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The psychological problems of children with HIV/AIDS in Tshwane

by

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I dedicate this work to my Mom, who taught me to love books.

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Abstract

In order to determine what mental health problems South African children living with HIV experience, interviews were conducted with HIV-positive children and their caregivers at a paediatric HIV clinic in Tshwane. The interviews with the children included assessments that focused on the children's self-esteem (Self-Description Questionnaire), experiences of anxiety (RCMAS), and the coping strategies that they employed in daily living (Kidcope). The interviews with caregivers included a questionnaire about demographic details, the Parental Stress Index (PSI), and the Coping with Children's Negative Emotions Scale (CCNES). Caregivers also completed the Child Behaviour Checklist (CBCL), which assesses a range of psychological problems in children. These results were compared to a sample of HIV-negative children and their caregivers from the same community.

Although many children living with HIV-infection displayed clinical levels of somatic and depressive symptoms, these did not differ at statistically significant rates from the HIV-negative comparison group. Furthermore, children living with HIV were not found to experience clinically significant levels of anxiety as assessed by the RCMAS. Children living with HIV were found to employ more adaptive coping strategies than maladaptive coping strategies and significantly fewer maladaptive coping strategies than HIV-uninfected children use. Children living with HIV were also found to have significantly higher positive self-evaluations than HIV-uninfected children.

The results of the caregiver assessments indicated that caregivers of children living with HIV experience more distress in their relationship with their child and tend to engage less with negative emotional displays of their children than do caregivers of HIV-uninfected children.

Key Terms: Affective problems, Caregivers of children living with HIV, Children living with HIV, Child mental health, Comparative study, Paediatric HIV in South Africa, Somatic problems

Abbreviations and Acronyms

ADHD - Attention Deficit/Hyperactive Disorder

AIDS - Acquired Immunodeficiency Syndrome

ART - Antiretroviral Therapy

ARV - Antiretroviral

CBCL - Child Behaviour Checklist

CCNES - Coping with Children's Negative Emotions Scale

CD4 - T-Lymphocyte cell bearing CD4 receptor

DSM - Diagnostic and Statistical Manual of Mental Disorders

HAART - Highly Active Antiretroviral Therapy

HIV - Human Immunodeficiency Virus

ICD-10 - International Classification of Diseases

PDM - Psychodynamic Diagnostic Manual

PEPFAR - President's Emergency Plan for AIDS Relief

PLWHA - People living with HIV/AIDS

PMTCT - Prevention of mother to child transmission of HIV

PSI-SF - Parenting Stress Index - Short Form

PTSD - Post-Traumatic Stress Disorder

RCMAS - Revised Children's Manifest Anxiety Scale

SDQ - Self-Descriptive Questionnaire

UNAIDS - Joint United Nations Programme on HIV/AIDS

Declaration

I, Hilda Elizabeth Hecker, hereby declare that the work on which this dissertation is based, is original, except where acknowledgements indicate otherwise, and neither the whole work nor part of it, has been, is being, or is to be submitted for another degree at this or another university or tertiary education institution or examination body.

Table of Contents

List of Figures

List of Tables

Appendices

Chapter One

1.1 Introduction to the Research Problem

HIV is a global epidemic in the truest sense. With more than 70 million infections to date and an estimated 35 million deaths, few other diseases have been this devastating and challenging (World Health Organisation, 2016).

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), the global prevalence of HIV-infection is estimated at between 34 and 39,8 million people. The global number of HIV-positive children under the age of 15 is estimated at 1.8 million (UNAIDS, 2015a). South Africa has the highest number of HIV-positive individuals in the world, with an estimated HIV-prevalence rate ranging between 6.7 and 7.4 million. This includes 240 000 children under the age of 15 living with the disease in South Africa (UNAIDS, 2015b).

The HIV epidemic is one of the great global challenges of the last three decades. This is particularly true for South Africa. In South Africa, millions of lives have been affected and lost by this devastating disease. Families and communities have been disrupted, economies affected, and health care systems overwhelmed (Abdool Karim & Baxter, 2010; Colvin, 2010; Frohlich, 2010; Whiteside, 2010).

Before the implementation of widespread prevention of mother to child transmission (PMTC) initiatives in South Africa, the HIV epidemic spread rapidly among the country's paediatric population. This resulted in large numbers of infected babies dying from AIDS and few HIV-infected children surviving past their fifth year without treatment (Gouws & Abdool Karim, 2010).

However, due to the increase in effective HIV treatment and the success of the prevention of mother to child transmission treatment (PMTCT), far less babies acquire HIV from their mothers during and after birth (reference). Additionally, the availability of anti-retroviral therapy (ART) in recent years, the AIDS mortality rate has declined drastically in South Africa (Coovadia, 2010). This has also led to a decline in AIDS-related deaths among South African children, and consequently more of the HIV-infected children and adolescents are living a longer life with HIV. However, the reduction in mortality poses a new challenge which concerns the psychosocial effects of growing up with HIV (Morobadi & Webber, 2014).

In the initial stages of the epidemic the focus was solely on the physical and medical aspects of the disease. Initially, research pertaining to mental health issues focused on adults and the issue of psychological well-being of children living with the disease was greatly

neglected. The current study endeavours to examine whether, and to what extent, a sample of HIV-positive South African children experience mental health problems.

1.2 HIV and Mental Health

HIV has many comorbid and secondary health complications (Van Dyk, 2001). However, these are not limited to only physical conditions. Numerous studies have confirmed a significant prevalence of mental health problems of HIV in adults. The most prevalent mental health problems found amongst adults with HIV across studies include depression, anxiety, substance abuse, and post-traumatic stress disorder (Brandt, 2009; Breuer, Myer, Struther, & Joska, 2011; Mayston, Kinyanda, Chishinga, Prince, & Patel, 2012; Myer et al., 2008).

As the research focus began to shift towards the problems faced by children and adolescents living with HIV, research also started to include psychological, psychiatric and broader mental health problems. Studies found that HIV has a significant effect on the mental health of children and adolescents, identifying mood, anxiety, ADHD and disruptive behavioural disorders as the most prevalent (Benton & Ifeagwu, 2008; Bomba et al., 2010; Brown, Lourie, & Pao, 2000; Rao, Sagar, Kabra, & Lodha, 2007; Scharko, 2006).

Children's developmental immaturity has also been found to further predispose them to neurodevelopmental and neurocognitive complications, which often have life-long consequences (Nozyce et al., 2006; Van Rie, Harrington, Dow, & Robertson, 2007).

Children's dependency on adults, their different experiences of their social environment, and their often greater vulnerabilities to environmental and psychosocial stressors, all result in their experiences of living with HIV being different to those of adults. In this regard, Roa and colleagues (2007) stress that findings from research conducted with adult populations cannot be extrapolated to children.

Although research has shifted somewhat to include mental health issues in children, a vast majority of these studies have been conducted in developed countries, and there is a dearth of research conducted in South Africa. When one takes into account the magnitude of South Africa's paediatric HIV-infection prevalence, research that specifically focuses on South African children may be particularly useful.

1.2 Background to the Study

The impetus for this research flows from the involvement of the University of Pretoria's Department of Psychology with the Paediatric HIV Clinic of Kalafong Hospital.

Kalafong Hospital is situated near Atteridgeville, a suburb on the western outskirts of the Tshwane Metropolitan Municipality. The Paediatric HIV Clinic was established in 2004, after the South African Government initiated ART provision at public healthcare facilities. As not all surrounding primary healthcare clinics provided ART to children, the Paediatric HIV Clinic at Kalafong Hospital became a core site for providing these services (Massyn et al., 2013).

As the utilisation of the clinic's services expanded and younger patients entered into adolescence, the clinic expanded its services to include adolescents in 2007. To provide the children, adolescents and their caregivers who attend the clinic with comprehensive care that also addresses secondary complications and psychosocial issues related to the HIV epidemic, a multi-disciplinary team was established.

Kalafong Hospital serves as one of the main training hospitals for the University of Pretoria's medical and allied professions' students. To this effect, the Department of Psychology of the University of Pretoria was approached to form part of the multi-disciplinary team. In order to determine how psychological services could best be rendered, the Department of Psychology proceeded with a needs assessment. The data used in the present study was collected as part of the needs assessment (See Appendix A).

1.3 Aims of the Study

As there exists a dearth of research pertaining to mental health problems of South African children with HIV, the present study aims to determine whether HIV-positive children who attend the paediatric HIV clinic at a hospital in Tshwane experience mental health problems.

This study will firstly aim to gain an understanding of the nature and extent of mental health problems and coping strategies used by the HIV-positive children who attend the clinic.

Secondly, these findings will be compared to an HIV-negative comparison group of children from the same area, to allow for a relative measure of comparison.

In the third instance, the present study will focus on the child-rearing experiences of the caregivers of both the HIV-positive and HIV-negative children, in order to identify variables that can play a role in contributing to mental health or mental health problems of children who are diagnosed as HIV-positive.

The results of this study will be interpreted using the Extended Stress Coping Model (Maes, Leventhal, & De Ridder, 1996). This model provides a systemic framework specifically for conceptualising how individuals cope with chronic illnesses.

This will allow for a better understanding of the mental health problems and coping strategies of children living with HIV and the people involved in caring for them. In having a better understanding of these needs, more appropriate and effective interventions could be introduced.

1.4 Chapter Outline

The dissertation stretches over five chapters. This chapter introduced the topic of paediatric HIV and the dearth of research on the mental health of these children. The context of the research was introduced and the motivation for this research. Chapter 2 will provide an extensive literature review of existing research about mental health problems related to the HIV epidemic, specifically those of children. Following this, Chapter 3 will discuss the research method and assessments used in this study. In Chapter 4 the results of the processed data will be given. In Chapter 5, the final chapter, these results will be discussed, followed by a critical evaluation of the research, and a brief discussion of the potential value thereof.

Chapter Two – Literature Review

2.1 Introduction: Healthy Body, Healthy Mind

Even before René Descartes brought the question of body-mind duality to prominence in the 17th century, this issue was of immense interest and contention. Philosophers, from Gautama Buddha, Plato, Aristotle, and Kant, through to the more recent conceptions of neuroscience, have all explored how the body and mind interact, or even whether a distinction between the two can be made (Crane & Patterson, 2000).

One way of taking a more pragmatic view of how this debate has been manifesting is by turning to the field of health care. In Western health care, this is broadly covered by medicine and psychology, bridged by psychiatry. The Eastern philosophical and healing traditions have taken a much more integrated approach in working with the body and psyche. It is only recently that the Western paradigm has begun a similar integrated approach towards mental and physical health. Although the exact mechanisms of the interplay between physical and mental disorders are still not completely understood, research repeatedly corroborates this inter-connection (Behan, Doyle, Masterson, Shiers, & Clarke, 2015).

Before one can define psychological or mental health problems, one would first need to define the concepts of *psyche* and *mental health*.

In psychology, the term *psyche* is used to describe the totality of the human mind, both conscious and unconscious. The psyche is also considered fundamental in directing a person's thoughts, behaviours and personality (Reed, 1996).

In the field of mental health, some of the most important classification systems are the *Psychodynamic Diagnostic Manual* (PDM), *International Classification of Diseases* (ICD-10), and the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). The ICD-10 and the DSM follow rather similar conceptualisations of *mental health* and *mental health disorders*.

The PDM describes itself as "…a diagnostic framework that attempts to characterize an individual's full range of functioning − the depth as well as the surface of emotional, cognitive, and social patterns." (Psychodynamic Diagnostic Manual Task Force, 2006, p. 1). The PDM does not consider mental health as merely the absence of observable psychopathological symptoms, but rather regards a person's overall mental functioning as the determining factor. In an attempt to cover the full complexity of individual functioning, this conceptualisation includes relationships; emotional depth, range, and regulation; coping capacities; and self-observing abilities.

The authors of the DSM-5 engage judiciously with a definition of the term *mental disorder*:

> A mental disorder is a syndrome characterized by a clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities. (American Psychiatric Association, 2013, p. 20).

The DSM-IV-TR describes a mental disorder as "…a behavioural or psychological syndrome or pattern associated with distress… or with a significantly increased risk of suffering, death, pain, disability, or an important loss of freedom" (American Psychiatric Association, 2000, pxxxi).

Although the DSM-5 (American Psychiatric Association, 2013) is steering away from normative psychology such as that of the DSM-IV-TR (American Psychiatric Association, 2000) and its predecessors, it still contains normative cultural specifiers. The PDM, however, places much more emphasis on the individual's subjective experience and functioning.

These nosologies differ somewhat in their definitions of mental disorder and conception of mental health. However, common and central to their formulations are the notions of *impairment of functioning*, and *distress* or *suffering*.

For the purpose of the present study, the nosology of the DSM-IV will be used to frame the understanding of psychological problems. However, this will be complimented by further considering broader systemic factors, as well as the adaptive functioning of children living with HIV that may influence their psychological functioning such as coping, self-esteem, and caregiver relationships.

Having now defined the concepts of mental health and mental health problems, this chapter will explore the comorbidity of physical and mental disorders, with greater focus on children living with HIV. To confirm the supposition that children living with HIV experience psychological problems, the following questions will be addressed in the rest of this chapter:

- What is the relationship between physical and mental disorders?
- To what extent does HIV impact on mental health?
- Is HIV related to specific mental health problems in children?
- Are there risk and protective factors which may inform prevention and treatment efforts?

2.2. Physical Illness and Mental Health

Mental health problems have become a significant factor in the global disease burden, with an estimated prevalence of 14% globally. Often, mental health problems do not occur in isolation, but co-occur with physical illnesses (Prince et al., 2007).

Epidemiological research by Iacovides and Siamouli (2008) focused on this relationship between physical and mental disorders. The most prominent physical disorders related to mental disorders identified by these researchers include cardiovascular disease, hypertension, respiratory disorders, diabetes mellitus and other metabolic diseases. Depression and anxiety were the two mental disorders with the greatest comorbidity with physical disorders (Iacovides & Siamouli, 2008).

Further research by Scott et al. (2007) investigated the comorbidity of ten chronic physical conditions with depressive and/or anxiety disorders. These physical conditions included obesity, diabetes, asthma, hypertension, arthritis, peptic ulcers, heart disease, back and neck problems, chronic headache and multiple pains. The research focused on the comorbidity of these disorders in individuals with either depression, or anxiety disorder, or those who suffer from both.

The results indicated that there was a variability between the type of the physical disorder and the psychological disorder(s). Chronic pain conditions had the highest correlation with anxiety and depressive disorders. The second highest correlation was with ulcers and heart disease. The researchers concluded that physical disorders mostly occur with a *combination* of anxiety and depression (Scott et al., 2007).

Despite the prevalence of mental health problems and the extent of their comorbidity with physical disorders, the interconnectedness of physical and mental health is still being underestimated. As a result, psychological and psychiatric interventions and awareness in both the health care and public spheres are still inadequate (Collins, Tranter, & Irvine, 2011; Prince, 2007).

The situation in South Africa is unfortunately no different. In the last two decades, the number of beds in psychiatric hospitals has decreased by 7.7%, with no compensatory increase in primary mental health services (Lund et al., 2010). Lund and colleagues further highlight the shortage of psychiatrists, psychologists, and mental health nurses. According to Lund et al. (2010), funding shortages, poor resource allocation and planning are contributing to the fact that nearly 75% of South Africans with mental healthcare needs are not receiving adequate treatment.

This outlines the relationship between physical and mental disorders. It is now necessary to specifically focus on the comorbidity of physical and mental disorders in children.

2.2.1 Comorbidity of mental and physical disorders in children.

Research conducted by Perou et al. (2013) for the Centre for Disease Control and Prevention indicated that 13%–20% of children in the United States suffered from a mental health disorder in a single year (for the years 2005-2011).

This is in keeping with Kieling and colleagues (2011), who found that 10%–20% of children and adolescents experience mental health problems globally. Keiling et al. (2011) state that despite these alarming numbers, child and adolescent mental health is still a neglected field of study.

Child mental health problems are compounded by the fact that research, diagnosis, treatment, and resources have received less attention than those of adults. This is especially true in the case of developing countries. Given the crisis proportions of physical illness in developing countries, the mental health concerns of children seem to be a lesser priority (Kieling et al., 2011; World Health Organization, 2005).

Similarly, comorbid mental and physical disorders in children are not as extensively studied as in adult populations (McCloughen, Foster, Huws-Thomas, & Delgado, 2012). However, research about children with chronic physical illnesses indicates that they too are at a greater risk of developing mental health problems (Combs-Orme, Heflinger, & Simpkins, 2002; Hysing, Elgen, Gillberg, Lie, & Lundervold, 2007). It is therefore not unexpected to find that children living with HIV are at an increased similar risk (El-Mallakh, Howard, & Inman, 2010).

Before the comorbidity of mental health problems in children living with HIV will be scrutinised, the following section will first discuss the HIV epidemic in more general terms.

2.3 HIV

The medical presentation and course of HIV in infants and children differ somewhat from that of adults. However, there is also a significant overlap in disease progression, stages of the disease symptoms, and treatment. Children, and especially infants, have immature immune systems which render them far more susceptible to opportunistic infections, and they are less capable of successfully recovering from these. The developing nature of a child's body and

nervous system also compounds the direct and indirect effects of HIV-infection (Wachsler-Felder & Golden, 2002).

The following section will give a brief summary of the most prominent medical features of HIV, with a greater focus on children.

2.3.1 Physical repercussions of HIV.

2.3.1.1 Diagnosis, stages and symptoms of HIV and AIDS.

Without treatment, the average life expectancy of an HIV-positive adult ranges from between three to ten years. Secondary factors, such as nutrition and the state of the person's general health do, however, play a significant role. In cases where the infected person receives adequate treatment, life expectancy can be extended by decades (Puren, 2010; Van Dyk, 2001). The course of untreated HIV in infants and children is much more rapid compared to adults. The mortality rate in untreated children is estimated at 55% by two years and 98% by five years (Coovadia, 2010).

As with the progression of the disease, diagnosing HIV in children also poses a different challenge. It is difficult to accurately diagnose HIV in children under the age of 18 months with HIV-antibody tests which are used for adults because their blood may still contain HIV antibodies transferred from their mothers before and during birth (Van Dyk, 2001).

The World Health Organisation (2010) lists certain accompanying conditions that can aid diagnosis in light of uncertain or unavailable serology or HIV-virology instruments. Amongst these are the following conditions that commonly present in infants and children living with HIV:

- failure to thrive and weight-loss,
- developmental delays and developmental losses due to regression,
- recurrent bacterial infections,
- tuberculosis,
- chronic gastric conditions,
- generalised lymphadenopathy,
- enlargement of organs and glands,
- skin conditions, and
- neurological conditions (WHO, 2010).

HIV-positive children also present with common paediatric illnesses, but these tend to occur more often, with greater severity, and are less responsive to treatment. When HIV has progressed to AIDS, children also present with more specific *AIDS-defining* conditions such as Kaposi's sarcoma, toxoplasmosis and pneumocystis carinii pneumonia (WHO, 2010).

HIV presents in two stages: HIV-infection, and (active) AIDS. Table 2.1 provides a brief summary of the stages of the disease and the most prominent symptoms in both adults and children.

Table 2.1

Stages of HIV-infection

Stage of infection	Characteristics
1. Acute seroconversion stage	Glandular fever-like symptoms
2. Asymptomatic latent phase	Very few symptoms
3. Minor symptomatic phase	Immune system becomes compromised and symptoms begin to increase
4. Major symptomatic phase	Immune system becomes even further compromised with a significantly higher viral load and various opportunistic diseases
5. AIDS – also described as the severe symptomatic stage	Immune system completely fails

(Van Dyk, 2001; WHO, 2010)

2.3.1.2 Treatment, side effects and adherence.

The treatment of HIV in paediatric populations poses a bigger challenge than for adults due to fewer anti-retroviral medications available to children, higher treatment costs, and the fact that children depend on their caregivers for correct medication administration and adherence. The concomitant medical treatment of a child living with HIV is also more complex than the more standard treatment regimens of adults (UNAIDS, 2014).

Despite these challenges, antiretroviral therapy (ART) and highly active antiretroviral therapy (HAART), has allowed for significant progress to be made in treating paediatric HIV. Since South Africa's Department of Health initiated ART for children in 2004 there has been a substantial decrease in the morbidity and mortality rates of HIV-positive infants and children (Sutcliffe, Dijk, Bolton, Persaud, & Moss, 2008). The South African National Department of Health's (2014) treatment protocols prescribe that all HIV-positive children four years or younger receive ART, irrespective of CD4 counts. When children are older, treatment is guided by age, weight, the presence of symptoms, and CD4 counts.

Successful HIV treatment and management also have a direct bearing on children's mental health. Misdrahi, Funk-Brentano, Tardieu, Blanche, and Mouren-Simeoni (2004) showed a significant correlation between low CD4 lymphocyte counts and psychiatric complications in children living with HIV.

Although there is still no cure for HIV, diagnostic and treatment advances have greatly improved the quality of life and life-expectancy of those living with HIV. Unfortunately, HIV treatments also have negative complications. Not only are there financial costs and practical issues involved, but there are also extensive side-effects and complications. Consequently, the benefits of early initiation on ART regimes have to be weighed against drug side-effects and toxicity (Greene, 2007; Van Dyk, 2001).

Adverse side-effects and the lack of availability of medication often lead to poor or even non-adherence. Non-adherence to treatment is one of the main causes of drug resistance in both HIV and tuberculosis treatment. Drug resistance greatly reduces the gains made in the treatment and increases the spread of the HI virus (Uzochukwu et al., 2009; Volberding & Deeks, 2010).

Before investigating how HIV specifically affects the mental health of children, one has to have a general understanding of the relationship between HIV infection and mental health, which will be discussed next.

2.3.2. Mental health disorder comorbidity for adults with HIV.

Both international (Breuer, Myer, Struthers, & Joska, 2011; Shacham, Basta, & Reece, 2008) as well as South African (Myer et al., 2008; Olley, Seedat, & Stein, 2006) research indicate a significant prevalence of psychological problems among people living with HIV. Research shows that as many as 48% of adults with HIV in South Africa also suffer from mental disorders (Myer et al., 2008).

Brandt (2009) published a review of literature focusing on the mental health of adults living with HIV in Africa. Brandt found that the majority of the research pointed to high levels of mental health problems among people living with HIV. Depression was found to be the most prevalent mental health problem (Brandt, 2009). These findings were comparable to those in other parts of the world.

A number of studies indicated clinically significant depressive symptoms, or levels that exceeded those of HIV-negative populations, as well as significant levels of anxiety, substance abuse and post-traumatic stress disorder (PTSD) (Kaharuza et al., 2006; Mfusi & Mahbeer, 2000;

Rochat et al., 2006; Sebit et al., 2003; Simbayi et al., 2007; Stangl, Wamai, Mermin, Awor, & Bunnell, 2007).

Some studies indicated that there is a gender difference in mental health problems. Findings indicated that men are more likely to engage in substance abuse than women, while women were found to experience more depression, PTSD, anxiety and somatisation (Kaharuza et al., 2006; Myer et al., 2008; Olley et al., 2006; Reece et al., 2008; Sebit et al., 2003).

Brandt (2009) noted that factors such as age, marital status, financial insecurity, and education may be implicated in the mental health status of HIV-infected individuals.

The mental health of people living with HIV has a direct bearing on their adherence to treatment. Mayston et al. (2012) found that depression was associated with non-adherence in 10 out of 12 reviewed studies, and alcohol abuse was associated with non-adherence in 10 out of 11 studies. Similarly, Sledjeski, Delahanty, and Bogart (2005) showed that PTSD and comorbid depression negatively influenced adherence to highly active antiretroviral therapy (HAART).

Other research indicates a significant prevalence of mental health problems among people living with HIV and the detrimental impact that this has on adherence, treatment outcomes and behavioural practices. Olagunju, Ogundipe, Erinfolami, Akinbode, and Adeyem (2013) and Mellins et al. (2004) justifiably advocate for the integration of mental health services into HIV care and treatment.

Dos Santos (2015), who performed a situational analysis of mental health/HIV services in South Africa, reiterates this call for greater availability and integration of mental health services with HIV treatment programmes, as well as an upscaling of training and awareness.

The next section will discuss the mental health consequences for children living with HIV.

2.4 HIV and the Mental Health of Children

2.4.1 Introduction.

In addition to the purely medical implications of the HIV epidemic, the disease also poses many other challenges. Nearly every sphere of a child's functioning is affected by the disease. Amongst these are the cognitive, developmental, emotional, behavioural, social and educational areas of functioning (Steele, Nelson, & Cole, 2007; Stein et al., 2014; Wachsler-Felder & Golden, 2002).

Because children are still developing, the virus affects them differently than it does adults (Lowenthal, Cruz & Yin, 2010). What is known about HIV in adults can therefore not necessarily be extrapolated to apply to children.

The reality with children might be more complex, because children are more vulnerable to influences from the environment and have less control over their circumstances. It also seems that their coping mechanisms in dealing with illness, stress and trauma might be different (Ebersohn & Eloff, 2002). In the following sections a closer look at the plight of children living with HIV will be scrutinised from previous research.

A useful starting point before moving on to specific disorders is a review conducted by Scharko (2006) which sought to evaluate literature specifically focusing on DSM psychiatric disorders in the context of paediatric HIV. The ages of the subjects ranged from 4 to 21 years. The average prevalence rates for psychiatric disorders were 28.6% for attention deficit hyperactivity disorders (ADHD), 25% for depression, and 24.3% for anxiety disorders. Other studies have had similar findings, indicating ADHD, depression, anxiety, and disruptive behavioural disorders as the most prevalent (Brown et al., 2000; Misdrahi et al., 2004; Rao et al., 2006).

