



UNIVERSITY OF
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**Paediatric Human Immunodeficiency Virus/Acquired Immune
Deficiency Syndrome related neurological illnesses: The
Multidisciplinary Perspective in an acute quaternary setting**



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Masters in Occupational Therapy



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DECLARATION



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DEDICATION



All challenging work requires self-effort and the guidance of elders especially those who hold a very special place in our hearts.

This study is dedicated to my late grandfather, Mr Sagadavan Mookkunthoo who is my guiding light and inspiration and has steered me through this process.

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First and above all, I praise God for providing me with this opportunity and for granting me the capability to successfully complete this Masters. This thesis appears in its current form due to the assistance and guidance of several people. I would therefore like to offer my sincere thanks and gratitude to all of them.

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I cannot finish without thanking my family. I am eternally grateful to my parents Mr Mannie Sagadavan and Mrs Kogie Sagadavan for their love, inspiration and spiritual support in all aspects of my life. I also would like to thank my sister Samasree Sagadavan for her support and encouragement. Lastly I would like to thank my 90-year-old grandmother, Mrs Muniamma Mookkunthoo, who constantly encouraged and supported me throughout the study.

MY STORY OF LIVING WITH HIV

Nkosikhona Khumalo is a young adult who is diagnosed with HIV. As part of a creative writing initiative, he wrote the following narrative. The article was featured on the 04/12/2016 on News 24. The narrative clearly illustrates the impact of HIV infection on a child. The interaction with the team as well as support groups was identified in the narrative. Furthermore, the impact that a diagnosis of HIV has on a family unit, the loss of roles of the child and the stigma associated with the diagnosis were highlighted. Excerpts from the narrative are emphasized below:

“My story of living with HIV”

“Makhulu¹, why am I always sick?” I asked my aunt. She winced and sat me down. It was strange because she never did this. But before she could even answer the question, I asked: “Makhulu¹, why am I drinking these unpleasant things from the hospital?” I was seven years old and in second grade at Intokozo Primary School in Katlehong, and for as long as I could remember, I had been a weak child who used to go to and from hospital – but I didn’t know why. My now late aunt would just say: “Nkosikhona, we have to wake up at 5am and go to the hospital. You need to be checked.”……Makhulu¹ paused and said: “My child, you are HIV positive. That’s why you drink these medicines, and that’s why I have to ensure you drink them at the correct time and ensure that you eat healthily so you can get better and go to school on a regular basis like every child.”……

“Why are you suddenly concerned, my child?” Makhulu¹ asked me, looking worried.

“It’s because the other children at school always ask me why I am always looking sick.”

“Don’t worry my boy. You drank your medicine, right?” I nodded. “Yes. You’ll be fine soon. Next time they ask you, tell them that you’re sick with asthma.” That’s how I responded to personal health questions from my peers at primary school. I said I had asthma. Because of my illness, I would often miss school. On the days when I didn’t go to school, I was either going to the hospital or to physiotherapy…

It was always fun at the physio because I played a lot of the time. The physiotherapists liked me and gave me a big purple exercising ball. I would kick the bottom of the ball and it would bounce across the room. But I missed being in school. On the days when I was well enough to go, I would get excited. My teachers would also be happy because I was a quick learner who would answer any question asked in class.

But other supposed friends of mine shunned me, claiming I was going to infect them with the virus. Their parents told them to keep their distance. It broke my heart and I was filled with confusion that people were so wrong about the virus. The stigma made me feel deeply isolated. After school, my aunt would take me to a community-based facility called Philafuthi, which dealt with issues such as HIV/AIDS……The doctors were impressed as time went by, and my aunt was happy that I was becoming a normal child. The dark cloud in my life disappeared, like a shadow in the presence of light. I became more confident in myself because I got a chance to live a better life again. Since then, many years have gone by. I am now 19 years old and have just finished my final matric examinations. I am anticipating good results. These past years have been nothing but a journey of perseverance and resilience. This is my story.

Through all I faced in my childhood – the stigma, confusion, sickness and sometimes feeling sad – I still held something deep within me: courage and living a positive life (I hope you get the pun!).

¹Makhulu- Xhosa term of respect for an “older woman”

ABSTRACT

***Introduction:** The HIV/AIDS pandemic has adverse medical and psychosocial effects on affected children, caregivers and imposes significant challenges on health care professionals. The prevalence of Paediatric HIV/AIDS in South Africa and KwaZulu Natal is well documented. The adverse neurological effects of HIV impair optimum neurodevelopment and hence a multidisciplinary team is essential in the management of the sequelae of neurological and neuropsychiatric symptoms associated with HIV/AIDS. The caregiver is regarded as an important partner in the treatment process to ensure adherence and compliance of both medical and rehabilitative components, completion of home programmes and providing of critical collateral information. The lens through which children with HIV/AIDS related neurological illnesses view the rehabilitation process is also crucial to determine effectiveness of therapeutic intervention. **Aims:** This study comprised of three phases. Firstly a profile of the children diagnosed with HIV/AIDS related neurological illnesses admitted to an acute quaternary health care facility was initiated. The second aim was to describe the roles and responsibilities of the multidisciplinary team, their priorities of care as well as to explore the challenges and enablers of service provision as experienced by the team. Furthermore the researcher sought to describe the experiences of primary caregivers and their children who are diagnosed with HIV/AIDS related illnesses in order to highlight some of the challenges and barriers experienced by these end users regarding the service provided by the paediatric neurodevelopmental team. **Methods:** A mixed methods explanatory sequential study design within a multistage framework was utilised. Phase one consisted of a file audit (n=139) to determine the profile of HIV related neurological illnesses in affected children admitted to an acute quaternary paediatric neurology ward. Statistical analysis included the Wilcoxon signed rank test, the Kruskal -Wallis equality of populations rank test, Spearman correlation and the Mann Whitney test. Phase two comprised of the*

administration of a questionnaire to the multidisciplinary paediatric neurodevelopmental team (n=27) followed by a focus group (n=6). The study was concluded with phase 3 detailing semi-structured interviews with primary caregivers (n=5) and children with HIV/AIDS related neurological illnesses (n=3). **Results:** The neurological and neuropsychiatric deficits as a result of HIV/AIDS were identified with the most common central nervous illness being HIV Encephalopathy. Physiotherapy was the predominant service offered to this profile of children. The majority of the functional status scores were categorised between mildly-moderately abnormal except for those children who demised (n=7) who demonstrated severely abnormal - very severely abnormal scores. The multidisciplinary paediatric neurodevelopmental team identified priority management strategies, which informed treatment approaches, roles and responsibilities and barriers and enablers of integrated and holistic care. Primary caregivers of children with HIV/AIDS related neurological illnesses highlighted numerous stressors as well as psychosocial factors relating to the diagnosis and prognosis of HIV/AIDS. Children with HIV/AIDS related neurological illnesses drew on their perspectives when engaging in therapy using both narrative and diagrammatic representation of their experiences. **Conclusion:** The study highlighted the multifarious presentation of paediatric HIV/AIDS related neurological illnesses in an acute quaternary health care facility. Future studies can identify models for intervention and to develop clinical guidelines and protocols as well clinical care pathways for managing children diagnosed with HIV/AIDS related neurological illnesses.

Key words: Paediatric HIV/AIDS, Neurological illnesses, Multidisciplinary team,
Caregiver and Rehabilitation

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DEFINITION OF TERMS

AIDS: AIDS stands for Acquired Immunodeficiency Syndrome. AIDS is the final stage of HIV infection, and not everyone who has HIV advances to this stage. AIDS is the stage of infection that occurs when the immune system is very weak and can become vulnerable to opportunistic infections. When the CD4 cells falls below 200 cells per cubic millimeter of blood (200 cells/mm³), then the infection is considered to have progressed to AIDS (AIDS.gov, 2016).

HIV: Human Immunodeficiency Virus is a retrovirus that infects cells of the immune system, destroying or impairing their function. Infection with the virus results in progressive deterioration of the immune system, leading to immune deficiency (WHO, 2016).

HIV1: HIV-1 is the isolated retrovirus and recognized as the etiologic (i.e. causing or contributing to the cause of a disease) agent of AIDS. HIV-1 is classified as a lentivirus in a subgroup of retroviruses (UNAIDS 2015). Infection with HIV type 1 occurs typically across mucosal surfaces or by direct inoculation (Kassutto & Rosenberg).

HAART: Highly Active Antiretroviral Therapy refers to the use of a combination of antiretroviral medicines that, when used together, can prevent HIV replication and suppress viral load. Often used interchangeably with ART (UNAIDS 2015).

ART: Antiretroviral Therapy is highly active in suppressing viral replication, reducing the amount of the virus in the blood to undetectable levels and slowing the progress of HIV disease (UNAIDS 2015).

Opportunistic infections: Are infections caused by various organisms, many of which

usually do not cause disease in persons with healthy immune systems. Persons living with advanced HIV infection may have opportunistic infections of the lungs, brain, eyes and other organs. In many countries, tuberculosis is the leading HIV-associated opportunistic infection (UNAIDS 2015).

HIV Encephalopathy: HIV Encephalopathy refers to the disease, damage or malfunction of the brain caused by HIV-1. Static HIVE is an unchanging type of encephalopathy, whereas, progressive HIVE is associated with neuroregression (Donald, Walker, Kilborn, Carrara, Langerak, Eley & Wilmshurst, 2015). Encephalopathy must include criteria in at least one of the following areas for at least 2 months in the absence of a concurrent illness: a) failure to attain or loss of developmental milestones or loss of intellectual ability, b) impaired brain growth or acquired microcephaly and/or c) acquired symmetric motor deficit (Center for Disease Control and Prevention, 1994).

CD4: A CD4 count is a lab test that measures the number of CD4 T lymphocytes (CD4 cells) in a sample of blood. In people with HIV, it is the most important laboratory indicator of how well the immune system is working and the strongest predictor of HIV progression. CD4 cells (often called T-cells or T-helper cells) are a type of white blood cells that play a major role in protecting the body from infection. The CD4 count of an uninfected adult/adolescent who is generally in good health ranges from 500 cells/mm³ to 1,600 cells/mm³. A very low CD4 count (less than 200 cells/mm³) is one of the ways to determine whether a person living with HIV has progressed to stage 3 infection (AIDS) (AIDS.gov, 2016).

Viral Load: The term “viral load” refers to the amount of HIV in a sample of blood. A viral load test is a lab test that measures the number of HIV virus particles in a milliliter of blood. These particles are called "copies" (AIDS.gov, 2016).

Multidisciplinary: Different disciplines that are working on a problem in parallel or sequentially, and without challenging their disciplinary boundaries (Choi & Pak, 2006).

Transdisciplinary: Involves scientists from different disciplines as well as non-scientists and other stakeholders and through role release and role expansion, transcends the disciplinary boundaries to look at the dynamics of whole systems in a holistic way (Choi & Pak, 2006).

Caregiving: Caregiving is the process of helping another person who is unable to do so in a holistic (physically, mentally, emotionally and socially) manner. Caregiving is facilitated by certain character traits, emotions, skills, knowledge, time and an emotional connection with the care recipient (Hermanns & Mastel-Smith, 2012).


Rehabilitation: Rehabilitation of people with disabilities is defined as a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools that they need to attain independence and self –determination (WHO, 2016).

Neurodevelopment: Neurodevelopment is a term referring to the brain's development of neurological pathways that influence performance or functioning.

Quaternary care: Quaternary care is considered to be an extension of tertiary care- even more specialised and highly unusual.

Interventions: An intervention is a combination of program elements or strategies designed to produce behaviour changes or improve health status among individuals or an entire population.

ABBREVIATIONS



AIDS:	Acquired Immunodeficiency Syndrome
ART:	Anti-Retroviral Therapy
CNS:	Central Nervous System
HAART:	Highly Active Antiretroviral Therapy
HIV:	Human Immunodeficiency Virus
HIVE:	HIV Encephalopathy
KZN:	KwaZulu Natal
MDT:	Multidisciplinary Team
MTCT:	Mother-to-child transmission
SA:	South Africa
SSA:	Sub-Saharan Africa
WHO:	World Health Organization
UNAIDS:	Joint United Nations Programme on HIV/AIDS

OUTLINE OF THE DISSERTATION

The ***Introductory Chapter*** (Chapter 1) comprises of an overall introduction to the study including the relevant literature, context of study, research questions, aims and objectives, problem statement and rationale as well as a brief overview of the methodology, ethical considerations and the theoretical framework guiding the study.

The ***First Manuscript***, (Chapter 2) is entitled: ***A Retrospective Review and Evaluation of Functional Status: Profile of children admitted to an acute quaternary institution with HIV/AIDS related neurological illnesses over a 6-year period.*** The manuscript focuses on the neurological and neuropsychiatric co-morbidities of HIV infected children and describes their functional status and participation in activities of daily living. The manuscript is formatted according to the guidelines instituted by The South African Journal of Child Health (SAJCH). This includes an abstract, introduction, methodology, results, discussion and conclusion. Tables and figures are embedded within the text to allow for ease of reading.

The ***Second Manuscript*** (Chapter 3) is entitled: ***Potential for best practice: Management of Paediatric HIV/AIDS related neurological illnesses: The multidisciplinary team perspective.*** The manuscript focuses on the roles and responsibilities of the MDT as well as the priorities of care in managing children with HIV/AIDS related neurological illnesses. The functional outcomes that the team works towards will be described as well as various challenges and barriers impacting on care will be highlighted. The manuscript is formatted according to the author guidelines recognized by the Journal of Developmental Medicine and Child Neurology. The

manuscript includes an abstract, introduction, methodology, results, discussion and conclusion. Tables and figures are embedded within the text to allow for coherency.

The ***Third Manuscript*** (Chapter 4) is entitled: ***The Paediatric Neurodevelopmental Team: Did we get it right? The voices of the caregivers and children.*** This manuscript focuses on the experiences of primary caregivers and children diagnosed with HIV/AIDS related neurological illnesses. The manuscript is formatted according to the guidelines provided by The South African Journal of HIV Medicine. This manuscript includes an abstract, introduction, methodology, results, discussion and conclusion. Tables, drawings and figures are embedded within the text to allow for ease of reading.

A ***Synthesis*** (Chapter 5) provides a summary of the study, highlighting the significance and implications of the study, conclusions and recommendations.

CHAPTER 1

INTRODUCTION

1.1 BACKGROUND AND CONTEXT OF THE STUDY

Human immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) is defined as an immune deficiency retrovirus that infects cells of the immune system, destroying or impairing their function. As the infection progresses, the immune system becomes weaker and the person becomes more susceptible to infections (World Health Organisation (WHO), 2016).

HIV1 is defined as the isolated retrovirus and is the etiologic agent of AIDS. It is classified as a lentivirus in a subgroup of retroviruses (UNAIDS, 2015). Primary HIV 1 infection involves a highly active relationship between the host and the virus (Kassutto & Rosenberg, 2004).

HIV remains a major global public health concern. In 2015, approximately 1,1 million people succumbed to HIV-related deaths. Statistics on a global level indicated that at the end of 2015 there were approximately 36,7 million people living with HIV with almost 2,1 million people becoming newly infected with HIV. Sub-Saharan Africa (SSA) is the most affected region. Statistics specify that in 2015 roughly 25,6 million people were living with HIV. Furthermore SSA accounts for two-thirds of the global total of new HIV infections (WHO, 2016).

South Africa (SA) has the largest incidence of the HIV pandemic with a prevalence rate of approximately 40% in KwaZulu-Natal (KZN) (Ubesie, 2012). The estimated number of HIV-infected children in each province was recorded as nearly 100,000 in KZN and <3000 in the Northern Cape (Meyers, Moultrie, Naidoo, Cotton, Eley & Sherman, 2007). Consequently there has been an exponential increase in the number of children infected

with HIV. Paediatric HIV/AIDS is one of the leading contributors of childhood morbidity and mortality (Onankpa, Airede, Paul & Dorcas, 2008).

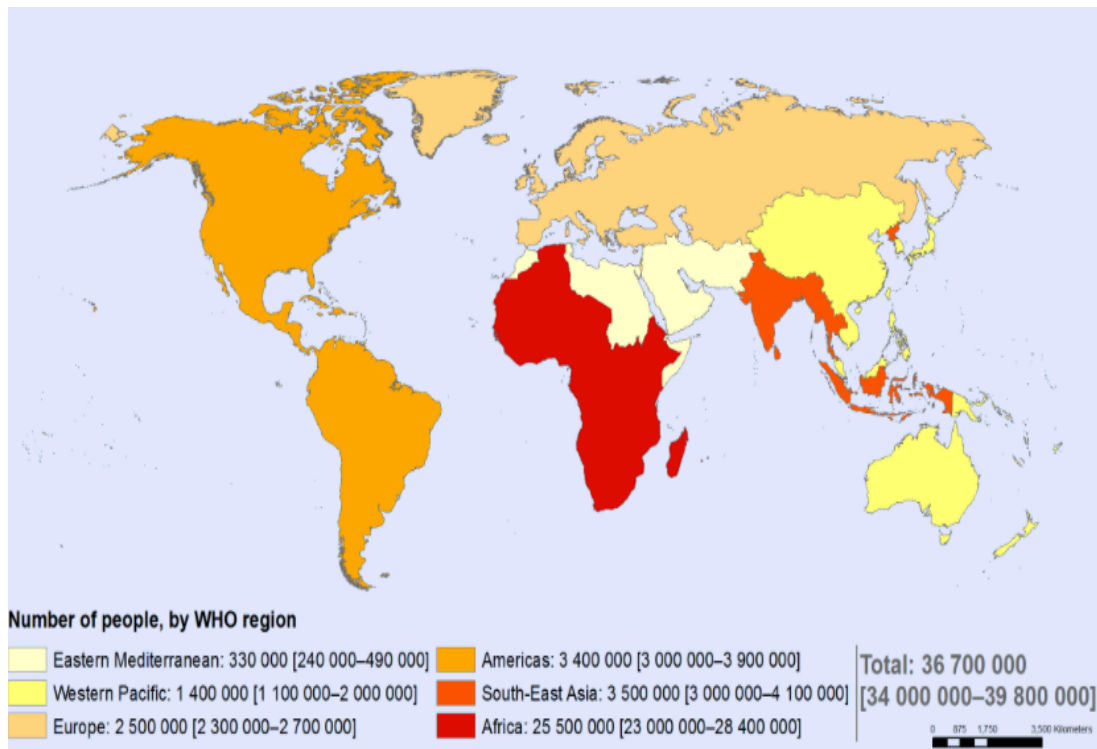


Figure 1 World Statistics: Adults and children estimated to be living with HIV, 2015 –WHO region (WHO, 2016)

Neurological abnormalities such as language deficits and developmental delays are frequently associated with HIV1 infected children with neuroimaging demonstrating ventricular enlargements and or sulcal widening as well as white matter lesions (Van Arnhem, Bunders, Scherpbier, Majoie, Reneman, Frinking, Poll-The, Kuijpers & Pajkrt, 2013).

The effects of HIV on a child is extensive and can impact on multiple systems such as the nervous system, musculoskeletal system, circulatory system, special senses, skin and respiratory system. HIV manifests in numerous domains of a child’s development. As a result of HIV infection, deficits can be seen in physical, motor, sensory–perceptual, cognitive and speech and language development. There has been some research into Paediatric HIV and neurodevelopment in SSA. Abubaker, Van Baar, Van de Vijver,

Holding & Newton (2008) established that the development of sensorimotor skills were delayed, with motor development being one of the most commonly assessed developmental milestone that provided evidence of delay in HIV infected children of all ages.

Van Rie, Mupuala & Dow (2008) described the neurodevelopmental outcomes of preschool aged children infected with HIV as a result of the HIV/AIDS pandemic in the Congo. The results from this study confirmed the multiplicity of deficits and delays in the developmental sequelae of children infected with HIV. Sixty percent (60%) of HIV infected children demonstrated severe delays in cognitive functioning whilst twenty nine percent (29%) presented with severe motor delays. Language expression and comprehension yielded significantly higher deficits (85% and 77% respectively) (Van Rie et al, 2008).

Paediatric HIV/AIDS can be described as a multidimensional and multigenerational disorder. The initial diagnosis has endless implications for both the family and the child. HIV/AIDS continue to bear adverse consequences on affected children and a variety of neurodevelopmental deficits have been described. The health concerns in view of the neurological and neuropsychiatric manifestations require integrated medical, nursing, psychosocial and rehabilitative intervention.

1.2 OVERVIEW OF LITERATURE REVIEW

1.2.1 Introduction

In this section, concepts regarding the Epidemiology of HIV/AIDS, International Policies such as the Sustainable Development Goals as well as South African legislation and frameworks will be discussed. Concepts pertinent to this study include paediatric HIV/AIDS, neurodevelopmental deficits and the neurological and neuropsychiatric manifestations of HIV/AIDS affecting this paediatric population. Thereafter the multidisciplinary team approach, the caregivers' perspective as well as the child's perspective in a hospital setting will be presented.

Various articles were found searching PubMed, Google Scholar and KZN Health Intranet e-Learning Online Study Material. Search terms used included the following: “Pediatric HIV/AIDS, Paediatric HIV/AIDS, Neurodevelopment of HIV infected children, Multidisciplinary team work in paediatrics; Caregivers of HIV infected children and Developmental delays in HIV infected children”.

1.2.2 Epidemiology

According to the WHO, Global summary of the AIDS Epidemic 2015, the number of children (<15 years) living with HIV is 1,8 million. Approximately 150 000 children have been newly infected with HIV in 2015. The magnitude of morbidity was emphasised as the number of AIDS related deaths for children (<15 years) was recorded as 110 000. The reported number of children (0-14 years) receiving antiretroviral therapy in SSA was estimated at 495 700. The burden of the disease was further highlighted as SSA remains the most severely affected region with statistics signifying that 1 in every 25 adults (4,4%) are living with HIV. SSA accounts for nearly 70% of the global total of new HIV infections (WHO, HIV Department, 2016).

Statistics SA (2016) projected the mid-year population as 55,91 million. KZN was described as the province with the second largest population with approximately 11,1 million people (19.9%) residing in this province. The statistics further reported that nearly 30,1% of the population are aged younger than 15 years and of those younger than 15 years, approximately 23,0% (3,86 million) reside in KZN. The estimated overall HIV prevalence rate is approximately 12,7% of the total South African Population. The total number of people living with HIV in SA is projected at approximately 7,03 million in 2016 (Statistics South Africa, Mid-year estimates, 2016).

The highest provincial HIV prevalence was recorded in KZN, which has increased from 37,4% in 2012 to 40,1% in 2013. In 2013 five health districts, all located in KZN recorded the highest HIV prevalence ranging from between 40,0% to 45,9%. These five districts

were UMkhanyakude (44,1%), eThekwini (41,1%), UMgungundlovu (42,5%), UGU (41,1%) and UThukela. Moreover, statistics in 2013 indicated that two in every five pregnant women attending antenatal care in KZN public health clinics were HIV positive (National Antenatal Sentinel HIV Prevalence Survey, 2013).

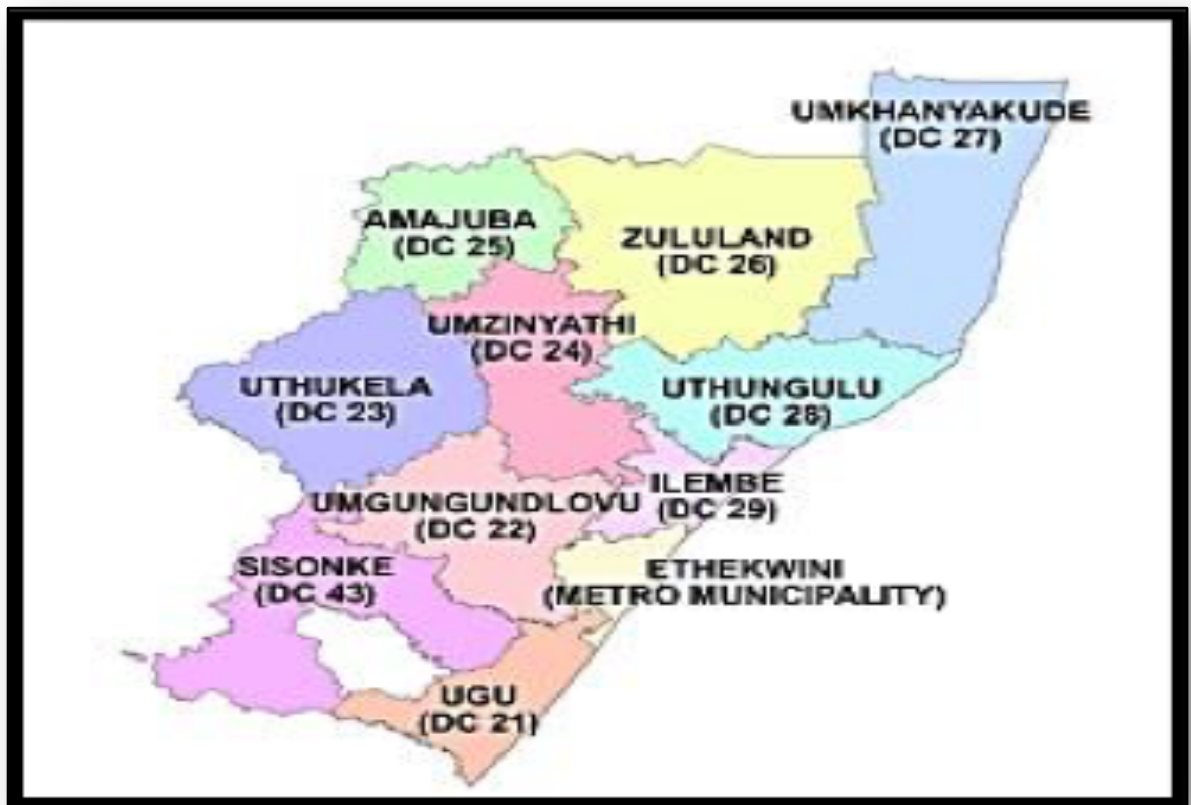


Figure 2 Map of the districts of KwaZulu-Natal (Trade & Investment: KwaZulu Natal, 2016)

The Actuarial Society of South Africa estimated that in 2010 the total number of HIV positive people living in KZN was 1 599 512 and the cumulative AIDS deaths was recorded as 1 487 357. In 2010, infant mortality rates in KZN were reported as 61 per 1000 live births and child mortality rates as 122 per 1000 live births (Dorrington, Bradshaw & Budlender, 2002). Accordingly children aged 0-4 accounts for 10,4% of all deaths in SA. Forty percent (40%) of deaths in children under the age of five are caused by HIV related illnesses (UNICEF, 2007).

1.2.3 Health Policies, Frameworks and Legislations

The *Sustainable Developmental Goals* were adopted at the United Nations General Assembly (United Nations Development Programme, 2016). The goal pertaining to this study is to ensure healthy lives and wellbeing of people of all ages. These goals predict that by 2030 there should be an end to all avoidable deaths of new-borns and the under-five age group as well as an end to the AIDS epidemic (Universal Sustainable Development Goals, Osborn, Cutter & Ullah, 2015).

Due to the alarming statistics and the direct bearing on the health sector in SA, legislations, frameworks, models and approaches have been adapted to meet the challenge of HIV/AIDS.

The *National Strategic Plan of the Department of Health*, Republic of SA for the period 2012-2016 is a framework designed to monitor activities relating to HIV, STI's (Sexually transmitted infection) and TB (Tuberculosis) as well as to deliver goals and strategies relating to diseases that the country face. The goals relating to HIV, as outlined by the National Department of Health, include reducing the numbers by half of new HIV infections, to guarantee that at least 80% of people who are entitled to HIV treatment are in receipt of it, to safeguard the rights of those living with HIV and to decrease the stigma and discrimination associated with being infected with the HIV virus. Increasing life expectancy and supporting the health and the wellbeing of all people infected with HIV/AIDS is deemed essential with core approaches identified as decreasing the number of deaths and disabilities acquired as a result of HIV, speedy referrals of all complex cases and implementation of specific policies in the treatment of paediatric patients infected with HIV/AIDS. This is to ensure that all South African's diagnosed with HIV/AIDS are followed up within the health sector and that interventions offered are compatible to their needs (The South African National Strategic Plan 2012-2016).

The *Aids Effectiveness Framework for Health in SA* has acknowledged that HIV/AIDS and TB are the greatest detriments to the wellbeing of all South Africans. Accordingly this has

placed a paramount burden on the health system. The challenge continues to prevail which has resulted in woman and children being exposed to South Africa's high and alarming growth rate of burden of diseases where numerous children have succumbed to diseases on a yearly basis (Aids Effectiveness Framework for Health in SA, 2011).

Clinical staging of Paediatric HIV is classified by WHO from stage 1 to stage 4 increasing in severity, with stage 3 described as moderate symptoms and stage 4 as severe. This is necessary as it assists with defining prognosis and commencement of antiretroviral therapy (National Department of Health, 2010).

1.2.4 Models for Paediatric HIV Management in SSA

Naidoo and Willis (2002) described the eradication of Paediatric HIV in SSA based on the premise of five models. The first medical model describes that it is the responsibility of health care workers to ensure holistic care of HIV infected children, those affected children as a result of the burden of HIV/AIDS as well as their families. It was proposed that there should be a shift from isolated services and intervention to a more integrated approach. The second model describes behavioural change. The third model highlights the social aspect, which suggests that certain cultural practices influence the management of Paediatric HIV/AIDS in SSA. Empowerment as the fourth model suggests that HIV infected children should demonstrate autonomy in their care, managing their diagnoses and relying on various support structures. The radical change model was described as change that is required in SSA to bridge the gap that governs Paediatric HIV/AIDS. Inadequate human resources, lack of suitable infrastructures at health establishments and ineffective health guidelines were cited as reasons for poor health systems in SSA (Ubesie, 2012).

1.2.5 Neuropathology and neuro-pathogenesis of HIV 1

The central nervous system (CNS) is protected from toxins and infectious pathogens by

the blood brain barrier. All components of the neural axis comprising of the brain, spinal cord and peripheral nerves are infected by the lentivirus which results in virus mediated damage. HIV enters the CNS through a process described as neuroinvasion. HIV 1 infects the leukocytes. These infected leukocytes cross through the blood brain barrier and the virus enters the CNS. The HIV virus infects infiltrating macrophages, astrocytes and microglia. Subsequently this process results in injury to the neurons, neural stem cells and astrocytes (Boissé, Gill & Power, 2008).

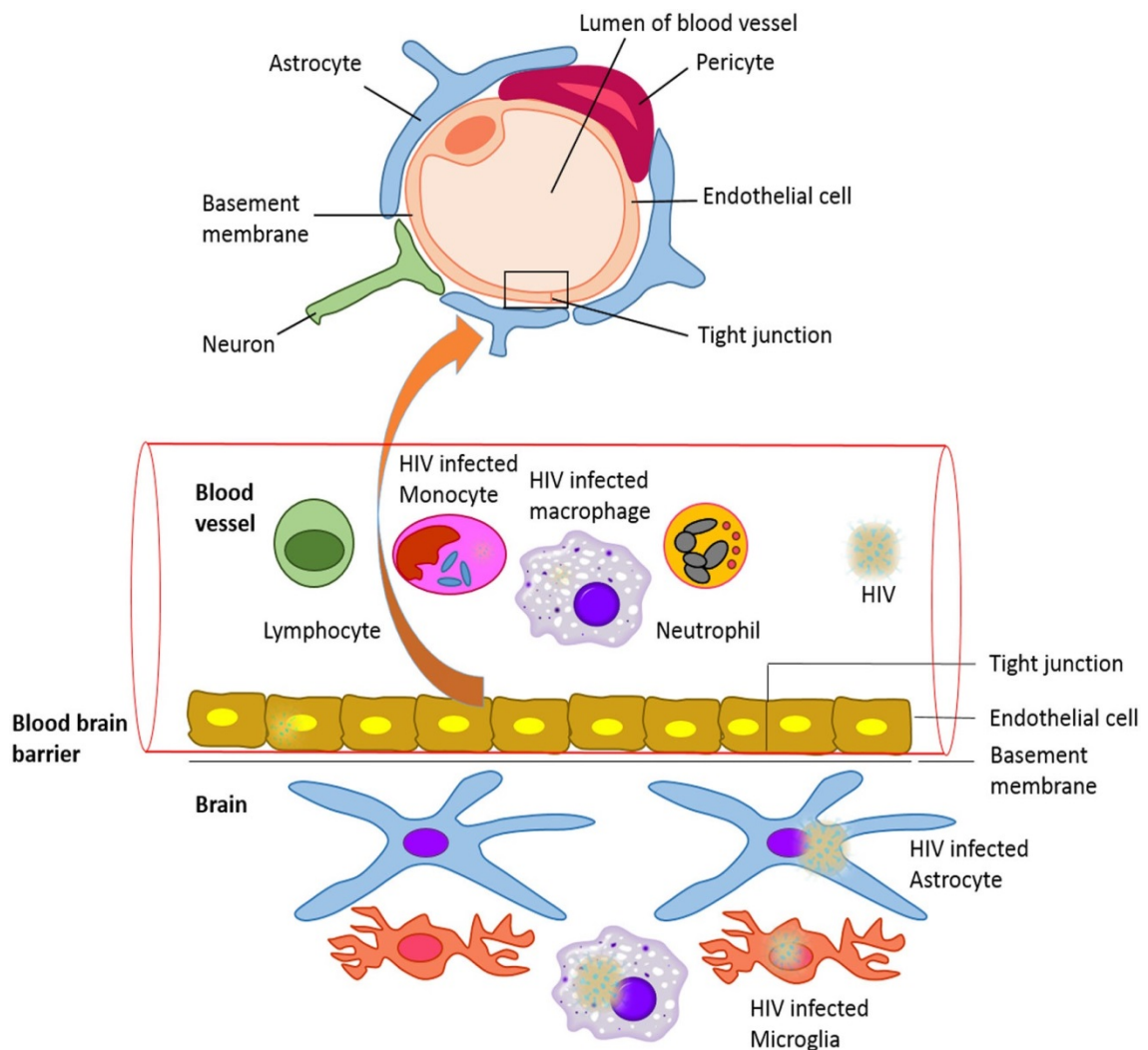


Figure 3 The blood-brain barrier with HIV infected cells: Schematic representation of structure of the blood brain barrier and HIV infected cells in blood and CNS (cited in Atluri, Hidalgo, Samikkannu, Kurapati, Jayant, Sagar & Nair, 2015)

1.2.6 Highly Active Anti-Retroviral Therapy (HAART)

With the initiation of HAART many children have a prolonged life expectancy. In a study conducted in KZN, the preliminary outcomes of a cohort of 151 paediatric patients over a 25-month period were reported upon. The findings suggested that a family centred HAART program in a resourced limited environment could be effective. Despite the economic and social burden placed on HIV infected children, the study indicated that this cohort of children with an advanced level of HIV disease responded to treatment (Reddi, Leeper, Grobler, Geddes, France, Dorse, Vlok, Mntambo, Thomas, Nixon & Holst, 2007).

1.2.7 Mother to child transmission (MTCT)

Mother to child transmission (MTCT) is considered to be the most common path of transmission to children infected with HIV. The risk of vertical transmission from HIV-infected mothers to their infants within a South African context is estimated to be around 19% - 36%, depending on whether or not the mother is breastfeeding. However, a study conducted in Khayelitsha, SA, with a population of 535 mother and infant pairs receiving primary mother to child transmission (PMTCT) intervention recorded the rate of transmission of HIV from mother to child as 8,8% (Coetzee, Hilderbrand, Boulle, Draper, Abdullah & Goemaere, 2005). PMTCT is an integral component in preventing HIV transmission to infants. Various recommendations within a South African context have been outlined to deal with improving PMTCT as well as services to provide antiretroviral therapy to children (Meyers et al, 2007).

1.2.8 Paediatric HIV/AIDS

The progression of HIV infection to AIDS in children is more rapid as compared to adults. Early identification of paediatric patients diagnosed with HIV is essential to allow them access to holistic care. KZN has successfully increased the number of children in receipt of antiretroviral drugs (Meyers et al, 2007).

Several studies have described the effects of HIV/AIDS on the paediatric population. Research has discussed the manifestations of the HIV/AIDS pandemic and the neurodevelopmental outcomes and challenges that these children are faced with. (Mawela, 2007, Abubaker et al, 2008 & Meyer et al, 2008).

Studies conducted in SSA are of paramount importance to the global stance on the management of paediatric HIV/AIDS as approximately 80% of all HIV1 infected children are from SSA (Abubaker et al 2008).

There are numerous HIV related illnesses in infected children. Common conditions associated with HIV include HIV Encephalopathy (HIVE), seizures, respiratory deficits such as pneumonia, bronchiectasis, renal and cardiac conditions, gastro-intestinal and haematological related disorders (Rabie, Marais, Van Toorn, Nourse, Goussard, Sellers & Cotton, 2007). Developmental milestones were assessed and it was established that HIV infected children were significantly delayed as compared to their uninfected counterparts (66.6% vs. 5.7%) (Sherr, Mueller & Varrall, 2009).

1.2.9 Facets of impaired neurodevelopment

1.2.9.1 *Cognitive Development*

Sherr et al, (2009) systematic review affirmed that approximately 81% of studies reported an unfavourable effect of HIV on the neurocognitive development of HIV infected children as compared to control groups. Out of the eight studies analysed, seven were from SSA. Children infected with HIV scored lower in both accuracy and speed of cognitive aptitudes. Cognitive abilities involving executive functions proved problematic for HIV infected children. Children with HIV are likely to present with scholastic difficulties and will require special care and consideration due to possibilities of cognitive decline in various areas of development. It was suggested that early onset childhood intervention with sensory stimulation be afforded to these children to halt the progression of cognitive deficits (Sherr, Croome, Castaneda, Bradshaw & Romero, 2014). When compared to age

specific norms, HIV infected children scored poorer on neuropsychological testing relating to executive functions such as mental flexibility. Correlation between higher CD4 percentages and initiation of HAART and increased duration of treatment were associated with improved outcomes in executive mental function (Koekkoek, de Sonnevile, Wolfs, Licht & Geelen, 2008).

