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THE CHARACTERISTICS OF A GROUP OF YOUNG CHILDREN INFECTED WITH HIV/AIDS AT A REGIONAL HOSPITAL IN GAUTENG

BY

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ABSTRACT

The effects of HIV/AIDS and subsequent opportunistic infections and/or associated conditions on the development of infected children are substantial. Considerable delays and/or disorders in communication development have been noted in the HIV/AIDS infected child, as well as the need for Early Communication Intervention (ECI) services for this population. A dearth of locally relevant data regarding the speech, language and hearing development of HIV/AIDS infected children within the South African context currently exists.

The objective of this study was to describe the characteristics of a group of HIV/AIDS infected children being managed at an outreach clinic of regional hospital in Gauteng. A cross-sectional, retrospective, non-experimental, descriptive, quantitative research design was used in this study. The main objective was achieved by analysing the clinic records of 203 children infected with HIV/AIDS between the ages of 0 – 5 years 11months through the use of a pre-designed checklist. A questionnaire completed by four medical doctors practicing at the HIV/AIDS clinic within the hospital was also used. This allowed for the perceptions and practices of the medical doctors to be described.

Results revealed that the majority HIV/AIDS infected children being managed at the outreach clinic were significantly immunocompromised and diagnosed with Stage III or Stage IV HIV/AIDS infection. Furthermore, results indicated the presence of several opportunistic infections and HIV/AIDS associated conditions (such as Tuberculosis, Candidiasis and Encephalopathy). A positive finding was that 76% of the HIV/AIDS infected children (n=153) were receiving Highly Active Antiretroviral Therapy (HAART) at the time of data collection. The most outstanding finding was that very few of the children with HIV/AIDS being managed at the outreach clinic were recorded as having speech, language and/or hearing delays and/or disorders. Similarly, referrals to other professionals as recorded in the children's hospital records seemed to be limited to Social Workers and

Dietitians, with only one child recorded as being referred to a Speech-Language Therapist and Audiologist for further management. It was unclear whether more children were in fact referred for additional intervention by other professionals and this was simply not recorded in the children's records, or whether these referrals were in fact not made.

Results from the questionnaires completed by the medical doctors working with the pediatric HIV/AIDS population within the outreach clinic were significant. Findings indicated that the majority of the respondents believed that HIV/AIDS infected infants were more at risk for developmental and communicative delays and/or disorders than the general population, and that this population would likely benefit from Speech-Language Therapy and/or Audiology intervention services. Respondents indicated that medical doctors working with the pediatric HIV/AIDS population were often not adequately informed regarding the effects of HIV/AIDS on communication development and that they would benefit from further training in this regard.

The need for further research regarding the characteristics of the pediatric HIV/AIDS population, particularly on a larger sample, was described. This would assist in the development of a guideline for ECI service delivery for children infected with HIV/AIDS. The need for further training of other professionals regarding the effects that HIV/AIDS has on the communication development of the infected child, to assist with necessary referrals and teamwork, was also highlighted.

Key words:

Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome (HIV/AIDS), pediatric, Early Communication Intervention (ECI), opportunistic infection, HIV/AIDS associated conditions, immunocompromised, Highly Active Antiretroviral Therapy (HAART), Speech-Language Therapist and Audiologist.

OPSOMMING

Suid-Afrika is een van die lande ter wêreld, wat die hoogste voorkoms van Menslike Immuniteitsgebrekvirus/ Verworwe Immuniteitsgebreksindroom (MIV/VIGS), toon - met die pediatriese populasie op die voorfront van hierdie epidemie. Die effek wat MIV/VIGS en opeenvolgende opportunistiese infeksies en/of ander geassosieerde toestande op die ontwikkeling van kinders het, is verreikend. Internasionale literatuur beskryf agterstande en/of akwykings in die kommunikasie ontwikkeling van kinders wat met MIV/VIGS geinfekteer is. Die behoefte vir Vroeë Kommunikasie Intervensie (VKI) vir hierdie populasie word ook gemeld. Daar bestaan egter slegs ‘n beperkte hoeveelheid relevante, plaaslike literatuur met betrekking tot die spraak-, taal- en gehoorontwikkeling van kinders met MIV/VIGS binne die Suid-Afrikaanse konteks.

Die doelwit van hierdie studie was om die kenmerke van ‘n groep kinders, wat met MIV/VIGS besmet is en by ‘n streekshospitaal in Gauteng behandel word, te beskryf. ‘n Kwantitatiewe, nie-eksperimentele, terugwerkende, dwarsdeurige, beskrywende navorsingsontwerp is gebruik. Die hoofdoelwit was bereik deur die kliniekrekords van kinders wat met MIV/VIGS besmet is, te analiseer deur van ‘n vooraf-ontwerpte merklys gebruik te maak. Data is ook ingesamel deur middel van vraelyste wat deur mediese dokters, wat by MIV/VIGS klinieke binne die hospitale werk, voltooi is. Dit het toegelaat dat die persepsies en praktyke van die mediese dokters ook beskryf kon word.

Resultate het getoon dat die meerderheid kinders met MIV/VIGS, wat by klinieke behandel word, se immuunsisteme ernstig onderdruk was en dat hulle met stadium III of stadium IV van MIV/VIGS gediagnoseer was. Die resultate het verder ook die voorkoms van verskeie opportunistiese infeksies en MIV/VIGS geassosieerde toestande aangedui. ‘n Positiewe bevinding was dat 76% van die kinders (n=153), wat met MIV/VIGS geinfekteer was, tydens die proses van data-insameling reeds Hoogsaktiewe Antiretrovirale Terapie (HAART) ontvang het. Die mees uitstaande bevinding was dat slegs ‘n geringe hoeveelheid kinders met MIV/VIGS by die

kliniek, as met ‘n agterstand en/of afwyking in spraak, taal en/of gehoor, aangeteken is. Beperkte verwysings na ander professionele persone is ook in die kliniekrekords opgemerk. Verwysings was beperk tot Maatskaplike Werkers en Dieëtkundiges. Daar was slegs een aantekening van ‘n kind wat vir behandeling na ‘n Spraak- en Taalterapeut en Oudioloog verwys is. Dit is egter onduidelik of daar werklik meer verwysings na ander professionele persone gemaak is, maar net nie in die kinders se kliniekrekords aangedui is nie, of dat daar werklik min verwysings na ander professionele dissiplines gemaak is.

Bykomend, was die resultate van voltooide vraelyste deur mediese dokters, wat met die pediatriese MIV/VIGS populasie in die kliniek werk, insiggewend. Bevindings dui aan dat die meerderheid proefpersone, wat aan die studie deelgeneem het, van mening is dat kinders wat met MIV/VIGS besmet is wel ‘n hoër risiko toon vir ontwikkelings- en kommunikasie agterstande en/of afwykings in vergeleke met die algemene populasie. Die proefpersone is verder ook van mening dat hierdie populasie wel van spraak- en taalterapie en/of oudiologiese intervensie sal baatvind. Proefpersone het verder aangedui dat mediese dokters, wat met die pediatriese MIV/VIGS populasie werk, nie ten volle ingelig is omtrent die effek van MIV/VIGS op kommunikasie ontwikkeling en dat hulle van verdere opleiding sal baatvind.

Die behoefte vir verdere navorsing in die veld van pediatriese MIV/VIGS en kommunikasie ontwikkeling, binne die Suid-Afrikaanse konteks, word in hierdie studie beskryf. Dit sal as riglyn vir VKI dienslewering aan hierdie populasie dien. Daar is ook ‘n groot behoefte vir verdere opleiding van ander mediese professionele persone met betrekking tot pediatriese MIV/VIGS en die effek wat die op die kind se kommunikasie ontwikkeling het.

Sleutelwoorde:

Menslike Immuniteitsgebrekvirus / Verworwe Immuniteitsgebreksindroom (MIV/VIGS), pediatries, Vroeë Kommunikasie Intervensie (VKI), opportunistiese infeksie, MIV/VIGS-verwante siektes, immuniteitsgekompromiseerd Hoogsaktiewe Antiretrovirale Terapie (HAART) Spraaktaalterapeut en Oudioloog.

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CHAPTER 1

HUMAN IMMUNODEFICIENCY VIRUS / ACQUIRED IMMUNODEFICIENCY SYNDROME (HIV/AIDS) AND CHILDREN IN SOUTH AFRICA: A GENERAL ORIENTATION AND MOTIVATION FOR RESEARCH

Aim: The aim of this chapter is to describe the current HIV/AIDS pandemic in South Africa, as well as to review HIV/AIDS treatment standards that have been identified both internationally and locally, for the purposes of this research study.

1.1 INTRODUCTION

1.1.1 The pediatric HIV/AIDS population in South Africa

The impact of HIV/AIDS in South Africa has reached pandemic proportions. According to mid-year population estimates for South Africa in 2009 (http://www.statssa.gov.za), the estimated overall HIV-prevalence rate is approximately 10,6%. The HIV/AIDS population is estimated at approximately 5,21 million, making South Africa the country with the largest number of HIV/AIDS infections in the world.

Children are severely affected by the global HIV/AIDS epidemic, nowhere more so than in sub-Saharan Africa, the region that carries the brunt of the HIV disease burden (Marais, Kangwana, Rabie & Cotton, 2007: 18). Vertical transmission from mother to child is the dominant route of HIV transmission to infants and children. A mother-to-child transmission rate (the percentage of babies born to HIV-positive mothers who will also become HIV-positive) of 32% is assumed (if no treatment program is followed) and 11% if a treatment program

is in place. These vulnerable children experience rapid disease progression with more than 30% mortality during the first year of life (Van Dyk, 2005: 46).

The earliest cases of HIV/AIDS infection in South Africa were identified in the 1980s. Since then HIV/AIDS has been an important public health challenge in South Africa. The first meaningful programme against HIV/AIDS was only initiated by the government of national unity, which took office in 1994. A number of strategic documents and actions guided South Africa's interventions. These included the African National Congress Health Plan, NACOSA plan for HIV/AIDS and subsequently the Operational plan for Comprehensive HIV/AIDS Care, Management and Treatment (2004) and finally the National Strategic Plan for HIV/AIDS 2007-2011 (Declaration of Commitment on HIV/AIDS, South Africa, 2007: 1).

