Table 9). The results of the independent t-test, which aimed to detect whether HIV-positive children's neurocognitive development had been impacted by any of the independent variables according to the type of primary caregiver (*biological vs. non-biological*) who raised them, showed no significant impact (t[151] = 0.38; p > 0.05). The global neurocognitive functioning of HIV-positive children is not influenced by any of the independent factors, irrespective of the caregivers' relationship to the HIV-positive child. This indicates that no significant difference in the HIV-positive children's global neurocognitive development was observed, suggesting that the neurocognitive outcome of HIV-positive children in this study were more or less equally negatively impacted, irrespective of whom their caregivers are.

To investigate the factors associated with the neurocognitive functioning of HIV-positive children according to the age of the caregiver, a t-test of independence was conducted (See Table 9). The results from this t-test showed no significant association between the global neurocognitive functioning of HIV-positive children and any of the independent variables in accordance with the age (younger [18 to 35 years] vs. older [36 years and above]) of the primary caregiver (t [151] = 0.59; p > 0.05. Consequently, primary caregiver age does not appear to have an impact on the neurocognitive functioning of HIV-positive children in the study sample.

Based on the t-test, which was used to assess gender differences in neurocognitive functioning in the HIV-positive children; the results show that boys were worse off than girls on global neurocognitive functioning in this study (see Table 9), with girls scoring higher

(*M*=83.33, *SD*=12.48) when compared to boys (*M* = 78.98, *SD* = 12.91) on the global neurocognitive measure FSIQ (*t*[150] = 2.09, *p* < 0.05).

Table 9: Independent t-test

Variables/Dimensions	Non-Biological Caregivers		Biological Caregivers		t
	Mean	*SD*	*Mean*	*SD*	
FSIQ	81.78	13.42	80.96	11.82	0.38
VIQ	77.38	12.26	78.12	9.38	0.39
PIQ	90.39	17.68	88.28	15.79	0.74
PSQ	71.96	17.82	73.28	15.02	0.38
GLC	68.16	18.13	66.51	17.17	0.55
SDQ	22.80	5.53	22.91	4.74	0.13
HSQ	20.27	6.11	17.47	5.26	2.88[**]
BDI	4.05	6.58	5.00	6.88	0.85

Variables/Dimensions	Younger Caregiver (18-35 years)		Older Caregiver (36 and above)		*t*
	Mean	*SD*	*Mean*	*SD*	
FSIQ	80.62	12.41	81.93	13.06	0.59
VIQ	77.38	10.77	77.81	11.54	0.22
PIQ	89.51	15.79	89.65	17.66	0.05
PSQ	70.24	14.91	73.29	17.73	0.88
GLC	66.72	17.66	67.98	17.86	0.42
SDQ	23.15	4.55	22.68	5.58	0.53
HSQ	19.30	5.80	19.18	6.05	0.12
BDI	4.81	6.91	4.19	6.59	0.54

Variables/Dimensions	**Boys**		**Girls**		*t*
	Mean	*SD*	*Mean*	*SD*	
FSIQ	78.98	12.91	83.33	12.48	2.09[*]
VIQ	76.51	10.49	78.52	11.75	1.09
PIQ	86.08	15.61	92.23	17.56	2.24
PSQ	71.42	16.14	73.08	17.57	0.52
GLC	69.54	17.92	66.05	17.56	1.20
SDQ	22.63	5.26	23.00	5.24	0.43
HSQ	18.74	6.18	19.59	5.77	0.87
BDI	4.20	5.96	4.56	7.21	0.33

Significance level [*]*p* < 0.05; [**]*p* < 0.01

On the subscales, differences only existed in the performance domain, where girls obtained better scores ($M = 92.23$, $SD = 17.56$) than boys ($M=86.08$, $SD=15.61$) for the current study. These results indicate that in the study sample girls performed better on global neurocognitive functioning compared to boys.

To investigate whether age is associated with neurocognitive development in HIV-positive children, a one-way ANOVA was conducted on the full scale (FSIQ) and subscales (PIQ and VIQ) as well as the different age groups (See Table 10). While no significant differences in age were found on the global neurocognitive functioning (FSIQ) of the HIV-positive children, differences nevertheless exist in the sub-neurocognitive domains. Significant differences in age groups were found on verbal neurocognitive functioning (VIQ), $F(2,149) = 14.42$, $p < 0.001$, where the three- to four-year age group ($M = 82.33$) scored higher than those of six years and above ($M=72.53$). Correspondingly, significant differences in age existed on GLC, $F(2,149) = 4.33$, $p = 0.02$, where the three- to four--year-old age group ($M = 72.03$) group scored better than those aged six and above ($M = 64.33$). These results suggest that age has an impact on the neurocognitive developmental outcomes of HIV-positive children, and showed that younger HIV-positive children in this doctoral study had better neurocognitive development, especially in sub-neurocognitive developmental domains.

Table 10: One-way ANOVA results for age group differences among HIV+ children and the key variables in the study

Source of Variance	Mean Squares	df	F Values	P
FSIQ	133.97	2	0.82	.445
VIQ	1546.97	2	14.42	.000***
PIQ	736.733	2	2.61	.077
PSQ	62.80	2	0.22	.806
GLC	1303.42	2	4.33	.015*
SDQ	97.75	2	3.69	.027*
HSQ	516.47	2	17.89	.000***
BDI	9.15	2	0.20	.817

Significance level *$p < 0.05$; ***$p < 0.01$

Relationship between Predictors and Socioemotional outcome in the sample of HIV+ Children

Relationship to HIV+ child psychological and emotional functioning

In keeping with the quantitative investigations in this doctoral study, a series of correlations coefficients were computed to determine what factors were significantly associated with the psychological functioning of HIV-positive children. The results are presented in Table 6. The SDQ as a measure of the HIV-positive child's psychological and emotional function was only significantly associated with the BDI-III as a measure of caregiver depression ($r = 0.31$, $p < 0.01$). This suggests that HIV-positive children cared for by depressed caregivers are more likely to suffer from emotional and psychological problems.

Factors associated with the psychological and emotional functioning of HIV-positive children in relation to their primary caregiver

Caregiver type: A relationship between caregiver depression and the HIV-positive child's socioemotional and psychological function was confirmed. Caregiver depression as measured on the BDI=III was the only independent variable that significantly correlated with the

child's socioemotional and psychological functioning (SDQ) ($r = 0.41$, $p < 0.01$). These results are presented in Table 7. In this study a positive association was also found between the HIV-positive child's socioemotional and psychological wellbeing and that of their non-biological ($r = 0.27$, $p < 0.01$) and biological caregivers ($r = 0.41$, $p < 0.01$). This suggests that poor psychological functioning in children was significantly associated with greater severity of depression in caregivers and this association existed irrespective of the type of caregiver (i.e. biological or non-biological). However, this association was more negative when the HIV-positive children were raised by their biological caregivers as compared to when raised by extended relatives. Caregiver depression was also significantly associated with poor emotional functioning in the children irrespective of age ($r = 0.33$, $p < 0.01$) (See Table 8). These finding suggests that the emotional functioning of an HIV-positive child cared for by a depressed caregiver will be affected negatively, irrespective of the caregiver's age or relationship to the child.

A one-way ANOVA was used to determine whether the level of a caregiver's depressive symptoms had any effect on their child's emotional and psychological symptoms as measured by the SDQ (Total SDQ, Emotional (depressive), Hyperactive, Conduct, and Peer Relation subscales) (See Table 11). Caregiver scores on the BDI-II was categorised into three groups: No symptoms = 0, low-to-mild symptoms =1, and high-to-severe symptoms = 2. The results showed that the level of caregiver depression influenced a child's overall psychological functioning ($F[2,149] = 6.44$; $p = 0.002$) (see Table 12) . The results indicate that psychological functioning in the children decreased with higher parental depressive symptoms. Further analysis using multiple comparison Post hoc Tukey analysis, there was a significant difference in psychological symptoms in children of parents with no depressive symptoms ($M = 15.18$) and those with high levels of depressive symptoms ($M = 20.55$) ($p = $

0.002); and also between those with low-to-moderate (M = 16.71) and high depressive symptoms (M = 20.55) (p = 0.046). However, no difference was found in the psychological functioning of HIV-positive children whose caregivers reported no depressive symptoms and those with low-to-moderate depressive symptoms.

Table 11: One-way ANOVA results for different levels of caregiver depressive symptoms on psychological functioning of HIV infected children

	Depressive Symptoms	Mean	SD
Total SDQ	NS	21.66	4.14
	LMS	23.60	6.15
	HSS	27.09	3.86
Emotional	NS	3.72	1.85
	LMS	4.68	2.65
	HSS	6.45	2.12
Hyperactive	NS	5.09	1.57
	LMS	5.35	1.91
	HSS	6.09	1.45
Conduct	NS	2.96	2.18
	LMS	3.15	2.15
	HSS	4.18	2.27
Peer relation	NS	3.41	1.40
	LMS	3.53	1.56
	HSS	3.82	1.33

Note: NS=No Symptoms, LMS=Low-to-mild symptoms, and HSS=High-to-severe symptoms

On the sub-scales of the SDQ, a significant difference was observed only the emotional subscale, suggesting that parental depressive symptoms had an effect on poor emotional functioning of HIV-positive children in this doctoral study (F[2,149] = 8.67; $p < 0.001$) (See Table 12). This suggests that high levels of parental depression had corresponding high levels of emotional symptoms in HIV-positive children. Multiple comparison using Post hoc Tukey analysis revealed that a statistical difference was observed in emotional symptoms between children of parents with no depressive symptoms (M = 3.72), low-to-mild depressive

symptoms ([M = 4.68], p = 0.034), and high levels of depressive symptoms ([M = 6.45], p = 0.001).

Table 12: One-way ANOVA on caregiver depressive state and an HIV-positive child's psychological functioning

Source of Variance	Mean Squares	df	F Values	P
Total SDQ	172.31	149	6.44	0.002**
Emotional	43.16	149	8.67	<0.001***
Hyperactive	5.23	149	1.79	.171
Conduct	7.21	149	1.52	.221
Peer relation	0.93	149	0.44	.65

Significance level **p < 0.01; ***p < 0.001

Gender differences in child emotional and psychological functioning

To investigate whether differences exist in HIV-positive children's emotional and psychological function according to the different age groups, a one-way ANOVA was conducted according to three age groups of children (three to four years, five years, and six years and over) (See Table 10). The results suggest that the younger age group had more psychological difficulties compared to the older children in the study (F[2,149] = 3.69, p = 0.027) (See Table 10). The multiple comparison Post hoc Tukey test, showed significant differences between children aged three to four and those of five years and six –year-olds and above. The three to four year group of children (M = 23.45) scored higher on the SDQ than the group of five year olds (M = 20.17) (p= 0.024) and the group of six-year-olds and above (M = 23.17) (p = 0.049).

To investigate whether gender influenced the emotional and psychological functioning of HIV-positive children, an independent t-test was conducted to compare the emotional and

psychological functioning of boys with girls. As shown in Table 13, the results indicate that there were no gender differences in HIV-positive children's psychological adjustment in this doctoral study, suggesting that boys and girls struggle with more or less the same psychological challenges, living as HIV-positive.

Table 13: Gender differences on HIV-positive children's psychological functioning

Variables/Dimensions	Boys		Girls		t
	Mean	*SD*	*Mean*	*SD*	
Conduct Problems	3.00	2.13	3.22	2.23	.330
Hyperactivity	5.32	1.81	5.23	1.65	.202
Emotional Symptoms	4.35	2.24	4.28	2.43	.609
Peer Problems	3.57	1.48	3.47	1.45	.152

To investigate whether differences exist in children's psychological functioning based on whether the HIV-positive child is raised by a biological or non-biological caregiver, an independent t-test was conducted, with the results presented in Table 9. The outcome indicates that no significant differences between children raised by biological caregivers ($M = 22.91$, $SD = 4.74$) and non-biological caregivers on ($M = 22.80$, $SD = 5.53$) on children's psychological functioning, $t[151] = 0.13$; $p > 0.05$). This suggests that the caregivers have a more or less equal impact on the emotional and psychological functioning of their HIV-positive children, irrespective of their relationahip to the children. The results as presented in Table 9 also showed that younger and older caregivers generally have more or less an equal impact on the HIV-positive child's emotional and psychological function, as no significant differences were ascertained in relation to the age of their caregivers.

Relationship to home environment and nutritional status of the HIV+ Children

The only other significant relationship that emerged in this study was between the quality of home environment and the anthropometric indices of the HIV-positive children investigated (See Table 6). The results showed that home environments were positively associated with poor anthropometric indices which was used as a measure of children's nutritional status in this study; weight for age (r=0.24, p<0.01) and height for age (r=0.18, p<0.05). Furthermore, HIV-positive children with wasting, stunting (growth retardation) and underweight were also more likely to live in dense and overcrowded home environments (r=0.19, p < 0.05).

Factors associated with the home environment and nutritional status of HIV-positive children in relation to their primary caregiver

Correlational analysis was conducted to investigate the factors associated with home environment and wasting, stunting and underweight status of HIV-positive children in relation to the primary caregivers.

Caregiver type: The home environment of HIV-infected children raised by biological caregivers was significantly and positively correlated with stunting (r=0.35, p <0.01), wasting (r= 0.52, p<0.05), and being underweight (r=0.42, p <0.01), suggesting that poorer home environment of HIV-infected children may lead to higher levels of stunting, wasting and being underweight. (r=0.42, p <0.01),(see Table 7).

Caregiver's age: The home environment of children raised by younger caregivers was also positively associated with being underweight (r = 0.31, p < 0.05) and wasting (r=0.58, p<0.01), but negatively associated with caregiver depression (r=-0.29, p<0.05), thus suggesting that children raised by younger depressed caregivers are more likely to live in

unfavourable home environments with poor stimulation and inadequate nutritional provision, which may have negatively impact their developmental outcome (See Table 8). The study also revealed home environment to be associated with children's weight for age when caregivers were older.

Factors impacting on home environment and nutritional status of HIV-positive children

Home environment

A One-way ANOVA was used to determine if differences in the quality of stimulation in the home environment existed amongst various age-groups of HIV-positive children in this study (See Table 10). Results on the HSQ reports that there were significant age-group differences in the HIV-positive children on the Home Stimulation measure (F[2,149]=17.89, p <0.001), where children in the six-year-and-above group (*M*=21.98) scored far worse than both the five year (*M*=20.43) and three-to-four-year (*M*=16.42) age groups.

Moreover, t-test analysis was conducted to ascertain if differences exist in home environment stimulation of HIV-positive children raised by non-biological and biological caregivers. The HSQ results indicate a difference in home environment stimulation between HIV-positive children raised by non-biological caregivers and those raised by biological caregivers (See Table 12). HIV-positive children of non-biological caregivers were found to score higher on the HSQ (*M*=20.27, *SD*=6.11) when compared to those cared for by biological caregivers (*M*=17.47, *SD*=5.26) (t [150]=2.88, p<0.01 two-tailed). One could thus infer that HIV-positive children in this study who were raised by biological caregivers as opposed to non-biological caregivers were exposed to less environmental stimulation that would optimise developmental outcomes (Table 9).

Nutritional status

Chi-squares were conducted to ascertain the relationship between stunting, underweight, and wasting on age and gender of HIV-positive children, as well as the age and relationship of their caregivers (biological vs. non-biological) (See Table 14). For the HIV-positive children there were no gender differences in relation to these anthropometric data (X^2[N=150] = 0.379, $p > 0.05$), meaning that HIV-infected boys and girls were equal on these anthropometric measures of nutritional status. However, differences were found with regards to status and the age of an HIV-positive child. In relation to stunting, the three-to-four-year age group were more stunted (43.4%) than those in the five (30.4%) and six years and older age groups (35%) (X^2[N=152] = 14.79, $p = 0.005$). No age-group differences were found amongst the HIV-positive children with regards to being underweight (X^2[N=152] = 6.39, $p = 0.171$ and wasting (X^2[N=152] = 1.49, $p = 0.475$. Although not significant, a close inspection of the results, showed that younger HIV-positive children (17.7%) were found to be more underweight than older children [5 years = (4.3 %), 6 years-and above = (8.5%)] (See Table 14).

Table 14: Demographic characteristics and their association with the nutritional status of HIV+ Children

Variable	Gender of children			Age-groups of children				Type of caregivers		
	Males N (%)	Females N (%)	χ2 (p-value)	3 – 4 years N (%)	5 years N (%)	6 years and above N (%)	χ2 (p-value)	Biological N (%)	Non-biological N (%)	χ2 (p-value)
Stunting			0.638				**0.005**			0.838
Normal	42 (64.4)	55 (63.2)		39 (56.5)	16 (69.6)	42 (70.0)		59 (62.1)	38 (66.7)	
Moderate	10 (15.4)	18 (20.7)		9 (13.0)	6 (26.1)	13 (21.7)		18 (18.9)	10 (17.5)	
Severe	13 (20.0)	14 (16.1)		21 (30.4)	1 (4.3)	5 (8.3)		18 (18.9)	9 (15.8)	
Underweight			0.827				0.171			0.687
Normal	57 (89.1)	75 (87.2)		56 (67.0)	22 (95.7)	54 (91.5)		82 (87.2)	50 (89.3)	
Moderate	5 (7.8)	9 (10.5)		8 (33.0)	1 (4.3)	5 (8.5)		10 (10.6)	4 (7.1)	
Severe	2 (3.1)	2 (2.3)		4 (3.1)	-------	-------		2 (2.1)	2 (3.6)	
Wasting			0.198				0.475			0.603
Normal	61 (95.3)	82 (98.8)		66 (95.7)	22 (100.0)	55 (98.2)		89 (96.7)	54 (98.2)	
Moderate	3 (4.7)	1 (1.2)		3 (4.3)	-------	1 (1.8)		3 (3.3)	1 (1.8)	
Severe	-----	-------		-----	-------	-------		-------	-------	

Significance level *p<0.05; ** *p<0.01

Predictors of poor neurocognitive and socioemotional function of HIV+ children

To determine the predictors of poor neurocognitive and socioemotional functioning in HIV+ children, a regression model was conducted using Total HSQ scores, weight for height z-scores (WHZ), weight for age z-scores (WAZ), height for age z-scores (HAZ), density (number of persons per bedroom), caregiver type, and Total BDI (caregiver depression) as predictors. In the regression analysis, FSIQ (Global IQ function), PIQ (Performance IQ), VIQ (Verbal IQ), and BDI-II (caregiver depression) were criteria or dependent variables. The results of the analysis are presented in Table 15.

In the second model, the results showed a non-significant joint influence of the predictors on VIQ (R^2=0.004, F=1.02; p>0.05). The results indicate that only 0.4% of the variance in VIQ could be explained by the predictors, with none of the predictors having any significant effect on the verbal neurocognitive functioning of HIV positive children in this study.

The third model also showed a non-significant joint influence of the predictors on PIQ (R^2=0.008, F=1.04; p>0.05) indicating that only 0.8% of the variance in PIQ could be explained by the predictors. More so, none of the predictors had any significant effect on the non-verbal neurocognitive functioning of HIV-positive children in this study.

The final model showed a significant joint effect of the predictors on socioemotional functioning (R^2=0.196, F=2.29; p<0.05), and explained 19.6% of the variance in socioemotional functioning of HIV-positive children in this doctoral study. The independent predictors revealed that only caregiver depression (β=0.53; t=3.50; p<0.01) was a significant predictor of socioemotional functioning in HIV positive children, while the remaining predictors had no significant influence on HIV-positive children's socioemotional well-being in this doctoral study.

Table 15: Summary of Multiple Regression of the best predictors of socio-emotional and neurocognitive functioning of HIV+ Children

Models/Criterion Variables	Predictors	Collinearity Statistics					
		B	*SE B*	*β*	*t*	*R²*	*F*
FSIQ (Global IQ function)	Total HSSQ score	0.14	0.54	0.05	0.26		
	WHZ	2.43	21.75	0.32	0.11		
	WAZ	-3.22	31.12	-0.36	-0.10	0.019	0.90
	HAZ	3.21	18.48	0.65	0.17		
	Density	-6.00	4.66	-0.23	-1.29		
	Caregiver	-3.47	4.83	-0.12	-0.72		
	Total BDI	-0.36	0.29	-0.21	-1.24		
VIQ	Total HSQ score	0.20	0.44	0.09	0.46		
	WHZ	1.27	17.77	0.20	0.07		
	WAZ	-3.25	25.43	-0.45	-0.13		
	HAZ	2.58	15.10	0.63	0.17	0.004	1.02
	Density	-1.15	3.81	-0.05	-0.30		
	Caregiver	-3.11	3.95	-0.13	-0.79		
	Total BDI	-0.41	0.24	-0.29	-1.74		
PIQ	Total HSQ score	0.03	0.58	0.01	0.05		
	WHZ	3.54	23.56	0.42	0.15		
	WAZ	-3.07	33.72	-0.32	-0.09	0.008	1.04
	HAZ	3.63	20.03	0.67	0.18		
	Density	-9.80	5.05	-0.34	-1.94		
	Caregiver	-3.55	5.23	-0.11	-0.68		
	Total BDI	-0.25	0.31	-0.14	-0.81		
Total SDQ	Total HSQ score	-0.04	0.16	-0.04	-0.21		
	WHZ	-4.70	6.54	-1.81	-0.72		
	WAZ	6.59	9.35	2.21	0.70		
	HAZ	-4.16	5.55	-2.50	-0.75	0.196	2.29*
	Density	0.59	1.40	0.07	0.42		
	Caregiver	-0.23	1.45	-.024	-0.16		
	Total BDI	0.30	0.09	0.53	3.50**		

Note. HSQ= Home Screening Stimulation Questionnaire; BDI= Beck Depression Inventory;

WHZ= Weight for height zscore, WAZ= Weight for age zscore, HAZ= Height for age zscore

Significance level   *$p<0.05$; ** $p<0.01$

Summary of Quantitative findings

<u>Psychosocial characteristics:</u> The majority of the HIV-positive children in this study were being cared for by a non-biological caregiver who had a 50% chance of battling with depression, given the finding that close to 50% of all caregivers (biological and non-

biological) were displaying depressive symptoms. There were slightly more HIV-positive girls in the sample of HIV-positive children in the study (52.7%), while the average age of the sample of HIV-positive children was 63.13 months; with at least 21.7% of them in grade one. The quantitative findings confirm that children infected with HIV are also living with concomitant socioeconomic challenges, as the majority of the HIV-positive children were living in dense and overcrowded homes (68%), with the main source of income for these families being sourced from government social grants. Additionally, just over half of the sample of HIV-positive children in this study was found to have poor outcomes on anthropometric measures of nutritional status (wasting, stunting and underweight). The prevalence of stunting among these children (aged between 31.38 and 92.78 months) was 36.2%. Furthermore, 12% of the sample was identified as being underweight, with those with wasting just below three percent of the children under study. Significantly, the overall sample of HIV-positive children were raised in home environments lacking in quality interactions required for physical, emotional, and social development.

Neurocognitive functioning: The quantitative findings of this doctoral study indicate that a large percentage of HIV-positive children displayed poor neurocognitive development. More than 70% of the HIV-positive children obtained a score that fell within the below average to extremely low range on global neurocognitive functioning scales. Similarly, on the subdomain of verbal neurocognitive development close to 50% of the children scored within the borderline cognitive range, while only 8.7% were functioning in the normative range of non-verbal neurocognitive function. Overall, the performance of this sample of HIV-positive children on these subscales of the WPPSI-III was consistently low. These results do, however, need to be interpreted with caution given that the WPPSI-III has not been validated for the South African context.

Regarding the relationship between neurocognitive functioning and the psychosocial predictive variables, results were only significant for anthropometric measures of nutritional status and stimulation in the home environment. HIV-positive children who were found to have neurocognitive impairment were also more likely to be stunted. Furthermore, the study sample of HIV-positive children was found to be vulnerable to developing emotional problems, irrespective of their relationship to the primary caregiver. Additionally, the HIV-positive children's gender and age also appeared to be associated to their neurocognitive outcome, with the boys being worse-off than the girls in terms of neurocognitive development. Neurocognitive impairment was also found to be worse among the older age group of HIV-infected children. One of the reasons for this age difference could perhaps be attributed to the fact that availability and accessibility to ARVs in South Africa have improved over the past few years to the extent that it has become mandatory for every child to be put on the treatment, irrespective of their CD-4 count, and as part of South Africa's response to combating the pandemic, with the younger group being advantaged in this way. Notwithstanding these associations, no independent variables emerged as predicting neurocognitive outcomes when subjected to multiple regression analysis.

Socioemotional and psychological functioning: Close to half of the sample presented with socioemotional difficulties. Girls and boys were more or less equally negatively affected in the emotional and psychological domains, suggesting that they struggle with more or less the same psychological difficulties. The younger age group of HIV-positive children in this study were, however, found to be significantly worse off emotionally and psychologically than the older age groups.

A significant relationship was found between caregiver depression and the HIV-positive child's emotional and psychological adjustment. Children who were reared by depressed

caregivers were more likely to have emotional and psychological problems and this relationship was stronger for HIV-positive children who were living with a depressed biological caregiver, although not significantly so. In relation to the psychosocial domain, HIV-positive children were found to struggle more with peer-relatedness, hyperactivity, and depressive behaviour, as per caregiver reports.

Strongest predictor of neurocognitive and socioemotional function: Caregiver depression emerged as the only significant predictor of HIV-positive children's emotional functioning.

CHAPTER SIX

QUALITATIVE FINDINGS

Introduction

Emerging from the qualitative component of this study is the finding that caregiving gets performed, not only in the context of maternal HIV-infection, but also in the contexts of inadequate material and financial resources, and single-head households where women assume the primary caregiving role. Moreover, caregiving is also complicated by the issue of maternal death and abandonment, where relatives (in the main grandparents), assume the role of primary caregivers of children infected with HIV. The emerging qualitative results, as reflected in the narratives of these caregivers, demonstrate the psychosocial aspects associated with caregiving in the context of HIV, which complements the findings from the quantitative study in this doctoral research. The overarching themes emerging were: i) Contextual challenges impacting on caregiving in the context of HIV; ii) Impact on psychological and social functioning of children and caregivers; and iii) Coping strategies. Subthemes are reported under each of these overarching themes. For uniformity respondent will be used to indicate the caregivers.