1.2.9.2 *Motor development*

Children with HIV present with delays in all domains of functioning with the most noticeable dysfunction recorded in motor development across all age groups. A moderate level of impairment was noted as early as 6 months of age and a severe impairment was noted by 18 months of age (Abubaker et al 2008). Forty HIV infected infants from the age band 18-30 months were assessed at Chris Hani Baragwanath Hospital and findings indicated that 85% (n=34) presented with delayed gross motor skills and mean motor age was delayed by approximately 9,65 months (Baillieu & Potterton 2008). Similarly in a study conducted in Cape Town comprising of 51 HIV infected children, two thirds (66,6%) presented with motor delay as compared to 7,7% in the age matched group (Ferguson & Jelsma, 2009). Children who present with motor delays at an early onset serve as a predictor of being at risk of disease progression (Pearson, McGrath, Nozyce, Nichols, Raskino, Brouwera, Lifschitz & Englund, 2000).

1.2.9.3 *Behavioural*

Anxiety, depression and attention deficit disorders are behavioural difficulties noted with HIV infection (Donald, MPhil, Hoare, Eley & Wilmshurst, 2014). A study conducted in the Dominican Republic comprising of a sample of 43 children with HIV from the age band 2-8 years indicated a high proportion of clinical ranges (40%-46%) for anxiety, withdrawal, depression and the internalisation of feelings. The older age group of children in the study displayed aggressive behaviour (Mendoza, Hernandez-Reif, Castillo, Burgos, Zhang & Shor-Posner, 2007). Contrary to this, behavioural functioning was measured and it was

recognised that HIV infected children when compared to children with other diagnoses such as asthma indicated that the HIV infected child displayed improved outcomes in terms of social behaviours and friendship abilities. This was documented due to a well-established and integrated multidisciplinary approach (Sherr et al, 2014).

1.2.9.4 *Language and hearing development*

Linguistic development is a higher order function of the brain and delays in speech and language was noted across all age groups (Smith, Adnams & Eley, 2008). Language delays were noted in children infected with HIV. Expressive language was considerably impaired as compared to receptive language and despite anti-retroviral therapy both domains of language skills declined significantly (Wolters, Brouwers, Civitello & Moss, 1997). Hearing loss coupled with developmental delays in children with AIDS can pose significant difficulty with communication and language (Layton & Davis-McFarland, 2000).

1.2.10 HIV/AIDS Related CNS Manifestations

One of the most severe complications of HIV is CNS involvement. Knight, Mellins, Levenson, Arpadi & Kairam (2000) suggested that CNS is the prime pathway through which HIV affects mental and psychomotor development (Knight et al, 2000). The management of HIV/AIDS infected children in SSA remains inadequate. Approximately 50%-90% of HIV infected infants and children without antiretroviral therapy will develop CNS complications (Donald et al 2014).

1.2.10.1 *HIV Encephalopathy*

Encephalopathy may occur in the early phase of HIV infection and approximately 88,1% of children may show signs in their first two years of life. In vertical transmission of HIV, infection to the CNS occurs when the brain is still immature. The pattern of disease progression depends on the stage of the developing brain and period of infection. As a

result of prenatal HIV 1 infection to the brain there is a decrease in brain cell production leading to impaired brain growth and atrophy (Hilburn, Potterton & Stewart, 2010).

Neurological illness can be classified as direct or indirect. Direct complications involve the CNS and the most commonly seen diagnosis is HIVE (Donald, Walker, Riordan, Govender & Wilmshurst, 2012). According to WHO the clinical diagnosis of HIVE informs that the child should present with at least one following presentations; failure to attain or loss of developmental milestones or loss of intellectual ability or progressive impaired brain growth demonstrated by stagnation of head circumference or acquired symmetrical motor deficits accompanied by two or more of the following: paresis, pathological reflexes, ataxia and gait disturbances (WHO Case definitions, 2007).

HIVE can be further divided as progressive, where there is failure to achieve developmental milestones or static where affected children present with some delay as compared to their counterparts and abilities are achieved at a slower rate (Donald et al, 2012). Smith et al (2008) reported similar findings in that the HIV virus affects the CNS and the incidence of HIVE is between 13%-35%. HIVE is usually the first sign of disease progression to AIDS in approximately 18% of HIV infected children (Smith et al, 2008).

HIVE in SSA has been recognised and documented. It is imperative to note that severe delays are seen in motor, language and cognitive domains as a result of HIVE. Motor delays were the most noticeable as children use movement skills to interact with the environment. Hence this has a negative effect on children diagnosed with HIVE, as they are restricted with stimulation and social interaction. Therefore physical therapy plays an instrumental role in the treatment, management and early identification of neuro-regression and developmental delays associated with HIVE (Hilburn et al, 2010).

1.2.10.2 *Other Neurological illnesses*

Stoke or cerebro-vascular conditions account for approximately 2,6% of focal neurological deficits. Nearly 5% of HIV 1 infected children may be susceptible to peripheral

neuropathies and clinical signs include loss of muscle power, pain, sensory changes and impaired mobility. The clinical presentations of myopathies include loss of muscle strength in limbs. Disease specific complications include epilepsy with the presence of seizures. Bacterial meningitis and tuberculous meningitis are common opportunistic infections seen in HIV 1 infected children. CNS lymphomas is the most common form of oncology related diagnosis seen in paediatric HIV/AIDS (Donald et al, 2012). HIV infected children are predisposed to opportunistic infections and thromboembolic strokes (Smith et al, 2008).

1.2.10.3 *Neuropsychiatric manifestations*

Neuropsychological manifestations with poor concentration and attention skills and hyperactivity are also noted with children diagnosed with HIV (Donald et al, 2012). The prevalence for psychiatric disorders in perinatally infected children varies between 55%-61% (Vranda & Mothi, 2013). HIV infected children are predisposed to additional risks for psychiatric illnesses including but not limited to poverty, limited social support and chaotic home environments. Children diagnosed with HIV/AIDS are susceptible to psychiatric hospitalisation during childhood and early adolescence (Gaughan, Hughes, Oleske, Malee, Gore & Nachman, 2004). Children and adolescents with HIV may be predisposed to psychiatric conditions such as affective disorders, attention-deficit hyperactivity disorder and psychosis which can result in poor adherence and compliance to treatment, increased suicidal risk and distress (Brown & Lourie, 2000).

1.2.11 Paediatric HIV/AIDS and Intervention

Management of the HIV infected child in Africa is restricted and for effective management, all children require access to health care workers and for those team members to organise a therapeutic intervention plan that is specific to the individual needs of each child (Mawela, 2007).

Crucial to the management of an HIV infected child with neurological deficits is the multidisciplinary team (MDT) approach. Hilburn et al 2011 described the importance of physical therapy in the treatment of HIV as therapists are adequately trained to assess neurodevelopmental outcomes. In resource scarce settings individualised home programmes are necessary to encourage development. The MDT therefore incorporates a family centred care approach (Hilburn et al, 2011).

A multidisciplinary approach is recommended for the treatment and management of HIV-infected children with CNS involvement. As such paediatric HIV/AIDS patients with severe neuro-regression and failure to achieve developmental milestones require intervention from the rehabilitation team (Donald et al, 2012).

Services namely physiotherapy, occupational therapy and speech therapy were identified as rehabilitative interventions required in managing neurological conditions associated with HIV as well as collaboration with caregivers to improve functional prognosis (Rabie, et al 2007).

Mubaiwa, Rapiti & Govender (2005) proposed the following model of multidisciplinary care in the management of children with HIV related developmental disabilities. A multidisciplinary team approach is best suited to manage children with HIV associated neurological illnesses and children should be reviewed every three months (Mubaiwa, Rapiti & Govender, 2005).

Multidisciplinary approach

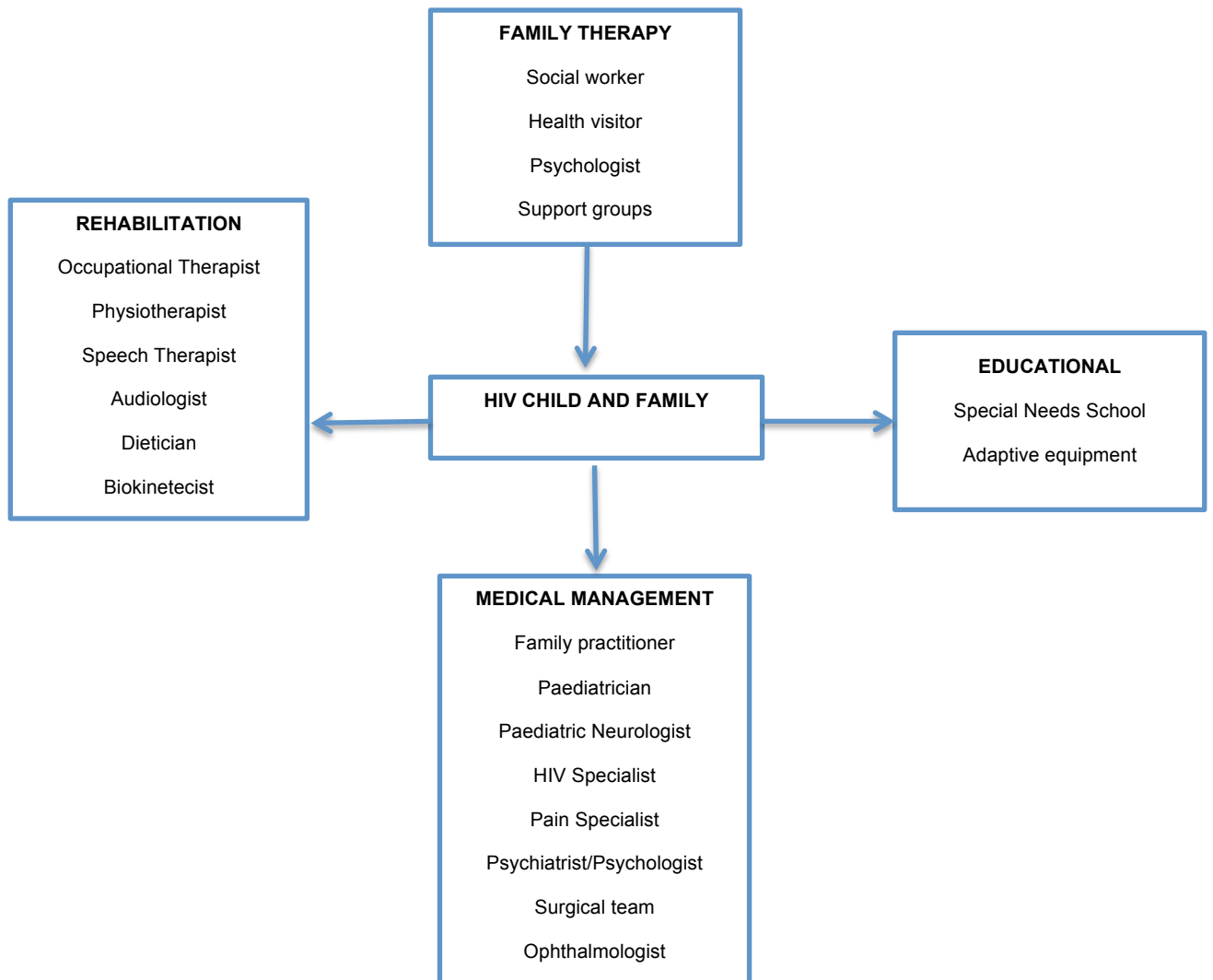


Figure 4 Multidisciplinary team approach for children with HIV related developmental disabilities (Mubaiwa, Rapiti & Govender, 2005)

Merely 39% of HIV infected children at age 2 undergo a neurological examination. Children with HIV/AIDS from Africa are exposed to low socio-economic factors, decreased stimulation and poverty. Therefore to enhance development, programmes should be geared towards addressing all domains of a child's functioning i.e. the physical, emotional and the social aspect (Donald et al, 2014).

1.2.12 Hospital services

Due to the high burden and prevalence of HIV/AIDS referral to the applicable level of care is necessary based on the treatment required for the child. Dedication and responsibility is required by all ranks of management in order to decrease childhood mortality rates (Feucht, 2013).

HIV infection and in-hospital mortality rates in an academic hospital in SA (Chris Hani Baragwanath Hospital) have increased. In 1996 approximately half of the deaths at the hospital were related to HIV. Additionally high rates of mother to child transmission were recorded between 26% - 42%, thereby increasing the incidence of Paediatric HIV infection (Zwi, Pettifor, Soderlund & Meyers 2000).

Approximately 1,5-29% of hospital admissions were accounted for children with HIV in Africa. Within a tertiary setting the findings correlate with the above study where prevalence of mother to child transmission is ever increasing and paediatric HIV/AIDS remains a major cause of childhood mortality and morbidity (Onankpa et al, 2007).

Child neurology services in Africa and referral patterns from primary to tertiary care were described as unpredictable. A need was established to enhance training and development across Africa to manage and treat paediatric neurological conditions from a primary level to a specialist centre (Wilmhurst, Badoe, Wammanda, Mallewa, Kakooza-Mwesige, Venter & Newton 2011).

Paediatric Neurology services in SA as identified by Wilmhurst in 2009, reported that approximately 60% of admissions to general paediatric wards in KZN are as a result of HIV. The plight of services at that stage was outlined regarding specialists employed in the government sector in KZN. This was recorded as one neurodevelopmental paediatrician and three paediatric neurologists (Wilmhurst, 2009).

Dong, Thabethe, Hurtado, Sibaya, Dlwati, Walker & Wilson (2007) indicated that HIV infection is a major challenge for the public sector in KZN.

1.2.13 Children and Families affected by HIV/AIDS

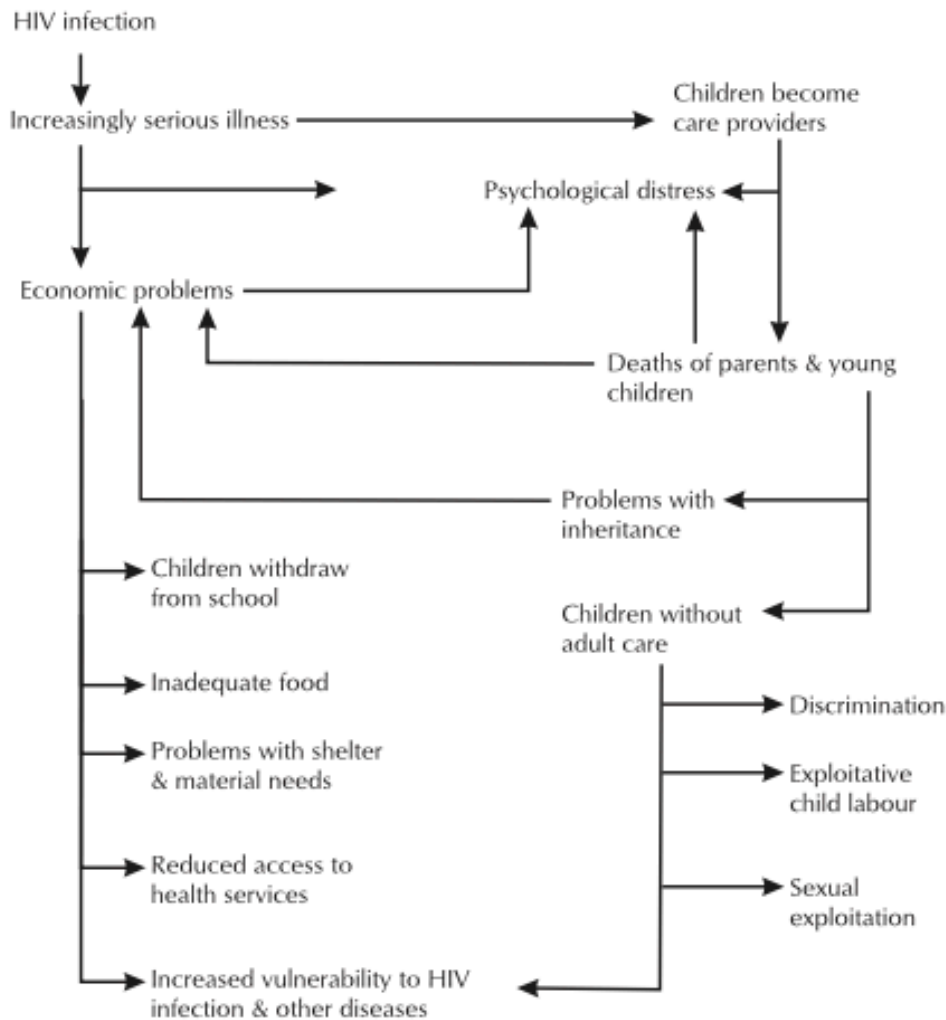


Figure 5 Children and Families affected by HIV (cited in Foster & Williamson, 2000)

The above model describes the impact of impact of HIV/AIDS on children in SSA. A greater understanding of the impact of HIV/AIDS on children is important. The impact of HIV/AIDS on children and their families and caregivers are compounded by poverty, inadequate infrastructure and reduced access to basic services. Due to HIV/AIDS children are affected by the pandemic and are often orphaned at early age or are expected to take on many more responsibilities. As a result of parents demise, children affected by HIV/AIDS are now the responsibility of the extended family (Foster & Williamson, 2000). The psychosocial implications of HIV/AIDS and its bearing on caregivers impacts on the child's development. In households affected by HIV/AIDS a child's attendance at school is

affected due to reduced financial resources. Long-term psychological effects of emotional deprivation are found in children affected by HIV/AIDS (Richter, 2004).

1.2.14 Multi -disciplinary teamwork

A MDT consists of healthcare practitioners working together with different scopes of practice. Benefits of working within a MDT were described as discussing patient care and the plan of intervention, working in collaboration rather than in isolation and engaging each member of the MDT with difficult cases. Working within a MDT helps reduce burnout and fatigue and helps reduce stress especially when dealing with children with poor prognosis. Goal setting, good communicative skills, respect and mutual consideration and recognition of each team member's contribution are integral for the functioning of the MDT. Institutional factors such as lack of infrastructure, budget constraints, increased patient loads and poor conflict management may result in stress within the workplace. Recognition of effort, career pathing and fairness within the work environment may lead to gratification within the workplace (Gulati, Dix & Klassen 2014).

Factors for effective teamwork were highlighted by a study in a neonatal unit where it was suggested that team members need to identify common goals and intervention plans, display good communication and collaborative skills and show respect towards each member of the team (Brown, Ohlinger, Rusk, Delmore & Ittmann 2003). These sentiments were further echoed in a study involving paediatric diabetes where the best possible outcome for treatment was through a prepared MDT that focused on providing a high level of care and service delivery (Bowen & Rothman, 2010).

Successful outcomes in health care are related to inter-professional and transdisciplinary teamwork. Factors that influence success of inter-professional teamwork include transparency, good management and leadership, common goals, effective communication as well as the expertise of health care workers. A mutual care plan is necessary for effective management in the health care sector (Vyt 2008).

Similarly Wilson & Pirrie (2000), established that facilitators of multidisciplinary teamwork include commitment of team members, having a common vision, negotiation of roles and responsibilities of the team members and support from the institution. Inhibitors of multidisciplinary teamwork include restricted infrastructure and resources and negative attitudes of the team members (Wilson & Pirrie, 2000).

1.2.15 Caregiver of Paediatric patients

Caregivers of children with HIV have increased levels of stress. Emotions and feelings of helplessness were reported as these caregivers experience difficulty in providing adequate care for their children. Often caregivers themselves are diagnosed with HIV and experience difficulty in managing their own diagnosis. Poverty and financial constraints were reported as factors that impact on stress. Caregivers should be referred to the MDT as these supportive measures are linked to decreased parenting stress (Potterton, Stewart & Cooper 2007).

Murphy, Christian, Caplin & Young (2006) highlighted similar findings with caregiving of children with disabilities. The study reported of increased levels of stress, negative impact on the caregiver's health, difficulty in dealing with the burden of a having a sick child and the uncertainty regarding the future (Murphy et al, 2006).

Providing caregivers with tools that they can identify with, scheduling of visits and providing written information such as resource materials emerged as themes that would assist caregivers and facilitate team intervention (Fisher & Dusick 2014).

1.2.16 Child's perspective

Children view hospitalisation as a stressful event. Health professionals need to acknowledge adverse events that impact on the child's stay in hospital. Effective

communication skills between all health care members and a “*child- centred*” approach is essential to improve participation in the intervention plan (Coyne, 2006:68-69).

Similar findings were underpinned in a study conducted by Söderbäck, Coyne & Harder (2011). The views of a child should be supported allowing them to be involved in the “*decision- making process*” (Söderbäck et al, 2011:104).

Health care professionals are tasked in designing programmes based on the individualised needs of each child. A familiar and non-threatening environment should be provided so that they are more likely to participate in treatment as well as being allowed to express an opinion in their intervention plan (Runeson, Hallstrom, Elander & Hermeren 2002).

1.2.17 Functional Status Score and Modified Barthel

The Functional Status Score was developed following consensus by a multidisciplinary team. Domains of functioning include: mental status, sensory, communication, motor, feeding and respiratory. These domains are classified from normal to very severely abnormal.

A study by Pollack et al described this tool as an appropriate means to categorise functional status (Pollack, Holubkov, Glass, Dean, Meert, Zimmerman, Anand, Carcillo, Newth, Harrison & Willson, 2009). The Modified Barthel Index was previously used on children with low-grade gliomas and provided an estimate of the overall wellbeing of the child and ultimately the impact on quality of life (Jalali, Dutta, Kamble, Gupta, Munshi, Sarin & Dinshaw, 2008).

1.2.18 Future trends

In 2020 approximately 1,86 - 2,22 million children are expected to be living with HIV. Improved mother to child transmission programmes, early identification of infants infected with HIV, optimizing drug provision and the development and up scaling of service

delivery are required to reduce paediatric HIV infection (Penazzato, Martina, Bendaud, Victoria, Nelson, Lisa, Stover, John, Mahy & Mary, 2014). This is supported by the UNAIDS where strategies identified to reduce the paediatric HIV epidemic requires a holistic approach by service providers which encompass medical, psychosocial, legal and community support services (UNAIDS 2014).

1.2.19 Conclusion

HIV/AIDS remains a chronic medical condition. It is a disease that affects all spheres of a child's life. Due to the multi system involvement, HIV/AIDS can pose severe detriments on a child's potential to participate in activities of daily living such as school, home and community survival. Therefore a MDT approach is necessary to decelerate the effects of HIV/AIDS and manage the neurological complications associated with this disease. Perusal of literature surrounding the research revealed limited articles relating to the involvement of the MDT in treating children diagnosed with HIV/AIDS related neurological conditions. Therefore this study is crucial in highlighting the experiences of the MDT employed within an acute quaternary setting in treating and managing these children so as to provide optimal service delivery. Furthermore due to the paucity in literature surrounding the MDT and paediatric HIV related neurological diseases, this study serves to identify gaps and help improve clinical care pathways and standards of practice.

1.3 PROBLEM STATEMENT AND RATIONALE

Paediatric HIV associated neurological complications have been documented in about 50%-60% of children with CNS involvement (Donald et al, 2012). The neurological impediments of HIV-1 can be classified into direct and indirect complications. Direct involvement of the CNS includes those conditions related to HIV 1 infections of the brain. Indirect complications include opportunistic infections. The most frequently documented direct complication relating to the CNS in Paediatric HIV is HIVE. Other neurological

manifestations of Paediatric HIV include cerebral-vascular accidents, peripheral neuropathies and myopathies, epilepsy, opportunistic infections, behavioural and neuropsychological deficits (Donald et al, 2012).

The impact of HIV/AIDS is compounded by socio-economic factors and barriers such as poverty, unemployment, the increase in orphaned children with HIV, poor nutrition, lack of infrastructure and restricted child stimulation.

Sherr et al, (2014) study outlined the developmental challenges experienced by HIV infected children. This updated review highlighted that for appropriate care to be rendered to HIV positive children it is integral to understand the cognitive abilities and developmental indicators in order to treat effectively and plan appropriate services (Sherr et al, 2014).

The study is located at the first central quaternary public hospital in SA, which was opened in 2002. This hospital provides accessible quality patient care to all persons in KZN and part of the Eastern Cape. A quaternary hospital provides sub-specialised services. The hospital functions on the basis of a private public partnership. The quaternary hospital has a specialised unit for paediatric neurology and the hospital's main catchment area is KZN and part of Eastern Cape. The specialist hospital does not have a specific outpatient facility for treatment of children diagnosed with HIV/AIDS. Therefore all cases referred to this quaternary institution are complex and involve the complications associated with HIV/AIDS within a neurological context such as children with uncontrolled seizures. To this end care offered by medical practitioners and clinicians are highly specialised, acute and in need of a holistic approach.

The current care plan from the Department of Health 2014 indicates a continuum of care from the initial stages of HIV testing and counselling, commencement of care and treatment, to overall HIV care and retention in care. It also recognises that the patient may

cycle in and out of care. Furthermore it includes all aspects of Anti-retroviral Therapy (Department of Health, 2014).

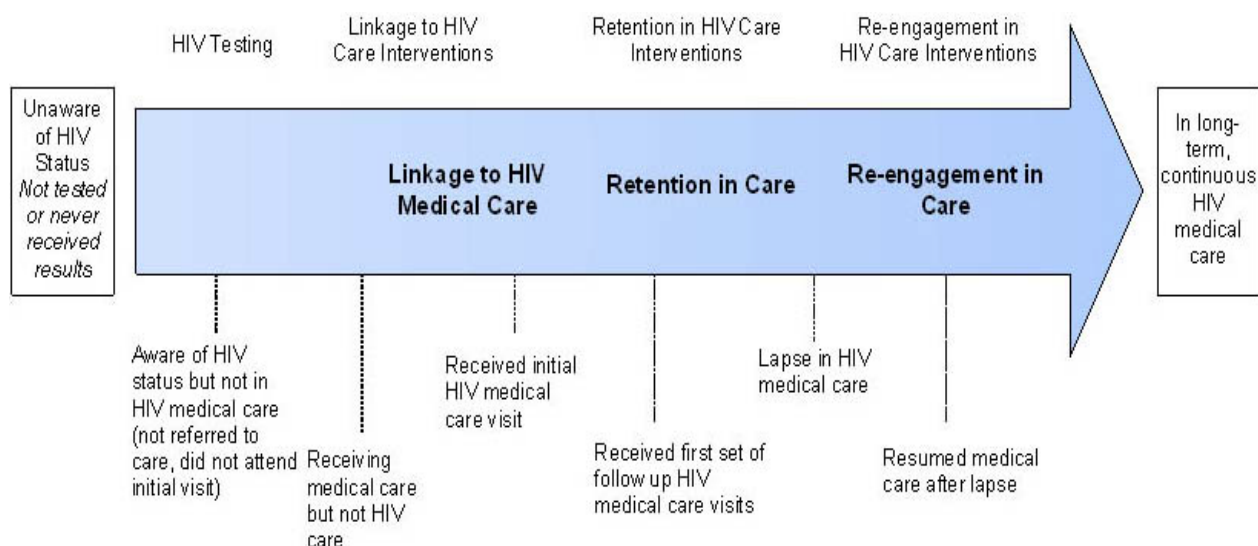


Figure 6 The HIV Continuum of Care approach (National consolidated guidelines for the Prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults, 24 December 2014, Department of Health)

At the quaternary hospital, the policy for care of HIV infected Paediatric Patients states that the management of these children requires a team of compassionate health care workers due to the HIV illnesses, to treat and manage opportunistic infections, reduce threat of cross infection and acknowledge despairing parents. The procedure outlined that the application of universal procedures for infection control must be adhered to, to identify early signs of infection, to take cognisance of opportunistic infections and the immuno-compromised child, referral to the social worker for financial assistance and counselling and to ensure that the child is adequately nourished (Hospital policy and procedure number MC56).

The Occupational Therapy department currently does not have a specific clinical protocol or procedure for paediatric neurology or for the care of the child infected with HIV. The Occupational Therapist will assess a child referred from Paediatric Neurology and complete a musculoskeletal and functional assessment. Treatment is then directed

towards managing the physical and cognitive manifestations and includes but is not limited to splinting, rehabilitation to minimise contractures or deformities, normalisation of tone, facilitation of normal movement patterns using neurodevelopmental approaches, play and sensory stimulation, activity participation to improve level of function, caregiver programmes and ordering of adaptive and surgical appliances.

As per the referral policy at the specialist quaternary health care facility, these children are then discharged to the base hospital where intervention and rehabilitation is focused and geared towards the reintegration of the child back into the home, community and school.

The quaternary health care facility requires regular attendance at ward rounds to ensure patient care, to ensure MDT activities are working towards a common goal, to communicate information to caregivers, to evaluate progress and facilitate learning and teaching by all members of the team (Hospital policy and procedure N160).

The Occupational Therapist is required to attend ward rounds so as to adopt a MDT approach to treat holistically, to provide efficient treatment and to inform the team regarding progress (Occupational Therapy policy number OCTH 03).

The Department of Health, National core standards indicator supporting multidisciplinary teamwork indicates that therapeutic support services contribute to the holistic care and rehabilitation of patients (National core standards for health establishments in SA, 2011).

Baseline assessments are often completed at the referral hospitals and diagnoses are confirmed at the specialist quaternary hospital, following intensive medical and radiological investigations. Subsequently the management and treatment of paediatric HIV/AIDS related neurological illnesses is reliant on an integrated and multidisciplinary approach of the medical and nursing team, rehabilitative experts, the primary caregiver as well as compliance of the patient and adherence to the management and treatment plan.

In a developing country there is limited information available on the MDT approach in

managing paediatric patients with HIV/AIDS related neurological illnesses. Furthermore there is limited research that includes both the child and caregiver perspective, which has not been identified as a priority within a developing health care system. Therefore it is from this perspective that it has become necessary to conduct this research study to identify the multidisciplinary perspective in the management of Paediatric HIV/AIDS related neurological illnesses. A multi-dimensional approach to Paediatric HIV/AIDS related neurological illnesses is required taking into account the developmental markers on a physical, cognitive and psychosocial level. Taking cognizance of the above will serve to answer questions that will help improve and understand the dynamic patterns associated with Paediatric HIV/AIDS related neurological illnesses and assist health care practitioners to holistically manage this vulnerable population.

1.4 RESEARCH QUESTIONS, AIMS AND OBJECTIVES

1.4.1 Research Questions

- What is the profile of paediatric patients with HIV/AIDS related neurological illnesses referred for intervention to the paediatric neurodevelopmental team within a 6-year period?
- How does the paediatric neurodevelopmental team manage paediatric patients diagnosed with HIV/AIDS related neurology?
- What is the experience of primary caregivers and patients with regards to MDT intervention?

1.4.2 Aims and objectives

Aim 1: To ascertain the profile of paediatric patients with HIV/AIDS related neurological illnesses referred for intervention to the paediatric neurodevelopmental team at the specialist quaternary health care facility between January 2010 to December 2015.

Objectives

- To describe the demographics and socio-economic status of the paediatric patients referred for intervention to the paediatric neurodevelopmental team.
- To determine the primary diagnosis and other co-morbidities or differential diagnosis of the paediatric patients.
- To describe the medical, radiological and rehabilitative interventions offered to the paediatric patients and prognosis and prognostic indicators outlined by last assessing practitioner.
- To determine the duration of stay and repeated admissions of the paediatric patients.

Aim 2: To explore and describe how the MDT manages paediatric patients with HIV/AIDS related neurology in an acute quaternary setting.

Objectives

- To identify the healthcare workers that form part of the MDT in the care of paediatric patients with HIV/AIDS related neurological conditions.
- To identify the priorities of care that the MDT adopts in order to provide holistic, comprehensive and integrated care.
- To ascertain the roles, interventions and responsibilities of the MDT in the management of children with HIV/AIDS related neurological disorders.
- To explore the functional outcomes that the MDT works towards when treating children with HIV/AIDS related neurological abnormalities in an acute tertiary setting.
- To explore the enabling factors that facilitate successful management of children with HIV/AIDS related neurological disorders.

- To determine the challenges and barriers that impact on an effective team approach.

Aim 3: To explore the experiences and perceptions of primary caregivers and children diagnosed with HIV/AIDS related neurological illness with regards to intervention offered by the paediatric multi-disciplinary neurodevelopmental team.

Objectives

- To explore primary caregivers experience of having a child with HIV/AIDS related neurological illness with regards to the MDT therapeutic intervention they received.
- To explore the experience of children in their rehabilitative process.

1.5 GENERAL METHODOLOGY

This section describes the research methodology used in the study and includes the setting, population, sampling, data collection method, pilot study, data collection process, data analysis and data management.

1.5.1 Research Design

This study followed a mixed methods explanatory sequential design within a multistage framework. This design is characterized by the analysis of the quantitative data followed by the collection of qualitative data, which builds on and informs the results of the initial quantitative data (Creswell, 2013).

The advantages of an explanatory sequential design is that it provides an opportunity to explore quantitative results in detail and when unexpected results may arise from the quantitative aspect of the study (Ivankova, Creswell & Stick, 2006).

The multistage framework is defined by multiple stages with the research study (Fetters, Curry & Creswell, 2013). The multi stage mixed methods framework was selected, as there were multiple stages of data collection. This study involved three phases within the larger study of the management of Paediatric HIV/AIDS related neurological illnesses. In a health care environment the study generated ideas associated with the performance and perspectives of the multidisciplinary team. The data were integrated and reported through a narrative where the researcher described the qualitative and quantitative findings in a series of manuscripts (Fetters et al, 2013).

1.5.2 Location of the Study

The study was conducted at a specialist quaternary central hospital. The hospital hosts highly specialized referral units, which together provide an environment for multi-specialty clinical services, innovation and research and provides the highest level of health care. The quaternary specialist health care facility is located in the Ethekewini district of KZN, SA. It provides specialist services to patients from KZN and part of the Eastern Cape.

1.5.3 Study Population, Recruitment and Sampling

Three sets of participants were included in the study, namely the MDT, the paediatric patients and primary caregivers. Homogenous purposive sampling was used (Patton, 1990). According to Patton (1990), the reason and strength behind purposeful sampling is in selecting information rich cases for in-depth study. Information rich cases refer to those cases where one can acquire a vast amount of information central to the purpose of the research. Purposive sampling is used in both qualitative and quantitative research designs and is most effective when one needs to research a particular cultural realm with well-informed experts (Tongco, 2007).

1.5.3.1 Phase A: File Audit and Profile

Retrospective patients (n=139) were accessed using the paediatric neurology electronic database. All medical files between the periods January 2010 to December 2015 were audited. Patients with a confirmed diagnosis of HIV infection and presenting with neurological complications were included in the study. Neonates were excluded from the study as they are admitted into the neonatal intensive unit. Retrospective research is encouraged as medical files represent important forecasts when used for the benefit of the patient and may assist in answering critical medical questions by linking pre-existing medical data (Gearing, 2006).

1.5.3.2 Phase B: MDT

The paediatric neurodevelopmental team employed at the specialist quaternary health care facility include the Paediatric Neurologist, Medical Officers, Registrars, Nurses, Physiotherapists, Occupational Therapists, Speech Therapist and Audiologist, Social Worker, Dietician and Psychologist. As this is an acute institution there are no community service officers and interns employed in the medical and allied to medical departments. Therapists work within a ward rotation basis for a specific time period or through a handover system in a colleagues' absence. Therefore in all likelihood they may have treated paediatric patients with HIV/AIDS neurological related illnesses.

Approximately 27 participants within the MDT were involved in the study. A staff list accessing the hospital's main telephone directory was used to invite the MDT to participate in the focus group (n=6). Focus groups are used to generate collective information and views, the meanings behind these views and are necessary to provide a rich and in-depth understanding of the participant's beliefs and perspectives (Gill, Stewart, Treasure & Chadwick, 2008).

An email outlining the purpose and benefit of study was provided to each of the participants. Members of the MDT who had interaction and hands on approach in

assessing and treating the child diagnosed with HIV/AIDS related neurological illnesses were included in the study. Members of the MDT who did not have any physical therapy time with the child, other than for diagnostic purposes e.g. Radiologist and Clinical Technologist were excluded.

1.5.3.3 Phase C: Child and Caregiver

1.5.3.3.1 Children

Depending on the severity of diagnosis paediatric patients are admitted into the Paediatric ICU (ICU4), once stable they are transferred to Paediatric High Care (C4W) or directly to the ward (B1E). Most of the rehabilitation occurs in the ward. Depending on the cognitive status of the patient, the age group selected allowed for communication and interaction to explore the experiences of the child. Children diagnosed with HIV/AIDS related neurological illness, who were cognitively alert and were able to converse with the researcher in either English or IsiZulu were included. An Interpreter was utilised to facilitate the process. The age group 4 - 12 years was targeted. Children with low Glasgow Coma Scales, those admitted for palliative care and with significant premorbid complications e.g. recurrent seizures were excluded from the sample. Moreover any child admitted to the ward by a family member unaware of the child's HIV status was excluded. Overall 3 children were included in the sample.

1.5.3.3.2 Caregivers/Parents

Certain caregivers were accommodated at the Mother's Lodge. The Hospital policy on Mother's Lodge/Boarder Mothers states that the mother will be accommodated at the hospital if they are breastfeeding, if the child is critically ill or with special needs (Hospital policy and procedure MC11). The researcher purposively selected five primary caregivers to participate in the study. The caregivers all had a child diagnosed with HIV/AIDS related neurological complications who were admitted to the paediatric neurology ward.

1.5.4 Data Collection Strategies

Several forms of data collection tools were used in this study namely a file audit data extraction sheet, questionnaire, focus group and semi-structured interviews.

1.5.4.1 Phase A: File audit

A file audit data extraction sheet (Annexure 4) was used to extract data from Soarian (the electronic medical reporting system at the specialist health care facility).

The following information was accessed:

Demographic profile (age, gender and race)
Socio-economic status of the family (area of residence)
Primary diagnosis
Differential/secondary diagnosis and co-morbidities
Medical, rehabilitative and radiological investigations and intervention
Length of admission and if the child has had any repeated admissions
Prognostic details using the Functional Status Scale (admission and discharge summaries)
The Modified Barthel Index (level of independence in activities of daily living)

1.5.4.2 Phase B: MDT

A questionnaire (Annexure 9) was designed and administered to all members of the MDT (n=27). Currently there is no standardised data collection tool on the management of paediatric HIV/AIDS related neurological illnesses and involving a multidisciplinary team perspective. As such the researcher designed a questionnaire that was informed by literature on paediatric HIV/AIDS related neurological illnesses and the multidisciplinary team approach. Boynton & Greenhalgh (2004) reported that questionnaires allows for objectivity by means of collecting information regarding a person's knowledge, attitudes, beliefs, and behaviour.

