The motor function, muscle strength and health related quality of life of children aged 5-10 years, perinatally infected with HIV, in an urban setting in South Africa

Cassandra Rego

794171

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Physiotherapy.

Johannesburg, 2021

Abstract

Background: It has been well documented that developmental delays are common in infants and toddlers infected with Human Immunodeficiency virus (HIV). Gross motor development is the domain most affected in infants and toddlers. There are few studies that show the impact of HIV on motor function in older children, who are now starting to enter the schooling world.

Aim: The aim of this study was to determine the motor function, muscle strength and health related quality of life of children aged 5-10 years who have been perinatally infected with HIV and are on antiretroviral therapy.

Methods: Children attending the HIV clinic at Tambo Memorial hospital were recruited for this study. Ethical clearance to conduct the study was obtained and informed consent and assent were obtained prior to assessment. The participants were assessed once off at the HIV Clinic, on the day that they attended for their doctors follow up appointments. They were assessed using the Movement Assessment Battery for Children – 2, Standing broad jump test, Peds-QL^{TM} and a sociodemographic questionnaire. Results were documented and frequencies, means and correlations were determined.

Results: Thirty participants took part in the study and data was analysed from the respective assessments. The mean age of the participants was seven years old, with 56.7% of the participants being boys. Mothers were mostly the primary caregivers at 76% and the overall highest level of education among them is very low with only 26.67% of caregivers having completed matric. The majority of primary caregivers (56%) were unemployed and those who were employed, were employed in minimum wage earning jobs. The primary source of income for most of the primary caregivers was the government stipend, most commonly in the form of the child support grant.

The M-ABC showed that 60% of the children assessed were either at risk of developmental delay or were already delayed. The domain of manual dexterity was the most affected. The SBJT showed that the participants had a weaker muscle strength overall compared to HIV uninfected children in other national and international studies. The Peds-QL^{TM} demonstrated that emotional functioning had the lowest overall scores, and attributed to 59% of the variance in HRQOL. Of note the Peds-

QL™ demonstrated that the overall HRQoL score, of the participants was high, with a maximum total score of 97.82% and the lowest total score being 60.89%.

Conclusion: The results of the study clearly indicate that children between the ages of 5-10 who have been perinatally infected with HIV, and are on ART, are at a significant risk of acquiring or already demonstrating developmental delay in their motor function. Muscle strength is also an area of concern in these children. The results also speak to the lower emotional health related quality of life of children living with HIV and the importance of not overlooking this population, despite the lack of obvious disability. There is a definite need for more research in this population, and the design and implementation of programs to assess and treat their developmental needs throughout childhood.

Declaration of Originality

I Cassandra Rego, declare that this research is my own, original work. It is being submitted in partial fulfilment of the requirements for the Master of Science in Physiotherapy degree, at the University of the Witwatersrand. It has not been submitted for any other purposes or degrees, at this university or any other.

Cassandra Rego

September 2021

Acknowledgements

I would like to acknowledge the following individuals and groups for the contributions they made to my research journey:

- The caregivers and the participants who were willing to take part in this study.
- Wits University Physiotherapy Department for the use of the Movement Assessment Battery for Children-2.
- Tambo Memorial Hospital CEO for allowing me to conduct the study as well as Emthonjeni Clinic and all the staff for their support and encouragement.
- The Gauteng Department of Health, for the opportunity to study the degree of Master of Science in Physiotherapy.
- Professor Joanne Potterton for all the guidance, patience, care and support.
- My family for their unwavering patience, encouragement and care.

List of Abbreviations

The abbreviations below have been used in text and/or in figures and tables presented in upcoming chapters.

ART: Antiretroviral Therapy

ABC: Abacavir

AZT: Zidovudine

BMI: Body Mass Index

CLT: Central Limit Theorem

Cm: Centimetres

CNS: Central Nervous System

DNA: Deoxyribonucleic acid

EFV: Efavirenz

HAZ: Height for age Z-Score

HIVE: Human Immunodeficiency Virus Encephalopathy

HIV: Human Immunodeficiency Virus

HRQOL: Health Related Quality of Life

Kg: Kilogram

M-ABC: Movement Assessment Battery for Children

NAE's: Non-Aids Events

PaedsQL: Paediatric Quality of Life

QOL: Quality of Life

RNA: Ribonucleic acid

SBJ: Standing Broad Jump Test

SN: Sensory Neuropathy

WAZ: Weight for age Z-Score

1 RM: one repetition maximum

3TC: Lamivudine

Table of Contents

List of Figures

List of Tables

Chapter 1: Introduction

1.1 Background

According to UNAIDS, the estimated prevalence for 2020 of people living with Human Immunodeficiency Virus (HIV) in South Africa is 7.5 million (UNAIDS, 2020). That is a 19% prevalence rate in the age ranges of 15-49 years. However, there has been a decline in the prevalence among people aged between 15-24 years, from 8.17% in 2002 to 4.30% in 2019 (StatsSA, 2019). According to UNAIDS 2020 there are 340 000 children aged 0-14 years living in South Africa with HIV, only 47% of these children are receiving antiretroviral therapy (ART) (UNAIDS, 2020). The final vertical transmission rate in South Africa from mother to child, including breastfeeding, stands at 3.31 (UNAIDS, 2020).

According to Melhuish and Lewthwaite, 2018, an 80% decrease in mortality has been reported since the introduction of ART (Melhuish and Lewthwaite, 2018). Despite the benefits of these drugs, many of them have long term effects of toxicity on the body and they all have side effects (Melhuish and Lewthwaite, 2018). In pregnancy most antiretroviral drugs have not been classified as safe for the foetus by the FDA, but the reduction in perinatal transmission rates with the use of Zidovudine and Lamivudine and Nevirapine has been seen too far outweigh the potential risk for harm (Carr and Cooper, 2010).

Due to the research that has been done on HIV pathophysiology, transmission, treatment and possible cures in recent years, quality of life as well as life expectancy in people and children living with HIV has drastically improved (Melhuish and Lewthwaite, 2018). Health related quality of life (HRQOL) is a multifaceted construct that is constantly changing in order to encompass components of behaviour, social, mental, emotional and physical well-being and functioning as perceived by a person (Stevanovic, Tadic and Novakovic, 2011). HRQOL in children with HIV was investigated by a number of studies which have found that children with HIV had a lower HRQOL especially when looking at physical functioning in comparison to non-infected control groups (Bomba *et al.*, 2010; Stevanovic, Tadic and Novakovic, 2011; Melhuish and Lewthwaite, 2018).

HIV is now becoming a chronic condition that many children, adolescents and adults are having to live with for the rest of their lives (Brassell and Potterton, 2019). As

children infected with HIV grow, they have a high risk of developing minimal to severe impairments in their development. These impairments span across all areas of development from visual, auditory, language, gross and fine motor to epilepsy and neurocognitive issues (Brassell and Potterton, 2019).

Van Rie et al, (2009), stated that younger children infected with HIV in comparison to older children infected with HIV are more likely to have severe motor and mental developmental delay. It is also been found that motor function is more significantly affected than any other type of development (Baillieu and Potterton, 2008; Hilburn *et al.*, 2011; Laughton *et al.*, 2012; Potterton, Hilburn and Strehlau, 2016), Cognition and language development may be moderately to severely affected (Baillieu and Potterton, 2008; Potterton *et al.*, 2009; Van Rie and Dow, 2009).

Fewer studies have been done to investigate the impact of HIV on the development of older children. Recent studies by Boyede et al, (2013), Lowick et al, (2012) and Potterton et al, (2016), look into pre-schoolers affected with HIV. All three studies found that children in preschool have significant developmental delays in one or more areas (Lowick, Sawry and Meyers, 2012; Boyede *et al.*, 2013; Potterton, Hilburn and Strehlau, 2016). Potterton et al, (2016), found that the children had a three to 12-month delay when compared to a normative sample (Potterton, Hilburn and Strehlau, 2016). Of note, Boyede et al, (2013), stated in his study that socioeconomic factors such as maternal age and education, and a low level of income were correlated with the high decrease in cognitive function in the school going children infected with HIV (Boyede *et al.*, 2013).

Brassell and Potterton, (2019), found that 50.5% of children living with HIV between 2-9 years of age had developmental or functional impairments or disabilities (Brassell and Potterton, 2019). The decline in prevalence of children found to have significant developmental delay may be partly attributed to earlier initiation of ART, or it could be due to the fact that as children infected with HIV get older, their impairments may be less severe, and therefore not as noticeable.

There are many reasons that motor function can be disrupted in a child who is HIV positive. However, there is minimal research on the impact of HIV on the health and development of children across childhood (Potterton, Hilburn and Strehlau, 2016).

Thus there is a need for further studies on pre-schoolers and young children infected with HIV and their motor function and quality of life.

1.2 Research Question

What is the motor function, muscle strength and health related quality of life of children aged 5-10 years who were perinatally infected with HIV and are on ART in an urban setting, South Africa?

1.3 Research Aim

To determine the motor function, muscle strength and health related quality of life of children aged 5-10 years who were perinatally infected with HIV and are on ART.

1.4 Objectives

The objectives of this study were to determine;

- To investigate the relationships between motor function and muscle strength with CD4 count and viral load, BMI and health related quality of life.
- the motor function, in a sample of children aged 5-10 who were perinatally infected with HIV.
- muscle strength, in a sample of children aged 5-10 who were perinatally infected with HIV.
- the health related quality of life of children aged 5-10 who were perinatally infected with HIV.
- To describe anthropometric measurements, clinical presentation and demographic information of South African children aged 5-10 who were perinatally infected with HIV.

1.5 Significance

The outcomes of this study will provide additional information on the motor function, muscle strength, health related quality of life and the socio-demographic backgrounds of children living with HIV. This will aid in decisions and planning of prospective treatments, projects or creation of more rehabilitation services for this population and possible implementation of these at the study site.

The next chapter will critically review the available literature on the pathophysiology of HIV and its current treatment and this virus's effect on children as they develop, as well as the outcome measures used in the study.

Chapter 2: Literature Review

The literature review will discuss and critique recent studies on the human immunodeficiency virus (HIV), its pathophysiology, epidemiology, pharmaceutical management and the impact of the virus on the developing brain and central nervous system as a whole.

Search engines used include but are not limited to: Google Scholar, Pubmed, Clinical Key, Cochrane Library of systematic reviews and Science direct. Only English articles or articles translated into English were used. No date restrictions were used.

Key words used in searches included: HIV, children, developmental delay, ARV's, ART, HIV encephalopathy, muscle strength, motor function, health related quality of life, neurodevelopment.

2.1 Human Immunodeficiency Virus

2.1.1 Definition of HIV

Human Immunodeficiency virus (HIV) is a virus known as the lentivirus, that originates from the Retroviridae family (Melhuish and Lewthwaite, 2018). This retrovirus weakens the immune system, by attacking the T-cells or CD4 cells. The virus carries its own ribonucleic acid (RNA) as well as the enzyme reverse transcriptase. This enzyme transcribes the RNA genome of the cell it has infected into a copy of deoxyribonucleic acid (DNA). This DNA is then able to integrate into the human chromosomes and is stored as a provirus, which is then able to create many replicas of the HIV RNA genome causing an irreversible infection (Meyer and Alder, 2017).

The virus was transmitted to humans from primates and the earliest proven HIV infection was as far back as 1959. Originating in Central Africa in the 20th century, most people that became infected with HIV died, as there were very few treatments available (Melhuish and Lewthwaite, 2018). The HIV infection does not always show symptoms straight after infection. There is a period, on average, of five to ten years in infected, untreated adults to start showing signs of HIV (Meyer and Alder, 2017). However, in other people, there is a rapid decline between 6 -12 months, in CD4 count causing symptoms at a much earlier stage of infection (Melhuish and Lewthwaite, 2018).

HIV is transmitted through direct contact of human bodily fluids, such as semen, blood, breast milk and vaginal fluids (Meyer and Alder, 2017; Melhuish and Lewthwaite, 2018). Thus perinatal transmission takes place from an HIV infected mother to her child, either through breast feeding or during childbirth (Meyer and Alder, 2017).

2.1.2 Epidemiology

Globally there are 38 million people affected with HIV, 1.8 million of them being children under the age of 15. Out of the 1.8 million, 340 000 children are living with HIV in South Africa (UNAIDS, 2020). In total only 53% of children globally, have access to antiretroviral therapy (ART) and across Eastern and Southern Africa 72% of children are accessing ART (UNAIDS, 2020).

2.1.3 Antiretroviral Therapy

ART is the treatment given to patients who are HIV positive. According to Melhuish and Lewthwaite, (2018), an 80% decrease in mortality has been reported since the introduction of ART (Melhuish and Lewthwaite, 2018). These drugs break the RNA/DNA replication cycle, thus lowering the viral load in the body. Once the viral load is diminished or undetectable, the body is able to regain strength of its immune system, giving the patient a better chance at fighting off opportunistic diseases.

For children in South Africa who weigh 20 kilograms (kg) or who are younger than ten years old, the first line ARV regime is Abacavir (ABC), Lamivudine (3TC), Dolutegravir (DTG) (South African National Department of Health, 2019). Once they are older than ten years and weigh more than 35kg they can be considered for change onto an adult regime. The children need to be reviewed by their doctor monthly until they have been on treatment for six months. Their viral loads are taken and depending on whether it is lower than detectable or detectable the regime will be adjusted and the regime is reviewed every three months (South African National Department of Health, 2019).

Despite the benefits of these drugs, many of them have long term effects of toxicity on the body and they all have side effects (Melhuish and Lewthwaite, 2018). Some of the commonly noted side effects in children are anaemia, lipodystrophy and hypersensitivity reactions (Mulenga *et al.*, 2015). Studies have however shown that

the hypersensitivity reactions are minimal and that anaemia may not necessarily be caused by ABC but instead by HIV itself (Mulenga *et al.*, 2015; Jesson and Penazzato, 2016).

Therefore, it is very important for people and children infected with HIV to maintain a healthy and active lifestyle, filled with a balanced, nutritious diet, exercise, good sleeping habits and up to date immunizations for the young (Melhuish and Lewthwaite, 2018).

2.2 Impact of HIV on the developing Central Nervous System

HIV encephalopathy (HIVE) is one of the consequences of HIV infection spreading into the developing central nervous system (CNS). The virus creates a large immune mediated cascade of physiological events which allows it to enter the CNS by permeating the blood brain barrier (Strehlau, 2013; Mann *et al.*, 2017). HIV creates a collection of virus in the CNS which is distinguishable from the plasma viral loads (Mann *et al.*, 2017). The virus's involvement in the developing CNS is characterised by impaired brain development or microcephaly, neurodevelopmental delay or loss of attained milestones and progressive motor dysfunction, such as a disruption in pathological reflexes or gait (Donald *et al.*, 2014; Mann *et al.*, 2017). At least one of these characteristics have to be present for a minimum of two months in order to be diagnosed with HIVE according to the Centres for Disease Control criteria (Mann *et al.*, 2017).

The areas of the brain that are affected have been well documented through the use of CT scans and MRI scans. According to Mintz and Epstein, (1992), the basal ganglia and the brain stem are largely affected as well as a diffuse area of white matter astrocyte. Hoare et al, (2018), further elaborated and reported that macro structural abnormalities – most commonly in perinatally infected children- are cortical and subcortical atrophy, enlargement of the ventricles, calcification and thus damage to the corpus collosum and in agreement with Mintz and Epstein, involvement of the basal ganglia and white and grey matter in the frontal cortex (Hoare *et al.*, 2018).

HIVE presents variably in children, and it is often dependent on many factors such as age, developmental stage and how severe the disease progression was before

treatment was initiated. It has been documented that the younger the child is, the worse the manifestation of the infection, thus causing a poorer global neurological functioning – the dysfunction is more severe- while older children tend to have more localised and specific indicators (Donald *et al.*, 2014). HIVE can be divided into two categories; progressive or static.

Progressive HIVE is subdivided into two categories; subacute and plateau. These children have a regression of acquired milestones or skills and are unable to acquire new skills as they have stagnated (Donald *et al.*, 2014). Langerak stated that this is due to primary infection of the CNS that continues and forms more severe neurological deficits (Langerak *et al.*, 2014). Static HIVE is less severe and it is usually found in children who are on ART and their viral loads are well controlled (Langerak *et al.*, 2014). It also means that even if they are slower than a child who is uninfected with HIV, they should be able to acquire new skills and reach milestones (Donald *et al.*, 2014).

A common neurological deficit due to HIVE, presents itself in the form of spastic diplegia (Langerak *et al.*, 2014). This is due to damage to the corticospinal tracts, and the symptoms displayed can reduce or recover with ART but residual spastic diplegia can also result (Langerak *et al.*, 2014). Gross motor function and deficits in both structure and function may manifest as changes in muscle tone, strength, balance, muscle length and motor control, leading to secondary complications such as contractures, hip dislocation or displacement and deformities in the bones (Langerak *et al.*, 2014). All of these abnormalities create impaired gait patterns and functioning in activities such as walking, running, jumping, standing or climbing stairs (Langerak *et al.*, 2014; Mann *et al.*, 2017). Despite the abnormalities that may occur the range of disability is wide and there can be children who display minimal impairments as well as those with severe impairments (Mann *et al.*, 2017).

The lack of access to early ART, leads to an increased viral load and thus an increased risk of CNS infection, increasing the likelihood of HIV encephalopathy (Mann *et al.*, 2017).

2.3 Neurodevelopmental delay in HIV

A systematic review by Sherr, et al, (2014), states that there is neurodevelopmental delays especially cognitive delays in children both HIV infected and HIV exposed (Sherr, Croome, Bradshaw, *et al.*, 2014). Blanchette et al, (2001), expressed that children with HIV are at risk of presenting with neurodevelopmental delay because there is a period of rapid myelination which occurs in the brain during infancy, thus correlating with the gain of important milestones in the areas of motor, cognition and behaviour (Blanchette *et al.*, 2001). Therefore, if there are any disturbance to the processes of myelination, we can expect to see some form of developmental delay (Blanchette *et al.*, 2001).

In agreement with this, Robertson et al, (2008), as well as Potterton et al, (2016), stated that in order to understand the extent of the neurological deficits, one needs to look at the various factors. The developmental stage the child was at when HIV was acquired, their viral load at the time and their level of immunosuppression are important to note (Robertson *et al.*, 2008; Potterton, Hilburn and Strehlau, 2016).

Since the relationship between HIV and neurodevelopment has been found, many studies have been conducted with infants who are infected with HIV, so that we can better understand at what stage they are having problems with development, what these difficulties are and what can be done to assist in correcting these issues.

In 2014, Innes et al, showed that infants already have progressive HIV disease, even though ART was started early in life, at eight to 12 weeks after birth. This progressive HIV disease is a risk factor and exposes infants to neurological complications (Innes *et al.*, 2014; Potterton, Hilburn and Strehlau, 2016). Hilburn et al, (2011), also stated that ART's initiated early, at less than three months of age, is effective at lessening the risk of neurodevelopmental delay, HIVE, as well as the progression of the disease (Hilburn *et al.*, 2011).

When compared with infants or young children who are not infected with HIV, or have been exposed to HIV during birth, but are uninfected, children infected with HIV are found to be at the greatest risk of developing neurodevelopmental difficulties. When comparing infants who are HIV positive, with infants who have been exposed but not infected with HIV, large discrepancies in their development are found, across all areas from as young as four months of age (Hutchings and Potterton, 2014; Whitehead,

Potterton and Coovadia, 2014; Potterton, Hilburn and Strehlau, 2016). However, a more recent study done by Chaudhury et al, (2017), in Botswana found that HIV exposed uninfected children did not show signs of developmental delay at 24 months, nor did they find any adverse effects of the ART exposure on neurodevelopment (Chaudhury *et al.*, 2017).

A new long term study by Laughton et al (2018) further researched the neurodevelopmental outcomes over a five-year period in HIV infected children. They studied what the developmental effects are when ART are given early, but for limited time, versus given continuously but at a deferred time period (Laughton *et al.*, 2018). They showed that when using The Griffiths Mental Development Scales (GMDS) across all experimental (ART given early and time limited 48 weeks and 90 weeks) and control (deferred ART's but continuous) groups the scores across all tested subsections were decreased (Laughton *et al.*, 2018). Over the period of the longitudinal study the largest significant difference between all the groups was locomotion. In their first three assessments the experimental groups with children infected with HIV scored lower than the control groups, 11 to 60 months of age, however as the study continued the groups' scores started to become more similar (Laughton *et al.*, 2018). Laughton et al, (2018), found in conclusion that if limited ART interruption is started in children who are asymptomatic at ≤ 12 weeks, under strictly monitored clinical guidance, the children will not have any deficits on their neurodevelopmental outcomes across the first five years.

2.4 Muscle Strength

Muscle strength in the HIV population is well researched in adults, and only beginning to be studied in preadolescent and younger child populations. There are many factors that can affect muscle strength in a child with HIV and that is the disease process itself, and the long term use of ART (Somarriba *et al.*, 2013; Humphries, Potterton and Mudzi, 2014; Macdonald *et al.*, 2017).

Skeletal muscle involvement can occur in people infected with HIV and can occur at any stage of infection (Potterton *et al.*, 2021). This can occur even in people who are on ART (Potterton *et al.*, 2021).

The effects of HIV on protein metabolism, metabolic abnormalities such as lipodystrophy, poor nutrition and a more sedentary lifestyle has been hypothesized to be some of the contributing factors of poorer muscle strength in children with HIV (Somarriba *et al.*, 2013; Humphries, Potterton and Mudzi, 2014; Macdonald *et al.*, 2017). In communities where there is a lack of adequate access to nutritious food, children are unable to maintain their nutrient stores and build muscle. Children with HIV are recommended to consume ten percent more protein than the average child in order to allow for normal protein levels in the body (Humphries, Potterton and Mudzi, 2014).

Children who have been on ART containing protease inhibitors have been found to have more central adipose tissue and be slightly shorter than the normative data for age and their growth has also been shown to be stunted by 0.7cm (Humphries, Potterton and Mudzi, 2014).