The majority of research regarding the mental health of children living with HIV have, however, been conducted in developed countries situated in the western context. In the literature research the researcher struggled to find specific research on the mental health of children living with HIV in South Africa. Ebersohn and Eloff (2002) published a paper in which they discussed the psychosocial and coping challenges faced by South African children living with HIV. This did, however, not involve any quantifiable measures of mental health problems experienced by South African children. Similarly, Pienaar and Visser (2012) published qualitative research about the experiences of South African adolescents living with HIV but did not specifically focus on mental health problems. Research conducted in South Africa in the context of mental health and HIV have focused mainly on the following areas:

- Mental health problems and coping of adults living with HIV (Kotzé, Visser, Makin, Sikkema, & Forsyth, 2013; Myer et al., 2008; Olley et al., 2006).
- Mental health and psychosocial problems of mothers living with HIV and parenting interventions (Amzel et al., 2013; Boeving Allen et al., 2013; Eloff et al., 2011; Eloff et al., 2014; Lachman, Cluver, Boyes, Kuo, & Casale, 2014).
- Mental health and psychosocial functioning of children who have parents living with HIV (Sipsma et al., 2013).
- Mental health problems and psychosocial functioning of orphans and children made

vulnerable by AIDS (Cluver, Bowes, Gardner, 2010; Cluver & Gardner, 2006; Cluver, Orkin, Gardner, & Boyes, 2012).

The following sections will look more closely at specific mental health problems identified in existing literature among children living with HIV.

2.4.2 Attention-deficit/hyperactivity disorders.

As stated previously, most research regarding mental health problems among children living with HIV identified ADHD as one of, if not the most prevalent of identified disorders (Roa et al., 2006; Scharko, 2006). From the literature reviewed by Scharko (2006) the estimated prevalence of ADHD is 28.2% among children living with HIV.

Hardly any studies distinguish between the subtypes of ADHD. One of the few studies that makes the distinction was that of Nozyce et al. (2006). The researchers identified hyperactivity in 20%, and impulsive-hyperactivity in 19% of their sample of clinically stable children living with HIV.

It should, however, be noted that the findings of Mellins et al. (2006), which was one of the few studies that included a demographically matched comparison group of HIV-negative children, ascribed the high prevalence of ADHD symptoms among HIV-positive children to other factors than the children's HIV-status. Rather, Mellins and colleagues (2006) attributed the high rates of ADHD among the HIV-positive children to family disruptions, poverty, trauma, parental drug use and parental mental illness.

Similarly, Brown et al. (2000) and Nassen et al. (2014) stressed that differential diagnostic considerations should be taken into account when considering attention problems in children diagnosed with HIV, such as medication side effects, anaemia and malnutrition.

2.4.3. Depression.

Although there are some reports of mania and bipolar disorder among children living with HIV (Nassen et al., 2014), the most frequent reported affective symptoms fall into the depressive range (Brown et al., 2002; Gaughan et al., 2004; Nassen et al., 2014; Roa et al., 2007; Scharko, 2006). Scharko (2006) reviewed research, spanning from 1988 to 2004, related to DSM (III and IV) psychiatric disorders amongst children with HIV. The author indicated that amongst the studies that employed quantifiable measures, the average prevalence rate of depression was 25%. Gaughan et al. (2004) conducted research on the psychiatric hospitalisations of children and adolescents living with HIV. From a study population of 32, depression contributed to half

of the subject's admissions (some underwent admission for multiple symptoms). In six cases, suicidal ideation was present (Gaughan et al., 2004). Research conducted by Misdrahi et al. (2004) yielded similar results, with 47% of cases presenting with depression.

It is interesting to note that findings related to the prevalence and severity of depressive symptoms differ between those reported by HIV-positive children and those reported by their caregivers. The latter tend to report higher frequencies as well as greater severity of symptoms than the children (Mellins et al., 2006; Roa et al., 2006).

When considering affective disorders amongst children and adolescents living with HIV, Roa et al. (2007) however cautions against making over-simplistic diagnoses. Certain non-pathological states, such as grief and mourning, which children living with HIV may experience, may present in the form of depressive symptoms.

2.4.4 Anxiety-related disorders.

Anxiety is a normal reaction to certain stressors, and can often serve as an adaptive response by alerting a person to potential threats. However, it becomes maladaptive when the duration and intensity impairs a person's daily functioning and quality of life (Sadock, Kaplan, & Sadock, 2007).

Anxiety disorders are common mental health problems amongst children and adolescents in the general population (Perou et al., 2013), as well as in children experiencing medical illness (Pao & Bosk, 2011). Similarly, Benton and Ifeagwu (2008) found anxiety disorders to be one of the most prevalent mental health problems experienced by children living with HIV. Several researchers confirmed these results (Misdrahi et al., 2004; Roa et al., 2007; Scharko, 2006). Research conducted in Rwanda which explored local understandings of mental health problems in the context of child and adolescent HIV, also identified numerous anxiety-related symptoms (Betancourt, Rubin-Smith, et al., 2011).

The term *anxiety disorders* encompasses a large cluster of disorders – some with very distinct features. Many studies do not distinguish between different types of anxiety of children living with HIV. Those that do provide specifics on the nature of the anxiety disorder, identified generalised anxiety disorder, separation anxiety and panic attacks as most prevalent (Scharko, 2006).

A substantial amount of concurrent biopsychosocial factors relating to paediatric HIV has a direct bearing on generalised anxiety disorder, such as excessive worry about school performance, peer relations, material resources and a variety of physical symptoms (American

Psychiatric Association, 2013).

Separation anxiety may be attributed to frequency of separation, or loss of significant attachment figures, as children living with HIV are often faced with the death or illness of their parents (American Psychiatric Association, 2013; Cluver et al., 2012).

PTSD symptoms were also identified as common in children living with HIV (Nassen et al., 2014). As children living with HIV (specifically those in developing countries where the population in general faces more hardships) are often exposed to numerous traumatic events such as the death of a loved one, receiving an HIV-positive diagnosis, and physical and sexual abuse, PTSD can be expected. As some of the traumas that accompany paediatric HIV do not necessarily resolve, an argument could be made for a chronic form of PTSD in some cases. This seems likely, as PTSD has also been found highly prevalent among adolescents (Marhefka et al., 2009) and adults (Moradi, Miraghaei, Parhon, Jabbari, & Jobson, 2013) living with HIV.

While the specific nature of panic attacks in children living with HIV has not been identified, panic attacks are known to be a symptom of other anxiety disorders such as generalised anxiety disorder or PTSD. Furthermore, panic attacks may also be the result of concomitant medical disorders or medication side-effects (American Psychiatric Association, 2013).

Although symptoms of anxiety are often reported among children living with HIV, Brown et al. (2002), however, notes that these symptoms may be over-estimated in studies that employ measures that only use caregiver reports. It should therefore be kept in mind that research may also reflect the anxiety experienced by parents and caregivers about their children's illness.

2.4.5 Neuro-cognitive and developmental disorders.

Considering that HIV has substantial effects on the central nervous system, and especially on the developing brains of infants and children (Lowenthal et al., 2010; Nassen et al., 2014; Van Rie, Harrington, Dow, & Robertson, 2007), it is not surprising that disorders that specifically involve neuro-cognitive and neuro-developmental factors are common among children living with HIV.

Nassen et al. (2014) estimated that the prevalence rates of neuro-cognitive disorders and specifically HIV-encephalopathies, among children who did not receive ART, varied between 8% and 60%. Since the advent of ART this prevalence has significantly decreased to estimates of between 2 and 15% (Lowenthal et al., 2010; Patel et al., 2009; Van Rie et al., 2009).

Feucht, Meyer, Thomas, Forsyth, and Kruger (2015) call attention to the fact that despite South Africa's progress in HIV testing, many children are only diagnosed with HIV and receive treatment once they are symptomatic. Their nervous system development has usually been significantly compromised by extended exposure to the virus, which often results in preventable HIV encephalopathy.

In children with HIV, encephalopathies tend to present in different ways – either static or progressive. In static encephalopathies the neurological and neurodevelopmental deficits are not progressive. The child is able to acquire new skills, albeit at a much slower pace than their healthy peers. The primary features of progressive HIV-encephalopathy include impaired brain growth (microcephaly), delay or loss of developmental milestones, and pyramidal tract motor deficits, with a continued decline in cognitive functioning (Lowenthal al., 2010; Roa et al., 2007; Van Rie et al., 2007). Although children may appear healthy, many may still display more subtle indications of neuropsychological deficits. These include impairment in language and motor skills (specifically expressive language development), memory and attention difficulties, impaired visual-spatial integration, and impaired executive functioning (Roa et al., 2007; Smith & Wilkins, 2014; Van Rie et al., 2007). Nozyce et al.'s (2006) research also revealed that immunologically compromised children scored lower on intelligence measures.

In children where the disease had progressed to AIDS, progressive HIV-encephalopathy was found to be much more common. Other neurocognitive changes such as progressive bradykinesia, spasticity, and, less commonly, psychotic symptoms were identified. This cluster of symptoms can be compared to AIDS-related dementia in adults (Roa et al., 2007; Smith & Wilkins, 2014; Van Rie et al., 2007; Wachsler-Felder & Golden, 2001).

The impact that HIV infection has on the developing central nervous system is complex, thus only a condensed explanation thereof will be given. The virus is found in both the brain and cerebrospinal fluid of infected children. Although neurons themselves are not infected, they become surrounded by a toxic environment as a result of numerous cellular processes and chronic auto-immune inflammatory response (Leventhal et al., 2010; Wachsler-Felder & Golden, 2002).

Other neuro-biological influences such as toxicity from medication, viral and opportunistic infections also affect a child's central nervous system. This in turn further compromises their behavioural and emotional functioning (Lowenthal et al., 2010; Wachsler-Felder & Golden, 2002).

Researchers (Brown et al., 2000; Rie et al., 2007; Smith & Wilkins, 2014) do, however, draw attention to the fact that neuropsychological deficits in children living with HIV may also

be the result of environmental and socio-economic variables such as low levels of maternal literacy, maternal illness or substance abuse during pregnancy, poor socio-economic status, poor quality of interaction between caregiver and child, low birth weight, and malnutrition.

2.4.6 Disruptive behavioural disorders.

Before research about this cluster of disorders in children with HIV can be discussed, a note of clarification is needed. In the literature scrutinised, the term *behavioural disorders* is often used in conjunction with *emotional disorders* to denote the whole spectrum of mental health problems. In other cases it is used to refer specifically to conduct or oppositional defiant disorders. However, Sadock et al. (2007) indicate that the term *disruptive behavioural disorders* refers exclusively to conduct or oppositional defiant disorders.

A literature review by Scharko (2006) shows that when reporting on clinically *observed* mental health problems, conduct disorders were identified once amongst nine studies reviewed (Pontrelli et al., 1999 cited in Scharko, 2006). However, in eight studies which reported specifically on diagnosed DSM disorders, only oppositional defiant disorder was identified once (Havens et al., 1994 cited in Scharko, 2006).

Disruptive behavioural disorders were also identified in literature reviewed by Rao et al. (2006), although there was no indication of specific research on either conduct or oppositional defiant disorder.

Research conducted by Mellins et al. (2006) on perinatally infected children and youths (aged 9-16) found conduct disorder amongst 13% of their sample and oppositional defiant disorder amongst 11%.

Research by Nozyce et al. (2006) which looked at the behavioural and cognitive profiles of clinically stable children living with HIV, identified conduct disorder amongst 16% of their sample. Nozyce and colleagues also found that the lower a child's CD4 count, the more likely they were to present with conduct disorder. It appeared that living with a biological parent is a protective factor, as these children were less likely to present with conduct problems. Nozyce et al. (2006) however, caution against drawing oversimplified causal conclusions as they point out that it may be the greater exposure to other adversities (such as the loss of a parent) that may be contributing to these findings.

When Bomba et al. (2010) assessed, perinatally infected Italian children receiving HAART with the Child Behaviour Checklist (CBCL), results showed that these children were at a significantly elevated risk for delinquent behaviour, but not aggressive behaviour. This risk also increased with children's viral load (Bomba et al., 2010).

Rao et al. (2007) speculated that disruptive behavioural disorders observed amongst children with HIV may also be in part attributable to the child's attempts at coping, and an expression of distress caused by the disease and its consequences.

Although research has established physiological causes of behavioural problems in children with HIV, psychosocial factors such as disrupted parent-child relationships and parenting style should not be discounted (Aunola & Nurmi, 2005; Johnston & Mash, 2001).

After a review of research about antisocial and violent behaviour, Raine (2002) warned that these outcomes are, in most cases, the result of a complex interplay of social and biological processes. This is valuable to keep in mind, as it applies to other mental health problems in the context of paediatric HIV as well.

2.4.7 Interrogation of possible causal and mediating factors.

The following section will attempt to identify some of the contributing, predisposing and risk factors that may play a role in the development of mental health problems in children living with HIV. Research findings will be highlighted and hypotheses that specifically interrogate the situation of South African children will be considered.

In an attempt to simplify this exploration, the biopsychosocial perspective suggested by Roa et al. (2007) will be used. The biopsychosocial model's conceptualisation includes both the mental and physical spheres of illness, and uses the interdependence of biological, psychological, and social factors to describe and understand illness. It should, however, be noted that any attempt to categorically classify these extensive factors remains an oversimplification.

2.4.7.1 Biological factors.

Often mood and other psychiatric disorders are the direct consequence of organic conditions, ranging from a compromised nervous system, brain cell death due to neuro-toxicity and malnutrition, to stunted growth (Brown et al., 2000; Nassen et al., 2014; Roa et al., 2007; Tardieu, Chenadec, & Persoz, 2000).

Some HIV-medications have negative side-effects which could cause mental health problems. Research indicates that many psychotropic medications also have adverse interactions with ARV or HAART regimes. This makes the treatment of psychiatric disorders in children living with HIV especially difficult (Brown et al., 2000; Nassen et al., 2014; Roa et al., 2007).

Physical symptoms, either as a direct consequence of HIV-infection or from comorbid conditions can play a significant part in the development of mental health and associated problems.

One of the consequences of HIV infection is the experience of pain. Research conducted by Yaster and Schechter (1996) found that nearly 60% of children living with HIV surveyed in their study experienced pain. McCollum and Pittman (2010) further underscored that children living with HIV generally experience pain throughout all the stages of the infection and that they often underreport these symptoms. Pain in turn can have a negative effect on a child's quality of sleep and general vitality. Pain on its own, or combined with inadequate sleep, can contribute to poor school performance and depressive symptoms (De Ridder, Geenen, Kuijer, & Van Middendorp, 2008; McCollum & Pittman, 2010; Nöstlinger et al., 2006).

Some of the more visible symptoms of HIV are chronic dermatological conditions and delayed physical development (Gaughan et al., 2004). This could lead to a negative body image and poor self-esteem, resulting in depression or anxiety symptoms.

2.4.7.2 Psychological factors.

Living with HIV also entails having to face numerous psychological challenges. One of the most difficult could be considered the awareness that one has HIV. A child's knowledge of their HIV-status could be considered to fall into two stages – an initial, acute phase after receiving such news, and a longer, chronic phase.

Children's reactions to the news that they are HIV-positive depend on chronological age and developmental stage. These could range from not understanding or comprehending the implications of an HIV-diagnosis, accompanied with little distress. Being fully aware of the implications of the diagnosis may result in overreaction, which includes catastrophising, feeling overwhelmed, helplessness and anxiety symptoms associated with PTSD.

The manner in which the diagnosis is related and explained to the child might also have a significant effect on how he or she will subsequently cope. If the information is imparted in a supportive and informative way, the child might develop realistic expectations and adequate coping skills (Skovdal & Belton, 2014; Steele et al., 2007).

Brown et al. (2000) makes the important observation that a child's parents' own adaptations to HIV have a significant influence on their child's reaction and ways of coping. In South Africa, parents are often ill-equipped to cope with their own HIV-diagnoses, owing to socio-economic and healthcare challenges (Boeving Allen et al., 2013; Eloff et al., 2011). If parents have difficulty accepting their HIV-statuses, their children will inevitably also struggle

to deal with this knowledge. This could result in numerous mental health problems, ranging from depression, social withdrawal, numbness, loneliness, unresolved anger, acting out, confusion, and a pessimistic view of the future.

Regarding the disclosure of maternal HIV-infection, Sipsma et al. (2014) found that children had less internalising and externalising behaviour when they were told that their mothers suffered from a physical illness, but not that they were HIV-positive, compared to children who had not been told anything. Where children were aware that their mothers were HIV-positive, this knowledge only appeared to affect their behaviour negatively when mothers displayed physical symptoms (Sipsma et al., 2013).

There are, however, conflicting findings regarding the effects that knowledge of their own HIV-positive status have on depression in children. Earlier research by Riekert, Wiener and Battles (1999) indicate that the level of depression decreased when children were aware of their own HIV-positive status, while research by Gaughan et al. (2004) showed that the children in their research who were aware of their HIV-positive status were six times more likely to undergo psychiatric hospitalisations than those who were not aware of their status.

A fear of death and suffering (Roa et al., 2007) is inevitably tied to receiving, and living with an HIV-positive diagnosis. How a child experiences this depends on age, developmental stage and their knowledge of the disease. For example, younger children may fear more concrete, experiential elements such as needles and pain. Older children may be overwhelmed by more abstract aspects such as fear of illness, disability and death, with ensuing depression and even suicidal ideation. This on its own can be a risk factor for the development of depression. Parents of these children face similar losses, as well as having to face other daily struggles such as poor socio-economic conditions and their own health problems, and may therefore be less capable of helping the child through their grieving process (Boeving Allen et al., 2013; Cluver & Gardner, 2006). Complicated grief attached to losing a loved one from AIDS may result in a variety of symptoms, including suicidality, depression, somatisation and sleep disturbances. The stigma attached to dying from AIDS, may further complicate the grieving process (Brown et al., 2000).

2.4.7.3 Familial and social factors.

Issues surrounding the process of disclosure, in the context of paediatric HIV, are extremely complicated. First, there is the question of whether to inform the child of their HIV-positive status. Lesch and colleagues (2007) reviewed research regarding pertinent issues that involve the disclosure of a child's HIV status to him or her. Lesch et al. (2007) found that caregivers

and healthcare workers differ in terms of their perceptions regarding disclosure and its consequences. Healthcare workers are more inclined to support disclosure as they consider age-appropriate disclosure and dispensing of information as having the potential to empower a child to adapt successfully to living with HIV, and non-disclosure as unethical. Contrarily, caregivers of children living with HIV are more reluctant to support disclosure for a number of reasons. These include the fear that disclosure may expose the positive HIV-status of other family members, fearing that the child may accidentally disclose to others, fears of stigma and discrimination, and the worsening the child's emotional or physical health. Caregivers often view children as emotionally and cognitively too young to understand an HIV-positive diagnosis and its myriad complications and see disclosure as a distressing experience from which they wish to protect the child. Caregivers' reticence concerning disclosure may further be related to their own negative and painful disclosure experiences (Lesch et al., 2007).

As there are only guidelines as to when and how a child should be disclosed to, and each child's situation is unique, the caregiver is still tasked with the final decision (Chazal, 2005). This alone can place enormous stress on the caregiver, which may affect the child indirectly (Cluver, Operario, Gardner, & Boyes, 2011; Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013).

Second, once a child is aware of, and understands their HIV-positive status, they too have to face the question and fears of whom to disclose their status to. There are, however, not only negative attributes to disclosure. Steele et al. (2007) indicate that when a child is able to safely confide their HIV-positive status in friends or family, it may alleviate some mental health problems.

An HIV-positive child's relationship with other siblings may become a source of distress when siblings are aware of the HIV-status. Uninfected siblings may harbour resentment and blame. The relationship may also be further complicated by fears of HIV-transmission. This could lead to stigmatisation and ostracisation within the family (Fanos & Wiener, 1994). Where a child's HIV-status is being kept secret from other family members, the dynamics involved in familial secrets may also be a source of distress (Close, 2010).

Inadequate social support from parents, siblings, and close family may impede a child's ability to cope with the illness and has been found to adversely affect mental health (Gaughan et al., 2004; Steele et al., 2007).

Similar to adults, children with HIV are also faced with stigma, discrimination and ostracisation (Nöstlinger et al., 2006; Vreeman et al., 2013). Bond and Nyblade (2006) found that often stigma is not only directed towards the person who is HIV-positive, but also at their

families. Consequently, children with HIV may also have to contend with the stigma attached to their HIV-positive relatives (Bond & Nyblade, 2006). This may have extensive consequences, ranging from being teased by friends to complete ostracisation, exclusion, and even physical violence. It may further result in increased depression, anxiety, post-traumatic stress, peer- and school-related problems (Skinner & Mfecane, 2004; Vreeman et al., 2013).

Research by Nöstlinger et al. (2006) has revealed that children living with HIV-positive parents experience internalised psychological problems, such as nervousness, depression and anxiety. Similarly, Bauman et al. (2006) investigated the psychosocial effects experienced by children who had to take care of their ill HIV-positive mothers. As the parent's health deteriorates, the child has to assume more responsibility in the house. This often results in role reversal and parentification of the child (Bauman et al., 2006).

2.4.7.4 Socio-economic realities, and access to resources.

As the biopsychosocial model does not address socio-economic factors and the impact that a lack of material resources has on living with HIV, this section will briefly address these as potential contributing factors to the mental health problems of children living with HIV.

Socio-economic factors tend to coincide with the HIV epidemic. Poverty and a lack of physical resources were found to be significant indicators for a higher prevalence of mental health disorders among adults (Lund et al., 2011). These findings appear to extend to children living with HIV. For example, it was found that HIV-positive children from low income families who also suffered parental loss displayed significant behavioural and emotional problems (Tadesse, Tsehay, Belaineh, & Alemu, 2012).

On a macro level, a country's inability to provide access to adequate healthcare, education and social support places enormous strain on individuals and families faced with such a serious illness (Mellins et al., 2008; Steele et al., 2007).

As a developing nation and the country with the largest number of HIV-positive children, it is much more difficult for South Africa to provide its paediatric HIV-positive population with sufficient resources such as medical and mental health treatment. These include maternal HIV screening and treatment, the provision of adequate primary healthcare to mothers and children, and the availability of medication and psychosocial support. Due to travel constraints in rural areas and the remoteness of clinics, treatment is also often interrupted. This contributes to drug resistance, which further compromises treatment (Morobadi & Webber, 2014; Sutcliffe et al., 2008).

Where caretakers cannot provide for the most basic needs of children with HIV, repercussions such as malnutrition and developmental delays ensue. Research conducted in South Africa regarding the growth of children receiving long-term ART revealed that many of these children suffer from malnutrition (Feucht et al., 2016). Factors such as these negatively impact the physical and mental well-being of these children. Proper nutrition is an essential component of a child's physical and cognitive development, as well as the maintenance of a healthy immune system. This is even more important for infants and children who are HIV-positive. Children from poorer communities often suffer from malnutrition, compounding the effects of an already compromised immune and nervous systems (Feucht et al., 2016; Sutcliffe et al., 2008).

Researchers stress that children with HIV are, more often than not, faced with a multitude of challenges and risk factors that may predispose them to mental health problems. As many of these factors are interdependent, they tend to compound the development and extent of such mental health problems (Steele et al., 2007; Stein et al., 2014).

Despite this array of potential risk factors, some protective factors have also been identified. Sensitive and developmentally appropriate disclosure, familial and social support, and healthy child and caregiver coping strategies can lead to healthy adaptation (Skovdal & Belton, 2014; Steele et al., 2007; Stein et al., 2014).

Roa et al. (2006), however, asserts that the research findings about the mental health problems of children with HIV are not uniform. No sweeping conclusive statements can therefore be made about the effect of HIV on children's mental health.

2.5 Theoretical Framework

The purpose of the present study is not only to determine whether HIV-positive children experience mental health problems and to what extent, but also to ascertain whether there are any protective factors which buffer against the development or exacerbation thereof. Consequently, the present study also makes use of measurements that assess the coping strategies and self-esteem of the children in the study, as well as assessments which focus on the parental experience of the children's caregivers.

In light hereof, the results of the present study will be discussed and contextualised within the Extended Stress-Coping Model (Maes, Leventhal, & de Ridder, 1996) in Chapter 5. The Extended Stress-Coping Model provides a systemic integration of the biological, psychological and social aspects identified by the biopsychosocial model, as well as incorporating aspects such

as other available resources.

The theoretical background in which the model by Maes et al. (1996) is rooted in, is that of coping theory. Before elaborating on the Stress-Coping Model, a brief explication of the field of coping and how it has been applied specifically to coping with HIV will be given.

2.5.1 History and research pertaining to coping.

The concept of coping emerged from psychoanalytic theory, initially in the guise of defence mechanisms. Defence mechanisms primarily referred to psychological and behavioural manoeuvres used to evade anxiety-provoking situations and emotional states (Burish & Bradley, 1983; Parker & Endler, 1996). The work of Anna Freud promoted the idea that different defence mechanisms could each be considered pathological to lesser or greater degrees (as cited in Parker & Endler, 1996).

This idea initiated the conceptualisation of defence mechanisms, where some were considered as non-pathological or adaptive, and those that were pathological as maladaptive. From this developed the notions of adaptive and maladaptive coping (Lazarus, 1992; Parker & Endler, 1996). Researchers stressed that the value of effective coping lay in enabling a person to adapt positively to changes in their circumstances or environmental demands (Holahan, Valentine, & Moos, 1995; Lazarus, 1993; Lazarus & Folkman, 1984; Moos & Holahan, 2007).

2.5.2 Coping styles and coping with HIV.

Since the inception of research about coping, scholars have sought to identify coping styles and their resulting outcomes. The Lazarus and Folkman Stress-Coping Model, on which the Extended-Stress Coping Model is based, distinguishes between *problem-focused* and *emotional-focused* coping (Lazarus & Folkman, 1984). This constellation of coping styles (problem-focused versus emotion-focused coping) is one of the most prominent in research regarding coping (Coyne & Downey, 1991; Parker & Endler, 1996).

Problem-focused coping involves efforts that address the problem that causes the distress, whereas emotion-focused coping uses strategies to reduce the emotional ramifications caused by the problem through affect regulation. Both of these coping styles can involve the use of cognitive or behavioural strategies (Coetzee & Spangenberg, 2003; Lazarus & Folkman, 1984).

Coetzee and Spangenberg (2003) and Lazarus (1993) stress that no coping style is inherently positive or negative, but that it should be judged in terms of its ability to not only reduce tension for an individual, but also to enable the person to function in their unique

situation. It should also be taken into account that having a chronic illness presents an individual with multi-faceted challenges, each of which may be better addressed by a different coping style or skill. This is especially true in the case of children and adolescents, as their developmental levels also play a role (Schmidt, Petersen, & Bullinger, 2003; Sopena, Evangeli, Dodge, & Melvin, 2010).