Adequate representation from all members of the paediatric neurodevelopmental team was obtained thereby providing a holistic picture of the management of Paediatric HIV/AIDS related neurological conditions in an acute quaternary setting.

The questionnaire included the following subsections:

Section A: Profile and Demographics (Question 1 and 2)

Section B: Vocational History and Training (Question 1 to 9)

Section C: Management of Paediatric HIV/AIDS related neurological illnesses (Question 1 to 16)

Section D: MDT Management of Paediatric HIV/AIDS related neurological illnesses (Question 1 to 14)

Section E: Caregiver involvement (Question 1 to 3)

Section F: Teamwork (Question 1 and 2)

A Focus group (Annexure 13) was completed with 6 members of the paediatric neurodevelopmental team. The team members included a Medical Doctor, Physiotherapist, Occupational Therapist, Clinical Psychologist, Social Worker and Nurse. The paediatric neurodevelopmental team completed a biographical questionnaire (Annexure 12). Focus group methodology is a means of collecting qualitative data by engaging a group of people, offering various perspectives as participants share their experiences, views and ideas on the specific issue (Wilkinson, 2004).

The focus group was held in a seminar room to ensure privacy, confidentiality and minimal distractions. The duration of the focus group was approximately 60 minutes. The details pertaining to the focus group and agenda were outlined at the initiation of the meeting. A digital voice recorder was used to audiotape information shared during the discussions. Informed consent was obtained from all participants.

1.5.4.3 Phase C: Caregiver and Children

Semi-structured interviews were conducted with primary caregivers (Annexure 15) and children (Annexure 19). The purpose of the semi-structured interview with the children was to determine their experiences of the therapy and medical intervention they had received. Semi-structured interviews are well suited for exploring the perceptions and opinions of participants regarding complex and sometimes sensitive issues and allowing the researcher to probe and clarify responses (Barriball & While, 1994). Children were requested to use diagrammatic representation detailing their experiences with intervention. Only one child completed a drawing providing a diagrammatic narrative of the stay in hospital. Art can serve as a means of facilitating communication with children and can be seen as advantageous as it is non-directive and helps to identify emotions (Aminabadi, Ghoreishizadeh, Ghoreishizadeh, & Oskouei, 2011).

Information gathered from the semi-structured interviews with the primary caregiver included dialogues relating to their experiences with the therapeutic interventions received, their difficulties in managing the child diagnosed with HIV/AIDS related neurological illnesses and recommendations for improved care by the team. Prior to the semi-structured interview the caregiver completed a biographical questionnaire (Annexure 16). The semi-structured interview was approximately 20 -30 minutes in duration.

An Interpreter translated the semi-structured interview into IsiZulu, as this was the children and caregivers primary language. The information was translated back from IsiZulu to English. This ensured that the participants felt comfortable in sharing their stories. A comfortable and non-threatening environment was provided for the child.

1.5.5 Pilot Study

A pilot study was conducted in order to refine and develop the data collection instruments utilised in this research study. One of the advantages of conducting a pilot study is that it

might give a prior indication of difficulties within the research, whether research protocols may/may not be followed and if instruments and methods are complicated and ineffective (Van Teijlingen & Hundley, 2002).

1.5.5.1 Phase A: File Audit and Profile

For the file audit, preselected criteria were identified as per the objectives of this phase of the research. A patient's file, meeting the inclusion criteria was accessed utilising the departmental statistics. Data was recorded onto the data extraction tool highlighting the relevant information i.e. demographical information, socioeconomic status, primary and differential diagnosis, medical history pertaining to admissions, tests and investigations, rehabilitation and prognostic indicators using the Functional Status Score (Annexure 5) and the Modified Barthel Index (Annexure 6). The relevant data was then recorded onto an Excel spreadsheet.

1.5.5.2 Phase B: MDT

The questionnaire was piloted on colleagues from the Physiotherapy Department as they represented a larger number (15 Physiotherapists as compared to 3 Occupational therapists). Feedback and critical appraisal was acknowledged and implemented in the final template of the questionnaire. Content validity refers to the expert opinion concerning whether the scale items signify the proposed aspects the questionnaire is intending to quantify (Rattray & Jones 2007). The questionnaire was adapted prior to initiating the main study by reducing ambiguity in the ranking items. The focus group questions were piloted on an Occupational Therapist.

1.5.5.3 Phase C: Child and Caregiver

The semi-structured interview was piloted on a caregiver and their child who was admitted to the paediatric neurology ward.

1.5.6 Data Management

Ethical considerations were strongly adhered to at all times and accurate data management was followed so as to ensure the integrity of the research process. Each member of the paediatric neurodevelopmental team participating in the study received the same questionnaire. Data received was stored in a secure encrypted hard drive requiring password access to protect the contents from being read by entities other than the researcher. The information was backed up onto a USB. The content of the data collected will be incinerated after the end of five years post-study, and this information will only be used for study purposes. Hard copies of the questionnaire and transcripts from the focus group and semi-structured interviews are being stored in a controlled access cabinet to ensure the data is not changed or corrupted.

1.5.7 Data Analysis

According to Creswell (2009) data analysis entails the collection of data that is acquired through general questions and compiling an analysis based on the information from participants.

1.5.7.1 Quantitative Data Analysis

1.5.7.1.1 File Audit Data

A statistician was contacted, through the University of KwaZulu-Natal, Public Health Department to assist the researcher in the analysis of the quantitative data (file audit). The data was first coded and transferred onto an Excel spread sheet on Microsoft Excel 2013. The analysis was based on descriptive statistics including percentages, medians, frequency, means, ranges and standard deviations. STATA software, version 13,1 was used for statistical analysis. The Wilcoxon signed rank test, the Kruskal -Wallis equality of populations rank test, Spearman correlation and the Mann Whitney test were used for statistical correlations. A p value score of 0.05 was regarded as statistically significant.

The results were represented in tables or figures and were interpreted from the statistical testing.

1.5.7.1.2 *Questionnaire MDT*

The questionnaires were analyzed using descriptive statistics including percentages and frequencies.

1.5.7.2 ***Qualitative Data Analysis***

1.5.7.2.1 *Semi-structured Interviews and Focus Groups*

The semi structured interviews and focus groups were audiotaped and transcribed verbatim. Thematic data analysis was used. Thematic analysis emphasises identifiable themes and patterns of living as well as behaviour (Aronson 1995). The process for constructing patterns of themes was used by the process outlined by Braun & Clark (2006).

The following steps were systematically followed during the thematic analysis process (Braun & Clarke, 2006):

- Once the data was transcribed from the audio recordings, the researcher familiarised herself with the content of the data by reading and re-reading the transcripts.
- The researcher also listened to the audio recordings together with the transcripts to verify the data.
- First level coding was then identified.
- The codes were then organized into categories and themes. Quotes were used to ensure that the authentic voice of the participants was represented.

The data collection and analysis process is described in the flow chart below (Figure 7). The data was analysed in a sequential manner and reported upon in three separate manuscripts.

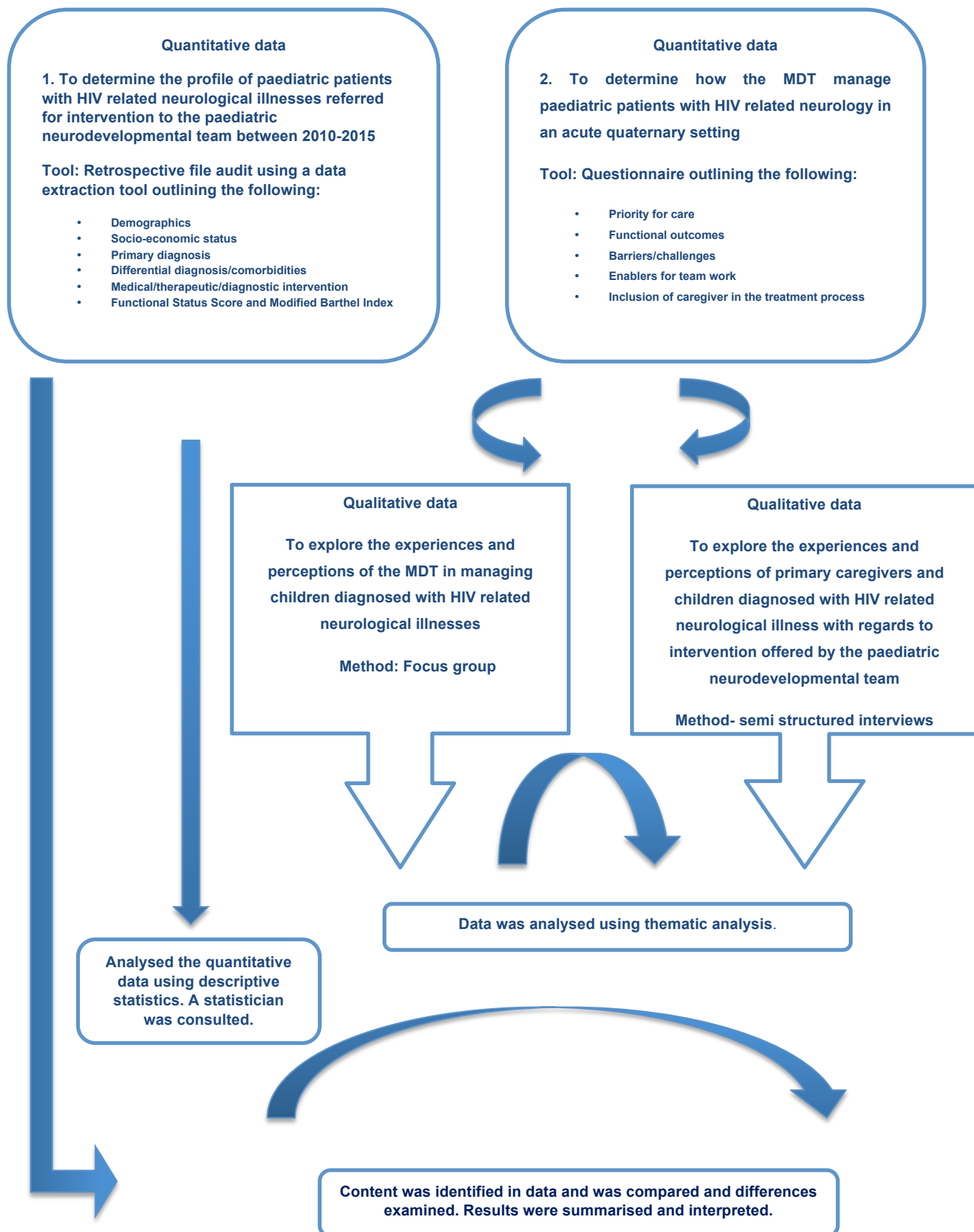


Figure 7 Data Analysis

1.6 ETHICAL CONSIDERATIONS

1.6.1 Ethical approval

Ethical approval was obtained from the Biomedical Research Ethics Committee of the University of KwaZulu-Natal - Reference number BE057/1 (Annexure 3). Gatekeeper permissions were also granted at an institutional (Annexure 1) and provincial level by the Department of Health KwaZulu Natal (Annexure 2).

1.6.2 Informed Consent

As this research involved the paediatric population, informed consent was obtained from the primary caregiver. Gill (2003: 455) highlighted that “*biomedical research involving children as the subjects of research is only permissible when such research is necessary to contribute to the healthcare of children*”. Therefore the guiding principles of requesting informed consent from a child participant should include respecting the dignity of the child, safe guarding and protecting the rights of the child and to maintain respect and confidentiality (Gill 2003). All members of the MDT, children and caregivers were informed about the purpose of the study and informed consent was obtained from all participants. They were informed of their right to withdraw and the voluntary nature of the study. Furthermore informed consent was obtained for audio recording the focus group with the MDT and the semi-structured interviews (Annexure 11). Written assent (Annexure 17) was obtained from the children prior to the commencement of the semi-structured interview. The primary caregivers of the children provided informed consent (Annexure 18). Informed consent included the purpose of the study, the nature and intent of the study, possible benefits and risks identified and the process of confidentiality. This was done through a written document given to each participant (Annexure 7,14).

1.6.3 Respect for Persons

Due to the nature of questions posed, when conducting the semi-structured interviews with the caregiver and child, the researcher was aware of the emotional considerations

and was prepared to conduct supportive counselling if the caregiver or child demonstrated signs of emotional trauma.

1.6.4 Right to privacy and confidentiality

Anonymity and confidentiality was maintained with regards to the individual participants as well as the organisation, units and groups of participants. Confidentiality was maintained throughout the study. The completed demographic and biographical questionnaires, data collection tools and recordings are being safely kept in password-protected files that can only be accessed by researcher and the supervisors. The primary way that researchers serve to protect participants is through anonymisation by providing each research participant with a pseudonym (Wiles, Crow, Heath & Charles, 2008). Accordingly confidentiality was maintained by using pseudonyms to replace actual names of the caregivers and children.

1.6.5 Non-maleficence

Non-maleficence was assured by answering questions required by the child and caregiver. Questions posed that were emotionally daunting were presented in a supportive environment with no loss of self-respect, shame, embarrassment or regret. Furthermore the participants did not participate in any procedures or tests that may have any harmful side effects. Additionally they did not commit an act, which might diminish self-respect or cause them to experience shame, embarrassment or regret.

1.6.6 Justice

Justice will be ensured in that all participants will receive equal benefit from the research, which is being completed through publication of the research results.

1.6.7 Beneficence

A Feedback meeting will be conducted to highlight the results from the study. The MDT and the Hospital's senior management will be invited to a strategic meeting and the study results will be discussed.

1.7 TRUSTWORTHINESS, RELIABILITY AND VALIDITY

1.7.1 Ensuring Trustworthiness

For this particular study, adhering to the principles of credibility, dependability and confirmability ensured trustworthiness (Shenton, 2004). With regards to credibility, participants with various experiences were selected through purposive selection, which increased the value of data collected. Credibility was confirmed by ensuring the representation of the data collected accurately reflected the viewpoints of the study participants, i.e. representation of all disciplines within the MDT. Recording devices were used throughout the duration of the focus group and the semi structured interviews with the participants to ensure data was accurately recorded.

Dependability was guaranteed through ensuring a clear audit trail as well as accurate implementation of data collection and analysis methods. By following the prior mentioned details within the methodology, the process of this research study was logical and clearly documented so that if the study was repeated in the same context, with the same methods and participants, similar results will be obtained (Shenton, 2004).

The researcher took cognisance of confirmability, and the necessary steps to ensure the study findings were the result of participant's experiences rather than other preferences (Shenton, 2004).

Bracketing was taken into consideration in the data collection and analysis process. Bracketing is a method used in qualitative research to mitigate the process of being unbiased and accurately reporting the experiences and data during the research process

(Tufford & Newman, 2012). The researcher was aware of potential biases being involved in working in the same environment and suspended judgements during the data collection processes.

1.7.2 Reliability and Validity

In order to ensure reliability, it was important to ascertain that there was no ambiguity in the questionnaire. This was done via the pilot study, where editing according to the comments received were completed. Statements in the questionnaire were simple and the language used was familiar to the participants (Hinkin, 1998). Content validity assessment of the questionnaire was necessary to serve as a pre-test to permit the deletion and addition of items (Hinkin, 1998).

The Functional Status Score was developed following consensus by a multidisciplinary team, which included paediatricians, paediatric neurologists, paediatric developmental psychologists and psychiatrists, paediatric intensivists and paediatric respiratory therapists (Pollack et al, 2009). The domains of functioning assessed were mental status, sensory, communication, motor, feeding and respiratory. They were classified from normal to very severely abnormal. Total scoring between the numerical categories 6-7 indicated “good” functioning, 8-9 as “mildly abnormal”, 10-15 as “moderately abnormal”, 16-21 as “severely abnormal” and more than 21 as “very severely abnormal”. Pollack et al described this tool as an appropriate means to categorise functional status where it was used in a 7-institution study comprising of 836 patients with a high risk of functional disability. The findings indicated that this tool is suitable for hospitalised patients. In a further study conducted by Pollack et al, comprising of 8 paediatric hospitals with general, medical and cardiac intensive care units and a sample of 5017 patients, indicated that the functional status score is suitable for large paediatric studies. Administering this scale will assist researchers in better describing functional outcomes in critical care (Pollack, Holubkov, Funai, Clark, Moler, Shanley, Meert, Newth, Carcillo, Berger, Doctor, Berg, Dalton, Wessel, Harrison, Dean, & Jenkins, 2014).

The Modified Barthel Index was previously used on children with low-grade gliomas and provided an estimate of the overall wellbeing of the child and ultimately the impact on quality of life (Jalali et al, 2008). Interpretation of the Modified Barthel is on a scale of 00-20 as “total dependence”, 21-60 as “severe dependence”, 61-90 recorded as “moderate dependence”, 91-99 as “slight dependence” and 100 as “independence” (Kucukdeveci, Yavuzer, Tennant, Suldur, Sonel & Arasil, 2000).

1.8 Use of an Interpreter

The researcher ensured that the Interpreter was briefed and adequately trained on the precise representation of content that was to be interpreted. This included the interpretation of meaning and clarifying any misunderstandings. It was essential to ensure that information was correctly interpreted so as to ensure that the quality and ethics of the study was maintained. Language barriers in qualitative research are frequently mediated through the use of an interpreter (Squires, 2009). The researcher ensured that the conversation was directed towards the participants and not to the interpreter. This was necessary to ensure the maintenance of a good researcher-participant interpersonal rapport.

1.9 THEORETICAL MODEL AND FRAMEWORK

Theories are created in order to envision and understand phenomena as well as to confront and expand on existing knowledge. The theory of a research study explicates the research problem, which is supported by the theoretical framework or model (Swanson & Richard, 2013). The Integrated (Healthcare) Team Effectiveness Model and the International Classification of Functioning and Disability were used to guide this study.

1.9.1 The Integrated (Healthcare) Team Effectiveness Model

Multidisciplinary teamwork in the management of paediatric HIV/AIDS related neurological illnesses is one of the main foci of this research. Various teamwork principles have been identified for effectiveness in the health care setting which includes goal sharing, defined roles and responsibilities, mutual trust, good communication and measurable outcomes of care (Mitchell et al, 2012). One such model focusing on collaboration and cohesion in the health care setting is a model for integrated care, namely, the Integrated (Health Care) Team Effectiveness Model (ITEM), which provides insight into team effectiveness (Lemieux-Charles & McGuire, 2006).

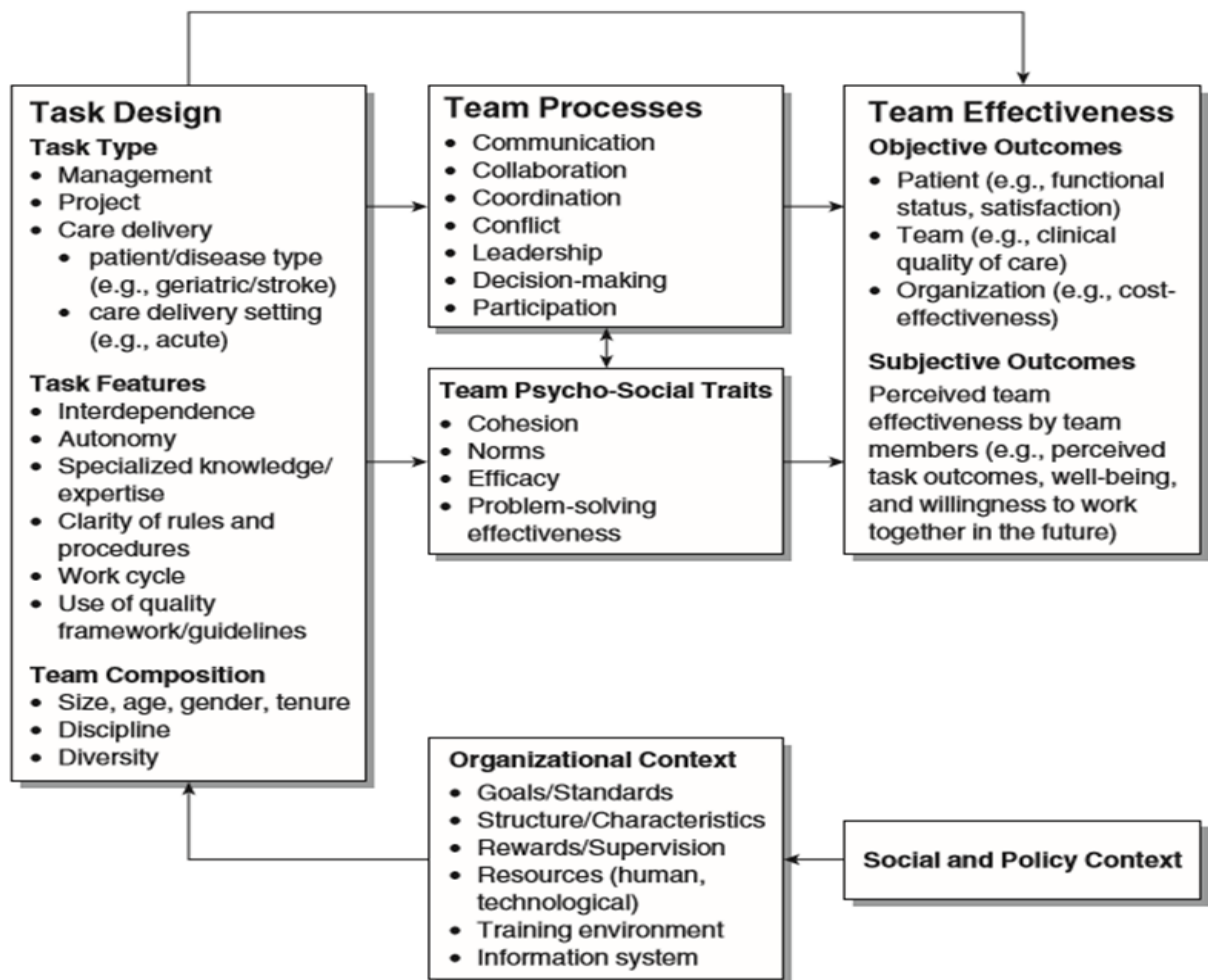


Figure 8 Integrated (Health Care) Team Effectiveness Model (ITEM) (Lemieux-Charles & McGuire, 2006)

The Integrated (Health care) Team Effectiveness Model considers the type of team, task features, team composition and organizational context. Team types most commonly found in the health care setting include management teams, project teams such as quality improvement type teams and care delivery teams. Management of paediatric HIV/AIDS related requires an integrated care delivery team. Care delivery team types relate to the patient population or nature of disease and the care delivery type of setting. This study focused on a paediatric population group diagnosed with HIV/AIDS related neurological illnesses who were admitted to an acute quaternary hospital.

In this model, tasks features relate to factors such as level of independence and autonomy, the need for specialized expertise and clarity of rules and procedures. Children with HIV/AIDS present with numerous developmental disabilities and neurological dysfunction and require specialized knowledge and expertise of the MDT to provide an integrated care plan.

Team composition considers factors such as diversity in age, gender and discipline. The Integrated (Health care) Team Effectiveness Model identifies various organizational contextual factors, which include information systems, human resources, rewards and supervision. These essential factors influence elements of task design as the model highlights that the organizational context in which a team operates can indirectly impact or influence the team's effectiveness. These concepts have an effect on the team processes. Team process relate to factors such as communication, collaboration, leadership and decision-making. The psychosocial traits of the team involve concepts such as team cohesion, norms and problem solving. Paediatric HIV/AIDS related neurological illnesses being a condition with variability in presentation requires the complex interaction between the task design, team processes and the team's psychosocial traits for effective outcomes.

Task design factors can be influenced by the external environment and can be manipulated by team leaders or managers to enhance team effectiveness. Team effectiveness can be measured by looking at objective outcomes (e.g. patient satisfaction, quality of care) and subjective outcomes, which relate to attitudinal factors of the team (e.g. effectiveness as perceived by team members). Furthermore team design factors can directly impact on team outcomes or can influence outcomes via impact on team processes and team psychosocial traits. Team processes and team traits interact with each another and are influenced by task design, which impacts on team outcomes and performance.

While not a definitive model of health care team effectiveness this model allows for some interpretation relating to the dimensions of teams in a health care environment and the processes and outcomes that might be impact on the teams functioning.

Therefore, in the management of paediatric HIV/AIDS related neurological illnesses this model is applicable as it provides objective and subjective outcomes, which allows for measurable improvements in the treatment plan of this vulnerable population group. The characteristic components of effective teamwork as highlighted above are integral in the management of paediatric HIV/AIDS related neurological illnesses and are depicted as drivers of team processes which requires cohesion and collaboration

In conclusion the Integrated (Health care) Team Effectiveness Model is a suitable framework for this study as it highlights the effects of diversity in health care teams and the impact on team effectiveness. These factors are crucial, as children diagnosed with HIV/AIDS related neurological illnesses require a diverse and collaborative MDT to deliver an integrated care plan considering the vast neurological and neurocognitive manifestations.

1.9.2 ICF- The International Classification of Functioning, Disability and Health

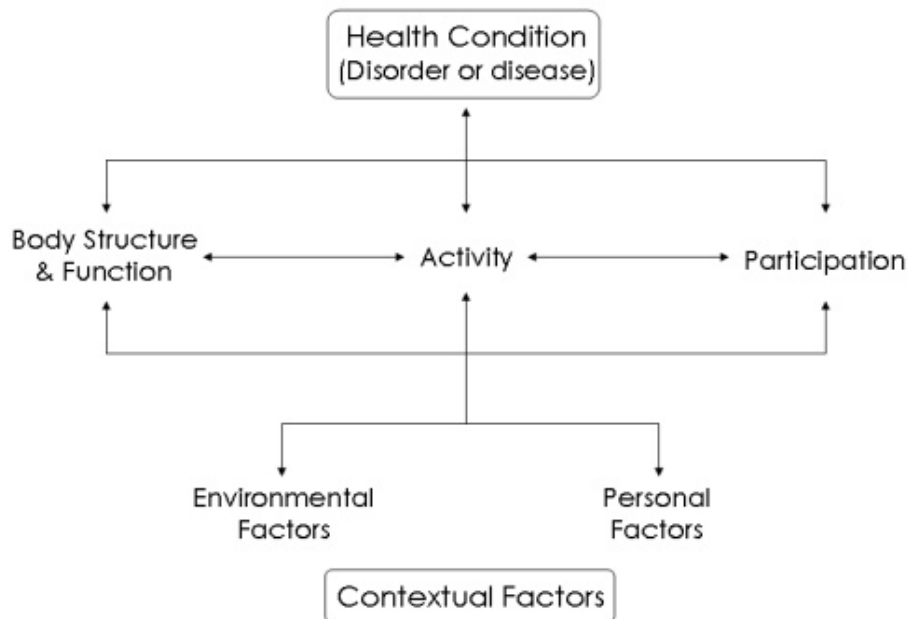


Figure 9 ICF Model (WHO, 2007)

The World Health Assembly approved the International Classification of Functioning, Disability and Health (ICF) in 2001 (Simeonsson, Leonardi, Lollars, Bjork-Akesson, Hollenweger & Martinuzzi, 2006). The ICF offers a framework and common terminology to classify and research complications associated with body structures and functioning, activity limitations and participation restrictions. Influencing external factors, both positive and negative are also included. Furthermore, the ICF is considered an important modality to enable multidisciplinary work by providing a common language amongst involved professionals and can serve as a model in rehabilitation (Schulz, 2008).

Hemmingsson & Jonsson (2005) assert that Occupational Therapy considers the relationship between health and daily occupations as well as environmental influences and therefore the ICF plays a vital role in healthcare, rehabilitation and Occupational Therapy.

Health conditions are often the attention of HIV care and treatment. For a child living with HIV, the ICF pays attention to the life related challenges that can be assisted by rehabilitative intervention. As a result of HIV, impairments are seen in body function i.e. the physiological and/or psychological functions and well as structure related to anatomical body parts such as loss or muscle strength, spasticity, hypotonia and cognitive decline.

Activity limitations result in an inability to perform certain tasks and actions. Therefore a child diagnosed with HIV related neurological illnesses might experience difficulties in completing activities of daily living e.g. dressing, communication and ambulation. A combination of activity limitations and impairments can result in a child experiencing difficulty with reintegration in the school, community and home. Hence a holistic approach by the MDT that is child centred is necessary to decelerate the sequelae of symptomatology associated with HIV/AIDS related neurological illnesses.

Contextual factors relate to a child's experience of these life related impact of health conditions. Environmental factors refer to the physical, social and attitudinal environment in which the child lives in e.g. accessibility due to impaired gait patterns thus requiring a mobility device to access terrain and negotiate stairs. It also includes determinants of health associated with HIV/AIDS i.e. poverty and poor access to housing and food. Personal factors are intrinsic and relate specifically to each individual child. This is not limited to their past medical history (a child with HIV may be susceptible to opportunistic infections), coping mechanisms and educational level.

Therefore the ICF can serve as a universal framework to place emphasis on children's rights with regards to disability. It provides a common language when clinicians and medical experts are reporting on the disability of children. For purposes of this study the ICF can serve as a means to assist the MDT to document the disability characteristics of a child so as to enhance development, provide rehabilitation that is optimal and to

understand challenges facing children diagnosed with HIV/AIDS related neurological illnesses.

1.10 CONCLUSION

Chapter one documented the literature review underpinning this study, the research questions, aims and objectives as well as the methodology. The Integrated Healthcare Team Effectiveness Model and The International classification of Functioning, Disability and Health were the models selected to guide the study. The methods used to achieve the overall aim and objectives of the study, which was to explore the management of Paediatric HIV/AIDS related neurological illnesses in an acute quaternary setting from a multidisciplinary perspective was explained in this chapter. Chapter 2, 3 and 4 will outline the manuscripts that formed part of this thesis.

CHAPTER 2

MANUSCRIPT 1

A Retrospective Review and Evaluation of Functional Status:
Profile of children admitted to an acute quaternary institution with HIV/AIDS related neurological illnesses over a 6-year period

2.1 INTRODUCTION

Paediatric HIV/AIDS is a public health challenge. Therefore it was deemed necessary to determine the profile of children diagnosed with HIV/AIDS related neurological illnesses who were admitted to the acute central quaternary hospital. Children with HIV/AIDS related neurological illnesses present with a wide spectrum of clinical signs and symptoms. It is crucial to understand the epidemiology of paediatric HIV/AIDS related neurological illnesses in KZN. KZN is identified as the province that yields the highest prevalence of HIV. This manuscript highlights the burden of disease in KZN. Furthermore this manuscript describes the clinical and rehabilitative intervention and the functional outcomes of children with HIV/AIDS related neurological illnesses.

2.2 JOURNAL DETAILS

The South African Journal of Child Health is an online peer reviewed medical journal dedicated to all aspects of health, and healthcare of neonates, infants and children. It is of particular relevance and interest to its Southern African readership. The journal is listed on the Department of Higher Education and Training (DoHET).

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2.3 SUMMARY

The study of HIV/AIDS associated illnesses is essential for establishing and defining intervention strategies as various co-morbidities can lead to morbidity and mortality. The objectives of phase one of the study have been achieved. The distribution of paediatric patients with HIV/AIDS related neurological illnesses according to the demographics, co-morbidities and clinical and rehabilitative outcomes have been described. This manuscript established the burden of disease in KZN. Moreover the manuscript described the array of neurological and neuropsychiatric manifestations that children with HIV/AIDS related neurological illnesses present with. Due to the magnitude of HIV infection it is evident that a MDT approach is needed to manage the diverse variability in presentation. Therefore it is necessary to identify the priorities of care and roles and responsibilities of the paediatric neurodevelopmental team in an acute setting, which differs from that of a district hospital or roll out HIV clinic. Most of the children resided in resource constrained areas such Umlazi and Kwa Mashu and this information could serve to help improve initiatives in these areas. Moreover this information will be useful in assisting health care practitioners to make evidence informed decisions when managing this paediatric population with HIV/AIDS related neurological illnesses. It is crucial to explore the experiences of the MDT to identify the challenges and enabling factors that contribute towards effective teamwork. “It takes a village to raise a child” is a phrase that leverages on the understanding and faith that it takes an entire community to raise a child: Similarly a child diagnosed with HIV/AIDS related neurological illnesses has the best ability to progress and develop if the entire MDT plays an active role in contributing to the management and care of the child.

2.4 MANUSCRIPT

This manuscript was formatted according to the specifications for the South African Journal of Child Health. The tables and figures are embedded within the main text to facilitate reading. Note that authors’ names (supervisors) have been removed.

**A Retrospective Review and Evaluation of Functional Status: Profile of children
admitted to an acute quaternary institution with HIV/AIDS related neurological
illnesses over a 6-year period**

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Abstract

Background: HIV associated neurological diseases are increasingly prevalent in Sub Saharan Africa. Paediatric HIV/AIDS has been widely studied highlighting extensive neurological and neuropsychiatric deficits. There is limited publication in an acute South African context that describes the rehabilitative intervention provided as well as the functional status of children with HIV/AIDS related neurological illnesses. **Objectives of study:** The objective of this article was to profile the children diagnosed with HIV/AIDS related neurological illnesses who were admitted to the paediatric neurology ward at a specialist central quaternary hospital in KwaZulu Natal. **Methods:** A retrospective file audit of children (n=139) admitted with HIV/AIDS related illnesses between 2010-2015 were conducted. Key information and data obtained included demographics and socio-economic status of the paediatric population, the primary diagnosis and co morbidities, interventions offered by the paediatric neurodevelopmental team, the duration of stay and repeated admissions were described. The Functional Status Score was used to determine prognosis (scores at admission and discharge) and the Modified Barthel Index provided information relating to the functional abilities in each of the domains of activities of daily living. Data was analysed using the statistical software STATA version 13.1. **Results:** 139 children with HIV/AIDS related neurological illnesses were included in the study. 42 children (30%) were diagnosed with HIV encephalopathy. The remaining 97 children (70%) were diagnosed with related HIV central nervous system disease. Seven children (5%) demised, whilst 101 (73%) were transferred to a base hospital. The remaining 31(22%) were transferred home. The median number of total therapy sessions was seven. The spearman correlation between the discharge score and total number of sessions was positive $r = 0.37$, $p < 0.001$. The spearman correlation between the discharge score and the total number of co morbidities was 0.18, $p = 0.03$. This indicated that the more co-morbidities a child presented with the higher the functional status score at discharge. The

Spearman correlation between the change in score and total number of sessions was [$r = -.22, p = 0.009$]. This indicated that as the number of sessions increased the discharge score decreased relative to the functional status admission score. The discharge scores were correlated to the Modified Barthel scores indicating that the higher the functional status score the more dependent the child was in activities of daily living, $p=0.0001$. **Conclusion:** This study highlights the diverse neurological and neuropsychiatric deficits that are common with children with HIV infection. The authors conclude that rehabilitative intervention is crucial and impacts on core functional outcomes.

Introduction

The World Health Organisation estimated the number of children (<15 years) living with HIV in 2015 as 1,8 million. Approximately 150 000 children under the age of 15 have been newly infected and nearly 110 000 children have succumbed to AIDS related deaths.¹ Sub Saharan Africa remains the epicentre of the HIV epidemic where approximately 91% of the children under the age of 15 are living with HIV.² The number of children (younger than 15 years) receiving anti-retroviral therapy (ART) in low-middle income countries have doubled from 2009 to 2013 i.e. 355 000 to 740 000.¹

South Africa has approximately 3.4 million people on treatment, more than any other country in the world.³ In South Africa children aged 0-14 living with HIV in 2015 is estimated at 340,000 and orphans aged 0-17 due to AIDS is estimated at 2,300,000.⁴

The total number of people living with HIV in South Africa in 2015 was projected at approximately 6.19 million.⁵ The highest provincial HIV prevalence rate was recorded in KwaZulu Natal (KZN), which has increased from 37.4% in 2012 to 40.1% in 2013. In 2013 five health districts, all located in KZN recorded the highest HIV prevalence ranging from between 40.0%-45.9%. These five districts were UMkhanyakude (44.1%), eThekwini (41.1%), UMgungundlovu (42.5%), Ugu (41.1%) and UThukela. Moreover, statistics in 2013 indicated that two in every five pregnant women attending antenatal care in KZN public health clinics were HIV positive.⁶ Subsequently, there has been an exponential increase in the number of children being infected with HIV.

There are numerous HIV related illnesses in infected children which include HIV Encephalopathy, seizures, respiratory deficits such as pneumonia, bronchiectasis, renal and cardiac conditions, gastro-intestinal and haematological related disorders.⁷ Stoke or

cerebro-vascular conditions account for approximately 2,6% of focal neurological deficits.⁸ Nearly 5% of HIV 1 infected children may be susceptible to peripheral neuropathies and clinical signs include loss of muscle power, pain, sensory changes and impaired mobility. Bacterial meningitis and tuberculosis meningitis are common opportunistic infections seen in HIV 1 infected children.⁸ Central nervous system (CNS) lymphomas is the most common form of oncology related diagnoses seen in paediatric HIV/AIDS. Neuropsychological manifestations with poor concentration and attention skills and hyperactivity are also noted with children diagnosed with HIV.⁸

Supportive services namely Physiotherapy, Occupational Therapy and Speech Therapy were identified as rehabilitative interventions that may be required to manage HIV related conditions.⁷ A multidisciplinary approach is recommended for the treatment and management of HIV-infected children with CNS involvement to halt neuro-regression and developmental delays.⁸

Methods

Design: This study consisted of a retrospective file audit to ascertain the profile of paediatric patients diagnosed with HIV/AIDS related neurological illnesses admitted to the paediatric neurology ward between 2010 and 2015.

Setting: The acute quaternary specialist health care facility provides accessible and quality patient care to all persons in KZN and part of the Eastern Cape. It hosts a specialised unit for paediatric neurology and does not have a specific outpatient facility for the treatment of children diagnosed with HIV/AIDS. Therefore all cases referred to this quaternary institution are complex involving the neurological complications associated with HIV/AIDS. Specialised multidisciplinary team and holistic quaternary care is offered to the patients.

Sampling and recruitment procedure: The inclusion criteria included patients with a confirmed diagnosis of HIV/AIDS and with neurological disorders. The selected patients were identified from the paediatric neurology electronic database of children admitted to the paediatric neurology ward of the hospital. All medical files between the period January 2010 to December 2015 were audited. The final sample comprised of 139 records of children who met the selection criteria.