At the first-ever Special Session on HIV/AIDS of the United Nations General Assembly (UNGASS) in 2001, UN Member States strengthened the response to Millennium Development Goal 6 by unanimously endorsing the *Declaration of Commitment to HIV/AIDS*. This Declaration included time-bound pledges to generate measurable action and concrete progress in the AIDS response. At the five-year review of implementation of the *Declaration of Commitment to HIV/AIDS* in 2006, UN Member States reaffirmed the pledges made at the 2001 Special Session. Also, in the *Political Declaration on HIV/AIDS*, they committed to taking extraordinary action to move towards universal access to HIV prevention, treatment, care, and support by 2010. These commitments breathe hope to a struggling, disparaged South Africa ravaged by the HIV/AIDS atrocity. By implication, children and their families have been given the anticipation of positive changes in general health and quality of life. The perceived implication would be improvement in the global development of HIV/AIDS infected children, as well as the access to the full spectrum of professional intervention and habilitation services.

In November 2003 the South African government published their statement on a plan for the comprehensive treatment and care for HIV/AIDS in South Africa. It was envisioned in the plan that, within a year, there would be at least one service point in every health district across the country and, within five years, one service point in every local municipality. This would provide those living with HIV/AIDS access to the appropriate HIV/AIDS services in the community in which they live, as well as enhance the national HIV/AIDS prevention campaign.

According to the HIV/AIDS and STI Strategic Plan (NSP 2007-2011), the prevention target is to reduce the national HIV incidence rate by 50% by 2011. With regard to the treatment, care and support of this vulnerable population, the target is to provide an appropriate package of treatment, care and support services to 80% of people living with HIV and their families by 2011 in order to reduce morbidity and mortality as well as other impacts of HIV/AIDS. People living with HIV infection should be provided with a continuum of care and support services that respond to their changing needs over the course of their infection. Components of this continuum of care include: prevention-related interventions; voluntary counselling and HIV testing (VCT); medical care and treatment by a dedicated, trained medical team; psychosocial support; nutritional assistance; social supports; and as needed, community-based services and home-based care (Operational Plan for Comprehensive HIV/AIDS Care, Management and Treatment for South Africa, 2003: 54).There are, however, significant shortfalls in the progress of Highly Active Antiretroviral Therapy (HAART) rollout to the pediatric population in South Africa.

According to a Stocktaking Report by UNICEF in 2007, only one in ten children needing antiretroviral treatment globally receives it, the remaining face a bleak and probable short-lived future. Of the total pediatric population infected with HIV/AIDS in South Africa, less than 40% were receiving the necessary antiretroviral treatment in 2007 (Report on Progress towards Universal Access in South Africa, 2008: 8). South Africa has recognized skilled human resource capacity as a major impediment towards the rapid progression of intervention

programmes. This is a major challenge since human resource capacity, particularly in specialised fields of the healthcare sector, cannot simply be developed overnight. Other challenges include low uptake of prevention and weak service delivery structures particularly at lower levels. Conversely, South Africa has made great strides in addressing the issue of sustainable financing, ranking second in the world in terms of domestic spending on HIV/AIDS (Report on Progress towards Universal Access in South Africa, 2008: 19). It is within this context that locally relevant research is essential for the development of service delivery for the pediatric HIV/AIDS population.

"Although some countries are on course to meet the 2010 targets in the Declaration of Commitment, others are not. Without a substantial strengthening and acceleration of the HIV response, many countries will not achieve universal access to HIV prevention, treatment, care, and support by 2010 or begin to reverse the epidemic by 2015". (UNAIDS: Report on the Global AIDS Epidemic, 2008: 27).

1.1.2 Disease progression in the HIV/AIDS infected child

Childhood illnesses in the HIV-infected child can be avoided through vaccines, immunizations and good nutrition. Most routine vaccines are safe in children living with HIV and are strongly recommended, although 'live vaccines' (where a weakened or killed version of a virus is injected, so that the body builds up an immunity to it) are not generally considered to be safe. Opportunistic infections can be prevented using drugs such as cotrimoxazole: a relatively inexpensive antibiotic that has been proven to significantly reduce the rate of illness and death among HIV/AIDS infected children. Countless lives could be saved if drugs such as cotrimoxazole were made more widely available, but at the moment it is estimated that around four million children who could be benefiting from the drug are not receiving it (UNAIDS/WHO 2003, 40).

It is estimated that more than 90% of children living with HIV acquired the virus during pregnancy, birth or breastfeeding—forms of HIV transmission that can be prevented. A small fraction of HIV infections in children are caused by contaminated injections, the transfusion of infected blood or blood products, sexual abuse, sexual intercourse (although this is a significant mode of transmission among adolescents), or scarification (UNAIDS Report on the Global AIDS Epidemic: 2008: 37).

The clinical course of HIV/AIDS infection in children differs significantly from that in adults. The time lapse between primary infection and the onset of clinical staging of AIDS is usually much shorter in children, usually within the first year of life. HIV viral activity in children is also different from that in adults. In adults, high viral levels occur in the first few weeks post-infection and levels reach a steady state 4-6months after the primary infection. In children infected at birth there is a very rapid increase in the HIV viral level in the first weeks of life, which remains very high for the following one to two years, after which it gradually declines and reaches a steady state by the age of five or six years (Van Dyk, 2005: 46).

According to Marais et al. (2006: 52) the major cause of disease and death in HIV/AIDS infected children is increased susceptibility to infections, with severe respiratory infections consistently reported as the most common cause of death in this population. Children who are pre-, peri- or postnatally infected with HIV can be divided into two groups: rapid progressors and slow progressors. Children in the rapid progression group usually become symptomatic between 6-12 months of age, and will usually die within two years. Approximately 40-60% of HIV/AIDS infected children are rapid progressors, with high viral loads and low CD4 percentage (Van Dyk, 2005: 46).

The disease progression in children may also be accelerated by poor nutrition and illnesses such as gastroenteritis, which may be associated with poor socio-economic status (Van Dyk, 2005: 46). Providing good basic care with nutritional support, aggressive management of intercurrent infections and regular follow up have been shown to improve outcome even in the absence of highly active antiretroviral therapy (HAART). In addition, the timely initiation of HAART does prevent severe opportunistic infections associated with stage 4 disease, and may be seen as part of good basic care (Rabie et al., 2007b : 40).

"We must advocate and promote a comprehensive approach to HIV prevention: one that is rights-based, evidence informed and comprehensive in nature. That's the only honest approach, reflecting international best practice." Steve Kraus, UNICEF (2007: 13).

1.1.3 Highly Active Antiretroviral Therapy (HAART)

Highly active antiretroviral therapy (HAART) has dramatically reduced the morbidity and mortality of individuals living with HIV/AIDS, making it a manageable chronic disease (Rabie, Marais & Cotton, 2006: 54). However, it is estimated that less than 5% of Africa's infected children are receiving antiretroviral drug therapy (Marais et.al., 2007: 18). In August 2006 the World Health Organisation published new guidelines recommending that all developing countries should introduce "dual therapy" – whereby HIV-positive women are given the drug azidothymidine (AZT) as well as nevirapine – as a national policy. This approach had been employed in the Western Cape Province since 2004, where the rate of mother-to-child transmission was cut to 8%, compared to 22% in KwaZulu-Natal, where only nevirapine was used.

Although the government acknowledged that dual therapy should be introduced, a policy on implementing this improvement was not published until February 2008. Before this publication, doctors in most provinces were prohibited from providing AZT for preventing mother-to-child transmission (PMTCT). The protocol

described in the new South African guidelines – though much better than nevirapine alone – is still inferior to what the World Health Organisation recommends. PMTCT in South Africa is thus, to date, not on par with internationally recommended standards. Children continue to become infected before, during or after the birth process, when this could otherwise have been prevented. It is estimated that during 2006, around 64,000 children became infected through mother-to-child transmission in South Africa.

The best time to initiate antiretroviral therapy remains a subject of debate. WHO advises clinicians working in settings where CD4 testing is available to consider initiating treatment when a patient's CD4 count falls below 350 cells per mm^3 and to initiate treatment in all patients under 200 CD4 cells per mm^3. Where CD4 testing is unavailable, WHO recommends that antiretroviral therapy be started when patients exhibit clinical signs of advanced or severe immune suppression.

Currently, there are two sets of guidelines for indications to initiate HAART in South Africa compiled by the National Department of Health, one for the private and another for the public sector because of financial implications (Rabie et al., 2006: 56). Indications for the initiation of treatment in children with confirmed HIV infection are based on both immunological and clinical areas. Children infected with HIV/AIDS often present with non-specific conditions that are common in childhood, namely: prolonged fever, chronic diarrhoea and gastroenteritis, tuberculosis (pulmonary and extrapulmonary), lymphoid interstitial pneumonitis, anaemia, pallor, nose bleeds, persistent generalized lymphadenopathy (PGL), hepatomegaly, splenomegaly, extensive dermatitis, herpes infections, inflammation of the parotid gland, complicated chickenpox or measles, and pneumocystis carinii pneumonia (PCP) (Van Dyk, 2005: 46). Infections such as these tend to be more persistent and severe in HIV/AIDS infected children, where response to treatment is not always successful and there is a greater risk for suffering life-threatening complications. Another condition is failure to thrive (FTT), which, together with weight loss, may be due to the direct effect of the

virus on the child's gastrointestinal tract, secondary opportunistic infections or poor nutritional intake (Van Dyk, 2005: 45). Recurrent oral candidiasis may also further contribute to the poor feeding abilities that children with HIV/AIDS display. (See Appendix A for list of antiretroviral drugs to be used in the pediatric HIV/AIDS population within the South African context as taken from Rabie et al., 2006:6).

"We have the tools. We have the know-how. We just have to find a way to deliver for the hundreds of thousands of children in immediate need of treatment."
Mark Kline, UNICEF, (2007: 9).

1.1.4 Pediatric HIV/AIDS and the role of the Speech-Language Therapist and Audiologist

Children with HIV/AIDS fall into the established-risk category for communication delay (Rossetti, 2001: 3). This implies that HIV/AIDS infected children are expected to present with delays in acquiring communicative milestones to some degree. Children in the established-risk category may display developmental delay secondary to the main medical disorder/infection present (Rossetti, 2001: 4). Thus, children with HIV/AIDS display delays and/or disorders in several developmental areas due to the presence of the HIV/AIDS as an underlying cause. Developmental delays are the principal sequelae of HIV/AIDS infected children. Nearly all infected children require communication intervention services, particularly in the areas of phonology, language and social interaction (Screen & Lee-Wilkerson, 2007: 44). To identify neurodevelopmental delays as early as possible, children with HIV/AIDS require regular developmental assessment. Once delays have been identified and comprehensively assessed, children who are 3 years old and younger should be enrolled in an early intervention programme (Rossetti, 2001: 33). Children infected with HIV/AIDS across South Africa require communication intervention services in order to meet international

standards on service delivery to this vulnerable population, which could greatly improve their quality of life.