As was discussed in the previous section, Ebersohn and Eloff (2002) suggested that South African children who have to cope with HIV are faced with many other challenges besides being HIV-positive. They highlighted factors such as poverty, often living with family members who also have HIV, parentification, orphanhood and educational effects, which may severely undermine a child's ability to cope. However, the authors also pointed out several protective factors such as a stable, supporting family environment and other forms of social support, access to material resources, and environmental support such as good infrastructure, which may in turn facilitate adaptive coping (Ebersohn & Eloff, 2002).

2.5.3 Extended Stress-Coping Model.

The Extended Stress-Coping Model by Maes, Leventhal and De Ridder (1996) has been chosen to contextualise and integrate the results of the present study. This model of coping was specifically developed as a representation of the aspects involved with coping with a chronic illness. As the focus of the research is on the psychological difficulties that children living with HIV, which is a chronic illness, experience, this is particularly fitting.

The model by Maes et al. (1996), described in more detail in Figure 2.1, strives to give a systemic representation of variables that influence coping with chronic illness as a multifaceted process. The model posits that other life events, together with disease and treatment characteristics, disease-related events, and demographic characteristics influence how a person appraises the demands and goals of their chronic illness, and their emotional and cognitive responses. All of these factors, mediated by a person's external and internal resources contribute to what is termed coping behaviour. Coping behaviour can in turn result in psychological, social and/or physical consequences (Maes et al., 1996). Maes et al. (1996) stress the inclusion of other life events because such events influence how a person appraises disease-related events. In the case of HIV-infected children, it should be taken into account that experiences such as the loss of a family member or close relative due AIDS can have a significant impact on a child (Atwine, Cantor-Graae, & Bajunirwe, 2005; Ebersohn & Eloff, 2002).

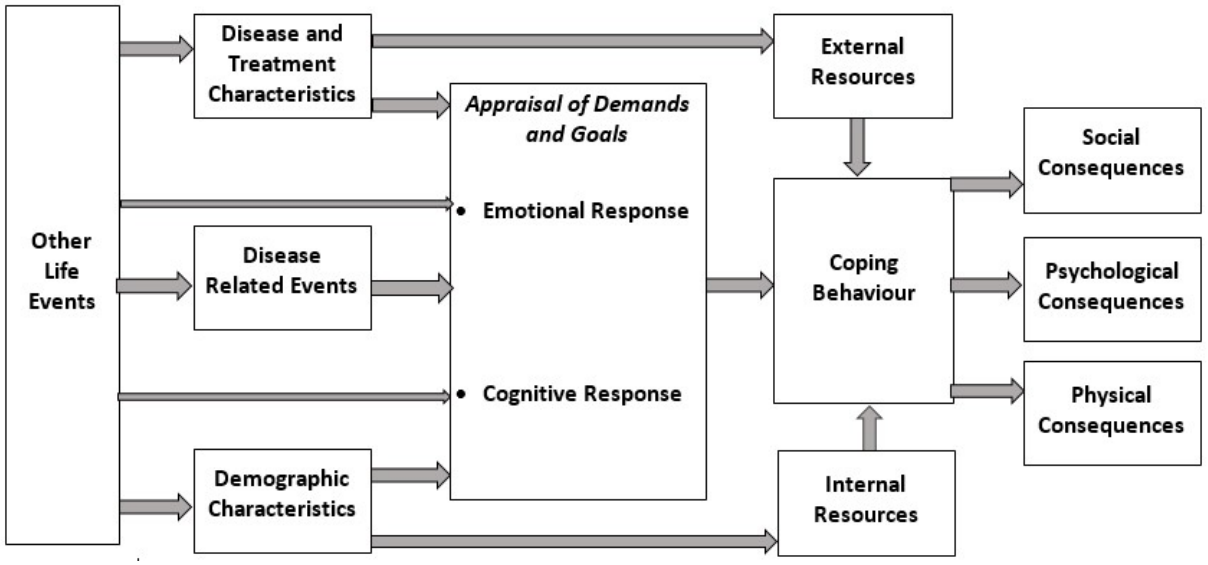

Figure 2.1 Extended Stress-Coping Model (Maes et al., 1996, p. 229)

Another factor that influences how a person appraises his or her illness is the specific characteristics of the disease and its respective treatment(s). Specific characteristics of a disease, such as a lack of controllability, changeability, ambiguity and likelihood of recurrence also influence the form of coping a person is likely to employ. This goes hand-in-hand with how the treatment characteristics of a specific disease can influence a person's experience thereof (Maes et al., 1996). In the case of paediatric HIV these would include aspects such as painful blood tests, a daily medication regime, regular clinic visits, and, in the case of secondary illnesses, many other medical treatments.

Maes et al. (1996) state that despite often being overlooked, demographic characteristics such as age, gender, race and social class also influence how a person interprets their illness and the resulting coping methods employed. In the case of the present study, aspects such as the age and poor socio-economic status of the participants are expected to be the most prominent (Ebersohn & Eloff, 2002).

Another key contributing factor to the coping behaviour is how a person appraises the demands made by the disease and how these demands frustrate the attainment of their current life goals. The greater the degree of demand/goal conflict and the less confidence a person has in his or her ability to obtain a specific goal, the greater will be the amount of related stress experienced, as well as the likelihood of giving up on a goal (which is in itself a stressful experience) (Maes et al., 1996).

The final two components that influence coping behaviour are the external and internal resources available to a person. Maes et al. (1996) describe such resources as "...internal or

external conditions that can be used to cope with demand/goal conflicts" (Maes et al., 1996, p.232). They identify financial resources, time, distance from professional help, and social support as examples of external resources. Internal resources are said to consist of the person's available energy or physical strength and certain personality characteristics. The personality characteristics that Maes et al. (1996) identify as mediating goal conflicts are intelligence, trait anxiety, depression, optimism, autonomy, ego-strength, hardiness, focus of control, and self-efficiency.

Maes et al. (1996) describe effective coping as a relationship between coping behaviour and successful psychological, social, and physiological outcomes. Maes et al. (1996) point out that there is a definite distinction between the results of passive/avoidant or emotion-focused, and more active problem-focused coping strategies. The utilisation of active problem-focused strategies allows for better adaptation to chronic disease than avoidant emotion-focused strategies (Maes et al., 1996).

2.6 Conclusion

It is evident that the HIV epidemic has complex and far-reaching consequences for infected children that stretch beyond being only a physical illness. Besides the physiological and direct neurological implications of the disease, there exist complex interactions, ranging from socio-economic factors to interpersonal relationships, which can contribute to mental health problems. Given the complexity involved in the mental health of HIV-positive children, an integrated approach is called for.

Unfortunately few studies about mental health problems among children with HIV have been conducted in Africa. There is a dearth of data pertaining specifically to the mental health problems among children living with HIV in the South African context.

If one, however, considers the extent of South Africa's paediatric HIV-infection, in addition to socio-economic hardships, and often poor access to health and mental health services, the potential scale of the problem may become evident. Nassen et al. (2014) stress the need for mental health interventions for children and adolescents with HIV. They point out that, if left untreated, mental health problems can affect ART adherence, educational and medical outcomes.

Research that can shed more light on the specific mental health problems faced by South African children living with HIV may therefore be valuable in determining what the current situation is, but also providing insights into possible solutions (Ebersohn & Eloff, 2002). This

study will therefore not only seek to identify mental health problems among children living with HIV, but also look at which coping strategies they find useful, as well as the how their caretakers tend to cope with this situation.

Chapter Three - Research Method

3.1 Introduction

In this chapter, the various methodological considerations will be discussed, specifically how these will serve to address the three aims of the present study. The study aims to determine whether and to what extent HIV-positive children experience mental health problems, how these compare to those of HIV-negative children, as well as identify any mediating variables in the presentation of these. These aims are translated into the three research questions stated in section 3.2. For these purposes, data was gathered from HIV-positive and HIV-negative child-caregiver pairs, in the form of interviews and various psychological assessments. As children living with HIV have often lost one or both of their parents, many are looked after by relatives. Therefore, the term *caregiver* will be used to refer to a child's parent or guardian.

3.2 Research Questions

The present study seeks to answer the following research questions:

- What mental health problems, if any, do HIV-positive children that attend the Kalafong Paediatric Clinic experience? From the literature scrutinised, it seems that HIV-positive children can experience specific psychological problems, especially affective, anxiety, ADHD and disruptive behavioural problems.
- Do HIV-positive children differ from HIV-negative children who live in the same community in terms of psychological problems? Very little research has been done on the topic that employs comparison groups. Even though the expectation is that HIV-positive children may experience more problems than children not living with HIV.
- Which variables possibly play a role in contributing to mental health or mental health problems of children who are diagnosed HIV-positive and receive treatment at an outpatient clinic?

3.3 Research Design

The present study employs a comparative correlational strategy, which is situated within the broader quantitative methodology. To this respect, the present study relies on numerical data, which Whitley (2002) identifies as the main attribute that distinguishes qualitative research from quantitative research.

In this study, HIV-positive children attending Kalafong Paediatric HIV Clinic and their

caregivers were interviewed to determine the mental health status of the HIV-positive children. This was done by administering psychological assessments to both caregivers and children. In addition, caregivers completed a survey that ascertained demographic information about themselves and their children.

A similar dataset from a group of HIV-negative children and their caregivers was used to determine whether the rates of mental health problems assessed differed significantly between the two groups. This information was then used to determine whether any correlations or differences between the demographic information of the two groups and their caregivers, and the results of the assessments could be established.

In the field of epidemiology, this type of correlational research is akin to *ecological* research, which is the type of observational study that analyses the relationship between the health status and other variables of groups of people (Bonita, Beaglehole, & Kjellstrom, 2006).

It should be kept in mind that although this research design may allow one to determine whether there is a correlation between the HIV-status and mental health problems of children, it does not allow for establishing any causal relationships (Bonita et al., 2006; Whitley, 2001).

As ethical considerations do not allow for employing experimental research with a control group in the present research setting (Bonita et al., 2006; Whitley, 2001), the fact that the present study employs a comparison group distinguishes it from most other studies in the field of mental health and HIV infection in children.

3.4 Research Procedure

3.4.1 Participants.

The total sample consisted of 167 children and their caregivers. This consists of a focus and a comparison group. The focus group consisted of 54 HIV-positive children and their caregivers. The comparison group consisted of 113 HIV-negative children and their caregivers.

The focus group was recruited at the Kalafong Paediatric HIV Clinic, where children receive medical treatment and their routine medication every month. The ages of the children ranged between 6 and 12 years. These children live in Attridgeville and surrounding areas situated in the Tshwane metropolitan area.

In order to be included in the focus group of the research, participants had to meet the following criteria:

- The age of the child had to range between 6 and 12 years
- The HIV-positive status of the child had to be documented in their medical file

- Children had to be accompanied by a person that had the capacity to act as their legal guardian
- Children had to be able to understand and speak at least one of the four local languages – Sepedi, Sesotho, Setswana, or isiZulu – or English.

The comparison group consisted of HIV-negative children of the same age range and geographic area. These children and their caregivers attended a clinic in the Attridgeville area at the same time that the research was conducted and it was noted in their medical files that both the caregivers and the children were HIV-negative.

3.4.2 Sampling procedure.

This section will describe how the participants of this study were selected.

The majority of South Africa's HIV-positive paediatric population fall into lower socio-economic groupings and reside in rural or township areas, with limited access to resources (Shisana et al., 2014). Therefore, an area such as Attridgeville, in the Tshwane Metropolitan Area of South Africa, could be considered a good representation of the personal and broader social circumstances the majority of children living with HIV in South Africa face.

For the focus group, a systematic sampling method was used to recruit participants. On the two clinic days at the Kalafong Paediatric Clinic, when only HIV-positive children and their caregivers attend the clinic, children and their caregivers usually queue to see the doctor and receive their routine medication. Every patient receives a number and the medical team sees the patients in that sequence. Every fifth caregiver waiting in the queue was approached, informed of the research and asked whether interviews could be conducted with the caregiver and child. If the caregiver gave consent and the child gave assent, the interviews were conducted (See Appendix B). To obviate inconvenience, participants retained their number and could re-join the queue after the interviews were conducted.

As the data was gathered over a period stretching over more than three months, it so happened that a large number of the caregivers and children who regularly attend the clinic were interviewed by the time that the data gathering concluded.

The data of the comparison group was gathered as part of the *Kgolo Mmogo Project* (Eloff et al., 2011; Eloff et al., 2014; Sipsma et al., 2013). This research was conducted in the same area at clinics referring patients to Kalafong Hospital. This group of caregivers and children aged 6 to 12 were recruited because neither the mother nor the child was HIV-infected. They recently received routine HIV tests and it was noted in their medical files that they were

HIV-negative. This group of participants was selected by the Kgolo Mogo project as a control group for an HIV-affected sample – where the mothers were HIV positive, but the children were not (Eloff et al., 2011; Eloff et al., 2014; Sipsma et al., 2013). Of the data from this control group, caregiver-child data was used where the child was between 6 and 12 years old.

3.4.3 Data gathering procedure

In this section, the focus will be on how the data was collected from the participants.

After a caregiver consented to the research, the caregiver and the child were interviewed simultaneously by two different interviewers in two quiet rooms in the clinic. Interviews and questionnaires were structured and conducted in the vernacular of the caregiver and the child, by trained research assistants. The interviewers were trained in conducting interviews, how to complete the questionnaire, when to ask for more information, and adherence to ethical principles. Caregivers and children received a cold drink and a snack as sign of appreciation for their participation in the study. The completed paper-format interview was entered into a Microsoft Excel document directly after the interview.

The interview schedules of the caregivers contained biographical information about themselves and their children, data on disclosure of the children's HIV statuses, psychological assessments on their parenting styles (CCNES and PSI-SF) and a scale to assess child mental health (CBCL). The Interview schedules of the children consisted of three psychometric scales that assess self-esteem (SDQ-I), anxiety (RCMAS) and coping skills (Kidcope). The interviews took about 30 to 45 minutes.

All the scales used in data gathering have already been used as part of the Kgolo Mmogo Project conducted at the Kalafong Hospital and surrounding clinics. As part of the Kgolo Mmogo Project, these scales were reviewed by the research team for conceptual applicability and by local community advisors for cultural relevance. The instruments were thus adapted for use in the specific population. All instruments were translated into four local languages, back-translated and then piloted with 20 mothers (Eloff et al., 2011; Eloff et al., 2014; Sipsma et al., 2013). Similar data was thus collected for the focus group of HIV-positive children and the comparison group consisting of HIV-negative children.

3.5 Measurement instruments

3.5.1 Data gathered from caregivers.

The structured interview with the caregiver consisted of the following questions and scales that

were asked verbally by the interviewer. The interviewer completed the questionnaire from the verbal responses of the caregiver.

3.5.1.1 Biographical and other data pertaining to disclosure of the child's HIV status.

The following data was collected from the caregivers:

- Age of caregiver
- Educational status of caregiver
- Marital status
- Use of community resources
- Household composition
- Age of the child
- Whether child has ever repeated a grade in school
- Health status of the child
- Disclosure of child's HIV-status to them
- Disclosure of caregiver's HIV-status to child (Appendix C)

3.5.1.2 The Child Behaviour Checklist (CBCL).

The children's emotional and behavioural problems were measured with the parent-report of the Child Behaviour Checklist (CBCL) (Achenbach & Rescorla, 2001) (Appendix D). The first edition of the CBCL was published in 1983, and used a sample of 2,300 children from the United States, aged 4 to 16 (Achenbach & Edelbrock, 1983). This was followed by numerous revisions and versions. The CBCL has become one of the most widely used parent-report assessments of mental health problems in children and adolescents (Nakamura, Ebesutani, Bernstein, & Chorpita, 2008).

Achenbach and Rescorla (2001) released a revised edition of the assessment of children ages 6 to 18 in 2001. It is based on data from a non-referred sample of 1,753 children and adolescents from 40 states in the United States of America, Australia, Canada, Jamaica, and the United Kingdom. The average ethnic composition of the sample was 59% Caucasian, 20% of African descent, 11% Hispanic/Latino, and 11% mixed or other (Achenbach & Rescorla, 2001).

Caregivers were asked to rate the characteristics and typical behaviours of children, which had occurred during the preceding six months. Caregivers had to score these on a three-point Likert scale as 0 (absent), 1 (occurs sometimes), or 2 (occurs often).

For the purpose of this study, the DSM-orientated scales of the CBCL/6-18, which are consistent with DSM-IV diagnostic categories, were used (Achenbach & Dumenci, 2001). It includes the following six subscales:

- Affective Problems: based on ratings for dysthymia and major depressive disorder.
- Anxiety Problems: based on ratings for generalised anxiety and separation anxiety disorder, and specific phobias.
- Somatic Problems: based on ratings for somatisation and somatoform disorder.
- Attention Deficit/Hyperactivity Problems: based on ratings for hyperactive-impulsive and inattentive types of attention deficit/hyperactivity disorder.
- Oppositional Defiant Problems: based on ratings of behaviour associated with oppositional defiant disorder.
- Conduct Problems: based on ratings of behaviour associated with conduct disorder.

The DSM-oriented scales of the CBCL/6-18 were constructed by identifying DSM-IV diagnostic categories consistent with behavioural and emotional problems that could potentially be related to items in the CBCL/6-18. A multi-cultural group of 22 psychologists and psychiatrists specialising in psychopathology then rated the degree of consistency of these items with the DSM-IV categories. Items which were rated as being "very consistent" were then incorporated with existing data of the CBCL/6-18 to determine percentiles, T scores, and clinical cut-off points for each subscale, according to age and gender.

The DSM-oriented scales of the CBCL/6-18 has the following psychometric properties: internal consistency ranging from $\alpha = .75$ to $\alpha = .84$ (overall mean = .80) and test-retest reliability (over a period of 8 to 16 days) ranging from $\alpha = .78$ to $\alpha = .88$ (overall mean = .83) (Achenbach & Rescorla, 2001; Achenbach & Dumenci, 2001; Achenbach, Dumenci, & Rescorla, 2003).

Nakamura et al. (2008) confirmed the sound psychometric properties of the DSM-oriented subscales of the CBCL/6-18 through research with a clinical sample of 637 children and adolescents finding acceptable validity, reliability, and internal consistency of the scales.

The CBCL is often used for assessments in medical settings (Achenbach & Ruffle, 2000), and has been used in research on the mental health functioning of Italian children living with HIV (Bomba et al., 2010). The CBCL has not been standardised for South African samples, although it has been used in several studies based on South African samples (Boeving Allen et al., 2013; Cluver, Gardner, & Operario, 2007; Eloff et al., 2014; Sipsma et al., 2013).

In the present study, US norms (Achenbach, et al., 2003) for the DSM-Orientated subscales are used to categorise the behaviour of the children, as multi-cultural norms for the

CBCL DSM-Oriented subscales are not available for the hand-scored profiles (Appendix E). Any issues that can exist with the use of these norms, can be cancelled out with the data of the comparison group.

3.5.1.3 Coping with Children's Negative Emotions Scale (CCNES).

The CCNES (Fabes, Eisenberg, & Bernzweig, 1990; Fabes, Poulin, Eisenberg, & Madden-Derdich, 2002) was used to assess caregivers' typical reactions to children's negative emotions (Appendix F). The caregiver is presented with 9 hypothetical situations in which the child becomes upset or angry and asked to rate how likely he or she is to respond in a specific way. Caregivers have to rate their reactions on a 6 point Likert scale ranging from "very unlikely" to "very likely".

The present study uses the distinction made by previous research amongst a similar population between *supportive* and *non-supportive response* or *positive* and *negative parenting domains* (Boeving Allen et al., 2013; Eloff et al., 2014). Supportive responses are those that are considered to foster positive attachment and social adjustment, whereas negative responses are those that are related to maladjustment and anti-social behaviour (Carlo, Mestre, Samper, Tur, & Armenta, 2011).

Higher scores on a particular subscale are indicative of more frequent use of that specific response style. Supportive response scales are:

- Expressive Encouragement is used in a situation where the child is encouraged to express negative affect or where negative emotion is validated.
- Emotion-Focused Reactions are intended to help the child feel better.
- Problem-Focused Reactions are intended to help the child solve the problem that caused the distress.

Non-supportive response scales are:

- Distress Reactions, which measure parental distress in response to the child's negative affect.
- Punitive Reactions occur when the child is punished physically or verbally.

The following is an example of one of the scenarios posed to the caregiver and the type of responses which would be indicative of a specific response style. "If my child becomes angry because he or she can't play with his or her friends, I would:

- "…encourage my child to talk with me about his or her feelings." – Expressive Encouragement
- "…soothe my child and try to help him or her calm down." – Emotion-Focused Reaction

- "… help my child think about other ways that he or she can have fun." – Problem-Focused Reaction
- "… get angry at my child." – Distress Reaction
- "… make my child sit and be quiet." – Punitive Reactions

The internal reliability, test-retest reliability and construct validity of the CCNES were tested in a sample 101 parents of 3- to 6-year-old children from a metropolitan area in the United States. The socio-economic status of the parents was primarily middle-class and the racial composition consisted of 86% Caucasian, 9% Hispanic, 3% Black, 1% of Asian heritage, and 1% of mixed origin. The CCNES was found to have an acceptable internal consistency (α = .69 to .85), test-retest reliability over a four-month period (α = .56 to .77) and construct validity relative to other measures of parenting behaviour (Fabes et al., 2002).

The authors, however, stress that the reliability and validity of the CCNES may differ in other countries and cultures. However, the situational prompts and specific language used to describe parenting responses were adjusted in order to be relevant in the South African context as part of the Kgolo Mogo Project (Boeving Allen et al., 2013). In this research, parental responses were summed into positive and negative responses with Cronbach alphas, .792 and .667 respectively (Boeving Allen et al., 2013).

3.5.1.4. Parenting Stress Index - Short Form (PSI-SF).

Two subscales of the short form of the Parenting Stress Index (Abidin, 1995) were employed to measure caregiver experience in the parenting role (Appendix G). The Parenting Stress Index is a measurement that screens parents for stress experienced in their relationship with their child.

In the present research, the *Parent-Child Dysfunctional Interaction* (PCDI) and *Parental Distress* (PD) scales, consisting of 22 questions, were used.

The Parent-Child Dysfunctional Interaction domain measures whether the parent perceives their child to meet the parent's expectations and reciprocates positive interactions. The following is an example of a question which loads on the Parent-Child Dysfunctional Interactions domain: "My child rarely does things that make me feel good."

The Parental Distress domain assesses parental stress in relation to perception of child-rearing competency, spousal or partner conflict, lack of social support, and other limitations experienced as a result of the parenting role. An example of a question that falls into the Parental Distress domain reads, "I often have the feeling that I cannot handle things very well."

Questions consist of statements to which the parent has to indicate their level of agreement, on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores indicate greater levels of stress (Abidin, 1995).

The population used for the development of the measure consisted of 840 mothers and children from Virginia, United States of America. The ethnic composition included 87% White, 10% African-American, and 3% other cultures (Abidin, 1995). Other research did not find significant differences related to a child's gender (Baker et al., 2003; Schiller, 2003).

The PSI-SF has an acceptable test-retest reliability after 6 months (α = .79) and acceptable internal consistency for the Parental Distress domain (α = .87), and Parent-Child Dysfunctional Interaction (α = .80) (Abidin, 1995). Other research indicates that the PSI-SF shows strong content and construct validity across all constructs that are in keeping with the long form of the PSI (Haskett, Ahern, Ward, & Allaire, 2006; Reitman, Currier, & Stickle, 2002; Whiteside-Mansell et al., 2007)

The PSI-SF has previously been used in diverse populations and was found to be reliable and valid amongst populations from lower socio-economic status (Abidin, 1995; Waisbren et al., 2004; Whiteside-Mansell et al., 2007).

3.5.2. The structured interview with the child between 6 and 12 years.

The interviews with the children comprised of the following three assessments, which were administered verbally to them.

3.5.2.1 Self-Descriptive Questionnaire (SDQ-I).

In order to assess the self-concept of children in this study, the Self-Descriptive Questionnaire (Marsh, 1988) for pre-adolescents (SDQ-I) was employed (Appendix H). The Self-Descriptive Questionnaire (comprised of three age levels) is one of the most widely-used and extensively-researched instruments for assessing self-concept (Butler & Gasson, 2005; Byrne, 1996; Rosen, Glennie, Dalton, Lennon & Bozick, 2010).

The population used to develop the SDQ-I consisted of 3,562 Australian, 303 British, and 471 Canadian children, aged 7 to 13. The SDQ-I comprises 24 items which assess a child's Academic Self-Concept (with three subscales), 32 items that assess Non-Academic Self-Concept (with four subscales), 8 that assess General Self-Concept and 12 negatively-worded items to reduce positive response bias (Marsh, 1988).

For the purpose of this study, only items that assess the Non-Academic (excluding the Physical Abilities subscale) and General Self-Concept were included as the focus of the present

study is on the wellbeing of the children. This left a total of 32 items to which respondent indicated his or her agreement on a 4-point, forced choice scale with the end points of "No never" and "Yes always".

Listed below are the subscales that constitute the Non-Academic Self with examples of statements that relate to each (Marsh, 1988).

- Physical Appearance – "I like the way I look."
- Peer Relations – "I make friends easily."
- Parent Relations – "I like my parent(s)."

An example of a statement that loads onto the General Self subscale reads, "I like being the way I am" (Marsh, 1988).

The reliability values of the Total Non-Academic (comprised of the Non-Academic subscales) is α = .92 and the reliability score for the General Self scale α = .81. The construct validity ranged from α = .80 to α = .92 for the seven subscales that constitute the Academic and Non-Academic subscales, while the General Self-concept showed good convergent and divergent validity (Marsh, 1988).

3.5.2.2 Revised Children's Manifest Anxiety Scale (RCMAS).

The Revised Children's Manifest Anxiety Scale (RCMAS) (Reynolds & Richmond, 1978) was used to assess the anxiety experienced by the children in this study (Appendix I). The purpose of the RCMAS is to measure the extent and nature of children's and adolescent's anxiety (Gerald & Reynolds, 1999, p. 323). The RCMAS has been standardised for children from 8 to 12 years. It consists of 37 self-reported items, which are answered with yes/no responses.

Twenty-eight of the items load onto three anxiety subscales, consisting of *Physiological Anxiety* (10 items), *Worry/Oversensitivity* (11 items) and *Social Concerns/Concentration* (7 items). The remaining nine items load onto a lie scale, which screens for social desirability (Reynolds & Richmond, 1978).