Children who are not on ART have a weaker immune system and a correlation between CD4 counts and muscle strength has been found. However once the child is on ART and the viral load starts to become under control, the CD4 count rises, but their muscle strength does not concurrently increase, thus the use of ART does not facilitate any increased muscle building (Humphries, Potterton and Mudzi, 2014) and further strengthening may be needed. It is to be noted that the study by Humphries et al, (2014), was a pilot study and more data needed to be collected to confirm their outcomes. Somarriba et al, (2013), suggests that the reason for the poor increase in muscle strength once the virus is under control and CD4 counts are rising, is because ART causes metabolic disturbances – after long term treatment- that have a direct effect on organs such as the liver and specifically muscle fibres themselves, causing toxicity and predisposing these children to deconditioning. Somarriba et al, (2013), also stated that due to the deconditioning and sedentary lifestyle, there is a high risk of cardiovascular disease in children and especially as they become adults.

A study by Ramos et al, (2013), showed that children with HIV had normal muscle strength but that they had poor anaerobic power when compared to their matched control group (Ramos *et al.*, 2013). This study however only had a sample size of 15 children and thus more studies would need to be done to ascertain the validity and reliability of their outcomes. A study by MacDonald et al, (2017), measured muscle function by use of a dynamic test i.e. jumping. They found that children with HIV have

a significantly lower muscle power but they were one of the only studies to assess muscle power in such a manner.

A recent study, assessed muscle strength, using a hand held dynamometer, in children between the ages of 5-11 in Johannesburg, South Africa. They assessed 175 children who were perinatally infected with HIV and 171 children without HIV, from the same socioeconomic backgrounds (Potterton *et al.*, 2021). They concluded that the children with HIV, were all started on ART early in life, and thus had muscle strength that was comparable, to their otherwise healthy peers. Thus if the HIV disease process is well controlled from an early age, and viral suppression is achieved early on, normal muscle strength can be attained (Potterton *et al.*, 2021).

2.5 Growth and Physical Activity in Children with HIV

The effects on growth and growth in children with HIV has been widely studied (Baillieu and Potterton, 2008; Whitehead, Potterton and Coovadia, 2014; Potterton, Hilburn and Strehlau, 2016). Before the use of ART, studies frequently reported stunting of growth as a significant side effect of HIV (Benjamin-Damons, 2019). With the frequent use of ART and the multitude of interventions used to manage children with HIV, growth has improved, however it is still being affected (Sutcliffe *et al.*, 2011; Sherr, Croome, Parra Castaneda, *et al.*, 2014; Potterton, Hilburn and Strehlau, 2016; Benjamin-Damons, 2019).

Early studies showed a positive change in growth once the use of ART was implemented (Sutcliffe *et al.*, 2011; Benjamin-Damons, 2019). One of the studies showed the higher the participants viral load, and the younger the participant, the faster the weight and height increased respectively (Benjamin-Damons, 2019), while the second study found that the weight of the participants increased steadily over time, but after six months plateaued (Sutcliffe *et al.*, 2011).

In order to measure the anthropometry of these children in relation to the general populous, z-scores are used. Z-scores are scores that relate a child's growth measurements to their age, i.e. their growth for their age is charted according to percentiles, thus what the average child of that age is supposed to measure in that area of growth, whether it be height, weight or BMI. This allows one to determine if the

child is growing normally, or if they are stunted or above the average for their age category.

It is well known that people living with HIV are now facing longer standing chronic conditions, as opposed to just the virus itself. Children are no different to adults, in the way that they too face chronic conditions as a result of having HIV. One of the benefits of ARV's is that they lessen the risk of a child contracting an opportunistic infection, however non-AIDS defining illnesses or Non-AIDS events (NAE's) are fast becoming a major threat to the complex organ and immune systems of this population (Gopalan *et al.*, 2020).

NAE's affect systems such as the renal, liver and cardiovascular systems and may also present in the form of diabetes, malignancies or neuropsychiatric disorders (Gopalan *et al.*, 2020). The cause of these NAE's is thought to be due to the rapid aging of the immune system, as a result of HIV causing repeated chronic inflammatory bouts (Gopalan *et al.*, 2020). Due to the complex nature of the human immune system and the feedforward and feedback systems that are constantly in play, finding a treatment or prevention for chronic inflammation is proving to be quite a challenge.

Physical activity has widely known positive effects on the human body across all ages and stages of life. Gopalan et al, (2020), states that regular physical activity, in conjunction with a good ARV program, has shown benefits in the control of immune activation, chronic inflammation and cardiometabolic health in adults (Gopalan *et al.*, 2020). Gopalan et al, (2020), demonstrated that structured exercise programmes in children, over a period of two years, yields similar results to adults, and reduces the future risk of cardiovascular diseases and NAE's.

A study conducted by Wong et al, (2016), in South Africa shows that girls infected with HIV are less likely to participate in vigorous physical activity, and thus have a lower overall participation in after school sports and physical education during school (Wong *et al.*, 2016). The study however, did not look into the reasons as to why girls were less involved in vigorous physical activity, and more research is warranted to make a conclusion on this group of the population.

2.6 Motor Function

Motor function is one's ability to carry out or learn a voluntary posture or movement pattern in a controlled manner, while being able to make modifications where necessary (Medical Dictionary for the Health Professions and Nursing., 2012). We know that HIV and the way in which it causes damage to the developing CNS in infants can disrupt one's ability to not only carry out certain tasks, but to develop typically as well. Many studies have comprehensively described the impact of HIV on neurodevelopment across all spheres in children (Potterton *et al.*, 2009; Van Rie and Dow, 2009; Hilburn, Potterton and Stewart, 2010; Lowick, Sawry and Meyers, 2012; Boyede *et al.*, 2013; Sherr, Croome, Parra Castaneda, *et al.*, 2014; Potterton, Hilburn and Strehlau, 2016; Brassell and Potterton, 2019).

Studies that look into pre-schoolers infected with HIV have found significant developmental delays across more than one area of development with the worst areas ranging from motor function to cognition (Lowick, Sawry and Meyers, 2012; Boyede *et al.*, 2013; Potterton, Hilburn and Strehlau, 2016). Brassell and Potterton, in 2019 found that 50.5% of their study population, aged between two and ten years, had developmental and or functional impairments. Hilburn and Potterton, (2010), debate the cause of neurodevelopmental delay, with the reasoning being either it is the HIV infections effect on the CNS itself or it is the chronicity of the disease and the damage it is able to cause across multiple systems of the body.

This brings into light the effect of HIV on muscle strength. Thus the question states are children developing delays in the area of gross motor function due to muscle weakness or is it due to the CNS damage to the pathways (Hilburn, Potterton and Stewart, 2010). It is likely due to a combination of both, as well as the effects of long term use of ART.

2.7 Quality of Life

According to the WHO, quality of life (QOL) is one's perception of themselves and their lives in relation to their morals, values and cultural beliefs, in the context of their standards, goals, expectations and concerns (WHO, 1998). It is a wide ranging concept that is affected by various factors such as beliefs, societal relationships, the environment as well as one's physical and mental state and health (WHO, 1998).

It has been researched that adults with HIV have a poorer QOL and have a higher incidence of depression (Shriharsha and Rentala, 2019; Xiao *et al.*, 2019). Before the era of ART, QOL was extremely poor as one deteriorated quickly due to the disease progression, but more along the lines of physical and functional QOL. Mental QOL seemed to be more or less stable throughout the stages of the disease (Banerjee, Pensi and Banerjee, 2010). However, with the development of ART, the average person living with HIV has a much longer life expectancy which brings challenges such as side effects from medications, co-morbidities and opportunistic infections, stigma, discrimination, poverty or socioeconomic challenges and anxiety with big events, such as relationships, pregnancy, the effects of cultural beliefs and practises (Shriharsha and Rentala, 2019). The rate of depression is said to be three to five times higher in people with HIV (Shriharsha and Rentala, 2019). Thus the effect on QOL by the development of ART is controversial (Banerjee, Pensi and Banerjee, 2010).

2.8 Health Related Quality of Life

Health Related Quality of Life (HRQOL) encompasses all aspects, mentally and physically, that can affect one's health (CDC, 2020). It has been defined by the CDC as perceived physical and mental health over time, for either a population or an individual (CDC, 2020). This can include aspects such as emotions, mood, functional ability, socioeconomic status and available social support structures, as well as the policies and public health practises that influence a populations health (CDC, 2020)

Adults living with HIV have many physical and mental health factors that contribute to their HRQOL on a daily basis. An example of a lower HRQOL is being of male gender and older age. Conversely, the stage and time of HIV diagnosis, the severity of the symptoms and the disease process, as well as being placed on ART contributed to a

better HRQOL (Xiao *et al.*, 2019). People who have a more stable family unit, better social support and socioeconomic statuses also had a better HRQOL, than those who had none of the above (Xiao *et al.*, 2019).

Children living with HIV have many social and clinical factors which affect their QOL and HRQOL (Missmer *et al.*, 2000). ART along with the toxicities and side effects, access to health care and hospitalizations, malnutrition due to socioeconomic status, but also due to the disease process in the body and poor functional status due to any reason contributes significantly to a poor HRQOL and QOL in children living with HIV (Missmer *et al.*, 2000). This is also compounded greatly by the effects of the ever prevalent stigma around HIV as well (Cohen *et al.*, 2015; Cuéllar-Flores *et al.*, 2019).

A study on Italian children with HIV, using the Peds-QL^{TM}, showed low scores for HRQOL in the physical and psychosocial sections of the self-reported questionnaire. They also identified that children who had poorly controlled disease, i.e. they had high viral loads, seemed to show worse behavioural problems, that those who's viral loads were lower than detectable (Bomba *et al.*, 2010).

A study done in India showed that the overall effect of HIV on HRQOL was negative, with children scoring low in areas of school, physical and emotional functioning and health related symptoms. These results were similar to the results of studies done on adults with HIV (Banerjee, Pensi and Banerjee, 2010). In agreement with the above findings, a study from Spain, on adolescents and youth with perinatal HIV infection, also demonstrated poorer overall outcomes in physical and psychosocial HRQOL whether in relation to the HIV negative control group, or the overall Spanish norms (Cuéllar-Flores *et al.*, 2019).

In contrast to other literature, a study done in the Netherlands, on children who had been perinatally infected with HIV, showed that there was no major difference, on a group level, between the HRQOL of children with HIV and those without HIV, when their socioeconomic statuses were the same (Cohen *et al.*, 2015). They did however find a significant difference between the two groups, on the school subscale of the Peds-QL^{TM}, but suggest it is rather caused by cognitive impairments in children with HIV (Cohen *et al.*, 2015).

Almost all the literature, which very little focuses solely on children, demonstrates a variable disturbance to the HRQOL of children who have been perinatally infected with HIV and strong correlations to socioeconomic status.

2.9 Outcome Measures

In order to monitor the health and wellbeing of children living with HIV it is important to use standardised outcome measure so that children's progress can be monitored and studies from around the world can be compared. Some of the more appropriate outcome measures available will be discussed in this section.

2.9.1 Developmental Assessment

Development is the change or evolution of a zygote into an infant until complete development into independent adulthood (Bellman, Byrne and Sege, 2013; Merriam-Webster, 2020). Development happens across all systems of the infant, including growth and change in the brain and the central nervous system. Brain development and growth commences at the fourth week of gestation and continues at least until the second decade of life (Bellman, Byrne and Sege, 2013). The areas of brain development are classified into four groups, namely; gross and fine motor skills, speech and language, social and personal and activities of daily living and lastly performance and cognition (Bellman, Byrne and Sege, 2013). All these areas may not develop at the same time, but as the infant grows, each of these areas develop in their own time and way (Bellman, Byrne and Sege, 2013; Fieggen, Lambie and Donald, 2019).

Children will either have typical or atypical development. Typical development is the development of an infant within a set of parameters that has been found to be the timeframe in which the average child will acquire that specific skill or is able to complete a certain task (Bellman, Byrne and Sege, 2013). The time each child takes to reach a milestone or goal is variable, but most children tend to achieve them before a certain age (De Onis, 2006).

The WHO has a window of achievements graph, that was created from a motor development study done in 2006, that illustrates six different gross motor milestones and the age ranges in which they should be achieved. The window of time in order for the goals/milestones to be achieved is rather large, as each child develops at their own pace. For example, sitting independently without support can be achieved anywhere between three and a half months and nine and a half months, thus a child who only achieves this at 11 months would be reason for concern (De Onis, 2006).

Atypical development can be described as deficits or delays in at least two areas of function (Fieggen, Lambie and Donald, 2019). These delays or deficits present themselves during the developmental stages. These delays or deficits could be due to a large range of factors such as neurological damage in utero or soon after birth, and commonly in South Africa, secondary factors and exposures such as HIV, prenatal alcohol exposure, and congenital infections, which contribute significantly (Fieggen, Lambie and Donald, 2019).

In developing children, the easiest way to see if there are developmental problems in an objective, valid and reliable manner, is to conduct an assessment. “Developmental assessment is the process of mapping a child’s performance compared with children of similar age” (Bellman, Byrne and Sege, 2013). Assessment allows us to understand if a child is still within the normal ranges, or if interventions and therapies need to be carried out. It also enables us to maintain a baseline score of the child’s function, so as to compare during and after interventions.

There are many types of assessments available worldwide that look at childhood development at many different ages. Most of these tools allow us to identify if the child is developing normally, is at risk of any delays, or if they definitely have a deficit in development. Certain tools allow us to pinpoint in which of the four functional areas the deficit or delay lies, while others give a much broader idea of the child’s abilities. There are also developmental tools that are considered to be the gold standard. A gold standard tool, is the best available diagnostic tool or benchmark in an ideal environment. The Alberta Infant Motor Scale, Bayley Scales of Infant and Toddler Development (gold standard), and the Movement Assessment Battery for Children (M-ABC) are some of the tools available to assess gross and fine motor, language and

cognitive development. Some of the tools are able to assess all of the above, while others focus specifically on one area of development.

2.9.2 Movement Assessment Battery for Children

The M-ABC is an assessment tool which is used to identify movement difficulties in children (Henderson, Sugden and Barnett, 2007). The authors of the examiners manual describe how skilled movement is an important basis for human life, and that without the basic motor acts that are part of complex processes which we use daily, one would struggle to do explore and master the physicality of the environment in which we live (Henderson, Sugden and Barnett, 2007).

Thus the M-ABC has been designed to assess three groups of functioning across three separate age bands; age band one: 3 to 6 years, age band two: 7 to 10 years and age band three: 11-16 years. There are eight tasks that are divided up into three groups;

aiming and catching: rolling a ball, bouncing and catching a ball or a beanbag, throwing the ball at a wall etc.

manual dexterity: threading beads, drawing a line in between a predesigned pathway, shifting pegs by rows etc.

balance: one leg balance, heel-to-toe walking, hopping in squares etc. (Venetsanou *et al.*, 2011).

The tasks increase in difficulty as the age ranges increase, for example, instead of posting six coins into a box at the first age band, the second age band will need to place pegs into a peg-board (Venetsanou *et al.*, 2011).

The activities or tasks have been chosen because they make up vital areas of development and functioning. Manual dexterity is assessed because children explore the environment with the use of their hands from a very young age, thus showing us the importance of having good hand control and function in order to have normal motor development (Henderson, Sugden and Barnett, 2007). Aiming and catching was chosen to be assessed because catching as well as aiming has been shown to be a skill we do often in daily tasks, without conscious thought. However, the ability to deliver or receive moving objects has been argued to be highly based on cultural,

gender and experiential factors. Thus the simplest tasks were chosen for this section of the MABC, and more practise opportunities given (Henderson, Sugden and Barnett, 2007) Lastly, balance was chosen for assessment because in order to move or perform tasks one first needs to be able to stabilise the body. If one cannot balance or acquire good postural control, the ability to perform both fine and gross motor tasks is severely affected (Henderson, Sugden and Barnett, 2007).

According to Henderson et al, (2007), the participant must be tested individually and each test takes between 20-40 minutes to administer dependant on the skills and age of the participant as well as the experience of the examiner (Henderson, Sugden and Barnett, 2007).

The tasks are then scored based on the manner of testing, for example timed tasks or tasks where the amount of successful tries are documented (Henderson, Sugden and Barnett, 2007). These raw scores are then linked with the age-appropriate standard score and percentiles. The age related percentiles range from ≤5th and ≤15th percentiles (Venetsanou *et al.*, 2011). If the participant scores below the fifth percentile they are definitely motor impaired, but if the participant scores between the sixth and 15th percentiles they are deemed as at risk of motor impairments and over the 15th percentile indicates typical development. The final score and percentile are used to indicate whether the child tested is definitely motor impaired, at risk of motor impairment or is developing within accepted norms (Henderson, Sugden and Barnett, 2007). These norms are of American children of different ethnic backgrounds in the 1980s (Venetsanou *et al.*, 2011). The percentiles are also linked to a “traffic light” colour system, thus the participant will fall into the red zone if they score on or below the 5th percentile, the yellow zone scoring between the 5th and 15th percentiles and the green zone if they fall above the 15th percentile.

In addition to the quantitative data collected, the M-ABC has a checklist which can be completed by parents or teachers and this gives a qualitative result. The checklist has three sections, section A – Movement in a static and/or predictable environment, section B- Movement in a dynamic and/or unpredictable environment and section C- Non-motor factors that might affect movement. This along with the description tick boxes in the M-ABC assessment allow for the collection of qualitative data

(Henderson, Sugden and Barnett, 2007). This allows us to describe how the child is performing tasks i.e. their posture, speed, concentration and control at the time of completing the task. This allows the examiner to assess non-motor aspects that may have influenced the child's abilities during their motor assessment (Henderson, Sugden and Barnett, 2007).

According to Smits-Engelsman et al., (2008), there is a good interrater reliability of the M-ABC, with the kappa coefficients ranging from 0.95-1.00 (Smits-Engelsman *et al.*, 2008). Henderson et al., (2007) states that there have been three studies that have assessed the test retest reliability of the M-ABC. A study published in 2001 by Croce, Horvat and McCarthy gave an ICC of 0.95, in 2003 Chow and Henderson gave an ICC of 0.77 for the test as a whole and lastly in 2007 Van Waelvelde et al, found a 0.88 ICC with a 95% confidence interval ranging from 0.79 to 0.93 (Henderson, Sugden and Barnett, 2007). Wagner et al., (2011), state that their study proved factorial validity of the M-ABC and thus its use in therapeutic practise is supported (Wagner *et al.*, 2011). Furthermore, Schulz et al., (2011) stated that the structural validity of the M-ABC was confirmed by their factor analyses that they performed in comparison over the three age groups (Schulz *et al.*, 2011).

There are currently no norms for South African children, however the M-ABC has been used successfully in multiple studies in South Africa, across various conditions (Corten and Morrow, 2020; van der Walt, Plastow and Unger, 2020).

The M-ABC has thus been shown in current literature to be valid, reliable and a good identifier of motor deficits in children aged three to 16 years of age. It covers three large groups of basic motor skills and allows some qualitative insight into how the children are completing the tasks. Development is the growth across all parts of the body and central nervous system and each child develops slightly differently within a set of normal or typical parameters. Continued assessments and screenings with well researched tools will allow for early identification and intervention of motor difficulties in children at risk of developmental delay.

2.9.3 Standing Broad Jump Test

The Standing Broad Jump (SBJ) test is a test of lower limb explosive muscle power which gives a good indication of general body muscle strength (Krishnan *et al.*, 2017). The SBJ test is an inexpensive, time saving, practical and reliable test that has been strongly associated with many other upper and lower limb strength tests (Hardy *et al.*, 2018). It has also shown to be participant and user friendly and not cause strain on the participant's body, thus providing a good overall idea of muscle strength in young children (Fernandez-Santos *et al.*, 2015; Hardy *et al.*, 2018).

The anatomical make up of a person's muscle fibres or if their muscle is affected by disease process with directly influence the amount of force the muscle fibres can generate. This will the directly influence the distance one is able to jump (Krishnan *et al.*, 2017). Hardy et al, (2018), found that there were differences in the distance jumped by children from different socioeconomic backgrounds. They found that children from low and middle-income socioeconomic backgrounds had a decreased jumping distance compared to those from a higher socioeconomic background (Hardy *et al.*, 2018). This could be due to multiple reasons, but when looking at protein and children with HIV, malnourishment could be a key factor here. Interestingly another factor that can play a role in the distance a child can jump is their daily physical activity. Children who are more physically active and participate regularly in exercise have stronger muscles and are generally able to jump a greater distance (Hardy *et al.*, 2018).

Krishnan et al, (2017) concluded in their study that the SBJ test is a valid field test which measures anaerobic power and that it can be used to assess lower limb strength as it is a valid indicator of this (Krishnan *et al.*, 2017). Fernandez-Santos et al, (2015) found that the standing broad jump test's validity was the most closely associated with the criterion measure 1RM leg extension test (which is the gold standard test, to measure muscle strength in children) (Fernandez-Santos *et al.*, 2015), thus making it a valid field test in children to measure lower limb strength (Fernandez-Santos *et al.*, 2015). The tests done by Fernandez-Santos et al, (2015) showed a high reproducibility for the SBJ, thus making it a reliable test.

The SBJ has been used in multiple countries around the world, including South Africa, in multiple studies (Monyeki *et al.*, 2005; Armstrong, Lambert and Lambert, 2011). The study by Armstrong et al, (2011), had a sample that consisted of children between the ages of 6-13 years, from at least five schools across South Africa, of different socioeconomic standing. The sample was representative of all ethnic groups in South Africa as well. Their results showed that the SBJT scores differed between genders, ethnicity, socioeconomic standing and with age (Armstrong, Lambert and Lambert, 2011).

2.9.4 Paediatric Quality of Life 4.0 Generic Core Scale

The Paediatric Quality of Life (Peds-QL™) 4.0 Generic Core Scale is the most widely used measure for child health related quality of life (Amin *et al.*, 2012). It has been found to be a valid measure in children with HIV as well as those whom are uninfected (Banerjee, Pensi and Banerjee, 2010).