McFarland (2000) describes many of the symptoms regarding the nature and character of language compromises in the HIV/AIDS infected child. One of the characteristics of pediatric HIV/AIDS infection is central nervous system (CNS) dysfunction resulting from encephalopathy, which causes muscle tone abnormalities that may compromise oral-motor development or result in a loss of oral-motor developmental milestones (McFarland, 2000: 68). International research documents delays in receptive and expressive language aspects of linguistic functioning for HIV/AIDS infected children, where delays in expressive language development are reported more so than in receptive language development (Screen & Lee-Wilkerson, 2007: 48).

Muscular weakness, gait changes, ataxia as well as fine and gross motor deficits are reported to occur in the pediatric HIV/AIDS population. In the young child, compromised suck-breathe-swallow mechanisms, which have a profound effect on the development of sucking, eating, breathing, swallowing and articulation are a common difficulty experienced by infected children. Oropharyngeal lesions as well as oropharyngeal candidiasis may occur, which appears as greyish-white patches on the tongue, palate, cheeks or gums and may also be found in the esophagus. Severe candidiasis causes oral and esophageal pain that may interfere with eating and swallowing, as well as compromise respiratory support for speech (McFarland, 2000: 14; McNeilly, 2000; 71).

Common communication and voice disorders in HIV/AIDS infected children include weak, breathy voice that lacks pitch and variability, the latter contributing to abnormal prosody. Children with HIV/AIDS often produce vocal intensity levels that are too low (McNeilly, 2000: 69). Resonance problems in these children typically result from incomplete velopharyngeal closure that can produce a hypernasal vocal quality and audible nasal emission. Respiratory problems due

to opportunistic infection are more often than not the cause of such deviations (McNeilly, 2000; 68). The above-mentioned symptoms may occur secondary to the HIV/AIDS infection and may severely impact on the development of communicative abilities in the infected child (McFarland, 2000; 19).

The developmental delays in children with HIV/AIDS may also be affected by other biological and environmental factors, such as prenatal drug exposure, prematurity, low birth weight, and failure-to-thrive (FTT). Long-term hospitalization, chaotic family environments, and under-stimulation may also add to the noted patterns of delay. These factors perpetuate the social isolation that is often associated with HIV/AIDS (Rossetti, 2001: 33).

Approximately 60% of children in South Africa live in poverty, mostly in rural areas, making access to health care facilities difficult (Louw, 2004). Globally, as of 2005, an estimated 15.2 million children had lost one or both parents to AIDS. Some 80% of these children – about 12 million – live in sub-Saharan Africa (UNICEF, 2007: 16). Children orphaned by HIV/AIDS not only have to face the trauma of grieving the loss of a parent, but are often also faced with the likelihood of poverty due to the loss of a breadwinner as well as being separated from their siblings (Children in 2001, 2000; in Swanepoel, 2004: 13). It is estimated that, without change in behaviour and interventions such as antiretroviral therapy, there will be 3.1 million HIV/AIDS orphans below 18 years of age by 2015 in South Africa alone (Van Dyk, 2005: 269). Studies have shown that death rates amongst children orphaned by HIV/AIDS are 2.5 to 3.5 times higher than those of children who live with one or both parents (HIV Child Care Programme, 2000).

Due to the myriad of developmental, communication and social disorders that may affect the young child infected with HIV/AIDS, Early Communication Intervention (ECI) is essential to reduce deviant developmental patterns in the pediatric HIV/AIDS population (McNeilly, 2000: 70), and improve these children's quality of life. For these children, it is the Speech-Language Therapist and

Audiologist's responsibility to provide intervention in a culturally appropriate manner (Screen & Lee-Wilkerson, 2007; 48).

Speech-Language Therapists and Audiologists who provide assessment and intervention services to children infected with HIV/AIDS have done so without much clinical information available in the literature with regard to the specific delays and disorders typically identified in this population (Screen & Lee-Wilkerson, 2007: 39). Current service delivery is based on international findings and recommendations and thus professionals in the South African context are at an even greater disadvantage due to the lack of locally relevant research available on the communication profiles of HIV/AIDS infected children. The current challenge facing the Speech-Language Therapist and Audiologist in providing ECI services to the pediatric HIV/AIDS population is a lack of locally relevant, culturally appropriate literature describing the pediatric HIV/AIDS infected population in South Africa. Although extensive international literature exists regarding the description of the communication characteristics of children with HIV/AIDS (such as Speigel and Bonwit, 2001; McNeilly 2000; Davis-McFarland 2000), limited research has been conducted on young children living with HIV/AIDS within the South African context.

With such a vast number of South Africa's children infected with HIV/AIDS to date, health care professionals should prioritize providing appropriate services to this vulnerable population. With the introduction of a compulsory public service community year by the Department of Health for health care professionals in South Africa, newly qualified professionals are required to provide services to populations infected and affected by the HIV/AIDS pandemic. Past research has highlighted that Speech-Language Therapists and Audiologists working at state facilities in Gauteng are indeed providing assessment and intervention services to children infected with HIV/AIDS. The majority of these professionals stated that 25-75% of their total pediatric caseload consisted of HIV/AIDS infected children (Hattam, 2005: 18), with a large percentage of these children being

between the ages of 0 to 5 years (Hattam, 2005: 19). Bam et al., (2003: 44) describe that all the HIV/AIDS infected children from care centers in Gauteng that were assessed in their study, were found to present with general developmental delay, with particular impediment in communication development. The stark reality is that these vulnerable children are indeed being assessed and treated by Speech-Language Therapists and Audiologists, but without a research-based protocol in existence to guide service delivery. Such services are based on international literature which may neither be appropriate nor applicable to the South African context.

1.2 STATEMENT OF THE PROBLEM, RESEARCH QUESTION AND RATIONALE FOR THE STUDY

Based on the argument above, the following statement of the problem, research question and rationale for conducting the study were formulated:

The current situation that exists within the South African context with regard to communication intervention services to the pediatric HIV/AIDS population can be summarised as follows:

- A lack of locally relevant literature describing the pediatric HIV/AIDS population in South Africa exists.
- Speech-Language Therapists and Audiologists working with children with HIV/AIDS have no researched-based protocols to guide the assessment and intervention process.
- Service delivery to the pediatric HIV/AIDS population cannot meet international standards of best practice. According to Rossetti (2001: 265) most promising practices are referred to as exemplary and innovative developments, generated by applied research efforts and designed to validate effective strategies of intervention. Thus, locally relevant research as an ongoing practice is required in order to ensure the pediatric

HIV/AIDS population receives the exemplary standard of service they are entitled to.

Children infected with HIV/AIDS present with a myriad of disorders that may impact on the appropriate development of speech and language skills. There is an urgent need for the Speech-Language Therapist and Audiologist to be included as a key member of the professional team involved in the assessment and treatment of this vulnerable population. The current study attempted to describe the above-mentioned medical characteristics of the target HIV/AIDS infected children, therefore adding to the description of the local pediatric HIV/AIDS population. Such information will serve as background information to the development of research based assessment and intervention protocols for pediatric HIV/AIDS communication intervention in the future.

The preceding challenges highlight the necessity for the formulation of a comprehensive service delivery guideline for working with the pediatric HIV/AIDS population in South Africa. In order to assist in the development of such guidelines, the medical and developmental characteristics of HIV/AIDS infected children need to be determined, as this may have a significant influence on the child's general and communicative development. The following research question is formulated: *What are the medical and developmental characteristics of a group of HIV/AIDS infected children aged 0 – 5 years in a large regional hospital in Gauteng?*

The current study will address the dearth of locally relevant research by describing the characteristics of children between the ages of 0-5 years infected with HIV/AIDS. This will address the need for information on the general and communicative development of this population within the South African context (Hattam, 2005). The communication profiles of such children in ECI programmes in health care settings could be compiled by Speech-Language Therapists and Audiologists, in order to enable the expansion of contextually relevant database

of communication disorders in South Africa. Such profiles could serve as a useful tool for the development of uniform guidelines for the assessment and intervention of this vulnerable population within the health care context. Such guidelines would consider several aspects such as the child's medical status, presence of opportunistic infections, ARV drug regimen, social implications, as well as communicative and other important developmental milestones. The current study will attempt to address the scarcity of locally relevant data on the pediatric HIV/AIDS population.

The aim of the current study is therefore to describe the characteristics of a group of children between the ages of 0–5 years infected with HIV/AIDS at a large regional hospital in Gauteng.

"AIDS is redefining the very meaning of childhood for millions, depriving children of many of their human rights-of the care, love and affection of their parents; of their teachers and of other role models; of education and options for the future; of protection against exploitation and abuse. The world must act now, urgently and decisively, to ensure that the next generation of children is AIDS free" - UNICEF, A call to Action: Children, the missing face of AIDS. Children and AIDS: A Stocktaking Report (2007: 2).

1.3 CLARIFICATION OF TERMINOLOGY

The following frequently used terms within the context of this study are clarified below:

Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome (HIV/AIDS)

Human Immunodeficiency Virus (HIV) is a complex retrovirus responsible for compromising the infected individual's immune system by directly attacking the

fighter (CD4) cells. Acquired Immunodeficiency Syndrome (AIDS) is a syndrome of opportunistic infections, diseases and certain cancers due to a compromised immune system due to HIV/AIDS infection (Van Dyk, 2005: 4). The information highlighted in this study was of children infected with HIV/AIDS between the ages of 0-5 years.

CD4 count

The single most useful clinical assessment in an immuno-compromised individual is determining the CD4 lymphocyte count, which further predicts the risk of opportunistic infections in HIV/AIDS infected individuals (Van Dyk, 2005: 71). CD4 percentage values allow clinicians to quantify the child's stage of infection and thus determine whether treatment initiation is possible.

Table 1: New (2005) WHO Immunological staging of HIV/AIDS in infants and children

IMMUNE STATUS	AGE		
	< 1 year	1-6 years	> 6 years
No Suppression	>35%	>25%	>500 cells
Mild Suppression	25-25%	20-24%	350-499 cells
Advanced Suppression	20-24%	15-19%	200-349 cells
Severe Suppression	<20%	<15%	< 200 cells

Stages of HIV infection

The World Health Organization (WHO) published a new four stage pediatric clinical staging system in 2005. The new WHO clinical staging system takes into consideration frequently observed problems facing clinicians in the developing world. The staging system differentiates conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations,

from those where confirmatory testing is required. The creation of four stages provides the additional advantage of synchronizing pediatric and adult staging systems, resulting in less confusion for healthcare workers and allowing an easier transition from pediatric to adult care (Rabie et.al., 2006: 56). There is a need for locally relevant information regarding the correlation between the stage of HIV/AIDS infection and the infected child's level of development. This information is important in order to ensure that intervention to HIV/AIDS infected children is able to fulfill the specific need that a particular child requires. Children presenting at different stages of infection will require different assessment and intervention techniques.

