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The Stress Levels of Parents whose Children are on Antiretroviral Therapy

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A Research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfilment of the requirements for the degree

of

Master of Science (Physiotherapy)

Johannesburg, 2009

DECLARATION

I, Linley Verster declare that this research report is my own work. It is being submitted for the degree of Master of Science (Physiotherapy) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

_____[Signature of candidate]

_____day of_____ [month], 2009

ABSTRACT

HIV is having devastating effects on Africa as a whole and more specifically on Sub-Saharan Africa. Children are vulnerable to the disease and in most cases being hit the hardest. Parenting at the best of times involves some form of stress, and caring for a chronically ill child increases the parenting stress levels. Antiretroviral treatment has a positive effect on children with HIV, however it is not well understood what effect antiretroviral treatment has on the parenting stress levels of the caregivers of children with HIV.

The aim of the study was to establish whether caregivers of children diagnosed with HIV show a change in stress levels after commencement of anti-retroviral treatment for their children. The objectives of the study were: to determine if any of the subsections of the PSI-SF were affected by the commencement of anti-retroviral treatment in the children; to determine if a correlation existed between the CD4 count of the child and the parenting stress level of the caregiver and to determine whether the age of the child impacted on the scores of the PSI-SF. The demographic data of the participants were also analysed.

This study involved secondary analysis of existing data for the study "A longitudinal study of neurodevelopmental delay in HIV positive children" conducted by Joanne Potterton utilising a longitudinal pre-post test study design where participants were compared to their own baseline scores. The Parenting Stress Index Short Form (PSI-SF) was used to establish the parenting stress levels within its three different subsections. The PSI-SF was completed by the caregivers at visit one, two and three. These visits were to the Harriet Shezi Clinic at Chris Hani Baragwanath Hospital, Soweto, Johannesburg. The children were antiretroviral naïve at visit one, and at visit two which was six months later, they commenced antiretroviral treatment with a six months follow-up which was visit three.

Forty-five participants were included in the study. The paired ‘t’ test showed a significant change (‘p’ = 0.02) in the subsections Parent Child Dysfunctional Interaction and Difficult Child(change in mean -3.31 and -2.78 respectively), while the subsection of Parenting Distress had no significant change between visit one and visit two (change in mean -2.09). The change in mean between visit two and three was -1.84 for the Parental Distress subsection, 0.6 for the Parenting Child Dysfunctional Interaction subsection and 0.8 for the Difficult Child subsection. The paired ‘t’ test was applied to visit one and three and the subsection Parenting Distress showed the greatest positive change of 'p' = 0.00 with a change in mean of -3.93. There was no correlation between the CD4 count of the child and the PSI of the caregiver at any of the visits (r=-0.2, 0.11,0.3, p=0.15, 0.5, 0.06 respectively). There was no correlation between the age of the child and the parenting stress of the caregiver at any of the visits (r=0.13,0.08,0.5 p=0.39,0.6 and 0.1 respectively).

The stress levels of the caregivers decreased over the study period however there was no significant decrease with the commencement of antiretroviral treatment.

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CHAPTER 1

1. INTRODUCTION

1.1 Background and Need

HIV/AIDS is a cause of great global concern. Every country is affected both socially and economically by this disease (Lau and Muula, 2004). Sub-Saharan Africa is at high risk for the spread of infectious disease due to population relocation, increased migration due to a mobile infrastructure, civil unrest as well as gross inequality (Lau and Muula, 2004). In South Africa (SA) in particular, the post apartheid government has had to deal with a fragmented state as well as the atrocities of the past, namely the social engineering of the black population into overpopulated homelands and rural areas. Families were split and the poor quality of land in the rural areas (both shortages and soil degradation) ensured that poverty, poor health and malnutrition were evident (Loening-Voysey, 2002).

World-wide there are more than two million children infected with HIV (UNAIDS 2007). Southern Africa accounts for more than 90% of these cases, with HIV-related illness being the leading cause of death in children under five (Potterton et al., 2009). HIV affects not only the children with the disease, but the entire family unit who care for the infected children. The community in which they live are also directly affected (Lau and Muula, 2004). There are more than 14 million children who have been orphaned by AIDS in Sub-Saharan Africa (Lau and Muula, 2004). The families left behind by parents who pass away usually take care of these orphans and the increase in stress is evidenced by the fact that many of these families collapse (Lau and Muula, 2004).

The role of parenting is inherently stressful (Abidin, 1995). Parents looking after a child with HIV have shown increased stress levels (Hansell et al., 1996). Ostberg and Hagekull (2000) showed that there is a relationship between an increase in stress and a decrease in the optimal functioning of the parent. Many studies have shown that caring for a child with HIV or a disability increases the parenting stress levels of the caregiver (Antle et al., 2001; Bithoney et al., 1995; DeMatteo

et al., 2002; O'Neil et al., 2001; Ostberg and Hagekull, 2000; Potterton et al., 2007).

Antiretroviral treatment (ART) has changed HIV from an acute illness to a chronic one but requires strict adherence and complete dedication to the administration of the drugs (Mellins et al., 2004). Antiretroviral treatment has a positive effect on the clinical health of children (Ghafouri et al., 2006), however it is not well understood what effect antiretroviral treatment has on the parenting stress levels of the caregivers of children with HIV/AIDS. Antiretroviral treatment has a positive effect on the CD4 count of children (Ghafouri et al., 2004) however it is not well understood what the effect of the CD4 count has on the parenting stress levels of the caregivers of children with HIV. Until April 2004 most paediatric clinics in South Africa did not see children with HIV under the age of two. There is still a general lack of experience in managing children with HIV (Potterton et al., 2009). It is not well understood what the effect of age is on parenting stress levels in children with HIV.

1.2 Problem Statement

HIV is a major global health concern and the effects are being realised across the world and particularly in South Africa. As mother-child transmission rates remain high (29%), children are being infected at an alarming rate. Parenting stress has been found to be increased in caregivers of HIV infected children. ART was recently introduced into the South African context (April 2004 in the public sector) and currently there is little to no research which investigates the effects that anti-retroviral treatment of children has on parenting stress levels.

1.3 Research Question

How do stress levels of caregivers change after the introduction of antiretroviral treatment for their children?

1.4 Aim

To establish whether caregivers of children diagnosed with HIV show a change in stress levels after commencement of anti-retroviral treatment for their children.

1.4.1 Objectives

1. To determine which, if any, of the subsections of the Parenting Stress Index Short Form (PSI-SF) change after the commencement of anti-retroviral treatment in the children.
2. To determine whether a correlation exists between the CD4 count of the child and parenting stress level of the caregiver.
3. To determine whether the age of the child impacts on the scores of the PSI-SF.
4. To analyse the demographic details of the participants included in the study.

1.5 Significance of Study

In South Africa HIV/AIDS has reached epidemic proportions and is having a substantial impact on the health care profession. Antiretroviral therapy is the treatment available and currently there is limited research on the effects of this treatment on the family unit and less on the effects of antiretroviral treatment of children on parenting stress levels. The results from this study may help towards increasing the understanding of the psychosocial aspects of the caregiver of a child with HIV/AIDS.

CHAPTER 2

2. LITERATURE REVIEW

2.1 Introduction

The literature that was reviewed was sourced from the Pubmed, Cochrane, Medline and Pedro databases, a hand search was conducted at the Health Sciences Library of the University of the Witwatersrand for books and journals pertinent to the review. The following words were used in the search strategy: HIV/AIDS; childhood diseases; Antiretroviral therapy; disability in Children; physiotherapy in HIV/AIDS.

HIV prevalence in both women and children is discussed as these are the study's participants and the rate of their infection is important in understanding the topic discussed. The history of HIV in South Africa is discussed to explain the rapid spread of HIV, as well as why treatment was delayed. Many of the barriers to the commencement and effective roll-out of antiretrovirals are better understood when placed in the light of South Africa's turbulent past. Understanding the history of South Africa also explains some of the issues of stigmatisation and fear of testing which is important for all health workers in South Africa to be aware of.

The diagnosis of HIV and the role of the CD4 count are discussed in detail as these two are integral to the commencement of antiretroviral treatment. The role of the CD4 count is also expanded upon as it is an objective of this study. The mode of transmission is discussed as it helps explain the rapid rate of HIV infection in South Africa and also puts into perspective how both the mother and child can be infected.

The impact of HIV in children and the treatment of HIV are discussed, as these topics are key to understanding the effect of HIV in children and the current treatment regimes which are used. The topic of nutrition was added as it is interlinked with the treatment of HIV and the general health of children with HIV. The children included in this study also received nutritional advice at the clinic and as one of the support strategies, something that may have played an important role in determining the stress levels of the caregivers. The effects of

HIV on the family context, psychological concerns around HIV, and caregiver stress were included to shed more light on the topic in question, that is the effect of anti-retroviral treatment of children with HIV on the stress levels of their caregivers.

2.2 HIV Prevalence in Women and Children

World-wide the human immunodeficiency virus (HIV) has ripped into every continent on the globe with devastating effects (UNAIDS, 2007). Currently there are an estimated 33.2 million people living with HIV and 2.1 million people who have died of AIDS (UNAIDS, 2007). Of these, 6.6 million people are situated in South Africa (SA) (UNAIDS, 2007).

In Sub-Saharan Africa there are 3.2 million children who have been diagnosed with HIV, this accounts for 80% of paediatric infections world wide. (UNAIDS, 2007). South Africa has the highest number of children diagnosed with HIV in the world (UNAIDS, 2007). The prevalence of HIV in SA is largely unknown, as a common method of measuring HIV prevalence is to study blood test results taken from pregnant women who attend antenatal clinics. This method is not ideal as some areas of SA do not have antenatal facilities, many women do not take the HIV test during pregnancy, and this method only measures sexually active women, some of whom, due to the stigma of the disease are reluctant to allow the test to be performed (UNAIDS, 2006).

In South Africa, women of child bearing age have the highest prevalence of HIV infection rate (29% of women in this age group have contracted the virus) (UNAIDS, 2007). According to Kouyoumdjian et al. (2005), mother to child transmission rate is approximately 30% in SA which is high (UNAIDS, 2007). Taking this into consideration, it is evident why in South Africa there are large numbers of children infected with HIV. In the first nationwide study of HIV prevalence in children conducted in 2004, Brookes et al. found that 5.4% of South African children were HIV positive. Shishana et al (2002) found that HIV prevalence in SA in children aged two and older was estimated at 10.8%. Female children had the highest prevalence at 13.3% when compared to males

(8.2%) (Shishana et al., 2002). This study also showed that there was poor knowledge of the prevention of mother to child transmission programmes. Shishana et al. (2002) indicated that 13.4% of persons interviewed would lie about the HIV status of a sick family member and that 55.7% feared stigmatisation if they were honest about their status.

There has been a rapid improvement in the number of people receiving treatment for prevention of mother to child transmission (Shishana et al., 2005). Shishana et al. (2005) showed that in SA from 2001 to 2006 there has been a three time improvement in the number of people receiving treatment to prevent mother to child transmission. The prevention to child transmission programme increased from 22% to 30% by the end of 2005 (Shishana et al., 2005). UNICEF estimates that only 30% of HIV pregnant women in need of prevention of mother to child transmission were receiving it by 2005, while only 18% of children in need received the treatment required (Shishana et al., 2005). Shishana et al. (2005) stated that 13.0% of children between the ages of two to 14 had lost a mother, father or both due to HIV.