Listed below are the subscales that constitute RCMAS and examples of items that load onto the respective subscales (Reynolds & Richmond, 1978):

- Physiological Anxiety – "It is hard for me to get to sleep at night."
- Worry/Oversensitivity – "I worry a lot."
- Social Concerns/Concentration – "Others seem to do things easier than I can."
- Lie Scale factor – "I like everyone I know."

The RCMAS (Reynolds & Richmond, 1978) was originally based on two non-clinical

samples of school-aged children in the United States. One sample consisted of 329 children ranging from grades 1 to 12 and the other of 167 children in grades 2, 5, 9, 10, and 11. The second sample was used for cross-validations. Reynolds and Richmond (1978) reported the reliability of the first group of children as $\alpha = 0.83$, and that of the second group as $\alpha = .85$.

This research was replicated by Reynolds and Paget (1981) with a larger sample of 4,972 children and adolescents aged between 6 and 19 from 13 states across the United States, which confirmed the construct reliability of the measure across grade, race and gender.

In later research with 534 children, Reynolds (1981) determined the nine-month test-retest reliability of the instrument as .68.

The RCMAS was also shown to have a sufficient concurrent validity with other measures of child and adolescent anxiety (Muris, Merckelbach, Ollendick, King, & Bogie, 2002).

Although the RCMAS was predominantly designed as an assessment for anxiety, it also taps into factors related to mood, impulsivity and peer interaction (Muris et al., 2002; Ryngala, Shields, & Caruso, 2005).

3.5.2.3 Kidcope.

In order to assess which coping strategies children living with HIV find useful, the Kidcope (Spirito, Stark & Williams, 1988) version for 7 to 12-year-old children was used (Appendix J). The Kidcope is a self-report measure of child and adolescent coping strategies. Ten different coping strategies are assessed with the 15-item scale. The scale is answered in a yes/no format to determine which coping strategies children use most.

Further research has allowed for a distinction between adaptive and maladaptive coping strategies. Adaptive coping strategies assessed include *Cognitive Restructuring*, *Problem Solving*, *Emotional Regulation*, and *Social Support*. Maladaptive coping strategies include *Distraction*, *Social Withdrawal, Self-criticism*, *Blaming Others*, *Wishful Thinking*, and *Resignation* (Spirito et al., 1988; Stallard, Velleman, Langsford, & Baldwin, 2001).

The Kidcope has shown test-re-test reliabilities ranging from $\alpha = .41$ to $\alpha = .83$. The validity of the Kidcope was determined by comparing it to two other coping measurements: the Coping Strategies Inventory (CSI) and the Adolescent-Coping Orientation for Problem Experiences Inventory (ACOPE). Both of these measures have been standardised. The strongest correlations were found between items of the Kidcope and the CSI, as several items on the Kidcope are relatively similar to the subscales of the CSI (Spirito et al., 1988).

The brevity of the Kidcope has advantages and disadvantages. The short scale is a benefit

when it comes to assessing populations that have been found to disproportionately suffer from attention deficits (Misdrahi et al., 2004; Nozyce et al., 2006). The length of this scale also aids in limiting administration time when children are assessed with multiple assessments. However, the test-retest reliability of the Kidcope is difficult to determine because each coping strategy is assessed with a very limited number of items. Spirito et al. (1988) however point out that because coping is a process that changes over time, the soundness of a coping measurement is probably not best determined by high test-retest correlation coefficients.

Research by Donaldson, Prinstein, Danovsky and Spirito (2000), with a sample of 9 to 17-year-old children and adolescents indicated that the preference for certain coping strategies varied according to gender and age. For example, females preferred emotional expression more than males, while males showed a greater preference for resigned acceptance than females. Younger children also appeared to make more use of wishful thinking, while older children employed a broader range of coping strategies (Donaldson et al., 2000). Differences in coping strategy preference were also identified by the original work of Spirito et al. (1988).

All of the above scales used in data gathering have been used in another South African study – the Kgolo Mogo Project. The Kgolo Mogo Project (Eloff et al., 2011; Eloff et al., 2014; Sipsma et al., 2013) adapted the scales to be appropriate for use in the specific population and translated the questionnaires into Sepedi and Setswana.

3.6 Data analysis

The quantitative data was analysed using the Statistical Package for the Social Science (SPSS) version 22. Categorical demographic information was determined through frequencies and percentages.

Concerning the three aims of the present study, the following breakdown explains which assessments and analyses were employed to investigate each:

Aim 1: Ascertaining what mental health problems do HIV-positive children that attend the Kalafong Paediatric Clinic experience.

- Assessment of HIV-positive children with the CBCL and comparing children's scores on the DSM-Orientated subscales with the norms provided for hand-scored profiles.
- Assessment of HIV-positive children with the RCMAS and comparing their scores with

the gender norms.

Aim 2: Ascertaining whether HIV-positive children differ from HIV-negative children who live in the same community in terms of mental health problems.

- Chi-Squared test statistic was used to compare nominal data in the following instances:
    - Comparing HIV-positive and HIV-negative children's scores across the normal, borderline and clinical ranges of scores on the CBCL DSM-Oriented subscales.
    - Comparing HIV-positive and HIV-negative children's scores across the below normal, normal, and above normal ranges of the RCMAS age norms.
    - Comparing HIV-positive and HIV-negative children's use of coping strategies on the Kidcope.
- The t-test for equality of means was used to compare the mean raw scores of HIV-positive and HIV-negative children on the subscales of the RCMAS
- In order to test whether differences exist between samples, but where the data did not meet the requirements for normally distributed samples or interval data, the Mann-Whitney U test statistic was used to compare HIV-positive and HIV-negative children's results on the SDQ, and the two caregiver populations on the PSI-SF and CCNES.

Aim 3: Identifying which variables possibly play a role in contributing to mental health or mental health problems of children who are diagnosed HIV-positive and receive treatment at an outpatient clinic.

- The demographic variables of children and caregivers and the scale scores of all the measures were compared and correlated to the CBCL scale scores to determine possible relationships.
- Chi-Squared test statistic were used to compare the scores of HIV-positive children who had previously been seriously ill to those who have not, across the normal, borderline, and clinical ranges of the CBCL DSM-Orientated subscales.
- One way analysis of variance (ANOVA) was used to examined the possible relationships between the following variables:
    - The age of HIV-positive children and their results on the mental health assessments.
    - The relation of caregiver's assessment results to children's results on the CBCL DSM-Orientated subscales.
- Spearman's rank order correlation was used where only ordinal data was available in the

case a possible correlation of the number of people living in households and assessment results of HIV-positive children and their caregivers.

The present study initially intended to employ multiple regression analysis to determine variables (for example: children's and caregivers' demographic variables, children's choices of coping strategies, caregivers' assessment results) that could predict the mental health outcomes of children infected with HIV. However, as few strong correlations between variables were identified, the multiple regression analysis was abandoned.

3.7 Ethical Considerations

Before the study was conducted, ethical clearance was obtained from both the Ethics Committee of the Faculty of Humanities of the University of Pretoria, as well as the Kalafong Paediatric Clinic. The data collection of the comparison group was ethically approved by the Faculty of Health Sciences Research Ethics Committee of the University of Pretoria.

Respondents were asked to voluntarily participate in the research. All caregivers gave informed consent and signed informed consent forms. The children also gave informed verbal assent before interviews were conducted with them. Participants were informed that they could withdraw at any time and that information would be anonymous and confidential.

To ensure confidentiality, the following steps were taken. No identifying information was recorded on the questionnaires, and the documents were kept in the safe of the Department of Psychology and were only scrutinised by the researcher and supervisor for analysis.

The project leaders of the Kgolo Mogo Project gave permission for the use of the data of the comparison group in this project. This data will be stored electronically in a research storage area in the Department of Psychology for a period of 15 years.

3.8 Conclusion

This chapter has provided an overview of the research method used in the present study. The study describes and compares quantitative data from a sample of HIV-positive children and their caregivers with a sample of HIV-negative children and their caregivers in Tshwane. The data is then further analysed to determine which variables relate to mental health to identify possible predisposing or protective factors to mental health problems. This study uses data gathered for a needs assessment at the Paediatric HIV Clinic of the Kalofong Hospital for the focus group. Data gathered as part the Kgolo Mogo Project is used to serve as the comparison group.

Chapter 4 – Results

This chapter is divided into three sections. The first section describes the participant characteristics of both children and caregivers. The second section is presented in two subsections. The first subsection presents the results of the mental health assessments, a self-esteem measure, and coping strategies used by the children in this study. The second subsection presents results from the assessments of the caregivers on their experience of stress in the caregiving role, and their experience of their relationships with the child. The final section is dedicated to investigating which factors may play a role in HIV-positive children's mental health functioning, self-esteem, and use of coping skills, and why these may differ from their HIV-negative counterparts.

4.1 Participants' Characteristics

In this section, the focal demographic characteristics of the participants are presented. The information in this section is gleaned from questions asked of the children's caregivers. First, information about the focus group of HIV-positive children is given. This is followed by comparisons of HIV-positive and HIV-negative children and caregiver groups. Lastly, information is presented that describes the children's insight into and awareness of their own and their caregivers' HIV status and health.

4.1.1. Children.

The demographic characteristics of HIV-positive children are given in Table 4.1.

Table 4.1
Demographic Characteristics of HIV-Positive Children

	Male (n = 25)	Female (n = 29)	Total (n = 54)
Mean age	7.92 years (7 years, 11 months)	8.55 years (8 years, 6 months)	8.26 years (8 years, 3 months)
Attends school	25 (100%)	28 (97%)	53 (98.15%)
Grade in School	Grade 2 (n = 21)*	Grade 3 (n = 19)*	Grade 2-3 (n = 40)*
Repeated a grade in school	6 (28.57%) (n = 21)*	7 (36.84%) (n= 19)*	13 (32.5%) (n = 40)*
	Male (n = 25)	Female (n = 29)	Total (n = 54)
How many close friends	3	3	3

Child has siblings	16 (80%) (n = 20)*	20 (75%) (n = 15)*	36 (78%) (n = 35)*
Child has problems at school as indicated on CBCL	5 (23.81%)	2 (10.53%)	7 (17.50%)
Child has suffered a serious illness	15 (60%)	19 (66%)	34 (63%)

Note. *n is number of caregivers that answered the question

Table 4.2 provides a summary of the basic characteristics of the HIV-positive children in comparison with the HIV-negative children that were part of the study.

Table 4.2

Comparison of demographics information HIV-positive Children and HIV-negative Children

	Children with HIV-positive status (n = 54)	Children with HIV-negative status (n = 113)
Male	25 (46.30%)	63 (55.75%)
Female	29 (53.70%)	50 (44.25%)
Age	8.26 years (8 years, 3 months)	7.75 years (7 years, 9 months)
Mean grade in school	Grade 2	Grade 2

As the HIV-positive children form the central group of participants in this study, a more detailed description of their demographic characteristics is given. This sample consisted of 54 children, 25 males and 29 females.

The ages of the children range from 6 to 12 years, with the mean age of the group being 8.24 years (8 years and 3 months). The females of the group are slightly older, which is also reflected in the mean grade for females being grade 3, whereas males are, on average, in grade 2. The data show that the children, on average, have three close friends and that most of the children have siblings (78%). From this, it can be gathered that the children are not growing up in social isolation.

The majority of children in this sample attend school (98.15%). Although 32.5% of children have had to repeat a grade, caregivers only indicated that children experienced problems at school in 17.5% of instances. What is interesting to note, is that although more females (36.84%) than males (28.57%) had to repeat a grade, caregivers indicated that male children (23.81%) experienced more problems at school than female children (11.53%). The subjective experiences of caregivers can play a role in their experience of children's problems.

Of the four caregivers who indicated that their children did experience problems at school, two indicated that their child is a slow learner, one responded that their child stayed

away from school due to the reactions of other children, and one caregiver indicated that their child struggles to listen. (The last response indicates more a problem with paying attention than a physical hearing problem.)

Caregivers were asked to indicate whether their children had suffered from a serious illness in the preceding six months, to which 63% answered affirmatively. The illnesses identified most frequently were tuberculosis, pneumonia and abdominal problems. As these illness are some of the most prominent comorbid conditions to HIV, it is fair to assume that despite being on treatment, these children are experiencing some physical consequences of their HIV-infection.

The comparative data provided in Table 4.2 show that the HIV-positive sample consists of more females (53.70%) and the HIV-negative sample of more males (55.75%). Children in the HIV-positive sample are on average four months older than those of the HIV-negative sample (8 years, 3 months vs. 7 years, 9 months). Despite these differences, the two groups can still be regarded as comparative.

4.1.2 Caregivers.

Table 4.3 provides a comparison of the mean age and highest educational level obtained by caregivers of the HIV-positive and HIV-negative children.

Table 4.3
Comparison of Caregivers of HIV-positive and HIV-negative Children

	Caregivers of HIV-positive children (n = 54)	Caregivers of HIV-negative children (n = 113)
Mean age	35.35 years	32.67 years
Mean highest grade completed*	Grade 10.87	Grade 10.36

Note. * range from Grade 0 to 12

Caregivers of HIV-positive children were on average nearly three years older than caregivers of HIV-negative children. Educational levels were assessed by asking caregivers to indicate their highest grade obtained at school. Caregivers of HIV-positive children had marginally higher educational levels than caregivers of HIV-negative children.

The following sets of graphs present information about what HIV-positive children know about, and understand about their own and their caregivers' HIV status, and how health issues are discussed within these families.

4.1.3 Children's awareness of HIV status.

Caregivers were asked what they told their children about their children's HIV status (Figure 4.1).

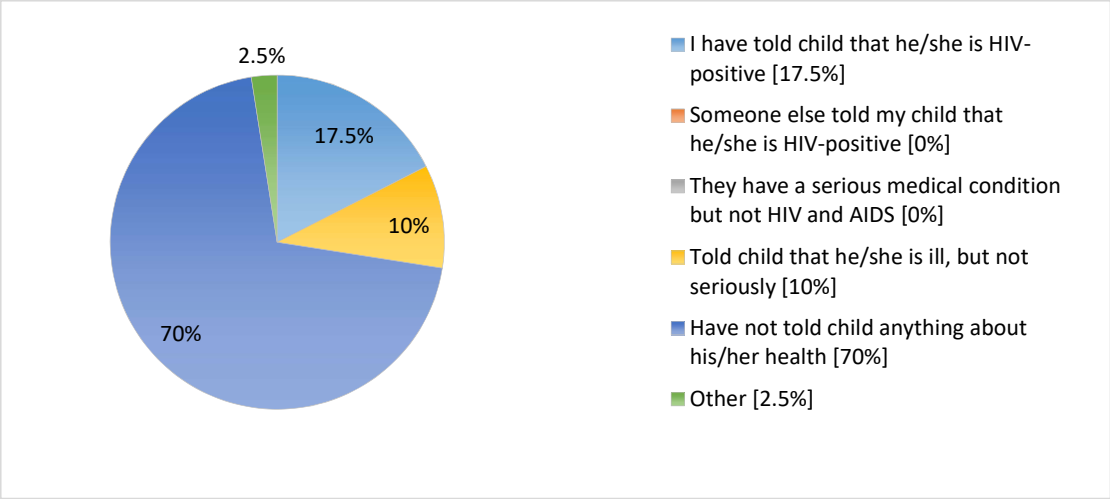

Figure 4.1 What HIV-positive children have been told about their own HIV status

Figure 4.1 presents information about what and how HIV-positive children have been told about their HIV status. Only 17.5% of caregivers have conveyed their children's HIV-positive status to them. A further 10% told their children that they are ill, but that it is not a serious illness. The majority of caregivers have not shared any information about their children's health status with them (70%).

Where caregivers did share their children's HIV-positive status with them, the following were some of the children's emotional reactions reported: "Sad, but she understands", "Shocked", and "Sad and angry."

A question about the frequency of discussions about the children's health was also posed to caregivers. Their responses are summarised in Figure 4.2.

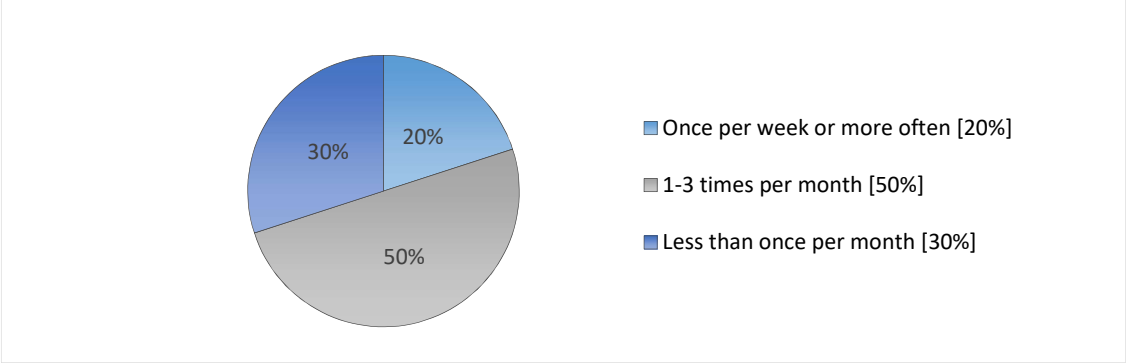

Figure 4.2 How often child's health is discussed

Half of the caregivers indicate that their children's health is discussed 1 to 3 times per month. Of the remaining half, 20% indicated that the subject was discussed weekly, while 30% indicated that it was discussed less than once per month. Caregivers were also asked how well they thought that their children understood these discussions. Caregivers indicated that 27.27% understood very well, 36.36% understood somewhat, and that 36.36% did not understand at all.

Caregivers were asked what they had disclosed about their own HIV status to their children (Figure 4.3).

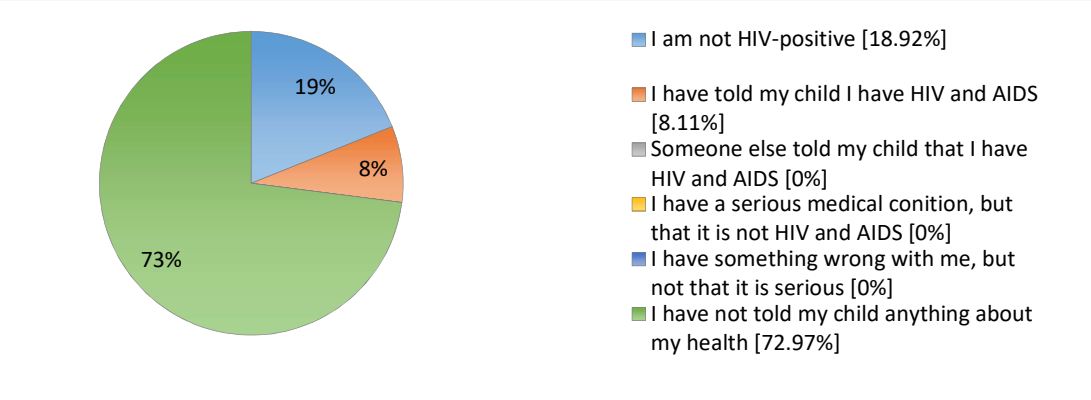

Figure 4.3 What child has been told regarding caregiver's HIV status

Similar to the disclosure levels of the children's HIV status, 72.97% of caregivers had not told their children anything about their health. A minority (8.11%) indicated that they had shared their HIV-positive status with their children, while 18.9% told their children that they were not HIV-positive. In the cases where caregivers did not tell their children anything about their health, the caregivers were asked to indicate whether their children suspected that the caregivers were ill. Six (28.57%) caregivers indicated that their children suspected that they were ill, whereas 21 (77.78%) did not think that their children suspected anything. Figure 4.1 and Figure 4.3 thus indicate that disclosure levels of both a child's own HIV status and that of the caregiver's to the child, are fairly low.

4.2 Mental Health of the Children

This section scrutinises results obtained from assessments that reflect on the mental health and coping strategies of children, including those reported by caregivers. The next section will look at the results obtained from the two measures completed by the caregivers, which assesses their experience of stress and child-caregiver interaction. The different age cut-offs for each

assessment are indicated in the discussion of respective assessment's results. However, as not all children who qualified for a specific assessment gave valid responses, and there were cases of missing values, the number of participants used to calculate the results of each test differ, and will be indicated.

4.2.1 Child assessments.

4.2.1.1 Child Behaviour Checklist.

Table 4.4 presents comparative data on mental health problems of the children in this study as reported by their caregivers according to the DSM-Orientated Subscales of the Child Behaviour Checklist (CBCL) (Achenbach & Rescorla, 2001). Clinical, borderline and normal ranges are indicated for each subscale according to the US norms. As of yet, there are no South African norms for the DSM-Orientated subscales of the CBCL. The age ranges for children included in this assessment are 6 to 12 years. The percentage of children that fall in each category (clinical, borderline and normal) of the DSM oriented sub-scales is given. A Chi-Square test statistic was used to compare the results of the HIV-positive and HIV-negative children.

Of the six mental health problems assessed by the CBCL DSM-Orientated subscales, data show no statistically significant differences ($p < .05$) between the HIV-negative and HIV-positive groups of children. However, differences on the following subscales are noteworthy: Affective Problems ($p = .054$), and Somatic Problems ($p = .074$).

Results of the *Affective Problems* subscale indicate that 37% of HIV-positive children show borderline or clinical levels of affective problems – indicative of dysthymia and major depressive disorder. This compares with 21.2% of the HIV-negative sample. The difference between the two samples shows some significance ($p = .054$).

On the *Anxiety Problems* subscale, which measures generalised anxiety, separation anxiety disorder, and specific phobias, neither the HIV-positive nor the HIV-negative groups of children obtained scores that fall into the clinical range. For the borderline score range, 13.5% of the HIV-positive children, and 11.1% of the HIV-negative children obtained scores that fall into this range. The majority of children of both groups obtained scores that fall into the normal range of the Anxiety Problems subscale. There is no significant difference between scores of the two groups for the Anxiety Problems subscale ($p = .667$).

Table 4.4
Comparison of HIV-positive and HIV-negative Children on CBCL DSM-Orientated Subscales

Affective Problems				
Range	HIV-positive children	HIV-negative children	T value	*p* *
Clinical	13 (24.1%)	12 (10.6%)	.002	.054
Borderline	7 (13.0%)	12 (10.6%)		
Normal	34 (63.0%)	89 (78.8%)		
Total	54 (100%)	113 (100%)		
Anxiety Problems				
Range	HIV-positive children	HIV-negative children	T value	*p**
Clinical	0 (0%)	0 (0%)	1.013	.667
Borderline	7 (13.5%)	12 (11.1%)		
Normal	45 (86.5%)	96 (88.9%)		
Total	52 (100%)	108 (100%)		
Somatic Problems				
Range	HIV-positive children	HIV-negative children	T value	*p**
Clinical	15 (27.8%)	15 (13.3%)	-.493	.074
Borderline	8 (14.8%)	20 (17.7%)		
Normal	31 (57.4%)	78 (69.0%)		
Total	54 (100%)	113 (100%)		
Attention Deficit/Hyperactivity				
Range	HIV-positive children	HIV-negative children	T value	*p**
Clinical	2 (3.7%)	9 (8.0%)	1.912	.583
Borderline	5 (9.3%)	10 (8.8%)		
Normal	47 (87.0%)	94 (83.2%)		
Total	54 (100%)	113 (100%)		
Oppositional Defiant Problems				
Range	HIV-positive children	HIV-negative children	T value	*p**
Clinical	2 (3.7%)	8 (7.1%)	1.316	.145
Borderline	0 (0.0%)	6 (5.3%)		
Normal	52 (96.3%)	99 (87.6%)		
Total	54 (100%)	113 (100%)		
Conduct Problems				
Range	HIV-positive children	HIV-negative children	T value	*p**
Clinical	6 (11.1%)	20 (17.7%)	1.309	.368
Borderline	6 (11.1%)	17 (15.0%)		
Normal	42 (77.8%)	76 (67.3%)		
Total	54 (100%)	113 (100%)		

Note. * $p < .05$

Although differences in scores between the two groups of children on the Somatic Problems subscale, which assesses somatisation and somatoform disorder, are not statistically significant, it can still be considered a noteworthy difference (p = .074). The large number of HIV-positive children who obtained scores that fall into the clinical (27.8%) and borderline (14.8%) range is also of note. This contrasts with the HIV-negative children, of whom 13.3% obtained scores that fall into the clinical range and 17.7% in the borderline range.

On the Attention Deficit/Hyperactivity Problems subscale the HIV-positive group of children obtained slightly lower scores that fall into the clinical-borderline range (13%) than the HIV-negative children (16.8%). The majority of both groups obtained scores that fall into the normal range. Differences in these scores are not significant (p = .583).

Although differences in scores on the Oppositional Defiant Problems subscale are not considered significant (p = .145), it is worth noting that very few HIV-positive children obtained scores that fall into the clinical-borderline range (3.7%). This compared to 12.4% of the HIV-negative children. The majority of both groups of children obtain scores that fall into the normal range: 96.3% of HIV-positive children and 87.6% of HIV-negative children.

Scores on the Conduct Problem subscale which assesses behaviour associated with conduct disorder, indicate that 22.2% of HIV-positive children and 32.7% of the HIV-negative children fall into the clinical-borderline range of this subscale. Of the HIV-positive children, 77.8% obtained scores that fall into the normal range, as opposed to 67.3% of the HIV-negative children. It is noted that more HIV-negative children fall into the clinical and borderline categories. Differences in scores on the Conduct Problem subscale are not considered significant (p = .368).

4.2.1.2 Revised Children's Manifest Anxiety Scale.

The Revised Children's Manifest Anxiety Scale (RCMAS) was developed as a self-report inventory to assess anxiety in children and adolescents (Reynolds & Richmond, 1978). This assessment was administered to children from the age of 8 to 12 because of the age specifications of the scale. It consists of 37 items, where each item is given a score of one for a "yes" response. This yields a *Total Anxiety* score, three anxiety subscales scores (*Physiological Anxiety, Social Concerns/Concentration,* and *Worry/Oversensitivity*) and a *Lie Scale* score, which screens for acquiescence.

Table 4.5 provides a comparison of the mean raw scores obtained on the RCMAS subscales and Total Anxiety score for the HIV-positive and HIV-negative children. A t-test for equality of means was used to calculate the *p* values for this assessment.