HIV prevalence

National estimates of HIV/AIDS prevalence in countries with HIV/AIDS epidemics are based on data about pregnant women tested for HIV at antenatal clinics (UNAIDS, 2003:6). This assumes that HIV/AIDS prevalence among pregnant women is similar to that of the rest of the adult population. A number of African studies have been conducted comparing prevalence from antenatal clinics and those from voluntary testing centers, which confirmed this assumption. Thus, data from antenatal clinics are especially useful for assessing HIV/AIDS trends, and national surveys help to clarify the nature of the epidemic (Van Dyk, 2005: 6). Pediatric HIV/AIDS infection rates in South Africa are thus the driving force behind the need for locally relevant research.

Table 2: WHO Clinical staging of HIV/AIDS in infants and children (2005)

Stage I
• Asymptomatic
• Persistent Generalized Lymphadenopathy (PGL)

Stage II
• Hepatosplenomegaly
• Papular pruritic eruptions, Seborrhoeic dermatitis
• Extensive human papilloma virus infection, Molluscum contagiosum
• Herpes zoster
• Fungal nail infections
• Parotid enlargement
• Recurrent oral ulcerations, Lineal gingival erythema (LGE), Angular cheilitis
• Recurrent or chronic RTI's (otitis media, otorrhoea, sinusitis)

Stage III
Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations
• Moderate unexplained malnutrition (between the 3rd percentile and 60% of expected weight)
• Unexplained persistent diarrhoea (14 days or more)
• Unexplained persistent fever (intermittent or constant, for longer than one month)
• Oral candidiasis (outside neonatal period)
• Oral hairy leukoplakia, Acute necrotizing ulcerative gingivitis/periodontitis
• Severe recurrent presumed bacterial pneumonia
• Pulmonary TB
Conditions where confirmatory diagnostic testing is necessary
• Chronic HIV-associated lung disease, including brochiectasis
• Lymphoid interstitial pneumonitis (LIP)
• Unexplained anaemia (<8g/dl), and or neutropenia (<1000/mm3) and or thrombocytopenia (<50 000/ mm3) for more than one month

Stage IV
Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations
• Unexplained severe wasting or severe malnutrition
• Pneumocystis pneumonia
• Extrapulmonary TB
• Oesophageal candidiasis
• Recurrent severe presumed bacterial infections (excluding pneumonia)
• Chronic herpes simplex infection (orolabial or cutaneous of more than 1 month duration)
• Kaposi's sarcoma
• CNS toxoplasmosis (outside the neonatal period)
• HIV-associated encephalopathy
Conditions where confirmatory diagnostic testing is necessary
• CMV infection (CMV retinitis or infection of organs other than liver, spleen or lymph nodes; onset at age one month or more)
• Extrapulmonary cryptococcosis including meningitis
• Any disseminated endemic mycosis
• Cryptosporidiosis, Isosporiasis
• Disseminated non-tuberculous mycobacteria infection
• Candida of trachea, bronchi or lungs
• Visceral herpes simplex infection
• Acquired HIV-associated rectal fistula
• Cerebral or B cell non-Hodgkin lymphoma
• Progressive multifocal leukoencephalopathy (PML)
• HIV-associated cardiomyopathy or nephropathy

HIV Testing Procedures

HIV/AIDS infection can be objectively diagnosed by the use of an HIV antibody or viral test. The most commonly used test is the ELIZA HIV antibody test, which has high sensitivity and reliability and has very few false negatives. In South Africa, with its high HIV prevalence, two positive HIV ELIZA tests are considered adequate evidence of HIV infection. The PCR (polymerase chain reaction) technique is another form of testing. It is the most valuable tool for directly detecting the presence of the HI virus (Van Dyk, 2005:67). This study thus focuses only on those children who have already been diagnosed as HIV-positive through one of the above-mentioned test procedures and are not based on clinical presentation alone.

Antiretroviral Therapy (ART) and Highly Active Antiretroviral Therapy (HAART)

Antiretroviral Treatment (ART) was introduced and approved for use in 1987, with the first drug AZT (ziduvudine) currently in use. The principle underlying HAART (Highly Active Antiretroviral Therapy) is that Antiretroviral (ARV) drugs from different classes are combined to achieve maximal and long-term suppression of viral replication, as it reduces the risk of random drug resistance (Rabie et al., 2006: 54). Achieving and maintaining a significant reduction in the viral load, preferably down to undetectable levels, is the main therapeutic aim. This study aimed to quantify the percentage of HIV/AIDS infected children between the ages of 0-5 years that were/were not receiving HAART treatment from the outreach clinic.

Viral Load

The HIV RNA viral load test (measured with a quantitative PCR technique) measures the number of viral particles (virus copies) per ml of blood. An increasing viral load is usually an indication of active HIV disease and the rapid development of immune deficiency (Van Dyk, 2005: 72). Knowing the viral load is

very useful for assessing the effect of antiretroviral therapy (ART) as well as for the ongoing monitoring of ART. A rising viral load in an individual is an indication that the ART is not effective.

Orphan

There are various definitions of what makes a child an orphan, and local ones should be used. UNAIDS (2004) defines an orphan as a child under the age of 18 who has lost one parent to death. The 2003 draft of the South African Children's Bill identifies an orphan as a child who has no surviving parent caring for him or her (www.info.gov.za). The primary caregivers of children targeted in the study were recorded during the data collection process.

Prelinguistic Communication Skills

There are a number of prelinguistic components to communication before the emergence of a child's first purposeful word. Interaction, attachment, play, pragmatics and gesture are all important aspects in the child's development of age-appropriate communication skills (Rossetti, 2001: 215). The term prelinguistic communication implies the child's intentional communication behaviours which do not involve spoken language. The relationship between delayed prelinguistic communication development and linguistic communication development is well established. Targeting prelinguistic development early in the intervention process will result in elevated linguistic development (Rossetti, 2001: 215). This is thus an important component in the Early Communication Intervention process.

Delayed Communication Development

Delayed communication development is the most common symptom of developmental disability in children under three years of age, affecting

approximately 5-10% of that population (Rossetti, 2001: 1). For children with established risk factors there is an increased incidence of communication delay. Generally communication skills provide the highest predictive correlation with later intelligence attainment and school performance. Children with HIV/AIDS fall into the established-risk category, meaning that they display developmental delay secondary to the factor that places them in the established-risk category initially (Rossetti, 2001: 4). This was assessed during the data collection process in order to provide necessary information regarding the general development of the HIV/AIDS infected children.

Multidisciplinary Team

HIV/AIDS affects all areas of development, from psychosocial, emotional, gross and fine motor, to cognitive, linguistic, feeding and physical health (McFarland, 2000). Thus, due to the extensive impact that the virus has on the infected child, a team approach to assessment and intervention of this vulnerable population would be optimal. Hegde and Davis (1992) believe that in order to deliver the best care for patients, Speech-Language Therapists and Audiologists must work alongside other professionals, such as Occupational Therapists, Physiotherapists, Nurses and Physicians. Service delivery should be aimed at meeting each individual need of the child and his/her family (Rossetti, 2001; 113). The multidisciplinary approach represents a parallel model of service delivery. The professionals involved may be determined by a team leader, which is generally a Physician if the services are hospital-based (Rossetti, 2001: 117). Exploring the nature of the teamwork currently being enforced within HIV/AIDS clinics in South Africa will serve as valuable information for the Speech-Language Therapist and Audiologist, as presently the trend for team intervention is unclear when working with the pediatric HIV/AIDS population within South Africa.

Early Communication Intervention (ECI)

The term Early Intervention refers to services given to very young children with special needs, beginning as early as possible, preferably from birth. Early Communication Intervention is the provision of intervention to children at-risk or with established risk for abnormal or delayed communication development. Due to a myriad of communication disorders that may affect the young child infected with HIV/AIDS, ECI is essential to reduce deviant developmental patterns in the pediatric HIV/AIDS population (McNeilly, 2000). To identify neurodevelopmental delays as early as possible, children with HIV/AIDS infection need developmental assessment at regular intervals. The suggested schedule for assessment according to international literature includes developmental evaluation by two months of age, with follow ups at least every six months for the first two years of life. After two years of age, children should be reevaluated at least yearly if they remain asymptomatic (Rossetti, 2001: 33).

1.4 OUTLINE OF CHAPTERS

The main aim of this study is to describe the medical and developmental characteristics of HIV/AIDS infected children between the ages of 0-5 years at a large regional hospital in Gauteng. The following table delineates the division of chapters in this research study and provides a short summary of the contents of each chapter.

Table 3: Division and content of chapters

Chapter 1	Introduction, problem statement and rationale	Chapter one provides an introduction to pediatric HIV/AIDS in South Africa; disease progression in the HIV-positive child; HAART and HIV/AIDS and the Speech-Language Therapist and Audiologist. The statement of the problem, research question and the rationale for the study are made against this background. Definitions of terms related to this study are given.
Chapter 2	Review of current literature regarding pediatric HIV/AIDS and Communication Disorders	This chapter reviews local and international literature available on pediatric HIV/AIDS and Communication Disorders and relates controversies, benefits and limitations in this field.
Chapter 3	Methodology	Chapter three describes and outlines the following relative to the study: • Research aims • Research design and method • Research procedures • Validity and reliability • Ethical issues
Chapter 4	Results and discussion	The results obtained are presented and discussed according to the objectives stipulated in Chapter 3. Interpretation, value and meaning according to the literature are discussed.
Chapter 5	Conclusions and implications	Chapter five outlines significant findings and describes the clinical implications of this study. Future research recommendations are provided and a conclusion regarding the study is formulated.

1.5 CONCLUSION

Due to the magnitude of the HIV/AIDS crisis in South Africa, there is a dire need for Speech-Language Therapists and Audiologists to provide much needed ECI services to infected children and their families. HIV/AIDS affects all areas of development in the infected child, with the development of receptive and expressive language skills significantly affected (McFarland, 2000; McNeilly, 2000). Previous research has shown that Speech-Language Therapists and Audiologists in South Africa are indeed providing assessment and intervention services to HIV/AIDS infected children (Hattam, 2005). With a dearth of locally relevant literature to guide service delivery in clinical settings, it is vital that research within the South African setting be conducted. This will assist in the future development of a profile of the local pediatric HIV/AIDS population, with the intention of the development of a national assessment and intervention program that can be implemented by all clinicians working with this vulnerable population. The purpose of this research study is thus to provide much needed clinical information regarding the local pediatric HIV/AIDS population.