2.3 History of HIV/AIDS in South Africa

South Africa has a turbulent past which is relevant to how explosively HIV has spread. There was also the use of zoned, separated living areas for different races. The African National Congress (ANC) in 1955 fought for equal rights and in 1966 many activists including Nelson Mandela were arrested for high treason. He was released in 1990 and the political unrest in the country accelerated. It was during these troubled times, in 1982, that HIV began to be diagnosed in SA (Jackson, 2002). The first ever diagnosed cases with HIV were among homosexual white males. As the number of cases increased, HIV began to be spread to all levels and classes of society. In 1985 an AIDS advisory group was appointed, and in 1990 antenatal surveys were done in order to test for HIV prevalence (Jackson, 2002). This survey showed that 0.8% of women surveyed were HIV positive (Smart, 2000). In 1992 2.4% were surveyed positive and the first governmental response to AIDS was by Nelson Mandela to the National

AIDS Convention of South Africa (NACOSA). This body was trying to develop a national strategy in order to cope with the growing epidemic. By 1994 the prevalence was at 7.6% (Jackson, 2002).

In 1996 the prevalence was at 14.2% and the International Conference for people living with HIV/AIDS was held in South Africa (Jackson, 2002). By 1998 the rate was at a staggering 22.8% (Hassan, 1997). In this year alone 49,280 incidences of rape and sexual assault were reported (Jackson, 2002). Gugu Dlamini - an AIDS activist announced her HIV status to be positive on World AIDS day and was later stoned by a mob (Jackson, 2002).

South Africa has gained positive ground politically (Jackson 2002). However, more attention was given to the political status and not the HIV status of the country (Jackson 2002). The roll out of antiretroviral treatment has been one of political debate and has not gained the momentum hoped for (Potterton et al., 2009). The roll out of antiretrovirals was delayed and is still met with many barriers (Potterton et al., 2009). There still remain issues of stigmatisation, isolation as well as fear of testing (Smart, 2000). Unfortunately the history of South Africa has played a large role in why one of the most affected groups in SA is the children (Loening-Voysey, 2002).

2.4 Diagnosis of HIV and the Role of CD4 Count

In the Sub-Saharan context the clinical diagnosis of paediatric HIV is extremely important. Many children in Sub-Saharan Africa are at risk of malnutrition and are more susceptible to many infectious diseases (Salojee and Pettifor, 2005). There are 51% of households who have access to safe water and only 4% who have adequate sanitation (Pizzo and Wilfert, 1998). This situation results in socioeconomic conditions which result in a high maternal (980 per 100 000 live births), child (106 per 1000 live births) and younger-than-5 (175 per 1000 live births) mortality rate (Pizzo and Wilfert, 1998).

AIDS was first diagnosed in 1981 in adults with pneumocystis carinii pneumonia (Volberding and Sande, 1997). Paediatric infections were first diagnosed in 1982 (Oleske et al., 1983). More research was started and serologic assays were

rapidly developed which detected antibodies to the human retrovirus. These assays were called enzyme immunoassays (EIA), which captured potential patient antibodies in a serum sample by cell cultured-propagated HIV proteins (Pizzo and Wilfert, 1998). These assays, however, have a chance of a false-negative and false-positive result and so it became necessary for confirmation of the HIV-specific affinity of EIA-detected antibodies. This confirmation is usually done by means of the western blot test which determines the HIV protein specificity of antibodies in the patient sample (Ziechner and Read, 2005). The western blot involves the virion proteins being solubilised then physically separated (through polyacrylamide gel electrophoresis) and then transferred to a membrane strip. This strip is incubated with the western blot strip. If bands are noted there are specific criteria for the banding patterns which are diagnostic, indeterminant or nonreactive (Pizzo and Wilfert, 1998).

In order to diagnose HIV, the use of EIA confirmed by the western blot test is used in order to detect HIV-specific antibodies. It is accurate for adult populations and children older than 2 years of age (Pizzo and Wilfert, 1998). The limitations of the tests above are due to the numerous perinatally- transmitted infectious agents. Maternal antibodies travel through the placenta especially during the third trimester and therefore any detection of antibodies neonatally effectively reflect maternal antibody status (Ziechner and Read, 2005). IgA specific assays detection is 95-100% sensitive to HIV infection; however HIV-IgA detection is poor from birth to 3 years (Ziechner and Read, 2005). In Africa the biological diagnosis of paediatric infection is based on indirect criteria usually the identification of IgG specific serum antibodies (Ziechner and Read, 2005). This is only accurate from 15-18 months of age due to the presence of maternal antibodies prior to this time (Pizzo and Wilfert, 1998). IgA specific serum antibodies confirm diagnosis as they do not cross the placental barrier (Pizzo and Wilfert, 1998).

The HIV DNA polymerase chain reaction (PCR) is a rapid viral diagnostic assay which can be performed within 24 hours and by using this test the HIV provirus is detected within mononuclear cells after numerous enzymatic amplification of the

target molecules (Ziechner and Read, 2005). The HIV PCR process is extremely useful as the virus does not have to be replication competent or infectious in order to be detected (Pizzo and Wilfert, 1998).

The p24 antigen assay can be directly exposed to the plasma of the serum sample in order to allow for viral protection detection (Volberding and Sande, 1997). The p24 antigen detection after dissociation of immune complexes is a better tool for diagnosis, however this test is not accurate in children particularly in their first month, and antigen-antibody complexes are not detected thereby being a problem in the neonatal period due to the maternal antibodies still present (Ziechner and Read, 2005). The p24 antigen detection is also a marker of the disease process and the response to treatment.

Plasma viral RNA detection within the plasma compartment is another diagnostic tool, one which is particularly specific in neonates (Volberding and Sande, 1997). In Africa the diagnosis of HIV prior to 15 months of age is difficult due to lack of laboratory facilities for detection of HIV infection (Ziechner and Read, 2005). It is for this reason that many children die without a correct diagnosis (Volberding and Sande, 1997)

In recognition of these obstacles which prevent a confirmed diagnosis, the World Health Organisation (WHO) has developed algorithms or clinical criteria and treatment for clinical management of common problems in children with HIV (Pizzo and Wilfert, 1998). These are:

1) Major signs are weight loss or failure to thrive; chronic diarrhoea (>one month); prolonged fever (>one month)
2) Minor signs are; generalised lymphadenopathy; oropharyngeal candidiasis; repeated common infections; generalised pruritic dermatitis and confirmed maternal HIV infection (Pizzo and Wilfert, 1998).

The CD4 count of a patient is closely related to the T-cell activation of that patient. There is an elevated T-cell activation in patients with a decreasing CD4 count, and is correlated to an increase in the disease progression of HIV (Ruel et

al., 2009). It has been shown that there is an elevated T-cell activation in people of African nationality with HIV when compared to residents of Europe or America with HIV (Ruel et al., 2009). Ruel et al. (2009) conducted a study monitoring the effect of anti-retroviral treatment on the T-cell activation in HIV infected Ugandan children. In this particular study there were three groups; one consisting of children receiving antiretroviral treatment (199 children); one consisting of children who were antiretroviral naive but were HIV positive (57 children); and one consisting of HIV uninfected children (30 children). The children on antiretroviral treatment had an inversely correlated CD4 count compared to T-cell activation. T-cell activation in this group was lower than the group consisting of antiretroviral naive children however it was still higher than in the uninfected group. This study raises interesting questions about ethnicity, however the large variants in group size and ages of the children were not accounted for.

The CD4 count; either the absolute count or CD4 % is currently the best measurement available to assess immune deficiency (WHO 2006). Although the CD4 count is widely used it must be applied as an adjunct to the clinical assessment of the child as the CD4 count in most cases decreases prior to the clinical progression of the disease (WHO 2006).

Table 1.1 The WHO classification of HIV-associated immunodeficiency using CD4 count.

Classification of HIV-associated immunodeficiency	Age-related CD4 values	Age-related CD4 values
	< _ 11 months (CD4%)	12-35 months (CD4%)
Not significant	>35	>30
Mild	30-35	25-30
Advanced	25-29	20-24
Severe	<25	<20

Dunn and his colleagues from the Medical Research Council in London and the Medical School of London in 2007 compared two large studies which both analysed the association of the CD4 count with the short-term risk of disease progression in untreated HIV-infected adolescents from 15 years and above with perinatally infected children from birth to 14 years (Dunn et al., 2007).The study which monitored children from 15 years and older, was conducted by a collaboration called concerted action on seroconversion to AIDS and death in Europe (CASCADE), whereas the study monitoring perinatally infected children was conducted the HIV paediatric prognositic markers collaborative study (HPPMCS). Both investigatory groups used a common methodology. The analysis completed by Dunn and his collegues included 6741 patients. There were reported 949 deaths related to HIV from the HPPMCS study and 945 deaths related to HIV from the CASADE study. The children infected perinatally showed higher rates of disease progression compared to the older children (Dunn et al., 2007).

Dunn et al. (2007) concluded that in children older than five, similar CD4 count criteria for starting antiretrovirals can be used, however in children younger than five the situation is problematic and more studies need to be conducted to ascertain the accuracy of CD4 count of CD4 % as an appropriate indicator for treatment in this group.

2.5 Mode of Transmission for HIV in children

Children are mostly infected with HIV through vertical transmission (Ziechner and Read, 2005). Mother-to child-transmission accounts for 90% of paediatric infections and parental transmission account for the remaining 10% (Pizzo and Wilfert, 1998). This pandemic impacts children at a rapid rate. There are about 600 000 new paediatric infections each year with more than 90% of these in Sub-Saharan Africa (UNAIDS, 2007). Children contract this disease mostly in the uterus via the placenta or by maternofoetal transfusion. Transplacenta transmission accounts for less compared to maternofoetal transmission as the placenta usually acts as an effective barrier against intrauterine infections; however placental trophoblasts and macrophages are susceptible to the virus in vitro (Bertolli et al., 1996). Intrapartum transmission of HIV can occur via maternofoetal transfusion in labour or post labour with blood transmission. Children can also aspirate the fluids. HIV has been detected in 30-40% of gastric aspirates in new-borns of HIV positive mothers (Bertolli et al., 1996). Caesarean sections have shown to be protective against transmission, and invasive procedures (amniocentesis), ruptured membranes, high viral load during delivery and during pregnancy increases the transmission rates. Breast milk and colostrum are definite forms of transmission with 12-14% of children not infected at birth being infected via this form of transmission (Bertolli et al., 1996). Antiretroviral treatment has helped to decrease perinatal transmissions (DeMartino et al., 2000).

2.6 Impact of HIV/AIDS in Children

HIV in children has been shown to rapidly progress to acquired immune deficiency syndrome (AIDS) (Hansell et al., 1996). HIV impacts negatively upon

children's health with diarrhoea and pneumonia being the most prevalent causes of morbidity in infected children (Bobath et al., 1998). In a cohort study in Kampala, Uganda, early mortality was shown to be prevalent among children (Pizzo and Wilfert, 1998). HIV-infected women in their second trimester were compared to age-matched HIV negative women. Child mortality rate was higher in the HIV infected women. Children with HIV in Africa have a shorter life span due to the fact that they have acute infections at an early stage of the disease (Ziechner and Read, 2005).

Lymphadenopathy, skin rashes, failure to thrive , candidiasis, pneumocystis carinii pneumonia (PCP), lymphoid interstitial pneumonitis (LIP), developmental delay and HIV encephalopathy are just some of the many causes of morbidity and mortality in HIV infected children (Potterton et al., 2005). Children with HIV often present with neurodevelopmental problems and neuropsychiatric symptoms such as dementia, decreased cognitive functioning and developmental delay (Lewis et al., 1996).