Table 4.5

Comparison of HIV-positive and HIV-negative Children's Mean Raw Scores on RCMAS Subscales

Subscale	HIV-positive Children (n = 32)	HIV-negative Children (n = 111)	Maximum Raw Score	*p**
Physiological Anxiety	3.765	2.593	10	.005
Social Concerns/ Concentration	1.849	1.712	7	.702
Worry/Oversensitivity	4.543	4.063	11	.384
Total Anxiety	10	8.266	28	.125

Note. * $p < .05$

Although the group of HIV-positive children obtained a higher average score on the *Total Anxiety* scale than their HIV-negative peers, the difference was not statistically significant. Stallard et al. (2001) recommend that an overall cut-off point of 19 out of 28 be used to identify children experiencing clinically significant levels of anxiety on the Total Anxiety scale. This indicates that neither of the two groups of children can be considered as experiencing elevated anxiety levels. This is in keeping with the anxiety scores of children as reported by their caregivers on the CBCL.

The Physiological Anxiety subscale assesses somatic symptoms of anxiety such as sweaty hands, stomach-aches and sleep difficulties. This is the only subscale where there is a significant difference ($p = .005$) between the scores of the two groups of children, with HIV-positive children having higher scores.

The Social Concerns/Concentration subscale indicates whether a child is likely to feel that he or she is unable to meet the expectations of other important people, performs inadequately, and is unable to concentrate on tasks. There was no significant difference between the scores of the two groups of children on this subscale ($p = .702$).

There was also no significant difference between the scores that the two groups of children obtained on the Worry/Oversensitivity subscale ($p = .284$). This subscale assesses

whether a child internalises their experiences of anxiety and whether he or she feels overwhelmed and withdrawn.

Table 4.6 provides a summary of how the two groups of children per gender group compare according to the RCMAS age norms. The norms that provide ranges for normal, above normal and below normal indicators of anxiety were used. A Chi-Square test statistic was used to compare the results of the HIV-positive and HIV-negative children. There were no significant differences found between the two male samples (p = .407), the two female samples (p = .603), or between the combined HIV-positive and HIV-negative gender groups (p = .410).

Table 4.6

RCMAS Gender Norm Comparison

Gender	Range	HIV-positive Children (n = 32)	HIV-negative Children (n = 111)	Total	*p**
Male	Above Normal	0.0%	4.8%	3.8%	.407
	Normal	68.8%	52.4%	55.7%	
	Below Normal	31.3%	42.9%	40.5%	
Female	Above Normal	6.3%	4.0%	4.5%	.603
	Normal	50.0%	38.0%	40.9%	
	Below Normal	43.8%	58.0%	54.5%	
Total	Above Normal	3.1%	4.4%	4.1%	.410
	Normal	59.4%	46.0%	49.0%	
	Below Normal	37.5%	49.0%	46.9%	

Note. * p < .05

Results obtained from the RCMAS assessment do not indicate that the HIV-positive children in this study reported significantly higher levels of generalised anxiety than the HIV-negative children. The majority of children from both the HIV-negative and HIV-positive groups also obtained scores that fall into the normal or below normal ranges for anxiety levels.

Besides HIV-positive children scoring significantly higher on the Physiological Anxiety subscale, no other significant differences were found in the anxiety subscales. What may be worth considering is that both groups appear to experience less anxiety than expected.

4.2.1.3 Self-Description Questionnaire.

The Self-Description Questionnaire (Marsh, 1988) for pre-adolescents (SDQ-I) was used to assess how the two groups of children view themselves. Similar to coping strategies, self-esteem and self-concept have been tied to a child's ability to adapt successfully to life in general and to difficult circumstances (Craven & Marsh, 2008).

The SDQ originally employs 40 questions that assess a child's self-concept across five subscales, with eight questions each that load onto these. This study did not include the *Physical Ability/Sports* subscale, resulting in only 32 questions used. Higher scores indicate more positive self-evaluations.

The data in Table 4.7 were analysed using the Independent Samples Mann-Whitney U Test. The results indicate that HIV-positive and HIV-negative children differ at significant levels across all four of the *SDQ* subscales assessed (p = .000). HIV-positive children consistently rated themselves higher on the respective subscales.

For example, HIV-positive children rated themselves more positively with regard to their appraisal of their physical appearance than HIV-negative children (121.76 compared to 52.37). HIV-positive children rated their ability to engage successfully with their peers higher than HIV-negative children did (119.43 compared to 53.54), as well as viewed their relationships with their caregivers more positively (121.29 compared to 52.60).

This pattern was repeated on the *Self-Evaluation* subscale, which assesses children's overall evaluation of themselves and can also be viewed as their general sense of self-esteem (121.39 compared to 52.56).

Table 4.7

SDQ Subscale Mean Ranking Comparison

Subscale	HIV-positive Children (n = 50)	HIV-negative Children (n = 100)			
	Mean Rank	Mean Rank	*p* *	X	SD
Physical Appearance	121.76	52.37	.000	27.67	7.269
Social Ability	119.43	53.54	.000	26.13	7.300
Relationship with Parents	121.29	52.60	.000	26.95	7.732
Self Evaluation	121.39	52.56	.000	26.94	7.245

Note. * p < .05

4.2.1.4 Kidcope.

Coping behaviour, specifically the type of coping strategies employed, has been identified as a factor that plays a significant role in how successfully a child adapts to living with a chronic disease (Piazza-Waggoner, Adams, Wilson, & Hogan, 2006).

To assess the coping strategies used by the children in this study, the Kidcope (Spirito et al., 1988) was employed to assess which coping strategies the HIV-positive children used most and how these compared with their HIV-negative peers. It assesses the use of 10 different coping strategies, four of which are considered adaptive coping strategies and six, which are considered maladaptive coping strategies. A Chi-Square test statistic was used to compare the results of the HIV-positive and HIV-negative children.

The three coping strategies in which statistically significant differences were found, will be addressed first, followed by a discussion of the most used coping strategies and how the two groups compare on these.

Table 4.8 indicates how many children from the HIV-positive and HIV-negative samples used each coping strategy, and how they compared. The coping strategy with the greatest difference in frequency of use between the two groups is *Self-Criticism* ($p = .000$). Almost half of the children (48.9%) who were HIV-positive indicated that they used this strategy, compared to only 16.1% of HIV-negative children. *Self-criticism* refers to children being critical of themselves, focussing on their own weaknesses and faults, and locating blame in themselves.

The second coping strategy where a statistically significant difference was found, was *Social Withdrawal* ($p = .006$). Two thirds (66.7%) of HIV-negative children indicated that they used this strategy, compared to 42.6% of HIV-positive children. *Social Withdrawal* entails children choosing not to engage with others or discuss their problems with them.

The third statistically significant difference was between the use of *Blaming Others* as a coping strategy ($p = .010$). Here, 59.1% of HIV-negative children indicated that they used this strategy, compared to 36.2% of HIV-positive children. The use of this skill refers to children placing the cause of and responsibility for a problem on others.

All three of the coping strategies where statistically significant differences were found, formed part of the maladaptive set of coping strategies. No significant differences in the use of the respective adaptive coping strategies were found.

Table 4.8 and Figure 4.5 show which coping strategies were used most overall, and how children of the respective HIV-positive and HIV-negative groups compare to this average.

Wishful Thinking was not only the most used maladaptive coping strategy by both groups of children (95.7%), but also the most utilised strategy overall. Of the HIV-positive children, 93.6% made use of this strategy and of the HIV-negative children, 96.8%. This coping strategy refers to a child imagining that the problem does not exist, or hoping that it will simply disappear.

The second-most used coping strategy was *Emotional Regulation* (87.9%). HIV-positive children (83.0%) used this strategy slightly less than did HIV-negative children (90.3%). *Emotional Regulation* refers to children expressing their emotions in a non-harmful manner such as screaming or attempting to calm themselves.

The third-most used coping strategy was *Distraction* (81.4%). HIV-positive children (76.6%) made less use of this skill than did HIV-negative children (83.9%). This is considered a maladaptive coping strategy that entails a child attempting to forget the upsetting event or actively directing their attention away from it.

Table 4.8

Comparison of Coping Strategies used by HIV-positive and HIV-negative Children

Coping Strategy		HIV-positive Children who Used Strategy (n = 47)	HIV-negative Children Who Used Strategy (n = 93)		
		Frequency %	Frequency %	Combined use of skill %	*p*
Adaptive Strategies	Cognitive Restructuring	34 (72.3%)	65 (69.9%)	99 (70.7%)	.764
	Problem Solving	35 (74.5%)	74 (79.6%)	109 (77.9%)	.492
	Emotional Regulation	39 (83.0%)	84 (90.3%)	123 (87.9%)	.209
	Social Support	38 (80.9%)	71 (76.3%)	109 (77.9%)	.544
	Total Adaptive	78.19%	79.03%		
Maladaptive Strategies	Distraction	36 (76.6%)	78 (83.9%)	114 (81.4%)	.296
	Social Withdrawal	20 (42.6%)	62 (66.7%)	82 (58.6%)	.006
	Self-Criticism	23 (48.9%)	15 (16.1%)	38 (27.1%)	.000
	Blaming Others	17 (36.2%)	55 (59.1%)	72 (51.4%)	.010
	Wishful Thinking	44 (93.6%)	90 (96.8%)	134 (95.7%)	.384
	Resignation	17 (36.2%)	35 (37.6%)	52 (37.1%)	.866
	Total Maladaptive	55.57%	60.03%		

Note. * $p < .05$

Problem Solving and *Social Support* were both used equally overall (77.9%). However, HIV-positive children made slightly less use of *Problem Solving* (76.6%) and more use of *Social Support* (80.9%). This is the inverse of HIV-negative children, who made more use of *Problem Solving* (83.9%) and slightly less use of *Social Support* (76.3%).

Both of these coping strategies are considered adaptive. *Problem Solving* entails a child attempting to think of a solution to his or her problem, speaking to someone about it or attempting to do something about it. *Social Support* refers to a child attempting to feel better by spending time with friends or family.

The next-most used coping strategy was *Cognitive Restructuring* (70.7%). This coping strategy is an adaptive strategy used equally by both groups. *Cognitive Restructuring* involves a child trying to change the way they think about a problem by casting it in a more positive light.

This was followed by *Social Withdrawal* and *Blaming Others*, as discussed above. These were followed by the use of *Resignation*. This is the maladaptive coping strategy that the two groups of children used almost similarly (p = .866). *Resignation* refers to a child experiencing a situation as hopeless and therefore accepting that nothing can be done to change it.

The least-used strategy overall was Self-Criticism (27.1%). However, it was the coping strategy with the largest significant difference between the two groups, as mentioned above. It is noteworthy that HIV-positive children utilised this strategy significantly more than HIV-negative children. HIV-positive children made less use of the other maladaptive coping strategies than did HIV-negative children.

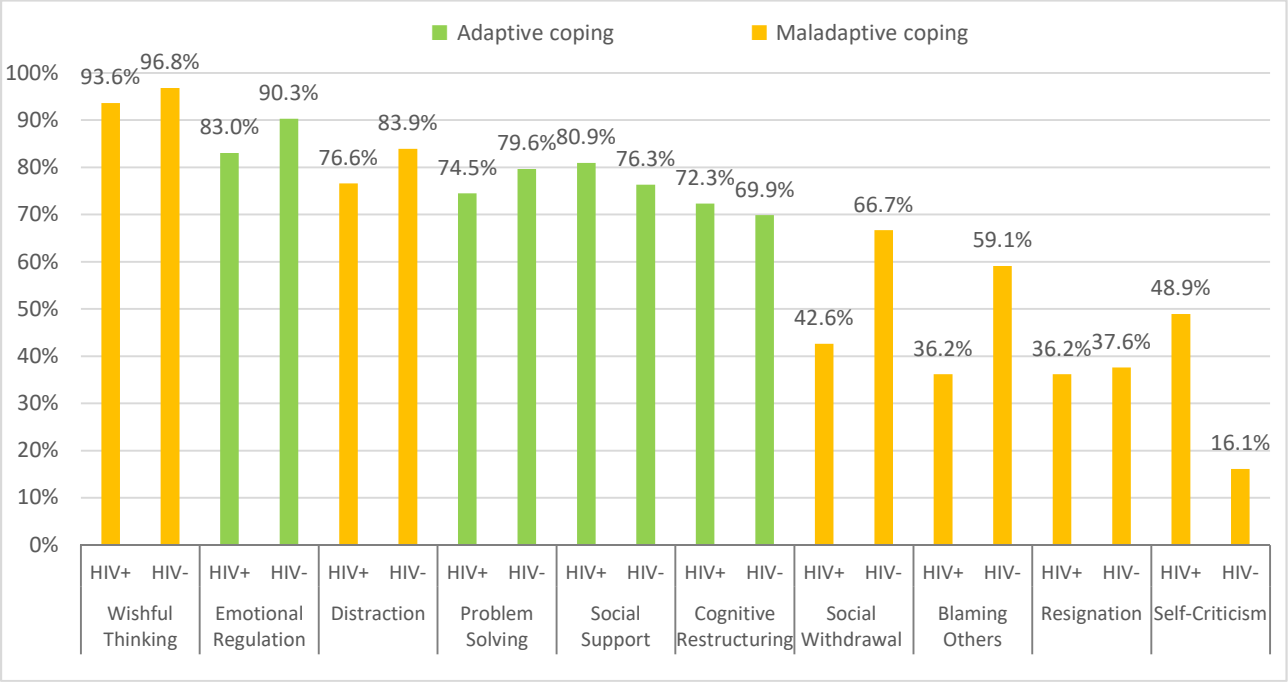

Figure 4.5 Ranking of most used coping strategies

The data from the *Kidcope* assessment indicate that both HIV-positive and HIV-negative children often use coping strategies which are considered adaptive (78.19 % of HIV-positive children; 79.03% of HIV-negative children). It also indicates that HIV-positive children use fewer maladaptive coping strategies than HIV-negative children, which could be implicated in better adaptation (55.57% of HIV-positive children; 60.03% of HIV-negative children), although the findings were not statistically significant.

It is interesting to note that although the HIV-positive children have more positive self-concepts as indicated by the SDQ results, this group of children also made significantly more use of *Self-Criticism* as one of the maladaptive coping strategies identified by the *Kidcope* (See Figure 4.5).

4.3 Caregiver Assessments.

4.3.1 Parental Stress Index.

The Parental Stress Index (Abidin, 1995) was used to assess caregiver stress in relation to their parenting role. For the purpose of this study, the following subscales were used: *Parental Distress* and *Parental Child Dysfunctional Interaction*. Higher scores are indicative of higher levels of distress experienced on the respective subscales. The Mann-Whitney U Test was used to obtain the mean rankings of the caregivers' scores on these two subscales.

The scores obtained by the caregivers of the HIV-positive and HIV-negative children on the *Parental Distress* subscale do not show a significant difference (p = .713). This subscale reflects on a caregiver's experience of their parenting role as a whole. These results indicate that the caregivers' experiences and perceptions of their child-rearing competency, their interactions with their partners or spouses, and other limitations experienced as a result of parenting, are similar.

The results obtained from the comparison of caregivers' scores on the Parent-Child Dysfunctional Interaction subscale do, however, indicate that there is a significant difference in how the two groups of caregivers experience their relationships with their children (p = .001).

The caregivers of HIV-positive children obtained significantly higher mean rankings on this subscale. This would indicate that they experience their relationships with their children as more conflicted. They experience less positive reciprocation in their interactions with their children and see their children as less able to meet expectations.

Table 4.9

Comparison of Caregiver PSI-SF Scores

PSI-SF Subscale	Caregivers of HIV-positive Children (n = 54)	Caregivers of HIV-negative Children (n = 113)	
	Mean Rank	Mean Rank	*p* *
Parental Distress	86.9	84.03	.713
Parental Child Dysfunctional Interaction	104.10	77.92	.001

Note. * $p < .05$

4.3.2 Coping with Children's Negative Emotions Scale.

In order to assess caregivers' parenting style, the Coping with Children's Negative Emotions Scale (CCNES, Fabes et al., 1990) was used. The scale measures the likelihood of five specific response styles to children's expression of negative emotions. Three of the response styles are considered as supportive and two as non-supportive. The data was subjected to a Mann-Whitney U analysis. The results of the CCNES assessment indicate definite differences in how the caregivers of HIV-positive children and the caregivers of HIV-negative children respond to negative emotional expressions of their children.

Table 4.10

Comparison of Caregiver CCNES Scores

Response Style		Caregivers of HIV-positive Children (n = 54)	Caregivers of HIV-negative Children (n = 113)	
		Mean Rank	Mean Rank	*p* *
Supportive Responses	Expressive Encouragement	77.76	92.63	.064
	Emotion-Focused Reactions	58.10	102.97	.000
	Problem-Focused Reactions	59.94	99.03	.000
Non-Supportive Responses	Distress Reactions	91.81	84.51	.363
	Punitive reactions	76.05	92.67	.038

Note. * $p < .05$

Caregivers appear to use *Expressive Encouragement* similarly between groups (p = .064). This style entails the acceptance and active encouragement of a child's negative emotional expressions.

Caregivers of HIV-negative children use *Emotion-Focused Reactions* significantly more than caregivers of HIV-positive children (p = .000). *Emotion-Focused Reactions* refer to responses by caregivers that are intended to make the child feel better, such as comforting or distracting them.

Caregivers of HIV-negative children also seem to use *Problem-Focused Reactions* more than caregivers of HIV-positive children (p = .000). *Problem-Focused Reactions* refer to pragmatic responses by which caregivers attempt to solve or address the cause of their children's distress.

Although caregivers of HIV-positive children obtained higher scores on the *Distress Reactions* subscale, this difference is not significant (p = .363). *Distress Reactions* indicate a response style where the caregiver becomes distressed and focuses more on their own emotions than on those of the children.

Caregivers of HIV-positive children indicated that they used significantly fewer *Punitive Reactions* than caregivers of HIV-negative children (p = .038). *Punitive Reactions* are responses that employ verbal or physical punishment as an attempt to control or curb a child's negative emotional display.

The results discussed above and presented in Figure 4.6 indicate that caregivers of HIV-negative children react with more supportive as well as non-supportive responses than do caregivers of HIV-positive children.

Although this means that caregivers of HIV-positive children employ fewer non-supportive responses, which can be considered to reflect a more positive parenting style, it should be kept in mind that caregivers of HIV-positive children are, overall, less responsive towards their children.

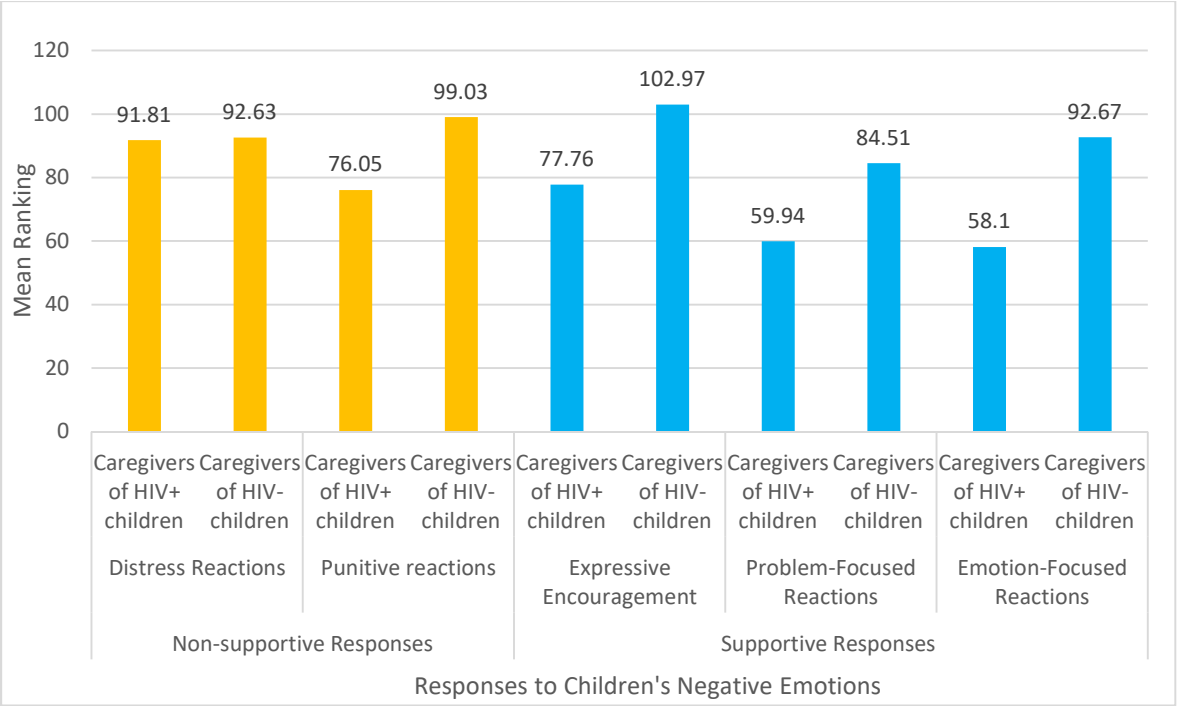

Figure 4.6 Comparison of caregiver responses to negative emotional expressions of children

From the results obtained from the two assessments of the caregivers, it appears that caregivers of HIV-positive children struggle more with their role as parents, as they experience the parent-child relationship as more conflicted, and respond with less support towards their children.

4.4 Relationships between the mental health of HIV-positive children and other variables

The following section presents findings regarding possible relationships between variables that may play a role in HIV-positive children's mental health functioning, self-esteem, and use of coping skills, and how these may differ from their HIV-negative counterparts.

Numerous potential relationships were investigated, for example, whether a child's age or sex had any bearing on their or their caregiver's results. First investigations where no statistically significant results were found will be listed, followed by a more detailed discussion of significant results.

No statistically significant results were obtained for the following variables:

- Gender of the child and their scores on the Kidcope and SDQ, and their caregiver's scores on the CCNES and PSI-SF
- Age of children and their caregiver's scores on the PSI-SF
- The age of HIV-positive children and their scores on the RCMAS
- The number of people living in the caregivers home and their scores on the PSI-SF and

children's CBCL scores

- The highest school grade achieved by a caregiver and children's scores on the Kidcope, SDQ, and RCMAS
- HIV-positive children who have previously been seriously ill and their scores on the RCMAS
- Caregivers' scores on the PSI-SF, and children's scores on the RCMAS and SDQ.

Variables were some relationship exists with the mental health scores of the children are discussed below.

4.4.1 Age of HIV-positive children.

In order to determine if the age of the child played a role in their mental health assessments, a series of one-way analysis of variance (ANOVAs) were computed for each subscale of the CBCL, followed by a post hoc Scheffe analysis where ANOVAs indicated statistically significant values by comparing children's age distribution across clinical, borderline, and normal ranges.

For Affective Problems, a significant main effect was found in the analysis ($F(2,50) = 4.079$, $p = .023$). The post hoc Scheffe analysis showed that more younger children were in the clinical and borderline ranges for the Affective Problem subscale than older children.

A significant main effect was found for age and the Attention Deficit/Hyperactivity Problems subscale ($F(2,50) = 3.283$, $p = .046$). Younger children were more likely to suffer from ADHD-related symptoms.

A significant main effect was also found for the Oppositional Defiant Problems subscale ($F(1,50) = 4.383$, $p = .041$). Again, more younger children fell into the clinical range of the Oppositional Defiant Problems subscale than older children.

The results from this analysis would indicate that younger HIV-positive children are disproportionally represented on the pathological ranges of the Affective, ADHD and Oppositional Defiant subscales of the CBCL. This indicates that there is some relationship between age and the experience of mental health problems.

4.4.2 Effects of serious illness on HIV-positive children.

A Pearson Chi-Square Test was performed in order to determine whether there is an association between having suffered any serious illness and the psychological wellbeing of children living with HIV. HIV-positive children whose caregivers reported that their children had been seriously ill in their lifetime (n = 34) were compared with HIV-positive children whose caregivers did not report them to have been seriously ill (n = 20) across the clinical, borderline and normal ranges of the CBCL DSM-Orientated subscales. Statistically significant differences were found for the following two subscales.

Results for the *Affective Problems* subscale were found statistically significant (x^2 (2, N = 54) = 8.519, p = .014). Of children who have previously been seriously ill, 29.4% fell into the clinical range of Affective Problems, compared to 15% of children who had not been seriously ill. This indicates significantly higher levels of Affective Problems amongst HIV-positive children who have suffered a serious illness compared to those who have not.

Statistically significant differences were also found for the *Conduct Problems* subscale (x^2 (2, N = 54) = 13.976, p = .001). Of the children who have previously been seriously ill, 17.6% fell into the borderline-clinical range of the subscale, compared to 30% of children who had not previously been seriously ill. This would indicate that HIV-positive children who have experienced a serious illness display less behaviour that qualifies as conduct problems.

Results did not indicate a statistically significant difference between children that have previously been seriously ill and those that have not, across other subscales: Anxiety Problems, Somatic Problems, ADHD Problems, and Oppositional Defiant Problems (p's > .05).

4.4.3 Number of people living in households and scores on the CCNES, PSI-SF and SDQ of caregivers of HIV-positive children and HIV-children.

A series of Spearman rank-order correlations were conducted in order to determine if there were relationships between the number of people living in households and assessment results of HIV-positive children and their caregivers. The number of people that live in the households with caregivers of HIV-positive children appears to have some correlation with how caregivers respond to their children's negative emotional expressions (CCNES) as well as their experiences of parental stress (PSI-SF). It also correlated with the children's relationships with their caregivers (SDQ).

The Spearman's rho revealed a moderately statistically significant correlation between the number of people living in the household of the caregiver and how they responded to their

child's negative emotional expressions on some of the CCNES subscales. The Number of People Living in the Household was negatively correlated with Problem-Focused Reactions (r(44) = -.418, p <.01, two-tailed), Expressive Encouragement (r(47) = -.314, p < .05, two-tailed), and Emotion-Focused Reactions (r(47) = -.306, p < .05 two-tailed).

These results indicate an inverse relationship between the number of people living with caregivers in their households and caregivers' use of supportive responses to their children's expressions of negative emotions. This could mean that the more people in a household, the more strain is put on the caregiver-child relationship, or that the caregiver has less emotional resources for the child.