1.6 SUMMARY

This chapter highlighted the severity of the HIV/AIDS epidemic in South Africa, as well as the impact of HIV/AIDS on the general and communicative development of the infected child and toddler. The need for locally relevant research regarding the pediatric HIV/AIDS population in South Africa, which would assist in the formulation of a medical and developmental communication profile of this vulnerable population, was argued. A statement of the problem was described and a research question was formulated, as well as a rationale for the study explained. A list of terminology which is to be used in the study was presented and described. Lastly, an outline of the chapters included in the dissertation was presented.

CHAPTER 2

PEDIATRIC HIV/AIDS WITHIN THE SOUTH AFRICAN CONTEXT

Aim: This chapter reviews the existing evidence and literature surrounding pediatric HIV/AIDS and communication disorders, as well as the need for Early Communication Intervention (ECI) with the pediatric HIV/AIDS population within the South African context.

2.1 INTRODUCTION

HIV/AIDS remains a global health problem of unprecedented dimensions. Unknown 27 years ago, HIV has already caused an estimated 25 million deaths worldwide and has generated profound demographic changes in the most heavily affected countries (UNAIDS: 2008 Report on the Global AIDS Epidemic: 30). Of all the disparaging figures and statistics that this epidemic presents, the most bleak is that two-thirds of all those living with HIV/AIDS in the world are in Sub-Saharan Africa and that 90% of these individuals are from developing countries (Walker, Reid & Cornell, 2004: 7). Children, however, bear the brunt of the disease.

HIV/AIDS has altered the way children around the world are growing up. Not only are children plagued by the direct impact of the virus on their own health and development, but many of those infected and affected by HIV/AIDS are faced with social issues of poverty, neglect and the despair associated with the disease. The virus progresses rapidly in children, with an estimated one third of children dying by the time they reach their first birthday and half by their second birthday (Stocktaking Report, UNICEF, 2007: 9). UNAIDS and WHO estimates show that in 2007 alone some 370,000 young people under the age of 15 were

newly infected (approximately 1000 per day) and 270,000 died, the majority under the age of 5. According to the WHO Country Health System Fact Sheet for South Africa (2006: 3), between 2000 and 2003, HIV/AIDS constituted 57% of the total distribution of causes of death of children below five years of age.

Mother-to-child transmission (MTCT) of HIV/AIDS, also referred to as vertical transmission, is one of the major causes of HIV transmission in the pediatric population. Children are the backbone of society and hold the key to a country's future. Prevention of Mother-to-Child transmission of HIV/AIDS (PMTCT) is the stepping stone to ensuring an HIV-free generation of children The WHO (2008) estimates show that MTCT accounts for 90% of HIV infection in children.

"..those figures starkly mirror the more general disparities in our world between those who control and those who do not; between those who have taken possession and those who have been dispossessed; those who have, and are surrounded, and have well attended, and those whose circumstances are the opposite. AIDS therefore mirrors, but it also accentuates, the disparities of our world" - Mr. Justice Edwin Cameron, in Walker, Reid and Cornell (2004: 7-8).

2.2 MOTHER-TO-CHILD TRANSMISSION

The risk of becoming infected with HIV during unprotected vaginal intercourse is between two to four times higher for women than it is for men (WHO, 2000: 22). Apart from their biological vulnerability, women are more vulnerable in those societies in which they are seen as having lower social status than that of men (Van Dyk, 2004: 25). This profoundly affects a woman's ability to influence safe sex practices both in monogamous and open relationships.

HIV/AIDS infected women have become central to a large amount of research due to the fact that they are the primary source of infection for children. Many of these women are only diagnosed with HIV/AIDS very late into their pregnancies or after childbirth (Campbell, 1990: 47). A study conducted by Joseph and Bhatti

(2004) showed that most HIV/AIDS infected woman were exceptionally fearful of delivering an HIV-positive child, and had extreme feelings of guilt for being the direct cause of their child's HIV infection. Broun (1999: 122) quotes one of her clients as saying *"A mother should be able to protect her child. Not only can I not do that, I have killed him simply by bringing him into the world".* Many HIV/AIDS infected women thus not only have to cope with the emotional aspects of their own illness, but also with that of their child.

MTCT is the major route of HIV infection in infants and children. MTCT can occur before, during or after delivery. In the absence of active intervention and with routine breast- and/or mixed feeding transmission rates are estimated to range from 15-34%. Under these circumstances an estimated 14-34% of transmission occurs in the pre-partum period, 65% intra-partum and 12% late post-partum (Rabie et al., 2006:35). MTCT is also more likely if the mother has advanced symptomatic disease with a low CD4 count and/or symptoms of AIDS (Van Dyk, 2005: 31). A study conducted at the Chris Hani Baragwanath Hospital in Soweto found that 1 in 3 babies born to mothers diagnosed HIV/AIDS infected dies within twelve months, compared to 1 in 59 babies born to HIV-negative mothers (www.suntimes.co.za/2000/07/09).

HIV/AIDS prevalence has been consistently monitored in South Africa through antenatal HIV/AIDS and syphilis prevalence surveys, which have been conducted since 1990. The trends suggest a tendency towards stabilization of the prevalence among pregnant women who access antenatal care services from the public health sector. This has been observed since 2004. Access to services for preventing mother-to-child transmission in low- and middle-income countries continued to expand in 2008. Twenty one percent of pregnant women received an HIV test in 2008, up from 15% in 2007, and 45% [37–57%] of pregnant women living with HIV/AIDS received antiretroviral drugs to prevent mother-to-child transmission (UNAIDS, 2009: 5). This is a particularly encouraging trend, a decline from 16% in 2004 to 13.5% in 2006 among women younger than 20

years of age as well as a decline in prevalence in those between 20 and 24 years of age (from 30.6% in 2005 to 28.0% in 2006). This could be the beginning of the long-awaited downward trend of HIV/AIDS prevalence among pregnant youth in South Africa. At least two more survey rounds with the same 2006 expanded sampling methodology will be necessary to draw a conclusion on the downward HIV/AIDS trend among pregnant women (Declaration of Commitment on HIV/AIDS, South Africa, 2007: 4). HIV/AIDS prevalence varies considerably throughout South Africa. Some provinces are more severely affected than others with the highest antenatal prevalence in 2006 being in KwaZulu-Natal (39.1%) and the lowest in the Western Cape (15.1%) (www.statsa.gov.za).

Effective methods of prevention of mother-to-child transmission (PMTCT) have been well demonstrated both in resource-rich as well as poor countries. Combination AZT and nevirapine has been demonstrated to be highly effective in PMTCT in non-breastfeeding women (Meyers et al., 2005: 9). The 2006 WHO guidelines recommend clinical and immunological screening of all pregnant women who test positive for HIV. Pregnant women living with HIV/AIDS found eligible to receive antiretroviral therapy should receive it immediately. Initiating antiretroviral therapy among pregnant women who need it not only improves their own health but also significantly reduces HIV transmission to their children. Securing the health of mothers improves children's well-being and survival. For pregnant women with HIV/AIDS who do not yet require antiretroviral therapy, the WHO guidelines recommend the use of combination antiretroviral prophylactic regimens to prevent the mother-to-child transmission of HIV. The recommended regimen by WHO is based around zidovudine (from 28 weeks of pregnancy or as soon as possible thereafter) plus single-dose nevirapine and lamivudine during labour (refer to Appendix A). A 7 day regimen of zidovudine and lamivudine is recommended for the mother, and a single dose of nevirapine as well as 1 or 4 weeks of zidovudine for the child (UNAIDS, 2009: 103).

HIV/AIDS disease in children often leads to multiple nutritional deficiencies due to decreased intake, impaired absorption and increased nutrient requirements HIV-infected women should be counseled during pregnancy about child feeding choices so that they may make an informed decision regarding which child feeding practice to implement once their baby is born. HIV/AIDS may be transmitted by breastmilk and can give an additional 5–16% risk of infection after birth, depending on the pattern and duration of breastfeeding. Approximately 20-30% of children who become infected with HIV through MTCT acquire the virus through breastfeeding (Van Dyk, 2005: 32). Breastmilk does, however, provide the child with all the required nutrients as well protecting the child against common infections. Breastmilk also stabilises the intestinal mucosa. This prevents transmission of HIV to the child. However, this protection is reduced if any other substance, even water, is fed to the child during this phase of exclusive breastfeeding (Meyers et al., 2005: 26).

Exclusive replacement feeding (exclusive formula feeding) may be difficult in many places, particularly where water, fuel or cleaning utensils and materials are scarce or where the family expects the mother to breastfeed. Exclusive formula feeding under such circumstances subjects the child to the risk of developing potentially fatal gastroenteritis and other infections. Where exclusive replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), avoidance of all breastfeeding is recommended. When all these conditions cannot be met, exclusive breastfeeding for the first few months is recommended. Breastfeeding should stop at 6 months or earlier if these conditions can be met (Meyers et al., 2005: 27). Mother-to-child prevention of HIV/AIDS may also be prevented if expressed breast milk is pasteurised. A study conducted at Kalafong Hospital showed that expressed breast milk from HIV/AIDS infected mothers heated to 62.5° for 30 minutes successfully rendered the HI virus inactive (Prevention of Mother-to-Child Transmission, 2000). The feasibility of this process being utilized in developing countries is unclear, as many homes may

not have proper access to electricity and other tools necessary for this procedure to be implemented sufficiently.

It is essential to deliver more effective antiretroviral regimens to women – not only to prevent transmission to their children but also to preserve their own health, thereby improving the well-being and survival of millions of children by safeguarding the lives of their mothers living with HIV/AIDS (UNICEF, 2009: 7). It is also only through these means that the alarming rate of HIV/AIDS can begin to be managed.

2.3 CHILDREN ORPHANED BY HIV/AIDS

Mid-year population estimates for 2009 in South Africa show that there are 1,91 million children orphaned by HIV/AIDS (www.statssa.gov.za). More and more children are living in homes and communities ravaged by the effects of HIV/AIDS. The extended family system is more often than not overstretched in such communities, making it extremely difficult to appropriately care for its orphans (Van Dyk, 2005: 269). Much of the burden of caring for children orphaned as a result of HIV/AIDS becomes the responsibility of the elderly, especially grandmothers who step in when one or both parents have died, many with limited capacity for taking on parenting responsibilities. Surveys in rural South Africa have detected an increase in the number of households headed by individuals over 50 (UNAIDS, 2008: 164). Many orphans will become street children or will form child-headed households to avoid being separated from siblings (Mengel, 2003: 4).