Invasive bacterial infections in children with HIV have become an AIDS-defining condition (ADC) (Volberding and Sande, 1997). Within the first year of life, the most common infections include bacteraemia and meningitis with encapsulated pathogens (e.g. S. pneumoniae, Haemophilus infuenza b, and Neisseria meningitides). The neonate is born with an immature immune system (Pizzo and Wilfert, 1998). The neonatal T cells do not produce sufficient IL-2 as a response to agents activating the T-cell antigen receptor complex. Due to the reduction in the number of lymphokines there is an increased chance of infection and therefore a decreased amount of T- and B-cell response. The neonate has an immature immune system and is immunologically naïve and is therefore more susceptible to pathogens especially encapsulated bacteria (Volberding and Sande, 1997)

Recurrent fungal infections are common in children infected with HIV. Oral candidiasis is usually prevalent (Mayer and Pizer, 2005). The cytomegalovirus infection (CMV) is common in children with advanced cases of HIV. Infections

from CMV include retinitis, encephalitis, colitis, oesophagitis or pneumonitis (Lewis et al., 1996).

Herpes simplex virus infections (HSV) often re-occur in children with HIV (Pizzo and Wilfert, 1998). Mycobacterial infections are also common in children with HIV. Children with HIV are more susceptible to TB due to their immunodeficiency state (Volberding and Sande, 1997). Cryptosporidiosis is the general cause of chronic, watery diarrhoea in infected children. Staphylococcus pneumoniae and staphylococcus aureus are also a major cause of morbidity in children with HIV (Lewis et al., 1996).

The central nervous system is often affected in children with HIV. The effects of HIV infection include cognitive and motor impairment (Potterton et al., 2009). HIV infects the microglia in the brain tissue itself. HIV encephalopathy presents with developmental delay or as regression in children infected with HIV (Potterton et al., 2009)

Children with HIV/AIDS may also show signs of renal disorders, such as severe nephrotic syndrome and renal failure. HIV cardiomyopathy is a late manifestation of HIV while congested heart failure is another complication of HIV (Volberding and Sande, 1997)

2.7 Treatment of HIV/AIDS

Antiretroviral treatment was introduced in the late 1990s and led to improvements in the care and treatment of children with HIV (DeMartino et al., 2000; Gortmaker et al., 2001). Highly Active Antiretroviral Therapy (HAART) is a combination of at least three drugs that prevent different aspects of viral replication and have a combination of reverse transcriptase inhibitors as well as protease inhibitors (Ghafouri et al., 2006). HAART is capable of improving immune function, suppressing viral replication and decreasing the frequency of HIV related CNS symptoms and the prevalence of opportunistic infections (Ghafouri et al., 2006).

Children with HIV have shown changes in their blood lymphocyte subpopulations with the commencement of antiretrovirals (Zaccorelli-Filho et al., 2007). Zaccorelli-Filho et al. (2007) investigated the effect of anti-retroviral treatments on

these subpopulations. In this study HIV infected children were divided into groups according to their responses to anti-retroviral treatment based on viral load measurements. The groups were good, partial or poor respondents. These results were then compared to those of 20 uninfected children. The 'poor' viral load groups showed the lowest lymphocyte counts as well as lower total and naive CD4 and T-cell counts. The 'poor' group also showed markedly low central memory CD4 + and CD8+ T-cell percentages. There was a higher cellular activation of CD8 and T-cells in all groups of HIV infected children (Zaccorelli-Filho et al., 2007).

Failure to thrive and growth retardation are commonly seen in children with HIV (Potterton et al., 2009; Verweel et al., 2002). If infected children are treated with either a mono or dual nucleoside analogue reverse transcriptase inhibitor there is a temporary increase in their weight and linear growth rate. Adults show a sustained weight gain when treated with antiretrovirals which include a protease inhibitor. The limited studies available which looked at protease inhibitors and growth in children mainly focused on the effects of these on short-term growth.

Verweel et al., (2002) analysed growth parameters, clinical data and laboratory results in order to evaluate the effect of antiretroviral treatment on growth in children with HIV. Verweel et al., (2002) showed that there was an increase in height, weight and body mass index (BMI) after 96 weeks of antiretroviral treatment, however their sample size consisted of 24 patients. Eleven of these patients had been antiretroviral naive prior to the commencement of the study, while 13 patients had used monotherapy prior to the commencement of the study. Within these 24 patients there was a different regime of treatment used for the patients. This study failed to take into consideration the effect of prior antiretroviral treatment on their results.

The overall results of the study by Verweel et al. (2002) showed improvements in height and weight after 96 weeks, however no improvements were shown in BMI. The data were separated into virologic responders and non-responders. The virologic responders showed a significant increase in height and weight whereas

the virologic non-responders did not change. The BMI scores did not show any changes in either group. Although these data were positive in showing weight gain it was again over a limited period of 96 weeks and more research is required on the long term effects (Verweel et al., 2002).

Even with the use of HAART, neuronal cell death is still often found in the brains of children with HIV (DeMartino et al., 2000). HAART has successfully prevented many of the end-stage AIDS complications, however as there are now increased survival times, there has been an increased prevalence of HIV-1 associated cognitive impairments present in patients with HIV/AIDS (Ghafouri et al., 2006). HIV associated dementia (HAD) is currently still prevalent in patients treated by HAART (Ghafouri et al., 2006). The most common virus infecting the brain is HIV, with other causes including herpes simplex virus type 1, varicella zoster virus, cytomegalovirus, Epstein-Barr virus causing encephalitis and severe brain dysfunction (Wang et al., 2006).

The goal of antiretroviral treatment is to increase the child's survival rate. Adherence to antiretroviral treatment in HIV infected children has been shown to be a complex and substantial challenge (Mellins et al., 2004). The treatment of HIV/AIDS has psycho-social considerations which include the presence of an identifiable caregiver who can administer the medication where children are concerned. This caregiver has to demonstrate reliability and show motivation to adhere to chronic care regimens (Mellins et al., 2004). The study by Mellins et al. (2003b) was a longitudinal study which examined mental health, the abuse of substances as well as psychological predictors of long term adherence to antiretroviral treatment. This study was conducted in an urban medical centre in America. They used a model of health behaviour to examine psychiatric and psychosocial predictors of adherence to antiretroviral treatment. Individual interviews were conducted at baseline and then eight and eighteen months later. They showed that the presence of a psychiatric disorder, negative stressful life circumstances, an increased number of household members and parenting stress were significantly associated with poor adherence to antiretroviral treatment and an increased number of missed doctors' appointments.

The accessibility of antiretrovirals is a large concern for health-care workers in South Africa. By mid 2005 only one in ten African people who needed antiretrovirals were receiving them (UNAIDS 2005). Prior to April 2004 most paediatric clinics in South Africa only supplied antiretrovirals to children who were over the age of two, as these children had a better prognosis compared to children below two. It was only after the government roll-out of antiretroviral treatment in April 2004 that antiretroviral care extended to children below the age of two (Potterton et al., 2009). The roll-out of antiretrovirals has been slower than expected and has not gained the expected momentum that was hoped (Potterton et al., 2009) There are also added concerns on the adherence being poor in the South African context (Chesney 2003, Potterton et al., 2009).

There have been many challenges in the maintenance of long term adherence to antiretroviral treatment (Chesney, 2003). Farley et al. in 2003 established that by using the Medication Event Monitoring System, 42% of the participants had less than 80% adherence. Eighty percent adherence is well below the necessary percentage needed for viral suppression (Chesney, 2003). Adherence is a good overall predictor of viral suppression and immunological recovery. Adherence of greater than 95% is needed for successful viral suppression (Byrne et al., 2006).

Adherence to antiretroviral drugs is extremely difficult taking into consideration large pill numbers, limited availability of paediatric formulations, drug toxicities, side effects of the drugs, poor tasting of many of the liquid drugs and infringement of the patients' and caregivers' normal activities (Boni et al., 2000, Havens et al., 2000). Some caregivers choose not to disclose their child's status until they are in their teens which potentially impedes their cooperation in their treatment (Mellins, 2003a). Education of the caregivers on the importance of the antiretroviral drugs and what they can achieve is important to improve adherence (Byrne et al., 2006).

Mellins et al, in 2004 in New York studied children aged three -13 years who were on HAART and underwent follow-up assessments with their caregivers on their adherence to the therapy. A number of psychological assessments and

self-reported data on adherence were used. The caregivers who did not report missing a dose were then compared to those which had. They showed that 40% of the caregivers and 56% of the children reported missed doses of medication in the previous month. The families who demonstrated non-adherence were significantly associated with poorer parent-child communication, increased caregiver stress and lower perceived quality of life of the caregiver. Non-adherence was associated with poorer parent-child communication, higher caregiver stress and lower caregiver quality of life. They concluded that to improve adherence to complex antiretroviral treatment developmental, psychosocial and family factors need to be addressed (Mellins et al., 2004).

Adherence to antiretroviral drugs was not associated with CD4 loads and demographic data including gender, ethnicity, education and marital status were not predictors of which families would be non-adherent (Mellins et al., 2004). A study conducted by Mellins et al. in 2003a suggested that an important part of interventions to improve adherence to antiretroviral treatment was to address the family's lives by decreasing stress, improving support, and increasing disclosure of individuals.

Currently in South Africa another major concern is the fact that children only receive antiretroviral treatment once the child's CD4 count is below 20% (Dept of Health, South Africa, 2005). Luzuriaga and Sullivan (2002) argue that antiretroviral treatment should begin as early as possible (within the first few months of life) as it is impossible to differentiate which children will be rapid progressors. Delaying the commencement of antiretrovirals leads to increased morbidity and mortality (Badri et al., 2006). Children in South Africa therefore are often severely immunocompromised when they do first receive antiretrovirals (Potterton et al., 2009). This is obviously an area of great concern and maybe requires policy review.

In recent years, there have been the main focus of prevention to child transmission has been focused on the provisionof single-dose intrapartum and

neonatal nevirapine which has decreased HIV transmission by more than 40 % (UNAIDS 2008).

2.8 Nutrition and HIV/AIDS

Nutrition is an important issue to both HIV/AIDS infected women and their children. Children with HIV often acquire multiple nutritional deficiencies and so often require additional nutritional support (Ziechner and Read, 2005). Depending on what nutrients are deficient the malnutrition will present differently, and many systems namely the central nervous system (CNS), immune function and physical growth may be affected (Ziechner and Read, 2005). The malnutrition conditions caused by HIV are commonly known as nutritionally acquired immune deficiency syndromes (Ziechner and Read, 2005). Where there is a chronic protein-calorie malnutrition the T-lymphocyte numbers and functions are adversely affected, as well as a negative effect on delayed type hypersensitivity, complement levels as well as a decrease in new antibody responses; which all cause atrophy of the lymphoid tissue (Pizzo and Wilfert, 1998). Malnutrition in children has been shown to cause a decrease in myelinisation and cause abnormal growth of neurons (Ziechner and Read, 2005).

HIV infected children's height and weight are both affected by the virus and may present with failure to thrive (FTT) (Pizzo and Wilfert, 1998). With HIV there is associated immunodeficiency which is made worse by malnutrition. The survival rate in HIV is directly linked to the nutritional status of the child (Ziechner and Read, 2005).