The measure is composed of four subscales that assess health related quality of life across school (five questions), physical (eight questions), social (five questions) and emotional (five questions) domains (Varni *et al.*, 2003; Limbers *et al.*, 2011; Amin *et al.*, 2012). The questions were developed through consultation, literature reviews and interviews with parents, healthcare professionals and children (Varni *et al.*, 2003; Limbers *et al.*, 2011; Amin *et al.*, 2012). The scales are made up of self-report and proxy parent reports and it is designed for specific age groups (Varni *et al.*, 2003). Child self-report includes ages 5-7, 8-12 and 13-18, while the parent proxy report includes ages 2-4, 5-7, 8-12 and 13-18. The proxy parent report is assessing what the parent's perceptions are of their child's HRQOL. The items that are used in the Peds-QL™ 4.0 have been chosen in order to be universally identifiable with most common concerns in childhood (Varni *et al.*, 2003).

The Peds-QL™ has a question which asks how much of a problem a certain item has been over the past month for self-report the child can select one of five responses; 'never' (0), 'almost never' (1), 'sometimes' (2), 'often' (3) and 'almost always' (4) (Varni *et al.*, 2003; Banerjee, Pensi and Banerjee, 2010). The responses are converted to make a higher score reflect a better HRQOL (Varni *et al.*, 2003; Banerjee, Pensi and Banerjee, 2010). For younger children the scale is simplified to a three point scale that

is also attached to a face that displays a happy-sad face emotion (Limbers *et al.*, 2011). In this scale 0=not at all a problem, 1=sometimes a problem and 4= a lot of a problem. The entire assessment takes around five minutes to administer (Varni *et al.*, 2003; Limbers *et al.*, 2011).

Internal consistency reliability across all self-report and proxy parent report scales has been shown to exceed the minimum standard of 70 that is required (Varni *et al.*, 2003; Banerjee, Pensi and Banerjee, 2010). When the summary scores were assessed the internal consistency reliability was higher in the proxy parent report that for the child self-report but only by a small amount (Banerjee, Pensi and Banerjee, 2010).

The Peds-QL^{TM} was also found to be reliable as the intra-class correlation coefficient exhibited larger values for parent proxy report over the self-reports by the children (Banerjee, Pensi and Banerjee, 2010). In conclusion of their study Banerjee et al., 2010 reported adequate reliability and validity in HIV-infected children (Banerjee, Pensi and Banerjee, 2010).

2.10 Socioeconomic Status

Socioeconomic status in a country such as South Africa, is of importance when researching a topic such as HIV, as we have seen above that HIV affects the body across multiple systems in a variable way. In limited resource countries, such as South Africa, children often don't have access to nutritious food, which is required in order to grow a healthy and strong body and mind (Nkirote *et al.*, 2019). Many of the ways in which it affects the body can be aided or avoided with the correct supplementation, nutrition, intervention and treatment (Nkirote *et al.*, 2019). Therefore, access to these basic needs and services makes a huge impact on whether certain outcomes and or comorbidities can be avoided or not. This refers to anything from financial means to aid in attaining a nutritious diet, access to medication at the local health care facilities or access to knowledge and education on the disease processes.

2.11 Conclusion

Research shows that one of the most common developmental delays in infants and toddlers infected with HIV is gross motor delays. Research directs possible causes of gross motor delay to poor muscle strength, decreased physical activity, health related quality of life as well as opportunistic infections and poor nutrition. There are few studies that show the impact of this virulent virus on motor function in older children, who are now starting to enter the schooling world. This study aims to give some insight into this population, in order to educate decisions made in regards to the health and welfare of these children.

The next chapter will describe the methodology of the study in detail.

Chapter 3: Methodology

The chapter below will describe in detail the study's design, hypothesis, population involved in the sample used, and the steps taken to conduct the research.

3.1 Study Design

This study had a quantitative cross-sectional descriptive design whereby each child was assessed at a single time point. A Cross-sectional study design is a type of observational study design. Cross-sectional studies simultaneously measure the outcome and exposures in the study participants at the same time. A cross-sectional study allows for participants to be selected based on an inclusion and exclusion criteria. This type of study is useful for population-based surveys and assessing the prevalence of a disease, while being relatively inexpensive and conducted over a short period of time (Setia, 2016).

3.2 Hypothesis

Null hypothesis: the study will show that muscle strength, physical activity and motor function are unaffected in children between the ages of 5-10 that were perinatally infected with HIV.

Alternate hypothesis: the study will show that muscle strength, physical activity and motor function are decreased in children between the ages of 5-10 that were perinatally infected with HIV.

3.3 Location

This study was conducted at Tambo Memorial regional hospital (TMH). TMH is a 540 bed government hospital in Boksburg South Africa. TMH has a catchment area of approximately 1,2 million people. The community that is served by TMH is made up of low to middle income households. The hospital also has an antiretroviral clinic known as Emthonjeni. Emthonjeni is a clinic for all children from birth to adults, who are HIV positive. The clinic is part of a government hospital which is publically funded.

3.4 Study Population and Sample Selection

Participants for this study were drawn from the Emthonjeni antiretroviral clinic.

Inclusion criteria

Children were included in the study if they met the following criteria:

-Male or female children aged from 5-10 years of age

- Perinatally infected by HIV
- HIV positive status confirmed by PCR and child on ART
- Accompanied by a care giver or legal guardian
- Participants must be ambulatory

Exclusion criteria

Children were excluded from the study using the following criterion:

- If the participant had been declared not medically fit for assessment by the doctor at the clinic
- The medical team (doctors and nurses in the clinic) were informed of the nature of the study and the inclusion criteria, and were able to assist the researcher to screen eligible patients for participation.

3.5 Sample Size Calculation

Initially, sample size was calculated based on the population of 257 children between 5-10 years who attended the HIV clinic every 3 months in 2019. Raosoft (R) sample size calculator was used. A sample of 101 participants would have had a confidence level of 80% and a margin of error of 5%.

Due to the Covid-19 pandemic and subsequent lockdown, clinic services were drastically curtailed in 2020. Very few children attended the clinic if they were stable. Caregivers collected medication on their child's behalf but did not bring the children with them to the clinic. For this reason, the sample size had to be reconsidered. The Central Limit Theorem was used. The Central Limit Theorem (CLT) states "given a sufficiently large sample size, the sampling distribution of the mean for a variable will approximate a normal distribution regardless of that variable's distribution in the population" (Frost, 2018). Thus the samples distribution across the population, will guide how large the sample size would be, and the CLT suggests a sample size of 30 participants is adequate.

3.6 Data Analysis

The researcher that assessed, captured the data in an Excel spreadsheet and then imported the Excel spreadsheet into SPSS for statistical analysis. Appropriate measures of association were used to determine association between muscle strength and motor function and clinical and demographic factors. Descriptive data was used to summarise the clinical and demographic data. Means and standard deviations or frequencies and percentages were used as appropriate. Associations and correlations were done between the factors assessed. P value= ≤0.05

3.7 Variables (dependent, independent, confounding)

The variables considered in this study are presented in table 3.1 below:

Table 3.1 Variables relating to this study

Dependent variables	Independent variables	Potential confounding variables
• Muscle strength • Motor function • Quality of life	• Age for grade • Gender • Anthropometry • Clinical factors (CD4, VL, age at ART initiation)	• Noisy environment • Lack of concentration • Cognitive or learning disabilities • Poverty • Malnutrition

3.8 Study procedure

3.8.1 Recruitment of Participants

The researcher and a nurse recruited participants at the Emthonjeni HIV clinic. Convenience sampling was used in this study. Consecutive children and their caregivers who come into the Emthonjeni clinic and met the inclusion criteria were invited to participate in the study.

The researcher and a nurse (who was aware of the study criteria and protocol) approached caregivers, who brought their children for their follow up appointment at the clinic, in the waiting area or as they registered at the reception. All participants, who fit the inclusion criteria, were given an information sheet, a consent form as well as an assent form (Appendix 1, 2 and 3 respectively). They were given 30 minutes to

read the documentation and ask any questions that they had. An interpreter was available if needed, to make sure the participant and the caregiver were in full understanding of what the study entailed. If participants and their caregivers agreed and signed both the consent form and the assent form, the assessments took place on the same day.

3.8.2 Procedure

Once the participants had been seen by the doctor, they came to a physiotherapy station, that was set up in a consultation rooms. This room was in the clinic and it was to make sure participants were comfortable and in a private environment. A participant code was assigned to all documentation for the specific participant.

First a general socioeconomic and demographic questionnaire (Appendix 4) was administered by the researcher to the caregiver as well as the participant. After this the researcher administered the Peds-QL™ (Appendix 5) to the participant, and help with translation was attained if needed. The Peds-QL™ has a template with three faces showing three different emotions for the ages 5-7 years. The participant pointed to the face that best describes their answer to a specific question, which was asked by the researcher.

Anthropometric data was collected in the form of height and weight so that BMI can be calculated at a later stage. Height and weight was taken with a Seko stadiometer electronic scale.

Once this had been completed the Standing broad jump (SBJ) test (Appendix 6) was conducted. The SBJ test was carried out on a hard surface (the consultation rooms floor is screed) and a starting line was marked off on the floor with tape. The participant was barefoot. The participant was then asked to stand with their toes behind the starting line, keeping their feet slightly apart (Hardy *et al.*, 2018). They were then told to bend their knees – the amount of flexion was the participant's choice- and then place their arms behind them (Krishnan *et al.*, 2017). They were then asked to jump as far as they can using both feet at take-off and landing (Hardy *et al.*, 2018) and swinging their arms forward as they jumped (Krishnan *et al.*, 2017). Children were allowed two attempts. The distance from the start line to the back of their heel that was closest to the line was measured in centimetres (Hardy *et al.*, 2018) using a tape

measure. Due to some language barriers experienced, a test attempt with a demonstration, was given before their two final recorded attempts, to make sure that the participant understood what they were supposed to do. Results were captured on the data capture form.

Lastly the participant participated in the Movement ABC test (Appendix 7), which was done according to their age group. This encompassed eight tests under three subsections; balance, ball skills and manual dexterity. The test was administered according to the guidelines provided and results were recorded on the test form.

Participants were thanked for their participation and refreshments were provided on completion of the assessments. Participants were informed that once the study has concluded all the anonymised results will be made available to the Emthonjeni clinic.

3.9 Ethical Considerations

Ethics was applied for from the University of Witwatersrand Human Research Ethics (Medical) Committee. Unconditional approval was obtained, and the ethics clearance certificate number is M190656 (Appendix 8). The below ethical considerations were used throughout the study:

Patient population:

The population group that had been identified to take part in the study, was noted to be a vulnerable population, and all ethical guidelines according to both the HPCSA and The declaration of Helsinki was strictly adhered to. Approval for the study was obtained by the University of Witwatersrand Human Research Ethics (Medical) Committee (Appendix 8), the Gauteng Department of Health (Appendix 9) and Tambo Memorial Hospital.

The permission document also included permission to access information in patient files. Once permission was received, the physiotherapy HOD, the head nurses and the doctors in the Emthonjeni clinic were informed about the ethical clearance as well as exactly what the study entailed.

If the participants decided to participate in the study written consent from the legal guardian as well as assent from the children was obtained (Appendix 2 and 3 respectively). The information sheets that the participants were provided with prior to consenting had detailed information about the study, stating all possible risks and/or

benefits (Appendix 1). Participants were informed that they had the right to withdraw from the study at any time without having to provide explanation or reason. All participants were referred to any necessary allied health or medical practitioner if the results showed a need for it.

Assessing the participants on the same day of their doctors follow up, meant that they would have an overall longer stay at the clinic that day. However, asking the participants to return to the clinic on a separate day, to solely take part in the study, would incur additional transport costs, as well as more time off school. Thus, assessing them on the day of presentation to the clinic was deemed overall better for the participants.

Data collection:

Participants were informed that all personal and medical information was to be kept confidential at all times. All data entries were made using a study participant code that had been assigned to each participant. All data was stored under a computer protective password that only the researcher and supervisor knew and had access to. Any data collected during the study was not divulged to any other research studies without the informed consent from all participants of the study. Now, with the conclusion of the study, all data will be kept safe for two years following publication, or six years following the study if no publication occurs, until destroyed as according to the HPCSA Research Guidelines.

The results for this study will be presented in chapter four.

Chapter 4: Results

The following chapter describes the results obtained from the study.

Thirty participants took part in the study and their results for the respective assessments are displayed below.

4.1 Demographic and Socioeconomic information

The demographic and anthropometric data for the participants is presented in table 4.1 below.

Table 4.1 Demographic and Anthropometric results of participants

	N	Minimum	Maximum	Mean	Std. Deviation
Age (months)	30	60.00	120.60	93.15	19.90
Height (cm)	30	100.00	132.20	119.59	7.49
HAZ (cm)	30	-2.61	1.68	0.00	1.00
Weight (kg)	30	14.50	34.0	22.74	4.33
WAZ (kg)	30	-1.90	2.60	0.00	1.00
BMI	30	11.98	19.45	15.75	1.58
BMIZ	30	-2.39	2.35	0.00	1.00
Valid N (listwise)	30				

Key:
HAZ: Height-for-age Z-Score
WAZ: Weight-for-age Z-Score
BMI: Body Mass Index
BMIZ: Body Mass Index Z-Score

Table 4.1 shows the ages, height and height-for-age z-scores (HAZ), weight and weight for age z-scores and the BMI of the participants involved in the study. The mean age was 7.73 years, with age ranging from five to 10 years.

According to the WHO, weight-for-age is used to assess whether a child is underweight or severely underweight. Weight is relative to the child's age on that day, and thus is not used to classify if the child is overweight or obese. One also needs to note, that a child may appear to be underweight, but it may be due to their height/stunting (World Health Organization, 2008).

Length-for-age determines the child's height at that specific age, on that specific day. This helps one to determine if the child is stunted or short due to lack of adequate nutrition over a long period of time, or due to chronic/repeated illness. Tallness can also be identified, but this is usually not an issue, unless excessive (World Health Organization, 2008).

BMI-for-age is the indicator that is useful in determining if a child is overweight or obese (World Health Organization, 2008).

Below Figure 4.2 shows a summary for interpretation of growth indicators by WHO.

Z-score	Growth indicators			
	Length/height-for-age	Weight-for-age	Weight-for-length/height	BMI-for-age
Above 3	*See note 1*	*See note 2*	*Obese*	*Obese*
Above 2			*Overweight*	*Overweight*
Above 1			*Possible risk of overweight (See note 3)*	*Possible risk of overweight (See note 3)*
0 (median)				
Below −1				
Below −2	*Stunted (See note 4)*	*Underweight*	*Wasted*	*Wasted*
Below −3	*Severely stunted (See note 4)*	*Severely underweight (See note 5)*	*Severely wasted*	*Severely wasted*

Notes:

1. *A child in this range is very tall. Tallness is rarely a problem, unless it is so excessive that it may indicate an endocrine disorder such as a growth-hormone-producing tumor. Refer a child in this range for assessment if you suspect an endocrine disorder (e.g. if parents of normal height have a child who is excessively tall for his or her age).*
2. *A child whose weight-for-age falls in this range may have a growth problem, but this is better assessed from weight-for-length/height or BMI-for-age.*
3. *A plotted point above 1 shows possible risk. A trend towards the 2 z-score line shows definite risk.*
4. *It is possible for a stunted or severely stunted child to become overweight.*
5. *This is referred to as very low weight in IMCI training modules. (Integrated Management of Childhood Illness, In-service training. WHO, Geneva, 1997).*

Figure 4.2 WHO summary for interpretation of growth indicators (World Health Organization (2008) *Training Course on Child Growth Assessment WHO Child Growth Standards*, *World Health Organization*. Geneva: WHO)

Figure 4.2 indicates for length-for-age (height), that children whose z-scores, fall below -2 are stunted and below -3 are severely stunted. The category for weight-for-age, children who's z-scores fall below -2 are underweight, and below -3 are severely underweight, and lastly, BMI-for-age, children who's z-scores fall at +3 are obese, +2 overweight, +1 are at risk of being overweight and conversely if they fall below -2 wasted, and below -3 are severely wasted (World Health Organization, 2008).

The mean height and weight amongst the participants was 119cm and 22kg respectively. The mean BMI was 15.75kg/m^2 ranging from 11.98kg/m^2 to 19.45kg/m^2. The mean HAZ was 0.00 which means on average the children who participated in the study, had a normal height for their ages. The mean WAZ was 0.00, thus indicating that the weight for age on average was normal for the participants in this study. Lastly, the BMIZ mean was also 0.00Kg/m^2, indicating, the participants on average had a normal BMI.

The minimum and maximum WAZ scores, indicate that none of the participants were underweight or overweight as all scores fell between -2 and +2 standard deviations of the mean. The HAZ scores, once again show that none of the participants were too tall, however, it did indicate that there were participants that were stunted in their growth having scores of more than two standard deviations below the mean.

According to the BMIZ, there was one participant that was found to be wasted (falling below two standard deviations from the mean), while the majority fell into the normal zone. There were two participants that were at risk of being overweight, falling above one standard deviation from the mean and one that was overweight, falling above two standard deviations from the mean. The HAZ showed that two participants were stunted, and the rest fell within the normal range for height.

There were more males than females in the study sample. Thirteen (43.3%) females participated in the study and 17 (56.7%) males participated in the study.

Table 4.3 details the viral loads and the CD4 counts of all the participants that took place in the study. It shows the minimum and maximum values, as well as the mean and standard deviations.

Table 4.3 Clinical information

	N	Minimum	Maximum	Mean	Std. Deviation
CD4 count (cells/mm3)	22	286	2839	1064.05	589.826
Viral Load (copies/mililiter)	30	0	72900	5354.23	15506.14
Valid N (listwise)	30				

Some CD4 counts were not logged on the lab track systems, and other viral loads were lower than detectable (36.6%). The highest Viral load was 72900 copies/mililiter which is very elevated, and indicative of virulent disease process, while the lowest CD4 count was 286 cells/mm3.

All participants in the sample were all currently on ART regimens. The most common medications being taken are ABC, 3TC and Efavirenz (EFV) with 36.7% of the sample receiving this regimen. The next most common combination of medications is Zidovudine (AZT), 3TC and Alluvia at 16.7% of the sample on this regimen. The remainder of the sample take various other medications including Dolugravir or Dumiva.

Out of the 30 participants, 22 had history of prior admission to hospital. There was a mean of 1.45 admissions with a standard deviation of 0.963. The most prevalent cause of admission was due to ARV initiation side effects, followed by anaemia, Tuberculosis and unspecified infections. This is tabulated below in Table 4.4.

Table 4.4 Cause of hospital admission

		Frequency	Percent
Valid			
	Anaemia	2	9.1
	ARV initiation side effects	9	40.9
	GIT symptoms	1	4.5
	EFV toxicity	1	4.5
	Cardiac	1	4.5
	Infection (Unspecified)	2	9.1
	Malaria	1	4.5
	Non-compliance to ARV's	1	4.5
	Unknown	1	4.5
	Seizures	1	4.5
	Tuberculosis	2	9.1
	Total	22	100.0

None of the participants in the sample had any other coexisting co-morbidities or required long term medication for any other conditions.

The table below shows that the majority (80%) of the participants and their caregivers relied on public transport. This could be an inference of the socioeconomic status of the families attending the clinic. **Table 4.5 Mode of transport**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Both	1	3.3	3.3	3.3
	Private	5	16.7	16.7	20.0
	Public	24	80.0	80.0	100.0
	Total	30	100.0	100.0	

Most children were cared for by their mothers, while notably, two grandfathers were the primary caregiver for two participants. Fathers who accompanied their children to the clinic appointments, did not identify themselves as the main caregivers of their children, but rather just the caregiver available to accompany their child to the appointment on that day. The table below details whom the primary caregivers were.

Table 4.6 Primary caregiver

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Aunt	3	10.0	10.0	10.0
	Grandfather	2	6.7	6.7	16.7
	Grandmother	2	6.7	6.7	23.3
	Mother	23	76.7	76.7	100.0
	Total	30	100.0	100.0	

The age of the primary caregivers is presented in table 4.7 below.

Table 4.7 Primary caregiver age

	N	Minimum	Maximum	Mean	Std. Deviation
Primary care giver age	29	21	69	40.59	11.648
Valid N (listwise)	29				

The mean caregiver age was 40 years, with the maximum being 69 years old and the minimum as young as 21 years old. One caregiver did not report on their age.

Figure 4.8 below shows the primary caregiver's highest level of education.