Contextual challenges impacting on caregiving in the context of HIV

Unfavourable physical environment

Poor quality social conditions: Caregivers of children infected with HIV confront various socio-economic challenges, among them the reality of living in poor social (physical) conditions. Caregiving often gets performed in unfavourable physical environments, where a lack of structural resources is a constant reality. Consequently, living and raising a child in a shack or hut is the reality for some of these women and is clearly reflected in the responses of some of the women:

Respondent: And the house we live in has a leaky roof.
While another said:

> Respondent: We live in a hut in the village and it leaks when it rains, no tap
> for water and toilet.

Overcrowding (density). Another common feature reported by the women in this study is the issue of living in an overcrowded home environment. The following response from a person living in a two room home clearly demonstrates this environmental challenge:

> Interviewer: Okay, how many of you are at home?
> Respondent: It's me, my grandmother and grandfather, two uncles, my sister,
> and my two children, and my uncle's child.
> Interviewer: All in all?
> Respondent: There're 10 of us.
> Interviewer: Of those people you live with, who is working?
> Respondent: No one. My grandparents are on pension.

<u>Socioeconomical challenges</u>

Lack of financial resources and support: Caregivers of HIV infected children are often confronted with socioeconomic stressors associated with a lack of financial resources and support, which could potentially exacerbate the already negative effects of HIV on both the caregiver and the child. The majority of women reported not having adequate finances to meet the needs of their children. As one caregiver said:

> Respondent: It has affected it (lack of financial support affects their daily
> quality of living), sometimes it's the middle of the month and there's no food
> at home. The money's finished. And you think that the children need to eat
> and she has lots of energy and will want to eat.

This financial limitation poses a stressor not only for biological caregivers, but also non-biological caregivers, as reflected in the following responses from some of these women:

> Respondent: …because the baby is sick so I can't work. And my husband is
> also sick. So I knew I couldn't and lived through it.

and:

Respondent: … example when it's cold and I have to come to hospital. I know there's no helping it and I have to walk. With him on my back.

The stress associated with a lack of financial resources for both biological and non-biological caregivers of HIV positive children is perhaps entrenched in the various responsibilities of having to care for an ill-child. Apart from meeting their basic needs, caregivers also have to ensure that their physical needs are met for stable health progression. However, for these children quality of health is directly linked to available financial resources, as indicated in the following response not unusual for most of the women:

Respondent: We buy flour, maize meal, soups; we then aren't able to afford the fruits and vegetables the hospital recommends.

These caregivers find themselves in debt as a result of having to source money through loans to buy food and get taxi-fare required to attend their hospital appointments.

Respondent: Yes. When we get a date in the middle of the month when we've no money. We have to borrow money with exorbitant interest rates.

Social grant. For most of these caregivers the reality of financial deprivation is reflected in their need to access a social grant. The majority of the families in this study reported that they access social grants, whether in the form of child support grants, old age pensions, or disability grants.

Most caregivers are dependent on social grants to meet the basic needs of these ill children. In the absence of this limited financial support, most families struggle to make ends meet and often have to prioritise in order to provide for the whole family by buying food, electricity, or fuel, instead of tending to the ill child's needs. Constant hospital follow-ups also add to their financial burden, and the following quotes reflect how caregivers are constantly confronted by the challenge of not having money to attend hospital appointments or running out of

money half-way through the month, which results in them being unable to provide their ill children with food:

> Respondent: When I have to come to check-ups I have no money for taxi to come. It's difficult.
> Respondent: Big time, it's very hard. I told her mother. She gets the R280 a month. Which is like nothing, because we have to feed her with it, clothe her with it.

Unemployment. Not having a job or no one in the household working emerged as a common feature of these families. For most caregivers relying on a child support grant, old age pension, or disability pension was the only sources of income. This is a reality that was clearly depicted and supported in the quantitative findings of this study, with social grants emerging as the main source of income (88.8%) for the families of HIV-infected children (see Table 1). The majority of these caregivers and family members are undereducated and as a result not employable in high-income professions. For those caregivers who have a job, caring for their ill child takes priority over employment, despite knowing that they might struggle to cope financially. The following emerged from this component of the study:

> Respondent: That cost me my job because after she was with me, when I'd gone to work and had left her with someone, I'd come back and she'd have diarrhoea. Which caused frequent trips to hospital; I decided if I want her to pull through I'll have to stay at home.
> Respondent: But I couldn't work because the baby is sick so I can't work. And my husband is also sick. So I knew I couldn't.

Thus, the burden of caring for an HIV-infected child reduces caregivers' capacity to work.

Lack of nutritional provision. As a result of limited finances, it is not surprising that poor nutritional provision is a common feature of HIV-positive children. This finding is corroborated by the more than 30% of HIV-positive children in the quantitative component of this study that were found to be stunted. Most of the caregivers reported that they are unable

to adequately meet the nutritional needs of their children owing to a lack of resources available to them. This remains a serious challenge, especially as these children and some of their caregivers are on ARTs or other medication that should be taken with food. This emerged clearly in the following reports by some of the caregivers:

> Respondent: In the middle of the month and there's no food at home. The money's finished. And you think that the children need to eat and she has lots of energy and will want to eat.
> Respondent: It happens half way through the month when food runs out
> Respondent: Yes, I've been told here in the hospital to get special foods for her. But we get village food. And things don't go as planned.
> Respondent: We buy flour, maize meal, soups, we then aren't able to afford the fruits and vegetables the hospital recommends.

Associated Health Challenges

Child continuous health problems. While it is common practice now for all children to have access to Antiretroviral Therapy (ART), common infections and associated illnesses are still something that infected children are confronting on a daily basis, as reflected in the following reports:

> Respondent: At times she gets ear infections and it just leaks fluid. Other times stomach aches.
> Respondent: But we keep going to the hospital, it is a lot of struggle, especially after his mother passed away.

The panic associated with the child getting sick combined with other stressors, such as limited resources, can exacerbate the negative consequences of HIV on the health and wellbeing of the child and even the caregivers. On a daily basis caregivers have to confront minor to severe health challenges, ranging from headaches to conditions such as epileptic seizures in their children. Having to battle with a child's illness emerged as extremely burdensome, anxiety provoking, and stressful to caregivers.

> Respondent: When he starts coughing I don't waste time for it to get worse.
> Respondent: Every now and then. She had to go every other day to hospital and you know the transport costs attached to that.

Respondent: He had eczema. I kept taking her so she would get the creams for it.

Caregiver health problems. In the qualitative study 47.7% of the caregivers interviewed were HIV positive, compared to the 36.8% of biological caregivers in the quantitative study. This means confronting and managing one's own illness is also of importance, with, some women reporting additional challenges, apart from HIV, that seem to present as obstacles. One caregiver spoke about her mental illness and alcoholism:

Respondent: Because of a mental illness [I] took amitriptyline treatment but (was) not taking it properly too…Yes, even though on amitriptyline I was still drinking.

Another caregiver's story encapsulated the entrenched dilemma of having to care for herself and her child, which is reflective of most caregivers in the qualitative component of this study:

Respondent: When I think about it, I just think if only I was the only one sick. Because, for example, I'm on TB treatment (and) taking ARVs. Sometimes I forget to give (him) his treatment.

However, even for those caregivers who were not HIV positive (52.3% in the qualitative - study and 63.2% in the quantitative study), having a lifestyle-related chronic illness was not uncommon, as the majority of them were grandmothers. As one of the caregivers reported:

Respondent: I am already on Diabetes medicine and used to pills, we both had to eat pills only difference is I'm old and have no qualms about death but he is still a baby.

Relatives and other children with health problems. In addition to caring for the HIV positive child, caregivers also reported that it was generally expected of them to assume the role of primary caregiver to all household members, irrespective of their own health status. This

theme is illustrated in the responses of some caregivers as they reflected on the people in their homes they cared for, in addition to the HIV positive child:

> Respondent: My husband is also sick, he gets seizures, and he's on medicine as well.
> Respondent: Yes, [the] last born has Down syndrome. She is 14 and is a girl.

Paradox of Disclosure

Uncertainty and the fear of stigma and discrimination permeated caregivers' realities and affected their decision-making ability whether to disclose or not disclose their own status (in case of biological caregivers) or that of their children. This is accompanied by fear and anxiety which entraps caregivers, rendering them socially isolated.

> Respondent: I'm not someone who likes to go to other people's houses, I just stay at home because people judge you for being HIV positive and I'm avoiding that.

For some, not disclosing is part of maintaining their secret and avoiding the stigma for the sake of both caregiver and child.

> Respondent: I keep the knowledge of her situation within the walls of our house.

This dynamic took place in relation to partners and/or family members. Moreover, these women find themselves at risk of confronting divorce or separation from their partners, disrupted family systems, and potential rejection from their family home should the "secret" be disclosed. For some women in the study who decided to disclose, vulnerability to being rejected was a possible consequences.

> Respondent: The father and mother they were living together. There were mishaps after the positive test. They had lived peacefully before Thando (pseudo name) was born. Once he found out, he stop supporting.

This is extremely troublesome for the women, especially if they are financially and otherwise

dependent on the partner.

> Respondent: It ended up costing me, and I was unable to provide for my kids as much as I used to. I found myself having to look after the kids on my own…my family suffered.

Furthermore, some family members tended to distance or disassociate themselves from HIV-positive family members due to fear of being labelled as HIV-positive as well (associative stigma) as explained in the following extract:

> Respondent: I tried to get my cousin to bring her [HIV positive child to hospital] but she was ashamed so I told myself I would bring her until she could come on her own.

Nevertheless, there are some HIV-positive women who internalised the stigma, thus preventing them from disclosing. The following quote captured this dynamic:

> Respondent: Even when I'm walking down the road I get the feeling that as they see me they are saying "don't be fooled by how healthy she looks, she is HIV positive". Even when there's discussions about HIV, It seems they do it in my presence so that I hear it.

As a result of HIV denial, some family members often only found out about the illness when the patient was sick and unable to care for herself and the child. This is reflected in the following extract where a caregiver explains how she got to know about her daughter and grandchild's status:

> Respondent: From his mother before she passed away. In 2010. I was shocked. I asked why she didn't tell me and she said she was dreading it.

Not disclosing the HIV diagnosis and maintaining secrecy had the potential of denying HIV-positive caregivers of social support. The following extract depicts a caregiver's explanation of how she came to accept the diagnosis and focus on the child she cares for after his biological mother disclosed their status shortly before her demise:

Respondent: At first I was resentful and being difficult but ended up accepting him as my child. I'm also happy...I accepted it because he is my baby now and I have to look after him. I never asked for him to be sick...I feel like this child's life is in my hand.

The Need for Correct HIV/AIDS Information

Inaccurate information

Inaccurate information can foster inaccurate beliefs about HIV, which in turn can lead to increased fear and discrimination, thus resulting in stigmatization of people living with HIV. This was reflected in the following caregiver's responses:

Respondent: I was afraid people are not going to like my child now because of the HIV. So I tell myself I'm going to keep this a secret.
Interviewer: But you didn't tell anyone?
Respondent: Yes, I did tell my sister and his auntie.
Respondent: It was very bad, very bad. His auntie did not want to wash him anymore she says she going to get HIV. She was very bad to him, she don't want her children to play with him. And she tells the neighbours when she is drunk she shouts about his sickness, it was very bad.

Misconception or misunderstanding. Lack of accurate information about individuals living with HIV resulted in misperception among the caregivers (both HIV positive biological caregivers and HIV-negative non-biological caregivers). Not knowing the facts about HIV/AIDS and how it manifests or affects someone physically, causes most caregivers to believe and expect the worst outcomes regarding their children's health progress. As a result caregivers become preoccupied with the well-being of the HIV-positive child at the cost of other children and responsibilities.

Respondent: During that whole process, I had no clear understanding of what happens to people with HIV, it ended up costing me, and I wound up unable to provide for my kids as much as I used to. Because everything I spent on her [HIV+ child].

A lack of accurate information also resulted in increased levels of stress and worry by caregivers about the child's health and possible demise.

Respondent: I think because of the way I viewed HIV. I had the misconception that she would die soon. So I was vigilant of the fact in an effort to prevent her death. It felt like while I was at work I'd get home and hear that she died.

Accurate information

On the other hand, the benefits of proper information dissemination about the progression of HIV meant that caregivers could manage their child's disease more confidently and in the case of HIV-positive caregivers, their own health. This is illustrated by one of the HIV positive caregivers, but reflects the view of most of the caregivers in the study:

Interviewer: So, how did you feel when you found out both you and your son were HIV positive? How did you deal with that?
Respondent: I was already on my treatment for that at that point, I was in a group, and I was able to look after him at that point.
Interviewer: Okay.
Respondent: I knew what to look out for and when to give him his meds, and going by how I felt I could empathise with what he might be feeling.

And other caregivers (not HIV-positive) had this to say after they were counselled at the hospital on their child's illness:

Respondent: We took the baby to the parent and told her that the treatment should never run out.
Respondent: They explained a lot to me and when I got here to the clinic, I told them of my situation and asked for advice on the child.

In addition to this, accurate information also led to greater acceptance about caring for an HIV-positive child. Caregivers who had proper knowledge of the associated effects of the disease's progression, reported they were more willing and at ease when it came to caring for a child with HIV.

Respondent: In the first three months it was extremely difficult, she [HIV+ child] was only four months and due to the fact that she wasn't my own child I didn't expect such a situation…I felt that the social workers should take her and see what they can do with her…after learning about HIV and how to treat it, things improved… [I] make peace with it.

While for another caregiver, having helped people living with HIV before assisted her in accepting her role as the caregiver of an HIV-positive child:

> Respondent: I was used to working with people who are positive because we used to run support groups… my mom [also] helped people who were positive too and that opened my eyes.

Impact of HIV on psychological and social functioning of infected children

Emerging from the present study is the fact that children living with HIV are challenged to live their lives in the context of an uncertain future. For those whose biological parents are still alive, this was complicated by the presence of their biological caregivers, and disrupted family units, multiple death experiences, and living with extended relatives are a common reality. In this study, two of the children had both parents deceased, while four children's fathers had passed away, fourteen had lost their mothers, with another 19 not knowing their fathers, and five of the children's mothers being absent from their lives. This corroborates the quantitative findings supporting the fact that the majority of children in the study were raised by a person other than a biological caregiver. For some being infected often meant living in isolation, as caregivers committed to secrecy and silence for fear of being stigmatised. Some of the consequences were that many of these children were denied access to health services and support, and it was not uncommon for children to be vulnerable to secondary diseases, have emotional and behavioural problems, and to experience developmental challenges. All of this proved consistent with the quantitative findings of this doctoral study.

Psychological and behavioural challenges in HIV-positive children

Caregivers often reported that their children experienced multiple psychological, behavioural, and developmental challenges.

Symptoms of Hyperactivity. Caregivers reported that children frequently presented with problems of over-activeness and disruptive behaviour. This observation was not only made within the home environment, but also in relation to the schooling and crèche context. One of the caregivers gave the following report of her child's behaviour:

> Respondent: She can go into your house when she doesn't know anyone there, she does some work and she can take your TV and place it on the ground, then put it back where she found it. And she leaves things all over the place. She does everything hurriedly.

Another caregiver emphasised how her child's behaviour is disruptive:

> Respondent: She jumps around, goes on the bed, opens fridges and cupboards;

and playful as indicated by the reports of these caregivers:

> Respondent: She is hyperactive. Very playful;
> Respondent: He's an overactive kid, he loves to play.

At the time of this interview one of the children was on Ritalin to control the severity of his hyperactivity and behavioural problems.

Symptoms of disruptive behaviour. Displays of violent behaviour in children were also reported by caregivers in this study, and were often observed in the children when they played with their peers. The children were unable to engage in reciprocal play, which is captured in the following response:

> Respondent: I usually put her with other kids and watch as she plays with them. But she has a problem with hitting. She hits them.

Also as captured in another caregivers story:

> Respondent: At home we have a nine month old baby, my grandchild. She hits that baby a lot. Which she never did before, sometimes she blocks the nose, she even pushed the baby against the wall and she knows it's wrong.

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Apart from the fighting, caregivers reported that children failed to listen, follow orders given to them, and are stubborn, as illustrated by these caregivers:

> Respondent: Even when you hit her, you could take a knife and cut her it would not change a thing. She doesn't *listen.*
> Respondent: When you talk to her she can *ignore* you and is quite cheeky.
> Respondent: If they tell her to do something and she doesn't want to, she won't do it.

The caregivers were all in agreement on the fact that these observed behaviours in the children were problematic and at times rendered them unmanageable.

Symptoms of Distractibility. Caregivers also reported that children were easily distracted. They found this problematic, especially as they were responsible for ensuring the child behaves in accordance with the norms of society. Not only was this reported to impair pro-social behaviour, but it also impeded their capacity to learn. One of the caregivers reflected on this in her story, as the teacher holds her accountable for the child's behaviour and to "solve" it:

> Respondent: And she loves it when the teacher is teaching she also pretends to teach and loves the attention. This ends up distracting the other kids and the teachers looks to me to solve it.

Affective and cognitive symptoms. Caregivers also recognised emotional symptoms in their children. One caregiver noticed the following in her child:

> Respondent: She gets easily bored.
> Respondent: It was difficult, I knew how he felt as he was grieving for the loss of his mother…when he would be playing with other kids and they would be talking about their mothers he would say that 'my mom has passed away, I don't have a mom'.

Caregivers find themselves having to cope with the extra demands of behavioural and emotional problems in their children. Seeking help from family members appeared to be a common recourse for the caregivers.

> Respondent: The only person I depend on in those situations is my mother.
> Respondent: I am supported at home by my parents and siblings.

Associated learning difficulty in HIV-positive children

Another theme that emerged was a concern regarding children's school functioning. Findings highlight that the HIV-positive children in the study were at risk of poor scholastic functioning. Caregivers reported:

> Respondent: She is slow in everything she does, very slow.
> Respondent: Well, she is a bit underdeveloped, at school if she misses one day she gets far behind.

The consequence of this difficulty is that it has the potential to impede a child's scholastic progress and contribute to additional caregiver stress and frustration. One of the caregivers recognised this:

> Respondent: She's a very slow learner…at times it takes so long that you might end up raising your voice.

Accordingly, poor reading and writing ability was also highlighted as learning barriers to the children's progress.

> Respondent: Yes, they bring their books home with them. The teacher comments at the back and tells me of the problems. "He has a problem with Xhosa, can you get him to read certain pages".

Given the behavioural and emotional problems displayed by the children, it is not surprising that they presented with learning problems. The following response captures this clearly:

> Respondent: The teacher has told me the problem she has with him, is that if you're teaching him something, there's a short window of time where you can

and he loses interest. And he dislikes writing. He doesn't mind talking. He prefers to talk rather than write.

Interestingly, and perhaps importantly for HIV positive children in the study, was that caregivers recognised the importance of spending time with the child to help with their school work. Most caregivers, both biological and non-biological, despite contextual and health complications, made the effort to spend time with their children and assist where they could.

> Respondent: We can write together, she isn't able to write words though, but if I write a word and tell her to copy it, she does it.

This is a very important observation, as it challenges the view that caregivers of HIV+ children are unable to care for their children. This finding shows that there are also caregivers who show resilience and work very hard to care for their children. This also reflects the dedication of caregivers to their children and this most likely acts as a buffer against the negative effects of HIV and contextual challenges on the children's developmental outcome. This is an aspect that perhaps needs inclusion in future research, especially as it stands to act as apossible buffer against the negative effects that the virus has on familial systems.

Developmental Delays

Some of the caregivers reported delays in achieving developmental milestones in the areas of walking, speech, and potty training. One of the children was attending a special needs school, while another was consulting an occupational therapist to assist with managing their developmental delays.

> Respondent: Well, she is a bit underdeveloped. Sometimes, without tripping on anything, she just falls down.
> Respondent: He's a slow developer; it took him a while to walk on all fours, and a while to walk. And it took him a while to start speaking.
> Respondent: I want to see her when she's 8, because she still wears a nappy. At times she tries to talk and says "Spha wants to pee". (pseudonym)

Emerging from the interviews with the caregivers is the reality that caring for their children was hard work and required a lot of patience. Furthermore, as previously shown, the health and wellbeing of the child took priority over that of the caregiver.

These findings are particularly important and alarming, as they corroborate the quantitative survey results, which proved that about 50% of the children who took part in this study and are living with HIV displayed moderate to severe levels of psychosocial difficulties, while more than 70% displayed subnormal neurocognitive functioning.

Impact of HIV on psychological and social functioning of caregivers

Emerging from the caregiver interviews, HIV-positive biological mothers still perceive their diagnosis and that of their children as putting them at risk of being stigmatised and rejected by family and friends. However, not disclosing their status also means risking the opportunity of receiving acceptance and social support. Maintaining secrecy regarding their status was often accompanied by fear and self-blame, and made them vulnerable to depression and anger. For the majority of the non-biological caregivers (in the main grandmothers) in the study, disclosure was often unintended and forced as a result of their daughters' ill health or death, or their grandchildren's ill-health. While shock and surprise was a common reaction for these assumed caregivers, they nevertheless accepted the illness. Both biological and non-biological caregivers found disclosure stressful and challenging, but also understood that they had to do everything in their ability to create and maintain normalcy in the lives of these HIV positive children.

Some of the caregivers first had to deal with emotions such as shock and hurt. This is what an HIV positive caregiver had to say after she found out her child was HIV-positive:

Respondent: I was shocked. Shocking, hurtful and confusing.

Increased levels of stress were also commonly reported. The majority of caregivers were single heads of households and have to care not only for themselves and their ill child, but most often also for additional family members.

Respondent: You feel like you're in way over your head and can't cope.

Caregivers also reported fatigue associated with caring for an HIV-infected child, yet felt they had no choice but to pull through for the sake of the child. This is reflected in the responses below:

Interviewer: So when you feel like that, you're usually tired?
Respondent: Yes.
Interviewer: So what do you usually do in that situation?
Respondent: You usually pick yourself up and tell yourself to deal with it.

Furthermore, another HIV-positive caregiver had this to say in response to the interviewer's question:

Interviewer: Do you ever feel tired?
Respondent: There are times like that…but I have to provide for them [the children] I can't disappoint my children.

While this HIV caregiver reported that fatigue affected her role, especially given the demands of her own illness:

Respondent: I have to make an effort to be able to make it to the hospital.
Others were trouble by feelings of helplessness and hopelessness, such as this person:

Respondent: Since I'm facing this alone, there are days where you feel like you're stuck and don't know what to do.

Additionally, some caregivers reported struggling with vegetative symptoms, such as moodiness, lack of appetite, and lack of energy, which impaired their capacity to effectively respond to their child's needs.

Respondent: sometimes my head feels hot, and feel so tired I just skip supper…Its hard for me to eat, I had no appetite. It's all on me…having to take care of a sick child.

Over-/under involved caregiving/mothering as a consequence. For some caregivers, the HIV infection in their children motivated them to take much better care of their children, than they would have done under normal circumstances. The narratives of both these biological and non-biological caregivers underscore this finding:

Respondent: I wanted to look after her, and ensure that nothing would hurt her, so that she's never in any pain. Or get affected by other children. I just want to stay with her all the time. (HIV positive caregiver).
Respondent: No matter where I'm going , even if I'm going back to the village, I prefer taking her with me because I don't trust her mom as she is the one who has to look after her if I leave Thandi (pseudonym) (Non-biological caregiver HIV negative).
Respondent: If I'm far away, I'm going to think who is looking after my kids? I have to do everything with myself vigilantly (HIV- positive caregiver).
Respondent: I pay very close attention to him, I know what to do in all situations that arise. When he starts coughing I don't waste time for it to get worse.

Hypervigilance about any physical signs or symptoms was necessary for these caregivers to ensure that their children remain healthy.

Respondent: First of all, you have to accept your situation and understand it won't change. Then be vigilant with the treatment so that the baby is healthy. The virus won't leave. Just so the child can live like other children. Just make sure she gets her pills.
Respondent: I just tell myself no matter what. I have to make sure she's taken care of first and foremost.

On the other hand, the stigma surrounding HIV prevented some caregivers from adequately caring for their children. Secrecy regarding a child's status denied caregivers the opportunity to access adequate healthcare and family support, which impacted negatively on the child's health.

Respondent: When she was sick often, she wasn't being fed her medicine properly. Even the TB medicine she had; which the mother never said were for

TB but from my experience I know what they were. The mother didn't give her properly. She was neglecting to feed the baby medicine. Because she'd placed them in the wardrobe in an attempt to hide them from me…That's when I heard the baby is positive and became sure it was true and looked after her.

Respondent: A lot, at the time she had the sores, grandma wasn't too old and would bring her to hospital. Then as time went on, I saw that she was being neglected. I noticed that they weren't feeding her pills properly… This is when I noticed that when she wakes up in the morning, she is unwell. And I brought her to her doctor…I decided to take responsibility for her, because I feared what would happen in that situation.

Care burden. Caregivers are often required to manage their own health, that of their ill child, and that of the family. Focusing on the ill child often came at the cost of sacrificing relationships with other children owing to the entrenched difficulty associated with caring for an HIV-ill child.

Respondent: There's a lot that happens, because you have to look after your child and yourself. It's harder if you have other children.

In this study, the majority of women were the sole caregivers of the HIV positive children. This role was especially difficult for those who did not want to be a burden to anyone else.

Respondent: I never leave him if I go anywhere. I don't want to burden anyone else.

Frequent medical appointments, unexpected hospitalisations that occur from time to time, in addition to the day-to-day caregiving needs of the children were reported to be a huge burden to caregivers.

Respondent: It becomes especially difficult if you're working, because you will have to leave work at any time due to phone calls about the baby being sick.

Respondent: There's a lot that happens, because you have to look after your child and yourself. It's harder if you have other children. Then if the baby gets sick and gets admitted into hospital, you have to take care of the other children, as well as working. After she gets out you have to be watchful.

While these caregivers understood their role as caregivers to their children, they nevertheless felt that their capacity to be effective parents was challenged as a direct result of the physical demands of caring for a child with HIV. Moodiness, frustration, feelings of helplessness, and wanting to give up were all emotions experienced by the caregivers in this study.

> Respondent: Especially when she is being disobedient, and I ask myself why do I bother wasting my time raising her.
> Respondent: There are days where you feel like you're stuck and don't know what to do. And you feel like you're in way over your head and can't cope. Especially if you're alone…

Biological and non-biological caregivers (many having other chronic conditions) also experienced an ongoing struggle related to the balancing of their own health concerns with the health demands of their child.