Gastrointestinal disorders, oropharyngeal lesions as well as dental caries are common, and provide additional barriers to good nutrition in people affected with HIV/AIDS (Volberding and Sande, 1997). Should nutritional support be necessitated, a high calorie and high protein diet should be provided. Foods which carry a high risk of infectious organisms (such as Salmonella, Listeria, Giardia, and Campylobacter) need to be avoided (Volberding and Sande, 1997). Total parenteral nutrition (TPN) is the last resort. Prior to insertion of a TPN the

risks associated with an in-dwelling catheter need to be considered (Volberding and Sande, 1997).

The concept of HIV and nutrition is exceptionally important to women as it is usually their responsibility to provide food for their families as well as care and nutrition for other family members dying of AIDS (Piwoz and Bentley, 2005). Women in SA also have an HIV prevalence rate which is three times higher than in males (UNAIDS, 2007). HIV infection causes an increase in energy expenditure even at rest; reduces daily nutritional intake; malabsorption of many nutrients as well as complex metabolic alterations which result in weight loss (Melchior et al.,1991; Bogden et al., 2000). The nutritional status of an HIV infected person is affected early on in the course of the disease (Beach et al., 1992; Bogden et al., 2000). Pre-morbid malnutrition increases the effects of HIV as it weakens the immune system through mechanisms that include depletion of CD4 T cells, suppression of delayed hypersensitivity and B-cell responses (Gorbach et al., 1993).

Energy expenditure and energy requirements are increased with HIV infection (WHO, 2003). These increased requirements together with common HIV related illnesses such as diarrhoea, appetite loss and TB place a large nutritional risk on HIV infected pregnant and breast feeding women (Brocklehurst et al., 1998). Immune function and the development of a young child is impaired by malnutrition during pregnancy as this results in low foetal stores of some nutrients (Dreyfuss et al., 2002).

Nutrition is extremely important in determining good health (Piwoz and Bentley, 2005). Poor or insufficient nutrition leads to poor health and a lowered immune function (Gorbach et al., 1993). Poor health leads to an increase in stress levels (Hansell et al., 1996).

2.9 The Effects of HIV on the Family Context- Parenting Stress

Parenting in itself is a stressful experience without the added stressors which accompany having a child with HIV. Negative as well as dysfunctional parenting, have been shown to be related to increased parenting stress levels (Ostberg and

Hagekull, 2000). Osteberg and Hagekull (2000) showed that there are many empirical studies which have shown a positive relationship between increasing parenting stress and a decrease in optimal functioning in the parent-child as well as family relationships. This is confirmed by a study performed by Hansell et al. (1996) which showed that caring for a child with HIV has added stressors. This is because the challenges of caring for a developing child are added to dealing with episodes of re-occurring acute illnesses. Many studies have shown a positive relationship between the child / child's HIV positive status or disability and an increase in parenting stress levels (Antle et al., 2001; Bithoney et al., 1995; DeMatteo et al 2002; O'Neil et al., 2001; Ostberg and Hagekull, 2000).

Ostberg and Hagekull (2000) studied 1081 Swedish mothers of healthy children. They showed that an increased work load, lack of social support, their child being perceived as 'difficult', and an increased number of children to care for led to increased stress levels. This study was well conducted however it was carried out in a first world country and the children were healthy. These results are therefore difficult to apply to the South African context, and even more difficult to apply to a study looking at very sick children. The study conducted by Ostberg and Hagekull (2000) shows that raising children is naturally a stressful task even with healthy children, and hence it can be postulated more so with unhealthy children.

Chronic sorrow in parents of children with HIV has been shown to be unchanging, irrespective of their child's medical status or changing needs (Antle et al., 2001). Antle et al. (2001)'s study showed that caregivers whose children had physical and developmental disabilities had the highest risk of psychological distress as well as physical health problems.

Having a child with a chronic illness impacts negatively on the entire family unit. Every illness has different characteristics and unique factors which all affect the family unit (Boland, 2000). Antiretroviral therapy has changed HIV from an acute illness to a chronic one, yet the diagnosis of HIV/AIDS to usually multiple family members, makes this disease different to all others. Women with HIV have

reported that even when they were diagnosed with HIV/AIDS, the most stressful issues were poverty, safety, food and shelter (Boland, 2000). The National Health Survey which was done in SA in 1999 showed that chronic diseases increased the chances for behavioural problems in children (Boland, 2000).

The time following the diagnosis of HIV is the greatest time of personal turmoil. In a study of 110 adults with HIV, a high level of stress was shown to be common and the majority of people reported that the level of stress did not subside (DeMatteo et al., 2002). This study also showed that a "good" CD4 count had a positive effect on decreasing the level of stress in the patient. Social support was shown to be of utmost importance (DeMatteo et al., 2002). A study done by Black et al in 1994a showed that despite the knowledge that HIV is a fatal illness, it did not change the parenting attitudes or behaviours of mothers with children diagnosed with HIV. This study however was conducted in the United States of America and none of the children's conditions had yet deteriorated to AIDS. The effects in the SA context therefore need to be investigated.

Due to the impact of HIV/AIDS on the family unit as a whole, it has become increasingly important for all health care providers to focus on psychosocial problem solving. Families not only have to cope with the stress of possible death of their child/children but parents themselves, if infected, have to address their own prognosis (Black et al., 1994b). Reidy et al (1991) showed that children with HIV are in need of nurturing as well as care directly because of their illness. This increases the burden on the primary caregiver who may be HIV positive themselves (Potterton et al., 2009). Caring for a child with HIV increases the burden on the caregiver as well as often making the caregiver feel inadequate about their own abilities as a parent (Potterton et al., 2007).

Many of these parents are already confronted with the compounded effects of poverty, unemployment and single parenthood (Black et al., 1994a). Due to the profound impact upon the family unit, the role of the health professional has shifted from child-centred intervention to family-centred intervention. Family-

centred intervention has been shown to be of great importance in families of children with special needs (O'Neil et al., 2001).

As HIV infections impact on children's development, it thereby affects their social interactions and may increase fear and the feeling of rejection (O'Neil et al., 2001). Even though there has been much education around HIV 13.4% of people surveyed in SA stated that they would keep it a secret if someone in their family died of HIV (Shisana et al., 2005). Fifty six of those surveyed said that they feared stigmatisation (Sishana et al., 2005). Often both parents have the disease and future planning therefore becomes even more difficult. Parents are often reluctant to plan for the future of their children due to many factors which include guilt, fear of stigmatisation, and denial (Black et al., 1994a).

2.9.1 Psychosocial Concerns around HIV/AIDS

Many women who have HIV/AIDS are diagnosed at the time of pregnancy. It is not possible to know if the unborn child is HIV positive or not at this early stage. Many awaiting mothers are adjusting to their diagnosis and simultaneously awaiting confirmation of their child's status. This obviously has a huge impact on their psychological state (Hackl et al., 1997). Often families only enter the health care system later on when their child shows HIV related illnesses (Hackl et al., 1997). Once the child is diagnosed there are implications for the mother and often both parents (Hackl et al., 1997).

The issue of disclosure or non-disclosure increases the psychological stress and burden. Farley et al. (1993) showed that early disclosure of a terminal illness was associated with long term emotional and social stress. HIV/AIDS generates multigenerational losses, and therefore impacts people psychologically in different ways. A grandparent may have to bury a child followed closely by a grandchild (Hackl et al., 1976).

2.9.2 Families with Disabled Children: Impact of HIV/AIDS

Fifty five percent of families with disabled children in the UK were described as being the poorest of the poor (Sloper and Beresford, 2006). Their financial situations were seen to be associated with the costs of raising a disabled child which has been estimated to be three times that of a non-disabled child (Sloper and Beresford, 2006). Mothers with disabled children are less likely to work due to the disabled child's care needs and regular medical appointments. UK families which include a disabled child rely on state benefits to contribute towards 90% of household expenses (Sloper and Beresford, 2006).

HIV/AIDS can lead to various disabilities in children. One of the first clinical signs of a child with HIV/AIDS is encephalopathy (Potterton et al., 2009). HIV infected children can also present with developmental delay, poor milestone development and ultimately spastic quadriparesis and regression of the child's milestones (Potterton et al., 2009).

Studies in the United States show that there is an increased level of chronic care needed in women with HIV/AIDS, and these women with varying ethnic backgrounds and cultures are the primary caregivers in the family (Anderson et al., 1999; Hammond, 1997; Whyte and Dawson, 2001). DeMarco et al. (2002) described how women have been shown to "silence themselves" in order to empower themselves in difficult and trying situations. These behaviours may protect the women and their children from stigma related to HIV, however there are severe negative outcomes to the woman's self esteem, value system and mental health (DeMarco et al., 2002). Prior to the successful use of HAART and Zidovudine, Andrews et al. (1993) showed that in an HIV positive family, children are a source of stress mostly because of the stigma of the disease (DeMarco et al., 2002).

HIV/AIDS is a progressive chronic illness and infected children accumulate more disability as the disease progresses, this consequently leads to parents/caregivers who care for children with the disease having chronic sorrow and increased stress (Potterton et al., 2007).

2.9.3 Caregiver Stress

Caregiver stress is where a person who is looking after another person, experiences stress due to the difficult circumstances which they are facing, as well as the increased stress of caring for someone else (Amirkhanyan and Wolf, 2006). Primary stressors include the care recipient's impaired conditions as well as the caregivers' emotional layered reaction to the condition. Secondary stressors include problematic issues outside the realm of the caregivers' care giving roles.

Amirkhanyan and Wolf in 2006 conducted a study whereby subjects caring for their parents or parents-in-law were monitored by an 8 item scale of depressive symptoms. Their results confirmed the well established literature that there are diverse mental health consequences for providing care to a disabled or dependent elderly family member. Amirkhayan and Wolf (2006) showed that the adverse mental health consequences were greatest in women. Caring for any child is in itself stressful and probably the most challenging responsibility for any parent (Nystrom and Ohrling, 2004). Nystrom and Ohrling in 2004 showed through a literature search that parents of children under one year suffer from increased stress and in general parents felt overwhelmed by the task at hand. The first year of a child's life is the foundation of development and significant growth occurs (Nystrom and Ohrling, 2004). This study included only healthy children and shows that there is a 'normal' level of stress with is experienced by all parents.

Ostberg (1998) used a revised Swedish version of the Parenting Stress Index (Parent Domain) to measure parenting stress of 75 mothers and 65 fathers who were seeking help for their young child. The mother's stress levels were compared to father's stress levels in the same family as well as a population sample of 1500 mothers who were similar in age. The maternal stress levels were increased compared to both the paternal stress levels as well as the sample group. The study concluded that any intervention to decrease stress levels needs to be aimed at the entire family. This study was conducted in a first world

country with highly evolved social support structures. It is more difficult in South Africa to achieve the ideal concluded by Ostberg (1998).

Women and in particular mothers who are themselves infected with HIV are at a greater risk for increased stress, both acute and chronic stress, when compared to mothers who are not infected with HIV. This increase in stress experienced by mothers can be attributed to problems arising from their own HIV status, cultural lives, economic and living conditions and compounded if they are caring for a child with the same status (Glover et al., 2009). Glover et al. (2009) conducted a randomized-control trial whereby mothers living with HIV were compared to mothers without HIV, in regards to stress biomarkers of cortisol and catecholamines (collected by a self conducted urine test) and basic health markers (blood pressure, height and weight and hip-waist ratio). The groups were demographically matched. The outcomes showed that as expected, the mothers with HIV had significantly higher biomarkers.