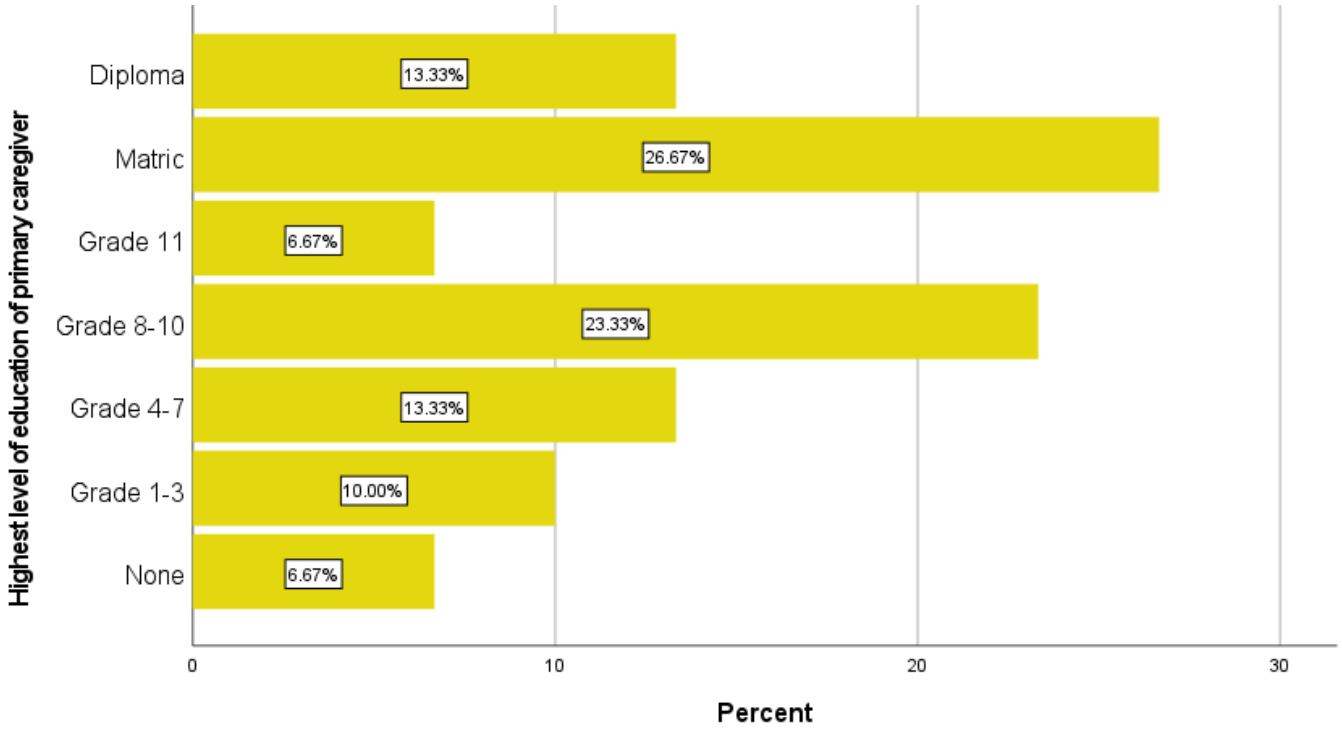


Figure 4.8 Level of education of caregiver

A small number of caregivers at 13.33% have a diploma, while only 26.67% of the caregivers have a matric certificate. Almost half (46.66%) of caregivers range from a Grade 1-10 schooling level, while 6.67% have no level of education at all. It is important to note that 60% of the caregivers had not completed their schooling, and that none of the caregivers had a university level of education.

The table below, 4.9, shows the different sources of income of the primary caregivers.

Table 4.9 Sources of income

	N	%
Employed	11	36.7%
Pensioner	2	6.7%
Unemployed	17	56.7%

Out of the 11 people employed, nine of them worked as domestic workers. Notably 56.7% of the participants' caregivers were unemployed, however 73.3% of the caregivers received financial aid in the form of a government grant. Out of the caregivers receiving the Government grant, 30% of the caregivers did not know which type of grant they were receiving, while 70% of those receiving the grant, received the child support grant.

4.2 Results for Motor Function

The table below depicts the results for the M-ABC test. The table details the component and standard scores as well as the percentile for each component of the M-ABC.

Table 4.10 Movement ABC Results

N=30	Minimum	Maximum	Mean	Std. Deviation	Skewness		Kurtosis	
					Statistic	Std. Error	Statistic	Std. Error
Manual Dexterity								
Manual Dexterity _Component score	3	29	17.80	7.49	-0.21	0.43	-1.13	0.83
Manual Dexterity Standard score	1	10	5.60	2.65	0.01	0.43	-1.20	0.83
Manual Dexterity Percentile	0.1	50.0	13.85	15.33	1.12	0.43	0.24	0.83
Aiming and Catching								
Aiming and Catching Component score	8	23	16.67	4.45	-0.62	0.43	-0.98	0.83
Aiming and Catching Standard score	2	12	8.30	2.84	-0.81	0.43	-0.53	0.83
Aiming and Catching Percentile	0.5	75.0	35.98	24.05	-0.20	0.43	-1.22	0.83
Balance								
Balance Component score	8	37	26.30	9.07	-0.64	0.43	-0.76	0.83
Balance Standard score	1	15	8.57	3.82	-0.15	0.43	-0.67	0.83
Balance Percentile	0.1	95.0	39.40	32.75	0.33	0.43	-1.34	0.83
Total Test Score								
Total Test Score	30	88	60.43	16.51	-0.15	0.43	-1.07	0.83
Total Standard	2	12	6.50	3.03	0.12	0.43	-1.05	0.83
Total Percentile	0.5	75.0	21.18	22.84	1.03	0.43	0.02	0.83
Valid N (list wise)								

The results of the M-ABC show that the Aiming and Catching and Balance components had better performance by participants than in the Manual Dexterity component. The Manual Dexterity component had the worst percentile score on average, of 13.85. This places the mean total of participants in the Amber zone, thus at high risk of delay, in the area of development for manual dexterity. The mean total score of the M-ABC was 60.43, which placed participants in the 21.18 percentile. This places participants on average in the Green zone.

Figure 4.11 shows the 'traffic light' system, that is used in classification of the final M-ABC scores.

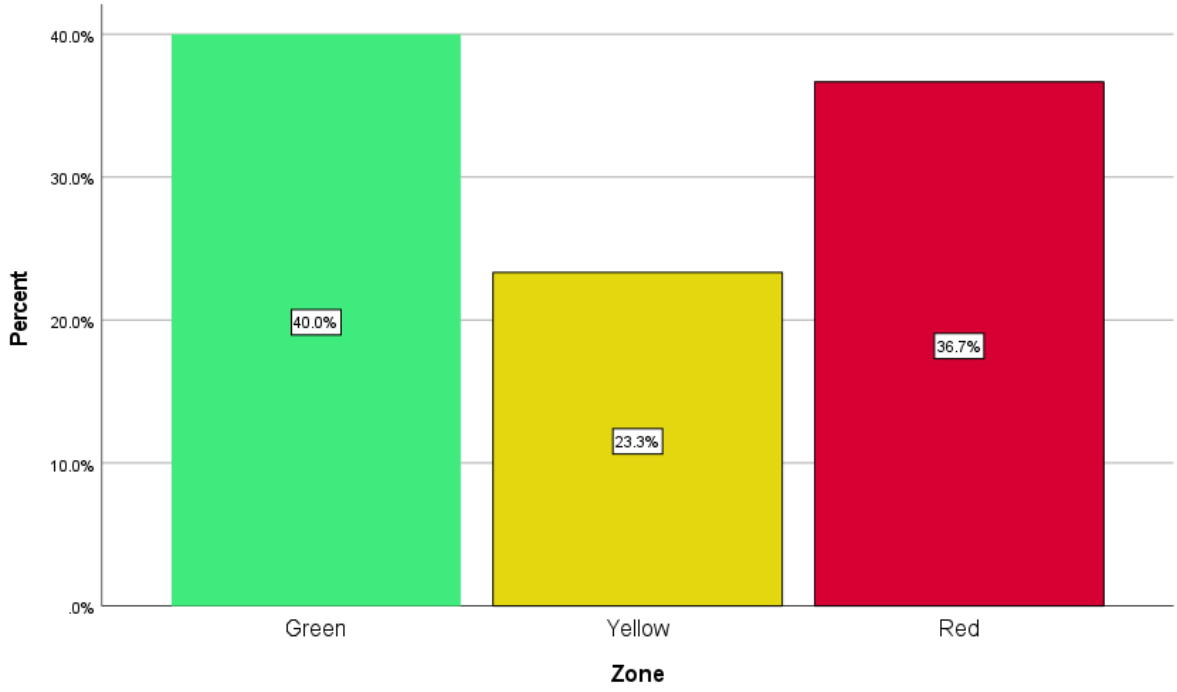


Figure 4.11 Zones and percentages of the M-ABC results

Figure 4.11 shows that 40% of the sample population were in the Green zone, indicating they had good motor function with no delay. Almost a quarter (23.3%) of the sample were placed in the Amber zone, indicating there was a high risk of motor delay and lastly, 36.7% of the sample fell into the Red zone, which indicates that they have definitely motor delay.

The below table shows each component of the M-ABC, and the number of participants who scored, in the green, amber or red zones for each component.

Table 4.12 Individual components of the M-ABC scores classified into zones (traffic light system)

	Green n(%)	Amber n(%)	Red n(%)
Manual dexterity	13 (43.33)	3 (10)	14 (46.67)
Aiming and Catching	22 (73.33)	1 (3.33)	7 (23.33)
Balance	20 (66.67)	3 (10)	7 (23.33)
n=30			

By component, it is observed that Manual Dexterity had the overall worst scores, with 46.67% of participants falling into the red zone, while Aiming and Catching had the overall best scores, with 73.33% of participants falling onto the green zone. It is of note, that participants either did well (Green zone), or poorly (Red zone). Very few participants fell into the Amber zone, especially in the Aiming and Catching component of the M-ABC.

4.3 Results of the Standing Broad Jump Test

The results of the Standing Broad Jump Test are in table 4.13 below. Children were given one practice jump and then two further jumps with the maximum distance jumped recorded.

Table 4.13 Standing Broad Jump Test scores

	Minimum	Maximum	Mean	Std. Deviation	Skewness		Kurtosis	
					Statistic	Std. Error	Statistic	Std. Error
SBJT (cm)	63	145	99.00	24.62	-0.18	0.43	-1.23	0.83

All these variables are normally distributed; the main variable is SBJT which is the maximum of the 2 tests. It has slight negative kurtosis (-1.234). The standing broad jump mean is 99cm with a standard deviation of 24.62. The minimum score is 63cm and maximum score is 145cm. The mean length jumped by male participants was 107,64cm, while for female participants it was 87,70cm. This indicates that females overall have weaker muscle strength than males.

The SBJT had a very strong internal consistency. A Cronbach Alpha coefficient of 0.886 was calculated, indicating very good reliability.

4.4 Results of the Peds-QL™

Table 4.14 demonstrated the results for the Peds-QL™ across all subsections as well as the total score.

Table 4.14 Peds-QL™ **results**

	Minimum	Maximum	Mean	Std. Deviation	Skewness		Kurtosis	
					Statistic	Std. Error	Statistic	Std. Error
Physical functioning	62.50	100.00	87.50	11.10	-0.72	0.43	-0.46	0.83
Emotional functioning	30	100	77.33	21.65	-0.658	0.427	-0.796	0.833
Social functioning	30	100	80.67	17.41	-1.16	0.427	1.20	0.83
School Functioning	20	100	75.17	18.777	-.911	.427	1.03	0.833
Peds-QL™ Total mean score	60.89	97.82	81.34	10.22	-.239	0.43	-0.82	0.83

The Peds-QL™ demonstrated an almost normal distribution. The subscale for social functioning was the only subscale that was slightly negatively skewed, however on all other subscales it was normally distributed. Both Social Functioning and School Functioning are slightly platykurtic indicating a more flattened distribution (i.e. there is possibly an outlier or extreme score in the data set).

The internal consistency of the Peds-QL™ is moderate with a Cronbach alpha value of 0.658. This could be due to the diversity of the tests subscales it assesses across the health related quality of life topic.

Correlations done between the Peds-QL™ and its subscales, one would expect strong correlations. The strongest correlations occur between the Peds-QL™ total scores and each of the individual subscales. Specifically, Physical Functioning and the total quality of life score have a significant moderate to strong correlation of 0.56, while School Functioning had a slightly weaker but still significant correlation to the total score of 0.45. Social Functioning had a positive and strong significant correlation of 0.66 with total quality of life and finally, emotional functioning had the strongest significant correlation with quality of life with a Pearson's r of 0.77 (all at α=.05). Fifty-nine percent of the variance of quality of life is explained by Emotional Functioning. Only 20% of the variance of quality of life is explained by School Functioning.

4.5 Associations between Variables

Table 4.15 shows correlations between CD4 count, viral load, MABC standard scores, SBJT and total Peds-QL™ scores.

Table 4.15 Correlations between CD4 count, Viral load and all outcome measures

		CD4 count (cells/mm3)	Viral Load (copies/millilitre)	Manual Dexterity	Aiming and Catching	Balance	Total MABC	SBJT	PedsqQL Total
CD4 count (cells/mm3)	Pearson Correlation	--							
	N	22							
Viral Load (copies/mililiter)	Pearson Correlation	-0.05	--						
	Sig. (2-tailed)	0.84							
	N	22	30						
Manual Dexterity	Pearson Correlation	-0.11	-0.00	--					
	Sig. (2-tailed)	0.63	0.99						
	N	22	30	30					
Aiming and Catching_	Pearson Correlation	-0.21	0.13	0.47**	--				
	Sig. (2-tailed)	0.344	0.50	0.01					
	N	22	30	30	30				
Balance	Pearson Correlation	-0.11	-0.36	0.44*	0.26	--			

	Sig. (2-tailed)	0.64	0.05	0.02	0171				
	N	22	30	30	30	30			
Total MABC	Pearson Correlation	-0.106	-0.153	0.82**	0.57**	0.81**	--		
	Sig. (2-tailed)	0.6438	0.42	0.00	0.00	0.00			
	N	22	30	30	30	30	30		
SBJT	Pearson Correlation	-0.30	-0.16	0.53**	0.34	0.46*	0.52**	--	
	Sig. (2-tailed)	0.18	0.39	0.00	0.07	0.01	0.00		
	N	22	30	30	30	30	30	30	
Peds-QL™ Total mean score	Pearson Correlation	-0.11	-0.15	-0.23	-0.30	0.33	0.01	-0.03	--
	Sig. (2-tailed)	0.62	0.44	0.23	0.12	0.07	0.98	0.86	
	N	22	30	30	30	30	30	30	30

**. Correlation is significant at the 0.01 level (2-tailed); *. Correlation is significant at the 0.05 level (2-tailed).

There is a negative and non-significant relationship with CD4 count in relation to the viral load and the components of the M-ABC and the Peds-QL^{TM}. These relationships are not significant as there are many variables in relation to the sample size. This may not be an accurate representation.

Viral load also has a negative and non-significant or very weak relationship with the M-ABC, SBJT and the Peds-QL^{TM}. Thus the higher the viral load, the lower the scores on the respective outcome measures.

SBJT is positively and significantly related to Manual Dexterity of the M-ABC (r (30) = 0.53 $p<.003$), as well as balance (r (30) = 0.45; $p<0.01$), and total M-ABC (r (30) = 0.52; $p< 0.003$). This indicates that the higher the participants standing broad jump test score, the higher their MABC scores as well. Furthermore, the proportion of variance explained by both manual dexterity and SBJT is $r^2 = 0.28$, meaning, the amount of variation that can be explained by both manual dexterity and SBJT is 28%. This was found to be similar for the other components such as balance $r^2 = 0.20$, and total M-ABC scores $r^2 = 0.27$). Overall the SBJT had a positively significant relationship to the M-ABC and all its components.

Below, Table 4.16 shows correlations between BMI and the outcome measures used in the study, the M-ABC, Peds-QL™ and the SBJT.

Table 4.16 Correlation between BMI, MABC, Standing broad jump and Peds-QL™

		BMI	Manual Dexterity	Aiming and Catching	Balance	Total Peds-QL™ _	SBJT
BMI	Pearson Correlation	--					
Manual Dexterity	Pearson Correlation	0.24	--				
	Sig. (2-tailed)	0.21					
Aiming and Catching	Pearson Correlation	0.20	0.44*	--			
	Sig. (2-tailed)	0.29	0.02				
Balance	Pearson Correlation	0.57**	0.43*	0.30	--		
	Sig. (2-tailed)	0.00	0.02	0.11			
Total Peds-QL™	Pearson Correlation	0.43*	0.78**	0.57**	0.81**	--	
	Sig. (2-tailed)	0.02	0.00	0.00	0.00		
SBJT	Pearson Correlation	0.48**	0.53**	0.35	0.41*	0.52**	--
	Sig. (2-tailed)	0.01	0.00	0.06	0.02	0.00	

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

N=30

Table 4.16 shows the correlations between BMI and the M-ABC (each subscale and the total measured in percentiles), Standing broad jump test and the Peds-QL™ (subscales and the total). The correlations show that BMI and the Balance component

of the M-ABC have a strong and significant relationship (r=0.57; p< 0.00). This means that BMI, accounts for 33% of the variance seen in the balance component. The total score for the M-ABC is also significantly and positively correlated with BMI (r= 0.43; p< 0.02), while Aiming and Catching and Manual Dexterity weren't significantly associated to BMI. Thus the higher or lower a participants BMI was, had no effect on their ability to perform well in the categories of Aiming and Catching or Manual Dexterity.

The SBJT was significantly and moderately related to BMI (r=0.48; p< 0.01). Once again, as previously stated in table 4.13, the M-ABC has a strong and positive relationship with the SBJT.

4.6 Conclusion

The results of the study demonstrate that children aged 5-10 years, who have been perinatally infected with HIV, have poor motor function, especially when looking at the domain of manual dexterity. Their HRQoL was overall deemed good, but with poor emotional and school functioning scores to be noted. According to the results of the SBJT, females have weaker muscle strength than males, and jumped shorter distances overall. The socioeconomic data infers that the sample was mostly in a lower socioeconomic bracket, and that the primary caregivers generally had very low levels of education and were reliant on the government child support grant.

The results of this chapter, will be discussed in detail in Chapter Five.

Chapter 5: Discussion

The results presented in chapter four will be discussed below.

The results of the study demonstrate that children aged 5-10 years, who have been perinatally infected with HIV, have poor motor function, poor emotional and school functioning health related quality of life, and that females have weaker muscle strength than males. The socioeconomic data infers that the sample was mostly in a lower socioeconomic bracket, and that the primary caregivers generally had very low levels of education.

5.1 Demographics and Socioeconomic Data

5.1.1 Anthropometric Data

All anthropometric data, height and weight, was compared to the WHO, weight for age and height for age charts. The WHO uses data from the WHO Multicentre Growth Reference Study which was done from 1997-2003, in order to develop growth scale norms for children. Children from different ethnic and cultural backgrounds were used in the data collection (Garza and de Onis, 2004). Notably the height, weight and BMI charts for boys and girls are developed separately. The weight and height and BMI z-scores for the participants in the study, on average were within the normal range. Almost all the children fell into normal growth for age, except two who were stunted according to their HAZ and one who was overweight according to BMIZ and one who was wasted according to the BMIZ.

In general children living with HIV have been shown to be at risk of poor growth outcomes (Brassel and Potterton, 2019). A recent study by Benjamin-Damons, N, (2019), found that on average, all children fell below the normal z-score for both height and weight, thus showing that the participants were both shorter and weighed less that what they should have for age (Benjamin-Damons, 2019). The children in that study were between the ages of four and ten. Similarly another study done in Johannesburg, South Africa, on children perinatally infected with HIV between the ages of 5-11, showed that 12% of the participants were underweight and 16% of the participants were stunted for their age (Potterton *et al.*, 2021). This is notably different from the participants in the current study where very few of the participants were malnourished

or stunted in any way. This could be due to many factors, such as nourishment, age of HIV diagnosis and the age at commencement of ART.

All three of the abovementioned studies were conducted at urban paediatric HIV clinics in Gauteng. Further investigation would be needed to compare socioeconomic factors and nutritional status of children from these areas.

Another reason for the notably different results could be the rising inactivity of children with HIV. A study done on adolescents with HIV in Brazil, showed that there is a large number of adolescents, who live sedentary lifestyles, and are generally not involved in physical activity (Tanaka *et al.*, 2015). This was more prevalent among girls than boys. This places them at high risk of being overweight, or becoming obese (Tanaka *et al.*, 2015). Obesity and sedentary lifestyles are fast becoming a huge problem not only in developed, but developing countries as well (Tanaka *et al.*, 2015; Wong *et al.*, 2016). This is echoed by a study done in South Africa, on children with HIV (Wong *et al.*, 2016). The children in the current study, may be similar to the children in these previous studies, and that could explain why the results are so different from previous studies such as the one done by Benjamin-Damons, (2019).

The mean age of children who participated in the current study was seven years old, with the most frequent age being eight years old. Notably, 74% of the children that participated in the study were between the ages of 7-10, with only 26% of the sample making up the ages 5-6 years. This could be due to the convenience sampling methods used, or it could be inferred that due to the introduction of PMTCT in 2010, and the vast reduction in perinatal transmissions in South Africa, there are fewer young children with HIV born five years ago, than there are born seven to ten years ago.

5.1.2 Clinical Data

All children who attend the clinic get their bloods drawn monthly, until they have been on their ART regimen for six months with no irregularities. Once the treating doctor is satisfied with the child's viral load and CD4 count, they only need to be followed up every third month. The participants in the study on average had a viral load of 8920 copies/millilitre and CD4 count of 1064 cells/mm3. The absolute CD4 counts, or the total amount of CD4 cells per cubic millimetre of blood, is used to determine whether a child has immune suppression and its extent. The normal CD4 counts for children

between the age of 1-5 is 1000 cells/mm3 and between the ages of 6-12 is 500 cells/mm3 (Berhan, 2011). Eight participants CD4 counts were not logged on the lab track systems, and thus could not be recorded, but they were assumed to be of normal level in accordance to their viral load measurements. The lowest CD4 count was 286 cells/mm3, in a six-year-old child, thus indicating moderate immunosuppression. Out of the sample of 22 participants who had CD4 count data, five of them were moderately suppressed, and none were severely immunosuppressed.

Viral load was lower than detectable in 11 (36.6%) of the participants and was determined as a low viral load (<10 000 copies) in 17 participants. The remaining two (6.6%) participants had high viral loads. The highest viral load was 72900 copies/millilitre which is very elevated, and indicative of virulent disease process. This participant possibly had poor adherence or a suboptimal response – virological failure- to the current ART, or has just started on a new regimen.

A study by Potterton et al, (2021), showed out of 175 participants, 133 (76%) had a viral load that was lower than detectable, while only 9 (5.1%) had a viral load higher than 1000 copies/ml. Similarly, the study conducted by Benjamin-Damons, (2019), showed the mean viral load for the participants in that study was 1.709 log 10/ml, which is equal to 50 copies/ml while the participants in this study had a mean viral load of at 8920 copies/ml.

Thus in comparison, the participants involved in this study, had viral loads much higher, than the participants involved in both the Potterton et al, (2021), and Benjamin-Damons, (2019), studies. This may be due to a multitude of factors, such as adherence, type of ART regimen, age at ART initiation and viral load on starting ART.

Both of these studies showed that better virological control is possible for children (Benjamin-Damons, 2019; Potterton *et al.*, 2021), and that muscle strength in children who have well controlled disease, can be comparable to peers, who do not have HIV (Potterton *et al.*, 2021).