> Respondent: When I think about it, I just think if I only. If I was the only one sick. Not the child as well. Because for example I'm on TB treatment, taking ARVs, sometimes I forget to give him his treatment. And sometimes I'm in bed feeling awful and I have to get up and take care of him.

In the extract below from a biological parent we see guilt that is twofold; on the one hand they feel guilty about the child being infected because of them, and on the other hand they feel guilty about not being able to adequately care for the child due to their own physical condition

> Respondent: When I think about it, I just think if I was the only one sick…and wish the situation changes and she becomes negative…it's better if you are positive with no children who are positive. Then you don't suffer…sometimes I'm in bed feeling awful and I have to get up and take care of him.

These findings reflect the plethora of risk factors that add to caregivers' psychological vulnerability and complements the high levels of depressive symptomatology reported in the quantitative findings of this doctoral study among biological and non-biological caregivers of HIV-positive children.

Coping

Positive coping

HIV-positive child as a source of inspiration. Some biological caregivers find caring for their HIV-positive child a source of inspiration for negotiating with their inner fears, especially those associated with their own illness and having a future.

> Respondent: There's no way he won't make it. Not while I'm still alive…what keeps me tough…the thing that keeps me going is the fact that I want to see him when he's grown up. Everything I do I do for him.

Some non-biological caregivers adopted a similar stance despite many of them having lost a child. The availability and accessibility of treatment for their children are core to their optimism.

> Respondent: He was given different treatment and I was told that if he eats it properly he will live a long life. Being positive won't affect him.

Faith in God as a source of support. For most of the caregivers in the study, drawing strength from their faith was essential for them to accept and cope with the diagnosis of HIV. As one of the caregivers indicated, she is able to cope by telling herself to try "if God gives me strength". Another HIV positive caregiver found refuge in prayer and fellowship with other Christians, as it dissolved the fear of her husband's and child's inevitable death. This is what she had to say:

> Respondent: I'm a church goer and I know the Lord. I [have] no fear of her dying or anything bad happening…I prayed for that not to happen.

Some caregivers were also of the belief that God was at play in calling them to accept and look after their HIV-positive child. One of the grandmothers to an HIV positive child indicated this:

> Respondent: as she arrived, I was working, as the problem arose after 4 months, I felt that the social workers should take her [the child] and see what

they do with her. On the others hand I considered that God felt that this child should fall into my hands and I should just make peace with it.

while another caregiver said:

Respondent: she was brought to me to raise, the first thing I did before I took the child. I knew her mother had died of AIDS and when she arrived I locked myself in my room and prayed so that I could accept the child and love her unconditionally. God gave me strength and I never had any problems and I was able to accept them into my heart.

Family and friends as sources of support. Despite the fear associated with disclosure and the stigma attached to HIV, some of the caregivers were able to reach out for support. From their stories it was clear that disclosure did not always result in negative consequences, such as rejection and discrimination, but also provided the opportunity to give and receive support. Some of the caregivers reported the greatest source of support was their family. Mothers and partners (if present) emerged as important sources of support, as reflected in the responses below:

Respondent: …when I found out he is positive I had to tell her [mother] because she spends a lot of time with him [HIV positive child]…she had no problem with the news, and told me "let him stay with me and I'll feed him his medicine"…

Respondent: I was lucky that my husband had no other children and this was his first child. He focus greatly on her…He was the reason it was easy for me to accept the baby's status.

For another HIV-positive caregiver, having an older child whom she was able to disclose to helped her with acceptance and caregiving.

Respondent: That's the reason I'm coping, I have an older child who is 18 years. I usually talk to him. I have a support structure. I can't sit around thinking about death.

While others found solace in additional relatives who assisted in alleviating the burden associated with caring for an HIV-positive child.

Respondent: I usually leave on weekends, and come back, I know that he [HIV-positive child] is taken care of because people at home…my aunts, my grandparents.

A grandmother who was caring for an HIV-positive child also mentioned calling on her sister for support and was not an uncommon occurrence.

Respondent: I call my sister…when she is available.

Health staff as a source of support. For several caregivers the help and proper information exchange from their healthcare providers assisted with acceptance and coping.

Respondent: The thing that helped me a lot was being counselled here in the hospital… was fine after that.
Respondent: now they explain things in detail to you…you have to accept your situation and understand…
Respondent: They [medical staff] counselled me so it [HIV diagnosis of child] wouldn't bother me and it's common.

Additionally, the Department of Health also assists with food parcels to supplement the child's nutritional needs.

Respondent: I got a lot of support from a nurse who works here [at the hospital]…I ended getting food from the hospital…I just accepted it [the diagnosis of HIV].

Negative coping

Concealment of health status as a coping strategy. Biological mothers often utilised concealment as a means of coping with the illness. Fear and social rejection were some of the reasons mentioned for keeping the diagnosis secret. Naturally, concealment as a coping strategy had severe negative repercussions for the health of the children and their biological mothers. As reported by a non-biological caregiver, this had prevented her child from previously getting appropriate treatment and support.

Respondent: She was scared of me and didn't tell me…she evaded the question and I left it at that. Then the baby got sick again. She has all the

medicine hidden on top of the wardrobe. I tried to read it [the folder]. She'd take it from me, and tell me to disregard it.

Furthermore, the majority of children in the study were not disclosed of their HIV status. Most caregivers believed that the children were not mature enough to understand the diagnosis. The extract below illustrates this belief:

Respondent: She is already asking why she is taking medicine when other kids don't…there's an answer, but I don't know how to shape it, or how much she knows. They [medical staff] say she needs to know by age of 7.

Summary of qualitative findings

The qualitative findings highlight caregivers' need of social/financial support and infrastructure, employment and skills, appropriate health information dissemination, and social support. It perpetuates the view that infected caregivers in the study are women who are younger, of childbearing age and mostly unemployed, while the non-biological caregivers of orphans generally come from the -middle- to old-age group. Consistent with the trend of the HIV/AIDS pandemic, this study's qualitative findings echo the reality that these caregivers of HIV-positive children are women from resource-limited socioeconomic backgrounds and are worse affected by the adverse consequences of both the HIV/AIDS pandemic and poverty.

The findings also emphasise the fact that HIV remains stigmatised and discriminated against, thus rendering it a scourge that threatens support networks, as well as timeous and free accessibility to healthcare (health seeking behaviour). Additionally, a lack of accurate information emerged as one of the underlying reasons for the continuing existence of stigma and discrimination, which in turn complicates and creates additional challenges for caregivers. The decision to disclose or not disclose one's status or that of one's child emerged

from the study as a major internal conflict that further frustrated caregivers. Individuals who chose to disclose were exposed and subjected to discrimination, rejection, and relationships disruptions on the one hand, while on the other hand some found that disclosure meant being able to name the observed signs and symptoms of the disease in addition to providing and receiving social support that would otherwise have been denied. It also meant a decrease in the level of anxiety and worry that accompanies an already stress-inducing caregiving process.

For the majority of caregivers in the study, parenting an HIV-positive child with additional psychological, behavioural, and learning difficulties was a reality. From the interviews it emerged that the burden of care was large, with children requiring extra attention and time. As a result most caregivers felt it was too difficult to juggle a job and caring for their children, with most of their time and energy dedicated to the well-being of the family. Moreover, caregivers also had to confront their own health (HIV-positive caregivers or grandmothers with compromised health), while at times also looking after other relatives with certain health challenges. The qualitative findings of this doctoral study highlight the enduring struggle caregivers confront in trying to balance their own health demands against those of their child and family. Despite this most of them attempted to create an environment conducive to caring for the child, by drawing inspiration from God and the child. Social support, especially from families, as well as health information support and counselling were also reported as being helpful.

CHAPTER SEVEN

DISCUSSION

Introduction

This chapter draws on the quantitative and qualitative findings of this doctoral study. The findings in this study contribute to research literature on the neurocognitive profile and socioemotional functioning of pre-and school aged children from a resource limited community with vertical HIV-infection on cART. For the purpose of clarity, findings from this study will be denoted by the term doctoral research or study to differentiate it from referenced research. The primary goal of this doctoral study was to explore the association between psychosocial factors and poor neurocognitive and socioemotional functioning of children with vertically acquired HIV on cART, due to the scarcity of studies on this topic within the South African context. The content of this chapter commences with a discussion on the characteristics of HIV-positive children and their caregivers in relation to aspects of socio-demographics, caregiver depression, nutritional status, and home environment. The second part attempts to provide an integrative discussion on the impact of these factors on the neurocognitive and socioemotional functioning of HIV-positive children that emerged from both the quantitative and qualitative findings of this doctoral study. The discussion will attempt to locate and consolidate the findings of this research project (both quantitative and qualitative) in previous research, while adhering to the framework of Bronfenbrenner's Social Ecological Theory that informs our understanding of the developmental outcomes of HIV-positive children in this doctoral study.

Characteristics of HIV-positive children and their caregivers

Socio-demographics characteristics of HIV-positive children and the caregivers

Consistent with the ecological systems theory, the finding of the study identified various intrapersonal, familial, and contextual factors that are pertinent to understanding the neurocognitive and socioemotional development outcomes of children living with HIV. The children in this study were not only HIV-positive, but also black African and lived in poor social contexts with limited resources. Research has consistently indicated that children who have a higher risk of getting HIV are black (Shisana, 2005; Brooks, Shisana & Richter, 2004). No age and gender differences were observed given the sample was a heterogeneous group on both variables. Consistent with existing literature, both the qualitative and quantitative findings identified biological caregivers in this study as women of childbearing age, while the non-biological caregivers appeared to be middle- to old-aged women, concurring with previous findings that grandmothers seem to be the ones who are caring for HIV-positive orphans in South Africa (Bateman, 2008; Brooks, Shisana & Richter, 2004). The finding that 63.3 % of caregivers were non-biological, supports the reality that foster care of HIV children has become prevalent in South Africa and elsewhere in the world (Jelsma, Davids, & Ferguson, 2011). However, in South Africa the type of care arrangement is most of the time not formalised but a duty that is assumed by a relative (Brooks et al., 2004). The results also indicate that unemployment is a major problem for the caregivers who took part in this doctoral study, with a lack of financial resources posing a daily challenge. Baillieu and Potterton (2008) found that more than 90% of the sample of HIV-positive children in their study were living in households characterised as being below the South African poverty line. The finding is consistent with Bronfenbrenner's macrosystem risk factors associated with children living with HIV, e.g. general economic challenges that have the potential of interacting/penetrating at specific levels in these children's ecology and impact their

neurodevelopment and socioemotional outcomes (Bronfenbrenner, 1979; 2005). The majority of caregivers in the study relied on social welfare grants, such as old-age pensions or child support grants (Peltzer, 2012). The qualitative findings further suggest that, while the majority of families in this study depended on a social grant, they continued to struggle coping financially and to meet the basic needs of their children. This proved consistent with the quantitative findings of this doctoral study. In a cross-sectional study conducted in rural Eastern Cape among people living with HIV (PLWHIV), it was found that not having access to a disability grant was associated with a lack of food, inadequate nutritional provision, low CD-4 counts, and inadequate access to vital treatment (Phaswana-Mafuya, Peltzer, & Petros, 2009). This is a reality that was mirrored in this study. Furthermore, some research revealed that people who have HIV or who care for an individual/child with the disease are less likely to be in a position to take up employment (Peltzer, 2012). This is particularly true for the caregivers and children in this doctoral study, as close to 40% of the HIV-positive children were cared for by HIV-positive caregivers (biological mother), living within a context of associated poverty; characterised by unemployment, limited financial and structural resources. The quantitative results from this doctoral study further indicates that close to 20% of the children still lived in shacks and more than sixty-five percent lived in over-crowded conditions. This resonates throughout the results from the qualitative phase of the doctoral study, which revealed that poor quality social conditions and dense home environments emerged as some of the contextual challenges associated with caring for those infected with HV/AIDS. This is an important finding, as the family and the proximal context remains the most influential part of the child's micro- and mesosystem (Bronfenbrenner, 1979). The influence of family extends beyond just the physical space of the child and impacts on all aspects of his/her neurodevelopment (Kagitcibasi, Sunar, Bekman, Baydar, & Cemalcilar, 2009). These challenges remain a reality for many black children raised in South Africa, and

it makes them particularly vulnerable for disease, sexual abuse, and poor developmental outcomes, to mention but a few (Iversen, du Plessis, et al., 2011).

Neurocognitive functioning of HIV-infected children

The quantitative findings of this doctoral study found that HIV infected children on cART typically scored below average on the composite measure of neurocognitive functioning. The results indicate that the majority of the children scored in the low average to average range (<90). The global neurocognitive (FSIQ) scores for these children fell more than one standard deviation below that of the normative standardised sample (M=100) on the WPPSI-III, with scores ranging from mentally deficient (IQ=69 and below) to high average (IQ=110-119). This doctoral study found that a large percentage (>70%) HIV-positive children who were raised by either biological or non-biological caregivers present with subnormal global neurocognitive functioning. These findings should however be interpreted cautiously as the WPPSI-III has not been normed for the South African population and no comparison was made between controls groups of non-HIV+ children given that the aim of the study was to look at the relationship between the psychosocial factors and neurocognitive function.

Notwithstanding these limitations it can be cautiously argued that these findings are consistent with existing international studies from the USA (Clark, 2005, Tardieu, 1995, Brocki & Bohlin, 2004), Canada (Blanchette et al., 2001), Brazil (Tahan et al., 2006), as well as other studies conducted in Africa, such as in the Congo (Van Rie et al., 2008; 2009), Kenya (Abubakar et al., 2009; 2013), Uganda (Boivin et al.,2010; 2009), and South Africa (Smith et al., 2008; Lowick et al., 2012; Jelsma et al., 2011; Baillieu et al., 2008 & Ferguson et al., 2009; van Loon, 2009).

Clark (2005), in a study conducted among African American children, found that HIV-infected children performed at least one to two standard deviations below the normative range for cognitive function on WISC-III and WPPSI-R, presenting with global cognitive impairments. Locally, Smith et al. (2008) conducted a study on 39 black South African HIV-infected children (mean age 46 to ±60 months) in Cape Town and found that, despite a six month follow-up after the initiation of HAART, the children evidenced subnormal global neurocognitive functions on the majority of the neurodevelopment measures, showing no significant changes in neurodevelopmental deficits of HIV-infected children in response to short-term highly active antiretroviral treatment. Likewise, van Loon (2009) examined whether any differences in cognitive functioning existed in HIV-positive and uninfected children in Johannesburg and Kwazulu Natal, South Africa. The researcher found that HIV-positive children scored significantly lower on the Ravens Coloured Progressive Matrices (CPM) (standardised non-verbal cognitive test used in South Africa), than the HIV-negative children matched on demographics (van Loon, 2009).

Some international studies have, however, demonstrated the contrary, with variations in the relationship between neurocognitive function and paediatric HIV being evident (Bisiacchi et al. 2000; Fishkin et al., 2000). For example, Bisiacchi et al. (2000), in their study of HIV-positive children, found no differences in global neurocognitive functioning in these children as compared to uninfected children. Their results indicated that most of the children scored within the normal range of global neurocognitive functioning comparable to that of the HIV-negative group, but displayed subtle deficits on the measures of subdomains. Fishkin and colleagues assessed a sample of 40 HIV-infected children (age range three to six years) on the WPPSI-R, and found no significant differences in global neurocognitive functioning when match to uninfected controls (Fishkin et al., 2000) and Bagenda, Nassali, Kalyesubula,

et al. (2006) reported normal cognitive functioning among ART-naïve, HIV-infected school age children from the resource limited country of Uganda.

It is perhaps important to note that these studies had relatively small samples of HIV positive children which could have contributed to the inconsistencies observed. The differences could perhaps also be due to the fact that the measures used in these studies were not sensitive enough to gauge the involvement of HIV on global neurocognitive functioning, but rather more so in tapping into subtle and specific deficits of HIV-positive children on HAART (Koekkoek et al., 2008). Perhaps also the timing of ART initiation may have played an important role, especially since early initiation of treatment has been associated with better neurocognitive functioning (Smith & Wilkins, 2015)

The results from this doctoral study also suggest that HIV-positive children present with more specific deficits, such as those measured on the subscales. The children performed in the subnormal range on both the PIQ and the VIQ, which suggest that they have specific impaired cognitive functioning in non-verbal and verbal domains of neurocognitive development (Smith, 2006; Kandawasvika et al., 2014). A high percentage- over half of the sample, did worse on processing speed, general language and verbal IQ. This is consistent with findings from previous studies of vertically HIV-infected children, which showed that they present with subtle deficits in specific areas of their neurocognitive domains (Bisiachhi et al., 2000; Kandawasvika et al., 2014; Koekkoek et al., 2008). The HIV-infected children in this doctoral study scored significantly lower on the VIQ (*M*=77.66, *SD*=11.24) compared to the PIQ (*M*=89.60, *SD*=16.98).   Similarly, Clark found in her study that HIV-infected children scored more than one standard deviation from a normative sample on the subscales measuring verbal and nonverbal cognitive functioning (2005). Furthermore, significant

differences between these domains were also confirmed, which suggest that verbal neurocognitive development is more negatively affected than non-verbal neurocognitive development in HIV-infected children (Clark, 2005). This finding was confirmed in this doctoral study, which indicated that vertical HIV-infected children, despite being on cART, do not only present with gross neurocognitive impairment, but also have more specific deficits that affect their verbal domain more severely than their nonverbal neurocognitive development. This doctoral finding is also consistent with a recent study by Kanawasvika et al. (2014) who found similar results in a sample of Zimbabwean school aged children living with HIV. The researchers reported that the HIV-positive children scored worse in verbal, memory, and quantitative scales when compared to uninfected matched peers (Kanawasvika et al., 2014). Boivin and colleagues in a study conducted among Ugandan, HIV-infected ART-naïve children (N=102; mean age eight years) found that children with both subtypes A and D had overall subnormal cognitive functioning. However, children with HIV-type A performed much poorer than children with type-D on both global and subtest neurocognitive domains (2010). Thus, based on the findings of this doctoral study one can argue that HIV-positive children's verbal and nonverbal abilities are not evenly developed, contrary to what some researchers have suggested (Martin et al., 2006). Although this finding is significant, it should be interpreted with caution, as the verbal scale in this context may not be the best indicator of cognitive function among this sample of children. The measure was developed in English and is not validated for the South African non-English speaking black population. Alternative interpretations for the poor performances can be that due to the fact that the scale was not validated in isiXhosa could potentially, in part, explain the low scores in the verbal domain. Cultural and linguistic differences may have existed that potentially contributed to the difference in performance in the domains. This is highlighted as one of the limitation of the study and needs to be kept in mind while interpreting the findings. It may be that

performance IQ which is not fully language based may be more accurate, even though a different domain (Koekkoek et al., 2008).

The findings reported is also in accordance with the findings of a study conducted by Gevins and Smith who assessed the relationship between verbal and non-verbal and global neurocognitive functioning (2000) amongst healthy young individuals (mean age 21.4 years). Their results showed that the sample of healthy young individuals displayed similar relationship between verbal and non-verbal neurocognitive functioning to that found in the doctoral study. Furthermore, their findings illustrated that the participants with higher global cognitive functioning made greater use of the parietal regions of the brain whereas participants with general poor cognitive skills made greater use of the frontal lobe regions (Gevins & Smith, 2000). It can this be implied that the HIV-sample in this study relied on similar regions of the brain given their general low performance on global and specific sub-domains of neurocognitive function as measured on the WPPSI-III. Given the link observed between the frontal lobe and intellectual and cognitive ability in the study by Gevins and Smith (2000) it is possible to suggest that the HIV-positive children in this doctoral study may have relied heavily on the frontal lobe. Arguably the observed deficits in this sample of HIV-positive children in this doctoral study can be explained by the fact that the HIV places greater pressure on the frontal lobes (Gevins & Smith, 2000).

Literature suggests that the HIV may have a diffuse effect that impacts the brain more widely (Rhodes, Riby, Park et al., 2010). The diffuse effects are observed in executive dysfunctions, frontal lobe dysfunction and deficits in working memory in the prefrontal cortex. Thus it appears to have had a greater impact on the neurodevelopment of children, including areas of higher order function including verbal and nonverbal neurocognitive development. The

prefrontal cortex appears to be largely impacted on by the diffuse effects of the virus, resulting in major implication, especially as it is implicated in verbal and nonverbal skills and working memory (Rhodes, Riby, Park et al., 2010).

While these findings focus on specific deficits and should be interpreted with caution given that the WPPSI-III has not been validated for a South African population, it suggests that important aspects of executive function, such as abstraction, planning and organisation, cognitive flexibility, attentional control, as well as broadly working memory, are impaired in children infected with HIV despite being on cART, given the impact on global neurocognitive functioning. The findings were supported by Gevins and Smith's study which showed poor global cognitive ability on the Raven's Progressive Colour Matrices. The results revealed greater executive dysfunction and poor cognitive control among the sample on the non-verbal neurocognitive ability tasks (Gevins & Smith, 2000). Their scores were particularly dissatisfactory on working memory and language (vocabulary, information, and word reasoning respectively), attention to visual stimuli or detail (picture completion), visuospatial organisation and planning (block design and object assembly), and processing speed (coding and symbol search) (Wechsler, 2002). These underlying abilities of neurocognitive functioning have been described as aspects of executive functioning, which involve higher levels of cognitive and mental processing comprising manipulation of information, attentional flexibility, visuospatial or organisation, and planning (Rhodes, Riby, Park et al., 2010; Koekkoek et al., 2008). This finding is consistent with other studies that have identified specific impairments amongst HIV-positive children in working memory and language, and processing speed (Blanchette et al., 2002; Bisiacchi et al., 2000; Koekkoek et al., 2008). Some studies have demonstrated and argued that executive function is the most sensitive neurocognitive measure in relation to HIV disease progression in infected children

(Koekkoek et al., 2008). These are challenges that are also very common in children with HIV-infections, as seen in this study. Executive dysfunction has been found to result in neurodevelopmental disorders (i.e. ADHD, aggression/conduct disorders, emotional lability disorders) and correlates highly with several brain areas, including frontal, temporal, and amygdalo-hippocampal regions (Rhodes et al., 2010). Subtle executive dysfunction has also been implicated in cognitive, behavioural, and learning problems in children with chronic illness, which have also shown to cause poor academic performance, higher behaviour problems, and attentional problems in these children (Koekkoek et al., 2008). This observation was reiterated in the caregivers' qualitative reports on the HIV-positive children they take care of. They identified learning problems and associated behavioural problems in these children to be a major concern, and were confirmed for children raised by both biological and non-biological caregivers. Also commonly emerging from the qualitative findings, as reported by the caregivers, were problems with reading, writing, and especially concentration and attention difficulties, which manifested through poor scholastic functioning in the HIV+ children and added to the caregiver's burden. Gleaned from this doctoral study, the aforementioned finding is significant, as it underscores the congruence of both quantitative and qualitative findings, which suggest that children living with HIV are particularly vulnerable to neurocognitive deficits. Evidence of this vulnerability can be observed in the impairment aspects of daily functioning, e.g. learning ability/problems and emotional/behavioural problems. These findings also highlight the importance of both micro- and meso-system variables, such as the importance of quality parent/child interaction, adequate language stimulation through dialogue, and availability of tools within the home and school environment that could act as a buffer against the negative effects of HIV on the infected child's developing brain. Further research on this is required to unpack possible protective factors to act as buffers against the negative effects of the HIV.

Based on the quantitative measures in this doctoral study it was also found that more than 40% of the HIV-infected children scored in excess of two standard deviations from that of the normative mean in both speed processing and general language development, thus falling within in the extreme low cognitive range. This is an important finding, especially since it has been argued by others that processing speed, which includes both mental and motor speed, as well as language development are both important indicators of the extent of neurocognitive impairment (Jelsma et al., 2011; Ferguson et al., 2009; Smith et al., 2008). This has further implication on a child's overall learning ability as it can negatively impact their learning capabilities. However, caution must be taken in interpreting the results of the language scale at face value, especially given the fact that the children did not have English as their native language but as an additional language. The implication of testing someone in a language in which (s)he is not proficient can pose a serious threat to fair testing process. Nevertheless, to maintain the standard protocol of the test, an additional step was taken to use an interpreter to ensure understanding and access to expression. This mediated process has been shown to add value to maintain test validity in administering the test to individuals with dual language background. Moreover, inherent in the test was practice items (which allowed participants to engage more than once with an item) and while instructions on the test are in English, an interpreter was used equally so for verbal and non-verbal items. The assumption is therefore made that the cultural differences and test-wiseness equally impacted on both domains. Moreover, this finding holds fast, in relation to the reference group (Wechsler, 2002).

Jelsma and colleagues (2011) for example found in their study, which was conducted in Cape Town, that HIV positive children had significant delays, especially in the sub–areas (attention, motor function, and executive function), when compared to HIV-negative children. Furthermore, three South African studies conducted in Cape Town (Ferguson et al.,

2009; Smith et al., 2008) and Gauteng (Baillieu et al. 2008; Hilburn, Potterton, Stewart, & Becker, 201; Potterton et al., 2009) found that HIV-infected children presented with cognitive, language, and motor deficits, while Baillieu et al. (2008) established that the HIV-infected children in their study were developmentally delayed by up to 10 months. Notably, the HIV-positive children in the Baillieu et al. (2008) study were not on any HAART. Concurrently, Ferguson et al. (2009) in their study of a sample of HIV-infected children with a mean age of 15.8 months, who were on antiretroviral therapy found similar results. The researchers reported that even in the absence of opportunistic infections, more than 70% of the HIV infected children presented with significant neurodevelopmental delays, with their motor development the greatest affected. Like the findings in this doctoral study, Hilburn et al. (2011) reported severely impaired motor development in a sample (N=112) of HIV-infected infants between six and eighteen months of age who were treated on HAART in a hospital in Gauteng.