Data collection strategy: A data extraction tool was used to document medical data accessed from the electronic medical reporting system. Demographic profiling of age, gender, race group, socio-economic status and area of residence was collected. In addition, where available CD4 counts, viral loads and type of tuberculosis (TB) treatment were collated. The diagnoses and co-morbidities were determined. Medical, rehabilitative and radiological investigations and intervention as well as length of admission were collated. Finally the Functional Status Score and the Modified Barthel Index were used to determine functional prognosis and participation in activities of daily living.

Content Validity: The Functional Status Score was developed following consensus by a multidisciplinary team, which included paediatricians, paediatric neurologists, paediatric developmental psychologists and psychiatrists, paediatric intensivists and paediatric respiratory therapists.⁹

The domains of functioning assessed were mental status, sensory, communication, motor, feeding and respiratory. The domains were classified from normal to very severely abnormal. Total scoring between the numerical categories 6-7 indicated “good” functioning, 8-9 as “mildly abnormal”, 10-15 as “moderately abnormal”, 16-21 as “severely abnormal” and more than 21 as “very severely abnormal”. Pollack et al described this tool as an appropriate means to categorise functional status. The Functional Status Score was used in 7 institutions comprising of 836 patients with a high risk of functional disability. The findings indicated that this tool is suitable for hospitalised patients.⁹ In a further study conducted by Pollack et al, comprising of 8 paediatric hospitals with general, medical and cardiac intensive care units and a sample of 5017 patients, indicated that the Functional Status Score is suitable for large paediatric studies. In addition using this scale will assist in better describing functional outcomes in critical care.¹⁰

The Modified Barthel Index was previously used on children with low grade gliomas and provided an estimate of the overall wellbeing of the child and ultimately the impact on quality of life.¹¹ Interpretation of the Modified Barthel is on a scale of 00-20 as “total dependence”, 21-60 as “severe dependence”, 61-90 recorded as “moderate dependence”, 91-99 as “slight dependence” and 100 as “independence”.¹²

Data Analysis: The data was analysed using the statistical software STATA version 13.1. The Shapiro-Wilk test, Spearman correlation, Wilcoxon signed rank test, the Kruskal

Wallis equality of populations rank test and the Two sample Wilcoxon Rank-sum (Mann Whitney) test were used to correlate variables. A *p* value score of 0.05 was regarded as statistically significant.

Ethical Approval: Ethical approval was obtained from the Biomedical Research Ethics Committee (reference number BE057/16) of the University of KZN. Gatekeeper permissions were also granted at an institutional and provincial level by the Department of Health, KZN.

Results

Demographics: According to the hospital statistics software, Speed miner, during the period January 2010- December 2015 there were approximately 4392 admissions into the paediatric ward. Paediatric medical domain accounted for 1474 of these admissions. Paediatric Neurology accounted for 639 of the admissions. One hundred and thirty nine children (n=139) with a confirmed diagnosis of HIV/AIDS related neurological illnesses were recruited into the study. This indicates a 21% burden of HIV related CNS illnesses.

Table 1 Demographic Profile of Children

	Number	Percentage
Gender		
Males	73	53%
Females	66	47%
Age band		
<5 years	43	31%
5-9 years	61	44%
10-14 years	35	25%
Race group		
African	135	97%
Mixed ethnicity	4	3%

53% were male (n=73) and 47% were female (n=66). The ages ranged from 44% (n=61) for the 5-9 year age band with 31% (n=43) in the <5 years age group. The 10-14 year age

band comprised of 25% (n=35) of the sample. Ninety seven percent (n=135) of the children were classified as African. The remaining 3% (n=4) were identified as mixed ethnicity. The three predominant geographical areas that these patients resided in were Umlazi (n=19), which accounted for 14% of the total population, Kwa Mashu (n=15) being the second largest area translated to 11% of the population and Inanda (n=12), which accounted for 9% of the total paediatric population.

Hospital Stay: Thirty-one children (22%) were well recovered and discharged home whilst 101 (73%) children were transferred to their base hospitals. Seven children (5%) succumbed to their illness and demised. The maximum length of stay was 107 days. The mean length of stay was 14,36 days and the median was recorded as 9 days. One child (n=1) had up to six readmissions, whilst 28 children had one readmission to hospital. Readmissions to hospital highlight the severity of the presentation of the children who required further intervention at a quaternary level rather than being managed at their base hospitals.

Diagnosis and Co-morbidities: Children with HIV/AIDS related neurological illnesses present with multiple co-morbidities. Seven children (5%) presented with nil co-morbidities whilst 33 children (24%) presented with a single comorbidity. Approximately, 34% of the children (n=47) presented with two co-morbidities whilst 24% (n=34) were diagnosed with three co-morbidities. Additionally, 8% of the children had four co-morbidities. Five children (4%) had 5 co-morbidities whilst 2 children (1%) had 6 co-morbidities. This illustrates the complexity of the disease and the varying presentation of the condition. The median number of co morbidities was two. Thirty percent (n=42) of the children were diagnosed with HIV Encephalopathy. The remaining 70% (n=97) were diagnosed with related HIV CNS disease. Forty-seven children (34%) were diagnosed with epilepsy of different subtypes. Thirty-three patients (24%) were diagnosed with hemiplegia, the left being predominant (n=19, 58%) compared to the right (n=14, 42%). Twenty-two patients (16%) were diagnosed with ophthalmic defects. These were classified into inflammatory (n=5, 23%), e.g. conjunctivitis, vision defects (n=13,59%) e.g. retinopathy, movement disorders (n=3, 14%) e.g. strabismus and ophthalmoplegia (n=1, 4%).

Thirty-two children (23%) were diagnosed with movement disorders. Of the thirty-two children, 84% (n=27) were cerebellar in nature e.g. pan cerebellar syndrome and 16% were

related to the basal ganglia (n=5) e.g. chorea. 108 children (78%) with HIV related CNS disease presented with different cerebral lesions. Fifty-six children (40%) had infectious/inflammatory co-morbidities of the brain. In this category tuberculomas were identified in twelve children and meningitis and hydrocephalus were diagnosed in 29 children. Thirty-three children (24%) had vascular related co-morbidities e.g. cerebral infarcts of the brain. Mass lesions and tumours were accounted for in 10 children (7%) whilst in 3 children (2%) it was related to demyelination of the brain e.g. encephalomyelitis. Other co-morbidities of the brain not specific to the above categories were identified in 6 children.

Seven children (5%) were diagnosed with neuro-psychiatric disorders, which included visual and auditory hallucinations. Thirteen children (9%) were diagnosed with cranial nerve palsies. Other neuro-deficits included 5 children (3,5%) each diagnosed with peripheral neuropathies and Guillain-Barre syndrome.

Laboratory findings: The CD4 counts were calculated on available data (n=68, 49%) with the mean CD4 count being recorded as 590,89 cells/ μ L, standard deviation as 561,64 cells/ μ L and median CD4 count as 496,50 cells/ μ L. The minimum CD4 count was 3 cells/ μ L and maximum was 3012 cells/ μ L. The median viral load was 31457 copies/mL and the mean was recorded as 624800,1 copies/mL. Only ninety -seven children (70%) were on ART. Those children that were not ART showed a severity in clinical presentation. Forty-three children (31%) were on TB treatment.

Tests and investigations: 17% (n=24) of children underwent a Computed Tomography (CT) of the Brain whilst 82% (n=114) of the participant's had a Magnetic resonance Imaging (MRI) of the brain. Nineteen children (14%) underwent a MRI Brain Angiography. 15% of children had an MRI of the cervical spine (n=21) and of the thoraco lumbar region (n=22).

Multidisciplinary team intervention: In the neurology admission dating from January 2010-December 2015, 92 children (66%) received physiotherapy intervention with an accumulative amount of 812 sessions. This included both chest physiotherapy and rehabilitative sessions and where indicated treatment over the weekend. Fifty-four (39%) participants received 164 sessions of Occupational Therapy. Only 4 children underwent standardised testing using the Beery Test of Visual Motor Integration, Durrell writing test and the Good enough Draw a Man test. This demonstrated the severity of presentation in

an acute setting where the majority of children could not cope with the cognitive demands of standardised visual perceptual testing. Thirty splints were made for the 54 children. Forty-one children (29%) received a total of 150 Dietetic sessions. Nineteen children (14%) received Social Work intervention whilst only 6 (4%) children attended Psychology. Twenty-two children (16%) attended Speech therapy whilst nine children (6%) attended Audiology. The median number of total therapy sessions was 7. It should be noted that the authors were unable to quantify the duration of the treatment sessions.

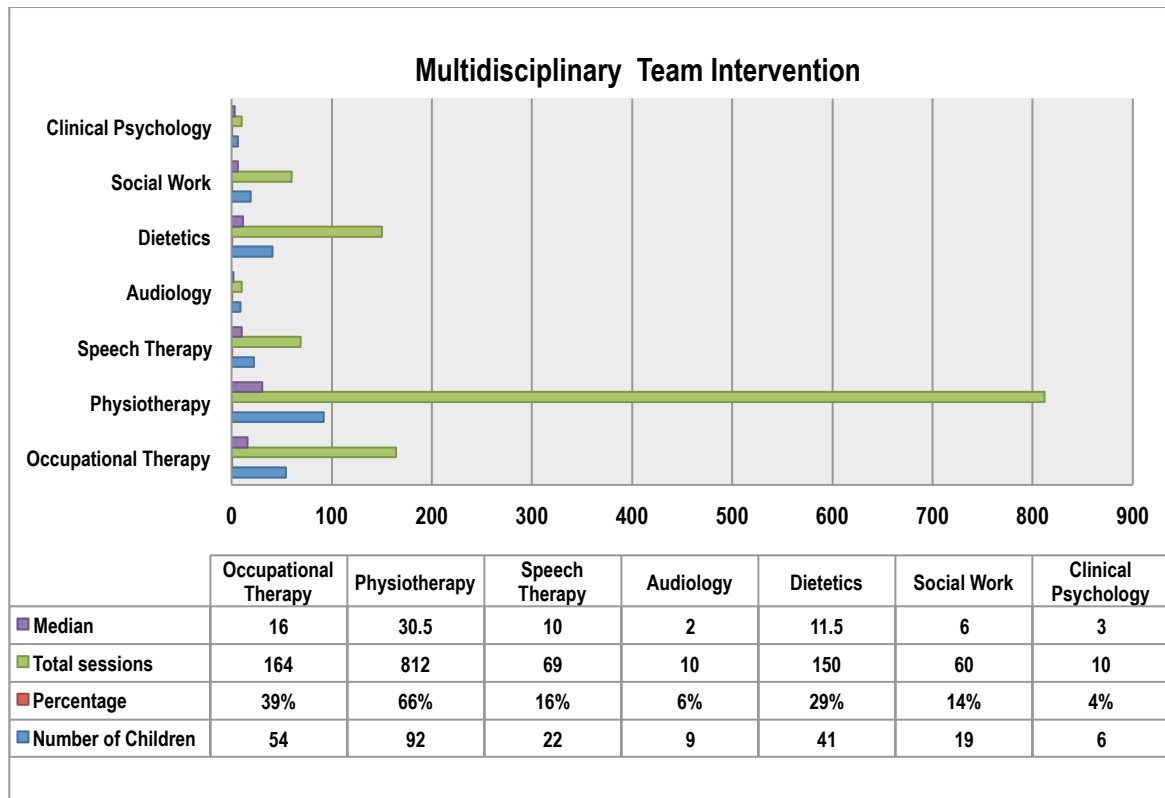


Figure 1 Therapy sessions in the Neurology admission

Functional Status Score and the Modified Barthel Index

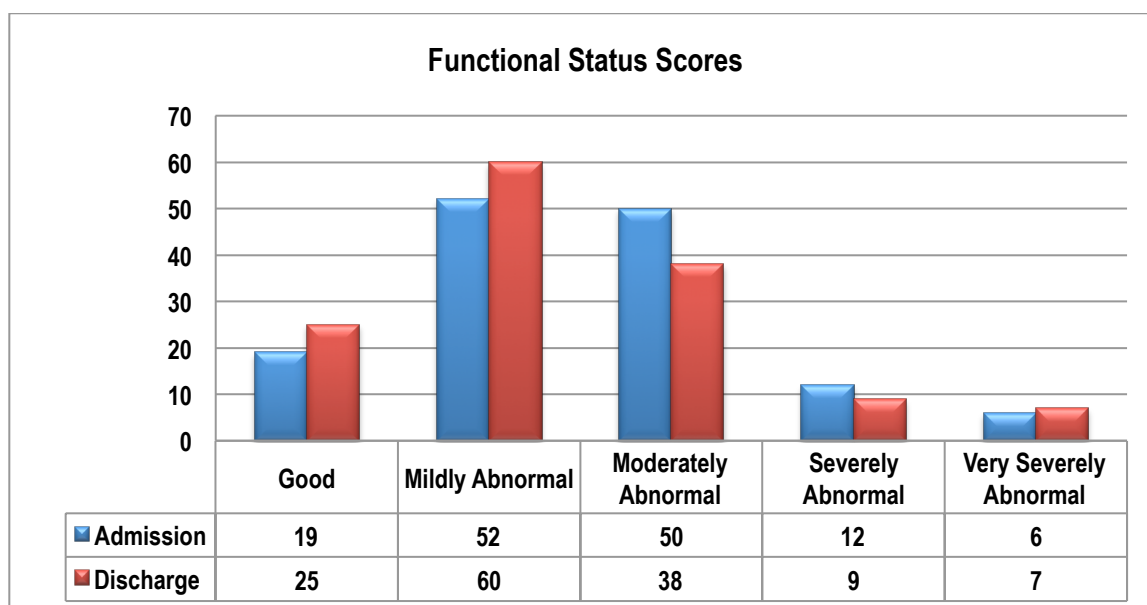


Figure 2 Functional Status scores at admission and discharge

On admission to hospital 19 children (14%) demonstrated good functional status scores. Fifty-two children (37%) presented with mildly abnormal Functional Status Scores whilst 36% (n=50) had a moderately abnormal score. Almost 9% (n=12) demonstrated severely abnormal scores whereas 6 children (4%) had very severely abnormal Functional Status Scores. Comparatively, the scores at discharge indicated that twenty-five children (18%) displayed good Functional Status Scores whilst 43% (n=60) of the children presented with mildly abnormal Functional Status Scores. Thirty-eight children (27%) demonstrated a moderately abnormal score. Approximately 6% (n=9) had severely abnormal scores whereas seven children (5%) presented with very severely abnormal scores.

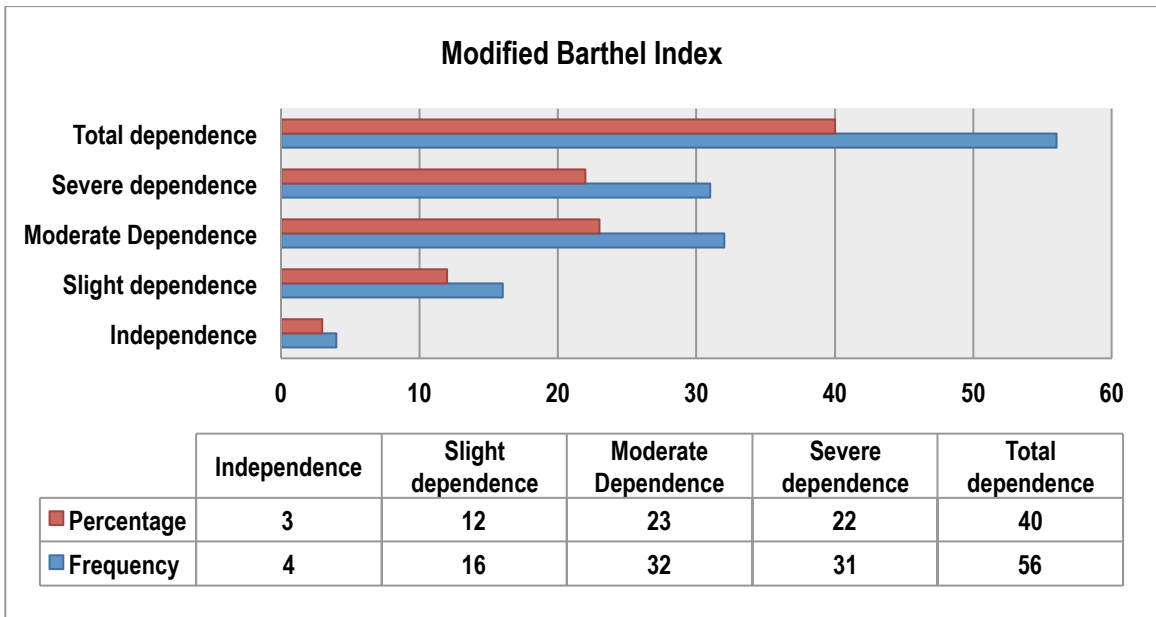


Figure 3 Modified Barthel Index

Forty percent (n=56) of children were totally dependent for participation in activities of daily living whilst 22% (n=31) demonstrated severe dependence. Twenty three percent (n=32) of children were moderately dependant whilst sixteen children (12%) were slightly dependent for participation in activities of daily living. Four children (3%) were independent in activities of daily living.

Functional status scores, total sessions and total co-morbidities

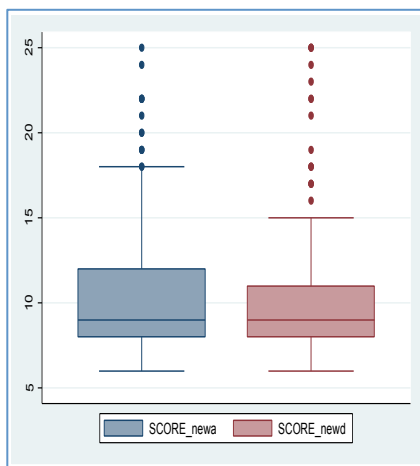


Figure 4(a) Score admission and discharge

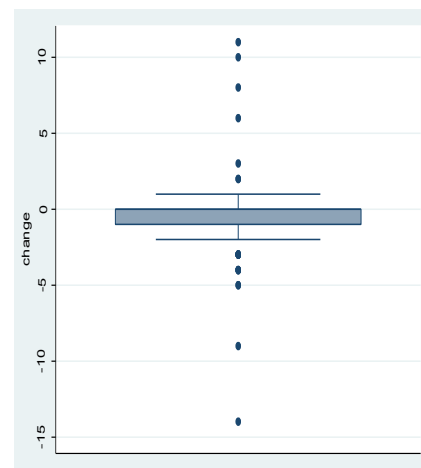


Figure 4(b) Change in scores

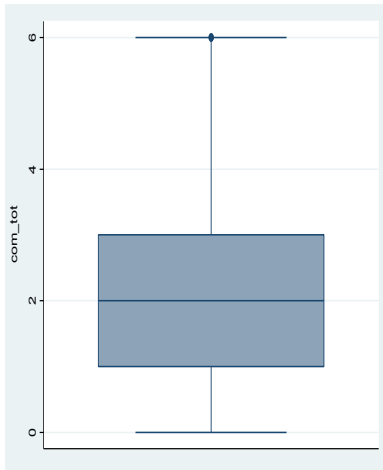


Figure 4(c) Total co-morbidities

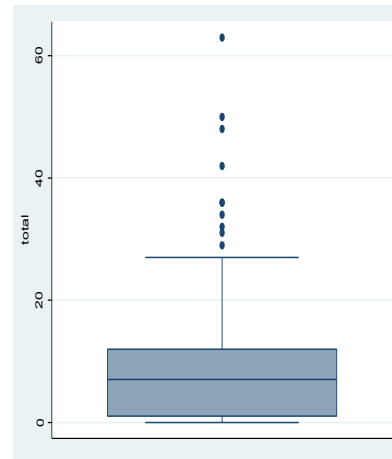


Figure 4 (d) Total Sessions

Figure 4 Box plots

The functional scores, the change in the score between discharge and admission and the total number of sessions and total co morbidities are not normally distributed as indicated by the Shapiro-Wilk test. The box plots show that the scores and the total sessions are right skewed and the change score has a wide variation.

Statistics	Admission score	Discharge score	Change score
N	139	139	139
p50	9	9	0
p25	8	8	-1
p75	12	11	0
Iqr	4	3	1

Table 2 Change in scores from admission to discharge

This table shows the median scores for the functional status score at admission, the discharge score and change score (discharge-admission). The median score at both admission and discharge was 9 and the median change in score was 0. However the Wilcoxon signed rank test showed a significant difference between the discharge and admission score, $p < 0.001$.

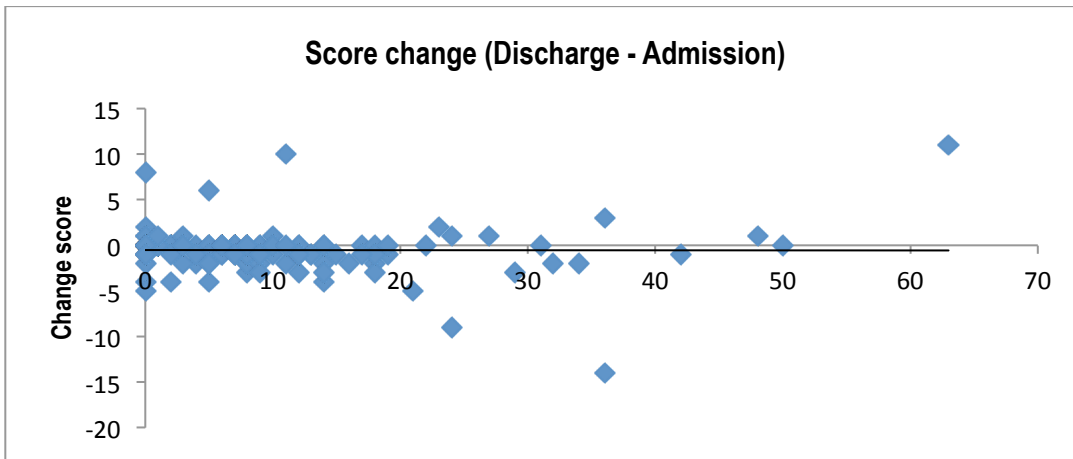


Figure 5 Change in scores: Discharge-Admission

Variables associated with Functional status scores, the total sessions and comorbidities: The spearman correlation between the discharge score and total number of sessions was positive $r = 0.37$ which is a moderate positive correlation and is significant, $p < 0.001$. The spearman correlation between the discharge score and the total number of comorbidities was 0.18 which is considered a weak positive correlation but is statistically significant, $p = 0.03$. This indicated that the more co-morbidities a child presented with the higher the functional status score at discharge.

The admission score and discharge score were highly correlated. The Spearman correlation between the change in score and total number of sessions is $r = -.22$ which is weak negative correlation but significant, $p = 0.009$. This indicated that as the number of sessions increased the discharge score decreased relative to the admission score.

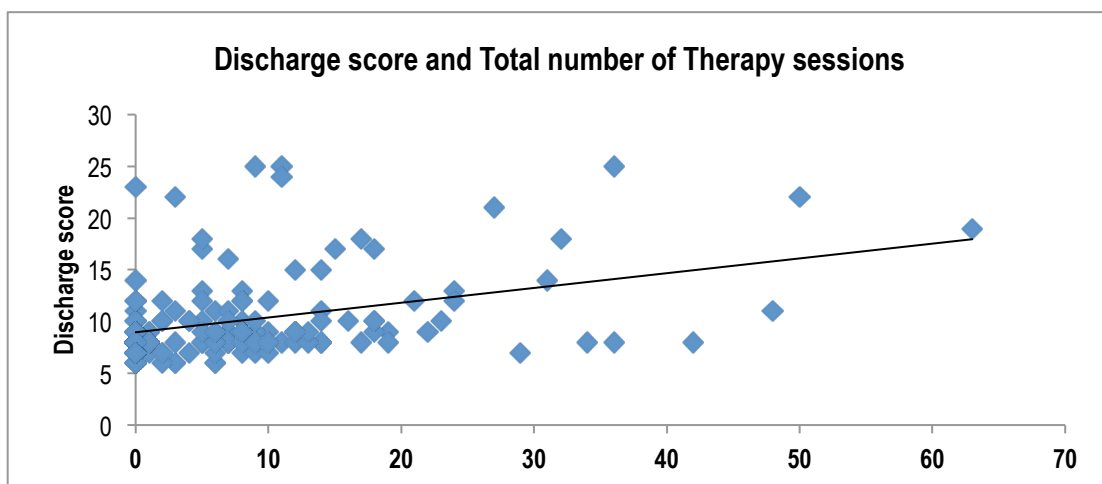


Figure 6 Discharge score and Therapy sessions

Correlation between The Modified Barthel score and The Functional Status score at Discharge

Interpretation	N	p50	IQR	Rank Sum
Independence	4	6	.5	32,50
Moderate dependence	32	8	2	1616,00
Severe dependence	31	9	2	2200,50
Slight dependence	16	7	1,5	413,50
Total dependence	56	11	8	5467,50

Table 3 Modified Barthel and Discharge scores

The Kruskal Wallis equality of populations rank test was used to determine the correlation between the Modified Barthel score and the discharge score. The discharge scores were correlated to the Modified Barthel scores indicating that the higher the functional status score the more dependent the child was in activities of daily living, $p= 0.0001$.

Discharge points and Functional Status Scores: The admission scores for the demised group ($n=7$) were recorded as two children with moderately abnormal scores, one categorised as severely abnormal and four children with very severely abnormal scores. At time of demise all seven children presented with severely abnormal scores indicating severity in clinical presentation. For those children in the demised group the mean admission score was 22 and discharge score was 24, which could serve as a prognostic indicator that the worse the functional status scores, the more severe the presentation of the child.

The Two sample Wilcoxon Rank-sum (Mann Whitney) test illustrated a p value of 0,0000 when comparing admission and discharge scores between the demised group and the rest of the population. Similarly the change in functional status scores highlighted a p value of 0.0010.

The Kruskal Wallis equality of populations rank test when compared to the admission and discharge scores to the type of discharge ($n=7$ demised, $n=101$, transferred to base hospital and $n=31$, transferred home) indicated a p value of 0.0001. Therefore when the discharge points were compared to the functional status scores, those children who were discharged

home had mildly abnormal scores compared to those who were discharged to base hospital presented with moderately abnormal scores.

Discussion

Neurological illnesses have been documented in approximately 10,2% - 68% of HIV infected children.¹³ The development of encephalopathy is considered one of the most significant complications of HIV, however the frequency of presentation at different age groups have been questioned.¹⁴ In this study approximately thirty percent of the children (n=42) were diagnosed with HIV encephalopathy. Since the introduction of combination ART there has been a decrease in the incidence of progressive HIV Encephalopathy. However neurocognitive deficits still persist in HIV infected children. This highlights the severity of the HIV disease and in utero infection highlighting the need to prevent mother to child transmission and early diagnosis and treatment.¹⁵

The majority of the children in this study belonged to the 5-9 year age band (n=61, 44%) whilst 31% were under the age of five. Approximately 34% of the children had 2 co-morbidities whilst 24% were diagnosed with 3 co-morbidities. Thirteen percent (13%) of the children had 4 or more co-morbidities. This highlights the severity of clinical presentation in an acute quaternary setting. A Cape Town based study at a dedicated HIV Neurology clinic where 87 children were diagnosed with HIV encephalopathy, indicated that the CNS damage was present from early infancy. Despite virological support the enduring effects of the HIV virus will continue to have a longstanding effect on the developing brain.¹⁶

The vast majority (97%) of the population were classified, as African and the predominant areas of residence were Umlazi, Kwa Mashu and Inanda. The plight in these areas were highlighted in the EThekweni district health plan 2015/16 where the statistics indicated that the total number of patients remaining on ART in Umlazi was 56066 and Greater Inanda was recorded at 46108.¹⁷ The burden of disease and spiralling HIV prevalence rates in these areas were noted. Umlazi was identified as a community that highlights South Africa's high HIV prevalence rate as approximately 10% of the townships' households are being headed by children orphaned due to AIDS.¹⁸

The mean CD4 count was 590,89 cells/ μ L with the minimum being recorded as 3 cells/ μ L. Only ninety-seven children (70%) were on ART. Forty-three children (31%) were on

treatment for TB. A Durban based study highlighted that TB and HIV co-infection in children is common which was confirmed in 48% of all culture proven cases. Hospital related mortality was higher in the HIV 1 infected group.¹⁹ South Africa faces the worst challenges of dual epidemics, HIV and TB which have impacted upon each other and is further compounded by multi drug resistant (MDR) and extensively drug resistant (XDR) TB.²⁰ TB is a significant occupational hazard among health care workers in the low-middle income countries and occupational categories such as nurses, clinical officers and physicians demonstrating a higher incidence of TB.²¹ In high prevalence countries the incidence of TB in HIV infected children is higher and in a South African retrospective study, the incidence of TB was estimated to be approximately 23 per 100 child-years among HIV infected children.²² A retrospective study was conducted at four paediatric HIV clinics in Johannesburg and Cape Town and findings suggested that the incidence of TB in HIV infected children was reduced by the initiation of HAART.²³

Forty-seven children (34%) were diagnosed with symptomatic epilepsy. In a hospital-based cohort of children (n=354) diagnosed with HIV, a subgroup of approximately 27 children (7,6%) presented with epilepsy and findings indicated that developmental delay and neurological deficits were more common in children with both HIV and seizures.²⁴

Nineteen children were diagnosed with left hemiplegia compared to the fourteen children who had a right hemiplegia. The loss of hand arm movements due to hemiplegia poses a detriment on fine motor skills and bilateral hand activity impacting on participation in activities of daily living.

An increased incidence (2,6%) of cerebrovascular disease is found in HIV infected children with a greater occurrence of aneurysms and ischaemic infarctions.²⁵ Twenty-two patients (16%) were diagnosed with ophthalmic defects. In a Ugandan study of HIV infected children the estimated overall rate of ophthalmic involvement in African paediatric patients was 35% and in 12% the most common finding was a non-purulent conjunctivitis.²⁶

HIV infection causes a reduction in grey-matter volume, white-matter lesions, and basal ganglia calcifications.²⁷ Thirty-two patients (23%) were diagnosed with movement disorders of which the majority were related to cerebellar dysfunction. The clinical presentation was varied, however in this study tuberculomas were identified in twelve children on radio imaging. Clinically tuberculomas may remain silent or may present as

intracranial space-occupying lesions thus the need for MRI's in HIV infected children.²⁸ Meningitis and hydrocephalus were diagnosed in 29 children. Opportunistic infections, particularly TB and cryptococcosis, were the most common causes for neurological deterioration post ART.²⁹

In this study approximately 17,2% of children underwent a CT of the Brain whilst 82% of the children had an MRI of the brain. Abnormal imaging of children with HIV related CNS illnesses is directly related to the degree of encephalopathy as well as the phase of disease and between 63-83% of CT imaging will be abnormal.³⁰

Currently there is paucity in literature outlining the multidisciplinary rehabilitation of children infected with HIV and those with subsequent neurological dysfunction. According to the International Classification of Functioning, Disability and Health (ICF), the role of rehabilitation professionals in the management of children with disabilities is to increase function, reduce disability and allow for activity participation. The importance of physical therapy in the management of paediatric HIV encephalopathy was identified which involves neurodevelopmental intervention.³¹ The rehabilitation of children with disabilities is a continuous and extensive process occurring at hospital and at home.³²

In this study therapeutic intervention was offered predominantly by Physiotherapists. Due to various organisational and fiscal challenges, Occupational Therapy rehabilitation was not offered on a daily basis. However, approximately 30 splints were made for the 54 children treated, whilst only four children underwent standardised testing. In a pilot study in Cape Town a few children infected with HIV were screened for neurological and cognitive deficits using similar standardised neurodevelopmental tools. The study showed that early neuro-cognitive and motor development delays occur in HIV infected children.³³

The harsh effects of HIV/AIDS that South African children are faced with were highlighted in a study and described their vulnerability. They presented with increased psychological stress, as they had to cope with grief, stigma, rejection and death. Therefore psychosocial support and counselling was indicated.³⁴ In this study nineteen children (14%) received Social Work intervention whilst a mere six participants (4%) attended Psychology. Seven children (5%) were diagnosed with neuro-psychiatric disorders, which included visual and auditory hallucinations. Psychological counselling should be offered to the caregivers of HIV infected children in order to alleviate stress, to reduce the burden and for improved follow up, adherence and compliance.³⁵

Upon discharge most of the functional status scores improved in that the mildly abnormal category increased by 6% and the severely abnormal category decreased by 3%. This was further emphasised as the number of therapy sessions increased the discharge score was reduced relative to the admission score indicating that as the child engaged in rehabilitation, improvement was noted in their functional presentation. In an acute health care setting this highlights the fundamental role rehabilitation plays in the care of children with HIV/AIDS related neurological illnesses. Basic home programmes were found to significantly improve the development of young HIV infected children on both a cognitive and motor level and should be a standard practice of care.³⁶ The paediatric population with HIV are at a multidimensional risk for early developmental delays. They require comprehensive assessments and intervention to achieve holistic development. Interdisciplinary approaches are necessary to identify children with risk of neurodisability.³⁷

The discharge scores and the Modified Barthel scores were correlated indicating that the higher the functional status score, the more severe the clinical presentation of the child and the more dependent the child was in activities of daily living. For those children in the demised group the mean admission score was 22 and discharge score was 24. The Functional Status Score is a reliable tool for outcome studies and the degree of functional status of paediatric patients.¹⁰ The Functional Status Scores indicated severely abnormal scores at admission and hence these scores at admission could served as an important predictor for functional gains as well as mortality and morbidity rates.

In a study focusing on the predicators for change in functional status of children with HIV showed a significant correlation in scores with repeated admissions and number of days hospitalised. Functional status declined over a period with growth factors, immunological status and social factors identified as such predictors of functional status in children infected with HIV.³⁸ A study conducted with 814 paediatric patients who received in patient rehabilitation, suggested that the majority of the children improved functionally with rehabilitation.³⁹

As this study is a retrospective file audit, incomplete clinical records and insufficient documentation was a limitation. Further due to various organisational limitations some of these children did not receive rehabilitation on a daily basis due to contingency plans being implemented by specific clinical departments. The most significant barrier impacting on

care and management of Paediatric patients with HIV/AIDS related neurological illnesses were a lack of human resources. Due to budget shortfalls many clinical departments are understaffed and were unable to cope with the high patient loads.

Multidisciplinary care is required to improve quality of life and functional outcomes of children with HIV/AIDS related neurological illnesses. Similarly a study conducted in a paediatric neonatal unit identified that multidisciplinary collaboration has the potential to improve the outcomes of neonatal intensive care.⁴⁰ Mutual collaboration between disciplines and institutions will ensure that outcomes based research encompasses the biopsychosocial aspects of life thereby enhancing quality and effectiveness of services provided to children with developmental disabilities.⁴¹ HIV/AIDS associated neurological and neurocognitive deficits spans a wide array of developmental disorders, numerous comorbidities which is further compounded by socio-economic factors and various organizational issues. Comprehensive neurodevelopmental assessments need to be conducted and translated to best clinical guidelines and evidence informed protocols.

During the study period approximately 639 of paediatric admissions were paediatric neurology, which indicates that nearly 21% of the patients were diagnosed with HIV/AIDS related neurological illnesses. This indicates the burden of disease in KZN. The majority of the children presented with co-morbidities. This has implications on the health system due to the cost involved in diagnosing and managing children with HIV infection. Human resource demands in terms of time is crucial when managing children with HIV infection due to the various neurological and neuropsychiatric manifestations. Challenges experienced included reduced daily rehabilitation. Children with HIV/AIDS related neurological illnesses require a multimodal level of care and adequate referral to base hospitals and supportive organisations. Children with HIV/AIDS related neurological illness require collaborative efforts to increase policymaking and resource intervention, which will lead to improved outcomes and quality of life.

Conclusion

The profile of Paediatric HIV/AIDS related neurological illnesses in terms of functional and rehabilitative indicators is not well documented in South Africa. Paediatric patients diagnosed with HIV/AIDS related neurological illnesses present with complex physical and neurocognitive deficits. This study described the profile of this population group as a

reference for the initiation of management protocols and pathways of care. The outcome of this study indicates that children with HIV/AIDS related neurological illnesses are managed with a MDT model of care. All members of the multidisciplinary team promote and improve functional outcomes of children with HIV/AIDS related neurological illnesses. Ultimately, the paediatric neurodevelopmental team plays a pivotal role where medical, rehabilitative and radiological intervention are interrelated to provide best practice and standards of care.

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Declaration of conflicting interests

The authors declare no potential conflicts in the research process and publication and authorship of the article.

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CHAPTER 3

MANUSCRIPT 2

POTENTIAL FOR BEST PRACTICE

Management of Paediatric HIV/AIDS related neurological illnesses – The Multidisciplinary Team Perspective

3.1 INTRODUCTION

The paediatric neurodevelopmental team is tasked with providing effective treatment to children diagnosed with HIV/AIDS related neurological illnesses. Comprehensive and integrated care is related to the bio-psycho-social model of functioning as well as indicators from the International Classification of Functioning, Disability and Health. This manuscript draws on the perspectives of the multidisciplinary team in determining how the team functions, how priorities of care are determined and the approaches required for best standards of practice and care. Moreover it highlights the enablers for successful management of children with HIV/AIDS related neurological illnesses, the level of communication, co-ordination and co-operation amongst members of the neurodevelopmental team in providing integrated and collaborative treatment. Lastly this manuscript brings to light the challenges and barriers to effective teamwork as experienced by the team.

3.2 JOURNAL DETAILS

For more than 50 years the Developmental Medicine and Child Neurology journal has defined the field of paediatric neurology and neuro-disability. It is regarded as one of the leading journals in the world in the realm of paediatrics and aims to enhance the care of disabled children and their families by disseminating clinical research relating to neurological conditions. The journal is listed on the Department of Higher Education and Training (DoHET).

JOURNAL	DMCN
ONLINE ISSN NUMBER	1469-8749
IMPACT FACTOR	3.615
STATUS OF ARTICLE	TO BE SUBMITTED

3.3 SUMMARY

This manuscript described the experiences of the MDT and how they manage paediatric patients with HIV/AIDS related neurological illnesses in an acute quaternary setting. The paediatric neurodevelopmental team must perform “in concert” as each member plays a vital role in managing paediatric HIV/AIDS related neurological illnesses. In doing so good clinical outcomes are achieved and best practice standards are adopted when treating children with HIV/AIDS related neurological illnesses.