5.1.3 Hospital Admissions

It is well known that children and adults with HIV are susceptible to opportunistic infections, ART toxicity and complications caused by both the virus and its treatment

(Mulenga *et al.*, 2015; Melhuish and Lewthwaite, 2018). Out of the sample, 28 children had previously been admitted to hospital, with one child never having been admitted and one caregiver unaware of any prior admissions. The reasons for admission, by parent report were commonly due to ART side effects, or at the time of ART initiation. This was experienced by 40.9% of the sample. Anaemia is a long term side effect of ART (Mulenga *et al.*, 2015) and it occurred in two of the participants in this study. AZT is commonly known to cause anaemia and neutropenia as a side effect, and thus close monitoring and full blood counts are required at the three and six month check-ups post initiation of AZT (South African National Department of Health, 2019). Brassel and Potterton, (2019), looked at what opportunistic diseases or infections the participants in their study contracted, 74.5% of their participants had one or more infection, with skin infections (53.5%) and TB (37%) being the two most common (Brassell and Potterton, 2019). In the current study, 9.1% of the participants contracted TB, which thus highlights the susceptibility of children with HIV to TB.

It is known that children with HIV have developmental delays, due to a large number of reasons. It is also known that children with HIV are prone to opportunistic infections. When children are hospitalized multiple times or for long periods of times, there is a lack of learning and exploring opportunities (Walker *et al.*, 2011). This could be due to confinement to a small room, or in more recent situations, no visitation hours due to the Covid-19 pandemic. A lack of caregiver interaction and early opportunities for learning contribute further to developmental challenges, and even loss of developmental potential walker (Walker *et al.*, 2011). Thus it is important to prevent opportunistic infections and unnecessary admissions to hospital, for these children.

5.1.4 Primary Caregiver

Most of the participants (76.7%) in the study were cared for by their mother, as their primary caregiver. The mean age of the caregiver was 40 years old, with the range being large, from a minimum age of 21 to a maximum age of 69 years. Significantly, there were no fathers who were identified as primary caregivers, and the only male figureheads to fill this role were two grandfathers.

A study done in Nairobi, Kenya, revealed similar results, with female caregivers accounting for 254 (97.7%) of their participants, while only 6 (2.3%) were male

caregivers (Nkirote *et al.*, 2019). This is echoed in earlier studies, such, which showed that the primary caregivers were mothers (Potterton *et al.*, 2010; Lowick, Sawry and Meyers, 2012) .

Potterton et al, (2009), commented that it was pleasing to note the high rate of biological mothers as caregivers, but that they faced a dual burden of being caregiver, as well as being infected with HIV themselves. Neither of the other studies commented further on the gender of the caregivers, but it is of note that in most African countries, men are the primary bread winners, often living far from home, while woman are keeping the home and raising the children (Mkhwanazi *et al.*, 2018). Fathers, or male figureheads, are not necessarily the biological father, but may be male figureheads such as maternal or paternal grandfathers, uncles, brothers, or figureheads in the community (Mkhwanazi *et al.*, 2018). It has been researched, that even in households where co-resident behaviour exists between father and mother, the mother is often always more involved with child-rearing activities (Mkhwanazi *et al.*, 2018).

A final reason for mothers being the more common primary caregiver, is that they are more willing to participate in treatment and psychosocial interventions for their children, if from early on in the management of the child, they are able to form good therapeutic relationships with the healthcare providers, have higher stress levels and lower socioeconomic circumstances, and poor social support structures (Potterton *et al.*, 2010). They are also HIV positive themselves, which means they are surviving, and are able to successfully fill their role, within their children's lives.

Although 36.7% of primary caregivers were employed, the majority of them, 30%, worked in menial jobs, which offer in some cases, below minimum wage. A large majority of the women worked as domestic workers, while the other 56.7% (17) of caregivers were unemployed. In a Kenyan study, results showed only six caregivers had regular employment while 215 were casual labourers. Despite some caregivers only having casual jobs, only 13 people were classified as unemployed, a mere 5% (Nkirote *et al.*, 2019), while in the current study a staggering 56.7% of caregivers were unemployed. South Africa is arguably one of the wealthier countries in Sub-Saharan Africa, so it is of interest, that the unemployment rate of caregivers in the current studies sample is so much higher than the sample in the Kenyan study. Much

of the data for the current study was collected during the Covid19 pandemic- a time where many people lost their jobs due to the lockdown restrictions. This factor may have influenced the high unemployment rate but would need to be verified with further investigation.

What the Kenyan study did not mention, was a social grant. This is a stipend given by the South African government to unemployed citizens, or citizens who earn below a threshold of R52800 if the caregiver is single, or R105 600 between both parents per annum (*Gov.za. 2021. Child support grant | South African Government*, 2021; Sassa, 2021). There are multiple different grants available in South Africa. The next most common source of income, besides employment for the caregivers in this study was the government child support grant of R460 per child, which 70% of caregivers were receiving. Those caregivers who are foreign nationals, are unable to receive any form of social support from the government, unless registered as permanent residents or refugees (Sassa, 2021).

Speaking to the unemployment figures, which are representative of the rate of unemployment in South Africa, which is currently, 32.5% (Statistics South Africa, 2020), was the primary caregivers highest level of education. Just over half (53.33%) of primary caregivers had a certificate for a grade less than matric, 6.67% had no education whatsoever and just 13.33% had a diploma outside of matric. In total 86.66% of the study's caregivers had some level of education which compared favourably to a study done in Kenya, where 92.6% of the caregivers had some level of formal education as well (Nkirote *et al.*, 2019). The only significant difference was that 13.33% of the studies caregivers had a qualification after matric, while the Kenyan studies participants only had up until secondary school. Another study done in South Africa by Potterton et al, (2009) showed only 26.7% of the caregivers reached matric (Potterton *et al.*, 2009), thus overall showing the level of education across caregivers was generally low. Maternal education has been shown to be an important factor associated to child development (Engle *et al.*, 2011; Walker *et al.*, 2011) and so efforts to improve child outcomes should include programmes for their mothers and caregivers as well.

Lastly, the most commonly used form of transport by 80% of the sample was public transport. Thus when looking at the employment status, level of education and type

of transport used by the primary caregivers in the sample, one may deduce that the overall socioeconomic standing of most participants and their families, is low.

A low socioeconomic standing is of significance because HIV is a multifaceted virus, that required many resources in order to achieve optimal management (Nkirote *et al.*, 2019). In limited resource countries, such as South Africa, children often don't have access to nutritious food, which is required in order to grow a healthy and strong body and mind (Nkirote *et al.*, 2019). It is well known that children with HIV have a very fast protein metabolism, and require on average up to ten percent more protein in their diet to keep up with their bodies requirements (Humphries, Potterton and Mudzi, 2014). If the participant comes from a household, with a low socioeconomic standing, a caregiver who potentially survives on a child support grant, would not be able to afford nutritious, protein rich food, public transport fare to and from hospital visits, as well as providing a clean and safe environment for their children. This compounds the risks associated with HIV (Potterton *et al.*, 2009). Such effects of HIV are the influencing factors on growth, cognition, overall development, ART compliance, access to the correct medical and rehabilitation management and possibly contributes to late presentation to hospital, either for diagnosis of HIV, thus increasing the risk of encephalopathies, or with opportunistic infections, increasing the risk of overall mortality and morbidity.

In summary children's developmental progress and the complications that may arise with their development has been shown to be negatively impacted on by poverty and low maternal levels of education in previous literature (Potterton *et al.*, 2009)

5.2 Motor Function

As noted previously, HIV has a significant effect on the overall development of a child from birth as they grow into adolescence and adulthood. Motor skills are attained and learnt from a young age and are used across all spheres of life, from play, to activities of daily living, such as grooming, dressing and eating (Benjamin-Damons, 2019). Various studies have measured motor development and performance in children living with HIV, some using the M-ABC and others using tests such as the Griffiths Mental Development Scales (GMDS) and the Bayley scales of infant development (Baillieu and Potterton, 2008; Van

Rie and Dow, 2009; Lowick, Sawry and Meyers, 2012; Sherr, Croome, Bradshaw, *et al.*, 2014; Benjamin-Damons, 2019).

The results of the M-ABC in the current study, clearly demonstrate that 60% of the participants, are deemed at risk or definitely delayed across their gross motor function. This means that they placed between the 6th and 15th percentile in the amber zone, or below the 5th percentile in the red zone respectively. Only 40% of the participants managed to score in the green zone, above the 15th percentile. Overall, participants either excelled, with good scores or they performed poorly. Very few participants fell into the amber zone, even when analysing each component separately. The results of this study are similar to a study done in a similar age group, looking at children with HIV and sensory neuropathy (SN). The M-ABC was also used to assess motor function, and the results showed 71% of the participants fell into an at risk category, i.e. either into the red or amber zones (Benjamin-Damons, 2019). These findings are very significant, as the children that were assessed in both this study and the current study, had not being routinely screened for motor delay before, thus these children would have been missed, and not referred for further assessment and rehabilitation possibly leading to increasing motor difficulties later in life.

Many studies done previously, looking at motor development in children with HIV, were focused majorly on pre-school aged children (Nkirote *et al.*, 2019). These studies found that motor function is more significantly affected than any other type of development (Baillieu and Potterton, 2008; Hilburn *et al.*, 2011; Laughton *et al.*, 2012; Potterton, Hilburn and Strehlau, 2016). Studies across Uganda and the Democratic Republic of Congo found that there was a motor delay in infants with a deceleration rate in their motor development and delays in motor skills respectively (Nkirote *et al.*, 2019). Baillieu and Potterton, (2008), found 87% of their participants had motor delay, which at the time was consistent with world findings of 50% of children with HIV having motor delay(Baillieu and Potterton, 2008). Fast-forward 11 years, in 2019, Brassell and Potterton, found that 50,5% of their study population had developmental and or functional impairments. Their age group was between 2-9 years, thus there is an overlap with the current studies age group, and echo's the findings of the current study's results.

Although much of the previous research shows that there are significant motor delays in development in infants and pre-schoolers, this current study, and the two more

recent studies by Benjamin-Damons, (2019), and Potterton, et al, (2019), show that the children's delays are continuing as they are growing older and starting school.

The study by Benjamin-Damons, (2019), is the only study found, using a similar age group and the M-ABC in order to assess motor function, in children with HIV. Although the study by Benjamin-Damons, (2019), was assessing children with HIV and SN, the M-ABC results showed no significant differences across all components of the M-ABC between the groups of participants who had HIV and SN and the group who had HIV and no SN (Benjamin-Damons, 2019). Thus the study allows for good comparison of results with the current study.

The results of each component of the M-ABC will now be discussed.

5.2.1 Manual Dexterity

Manual dexterity was by a number of items including posting coins, threading beads and drawing trails for the 5-6 year olds and placing pegs, threading lace and drawing trails for the 7-10 year olds. The overall mean standard score for manual dexterity was 5.60, placing the mean percentile as 13. This falls into the amber zone, which indicates there is a high risk of developmental delay. The manual dexterity component delivered the worst scores overall, with 14 participants placing below the 5th percentile.

The manual dexterity component in the study done by Benjamin-Damons, (2019), also yielded the worst scores overall, with most of the participants falling into the 50th percentile, and a small number below the 25th percentile. The participants in the current study, had a much lower average percentile, this could be due to factors such as core muscle strength or even hand-eye coordination. A study done on children with HIV, using the Griffiths Scales of Mental Development (GSMD), showed that showed that 26% of their sample struggled with hand eye coordination and or fine motor (Potterton, Hilburn and Strehlau, 2016). The results of the current study therefore confirm the need for further research into the manual dexterity challenges experienced by children living with HIV especially as they reach school going age and face greater fine motor demands.

5.2.2 Aiming and Catching

Aiming and Catching was assessed through items that include catching a beanbag and throwing a beanbag onto a mat for the 5-6 year olds, and catching with two hands and throwing beanbag onto a mat for the 7-10 year olds. The mean aiming and catching standard score was 8.30, which placed the sample at the 36th percentile. This places the participants firmly in the green zone overall, with only eight children exhibiting delays in this area. In comparison, most participants placed in the 75th percentile for this component in the Benjamin-Damons, (2019), study.

It is of note that the participants in the current study have scores which are lower in all components, when comparing to the study done by Benjamin-Damons, (2019). Once again Potterton et al, (2016), showed that 26% of their sample struggled with hand eye coordination, which is a very important skill, when throwing and catching objects, as well as 32.35% of their participants struggled with gross motor specifically (Potterton, Hilburn and Strehlau, 2016). This shows that children with HIV may not just be struggling with the general gross motor task of throwing or catching, but the hand eye coordination that is required to complete the task is difficult as well. Although the participants in the current study placed in the green zone, it is noteworthy, that their scores were still much lower than that of participants in other studies of similar ages.

5.2.3 Balance

Balance by items which included one-leg static balancing, walking heels raised (dynamic balancing) and jumping with two feet on mats for the 5-6 year olds, and single leg on board balancing, walking heel-toe forwards and hopping on mats for the 7-10 year olds. The mean standard score for balance was 8.57. The balance component scored in the highest percentile of all three components at the 39th percentile. Thus once again, the sample was found on average to be in the green zone. When comparing, the participants in the other HIV-SN study, scored mostly in the 50th percentile, with a small margin in the 95th percentile (Benjamin-Damons, 2019). Overall both studies participants fell into the green zone on average, and thus had normal balance.

Interestingly, although balance scored the highest out of all the components in the M-ABC in the current study, it is an important area to note. A study done in Brazil, showed that children infected with HIV, have a tendency to weight load on their hind foot, thus

showing changes in postural control, resulting in postural instability. The participants of this study showed disturbances in balance in the absence of neurological involvement (Pontes *et al.*, 2019).

5.3 Standing Broad Jump Test

The SBJT results were analysed using the furthest jump from the two trials, excluding the first attempt, which was a test trial. The mean length jumped was 99cm, with a standard deviation of 24.62. The minimum being 63cm and the maximum being 145cm. The data also displayed a slight negative kurtosis of -1.234.

The average length jumped by male participants was 107.64cm, while for female participants it was 87.70cm. According to the norms developed across Europe (Thomas *et al.*, 2020), there are eight female participants who's jump length is below the 10th percentile. That means that 61.5% of the female participants had a short jump length.

None of the male participants scored below the 10th percentile. The normative data only started from age six (Thomas *et al.*, 2020), thus the four five-year-old males, could not be compared to the normative data set.

This agrees with the data in the European study (Thomas *et al.*, 2020), that states that males are able to jump a further distance than females, especially as females begin the transition into puberty from around 12 years of age. Females have been found to be more physically inactive, and partake in more sedentary lifestyles, than males at the same age (Wong *et al.*, 2016). This would negatively impact on the muscle strength of females, thus give rise to lower distance jumped scores, in the SBJT.

A study was done in South Africa on primary school children, from multiple provinces, between the ages of 6-13 years. They accounted for ethnicity in the study, but they also agreed that as one grows older, their jump length increases, as well as the fact that males managed to jump a further distance than females (Armstrong, Lambert and Lambert, 2011). The results of the current study were also much lower than those of the Armstrong et al, (2011), study, across both males and females, with their mean score for males aged 6 being 117.1cm (Armstrong, Lambert and Lambert, 2011).

Muscle weakness and myopathy is a known effect of HIV on the body, due to the abnormal protein metabolism, malabsorption and depleted protein reserves in the body (Potterton *et al.*, 2021). However, they did conclude that when HIV is well controlled, with early use of ART and lower viral loads, children infected with HIV have comparable muscle strength in comparison to children without HIV in the same age category (Potterton *et al.*, 2021). The participants in the current study, did not all have optimally controlled viral loads, as only 11 participants had viral loads that were undetectable. This could explain why the current study participants had low scores in comparison to the European norms and the South African study.

A study done in Australia found that when children had a lower distance jumped, and a weaker muscle strength, they usually had a lower or middle socioeconomic status. This is echoed in the Armstrong et al, (2011), study, as they had statistically significant scores, when assessing a lesser distance jumped and socioeconomic status of the children (Armstrong, Lambert and Lambert, 2011). That could be another reason for why 61.5% of the female sample had very low scores (Hardy *et al.*, 2018). South Africa falls in the category of a low and middle socioeconomic income/status country and in order to build adequate muscle, especially when one has HIV as well, one would require adequate nutrition, especially protein (Humphries, Potterton and Mudzi, 2014). Due to the socioeconomic status of many families, this may not always be possible, thus also affecting the distance jumped scores overall.

5.4 Health related Quality of Life

The Peds-QL^{TM} was used to investigate the HRQOL of the children who participated in the study. The mean total score on the Peds-QL^{TM} was 81% with a standard deviation of 18. This is deemed very high as the subscales ranged from very high quality of life scores, to moderately high quality of life scores. Participants scored 87% for physical functioning, which demonstrates a good sense of HRQOL in relation to their physical wellbeing, and this was the highest score for a subsection. Participants scored social functioning at a mean of 80%, emotional functioning at 77% and the lowest score was school functioning at 75%. The results as shown in chapter four, demonstrate that the largest variance in HRQOL was the emotional subscale.

A study by Banerjee et al, (2010), found that children with HIV had lower HRQOL on the Peds-QL^{TM} in school, emotional and physical subscales. This confirms our lower scores in school and emotional subscales, however our sample had an overall good HRQOL in the physical subscale. Another study done on Thai children with HIV, yielded very similar results to our study, with the lowest and second lowest subscales being school and emotional respectively (Punpanich *et al.*, 2010).

Furthermore, a study done on children living with HIV and SN, in South Africa, had a total Peds-QL^{TM} score of 79.6%, a physical score of 81.4% and a psychosocial score of 78.9% (Benjamin-Damons, 2019). The study by Benjamin-Damons, (2019), used the scoring guidelines of the Peds-QL^{TM}, noting that >50% was considered a good QoL score (Benjamin-Damons, 2019). Interestingly, both the current study, and the study done by Benjamin-Damons, (2019), had very good HRQoL for the physical component of the Peds-QL^{TM} despite the difficulties these children showed when assessed on a standard score for motor function.

We know that cognition is one of the most affected areas of development of children with HIV especially as they get older (Blanchette *et al.*, 2001; Hilburn *et al.*, 2011; Lowick, Sawry and Meyers, 2012; Boyede *et al.*, 2013; Brassell and Potterton, 2019), and this could be a possibility why schooling was scored so poorly in terms of HRQOL. The other explanation could be that the Peds-QL^{TM} has two statements under school functioning, namely “I miss school because I’m not feeling well” and I miss school to go to the doctor or hospital”. The majority of children scored sometimes/often/almost always for these two questions, which would bring their school functioning related quality of life scores down, even if not directly related to their activities or wellbeing at school itself.

Thus in relation to the above studies, overall the participants in the current study had a good HRQOL across all aspects tested.

5.5 Associations between Variables

Tables 4.15 and 4.16 show correlations between all the main outcome measures. In terms of the CD4 count, there is a negative and non-significant relationship with viral load, the components of the M-ABC and the Peds-QL^{TM}. Thus the lower the CD4 count, the higher the scores on the respective outcome measures. However, it is not

significant as there are many variables in relation to the size of the sample, thus the relationship may have been skewed.

Viral load also has a negative and non-significant or very weak relationship with the M-ABC, SBJT and the Peds-QL^{TM}. Thus the higher the viral load, the lower the scores on the respective outcome measures. Although this relationship is weak, possibly due to the sample size, one does know that the higher the viral load in the body, the higher the potential for the virus to cause encephalopathy (Donald *et al.*, 2014; Mann *et al.*, 2017) and muscle weakness (Humphries, Potterton and Mudzi, 2014). Thus we would expect the overall scores on the participants' assessments to be lower than those of a child who has well controlled HIV.

There is a strong and significant relationship between BMI and Balance ($r=0.57$; $p<0.00$), with BMI accounting for 33% of the variance in Balance. Total Motor functions are also significantly and positively correlated with BMI ($r=0.43$; $p< 0.02$). Aiming and catching and manual dexterity were not significantly related to BMI.

The SBJT is positively and significantly related to the M-ABC components of; Manual Dexterity ($r (30) = 0.53$; $p<0.00$), as well as Balance ($r (30) = 0.45$; $p<0.01$), and the total M-ABC score ($r (30) = 0.52$; $p< 0.00$). This indicates that the further the distance jumped in the SBJT, the higher their M-ABC scores are as well. The relationship between SBJT and the M-ABC was very strong and all of the M-ABC's components were moderate to strong and significantly related. This could be due to the fact that all motor functions require an adequate amount of muscle strength in order to complete them. We know from previous studies done (Humphries, Potterton and Mudzi, 2014; Potterton *et al.*, 2021) that muscle strength is greatly affected in children with HIV, unless their viral loads are adequately controlled. Since the participants in the current study, were not all virally suppressed the lower scores in the SBJT, muscle strength, could thus be one of the contributing factors as to why the M-ABC showed so many of the participants to be delayed.

5.6 Clinical Implications of the Study

The results of the study clearly show the negative effect of HIV on the developing child, across physical, mental and emotional aspects. The effects to these developing children warrants immediate attention, and the chronicity of this pandemic can no

longer be ignored. There is a great need for therapeutic screening in this population in order to promote overall wellbeing and in order to play a preventative role as they grow older. The ages of 5-10 are a pivotal stage as children enter school, and lay the foundations of their education and functional abilities which in essence sets them up for their futures.

Screening at local clinics, much like the one where this study took place, and in schools, will allow for early identification of developmental delays in motor function and factors affecting health related quality of life. Those that then further require intervention can receive it at an early stage preventing further, and possibly more severe, complications as they grow older. This would also allow for large scale data to be collected and influence decisions made in the education sectors with regards to physical education, school-nutrition programmes, and mental health awareness and safeguarding.

This study hopes to enlighten physiotherapists to this 'forgotten population', and motivate for more decisive action, across all forms of intervention, education and promotion of wellbeing. HIV is ever evolving, and thus therapies should too.