Similarly Blanchette et al. (2002) found that that perinataly HIV-positive school-going age children exhibited great vulnerability for visual-motor deficits apart from their fine motor and motor strength deficits, which is consistent to the doctoral results. However, they were able to strengthen this finding by identifying the structural brain abnormalities associated with the deficits. Respectively, Noyce (1994); Blanchette (2002); and De Carli et al. (1993) found that HIV-infected children with both structural abnormalities in the brain especially in the regions of the frontal cortex and basal ganglia (which is critical areas for psychomotor development) are at greater risk for long standing neurodevelopmental delays associated with motoric functioning. This is in line with scientific literature on the motor system that involves the somatosensory cortex of the parietal lobe, the motor cortex of the frontal lobe, subcortical basal ganglia, cerebellum, brain stem and spinal cord, and motor neurons; all areas that have

been implicated to a more or lesser degree to be impacted negatively by the HI-virus (Kolb & Whishaw, 2009; Van Rie et al., 2007). It can therefore be argued that the current findings observed amongst the pre- and school aged HIV positive children in this doctoral study with motoric deficits rely predominantly on these above mentioned areas in the brain. The findings are congruent with existing knowledge as discussed above (Jelsma et al., 2011; Baillieu et al., 2008; Hilburn et al., 20011; Abubakar et al., 2009; Blanchette et al., 2002). Some research in the area of neurodevelopmental delays amongst vertical infected HIV-positive children has even suggested that motor deficits observed in early childhood continue to progress into adolescence (Abubakar et al., 2008; Noyce, 1994). This is even more alarming given the fact that the sample of children in this doctoral study was on cART, but nevertheless presents with gross motoric deficits. One therefore, can expect to see this picture to worsen over time. Although it is postulated that that findings of this doctoral study are linked to specific brain area activation based on supporting literature cited here, the recording of this lies beyond the scope of this doctoral study. Perhaps the direction future research can take to enhance these findings is to combine brain imaging studies that will aim to establish brain areas activated in HIV positive patients on task utilised.

The qualitative results in this doctoral study support the quantitative finding as it revealed that developmental delays among HIV-positive children were prominent and presents as a major difficulty for caregivers. Some of the caregivers reported that their children were consulting various developmental specialists to assist with speech and psychomotor rehabilitation as part of their management, in addition to treatment for the HIV-illness. Potterton et al. (2010), in a longitudinal study of neurodevelopmental delay in HIV-infected children in South Africa, found that after a year of parental stimulation intervention and highly active antiretroviral therapy, children showed no improvement in cognitive

functioning but evidenced improvement in motor development. However, this stands in contrast to what was presented by children in this doctoral study, who are living with HIV and on treatment, but continue to evidence significant deficits in their overall neurocognitive development, as well as in the sub-domain of psychomotor functioning. This could perhaps be ascribed to a lack of psychosocial stimulation in the home environment, which probably speaks to the fact that the children in this doctoral study are not being timeously assessed nor appropriately referred (Boyede et al., 2013). Moreover, it has been consistently argued in the literature that neurocognitive impairment may be directly related to the assault of the HI-virus on the developing brain of HIV-infected children (Rausch & Stover, 2001), allowing one to infer that the brain is one of the first targets of the HI-virus, as indicated by the literature cited above. Some studies also showed that these deficits can be attributed to the direct effects of the virus on the central nervous system (CNS), or the effects of CNS infections or neoplasm secondary to immune compromise (Willen, 2006; Rausch & Stover, 2001; Rausch & Davis, 2001; Msellati et al., 1993). Studies involving neuroimaging have even demonstrated that more impaired neurocognitive functioning outcomes were prominently observed in the presence of actual structural brain abnormalities in children infected with HIV, including cortical atrophy, white matter anomalies, and calcification (DeCarli et al., 1993; Coscia et al., 2001). It has also been suggested that immunologically asymptomatic HIV strains in children are associated with more encephalopathy, coupled with the impact of the virus on developing neural networks during sensitive periods of development, and is perhaps why variability in the neurocognitive presentation of HIV in children is observed (Boivin et al., 2010). The damage caused by the HI-virus in infants can occur as early as intra-utero and abnormalities may manifest in muscle tone weakness and poor coordination, which sees these children failing to achieve motor developmental milestones in time (Nozyce et al., 2014; Furguson & Jelsma, 2009). Chase, Ware, Hittelman, et al. (2000) examined the aspect of timing in

relation to cognitive and motor development among infants born to HIV-positive women. They assessed infected (n=114) and uninfected (n= 841) infants on the Bayley Scales of Infant Development, Mental Developmental Index (MDI), and Psychomotor Developmental Index (PDI), and concluded that a greater percentage of HIV-infected infants evidenced cognitive and motor delays as early as two years (Chase et al., 2000).

The significance of the findings from this doctoral study, like that of Ferguson et al. (2009), and Smith et al. (2008), is important as it puts to question the neuroprotective and rehabilitative aspect of cART in the sample of HIV-positive children studies, especially as they are consistent with studies where children were not treated with cART and exhibited impairments in the same neurocognitive sub-domains (Bissiachhi et al., 2000; Baillieu & Potterton, 2008). Although it has been shown that cART is able to arrest the progression of HIV-associated encephalopathy, reports of ongoing cognitive decline, even in viral suppression, have still been reported (Boyede et al., 2013). Perhaps this speaks to the need for early initiation of cART that can possibly prevent and/or reverse the observed deficits (Ruel et al., 2012). This is especially important in a country such as South Africa where tremendous strides have been made to early initiation, but where efforts are hampered by access problems which is associated with ongoing poverty (Simelela & Venter, 2014). Moreover, the results from this study have demonstrated that, apart from global cognitive function, specific abilities are impaired in HIV infected children, despite keeping in mind the question on the validity of the measure. This is important specifically in light of the fact that it has been argued by some researchers and neuropsychologists that specific subtest indices are more sensitive at measuring subtle deficits and provide a more accurate representation on neurocognitive status of HIV-infected children than others (Nozyce et al., 2014; Lezak, 2004; Martin et al., 2006). It thus provides supporting evidence to the importance of choosing appropriate

neuropsychological test batteries to trace the involvement of HIV on the developing brain of infected children who are on cART (Koekkoek et al., 2008). This could perhaps account for the difference in findings from those who detected no dissimilarities in the global cognitive scores of HIV-infected children when compared to control groups of uninfected children. Moreover, and significantly so, the findings allude to the importance of assessing *all* children born to HIV-infected mothers (HIV-exposed), but more specifically children presenting with asymptomatic HIV, for the very reason that subtle neurocognitive deficits exists among HIV-positive children on cART, as proven in this study. Furthermore, the overall findings are important as it allows us to trace the pattern of neurocognitive dysfunctions amongst HIV-positive children. In so doing it enable us to identify specific areas of neurodevelopmental weakness in children infected with HIV, especially those children that present as asymptomatic while accessing cART. This provides us with critical information as to the direction that should be taking in structuring appropriate interventions that are preventative and rehabilitative in nature for these children, especially if we want to hamper the longitudinal effects of the virus's insult on the central nervous system of the HIV-infected child.

The doctoral study also found an association between neurocognitive outcomes and demographic variables. In contrast to previous findings (Kandawasvika et al., 2014), gender differences among the children in this doctoral study were observed. The results suggest that girls performed better than boys on both global neurocognitive development and non-verbal skills. Unlike Kandawasvika et al. (2014), the finding from this doctoral study is consistent with a study conducted by Deary, Thorpe, Wolson, Starr, & Whalley, (2003) who observed gender disparities in cognitive abilities. Some research suggests that females performed better on various verbal intellectual batteries compared to male (Kolb & Whilshaw, 2001; Weiss et

al., 2003). However, this was not so for this current HIV-positive sample, as no differences were observed on verbal domain of neurocognitive development; yet were observed in the non-verbal abilities. Males have been reported to performed better on visual spatial, mathematical skills (Rosselli, Ardila, Matute, & Inozemtseva, 2009), which stands in contrast with the current findings in this doctoral study that found them to have performed worse than girls on the non-verbal domain. Gender disparities in neurocognitive functioning has been linked to both biological (*i.e.* neurological structure and functions, hormonal influences related to brain differentiation) and environmental factors (*i.e.* educational background, cultural influences, stimulation *etc.)* (*e.g.* Rosselli et al., 2009; Blanch, Brennan, Condon, Santosh, & Hadley, 2004; Burton, Henninger, & Hafetz, 2005). Perhaps future studies need to address the relationship between gender and neurocognitive development more robustly.

Consistent with other studies, age did not account for any significant difference on global cognitive function in this doctoral study. Similarly, Puthanakit et al. (2010) found, even after three years of cART, that age had no significant effect on the outcome of poor neurocognitive function in HIV-infected children. Related findings were observed by Martin, Wolters, & Taledo-Tamula, et al. (2006) in a sample 41 vertically infected children on HAART. Likewise, Malee, Williams, Montepiedra, et al. (2009) found in their sample that age had no significant relationship to the subnormal neurocognitive function of HIV-positive children.

Furthermore, in contrast to Puthanakit et al. (2010), no differences in impairment of global neurocognitive function existed among children who were raised by biological compared to non-biological caregivers in this doctoral study. It is well documented that social-ecological factors associated with limited financial security and associated poverty can create various obstacles that have the potential of affecting the most proximal space; the caregiver-child

microsystem; as depicted by Bronfenbrenner's social ecological theory (Evans, 2004). This in turn has the potential to negatively impact effective parenting and child rearing practices through inadequate nutritional provision, lack of time for cognitive stimulation and poor caregiver-child relationship or responsiveness associated with maternal stress (Grantham-McGregor et al., 1991; Puthanakit et al., 2010). The findings of the current doctoral study contradicts those of Nanthamongkolchai et al's (2009) study conducted in Thailand (while supporting those of Mellins' (2011) as previously cited). A possible explination for these results are that biological caregivers are themselves HIV+ and may be stressed and therefore not be in a position to adequately respond to the needs of the children.

Socioemotional Functioning of HIV-infected children

The results of this doctoral study support the argument that children infected with HIV and who are on cART are at significant risk for psychological problems. Based on the quantitative measures used to assess the children's psychological function, the overall sample of HIV-infected children in this study were found to have psychosocial difficulties ranging from mild difficulties to markedly high psychological difficulties. This is in keeping with studies conducted internationally (Bauman et al., 2002; Bachanas et al., 2001a, b; Mellins et al., 2003, 2006, 2013; Melvin et al., 2007; Wiener et al., 1999, 2007, 2011; Serchuck et al., 2010). The findings report that approximately fifty percent of the HIV-infected children in this sample were experiencing significant psychological adjustment problems, which is consistent with other studies that have demonstrated how children with chronic illness are at increased risk of significant mental health and adjustment difficulties (Reiter-Purtill, Gerhardt, Vannatta, et al., 2003; Lavigne & Faier-Routman, 1992). However, when the findings from this doctoral study were compared to HIV-infected children from other studies, a higher portion of the children in this study evidenced significant

psychological problems (Bachanas et al., 2001a; Riekert et al., 1999). In their study, Bachanas et el. (2001a) found that only twenty-five percent of the sample of HIV-positive children displayed significant levels of psychological adjustment distress, while Wiener et al. (1999) found anywhere from eight to 36% of the sample of HIV-infected children in their study to be in the clinical range of psychological distress. While an unswerving comparison is not permitted for multiple reasons, *i.e.* disease and sociodemographic variability, sample size etc., similarities does exist between these studies and this doctoral study (Riekert et al., 1999; Bachanas et al., 2001a). Riekert and colleagues studied a similar sample (caregiver and HIV positive child, from low social economic background) and same variables (*i.e.* the relationship between caregiver depression and HIV-positive child's psychological functioning) (1999). Likewise, when looking at the findings from Bachanas and colleagues study, consistent findings (*i.e.* current study found a strong association between caregiver depression and child psychological function) to this doctoral study was observed when they measured the same construct (*i.e.* relationship between caregiver depression and HIV-positive child psychological functioning) (Bachanas et al., 2001a). They attributed the findings to the impact of poverty and environmental stress on caregivers' adjustment (Bachanas et al., 2001a). The findings from this doctoral study likely reflect the impact of the mesosystemic variables (e.g. environmental stress factors) and microsystemic variables (e.g. caregiver well-being), which purportedly moderates the association between a child's HIV-infection and his/her neurocognitive and socioemotional functioning (Corscia et al., 2001; Wiener & Tayler-Brown, 2010).

Additionally, the children in this study displayed both internalising and externalising behavioural symptoms (New et al., 2007). Approximately 30% of them were reported to display severe emotional and behavioural problems. Similar findings were reported in a study

among HIV-positive African refugee children living in the UK (London) when assessed on the SDQ (Melvin et al., 2007). Likewise, New and colleagues (2007) found that 38% of the sample (N=16) of HIV-positive children in their study met a diagnostic criteria for psychiatric diagnosis, with 20% treated on psychotropics for depression and anxiety. The psychological symptoms most frequently reported by caregivers of the HIV-infected children who took part in the quantitative component of this doctoral study were hyperactivity, *i.e.* distractibility, nervousness, restlessness, and over activity. While the most common anxiety symptom was anger or temper-tantrums, the most frequent depressive symptoms appeared to be sadness and tearfulness, with somatic symptoms such as headaches and feelings of isolation being also observed. Furthermore, the most common externalising symptoms (*i.e.* "Lying and cheating and fighting with other") appeared to be of greatest concern to the caregivers of the HIV-infected children in this study. Therefore, it came as no surprise that the caregiver reports from the qualitative portion of this doctoral study revealed various psychological and behavioural challenges in their HIV-positive children, which is in line with findings from other studies conducted internationally (Forehand et al 2002; Melvin et al., 2007; Mellins et al., 2009).

However, different findings on hyperactivity were obtained by Melvin and colleagues (2007). Contrary to the results in this doctoral study, Melvin and colleagues found that parents of HIV-positive children reported less hyperactivity problems in their children in their study. Nevertheless, the results from this doctoral study are consistent with previous studies that found poor attention, concentration, and distractibility to be some of the main clusters of problematic symptoms reported by caregivers and specialists dealing with HIV-positive children, and is said to be a possible consequence of the early effects of HIV on an infected child's developing brain (*i.e.* impact on the prefrontal cortex, specifically frontal lobe insult)

(Gosling, Burns & Hirst, 2004). Furthermore, research that focused on microsystemic variables (child/illness) has been able to link various emotional disorders to executive dysfunction (e.g. intraindividual factors: bioecological models make provision for biological vulnerabilities). In a study conducted by Rhodes et al., (2010) it was found that ADHD, emotional problems, and oppositional problems, as measured on the Strengths and Difficulties Questionnaire (SDQ), correlated significantly to poor executive functioning. This may also account for the high levels of reported hyperactivity and other emotional problems, as seen in this sample of HIV-positive children in this doctoral research. Similar support has been shown for HIV unexposed children who presents with ADHD (Hewage, Bohlin, Wijewardena, & Lindmark, 2011). This is important, as executive function allows the execution of day-to-day activities and relies on the neurocognitive processes that control behaviour as a situation demands it, while on the other hand it is observed as a deficit in children with neurodevelopmental disorders such as ADHD (Hewage et al., 2011).

Though the results from this doctoral study are consistent with other studies, a clear contrast exists in the severity of psychological difficulties the HIV-positive children are reported to display. The results demonstrate that the sample of black South African HIV-positive children in this doctoral study are psychologically worse off when these findings are compared to studies conducted on HIV-positive children from countries such as the UK and US (as referred to above) (Melvin et al.,2007; Riekert et al.,1999). These differences could be ascribed to multiple factors, one of which may be that the sample of children's psychological problems reflect the limited access to a multidisciplinary health services (apart from medical care), such as social workers and mental health specialist to support them and their families. In other words, various micro- and meso-ecosystemic vulnerabilities are present within the context of South Africa, especially within the resource-limited rural

context from which the sample is drawn from, which is consistent with social ecological theory. Access to mental health services in a timeous fashion to curb the problem before it presents and/or spirals out of control is limited. Also, the issue of multiple losses, disruptive family systems, parental ill-health combined with poverty, places greater risk on the children to developing psychological and emotional adjustment problems that add to the picture that one observes among the black South African HIV-positive children in this study (Smith & Wilkins, 2015; Mellins & Malee, 2013; Costello et al., 2003; Richter, 2004a; Richter et al., 2010; Richter & Hay, 1990). While the services are available in the health facility where this study was conducted, referrals are not typically made by the paediatric unit unless an obvious crisis presents itself. This is particularly alarming as it has been shown that both internalising and externalising psychological problems adversely affect the overall functioning of the child (New et al., 2007; Fawzi et al., 2010). The observed lack of an interdisciplinary referral system was one of the primary motivators for this study, and one of the motivations of the study was to use the findings to motivate for a more inclusive and rigorous treatment plan for children infected with HIV. Perhaps the role of culture also attributed to the results as caregiver's perceptions of their children's well-being are very much culturally mediated (Small et al., 2014). In addition, again the results should be interpreted with caution given that while the SDQ is widely used in South Africa, it has not been validated for the context (Pappin et al., 2015). In the South African context, the issues of language, parenting styles and expectations may have also influenced the findings (Lomanowska, Boivin, Hertzman, & Fleming, 2015), with cultural beliefs being a factor that could have influenced what parents perceived as appropriate behaviour in their children, e.g., less tolerance for certain behaviours (*e.g.* acting out behaviour). Language differences related to translation is also a factor that cannot be overlooked, especially in relation to how parents may have interpreted questions.

Furthermore, it is well demonstrated in the mental health literature that a link exists between emotional dysregulation as a cause of changes in cognitive and memory faculties (Bishop et al., 2004; Zgaljardic, Foldi, & Borod, 2004; Ochsner, & Schacter, 2000), and while its short-term impact on the child may be a difficulty to cope and engage with others in addition to poor scholastic performance, it is the longer-term consequences that prove detrimental to their self-esteem, confidence, treatment adherence, and their ability to navigate risky sexual scenarios (Fawzi et al., 2010). Also, and consistent with the results from both the quantitative and qualitative measures in this doctoral study, children living with HIV were exposed to stressful family circumstances, and as a result are highly stress vulnerable which could have a negative impact on their emotional regulation, task performances, and learning abilities (Abubakar et al., 2013).

Gadow and colleagues (2010) found that HIV-infected children are at greater risk of mental health problems than their uninfected peers from similar environmental backgrounds. In their sample of HIV-infected children from the US and Puerto Rico they found that, not only did the HIV-infected children display significantly higher levels of psychiatric conditions when compared to uninfected children, they also had distinct academic and social functioning difficulties. Furthermore, the HIV-positive children had a higher lifetime rate of special education and psychiatric treatment compared to their uninfected peers (Gadow et al., 2010). Given the findings from previous studies and the results from the psychological adaptability measures of HIV-infected children in this doctoral study, it appears that assessment of the psychological problems in children living with HIV in South Africa should become common practice, and should occur in addition to the medical management of the disease. This may then deal with the impact of both the disease and associated mental health problems on infected children's overall emotional and psychosocial well-being.

Nutritional status of HIV-positive children

Findings from this doctoral study provide support that roughly more than half of children living with HIV have inadequate nutritional status. The results suggest that stunting and being underweight seem to be prevalent among the HIV-positive children who were part of this doctoral study, despite being treated with highly active antiretroviral therapy. Growth retardation (also known as stunting) was reported in more than 35% of the HIV-positive children who took part in the study, while 12% presented as underweight. Low weight-for-height or wasting was also found to be a problem, but occurred in less than three percent of the children in this sample. Similar to the findings of this doctoral study, nutritional deficits among children of both pre-and- primary school age was reported in studies from other developing countries (Kapavarapu, Omar, Perumpil et al., 2012; Kandawasvika et al., 2014; Iversen et al., 2011; Ahmed et al., 1999; Condo et al., 2015;). In a study conducted among HIV-positive orphaned children in India, Kapavarapu, Omar, Perumpil et al. (2012) found that 79% (67/85) of the children who took part were underweight, 72% (61/85) were stunted, and 27% (23/85) evidenced wasting. They also found that after providing the children with adequate nutrition and appropriate healthcare in absence of antiretroviral treatment (ART), they showed improvement in growth. Additionally, Kandawasvika et al. (2014) reported that, of the sample of Zimbabwean school-aged children in their study, 19% (42/306) evidenced growth retardation, and 24% (63/306) were underweight.

Furthermore, when comparing the results from this doctoral study to those of the National Food Consumption Survey-Fortification Baseline (NFCS-FB) which was conducted in South Africa in 2005 among children aged one to nine years, this study evidenced higher levels of inadequate nutritional outcomes among children living with HIV. The NFCS-FB found that the portion of children who were stunted and underweight were about 20% and 10%

respectively. Importantly, inadequate nutritional status among children is not unique to South Africa and has been reported in many parts of the world (Alderman, Hoogeveen, & Rossi, 2006, 2009; Cames, Mouqet-Rivier, et al., 2010; Grantham-McGregor et al., 1991, 1997, 2001).

The most informative comparison of the finding regarding nutritional status in this doctoral study was with a study conducted among HIV-positive children living in rural South Africa, which concluded that malnutrition remained highly prevalent (Kimani-Murage et al., 2011). In their cohort (N=671) of children between the age of 12 and 59 months, Kimani-Murage and colleagues found an 18% prevalence in stunting (height for age <2, standard deviation (SD) from median reference value) when using the WHO 2006 standards as indicators of nutritional status (2001). However, they found that when comparing HIV-infected children to their uninfected counterparts, the children living with HIV had significantly poorer nutritional statuses. Thus, the prevalence of stunting in the HIV-positive children was 29% as compared to the 18% who were uninfected. Being underweight was a problem for 10 % of the children living with HIV, while wasting was identified in 7% (Kimani-Murage et al., 2011). When comparing the findings in this doctoral study to that of Kimani-Murage and colleagues (2011), this study found a higher prevalence of HIV-positive children stunted and underweight, while the prevalence of wasting was significantly less. This may speak to the greater availability of and accessibility to cART, which has changed the face of the pandemic to a much more manageable but chronic disease.

Similarly to previous findings (Kimani-Murage et al. 2011), the age of the children in this doctoral study was differentially related to their nutritional status, as younger children had poorer outcomes with regards to stunting than older children, while weight for age and

wasting was more or less equally prevalent in children of all ages. On the other hand, while no significant age group differences were observed in terms of weight for age on the children in this study, it must be noted that the younger age group presented with poorer weight for age z-scores than their older counterparts. This speaks to the fact that higher rates of stunting in younger children have been found to be associated with low-birth weight and is often followed by a catch up growth spurt in older children (Saloojee, Maayer, Garenne, & Kahn, 2007). The findings from this doctoral study is similar to that of a recent study that found sex and age differences in nutritional status of 6-18 months old HIV-exposed children from Rwanda (Condo et al., 2015). The findings show that male children under the age of five years or less than girls the same age may be at higher risk for poor growth. Growth retardation has been found to be more typical than wasting in post-natal growth among HIV+ children (Webb, Manji, Fawzi, & Villamor, 2008; Venkatesh et al., 2010; Mda, van Raaij, Macintyre, de Villiers, & Kok, 2010). It must however be noted that the prevalence of stunted (growth retardation) children in the study does not by itself suggest treatment does nothing. It could be that factors other than the disease are contributing to what we observed; especially since the relationship of HIV in children and growth disturbances are considered to be multifaceted (Arpadi, 2005). This study reflects the continuing nutritional vulnerability of children from low resource settings in the context of HIV and poverty (Condo et al., 2015). Furthermore, research shows that Sub-Saharan Africa HIV+ children evidence growth disturbance early in life compared to uninfected children (Webb et al., 2008). Research from South Africa (Venkatesh et al., 2010; Bobat et al., 2001) and Tanzania (Webb et al., 2008) suggest that HIV+ children evidence early growth retardation, by 2 to 3 months, postnatally. It has further been found to be detectable before onset of opportunistic illness and to be independent of viral load and CD4+ cell count. Some research suggests that growth faltering is due to secondary causes associated with HIV-infection such as insufficient dietary intake,

diarrheal illness and anaemia (Mda et al., 2010). While other research have found that growth retardation and malnourishment in children have been associated with poor feeding practices, especially breastfeeding issues around HIV and environmental variables such as unhygienic living environments, lack of access to safe and proper drinkable water, and an increased proneness for infection in early childhood (Condo et al., 2015). This in turn was also associated with weaker or lowered immunity in children living with HIV (Saloojee, Maayer, Garenne, & Kahn, 2007; Venkatesh et al., 2010). Notably, this is a reality that was clearly reflected and supported through the caregivers' qualitative reports in this doctoral study, especially since most of the children were raised by a non-biological caregiver in a resource limited context. Thus, this evidence once again allows one to observe how a child's larger socioecological systems are associated with poor nutritional outcomes in those infected with HIV, which in turn creates greater vulnerability for overall poor neurodevelopmental outcomes.

Yet contrary to what other researchers have suggested, caregiver age and type (biological vs. non-biological) were not key determinants of children's nutritional statuses in this study. Kimani-Murage et al. (2011) found that HIV-positive children living in rural communities and who were born to younger mothers are at twice the risk of being stunted than those born to older mothers (>35 years). Some researchers also found that social and biological risk factors are associated with poor nutritional outcomes in HIV-positive children living in the rural communities of Limpopo, South Africa (Saloojee et al., 2007). They identified factors such as inadequate childcare practices and inexperience, which causes a vulnerability to poor nutritional outcomes in children. In addition, caregivers' biological characteristics, such as small maternal body size and maternal undernourishment, were identified as risk factors for low-birth weight children and poor nutritional status in later life (Salojee et al., 2007). While

some research from Tanzania found that apart from the immunological status and infant infection, that maternal schooling was an additional predictor of early growth in HIV+ children (Webb et al., 2008). Children of mothers who did not complete grade school evidenced sustained growth retardation compared to those who had.

Despite the lack of evidence, maternal mental health is suggested to have an influence on growth of child (Arpadi, 2005). It is argued that children raised by mothers who are depressed are more likely to evidence growth disturbance. While the current study was unable to find a significant correlation between caregiver psychological health and child's nutritional status, it is nevertheless an important area of research that requires further extensive exploration; especially given the high rate of depression observed among caregivers of PHIV+ children in this doctoral study from the periurban and rural area of Eastern Cape, South Africa.

Home environment of HIV-positive children

Converging evidence from both the qualitative and quantitative measures in this doctoral study showed that children living with HIV are being raised in poor quality home environments. The overall sample (*N*=152) of HIV-infected children were reported to be raised in conditions that were unfavourable and lacking in adequate stimulation, as measured on the HSQ. These findings are in keeping with results from other studies that have demonstrated how HIV-infected children grow up in less stimulating home environments (Coscia et al., 2001; Clark, 2005). Clark (2005) in her study found various aspects of home environment, such as adult-child ratio and death of a caregiver, are factors that impact on the quality of the HIV-positive child's home environment. Additionally, Coscia et al. (2001) found that home environment variables, such as a lack of cognitive stimulation in the home, a

lack of parental involvement, and an unstructured home environment are all associated with poor neurodevelopmental outcomes in children living with HIV.