Similarly, the Spearman's rho revealed a moderately statistically significant correlation between the number of people living in the household of the caregiver and their levels of stress as assessed by the PSI-SF. The Number of People Living in the Household was positively correlated with Parental Distress (r(43) = +.415, p < .01, two-tailed), as well as Parent-Child Dysfunctional Interaction (r(47) = +.420, p < .01, two-tailed).

These results show that the greater the number of people who live in the household with a caregiver, the greater the caregiver's experience of stress is in their general role as caregiver to the child, and within their relationship with their child specifically.

Where HIV-positive children's scores on the SDQ were correlated with the Number of People Living in the Household, the Spearman's rho showed a negative correlation between the child's relationship with their caregiver and the number of people in the household (r(38) = -.411, p < .05, two-tailed). This indicates a relationship between more people living in a household, and children experiencing their relationship with their caregivers in a less positive manner.

4.4.4 Relation of caregivers' experiences of stress to children's mental well-being.

In order to investigate whether a relationship exists between caregivers' experiences of stress and children's psychological well-being, a series of one-way analyses of variance (ANOVA) were conducted, followed by a post hoc Scheffe analysis, where significant main events were found. Results of the Parental Stress Index and the Child Behaviour Checklist are given.

The ANOVAs for both *Parental Distress* (F(2,160) = 13.009, p = .000) and *Parent-Child Dysfunctional Interaction* (F(2,164) = 16.747, p = .000) subscales of the PSI-SF and the *Affective Problems* subscale of the CBCL showed significant differences.

The post hoc Scheffe analysis revealed significant differences in *Parental Distress* of caregivers of children in the clinical (p = .000) and borderline categories (p = .042), compared to children in the normal category. The same differences were found between the *Parent-Child Dysfunctional Interaction* of caregivers with children in the clinical (p = .000) and borderline category (p = .000) and children in the normal category. This indicates that where children obtained higher scores on the *Affective Problems* subscale, their caregivers obtained higher scores on both the *Parental Distress* and *Parental Child Dysfunctional Interaction* subscales of the PSI-SF. Children's affective problems were thus related to parental stress.

ANOVAs for both *Parental Distress* (F(1,154) = 8.808, p = .003) and *Parent-Child Dysfunctional Interaction* (F(1,158) = 4.006, p = .047) PSI-SF scores and *Anxiety Problems* were statistically significant. Although no children were represented in the clinical range, results showed that *Parental Distress and Parent-Child Dysfunctional Interaction* scores were higher when children obtained borderline scores on the *Anxiety Problems* subscale than when they obtained normal scores.

The ANOVA for the *Parent-Child Dysfunctional Interactions* F (2,164) = 3.299, p = .039) subscale was found to be statistically significant on the *Somatic Problems* subscales of the CBCL. The post hoc Scheffe analysis showed that caregivers obtained higher scores on the *Parent-Child Dysfunctional Interactions* subscale when their child scored in the borderline range of the *Somatic Problems* subscale than when they scored in the normal range.

Although no causal links could be established, it seems that there is a relationship between the caregivers' experience of parental stress and the mental health of their child.

When planning the research, the researcher intended to do a multiple regression analysis to determine variables that could predict the mental health of children infected with HIV. Therefore, correlations were calculated between the mental health scores of the HIV-infected children and several variables included in this research. A few of the meaningful relationships are reported above. The finding was that there were not many variables that related to the mental health scores of the children. It was therefore not practically possible or appropriate to continue with the calculation of a regression analysis.

4.5 Conclusion

Although the results presented did not show many significant differences between HIV-positive and HIV-negative children on measures that identify mental health problems, some conspicuous

results were obtained. For example, here were some differences between the affective and somatic problems between the two groups of children.

Furthermore, although most of the HIV-positive children were not aware of their HIV status, they scored significantly higher on all the self-esteem subscales. Furthermore, both groups of children tend to use more adaptive coping strategies but there are significant differences between the frequency of use of maladaptive coping strategies between HIV-positive and HIV-negative children. Results from caregiver assessments indicate that caregivers of HIV-positive children experience significantly more stress in their relationships with their children. They also tend to react in a less responsive manner when their children express negative emotions.

In the next chapter, the results will be interpreted in terms of previous research results. The results will also be contextualised by using the Extended Stress-Coping Model (Maes et al., 1996).

Chapter Five – Discussion

In this final chapter, the findings of the present study are discussed and compared to other findings from the available literature. This section starts with an overview of the study and the research questions the study sought to answer.

This is followed by a discussion of the most salient findings on the mental health of the HIV-positive children. These findings are then compared to those of the HIV-negative comparison group.

Finally, variables that could have had an influence on the mental health of HIV-positive children are discussed in the context of the Extended Stress-Coping Model (Maes et al., 1996).

Hereafter, the limitations of the study will be considered, followed by a summary of its potential value and contribution to our knowledge about HIV-infected children and interventions needed.

5.1 Overview of the Study

The purpose of the present study was to provide a better understanding of the mental health problems of HIV-positive South African children. To such effect, the study sought to answer the following research questions:

- What mental health problems, if any, do HIV-positive children that attend the Kalafong Paediatric Clinic experience?
- Do HIV-positive children differ from HIV-negative children who live in the same community in terms of mental health problems?
- Which variables possibly play a role in contributing to mental health or mental health problems of children who are diagnosed HIV-positive and receive treatment at an outpatient clinic?

The first two research questions attempt to determine whether HIV-positive children experience mental health problems, to what extent they experience problems, and whether these experiences differ significantly from an HIV-negative comparison group.

The third research question seeks to identify factors that may be related to the exacerbation of mental health problems faced by HIV-positive children, and factors that may be related to improving their mental health status.

5.2 Discussion of Results

5.2.1 Results related to mental health problems of HIV-positive children.

Previous research investigating the mental health problems of children with HIV have shown that such children experienced elevated levels of depression, anxiety, ADHD and disruptive behavioural disorders (Bomba et al., 2010; Earls, Raviola & Carlson, 2008; Rao et al., 2007; Scharko, 2006).

The present study used the CBCL and RCMAS to investigate indications of psychopathology among HIV-positive children. The DSM-Orientated subscales of the CBCL allow for assessment of the following DSM-IV related disorders: mood, anxiety, somatic, ADHD, oppositional defiant and conduct (See Table 4.4). The parent report administration of the CBCL was used, in which caregivers completed questions about children's behaviour. It should be kept in mind that caregivers' evaluations about their children's behaviour could be influenced by their own emotions related to their HIV-positive children.

This study found that elevated scores on the *Somatic problems* subscale were the most noteworthy in the case of the HIV-positive sample. Results of this subscale indicated that 42.6% of HIV-positive children exhibited somatic problems that fall into the borderline or clinical range. This means that they experienced somatisation disorder and undifferentiated somatoform disorder. According to the DSM-IV-TR (American Psychiatric Association, 2000) on which these subscales are based, this refers to the subjective experience of pain, gastrointestinal and pseudo-neurological symptoms without an objective organic cause. In the case of undifferentiated somatoform disorder, this refers to unexplained physical symptoms that are not severe enough to classify as somatisation disorder (American Psychiatric Association, 2000).

These results are confirmed by the findings of Nozyce et al. (2007) but differ from most other studies where somatoform symptoms were not the most prevalent (Earls et al., 2008; Rao et al., 2007). It should be taken into account that somatic complaints are also symptoms of mood and anxiety disorders (American Psychiatric Association, 2000; Sadock et al., 2007).

In African and many other non-western cultures, people tend to express mood and anxiety disorders through somatic symptoms (Rohleder, 2012). This could have been the case in this data as well. Furthermore, it should be noted, that especially younger children express mental health problems differently compared to adults. For example, children often express mood and anxiety problems through irritability or somatic symptoms (Sadock, Kaplan, & Sadock, 2007).

Second, HIV-positive children were found to have high rates of affective problems. More than a third (37.1%) of the children in the HIV-positive sample obtained scores that place them in the borderline or clinical range. This subscale of the CBCL specifically applies to depressive and dysthymic symptoms. Other research has consistently identified affective or depressive symptoms among children living with HIV as among the most common mental health problems (Earls et al., 2008; Rao et al., 2007; Scharko, 2006). These high rates of affective problems will be discussed in the following section, where they are compared to the results of HIV-negative children.

Third, 22.2% of HIV-positive children obtained scores that place them in the borderline or clinical range for conduct problems. This is in stark contrast with HIV-positive children's scores on the *Oppositional Defiant* subscale, where only 3.7% of children obtained scores that fell into the borderline or clinical range. In the spectrum of disruptive behaviour disorders, oppositional defiant disorder is considered a less severe precursor to conduct disorders (Sadock et al., 2007).

Children's scores on the CBCL *Anxiety Problems* subscale and the *ADHD* subscale can also be considered as noteworthy when one takes into account how few of the HIV-positive children obtained scores that fell into the borderline or clinical ranges. These relatively low levels of anxiety (13.5%) and ADHD (13%) differed from the majority of other research, which indicated that children living with HIV tend to experience higher levels of anxiety and ADHD, with prevalence rates of both disorders above 20% (Earls et al., 2008; Roa et al., 2007; Scharko, 2006).

HIV-positive children's low scores on the CBCL *Anxiety Problems* subscale are confirmed by their similarly low scores on the RCMAS (See Table 4.5). On the *Total Anxiety* subscale of RCMAS, HIV-positive children obtained a mean raw score of 10 out of a possible 28. This fell short of a minimum score of 19 that is indicative of clinical levels of anxiety (Stallard, Velleman, Langford, & Baldwin, 2001).

When employing the RCMAS gender norms, similarly low scores were found (See Table 4.6). None of the HIV-positive males, and only 6.3% of females, obtained scores that fell into the above normal range for the *Total Anxiety* subscale. These findings regarding the general lack of anxiety in HIV-negative children are surprising. These results may be better interpreted in the context of the fact that the majority of the children in the sample group were not aware of their HIV-status. This will be discussed more comprehensively in Section 5.2.3.

5.2.2 Comparison of HIV-positive and HIV-negative children.

In this section differences between HIV-positive and HIV-negative children in terms of psychopathology measures will be discussed. Furthermore, differences in the children's self-descriptions and choices of coping strategies will be considered as possible factors that may contribute to the results discussed in the previous section. This section concludes with a discussion of the results of caregivers' assessments.

Few studies provided comparative data that included HIV-negative comparison groups. Although the instruments used by Bomba et al. (2010) do not allow for a direct comparison with the present research, their research indicated that a sample of HIV-positive Italian children experienced greater impairment in their social and school functioning when compared to a matched comparison group. Bomba et al. (2010) found that HIV-positive children experienced significantly more anxiety and depressive symptoms, more attention and thought problems, were more socially withdrawn and exhibited more delinquent and aggressive behaviour than the comparison group.

The findings of the present study correspond to those of Bomba et al. (2010) in relation to higher affective problems, though not significant. However, when results of the HIV-positive and HIV-negative children are compared, the findings of the present study need to be interpreted in a more circumspect manner.

5.2.2.1 Affective problems.

In the present study, many HIV-positive children experienced high levels of somatic (27.8%) and affective problems (24.1%) on the CBCL DSM-IV orientated subscales. These results, however, did not differ on a statistically significant level from the scores of HIV-negative children from the same community. The differences in the CBCL *Affective Problem* subscale between the two groups (24.1% of HIV-positive children fall in the clinical range compared to 10.6% of HIV-negative children), near significance with a *p*-value of .054 (Table 4.4). The elevated scores of HIV-positive children are thus noteworthy.

Despite the lack of significant differences, it should be kept in mind that the high rates of affective and somatic problems fell into the clinically significant range, and should therefore still be considered cause for concern and highlight potential areas for targeted interventions. This finding corresponds to most of the literature that reported affective and depressive symptom as one of the predominant mental health problems among HIV-positive children, with prevalence rates as high as 44% (Misdrahi et al., 2004).

The question that arises in this research is whether the elevated depression scores could be linked to the HIV condition per se, or if it is linked to other contextual variables. One must bear in mind that the majority of the HIV-positive children in the sample did not know about their HIV-status (See Section 4.1.3). It could be that living with an ill or depressed caregiver could have a negative effect on them and that this could contribute to their own depression.

Previous research found that HIV-positive mothers who experienced high levels of maternal depression also experienced high levels of parenting stress, which contributed to high rates of parent-child dysfunction, which had a negative effect on the child's emotional functioning (Boeving Allen et al., 2013). Research also revealed that where HIV-positive mothers were physically ill, this affected the mental health of their children (Sipsma et al., 2013).

On the other hand, although children might not know their HIV-positive status, somehow they must be aware that they have health problems, because of their frequent clinic visits and having to take medication on an ongoing basis. This could contribute to the high prevalence of affective problems.

It should also be noted that the comparison group of HIV-negative children also scored relatively high on affective problems. Contextual variables such as socio-economic problems in the area could contribute to children's affective problems.

5.2.2.2 Anxiety problems.

On the RCMAS (Reynolds & Richmond, 1978), HIV-positive and HIV-negative children differed significantly in terms of the *Physiological Anxiety* subscale, although not at clinically significant levels. A possible explanation of the slightly elevated scores of HIV-positive children on this subscale might be related to the physiological symptoms related to their HIV-infection or because of the side-effects of medication (Greene, 2007).

This would further indicate that other possible factors might be contributing to the elevated levels of somatic and affective symptoms in both HIV-positive and HIV-negative children. To this effect, Rao et al. (2007) caution against the over-simplistic diagnosis of mental health problems in children with HIV. Rao and colleagues stress that factors such as the developmental stage of the child, the presence of an HIV-positive caregiver, normal grief and mourning, organic causes or the side effects of medication may result in symptoms that can resemble psychiatric conditions. In the present study, such environmental factors could also have played a role in the experiences of children.

These findings prompt the question of whether HIV-positive children merely experience similar levels of mental health problems as the HIV-negative children, or whether there are other

factors that improve or worsen their abilities to cope with their circumstances. Consequently, the results obtained from the Self-Description Questionnaire, Kidcope and the parental scales may allow for a more comprehensive understanding.

5.2.2.3 Self-esteem.

On the Self-Description Questionnaire (SDQ) (Marsh, 1988), HIV-positive children obtained statistically significant higher scores on all the subscales. HIV-positive children have a higher general self-evaluation and rated their physical appearance, social ability, and relationship with parents more positively than HIV-negative children (See Table 4.7).

Research with HIV-positive Rwandan children identified self-esteem as a central protective factor against the development of mental health problems (Betancourt, Meyers-Ohki, et al., 2011). Similarly, a Medecins Sans Frontiers guide pertaining to HIV-status disclosure to children, identifies positive self-esteem as an important factor that facilitates healthy adaptation to living with HIV (Chazal, 2005).

5.2.2.4 Coping.

Results of the Kidcope (Spirito et al., 1988) assessment show that both HIV-positive and HIV-negative children made more use of adaptive than of maladaptive coping strategies. However, differences in the frequency of use of some of the coping strategies indicate that fewer HIV-positive children use maladaptive coping strategies such as blaming others and withdrawing from social interaction, than HIV-negative children do (See section 4.2.1.4). With the exception of HIV-positive children's greater use of self-criticism, these findings would indicate that HIV-positive children resort to effective and healthy ways of managing distressing situations.

5.2.2.5 Parental relationships.

In order to determine the extent of the caregivers' support and the strain caregivers may experience in their parent-child relationship, two assessments were administered to the caregivers of both HIV-positive and HIV-negative children. Results of the Parental Stress Index (PSI-SF) (Abidin, 1995) indicate that caregivers of HIV-positive children do not experience significantly more distress in their overall parenting role, which includes their perception of their competence as parents. However, they experience their relationships with their child as significantly more conflicted and less positive.

The Coping with Children's Negative Emotions Scale (CCNES) (Fabes et al., 1990) was used to assess how caregivers tend to respond to their children's negative emotional expressions. Caregivers of HIV-positive children used fewer supportive and non-supportive responses. Caregivers of HIV-negative children responded with significantly more *Emotion-Focused Reactions* and *Problem-Focused Reactions* (which are considered supportive responses) than caregivers of HIV-positive children. However, caregivers of HIV-negative children also had a tendency to use significantly more *Punitive Reactions* (which are considered non-supportive), than did caregivers of HIV-positive children. Hence, although caregivers of HIV-positive children make less use punishment, it appears that they struggle in their role as caregiver and tend to withdraw from this relationship.

These findings raise two pertinent questions. Firstly, why is there this disjunction between caregivers' negative experience of their relationships with their children, and HIV-positive children's overtly positive evaluation of their relationship with their caregivers? Secondly, when it appears that HIV-positive children receive less social support and positive engagement from their primary caregivers, what enables them to make better use of coping strategies and helps them to have higher self-estimations than the HIV-negative comparison group?

5.2.3. Variables related to the mental health of HIV-positive children conceptualised within the Extended-Stress Coping model.

The Extended-Stress Coping model (See Section 2.5.2.6) is a representation of coping specifically adapted to coping with a chronic illness. Various components and interactions of elements such as a person's history, demographics, and elements specific to the disease, their cognitive appraisals, available internal and external resources and the resulting coping behaviour are included as having an effect on coping and mental health. Coping behaviour is then expressed in terms of psychological, social and physical consequences or outcomes (Maes et al., 1996).

Although the types of assessments used in the present study, as well as the young age of the children, do not allow for an assessment of the cognitive element of the model, which refers to the appraisal of demands and goals, the model proves useful in better understanding various elements involved in the coping process and psychological outcomes of HIV-positive children.

5.2.3.1 Demographic characteristics.

The demographic characteristics that were investigated in this study included, amongst other variables, the age, sex, and socio-economic status of the participants. No differences in psychological variables were found between boys and girls in this study. However, the age of HIV-positive children had some correlation with their mental health outcomes. Younger children experienced significantly more affective, ADHD and oppositional defiant problems than older children (See section 4.3.3.2). This could indicate that as children grow older they acquire better coping skills, or it may be related to the natural maturation of children's nervous systems which allows for improved concentration, frustration tolerance and self-control (Sadock et al., 2007; Vander Zanden, Crandell, & Crandell, 2000).

Both HIV-positive and HIV-negative children presented with high rates of clinical, and borderline levels of some mental health problems, without significant differences between the two groups. This underscores the fact that both groups of children are exposed to stressors that affect their mental health. Here, the socio-economic realities of all the participants involved in the present research would be worth considering.

The effects of socio-economic deprivation on the mental health of both adults and children have been extensively studied. Research has shown that a struggle for, and lack of basic material resources contributes to the prevalence and extent of mental health problems (Lund et al., 2011; Reiss, 2013; Yoshikawa, Aber, & Beardslee, 2012). This is also true in the case of people living with HIV (Mellins et al., 2003; Van Rie et al., 2007; Smith & Wilkins, 2014). In this research, these factors may play a greater role than the HIV-status of the children.

5.2.3.2 Disease-related events.

5.2.3.2.1 Serious previous illness.

In the present study, a specific disease-related event pertaining to HIV-positive children referred to whether the child had previously been seriously ill. It was found that 63% of HIV-positive children had indeed suffered a serious previous illness. A statistically significant difference was found between HIV-positive children who had previously suffered a serious illness and those who had not, when their scores on the DSM-orientated scales of the CBCL were compared.

Children who had been seriously ill were more likely to display clinical ranges of affective problems (29.4%) than those who had not previously been seriously ill (15%). Statistically significant results also applied to children presenting with conduct problems. There

was a higher correlation between children who had not previously been seriously ill and instances of borderline and clinical levels of conduct disorder (30%), compared to children who had previously been seriously ill (17.6%).

These results may highlight the effect that a serious illness episode, and to a broader extent, children's physical health, have on their mental health and behaviour. In the case of elevated affective problems, research with chronically ill children has found positive correlations between the experience of being physically unwell – specifically experiences of pain and physical impairment – and depression (Benton et al., 2007; Kohut et al., 2013; Pinquart & Shen, 2011).

In as much as healthier children were more inclined to exhibited conduct problems, it should be noted that the majority of symptoms that pertain to the diagnosis of conduct problems are related to children's overt behaviour (American Psychiatric Association, 2000). Illness episodes would usually entail children's levels of physical activity being limited.

5.2.3.2.2 Disclosure.

Due to the effectiveness of ART, children who are not explicitly informed about their HIV-status may not necessarily be aware of their HIV-status, as they are not necessarily symptomatic.

In the present study, only a small number of HIV-positive children were aware of their HIV-status (17.5%, n = 7). This subset of the sample was too small to allow for meaningful statistical analysis of whether children's knowledge of their HIV-status had any bearing on their mental health. However, scrutinising their CBCL scores, it did not appear that the children who were aware of their positive HIV-status had elevated scores in particular.

The low disclosure rate found by the present study is not in keeping with findings of Madiba, Mahloko, and Mokwena (2013), whose research focused on the disclosure practices relating to HIV-positive South African children and teenagers. Madiba et al. (2013) found a 34% prevalent rate of disclosure among their sample. Madiba and colleagues (2013) indicated that the older a child was, the more likely they were to be informed of their HIV-status. The age range of the sample that Madiba et al. (2013) used included children and teenagers up to 17 years old. This may explain the lower rates of disclosure found by the present study, which only included children up to the age of 12 years.

Wiener, Mellins, Marhefka, and Battles (2007) scrutinised literature pertaining to disclosure practices surrounding HIV-positive children. Findings regarding the effects of disclosure on children's mental health showed varied results.

Steele, Nelson, and Cole (2007), however, found that appropriate disclosure generally contributed to improved adjustment among HIV-positive children. Both sets of authors, however, stress the importance of disclosure practices that consider children's emotional and cognitive developmental levels, and that it is done in a supportive environment (Steele et al., 2007; Wiener et al., 2007).

The low disclosure rate identified by the present study may be the result of numerous factors. For example, it may be the intentions of caregivers to protect children from the possible distress of knowing that they have HIV, the stigma associated with it, or thinking that children are still too young to cope with such a disclosure (Madiba et al., 2013; Ofunne, 2014; Shisana et al., 2014).

Although withholding children's HIV-positive diagnosis from them may serve a temporary protective function for younger children, this can have serious deleterious consequences at a later stage when these children have to become responsible for their anti-retroviral medication adherence or when they start to become sexually active as teenagers (Nassen et al., 2014; Wiener et al., 2007).

5.2.3.3 Disease and treatment characteristics.

5.2.3.3.1 Stigma.

Despite much progress in educating citizens, HIV-related stigmatisation is still prevalent in South Africa (Dos Santos, Kruger, Mellors, Wolvaardt, & Van Der Ryst, 2014). Although the present study did not gather quantitative data on the experience of stigma among children and caregivers, a brief mention is called for, as HIV-related stigmatisation was the reason given by a caregiver as to why their child did not attend school.

It should also be taken into account that caregivers who are themselves HIV-positive, may personally have been exposed to stigmatisation, which could have contributed to their reluctance to disclose their own and their children's HIV-positive status to them (Cluver, Bowes, & Gardner, 2010; Shisana et al., 2014; Steele et al., 2007; Wachira, Middlestadt, Vreeman, & Braitstein, 2012).

5.2.3.4. External resources.

5.2.3.4.1 Caregiver support.

The main external resource that the present research focused on was the emotional support that children received from their caregivers. Caregivers of HIV-positive children experienced their relationships with their children as more distressing than caregivers of HIV-negative children, and withdrew somewhat from their children regarding emotional engagement (See section 4.2.2). Caregivers of HIV-negative children, on the other hand, engaged more actively in their children's expressions of negative emotions than caregivers of HIV-positive children. This engagement, however, applies to response styles that include both supportive and non-supportive response styles.

There was a significant difference between the two groups of caregivers in relation to the punitive response style. Caregivers of HIV-positive children used less punitive responses, which could be related to them being more lenient towards their children due to the child's HIV-status. However, this would not explain the concomitant decrease in supportive response styles.

One should also consider the possibility that the caregivers of HIV-positive children, who are mostly themselves also HIV-positive, are likely to experience more physical and psychological ill health, and therefore have fewer emotional resources (Boeving Allen et al. 2013).

If one views the results of the two caregiver assessments in the context of social and emotional support as an external resource, one can conclude that caregivers of HIV-positive children are less able to provide emotional support to their children. In this regard, it seems that HIV-positive children are at a disadvantage compared to their HIV-negative peers.

Although no causal connections could be established between caregivers' scores on the PSI-SF and children's scores on the CBCL, some correlations were identified. (It should be noted that this pertained to caregivers of both HIV-negative and HIV-positive children.)

Where children obtained higher scores on the *Affective*, *Anxiety* and *Somatic* DSM-orientated subscales of the CBCL these were correlated with elevated scores on both the *Parental Distress* and the *Parent-Child Dysfunctional Interaction* subscales. This would indicate that caregivers' increased distress in their parenting role and a strained relationship with their children are associated with children experiencing higher levels of major depressive and dysthymic disorders, anxiety problems such as generalised anxiety, separation anxiety disorders, specific phobias, and somatisation and somatoform disorders.

These results corroborate the findings of Boeving Allen et al. (2013) who found that for HIV-positive mothers who experienced higher levels of parenting distress and dysfunctional parent-child relationships, their children's behavioural and functional outcomes were impaired.

5.2.3.4.2 Other forms of social support.

HIV-positive children were found to receive less support from their caregivers than HIV-negative children. However, HIV-positive children resorted to other forms of social support from friends and family members.

On the Kidcope, 80.9% of HIV-positive children indicated that they resort to *social support* as a means of coping with distressing situations. Significantly fewer HIV-positive children also indicated that they use *social withdrawal* than did HIV-negative children (See Table 4.8 and Figure 4.5). Demographic information further revealed that HIV-positive children on average have three close friends, which exclude siblings, and spend time with friends outside of school activities on average twice a week.

HIV-positive children's attendance at the Kalafong Paediatric Clinic for their ARV treatment may serve as a possible form of psychosocial support. This is also a distinguishing variable between the HIV-positive children and HIV-negative children in the present study.

At the clinic, children have access to a multidisciplinary team, consisting of, among others, HIV counsellors, nursing staff, medical doctors, an occupational therapist, a dietician and a social worker (Feucht, Kinzer, & Kruger, 2007; Feucht, Van Bruwaene, Becker, & Kruger, 2016; Ofunne, 2014). The personal attention and sense of caring that children receive here may contribute to their positive self-esteem and inclination to use less maladaptive coping strategies than HIV-negative children.