5.7 Limitations of the Research

Due to the unforeseen Covid19 pandemic and subsequent lockdown the sample size of this study was small and although all the data was normally distributed, a larger sample size would have been preferred. The study would also have been strengthened by having an HIV unexposed uninfected group of children as a control group. Due to data collection during the COVID-19 pandemic this however was unavoidable. Lastly, non-ambulant children were excluded from the study, and so children who may have severe HIVE, thus creating a bias in the results, towards higher functioning children.

5.8 Recommendations for further Research

The results of the study indicate there is a large percentage of children who are at risk or are already developmentally delayed. More research needs to look into the variance

of the effects of ART and the viral loads of children when they started ART to identify if the developmental delay risk is reduced with pharmacological intervention at birth.

Research into intervention programmes, which improve motor function, need to be developed, tested and implemented.

The SBJ test showed good correlation with the MABC. A study could be conducted to further evaluate this relationship, as the SBJ would be a very easy way to screen children at clinic visits. Those that perform poorly could then be referred for a full assessment.

Further investigation into fine motor and visual perception skills of school going children living with HIV is needed.

Chapter 6: Conclusion

"Education is spreading hope. Millions are now learning to live with HIV AIDS – instead of waiting to die from it. "– Laura Welch Bush

The literature clearly shows that with the improved access to ART, children with HIV are being granted the opportunity to grow into adolescents and adults, into their elderly days. The pandemic has evolved over the years, from almost certain mortality in a rapid space of time, to a lifelong chronic disease, that can we well controlled, as if it were any other comorbidity.

Along with the chronicity of the HIV virus, comes the ongoing consequences of this ever evolving immune assailant. Literature has stated time and time again, that the neurodevelopmental effects on infants are of major significance. The purpose of this cross-sectional study, was to determine how far reaching these neurodevelopmental issues are, as children grow and enter the ever complex period of schooling.

Thirty children with a mean age of 7.73 years participated in this study. They were cared for by their mothers and came from predominantly lower socio economic backgrounds.

More than half the children who participated in this study, were deemed to be at risk, or already developmentally delayed in terms of motor function. Of the three areas assesd by the M-ABC Manual Dexterity was where the children scored most poorly followed by Aiming and Catching and then Balance.

The standing broad jump test revealed many of the participants have weak muscle strength in comparison to both local and international groups. Local and international literature shows a strong association between muscle strength and poorer socioeconomic factors, which is a highly plausible association given our participants low scores, and the socioeconomic status of most of the population in this study, and in South Africa as a whole.

The HRQoL of the young children with HIV in the study, was optimistically high. Schooling and emotional quality of life were areas where the children did not score as well and where they may need additional support.

This study clearly succeeds in proving the hypothesis; that muscle strength, physical activity and motor function are affected in children between the ages of 5-10 that were perinatally infected with HIV, and that further care and rehabilitation is needed for this vulnerable group.

The study also clearly showed that there is a missing middle in terms of age range, across literature, and clinical assessment and management for these children, at such a crucial time of their development. The management of children with HIV needs to take a more holistic approach, and the assessment and management of their neurodevelopment, needs to be taken far more seriously. Changes need to be made across all sectors, involving all main stakeholders, and the opportunity is there for all to take the first step, in creating a better life for all children infected with HIV.

"Do all you can with what you have, in the time you have, in the place you are" – Nkosi Johnson (Childhood HIV/AIDS activist)

References

Amin, L. *et al.* (2012) 'Rasch analysis of the PedsQL: An increased understanding of the properties of a rating scale', *Journal of Clinical Epidemiology*. Elsevier Inc, 65(10), pp. 1117–1123. doi: 10.1016/j.jclinepi.2012.04.014.

Armstrong, M. E. G., Lambert, E. V. and Lambert, M. I. (2011) 'Physical fitness of South African primary school children, 6 to 13 years of age: Discovery Vitality health of the nation study', *Perceptual and Motor Skills*, 113(3), pp. 999–1016. doi: 10.2466/06.10.13.PMS.113.6.999-1016.

Baillieu, N. and Potterton, J. (2008) 'The extent of delay of language, motor, and cognitive development in HIV-positive infants', *Journal of Neurologic Physical Therapy*, 32(3), pp. 118–121. doi: 10.1097/NPT.0b013e3181846232.

Banerjee, T., Pensi, T. and Banerjee, D. (2010) 'HRQoL in HIV-infected children using PedsQL™ 4.0 and comparison with uninfected children', *Quality of Life Research*, 19(6), pp. 803–812. doi: 10.1007/s11136-010-9643-3.

Bellman, M., Byrne, O. and Sege, R. (2013) 'Developmental assessment of children', *BMJ (Online)*, 345(7891), pp. 1–9. doi: 10.1136/bmj.e8687.

Benjamin-Damons, N. A. (2019) *An investigation of HIV sensory neuropathy in children living with HIV*. Available at: https://hdl.handle.net/10539/28214.

Berhan, Y. (2011) 'Age and CD4 count of vertically HIV-infected children at the time of diagnosis: What are independent predictors for being symptomatic and CD4 counts drop?', *Journal of Tropical Pediatrics*, 57(1), pp. 14–23. doi: 10.1093/tropej/fmq032.

Blanchette, N. *et al.* (2001) 'Cognitive and motor development in children with vertically transmitted HIV infection', *Brain and Cognition*, 46(1–2), pp. 50–53. doi: 10.1016/S0278-2626(01)80032-4.

Bomba, M. *et al.* (2010) 'Poor health-related quality of life and abnormal psychosocial adjustment in Italian children with perinatal HIV infection receiving highly active antiretroviral treatment', *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 22(7), pp. 858–865. doi: 10.1080/09540120903483018.

Boyede, G. O. *et al.* (2013) 'Impact of sociodemographic factors on cognitive

function in school-aged HIV-infected Nigerian children', *HIV/AIDS - Research and Palliative Care*, 5, pp. 145–152. doi: 10.2147/HIV.S43260.

Brassell, S. E. and Potterton, J. (2019) 'Prevalence of disability in HIV-infected children attending an urban paediatric HIV clinic in Johannesburg, South Africa', *Vulnerable Children and Youth Studies*. Taylor & Francis, 14(2), pp. 95–115. doi: 10.1080/17450128.2019.1566682.

Carr, A. and Cooper, D. A. (2010) 'Adverse drug reactions Adverse effects of antiretroviral therapy', *October*, 356, pp. 1423–1430. doi: 10.1016/S0140-6736(00)02854-3.

CDC (2020) *Health Related Quality of life - HRQOL*, *Cdc.gov. 2020. HRQOL Concepts | CDC. [online]*.

Chaudhury, S. *et al.* (2017) 'Neurodevelopment of HIV-exposed and HIV-unexposed uninfected children at 24 months', *Pediatrics*, 140(4). doi: 10.1542/peds.2017-0988.

Cohen, S. *et al.* (2015) 'Health-related quality of life in perinatally HIV-infected children in the Netherlands', *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 27(10), pp. 1279–1288. doi: 10.1080/09540121.2015.1050986.

Corten, L. and Morrow, B. M. (2020) 'Motor Performance in South African Children with Cystic Fibrosis', *Physical & Occupational Therapy In Pediatrics*, 40(2), pp. 192–200. doi: 10.1080/01942638.2019.1647329.

Cuéllar-Flores, I. *et al.* (2019) 'Impact of HIV on the health-related quality of life in youth with perinatally acquired HIV', *World Journal of Pediatrics*, 15(5), pp. 492–498. doi: 10.1007/s12519-019-00281-z.

Donald, K. A *et al.* (2014) 'Neurologic complications of pediatric human immunodeficiency virus: Implications for clinical practice and management challenges in the African setting', *Seminars in Pediatric Neurology*. Elsevier, 21(1), pp. 3–11. doi: 10.1016/j.spen.2014.01.004.

Donald, Kirsten A. *et al.* (2014) 'Pediatric cerebral palsy in Africa: A systematic review', *Seminars in Pediatric Neurology*, 21(1), pp. 30–35. doi: 10.1016/j.spen.2014.01.001.

Engle, P. L. *et al.* (2011) 'Strategies for reducing inequalities and improving developmental outcomes for young children in low-income and middle-income

countries', *The Lancet*. Elsevier Ltd, 378(9799), pp. 1339–1353. doi: 10.1016/S0140-6736(11)60889-1.

Fernandez-Santos, J. . *et al.* (2015) 'Reliability and Validity of Tests to Assess Lower-Body Muscular Power In Children', *Journal of Strength and Conditioning Research*, 29(8), pp. 2277–2285.

Fieggen, K. J., Lambie, L. A. and Donald, K. A. (2019) 'Investigating developmental delay in south africa: A pragmatic approach', *South African Medical Journal*, 109(4), pp. 210–213. doi: 10.7196/SAMJ.2019.v109i4.13991.

Frost, J. (2018) *Central Limit Theorem Explained*, *Statistics by Jim*. Available at: https://statisticsbyjim.com/basics/central-limit-theorem/ (Accessed: 23 January 2021).

Garza, C. and de Onis, M. (2004) 'Rationale for developing a new international growth reference', *Food and Nutrition Bulletin*, 25(1 SUPPL. 1). doi: 10.1177/15648265040251s102.

Gopalan, B. P. *et al.* (2020) 'Effect of Structured Physical Activity on In fl ammation and Immune Activation Pro fi le of Antiretroviral Therapy-Experienced Children Living With HIV', pp. 73–80.

Gov.za. 2021. Child support grant | *South African Government* (2021). Available at: https://www.gov.za/services/child-care-social-benefits/child-support-grant?gclid=CjwKCAjw7J6EBhBDEiwA5UUM2jI2ZWK3gMLvFXnSIWKKQUm0ZfBBOJlvP8Q6KDgaij12Y7VEhiPyERoCM88QAvD_BwE# (Accessed: 27 April 2021).

Hardy, L. L. *et al.* (2018) '30-year changes in Australian children's standing broad jump: 1985–2015', *Journal of Science and Medicine in Sport*. Sports Medicine Australia, 21(10), pp. 1057–1061. doi: 10.1016/j.jsams.2018.04.005.

Henderson, S., Sugden, D. A. and Barnett, A. L. (2007) *Movement Assessment Battery for Children – Second Edition (Movement ABC-2)*. Second Edi. London, UK: The Psychological Corporation.

Hilburn, N. *et al.* (2011) 'The development of a screening tool to evaluate gross motor function in HIV-infected infants', *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 23(12), pp. 1619–1625. doi: 10.1080/09540121.2011.579942.

Hilburn, N., Potterton, J. and Stewart, A. (2010) 'Paediatric HIV encephalopathy in

sub-Saharan Africa', *Physical Therapy Reviews*, 15(5), pp. 410–417. doi: 10.1179/1743288X10Y.0000000013.

Hoare, J. *et al.* (2018) 'Structural brain changes in perinatally HIV-infected young adolescents in South Africa', *AIDS (London, England)*, 32(18), pp. 2707–2718. doi: 10.1097/QAD.0000000000002024.

Humphries, C., Potterton, J. and Mudzi, W. (2014) 'A pilot study to investigate the muscle strength of children infected with HIV', *International Journal of Therapy and Rehabilitation*, 21(1), pp. 19–24. doi: 10.12968/ijtr.2014.21.1.19.

Hutchings, J. and Potterton, J. (2014) 'Developmental delay in HIV-exposed infants in Harare, Zimbabwe', *Vulnerable Children and Youth Studies*, 9(1), pp. 43–55. doi: 10.1080/17450128.2013.778440.

Innes, S. *et al.* (2014) 'Early severe HIV disease precedes early antiretroviral therapy in infants: Are we too late?', *Journal of the International AIDS Society*, 17, pp. 1–6. doi: 10.7448/IAS.17.1.18914.

Jesson, J. and Penazzato, M. (2016) 'Adverse events associated with abacavir use in HIV-infected children and adolescents : a systematic review and meta-analysis', 3(February 2016). doi: 10.1016/S2352-3018(15)00225-8.

Krishnan, A. *et al.* (2017) 'Comparison between standing broad jump test and wingate test for assessing lower limb anaerobic power in elite sportsmen', *Medical Journal Armed Forces India*. Director General, Armed Forces Medical Services, 73(2), pp. 140–145. doi: 10.1016/j.mjafi.2016.11.003.

Langerak, N. G. *et al.* (2014) 'Spastic diplegia in children with HIV encephalopathy: First description of gait and physical status', *Developmental Medicine and Child Neurology*, 56(7), pp. 686–694. doi: 10.1111/dmcn.12319.

Laughton, B. *et al.* (2012) 'Early antiretroviral therapy improves neurodevelopmental outcomes in infants', *Aids*, 26(13), pp. 1685–1690. doi: 10.1097/QAD.0b013e328355d0ce.

Laughton, B. *et al.* (2018) 'Five year neurodevelopment outcomes of perinatally HIV-infected children on early limited or deferred continuous antiretroviral therapy', *Journal of the International AIDS Society*, 21(5), p. e25106. doi: 10.1002/jia2.25106.

Limbers, C. A. *et al.* (2011) 'Patient-reported pediatric quality of life inventory™ 4.0

generic core scales in pediatric patients with attention-deficit/hyperactivity disorder and comorbid psychiatric disorders: Feasibility, reliability, and validity', *Value in Health*. Elsevier Inc., 14(4), pp. 521–530. doi: 10.1016/j.jval.2010.10.031.

Lowick, S., Sawry, S. and Meyers, T. (2012) 'Neurodevelopmental delay among HIV-infected preschool children receiving antiretroviral therapy and healthy preschool children in Soweto, South Africa', *Psychology, Health and Medicine*, 17(5), pp. 599–610. doi: 10.1080/13548506.2011.648201.

Macdonald, H. M. *et al.* (2017) 'Muscle power in children, youth and young adults who acquired HIV perinatally', *Journal of Musculoskeletal Neuronal Interactions*, 17(2), pp. 27–37.

Mann, T. N. *et al.* (2017) 'HIV encephalopathy with bilateral lower limb spasticity: gross motor function and antiretroviral therapy', *Developmental Medicine and Child Neurology*, 59(4), pp. 407–411. doi: 10.1111/dmcn.13377.

Medical Dictionary for the Health Professions and Nursing. (2012) *Farlex*.

Melhuish, A. and Lewthwaite, P. (2018) 'Natural history of HIV and AIDS', *Medicine (United Kingdom)*. Elsevier Ltd, 46(6), pp. 356–361. doi: 10.1016/j.mpmed.2018.03.010.

Merriam-Webster (2020) *Definition of Development*. Available at: https://www.merriam-webster.com/dictionary/development (Accessed: 7 March 2020).

Meyer, R. and Alder, R. (2017) 'Human immunodeficiency virus (HIV)', *Magill's Medical Guide (Online Edition)*. Salem Press. Available at: http://0-search.ebscohost.com.innopac.wits.ac.za/login.aspx?direct=true&db=ers&AN=86194188&site=eds-live&scope=site.

Mintz, M. and Epstein, L. G. (1992) 'Neurologic manifestations of pediatric acquired immunodeficiency syndrome: Clinical features and therapeutic approaches', *Seminars in Neurology*, 12(1), pp. 51–56. doi: 10.1055/s-2008-1041157.

Missmer, S. . *et al.* (2000) 'Predictors of Change in the Functional Status of Children With Human Immunodeficiency Virus Infection', *Pediatrics*, 106(2), pp. 571–596. doi: 10.1542/peds.106.2.e24 The.

Mkhwanazi, N. *et al.* (2018) 'Negotiating the care of children and support for

caregivers', *South African Child Guage 2018: Children, Families and the State*, pp. 70–80.

Monyeki, M. A. *et al.* (2005) 'Body composition and physical fitness of undernourished South African rural primary school children', *European Journal of Clinical Nutrition*, 59(7), pp. 877–883. doi: 10.1038/sj.ejcn.1602153.

Mulenga, V. *et al.* (2015) 'Abacavir , zidovudine , or stavudine as paediatric tablets for African HIV-infected children (CHAPAS-3): an open-label , parallel-group , randomised controlled trial', *The Lancet Infectious Diseases*. Walker et al. Open Access article distributed under the terms of CC BY, 16(2), pp. 169–179. doi: 10.1016/S1473-3099(15)00319-9.

Nkirote, L. *et al.* (2019) 'Effects Of Nutrition Support On Attainment Of Motor Skills Milestones In Children Recieving Anitretroviral Therapy (ART) In Selected Slums Of Nairobi, Kenya', *Journal of Health, Medicine and Nursing*, 4(2, 3), pp. 30–49. Available at: www.iprjb.org.

De Onis, M. (2006) 'WHO Motor Development Study: Windows of achievement for six gross motor development milestones', *Acta Paediatrica, International Journal of Paediatrics*, 95(SUPPL. 450), pp. 86–95. doi: 10.1080/08035320500495563.

Pontes, S. *et al.* (2019) 'Variations in plantar pressure and balance in HIV-infected children in antiretroviral therapy', *Scientific Reports*, pp. 1–7. doi: https://doi.org/10.1038/s41598-019-41028-0.

Potterton, J. *et al.* (2009) 'Neurodevelopmental delay in children infected with human immunodeficiency virus in Soweto, South Africa', *Vulnerable Children and Youth Studies*, 4(1), pp. 48–57. doi: 10.1080/17450120802183728.

Potterton, J. *et al.* (2010) 'The effect of a basic home stimulation programme on the development of young children infected with HIV', *Developmental Medicine and Child Neurology*, 52(6), pp. 547–551. doi: 10.1111/j.1469-8749.2009.03534.x.

Potterton, J. *et al.* (2021) 'Muscle strength in young children perinatally infected with HIV who initiated antiretroviral therapy early', *South African Journal of Child Health*.

Potterton, J., Hilburn, N. and Strehlau, R. (2016) 'Developmental status of preschool children receiving cART: A descriptive cohort study', *Child: Care, Health and Development*, 42(3), pp. 410–414. doi: 10.1111/cch.12321.

Punpanich, W. *et al.* (2010) ‘Health-related Quality of Life of Thai children with HIV infection : a comparison of the Thai Quality of Life in Children (ThQLC) with the Pediatric Quality of Life Inventory TM version’, pp. 1509–1516. doi: 10.1007/s11136-010-9708-3.

Ramos, E. *et al.* (2013) ‘Anaerobic Power and Muscle Strength in Human Immunodeficiency Virus-Positive Preadolescents’, *Physical medicine and rehabilitation Journal*, 4(3), pp. 171–175. doi: doi:10.1016/j.pmrj.2011.11.009.

Van Rie, A. and Dow, A. (2009) ‘Neurodevelopmental trajectory in Kinshasa’, 72(2), pp. 181–204. doi: 10.1038/nature13314.A.

Robertson, K. *et al.* (2008) ‘Second assessment of NeuroAIDS in Africa’, *Journal of NeuroVirology*, 14(2), pp. 89–101. doi: 10.1080/13550280701829793.

Sassa (2021) *Child support grant*, *South African Governemnt, Department of Social Services*. Available at: https://www.sassa.gov.za/Pages/Child-Support-Grant.aspx (Accessed: 27 April 2021).

Schulz, J. *et al.* (2011) ‘Structural validity of the Movement ABC-2 test: Factor structure comparisons across three age groups’, *Research in Developmental Disabilities*. Elsevier Ltd, 32(4), pp. 1361–1369. doi: 10.1016/j.ridd.2011.01.032.

Setia, M. S. (2016) ‘Methodology Series Module 3: Cross-sectional Studies’, *Indian Journal of dermatology*, 61(3), pp. 261–264.

Sherr, L., Croome, N., Bradshaw, K., *et al.* (2014) ‘A systematic review examining whether interventions are effective in reducing cognitive delay in children infected and affected with HIV’, *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*. Taylor & Francis, 26(SUPPL. 1), pp. 70–77. doi: 10.1080/09540121.2014.906560.

Sherr, L., Croome, N., Parra Castaneda, K., *et al.* (2014) ‘Developmental challenges in HIV infected children-An updated systematic review’, *Children and Youth Services Review*. The Authors, 45(C), pp. 74–89. doi: 10.1016/j.childyouth.2014.03.040.

Shriharsha, C. and Rentala, S. (2019) ‘Quality of life among people living with HIV/AIDS and its predictors: A cross-sectional study at ART center, Bagalkot, Karnataka’, *Journal of Family Medicine and Primary Care*, 8(3), pp. 1011–1016. doi: 10.4103/jfmpc.jfmpc_411_18.

Smits-Engelsman, B. C. *et al.* (2008) 'Interrater Reliability of the Movement Assessment Battery for Children', *Physical Therapy*, 88(2), pp. 286–294. doi: 10.2522/ptj.20070068.

Somarriba, G. *et al.* (2013) 'Physical Fitness in Children Infected with the Human Immunodeficiency Virus : Associations with Highly Active Antiretroviral Therapy', 29(1), pp. 112–120. doi: 10.1089/aid.2012.0047.

South African National Department of Health (2019) '2019 ART Clinical Guidelines', (May).

Statistics South Africa (2020) *Quarterly Labour Force Survey (QLFS) – Q4:2020*. Pretoria. Available at: http://www.statssa.gov.za/?page_id=1854&PPN=P0211&SCH=72942.

StatsSA (2019) 'Midyear Population Estimate 2019', *Population Estimates*, (July).

Stevanovic, D., Tadic, I. and Novakovic, T. (2011) 'Health-Related Quality of Life in Children and Adolescents with Epilepsy: A Systematic Review', *Epilepsy in Children - Clinical and Social Aspects*, (September). doi: 10.5772/17558.

Strehlau, R. (2013) *Neurodevelopmental Delays in Children with Perinatally Acquired Human Immunodificiency Virus Infection, with Respect to Antiretroviral Therapy Initiation and Virological Suppression*. University of the Witwatersrand. Available at: https://pdfs.semanticscholar.org/e3a3/244a0124b1b6a883542133cd0edc97beeda7.pdf.

Sutcliffe, C. G. *et al.* (2011) 'Weight and height z-scores improve after initiating ART among HIV-infected children in rural Zambia: A cohort study', *BMC Infectious Diseases*. BioMed Central Ltd, 11(1), p. 54. doi: 10.1186/1471-2334-11-54.