There are, however, some studies that suggest that HIV+ children are not necessarily raised in home environments chacracterised by poor stimulation. For example, Drotar and colleagues (1997) conducted a study amongst HIV-positive Ugandian children and reported that that the children in their study did not live in a less stimulating home environment when compared to uninfected children from the same sociocultural context at six months and 12 month intervals. There is also literature that suggests that the relationship between the quality of early environment and emotional response by the child may be mediated by caregiver influence on said child's brain development (Hewage et al., 2011; Ferguson et al., 2013); through the primary caregiver's ability to create a stimulating proximal environment for the child, *i.e.* through medium of play, interaction, availability of toys, etc.

Nevertheless, it should be noted that the psychosocial context of children living with HIV has not received adequate investigation and the differences in the findings may perhaps illustrate a need for further exploration of whether HIV-positive children are at greater risk of living in suboptimal home environments when compared to uninfected children. This is important given that in many parts of the world, research have supported the notion that most HIV-infected children's social ecology are characterised by poverty and poor quality social conditions, such as a lack of resources and infrastructure, in addition to the loss of multiple caregivers and disruptive family systems that negatively impacts their quality of life (current doctoral study findings, Coscia et al., 2001; Abubakar et al., 2008; Herro et al., 2013; Ferguson & Jelsma, 2009).

Psychological functioning of HIV-positive children's caregivers

Proximally, almost half of the total study population of caregivers in this doctoral study experienced degrees of depressive symptoms ranging from mild to severe. This was for both biological (HIV-positive mothers) and non-biological (assume HIV-negative grandmothers, aunts, etc.) caregivers. The percentage of caregivers who had identifiable depressive symptoms in this doctoral study was higher than the rates of depression observed among the general population by the South African Stress and Health Study nationally and provincially. The national lifetime prevalence for major depression came in at 11.9% for ages 18 to 34 years and 16.5% for ages 50 and above (Herman et al., 2009), with the Eastern Cape having lower rates of lifetime prevalence for mood disorders estimated at 8.3% (Herman et al., 2009).

The findings of this doctoral study corroborate the results of previous studies that indicate that caregivers of HIV-positive children exhibit high levels of mental health related problems, such as stress, anxiety, and depression (Murphy et al., 2002a; New et al., 2007). Some of these studies suggest that caregiver depression is a result of one's own HIV illness (in the case of biological mothers) or that of the child (in the case of vertical transmissions) or both (Fawzi et al., 2010). Similarly, studies that have investigated the mental health of HIV-positive caregivers of non-infected children seem to suggest that HIV-positive caregivers, when compared to HIV-negative caregivers, demonstrate higher depressive symptomatology and other related mental health problems, such as guilt, blame, stress, and anxiety (Biggar & Forehand, 1998).

Interestingly, this doctoral study found that a higher percentage of biological caregivers than non-biological caregivers displayed depressive symptoms, with worse symptoms reported by

biological caregivers. Similar differences have also been observed in other studies which demonstrate that biological parents, when compared to non-biological parents (foster, relative, etc.), evidenced higher levels of psychological stress (Chalfin, Grus, & Tomaszeski, 2002). The qualititative findings from this study supports this and are important as it perhaps alludes to the biological caregiver's underlying feelings of guilt and self-blame associated with knowing that she is responsible for the child's HIV infection combined with the direct effects of her own HIV illness. More so, this will most likely influence the nature of caregiving between the biological caregiver and the HIV-infected child (New, Lee, & Elliot, 2007; Murphy, Marelich, Stritto, et al., 2002a) and may possibly reflect the lack of social support-seeking behaviour among the caregivers, as reported and supported through the qualitative interview findings in this study. Additionally, the strain of having to care for younger children, with a chronic illness, within the context of poverty are some of the factors associated with depression among older caregivers (Peltzer & Phaswana-Mafuya, 2013). These associated factors were clearly narrated by the older caregivers through the qualitative findings of this doctoral study.

The emerging results from this doctoral study are noteworthy, given that caregivers (biological and non-biological) who act as primary caregivers play an important role in the management of child HIV. The presence of depressive symptoms may impair a mother's ability to adhere to treatment and prevent her from making appropriate decisions about seeking healthcare, which may in turn negatively impact the child's HIV status (Murphy et al., 2002b; Peltzer & Phaswana-Mafuya, 2013). The findings of this doctoral study's qualitative interviews with caregivers, suggest that secrecy, denial, and fear of stigma promote psychological stress in caregivers. This was corroborated by the quantitative findings, which showed caregivers' vulnerability to depression, anxiety, and isolation. Aslo,

the qualitative study found that HIV stigma promoted living in silence, with caregivers fearing disclosing their status to relatives rendering them less able to access family, social support and treatment for their children timeously. Depression, in turn, inhibits caregivers' capacity to adequately care for their HIV-positive children. These qualitative findings corroborate findings from other studies that show how caregiver depression, stress, and anxiety makes caring for others more challenging (Ingram & Hutchinson, 2000).

Factors associated with poor neurocognitive and socioemotional functioning among HIV-positive children

Based on the multiple regression analysis, with several independent variables, only the caregiver depression variable accounted for a significant proportion of variance in the HIV-positive children's psychological functioning. Nevertheless, correlational analyses of the predictor variables (*i.e.* socioeconomic status [SES], nutritional status [NS], caregiver depression [CD], and home environment [HE]) indicated a relationship between the dependent variables of neurocognitive and socioemotional function, which are considered clinically meaningful and important.

In this doctoral study the global neurocognitive function of HIV-infected child was significantly positively associated with the predictor variable of nutritional status measured using anthropometric measures of stunting, wasting and underweight (p<0.05) independent from the caregivers' relationship to their HIV-positive children (biological and non-biological). This finding supports existing evidence that nutritional risk factors play a pivotal role in neurodevelopmental outcomes (Cirulli, Laviola, &Ricceri, 2009). This is an important finding, as it adds to the existing literature relating to those factors associated with global neurocognitive developmental outcomes in HIV-infected children. To my knowledge no

study exists in the South African context that explored the association between nutritional status and HIV in children, in relation to their neurocognitive outcomes. While Smith et al. (2008) conducted a study among black South African children infected with HIV in Cape Town; it did not explore the association between the neurocognitive outcomes and nutritional status of the HIV-infected children who participated in the study. Nevertheless, they observed that about 80% of the children were stunted, while more than 60% were underweight and presented with neurological and subnormal neurocognitive development.

On the other hand global neurocognitive functioning was associated with both nutrition status measured using anthropometric measures of stunting, wasting and underweight and the psychological functioning of the HIV positive child, respectively. This association was dependent on the age of the caregivers. HIV-positive children raised by an older caregiver were strongly associated with poor subnormal global neurocognitive functions, underweight, and insufficient stimulation tools (*i.e.* reading books, word-orientated games and scrabbles) in the home for quality stimulation to take place. On the other hand, HIV-positive children raised by younger caregivers' global neurocognitive functioning were strongly associated with the psychological development of the child. This suggests that a child who was raised by a younger caregiver who displayed global neurocognitive deficits were also more likely to be psychologically not well adjusted. These results perhaps are linked to the greater severity of depression observed in biological caregivers that could have impaired on the quality of interaction between the caregiver and child, and also cause caregivers not to be responsive to the nutritional needs of their HIV-positive children sufficiently. This may in turn leave them vulnerable to poor stimulation, malnutrition and emotional difficulty (Murphy et al., 2013).

A study conducted in Harare, Zimbabawe found under-nutrition to be associated with suboptimal cognitive functioning among 306 school aged children infected and affected by HIV compared to unexposed uninfected counterparts, although the difference was not statistically significant (Kandawasvika et al., 2014). The children were more or less equally affected by poverty, which is argued to be an independent factor impacting negatively on neurocognitive developmental outcomes in children from resource-constraint communities that have been experiencing deteriorating economic problems, such as Zimbabwe (Kandawasvika et al., 2014).

While the absence of sufficient comparative studies on HIV+ children limits the ability to conclusively comment on the impact stunting and other indicators of poor nutritional status has on the neurocognitive outcomes of HIV-positive children, associations between neurocognitive development and nutritional status has been found in the general population of children, both internationally (Grantham-McGregor et al., 1991) and in Africa (Bourn et al., 2007). Furthermore, under-nutrition has consistently been shown to result in high infant mortality and childhood diseases, such as diarrhoea and lower respiratory tract infections that are associated with poverty and co-exists with HIV/AIDS (Bourn et al., 2007). Poor nutrition has also been shown to have a negative effect on children's mental and motor development (Grantham-McGregor et al., 1991). Several studies have revealed that stunted children are more likely to have poor developmental attainment, poor scholastic achievement, and lower intelligence levels than children who display no growth retardation (Powell & Grantham-McGregor, 1985; Grantham-McGregor et al., 2007; Walker et al., 2007). In a sample of children from a resource limited community in Jamaica, Grantham-McGregor found that growth-retardation (stunting) was associated with poor mental, cognitive, and motor development (1991). Similar findings were observed in two poor communities in Kingston,

Jamaica among a sample (*N*=309) of children under the age of four years. Additionally, in a review of studies conducted among children in developing countries, Grantham-McGregor and colleagues estimated that more than 200 million children under the age of five years fail to attain adequate neurocognitive development as a result of poor nutritional status (2007).

Furthermore, some studies have even suggested that the effects of stunting in infancy can have far-reaching adverse effects on neurocognitive development into late childhood (Berkmam, Lescano, Gilman, et al., 2002). Berkmam and colleagues conducted a study on Peruvian children and found 32% (46/143) to be severely stunted at zero to two years of age. A follow-up study (using the Wechsler intelligence scale for children-revised [WISC-R]) found that at nine years old, 32% of the children evidenced lower cognitive functionality compared to children who were not stunted during infancy. The researchers concluded that stunting in infancy is significantly associated with subnormal cognitive development in later childhood (Berkmam et al., 2002). The findings from the abovementioned studies echo the importance of the results from this doctoral study (both qualitative and quantitative) of HIV-infected children, in that it demonstrates the heightened vulnerability of children as a direct result of both their illness and the squalid conditions in which they live. These results perhaps speak to the nature of caregiving (see the chapter discussing the qualitative findings of this doctoral study) and the strain involved in bearing this responsibility, which often occurs in co-morbid poverty conditions, as was indicated by the eighty-eight percent of caregivers who were relying on social government grants in this study.

Processing speed (psychomotor development indicator and information processing) was significantly negatively associated with being underweight among the sample of HIV-positive children in this doctoral study. It has been argued by others that processing speed

could be seen as a measure of executive function and is known to be compromised in children infected with HIV (Koekkoek, de Sonneville, Wolfs, et al., 2008). Moreover, children with HIV have been found to be less accurate and slow on tasks that typically demand executive functioning skills, such as speed, manipulation, and monitoring working memory content (Koekkoek et al., 2008). This is supported by the results from this doctoral study. Additionally, it has been argued that psychomotor development is a severely affected domain of neurocognitive development in children infected with HIV (Abubakar, Holding, Newton, et al., 2009; Abubakar, Holding, & van Baar, 2013; Hilburn et al., 2011). Consistent with the findings in this doctoral study, Abubakar et al. (2009) found slower psychomotor development in a sample of children living with HIV (mean age 19.9 months) compared to HIV-affected children and an HIV-unexposed reference group. The research reported that low weight-for-age z-scores independently predicted poor development (Abubakar et al., 2009), while being underweight was also shown to mediate disease severity and poor psychomotor development. Similarly, a study conducted in Kilifi, Kenya, by Abubakar, Holding, van Baar and colleagues (2013) reported poor psychomotor development in a sample of 31 HIV-infected ARV naïve children, which they compared to HIV-exposed children as a reference group. These researchers found that being HIV positive, underweight, and younger than two years significantly predicted the children's inability to complete the standardised psychomotor measure used in their investigation (Abubakar et al, 2013). In contrast to the samples of both Abubakar et al. (2009) and Abubakar et al. (2013), the children in this doctoral study, while in receipt of cART, nevertheless evidenced significantly poor psychomotor development and low weight-for-age.

This doctoral finding is important as it concurs with existing literature that shows that the association between HIV and the neurodevelopmental outcomes of children are most often

also compounded by extreme poverty and poor nutritional provision (Smith & Wilkins, 2014; van Rie et al., 2009; Hilburn et al., 2011; Kapavarapu et al., 2012; Abubakar et al., 2009; Abubakar et al., 2013). The vulnerability of psychomotor deficits in HIV-positive children is one of the most prevalent universal findings and some have argued that the observed deficits in this domain could be an indication of the chronicity of the disease, or that it could be a direct expression of central nervous system involvement, especially as motor function is known to be one of the domains adversely affected during the early stages of HIV infection in children (Baillieu & Potterton, 2008; Hilburn et al., 2011). Moreover, some studies have shown that deficits are already noticeable in infants infected with HIV as early as three months (Blanchette et al., 2001), while others have proven that brain development may be most sensitive to the effects of nutrition in the first twenty-four months of life (Walker, Chang, Vera-Hernández, et al., 2011). Even so, the findings of this study are important as it demonstrates the complex relationship between HIV, nutritional status, and neurodevelopment in children. Similar results have also been reported in study samples of uninfected children, but who were also living in poor resource settings where the effects of reduced nutritional status were associated with poor motor- and overall subnormal cognitive function (Walker et al., 2011).

Contrary to previous studies, global neurocognitive functioning was, however, not significantly associated with the home environment for HIV-positive children in this study. However, a significant negative association of the home environment with the sub-neurocognitive domain of verbal functioning was found. For children raised by younger caregivers the association was more negative. The results suggest that children who had access to physical stimulation, through play or by having a toy, may have had their verbal development positively impacted, while the opposite applies for children who did not have

access to stimulating resources. A lack of language stimulation owing to the limited availability of reading material in the home environment may negatively impact on the subdomain of verbal development in HIV-positive children. This finding is in keeping with studies conducted among children with low birth-weight and traumatic brain injury, which demonstrated that environmental variables, such as play, learning material, and parental involvement in language stimulation, have a mediating effect on cognitive and intellectual outcomes (Bradley et al., 1993; Button, Pianta, & Marvin, 2001; Yeates et al., 1997). Results from the qualitative aspect of this doctoral study suggests, however, that some caregivers who participated in caring for an HIV-ill child, were motivated to be actively involved in their HIV-positive children's lives by providing them with vital stimulation and support, while others found this decidedly challenging. Although the home environment variable did not demonstrate a relationship with global neurocognitive function, the study suggests that certain characteristics of the home are important to the development of the cognitive verbal domain. These findings underscore the importance of home environment as the most proximal space for the child's development, as informed by both the social ecological and attachment theoretical models. Characteristics in the home environment can significantly compromise neurocognitive development, and may include the direct effect of having a chronically-ill mother, which in turn directly affects the quality of attachment and caregiving, thus placing an emotional burden on the child and caregiver. Similarly, Hewage et al. (2011) found that HIV-unexposed children of migrant mothers displayed poorer executive functioning with regards to working memory, as well as higher externalising and internalising behaviours when compared to peers from similar backgrounds, but whose mothers were living in the same country. Consequently, home environmental risk factors, especially the physical and emotional unavailability of a significant attachment figure, were distinctly associated with the observed deficits (Hewage et al., 2011).

Similar to the findings of this doctoral study, a longitudinal study conducted by Clark (2005) among African American children living with HIV found that familial or home variables did not predict global neurocognitive function, as it accounted for less than one percent of variance in global cognitive function of HIV-positive children over time. Furthermore, research on HIV/AIDS continues to provide evidence that HIV-infected children and/or exposed children remain vulnerable, as many of them are also raised in poverty which creates its own challenges, apart from the HIV pandemic. As seen in this doctoral study many of the children were often raised by a non-biological caregiver, usually single individual with financial challenges. The family structures of these children are also often disrupted and as a result their immediate environment lacks sufficient human and structural resources, thus failing to meet their basic needs. Additionally, these types of social contexts usually lack appropriate stimulation, which has been proven to have adverse outcomes on neurocognitive functioning (van Rie et al., 2009).

However, the lack of home environment association on the global neurocognitive functioning of this doctoral sample of HIV-positive children stands in contrast to what was found by Coscia et al. (2001) and Kullgren et al. (2004). They determined that aspects of home environment were significantly associated with cognitive function, which could be ascribed to the variable difference between the current study and that of Coscia and Kullgren. Both studies employed measures that are different from this doctoral study, with Coscia et al. (2001), for example, using the paper and pencil option of the home environment measure, and Kullgren et al. (2004) using the ratio of children to adults in the home. There was also a concern that the caregivers in this doctoral study may not have fully understood certain questions in the HSQ, despite efforts made to provide clarification (see procedure section). Notably, Coscia et al. (2001) in their study found that aspects associated with cognitive

stimulation, parental involvement, and environmental structures are predictive of a child's neurocognitive function. Thus, the effects of home environment on the global neurocognitive functioning of the child were amplified in the context of severe stages of the disease (Coscia et al., 2001).

Notably, a relationship between the predictor variables home environment and nutritional status was observed in this doctoral study, with the former being significantly correlated with the latter. The results suggest that children raised by non-biological caregivers showed greater growth failure and poor weight-for-age than children raised by biological caregivers. Moreover, HIV-positive children in this doctoral study who evidence growth failure and were underweight, were also strongly correlated with living in overcrowded homes. Developmental psychologist Gary Evans (2006) conducted a study examining the effects of the physical environment on a child's development. He reported that a significant relationship existed between the physical environment and the child's well-being and development, and argued that the physical environment profoundly impacted on the children's developmental outcomes, including academic achievement, cognitive functioning, and socioemotional functioning (Evans, 2006). Overcrowding in itself has been associated with poverty and has been shown to detrimentally impact on the developmental outcomes of children (Evans, 2004; 2006). This doctoral study shows that density or number of people per room, as a measure of overcrowding (as was the case in this study), is a pertinent variable in measuring the effects of overcrowding on child development (Evans, 2006). These adverse effects are noticeable in the exosystemic space of the child's social ecology. For example, effects in early childhood or in children of pre-school age include failure to achieve age-appropriate developmental milestones, an inability to engage in constructive, age appropriate play, proneness to distraction, and emotional withdrawal as a result of growing up in an

unfavourable environment, while also being at higher risk of exposure to poor nutritional provision (Evans, 2006).

The results of this doctoral study in relation to HIV-positive children living in constrained environments are consistent with findings from other studies involving low-income children. A study conducted by Elizabeth & Sathy (1997) found a significant relationship between environment and anthropometric scores, as well as anthropometric and intellectual functioning in a sample (N=100) of moderately to severely malnourished, uninfected children aged six to 24 months. Similarly, a study conducted in Jamaica found an association between residing in a deprived home environment, malnourishment, and subnormal intelligence in children (Baker-Henningham1, Powell, Walker and Grantham-McGregor, 2003). Moreover, Brewster (2006) suggests that poor growth and nutrition during early infancy in HIV-positive children is associated with compromised environmental health, particularly with regards to hygiene and overcrowding. What is also important is to understand the context of these results with specific attention being paid to the structure of these children's home and family systems. The majority of these children are raised by non-biological caregivers (mostly grandparents), a phenomenon that has become all too well associated with the pandemic (Linsk & Mason, 2004). Parental absence or incapacity due to HIV-illness or death has taken away the safety net these children rely on, thus leading to the majority of them growing up vulnerably. These are all risk factors that contribute to weakened social ecological systems and poor attachment relationships, thus rendering the children vulnerable to poor developmental outcomes. Elderly grandparents, who are single heads of the household, often assume financial responsibility for the entire family on a single social grant, and research has shown that they are at risk of psychological and physical health problems, which adversely impacts on their caregiving capacity (Linsk & Mason, 2004). These are all factors that strain

an already vulnerable caregiver-child relationship (Evans, 2006), and was found to adversely affect the children's developmental outcomes.

In addition to finding an association between the predictor variable of caregiver's depressive symptoms, and the outcome variable HIV positive children's psychological symptoms (p<0.01), the findings showed that depression in caregivers accounted for a significant proportion of variance in the psychological and emotional outcomes of the HIV-positive children in this doctoral study. This is in keeping with literature in the field of neuroscience and bio-behavioural science, which suggests that psychosocial variables (e.g. a disruptive mother-child bond) play an important role in the shaping of brain functioning and causes vulnerability to psychopathology (Cirulli et al., 2009). Some studies suggest that children living with HIV are exhibiting high levels of psychological problems, while others have taken it further to highlight the association between caregiver depression and child psychological problems (Wiener, Battles, & Riekert, 1999; Tompkins & Wyatt, 2008; Biggar & Forehand, 1998). In this doctoral study, children's psychological functioning was strongly associated with their caregiver's depressive symptoms, in that, higher depressive symptoms in caregivers corresponded with higher levels of psychological difficulties in the HIV-positive children. Therefore, the results imply that an HIV-positive child's psychological and emotional adjustment in this doctoral study may have been affected by their caregiver's level of distress. Furthermore, while caregiver depression was strongly related with internalised and externalised symptoms in this sample of HIV positive children in this study (based on high levels conduct, hyperactivity, and peer related difficulties as measured on the Strengths and Difficulties Questionnaire [SDQ]), caregiver depression was found more significantly associated with child depression. This is an important finding given the link between executive dysfunction and psychopathology in children, especially when keeping in mind that

the sample of HIV+ children presented with subnormal neurocognitive functioning (Hewage et al., 2011).

Significantly, it emerged that the HIV-infected children in this doctoral study were more or less equally affected from a psychological perspective by their caregiver's depression, irrespective of whether the biological caregiver displayed higher levels of depressive symptoms compared to non-biological caregivers. The importance of this finding is that it suggests a child who is raised by a depressed caregiver, irrespective of the caregiver's relationship to the child, will nevertheless adversely be affected, thus highlighting the importance of context in the emotional development of children. The HIV positive child's psychological functioning cannot be removed from their ecological context, especially given the possibility HIV already exists in that context. Research has consistently demonstrated the extent to which a child's functioning and quality of life is dependent on, or a function of the proximal experiences within the family context (e.g. mother-child relationships) (Bronfenbrenner, 2005; Dutra et al., 2000). Equally, this dynamic has been identified in HIV research where children living with HIV may directly or indirectly be differentially affected by family relationships, most often with the primary caregiver being the biological mother who is infected with HIV (Sipsma et al., 2013; Murphy et al., 2002a). To date there are a number of research findings demonstrating how caregivers of children infected with HIV are exhibiting mental health problems ranging from levels of distress and anxiety to depression, which is similar to that of caregivers of children with other chronic illnesses (Mellins, Ehrhardt, Rapkin, & Havens, 2000; Havens, 1996, 1997; Murphy et al., 2002a). However, the bulk of these findings are based on research conducted in developed countries and most often on impoverished African American and Latina women (Mellins et al., 2000). Moreover, findings of high rates of substance abuse have also been associated with HIV+ infection

among these women (Elkington et al., 2010), and are therefore not directly comparable to the South African context. Some research even suggest that the prevalence of depression among HIV+ women from low and middle income countries might even be higher when compared to HIV+ women from developed countries (Bennett et al., 2015). Nevertheless, the researcher found some consistencies in the literature which alludes to caregivers of children with HIV exhibiting high levels of mental health related problems, such as stress, anxiety, and depression (Murphy et al., 2002a).   Some of these findings suggest that caregiver depression is a result of their own HIV illness (in the case of biological mothers), that of the child (in case of vertical transmissions), or both (Fawzi et al., 2010). In addition, it would also be important, in our understanding the association between caregiver depression and PHIV+ children; to consider the role of genetics as a possible risk factor associated with mental health problems (Mellins et al. 2009; Malee et al., 2011). Research has shown that HIV directly insults the central nervous system, affecting the neurocognitive development and mood regulation adversely (Hewage et al., 2011). PHIV+ children are also vulnerable prenatally to parental immune dysregulation and possible exposure to ARV's, which can have adverse outcome on the developing foetus. Furthermore, negative effects of exposure to substance use problems such as alcohol and illicit drugs; and sexually transmitted diseases are also contributory risk factors for additional negative effects on the developing brain of unborn child (Mallee et al., 2011). HIV+ children, who have brain effects or psychosocial effects of living with HIV, are also more likely postnatally to be confronted with the effects of possible suboptimal ARV treatment, abnormal immune function, neurotoxic effects of ongoing HIV replication and ARV drugs (Mellins & Wilkins, 2015). It goes without saying that genetics has an important role to play in understanding depression in PHIV+ children, but to be able to delineate its direct effects remains a problem, especially with HIV; where both environmental and biological factors have an influence. It is particularly difficult with

PHIV+ children to unpack the association, knowing that HIV directly insults the child's developing brain, rendering them vulnerable to possible neurotoxic effects of ARV, with the majority of them, being from resource- poor settings, also being exposed to ongoing psychosocial risk factors; such as poverty and nutritional deprivation, *etc*. (Ivers et al., 2009; Mellins, et al., 2009).

Studies that investigated the mental health of HIV-positive caregivers of non-infected children seem to suggest that HIV-positive caregivers, when compared to HIV-negative caregivers, demonstrate higher depressive symptomatology and other related mental health problems, such as guilt, blame, stress, and anxiety (Biggar & Forehand, 1998), which has a negative impact on the socioemotional functioning of their children. Tompkins and Wyatt found that children whose mothers were seropositive reported more externalising problems than children whose mothers were not infected with HIV (2008). Other studies (Sipsma et al., 2013; Fawzi et al., 2010) demonstrate that uninfected children of HIV positive mothers with depression found to display high levels of child and adolescent depression.