The HIV/AIDS pandemic poses major threats to the socio-economic and psychological welfare of children infected with and affected by HIV/AIDS. The pandemic can adversely affect the stability of households, children's access to education and healthcare, nutrition, and increase vulnerability to infection (Deacon & Stephney, 2007: 1). The term 'AIDS orphan' refers specifically to that

category of children who are orphaned by parental AIDS. An AIDS orphan is thus defined by UNAIDS as 'a child who has at least one parent dead from AIDS' and a dual orphan as 'a child whose mother and father have both died, at least one due to AIDS' (UNAIDS, 2008: 13). Two-thirds of the 16.3 million children in South Africa live below the poverty line and a fifth of children do not live with their mothers. By 2015 it is estimated that almost 12% of children living in South Africa will be orphaned due to HIV/AIDS (Walker et al., 2004: 58).

The policy response to children orphaned and made vulnerable by HIV/AIDS has significantly expanded since 1991, when UNICEF hosted the first international meeting on the issue. From the early focus on "AIDS orphans", programme responses have increasingly recognized the many different ways that HIV/AIDS may increase the vulnerability of children, including parental illness and loss of household income. South Africa has reached more than one million orphans and vulnerable children with support services, mostly in the form of child support grants (UNAIDS, 2008: 166). This may provide much needed monetary relief to families and caregivers who have taken over as primary caregivers to these orphans.

HIV/AIDS orphans as well as children living with parents/caregivers with HIV/AIDS are at increased risk for developmental delay. In a study by Van Rie, Mapuala and Dow (2008), HIV/AIDS infected children who presented for care at a pediatric HIV/AIDS care and treatment program in Kinshasa performed poorly compared to HIV/AIDS affected and control children on assessments of motor, mental, and language development. HIV/AIDS infected children 18 to 36 months of age demonstrated significantly higher rates of delay in language expression and language comprehension. Language expression but not language comprehension was delayed in the HIV/AIDS affected children (Van Rie et al., 2008: 127). HIV/AIDS orphans and children who were living with parents who had HIV/AIDS were also at increased risk for general developmental delay. Compared with the control group, they achieved lower scores for motor

development and tended to have lower scores for cognitive development. These findings suggest that HIV/AIDS affects the neurodevelopment of children through both a direct pathway (the presence of HIV in the CNS) and its effect on the child's living conditions. Children affected by HIV/AIDS in the family that were assessed in this study presented with higher frequencies of poor motor, mental, and language expression development (Van Rie et al.,2008: 127). The data suggest that HIV/AIDS in the family may lead to poverty, poor health, poor living conditions, and fewer positive parent–child interactions that are conducive to a child's neurodevelopment. The high rate of developmental delay in HIV/AIDS infected and HIV/AIDS affected children in this study highlights the need for screening for and prevention of neurodevelopmental delay at an early age. This calls for access to early intervention services, nutritional as well as care programs for these vulnerable children (Van Rie et al., 2008: 128).

Bam, Kritzinger and Louw (2003) explored the communication development of a group of HIV/AIDS infected children at two pediatric care centers in Gauteng. All the children that formed part of the study presented with general developmental delay, particularly with regard to communication development. Abnormal middle ear functioning highlighting probable recurrent otitis media, illness and/or excessive ear wax were present in all the children. The delayed communication development can be attributed both to the presence of HIV/AIDS infection and opportunistic infections and/or HIV/AIDS associated disorders, as well as to the likely non-optimal interaction and stimulation displayed by the children's caregivers within the care centers (Bam et al., 2003, 35).

It is essential for future studies to continue to investigate the long-term consequences of HIV/AIDS, alone and in combination with the several environmental stressors that affected and infected children are exposed to. Such research in the locally relevant South African context would provide invaluable information in this regard. With an improved understanding of the communication development of HIV/AIDS infected and affected children, the Speech-Language

Therapist and Audiologist will be better equipped to provide the necessary intervention services to both populations of children. With improved understanding of the risks inherent in HIV/AIDS-related illness as well as effective medical, educational, and psychosocial interventions, children and their families may be assured improved health and quality of life in the future (Smith et al., 2006: 861).

2.4 CLINICAL MANIFESTATIONS OF PEDIATRIC HIV/AIDS AND HIGHLY ACTIVE ANTIRETROVIRAL THERAPY (HAART)

Children with HIV/AIDS infection often present with non-specific conditions that are common in childhood (Van Dyk, 2001: 45). The disease progresses with opportunistic infections such as herpes simplex, candida and gastroenteritis (Rabie et al., 2007) becoming apparent and with a downward course much more rapid than in adults. This rapid progression of the disease is largely determined by the immature immune system. There are additional factors that may contribute to the rapid progression, such as the maternal viral load at birth. In 2008, 38% of the 730 000 children estimated to need antiretroviral therapy in low- and middle-income countries had access. The number of health facilities providing antiretroviral therapy to children increased by about 80% between 2007 and 2008 and 39% more children were receiving antiretroviral therapy. About 8% of children born to pregnant women with HIV initiated co-trimoxazole by two months of age, more than twice the percentage reported in 2007 (UNAIDS, 2009: 6). This is a positive indication that South Africa has begun to manage the devastating effects that HIV/AIDS has on the pediatric population.

The current South African guidelines by the Department of Health for 2007 state that any child with severe immune suppression should be considered for treatment (CD4% < 20% if < 18 months, or 15% if > 18 months of age). Alternatively, any child with WHO Stage III or IV qualifies for treatment (Meyers et.al., section 2, 2005: 7). Without antiretroviral treatment, most infected children

will begin to show signs of the disease by six months of age (Meyers et al., 2005, 2: 9), with HIV encephalopathy being the most common clinical manifestation of HIV in children and may be a presenting feature (Rabie et al., 2007: 19). According to the American Academy of Neurology AIDS Task Force, failure to develop or the loss of previously developed intellectual functions such as receptive and expressive language is one of the indications for the diagnosis of encephalopathy in children (Rabie et al., 2007: 29). The diagnosis is primarily made on clinical grounds. Regular measurement and charting of the head circumference in the first three years of life and careful assessment of the neurodevelopmental progress is an important part of the management of all HIV/AIDS infected children. The role of the Speech-Language Therapist and Audiologist therefore becomes extremely important. The assessment of such a child's communication development is necessary as part of a multidisciplinary team responsible for the diagnosis in the clinical manifestations of HIV/AIDS infection. This is a significant opportunity for the Speech-Language Therapist and Audiologist to assess the communication development of the HIV/AIDS infected child and begin the process of provide ECI services to the child and his/her family and/or caregivers.

Other significant features such as the presence of feeding difficulty, especially nasopharyngeal incoordination, may be an important pointer to neurological illness and may lead to other co-morbidities such as malnutrition and/or aspiration with chronic lung disease. A breakdown in the integrity of the CNS due to encephalopathy may contribute to muscle tone abnormalities resulting in poor oral-motor development and subsequent feeding difficulties, (Davis-McFarland, 2000: 25) making the HIV/AIDS population one that requires the specialized services of the Speech-Language Therapist and Audiologist. HIV related encephalopathy is a WHO Stage IV condition, mandating highly active antiretroviral therapy regardless of the CD4 count or percent (Rabie et al., 2007: 19). Motor, behavioural and cognitive areas of dysfunction may occur either in isolation or collectively. Expressive language deficit, learning difficulties, attention

deficit disorder, anxiety, spastic diparesis and developmental delays are all features associated with HIV encephalopathy (Rabie et a, 2007: 20), warranting the expert services of the Speech-Language Therapist and Audiologist as well as other allied health professionals.

Lymphoid Interstitial Pneumonia (LIP) represents 25 - 40% of the pulmonary disease burden in HIV/AIDS infected children. The natural history of LIP seems variable and is not fully understood. It was previously seen as a relatively benign manifestation of HIV/AIDS, but it may have severe consequences. Current WHO guidelines recommend a CD4-based approach, but it is the belief of several professionals that children with LIP together with recurrent pneumonia and/or signs of progressive illness should receive HAART regardless of their CD4 count (Rabie et al., 2007: 19). Similarly, bronchiectasis represents an abnormal and irreversible dilatation of the airways that disrupts normal airway functioning and usually results from severe and/or recurrent infections. It is a common problem and occurs in up to 16% of children with HIV/AIDS infection. Infected children are vulnerable to develop bronchiectasis for a number of reasons. These children may suffer from recurrent and/or severe pulmonary infections, as well as compromised local defense mechanisms (Rabie et al., 2007: 22). The presence of respiratory infections may adversely affect the HIV/AIDS infected child's ability to feed adequately, as well as influence speech production abilities, further contributing to the disordered communication profile of the HIV/AIDS infected child.

Failure to thrive (FTT) and poor weight gain in the HIV/AIDS infected child may have several causes (Van Dyk, 2005: 45). Poor food security, poor nutrition choices and infections of the gastrointestinal tract or chronic diseases such as TB may all contribute (Rabie et al., 2007: 23). Useful information regarding the diet, swallowing disorders, other intestinal complaints (diarrhoea and abdominal pain), and symptoms of systemic disease can be obtained from a comprehensive case history from the child's caregiver. If significant growth failure persists

despite regular deworming, the provision of adequate food and additional supplements as needed and after chronic diseases such as TB have been excluded, then HAART initiation is considered (Rabie et al., 2007: 24). The presence of FTT in the overall clinical presentation of the HIV/AIDS infected child may further impact the child's overall communication development, and it is essential that the Speech-Language Therapist and Audiologist be aware of the presence of FTT in this population.

The principle underlying HAART is that antiretroviral drugs (ARV's) from different classes are combined to achieve maximal and long term suppression of viral replication, as it reduces the risk of random drug resistance. Achieving and maintaining a significant reduction in the viral load, preferably down to undetectable levels, is the main therapeutic aim. A significantly reduced viral load is required for immune recovery and clinical improvement, while an undetectable viral load is the best safeguard against the acquisition of drug resistance (Rabie, Marais and Cotton, 2006: 49).