Tanaka, L. F. *et al.* (2015) 'High prevalence of physical inactivity among adolescents living with HIV / AIDS', *Revista Paulista de Pediatria (English Edition)*. Associação de Pediatria de São Paulo, 33(3), pp. 326–331. doi: 10.1016/j.rppede.2015.06.003.

Thomas, E. *et al.* (2020) 'Percentile values of the standing broad jump in children and adolescents aged 6-18 years old', 30(2), pp. 240–246.

UNAIDS (2020) 'Global Hiv Statistics 2020', *Ending the AIDS epidemic*, (June), pp. 1–3. Available at: https://www.unaids.org/en/resources/fact-sheet.

Varni, J. W. *et al.* (2003) 'The PedsQL™ 4.0 as a school population health measure: Feasibility, reliability, and validity', *Ambulatory Pediatrics*, 3(6), pp. 329–341. doi: 10.1007/s11136-005-1388-z.

Venetsanou, F. *et al.* (2011) 'Can the Movement Assessment Battery for Children-Test be the "gold standard" for the motor assessment of children with Developmental Coordination Disorder?', *Research in Developmental Disabilities*, 32(1), pp. 1–10. doi: 10.1016/j.ridd.2010.09.006.

Wagner, M. O. *et al.* (2011) 'Factorial validity of the Movement Assessment Battery for Children-2 (age band 2)', *Research in Developmental Disabilities*, 32(2), pp. 674–680. doi: 10.1016/j.ridd.2010.11.016.

Walker, S. P. *et al.* (2011) 'Inequality in early childhood: Risk and protective factors for early child development', *The Lancet*, 378(9799), pp. 1325–1338. doi: 10.1016/S0140-6736(11)60555-2.

van der Walt, J., Plastow, N. A. and Unger, M. (2020) 'Prevalence of motor skill impairment among Grade R learners in the West Coast District of South Africa', *South African Journal of Education*, 40, pp. 1–8.

Whitehead, N., Potterton, J. and Coovadia, A. (2014) 'The neurodevelopment of HIV-infected infants on HAART compared to HIV-exposed but uninfected infants', *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 26(4), pp. 497–504. doi: 10.1080/09540121.2013.841828.

WHO (1998) 'WHOQOL', (October), pp. 352–362.

Wong, M. *et al.* (2016) 'Decreased Vigorous Physical Activity in School-Aged Children with Human Immunodeficiency Virus in Johannesburg, South Africa', *The Journal of Pediatrics*. Elsevier Inc. doi: 10.1016/j.jpeds.2016.01.034.

World Health Organization (2008) *Training Course on Child Growth Assessment WHO Child Growth Standards*, *World Health Organization*. Geneva: WHO.

Xiao, Y. *et al.* (2019) 'Individual and family level factors associated with physical and mental health-related quality of life among people living with HIV in rural China', *BMC Public Health*, 19(1), pp. 1–7. doi: 10.1186/s12889-018-6352-2.

Appendices

Appendix 1

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Information Sheet

A Research Project Investigating The motor function muscle strength and health related quality of life of children aged 5-10 years perinatally infected with HIV, in an Urban setting in South Africa information sheet

Good day

My name is Cassandra Rego, I am a postgraduate physiotherapy student at Wits university. I will be conducting the research as described below. Please feel free to ask any questions you may have.

Introduction:

We would like to invite you and your child/children to participate in this project, which is concerned with the motor function and muscle strength of children aged 5-10 years old with HIV.

The study will take place at the Tambo Memorial Hospital, Emthonjeni ARV Clinic

Why am I doing this project?

This project is part of my master's research for a postgraduate degree in physiotherapy. I also would like to use this study to give some valuable information that could lead to further studies or changes in the treatment and assessment of children with HIV in childhood.

What do you have to do if you agree to take part?

If you agree to participate, you will give us your signed information and consent forms and your child will take part in an assessment. I will also ask for permission to get some information from your child's clinic file.

How much of your time will be taken by participation in the project?

The study is a once off assessment of your child and it will require a questionnaire answered by you, the guardian. This will take approximately 2 hours of your time.

If you participate in the project will your identity remain confidential?

If you choose to take part in this study and sign the consent forms you will be given a participant code, and your name will not be used or recorded on any of the assessment forms or results. All your information will be kept under the participant code ensuring complete anonymity.

Do you have to take part in the study?

Participating in this study is completely your own choice. This means the study is voluntary and you do not have to be involved if you do not want to or even if your child does not want to. If you decide that you would not like to take part, you do not need to give any reasoning and you will not be asked to participate again. If you choose to participate and sign the consent form, and during the assessments you change your mind, you are free to withdraw your consent at any point, again with no questions asked.

What happens now?

If you agree and sign consent form, I will show you and your child into the research room where the assessment will take place. Your child will perform two physical assessments, called the Movement ABC – which tests motor performance- and the Standing broad jump test- which will test muscle strength. I will also take your child's height and weight measurements. I will then administer a questionnaire to your child that asked questions about their physical activity and participation in daily activities. I will then ask you to fill out some socioeconomic questions about yourself and your child.

Once I have received all this information and all the assessments are completed, you are free to go.

Researchers:

Postgraduate Physiotherapy student from the University of the Witwatersrand: Cassandra Rego

Supervisor:

Professor Joanne Potterton, School of Physiotherapy, University of the Witwatersrand

I, _____ state that I have read through the information sheet and understand everything that has been written. I have been given the opportunity to ask questions, and my questions or the questions of my child have been answered by the researcher, and an interpreter was used if I needed one.

Signed_____

Date_____ Place_____

If you have any concern over the way the study is being conducted, please contact the chairperson of the Human Research Ethics Committee, Professor Clement Penny, who may be contacted by telephone on 011 717 2700/1234 and the email addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za .

Appendix 2:

Consent form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Faculty of Health Sciences

Physiotherapy department

1. **Consent form – Participation in Children with HIV study**

I, _____ Parent/Guardian of _____ hereby give Wits Physiotherapy Masters student Cassandra Rego my permission to assess and work with my child/children as part of her study on the motor function and muscle strength of children aged 5-10 years perinatally infected with HIV, in an Urban setting in South Africa. I give Cassandra Rego permission to utilise my information for the purposes of this research study only.

I also give permission that she may look at my child's file to get the extra information she needs.

I fully understand the nature of this study and what will be required of me.

Name: _____

Signature: _____

Date: _____

If you have any further queries or to report ethical concerns, please contact Prof Clement Penny on 011 717 2301.

Appendix 3:

Assent form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Faculty of Health Sciences

Physiotherapy department

Assent form – Participation by Children

Hi, my name is Cassandra Rego, I am a physiotherapist and I am studying further in physiotherapy at the University of the Witwatersrand.

I am conducting a study at Emthonjeni clinic, at Tambo Memorial Hospital, to find out what the muscle strength and motor function is, of children who are between the ages of 5-10 years old.

Your name and personal information will not be shared with anyone and you will be kept anonymous in our data.

If you would like to join in on the assessments, please write your name and today's date on the lines below.

I, _____ give my assent to be a part of the study describes above, and have been given the chance to ask any questions and have my questions answered in full, on this day _____ of _____ 20_____

Appendix 4:

Demographic and socioeconomic questionnaire for participant			
Participant code			
Consent form signed by parent			
Assent form signed			
Age			
Gender			
Height (cm)			
Weight (kg)			
Grade of participant			
Mode of transport			
CD4 count			
Viral Load			
Date ARV initiation			
What medication is being taken?			
Other medical conditions/ co-morbidities			
Previous hospital admissions	Yes /Number	No	Reason/s
Primary care giver age			
Who Is the primary care giver	Mother	Father	other

Highest level of education of primary caregiver	Grade 1-3	Grade 4-7	Grade 8-10	Matric	Diploma from course	Teknion degree/ diploma	University degree
Employment of primary care giver							
Social Grant	YES		NO		Type:		

Appendix 5:

ID#: _____

Date: _____

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

YOUNG CHILD REPORT (ages 5-7)

Instructions for interviewer:

I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these things might be for you.

Show the child the template and point to the responses as you read.

If it is not at all a problem for you, point to the smiling face

If it is sometimes a problem for you, point to the middle face

If it is a problem for you a lot, point to the frowning face

I will read each question. Point to the pictures to show me how much of a problem it is for you. Let's try a practice one first.

	Not at all	Sometimes	A lot
Is it hard for you to snap your fingers	☺	😐	☹

Ask the child to demonstrate snapping his or her fingers to determine whether or not the question was answered correctly. Repeat the question if the child demonstrates a response that is different from his or her action.

Think about how you have been doing for the last few weeks. Please listen carefully to each sentence and tell me how much of a problem this is for you.

After reading the item, gesture to the template. If the child hesitates or does not seem to understand how to answer, read the response options while pointing at the faces.

PHYSICAL FUNCTIONING *(problems with...)*	Not at all	Some-times	A lot
1. Is it hard for you to walk	0	2	4
2. Is it hard for you to run	0	2	4
3. Is it hard for you to play sports or exercise	0	2	4
4. Is it hard for you to pick up big things	0	2	4
5. Is it hard for you to take a bath or shower	0	2	4
6. Is it hard for you to do chores (like pick up your toys)	0	2	4
7. Do you have hurts or aches (*Where?*_____)	0	2	4
8. Do you ever feel too tired to play	0	2	4

Remember, tell me how much of a problem this has been for you for the last few weeks.

EMOTIONAL FUNCTIONING *(problems with...)*	Not at all	Some-times	A lot
1. Do you feel scared	0	2	4
2. Do you feel sad	0	2	4
3. Do you feel mad	0	2	4
4. Do you have trouble sleeping	0	2	4
5. Do you worry about what will happen to you	0	2	4

SOCIAL FUNCTIONING *(problems with...)*	Not at all	Some-times	A lot
1. Is it hard for you to get along with other kids	0	2	4
2. Do other kids say they do not want to play with you	0	2	4
3. Do other kids tease you	0	2	4
4. Can other kids do things that you cannot do	0	2	4
5. Is it hard for you to keep up when you play with other kids	0	2	4

SCHOOL FUNCTIONING *(problems with...)*	Not at all	Some-times	A lot
1. Is it hard for you to pay attention in school	0	2	4
2. Do you forget things	0	2	4
3. Is it hard to keep up with schoolwork	0	2	4
4. Do you miss school because of not feeling good	0	2	4
5. Do you miss school because you have to go to the doctor's or hospital	0	2	4

How much of a problem is this for you?

Not at all	Sometimes	A lot
		

ID# _____

Date: _____

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

CHILD REPORT (ages **8-12**)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

ABOUT MY HEALTH AND ACTIVITIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

ABOUT SCHOOL *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

Appendix 6:

Date:_____

Participant Code:_____

Standing Broad Jump Test Recording sheet

Trial	**Distance (cm)** (Heel foot closest to line to the line)
Test Trial	
Trial one	
Trial Two	

Appendix 7:

Movement Assessment Battery for Children – 2

Test Record Form Age Band 1 (3-6 years)

Name: Gender: M / F

Home address:

School: Class/year/grade:

Assessed by:

Referral source:

Preferred (writing) hand:	Year	Month	Day
Date tested			
Date of birth			
Chronological age			

Movement ABC-2 Checklist completed? Y / N

Item Scores and Equivalent Standard Scores

Item code	Name of item	Raw score (best attempt)	Item Standard Score
MD 1*	Posting Coins preferred hand		
	Posting Coins non-pref hand		
MD 2	Threading Beads		
MD 3	Drawing Trail 1		
A&C 1	Catching Beanbag		
A&C 2	Throwing Beanbag onto mat		
Bal 1*	One-Leg Balance best leg		
	One-Leg Balance other leg		
Bal 2	Walking Heels Raised		
Bal 3	Jumping on Mats		
Total Test Score Sum of 8 item **standard** scores:			

*For Posting Coins and One-Leg Balance, look up standard score for each limb, add these and divide by 2. If the result is above 10, round up; if below 10, round down.

Three Component Scores*

Manual Dexterity^ MD 1 + MD 2 + MD 3	Component score	Standard Score	Percentile
Aiming & Catching* A&C 1 + A&C 2	Component score	Standard Score	Percentile
Balance* Bal 1 + Bal 2 + Bal 3	Component score	Standard Score	Percentile

*In each case sum the item standard scores.

Total Test Score	Standard Score	Percentile Rank

*For confidence intervals, see Examiner's Manual p139 (Chapter 7)

Manual Dexterity 1: POSTING COINS

Note: 6 coins for 3-4 years, 12 for 5-6 years

Record: Preferred hand: R / L (should be same as for Drawing Trail); Time taken (secs); F for failure; R for refusal; I if inappropriate (note reasons below)

Preferred hand		Only administer a second trial if the first trial takes longer than the time stated below:						Non-preferred hand		Only administer a second trial if the first trial takes longer than the time stated below:					
Trial 1		3:0-3:5	3:6-3:11	4:0-4:5	4:6-4:11	5:0-5:11	6:0-6:11	Trial 1		3:0-3:5	3:6-3:11	4:0-4:5	4:6-4:11	5:0-5:11	6:0-6:11
Trial 2		16 secs	15 secs	13 secs	12 secs	22 secs	21 secs	Trial 2		21 secs	18 secs	15 secs	14 secs	25 secs	22 secs

Qualitative observations

Posture/body control

- Sitting posture is poor ☐
- Holds head too close to task ☐
- Holds head at an odd angle ☐
- Does not look at slot while inserting coins ☐
- Does not use pincer grip to pick up coins ☐
- Exaggerates finger movements in releasing coins ☐
- Does not use the supporting hand to hold box steady ☐
- Does extremely poorly with one hand (asymmetry striking) ☐
- Changes hands or uses both hands during a trial ☐
- Hand movements are jerky ☐
- Moves constantly/fidgets ☐

Adjustment to task requirements

- Misaligns coins with respect to slot ☐
- Uses excessive force when inserting coins ☐
- Is exceptionally slow/does not change speed from trial to trial ☐
- Goes too fast for accuracy ☐
- Other _____

Comments: _____

Manual Dexterity 2: THREADING BEADS

Note: 6 beads for 3-4 years, 12 for 5-6 years

Record: Time taken (secs); F for failure; R for refusal; I if inappropriate (note reasons below)

No. of seconds		Only administer a second trial if the first trial takes longer than the time stated below:					
Trial 1		3:0-3:5	3:6-3:11	4:0-4:5	4:6-4:11	5:0-5:11	6:0-6:11
Trial 2		78 secs	79 secs	53 secs	61 secs	60 secs	155 secs

Qualitative observations

Posture/body control

- Sitting posture is poor ☐
- Holds materials too close to face ☐
- Holds head at an odd angle ☐
- Does not look at bead while inserting tip of lace ☐
- Does not use pincer grip to pick up beads ☐
- Holds lace too far from tip ☐
- Holds lace too near tip ☐
- Finds it difficult to push tip with one hand and pull it through with the other ☐
- Changes threading hands during a trial ☐
- Hand movements are jerky ☐
- Moves constantly/fidgets ☐

Adjustment to task requirements

- Sometimes misses hole with tip of lace ☐
- Picks up beads the wrong way round ☐
- Is exceptionally slow/does not change speed from trial to trial ☐
- Goes too fast for accuracy ☐
- Other _____

Comments: _____

Manual Dexterity 3: DRAWING TRAIL 1

Note: Berol pen to be used

Record: Hand used : R/L/Both; No. of errors; F for failure; R for refusal; I if inappropriate (note reasons below)
Number of errors should be counted after testing using scoring criteria provided in Appendix A of the Manual.

	No. of errors
Trial 1	
Trial 2	

Do not administer a second trial if the child completes the first trial perfectly (i.e. no errors).

Qualitative observations

Posture/body control

- Sitting posture is poor ☐
- Holds head too near paper ☐
- Holds head at an odd angle ☐
- Does not look at trail ☐
- Holds pen with an odd/immature grip ☐
- Holds pen too far from point ☐
- Holds pen too close to point ☐
- Does not hold paper still ☐
- Changes hands during a trial ☐
- Moves constantly/fidgets ☐

Adjustment to task requirements

- Progresses in short jerky movements ☐
- Uses excessive force, presses very hard on paper ☐
- Is exceptionally slow ☐
- Goes too fast for accuracy ☐
- **Other** _____

Comments: _____

Aiming & Catching 1: CATCHING BEANBAG

Note: Trapping allowed for 3-4 year olds, not for 5-6

Record: Number of correctly executed catches out of 10; R for refusal; I if inappropriate (note reasons below)

Practice: ☐☐☐☐☐ 10 Trials: ☐☐☐☐☐☐☐☐☐☐ Total: _____

Qualitative observations

Posture/body control

- Standing posture is poor ☐
- Does not follow trajectory of beanbag with eyes ☐
- Turns away or closes eyes as beanbag approaches ☐
- Arms are not raised symmetrically for catching ☐
- Holds hands out flat with fingers stiff as the beanbag approaches ☐
- Hands and arms held wide apart, fingers extended ☐
- Fingers close too early or too late ☐
- Does not move until beanbag strikes body ☐
- Movements lack fluency ☐

Adjustment to task requirements

- Does not adjust body position for catching ☐
- Does not adjust position of feet as necessary ☐
- Does not adjust to height of throw ☐
- Does not adjust to direction of throw ☐
- Does not adjust to force of throw ☐
- **Other** _____

Comments: _____

Aiming & Catching 2: THROWING BEANBAG ONTO MAT

Note: Target is the whole mat, not just the orange circle

Record: Hand used R / L / Both; Number of successful hits; R for refusal; I if inappropriate (note reasons below)

Practice: ☐ ☐ ☐ ☐ ☐ 10 Trials: ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ Total:_____

Qualitative observations

Posture/body control

- Balance while throwing is poor ☐
- Does not keep eyes on target ☐
- Does not use a pendular swing of the arm ☐
- Does not follow through with the throwing arm ☐
- Releases beanbag too early or too late ☐
- Changes hands from trial to trial ☐
- Movements lack fluency ☐

Adjustment to task requirements

- Errors are consistently to one side of target (asymmetry striking) ☐
- Control of direction variable ☐
- Judges force of throw poorly (too much or too little) ☐
- Control of force is variable ☐
- **Other** _____

Comments: _____

Balance 1: ONE-LEG BALANCE

Record: Time balanced (secs); R for refusal; I if inappropriate (note reasons below)

		No. of seconds			No. of seconds
Right Leg	Trial 1		Left Leg	Trial 1	
	Trial 2			Trial 2	

Do not administer a second trial if the child maintains balance for 30 seconds

Qualitative observations

Posture/body control

- Body appears rigid/tense ☐
- Body appears limp/floppy ☐
- Sways wildly to try to maintain balance ☐
- Does not hold head and eyes steady ☐
- Makes no or few compensatory arm movements to help maintain balance ☐

- Exaggerated movements of arms and trunk disrupt balance ☐
- Does extremely poorly on one leg (asymmetry striking) ☐
- **Other** _____

Comments: _____

Balance 2: WALKING HEELS RAISED

Record: Number of correct consecutive steps from the beginning of the line; Whether entire line was walked successfully; **R** for refusal; **I** if inappropriate (note reasons below)

	No. of steps	Entire line?
Trial 1		YES / NO
Trial 2		YES / NO

Do not administer a second trial if the child completes 15 steps OR completes the whole line in fewer than 15 correctly executed steps.