These emerging results are noteworthy, given that mothers (biological or non-biological) as primary caregivers play an important role in the management of HIV in the child. The presence of depressive symptoms may impair a mother's ability to adhere to treatment and prevent her from making appropriate decisions about seeking healthcare, which could in turn have a negative impact on the child's HIV illness (Murphy et al., 2002a). Evidence supporting this emerged from the qualitative findings of this doctoral study. Caregiver depression may increase the burden of caring for oneself and one's ill child (Ingram & Hutchinson, 2000). Research exploring the care of HIV positive children showed that mothers attribute their inability to adequately care for their children to their own physical and

emotional health, as a consequence of their HIV illness (Ingram & Hutchinson, 2000). The struggle of these caregivers to match social norms and values and be the 'perfect mother', while confronting feelings of guilt, blame, and shame can be extremely burdensome, especially in the presence of a ravaging illness such as HIV/AIDS. Clearly the interconnectedness of the HIV illness and the depression of caregivers complicate the experience of caregiving (Nelms, 2005). Thus, maternal depressive symptoms among caregivers of children with HIV are important factors to consider when discussing the management of HIV at-risk children, as reinforced through both the quantitative and qualitative findings of this doctoral research. These results suggest the need for psychological care of HIV-positive children and their families.

There are, however some studies that have found no significant variances in matched uninfected child samples exposed and non-exposed to HIV (Tompkins & Wyatt, 2008; Biggar & Forehand, 1998; Wiener, Battles, & Riekert, 1999; Fawzi et al., 2010; New, Lee, & Elliot, 2007). These findings have been attributed to caregivers, as a result of worsening of their own illness, side effects and emotional distress; being less involved in the children's day-to-day supervision and care and as a result less aware of what psychosocial difficulties their children experiences (Tompkins & Wyatt, 2008). This may result in an under-, or even overestimate of psychosocial difficulties in their children (New et al., 2007). Wiener et al. (2009) suggest that mothers' associated guilt and self-blame for their child's infection may also bring about denial regarding the child's worsening behaviour and illness (Wiener et al., 2009).

This doctoral study corroborates findings from other research that a lack of accurate information frustrates an already compromised caregiving experience in the context of HIV

(Ingram & Hutchinson, 2000). The qualitative findings of this study highlighted the need to supply caregivers with accurate information on HIV transmission, symptoms manifestations, and treatment availability. In keeping with the findings of this study, previous studies have identified that many caregivers struggle with anxiety, which is associated with having insufficient knowledge of the physical manifestation of the HIV disease (Ingram & Hutchinson, 2000). For example, from the qualitative findings it emerged that not having accurate knowledge was the source of much inherent conflict in caregivers regarding their caregiving experiences. HIV was mistaken for AIDS and was consequently associated with imminent death. Psychosocially these individuals felt inadequate as caregivers, unless they were hypervigilant caregivers. They also worried about leaving their children at home in the care of others, as this could lead to symptoms not being detected, which in turn has the potential of harming the children. Caregivers deemed caring for HIV-positive children taxing in other ways, as caring for their HIV-positive child impacted on their capacity to appropriately care for other children and relatives. Having accurate knowledge about HIV was reported in this doctoral study to be helpful to caregivers, allowing them to feel less anxious and assisting them in making more appropriate decisions that benefited their entire family.

The qualitative findings of this doctoral study also highlighted the coping styles utilised by the caregivers of HIV-positive children. The extent to which caregivers were able to cope with their roles as caregivers of HIV-positive children was influenced by various meso-and exosystemic variables. The degree of social support from family and friends emerged as one of the sources of support for these caregivers. Many women who took part in the study found that disclosing was not always followed by rejection, and provided them the opportunity to receive support. This finding is supported by findings from previous qualitative studies

(Nelms, 2005). Likewise, the diagnoses of a child allowed some women to re-negotiate their sense of purpose and destiny and they were able to find inspiration in the form of hope. This had the potential to positively impact their lives, as it strengthened the caregiver-child microsystem and kept caregivers determined to live, as reflected in this quote of one of the caregivers: *"there is no way he [the HIV+ child] won't make it…the thing that keeps me going is the fact that I want to see him when he is grown up…"*. Importantly, these qualitative findings also reflect the astonishing selflessness and dedication to the children shown by most of the caregivers.

Similarly, religious beliefs, such as believing in God, and support from health staff assisted most women in this doctoral study to cope and accept their fate, thus enabling them to make constructive decisions around the well-being of their HIV-positive child (Nelms, 2005). However, a number of caregivers in this study reported that fear of rejection and discrimination kept them in a web of secrecy, and led to them to concealing the HIV status of their child (Tomkins et al., 1999).This in turn compromises their capacity to receive social support which was reported by respondents as helping them cope with caring for their HIV-positive child and highlights the potential role of stigma in mediating caregiving coping and child outcomes.

Further research is required to explore the various coping strategies associated with the psychosocial adjustment of both the caregiver and child exposed to HIV. The understanding gained from such an exploration has the potential to offer appropriate empirical backing for interventions to promote psychosocial adjustment of caregivers and children affected by and infected with HIV.

Summary of overall findings

Based on the overall results of this doctoral study, intrapersonal, interpersonal, structural, and society/community factors have been found to negatively associate with the neurodevelopmental outcomes of PHIV-infected child. At the interpersonal level, PHIV+ children display neurocognitive and socioemotional problems, despite being on cART. This perhaps illustrates the complex relationship between HIV and its effects on the central nervous system (CNS) (Joska et al., 2012; Ravindran, Rani, & Priya, 2014). HIV clearly has an effect on the CNS, but is generally thought to be lowered with viral suppression (Smith & Wilkins, 2015). However, studies in adults shows that even when there is an undetectable viral load in the blood, it can be found in the brain (Marra et al., 2009). In fact Marra et al. found that ARVs with high CNS penetration were still associated with poor neurocognitive performance in HIV+ adults (2009). Further, studies on infants and young children have demonstrated that early initiation of treatment with virologic suppression has a positive effect on the neurodevelopmental outcomes of HIV+ children (Crowell et al., 2015; Wood et al., 2009; Smith & Wilkins, 2014). No treatment to date has been found to be restorative although it can prevent a worsening of function (Ruel et al., 2012). This speaks to the reason why it is important to get children identified and treated as soon as possible. Unfortunately, a limitation of this study was that time of cART initiation was not obtained, so it was not possible to establish an association between poor neurocognitive functioning and delayed cART initiation. While universal roll-out of cART for HIV+ children came into effect around 2004 in South Africa, consistent access to treatment has not been uniform across the country.

This doctoral study, however, was able to demonstrate that the cohort of HIV+ children displayed psychological mal-adjustment. Apart from stimulation, the results also highlight the importance of adequate nutritional provision for HIV-positive children in order to not

only benefit their global neurocognitive development, but also their sub-neurocognitive domains. The importance of stimulation through medium of play and the proximal interaction between caregiver and child was also reinforced through these findings as an important aspect of child neurodevelopmental outcome and, more specifically, its association with neurocognitive development. This finding adds significant value to the body of literature, especially as some have argued about the sensitivity of biological factors versus environmental/contextual factors. Drawing on existing literature also provide consistent support of the relationship between executive dysfunction (the cognitive processes involved that allow for day-to-day decision making and behavioural action), and its association with compromised neurocognitive functioning and psychological functioning in children (Ravindran et al., 2014; Smith & Wilkins, 2015); and as such, this finding has major implications for interventions for both children and their caregivers.

The role of psychosocial factors and its association with the HIV-positive child's outcome has also been demonstrated. At an interpersonal level, within the caregiver-child proximal space, a relationship between caregiver's emotional state and the socio-emotional outcomes of their HIV+ children was demonstrated. Both qualitative and quantitative findings indicated that caregivers who had emotional difficulties (i.e. depression) also had children who are negatively affected psychologically. Doubt about the effectiveness of their mothering paired with the immediate reality of being single parents, was found to promote psychological stress in caregivers in the qualitative component of this doctoral study.

At societal level, high rates of poverty were associated with the living environments of HIV-positive children. At structural level gendered relationships remained a reality as the women remained solely responsible for the children, thus leading to a triple burden of caregiving. At

a distal level, this doctoral study demonstrated that insufficient resources remain a reality for these families as it perpetuates a negative social context for developmental outcome in children and parental coping. Caregivers often had to travel long distances to visit appropriate health facilities for monthly follow-ups, which posed a major problem as a result of financial constraints. Most of the families relied on government assistance in the form of disability or child support grants.

Interestingly, this doctoral study also brought to the fore a need to understand the contextual impact of stigma and disclosure. Within the larger socioecological system, the qualitative findings reinforce that family dynamics play an important role in determining whether biological caregivers would disclose their own or their children's HIV status (Murphy et al., 2002; Murphy, 2008; Nelms & Zeigler, 2008), which impacted both caregiver's and child's coping ability. Social support as a positive coping strategy was limited among caregivers, which influenced the children's outcomes. Fear and stigma operated as possible barriers to disclosure, which led many women to deny themselves and their children adequate support by concealing their illness. Where the illness was disclosed to families, the families often emerged as great sources of support, with a positive response to meeting the needs of the HIV positive child. Coupled with religion and medical staff support, caregivers were able to engage in cognitive reframing and re-evaluation of their realities as positive coping strategies as has been found by other studies (Nelms, 2005; Ingram & Hutchinson, 2000). In addition, having accurate knowledge defused unwarranted worry, contributed to effective caregiving, made disclosure less complicated, and served as an impetus to seek and receive social support.

CHAPTER EIGHT

Contribution to knowledge and implications; limitations and strengths;

recommendation and future research; and conclusion

Contribution to knowledge and implications

This study provides supporting evidence that HIV positive children whilst being on cART still presents with developmental deficits, albeit that this result needs to be interpreted with caution given that the WPSSI has not been normed for use in the South African context. Furthermore, they are vulnerable to psychosocial risk factors.

The study conducted a cross-sectional investigation of the relationship between neurocognitive functioning and socioemotional development in relation to psychosocial variables within the subgroup of vertically HIV-infected pre-and-primary school age children being treated with cART, who are living in a rural and semi-rural South African context. The use of a mixed-methods research design strengthened the outcome of the results in this doctoral study.

From a theoretical stance, given that children's development is rooted within social ecology; the study highlights the importance of including psychosocial risk factors when conducting an investigation of this nature, and it deepens our understanding on the relationship of neurocognitive and psychosocial development in children living with HIV. Consequently, this doctoral study highlights the plight of children infected with and families affected by HIV. The study serves to reinforce the fact that these families have a plethora of healthcare needs that move beyond just cART.

Importantly, male participants performed worse than female participants in the domains of non-verbal development, which may imply that boys and girls are not equally affected in these domains. Despite the current evidence it must be noted that contention remains regarding gender disparity in neurocognitive development (Deary et al., 2003; Weis et al., 2003; Iachini et al., 2005). The finding is supported by some research but is in contrast to research that has found males to be more superior to girls in non-verbal neurocognitive abilities (Gneezy, Leonard, & List, 2009). Furthermore, overall the HIV-positive children's verbal and non-verbal cognitive abilities are not evenly developed. This perhaps is due to the diffuse impact of the virus, with greater insult to the prefrontal cortex an area that is associated with higher order functioning pertaining to both verbal and non-verbal cognitive development (Kolb & Whishaw, 2009; Gevins & Smith, 2000). This nevertheless has implications for the developmental trajectory of both girls and boys. Cognitive skills are the foundation for optimal development, academic and future job attainment success. Most noteworthy is that these children were all treated with cART, yet they performed at least more than 1 to 2 standard deviation below the WPPSI-III norms in their neurocognitive development. What is of concern and major importance in this sample is that the results suggest that these HIV-positive children, despite having access to treatment with stable CD-4 counts, remain worse-off neuropsychologically than other HIV-positive children from a similar background. Having said this, it is important to reiterate that the measure used on this sample was not validated for the South African context and more importantly not among isiXhosa speaking HIV+ children; for this very reason one has to interpret thesefindings with caution as it may perhaps explain the low verbal scores (predominately language based) compared to performance (not so much language based) results. The measure was developed in English and not isiXhosa and perhaps verbal IQ may not be the best indicator of IQ. The performance IQ which is not fully language based may be a more valid reflection but still

indicated that this cohort of HIV+ children performed below the average range of neurocognitive functioning; even though a different domain. It is important to note that the use of an interpreter who is a clinician who was trained in the administration of the test was used during the assessment process as a means of enhancing the credibility of the findings.

Furthermore, the results demonstrate that a large number of HIV-positive children are poorly adjusted psychologically, which may have implications for children of school-going age. Together, these findings suggest that healthcare providers and teachers/educators should expect to encounter poorer socio-emotional and neurocognitive performance in many HIV-positive children, despite the fact that they are on treatment. This, in turn, will have unavoidable implications for learning, as well as behavioural/and or emotional adjustment, daily life interaction, and decision making. Generally the consequences of this will also affect caregivers and teachers, as it presents with adaptive challenges for all parties concerned. It would be important to identify the children timeously who present with challenges, in order to provide them with appropriately targeted interventions that will positively improve all domains of neurocognitive and socioemotional development in this population of children.

Deficits in language and cognitive development have the potential of impairing interpersonal and communicating skills in a child, especially given its argued association with high-level functioning of cognitive and intellectual development (Koekkoek et al., 2008). The associated problems may flow over into the HIV-positive child's ability to apply themselves successfully in academia and adapt in social contexts where they have to engage interpersonally and often navigate daily decision making behaviour. This also has implications for adolescence and adulthood, where negotiating sexual behaviour is very much part of their developmental trajectory.

It is apparent that psychological stress is a daily phenomenon experienced by people living with HIV. Depression is the most frequently diagnosed psychological disorder and results in major cognitive and affective changes that are linked to adverse health outcomes in children and their caregivers. For the HIV-positive children this has major clinical implications. If these children are not properly diagnosed or if they are misdiagnosed and go without treatment, it will have severe negative consequences in terms of disease progression. Psychological problems also have major implications for learning and development. As this study reports, a large number of HIV-positive children experience emotional and behavioural difficulties.

Poor caregiver psychological health was also found in this study, with an association between caregiver depression and child depression noted. Caregiver depression may also impact on a child's food and nutritional security, which in turn has adverse effects on the child's neurodevelopmental outcomes. An association between indicators of poor nutrional status and neurocognitive outcomes was found by this study. The need for nutrition supplementation programmes in vulnerable children is thus highlighted.

The home environment is another factor that has major implications for children infected with HIV and their caregivers, as it has the potential to impact negatively on the caregiving environment. It appears that a child's home environment or at least aspects thereof, are important when attempting to understand the neurocognitive and socioemotional adaptive behavioural outcomes in HIV-positive children. The findings highlight the importance of incorporating home, family, and environmental variables in the investigation of children living with and families affected by HIV, which is in line with both Attachment and Bronfenbrenner's Ecological Systems theoretical models. The link between environmental

variables, such as the availability of stimulating resources with language and cognitive development suggest the importance of these factors in current and future functioning of the HIV-positive child, given the fact that language development is continual and influenced primarily by the home environment, as the child's most proximal ecological space. The need for early enrichment programmes that have been found to positively impact on the long term psychosocial and economic prospects for children is thus indicated (See Kagitcibasi, Sunar, Bekman, Baydar, & Cemalcilar, 2009).

This doctoral study also suggests that in the context of living in poverty and caring for a chronically ill child where social support can buffer some of the accompanying stressors, stigma and discrimination impedes disclosure and caregiver's help-seeking behaviour, thus impacting negatively on support opportunities for both caregivers and their children.

Limitations and strengths

<u>Quantitative limitations</u>

There are several important limitations to this doctoral study that need to be discussed. Primarily, the data are cross-sectional, correlational, and descriptive in nature, which means it precludes drawing any conclusion based on causality. For example, one major barrier is not being able to establish the chronological progression of the neurocognitive and psychological statuses in the HIV children apart from just establishing association. Also, the lack of a comparison group or baseline data for neurocognitive scores prior to cART precludes assumptions made about pre-cART neurocognitive status or the effects of cART on neurocognitive functioning of this group of HIV-positive children.

Large scale longitudinal studies, such as CASAH and IMPAACT (Mellins & Malee, 2013) in the US; Predict in Thailand (Puthanakit et al., 2012), and the Cape Town Adolescent Antiretroviral Cohort Study (CTAAC) (2012-2017 ongoing) in South Africa that is focusing on this population from an early age into adolescence are perhaps the first step towards providing rich data that may enhance our understanding of the directional relationship. This is especially important and relevant as paediatric HIV will eventually become an adolescent and young adult epidemic as more and more children gain access to early cART, as seen in the US and Europe (Smith & Wilkins, 2014).

Furthermore, although all of the children were treated with cART, their treatment history was not accounted for in this study. Having the history of when cART was started would have been helpful to determine whether early initiation did have a protective effect on neurocognitive functioning in this sample. While the study aimed to obtain a sample representative of the black African perinatally HIV-infected paediatric population, these findings should caution against generalising beyond the parameters set by the sample characteristics. It is known, for example, that compared to Western counterparts the pandemic in South Africa has a specific profile of dynamics. For example, in the US the pandemic was earlier on fuelled by blood transfusion among mostly white haemophiliacs (Salkowitz et al., 2001); and substance abuse that resulted in maternal to child transmission of HIV among low income black African American women (McNair & Prather, 2004), which was not necessarily associated with the present sample. Caution must therefore be taken against generalising the findings to these groups of children. Moreover, behaviourally-infected children or other ethnicities and geographic regions may comparably differ from the current sample owing to unique challenges and presentation.

The sample for this study was drawn from a hospital-based population who resides in the broader poverty stricken semi-rural and rural areas of the Eastern Cape, with all the participants being treated with cART in the paediatric HIV clinic. The sample was homogenous in terms of racial and socioeconomic profile. It should be noted though, that the racial profile in this study may not be representative of the whole of South Africa's paediatric HIV population, and caution should be practiced in interpreting the findings from this study given the context.

The measures used in this study also posed additional limitations due to a lack of validation in local contexts. However, the reporting measures in this study were corroborated by other sources, for example in-depth interviews with caregivers and home visit observations, which served to enhance the accuracy of the findings. Efforts were thus taken to enhance the accuracy of the measures, and it should be mentioned that these measures had been well utilised in both clinical and research contexts within Africa and therefore had appropriate psychometric properties (See Methodology section). As mentioned, norms for South African children are not currently available for the WPPSI-III. The WPPSI-III can be criticised as a measure that is not fully contextually applicable given the diverse cultural and linguistic platform of South Africa. The JSAIS was considered as an alternative to the WPPSI-III, however the developmental ceiling of school aged proved problematic. The Junior South African Individual Scale (JSAIS) was initially normed and standardized for white children who received a number of years of school age English and Afrikaans instructions (Van Rooyen, 2005). Norms were also published specifically for Coloured children between ages of 6 years old to eight years (Robinson, 1989). The JSAIS explicitly excluded Black African children with an African language as mother-tongue who are from a resource-limited background. The major limitation of the JSAIS is that it lacks appropriate norms for the

diverse contemporary South African population. It also fails to assess gross motor and personal-social development as part of the child's developmental profile, *i.e.* lacks to assess all the domains of development. The SSAIS as test of cognitive and intellectual assessment is not used in other parts of the world and thus finding from this test lacks the ability to be correlated with research done with the WPPSI-III in other parts of the world.

Test such as the WPPSI-III is an extension of the WISC that measured intelligence of children between ages of 6 years and 16 years 11 months (Wechsler, 1974). The WPPSI extends the age range of the test to 2 years 6 months at the lower end to include children of pre-school age. Wechsler has been considered the golden standard of testing and legitimized the administration of the test locally, especially in the absence of test measures that comprehensively assess aspects of development, and that is standardized for a specific age group to the exclusion of others (Cockroft & Laher, 2013). It can be argued that despite relative cultural and linguistic differences, the test can be suitable to SA children across cultural groups as it has been shown to be widely applied to other context with similar difference (*i.e.* cultural and linguistic) profile as SA. Internationally the WPPSI measure is regarded as a suitable test of neurocognitive development in children. The test is widely used locally in clinical settings not only with HIV positive children but normal healthy South African children, across all racial and linguistic groups. Given cross cultural factors and resource constrains it is difficult in a country such as South Africa to standardize and norm all tests, but this on its own does not mean that these measures are not suitable for the South African context.

Furthermore, there are only specific standardized test for specific cultural-ethnic groups to the exclusion of others. Predominately limited numbers of standardized test are available to

measure the neurodevelopment of black African non-English pre- and school age children (Cockroft & Laher, 2013). To my knowledge no research to date has used the WPPSI-III locally, perhaps as part of deliberately avoiding using what is considered *linguistic bias context specific test (i.e.* picture naming which forms part of the general language composite scale). Unfortunately no record was kept as to how many participants completed the measures in English and how many in isiXhosa. This would have contributed to valuable information on the cultural and linguistic issues relevant to the measure. Vocabulary and cultural appropriateness could be questioned here. Hence, the present research acknowledges that language and cultural differences present as a limitation, especially with respect to the individuals with typical verbal deficits. Words do not always exist in the same way in different cultures and perhaps poor performance on the verbal scales could be related to this. This potentially explains low verbal scores compared to performance. Although this may very well be the case, perhaps as suggested earlier; focusing on the performance domain of neurocognitive function may provide a more valid assessment. Secondly, as means of remediating the limitation of language, an interpreter who was trained in the administration of the measure was utilized to minimize the entrenched problem. The researcher acknowledges that there are implications to administering psychological test to participants in a non-mother tongue language as it raises serious concerns to fair testing practices. However, this limitation cannot preclude that the findings from the present study made a valuable contribution to understanding the neurocognitive function of black South African HIV+ children in the Eastern Cape. Nevertheless, this limitation highlights the need for more cross cultural appropriate measures.

With regards to measuring child and caregiver psychological functioning, data was collected through caregiver self-report measures. Children did not complete any of the measures in this

study. Furthermore, this study did not ascertain whether these children were aware of their own diagnosis or that of their caregivers. Also, caregiver distress has the potential of impacting on the outcome and style of reporting. In other words, a depressed caregiver has the potential of either under-reporting or over-reporting the symptoms of their children. Caution should therefore be taken, as discrepancies in caregiver reports have been reported in previous research studies. Concerns around under-reporting or over-estimation of symptoms may very well have occurred (New et al., 2007).

With regards to the measurement of home environment, challenges were observed that could well be interpreted as limitations. Despite the use of an interpreter and completing the measurement in an interview format/style (Refer to Methodology section), caregivers still had difficulty in fully understanding the questions, which could have influenced their responses. Furthermore, this study also did not focus on exploring the potential interaction between environmental and biomedical markers (e.g. CD-4 count, viral load, etc.), except for the fact that the children were HIV positive and on cART, which limits the conclusion to some extent in this study.

The socioeconomic status (SES) variable also presented a conceptual problem. The lack of an existing reliable variable for measuring SES in this context saw the study relying on creating a SES index, which may be a limitation due to the fact that there is no consensus available in existing literature as to what should be included to constitute a reliable SES variable.

In addition, regarding the nutritional status; anthropometric measures of wasting, stunting and underweight were used. No measure of current food security was utilised apart from just the indicators of SES and whether the sample had access to vegetable garden, and running water.

This is acknowledged as a limititation, especially given the associative poverty and the impact of food insecurity on child growth. Perhaps future research can address this gap more robustly.

Strengths

The aforementioned limitations should however be read in conjunction with the strengths of the study. The research design and sampling methodology should be acknowledged. As far as it is known, the present study is one of very few to date in South Africa (if any exist locally) with a large sample size (caregiver/child dyads of 152) that specifically focused on HIV-positive children and their caregivers rather than on HIV-affected children and HIV-infected caregivers. There are a few longitudinal studies emerging, such as the cohort in Cape Town (CTAAC) and VUKA that are investigating the impact of psychosocial intervention on PHIV+ adolescent outcomes. VUKA is one of the few psychosocial interventions being evaluated for this population locally in South Africa (Bhana et al., 2013). Moreover, the strength of the mix-methods approach employed in this doctoral study allowed for the capturing of rich data through the corroboration of findings in both the quantitative and qualitative data collection tools used.

Recommendations

The findings of this doctoral study echo the relational dynamic between psychosocial factors and neurocognitive and socioemotional functioning in HIV-positive children which are consistent with the understandings from socio-ecological theory (Bronfenbrenner, 1977, 1979) and attachment theory (Bowlby,1969). It is therefore pertinent that recommendations are made that will allow for appropriate intervention strategies to target each layer of the

child's ecological system with the potential of influencing health and wellbeing outcomes in the child (Bronfenbrenner, 1997).

Proximal level

The caregiving environment of an HIV positive child is paramount to his/her developmental outcome. It is therefore important that greater emphasis is placed on interventions for caregivers and children infected with HIV/AIDS. The study highlights the need for interventions that specifically target improving the child-caregiver relationship. At this level support groups to help caregivers cope psychologically can prove beneficial to both the caregiver's and child's mental health outcomes. Furthermore, these environments could also be used to train caregivers in appropriate parenting skills, especially with regards to the needs of children with chronic illnesses, such as HIV. This would serve to empower them which could in turn positively influence the relationship within the caregiver/child dyad.

Additionally, caregiver training on practical strategies to facilitate an enabling developmental environment for the child could help promote optimal neurocognitive and socioemotional outcome. The need of early enrichment programmes is thus indicated. Mother training (home based intervention) that teaches mothers to engage with their children in cognitive stimulating structured activities (Kagitcibasi et al., 2009) and providing them with parenting support has found support to be beneficial in the promotion of positive parent child relationships (e.g. attachment) and strengthen the caregiver's competence in caregiving, thus fostering more positive relational dynamics within the dyad (Kagitcibasi et al. 2009). Immediate post-intervention results showed that apart from improved intellectual functioning, children whose mothers received training were also emotionally well-adjusted than children whose mothers were not exposed to training; and mothers reported also to be more emotionally

attuned and responsive to their children (Kagitcibasi et al., 2009). Through corrective emotional bonding and response (emotional experience), the caregiver is able to develop more confidence in her role as caregiver to a sick child (in this case of the HIV child), while gaining understanding, in addition to improving communication and interaction with the toddler or child. This in turn could bring about positive consequences for the caregiver's and child's socio-emotional functioning in the reality of HIV/AIDS. Safeguarding a positive and secure caregiver-child attachment relationship has the potential of translating positively into various aspects of neurocognitive, social, and emotional/psychological developmental outcomes (Cooper et al., 2002). The fact that increasingly older caregivers tend to care for these children warrants such an intervention even more, as they now have to re-adjust developmentally to having to care for a child.

This is an important area of intervention, especially as the first few years of a child's life are primarily shaped and influenced by the primary caregiver who lays the foundation required for both language and emotional development which informs interpersonal relations later on in life such as at school, with peers, and which is consistent with the Social Ecological Model.