3.4 MANUSCRIPT

This manuscript was formatted according to the specifications for author guidelines outlined by the Developmental Medicine and Child Neurology journal. The tables and figures are embedded within the main text to allow for ease of reading. Author’s names have been removed.

Potential for best practice: Management of Paediatric HIV/AIDS related neurological illnesses: The multidisciplinary team perspective

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ABSTRACT

AIM: This study aimed to explore the therapeutic interventions of the multidisciplinary team in the management of paediatric patients with HIV/AIDS related neurological illnesses in an acute quaternary hospital. **METHOD:** A mixed method explanatory sequential design was used. Data collection consisted of a questionnaire to the multidisciplinary team followed by a focus group interview with six participants. The focus group comprised of a medical doctor, nurse and allied health therapists. The questionnaires were analysed using descriptive statistics. Thematic analysis was used to analyse the qualitative data. **RESULTS:** Multidisciplinary teamwork in an acute quaternary setting when managing paediatric patients with HIV/AIDS related neurological illnesses emerged as a significant theme. Creating a collaborative culture in the work environment between health care professionals is meaningful in providing complex care to children with HIV/AIDS related neurological illnesses. The roles and responsibilities, priorities of care and functional outcomes that the team works towards were ascertained. Various challenges and barriers impacting on care were identified. Challenges included staff shortages due to budget constraints, increased workload, and reduced rehabilitative intervention impacting on team cohesion. The enablers and facilitators of collaborative care were described and recommendations were outlined to improve team cohesion. Currently the paediatric neurodevelopmental team is not adopting transdisciplinary teamwork at the health care facility. **INTEPRETATION:** This study outlined the approach that the multidisciplinary team adopts in the management of children with HIV/AIDS related neurological illnesses within an acute setting. Findings from this study could assist in informing standards of practice of care through integrated efforts by members of the multidisciplinary team. Furthermore the results suggest the need for evidence informed care plans from admission to discharge in the management of paediatric patients with HIV/AIDS related neurological illnesses. Indicators for facilitation of teamwork were identified which included the recognition that multidisciplinary teamwork requires collaboration, effective decision-making, skilled communication and liaising with governmental and non-governmental stakeholders to ensure that there is a continuum of care. Stronger consideration and support of transdisciplinary team measures is advocated. This will allow for the paediatric neurodevelopmental team to work together to provide comprehensive care and to alleviate the burden of management of paediatric patients with HIV/AIDS related illnesses due to a multiplicity of co-morbid factors and extenuating social and environmental factors.

What this paper adds

- A multidisciplinary team perspective on the management of Paediatric HIV/AIDS related neurological illnesses
- Priorities of care are highlighted as well as the roles and responsibilities of the team managing this paediatric population in an acute quaternary setting
- Functional outcomes that the team works towards, focusing on an integrative and holistic approach
- Barriers and challenges experienced by the paediatric neurodevelopmental team
- Facilitators of teamwork that encourage team cohesion and collaborative care

Introduction

Paediatric HIV associated neurological illnesses have been documented in approximately 50-60% of children with central nervous system involvement (CNS). In paediatric HIV, HIV encephalopathy (HIVE) is the most frequently documented direct complication relating to the CNS.¹ Other neurological manifestations of paediatric HIV include cerebral-vascular accidents, peripheral neuropathies and myopathies, epilepsy, opportunistic infections, behavioural and neuropsychological deficits.¹ Studies of HIV related neurodevelopmental manifestations have shown a high prevalence of HIVE in developing countries.² HIV infected children with neurological and neurocognitive deficits require appropriate intervention to improve their participation in activities as well as their quality of life. Considering the burden of HIV in KwaZulu Natal, the multidisciplinary team (MDT) approach is crucial for the care of paediatric patients with HIV/AIDS associated neurological illnesses. The MDT is essential to provide comprehensive, integrated and holistic care given the diversity of medical, physical and neurocognitive manifestations. The MDT is necessary to provide medical intervention, optimal rehabilitation, address educational needs and provide social support.³ Renewed focus on MDT assessment and management of HIV related neurodevelopment disabilities is still mandatory notwithstanding that paediatric highly active antiretroviral therapy (HAART) could be effective despite the challenges in a developing country.⁴ A MDT consists of healthcare practitioners with different scopes of practice, working in a parallel or sequential method and without challenging their discipline specific boundaries.⁵ The benefits of working in an MDT include knowledge sharing, support, co-ordinated goal setting and intervention planning. Collaborative care leads to reduction in burnout, fatigue and stress when dealing with children with poor prognosis.⁶ Identification of common goals and intervention plans, good communicative skills, respect and mutual recognition of each team member's contribution and collaborative skills are integral for the functioning of the MDT. Institutional factors such as lack of infrastructure, budget

constraints, increased patient loads and poor conflict management may result in stress within the workplace.⁶ The best possible outcome for treatment is through an established multidisciplinary team that ensures excellence in patient care.⁷ A mutual care plan is necessary for effective management in the health care sector.⁸

Methods

Study Design: A mixed method explanatory sequential design within a multi stage framework was selected.⁹ The quantitative component of the study comprised of the administration of a questionnaire to the paediatric neurodevelopmental team. The qualitative aspect comprised of a focus group drawing on the perspectives of the multidisciplinary team employed at a specialist hospital in KwaZulu Natal. The multi stage mixed methods framework was selected, as there were multiple stages of data collection within the larger study in the management of paediatric HIV/AIDS related neurological illnesses. Multistage mixed methods frameworks in health care research is favoured as it focuses on evaluation, implementation and assessment of intervention.¹⁰ Accordingly this study generated themes associated with the performance and perspectives of the multidisciplinary team employed at a quaternary health care facility.

Participants: The questionnaire was administered to all members of the team involved in the management of Paediatric HIV/AIDS related neurological illnesses (n=27). The paediatric neurodevelopmental team employed at the health care facility include the Paediatric Neurologists, Registrars, Nurses, Physiotherapists, Occupational Therapists, Speech Language Pathologists, Audiologists, Social Workers, Dieticians and Clinical Psychologists. Members of the team who did not offer physical therapy with the child, other than for diagnostic purposes were excluded. Homogenous purposive sampling was used to select a member from each discipline for the focus group (n=6) to facilitate in-depth exploration of the approach used by the MDT.¹¹ The same members of the MDT who completed the questionnaire also attended the focus group. The focus group was audio-recorded and then transcribed verbatim. The demographic profile of the participants who attended the focus group is summarized in table 1.

Data Analysis: The quantitative results were analysed using descriptive statistics including frequencies and percentages and informed the preparation for the focus group schedule of questions. The focus group was analysed thematically by using the procedure outlined by Braun and Clark.¹²

Ethics: Ethics for the study was obtained from the Biomedical Research Ethics Committee (reference number BE057/16). Permission was also received at an

institutional level and from the Department of Health KwaZulu Natal. All participants signed a consent form and were informed of their rights.

Results

Table 1 Demographic profile of the paediatric neurodevelopmental team who attended the focus group

Participant Number	Designation	Age	Race	Gender	Years of experience
PN1	Chief Supervisory Occupational Therapist	35	Asian	Female	15-20 years
PN 2	Social worker	48	Asian	Female	>20 years
PN 3	Professional Nurse	40	Black	Female	10-15 years
PN 4	Paediatrician- Paediatric Neurology Fellow	35	Asian	Male	10-15 years
PN 5	Clinical Psychologist	49	Asian	Female	15-20 years
PN 6	Chief Supervisory Physiotherapist	37	Asian	Female	10-15 years

Table 2 Demographic profile of the paediatric neurodevelopmental team who completed the questionnaire

Occupational class	Number of participants	Gender	
		Male	Female
Medical domain	5	N=1	N=4
Physiotherapy	10	N=1	N=9
Occupational Therapy	2		N=2
Nursing	5		N=5
Audiology	1		N=1
Speech Therapy	1		N=1
Social Work	1		N=1

Clinical Psychology	1		N=1
Dietetics	1		N=1
TOTAL	27	2	25

Demographic and vocational profile of the paediatric neurodevelopmental team

Thirty-eight questionnaires were distributed and a total of twenty-seven completed questionnaires were received (71% response rate). The majority of the respondents were female (n=25) which accounted for 92.5% of the total population. Seventeen of the practitioners (63%) were within the age group 31-40 years. Ten responses (37%) were received from Physiotherapists, 18,5% (n=5) from both the Medical and Nursing Domain and 7% (n=2) of responses were received from Occupational Therapy. The remaining allied departments i.e. Speech Therapy, Audiology, Social Work, Clinical Psychology and Dietetics each accounted for 4% of the total population.

With regards to Vocational milieu seventeen practitioners (63%) qualified at the University of KwaZulu Natal. Sixty three percent (63%, n=17) of the practitioners had no post-graduate studies. With regards to their skillset, the majority of respondents had no specific training in the management of HIV (n=16, 59%). None of the practitioners had any specific training in Paediatric HIV/AIDS related neurology. Above half of the practitioners (n=16,59%) reported they demonstrated some skills and knowledge to manage Paediatric HIV/AIDS related neurological illnesses.

Management of HIV/AIDS related neurological illnesses

Twelve members (46%) have treated between 1-10 patients whilst six practitioners (23%) have managed approximately 20-30 patients in the last 12 months. HIVE was described as the most common condition assessed and treated by the team (n=10). Four members of the MDT (23,5%) treated approximately five children diagnosed with HIVE whilst 17,6% of practitioners (n=3) treated approximately ten children on a yearly basis. With regards to other CNS HIV related illnesses 31.2% of the MDT (n=5) treated approximately ten children with neuro-regression whereas 18.7 %(n=3) indicated that they have managed five children on a yearly basis. Four members of the MDT (30%) managed approximately ten children diagnosed with cerebro-vascular accidents. Three practitioners (30%) treated approximately five children diagnosed with peripheral neuropathies within a 12-month period. Four team members (25%) treated approximately 5 children diagnosed with epilepsy. Similarly 23,5% (n=4) treated

approximately 5 patients diagnosed with seizures whilst 17,6% (n=3) managed approximately 20 children. Two team members (33,3%) treated approximately 5 children diagnosed with lymphomas. The average consultation time recorded by 61% (n=16) of the practitioners was approximately 0-30 minutes.

Multidisciplinary teamwork and thematic matrix

Thematic Analysis revealed seven themes with associated categories as illustrated below in table 3. In-depth comparative analysis findings of the themes and questionnaire are highlighted below and illustrated using relevant quotes.

Table 3 Thematic analysis highlighting themes and categories

	Theme	Category
THEME 1	Roles and responsibilities and priorities of care- “Playing the Role”	Managing the disease and minimising comorbidities, neurological dysfunction and opportunistic infections Quality of life Vulnerable child with special needs Rehabilitation Chest pathology Counselling and adherence Improved outcomes
THEME 2	Functional Outcomes and treatment goals- “Joining pieces of the child’s puzzle”	Reintegration into society Macro system impacts on the child Management of a complex chronic condition Education and compliance Developmental milestones and improving function Measurable outcomes Planning and Assessment based on individual patient needs Referral order request Quaternary setting and continuum of care
THEME 3	Quaternary setting: physical structure and environment	Pleasant and stimulating environment Mothers Lodge Procedure room and invasive procedures Lack of confidentiality in wards Modulated environment

		Electronic medical records Co-ordination of clinical activities
THEME 4	Perceived challenges and demands-“The Hardest puzzle”	Lack of human resource infrastructure Revolving door syndrome Lack of feedback and communication with base/referral hospital Reduced involvement of Non governmental organization’s and community resources Role confusion Reduced collaboration between Department of Health and Department of Education Reduced collaboration within MDT
THEME 5	Collaborative care and team cohesion- “The completed picture”	Increased collaboration via case discussions Knowledge sharing Outlining expectations and roles Open and effective communication
THEME 6	Recommendations for improved care-“When all the right puzzle pieces are put together”	Case conferencing, discussions and ward rounds Liaising with base/referral hospital Strategic plan
THEME 7	Transdisciplinary care- “The missing puzzle piece”	Common goal Professional boundaries and scope of practice

Theme 1- Roles and responsibilities and priorities of care

Majority of the participants (n=19, 73%) indicated that their management does not differ from other paediatric conditions. Majority of the practitioners (n=25, 93%) reported there is no specific treatment protocols or clinical guidelines within their specific departments for the management of paediatric HIV/AIDS related neurological conditions. However 7% (n=2) indicated that specific to this paediatric population warrants screening for opportunistic infections e.g. tuberculosis. A significant percentage of practitioners (n=21,81%) agreed that there is a MDT involved in the decision making of patients with HIV/AIDS related neurological illnesses. Twenty-one participants acknowledged that the paediatric neurologist and clinicians allied to medical were involved in the decision making process. The participants were divided on referral of patients with twelve practitioners (50%) reporting that they refer patients to the MDT whilst ten respondents (42%) related only referring selected cases.

The roles and responsibilities of the team are discipline specific. The roles are discrete and categorised as medical, psychosocial, rehabilitative intervention and nursing care. The combined expert knowledge of the different professionals is listed below.

Table 4: Job responsibilities and Domains of clinical practice

Discipline	Roles and responsibilities	Relevant Quote
Medical intervention	Managing a complex medical condition of the HIV virus, associated co-morbidities and neurological dysfunction.	<i>“our principal role would be to try and control the disease as well as identify certain co morbidities...those comorbidities could be things such as the developmental delay that they can get...opportunistic infections as well and screening them for things such as that”</i>
Psychosocial intervention	The Clinical psychologist is involved in the psychosocial aspect of the child and assesses the coping mechanism of the child and family.	<i>“we will see the mothers of patients if necessary to explain the diagnosis or coping or things like that but not specifically for HIV”</i>
	The Social worker’s role entails counselling services focusing on both the family and child, identification of risk factors and collaboration with Non governmental organisations for pre-discharge planning.	<i>“we explore any risk that this child is exposed to, remember the child has a neurological problem so might be at risk and we also intervene around that together with the NGO’s in communities, child welfare organisations as well as your disabled organisations ”</i>
Rehabilitative intervention	The Physiotherapists role includes holistic assessment and treatment of the child with special focus on chest physiotherapy	<i>“the assessment basically does cover chest ...specifically to a Paeds HIV neurology we would look at tone, developmental milestones sensation loss and the neurological implications as well as with HIV we would consider the immuno deficiency of the patient...also incorporate treatment to the caregiver”</i>
	The Occupational therapist’s role is to identify physical dysfunction and working towards functional outcomes e.g. schooling based on the child’s level of functioning.	<i>“...if there is physical co morbidities such as neuropathies or hemiplegia we will, the patients will get referred to us for splinting or rehab...developmental delay is another thing that that we get referred to often so we will do developmental stimulation with them”</i>
	The Speech Language pathologist’s role is not specific to HIV and their role thereof is to manage speech, language or feeding/swallowing difficulties.	<i>“our treatment of all paediatric patients is the same...it is not unique to HIV/AIDS status as opposed to the presenting Speech/Language/Feeding/Swallowing difficulties”</i>
	Behavioural and Electrophysiological testing depending on the patient’s level of alertness is used by the Audiologist to assess hearing status.	<i>“Identify and assess as early as possible the degree, type and severity of a possible hearing impairment...after diagnosis to effect appropriate management and monitoring”</i>

	The role of the Dietician is assessment of feeding or management of nutrition related complications.	<i>“referrals to dietetics would be for feeding or management of nutrition related complications”</i>
Nursing Care	Involves the administration of medication, ensuring compliance and follow through of intervention offered by therapists in the ward as well as handover to caregivers.	<i>“we ensure that the patient’s get all the basic care that they need such as we give them nutritious feeds so that they will pick up...whatever medication has been prescribed for them is being given at due times and give the medication to the caregivers or parents so that they comply with the treatment...also once the patient has been referred for splinting or any other specific care we ensure that we apply those splints as been ordered by the occupational therapist”</i>

This study established that the management of the child with HIV related neurological illness is hierarchically structured and guided by the medical doctor who is often the principal co-ordinator facilitating the referral process to other clinical departments.

“I think we often sort of play the role of being the main principal people involved in looking after the patient”. PN4

This was confirmed by all therapists’ attending the focus group indicating that they receive referrals from the medical doctor outlining the nature of treatment required.

“Because HIV related conditions is very vast our assessment and management of the patient also depends on what the doctor refers the patient for” PN 1.

The paediatric neurodevelopmental team agreed unanimously that the medical and rehabilitative priorities of care and review of these patients are dynamic and continuous in nature. This process allows for the continuum of care in an acute quaternary setting.

“our priorities are always dynamic ...to take cognisance of the fact that our treatments for example can also do side effects and harm so we have to be dynamic in regards to our approach and there is always the risk of IRIS [Immune Reconstitution Inflammatory syndrome] as well “ PN 4.

The priority of care of the medical doctor is to manage the disease and minimise comorbidities, neurological dysfunction and opportunistic infections. These findings were substantiated by 25% of practitioners (n=6) who described managing co-morbidities and secondary complications as their priority management strategy. Additionally 19 members (70%) strongly agreed that the goal of care is to manage co-morbidities and minimise the effects of secondary complications. Twenty eight percent (28%, n=6) of practitioners

acknowledged that disease progression contributes to the negative aspects when managing these cases.

Improving quality of life emerged as a common theme. Four practitioners (17%) identified quality of life as a priority management strategy. Additionally, 74% (n=20) of the participants indicated that facilitating the opportunity for children to achieve their maximum level of function and potential is the main goal of clinical care.

I would say quality of life, that is the most important thing I would like to give to these kids, prioritise that whatever that might be schooling or finance or whatever...”
PN 5.

Children who are diagnosed with HIV/AIDS related neurological illnesses were seen as a vulnerable population group and have special needs. Twenty-one (84%) of team members specified that their treatment encompassed a child centred approach. Therapist's reported that their rehabilitation intervention is evidence based and related to the patient's level of functioning. Forty six percent (n=6) of therapists' reported that they employ neuro-developmental techniques. Sixteen practitioners (59%) strongly agreed that one of the goals of clinical care is to minimise and delay musculoskeletal deformities.

“if the patient is very low level functioning is bed bound our priority of care would be splinting, preventing contractures, maintaining joint mobility...if they are higher functioning patients then we look at integrating back into school, doing scholastic assessments, the developmental stimulation and the functional component of rehab”
PN 1

Management of chest pathology and respiratory function was viewed as essential in an acute setting and was reported as a priority of care by 33% of members of the MDT. Cough and respiratory function was strongly favoured by 60% practitioners to be incorporated into the paediatric review. Counselling and adherence to both the medical, nursing and rehabilitative regimes was voiced as integral to limit the disease process and minimise co-infections. Guiding all therapy and intervention strategies the team described that one of the positive outcomes of managing children with HIV/AIDS related neurological illnesses is an improvement in their condition (40%).

Theme 2: Functional outcomes and treatment goals

Reintegration into society emerged as an outcome that the team works towards.

“the main long term goal would obviously be reintegration into society and trying to achieve the highest level of function for the patient” PN 1

The team also works towards improving the macro system impacts on the child, which includes factors such as education and basic infrastructure.

Education and compliance involved adherence to medication regime and ensuring caregiver involvement in the treatment process. Managing a complex medical condition involves disease control and treating opportunistic infections. Similarly nursing identified minimising secondary complications and adhering to infection control principles as an outcome of care.

“the functional outcomes would once again be individualised for each patient ...we as doctors would like to ensure and not only have the virological suppression and raised CD4 and the absence of the opportunistic infections but that the child is actually growing and thriving not only physically but also emotionally and cognitively as well. ” PN 4.

Twenty practitioners (74%) strongly agreed that achievement of developmental milestones was a clinical goal of the team to ensure that the child is able to function in their daily life.

Planning and Assessment formed the baseline of goal setting for the majority of the team. Goals defined by the team are individualised and specific to the patient's need and is further dependant on the referral. The team reported that the nature of a quaternary hospital and the patients limited length of stay influences goal setting with therapists having to rely on the base hospital to carry out the plan for future therapy and continuum of care.

*“...we often refer patients because we are a quaternary centre these patients are referred to base for further management so there is always a clear plan with regards to the base hospital this is what was found and this is what our plan is”
PN4*

The team works towards measurable outcomes incorporating multidisciplinary teamwork, which ultimately improves service delivery and patient care. Measurable outcomes can serve to determine the level of success in patient care and can assist in refining goals.

“so your functional outcomes that you achieve with the patient are a lot better and services compliment each other” PN1

Theme 3: Quaternary setting: physical structure and environment

The environment was described as pleasant and stimulating and access to Mother's lodge assisted the team members with obtaining collateral information.

“it is well documented that a child’s environment can either be stimulating or it can inhibit whether they explore and grow neurologically and cognitively and functionally as well ,so our ward is mainly child friendly as possible with paintings on the wall” PN 4.

Eighteen team members (66.6%) reported that their department is adequately equipped. The ward was described as safe and secure. The Procedure room was associated with anticipation of pain/distress by the children and the medical team attempted to limit invasive procedures. Team members indicated that maintaining confidentiality whilst consulting in the ward was difficult. A modulated environment and computer technology system were seen as factors contributing to an effective work atmosphere. Working within a multidisciplinary team requires interaction and team co-ordination of clinical activities between the different health care professionals.

“...joint sessions with physio and maximise treatment outcomes with the patient for example if we find that the patient is starting to contract [form a contracture] we would get the physio to stretch and get as much range at the joint before we splint so we get maximal range” PN 1

Theme 4: Perceived challenges and demands

The majority of the team members cited that the lack of human resources negatively impacts on the multidisciplinary team functioning. More than half of the respondents (65,3%) reported challenges when managing patients with HIV/AIDS related neurological illnesses.

“I don’t think anyone is against working that way it is just we cannot afford the time or that specific time to come together” PN 5.

A significant percentage of practitioners (n=19,73%) indicated that they do not participate in paediatric neurodevelopment clinics with 18% (n=4) of members citing staff shortages as a reason. The team expressed that these children are often lost to follow up and described this experience as a “Revolving door syndrome”.

“....they came back and they back either worse or back to square one “ PN 1

The lack of feedback and extension of communication with the base hospital was acknowledged by the team members where there is limited collaboration with the referral institution.

“I think the assessment and the goals and plans are made, but to what extent it is carried out we don’t get that feedback” PN 5

Some team members expressed that there is role confusion within the MDT resulting in inappropriate referrals.

*“Like with regards to the junior doctors the clarity between OT and physio, because most of the time when the patient requires splinting the referral does come to physio”
PN 6*

The team reported that increased involvement of community and non-governmental organisations is required to foster a partnership that will improve the overall management and service delivery to these children. There is also reduced collaboration between the Department of Education and Department of Health. Consequently, this impacts negatively on the educational aspect of the child as appropriate placement in special schools are delayed as well as remediation of scholastic difficulties.

“...to add we have challenges with the special school placements to get a memorandum of understanding with them, at a policy level we need to look at that as well as with the department of education “PN 2

Reduced Collaboration within the actual MDT was accepted as a factor impacting on patient care due to various institutional and fiscal challenges.

Theme 5: Factors contributing to collaborative practice/team cohesion

The team preferred collaboration within the MDT and frequent case discussions. Despite the poor staffing in most clinical departments the team was still willing to extend some form of multidisciplinary interaction. Four practitioners (15,3%) indicated that they met on a monthly basis to discuss patients. 95,8% reported that they enjoyed being involved in case discussions and 96% supported collaborative learning.

“... we need to actually have a case conference set up where our patients are case conferenced and the plan is actually discussed and collaborated amongst all the role players involved with that patient and I think that’s missing, that there is a gap here and we need to look into that “ PN2.

The MDT expressed that knowledge sharing of expertise facilitated teamwork and helped improve treatment outcomes.

“the rewards is that you also learn from each other, you learn more about the patient and the patient’s condition” PN 6

Outlining the expectations and roles and scope of team members was identified as a factor contributing to team cohesion.

“so I think it starts in-house, each person knows what the other one can and cannot do, their limitations and expectations and we also need to match that to what the patient wants” PN4

Open and effective communication was desired to improve team cohesion.

“...there is open communication amongst all the professionals in the MDT team and I think we have a very good system working here.” PN 1

The MDT identified several teamwork principles where team members (n=25) reported that they are comfortable with communicating with each other and advised that it is beneficial to learn from members of the MDT. Sixteen members (64%) of the MDT recognized that there is mutual respect within the team. The majority of the MDT acknowledged that the MDT they work within is rewarding (n=18,72%).

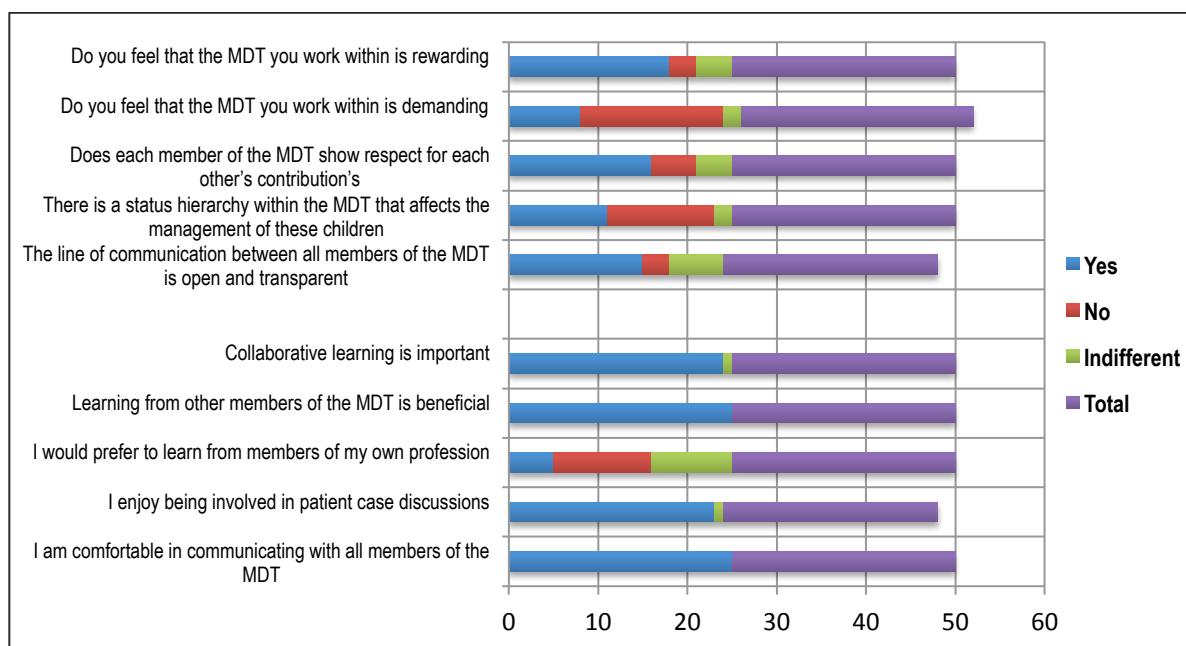


Figure 1 Teamwork principles

Theme 6: Recommendations for improved care

Case conferencing, discussions and attendance at ward rounds were recognized as means of fostering team cohesion and patient care.

“...having case discussions on certain patients it would be nice for the team to come together set goals together so everyone is on the same page and they know where they are going with the patient I think that will enhance teamwork as well” PN1.

All team members recommended increasing feedback and communication with the base/referral hospital.

“if we can set up some sort of system to get feedback from the people that we refer to, the feedback is very adhoc...provide them some kind of performance or report or whatever that the patients brings through at the next clinic appointment date I think that would take away that revolving door syndrome that we have. And we can actually move much faster with the case” PN5

Strategic planning at both a departmental and institutional level was advised to enhance multidisciplinary care.

“ Just to evaluate where we are, we are perhaps doing things adhocally and maybe jus map out a plan, a stat plan” PN2

Theme 7: Transdisciplinary teamwork

Currently transdisciplinary measures were not being practiced within this acute healthcare facility.

“..I’ll be honest we very rarely consider the trans disciplinary team measures out there” PN4.

However the team acknowledged that within this practice of care there is one common goal for the child.

“I mean with transdisciplinary there is basically one goal one plan for the patient not everybody has a plan for the patient that’s how I understand it so who is actually going to manage this case” PN 5

Concerns were raised as to the professional boundaries and the scope of practice of each profession if transdisciplinary teamwork were to be adopted.

“I think a scope of practice becomes a big thing, and the borders do get a bit blurred sometimes when you try to do your best for the patient and you may be tramping onto another professions toes” PN 1.

Contrary to this all team members who completed the questionnaire were supportive of transdisciplinary measures.

Discussion

The International Classification of Functioning Disability and Health (ICF) serves as a framework reference for any health care professional involved in rehabilitation.¹³ Specifically for a child living with HIV, the ICF pays attention to the life related challenges that can be assisted by both medical and rehabilitative intervention. Health care professionals should be aware of the signs and symptoms of developmental disabilities associated with HIV infected children as it impacts on all domains of a child’s development.³ Multi professional teamwork is critical for the implementation of integrated rehabilitation intervention strategies aimed at providing comprehensive care to patients with diverse health requirements.¹⁴ Specific to HIV the multidisciplinary team experts should include the doctors, therapists, dietician, social workers and should include

consensus with the department of health representatives and non-governmental organisations.¹⁵

This study finding concurs with literature, which indicates that children with HIV related neurological illnesses have neurodevelopmental and neuropsychiatric deficits which impacts on their development.¹ The HIV infection affects the CNS and the incidence of HIVE is between 13%-35%. HIVE is usually the first sign of disease progression to AIDS in approximately 18% of HIV infected children.¹⁶ In this study, the multidisciplinary team identified HIVE as the most common condition treated at the specialist quaternary hospital. HIVE is defined as damage or dysfunction of the brain as a result of HIV1 infection and can be described as static or progressive with neuroregression.¹⁷ The revised classification system for HIV infection in children under 13 defines the diagnosis of HIVE with one of the following symptoms which is a failure to achieve or a loss of developmental milestones, impaired brain growth with microcephaly and motor deficits manifesting as paresis, ataxia or gait difficulties.¹⁸

The assessment and management care pathway of children diagnosed with HIV/AIDS related neurological illnesses should be multimodal and incorporate a trans-disciplinary approach.³ Roles and responsibilities emerged and were classified independently based on occupational categories. Medical intervention focused on minimising disease progression and managing the neurological dysfunction and co-infections.

The disease progression in children is more complex as compared to the adult population. Tuberculosis and Pneumocystis pneumonia is a major cause of health complications with post mortem studies of African children showing respiratory disease as the leading cause of mortality.¹⁹ The increased incidence of Tuberculosis in health care workers was established in a study conducted in eight public hospitals situated in KZN. During the period 1999-2004, approximately 583 health care workers were diagnosed with Tuberculosis with Pulmonary Tuberculosis accounting for 76,5% of the population.²⁰ This highlights the risk of exposure that health care professionals are faced with.

Management of chest pathology and respiratory function in an acute setting is deemed a priority treatment modality. Rehabilitative intervention involved evidence based practice based on the level of functioning of the child, the stage of disease process and the extent of neurological impairment. Developmental delay may be the first sign of HIV infection progressing to neurological dysfunction including deficits in muscle tone, pyramidal tract signs, cerebellar signs and cranial nerve palsy.²¹

Perusal of literature indicates that there is limited information detailing the multidisciplinary care of children with HIV/AIDS related neurological illnesses. Paediatric HIV/AIDS related neurological illnesses are considered a chronic medical condition requiring complex multidisciplinary intervention. Studies involving other chronic

paediatric conditions such as type 2 diabetes have confirmed that multidisciplinary health care teams improve management and outcome measures.⁷ Similar sentiments were expressed in a study detailing the care to patients with Duchene muscular dystrophy which requires a multidisciplinary approach as well as early intervention to address the primary and secondary co-morbidities of the diagnosis.²² Furthermore children with chronic kidney disease followed up at a multidisciplinary clinic demonstrated better outcomes.²³ These studies have asserted that children with chronic medical conditions requires holistic and integrated multidisciplinary care for best practices and standards of care. Studies in an African context are limited to none in highlighting multidisciplinary care within a acute quaternary setting especially in the management of paediatric HIV/AIDS. However in Brazil HIV vertical transmission was reduced due to preventative programmes using a multidisciplinary team approach, which included, adherence and compliance of ART drugs, health education and the use of formula for exposed infants.²⁴

The paediatric neurodevelopmental team identified achieving developmental milestones as a priority, which encompasses all domains of a child's functioning. CNS associated illnesses can cause a detrimental effect on the child's function and impacts on the quality of life. This can result in increased periods of hospitalisation and subsequently impacts on educational performance warranting access to intervention.²⁵ In this study the core outcomes that the paediatric neurodevelopmental team works towards is improving the quality of life and function of this population group and ultimately reintegration into society. Counselling and adherence emerged as a factor to promote education of the disease process and compliance of the medical and rehabilitative regimes. Psychosocial intervention focused on child and family centred approaches and liaising with both governmental and non-governmental organisations. Therapists identified vocational specific modalities of care including splinting, rehabilitation employing neurodevelopmental techniques, screening for hearing status and speech and swallowing deficits as well as determining the nutritional needs of the child.

With the initiation of HAART many children have a prolonged life expectancy. In a study conducted in KZN, the preliminary outcomes of a cohort of 151 paediatric patients over a 25-month period were reported upon. The findings suggested that a family centred HAART program in a resourced limited environment could be effective.⁴ A reduction in the incidence of HIVE has occurred in perinatally infected children and adolescents since the initiation of HAART. ²⁶

A Malawian study of a cohort of 296 HIV infected children aimed to provide data on the prevalence of disability amongst children with HIV in Africa. This study highlighted that disability amongst children living with HIV were not isolated and that approximately half of the children had two or co-existing forms of disability. Furthermore the disabilities were across a wide spectrum i.e. speech, hearing and physical dysfunction and illustrated the

need for holistic and multidisciplinary rehabilitative services.²⁷ Consensus regarding the above was noted by Nixon et al, 2011 who indicated that HIV is not only related to medical outcomes but poses a concern for rehabilitation and disability. Therefore health care workers involved in HIV disability and care should understand their role thereby providing a continuum of care.²⁸ Similarly a systemic review outlining the risk and prevalence amongst HIV infected children and adults in Sub Saharan African suggested that HIV is linked to disabilities affecting a wide range of function and body structures. The review concluded that increased research is required to interpret the implications of disabilities associated with HIV so that appropriate intervention in this field can be developed.²⁹

In a cohort study of 7 public sector paediatric anti retroviral programmes in three provinces namely KZN, Gauteng and the Western cape showed a clinical benefit in those children accessing the national programme.³⁰ In SA the cost incurred in hospitalising HIV infected children are significantly more as compared to their uninfected counterparts.³¹ This was supported by a study with children with pneumonia conducted in SA in 2007 where the mean cost for HIV infected children was recorded as US\$639.06 in the public sectors. Comparatively for non HIV-infected patients, the cost was recorded as US\$399.45.³² This highlights the complex and multi-faceted presentation of children with HIV/AIDS requiring intensive medical, diagnostic and rehabilitative care.

Several challenges and barriers were identified as impacting on the team in managing paediatric HIV/AIDS related neurological conditions. This included reduced collaboration between team members, children being lost to follow up due to inadequate communication with the referral or discharge institution, poor collaboration with other governmental departments and stakeholders and the phenomenon described as a “revolving door syndrome”. Chetty et al, 2016 identified similar factors and asserted that reduced collaboration between the multidisciplinary team impacts negatively on HIV related rehabilitation.³³

Factors enhancing teamwork included increased collaboration and participation in patient team discussions. Health care professionals should work in a collaborative manner to address the complex bio-psychosocial needs of people with HIV.³⁴ Lack of communication between the multidisciplinary team can impact on the quality of care offered to patients with HIV associated disabilities.³⁵ Multidisciplinary meetings serves a means of improving communication, learning and development and improved relationships between the health care professionals.³⁶ Key factors promoting successful team work include defining clarity of roles, setting clear work values, commitment to a shared goal, establishing trust and confidence, acceptance of change, open communication, constructive and collaborative case discussions, receipt of constructive feedback and commitment to working towards emerging models in healthcare.³⁷

The paediatric neurodevelopmental team displayed conflicting views regarding transdisciplinary teamwork. The characteristics of transdisciplinary teamwork entails sharing and joint establishment of goals and care plans, the transference of knowledge and skills and role expansion and release through professional boundaries. Transdisciplinary teamwork is crucial when the patient has a complex medical diagnosis.¹³ The benefits of transdisciplinary approach of care involves providing an efficient service, decreasing cost factors, more logical and integrated care plans, less stress and interruption to the family system and improved skills and development among the professionals.³⁸

The authors are aware that this study is limited to an acute quaternary care facility. The study did not explore all levels of care as management in a chronic step down facility differs to that in an acute quaternary hospital. The study was also based in a public hospital and care plans and practice guidelines could vary in a private institution. Furthermore the perspectives of other health care professionals who are also involved in the care of Paediatric patients with HIV/AIDS related neurological illnesses have been excluded. Therefore by drawing on perspectives of all service providers will encapsulate a deeper understanding and insightful analysis of the functioning of the team when managing Paediatric patients with HIV/AIDS related neurological illnesses. Similarly there is a definitive need to screen for progress of children with HIV related developmental disabilities. This is reliant on the evaluation and collaboration of different health care professionals and the development of a strategic care plan to holistically manage children with HIV/AIDS related neurological illnesses.³⁹

Conclusion

In the ever-evolving healthcare of children with HIV/AIDS related neurological illnesses, this study served to inform and articulate information across different multi professional disciplines. A well functioning health care team requires synergy and commitment from all multidisciplinary health care professionals who hold the potential to transform management of paediatric HIV/AIDS related neurological illnesses. Whilst transdisciplinary care requires commitment for the ultimate level of team cohesion and integration, greater training is required in this form of health care.

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CHAPTER 4
MANUSCRIPT 3

The Paediatric Neurodevelopmental Team: Did we get it right?

The voices of the caregivers and children

4.1 INTRODUCTION

Caregivers of children with HIV/AIDS related neurological illnesses are faced with numerous stressors. Economic decline, stigma as well as their own health care requirements make parenting these children challenging. The caregiver is necessary as they contribute to the nature of the child's participation in activities and their behavior within the hospital environment. The caregivers of children with HIV/AIDS related neurological illnesses are required to fulfill numerous and complex roles.