Qualitative observations

Posture/body control

- ☐ Body appears rigid/tense
- ☐ Body appears limp/floppy
- ☐ Sways wildly to try to maintain balance
- ☐ Does not keep head steady
- ☐ Does not compensate with arms to maintain balance
- ☐ Exaggerated arm movements disrupt balance
- ☐ Is very wobbly when placing foot on line

Adjustment to task requirements

- ☐ Goes too fast for accuracy
- ☐ Individual movements lack smoothness and fluency
- ☐ Sequencing of steps is not smooth/pauses frequently
- ☐ **Other** _____

Comments: _____

Balance 3: JUMPING ON MATS

Note: Need only be continuous at 5-6 years

Record: Number of correct consecutive jumps (maximum of 5); **R** for refusal; **I** if inappropriate (note reasons below)

	No. of jumps
Trial 1	
Trial 2	

Do not administer a second trial if the child completes 5 perfect jumps on the first trial

Qualitative observations

Posture/body control

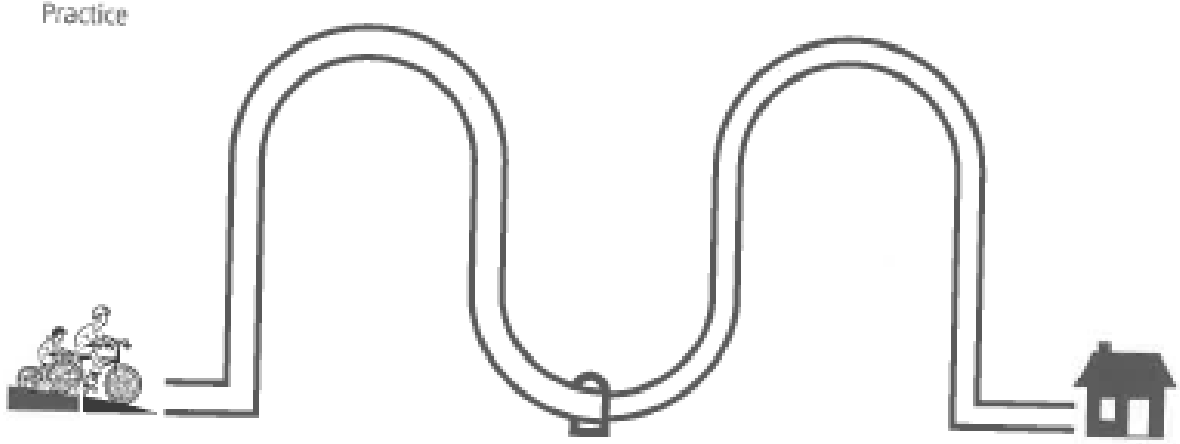
- ☐ Body appears rigid/tense
- ☐ Body appears limp/floppy
- ☐ Makes no preparatory crouch
- ☐ Jumps with stiff legs/on flat feet
- ☐ Arms swing out of phase with legs
- ☐ Arm movements are exaggerated
- ☐ Does not use arms to assist jump
- ☐ Lacks springiness/no push-off from feet
- ☐ Uneven take off and loss of symmetry in flight and landing
- ☐ Stumbles on landing

Adjustments to task requirements

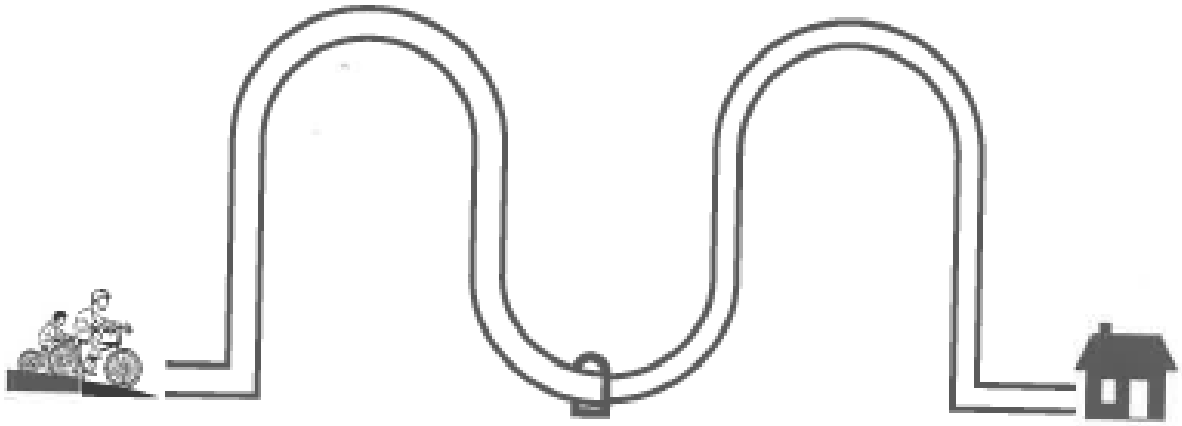
- ☐ Goes too fast for accuracy
- ☐ Does not combine upward and forward movements effectively
- ☐ Uses too much effort
- ☐ Movements are jerky
- ☐ **Other** _____

Comments: _____

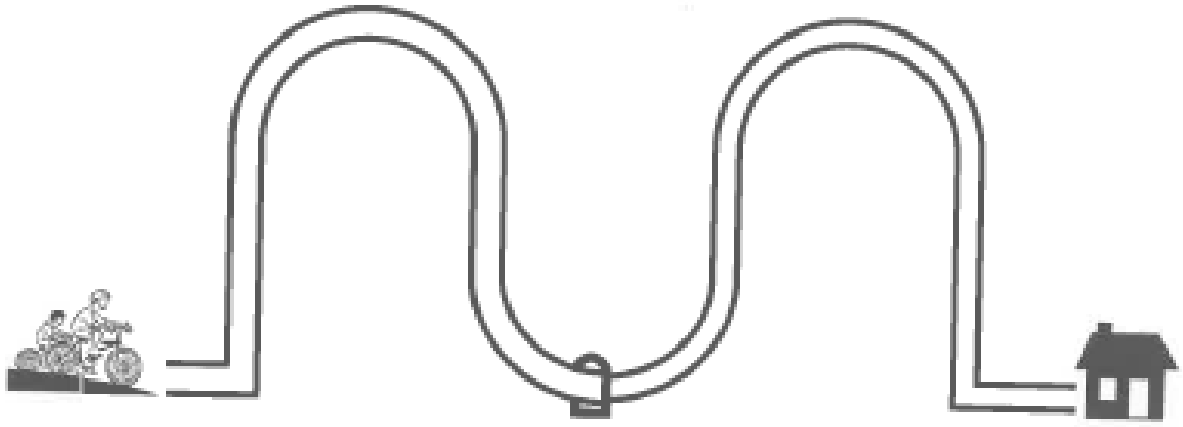
AB1
Practice



Trial 1



Trial 2



Movement Assessment Battery for Children – 2

Test Record Form Age Band 2 (7-10 years)

Name: Gender: M / F

Home address:

School: Class/year/grade:

Assessed by:

Referral source:

Preferred (writing) hand:

	Year	Month	Day
Date tested			
Date of birth			
Chronological age			

Movement ABC-2 Checklist completed? Y / N

Item Scores and Equivalent Standard Scores

Item code	Name of item	Raw score (best attempt)	Item Standard Score
MD 1*	Placing Pegs preferred hand		
	Placing Pegs non-pref hand		
MD 2	Threading Lace		
MD 3	Drawing Trail 2		
A&C 1	Catching with Two Hands		
A&C 2	Throwing Beanbag onto Mat		
Bal 1*	One-Board Balance best leg		
	One-Board Balance other leg		
Bal 2	Walking Heel-to-Toe Forwards		
Bal 3*	Hopping on Mats best leg		
	Hopping on Mats other leg		
Total Test Score Sum of 8 item **standard** scores:			

*For Placing Pegs, One-Board Balance and Hopping on Mats, look up standard score for each limb, add these and divide by 2. If the result is above 10, round up; if below 10, round down.

Three Component Scores*

Manual Dexterity* MD 1 + MD 2 + MD 3	Component score	Standard Score	Percentile
Aiming & Catching* A&C 1 + A&C 2	Component score	Standard Score	Percentile
Balance* Bal 1 + Bal 2 + Bal 3	Component score	Standard Score	Percentile

*In each case sum the item standard scores

Total Test Score	Standard Score	Percentile Rank

*For confidence intervals, see Examiner's Manual p139 (Chapter 7)

1

Manual Dexterity 1: PLACING PEGS

Record: Preferred hand: R / L (should be same as for Drawing Trail); Time taken (secs); F for failure; R for refusal; I if inappropriate (note reasons below)

Preferred hand	
Trial 1	
Trial 2	

Non-preferred hand	
Trial 1	
Trial 2	

Qualitative observations

Posture/body control

- Sitting posture is poor ☐
- Holds head too close to task ☐
- Holds head at an odd angle ☐
- Does not look at board while inserting pegs ☐
- Does not use pincer grip to pick up pegs ☐
- Exaggerates finger movements in releasing pegs ☐
- Does not use the supporting hand to hold board steady ☐
- Does extremely poorly with one hand (asymmetry striking) ☐
- Changes hands or uses both hands during a trial ☐
- Hand movements are jerky ☐
- Moves constantly/fidgets ☐

Adjustment to task requirements

- Misaligns pegs with respect to holes ☐
- Uses excessive force when inserting pegs ☐
- Is exceptionally slow/does not change speed from trial to trial ☐
- Goes too fast for accuracy ☐
- **Other** _____

Comments: _____

Manual Dexterity 2: THREADING LACE

Record: Time taken (secs); F for failure; R for refusal; I if inappropriate (note reasons below)

No. of seconds	
Trial 1	
Trial 2	

Qualitative observations

Posture/body control

- Sitting posture is poor ☐
- Holds materials too close to face ☐
- Holds head at an odd angle ☐
- Does not look at board while inserting tip of lace ☐
- Does not use pincer grip to hold lace ☐
- Holds lace too far from tip ☐
- Holds lace too near tip ☐
- Finds it difficult to push tip with one hand and pull it through with the other ☐
- Changes threading hands during a trial ☐
- Hand movements are jerky ☐
- Moves constantly/fidgets ☐

Adjustment to task requirements

- Sometimes misses hole with tip of lace ☐
- Gets muddled in the threading sequence ☐
- Is exceptionally slow/does not change speed from trial to trial ☐
- Goes too fast for accuracy ☐
- **Other** _____

Comments: _____

Manual Dexterity 3: DRAWING TRAIL 2

Note: BIC Atlantis pen to be used

Record: Hand used: R/L/Both; No. of errors; F for failure; R for refusal; I if inappropriate (note reasons below)
Number of errors should be counted after testing using scoring criteria provided in Appendix A of the Manual.

	No. of errors
Trial 1	
Trial 2	

Do not administer a second trial if the child completes the first trial perfectly (i.e. no errors).

Qualitative observations

Posture/body control

- Sitting posture is poor ☐
- Holds head too near paper ☐
- Holds head at an odd angle ☐
- Does not look at trail ☐
- Holds pen with an odd/immature grip ☐
- Holds pen too far from point ☐
- Holds pen too close to point ☐
- Does not hold paper still ☐
- Changes hands during a trial ☐
- Moves constantly/fidgets ☐

Adjustment to task requirements

- Progresses in short jerky movements ☐
- Uses excessive force, presses very hard on paper ☐
- Is exceptionally slow ☐
- Goes too fast for accuracy ☐
- **Other** _____

Comments: _____

Aiming & Catching 1: CATCHING WITH TWO HANDS

Note: With a bounce at 7 and 8; without a bounce at 9 and 10

Record: Number of correctly executed catches; R for refusal; I if inappropriate (note reasons below)

Practice: ☐☐☐☐☐ 10 Trials: ☐☐☐☐☐☐☐☐☐☐ Total: _____

Qualitative observations

Posture/body control

- Standing posture is poor ☐
- Does not follow trajectory of ball with eyes ☐
- Turns away or closes eyes as ball approaches ☐
- Arms are not raised symmetrically for catching ☐
- Holds hands out flat with fingers stiff as the ball approaches ☐
- Hands and arms held wide apart, fingers extended ☐
- Arms and hands do not 'give' to meet impact of ball ☐
- Fingers close too early or too late ☐
- Movements lack fluency ☐

Adjustment to task requirements

- Does not adjust body position for catching ☐
- Does not adjust position of feet as necessary ☐
- Judges force of throw poorly (too much or too little) ☐
- Does not adjust to height of rebound ☐
- Does not adjust to direction of rebound ☐
- Does not adjust to force of rebound ☐
- **Other** _____

Comments: _____

Aiming & Catching 2: THROWING BEANBAG ONTO MAT

Note: Target is the orange circle, not the whole mat

Record: Hand used: R / L / Both; Number of successful hits; R for refusal; I if inappropriate (note reasons below)

Practice: ☐☐☐☐☐ 10 Trials: ☐☐☐☐☐☐☐☐☐☐ Total:_____

Qualitative observations

Posture/body control

- Balance while throwing is poor ☐
- Does not keep eyes on target ☐
- Does not use a pendular swing of the arm ☐
- Does not follow through with the throwing arm ☐
- Releases beanbag too early or too late ☐
- Changes hands from trial to trial ☐
- Movements lack fluency ☐

Adjustment to task requirements

- Errors are consistently to one side of target (asymmetry striking) ☐
- Control of direction variable ☐
- Judges force of throw poorly (too much or too little) ☐
- Control of force is variable ☐
- Other _____

Comments: _____

Balance 1: ONE-BOARD BALANCE

Record: Time balanced (secs); R for refusal; I if inappropriate (note reasons below)

		No. of seconds			No. of seconds
Right Leg	Trial 1		Left Leg	Trial 1	
	Trial 2			Trial 2	

Do not administer a second trial if the child maintains balance for 30 seconds

Qualitative observations

Posture/body control

- Body appears rigid/tense ☐
- Body appears limp/floppy ☐
- Sways wildly to try to maintain balance ☐
- Does not hold head and eyes steady ☐
- Makes no or few compensatory arm movements to help maintain balance ☐

- Exaggerated movements of arms and trunk disrupt balance ☐
- Does extremely poorly on one leg (asymmetry striking) ☐
- Other _____

Comments: _____

Balance 2: WALKING HEEL-TO-TOE FORWARDS

Record: Number of correct consecutive steps from the beginning of the line; Whether entire line was walked successfully; **R** for refusal; **I** if inappropriate (note reasons below)

	No. of steps	Entire line?
Trial 1		YES / NO
Trial 2		YES / NO

Do not administer a second trial if the child completes 15 steps OR completes the whole line in fewer than 15 correctly executed steps.

Qualitative observations

Posture/body control

- ☐ Body appears rigid/tense
- ☐ Body appears limp/floppy
- ☐ Sways wildly to try to maintain balance
- ☐ Does not keep head steady
- ☐ Does not compensate with arms to maintain balance
- ☐ Exaggerated arm movements disrupt balance
- ☐ Is very wobbly when placing feet on line

Adjustment to task requirements

- ☐ Goes too fast for accuracy
- ☐ Individual movements lack smoothness and fluency
- ☐ Sequencing of steps is not smooth/pauses frequently
- ☐ **Other** _____

Comments: _____

Balance 3: HOPPING ON MATS

Record: Number of correct consecutive hops (maximum of 5); R for refusal; I if inappropriate (note reasons below)

		No. of hops			No. of hops
Right Leg	Trial 1		Left Leg	Trial 1	
	Trial 2			Trial 2	

Do not administer a second trial if the child completes 5 perfect hops on the first trial

Qualitative observations

Posture/body control

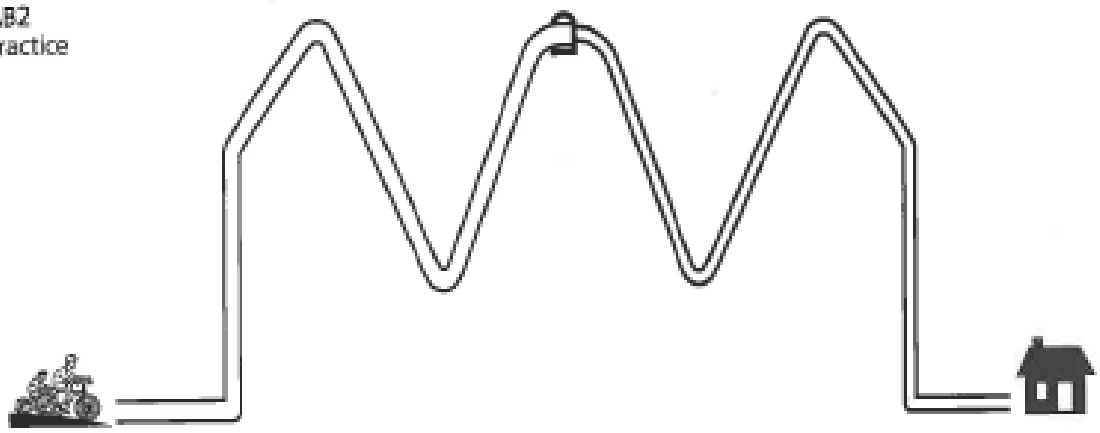
- ☐ Body appears rigid/tense
- ☐ Body appears limp/floppy
- ☐ Non-supporting leg held up in front of body
- ☐ Hops with stiff legs/on flat feet
- ☐ Lacks springiness/no push-off from feet
- ☐ Arm movements are exaggerated
- ☐ Arms swing out of phase with legs
- ☐ Does not use arms to assist hop
- ☐ Stumbles on landing
- ☐ Does extremely poorly with one leg (asymmetry striking)

Adjustments to task requirements

- ☐ Goes too fast for accuracy
- ☐ Does not combine upward and forward movements effectively
- ☐ Uses too much effort
- ☐ Movements are jerky
- ☐ **Other** _____

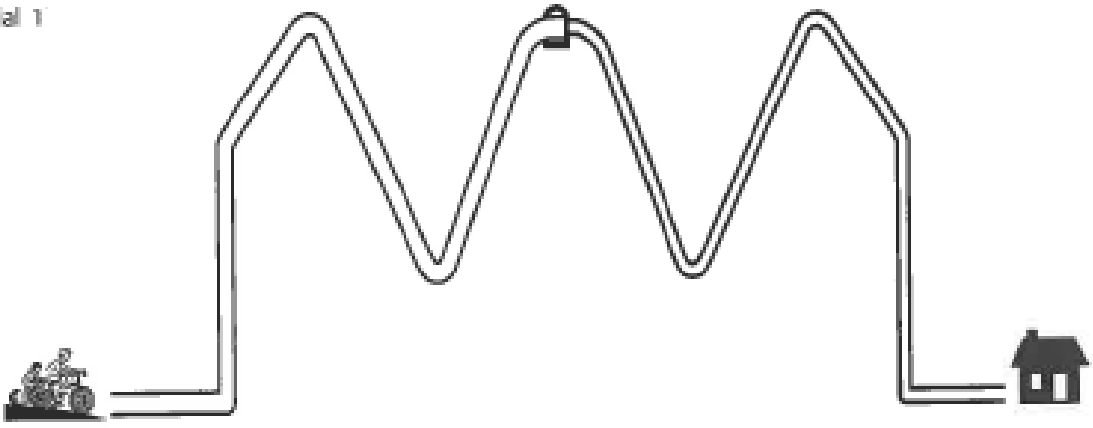
Comments: _____

AB2
Practice



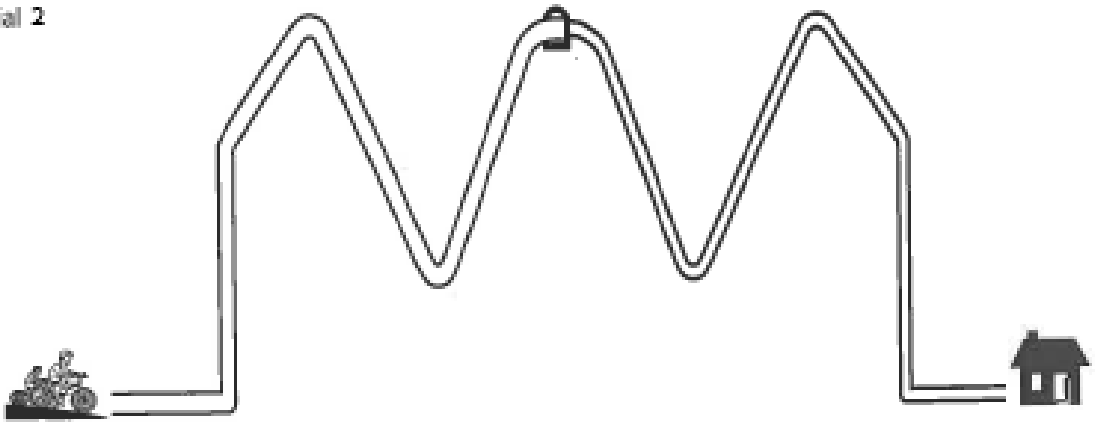
Name _____

Trial 1



Name _____

Trial 2



Name _____

Appendix 8:

Ethical Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Miss Cassandra Rego

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M190656

NAME: (Principal Investigator)	Miss Cassandra Rego
DEPARTMENT:	School of Therapeutic Sciences Department of Physiotherapy Tambo Memorial Regional Hospital
PROJECT TITLE:	The motor function, muscle strength and health related quality of life of children aged 5- 10 years, perinatally infected with HIV, in an urban setting in South Africa
DATE CONSIDERED:	28/06/2019
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Joanne Potterton
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	07/10/2019

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized
to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **June** and will therefore be due in the month of **June** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 9:

Gauteng Department of Health permission

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

OFFICE OF THE CEO
Mr Z K O Ndabula

Tambo Memorial Hospital
: (011) 898-8317
: (011) 892-0358
: Zenzo.Ndabula2@gauteng.gov.za

MEMO

To : Ms Cassandra Rego

From : Mr ZKO Ndabula
Chief Executive Officer

Date : 10 October 2019

Subject : **Request to Carry Out Research at Tambo Memorial Hospital: GP_202001_001**

This serves to grant permission Ms Cassandra Rego to carry out a research study*: The motor function, muscle strength and health related quality of life of children aged 5 – 10 years, perinatally infected with HIV, in an urban setting in South Africa* at Tambo Memorial Hospital. This permission is granted in light of improving the skill capacity of the Gauteng Department of Health.

The permission is granted in line with the code of ethics or research.

The information of the Gauteng Health Department will be used for the purpose of research and it will be utilized discreetly and confidentiality will be maintained at all times.

The permission is granted in good faith with the notion and understanding that the abovementioned clause is upheld.

Furthermore, there should be no financial implication to the hospital.

The collection of data will be the responsibility of the researcher.

Yours Sincerely,

Mr Z K O Ndabula
Chief Executive Officer

Tambo Memorial Hospital
Private Bag X2, Boksburg 1460
Tel No: 011 898-8000

Appendix 10:

Turn it in report

Turnitin Originality Report

Processed on: 27-Apr-2021 6:48 PM SAST
ID: 1571515388
Word Count: 24842
Submitted: 1

Cassandra Rego 794171 Final MSc Research Report By Cassandra Rego

Similarity Index	Similarity by Source
17%	Internet Sources: 14% Publications: 10% Student Papers: 5%

1% match () Chong, Kim Fung. "Food Preference, Foraging, Competition And Control Of The Long-Legged Ant, Anoplolepis Gracilipes (Fr. Smith) (Hymenoptera : Formicidae) [QL568.F7 C549 2008 f rb]", 2008
< 1% match () Potterton, Joanne Louise. "A longitudinal study of neurodevelopmental delay in HIV infected children", 2008
< 1% match () Goldberg, Linda Hazel. "An evaluation of the health related quality of life of children with HIV/AIDS", 2011
< 1% match () Steinberg, Mariam. "Motor development of children attending creches in the Platfontein community", 2017
< 1% match () Ngcobo, Cathrine Batesha. "Caregiver's perceptions of oral health related quality of life among children with special needs in Johannesburg", 2015
< 1% match () Rosie, Samantha Claire. "The neurodevelopmental outcomes of neonatal intensive care unit survivors attending the neonatal follow up clinic at a central academic hospital in Gauteng", 2016
< 1% match () Otten, Kirsty Mae. "The extension of the infant gross motor screening test to include infants from birth to five months in infants with HIV", 2018
< 1% match () Walker, Alison-Jane. "Preliminary investigation into the exercise endurance of HIV infected school going children aged seven to ten years", 2015
< 1% match () Brown, Diana. "Developmental differences between pre-term and full-term 18 month olds", 2010
< 1% match () Corten, Lieselotte. "The use of assisted autogenic drainage in children with acute and chronic respiratory disease", Division of Physiotherapy, 2017
< 1% match () Adams, Larissa. "Effect of school-based interventions on attention and academic performance of primary schoolchildren from lower socioeconomic communities in Port Elizabeth", Faculty of Health Sciences, 2019