The need to promote stimulation that will enhance early childhood development is also indicated (See Kagitcibasi et al., 2009). Home-based education interventions whereby caregivers were trained to stimulate the cognitive and intellectual ability of children have found to be beneficial "throughout their developmental trajectories- childhood, adolescence and adulthood" (Kagitcibasi et al., 2009, p. 13). Investing into early childhood development has proven to not only promote school readiness, improve cognitive and intellectual abilities, and emotionally well adjusted, but in the long term, also ensured higher school attainment,

better career opportunities; as such greater economic and social return for society (Kagitcibasi et al., 2009). The need for such an intervention is foregrounded by the impoverished backgrounds of most of the children in this study. Early enrichment programmes could help to mediate the negative effects of growing up in impoverished environments as well as buffer against the effects of the virus.

Role of stakeholder at proximal level (support groups)

Lay counsellors comprising caregivers of HIV-positive children can be trained to lead support groups for fellow women, thereby building a network of support. This method has already been demonstrated effectively in South Africa among depressed caregivers in Cape Town, where lay people trained as counsellors or "mentor mothers" (Tomlinson, 2013, p. 57) went to homes to provide mothers with support (Tomlinson, 2013). A similar model of support could be initiated and adapted for caregivers of children living with HIV. Social support structures for caregivers of HIV-positive children will enable them to cope better and promote hope. This has the potential of bringing about a reduction in associated stigma and discrimination, and to encourage open discussions among people affected by HIV. Ultimately, the above could enhance the overall psychological well-being of individuals who care for children living with HIV, which could in turn benefit HIV-infected children's emotional and neurocognitive wellbeing (Tomlinson, 2013).

Community level

School based intervention

Interventions directed towards children's learning environments should supplement and enrich resources for pre-school and school-aged children. It is important for educators to be able to identify and target those children with neurocognitive challenges and

emotional/psychological adaptive difficulties that may impact negatively on their overall learning and social-interactive ability within the schooling environment. Remedial options should be available to provide a protective net for these children, which should enable them to excel both academically and within the community. At present the inability to identify these children and provide them with appropriate remedial interventions deters their chances of successfully adapting and succeeding in a mainstream schooling environment.

Additionally, educators should be able to establish a relationship with the relevant child's primary caregiver to allow for transference of advice, skills, and directions as to how best the caregiver could meet the learning needs of the child within the home environment, thus lessening the stress already carried by caregivers caring for an HIV-positive child. Children identified as having unmanageable psychosocial difficulties should also be directed for proper interventions in a timeous fashion. The child's nutritional status could be improved at school by means of prompt access to governmental support, such as adequate nutritious provisions to poorly resourced schools. While efforts have been made in this regard, such as the National Schools Nutritional Programme, the programme is said to be subject to mismanagement and budgetary constraints; yet the positive benefits for growth, school attendance, and the cognitive performance in schools in receipt of this programme are evident (du Plessis et al., 2011). For this reason special attention should be directed at young children from poorly resourced communities in addition to those living with HIV.

Hospital/clinic based intervention

The study highlights an important recommendation with regards to the current model of paediatric HIV management. While much emphasis has been placed on the physical management of the HIV disease, very little has been done when it comes to the

neuropsychological and socio-emotional adaptability of HIV-positive children. This doctoral study paints an alarming picture of the neurocognitive and psychological functioning of children suffering from HIV and suggests that neurocognitive and emotional difficulties can be expected, despite being on cART. This finding highlights the urgent need, not only for early detection and treatment of the HIV-infection in children, but also to incorporate neuropsychological/cognitive testing and psychological evaluation of these children due to the high comorbid risk of neurocognitive and psychological dysfunction. It is recommended that as part of paediatric HIV management, routine screenings of neurocognitive and psychological functions should become standard practice of HIV care in children and should take place as early as possible.

Other practices that should be incorporated as part of primary, standard care principles include the timeous referral of infected children to supportive multi-disciplinary services. This is even more important in view of the fact that, despite having access to and being on cART, asymptomatic children continues to demonstrate compromised neurocognitive functioning and psychological challenges. It is therefore strongly recommended that each unit of paediatric HIV management should have a consultant paediatric psychologist as part of their team of specialists who can address and meet the ongoing neuropsychological challenges of children and families living with HIV. This recommendation is in line with the paradigm shift and understanding that HIV is no longer a life-threatening illness, but a chronic disease with major long-term neurodevelopmental and psychological consequences. Consequently, it is paramount that existing models of managing paediatric HIV reflect this shift in understanding. Moreover, early detection of neurodevelopmental problems has the potential of bringing about early remedial educational interventions for these children which will help promote future vocational benefits as adults.

The study highlights caregiver depression as a major barrier to child psychological adjustment and cognitive development as do other studies (e.g., Nyirenda et al., 2013; Cicchetti et al., 2000). Yet in South Africa standard screening for depression amongst HIV positive caregivers at both primary and tertiary healthcare centres is still not a routine procedure, despite the associated high risk of mental illness with HIV/AIDS. Given that depression is commonly associated with the disease, as reflected in these doctoral findings, it is vital that serious consideration be given to making such a screening process standard protocol and mandatory to all HIV-positive and HIV– exposed caregivers, as it can have potential major benefits for the health system at large and the parent/child dyad. Depression can adversely impact the health of a caregiver (e.g. adherence to treatment in case of biological caregivers and that of the child's, as the child's adherence is to a large extent dependent on the caregiver), the caregiver/child relationship, as well as their health and/or help seeking behaviour and coping capacity. In tandem, appropriate mental health services need to be in place to treat psychological problems as well as provide caregivers with support for dealing with issues like medical care or symptom management of infected children to reduce the impact of caregiving stress, depression, and other mental health related issues on the caregivers.

Dissemination of proper and accurate information in the community
The dissemination of inaccurate information remains a problem and research suggests it is one of the reasons for the existing stigma and discrimination that remain prevalent in society. Future messages of HIV prevention or risk reduction should incorporate educational material about the effects of HIV and the progressive nature of the virus. Many caregivers denied themselves the opportunity to social support because of inaccurate information, and as a result they failed to disclose regularly and timeously. It is also paramount that HIV messages

in interventions should reflect that disclosure does not always result in rejection, but could also bring about acceptance. Such positive messages have the potential for sensitising people to the reality of HIV and the need for people and children infected with HIV to have social support, as shown in this doctoral study.

Cultural based interventions

Gendered relationships are still central to HIV and rooted in power dynamics where women continue to be vulnerable and subordinate to men, while still having to carry the burden of the disease and having to care for ill children by themselves due to many being rejected by their male partners. It is therefore important that interventions focus on issues related to gendered power relationships, and should target both men and women. In relation to this, the issue of caregiving should be addressed as a matter that is the responsibility of both parents. Also, the role of men in living out this responsibility should be stressed as paramount to child developmental outcomes. This could be a task driven at the community level, as well as at a structural level and remains the responsibility of government at large. For example, Sixteen Days of Activism should be an intervention plan that is consistently run throughout the year and should incorporate more messages regarding the impact of gender relations and sociocultural dynamics of HIV/AIDS.

<u>Role of different stakeholders at community level</u>*: Psychologist, Occupational/Speech Therapist, Social Workers, and NGOs*

Health specialists have a responsibility to render psychosocial and rehabilitative support services to assist families infected with and affected by HIV/AIDS. They should be involved as part of a multidisciplinary health specialist team on child developmental aspects to identify and promote awareness of the neurodevelopmental and psychosocial effects of paediatric

HIV. There is a serious need for each paediatric HIV unit to have these specialists as part of the team managing this population. Accordingly, medical treatment of the illness is one aspect of management that is separate from the long term developmental, psychological, and social implications of the disease, which arguably has a direct impact on the medical/physical prognosis of the illness. There is a need for each child's neurodevelopment and psychological state to be routinely evaluated, starting from as early as possible. This is an important area that clinicians should target in order to identify those children who are already vulnerable, at risk, and in need of rehabilitative interventions. This, in turn, could increase survival among HIV positive children and foster positive coping and adjustment, in addition to promoting adherence to treatment.

Psychologists should be actively involved in assessing, diagnosing, and managing stress and clinical depression in HIV infected and affected caregivers. The role of a paediatric clinical psychologist should be to conduct routine neuropsychological and psycho-emotional assessments of the HIV positive child to ensure positive developmental outcomes. As these findings provide evidence linking the psychological and behavioural adaptation of children and their caregivers, it is important that psychologists integrate aspects of parenting into psychotherapeutic interventions with caregivers.

Psychologists and social workers should also be actively involved in teaching stress management techniques, problem-focused coping strategies, and timeous help seeking behaviour among caregivers, which has the potential of promoting social support and positively impacting on caregiving. Parental adjustment is a key factor in child adaptation as seen in this study, and it is therefore imperative that psychologists provide ongoing parenting training and psychotherapy that will positively enhance the affected home environments.

Occupational and Speech Therapists should be able to provide rehabilitation to children with neurodevelopmental deficits, in addition to supporting caregivers through home-based programmes that will promote positive growth, development, and cognitive development. These programmes should also be adapted to pre- and school-based settings to assist the children. Social Workers, in turn, should routinely assess the home environment of infected children and conduct needs-based assessments to ensure the family affected by HIV has the necessary support. Moreover, they should also ensure that there are community-based nutritional interventions in place for the families and children confronted by HIV-related challenges.

Furthermore, Educational Psychologists have a role and responsibility to ensure that the HIV-positive child has an adequate learning environment with sufficient resources for remediation to take place. This is supplementary to their responsibility to provide training and awareness to teachers, other scholars, and caregivers on issues of HIV education. Furthermore, guidance, advice, and research should be rooted as a core responsibility amongst the specialist stakeholders. Consultancy, advocating, and keeping the government accountable is another role that should be taken up by these specialists to promote optimal developmental chances for HIV-positive children and support HIV-affected families.

Non-governmental structures (NGOs) and the community itself has the responsibility to engage in this public health issue, ensure adequate measures of prevention are implemented, and should encourage the media and television programmes to promote awareness. Public rallies such as 'AIDS day' should be used to engage the communities through public participating programmes. There is a need for adequate and accurate knowledge to curb the effects of discrimination and stigmatisation that continue to hamper the progress of

programmes directed at restricting the spread of HIV/AIDS. Moreover, the importance of social and family support should be addressed at the highest level of government in order to disentangle construed belief systems rooted in certain cultural, gender, and religious value systems. At community level this can be achieved through ongoing campaigns aimed at dismantling constructed beliefs, the inaccurate transmission of information, and engaging cultural leaders in rural areas to take charge of existing misconceptions surrounding HIV/AIDS. The training of lay individuals within the community to provide support is also an aspect worth consideration. Local evidence attests to the benefits of training lay peri-urban women to provide support and guidance, promote sensitive and responsive parenting, as well as foster secure attachments that would result in reduced maternal depression (Cooper et al., 2009; Cooper et al., 2002). Such an intervention has the potential to promote community support, in addition to being sustainable, readily accessible, and cost effective to communities with limited socioeconomic resources (Cooper et al., 2009). Internationally, home-based visiting programmes promoting infant development and nurturing home environments combined with medical, educational, and family services have proven successful (Black et al., 1995; 2007).

Structural level

The high levels of poverty associated with HIV adversely affect the developmental outcomes of a child, as it increases caregiver stress and depression. This in turn results in inadequate child stimulation at home, thus compromising the child's neurocognitive development (Kandawasvika et al., 2014). Supportive structures for caregivers with depression (in this case mostly older caregivers) are not readily available, hence the high levels of observed depression among HIV-affected caregivers (most of whom are grandmothers). A couple of studies have already provided evidence as to how psycho-socioeconomic support has the

potential to protect older caregivers from common mental health disorders, such as depression and anxiety, while also being able to promote social well-being in the context of HIV (Schatz & Gilbert, 2012; Plagerson, Patel, et al., 2010). Therefore, it is recommended that the government should look into welfare support for these caregivers, especially those who have yet to reach old age or are only relying on a child support grant (estimated R240 currently).   These families are in need of welfare support to continue looking after the children who often have complex medical needs, require regular hospital visits, and present with unexpected emergencies associated with the HIV illness.   The benefits of social grants acting as psycho-socioeconomic support mechanisms within a household have been demonstrated, and proved to have the potential of significantly impacting on the well-being of a household, in addition to improving the growth and learning outcomes of infected children (Richter & Desmond, 2008). Government has a responsibility to ensure that relevant policy frameworks are in place to promote the relevant social welfare interventions suggested above. Appropriate social welfare policies should be in place that will allow families to enjoy financial support in the form of social assistance (e.g. universal social/poverty grant), especially given the reality that most caregivers are elderly women who are unemployable and have limited financial security. Furthermore, existing nutritional programmes should be improved and appropriately implemented to support people living in poverty, and especially those vulnerable to HIV at school and community levels.

Additionally, health policies should reflect the current understanding of HIV as a chronic rather than a deadly disease, yet still acknowledge its negative developmental, psychological, social, and learning implications. The Department of Health should reflect this shift at policy level, by ensuring that health facilities are adequately resourced with human capital and infrastructure in order to meet the chronic care needs of this population. Care of HIV-positive

children should be provided by a multi-disciplinary specialist team consisting of a medical doctor, paediatric psychologist, occupational/speech therapist, and a clinical social worker with knowledge of managing HIV in children and families.

Future research

The results from the present study suggest the need for a plethora of further research studies. The following recommendations are made:

1. Extend these findings to a broader scale with a larger sample size, thus ensuring sufficient power to further elucidate the predictive nature of psychosocial factors on neurocognitive and social functioning in HIV-positive children.

2. The use of a control/comparison group design (infected, affected, control) matched on age and socioeconomic status also has the potential of further elucidating the impact of environmental factors on children's neurocognitive and psychological outcomes.

3. Moreover, the present study did not explicitly collect data on school performance and additional research is necessary to explicitly explore how neurocognitive, adaptive, and socio-behavioural performances translate into scholastic performance in children infected with HIV.

4. Likewise, there is a need for strategies and interventions to be developed that could bring about improvements in neurocognitive functioning, socioemotional functioning, and scholastic performance in children living with HIV.

5. The study highlights the significant relationship between caregiver depression and the PHIV+ child's psychological functioning, and future research should seek to evaluate interventions designed to treat caregiver depression as well as promote appropriate skills to foster sensitive, responsive parenting styles as well as evaluate the long term cognitive and emotional developmental trajectories of these interventions.

6. With increased survival being dependent on adherence to medication, it is important for future research to look at how survival rates are affected/varies as a component of neurocognitive functioning and psychological adjustment in children and adolescents living with HIV.

7. Future research to develop and evaluate interventions to address stigma and discrimination that result in poor social support and inaccurate knowledge regarding the disease is indicated.

8. Future research could also explore in greater detail the impact of social isolation and lack of social support on psychological adjustment of HIV positive children and adolescents.

9. Furthermore, the present study relied mainly on caregiver reports and as a result none of the children completed any self-report measures. Future research should incorporate self-reported measures that are age appropriate to determine the level of distress that an HIV-positive child experiences as compared to what is reflected in the caregiver reports.

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Appendix 1

Ethical Clearance documents

28 November 2014

Mr A Lentoor
c/o Prof I Petersen
Discipline of Psychology
School of Applied Human Sciences
Howard College
UKZN

Dear Mr Lentoor

BREC APPROVAL: PROTOCOL: Selective psycho-social determinants of poor neurocognitive and socio-emotional development in children perinatally infected with HIV in South Africa BREC REF: BE252/11.

Your application to the UKZN SSHREC dated December 2011 refers.

SSHREC has referred the application to UKZN BREC for decision.

In view of the misleading information given in the approval letter from the former Faculty of Humanities, Development and Social Sciences emailed to you on 12th December 2011, a BREC subcommittee has agreed that you proceeded to collect this data in good faith, even though a further letter from the "University Research Committee" should also have been awaited – (although no such committee existed at the time).

Kindly note that it would have been prudent for you and your supervisor to inquire after such a letter before proceeding with the study.

Site permissions are noted.

BREC therefore approves this study effective from January 1st 2012.

Kindly furnish BREC with a report on the status of the study (sample enrolled, any adverse events) as soon as possible, citing this BREC reference number BE252/11.

Yours sincerely

Professor D R Wassenaar
Chair: Biomedical Research Ethics Committee

Biomedical Research Ethics Committee
Professor D R Wassenaar (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 2486 Facsimile: +27 (0) 31 260 4609 Email: brec@ukzn.ac.za
Website: http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx
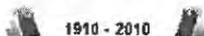
1910 - 2010
100 YEARS OF ACADEMIC EXCELLENCE
Founding Campuses   ■ Edgewood   ■ Howard College   ■ Medical School   ■ Pietermaritzburg   ■ Westville

Ethics Committee: E. L HOSPITAL COMPLEX

Postal Address :
C/o East London Health Resource Centre
PO Box 12882
Amalinda
5252
Telephone : 043 – 709 2032

Physical Address :
Cheltenham Road
East London
5201 South Africa

Fax no.:   043 – 7092386

30th January 2012

Antonio G Lentoor
East London Hospital Complex
Amalinda
East London
5200

Dear

RE: Selective psycho-social determinants of poor neurocognitive and socio-emotional development in children perinatally infected with HIV in South Afirca

We acknowledge receipt of the above mentioned proposal.

Having gone through your proposal, the committee has no ethical problems noted.

Please be advised that the committee has granted you the consent to do the research.

Yours sincerely

Dr P Alexander – Chairman Region C Ethics Committee
Ophthalmologist EL Hospital Complex

Reference: Dr. H Uys Tel: 027 43-708 2324 Fax: 027 43-7611158		CECILIA MAKIWANE HOSPITAL P.O. Box 9047 East London 5200

Mr A Lentoor

Psychology Department

East London Mental Health Unit

RE: Proposed research.

Dear Mr Lentoor

I have no objection to your proposed research and hereby grant you permission
to go ahead with your research once approval has been obtained from the
relevant committees as well as the institution.

Dr H Uys

HOD

06/03/12

EAST LONDON MENTAL HEALTH UNIT
CECILIA MAKIWANE HOSPITAL

Reference:

Enquiries : Mrs Maneli
Telephone: 043–7082526
Fax   : 043 - 7611158

Psychological Service
Private Bag X 13003,
Cambridge
5207

Mr A. Lentoor
Psychology Department
E.L Mental Health Unit

Dear Antonio

Re: Research Application

I have pleasure in granting you a go ahead with the research work as per request.

Good luck

Mrs N. Maneli (HOD/Snr Clinical Psychologist)
09/03/12

To: The Chairman – Dr Alexander

RE: **REQUESTING INSTITUTIONAL ETHICAL REVIEW**

My name is Antonio G. Lentoor, I am a Doctorate student at the University of KwaZulu-Natal, and School of Psychology preparing to conduct a research study as part of my Doctorate degree. I am a practicing Clinical Psychologist within the Mental Health Unit, Department of Psychology for East London Complex Hospital (ELCH).

The study has already been approved by the University of KwaZulu Natal, Faculty Higher Degrees, Research and Ethics Committee. The contact person if need to verify is Suzette van der Westhuizen, the Higher Degrees Officer.

The purpose of my study is to investigate the "Selective psycho-social determinants of poor neurocognitive and socio-emotional development in children perinatally infected with HIV in South Africa". I have undertaken the research with the objective of determining which factors are the strongest associated with poor neurodevelopmental outcome and to understand the challenges associated with caring for an HIV-positive child within the unique context of South Africa. The results of this study could be multifaceted in that it stands to enhance an understanding of the factors that differentially impact the neurocognitive and socio-emotional outcomes in HIV-infected children in South Africa. Furthermore, the results from this study can inform strategic interventions in both clinical and family settings that serve to promote quality of life for both the child infected with HIV and the caregiver.

A large part of the study will involve collection of data from HIV-positive patients (age 3-6 years) through psychometric testing. Individual interviews will be conducted with the caregivers of the HIV-positive child, Also, a Home Screening Stimulation Questionnaire and Beck Depression Inventory will be completed by the caregivers.

I would appreciate access to the sample of patients from the health institution for research purposes. Please note that the research will adhere to the highest ethical standard ensuring confidentiality throughout the research process. A brief outline of the research process is outlined below:
If granted access to use the hospital as a prospective research site and the participants agree
- individual interviews will be conducted with the caregivers of an HIV-positive child;
- psychometric testing will be conducted with each 150 HIV-positive children in the study

Please note that I will make myself available at your earliest convenience to provide clarity on any areas that you may have concerns. I would further sincerely request that you give due consideration to my request as it would have immense benefit for the patients and the hospital.

Looking forward to a favourable response. If you would like to verify the validity of the prospective study, please feel free to contact me or my promoter.

Kind regards,

Antonio G. Lentoor *(Clinical Psychologist)*
Doctorate Student
School of Psychology
Tel: 043 708 2521 or 0723169619
Email: 207524466@ukzn.ac.za or lentoor.antonio@yahoo.com

School of Psychology
University of KwaZulu-Natal
March, 1st, 2012

To: Head of Paediatrics, Dr Boon

My name is Antonio G. Lentoor, I am a Doctorate student at the University of KwaZulu-Natal, School of Psychology preparing to conduct a research study as part of my Doctorate degree. I am a practicing Clinical Psychologist within the Mental Health Unit, Department of Psychology for East London Complex Hospital (ELCH).

The purpose of my study is to investigate the "Selective psycho-social determinants of poor neurocognitive and socio-emotional development in children perinatally infected with HIV in South Africa". I have undertaken the research with the objective of determining which factors are the strongest associated with poor neurodevelopmental outcome and to understand the challenges associated with caring for an HIV-positive child within the unique context of South Africa. The results of this study could be multifaceted in that it stands to enhance an understanding of the factors that differentially impact the neurocognitive and socio-emotional outcomes in HIV-infected children in South Africa. Furthermore, the results from this study can inform strategic interventions in both clinical and family settings that serve to promote quality of life for both the child infected with HIV and the caregiver.

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I would appreciate access to the sample of patients from your department and/or unit for research purposes. Please note that the research will adhere to the highest ethical standard ensuring confidentiality throughout the research process. A brief outline of the research process is outlined below:

If the prospective participants agree

- individual interviews will be conducted with the caregivers of an HIV-positive child;
- psychometric testing will be conducted with each 150 HIV-positive children in the study

Kindly note the study already received Institutional Ethics Approval from both the university and the hospital.

Please note that I will make myself available at your earliest convenience to provide clarity on any areas that you may have concerns. I would further sincerely request that you give due consideration to my request as it would have immense benefit for the patients and the hospital.

Looking forward to a favourable response. If you would like to verify the validity of the prospective study, please feel free to contact me or my promoter.

Kind regards,

Antonio G. Lentoor
Doctorate Candidate
School of Psychology
Tel: 043 708 2521 or 0723169619
Email: 207524466@ukzn.ac.za or lentoor.antonio@yahoo.com

School of Psychology
University of KwaZulu-Natal
March, 1st, 2012

To: Head of Mental Health Unit & Psychiatry, Dr Uys
Cc: Head of Psychology, Mrs Maneli

My name is Antonio G. Lentoor, I am a Doctorate student at the University of KwaZulu-Natal, School of Psychology preparing to conduct a research study as part of my Doctorate degree. I am a practicing Clinical Psychologist within the Mental Health Unit, Department of Psychology for East London Complex Hospital (ELCH).

The purpose of my study is to investigate the "Selective psycho-social determinants of poor neurocognitive and socio-emotional development in children perinatally infected with HIV in South Africa". I have undertaken the research with the objective of determining which factors are the strongest associated with poor neurodevelopmental outcome and to understand the challenges associated with caring for an HIV-positive child within the unique context of South Africa. The results of this study could be multifaceted in that it stands to enhance an understanding of the factors that differentially impact the neurocognitive and socio-emotional outcomes in HIV-infected children in South Africa. Furthermore, the results from this study can inform strategic interventions in both clinical and family settings that serve to promote quality of life for both the child infected with HIV and the caregiver.

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 • psychometric testing will be conducted with each 150 HIV-positive children in the study
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Please note that I will make myself available at your earliest convenience to provide clarity on any areas that you may have concerns. I would further sincerely request that you give due consideration to my request as it would have immense benefit for the patients and the hospital.

Looking forward to a favourable response. If you would like to verify the validity of the prospective study, please feel free to contact me or my promoter.

Kind regards,

Antonio G. Lentoor
Doctorate Candidate
School of Psychology
Tel: 043 708 2521 or 0723169619
Email: 207524466@ukzn.ac.za or lentoor.antonio@yahoo.com

Appendix 2

Informed Consent Documents

SCHOOL OF PSYCHOLOGY
FACULTY OF HUMANITIES, DEVELOPMENT AND SOCIAL SCIENCE

Doctor of Philosophy - Ph.D. (Psychology)
Researcher: Antonio G. Lentoor
Supervisor: Prof. Inge Petersen

Dear parent/caregiver
Good day and thank you for taking the time to read this information. My name is Antonio G. Lentoor, a Clinical Psychologist working in the hospital. I am also a Doctoral student registered in the School of Psychology, Howard College Campus, University of KwaZulu – Natal, Durban, South Africa. My supervisor is Professor Inge Petersen of the School of Psychology, University of KwaZulu-Natal. I am busy doing my doctoral research to find out more about the development of HIV-positive children and how they are been cared for by their caregivers. My study is specifically interested at looking at the psychological and social factors that impact on HIV-positive child's normal development.

If you and your child meet the criteria for the study then I would like to ask you whether you and your child would participate in my study. I am doing this study to understand the psychological and social factors (this includes: quality of home environment, SES, caregiver depressive symptoms, nutritional status and caregiving: caregiver/child relationship) which specifically predict poor development in your HIV-positive child. The study also wants to find out which of the selective psychological and social factors in the study is the *most* responsible for your child's poor development. By participating in the study you and your child will benefit from having a clear indication of your child's neurodevelopment and will be able to access relevant services to address if there are any delays. Also, by participating we hope to improve on parent/caregiver-child relationship.

I will do a few psychological assessments to determine what your child can do. This will tell me about your child's development. I will also ask you to fill in a questionnaire and to do a 1hr interview with me to find out more about the stress you feel as a parent/caregiver. I will do this during your normal hospital visits. I will also look in your child's hospital folder to get the results of their last blood tests and information on their development from birth to date.