The comparison between the communication development of HIV/AIDS infected children using HAART and those not on an antiretroviral drug regime has not been documented, as far as is known, within the local setting. According to international literature (McFarland, 2002: 4) there is a difference in terms of communication outcomes when children receive HAART, with a significant link between health status and communication skills. It is, however, important to note the negative effects of HAART on the young child. Infants and children depend on adult caretakers to bring them to the clinic and as well as administer their medication; therefore, stable social circumstances and the identification of a reliable caregiver are essential. Small children are unable to swallow capsules and pills, although with adequate training, they may master this at an unexpectedly early age (Rabie et al., 2006: 55). There are also several adverse affects related to the specific class of drugs, such as lactic acidosis, anemia, hypersensitivity and poor attention (Rabie et al., 2006: 54), which are important

for the Speech-Language Therapist and Audiologist to consider, as this may further impact communication development in the pediatric HIV/AIDS population.

The introduction of HAART for use in the HIV/AIDS population has now meant that HIV/AIDS infected children have the opportunity to live a healthier, longer life. Timely HAART initiation implies that HIV/AIDS can be a manageable disease, rather than one in which child death is certain. The perceived impact for the Speech-Language Therapist and Audiologist would be that HIV/AIDS infected children can be provided with ECI services and show significant progress in the acquisition of communication skills as their general health status continues to improve. As the number of HIV/AIDS infected children receiving HAART continues to grow, so will the Speech-Language Therapist and Audiologist's caseload of HIV/AIDS infected children at various ages and levels of development. Once again the need for an ECI protocol to be developed and used within the South African setting is highlighted, with the focus on improving quality of life with the pediatric HIV/AIDS population.

2.5 HIV/AIDS AND COMMUNICATION DEVELOPMENT

Several international studies have targeted and documented the effects of HIV/AIDS on the communication development of infected infants and children, with the vast majority indicating speech and language delays in the symptomatic HIV/AIDS population. The results of a study by Smith, Malee and Leighty et.al (2006: 856) suggest that children with HIV infection who experienced an early AIDS-defining illness exhibited significant impairment in their overall cognitive abilities. A study of Rwandan children 6 months to 2 years of age observed that 40% of HIV/AIDS infected children had an abnormal neurodevelopmental examination at 18 months compared with only 5% of HIV/AIDS exposed uninfected children, and gross motor scores were significantly lower at all studied time points in HIV/AIDS infected children (Msellati, Lepage, Hitimana, et.al., 1993: 124). In a similar study by Van Rie, Mapuala and Dow (2008: 127)

moderate to severe delay in mental, motor, and language development was observed in the majority of HIV/AIDS infected children and in a substantial proportion of HIV/AIDS affected children. Young HIV/AIDS infected children demonstrated a more frequent and more severe delay in cognitive and motor development compared with older HIV/AIDS infected children.

Davis- McFarland (2000) describes many of the symptoms regarding the nature and character of language compromises in the HIV/AIDS infected child. Acquisition of preverbal and language milestones may be delayed in HIV/AIDS infected children and toddlers, probably due to encephalopathy as a presenting feature, and/or the presence of chronic otitis media and/or hearing impairment. A decline of expressive function may occur concurrently across several behavioural modalities such as speech and motor ability. As children grow older, language deficits may increase, which may significantly impact their ability to interact with their world. Language skills are central to the development of social functioning in childhood, and children with impaired language skills may experience significant disorder in social functioning.

Children with pediatric HIV/AIDS are also at an increased risk for experiencing chronic otitis media, which increases the risk of a possible delay in language development (Rossetti, 2001). Compromised hearing acuity may occur either as a result of the infection or due to HAART (Davis- McFarland, 2000). Rabie et al (2006: 38) site present pneumonia, history of otitis media, oral thrush and poor weight gain as symptoms indicative of possible HIV-infection, with poor weight gain despite nutritional support, neurodevelopmental delay and severe or repetitive bouts of tuberculosis (TB) as probable indicators of HIV-infection. The Speech-Language Therapist and Audiologist thus has an influential role in the early identification of children with potential HIV/AIDS infection. These clinical indicators can be used as indicators for the initiation of HIV testing in children.

One of the characteristics of pediatric HIV/AIDS infection is CNS dysfunction resulting from encephalopathy, which causes, amongst other impairments, muscle tone abnormalities that may compromise oral-motor development (Davis-McFarland, 2000). Muscular weakness, gait changes, ataxia as well as fine and gross motor deficits are reported to occur. In the young child, compromised suck-breathe-swallow mechanisms, which have a profound effect on the development of sucking, eating, breathing, swallowing and articulation are a common difficulty experienced by infected children. Oral-motor difficulties are also characterized by phonological errors, raspy and strained vocal quality exacerbated by candidiasis in the oral-laryngeal cavity (Screen & Lee-Wilkerson, 2007: 45). Common voice disorders in HIV/AIDS infected children include weak, breathy voice that lacks pitch and variability, the latter contributing to abnormal prosody. Children with HIV/AIDS often produce vocal intensity levels that are too low (McNeilly, 2000: 65). Respiratory problems due to opportunistic infection are more often than not the cause of such deviations (McNeilly, 2000: 67). This may impact on a child's ability to participate in meaningful interaction during communication, thereby further contributing towards reduced social interaction and communication development.

A study by De Lange (2003) showed that children in pediatric care centers in Gauteng presented with significant feeding difficulties as well as subsequent upper respiratory tract infections due to aspiration. Many of these children showed reduced lip closure and oral manipulation and control. Feeding difficulty, especially nasopharyngeal incoordination, may be an important pointer to neurological illness and may lead to other co-morbidities such as malnutrition and/or aspiration with chronic lung disease (Rabie et al., 2007: 19). Oropharyngeal lesions as well as Oropharyngeal Candidiasis (oral thrush) may occur, which appears as grayish white patches on the tongue, palate, cheeks or gums and may also be found in the esophagus. Severe thrush causes oral and esophageal pain that may interfere with eating and swallowing, as well as compromise respiratory support for speech (McNeilly, 2000: 70).

2.6 HIV/AIDS AND EARLY COMMUNICATION INTERVENTION (ECI)

HIV/AIDS affects all areas of a child's development, including psychosocial, emotional, gross and fine motor, cognitive, linguistic, feeding and physical health (McFarland, 2000). To identify neurodevelopmental delays as early as possible, children with HIV/AIDS need developmental assessment at regular intervals. Delayed communication development is the most common characteristic of developmental disability in children under 3 years of age (Rossetti, 2001: 1). As children infected with HIV/AIDS fall into the established risk category, they have expected patterns of development due to the HIV's interference with the normal processes of development. It is generally accepted that, among all areas of childhood development, communication skills provide the highest predictive correlation with later intelligence and school performance (Rossetti, 2001: 1).

Early identification of socio-communicative delay is essential on order to allow for the maximum improvement in the communicative status of the child (Rossetti, 2001: 45). It is therefore imperative that children with HIV/AIDS are identified at an early age. Rossetti (2001) highlights that once delays or disorders in development in children with HIV/AIDS have been identified, those children below the age of 3 years should be enrolled in an appropriate early intervention program. Early Communication Intervention services should be initiated by the Speech-Language Therapist and Audiologist working within the South African context as early as possible. A suggested schedule for assessment of children with HIV/AIDS includes developmental evaluation by 2 months of age, with follow ups at least every 6 months for the first 2 years of life (Rossetti, 2001: 33).

Federal mandates within several international contexts specify the need for assessment from birth for children who have been identified with at-risk conditions. Speech-Language Therapists and Audiologists working with the pediatric HIV/AIDS population should thus be striving for the provision of Early Communication Intervention services to all children born to HIV-positive mothers

within the South African context. The initiation of provision of ECI services to all HIV-exposed children would allow Speech-Language Therapists and Audiologists the opportunity to facilitate communication development and reduce the severity of communication disorders that the majority of HIV/AIDS infected children present with. It would also allow for children who may not have acquired the virus from their HIV-mothers to receive ECI services. This could better equip such children for the medical, social and emotional impact that HIV/AIDS will indisputably have on their family and home environment.

The role of the Speech-Language Therapist and Audiologist in working with the pediatric HIV/AIDS population is multi-faceted. Due to the far reaching effects of this disease on the developing child, the professional will be involved in providing several levels of therapeutic care. Speech-Language Therapists and Audiologists should be involved in health promotion and health consciousness within their communities (SASHLA, 2008/9: 2). This includes being involved in HIV/AIDS prevention campaigns within the health care context, as prevention of transmission of HIV/AIDS in children is currently the only way to prevent the ravages of the disease. Speech-Language Therapists and Audiologists should not only be involved in assessing and treating HIV/AIDS infected children but should strive to become integral members of the team involved in HIV/AIDS awareness and prevention, whilst in keeping with proposed ethical standards.

The South African Department of Health stresses the importance of continuously ensuring that ethical standards of practice are upheld when working with individuals with HIV/AIDS. The Speech-Language Therapist and Audiologist must ensure confidentiality regarding the HIV/AIDS status of children and/or their parents. ECI services must be aimed at fulfilling the needs of the child whilst making every effort to apply concepts of best practice into service delivery (Rossetti, 2001: 265).

The need for a team approach to assessment and intervention of the pediatric HIV/AIDS population and their families is necessitated by the far-reaching effects of HIV/AIDS on both the infected and affected child. Hegde and Davis (1992) believe that in order to deliver the best care for patients, Speech-Language Therapists and Audiologists must work alongside other professionals, such as Physiotherapists, Nurses and Physicians. Service delivery should be aimed at meeting each individual need of the child with HIV/AIDS and his/her family (Rossetti, 2001: 270). The Speech-Language Therapist and Audiologist has a crucial role to play in preventing and limiting the negative effects of the HIV-infection on the child's general and communicative development, as well improving the child's speech, language and communicative abilities (Spiegel & Bonwit, 2001).

Feeding problems in HIV/AIDS infected children are often chronic and severe. The intervention of a Speech-Language Therapist is important in this situation. Strategies such as manipulating the consistency of feeds and appropriate feeding technique frequently control the symptoms. The child's caretakers should be counseled and assisted with switching to solid food safely and with the use of cup feeds. In very severe cases, where no progress is made, a gastrostomy may be the only long term option. When this condition is due to HIV-associated neurodevelopmental delay then HAART may improve the problem (Rabie et al., 2007: 23).

HIV/AIDS in developing countries such as South Africa has had a great impact on the prevalence of hearing loss due to the known risk factor for chronic otitis media associated with HIV/AIDS (Swanepoel, Delport & Swart, 2004: 635). The Audiologist plays an essential role in the assessment and management of acute and chronic otitis media in the HIV/AIDS infected child (Davis-McFarland, 2002: 3) as well as assessing the possibility of conductive and/or sensorineural hearing impairment.