Stress prevails when the experienced demands (subjective) are inconsistent with the response demands. Parenting/caregiver stress is present when the parents/caregivers' capacity to fulfil their role is overtaken by the demands of the child (Pearson and Chan, 1993). Pearson and Chan (1993) hypothesised that in Guangzhan School in China for the handicapped children, mothers of children with a disability experienced great stress compared to mothers of children without a disability; that mothers of children with a disability were the recipients of less social support and that there was a negative relationship between stress levels of the mothers and the amount of social support. Using the Parenting Stress Index to measure stress, both the parenting stress and life stress scores of mothers of children with a disability were greater compared to mothers of children without a disability. The higher the level of education the less stress was experienced. The mothers of children with a disability showed that social isolation was the single most correlated variable with the total stress score. As stated by Schor (2003), stress within the family such as stress brought on by illness in the children can disturb normal parenting.

Abidin (1995) states that when using the PSI, any parent exceeding 260 on the total stress measured must be referred for professional consultation. In the study performed by Pearson and Chan (1993), 91.6% of the mothers of children with a disability exceeded this score. The hypothesis that mothers of children with disability receive significantly less support compared to their counterparts was shown to be correct. Due to the fact that HIV causes disability of some degree (Potterton et al., 2009), it can be hypothesised that the caregivers of children with HIV/AIDS will suffer from extreme levels of stress.

Adherence to anti retrovirals is complex and ensuring that the medication is given on time increases caregiver stress (Ghafouri et al., 2006). Caregiver stress is also increased by regular clinic visits and time taken from work (Potterton et al., 2009).

2.10 Review of Instrumentation

For data collection in the parent study of this study, the Parenting Stress Index Short Form (PSI-SF) was used. The PSI-SF is a valid and reliable method of assessing the stress levels of caregivers (Abidin, 1995). The original study by Abidin in 1995 was conducted in North Carolina in the United States of America. The Parenting Stress Index (PSI) (Abidin, 1995), was created in order to investigate a varying range of influences on parental attitudes and behaviours. This model comprises of 120 items and is a Likert type self-report questionnaire. It has 54 parent-focused and 47 child focused items. Collectively there are 13 subscales. Although this model is very comprehensive, it is regarded by clinicians and researchers as too time consuming to be used as a screening tool. To address these concerns Abidin in 1995 compiled the 36 item PSI-Short form (Reitman et al., 2002), (see Appendix 1).

The PSI-SF is a valid measure of stress in the parent-child system which can be administrated in under 10 minutes (Abidin, 1995). There are three subsections which are labelled: Parental Distress, Parent-child Dysfunctional Interaction and Difficult Child. The parental distress subscale incorporates the parents' perception of their child rearing abilities, conflict with their partner, availability of

social support and restrictions in their other life roles. The parent-child dysfunctional interaction section assesses the parents' perception of whether the child meets their expectations and the level of their interaction. The difficult child subsection observes the parents' idea of the child's temperament, defiance, compliance and level of neediness (Reitman et al., 2002). Each subsection is divided into 12 items which are rated from 1 (strongly disagree) to 5 (strongly agree). The subscales therefore range between 12 and 60 and the total scores between 36 and 180 (Reitman et al., 2002). The higher the score on the PSI-SF the greater the level of stress experienced.

Currently the Parenting Stress Index is the only valid and reliable test for measuring parenting stress. The Becks Depression Inventory is a well known and used measure however it does not look at parenting stress. There are many psychological test and caregiver stress questionnaires used in the literature, however the psychological tests are seldom given names and do not specifically measure parenting stress, while the caregiver stress tests are focussed on the adult population and the stress of caring for another adult.

2.11 Conclusion

HIV/AIDS has reached epidemic proportions world-wide and particularly in South Africa. This pandemic is impacting on children at a rapid rate. There are 600 000 new paediatric infections each year with more than 90% of these being in Sub-Saharan Africa. There are numerous stressors which parents experience on a daily basis which are compounded if the child has a HIV/AIDS. An increase in parenting stress leads to a decrease in the optimal function of being a parent. Poverty, lack of shelter, concerns over food and finances are usual concerns for parents or caregivers in SA. With the correct administration of ARVs, HIV is transformed from an acute to a chronic illness where the children' life expectancy is prolonged. ARVs have increased the survival rate of HIV infected children. The effect of this treatment on children on caregiver stress remains largely unknown.

CHAPTER 3

3. METHODOLOGY

3.1 Study Design

The data that were analysed for this study came from an ongoing longitudinal pre- post test study where participants were compared to their own baseline scores: namely “A longitudinal study of neurodevelopmental delay in HIV positive children” by Joanne Potterton from the University of the Witwatersrand. This study was a secondary data analysis of existing data from the parent study.

3.2 Source of Subjects

The data that were analysed was collected from subjects enrolled in the study “A longitudinal study of neurodevelopmental delay in HIV positive children” that was conducted at Harriet-Shezi Children’s clinic in Chris Hani Baragwanath Hospital (Johannesburg). Harriet-Shezi has over 3000 children registered at the clinic. The clinic sees over 100 children a day and the distribution of ARVs is according to government guidelines.

3.3 Sample Size

For the subscales A, B and C of the Parenting Stress Index Short Form, a sample size of (40; 39; 45 respectively) had 90% power to detect a difference in means of 4.8 (10% subscale), assuming a standard deviation of differences of 9.1; 8.9; 9.7 (respectively) using a paired t-test with a 0.05 two-sided significance level. Thus a sample of data of 45 caregivers was considered adequate for this study.

3.4 Sample Selection

Data from the participants of the main study, "A longitudinal study of neurodevelopmental delay in HIV positive children", that met the inclusion criteria were included in this study. The inclusion criteria for the parent study included; consecutive children under the age of two and a half who agreed to participate in the study. Children who were premature, institutionalised or showed any other clinically apparent congenital abnormalities were excluded. The parent study

included 122 children. The sample selection criteria for the secondary analysis included children and their caregivers who had full data sets and who met the inclusion criteria. Forty five participants met the secondary analysis inclusion criteria.

3.4.1 Inclusion Criteria

The data of children with the following criteria were used

- Children who enrolled in the main study titled “A longitudinal study of neurodevelopmental delay in HIV positive children”.
- Those children who were anti-retroviral naive on their first assessment.
- Children under 42 months.
- Those children accompanied by their primary caregiver.
- Children who went on antiretroviral treatment 6 months after their first PSI-SF was administered.

3.4.2 Exclusion Criteria

Data for the following children were excluded:

- Any child who was institutionalised.

3.5 Instrumentation and Outcome Measures

3.5.1 Parenting Stress Index Short Form

The PSI-SF was used to test for the level of stress experienced by the caregivers. The PSI-SF was administered at visit one, visit two and visit three (visits explained under procedure below).

The PSI-SF has been shown to be both a valid and reliable method of measuring the levels of stress experienced by the caregivers. The test-retest reliability of the PSI-SF was shown at 0.84 with the coefficient alpha shown as 0.91 (Abidin, 1995). The test-rest reliability was shown in 270 parents studied over a six month period. The total PSI-SF was 0.84 with subsections of 0.85, 0.68 and 0.78. The validity of the PSI-SF has not been shown but stated by Abidin (1995)

that due to its direct derivative from the PSI it is likely that the PSI-SF shares the validity of the PSI of 0.94.

For the longitudinal study the PSI-SF was translated into Zulu and Southern Sotho which were the two most commonly spoken languages in Soweto where the study took place. Both the Zulu and the Southern Sotho translations were accepted by the original author and Psychological Assessment Resources as official versions (Potterton et al., 2007). A pilot study was conducted for the longitudinal study in order to ensure test-retest reliability and to ensure that the Zulu and Southern Sotho versions were easily understood by the caregivers (Potterton et al., 2007). Both versions showed a very high test-retest reliability over a five day period for the total stress scores (Zulu r= 0.995, S Sotho r= 0.993) (Potterton et al., 2007).

3.6 Procedure

3.6.1 Main (Parent) Study

The data for the main study (from where data for this study were collected) were collected using an interviewer-administered PSI-SF. The data that were collected from the main study had a total of 122 children with 62 children in the control group and the remaining 60 in the experimental group. These data (both the experimental group and the control group) were combined and then screened using this study's inclusion and exclusion criteria. All the data of the participants who met the inclusion criteria were entered on a spreadsheet for statistical analysis. The first 45 participants with full data sets were included in this study.

Ethical clearance was applied for and granted for access to the data from the longitudinal study (parent study). No authorisation from the clinic was applied for as I had no direct contact with the participants and only the raw data. Informed consent was not required as this study was a secondary analysis, and there was no direct contact with the participants at any time point. The data were already coded and any no point did I have any access to the childrens' names.

Each visit to the clinic was done according to an appointment basis. The file was drawn and was placed in the queue to see the doctor. While waiting the

children's height, weight and head circumference was taken by a nurse at the clinic. After these measurements were taken the participants were given the PSI-SF (and demographic questionnaire at visit one – see appendix 3) to complete. The PSI-SF and demographic questionnaire were offered in English, Zulu and Southern Sotho. If the participants were unable to read, the research assistant read it to them and filled in the forms (including an information sheet- see appendix 4). A physiotherapist then completed a developmental assessment on the children. At no point did the patients lose their place in the queue and therefore no extra time was needed. The doctor assessed each patient and blood tests for CD4 count and viral load were performed. If necessary the participants were referred to a social worker, dietician or counseller (HIV counselling). The participants were given nutritional supplements if required and they then went to the pharmacy to receive the necessary drugs prescribed. The data were collected at the first visit, the second visit six months later and the third visit which was six months after the second visit therefore the study was done over a one year time frame.

3.6.2 Secondary analysis

The data received from the main study was placed onto an Excel spread sheet and the inclusion and exclusion criteria were applied to these data. The data of the first 45 candidates with full data sets who met the inclusion criteria were included in the study.

3.7 Ethical Considerations

Ethical clearance was obtained for the study from the University of the Witwatersrand Ethics Committee for Research on Human Subjects (clearance number M03-05-68), (see Appendix 2). All data were kept confidential and safe, no names and only raw data were included.

3.8 Data Analysis

The data were summarised by using the actual values, means and standard deviations for the changes in the PSI-SF between visit one and visit two, visit one and visit three, and between visit two and visit three. The paired 't' test was used

in order to assess for variance among the subsections of the PSI-SF. An item analysis was done for the subscales of the PSI-SF. The time points (visits to the clinic) were compared with respect to the abstraction vector (score for subscale A, B and C) using Hotelling's t squared test. Testing was done at the 0.05 level of significance. Pearson’s correlation test was used to test for correlation.

The results will be further elaborated on in Chapter 4.

CHAPTER 4

4.0 RESULTS

4.1 Introduction

In this chapter the data collected were assessed and analysed in the form of tables, graphs and pie charts and statistical analyses were done where appropriate (to ascertain relationships between variables).

4.2 Sample Size

The parent study included 122 children. The first 45 participants with full data sets which met the inclusion criteria were included in the data set for the secondary analysis. The sample consisted of data from 45 children and their caregivers. The children were patients at the Harriet Shezi clinic at Chris Hani Baragwanath hospital in Soweto, South Africa.

4.3 Demographic Details

Table 4.1 below indicates the ages of the parents and the children who they cared for.