A child diagnosed with HIV/AIDS related neurological illnesses are also faced with stressors impacting on function and loss of roles e.g. schooling. Although there has been some research into the child's role in the decision making process during hospitalization, there is paucity in research in describing the experiences of the child and their involvement with service providers within a hospital environment. The needs of caregivers and children in this context have not been well researched in developing countries.

It has emerged that the caregiver and child play a pivotal role in the treatment process and in managing the diagnosis. Therefore this manuscript highlights the experiences of primary caregivers and children with regards to the therapeutic intervention offered by the paediatric neurodevelopmental team.

4.2 JOURNAL DETAILS

The Southern African Journal of HIV Medicine focuses on HIV/AIDS treatment, prevention and related topics relevant to clinical and public health practice. The journal is listed on the Department of Higher Education and Training (DoHET).

JOURNAL	SAJHIVMED
ONLINE ISSN NUMBER	2078-6751
PUBLICATION	ONE ISSUE PER YEAR
STATUS OF ARTICLE	TO BE SUBMITTED

4.3 SUMMARY

Paediatric HIV/AIDS related neurological illnesses bears negative consequences on the entire family. The families of children with HIV/AIDS must cope with an array of psychosocial factors including the stressors associated with dealing with a chronic illness, concerns regarding medical and rehabilitative intervention as well as stigma and isolation. Due to the multi-systemic nature of HIV infection and its adverse effects on neurodevelopment a multidisciplinary team is crucial. Families of children with HIV/AIDS related neurological illnesses must be assisted by health care professionals to understand the various developmental disabilities so they can assist in enhancing the quality of life of their children. Therefore the success of the neurodevelopment approach to children with HIV infection is dependant on a collaborative team approach and the inclusion of the primary caregiver and child in the treatment process.

4.4 MANUSCRIPT

This manuscript was formatted according to the specifications for author guidelines as provided by the Southern African Journal of HIV Medicine. The tables, figure and drawings are embedded within the main text. Authors' names have been removed.

The Paediatric Neurodevelopmental Team: Did we get it right? The voices of the caregivers and children

Significance of work: There is paucity of publication on the knowledge, perceptions and attitudes of children with HIV/AIDS related neurological illnesses. HIV infection has a detrimental impact on a child's functioning across all domains, which include the physical, psychosocial, cognitive and economic sphere. The caregivers are faced with managing a complex medical condition. The paediatric neurodevelopmental team is tasked with engaging the primary caregiver as part of the treatment process and providing an approach that is child centred. This study explored to understand the experiences of children diagnosed with HIV/AIDS related neurological illnesses and that of their primary caregivers.

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Authors Contributions

K.S. analyzed the data and wrote the first manuscript. The co-authors contributed towards the scientific quality of the work and supervised the entire project. All the authors reviewed and contributed towards the final manuscript. Furthermore all the authors read and approved the final manuscript.

The Paediatric Neurodevelopmental Team: Did we get it right? The voices of the caregivers and children

Abstract

Background: It is important to understand the experiences and perceptions of children with HIV/AIDS related neurological illnesses and those of their primary caregivers. This promotes a family centred intervention by the paediatric neurodevelopmental team. The information allows for successful participation in treatment regimes and will ultimately lead to improved clinical outcomes and service delivery. **Objectives:** This study describes the knowledge, experiences and perceptions of primary caregivers and children who have been diagnosed with HIV/AIDS related neurological illness in terms of the intervention offered by the multi-disciplinary neurodevelopmental team. The aim of the study was to highlight some of the challenges experienced by these end users as well as the perceptions of the efficacy of the team in the provision of therapeutic intervention. **Method:** A mixed method explanatory sequential research design was utilized. Five caregivers and three children were conveniently selected. Semi-structured interviews were conducted one on one in English and translated into isiZulu with the use of an interpreter. The audio-recorded data was transcribed verbatim and translated into English. Data was analyzed using thematic analysis. Children's drawings were solicited to describe their stay in hospital. The quantitative aspect involved the administration of a questionnaire to the multi disciplinary team (n=27), detailing their perspectives on the inclusion of the caregiver in the treatment process. These findings were analyzed using descriptive statistics of frequencies and percentages. **Results:** The results revealed the negative and multi-faceted impact of HIV/AIDS related neurological illnesses, which was described using physical symptomatology and other co morbid factors. The caregivers highlighted overall satisfaction with the services offered by the paediatric neurodevelopmental team. All caregivers experienced feelings and emotions of sadness and despair. One child was able to describe in detail the interaction with the team. Pictures depicting the child's stay in hospital highlighted subjective experiences in a clinical setting. **Conclusions:** This study adds further valuable information of the perceptions and experiences of HIV/AIDS in a resource-limited environment. It will facilitate a positive change in service delivery when

managing children with HIV/AIDS related neurological illnesses. The findings of the experiences and perceptions of children with HIV/AIDS related neurological illnesses and that of their primary caregivers will allow for the inclusion of such members as meaningful contributors of the team working towards improved quality of life and health.

Introduction

Background

Caregivers of children diagnosed with Human Immunodeficiency Virus (HIV) report high levels of stress.¹ Additionally caregivers experience difficulty in providing adequate care for their children, which evokes feelings of helplessness. Often caregivers themselves are diagnosed with HIV and experience difficulty in managing their own diagnoses.¹ In the health care setting, the caregiver is considered the “hidden patient” or the “invisible client” as their health and occupational needs are often neglected.² Therefore caregivers should be referred to the multi disciplinary team (MDT) for therapy as these supportive measures are linked to reduced parenting stress.¹ Caregivers of children with disabilities report negative long-term physical, psychological and functional related consequences of caregiving. These include increased levels of parental stress, negative impact on the caregivers health, difficulty in dealing with the burden of having a sick child as well as the uncertainty regarding the future.³ Providing caregivers with information that they can identify with, scheduling of visits and providing written information as resource material emerged as themes that would assist caregivers and team intervention.⁴ Children often view hospitalisation as a stressful event.⁵ Health professionals need to acknowledge adverse events that can contribute to the child’s stay in hospital. Effective communication skills between all health care practitioners and a child- centred approach is essential to improve participation in the intervention plan.⁵ The views of a child should be supported allowing them to be directly involved in the decision- making process.⁶ Health care professionals are tasked in designing specific and individualised programmes based on the needs of each child. A familiar and non-threatening environment should be provided so that children are more likely to participate in treatment as well as being allowed the opportunity to express an opinion in their intervention plan.⁷ The Department

of Health in South Africa is governed by Batho Pele principles which state that effective services must be delivered to all South African citizens.⁸ Moreover good practice within paediatric care reflects the adherence to the Patient's Rights Charter.⁹

Research aim and objectives

Aim

The aim of the study was to explore the experiences and perceptions of primary caregivers and their children who are diagnosed with HIV/AIDS related neurological illness with reference to the intervention offered by the paediatric multidisciplinary neurodevelopmental team.

Specific objectives

The specific objectives of the study were:

- To explore primary caregiver's experiences of having a child with HIV/AIDS related neurological illness with regards to the therapeutic intervention they received.
- To explore the experience of the children in their rehabilitative process.

Contribution to field

The findings in this study serve to highlight the potential for evaluating and monitoring clinical practice in the management of paediatric HIV/AIDS related neurological illnesses through children and caregiver reported experiences. Consequently it will serve to inform and improve service delivery and clinical outcomes in the paediatric neurology sector and paediatric child health domain of care.

Research Design

Research Approach

A mixed method explanatory sequential study design was selected.¹⁰ A qualitative inquiry approach, using semi-structured interviews with primary caregivers (n=5) and children (n=3) with HIV/AIDS related neurological illnesses were employed.

In addition a small percentage of this study was quantitative in nature and drew on the perspectives of the paediatric neurodevelopmental team (n=27) employed at an acute quaternary health care facility in KwaZulu Natal (KZN). The MDT completed a questionnaire detailing perspectives regarding how they incorporated the caregiver in the treatment process and difficulties associated with inclusion of the caregiver in the intervention plan. Thirty-eight questionnaires were distributed to the MDT. A total of twenty-seven (71%) completed questionnaires were received.

Qualitative research can serve to enrich knowledge of health and health care.¹¹ This study is designed with a multi stage framework.¹² The choice of using this selected paradigm was motivated by the fact that the researchers were focused on obtaining a greater understanding of experiences of the caregiver and children surrounding the intervention they had received from the paediatric neurodevelopmental team.

Setting

The study was conducted in an acute specialist quaternary hospital in KZN, South Africa. This health care facility services patients from KZN and part of the Eastern Cape. It is the only hospital in KZN that hosts a specialized paediatric neurology ward and hence only specialized cases are referred to the institution. The hospital has a Mother's Lodge service and based on the age of the child, the caregivers are granted permission to board at this facility.

Study population and sampling

In this study participants were conveniently sampled. Children diagnosed with HIV/AIDS related neurological illness, those who were cognitively alert and were able to converse with the researcher in either English or IsiZulu were included in the study. The age group 4 - 12 years was targeted. Children with low Glasgow Coma Scales, those admitted for palliative care and with significant premorbid complications were excluded from the sample.

During the data collection period i.e. between June 2016 to August 2016 there were 7 children diagnosed with HIV/AIDS related neurological illnesses admitted to the paediatric neurology ward.

All of the caregivers (n=5) who were interviewed had children admitted to the paediatric neurology ward. Two caregivers were not interviewed, as they had not attended the hospital during the data collection phase. There were only 2 caregiver-child pairs that were interviewed.

The children (n=3) that were interviewed were in-patients and were diagnosed with HIV/AIDS related neurological illnesses. The age group targeted was 4-12 years. Four children could not be interviewed due to low Glasgow Coma scales and hence did not meet the inclusion criteria. The demographic characteristics of the participants (caregivers) are summarized below in Table 1.

The sample also consisted of the MDT employed at the hospital. The MDT included the medical doctors, nurses and therapists allied to medical.

Data Analysis

The quantitative results of the questionnaire were analysed using descriptive statistics including frequencies and percentages. The semi structured interviews were analysed thematically using the procedure outlined by Braun and Clark.¹³ Thematic analysis was used to present the information into core themes. Reduction of researcher bias and trustworthiness throughout the study was ensured through data triangulation, use of varied sources of data, creating a sequence of the evidence and forming a relationship between the data during the thematic analysis.^{14,15}

Process

The MDT completed a questionnaire detailing their interaction with caregivers of children diagnosed with HIV/AIDS related neurological illnesses. The primary caregivers completed a biographical questionnaire. This included information relating to their own educational and scholastic history, socio economic profile, their child's health, schooling and participation in daily activities. An interview guide was used throughout the study to ensure consistency across the interviews. The semi- structured interviews were approximately 20-30 minutes in duration. The interviews were conducted in a private setting to allow the participants to express their opinions freely. An IsiZulu speaking research assistant aided in translating the questions into the child's and caregiver's primary language. Only one child completed a drawing relating to the open-ended question, "Describe

your stay in hospital". The other two children were not agreeable to participate in the drawing activity. The unstructured format allowed the child to describe their experience and highlight issues that were not captured in a formal manner. The advantages of using drawings in paediatric research is that they provide a non verbal expression as children are creative when drawing.¹⁶ The drawings were analysed using a qualitative approach and attempted to illustrate a narrative regarding this child's experience in the hospital setting.

Ethics

Ethics for the study was obtained from the Biomedical Research Ethics Committee (reference number BE057/16). Ethical clearance and gatekeeper permission was obtained from the hospital CEO and from the Department of Health KZN. All participants consented to participate in the study and were informed of their right to withdraw and anonymity was preserved. Keeping all data safe and secure throughout the study ensured anonymity in the study.

Ethical considerations: As this research involved the paediatric population, guiding principles of requesting informed consent from a child included respecting the dignity of the child, safe guarding and protecting the rights of the child and maintaining respect and confidentiality.¹⁷ Written assent was obtained from the children prior to the semi structured interview. A participant information sheet with a brief explanation outlining the purpose and nature of the study was provided to the participants and explained in their home language. In addition the caregiver gave written parental consent for participation in the study. The children and caregivers were informed on the nature and purpose of the study. Informed consent was obtained for audio recording. Furthermore the publication of the drawing was anonymised. In addition, all members of the MDT were given an information sheet outlining the nature of the study. Informed consent was obtained from all members of the MDT.

Results

Table 1 Profile of caregivers

Caregiver	Age	Gender	Level of education	Relationship to child	Pseudonym
Participant 1	35 years	Female	Tertiary	Mother	Phindile

	education				
Participant 2	57 years	Female	Tertiary education	Grandmother	Jabulile
Participant 3	35 years	Female	Grade 11	Mother	Snegugu
Participant 4	40 years	Male	Grade 9	Father	Siyabonga
Participant 5	20 years	Female	Currently in grade 11	Mother	Dineo

All the caregiver's (n=5) first language was IsiZulu. They were able to speak an additional second language of English. Four of the participants (80%) were female and one was male. Two of the participants were employed in skilled vocational positions as Nurses. One of the participants previously worked as a domestic helper whilst one was employed in an unskilled capacity of a Gardner. In addition one caregiver was currently in grade 11. Four caregivers resided in brick homes and one in a traditional hut. Two of these homes did not have access to indoor plumbing. However all of the caregiver's homes had access to electricity. Four caregivers (80%) functioned as single parents.

Multidisciplinary team perspective on the inclusion of the Caregiver in the treatment process

Table 2 Profile of MDT

Profession	Total number of responses	Male	Female
Medical Domain	5	n=1	n=4
Physiotherapy	10	n=1	n=9
Occupational Therapy	2		n=2
Nursing	5		n=5
Audiology	1		n=1
Speech Therapy	1		n=1
Social Work	1		n=1
Clinical Psychology	1		n=1
Dietetics	1		n=1

The majority of the MDT was female (n=25) which accounted for 92.5% of the total population.

Ten responses (37%) were received from Physiotherapists, 18,5% from both the Medical Domain and Nursing and 7% of responses were received from Occupational Therapy. The remaining allied departments i.e. Speech Therapy, Audiology, Dietetics, Social Work and Clinical Psychology each accounted for 4% of the total population. All members of the MDT (n=27) regarded the caregiver as an important part of the treatment process. Reasons provided by 42,3% of the MDT stated that it was the caregiver's role to be directly involved in the treatment process. Furthermore the team (19,2%) suggested that the caregiver is also responsible for adherence and compliance of treatment in the form of caregiver education (19,2%) and carryover of treatment (15,3%).

95,8% of practitioners reported that they include the caregiver in their treatment approach. The majority of therapists (44%) reported that they provide exercise and home programmes. Education and provision of collateral information (32%) featured as method of inclusion of the caregiver in the treatment process.

Communication and language barriers where the majority of the patients and caregivers are IsiZulu speaking featured as common challenge experienced by 22 (81%) of the team members. Poor understanding of the medical condition (n=21, 78%) and cultural beliefs (n=16, 59%) of the caregiver were recognised as factors impacting on treatment. The team experienced other negative contributing factors related to the caregiver, which included absconding parents, inadequate finances and transport issues.

The experiences of Primary Caregivers of children with HIV/AIDS related neurological illnesses

Pathology to diagnosis: The sick child

The theme "pathology to diagnosis" highlighted the physical presentation and symptoms of children diagnosed with HIV/ AIDS related neurological illnesses on admission to hospital as identified by the primary caregiver. HIV/AIDS has a multi-systemic impact on a child's functioning. The caregivers described various co-morbidities relating to HIV infection i.e. seizures, visual impairment and gastrointestinal complications.

“she can’t able to stand by herself and she loses everything like she is weak..... can’t keep food in the stomach, she always vomits and she loses power” Dineo

“she was like kind of blind, now she can open her eyes.... doesn’t have fits anymore, she used to have fits” Snegugu

“the child had a stroke.... he is spastic, spasticity and hemiplegia, this side is hemiplegia [pointing to right]” Jabulile

The caregivers described the HIV illness as impacting negatively on the child’s function where there was a loss of roles e.g. attendance at school

“child had to stop schooling” Snegugu

The complex care and diversity in presentation of HIV / AIDS and the associated co-morbidities was identified as factors relating to the “sick child”.

“is diagnosed with TB meningitis he is getting TB treatment” Jabulile

Multidisciplinary therapeutic/bio psychosocial intervention

Majority of the caregivers (n=4) were exposed to and interacted with the MDT. However perspectives varied, as some were boarder mothers whilst others attended during visiting hours. The caregivers reported interaction with the Medical Doctor, Occupational Therapist, Physiotherapist, Nurse and Social Worker. They were able to describe the treatment modalities offered e.g. splints and types of intervention offered. Based on level of education and prior work experience, two caregivers were able to provide details regarding the reasons for certain treatment choices offered by the MDT. The vast array of developmental disabilities associated with HIV / AIDS necessitates an integrated approach by the MDT. Due to acute nature of the health care facility, a child with HIV infection and neurological dysfunction requires medical management, chest care, rehabilitation and psychosocial support. This is evidenced by the excerpts listed below:

Social work intervention: *“sat me down and asked how the child got sick, I told her everything.... if my child gets better what am I going to do with her” Snegugu*

Physiotherapy: *“The physio, they doing some exercise trying to loosen the muscles so that the muscles mustn’t be stiff and as lying down [banging chest] trying to help.... what*

she told me I must even while she is not in the ward even on weekend I must exercises all limbs” Jabulile

“I remember that the therapist and the physio.... they make some moves” Dineo

Occupational therapy: *“To put him that feet [splints] that you did [using hands to demonstrate feet in an upright position], because it help him a lot.... because his legs was just bending like this [using hands to demonstrate feet in an flexed position], but now it is straight” Dineo*

“Oh they make splints for to prevent drop feet and the hand splints.... they said that during the night I must put the splint the whole night but during the day I must put splint two hourly splints on and two hourly splints off” Jabulile

HIV/AIDS affects the entire family system and is associated with changes in family composition, reliance on extended family members and poverty. Due to these circumstances, one caregiver reported that he attended the hospital for the first time and contact with the team was limited.

“I can just tell you that the grandmother knows these things. Because for me it’s the first time coming here, I am coming here for the first time” Siyabonga

Caregiver knowledge and shared practice

This theme related to the giving and transferring of medical information and engaging the caregiver in shared practice / communication and collaboration.

Caregivers indicated that they would like to be advised on the HIV diagnosis and the associated neurological deficits, the cause of the symptoms and presentation of the child as well as the treatment options available to the child.

“I would like to know the core of the problem, which caused him to be admitted here and what did they discover” Siyabonga

A child diagnosed with HIV/AIDS related neurological illnesses require comprehensive evaluations, which will include assessments by medical and allied health professionals as well as diagnostic procedures. Four of the caregivers were able to identify some of the tests and investigations that their children were referred for and indicated that they were awaiting results and feedback. The excerpts below highlight the variability in knowledge of the caregivers, once again related to prior knowledge and work exposure.

“they check her everything and they tell me they are still investigating... they tell me when they take bloods because they usually take blood from her..... they said they going to check her brain and put strings on her head but I don't know what they said they were doing” Snegugu

“Yes MRI [Magnetic resonance imaging], Eye, EEG [electroencephalogram], LP [lumbar puncture] and took bloods At Greys they did explain to me about the MRI that was done there, here the Dr said to me he needs to check if there is no similar infection to the spine and they did the second MRI” Phindile

Families of children with HIV/AIDS related neurological illnesses experience an array of psychosocial concerns. Psychosocial intervention relate to education and counselling of the HIV infection and advocating compliance and adherence to treatment offered by the paediatric neurodevelopmental team. The caregivers indicated that upon discharge they would require hand over information from the team to adequately manage the child at home. These related to the types of treatment offered by the team and the reasons thereof, methods of improving overall care and administration of medication.

“The knowledge I would need, I would like to know if there is a change in treatment that she takes and if there is something more and above so I would like them to let me know so I know what exactly to do” Snegugu

“How to look after her in a healthier way” Phindile

Psychological impact

HIV/AIDS places a paramount level of stress on families and caregivers. The caregivers are expected to cope with a chronic illness, anticipation of loss, burden of a sick children as well as stigma and isolation. All of the participants reported feelings of sadness and pain now that their children were admitted to hospital. This related to the impact of the diagnosis of HIV, loss of role as a scholar due to the associated neurological and neuropsychiatric manifestations, change and impact of the medical condition and overall parental distress.

The psychological impact of receiving the diagnosis of HIV infection is highlighted in the excerpt below.

“Also he is diagnosed newly diagnosed because I didn't know the child is HIV because the mum was tested before twice then came to me [grandmother] as a shock

....that the child is diagnosed because the child didn't trouble me like because if a child is diagnosed as HIV or the mother was HIV positive the milestones are delayed is not coping well but this one didn't worry me about coughing or what what" Jabulile

Parental distress was a prominent category and all of the caregivers voiced their feelings of sadness and despair due to the impact of HIV, which affects development, social, behavioural and educational aspects of their children. The following quotations emphasise such emotions.

"It was so difficult so difficult for me in such a way that the time he was still in R K Khans I couldn't even eat, even at home, even here.... I was so stressed because the child was normally, was happy child doing everything at home so really I was so sad what happened to my grandchild" Jabulile

"I can't remember because my mind is absent... is difficult because the child wasn't born like this and suddenly the child is like this so that is the difficulty I am experiencing" Snegugu

"Eish I am hurting because it shows that the child is not well when he is in the hospital" Siyabonga

"I felt so sad... to feel my heart cry" Dineo

Caregiver perceived level of satisfaction

The participants described their experiences with the team as being positive. Caregivers were able to provide reasons for their overall satisfaction.

The following citations amply illustrate the overall level of satisfaction with the paediatric neurodevelopmental team.

"I think everything is great " Phindile

" I am comfortable because they are doing their best to help me, they are doing their best.... Dr said that if you need any help or if you want to know something or what to do something you can come to us and ask we will help you" Jabulile

"I see everything being done well when they do things to the child, I see them do it well. I don't have any complaints" Snegugu

Caregiver skill and ability

Due to the multifaceted presentation of children diagnosed with HIV/AIDS related neurological illnesses, caregivers are faced with managing a complex condition where there are both physical and neurocognitive deficits of varying intensities. The caregivers were able to provide some positive reflection on their skills and abilities in caring for their children thus far. However this was also related to prior work experience and knowledge.

*“I am trying because as he is in the condition he cant even turn himself, I’m turning him and even I am I handling him I’m trying as a nurse is that experience is helping me because I know how to handle him to bath him in the bathroom”
Jabulile*

Hope and spirituality

Some caregivers expressed hope and faith relating to the improved prognostic outcomes. This related to the neurological presentation of the child and the attainment of development and function.

“Yes that she can able to move again, to walk again by herself” Dineo

Some of the caregivers relied on their trust and support in religion.

“To believe in god, god can do wonders, god can do miracles so I trust in god that he can do he can make a change” Jabulile

Caregiver burden

HIV/AIDS impacts on the entire family system. This can result in the loss of a biological parent. This was evident where one of the participants was a single parent and relied on extended family to assist in the care plan and management of his child who is diagnosed with HIV related neurological illness.

“The biological mother passed awayit is not that difficult, but anyway a child needs a mother or a female” Siyabonga

Status Hierarchy

This was evident as the doctor was viewed as being trusted to lead the professional team to manage the child.

“I see doctors as good people because if they meet me they talk to me and they are right..... I hear everything when they tell me, I hear them.....I accept whatever they say” Snegugu

Barriers and environment

The hospital policy of accommodation of the caregiver at the Mothers Lodge facility within the hospital was reported as a barrier within the hospital system as based on the child’s age they are not considered eligible to be boarder mothers. Due to HIV infection and the secondary co-morbidities children are often dependant for activities of daily living and require assistance from their caregivers. The following quotation describes a mother’s need to be present with her child due to difficulties in activities of daily living.

“Mother’s lodge, it is difficult for the child to be with people she is not used to and to communicate with....I have to take my child to the loo, so I sleep next to her” Phindile

Perspectives of children diagnosed with HIV/AIDS related neurological illnesses

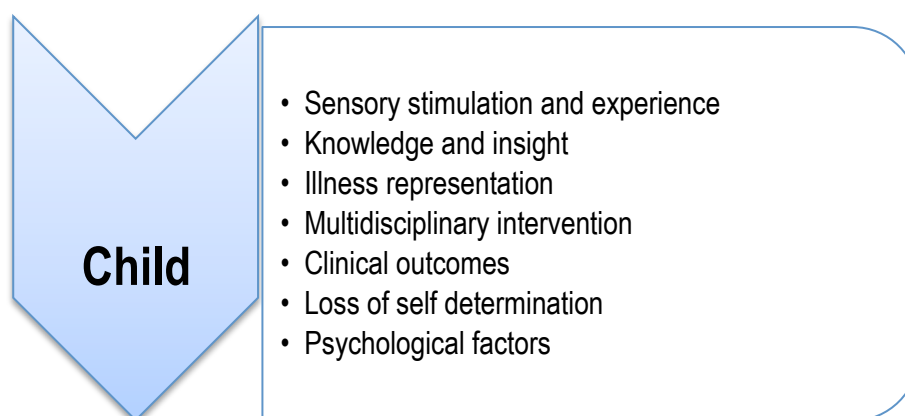


Figure 1 Common themes relating to the child

The above themes will be illustrated individually as it related to each child.

Child 1: "Ziyanda" 7-year-old female diagnosed with retro-viral disease, Devics disease, optic neuritis, metabolic leuko-dystrophy and progressive multifocal leuko-encephalopathy.

Ziyanda reported inadequate play facilities in the ward with limited sensory stimulation play items. Children with HIV/AIDS related neurological illnesses require exposure to sensory stimulation to enhance development.

"They are no balls here"

With regards to insight and experience into receiving therapy/intervention she was able to identify some members of the MDT.

"The nurses, doctor"

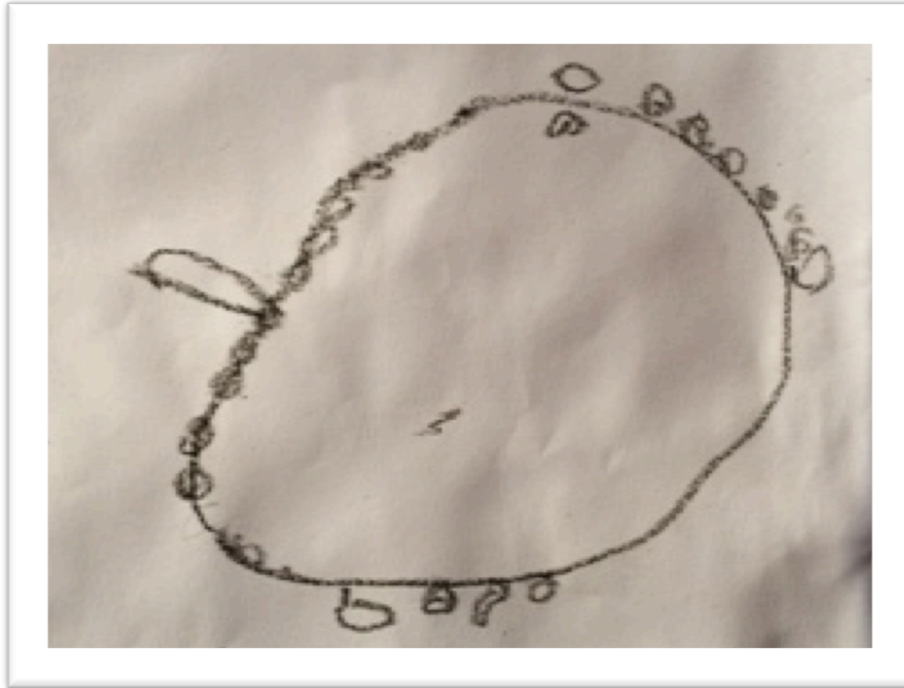
Furthermore she was demonstrated a lack of knowledge regarding her illness/physical dysfunction and reported *"I don't know"*.

On a positive note Ziyanda indicated that she was *"feeling better"* (since being in hospital).

When questioned about the negative aspect of hospitalisation she conveyed that she *"didn't like the food"*.

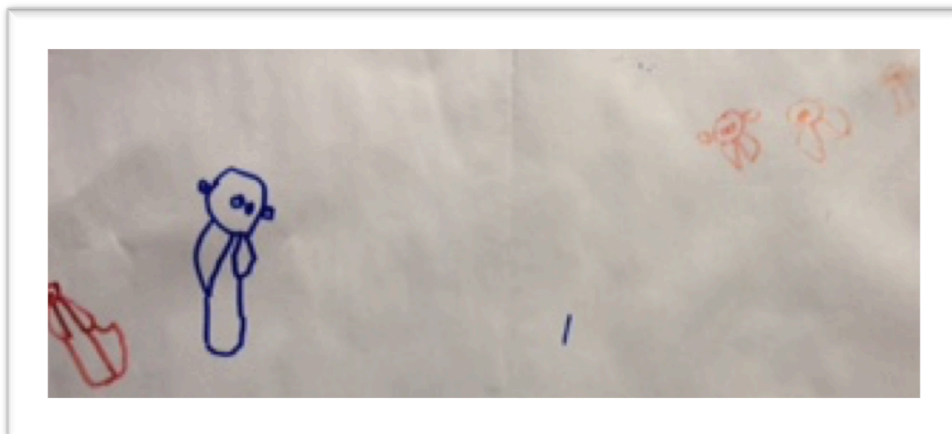
Child 2 "Andile" 4 years 10 month old male on HAART, diagnosed with leukodystrophy, strabismus with ataxia and with a history of a head injury.

Due to Andile's age he was unable to follow the schedule of the semi -structured interview. However he indicated that the reason for admission into hospital was that he *"fell"*. Andile described his stay in hospital by drawing a picture. Art therapy in a medical environment allows the individual to feel empowered and engages creative expression in the process of healing.¹⁸



Picture 1 Stay in hospital

Andile's self-reported narrative regarding the above picture was depicted as "a round [rondavel-traditional circular African dwelling] where the doctor's meet and talk". On closer analysis this picture could serve to illustrate clinical teaching and ward rounds where medical practitioners, clinicians, nurses and students convene around the child's bedside presenting the case. Ward rounds occur on a daily basis and hence the child viewed this meeting of the paediatric neuro-developmental team as part of his "stay in hospital".



Picture 2 Child's daily life

The above picture was drawn in context on the child's daily life and social relationships. The second drawing on the left was depicted as the child and the father next to him. The figures on the right were described as his grandmother, sister and cousin. He appeared to create a coherent narrative and indicated that the father had visited him in hospital. Additionally the picture could symbolise being away from his family as indicated in the distance between diagrammatic forms, thereby supporting the development of coping strategies and wellbeing.

Child 3: "Lerato" 12-year-old female on HAART, diagnosed with mitral regurgitation, infective endocarditis, cerebellar syndrome, opsomyoclonus, pulmonary tuberculosis and lobectomy and neuropsychiatric symptoms.

Lerato was able to provide a description of her HIV associated neuropsychiatric symptoms relating to visual hallucinations. This is explained by the quotation below.

"But sometimes I become alright, then somebody comes, I see a person, that I don't know... This person then wants to come closer to me, then I try to run away... I am the only one who sees this person"

She was able to identify some symptoms representing her HIV illness and loss of function.

"Sometimes I cannot breathe"

Lerato was able to specifically identify certain Doctors by their names and indicated *"Others doctors I don't know you"*.

She reported improved clinical outcomes and verbalised, *"I feel better"*.

On the psychological front she mentioned, *"I'm scared"*.

Often children with HIV are exposed to conditions of poverty and social and economic exclusion. Lerato attributed the negative aspect of being in hospital relating to her relationship with her mother, which is illustrated in the narrative below.

"It's because my mum bluffs me... she said she was going to come yesterday but she didn't come"

Lerato demonstrated some knowledge and insight regarding her understanding of the reason for hospitalisation.

“Because I am sick.... must I say my sickness”

Moreover Lerato was able to relay specific interactions with the doctor and was able to identify them by name, indicating the following:

Maybe the doctor comes and asks me if I can write maths... then I answer the doctor and tell him that I know.... Or he asks me questions about my life”

Due to the ensuing HIV related neurological deficits Lerato was referred to Physiotherapy. When probed about the engagement in therapeutic intervention and participation in an exercise programme she reported, *“Yes I do know them [exercise]”*

Lerato was able to provide specifics regarding her receipt of Physiotherapy.

“There is Malume [uncle in IsiZulu], who comes to the ward and gives me exercises... He comes and exercises, and tell me to lift up my arms, and then he tells me to count, maybe he would make me exercise to ten times, and then I will bend my feet, then my feet will go like this [demonstrated flexion/extension of lower limbs].... Then I will count, he will say I must count, then he holds me to make me walk”

With regards to her physical recovery she was demonstrated insight into the importance of engaging in rehabilitation.

“It’s important because if you not able to walk you end up walking, like me”

Discussion

Children with medical complexities require adequately trained service providers to enhance their outcomes and quality of life.¹⁹ In this study all members of the multidisciplinary team (n=27) regarded the caregiver as an important part of the treatment process. In a Ugandan study multidisciplinary management teams involved in paediatric HIV care comprise of nurses, clinicians, social workers and pharmacists. They met on a weekly basis to review functions and foster ties across various departments with the aim of providing family centred care.²⁰

HIV/AIDS continue to bear negative consequences on a child’s functioning in daily living and on their overall wellbeing. Caregiving practices may differ across

various cultural contexts.³ Cultural backgrounds within a health care setting is diverse and differences can result in contradictory accounts of health, illness and therapy and consequently impacts on outcomes in the recovery process.²¹ The role the family assumes in therapy depends on the organisation's stance and tenet of service delivery in which the therapist works, assumptions regarding the role the family plays in therapy, the therapist's sense of comfort in working with families from different cultural contexts, the therapist's belief relating to their roles and responsibilities and lastly language differences.²² The majority of therapists (44%) reported that they provide exercise and home programmes to the caregiver. The team (19,2%) suggested that the caregiver is also responsible for adherence and compliance of treatment in the form of caregiver education (19,2%) and carryover of treatment (15.3%). Occupational therapists must take cognizance of the fact that when health related information is shared by health care professionals, caregivers may not always recall such information due to the following reasons i.e. stress of the pending situation, information not being clear, the content of information being complicated or too general and the information not being individualized to meet the caregivers specific concerns.²³ Services are beneficial when it is presented constructively in a family centred manner and incorporates specific issues as identified by the parents.²⁴

A KZN study conducted with 13 women who were primary caregivers of child infected with HIV, found that a combination of poverty and stigma related to HIV was perceived to compromise the wellbeing of these children. Additionally, the caregiver's focus were primarily on economic survival.²⁵ A Thailand study of 35 caregivers of HIV infected children revealed four significant themes namely physical health related problems, negative impact on school performance, adherence and compliance to medication and changes in relationships.²⁶ Similarly, this study, highlighted that caregivers described the physical symptomatology and various co-morbidities of HIV that their children were diagnosed with and were able to identify the impact of HIV/AIDS related neurological illness on the roles and function of a scholar. Likewise in a developed country focus groups were conducted with 40 caregivers of children with disabilities. Four themes influencing parent wellbeing emerged viz. access to information and services, financial implications in accessing services, inclusion of children with disabilities in schools and communities and family support.²⁷ It was evident in this study that caregivers experienced high levels of psychological strain with all caregivers

reporting parental distress. Our findings corroborate with the sentiments of a study in Zimbabwe where caregivers of children with Cerebral Palsy demonstrated high levels of stress including anxiety and depression resulting in poor health related quality of life.²⁸

Hope and spirituality emerged as a theme where caregivers adopted coping strategies and relied on higher powers during the child's recovery. This was similar to findings in a study conducted in Ghana where the experiences of mothers with children hospitalised in an emergency unit viewed their relationship with God as a source of hope and comfort.²⁹ Understanding parents priorities and the context of issues lends itself to therapists engaging fully with family members to determine their hopes for treatment outcomes thereby allowing therapist's to determine the success of therapy.³⁰ Caregivers favoured shared practice and collaboration. They preferred the sharing and transferring of medical information relating to results from tests and investigations, rehabilitative exercise programmes and future medical regimes. The caregivers in this study indicated that they required information on the diagnosis and the cause of symptoms as well as the treatment options available for the child. Caregivers are expected to perform complex tasks, supervise, and make decisions as well as co-ordinate healthcare. Therefore health care providers should assist caregivers in acquiring skills and knowledge and in translating this knowledge into care to establish best clinical practice.³¹

In paediatric Occupational therapy practice, parents contribute invaluable information towards therapy intervention which include vital collateral information, factors impacting on activities of daily living, difficulties experienced with everyday activities and gains or challenges experienced with home programmes. Collaborative parent and therapist partnerships should be encouraged.³² Similarly for the caregiver to function as an effective contributor to the multidisciplinary team, training is required to increase mastery and decrease caregiver sense of burden.² In under resourced public health settings there is an urgent need to develop low cost interventions by enhancing and fostering partnerships with caregivers to improve the care of young hospitalised children.³³ Support group interventions have the potential to assist caregivers learn how to cope with and care for a child with HIV / AIDS.²⁵

Overall all of the caregivers expressed satisfaction with the service provided by the paediatric neurodevelopmental team. Likewise in a Kenyan study, a total of 1550 caregivers of children receiving anti retroviral therapy were interviewed of which approximately 89,4% attended public facilities and 62,8% accessed tertiary level facilities. The results of that study indicated that 63% of caregivers reported overall satisfaction.³⁴ Communication and language barriers, poor understanding of the condition and cultural beliefs were recognised as factors impacting on treatment. It is crucial that every health care professional understand the culture, values, morals and beliefs as well as expectations of their patients when providing rehabilitative intervention to children with disabilities.³⁵ Understanding a health care professionals roles and responsibilities as well as effective communication is related to core competencies for patient centred collaborative practice.³⁶

In this study none of the children disclosed their HIV status or described their illness with reference to HIV/AIDS. In a study conducted in Cape Town, approximately 70% of caregivers indicated that anti retroviral therapy made it necessary to disclose the child's status whilst 73% described barriers as being afraid of the child discussing the HIV infection with friends at school (89%) or with members in the community (59%). The caregivers also indicated that doctors should be involved in the disclosure of HIV infection to a child and that issues relating to disclosure should be prioritised to allow for improved quality of life.³⁷

The children's understanding of their diagnosis, treatment and interaction with the paediatric neurodevelopmental team varied. The development of a child's understanding of their illness occurs sequentially and as the child develops they gain a wider selection of medical terminology and their depth of understanding their illness increases.³⁸ At the age band of approximately 12- 13 years, children begin to understand the causes of illnesses, the bodies response to treatment and the agents used to cure illnesses.³⁹ Accordingly, the oldest child aged 12 was able to adequately describe the neurological and neuropsychiatric symptoms she presented with. Furthermore the child was able to differentiate between the different categories of staff involved in her care as well as the their different roles during the period of hospitalisation. This was contrary to findings in a study where the experiences of eight children were explored regarding acute hospitalisation where they did not seem to differentiate between the different groups of staff and identified them as one entity.⁴⁰ In a study of HIV disclosure in

children conducted in Sub Saharan Africa in the Democratic Republic of Congo, of a population of 259 children only 8 (3%) were informed of their HIV status. The study concluded that children appreciated knowing their HIV status and despite the negative feelings associated with disclosure the children did not report any negative consequences of learning their HIV status and this ultimately improved collaborations with health care professionals focusing on clinical care.⁴¹

A study conducted in a Tshwane haematology ward with a cohort of primary school children indicated that there should be areas where the child is able to play freely as well as a designs that will provide sensory stimulation and some control over the environment.⁴² Taking cognisance of this, one child indicated that there was limited play items in the ward. Similarly recreational activities were appreciated by children and could contribute to the child's positive experience during hospitalisation.⁴³

The first drawing in this study conceptualised the clinical environment that the child was exposed and can be described in terms of ward rounds and case discussions. In a study conducted with children with congenital heart defects findings demonstrated the distressing impact of routine clinical activities and practitioners should find a balance between essential clinical follow ups and participation in activities of daily living.⁴⁴ The oldest child in the sample indicated stresses relating to being separated from her mother, whilst the second drawing also highlighted the psychosocial implications of being divided from the family. In order to reduce anxiety and negative perceptions, children should be adequately prepared for the hospital stay prior to admission.⁴⁵ Given the opportunity, children and young people are eager and able to make decisions about their health care services, however there is paucity in research to evaluate whether or not these choices are acted upon.⁴⁶ Communicating with children about illness should be considered as children need to be included and therefore it is the responsibility of health care practitioners to present this information in an age appropriate manner.⁴⁷

HIV/AIDS is a family disease and therefore co-ordinated, holistic and comprehensive family centred intervention should be prioritised. A trans-agency collaborative model is proposed where this framework provides a formal assessment of the needs of the family, planning of services, implementing these

service plans, reviewing of the case, networking with external organisations and the provision of on-going support.⁴⁸

Children with HIV/AIDS related neurological illnesses experience physical and neurocognitive deficits, which ultimately impacts on all spheres of functioning. Therefore the narratives and drawings of these children as well as the perspectives of the caregivers should be considered so that the paediatric neurodevelopmental team can optimise service delivery. Capturing and understanding these views can improve family and patient related outcomes and direct the management of this vulnerable population in the future.