The social support that children receive at the clinic and that which they receive from friends and other family members may hence allow them to compensate to some degree for the shortcomings of emotional support from their primary caregivers.

5.2.3.4.3 Internal resources.

The present research identified HIV-positive children's positive appraisal of themselves as a key internal resource as identified by the SDQ (See Table 4.7). These positive self-evaluations may contribute to their resilience and ability to employ healthy coping strategies.

Eloff et al. (2014) conducted research on the value of an intervention programme aimed at promoting the resilience of young children of HIV-positive mothers. A part of the intervention

that focused on the children included building their self-esteem. Outcomes of the intervention programme included improvements in children's externalising behaviours, communication and daily living skills (Eloff et al., 2014). Similarly, resilience, which includes a positive self-esteem, has been identified as a key factor that enables HIV-positive children to resort to adaptive, as opposed to maladaptive means of coping (Betancourt, Meyers-Ohki, et al., 2011).

5.2.3.5 Coping behaviour.

The results of the Kidcope provide an indication of how effectively HIV-positive children cope. It appears that these children were coping fairly well. As mentioned in Section 5.2.1, HIV-positive children used more adaptive than maladaptive coping strategies, and significantly fewer maladaptive coping strategies than the HIV-negative children in the comparison group.

Adaptive coping was found to serve as a protective function against the development of mental health problems in HIV-positive children (Betancourt, Rubin-Smith, et al., 2011), other child populations with chronic illnesses (Compas, Jaser, Dunn, & Rodriguez, 2012), as well as adults living with HIV (Coetzee & Spangenberg, 2003).

5.2.3.6 Psychological consequences.

Although many HIV-positive children experienced clinical levels of affective and somatic problems on the CBCL, these findings were also true for HIV-negative children (See Chapter 4, Table 4.4). However, the HIV-positive children's results on the SDQ and Kidcope would indicate that these children have been able to access psychological resources that enable them to cope better with their circumstances than HIV-negative children.

5.4 Conclusion

The present study found that many HIV-positive children experienced clinical levels of somatic and affective problems, but lower-than-expected rates of anxiety problems. However, the prevalence of these rates of mental health problems did not differ significantly from a comparison sample of HIV-negative children. This draws attention to the fact that socio-economic difficulties may have negative consequences for the mental health of all children, irrespective of their HIV-status (Mellins et al., 2003).

The research further found that caregivers of children who are HIV-positive experience their relationship as strained, as well as struggle to engage in an emotionally supportive manner

with their HIV-positive children. Despite these shortcomings, it appears that children who are HIV-positive are able to cope fairly well and maintain positive self-evaluations and that social support may serve to mediate against the exacerbation of mental health problems.

These findings support arguments for interventions that focus on caregiver-child dyads and the further provision of psychosocial and mental health services for children and adolescents living with HIV and their families in South Africa, as well as expanding interventions to include broader social and community structures (Amzel et al., 2013; Earls et al., 2008; Eloff et al., 2014; Lachman, Cluver, Boyes, Kuo, & Casale, 2014; Malee et al., 2011; Petersen, 2010; Steele et al., 2007).

5.5 Limitations of the present study

The small sample size of the HIV-positive children (N = 54) in the study limited the data analysis and generalisability of the results. It should further be taken into account that children could only participate in the present study with the consent of a caregiver. Consequently, although the HIV-positive children in this sample are not necessarily living under the supervision of a parent, they are at least under the supervision of a caregiver. Hence, the results of this study may not apply to all HIV-positive South African children, and especially to those who have been orphaned due to AIDS, or part of child-headed households. This may limit the external validity of the present study (Whitley, 2001). These two groups of HIV-positive children may be particularly vulnerable to mental health problems (Cluver, Orkin, Gardner, & Boyes, 2012).

Although the present study used assessments that were adapted for the specific population (Sipsma et al., 2013), these assessments did not have norms specifically for South African children. It should be taken into account that cultural differences have an impact on the way that mental health problems are experienced, understood and expressed (Rohleder, 2012). This may compromise the internal validity of results obtained from the CBCL and RCMAS, as well as have implications for cut-off ranges for clinical levels of psychopathology for these assessments.

Mellins et al. (2006) and Roa et al. (2007) warn of a tendency among parents and caregivers to over-report mood and anxiety symptoms in children. Taking this into account, assessments that allow for parallel administrations or other self-report measures for mood disorders administered to the children may have been useful to corroborate the results of caregiver reports - as was done with the administration of the CBCL and RCMAS for the assessment of anxiety.

The present study was not able to determine any causal relationships between variables, but identified some correlations. Although information gleaned from this is useful, having been able to provide findings that could directly point to causes and protective factors relating to the mental health of HIV-positive children would have been of greater practical use for guiding possible interventions.

5.6 Value of the research

The present study provides information about the mental health of HIV-positive South African children and their coping strategies as well as insight into the parenting strategies and experiences of their caregivers. Research about the mental health problems of South African children living with HIV has thus far been extremely limited, despite South Africa having the largest paediatric HIV population worldwide (UNAIDS, 2015b). Furthermore, the inclusion of the Kidcope measure provides invaluable information about how these children cope with their situation, which may guide future interventions or areas of research focus.

The manner in which the sampling of the present study was constructed provides unique information, as very little research exists which includes both HIV-positive children and caregiver dyads with a comparison sample of uninfected children and their caregivers of a similar demographic group.

In showing that many HIV-negative children also experienced clinical levels of certain mental health problems, this study highlights the fact that children who grow up in challenging socioeconomic circumstances should be considered an at-risk population in South Africa. This would indicate that, as part of South Africa's fight against HIV, the greater socio-economic emancipation of all citizens must be considered.

Only recently have researchers started to focus on the psychosocial outcomes of children and adolescents living with HIV in South Africa. As children infected with HIV since birth are now able to reach adulthood in South Africa, knowledge about how to best aid them to successfully adapt to the various challenges that living with the disease entail, may not only improve the quality of their lives, but may also aid in reducing the incidence of HIV in South Africa.

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Appendix A – Clearance for Needs Assessment

100
1908 - 2008

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Denkleiers • Leading Minds • Dikgopolo tša Dihlalefi

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Faculty of Health Sciences
Department of Paediatrics & Child Health
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012 - 373-1038/1009
012 - 373-7977

Date: 14 April 2009

To: Prof Maretha Visser
Dept of Psychology, University of Pretoria

Dear prof Visser

Re: Needs assessment in the Kalafong Paediatric HIV clinic

Thank you for the support of the department of Psychology in improving the management of HIV-infected children cared for at Kalafong hospital. I have read the protocol regarding the planned needs assessment in the Kalafong Paediatric HIV clinic – and I welcome this initiative. We, as paediatric HIV clinic staff, have long identified the need for psychological support of our patients, but we have not been able to describe this need closer. So the needs assessment will be of use the better understand the needs of the children and their caregivers and to then implement targeted interventions.

Yours sincerely

Dr UD Feucht

MBChB, FCPaed (SA), MMed Paed (Pretoria), Dip HIV Man(SA), CAHM
SPECIALIST & SENIOR LECTURER
CLINICAL HEAD: PAEDIATRIC IMMUNOLOGY CLINIC
DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH
KALAFONG HOSPITAL & UNIVERSITY OF PRETORIA

Appendix B – Example of Caregiver Informed Consent Form

100
1908 - 2008

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Psychology

Dear participant

Needs assessment in Paediatric clinic

We would like to talk to you about the specific needs you and your child have to enable us to develop programs for the clinic to address those needs. We would like to know about your experiences of being a parent and your child's development.

We would like to talk to you for about 30 minutes to 45 minutes. You will keep your position in the queue and we can interrupt the interview if the doctor wants to see you. We would also like to talk to your child if your child is older than 8 years.

This research is voluntary, you can decide if you want to participate or not. The advantage of participating is that you will help us to develop good programs for you and the other patients of the clinic. We will give you something to eat and drink just to say thank you. There will not be risks involve, because we will treat your information with care and will not share it with anyone you know outside of the clinic. If there are questions that make you feel uncomfortable, you need not answer those questions. If you need someone to talk to afterwards, you can see the social worker of the clinic or one of the counsellors. If you choose not to participate, it is fine, you will not be penalised in any way.

You can get more information about the research by talking to Dr Ute Feucht at Kalafong Hospital or Prof Maretha Visser at the Psychology Department of the University (012 420 2549). The information from the study will be stored for 15 years at the University but it does not have your name on it and is confidential.

Declaration of consent

Hereby I acknowledge that I have been informed about the research and that I am willing to participate by answering specific questions. I am also allowing my child (if the child is older than 8 years) to be interviewed by one of the researchers. I know that I need not answer questions if I feel uncomfortable.

Signed: _____

Date: _____

Witness: _____

Appendix C – Biographical Data

Kalafong Paediatrics clinic needs assessment
(Questionnaire for mothers/caregivers)

Patient number__ _____ _____ **Date: (dd/mm/yyyy)**_____ ___

Thank you for being willing to talk to us. We need to understand some of your and your child's experiences to enable us to develop ways of helping families similar to yours. First I am going to ask you questions about yourself so that I can understand who you are and know a little bit about your background.

1. How old were you on your last birthday?_____

2. What is the highest grade you completed in school? (Please indicate with a X)
Grade [0] [1] [2] [3] [4] [5] [6] [7] [8] [9] [10] [11] [12] [Tertiary]

3. Which of the following best describes your current employment status?
- ☐ Working full time
- ☐ Working part time
- ☐ Self employed (including informal work such as selling goods at the market)
- ☐ Unemployed - looking for work
- ☐ Unemployed – not looking for work
- ☐ Other

4. Which of the following best describes your current marital status?
- ☐ Single (no partner)
- ☐ Not married but have a partner
- ☐ Married/Common Law Marriage
- ☐ Widowed

5. Are you living with your partner?
- ☐ Yes
- ☐ No

6. Within the last six months has your husband/partner provided you money you need for food, rent, and bills?
- ☐ Yes
- ☐ No

5. In the **PAST THREE MONTHS** what community resources have you used?
- ☐ Social workers
- ☐ Grants
- ☐ Food parcels
- ☐ Psychological (mental health) services
- ☑ Support groups
- ☐ Income generation or skills development projects
- ☐ Other_____
- ☐ None

6. How many people stay in your home with you?_____
They are:
- ☐ Partner/husband

☐ Family members
☐ Other adults to whom you are not related
☐ Your own children: How many? _____
☐ Other children who are not your own

7. In the **PAST 3 MONTHS**, did you visit a doctor of clinic for regular care or because you were sick?

☐ Yes → 21. What was your reason for going?
☐ Immunlogy for medication
☐ For what illness did you get treatment?
_____
_____

☐ No

8. Do you have energy for everyday life?

☐ Not at all
☐ A little
☐ Moderately
☐ Mostly
☐ Completely

9. How satisfied are you with your ability to perform your daily activities?

☐ Very dissatisfied
☐ Dissatisfied
☐ Neither satisfied nor dissatisfied
☐ Satisfied
☐ Very satisfied

Information about your child attending the clinic

10. What is your child's name? _____

11. What is your child's date of birth? (dd/mm/yyyy)_____

12. What treatment does your child currently get at the clinic? (check all that apply):

☐ See doctor : _____
☐ See social worker: _____
☐ See physiotherapist: _____
☐ See occupational therapist: _____
☐ N/A

13. Has your child ever had to repeat a grade level at school?
☐ Yes
☐ No
☐ Has not ever attended school

14. Has your child ever been seriously ill?
☐ Yes
☐ No

113a. When was that?

114a.Describe

I would like to know what you have told your child about his/her health. Remember, we are not going to share any of this information with your child. We only want to know what kinds of talks, if any, you have had with your child about his/her health.

15. What have you told your child about his/her HIV status?
☐ I have told my child he/she has HIV/AIDS.
☐ Someone else told my child that he/she has HIV/AIDS.
☐ I have told my child he/she has a serious health/medical condition, but not that it is HIV.
☐ I have told my child that he/she is sick, but have not said that it is serious.
☐ I have not told my child anything about his/her health.

144a. How long ago did you tell your child about his/her health?
Months_____ Years_____

145a. What did you tell your child?

What was his/her reaction?

146a. How often do you discuss his/her health status with your child?
☐ Once per week or more often
☐ 1-3 times per month
☐ Less than once per month

147a. How well do you think your child understands what you have told him/her?
☐ Very well
☐ Somewhat
☐ Not at all

16. What have you told your child about your own HIV status?

- ☐ I am not HIV+
- ☐ I have told my child I have HIV/AIDS.
- ☐ Someone else told my child that I have HIV/AIDS.
- ☐ I have told my child I have a serious health/medical condition, but not that it is HIV.
- ☐ I have told my child that I have something wrong with me, but have not said that it is serious.
- ☐ I have not told my child anything about my health.

144b. How long ago did you tell your child about your health?
Months_____ Years_____

145b. Did you tell your child that this information was a secret?
- ☐ Yes
- ☐ No

146b. How often do you discuss your health status with your child?
- ☐ Once per week or more often
- ☐ 1-3 times per month
- ☐ Less than once per month

147b. How well do you think your child understands what you have told him/her?
- ☐ Very well
- ☐ Somewhat
- ☐ Not at all

148b. Do you think your child might suspect that you are ill?
- ☐ Yes
- ☐ No

17. How does HIV in your family influence the interaction in your family?

_____

18. How does HIV influence your family's interaction with other members of your community?

_____

Appendix D – CBCL Questionnaire

21 (b) CBCL AGE 6 – 18
** Do not complete if child is younger than 6 years old

Please fill out this form to reflect *your* view of the child's behaviour even if other people might not agree. Feel free to write additional comments beside each item

Age of the child _____ Child's gender ☐ Boy ☐ Girl
241. GRADE IN SCHOOL _____ NOT ATTENDING SCHOOL ☐

Here is a list of items that describe children and youths. For each item that describes the child **now or within the past 6 months**, please circle the **2** if the item is **very true** or **often true** of the child. Circle the **1** if the item is **sometimes true** of the child. If the item is **not true** of the child, circle the **0**. Please answer all items as well as you can, even if some do not seem to apply to the child.

0 = Not true (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2	1. Acts too young for his/her age	0 1 2	16. Disobedient at home, naughty
0 1 2	2. Drinks alcohol/dagga/sniff glue without parents' approval (describe): _____	0 1 2	17. Does not listen at school
		0 1 2	18. Doesn't eat well
		0 1 2	19. Doesn't get along with other kids
0 1 2	3. Argues a lot	0 1 2	20. Doesn't seem to feel guilty after misbehaving
0 1 2	4. Fails to finish things s/he starts	0 1 2	21. Easily jealous
0 1 2	5. There is very little s/he enjoys	0 1 2	22. Breaks rules at home, school or elsewhere
0 1 2	6. Can't concentrate, can't pay attention for long	0 1 2	23. Fears certain animals, situations, or places, other than school (describe): _____
0 1 2	7. Can't sit still, restless, or hyperactive		
0 1 2	8. Clings to adults or too dependent		
0 1 2	9. Complains of loneliness		
0 1 2	10. Confused or seems to be dazed	0 1 2	24. Fears going to school
0 1 2	11. Cries a lot	0 1 2	25. Fears s/he might think or do something bad
0 1 2	12. Cruel to animals (describe): _____ _____	0 1 2	26. Feels s/he has to be perfect
		0 1 2	27. Feels or complaints that no one loves him/her
0 1 2	13. Cruelty, bullying, or meanness to others	0 1 2	28. Feels others are out to get him/her
0 1 2	14. Daydreams or gets lost in his/her thoughts	0 1 2	29. Feels worthless or inferior
		0 1 2	30. Gets hurt a lot, accident-prone
0 1 2	15. Deliberately harms self or attempts suicide	0 1 2	31. Gets in many fights
		0 1 2	32. Gets teased a lot

0 (1) 2	33. Demands a lot of attention	(0) 1 2	292. Hangs around with others who gets into trouble
(0) 1 2	34. Destroys his/her own things	(0) 1 2	293. Impulsive or acts without thinking
0, 1 ·2	35. Destroys things belonging to his/her family or others	(0) 1 2	294. Would rather be alone than with others
		0 1 2	295. Lying or cheating
		(0) 1 2	296. Nervous, on guard, or tense

0 = Not true (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

(0) 1 2	297. Nightmares	(0) 1 2	311. Runs away from home
(0) 1 2	298. Not liked by other kids	(0) 1 2	312. Screams a lot
(0) 1 2	299. Constipated, doesn't move bowels	0 (1) 2	313. Secretive, keeps things to self
(0) 1 2	300. Too fearful or anxious	(0) 1 2	314. Self-conscious or easily embarrassed
0 (1) 2	301. Feels dizzy or light-headed	(0) 1 2	315. Sets fires
(0) 1 2	302. Feels too guilty	(0) 1 2	316. Sexual problems (describe):
(0) 1 2	303. Overtired without good reason		_____
	304. Physical problems **without known medical cause:**		_____
0 (1) 2	a. Aches or pains (**not** stomach or headaches)	(0) 1 2	317. Too shy or timid
0 (1) 2	b. Headaches	(0) 1 2	318. Sleeps less than most kids
(0) 1 2	c. Nausea, feels sick	(0) 1 2	319. Sleeps more than most kids during day and/or night (describe):
(0) 1 2	d. Problems with eyes (**not** if corrected by glasses) (describe):		_____
	_____		_____
	_____	(0) 1 2	320. Does not pay attention or gets distracted easily
(0) 1 2	e. Rashes or other skin problems	(0) 1 2	321. Speech problem (describe):
0 (1) 2	f. Stomach-aches		_____
(0) 1 2	g. Vomiting, throwing up		_____
(0) 1 2	305. Physically attacks people	(0) 1 2	322. Sits and stares in front of him/her
(0) 1 2	306. Poor school work	(0) 1 2	323. Take things that does not belong to him/her at the house
(0) 1 2	307. Poorly coordinated or clumsy	(0) 1 2	324. Take things that does not belong to him/her outside the house
(0) 1 2	308. Prefers being with older kids	(0) 1 2	325. Stubborn, sullen or irritable
0 (1) 2	309. Prefers being with younger kids		
(0) 1 2	310. Refuses to talk		

Please be sure you answered all items. Then see the next page.

0 = Not true (as far as you know)	1 = Somewhat or Sometimes True	2 = Very True or Often True

0	(1)	2	326. Sudden changes in mood or feelings	(0) 1	2 341. Unusually loud
(0)	1	2	327 Sulks a lot	(0) 1	2 342. Uses drugs like cough syrup for non medical purposes (**don't** include alcohol or tobacco) (describe): _____
0	(1)	2	328. Suspicious		
(0)	1	2	329. Swearing or obscene language		
(0)	1	2	330 Talks about killing self		
0	(1)	2	331. Talks too much		
(0)	1	2	332. Teases a lot	(0) 1	2 343. Damages property of other people
0	(1)	2	333. Temper tantrums or hot temper	(0) 1	2 344. Wishes to be of opposite sex
(0)	1	2	334. Thinks about sex too much	(0) 1	2 345. Keeps to self a lot
(0)	1	2	335. Threatens people	0 (1)	2 346. Worries
(0)	1	2	336. Smokes or, chews tobacco, or sniffs glue		
(0)	1	2	337. Trouble sleeping (describe): _____		
(0)	1	2	338. Truancy, skips school		
(0)	1	2	339. Under active, slow moving, or lacks energy.		
0	(1)	2	340. Unhappy, sad, or depressed		

22. About how many close friends does your child have? (Do *not* include brothers and sisters)

☐ None ☐ 1 ☒ 2 or 3 ☐ 4 or more

23. About how many times a week does your child do things with any friends outside of regular school hours?

(Do *not* include brothers and sisters) ☐ Less than 1 ☒ 1 or 2 ☐ 3 or more

24. Compared to others of his/her age, how well does your child:

	Worse	Average	Better	
a.Get along with his/her brothers and sister?				X Has no brothers and sisters.
b. Get along with other kids?				
c. Behave with his/her parents?				
d. Play and work alone?				

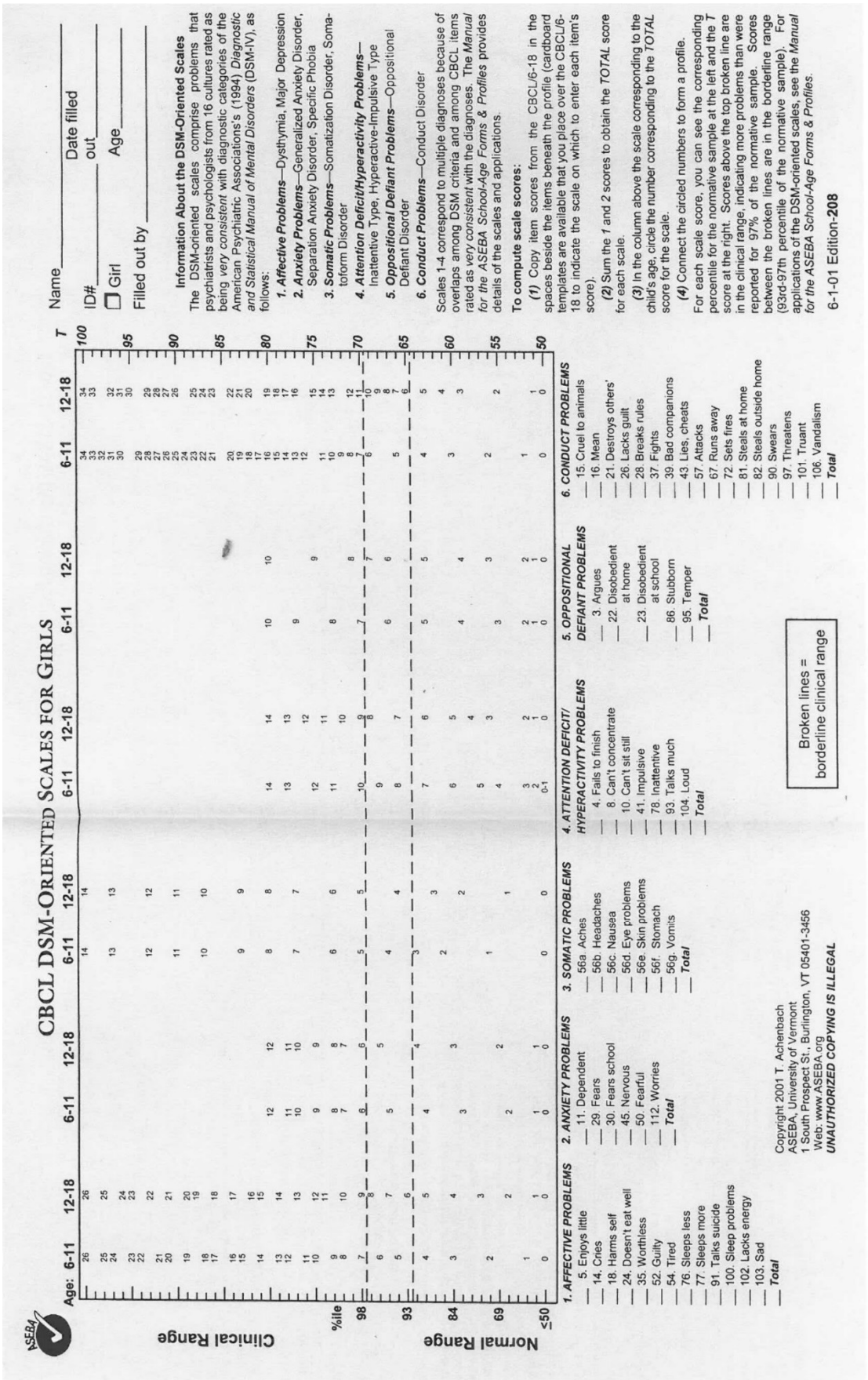
25. Do your child have any problems in school? ☑ No ☐ Yes – please describe

(1)

26. What concerns you most about your child (older than 6 years)?

THANK YOU FOR YOUR PARTICIPATION

Appendix E – CBCL DSM-Orientated Scales



CBCL DSM-ORIENTED SCALES FOR GIRLS

Name_____ Date filled out_____
ID#_____
☐ Girl Age_____
Filled out by _____

Information About the DSM-Oriented Scales

The DSM-oriented scales comprise problems that psychiatrists and psychologists from 16 cultures rated as being *very consistent* with diagnostic categories of the American Psychiatric Associations's (1994) *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), as follows:

1. ***Affective Problems***—Dysthymia, Major Depression
2. ***Anxiety Problems***—Generalized Anxiety Disorder, Separation Anxiety Disorder, Specific Phobia
3. ***Somatic Problems***—Somatization Disorder, Somatoform Disorder
4. ***Attention Deficit/Hyperactivity Problems***—Inattentive Type, Hyperactive-Impulsive Type
5. ***Oppositional Defiant Problems***—Oppositional Defiant Disorder
6. ***Conduct Problems***—Conduct Disorder

Scales 1-4 correspond to multiple diagnoses because of overlaps among DSM criteria and among CBCL items rated as *very consistent* with the diagnoses. The *Manual for the ASEBA School-Age Forms & Profiles* provides details of the scales and applications.

To compute scale scores:

(1) Copy item scores from the CBCL/6-18 in the spaces beside the items beneath the profile (cardboard templates are available that you place over the CBCL/6-18 to indicate the scale on which to enter each item's score).

(2) Sum the *1* and *2* scores to obtain the *TOTAL* score for each scale.

(3) In the column above the scale corresponding to the child's age, circle the number corresponding to the *TOTAL* score for the scale.

(4) Connect the circled numbers to form a profile.

For each scale score, you can see the corresponding percentile for the normative sample at the left and the *T* score at the right. Scores above the top broken line are in the clinical range, indicating more problems than were reported for 97% of the normative sample. Scores between the broken lines are in the borderline range (93rd-97th percentile of the normative sample). For applications of the DSM-oriented scales, see the *Manual for the ASEBA School-Age Forms & Profiles*.