Table 4.1: The ages of the parents at visit one and the children at visit one, two and three (n=45)

	Mean	**Standard Deviation**	**Confidence Intervals**
Age of parent (years) at visit one	29.3	±7.8	23.2-35.4
Age of child (months) at visit one	16.8	±8.0	14.6-19.2
Age of child (months) at visit two	23.5	±8.0	21.1-25.9
Age of child (months) at visit three	28.7	±7.8	26.3-31.0

The mean age of the caregivers at visit 1 was 29.3 years with a SD of 7.8. The mean age of the children was 16.8 months with a SD of 8.

The majority of children were cared for by their biological mothers (87%), the remainder of the children were cared for by female relatives, namely aunts and grandmothers. Sixty percent of the children were female and forty percent male.

Table 4.2 below indicates the number of children living in each household.

Table 4.2: The distribution of children per household in the study sample (n=45)

Number of Children	Frequency	Percentage (%)
1	2	10
2	6	30
3	4	20
4	3	15
5	1	5
6	2	10
7	1	5
8	1	5

Thirty percent of the households had 2 children with one household having 8 children (largest family). The mean number of children in the household was 3 (±1.9)

For the study sample sixty percent of the caregivers had left school at Grade 11. Twenty percent of the caregivers finished matric (Grade 12).

The type of housing the caregivers and children lived in is shown in Table 4.3 below.

Table 4.3: Distribution of the type of house caregivers and children lived in (n=45).

Housing	**Percentage (%)**
Flat	6.7
Room	15
Shared House	16.7
Informal settlement	21.7
Own House	39.9

Forty percent of caregivers owned the houses they lived in. Twenty one percent of the caregivers lived in informal settlements.

4.3.1 Monthly income for the households

The average monthly income of each household was R1187 with 30% receiving a social grant from the government. Of the participants' data that were analysed 55% owned a fridge, and none owned cars, 60% owned a TV, while only 5% owned a washing machine.

4.4 Summary of PSI-SF

Table 4.4 below indicates the summary of the parenting stress levels over a one year period.

Table 4.4: Summary of the parenting stress over a one year period (n=45)

	Parenting Distress	**Parent-child dysfunctional interaction**	**Difficult child**	**PSI/SF Total Stress**
Baseline (Visit 1)	38.89 (±7.48)	34.56(±8.05)	36.07 (±6.17)	109.51 (±7 .47)
Six Months (Visit 2)	36.8 (±7.51)	31.24 (±8.79)	33.29 (±8.6)	101.33 (±20 .58)
Twelve Months (Visit 3)	34.96 (±9.41)	31.84 (±11.08)	34.11 (±7.68)	99.24 (± 22.39)

The mean parenting stress decreased from 109.51 at visit one to 101.33 at visit two and 99.24 at visit three.

4.5 Effect of ARVS on Subsections of the PSI-SF

The change in total score of the PSI-SF was analysed, as well as each subsection of the PSI-SF was tested. The change in stress levels between the Parental Distress (PD), Parenting Child Dysfunctional Interaction (PCDI) and Difficult Child (DC) sections was analysed. The results on stress level differences (total score for PSI-SF) between visit one and visit two was -8.18 ('p' value = 0.00).

Table 4.5 below shows the mean and Standard Deviation between visit one and visit two, for all the subsections of the PSI-SF.

Table 4.5: The change in mean and standard deviations for subsections of the Parenting Stress Index SF between visits 1 and 2 (n=45)

Variable	Obs	Change in Mean	Std. Deviation	'p' Value
Parental Distress (between visit 1 & 2)	45	-2.09	7.91	0.08
Parenting-Child-Dysfunctional-Interaction (between visit 1 & 2)	45	-3.31	9.14	**0.02**
Difficult Child (between visit 1 & 2)	45	-2.78	7.64	**0.02**
Total PSI-SF scores (between visit 1 & 2)	45	-8.18	17.35	**0.00**

There was a decrease in stress levels on all the subsections of the PSI-SF between visits one and two. There was a marked decrease in the overall score of 8.18 (p= 0.00). There was not a significant decrease in Parental Distress. These time points indicate the change in stress levels between the time points of the child being antiretroviral naive at the start of the study, and the second visit (six months later), where there was the introduction of ARVs.

Table 4.6 below shows the mean and standard deviation between visit two and visit three, for all the subsections of the PSI-SF.

Table 4.6: The Change in mean and standard deviations for subsections of the Parenting Stress Index SF between visit 2 and visit 3 (n=45)

Variable	**Obs**	**Change in Mean**	**Std. Deviation**	**'p' value**
Parental Distress (between visit 2&3)	45	-1.84	7.46	0.1
Parenting-Child-Dysfunctional-Interaction (between visit 2 & 3)	45	+0.6	9.7	0.7
Difficult Child (between visit 2 & 3)	45	+0.8	7.76	0.5
Total PSI-SF (between visit 2 & 3)	45	-2.09	17.48	0.4

Antiretroviral treatment was begun at time two. The PSI-SF showed a decrease in stress of 2.09 (p=0.4). This indicates a positive outcome, however the change is not significant and both the Difficult Child and Parenting-Child-Dysfunctional-Interaction subsections showed an increase in stress, of 0.6 (p=.7) and 0.8 (p=0.5) respectively

Table 4.7 below shows the mean and standard deviation between visit one and visit three, for all the subsections of the PSI-SF.

Table 4.7: The Change in mean and standard deviations for subsections of the Parenting Stress Index SF between visit 1 and visit 3 (n=45)

Variable	**Obs**	**Change in Mean**	**Std. Deviation**	**'p' value**
Parental Distress (between visit 1 &3)	45	-3.93	7.18	**0.00**
Parenting-Child-Dysfunctional-Interaction (between visit 1 & 3)	45	-2.71	11.19	0.11
Difficult Child (between visit 1 & 3)	45	-1.96	8.79	0.14
Total PSI-SF (between visit 1 & 3)	45	-10.27	17.71	**0.00**

There was a significant change between visit one and visit three for the total scores of the PSI-SF. However the subsections PCDI and DC did not show a significant change when tested at the 95% significance level. The overall

decrease was 10.27 (p=0.00). This overall change in mean from visit one to three indicates a positive outcome. The change noted here is for the entire time period of the study of one year.

Table 4.8 below shows the comparison between visit one, two and three with regards to the change in mean and standard deviation as a summary of all the data.

Table 4.8: Overview of change in mean, standard deviation and 'p' value of the Parenting Stress Index between visit one, two and three (n=45)

Change V1 to V2	Subsections	Change in Mean	Standard Deviation	'p' Value
	PD	-2.09	7.91	0.08
	PCDI	-3.31	9.14	**0.02**
	DC	-2.78	7.64	**0.02**
Change V1 to V3		-	-	
	PD	-3.93	7.18	**0.00**
.	PCDI	-2.71	11.19	0.11
	DC	-1.96	8.79	0.14
Change V2 to V3		-	-	
	PD	-1.84	7.46	0.1
.	PCDI	0.6	9.7	0.7
	DC	0.8	7.76	0.5

The PD subsection showed the greatest decrease between visit one and visit three with a decrease of 3.93 (p=0.00). The PCDI subsection showed the greatest decrease between visit one and visit two, with a decrease of 3.31 (p=0.02). The DC subsection showed the greatest change between time one and two with a decrease of 2.78 (p=0.02). There was an increase in stress

between visit two and visit three in both the PCDI and DC subsections, (p=0.6 and p= 0.8 respectively, however these values are not significant).

4.6 Correlation between CD4 Count and the Child and Parenting Stress of the Parent

Table 4.9 shows the mean CD4 counts of the children at visit one, visit two and visit three.

Table 4.9: The mean CD4 counts of children at visit one, visit two and visit three (n=45).

	Mean CD4 count (%)	**Standard Deviation**
Visit 1	12.4	6
Visit 2	15.73	10
Visit 3	19.7	10

The average CD4 count of the children increased from visit one to visit three, with the greatest change between visit two and three, however the CD4 counts were still extremely low.

Table 4.10 below shows the change in CD4 count between the visits to the clinic.

Table 4.10: The change in CD4 counts between visit one, two and visit three (n=45).

	Change in CD4 count (%)	**Standard deviation**	**'p' value**
Visit 1-2	3.3	8.3	0.01
Visit 1-3	7.1	9.3	0.0
Visit 2-3	3.8	6.5	0.0

The CD4 count improved throughout the year of the study, with the greatest change between visit two and visit three.

Figure 4.1 below shows the relationship of the CD4 count of the child and the parenting stress level of the parent at visit one.

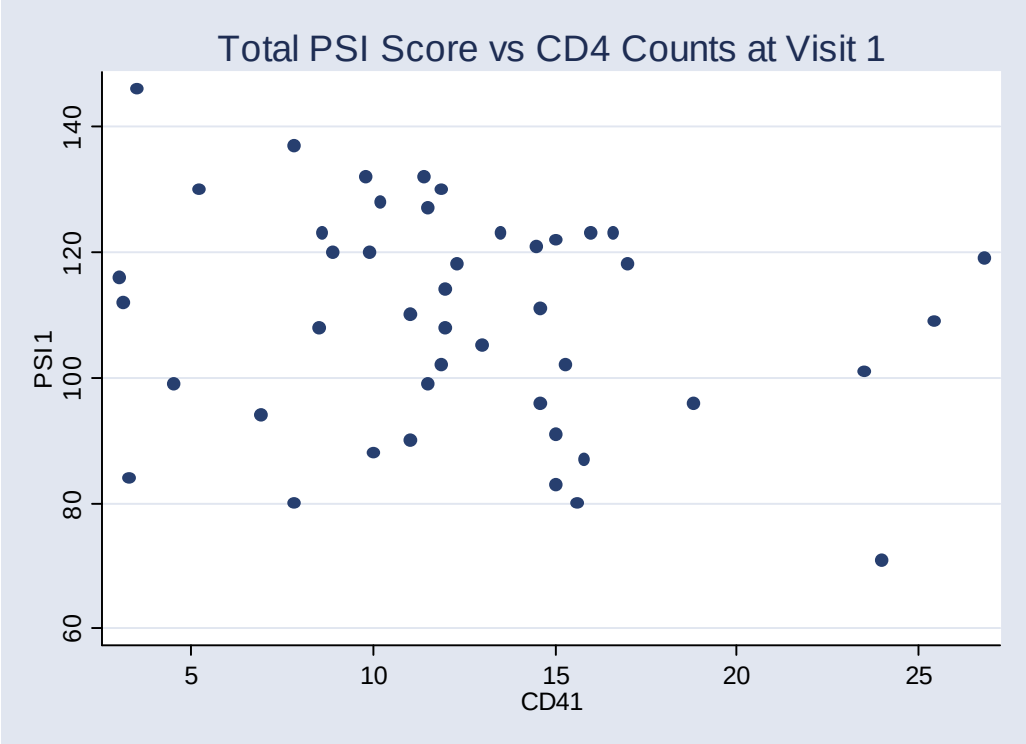


Figure 4.1: The relationship between the CD4 count of the child and the parenting stress levels of the parent at visit 1.

There is no correlation between the CD4 count of the child and the parenting stress levels of the parent at visit one, r= -0.2 and p=0.15

Figure 4.2 below shows the relationship between the CD4 count of the child and the parenting stress levels at visit 2.