Conclusion

The authors aimed to describe the experiences through the lens of children who are diagnosed with HIV/AIDS related neurological illnesses as well as perspectives of their caregivers. Caregivers in this study demonstrated an overall satisfaction with the paediatric neurodevelopmental team. This study drew on the perspectives of children and therefore taking cognizance of such views can lend itself to health care professionals being more in tune with child centered interventions. Ultimately such close collaboration will improve relationships between the end uses and the team, allow for priorities when planning interventions and sanction shared goals and practices.

Limitations of the study

Due to the acute setting and the nature of clinical presentation, some of the children who met the selection criteria could not be interviewed due to a low Glasgow Coma Scale. Further more this study was limited to in-patients and a more integrative and holistic picture could have been obtained if outpatients were included.

Recommendations

Therapeutic interventions should be evaluated in terms of their effectiveness and influence on clinical outcomes of children diagnosed with HIV/AIDS related neurological illnesses. Accordingly the knowledge, attitudes and practices of the caregiver and child are paramount in facilitating this process. A MDT approach is essential in managing HIV/AIDS related neurological illnesses and supports collaboration with the caregiver and the child. This will lead to improved clinical

and rehabilitative outcomes due to compliance of treatment offered by the MDT. The promotion of best practice in conjunction with other relevant standards and stakeholders should develop a set of guidelines to govern the best interest of children with HIV / AIDS related neurological illnesses.

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Competing interests

The authors declare that they have no competing interests, which may have influenced them in writing this article.

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CHAPTER 5

SYNTHESIS

5.1 Introduction

The prevalence and nature of HIV/AIDS within a South African context has been well documented. Accordingly, research in this field is dynamic and continuous especially in the background of paediatrics. The magnitude of prevalence of HIV infected children residing in KZN has been well recognized (Donald et al, 2014, Potterton et al, 2007, Rabie et al, 2007).

In this study, the researcher aimed to describe the management of paediatric HIV/AIDS related neurological illnesses in an acute quaternary setting. This novel research study, encapsulated the multidimensional profile of patients that were admitted to a quaternary hospital, the MDT approach involved in their care as well as the perspectives and experiences of caregivers and children diagnosed with HIV/AIDS related neurological illnesses.

A sequential explanatory mixed methods approach within a multistage framework was selected as the research design (Creswell, 2013). The study involved the collection of qualitative data after a quantitative phase in order to explain or follow up on the quantitative data in more depth.

The research commenced with a file audit between the period January 2010 to December 2015 and various identifying data, medical and systemic impacts as well as the socio-economic demographics of children with HIV/AIDS related neurological illnesses were ascertained. In addition the functional outcomes of children with HIV/AIDS related neurological illnesses were detailed. The second phase of the research study involved the administration of a questionnaire to the MDT. This was followed by a focus group with members of the paediatric neurodevelopmental team. The study concluded with semi-

structured interviews with primary caregiver/parents and children diagnosed with HIV/AIDS related neurological illnesses.

The following table describes how the research questions were met in the study by correlating them to the respective manuscripts and thereafter highlighting key knowledge gained from the study.

Research questions	Relevant Manuscripts	Key knowledge generated from the study
1. What is the profile of paediatric patients with HIV/AIDS related neurological illnesses referred for intervention to the paediatric neurodevelopmental team within a 6-year period	A Retrospective Review and Evaluation of Functional Status: Profile of children admitted to an acute quaternary institution with HIV/AIDS related neurological illnesses over a 6-year period	<p>The burden of disease was established in KZN with regards to the neurological and neuro-psychiatric co-morbidities of HIV infected children that attended the quaternary hospital.</p> <p>Functional status of children diagnosed with HIV/AIDS related neurological illnesses and their participation in activities of daily living were described.</p>
2. How does the paediatric neurodevelopmental team manage paediatric patients diagnosed with HIV/AIDS related neurology?	Potential for best practice: Management of Paediatric HIV/AIDS related neurological illnesses: The multidisciplinary team perspective	<p>The roles and responsibilities of the MDT as well as the priorities of care in managing children with HIV/AIDS related neurological illnesses were ascertained.</p> <p>The functional outcomes that the team works towards were described so that children with HIV/AIDS related neurological illnesses receive comprehensive and integrated care.</p> <p>The paediatric neurodevelopmental team highlighted various challenges and barriers impacting on the care of this vulnerable population group.</p>
3. What is the experience of primary caregivers and patients with regards to MDT intervention?	The Paediatric Neurodevelopmental Team: Did we get it right? The voices of the caregivers and children	<p>The caregivers of children with HIV/AIDS related neurological illnesses expressed overall satisfaction with services provided by the paediatric neurodevelopmental team.</p> <p>Children diagnosed with HIV/AIDS related neurological illnesses were able to describe their participation in therapy through verbal narratives and diagrammatic representation.</p>

Table 1 Research questions and relevant manuscripts

5.2 Integration and Synthesis of Findings

HIV/AIDS is a complex and multi-systemic illness. This study has highlighted the profile of patients in an acute setting and the sequelae of neurological and neurocognitive deficits as a result of HIV infection. Accordingly the study has contributed towards understanding the burden of HIV/AIDS in KZN. From the results it was evident that approximately 21% of the admissions to the acute quaternary hospital was due to HIV related CNS illnesses.

These findings concur with a community-based survey conducted between 2000-2001 in rural SA that indicated that HIV/AIDS was the cause of mortality in approximately 41% of deaths in the under 5-age band (Garrib, Jaffar, Knight, Bradshaw & Bennish, 2006).

In a study focusing on acute hospitalization in adolescents in Harare, Ferrand et al (2010) established that HIV/AIDS was the most common cause of acute admission and in hospital mortality. This bears significant implications of the health care setting, as adequate resources are required for managing children with HIV/AIDS related neurological illnesses. Resource allocations in terms of medical, pharmaceutical, rehabilitative and diagnostic avenues are deemed crucial to provide integrated assessments and intervention to children with HIV/AIDS related neurological illnesses.

Bhagwanjee & Scribante, (2007) conducted an audit of the public and private sector ICU units in SA. The results from the audit indicated that tertiary or quaternary health care facilities require a higher proportion of beds due to the complex care and complications requiring specialized therapeutic interventions (Bhagwanjee & Scribante, 2007). The central quaternary hospital that the study was conducted at consists of highly specialized referral departments that provide multi-specialized clinical services and research. The services provided by such a hospital will generally be of high cost and low volume and will require access to high status technology and multi disciplinary care teams to provide superior quality of care to patients (Cullinan, 2006). Therefore children admitted to this quaternary hospital with HIV/AIDS related neurological illnesses require specialized care,

diagnostic investigations and integrated medical and rehabilitative care.

Teamwork in a health care setting is a dynamic process involving the interaction between *“two or more health care professions with complementary backgrounds and skills, sharing common health goals and exercising concerted physical and mental effort in assessing, planning, or evaluating patient care”* (Xyrichis & Ream, 2008:238).

As identified in the study, the paediatric neurodevelopmental team at the specialist quaternary hospital comprises of the Medical doctors and Registrars, Physiotherapists, Occupational Therapists, Speech Therapists and Audiologists, Social Workers, Dieticians, Clinical Psychologists and Nurses. These team members are mandated to provide efficient and effective services to children with HIV related developmental disabilities.

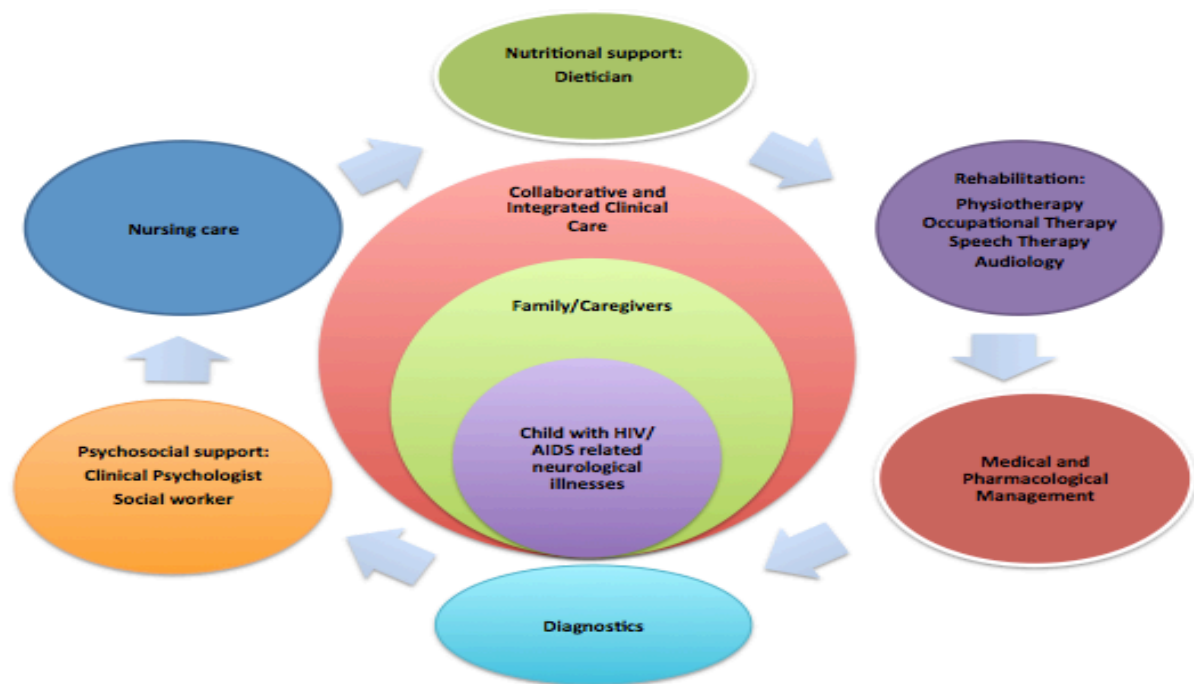


Figure 10 Multidisciplinary intervention at the specialist health care institution

Fay, Borrill, Amir, Haward & West, 2006 proposed that the increased number of different disciplines represented on a multidisciplinary team, the larger the range of knowledge, skills and abilities which in turn results in enhanced perspectives and improved team performance.

Approximately 30% (n=42) of patients in this study were diagnosed with HIVE. Similarly in a study conducted at Red War Memorial Children's Hospital, Donald et al, 2015 established that HIVE was the most common primary HIV related neurological disorder. The study by Donald et al, 2015 reported that of the population of 87 children, 85 children were referred to the neurology clinic due to an array of neuro-developmental disabilities, which included deficits in achieving developmental milestones, poor school performance and behavioral difficulties. This highlights the need for the paediatric neurodevelopmental team to be aware of the developmental disabilities associated with HIV infection. Comprehensive evaluations and regular screening of progress is warranted due to the complex nature of HIV/AIDS related neuro-pathology. The MDT employed at this institution agreed that the care plan is dependent on a multidisciplinary approach where the MDT is tasked with sharing of information, coordinating diagnostic investigations, conducting comprehensive assessments and the provision of clinical treatment activities. Therefore it is vital to provide a coherent care plan for children with HIV/AIDS related neurological illnesses.

A review of the literature has indicated that there is a paucity of studies in the field of the MDT and HIV associated neurological disorders. In this study the paediatric neurodevelopmental team identified their roles and responsibilities as well as their priorities of care in an acute setting. Furthermore the barriers impacting on service provision due to various organisational and budgetary constraints were identified. These barriers include a shortage of staff due to budgetary shortfalls and reduced rehabilitative intervention as a result of decreased number of staff employed at the health care facility. Therefore the MDT is faced with an increased workload. The gaps in the management and treatment of children with HIV/AIDS related neurological illnesses were highlighted.

Management of children with HIV/AIDS related neurological illnesses are most effective when it involves a team approach of the paediatric neurodevelopmental team, the primary caregivers and the compliance of child. Due to the multifaceted nature of this illness,

paediatric HIV/AIDS related neurological illnesses require a cohesive team with diverse skills.

Advantages of working with a MDT allows for evidence-based practice, adoption of clinical guidelines and review of performance and team effectiveness by clinical audits. Furthermore a MDT team approach allows for improved communication and a consensus approach to treatment care and planning in the management of children with HIV/AIDS related neurological illnesses. This inadvertently results in improved outcomes, efficacy within the acute health care system and ultimately satisfaction with the end users of the service.

The multidisciplinary model of care for assessment and intervention strategies for children with HIV related developmental disabilities proposed by Mubaiwa et al, 2005 are supported by this research as it allows for best neurological outcomes. The research findings from this study affirm the need for the concomitant support of the MDT, referral institutions, governmental and non-governmental initiatives as well as the perspectives of the caregiver and the child. A combination and interaction of the different facets of multidisciplinary care allows for best standards of practice in managing children with HIV/AIDS related neurological illnesses.

Drawing from the perspectives outlined in the multidisciplinary manuscript, the “puzzle” relating to the child with HIV/AIDS related neurological illnesses has now been defined. Each member of the MDT has specific roles and responsibilities so that when the “interlocking pieces of the puzzle” are joined, the needs of children infected with HIV/AIDS and their families are acknowledged to improve co-ordination of care. Individually each discipline can excel at identifying their specific “pieces of the puzzle” but it is the sum of the “interlocking pieces” that enhances the care of the child with HIV/AIDS related neurological illnesses.

Similarly in a study by Freir, Gordon, Richmond & Wheeler (2004) suggested that by conceptualising patients as being the epicentre of a jigsaw puzzle, health care professionals can evaluate their services, draw on their limitations and refer appropriately and timeously.

“Its always the small pieces of the puzzle that makes the big picture” leverages on the understanding that it takes careful consideration and comprehensive services by the MDT who are tasked with achieving best activity and functional outcomes in children with HIV/AIDS related neurological illnesses. Similarly the potential for best practice is reliant on the MDT working in collaboration and investing in the future of children with HIV/AIDS related neurological illnesses where there is tolerance and acceptance that “even the hardest puzzle has a solution”.

The MDT approach in the management of children with HIV/AIDS related neurological illnesses require a wide array of clinical expertise. The patient and the family should actively engage with the paediatric neurodevelopmental team. Therefore the concept of a family centre care approach should be adopted to provide holistic service delivery. Caregivers as well as the child are considered partners within the MDT sharing aims, responsibilities and information. In this study the caregivers were able to describe their interaction with the MDT.

In this study each team member was able to describe their expertise in managing children with HIV/AIDS related neurological illnesses. Roles and responsibilities and priorities of care were identified. A clear understanding of the knowledge of the team now allows for holistic and integrated assessment and treatment of children with HIV/AIDS related neurological illnesses. Furthermore team members shared treatment goals and when based in close proximity they were able to work together and compliment services in the management of children with HIV/AIDS related neurological illnesses e.g. physiotherapy

and occupational therapy when splinting and passive ranging of limbs occur simultaneously.

Cohesiveness relates to the linking of the team as a functional unit. Similarly the findings in this study illustrated that teamwork offers the potential to achieve positive outcomes when treating children with HIV/AIDS related neurological illnesses. Despite barriers within the health care environment the MDT worked towards functional outcomes of the child. The paediatric neurodevelopmental team have acknowledged that measurable outcomes are only achieved by members working in collaboration rather than in isolation. Decision-making processes are central and underpins the functioning of the MDT. The paediatric neurodevelopmental team were comfortable in communicating and managing information.

“All the world's a stage” is the phrase from William Shakespeare, which suggests that all human beings have a part to play in life. Similarly the MDT working with this profile of children have a role to play and their performance is dependent on good mutual understanding, skill and experience and good communication.

The understanding of how teams function and their effectiveness has been described using the theoretical approach of the Integrated Healthcare Model of Team Effectiveness (Lemieux-Charles & McGuire, 2006). This model highlights the interaction between task design, team processes and the team’s psychosocial traits that impact on the team’s effectiveness. With reference to task design, the study established the vital role and responsibility the paediatric neurodevelopmental team plays in managing paediatric HIV/AIDS related neurological illnesses.

With regards to team process in the Integrated Healthcare Team Effectiveness Model, it requires participation in clinical discussions. The paediatric neurodevelopmental team favored increased collaboration by being involved in case discussions, goal sharing,

progress sharing of children diagnosed with HIV/AIDS related neurological illnesses as well as extension of feedback from the referral institution. When there is collaboration between team members, treatment offered to children with HIV/AIDS related neurological illnesses are enhanced with the provision of efficient care delivery. In order to maximize and reinforce therapy splinting is continued by nursing staff over the weekends. This allows for improved team effectiveness as children with HIV/AIDS related neurological illnesses admitted to an acute quaternary setting require daily management. In this study, team process was affected, as certain clinical departments could not offer daily rehabilitation due to various organizational and departmental factors such as staff shortages. Physiotherapy was the predominant service provider that offered both rehabilitation and chest physiotherapy.

Team psychosocial traits as described in the Integrated Healthcare Team Effectiveness Model are considered a factor impacting on team processes thereby influencing team outcomes. A supportive work environment and good interpersonal relationships are team psychosocial traits that impact on team processes and effectiveness. As a result of the high workload and demands in management of children with HIV/AIDS related neurological illnesses due to multiple facets of impairments, the paediatric neurodevelopmental is faced with issues such a burnout. These factors impact on staff satisfaction and can result in decreased productivity in managing this vulnerable paediatric population group. In this study, the paediatric neurodevelopmental team expressed that there is reduced collaboration with referral institutions as well as both governmental and non-governmental organizations. As a result educational prospects as well as special school placement is affected due to reduced follow up as well as limited collaborative policies between the Department of Education and Department of Health. Accordingly these factors result in reduced holistic care of children with HIV/AIDS related neurological illnesses and less effective intervention in rehabilitative outcomes.

This study highlighted the various challenges experienced by the MDT, which included limited resources in terms of time, high patient numbers, shortage of staff and budgetary and organizational challenges. Similar findings were affirmed in a study describing the demands and rewards of working within a multidisciplinary team in paediatric oncology where staff and resource shortages were identified by the health care professionals which included time delays and increased workloads and ultimately resulting in burnout and stress (Gulati et al, 2014).

Therefore efficient management of paediatric HIV/AIDS related neurological illnesses is virtually synonymous and demands effective teamwork. Best practices within the MDT should ideally incorporate a holistic approach as well as a child centred approach. The study has highlighted the complex task the paediatric neurodevelopmental team is faced with when providing multidisciplinary care to children with HIV/AIDS related neurological illnesses. Due to the complex nature of HIV/AIDS, guidelines in HIV rehabilitation that incorporates all members of the health care team is supported (O'Brien, Wilkins, Zack & Solomon, 2011).

The paediatric neurodevelopmental team were able to manage the patients by merging the most current knowledge of HIV. However none of the members had any specific training or attendance at courses relating to paediatric HIV/AIDS related neurological illnesses. Buljac-Samardzic et al's systematic review of interventions related to team effectiveness suggested that team training can improve and enhance the effectiveness of multidisciplinary health care teams in acute hospital care (Buljac-Samardzic, Dekker-van Doorn, van Wijngaarden & van Wijk, 2010).

The management of HIV infection in children pose significant challenges to caregivers. Children with special health care requirements are described as children with an increased risk for chronic physical, psychosocial, behavioural and developmental conditions that require the service of health care professionals beyond that of the average

child (Gordon, Colby, Bartelt, Jablonski, Krauthoefer & Havens, 2007). Caregivers of children with complex and special health care needs are faced with multiple and diverse demands (Kuo, Cohen, Agrawal, Berry & Casey, 2011). In this study, the caregivers voiced an overall level of satisfaction with the paediatric neurodevelopmental team.

The study found that most of the caregivers expressed a level of emotional intensity regarding their feelings and hopes. The uncertainty regarding the future of their children emerged as a concern. All caregivers expressed an opinion regarding their involvement and participation in the care plan. The interaction between caregivers and healthcare professionals is an important factor with children with chronic health care needs. The context of the hospital and therapeutic intervention offered to these children facing a chronic lifelong illness proved to be a satisfactory experience.

Similarly in a study conducted at a multidisciplinary paediatric pain clinic comprising of a paediatric anesthesiologist, clinical psychologist, a licensed marriage and family therapist, and physical and occupational therapists affirmed that caregiver satisfaction with treatment rendered and health care professionals were highly correlated to adherence of treatment (Gordzinsky, Tran, Medrano, Fleischman, Anderson-Khan, Ladwig & Weisman, 2012). Furthermore, Gordzinsky et al, 2012 argued that caregivers supported structure within a MDT as well as the expertise and skill of the health care professionals and the MDT's compassion and care in managing their children.

Additionally, the study identified that through active participation in their treatment process the children were able to describe the treatment offered by the paediatric neurodevelopmental team. A literature search relating to children with HIV/AIDS related neurological illnesses and their experiences with health care indicated that there is limited information detailing how children viewed their involvement with service providers in an acute quaternary setting. Therefore this research is a valuable indication of the child's perspective and the development and the delivery of paediatric health care services. This

study affirmed that the child's experiences are crucial and that for holistic care to be rendered they have a right to be heard.

The results from the study strongly suggest that multidisciplinary care in children with HIV/AIDS related neurological illnesses is associated with comprehensive clinical assessments and care management plans, integrated diagnostics and investigations and the improved management of the complex co-morbidities.

The paediatric neurodevelopmental team employed at the acute quaternary health care facility strives to provide a continuum of care and embraces all areas of development of a child with HIV/AIDS related neurological illnesses as well as their psychosocial being.

5.3 Recommendations

The results from the file audit indicate the need for guidelines and documents to manage the portentous effects associated with the HIV epidemic. Programme and evaluation initiatives should advocate the developmental needs of children with HIV/AIDS related neurological illnesses and encompass all domains of functioning due to the repercussions of HIV/AIDS at both macro and micro levels. This research study has identified various avenues for further research.

Since the study was conducted at a quaternary hospital, which is the flagship of health care within KZN, the study outcomes will serve as a basis in goal setting and treatment planning. The researcher believes guidelines and protocols to manage paediatric patients with HIV/AIDS related neurological illnesses are lacking especially within a South African context. This research can serve to assist in the first steps towards developing and advocating clinical care pathways and standards for best practice for KZN.

Health care trends are now moving towards transdisciplinary approaches. Currently, the team has not adopted transdisciplinary teamwork principles. Further exploration is required to examine the different components and relationships required for effective

transdisciplinary teamwork.

Postgraduate studies will need to be prioritised as findings in this research suggest specialised training is required in the care of these children and to keep abreast with modern trends.

The study was conducted at a single site quaternary specialist health care facility. There is a need to explore district and regional care since most of the patients are managed at that level. Furthermore management within a private sector could differ to that of a public setting and therefore this study can be expanded to highlight such differences.

Further research is required to allow for awareness of the impact of HIV/AIDS related neurological illnesses affecting the paediatric population in the lower socio-economic areas and disadvantaged areas in other provinces. This research highlighted the plight of diseases in areas such as Umlazi.

Education and the implementation of basic screening of neurological dysfunction and developmental disabilities associated with HIV/AIDS are recommended at primary level of care. This includes referral to appropriate healthcare professionals required for initial diagnosis as well as referral to persons involved in counseling and education of the child's caregiver and family members. HIV-infected children with neurological impairments and developmental delays should be referred to early intervention programs. Furthermore, this includes appropriate referral to allied healthcare professionals for continued management and regular therapy intervention.

The findings of the study highlight challenges related to the education of children with HIV/AIDS related neurological illnesses. It is recommended that Department of Education investigate these challenges to assist in the improvement of service delivery for adequate school placement of children diagnosed with HIV/AIDS related neurological illnesses.

Moreover, this research study has identified the opportunity for further research to be

conducted on a larger and more comprehensive scale. This could involve research studies conducted at other provinces to determine perspectives and experiences of the multidisciplinary teams on a national level.

In this regard future research could assist in the development of a clinical pathways, standards of care guidelines as well as the hierarchical level of care, management and referral protocols by drawing consensus from all members of the multidisciplinary team, from all levels care as well as on a national level so as to provide holistic consideration of a child with HIV/AIDS related neurological illnesses.

5.4 Limitations

Several limitations have been identified. Despite this study being limited to a single site this study has emphasized vital clinical information. However, only members of the MDT involved in physical therapy of paediatric cases with HIV /AIDS related neurological illnesses have been included in the study. Other significant role players who are involved in the care but more on the diagnostic side of management have been excluded. Further studies in this field can be completed using other role players such as Lay Counsellors, Radiologists and Clinical Technologists to provide a more comprehensive understanding of the management of Paediatric HIV related neurological illnesses.

This study was conducted at a well-resourced acute quaternary health care facility. All levels of care involved in the management of children with HIV/AIDS related neurological illnesses should be detailed to describe the varying treatment strategies. These limitations would need to be addressed in order to show heterogeneity and diversity in management strategies. Therefore the researcher recommends future studies as this knowledge can guide practice and ensure that the needs of paediatric patients with HIV/AIDS related neurological conditions in different clinical and resources settings are met holistically and with established guidelines and competencies of the paediatric neurodevelopmental team.

The study was limited to children who were in patients at the acute quaternary hospital. Perspectives could vary if outpatients as well as caregivers attending the Paediatric Neurology Clinic were included.

5.5 Conclusion

The paediatric neurodevelopmental team is faced with managing a complex and chronic condition. In order for children diagnosed with HIV/AIDS related neurological illnesses to reap the benefits of proficient health care, it requires the collaboration of the MDT, the caregivers and the children themselves. Despite the challenges, it requires the MDT to rely on the resources they have at hand, good referral patterns, fostering partnerships with various organization dealing with HIV/AIDS and engaging stakeholders at a governmental level. The complexity in diversity and the myriad of consequences that children with HIV/AIDS related neurological conditions are faced with will require future research to understand this ever developing and evolving condition.

“There can be no keener revelation of a society's soul than the way in which it treats its children”...

Nelson Mandela

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ANNEXURES

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ANNEXURE 1 Gatekeeper Approval (Hospital)



health

Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE: MEDICAL MANAGEMENT

OFFICE OF THE MEDICAL MANAGER

Physical Address : 800 Vusi Mzimela Road, Mayville, 4058
Postal Address : Private Bag X03, Mayville, 4058
Tel: 031 240 1050 Fax: 031 240 1050 Email: ursulanun@ialch.co.za

Reference: BE057/16
Enquiries: Medical Management

31st March 2016

Ms K Sagadavan
Department of Occupational Therapy
Inkosi Albert Luthuli Central Hospital

Dear Ms K Sagadavan

RE: PERMISSION TO CONDUCT RESEARCH AT IALCH

I have pleasure in informing you that permission has been granted to you by the Medical Manager to conduct research on: **Management of Paediatric Human Immunodeficiency virus/acquired immunodeficiency syndrome related neurological conditions in an acute quaternary setting.**

Kindly take note of the following information before you continue:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Kindly ensure that this office is informed before you commence your research.
4. The hospital will not provide any resources for this research.
5. You will be expected to provide feedback once your research is complete to the Medical Manager.

Yours faithfully



Medical Manager

PERMISSION TO CONDUCT A RESEARCH STUDY/TRIAL

This must be completed and submitted to the Medical Superintendent/s / Hospital Manager/s for signature.

For King Edward VIII Hospital (KEH) and Inkosi Albert Luthuli Central Hospital (IALCH) studies please submit the document together with the following:

1. Research proposal and protocol.
2. Letter giving provisional ethical approval.
3. Details of other research presently being performed by yourself if in the employ of KEH, (individually or as a collaborator).
4. Details of any financial or human resource implications to KEH, including all laboratory tests, EEGs, X-rays, use of nurses, etc. (See Addendum 1)
5. Declaration of all funding applications / grants, please supply substantiating documentation.
6. Complete the attached KEH Form - "Research Details"

Once the document has been signed it should be returned to Mrs Patricia Ngwenya: at the Biomedical Research Ethics Administration, Room N40, Govan Mbeki Building, Westville Campus, University of KwaZulu-Natal.

To: Chief Medical Superintendent / Hospital Manager

Permission is requested to conduct the above research study at the hospital/s indicated below:

Site 1 address:
[Redacted]

Investigator/s:
Principal: Ms K Sagadavan
Co-investigator: _____
Co-Investigator: _____

Signature of Chief Medical Superintendent/Hospital Manager:
[Signature]

Date: 01/04/2016

Site 2 address:

Investigator/s
Principal: _____
Co-investigator: _____
Co-Investigator: _____

Signature of Chief Medical Superintendent / Hospital Manager:

Date: _____

NB: Medical Superintendent/s / Hospital Manager/s to send a copy of this document to Natalia

ANNEXURE 2 Gatekeeper Permission (Department of Health Approval)



health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

DIRECTORATE:

Health Research & Knowledge
Management

Reference: 103/16
KZ_2015RP49_717

Date: 14 April 2016

Dear Ms K. Sagadavan
Email: kesreesagadavan@gmail.com

Approval of research

1. The research proposal titled '**Management of Paediatric HIV/AIDS related Neurological conditions in an acute quaternary setting**' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for research to be undertaken at Inkosi Albert Luthuli Central Hospital.

2. You are requested to take note of the following:
 - a. Make the necessary arrangement with the identified facility before commencing with your research project.
 - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

Dr E Lutge
Chairperson, Health Research Committee

Date: 14/04/16

Fighting Disease, Fighting Poverty, Giving Hope

ANNEXURE 3 Ethical Approval (Biomedical Research Ethics Committee)



20 April 2016

Ms K Sagadavan
Discipline of Occupational Therapy
School of Health Sciences
karseesagadavan@gmail.com

Protocol: Management of paediatric human immunodeficiency virus/acquired immunodeficiency syndrome related neurological conditions in an acute quaternary setting.

Degree: M Occupational Therapy
BREC reference number: BE057/16

EXPEDITED APPLICATION

The Biomedical Research Ethics Committee has considered and noted your application received on 09 February 2016.

The study was provisionally approved pending appropriate responses to queries raised. Your responses dated 04 April 2016 to queries raised on 22 March 2016 have been noted and approved by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval.

This approval is valid for one year from 20 April 2016. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be RATIFIED by a full Committee at its meeting taking place on 10 May 2016.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

Professor J Tsoka-Gwegweni
Chair: Biomedical Research Ethics Committee

cc supervisor: naidoo@ukzn.ac.za
cc postgraduate office: ncop1@ukzn.ac.za

Biomedical Research Ethics Committee

Professor J Tsoka-Gwegweni (Chair)

Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X54001, Durban 4000

Telephone: +27 (0) 31 260 2488 Facsimile: +27 (0) 31 260 4608 Email: brec@ukzn.ac.za

Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>



Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville

Therapy:

Discipline	
Occupational Therapy	
Physiotherapy	
Speech Therapy	
Audiology	
Dietetics	
Social work	
Psychologist	

Therapy received at each admission: (no of sessions and type of therapy)

	Admission 1		Admission 2		Admission 3		Admission 4	
Physiotherapy								
Dietetics								
Speech								
Occupational Therapy								
Social Work								
Audiology								
Psychology								

Tests and Investigations:

Investigation	Site
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CT	
MRI	

Functional Outcome – Functional Status Score

Admission Score / Clerking note		
Discharge first follow up OPD visit		

Modified Barthel Index

Score		Interpretation	
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ANNEXURE 5 Functional Status Score

	NORMAL	MILD DYSFUNCTION	MODERATE DYSFUNCTION	SEVERE DYSFUNCTION	VERY SEVERE DYSFUNCTION	TOTAL
	1	2	3	4	5	
MENTAL STATUS	Normal sleep, wake, appropriate social responsivity	Sleepy but arousable to noise, touch or movements or periods of social non-responsivity	Lethargic and/or irritable	Minimal arousal to stimulus (stupor)	Unresponsive, comatose or vegetative	
SENSORY	Intact hearing and vision and responsive to touch	Suspected hearing or suspected vision loss	Non- reactive to auditory OR visual stimuli	Non- reactive to auditory AND visual stimuli	Absence of response to pain	
COMMUNICATION	Appropriate non-crying vocalizations, interactive facial expressiveness, or gestures	Diminished vocalization, facial expression or social responsiveness	Absence of attention getting behaviour	No demonstration of discomfort	Absence of communication (no cry)	
MOTOR FUNCTION	Co-ordinated body movements with normal muscle control and awareness of the action	1 limb functionally impaired	2 or more limbs functionally impaired	Poor head control	Diffuse spasticity, paralysis decerebrate or decorticate posturing	
FEEDING	All food by mouth with age appropriate help	NPO or need for age appropriate help with feeding	Partial or total tube feedings	Partial parenteral nutrition with enteral feedings	Total parenteral nutrition	
RESPIRATORY	Room air no artificial support	Oxygen or suctioning	Tracheostomy	CPAP for all or part of the day or mechanical ventilation for part of the day	Mechanical ventilation support for all of the day and night	
SCORE						
6-7			GOOD			
8-9			MILDLY ABNORMAL			
10-15			MODERATELY ABNORMAL			
16-21			SEVERELY ABNORMAL			
MORE Than 21			VERY SEVERELY ABNORMAL			

ANNEXURE 6 Modified Barthel Index



Appendix 3

MODIFIED BARTHEL INDEX (SHAH VERSION) : SELF CARE ASSESSMENT		
INDEX ITEM	SCORE	DESCRIPTION
<i>CHAIR/BED TRANSFERS</i>	0 3 8 12 15	<p>Unable to participate in a transfer. Two attendants are required to transfer the patient with or without a mechanical device.</p> <p>Able to participate but maximum assistance of one other person is require in <u>all</u> aspects of the transfer.</p> <p>The transfer requires the assistance of one other person. Assistance may be required <u>in any</u> aspect of the transfer.</p> <p>The presence of another person is required either as a confidence measure, or to provide supervision for safety.</p> <p>The patient can safely approach the bed walking or in a wheelchair, lock brakes, lift footrests, or position walking aid, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, transfer back into it safely and/or grasp aid and stand. The patient must be independent in all phases of this activity.</p>
<i>AMBULATION</i>	0 3 8 12 15	<p>Dependent in ambulation.</p> <p>Constant presence of one or more assistant is required during ambulation.</p> <p>Assistance is required with reaching aids and/or their manipulation. One person is required to offer assistance.</p> <p>The patient is independent in ambulation but unable to walk 50 metres without help, or supervision is needed for confidence or safety in hazardous situations.</p> <p>The patient must be able to wear braces if required, lock and unlock these braces assume standing position, sit down, and place the necessary aids into position for use. The patient must be able to crutches, canes, or a walkalette, and walk 50 metres without help or supervision.</p>
<i>AMBULATION/WHEELCHAIR</i> * (If unable to walk) Only use this item if the patient is rated "0" for Ambulation, and then only if the patient has been trained in wheelchair management.	0 1 3 4 5	<p>Dependent in wheelchair ambulation.</p> <p>Patient can propel self short distances on flat surface, but assistance is required for all other steps of wheelchair management.</p> <p>Presence of one person is necessary and constant assistance is required to manipulate chair to table, bed, etc.</p> <p>The patient can propel self for a reasonable duration over regularly encountered terrain. Minimal assistance may still be required in "tight corners" or to negotiate a kerb 100mm high.</p> <p>To propel wheelchair independently, the patient must be able to go around corners, turn around, manoeuvre the chair to a table, bed, toilet, etc. The patient must be able to push a chair at least 50 metres and negotiate a kerb.</p>

INDEX ITEM	SCORE	DESCRIPTION
<i>STAIR CLIMBING</i>	0	The patient is unable to climb stairs.
	2	Assistance is required in all aspects of chair climbing, including assistance with walking aids.
	5	The patient is able to ascend/descend but is unable to carry walking aids and needs supervision and assistance.
	8	Generally no assistance is required. At times supervision is required for safety due to morning stiffness, shortness of breath, etc.
	10	The patient is able to go up and down a flight of stairs safely without help or supervision. The patient is able to use hand rails, cane or crutches when needed and is able to carry these devices as he/she ascends or descends.
<i>TOILET TRANSFERS</i>	0	Fully dependent in toileting.
	2	Assistance required in all aspects of toileting.
	5	Assistance may be required with management of clothing, transferring, or washing hands.
	8	Supervision may be required for safety with normal toilet. A commode may be used at night but assistance is required for emptying and cleaning.
	10	The patient is able to get on/off the toilet, fasten clothing and use toilet paper without help. If necessary, the patient may use a bed pan or commode or urinal at night, but must be able to empty it and clean it.
<i>BOWEL CONTROL</i>	0	The patient is bowel incontinent.
	2	The patient needs help to assume appropriate position, and with bowel movement facilitatory techniques.
	5	The patient can assume appropriate position, but cannot use facilitatory techniques or clean self without assistance and has frequent accidents. Assistance is required with incontinence aids such as pad, etc.
	8	The patient may require supervision with the use of suppository or enema and has occasional accidents.
	10	The patient can control bowels and has no accidents, can use suppository, or take an enema when necessary.
<i>BLADDER CONTROL</i>	0	The patient is dependent in bladder management, is incontinent, or has indwelling catheter.
	2	The patient is incontinent but is able to assist with the application of an internal or external device.
	5	The patient is generally dry by day, but not at night and needs some assistance with the devices.
	8	The patient is generally dry by day and night, but may have an occasional accident or need minimal assistance with internal or external devices.
	10	The patient is able to control bladder day and night, and/or is independent with internal or external devices.