6-1-01 Edition-208

Age: 6-11 12-18 | 6-11 12-18 | 6-11 12-18 | 6-11 12-18 | 6-11 12-18 | T

Clinical Range / Normal Range | %ile: 98, 93, 84, 69, ≤50

1. *AFFECTIVE PROBLEMS*
   - 5. Enjoys little
   - 14. Cries
   - 18. Harms self
   - 24. Doesn't eat well
   - 35. Worthless
   - 52. Guilty
   - 54. Tired
   - 76. Sleeps less
   - 77. Sleeps more
   - 91. Talks suicide
   - 100. Sleep problems
   - 102. Lacks energy
   - 103. Sad
   - ***Total***

2. *ANXIETY PROBLEMS*
   - 11. Dependent
   - 29. Fears
   - 30. Fears school
   - 45. Nervous
   - 50. Fearful
   - 112. Worries
   - ***Total***

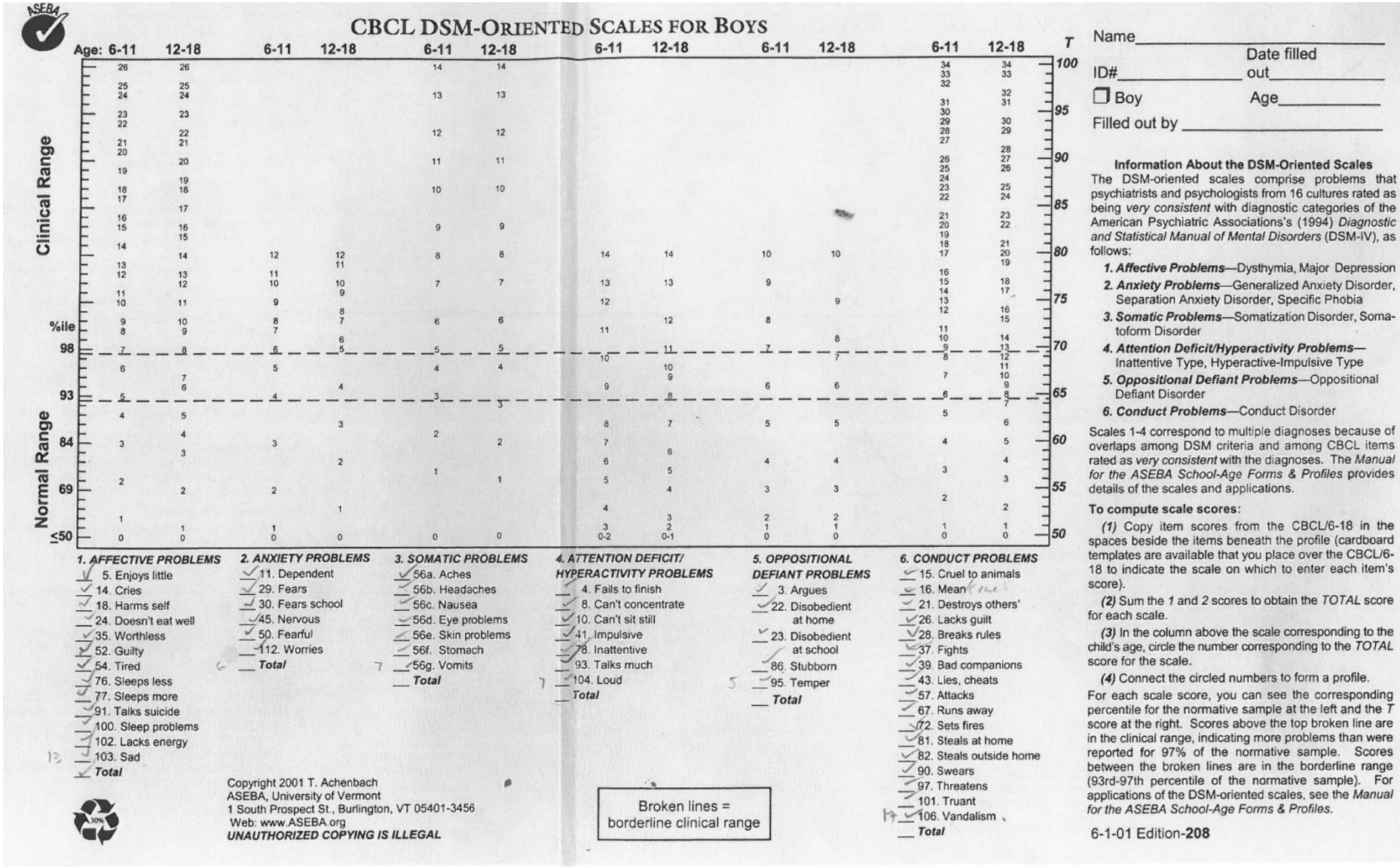
3. *SOMATIC PROBLEMS*
   - 56a. Aches
   - 56b. Headaches
   - 56c. Nausea
   - 56d. Eye problems
   - 56e. Skin problems
   - 56f. Stomach
   - 56g. Vomits
   - ***Total***

4. *ATTENTION DEFICIT/ HYPERACTIVITY PROBLEMS*
   - 4. Fails to finish
   - 8. Can't concentrate
   - 10. Can't sit still
   - 41. Impulsive
   - 78. Inattentive
   - 93. Talks much
   - 104. Loud
   - ***Total***

5. *OPPOSITIONAL DEFIANT PROBLEMS*
   - 3. Argues
   - 22. Disobedient at home
   - 23. Disobedient at school
   - 86. Stubborn
   - 95. Temper
   - ***Total***

6. *CONDUCT PROBLEMS*
   - 15. Cruel to animals
   - 16. Mean
   - 21. Destroys others'
   - 26. Lacks guilt
   - 28. Breaks rules
   - 37. Fights
   - 39. Bad companions
   - 43. Lies, cheats
   - 57. Attacks
   - 67. Runs away
   - 72. Sets fires
   - 81. Steals at home
   - 82. Steals outside home
   - 90. Swears
   - 97. Threatens
   - 101. Truant
   - 106. Vandalism
   - ***Total***

Broken lines = borderline clinical range



CBCL DSM-ORIENTED SCALES FOR BOYS

Age: 6-11 | 12-18 | 6-11 | 12-18 | 6-11 | 12-18 | 6-11 | 12-18 | 6-11 | 12-18 | 6-11 | 12-18 | T

Clinical Range

%ile

98

93

Normal Range

≤50

100 95 90 85 80 75 70 65 60 55 50

Name_____

Date filled out_____

ID#_____

☐ Boy Age_____

Filled out by _____

Information About the DSM-Oriented Scales

The DSM-oriented scales comprise problems that psychiatrists and psychologists from 16 cultures rated as being *very consistent* with diagnostic categories of the American Psychiatric Associations's (1994) *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), as follows:

1. ***Affective Problems***—Dysthymia, Major Depression
2. ***Anxiety Problems***—Generalized Anxiety Disorder, Separation Anxiety Disorder, Specific Phobia
3. ***Somatic Problems***—Somatization Disorder, Somatoform Disorder
4. ***Attention Deficit/Hyperactivity Problems***—Inattentive Type, Hyperactive-Impulsive Type
5. ***Oppositional Defiant Problems***—Oppositional Defiant Disorder
6. ***Conduct Problems***—Conduct Disorder

Scales 1-4 correspond to multiple diagnoses because of overlaps among DSM criteria and among CBCL items rated as *very consistent* with the diagnoses. The *Manual for the ASEBA School-Age Forms & Profiles* provides details of the scales and applications.

To compute scale scores:

(1) Copy item scores from the CBCL/6-18 in the spaces beside the items beneath the profile (cardboard templates are available that you place over the CBCL/6-18 to indicate the scale on which to enter each item's score).

(2) Sum the *1* and *2* scores to obtain the *TOTAL* score for each scale.

(3) In the column above the scale corresponding to the child's age, circle the number corresponding to the *TOTAL* score for the scale.

(4) Connect the circled numbers to form a profile.

For each scale score, you can see the corresponding percentile for the normative sample at the left and the *T* score at the right. Scores above the top broken line are in the clinical range, indicating more problems than were reported for 97% of the normative sample. Scores between the broken lines are in the borderline range (93rd-97th percentile of the normative sample). For applications of the DSM-oriented scales, see the *Manual for the ASEBA School-Age Forms & Profiles.*

6-1-01 Edition-**208**

1. AFFECTIVE PROBLEMS

- 5. Enjoys little
- 14. Cries
- 18. Harms self
- 24. Doesn't eat well
- 35. Worthless
- 52. Guilty
- 54. Tired
- 76. Sleeps less
- 77. Sleeps more
- 91. Talks suicide
- 100. Sleep problems
- 102. Lacks energy
- 103. Sad

Total

2. ANXIETY PROBLEMS

- 11. Dependent
- 29. Fears
- 30. Fears school
- 45. Nervous
- 50. Fearful
- 112. Worries

Total

3. SOMATIC PROBLEMS

- 56a. Aches
- 56b. Headaches
- 56c. Nausea
- 56d. Eye problems
- 56e. Skin problems
- 56f. Stomach
- 56g. Vomits

Total

4. ATTENTION DEFICIT/ HYPERACTIVITY PROBLEMS

- 4. Fails to finish
- 8. Can't concentrate
- 10. Can't sit still
- 41. Impulsive
- 78. Inattentive
- 93. Talks much
- 104. Loud

Total

5. OPPOSITIONAL DEFIANT PROBLEMS

- 3. Argues
- 22. Disobedient at home
- 23. Disobedient at school
- 86. Stubborn
- 95. Temper

Total

6. CONDUCT PROBLEMS

- 15. Cruel to animals
- 16. Mean
- 21. Destroys others'
- 26. Lacks guilt
- 28. Breaks rules
- 37. Fights
- 39. Bad companions
- 43. Lies, cheats
- 57. Attacks
- 67. Runs away
- 72. Sets fires
- 81. Steals at home
- 82. Steals outside home
- 90. Swears
- 97. Threatens
- 101. Truant
- 106. Vandalism

Total

Broken lines = borderline clinical range

Appendix F – CCNES

ID _____

Parent Attitude/Behavior Questionnaire

Instructions: In the following items, please indicate on a scale from 1 (very unlikely) to 7 (very likely) the likelihood that you would respond in the ways listed for each item. Please read each item carefully and respond as honestly and sincerely as you can. For each response, please circle a number from 1-7.

Response Scale: 1 2 3 4 5 6 7
Very Unlikely Medium Very Likely

---

1. If my child becomes angry because he/she is sick or hurt and can't go to his/her friend's birthday party, I would:

a.	send my child to his/her room to cool off	1 2 3 4 5 6 7
b.	get angry at my child	1 2 3 4 5 6 7
c.	help my child think about ways that he/she can still be with friends (e.g., invite some friends over after the party)	1 2 3 4 5 6 7
d.	tell my child not to make a big deal out of missing the party	1 2 3 4 5 6 7
e.	encourage my child to express his/her feelings of anger and frustration	1 2 3 4 5 6 7
f.	soothe my child and do something fun with him/her to make him/her feel better about missing the party	1 2 3 4 5 6 7

2. If my child falls off his/her bike and breaks it, and then gets upset and cries, I would:

a.	remain calm and not let myself get anxious	1 2 3 4 5 6 7
b.	comfort my child and try to get him/her to forget about the accident	1 2 3 4 5 6 7
c.	tell my child that he/she is over-reacting	1 2 3 4 5 6 7
d.	help my child figure out how to get the bike fixed	1 2 3 4 5 6 7
e.	tell my child it's OK to cry	1 2 3 4 5 6 7
f.	tell my child to stop crying or he/she won't be allowed to ride his/her bike anytime soon	1 2 3 4 5 6 7

3. If my child loses some prized possession and reacts with tears, I would:

a.	get upset with him/her for being so careless and then crying about it	1 2 3 4 5 6 7
b.	tell my child that he/she is over-reacting	1 2 3 4 5 6 7
c.	help my child think of places he/she hasn't looked yet	1 2 3 4 5 6 7
d.	distract my child by talking about happy things	1 2 3 4 5 6 7
e.	tell him/her it's OK to cry when you feel unhappy	1 2 3 4 5 6 7
f.	tell him/her that's what happens when you're not careful	1 2 3 4 5 6 7

4. If my child is afraid of injections and becomes quite shaky and teary while waiting for his/her turn to get a shot, I would:

a.	tell him/her to shape up or he/she won't be allowed to do something he/she likes to do (e.g., watch TV)	1 2 3 4 5 6 7
b.	encourage my child to talk about his/her fears	1 2 3 4 5 6 7
c.	tell my child not to make big deal of the shot	1 2 3 4 5 6 7
d.	tell him/her not to embarrass us by crying	1 2 3 4 5 6 7
e.	comfort him/her before and after the shot	1 2 3 4 5 6 7
f.	talk to my child about ways to make it hurt less (such as relaxing so it won't hurt or taking deep breaths).	1 2 3 4 5 6 7

Response Scale: 1 2 3 4 5 6 7
Very Unlikely Medium Very Likely

---

5. If my child is going over to spend the afternoon at a friend's house and becomes nervous and upset because I can't stay there with him/her, I would:

a. distract my child by talking about all the fun he/she will have with his/her friend 1 2 3 4 5 6 7
b. help my child think of things that he/she could do so that being at the friend's house without me wasn't scary (e.g., take a favorite book or toy with him/her) 1 2 3 4 5 6 7
c. tell my child to quit over-reacting and being a baby 1 2 3 4 5 6 7
d. tell the child that if he/she doesn't stop that he/she won't be allowed to go out anymore 1 2 3 4 5 6 7
e. feel upset and uncomfortable because of my child's reactions 1 2 3 4 5 6 7
f. encourage my child to talk about his/her nervous feelings 1 2 3 4 5 6 7

6. If my child is participating in some group activity with his/her friends and proceeds to make a mistake and then looks embarrassed and on the verge of tears, I would:

a. comfort my child and try to make him/her feel better 1 2 3 4 5 6 7
b. tell my child that he/she is over-reacting 1 2 3 4 5 6 7
c. feel uncomfortable and embarrassed myself 1 2 3 4 5 6 7
d. tell my child to straighten up or we'll go home right away 1 2 3 4 5 6 7
e. encourage my child to talk about his/her feelings of embarrassment 1 2 3 4 5 6 7
f. tell my child that I'll help him/her practice so that he/she can do better next time 1 2 3 4 5 6 7

7. If my child is about to appear in a recital or sports activity and becomes visibly nervous about people watching him/her, I would:

a. help my child think of things that he/she could do to get ready for his/her turn (e.g., to do some warm-ups and not to look at the audience) 1 2 3 4 5 6 7
b. suggest that my child think about something relaxing so that his/her nervousness will go away 1 2 3 4 5 6 7
c. remain calm and not get nervous myself 1 2 3 4 5 6 7
d. tell my child that he/she is being a baby about it 1 2 3 4 5 6 7
e. tell my child that if he/she doesn't calm down, we'll have to leave and go home right away 1 2 3 4 5 6 7
f. encourage my child to talk about his/her nervous feelings 1 2 3 4 5 6 7

8. If my child receives an undesirable birthday gift from a friend and looks obviously disappointed, even annoyed, after opening it in the presence of the friend, I would:

a. encourage my child to express his/her disappointed feelings 1 2 3 4 5 6 7
b. tell my child that the present can be exchanged for something the child wants 1 2 3 4 5 6 7
c. NOT be annoyed with my child for being rude 1 2 3 4 5 6 7
d. tell my child that he/she is over-reacting 1 2 3 4 5 6 7
e. scold my child for being insensitive to the friend's feelings 1 2 3 4 5 6 7
f. try to get my child to feel better by doing something fun 1 2 3 4 5 6 7

Response Scale: 1 2 3 4 5 6 7
Very Unlikely Medium Very Likely

---

9. If my child is panicky and can't go to sleep after watching a scary TV show, I would:

a.	encourage my child to talk about what scared him/her	1 2 3 4 5 6 7
b.	get upset with him/her for being silly	1 2 3 4 5 6 7
c.	tell my child that he/she is over-reacting	1 2 3 4 5 6 7
d.	help my child think of something to do so that he/she can get to sleep (e.g., take a toy to bed, leave the lights on)	1 2 3 4 5 6 7
e.	tell him/her to go to bed or he/she won't be allowed to watch any more TV	1 2 3 4 5 6 7
f.	do something fun with my child to help him/her forget about what scared him/her	1 2 3 4 5 6 7

10. If my child is at a park and appears on the verge of tears because the other children are mean to him/her and won't let him/her play with them, I would:

a.	NOT get upset myself	1 2 3 4 5 6 7
b.	tell my child that if he/she starts crying then we'll have to go home right away	1 2 3 4 5 6 7
c.	tell my child it's OK to cry when he/she feels bad	1 2 3 4 5 6 7
d.	comfort my child and try to get him/her to think about something happy	1 2 3 4 5 6 7
e.	help my child think of something else to do	1 2 3 4 5 6 7
f.	tell my child that he/she will feel better soon	1 2 3 4 5 6 7

11. If my child is playing with other children and one of them calls him/her names, and my child then begins to tremble and become tearful, I would:

a.	tell my child not to make a big deal out of it	1 2 3 4 5 6 7
b.	feel upset myself	1 2 3 4 5 6 7
c.	tell my child to behave or we'll have to go home right away	1 2 3 4 5 6 7
d.	help my child think of constructive things to do when other children tease him/her (e.g., find other things to do)	1 2 3 4 5 6 7
e.	comfort him/her and play a game to take his/her mind off the upsetting event	1 2 3 4 5 6 7
f.	encourage him/her to talk about how it hurts to be teased	1 2 3 4 5 6 7

12. If my child is shy and scared around strangers and consistently becomes teary and wants to stay in his/her bedroom whenever family friends come to visit, I would:

a.	help my child think of things to do that would make meeting my friends less scary (e.g., to take a favorite toy with him/her when meeting my friends)	1 2 3 4 5 6 7
b.	tell my child that it is OK to feel nervous	1 2 3 4 5 6 7
c.	try to make my child happy by talking about the fun things we can do with our friends	1 2 3 4 5 6 7
d.	feel upset and uncomfortable because of my child's reactions	1 2 3 4 5 6 7
e.	tell my child that he/she must stay in the living room and visit with our friends	1 2 3 4 5 6 7
f.	tell my child that he/she is being a baby	1 2 3 4 5 6 7

Appendix G – PSI-SF

PSI

The following are questions about your feelings as a parent and your relationship with your child. Please answer all the questions in regard to your child (or use name). While you may not find an answer which exactly states your feelings, please mark the answer which comes closest to describing how you feel.

YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER

For each statement, please answer whether you "Strongly agree", "Agree", "Disagree" or Strongly Disagree". If you don't agree or disagree, please mark with X "not sure"

PARENTING STRESS	STRONGLY AGREE	AGREE	NOT SURE	DISAGREE	STRONGLY DISAGREE	
1. I often have the feeling that I cannot handle things very well	5	4	3	2	1	
2. I find myself giving up more of my life to meet my child's needs than I ever expected	5	4	3	2	1	
3. I feel trapped by my responsibilities as a parent	5	4	3	2	1	
4. Since having this child, I have been unable to do new and different things	5	4	3	2	1	
5. Since having a child I feel that I am almost never able to do things that I like to do	5	4	3	2	1	
6. There are quite a few things that bother me about my life	5	4	3	2	1	
7. Having a child has caused more problems that I expected in my relationship with my partner (*instructions to RA: if N/A, leave this question blank with a note of explanation if no partner etc)*	5	4	3	2	1	
8. I feel alone and without friends	5	4	3	2	1	
9. When I go to a party or visit a friend, I usually expect not to enjoy myself	5	4	3	2	1	
10. I am not as interested in people as I used to be	5	4	3	2	1	
11. I don't enjoy things as I used to	5	4	3	2	1	
12. My child rarely does things that make me feel good	5	4	3	2	1	

13. Most times I feel that my child does not like me and does not want to be close to me	5	4	3	2	1	
14. My child smiles at me much less than I expected	5	4	3	2	1	
15. When I do things for my child, I get the feeling that what I do is not appreciated very much.	5	4	3	2	1	
16. When playing, my child doesn't often giggle or laugh	5	4	3	2	1	
17. My child doesn't seem to learn as quickly as most children	5	4	3	2	1	
18. My child is not able to do as much as I expected	5	4	3	2	1	
19. It takes a long time and it is very hard for my child to get used to new things	5	4	3	2	1	
20. I expected to have closer and warmer feelings for my child that I do	5	4	3	2	1	
21. Sometimes my child does things just t upset me	5	4	3	2	1	
22. I FEEL THAT I (X ONE)	AM NOT A GOOD PARENT	HAVE SOME TROUBLE BEING A PARENT	AM AN AVERAGE PARENT	AM A GOOD PARENT	AM A VERY GOOD PARENT	

Appendix H – SDQ-I

QUESTIONNAIRE FOR CHILDREN (8 – 13 YEARS)

	(1)	sometimes (2)	sometimes (4)	(5)	no (3)
4. My parent(s) **understand** me. (Explain as **"Know me"** for this first encounter.)	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
5. I do lots of **important** things. (Explain as **"Special"** for this first encounter.)	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
6. I like to run fast and play hard.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
7. I like the way I look.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
8. I make friends easily.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
9. I like my parent(s).	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
10. I like being the way I am.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
11. I enjoy sports and games.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
12. I have a nice looking face.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
13. I get along with other kids easily.	No		Yes		Child understands

	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	but does not state yes or no (3)
14. My parent(s) like me.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
15. I have lots of things to be proud of. Good dancer, I am beautiful	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
16. I am strong (Explain as "good muscles" if they don't understand.)	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
17. I am a nice looking person.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
18. I am easy to like.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
19. If I have kids I would bring them up the same way my parents raised me.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
20. I can do things as well as most children. (Explain as "Sports or school work" if they don't understand)	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
21. I am good at sports like soccer.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
STOP AND ASK THE CHILD TO STRETCH					
22. Other kids think I am pretty/ handsome.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
23. Other kids want me to be their friend.	No always	No	Yes	Yes always	Child understands but does not state yes or

	(1)	sometimes (2)	sometimes (4)	(5)	no (3)
24. My parent(s) and I spend a lot of time together.	No No always (1)	No sometimes (2)	Yes Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
25. A lot of things about me are good.	No No always (1)	No sometimes (2)	Yes Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
26. I can run a long way without stopping.	No No always (1)	No sometimes (2)	Yes Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
27. I have a good looking body.	No No always (1)	No sometimes (2)	Yes Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
28. I have more friends than most other kids.	No No always (1)	No sometimes (2)	Yes Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
29. My parent(s) are easy to talk to.	No No always (1)	No sometimes (2)	Yes Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
30. I'm as good as most other children.	No No always (1)	No sometimes (2)	Yes Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
31 I am a **good athlete**. (Explain as **"sports person"** for this first and only encounter.)	No No always (1)	No sometimes (2)	Yes Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
32. I'm better looking than most of my friends.	No No always (1)	No sometimes (2)	Yes Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
33. Other kids my age like me. ("Liked by kids" if they don't	No No always	No sometimes	Yes Yes	Yes always	Child understands but does not state yes or

understand.)	(1)	(2)	sometimes (4)	(5)	no (3)
34. I get along well with my parent(s).	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
35. Other people think I am a good person.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
36. I'm good at throwing a ball.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
37. I like the way my face looks.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
38. Most other kids like me.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
39. My parent(s) and I have a lot of fun together.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)
40. When I do something, I do it well.	No always (1)	No sometimes (2)	Yes sometimes (4)	Yes always (5)	Child understands but does not state yes or no (3)

Appendix I – RCMAS

(5) RCMAS

WHAT I THINK AND FEEL

1. I have difficulty making up my mind.	YES	NO
2. I get nervous when things do not go the right way for me.	YES	NO
3 Others seem to do things easier than I can.	YES	NO
4 I like everyone I know.	YES	NO
5. Often I have difficulty getting my breath.	YES	NO
6. I worry a lot.	YES	NO
7. I am afraid of a lot of things.	YES	NO
8. I am always kind.	YES	NO
9. I get cross easily.	YES	NO
10. Usually, I worry about what my parents will say to me.	YES	NO
11. I felt that others do not like the way I do things.	YES	NO
12. I always have good manners.	YES	NO
13. It is hard for me to get to sleep at night.	YES	NO
14. I worry about what other people think about me.	YES	NO
15. I feel alone even when there are people with me.	YES	NO
16. I am always good.	YES	NO
17. Often I feel sick in my stomach.	YES	NO
18. My feelings get hurt easily.	YES	NO
19. My hands feel sweaty.	YES	NO
20. I am always nice to everyone.	YES	NO
21. I get tired a lot.	YES	NO
22. I worry about what is going to happen.	YES	NO
23. Other children are happier than I.	YES	NO
24. I tell the truth every single time.	YES	NO
25. I have bad dreams.	YES	NO
26. My feelings get hurt easily when I am scolded.	YES	NO
27. I feel someone will tell me I do things the wrong way, like tasks at school or home (e.g. polishing shoes).	YES	NO
28. I never get angry.	YES	NO
29. I wake up scared some of the time.	YES	NO
30. I worry when I go to sleep at night.	YES	NO
31. It is hard for me to keep my mind on my school work.	YES	NO
32. I never say things I shouldn't	YES	NO
33. I wiggle in my seat a lot.	YES	NO
34. I am nervous.	YES	NO
35. A lot of people are against me.	YES	NO
36. I never lie.	YES	NO
37. I often worry that something bad will happen to me.	YES	NO

Appendix J – Kidcope

6 KIDCOPE

Please think about a stressful situation (or problem, or event) _____ that happened to you. Now answer the following questions about this situation.

Did you do the following…			If yes, how helpful was this?		
	Yes	No	Not at all (1)	A little (2)	A lot (3)
1. Try to forget it?	Y	N	1	2	3
2.Do something like listening to the radio or play to forget it?	Y	N	1	2	3
3. Stay on your own?	Y	N	1	2	3
4. Keep quiet about the problem?	Y	N	1	2	3
5. Try to see the good side of things?	Y	N	1	2	3
6. Blame yourself for causing the problem?	Y	N	1	2	3
7. Blame someone else for causing the problem?	Y	N	1	2	3
8. Try to solve the problem by thinking of answers?	Y	N	1	2	3
9. Try to sort it out by doing something or talking to someone about it?	Y	N	1	2	3
10. Shout, scream or get angry?	Y	N	1	2	3
11. Try to calm yourself down?	Y	N	1	2	3
12. Wish _____ (repeat stressor) had never happened?	Y	N	1	2	3
13. Wish you could make things different?	Y	N	1	2	3
14. Try to feel better by spending time with others like family or friends?	Y	N	1	2	3
15. Do nothing because the problem could not be sorted anyway?	Y	N	1	2	3