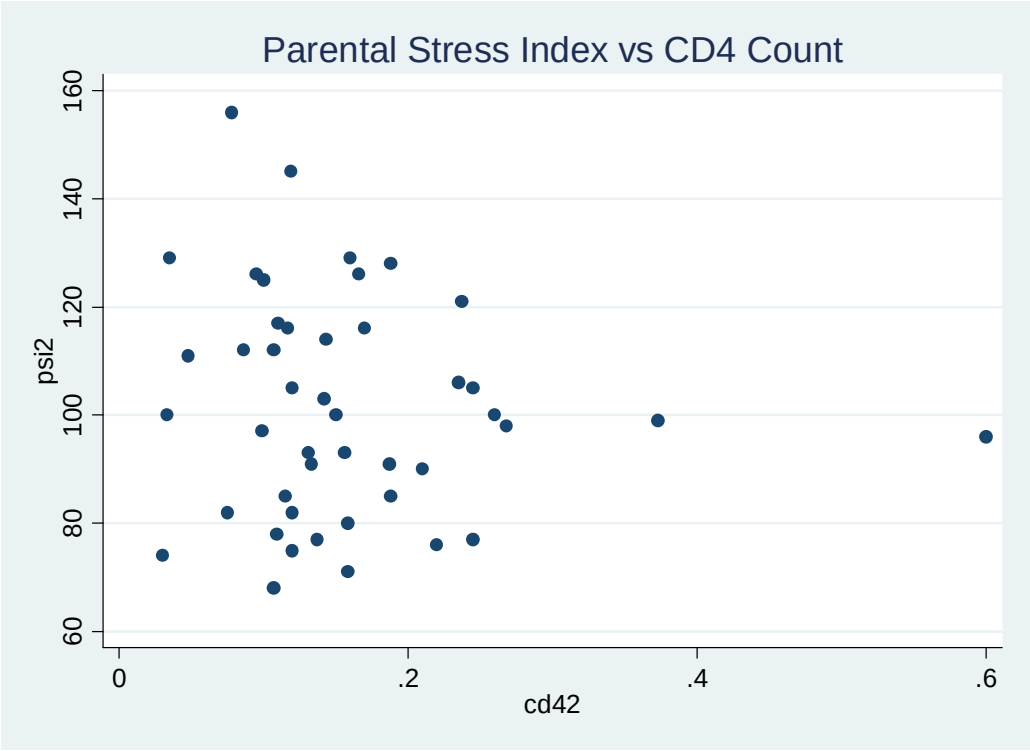


Figure 4.2: The relationship between PSI-SF and the CD4 count at visit two.

There is no correlation between the CD4 count of the child and the parenting stress levels of the parent at visit two, r= -0.11 and p=0.5.

Figure 4.3 below shows the relationship of the CD4 count of the child and the parenting stress level of the caregiver at visit three.

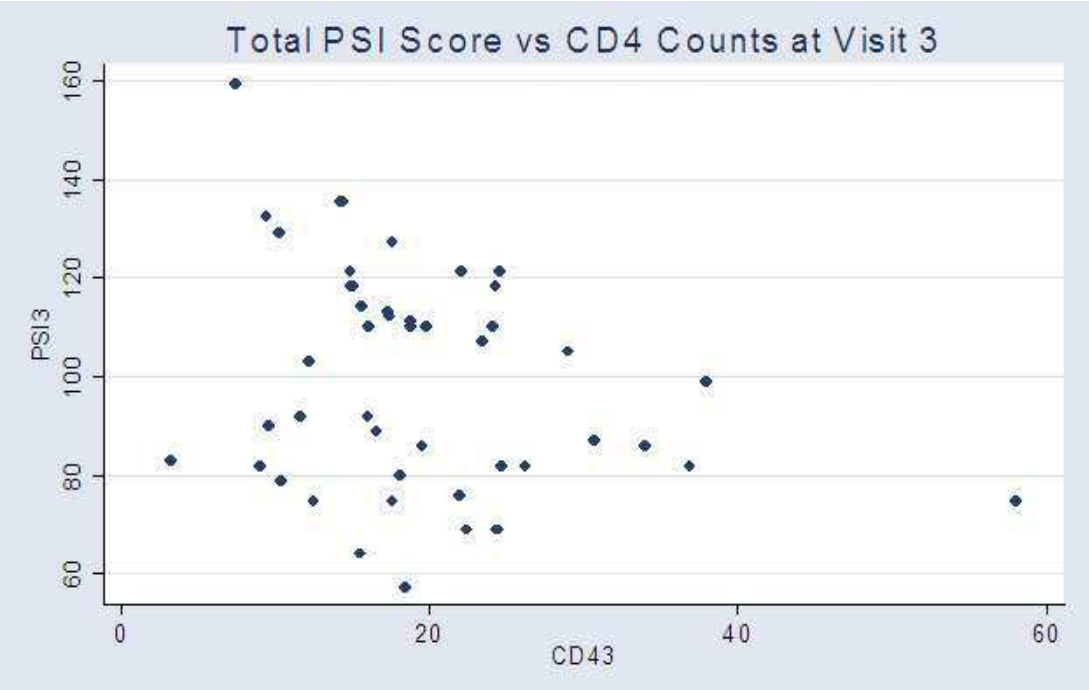


Figure 4.3: The relationship between the CD4 count of the child and the parenting stress levels of the caregiver at visit 3.

The graph indicates that there was no correlation between the CD4 count of the child and the parenting stress level of the caregiver at visit three. The correlation coefficient found was -0.2791 between visits one and three showing that there was no relationship between the CD4 count of the children and the parenting stress levels of the caregivers between visit one and visit three. The 'p' value was 0.06.

4.7 Impact of Child Age on the Scores of the PSI-SF

Figure 4.4 below indicates the relationship between the parenting stress levels of the caregiver and the age of the child at visit one.



Figure 4.4: The relationship of the PSI-SF score and the age of the child at visit one.

The graph indicates that there was no correlation between the age of the child at time one and the parenting stress of the parent. The correlation coefficient at time one was 0.13 (r value) and the 'p' value was 0.39

Figure 4.5 below shows the relationship of the PSI-SF and the age of the child at visit two.

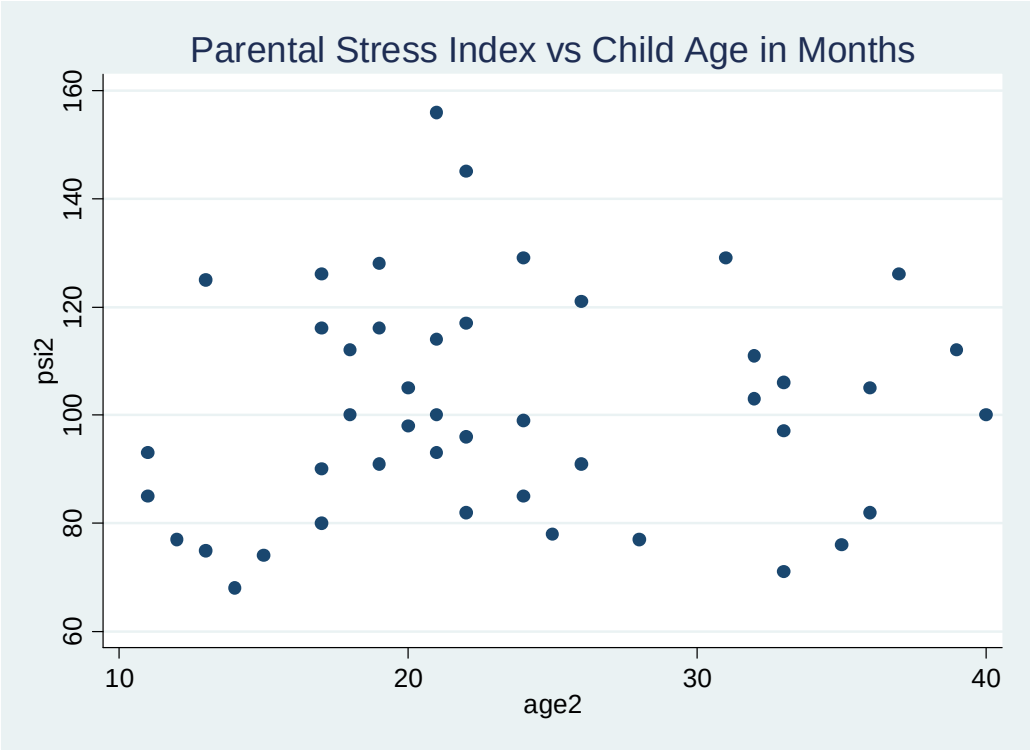


Figure 4.5: The relationship between the PSI-SF and the age of the child at visit two.

The scatter chart indicates that there is no correlation between the age of the child at time two and the parenting stress of the parent, r= 0.08 and p=0.6.

Figure 4.6 below indicates the relationship between the PSI-SF and the child at visit three.

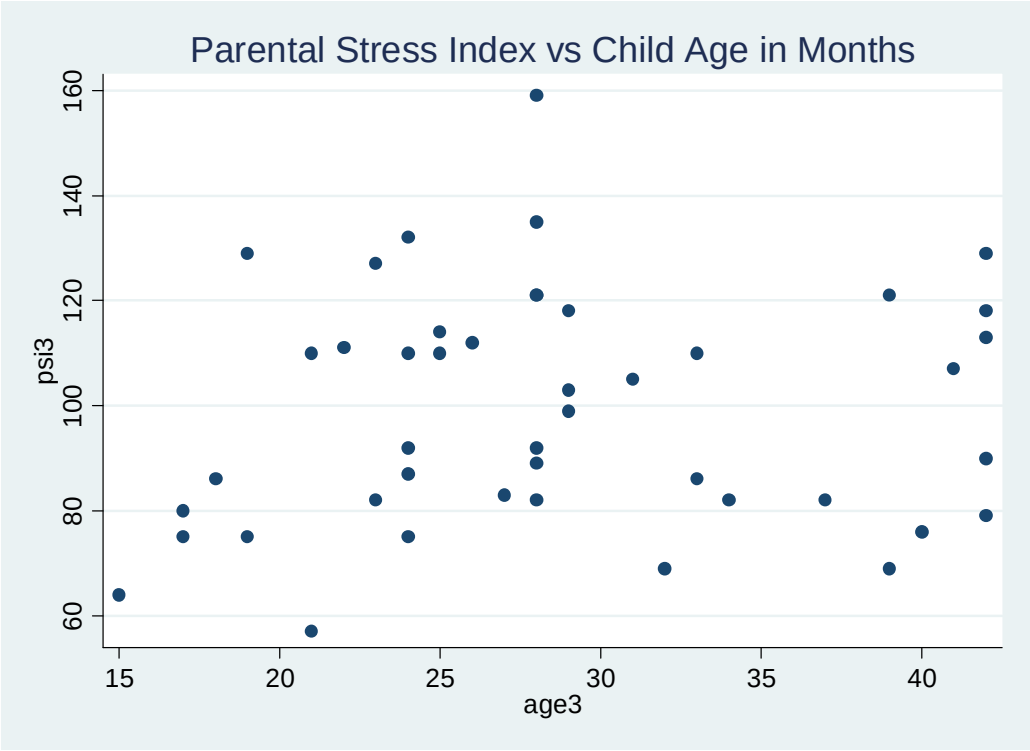


Figure 4.6: The relationship between the PSI-SF and the age of the child at visit three.

There is no correlation between the age of the child at time three and the parenting stress of the parent, r=0.5 and p=0.1.

These results will be discussed in further detail in Chapter 5.

CHAPTER 5

5.0 DISCUSSION

5.1 Introduction

This chapter will discuss the findings of the study and how these results compare to those of other studies.