All costs relating to the study will be borne by the researcher. It is not anticipated that you will incur any financial expenses resulting from participation in this study; should this occur, you will be fully reimbursed. Nothing that I do will hurt your child or you and all your information will be kept private and confidential. If you do not want to be part of this study you do not have to, and you will still get all the other services at the hospital. If you do participate in the study, you may change your mind and may take your child out of the study at any time, without any prejudice being held against you. Should you experience any discomfort during the interviewing process, you have the right to refuse to respond to certain questions, to discontinue or to withdraw from the interview process. Furthermore, if you need a qualified clinical psychologist would be able to be accessed to assist you psychologically.

Extracts from your interviews and results from your child's psychometric tests may be incorporated into my thesis, future academic articles, professional conferences and seminars that may emanate from this study, without revealing your identities. For the purpose of assessing the study's validity, I will maintain all relevant documents and artefacts pertaining to the study from the beginning of the research process through to the final report, including documents such as the questionnaires, audiotapes, verbatim transcriptions, and psychometric results, thereby enabling an independent

researcher not part of the study to track and assess links and connections between the raw data and the final report. These materials will be kept with my supervisor in a locked cabinet during this period. After five years upon completion of the study and the awarding of the degree, audiotapes and transcripts, questionnaires and tests materials will be destroyed. Tapes of interviews and transcribed material will be kept safe at all times by the researcher.

Should you agree for you and your child to participate in the study on the basis of having read and understood the nature and conditions of this research study, please sign the designated section below. You are free to withdraw from this study at any point after having signed this consent form. Should you require clarification or further information regarding the study, please do not hesitate to contact me or my supervisor. Relevant contact details are provided below. If you would like to obtain more information on your rights as a participant in this study please contact:
Phumelele Ximba,
Research Office,
University of KwaZulu-Natal,
Tel: 031 2603587

Contact details of Researcher:	Contact details of Supervisor:
Antonio G. Lentoor	**Prof. Inge Petersen**
School of Psychology	Postgraduate Academic Coordinator
Howard College Campus	School of Psychology
University of KwaZulu-Natal	Howard College Campus
Tel: 0723169629 (Cell)	University of KwaZulu-Natal
0437082521 (Office)	P. Bag X54001
e-mail: 207524466@ukz.ac.za	Durban 4000
	Work: 031- 260 2507
	Fax: 031- 260 7211
	e-mail: PETERSENI@ukzn.ac.za

PARTICIPANT'S DECLARATION

I ………………………………………………………….. (Full name of caregiver) hereby confirm that I understand the contents of this document and the nature of the research project, and agree that I and my child (Full name of child) …………………………………………………….will participate in the study. I agree that Antonio G. Lentoor may access and look at my child's hospital folder to get the blood results and any other relevant information required for the study. I also grant permission for interview to be audio taped, and for transcribed interview material to be utilized for research purposes.

I understand that we are at liberty to withdraw from the study at any time, should we so wish.

_____
Signature of parent/caregiver

_____
Date

_____
Witness

_____
Date

_____
Signature of researcher

_____
Date

ISIVUMELWANO SOKUTHSTHA INXAXHEBA KUPHANDO.
School of Psychology.
Faculty of Humanities. Development and Social Science.
Doctor of Philosophy.- (Ph. D. (Psychology).
Umphandi: Antonio G. Lentoor.
Supervisor: Prof. Inge Peterson.

Mzali Obekekileyo,

Ndiyabulisa , ndibulela ngokuthatha ixesha lakho ufunde le mbalelwano. Igama lam ndingu Antonio Lentooor, Clinical Psychologist esebenza esibhedlele. Ndikwangumfundi wesidanga sobugqirha (Ph. d). kwisikolo sePsychology , Howard College, kwi auanivesity yakwaZulu-Natal. I supervisor yam ngu Professor Inge Petersenokwisikolo se Pyschology, kwi University of Zululand.
Ndenza uphando kwizifundo zobuNzululwazi (doctoral research), apho ndifuna oluphangaleleyo hgabantwana abane HIV nokokuba bakhuliswa njani ngabo babakhathaleleyo. Uphando lwam lunomdla wokukhakngla iimeko zomphefumlo,nezokuhlala zaba bantwana, ukuba zibuchaphazela njani ubomi babokwa nokukhula kwabo.

Ukuba ngaba wena nomntana wakho nikolu luhlu, ndenza isiscelo sokuba nithathe inxaxheba kolu phando. Ndenza olu phando ukuze ndifumane ulwazi ngeemeko ngeemeko zokuhlala nezomphefumlo (psychological) kudibanise iimeko zekhaya; ezezmali; iimpawu zokudakumba komphefumlo; ukondleka komzimba; kwakunye nendlela umntana nomzali abanxulumana ngayo. Ezi zizinto / imeko ezikhokela kkungakhuli kakuhlc kumntana wakho o HIV+ .Olu phando lufuna ukufumananaziphna iimeko zomphefumlo nezentlalo zizezona zenza kube nzima ukukhkula komntana wakho.

Ngokuthatha inxaxheba kolu phando, wena nomntana wakho, ningazuza ukufumana ngokukucacileyo ingaciso yokukhula ngokwasengqondweni, kwaye ningakwazi ukudityaniswa noncedo olunifaneleyo, nezo zidingo enifumana ubunzima ukufikelela kuzo. Kwakhona, ngokuthatha inxaxheba kwenu, sinethemba lokuphucula ukuqondana nokunxulumana phakathi komzali nomntana.

Ndizakwenza itests ezimbalwa, ukujonga ukuba zeziphi izinto akwaziyo ukuzenza umntana wakho. Iziphumo zazo ziyakundazisa ukuba umntana wakho ukweliphi inqanaba lokukhula. Ndiza kukucela ukuba uphendule imibuzo mbalwa ,kudliwano-ndlebe oluya kuthatha malunga neyure apho ndifuna ukufumanisa ngoxinzelelo ulufumanayo njengomzali. Ezo zinto ndiyakuzenza ngethuba uhambele esibhsdlele njengesiqhelo. Ndizakujonga iinkcukacha zempilo yomntana kwincwadi yahe yasesibhedlele (hospital folder), ezifana neziphumo zegazi zokugqibela kwanolwazi ngokukhula kwakhe, kusukela ekuzalweni kwakhe.

Zonke indleko malunga noluphando ziyakuxhomekeka kumphandingoko akulindelekanga ukuba nizithwalele iindleko zolu phando. Ukuba kubekho iindleko ezinxulumene nolu phando, uya kubuyekezwa. Izinto endizakuzenza aziyi kumonzakaliso umntwana wakho kunye nawe. Zonke inkcukacha umntana wakho kunye nawe. zonke inkukacha ziyakugcinwa

ngokufihlakeleyo. Ukuba ngaba akufuni kuthatha nxaxheba kolu phando, awulindelekanga ukuba uzinyanzele kwaye uvumelekile ukuba ungazithshintsha ingqondo malunga nokuthatha inxaxheba, ungaphuma wena nomntana wakho nanini na. xa unokufumanisa ukungakhululeki yimibuzo ekudliwano-ndlebe, unalo ilungelo lokwala ukuyiphendula lo mibuzo okanye uzikhephe kulo. Kwakhona, xa ufuna uncedo lwe clinical psychologist uya kukwazi ukulufumana olo ncedo.

Izicatshulwa kudliwano-ndlebe kunye neziphumo zeetests ziya kuvela kwi thesis yam. nakwi articles zemfundo; kwiknomfa zezufundiswa ezinokuvunjululwa lolu phando, kodwa aziyi kuwaveaz amagama abathathi nxaxheba. Ukuzama ukukhangela ukunyaniseka kophando olu, ndiya kuzigcina zonke inkukacha zolu phandosukela ekuqaleni kophando de kube ziingxelo zokugqibela kwanoluncwadi olumalunga noluphando. Imibuzo, inguqulelo zodliwano-ndlebe, nziphumo zeetests ziyakugcinwa yi supervisor yam zithsixelwe. Emva kweminyaka emihlanu ligqityiwe olu phando,zonke ezi nkcukacha ziya kuthsatyalaliswa. Ushiilelo lodliwano-ndlebe neemguqulelo zalo ziya kuba seligcinwenilomphandi lonke ixesha.

auakuba ngaba uyavuma ukuba wena nomntana wakho nithathe inxaxhebakolu phando, wakube ufundilewaza wacacelwa ziimekozoluphando , Uyaclwa ukuba usayine kwisithuba esingezantsiesilungiselelwe oko.Khumbula ukuba unalo ithuba lokuphuma nokuba usayinile ngaphantsi apha. Xa uuna ingcaciso epheleleyo maunga nolu phando, ungathandabuzi ukunxulumana nam okanye I supervisor yam.

Nazi iinkcukaha zonxiblelwano.Ukuba ufuna ukwazi ngaphazulumalinga namalungelo akho njengomntu othatha inxaxheba koluphando, nceda unxulumaneno:

Phumlele Ximba.
Research Office.
University of KwaZulu-Natal.
Tel: 031 – 2603587.

INKCUKACHA ZOMPHANDI.

Antonio G. Lentoor.
School of Psychology.
Howard College Campus.
University of KwaZulu – Natal.
Tel: 0723169629 (cell).
        043- 7082521 (Office).
email: 207524466@ukzn.co.za

INKCUKACHA ZE SUPERVISOR.

Prof. Inge Petersen.
Postgrauate Academic Co-ordinator.
School of Psychology.
Howard College Campus.
University of KwaZulu- Natal.
P.Bag X 54001.
Durban. 4000.
email: PETERSEN 1 @ukzn.ac.za

ISIVUMELWANO SOMTHATHI NXAXHEBA.

Mna .... (igama elipheleleyo lomzali) ndiyangqina ukuba ndicacelwe kokuphethwe yile mbalelwano, nangenkcukacha zolu phando, kwaye ndiyavuma ukuba mna nomntana wam u .... (amagama omntana) siyakuthatha inxaxheba koluphando .

Ndiyavuma ukuba uAntonio G. Lentoor nommncedisi wakhe, afikelele kwi folder yesibhedlele afumane iingxelo zegazi kwakunye nezinye inkcukacha ezifunekayo koluphando. Ndinika imvume yodliwano-ndlebe olushicilelweyo, kwanoluguqulelweyo ukuba lusetyenziswe koluphando.

Ndiyaqonda ukuba ukuba sinemvume yokuyeka koluphando naninina xa sifuna ukuphuma.

Signature of the parent.

....   Date...........

Witness.

....   Date..............

Signature of researcher.

....   Date............

Appendix 3

Quantitative Research Instruments

BDI-II

Date: _____

Name: _____ Marital Status: _____ Age: _____ Sex: _____

Occupation: _____ Education: _____

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out **the one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

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

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

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

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

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

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

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

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

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

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

_____ Subtotal Page 1

Continued on Back

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11. Agitation

0   I am no more restless or wound up than usual.

1   I feel more restless or wound up than usual.

2   I am so restless or agitated that it's hard to stay still.

3   I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0   I have not lost interest in other people or activities.

1   I am less interested in other people or things than before.

2   I have lost most of my interest in other people or things.

3   It's hard to get interested in anything.

13. Indecisiveness

0   I make decisions about as well as ever.

1   I find it more difficult to make decisions than usual.

2   I have much greater difficulty in making decisions than I used to.

3   I have trouble making any decisions.

14. Worthlessness

0   I do not feel I am worthless.

1   I don't consider myself as worthwhile and useful as I used to.

2   I feel more worthless as compared to other people.

3   I feel utterly worthless.

15. Loss of Energy

0   I have as much energy as ever.

1   I have less energy than I used to have.

2   I don't have enough energy to do very much.

3   I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

0   I have not experienced any change in my sleeping pattern.

1a   I sleep somewhat more than usual.

1b   I sleep somewhat less than usual.

2a   I sleep a lot more than usual.

2b   I sleep a lot less than usual.

3a   I sleep most of the day.

3b   I wake up 1–2 hours early and can't get back to sleep.

17. Irritability

0   I am no more irritable than usual.

1   I am more irritable than usual.

2   I am much more irritable than usual.

3   I am irritable all the time.

18. Changes in Appetite

0   I have not experienced any change in my appetite.

1a   My appetite is somewhat less than usual.

1b   My appetite is somewhat greater than usual.

2a   My appetite is much less than before.

2b   My appetite is much greater than usual.

3a   I have no appetite at all.

3b   I crave food all the time.

19. Concentration Difficulty

0   I can concentrate as well as ever.

1   I can't concentrate as well as usual.

2   It's hard to keep my mind on anything for very long.

3   I find I can't concentrate on anything.

20. Tiredness or Fatigue

0   I am no more tired or fatigued than usual.

1   I get more tired or fatigued more easily than usual.

2   I am too tired or fatigued to do a lot of the things I used to do.

3   I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

0   I have not noticed any recent change in my interest in sex.

1   I am less interested in sex than I used to be.

2   I am much less interested in sex now.

3   I have lost interest in sex completely.

_____ Subtotal Page 2

_____ Subtotal Page 1

_____ Total Score

3 4 5 6 7 8 9 10 11 12 ABCDE

NR15645

Child's Name _____ Birthdate _____ Age _____

Parent's Name _____ Phone No. _____

Address _____ Date _____

HOME SCREENING QUESTIONNAIRE

Please answer <u>all</u> of the following questions about how your child's time is spent and some of the activities of your family. On some questions, you may want to check more than one blank.

1. How often do you and your child see relatives?
   ____never
   ____at least once a year
   ____at least 6 times a year
   ____at least once a month
   ____at least once a week

2. Do you subscribe to any magazines? YES   NO   If yes, what kind?
   ____home and family magazines
   ____news magazines
   ____children's magazines
   ____other

3. About how many hours each day does your child spend in a playpen, jump-chair, infant swing or infant seat?
   ____none
   ____up to 1 hour
   ____1 to 3 hours
   ____more than 3 hours

4. Does your child have a toybox or other special place where he/she keeps his/her toys?   YES   NO

5. How many children's books does your child have of his/her <u>own</u>?
   ____0: too young
   ____1 or 2
   ____3 or 4
   ____5-9
   ____10 or more

6. How many books do you own?
   ____0-9
   ____10-20
   ____more than 20
   Where do you keep them?
   ____in boxes
   ____on a bookcase
   ____other — explain _____

7. How often does someone take your child into a grocery store?
   ____hardly ever; prefer to go alone
   ____at least once a month
   ____at least twice a month
   ____at least once a week

8. How many different babysitters or day care centers have you used in the past three months? _____

9. Do you have any pets?   YES   NO
   (include dog, cat, fish, birds, etc.)

10. About how many times in the past week did you have to spank or slap your child to get him/her to mind?
    _____

11. Did you start talking to your child when he/she was
    ____0-3 months?
    ____3-9 months?
    ____9-15 months?
    ____when he/she was old enough to understand?

12. Most of the time do you feel that your child
    ____is usually smiling and pleasant
    ____prefers to be by himself/herself
    ____responds readily to affection
    ____gets angry when he/she doesn't get his/her way
    ____is often cranky

13. Do you talk to your child as you are doing the housework?
    YES   NO   TOO YOUNG

14. When your child gets a new toy do you usually
    ____explore it with him/her?
    ____let him/her explore it on his/her own?
    ____save it for a special occasion?

15. How often does someone read stories or show pictures to your child?
    ____hardly ever
    ____once or twice a month
    ____at least once a week
    ____at least 3 times a week
    ____at least 5 times a week

16. What do you usually do when your child gets bored?
    ____give him/her a cookie or something to eat
    ____put him/her to bed for a nap
    ____offer him/her a toy
    ____encourage him/her to keep himself/herself busy
    ____play with him/her

17. Which of the following do you let your child play with?
    ____water   ____food
    ____mud   ____fingerpaints
    ____dirt   ____none of the above
    ____sand

18. How often does your child eat a meal at the table (or sit at the table during a meal) with both mother and father (or father figure)?
    ____never
    ____at least once a month
    ____at least once a week
    ____at least 3 or 4 times a week
    ____at least once a day

19. Do you have any plants in your house?
    YES NO

20. About how often do you take your child to the doctor? _____

21. Do you have any friends with children about the same age as your child?
    YES NO

22. Do you sometimes try new recipes that you find in the newspaper or in magazines?
    YES NO

23. Does the father (or other adult male) provide some caregiving (such as babysitting, feeding, putting to bed, etc.) for the child? YES NO If Yes, how often?
    ____at least once a month
    ____at least once a week
    ____at least 3 or 4 times a week
    ____everyday

24. How often does your child get out of the house (backyard, for a walk, to the store, etc.)?
    ____at least once a month
    ____at least once a week
    ____at least 4 times a week
    ____at least once a day

25. Check the things which you (or other adult or older child in the home) have helped your child to learn.
    ____rolling over
    ____crawling
    ____feeding himself/herself
    ____walking
    ____colors
    ____saying new words
    ____song, prayers, or nursery rhymes
    ____none of the above
    Other: _____

26. Is anyone in the family presently taking a class at the college level? YES NO

27. Who does the grocery shopping for your family?_____

28. Most of the decisions about how the family income is to be spent are made by
    ____Mother   ____Grandparent
    ____Father   ____Friend
    ____Mother and Father

29. How often do you actively play with your child at this age?
    ____hardly ever: too young
    ____at least once a week
    ____at least 3 or 4 times a week
    ____everyday

30. Do you have a TV? YES NO
    a) About how many hours is the TV on each day? _____
    b) About how many hours does your child watch TV each day? _____

Strengths and Difficulties

QUESTIONNAIRE

TO BE COMPLETED BY A MAIN CARER OF A CHILD AGED BETWEEN 4 AND 16

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain, or the items seem daft! Please give your answers on the basis of the child's behaviour over the last six months.

Child's Name _____   Male/Female _____   Date of Birth _____

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	☐	☐	☐
Restless, overactive, cannot sit still for long	☐	☐	☐
Often complains of headaches, stomach-aches or sickness	☐	☐	☐
Shares readily with other children (treats, toys, pencils etc.)	☐	☐	☐
Often has temper tantrums or hot tempers	☐	☐	☐
Rather solitary, tends to play alone	☐	☐	☐
Generally obedient, usually does what adults request	☐	☐	☐
Many worries, often seems worried	☐	☐	☐
Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
Constantly fidgeting or squirming	☐	☐	☐
Has at least one good friend	☐	☐	☐
Often fights with other children or bullies them	☐	☐	☐
Often unhappy, downhearted or tearful	☐	☐	☐
Generally liked by other children	☐	☐	☐
Easily distracted, concentration wanders	☐	☐	☐
Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
Kind to younger children	☐	☐	☐
Often lies or cheats	☐	☐	☐
Picked on or bullied by other children	☐	☐	☐
Often volunteers to help others (parents, teachers, other children)	☐	☐	☐
Thinks things out before acting	☐	☐	☐
Steals from home, school or elsewhere	☐	☐	☐
Gets on better with adults than with other children	☐	☐	☐
Many fears, easily scared	☐	☐	☐
Sees tasks through to the end, good attention span	☐	☐	☐

Please turn over – there are a few more questions on the other side ...

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No difficulties	Yes – minor difficulties	Yes – more serious difficulties	Yes – severe difficulties
☐	☐	☐	☐

If you have answered 'Yes', please answer the following questions about these difficulties:

• How long have these difficulties been present?

Less than a month	1–5 months	5–12 months	Over a year
☐	☐	☐	☐

• Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

• Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
Home life	☐	☐	☐	☐
Friendships	☐	☐	☐	☐
Classroom Learning	☐	☐	☐	☐
Leisure activities	☐	☐	☐	☐

• Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

Signature _____

Date _____

Mother/Father/Other (please specify) _____

Thank you very much for your help

STRENGTHS AND DIFFICULTIES   5h

Strengths and Difficulties
QUESTIONNAIRE

TO BE COMPLETED BY A YOUNG PERSON BETWEEN 11 AND 16

Please read the questionnaire carefully. For each of the statements put a tick in the box that you think is most like you. It would help us if you put a tick for all the statements – even if it seems a bit daft! Please give answers on the basis of how you have been feeling over the last six months.

Your Name _____   Your age _____

	Not True	Somewhat True	Certainly True
I try to be nice to people. I care about their feelings	☐	☐	☐
I get restless, I cannot sit still for long	☐	☐	☐
I get a lot of headaches, stomach-aches or sickness	☐	☐	☐
I usually share with others (food, games, pens etc.)	☐	☐	☐
I get very angry and often lose my temper	☐	☐	☐
I am usually on my own. I generally play alone or keep to myself	☐	☐	☐
I usually do as I am told	☐	☐	☐
I worry a lot	☐	☐	☐
I am helpful if someone is hurt, upset or feeling ill	☐	☐	☐
I am constantly fidgeting or squirming	☐	☐	☐
I have one good friend or more	☐	☐	☐
I fight a lot. I can make other people do what I want	☐	☐	☐
I am often unhappy, downhearted or tearful	☐	☐	☐
Other people my age generally like me	☐	☐	☐
I am easily distracted, I find it difficult to concentrate	☐	☐	☐
I am nervous in new situations. I easily lose confidence	☐	☐	☐
I am kind to younger children	☐	☐	☐
I am often accused of cheating or lying	☐	☐	☐
Other children or young people pick on or bully me	☐	☐	☐
I often volunteer to help others (parents, teachers, children)	☐	☐	☐
I think before I do things	☐	☐	☐
I take things that are not mine from home, school or elsewhere	☐	☐	☐
I get on better with adults than with people my own age	☐	☐	☐
I have many fears, I am easily scared	☐	☐	☐
I finish the things I'm doing. My attention is good	☐	☐	☐

Please turn over – there are a few more questions on the other side ….

Overall, do you think that you have difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No difficulties	Yes – minor difficulties	Yes – more serious difficulties	Yes – very severe difficulties
☐	☐	☐	☐

If you have answered 'Yes', please answer the following questions about these difficulties

• How long have these difficulties been present?

Less than a month	1–5 months	5–12 months	Over a year
☐	☐	☐	☐

• Do the difficulties upset or distress you?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

• Do the difficulties interfere with your everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
Home life	☐	☐	☐	☐
Friendships	☐	☐	☐	☐
Classroom Learning	☐	☐	☐	☐
Leisure activities	☐	☐	☐	☐

• Do the difficulties make it harder for those around you (family, friends, teachers etc.)?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

Signature

Date

Thank you very much for your help

STRENGTHS AND DIFFICULTIES   6b

Appendix 4

Qualitative Interview Schedule

APPENDIX

INTERVIEW SCHEDULE

Parent/caregiver of an HIV-positive child

Interview schedule /guide
Questions for HIV-positive caregiver

1. How does being HIV positive impact on your personal relationships?
2. What are your experiences of being HIV positive and a caregiver of a HIV-positive child?
3. How do you as a caregiver come to terms with your own diagnosis and that of your child?
4. How did your sense of identity as a caregiver get influenced or changed after being diagnosed HIV-positive?
5. In what way did the HIV-positive diagnosis of your child influenced or changed your view of your child?
6. In what way did the HIV-positive diagnosis of your child influenced or changed your interaction with your child?
7. How has your HIV status influence your caregiving capacity the primary caregiver of your child? In what way has your own diagnosis of HIV impacted on your ability bond with your HIV-positive child?
   a) Do you or did you breast feed your HIV-positive infant or child? if not, did this have any impact on your ability to connect emotionally with your him/her?
   b) If yes, how has the experience influence your connectedness with your HIV-positive child?
   c) Do you avail time for stimulation interactions such as play, cuddle, sing, read a story etc. with your infant or child?
   d) How much time do you prioritise to interact in stimulating activities such as play etc. with your child?
8. Does poverty impact in any way on your ability to care for your HIV-positive child?
9. How does poverty impact on your experiences as an HIV-positive caregiver to care for your HIV-positive child?
10. Does having to live in an impoverished context have any impact on how you deal with you and your child diagnosis?
    a) If so, how?
11. Does having to live in an impoverished context have any impact on the overall physical and psychological health of you and your child?
    a) If so, how?
12. What expectations do you have for your HIV-positive child as an HIV-positive caregiver? / How does having HIV as a caregiver influence your expectations you have of your HIV-positive child?
13. How do you cope as an HIV-positive caregiver having to care for an HIV-positive child?
14. Do you have a network of support system that you can call on for assistance?

15. What impact does caring for an HIV-positive child having on your own emotional, psychological and physical well-being as an HIV-positive caregiver?

Questions for HIV negative caregiver of HIV-positive child

1. How does caring for an HIV-positive child impact on your personal relationships?
2. What are your experiences caring for an HIV-positive child?
3. How has the HIV-positive diagnosis of the child influence your caregiving capacity?
4. Does having to care for an HIV-positive child interfere in your ability to establish a bond with the child?
5. If so, why and in what way?
6. How often do you engage in stimulating activities with your HIV-positive child?
7. How does it feel having to raise a HIV-positive child and live in an impoverished context?
8. How do you handle having to raise a HIV-positive child in an impoverished context?
9. As a caregiver of an HIV-positive child, what are your expectations of the child?
10. How has the community responded to the diagnosis of the child?
11. Do you have a support system, i.e. family of friends that assists you financially or emotionally with caring for the HIV-positive child?
12. What impact does caring for an HIV-positive child have on your own emotional and psychological well-being?
13. How do you cope with having to care for an HIV-positive child?

RESEARCH INFORMATION SHEET (interview schedule)

Folder number: ....

Name: ....

Gender: ....

Age: ....

D.o.b: ....

Address: ....

Grade: ....

School/crèche: ....

ARVs   Yes or NO

Treatment regimen: ....

Weight: ....

Height: ....

Caregivers name: ....

Relationship to the child: ....

ID number: ....

Age: ....

Contact details: ....

Employed/Unemployed

Are you receiving grant ? YES or NO ....specify type :

ARV Treatment :   Yes / No

What type of dwelling do you live in ?

How many bedrooms does your house have?

How many people are living in your house?

Is anyone in the family presently taking a class in school or at college level?

Who buys groceries for the family?

Most of the decisions is about how the family income is to be spend are made by who?

Do you have any of the following appliances in the house?

Fridge	yes or no
Microwave	yes or no
Television	yes or no
Electricity stove	yes or no

Do you have running water? If yes?

Tap inside the house or outside the house

Communal tap

You collect water from river

Do you have a toilet?	Yes or No ...specify type
Do you have a veg garden	Yes or NO

Your highest level of education?

Are you currently employed?   Yes or NO