INDEX ITEM	SCORE	DESCRIPTION
BATHING	0	Total dependence in bathing self.
	1	Assistance is required in all aspects of bathing, but patient is able to make some contribution.
	3	Assistance is required with either transfer to shower/bath or with washing or drying; including inability to complete a task because of condition or disease, etc.
	4	Supervision is required for safety in adjusting the water temperature, or in the transfer.
	5	The patient may use a bathtub, a shower, or take a complete sponge bath. The patient must be able to do all the steps of whichever method is employed without another person being present.
DRESSING	0	The patient is dependent in all aspects of dressing and is unable to participate in the activity.
	2	The patient is able to participate to some degree, but is dependent in all aspects of dressing.
	5	Assistance is needed in putting on, and/or removing any clothing.
	8	Only minimal assistance is required with fastening clothing such as buttons, zips, bra, shoes, etc.
	10	The patient is able to put on, remove, corset, braces, as prescribed.
PERSONAL HYGIENE <i>(Grooming)</i>	0	The patient is unable to attend to personal hygiene and is dependent in all aspects.
	1	Assistance is required in all steps of personal hygiene, but patient able to make some contribution.
	3	Some assistance is required in one or more steps of personal hygiene.
	4	Patient is able to conduct his/her own personal hygiene but requires minimal assistance before and/or after the operation.
	5	The patient can wash his/her hands and face, comb hair, clean teeth and shave. A male patient may use any kind of razor but must insert the blade, or plug in the razor without help, as well as retrieve it from the drawer or cabinet. A female patient must apply her own make-up, if used, but need not braid or style her hair.
FEEDING	0	Dependent in all aspects and needs to be fed, nasogastric needs to be administered.
	2	Can manipulate an eating device, usually a spoon, but someone must provide active assistance during the meal.
	5	Able to feed self with supervision. Assistance is required with associated tasks such as putting milk/sugar into tea, salt, pepper, spreading butter, turning a plate or other "set up" activities.
	8	Independence in feeding with prepared tray, except may need meat cut, milk carton opened or jar lid etc. The presence of another person is not required.
	10	The patient can feed self from a tray or table when someone puts the food within reach. The patient must put on an assistive device if needed, cut food, and if desired use salt and pepper, spread butter, etc.

SCORE	INTERPRETATION
00 - 20	Total Dependence
21 - 60	Severe Dependence
61 - 90	Moderate Dependence
91 - 99	Slight Dependence
- 100	Independence

SCORE	PREDICTION
Less Than 40	Unlikely to go home - Dependent in Mobility - Dependent in Self Care
60	Pivotal score where patients move from dependency to assisted independence.
60 - 80	If living alone will probably need a number of community services to cope.
More Than 85	Likely to be discharged to community living - Independent in transfers and able to walk or use wheelchair independently.

ANNEXURE 7 Information Document for MDT



Information Document for written questionnaire completion- Multidisciplinary team

Dear Colleague,

I, Kesree Sagadavan am currently enrolled as a Masters Occupational Therapy student at the University of KwaZulu Natal. I am currently doing a study entitled "The management of Paediatric HIV/AIDS related neurological conditions in an acute quaternary setting".

The Aim and purpose of the study: To explore and describe how the Multidisciplinary team manage paediatric patients with HIV/AIDS related neurology in an acute quaternary setting.

Invitation to participation: I am inviting you to take part in the research study by answering the questionnaire.

What does the study involve: The study comprises of three components. A file audit will be undertaken to determine the profile of Paediatric HIV/AIDS related neurological illnesses that are referred to our departments for intervention. A questionnaire to the MDT is requested to help determine how the MDT manages paediatric patients with HIV related neurology in an acute quaternary setting. To supplement this information a primary caregiver and child will be interviewed to ascertain their experiences with regards to therapeutic interventions received. This is a request to complete the questionnaire form. It will take approximately 20-30 minutes of your time. You will be requested to answer each question truthfully and honestly. The initial questions highlighted will be based on age, gender, and years of experience, vocational history and training. Thereafter questions on how you manage Paediatric HIV/AIDS related neurological illnesses would be asked. Finally a few questions regarding your experiences and challenges faced while working with these children as well as facilitators and inhibitors impacting on effective teamwork will be discussed. Based on the number of responses received semi structured-interviews a focus group may be completed. The data from the questionnaire will be statistically analysed.

Are there any inherent risks involved in the study? No, there are no risks involved in this study.

When and where will the study be conducted? Completion of the questionnaire can be conducted at your earliest convenience.

Benefits of participating in the study: The results of the study will be available to you once the study has been completed.

Benefits of the study: I hope that this study will create awareness and insight into the management of Paediatric HIV/AIDS related neurological conditions considering the complexities associated with this diagnosis.

Participation is voluntary: Your participation in this study is entirely voluntary and you will be able to withdraw from the study at any time. Your views expressed will not jeopardise your profession or employment and accordingly you will not be treated unfairly or discriminated against.

Confidentiality: All information gathered will only be used for intended research purposes. The research data will be kept strictly confidential between the researcher and supervisor. Your personal details will not be published and information documented and presented will be grouped with other participants and will not be identifiable on an individual basis.

I humbly request your assistance to participate in the study by signing the attached consent form and completing the attached questionnaire.

The **contact details of my supervisors** as listed below:

XXX

This study has been approved ethically by the UKZN Biomedical Research Ethics Committee, (Approval number: BE057/16). If you have any further concerns, please feel free to contact this committee:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban, 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609, Email: BREC@ukzn.ac.za

Kind Regards,

Kesree Sagadavan

Masters Student – Occupational Therapy

<mailto:kesreesagadavan@gmail.com>

ANNEXURE 8 Informed consent for MDT



Informed Consent form to complete the written questionnaire

Management of Paediatric HIV/AIDS related Neurological illnesses in an acute quaternary setting- XXX

I _____ (**name**) hereby give my consent to participate in the study with regard to the Management of Paediatric HIV/AIDS related Neurological conditions in an acute quaternary setting.

I understand that by participating in the questionnaire that I am giving my informed consent to the researcher.

I am aware of the study objectives and that my identity will remain anonymous throughout my participation in this study. It is my right to refrain from answering any questions that I may feel uncomfortable with, or that I may choose not to participate in the study at any time if I so wish. I understand that if I withdraw from the study it will not jeopardise my profession or occupation at the hospital. I am fully informed that all information will not be disclosed to anyone and that I will have access to information that concerns me. I agree that the information obtained from the study may be published so that the findings may be of benefit to others.

Participant's name: _____

Date: _____

Participant's Signature: _____

Researcher's Name **Ms K. Sagadavan**

Date: _____

Researcher's Signature _____



QUESTIONNAIRE FOR MULTI DISCIPLINARY TEAM: Management of Paediatric HIV/AIDS illnesses in an acute quaternary setting

***Prior to commencement with the questionnaire, please make sure that you have read and understood the information provided to you on the information leaflet and signed/completed the consent form. The data will be treated confidentially.**

INSTRUCTIONS

Please answer all questions by marking a tick (✓) in the appropriate block(s) OR by referring to the specific instruction provided with certain questions.

SECTION A: PROFILE AND DEMOGRAPHICS

1. Age (years)
2. Gender

Male	
Female	

SECTION B: VOCATIONAL HISTORY AND TRAINING

1. Please list your highest level of education: _____
2. In what year did you obtain your qualification: _____
3. From which University did you attain your undergraduate qualification?

	University of Pretoria
	University of Witwatersrand
	Sefako Makgatho Health Sciences University

	University of KwaZulu Natal
	University of Western Cape Town
	University of Stellenbosch
	University of Free State
	Other (Please Specify)

4. Do you have any post-graduation qualifications?

Yes	
No	

If you have answered Yes please list these post-graduation qualifications and the year obtained:

Year	Post-Graduation Qualification

5. Please indicate your current job title: _____

6. Please indicate your previous work field/domain:

7. Do you belong to any regulatory bodies? E.g. OTASA (Occupational Therapy Association of South Africa) Please list:

--

8. Do you have any training in HIV/AIDS?

Yes	
No	

If you have answered Yes please list these training courses and the year obtained:

Year	Training course

9. Do you have any specific training in the management of Paediatric HIV/AIDS neurological related illnesses?

Yes	
No	

If you have answered Yes please list these training courses and the year obtained:

Year	Training course

SECTION C: Management of Paediatric HIV/AIDS related Neurological illnesses

1. How many paediatric patients with HIV/AIDS related neurological illnesses have you treated in the last 12 months?

0 patients	
1 – 10 patients	
20-30 patients	

30-40 patients	
40-50 patients	
>50 patients	

2. How often do you treat children diagnosed with Paediatric HIV/AIDS related neurological illnesses per month?

None	
Daily	
Once a week	
Twice a week	
Monthly	
Bi-Monthly	
Other (please specify in space provided below)	

3. On average how much time is an individual consultation session?

0-30 Minutes	
31-45 Minutes	
46-60 Minutes	
61-90 minutes	
>91 minutes	

4. Does your management of Paediatric HIV/AIDS related neurological illnesses differ from that of other paediatric conditions seen in the department?

Yes	
No	

If you have answered Yes please briefly describe how these protocols differ from other paediatric conditions:

5. Do you have any specific treatment protocol or clinical guidelines for the management of Paediatric HIV/AIDS related neurological illnesses?

Yes	
No	

If you have answered Yes please briefly describe these clinical guidelines:

6. Please provide a short job description of your role in the treatment of paediatric neurology patients with HIV/AIDS related illnesses admitted to XXX:

7. What are the common paediatric HIV/AIDS related Neurological illnesses treated? Please indicate the approximate number of each condition seen on a yearly basis.

(Tick more than one box if appropriate)

	Condition	Number
7.1 HIV encephalopathy		
7.2 Microcephaly		
7.3 Neuro-regression		
7.4 Cerebro-vascular disorders		
7.5 Peripheral Neuropathies		
7.6 Epilepsy		
7.7 Seizures		
7.8 Central Nervous system Lymphomas		
7.9 Other		

8. What is the most common presentation of paediatric patients with HIV/AIDS related neurological illnesses that you see in your department?

9. In your opinion what are the Goals of clinical care in the management of Paediatric HIV related neurological illnesses:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree

9.1 To manage co-morbidities and minimise the effects of secondary complications					
9.2 To ensure that children with HIV related neurological conditions have the opportunity to achieve their maximum function and potential throughout life					
9.3 To minimise/delay musculoskeletal deformities					
9.4 To improve development and function					

10. What are your priority management strategies for these paediatric patients referred for intervention to your department in the acute setting? Please elaborate below. [Priority management relates to goal setting, strategic planning and quality control of planning in the treatment of these children].

11. Please indicate below your view with regards to the components that should comprise of a paediatric review of these patients? [Is an assessment that establishes the child's clinical status and his/her category of illness to direct treatment and management priorities].

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
11.1 Diagnostic confirmation					
11.2 Posture and movement					
11.3 Pain					
11.4 Seizures					
11.5 Feeding and gastrointestinal symptoms including oro-motor/ saliva control, gastro oesophageal reflux, vomiting, constipation					

11.6 Cough and chest/respiratory symptoms					
11.7 Barriers to participation					
11.8 Use of splints and other equipment					
11.9 Gait pattern					
11.10 Hand function					
11.11 Personal care and activities of daily living					
11.12 Vision and hearing					
11.13 Communication, feeding and swallowing					
11.14 Bowel and bladder function					
11.15 Dentition					
11.16 Behaviour					
11.17 Sleep pattern					
11.18 Learning					
11.19 Cognition					
11.20 Perception					

12. Do you use specific treatment modalities as per your scope of practice in the management of Paediatric HIV/AIDS related neurological illnesses? [An example would include the use of handling techniques and equipment for the treatment of physical dysfunction by the use of therapeutic exercise and the application of modalities to restore or facilitate normal function and development].

Yes	
No	

If you have answered Yes please specify the commonly used modalities:

13. Do you use any specific standardised tests for the assessment of Paediatric HIV/AIDS related neurological illnesses?

Yes	
No	

If you have answered Yes please specify these tests

14. In your opinion is your department adequately equipped to manage Paediatric patients with HIV/AIDS related neurological conditions?

Yes	
No	

Please outline reasons below for your answer:

Yes	No

15. In your experience at XXX what Services and Assessments should be available at a specialist tertiary institution in order to treat these patients?

SECTION D: Multidisciplinary Team Management of Paediatric HIV/AIDS related Neurological illnesses

*** Inter-professional team approach-a group of professionals with the same profession working together to provide the patient with rehabilitation services.*

*** Multidisciplinary team approach-a team of individual disciplines working together to provide a patient with rehabilitation services*

*** Trans-disciplinary team approach-Involves scientists from different disciplines as well as non-scientists and other stakeholders and through role release and role expansion, transcends the disciplinary boundaries to look at the dynamics of whole systems in a holistic way*

****MDT –Multidisciplinary team**

1. Do you participate in Paediatric Neurodevelopment clinics?

Yes	
No	

Please specify reasons for your answer

Yes	No

--	--

2. Is there a MDT involved in the decision making of the management of these patients?

Yes	
No	

If the answer is **Yes**, who is involved in this decision-making?

(Tick more than one box if appropriate)

Paediatric Neurologist	
Registrar	
Doctors from other specialities	
Nurse	
Clinicians allied to health	
Other (please specify below)	

3. Who makes up the paediatric Neurodevelopmental MDT at XXX?

(Tick all that apply)

Paediatric neurologist	
Developmental/ Neurodisability paediatrician	
Physiotherapist	
Occupational therapist	
Speech and language therapist	
Dietician	

Orthotist	
Social worker	
Psychologist	
Clinical nurse	
Other (Please specify)	

4. Do you refer paediatric patients with suspected HIV/AIDS related illnesses to the MDT?

Yes	
No	
Selected cases only	

5. At what stage in the treatment process do you refer to the MDT?

At admission	
Once all tests and investigations have been completed	
If symptoms warrant a specific team member's intervention	
At discharge	
Other (please specify below)	

6. How often does the MDT meet to discuss case presentations of these patients?

Daily	
Once a week	
Twice a week	
Monthly	

Bi-Monthly	
Other (please specify in space provided below)	

7. What is your discharge and follow up protocol?

8. Is your approach in the treatment of Paediatric HIV/AIDS neurological illnesses “child centred”?

Yes	
No	

Please provide reasons for your response:

9. Do you experience any challenges with the management of Paediatric HIV/AIDS related neurological illnesses?

Yes	
No	

If Yes please specify in the space provided below:

10. Do you believe you have adequate skills and knowledge to manage Paediatric HIV/AIDS related neurological illnesses?

Yes	
No	
Some skills and knowledge	

In your opinion what would improve your skills and knowledge in the management of these children?

11. What are the positive aspects of treating Paediatric HIV/AIDS related neurological illnesses? Please specify in the space provided below:

12. What are the negative aspects of treating Paediatric HIV/AIDS related neurological illnesses? Please specify in the space provided below:

13. In general what services would you like to see in place for paediatric patients diagnosed with HIV/AIDS related neurological illnesses?

14. What are your thoughts about transdisciplinary approaches in the management of paediatric patients diagnosed with HIV/AIDS related neurological illnesses?

SECTION E: CAREGIVER

1. Do you consider the caregiver an important individual in the treatment approach of Paediatric HIV/AIDS related neurological illnesses?

Yes	
No	

Please elaborate on your answer in the space provided:

2. Do you include the caregiver in your treatment approach?

Yes	
No	

If Yes, how do you include the caregiver in your treatment plan?

Please specify in the space provided below:

If No, why do you exclude the caregiver in your treatment approach?

Please specify in the space provided below:

3. Do you experience any of the challenge(s) listed below when you include the caregiver in your treatment approach:

(Tick all that apply)

Poor understanding	
Cultural beliefs	
Communication and language barrier	
Other (please specify in space provided below)	

SECTION F: TEAM WORK

1. Please refer to the table below outlining teamwork principles. Kindly tick the correct response as it applies to you for each of the listed items.

		Yes	No	Indifferent
1	I am comfortable in communicating with all members of the MDT			
2	I enjoy being involved in patient case discussions			
3	I would prefer to learn from members of my own profession			
4	Learning from other members of the MDT is beneficial			
5	Collaborative learning is important			
6	The line of communication between all members of the MDT is open and transparent			
7	There is a status hierarchy within the MDT that affects the management of these children			
8	Does each member of the MDT show respect for each other's contribution's			
9	Do you feel that the MDT you work within is demanding			
10	Do you feel that the MDT you work within is rewarding			

2. Are there factors within the hospital organisation that impacts on treatment and management of Paediatric HIV/AIDS related neurological illnesses?

Yes	
No	

If Yes please specify in the space provided below:

Thank you for taking your valuable time to complete this questionnaire. All replies are treated with complete confidentiality and the results are anonymised for recording and data collection. However if you wish to make any additional comments please use the box provided below.



Information Document for Focus group

INFORMATION DOCUMENT

STUDY TITLE: Management of Paediatric HIV/AIDS related neurological conditions.

PURPOSE OF THE STUDY

My name is Kesree Sagadavan. I am conducting a study to explore the management of Paediatric HIV/AIDS related conditions in a quaternary setting.

STUDY PROCEDURES

In this research I would like to collaborate with you through discussions by means of a focus group and with the use of audiotapes (through voice recordings).

Each focus group is to run for a maximum of 45 minutes and the purpose of the focus groups is to encourage you, as a participant, to express your thoughts and feelings surrounding what your experiences related to the Management of Paediatric HIV/AIDS related conditions, your interaction with the MDT and roles and responsibilities. All discussions are private and confidential, and no one else will have access to this information. You will not be identified in any final report.

If you have any questions please do not hesitate to contact me.

I can be contacted at: 0837808866

Thank you for your interest in this research.

Regards,

Ms K. Sagadavan - Masters Student

ANNEXURE 11 Consent for Audiotaping



Letter of Consent for focus group and audiotaping

PURPOSE OF THE STUDY

The aim of this research project is to explore the Management of Paediatric HIV/AIDS related neurological conditions in an acute quaternary setting.

PARTICIPANTS UNDERSTANDING

- I confirm that I have been informed about the how the study will be conducted and the risks of the study.
- I have understood what the study is about after the information document was explained
- I understand that my participation is voluntary.
- I understand that discussions will be audio recorded and that the researcher may replay these audio recordings at later stages for data collection purposes
- I understand that I will not be identified by name in the study
- I know that all records will be kept confidential and secure
- I am aware that the findings of the study will be published in a research report and will be sent for possible publication
- I am aware that the researcher may give the findings to another researcher to validate the interpretations.
- I understand that I can withdraw my consent and participation in the study.

I consent to have focus group audiotaped Yes No

Participant's name: _____ (Please print)

Participant's signature: _____ Date: _____

Researcher's name: _____ (Please print)

Researcher's signature: _____ Date: _____

ANNEXURE 12 Biographical questionnaire for Focus group MDT



Biographical Information Questionnaire for Focus Group

Participant No: _____

1. Age: _____

2. Gender:

Male		Female	
-------------	--	---------------	--

3. Race

White	
Black	
Asian	
Coloured	
Other	

4. Current Occupation: _____

5. Year of Qualification: _____

6. Years of Experience:

2- 5 years	
5- 10 years	
10 -15 years	
15-20 years	
> 20 years	

7. Previous Work History:

DATE	PLACE OF EMPLOYMENT	JOB TITLE

ANNEXURE 13 Schedule of questions for focus group



1. Can you describe your areas of expertise in working with Paediatric HIV related neurological conditions?
2. How do you see your role in the management of these conditions?
 - a. Describe your key job responsibilities with regards to the management of Paediatric HIV related neurological conditions?
 - b. Do you think there is an expectation gap i.e. what your roles and responsibilities actually are versus what is perceived by other health care professionals and how do you attempt to bridge the gap?
 - c. Has there been any instance where you have deviated from your roles and responsibilities and how did this effect treatment of paediatric patients with HIV related neurological conditions?
3. What are your priorities of care in the management of Paediatric HIV related neurological conditions?
 - a. Can you elaborate as to why these are identified as key priority areas?
 - b. Are your priorities static or dynamic and what is the process for review if identified as continuous?
4. How do you define your treatment goals in the management of these patients?
5. Can you describe or explain the influence of the physical environment on your management of these children?
 - a. Can you elaborate on the impact on your treatment goals?
6. What is your opinion on transdisciplinary teamwork in treatment of these patients?
 - a. What are the positives/promoters/enablers?
 - b. What are the negatives/inhibitors?
7. What has been your experience of working within a MDT?
 - a. Tell me more about the demands?
 - b. Tell me more about the rewards?
 - c. For challenges identified elaborate on the steps taken to enhance teamwork?
8. What are your suggestions for effective management of these children in an acute setting?
9. With regards to the wider hospital organisation, describe key factors that impact on the care and management of these patients?



MANAGEMENT OF PAEDIATRIC HIV/AIDS RELATED NEUROLOGY

INFORMATION SHEET FOR THE CAREGIVER

Dear Parent/ Caregiver

Hello, my name is Kesree Sagadavan; I am an Occupational Therapist employed at XXX.

I am currently completing my Masters in Occupational Therapy, looking at the management of Paediatric HIV/AIDS related neurological conditions.

If you agree to participate in the study, I will be asking you questions relating to the care and management of your child by the multi-disciplinary team employed at XXX.

The questions can be translated into IsiZulu and there is someone to assist you with the questions. I will not be using your name or your child's name in the study so that your privacy will be kept at all times.

The information I get from you will assist in improving service delivery which will help in the management of Paediatric HIV/AIDS related neurologic conditions.

This study is voluntary and only if you choose to participate you will be included. If at any time you choose not to continue in the study, you are free to withdraw. This will have no effect on the treatment your child will receive from the hospital.

If you would like to participate in this study please fill in the form below.

If at any stage you have any questions about this research, please contact me on the number 0837808866.

Thank you so much.

Kesree Sagadavan

CONSENT FORM - CAREGIVER

I _____ agree to participate in the study.

I understand that I can withdraw from the study at any time.

Signed _____

Date _____

ANNEXURE 15 Schedule of questions with caregiver English and IsiZulu



Semi structured interview with caregiver

1. How did you feel when your child got admitted to hospital?
Wazizwa kanjani ngesikhathi umntwana wakho elaliswa esibhedlela?
2. What were the different types of treatment options available for your child?
Iziphi izinhlobo zokulashwa komntwana owanikwa zinana?
 - a. Did you understand these different options?
Waziqonda lezizinhlobo ezahlukene zokulashwa?
 - b. What questions did you ask the doctor about these options?
Imiphi imibuzo owaubuz u Dokotela ngalezizinhlobo zokulashwa?
3. Were you informed about the different tests being done?
Watshelwa ngokuhlowa okwahlukahlukeni okwakwanziwa?
4. How were you given information about what the test results were?
Wanikezwa kanjani imiphumela yalokho kuhlolwa noma izivivinyo?
5. How were you informed of the change in treatment? Did you understand why these changes were done?
Watshelwa kanjani ngoshintsho ekuhlolweni komntwana? Waqonda ukuthi lalwenziwelani lolushintsho?
6. Describe the relationship between you and the therapists working with your child?
Chaza ngobudlelwa owawunabo phakathi kwakho nama therapists awayesebenzisana nomntwana wakho?
 - a. Did you experience any problems with the therapist, and if yes, how did you correct it?
Wahlangabezana nezinkinga nama Therapists, uma kunjalo, wazilungisa kanjani?
7. Do you feel it is hard to care for your child?

Uzwa noma ubona sengathi kunzima ukunakekela umntwana wakho?

- a. What are the demands in caring for your child?
Ikuphi okuyizinselelo ekunakekeleni umntwana wakho?
- b. How do you cope with such demands?
Uhlangabezana kanjani nalezinselelo?
- c. What are the good aspects in caring for your child?
Iziphi izindlela ezinhle noma ezincono ekunakekeleni umntwana wakho?

8. What form of information was given to you by the therapist e.g. pamphlet and home programmes?

Iluphi uhlobo lowazi owalinikezwa I therapist, izibonelo, amabhukwanyana nezinhlalo ongazisebenzisa ekhaya?

- a. Did you find these helpful and easy to carry out?
Lolulwazi, wabona sengathi lunosizo futhi kulula ukulusebenzisa?

9. How did you feel when talking to the doctor and therapist about your child?

Wazizwa kanjani uma ukhuluma no dokotela ne therapist ngomntwana wakho?

10. Was it easy and were they helpful?

Kwakulula ukukhuluma nabo, futhi baba usizo kubo?

11. If not what did you do?

Uma kungenjalo, wabe usuwenzanjani?

12. Do you feel that the team was available when you needed help?

Ubona ukuthi iqembe elelapha umntwana wakho lalitholakala uma udinga usizo?

- a. Has there been any time where you felt that they did not assist you?
Sikesaba khona isikhathi la wezwa sengathi abakusizanga?
- b. Please provide an example of such an incident?
Uma kunjalo, nikeza isibonelo salokho

13. Upon discharge what information were you issued with for the care of the child at home?

Ngesikhathi usukhishwa eibhedlela, iluphi ulwazi owanikezwa lona ukuze ukwazi ukunakekela umntwana ekhaya?

a. How was this information explained to you?

Wachazelwa kanjani lolulwazi?

b. Did you understand what was required of you to carry out at home?

Waqonda ukuthi kwakulindleleke wenzeni ekhaya?

14. Describe the different support groups or community resources that you were referred to?

Chaza ngezi khungo zabantu abanezingqinamba ezifana nezakho owathunyelwa kuzo?

15. What can medical professionals do differently when treating your child?

Yini ochwepheshe bezempilo abangayenza ngokuhlukile uma belapha umntwana wakho?

16. Provide any suggestions in improving the care given to your child by the team?

Nikeza noma imuphi umubono kubalaphi ukuthuthukisa unakekelo lomntwana

ANNEXURE 16 Biographical questionnaire for Caregiver



Biographical Information Questionnaire for Caregiver

As part of your participation in my research project, please fill out the following questionnaire. You and your child's identities will be kept confidential.

Personal Details of Parent

Name and Surname:			
Date of birth:	Day/	Month/	Year/
Where do you live?	City	Town	
Where were you born/where did you grow up?	City	Town	
What is your first language?			
Do you speak a second language and if so what is it?			
Do you speak or understand any other languages?			
How would you describe your culture?			

Personal Details of Child

Name and Surname:			
Date of birth:	Day/	Month/	Year/
Does your child live at home with you? If not where and with whom does your child live?			
What is your child's first language?			
Does your child understand or speak any other languages and if so, what are they?			
Does your child attend informal or formal schooling? (crèche/preschool/playgroup) If so, for how long has your child attended there?			
What language does your child speak at school?			
Does your child have any diagnosed medical conditions?			
Does your child have any known disabilities?			
Has your child ever been seen by a therapist (Physiotherapist, Occupational Therapist, Speech Therapist)? If so, who did your child see, why and for how long?			
Has your child ever been assessed with a formalized assessment tool?			
Have you ever had to fill out a developmental assessment questionnaire of your child or any of your children?			

Educational and employment details of parent

1. Where did you go to school?

2. What level of schooling did you complete? If more apply, select the **highest** one.

- Primary school (grade 1 to 7)
- Secondary school (grade 8 to 10)
- High school (grade 11 - 12)
- Tertiary education (University, Technikon or Technical College)
- not yet graduated
- Postgraduate studies

3. Are you literate (able to read and write) in your first language?

4. Proficiency in Zulu

- Very Good
- Good
- Average
- Bad
- Very Bad

5. Are you literate in English?

6. Which of the following statements about occupational status apply to you?

- Not working at the moment
- Part-time or hourly work (< 15 hours per week)
- Part-time work (15 to 34 hours per week)
- Full-time work
- In training (apprentice or internship)
- Currently studying

7. If yes to working on the above, what is your **present** occupational position or (if no longer working) was your **last** position?

- Unskilled Labourer
- Trained on the job
- Skilled
- Professional
- Self-employed
- None of the above

8. What is the monthly household income, net income after taxes or deductions

- Less than R1500 PM
- R1500 to R2000 PM
- R2000 to R3000 PM
- R3000 to R4000 PM
- R4000 to R5000 PM
- R5000 to R6000 PM

Other Specify _____

9. Which kind of income do you receive?

- Earning from employment or self-employment
- Pension from former employer
- Child grant/s

- Income Support e.g. maintenance payment
- No source of income

Transport information of parent

1. What form of transport do you use?

2. How long does it take you to get to and from work?

3. How much does it cost you to travel to and from work per month?

4. Do you own a car?

Housing Information

1. What sort of house do you live in? (Please tick appropriate block and explain if necessary)
 - Brick house
 - Shack
 - Apartment/flat
 - Other
2. How many rooms does your home have? _____
3. How many people live in your home? _____
4. Do you have a garden/outside area in which your child can play?

5. Do you have electricity in your home?

6. Do you have indoor plumbing? (Toilets, running water, baths etc.)

Family information and access to resources

1. Parent information (Please tick appropriate block and explain if necessary)
 - Married and both living at home
 - Married but separated
 - Divorced
 - Single parent
 - Widow/Widower

2. How many children do you have and what are their ages?

3. Is there any history of disability in your family?

4. Who is mostly responsible for looking after your child?

5. How much time do you spend with your child per day?

6. Do you have access to private health care?

If not, how far from home is the nearest clinic?

7. Does your child have his/her own books or toys?

8. What does your child do during a typical day?

Thank you very much for providing these details.

ANNEXURE 17 Child Assent form



Management of Paediatric HIV/AIDs related Neurological conditions in an acute quaternary setting

WRITTEN CHILD ASSENT FORM

Principal Investigator: Kesree Sagadavan

Supervisors: XXXX

Hello, my name is Kesree Sagadavan. I am an Occupational Therapist.

An Occupational Therapist is someone who works in the hospital and help children that are unwell.

What is a research study?

The research is done to gather information about how you feel about the therapy you received at XXX.

Why is this study being done?

The study will tell me about the service we offer at the hospital when we treat children admitted with serious illnesses.

What will happen to me?

Today I would like to ask you some questions. It will take a few minutes to answer all the questions. The questions I would like to ask you are about the team of therapists who treated you whilst you were admitted to hospital.

If you would like to answer the questions, there is someone to help you with the questions and your mom can stay with you. While you are answering the questions, I will be looking at your file to get some information about you and your hospital visit.

How long will I be in this study?

The interview will take you about 10 minutes.

Do I have other choices?

You have a choice. You can be in the study or you can decide not to take part. If you choose not to answer the questions, no one will be upset with you. And if you choose to answer some questions and then stop, that also fine.

Will people know that I am in the study?


Nobody will know what you have told me. All the results will be put together and we will share this with other people, but your name will not be mentioned.


Is it OK if I say, “No, I don’t want to be in this study”?

You do not have to be a part of this study if you don’t want to. No one will be upset with you.

Do you understand and do you want to be in this study?

I understand. All the questions were answered.

I want to be in the study. 

I don’t want to be in the study. 

Your name

Your signature

Date

Signature of person explaining the study

Date

ANNEXURE 18 Parental consent for Minor



PARENTAL LETTER OF CONSENT FOR MINORS

Dear Parent

I am a postgraduate student in the Masters in Occupational Therapy under the supervision of XXX. The aim of the study is to understand the management of Paediatric HIV/AIDS related Neurology by the Multidisciplinary team employed at XXX.

I am requesting your child's participation. This will involve a semi-structured interview to gain your child's experience in the rehabilitative process. Your child's participation in this study is voluntary. If you choose not to have your child participate or to withdraw your child from the study at any time, there will be no penalty. Likewise, if your child chooses not to participate or to withdraw from the study at any time, there will be no repercussions. The results of the research study may be published and your child's name will not be used. An interpreter will be used to translate the prepared questions into IsiZulu. The interview will be audiotaped so that information can be translated and analysed.

If you have any questions concerning the research study or your child's participation in this study, please do not hesitate to contact me on 0837808866.

Sincerely,

Yours faithfully

Kesree Sagadavan

Masters Student – Occupational Therapy

kesreesagadavan@gmail.com

XXX

Research supervisor

XXX

ANNEXURE 19

Schedule of questions for child in English and IsiZulu



1. How old are you?

Uneminyaka emingaki?

2. Which school do you go to?

Ufunda kuphi?

3. What grade are you in?

Ufunda ibanga lesingaki?

4. Do you know why you are here in hospital

Uyazi ukuthi kungani ulapha esibhedlela?

5. What are your feelings about being in hospital?

Uzizwa kanjani njengoba ulapha esibhedlela?

6. Are there any activities that you cannot do now that you are in hospital?

Zikhona izinto ongasakwazi ukuzenza njengoba ususesibhedlela?

a. What are these activities

Iziphi lezizinto?

b. Why can't you do them?

Yini ungasakwazi ukuzenza?

c. How do feel now that you are unable to do the same things as before?

Uzizwa kanjani manje njengoba ungasakwazi ukwenza izinto njengasekuqaleni?

7. Do you know the people treating you?

Uyabazi abantu abakulaphayo?

a. What do these people do when treating you?

Bayaye benzeni lababantu uma bekulapha?

8. What was the information given to you by the people treating you?

Iliphi ulwazi abakunike lona labantu abakulaphayo?

9. Tell me about the activities you were given to complete in the ward?

Ngitshele ngezinto onikezwe zona ukuba uzenze e wodini?

10. Tell me about some of the different activities you do at therapy to make you better?

Ngitshele ngezinye zezinto ezahlukeneyo ozenzayo e therapy ukukwenza ubencono?

11. Tell me about the different places where you visited for therapy?

Isho izindawo ezahlukeneyo oke waya kuzo ukuyolashwa?

12. Why do you think it was important for you to complete all your exercises?

Ucabanga ukuthi bekubaluleke ngani ukuba ukwenze konke ukuzivocavoca?

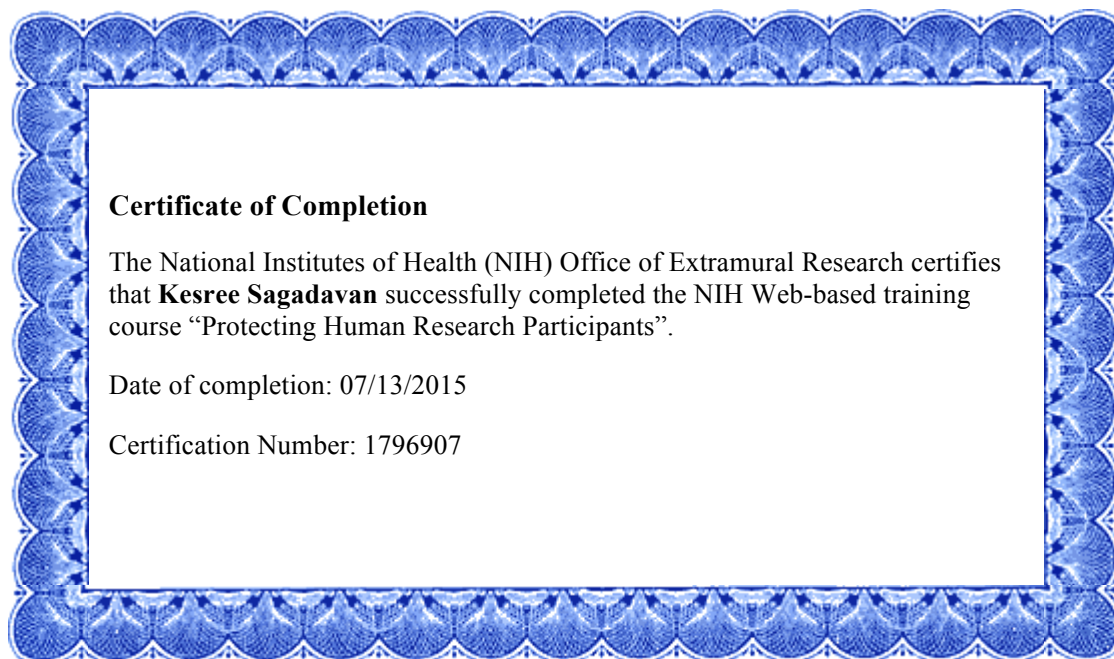
13. Tell me about the things you don't like about being in hospital?

Ngitshele ngezinto ongazithandi ngokuba sesibhedlela?

14. Do you share your feelings with your doctor or therapist and what did they do about it?

Uyabazisa o dokotela noma ama therapist imizwa yakho, base benzani ngalokho?

ANNEXURE 20 Ethics Certificate





CERTIFICATE OF COMPLETION

This is to certify that

Kersee Sagadayan

HPCSA Membership No.: OT0055808

Has successfully completed the course entitled

AN INTRODUCTION TO GOOD CLINICAL PRACTICE

With 99%

The HPCSA approved CPD reference is as follows:
MDB015/283/04/2014 Level 2: 12 points (Ethical=12)

SACRA/GCP/80/2013

Date: 05 APR 2014

A handwritten signature in black ink, appearing to read "Kersee Sagadayan", written over a horizontal line.

Course Facilitator