5.2 Demographic details and study sample

The demographic characteristics of the children and their caregivers in this study relate to other study findings that the majority of people with HIV/AIDS generally live in poverty at the lower end of the economic scale (Black et al., 2004a). People who live in poverty have been shown to live with poor health, poorer parenting practices and associated poorer child health (Emerson, 2007). Schor et al. (2003) confirmed this and showed that family income is related to the general health of the child.

The average age of the caregivers included in the study was 29.3 years, which places these caregivers in the age group where most new HIV infections occur (UNAIDS 2005). The average age of diagnosis of HIV is 16.9 months (UNAIDS 2007). The earlier the diagnosis of HIV, the more optimal the situation becomes (Schor et al., 2003). Having the possibility of both the mother and child infected by HIV and the diagnosis often at similar times would increase the caregiver stress levels (Hackle et al., 1997).

Most of the children were cared for by their biological mothers, which is obviously the optimal situation. The mothers' average age was 29 years old which places most of the women in the age category of those who are predominantly vulnerable to HIV infection (Potterton et al., 2009).

The study sample was adequate in number to see where there was a change, if any, in the overall scores as well as subsections of the PSI-SF. As there was no change shown after the introduction of ARVs a longer study would be optimal to see if there was a change noted over a greater time frame.

5.3 The influence of antiretroviral therapy on the subsections of the PSI-SF.

The importance of regular administration of the drugs cannot be understated. As stated by Mellins et al. (2004) adherence to the strict regime of antiretrovirals is very difficult and very important for the attainment of any reasonable clinical improvements following HIV infection. The mother-to-child transmission rate in SA is high at around 29% (Kouyoumdjian et al., 2004).

The overall stress levels decreased during the time frame of the study however the intervention of antiretroviral treatment did not have significant decrease in the scores. Despite this positive outcome of decreasing stress, the PSI-SF scores were still very high, indicating that the parents of children with HIV were still experiencing a great deal of stress. Abidin (1995) stated that parents who experience a total score of more than 90 experience clinically significant levels of stress. Abidin (1995) suggests that parents who do score more than 90 should be referred for professional counselling. The 50 percentile is a raw total score of 69 (see appendix 1)

The intervention at visit two was the introduction of antiretroviral therapy. At visit one all the children included in this study were HIV positive but antiretroviral naïve and the caregivers were all aware of this. At visit two there is no possibility that the antiretroviral therapy was working (they had not begun the treatment). The caregivers received social support through counselling, nutritional supplements, and dietetic advice. Ghafouri et al. (2006) showed that antiretroviral treatment is capable of improving immune function, decreasing the frequency of HIV related CNS symptoms as well as decreasing the prevalence of opportunist infections. The total score PSI-SF improved between each time frame (between time one and two, and time two and three). The only increase in stress levels were noted after the commencement of antiretrovirals (between time two and time three). The clinic's interventions of social support, counselling, physiotherapy, nutritional advice may have been the reason for the improvement between time one and time two. A possible reason for the increase in stress levels for the subsections PCDI and DC is the difficulty of administering the

antiretrovirals. The only two subsections which increased were the DC and the PCDI which is the interaction of the parent and child and that of the perception of the parent of the child. These subsections may have increased due to the burden of constantly giving medication. This is also a stark reminder to the parents that their children are sick and in need of greater care. As many of the parents were not living alone, the increased awareness of the family members to the amount of medication given to the child may cause stigmatisation as well as force the parent to acknowledge the status of the child where they may have wanted it to remain private. An identifiable caregiver (preferably only one) is required for the administration of the antiretrovirals (Mellins et al., 2004). Adherence to antiretroviral treatment is very important and more than a 95% adherence is required for viral suppression (Mellins et al., 2004). The goal of antiretroviral treatment is to increase the survival rate of the child, however adherence is a substantial challenge to the caregiver (Mellins et al., 2004).

Stress levels are very difficult to isolate to one particular cause and confound other variables. The caregivers included in this study were not isolated and so would have been impacted by general stressors which are impossible to remove as confounding variables. Caring for a child with HIV implies that additional care in the form of additional doctor's appointments, clinic check ups and possible hospitalisation are possible. The stress levels of the caregivers were significantly high throughout the study, which was also found by DeMartino et al. (2000).

Antiretroviral therapy is a combination of at least three drugs that prevent different aspects of viral replication and have a combination of reverse transcriptase inhibitors as well as protease inhibitors (Ghafouri et al., 2006). Antiretroviral therapy improves the immune function, suppresses viral replication, decreases the frequency of HIV related CNS symptoms and decreases the prevalence of opportunistic infections (Ghafouri et al., 2006). Once this happens, the health of the child improves and their ability to be independent (less demanding on the caregiver) improves and could result in better PSI-SF scores. As stated by DeMartino et al. (2000) and Gortmaker et al. (2001), both the care and treatment of children with HIV improve with the commencement of

antiretroviral therapy. Ghafouri (2006) showed that antiretroviral therapy has successfully prevented many end-stage AIDS complications.

Even though overall a decrease in PSI-SF scores were seen, a statistical decrease does not necessarily mean a clinically significant decrease in the stress levels of the caregivers. As the caregivers were possibly ill themselves, there is a possibility that during the course of the study they themselves began antiretroviral treatment. This is a major confounding variable and could be considered for further research. The children included in this study were very sick at the start of the study and it is likely that the caregivers themselves may have been HIV positive themselves. It is therefore possible that the parents of these children may in the future die from complications of HIV/AIDS. It is important to note that in SA the child and parent have different criteria for the commencement of antiretroviral therapy and the parent or caregiver may not start antiretroviral treatment at a similar time to the child. It is common to have both a sick parent and child in one family, which increase the overall stress of the caregiver (Glover et al., 2009). This unfortunate situation places a different dynamic on the family structure as in most cases when the caregiver passes away, a direct family member will take care of the child. This family member has to deal with the death of a family member as well as the added stress of taking care of their child. Osteberg and Hagekull (2000) showed that there are many empirical studies which have shown a positive relationship between increasing parenting stress and a decrease in optimal functioning in the parent-child as well as other family relationships. Therefore the caregivers have added stress and the family unit as a whole would be the poorer of it.

Many of the participants included in this study were identified on their first or second visit to the clinic. Due to the comprehensive nature of the care at the clinic, it is possible that this had the greatest impact on decreasing the stress levels of the parents.

5.4 The relationship between the CD4 count of the child to the parenting stress levels of the caregiver.

The effect of the children's CD4 count on the parenting stress level has not been researched, and hence this makes comparisons very difficult. Antle et al. (2001), Bithoney et al. (1995), DeMatteo et al. (2002), O'Neil et al. (2001), and Ostberg and Hagekull (2000) all found a positive correlation between increasing parenting stress levels and the HIV positive status of their child. No CD4 counts were monitored in these studies.

There was no correlation found between the CD4 count of the child and the parenting stress levels of the caregiver. This finding does not agree with similar studies such as that found by DeMatteo et al. (2002) who established that a "good" CD4 count had a positive effect on decreasing the level of stress in the patient. This study was done in the United States of America, and the CD4 count may have been explained in detail in addition to the fact that patients themselves were the ones with HIV and hence their own CD4 counts were being used. This might have meant that they paid particular attention to the CD4 counts and hence the positive correlation that was found in that study. This study also looked at the adults CD4 and cannot be compared fairly to a study where the CD4 count of the child is in question.

The CD4 counts of all the children were low (at visit one with a mean of 12 %). According to the WHO, HIV positive children less than 11 months old require CD4 levels of greater than 35% in order to be classified as not significant (classification of HIV-associated immunodeficiency). For children between 12-35 months the percentage needs to greater than 30%. This indicates that all the children included in the study were very ill at the time of their first visit. As the CD4 was very low in all the children, there was not a large comparative group in order to see if children with a "better" CD4 had a positive effect on decreasing the parenting stress levels.

The CD4 count of all the children was very low at visit one, and did improve as expected with the commencement of antiretroviral treatment; however an

improved CD4 count does not imply that the child is healthy. Even though the CD4 count improved it remained low which indicates that the children were all possibly still very ill, which would explain why the PSI-SF scores showed no correlation to the CD4 count, as a statistical change does not mean a clinical change which is what the caregivers would be hoping for.

5.5 The relationship between the age of the child and the parenting stress levels of the parent.

There was no correlation found between the age of the child and the parenting stress levels of the caregiver. There is a dearth of literature on this particular topic as well.

There are more than 14 million children who have been orphaned by AIDS is Sub-Saharan Africa (Lau and Muula, 2004). Most of these children are cared for by family members (Lau and Muula, 2004). Thus the caregivers not only have the task of caring for an orphaned child, but in many cases more than one from different families thereby compounding the situation. This burden has shown immense stress on the extended family (Lau and Muula, 2004).

Caring for any child is stressful and the children included in this study were at a particularly care demanding age. Further studies can be done on the differences in caring for a toddler versus a newborn. As all the children required a large amount of time and care it is possible that all parents found their children to increase their stress due to this burden. As stated before it is a topic for further research to investigate if as the children get older and care demands decrease if the parenting stress also decreases.

As all the children included in this study were sick and only began ARVs at visit two, the study could have been terminated too soon to see if any difference was seen as the children grew up in the parenting stress levels.

5.6 Limitations of the study

- The children were all in a relatively wide age range however there was a small sample size and therefore comparisons between different age groups could not be done.
- The children all had very low CD4 counts and therefore comparisons between their CD4 counts could not be done.
- The study only included six months of treatment and a longer time frame such as a year would have been more beneficial.

5.7 Conclusion

The results show that the caregivers included in this study were living in poverty and in a poor socioeconomic state. The parenting stress levels were extremely high at visit one although they did decrease by visit three, the stress levels were still high. The parenting stress levels did not decrease with the commencement of antiretroviral treatment. There was no correlation between the CD4 count of the children and the parenting stress of the parents. There was no correlation between the age of the child and the parenting stress of the parents.

The above discussion will be concluded in chapter 6.

CHAPTER 6

6.0 Conclusion and Recommendations

6.1 Conclusion

The stress levels of the parents decreased over the period of the study, however this decrease is not due to the introduction of antiretroviral therapy and possibly were due to the overall care given at the clinic. The stress levels of the parents were still above acceptable norms. There was no correlation between the CD4 count of the child and the parenting stress levels of the parent.

There was no correlation between the age of the child and the parenting stress levels of the caregivers. The age of the child did not impact on the PSI-SF scores.

6.2 Recommendations

6.2.1 Recommendations for further research

- Further research could be conducted with wider age groups examining if there would be a correlation between the age of the child and the parenting stress levels if larger age groups were used.
- Further research could be conducted focussing on the everyday stress of South African HIV positive population and the compounding factors such as having a child with HIV and the administration of antiretrovirals.
- Further research could be conducted looking at the health of the caregivers and if this changed their stress levels.
- Further research could be conducted over a longer time period, in order to see the long term effects on stress levels after the commencement of antiretroviral treatment.
- A qualitative questionnaire may allow the caregivers to express their feelings and frustrations more and give a greater insight to what causes and increases their stress levels.

6.2.2 Recommendations for clinicians

- The caregivers were shown to have extremely high levels of stress and clinical interventions to reduce stress as well as social interventions need to be encouraged at every contact with medical personnel.
- Employ and refer when necessary to a psychologist.
- Health care professionals need to acknowledge the high stress levels which are being experienced by parents.

CHAPTER 7

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