Due to the fact that the nature of HIV/AIDS necessitates that those infected require chronic progressive treatment aimed at improving length and quality of life, palliative care is an important part of the long-term care of children with HIV/AIDS. Palliative care is an interdisciplinary practice requiring input from several professionals across all spectrums including allied health care (Himelstein, 2006:163). The Speech-Language Therapist and Audiologist may be required to provide palliative care to children infected with HIV/AIDS so as to improve the quality of life for the child and their family/caregivers.

A multidisciplinary approach to ECI is beneficial when working with children who are high-risk for delayed and/or disordered communication development (Rossetti, 2001: 118) is ideally to be enforced when working with the pediatric HIV/AIDS population, preferably within an existing HIV clinic within the health care context. Physiotherapists should be providing services to address gross motor development as well as various respiratory aspects. Lymphoid Interstitial Pneumonia (LIP) represents 25 - 40% of the pulmonary disease burden in HIV infected children (Rabie at al, 2007: 20). Due to fine motor difficulties and aspects of Activities of Daily Living (ADL) that are affected, the Occupational Therapist can provide useful service delivery with the pediatric HIV/AIDS population. Poor weight gain is a symptom often associated with child HIV/AIDS infection and may have multiple causes. A full clinical assessment should be performed and special investigations requested as indicated (Rabie et al., 2007: 23). It is essential that a Dietician be involved in pediatric HIV assessment and management. Social Workers and Psychologists are best equipped to provide counselling services to affected families, as well as address possible social and welfare aspects. Children made vulnerable by HIV/AIDS who do not receive psychosocial support may suffer long-term social and emotional impairment and may be at risk for developing depression, anxiety, suicidal thinking, behavioural disorders, learning disorder, developmental delay and psychosomatic illnesses (Van Dyk, 2005: 273). It is imperative that these counselors provide the necessary support mechanisms for this vulnerable population.

The multilingual and multicultural nature of South African communities poses a unique challenge to the Speech-Language Therapists delivering ECI services to the pediatric HIV/AIDS population (Fair & Louw, 1999: 14). There is a limited number of speech-language therapists working in South Africa and very few of these professionals are proficient in one or more African languages (Fair & Louw, 1999: 17). This has a negative impact on ECI service delivery, as clinicians are not always able to provide children and families infected and/or affected by HIV/AIDS with the appropriate level of service delivery due to the presence of a language barrier. Druck and Ross (2002: 8) highlight the experience of burnout reported by several professionals working with the pediatric HIV/AIDS population. Team work would allow for professions to achieve the necessary support and networking amongst each other. Due to the extensive impact that the virus has on the infected child, as well as on the professional involved with such a child, a team approach to assessment and intervention of this vulnerable population would be optimal. Service providers need to collaborate and coordinate early intervention services offered to these children so that their developmental needs may be addressed and managed timeously and appropriately to reduce disabilities (Screen & Lee- Wilkerson, 2007: 40).

"*Professionals need to broaden their examinations from individual puzzle pieces to the expanded epidemiologic view of how the pieces combine to complete the whole puzzle. These principles require researchers to analyze the individual pieces as they relate to the whole. These interrelationships are complex and can broaden the perspective of those professionals concerned with the way speech, language, swallowing, voice, and otologic disorders fit within the overall puzzle of the immunocompromised populations that have been recognized only recently. To understand the full implications of HIV on language disorders, one has to look at the child's complete situation before making diagnostic judgments"* Screen and Lee-Wilkerson, (2007: 38).

The current pediatric HIV/AIDS situation in South Africa is dire. However, to the ever-aspiring Early Interventionist, the prospect to expand the delivery of ECI services to children who are most in need of them should triumph. The Speech-Language Therapist and Audiologist working within the local context has a major role to play in the intervention of children with HIV/AIDS, as well as those children affected by the ravages of the disease.

2.7 CONCLUSION

The Speech-Language Therapist and Audiologist has a key role to play in the assessment and treatment of children both infected and affected by HIV/AIDS, due to the vast impact the disease has on the development of communication. ECI services are required to be comprehensive, coordinated, and team based, according to the highest quality evidence available (ASHA Position Statement, 2008). The Speech-Language Therapist and Audiologist requires expanded, recent and relevant knowledge regarding the medical and social manifestations of pediatric HIV/AIDS in order to maintain these standards of ECI best practice, whilst maintaining ethical standards at all times. Teamwork provides the best standard of care when assessing and treating the pediatric HIV/AIDS population, and the Speech-Language Therapist and Audiologist is an integral member of this team.

2.8 SUMMARY

This chapter discussed theoretical perspectives on the pediatric HIV/AIDS situation within the South African context. Mother-to-child transmission as the primary mode of transmission was reviewed, as well as strategies for Prevention of Mother-to-Child Transmission (PMTCT) currently in place in South Africa. An overview of the clinical manifestations of HIV/AIDS in the pediatric population was provided. A discussion of the provision of HAART for HIV/AIDS infected children followed, emphasising the opportunity for children infected by the

disease to live longer with an improved quality of life. An argument surrounding the need for the Speech-Language Therapist and Audiologist to be a key member of the assessment and intervention team for services to this population was formulated. Lastly, the need for ECI services to be provided to the pediatric HIV/AIDS population was detailed. This provided the rationale for the description of the pediatric HIV/AIDS population within the South African context.

CHAPTER 3

METHODOLOGY

Aim: The aim of this chapter is to describe the methodology that was followed in planning and executing research to describe the characteristics of a group of young children infected with HIV/AIDS at a regional hospital in Gauteng.

3.1 INTRODUCTION

It is essential that researchers plan their overall research design and specific research methods in a functional, purposeful manner so as to acquire necessary data relevant to their research problem (Leedy & Ormrod, 2005: 3).

Relevant research within the South African context is essential to the Speech-Language Therapist and Audiologist as an effective Early Interventionist. Locally relevant research would inform clinical practice (and the reverse is also true), particularly when assessing and providing intervention for the HIV/AIDS infected child and his/her family/caregivers. The South African context is a unique research environment, necessitating its own research results. Results regarding the HIV/AIDS infected child and communication development from international literature cannot be generalized to the South African context, which highlights the need for research to take place within the local setting. The development of an ECI protocol suited to the South African context is essential in order to guide the Speech-Language Therapist and Audiologist in the management of HIV/AIDS

infected children, as well as to ensure the growth and development of the profession as a whole.

The aim of this chapter is to provide a comprehensive and detailed description of the method followed throughout this study. This chapter includes a description of the main aim and sub-aims, the research design, ethical considerations, data collection as well as data analysis procedures followed.

3.2 RESEARCH AIMS

The main aim of the research was to describe the characteristics of a group of children between the ages of 0 – 5 years infected with HIV/AIDS at a large regional hospital in Gauteng.

3.2.1 Research Objectives

The following objectives were formulated in order to achieve the main aim:

- To determine the prevalence of children infected with HIV/AIDS within the outreach clinic's caseload.
- To describe the current medical conditions of those children infected with HIV/AIDS within the specific hospital's pediatric caseload.
- To determine the presence of communication disorders in those children infected with HIV/AIDS within the specific hospital's pediatric caseload.
- To explore the current practices surrounding team assessment and intervention of the HIV/AIDS infected population within the specific hospital setting.
- To explore the perceptions and practices of medical doctors involved in the treatment of the pediatric HIV/AIDS population within the hospital's outreach clinic.

3.3 RESEARCH DESIGN

A cross-sectional, retrospective, non-experimental, descriptive, quantitative research design was applied through the use of a self-compiled checklist, allowing the researcher to collect all the necessary data at a single time from the child's hospital file (Leedy & Ormrod, 2004: 183). A questionnaire completed by medical doctors practicing at the HIV/AIDS clinic within the hospital was also used.

In a cross-sectional study, individuals from a broad category of age groups are sampled and compared (Leedy & Ormrod, 2004: 183). This study was retrospective in nature, as the hospital records of HIV/AIDS infected children within the outreach clinic were used for the data collection process. In the proposed study, HIV/AIDS infected children between the ages of 0 – 5 years were targeted, as the majority of the pediatric HIV/AIDS population receiving treatment at the target hospital are between the ages of 0 – 5 years.

Descriptive quantitative research examines a situation as it is (Leedy & Ormrod, 2004: 179). By describing the characteristics of the pediatric HIV/AIDS population, the researcher was able to obtain data relevant to answering the research question of the study. The use of both a checklist and questionnaire in the proposed study facilitated evaluation and quantification of the pediatric HIV/AIDS population at the target hospital. This research paradigm involves a systematic and disciplined approach to problem solving (Maxwell & Satake, 2006: 29).

Quantitative variables that were investigated in this study included: the prevalence of children infected with HIV/AIDS within the outreach clinic's caseload, a description of the current medical conditions of those children infected with HIV/AIDS, the presence of communication disorders in those children infected with HIV/AIDS, as well as an indication of the current practices

surrounding team assessment and intervention of the HIV/AIDS infected population in question. The perceptions and practices of medical doctors involved in the treatment of the pediatric HIV/AIDS population within the hospital's outreach clinic were also explored. Questionnaires were hand delivered to doctors working with the pediatric population in question and collected when convenient for both the respondents and the researcher. The advantages of this method include the fact that this type of survey is by far the most economical. Respondents can complete the questionnaire at their convenience and they are offered anonymity (Leedy & Ormrod, 2005: 184).

The research design used in the study was descriptive in nature. The aim of this study was not to modify the current practices within the outreach clinic, nor to describe the cause-and-effect relationships involved, but merely to describe the characteristics of a group of children aged between 0-5 years infected with HIV/AIDS, as well as to explore the perceptions and practices of medical doctors working with the pediatric HIV/AIDS population with the outreach clinic. This type of design falls within the quantitative paradigm.

3.4 ETHICAL CONSIDERATIONS

Ethical implications of research are an essential consideration (Leedy & Ormrod, 2001: 101). The pediatric HIV/AIDS population are an extremely vulnerable population (Louw, 2004), thus it is important to ensure that a high standard of research ethics is maintained throughout the research process. Research was conducted in a fair, professional and ethical manner throughout the process of this study. The following aspects were considered in order to meet the ethical conduct of research:

- **Action and Competence of the Researcher**

The researcher strived to maintain consistency, objectivity and integrity throughout the research study. Research results were completely and accurately represented in an honest fashion (Leedy & Ormrod, 2001: 102).

The South African Medical Association's manual for Human Rights and Ethical Guidelines on HIV/AIDS (2006:13) states that the handling of health records and disclosure to others may only take place as is necessary, for legitimate purposes and within the ordinary course and scope of the other person's duties. The World Medical Association's Declaration of Helsinki is the most important ethics document for medical practitioners worldwide (Human Rights and Ethical Guidelines on HIV/AIDS: A Manual for Medical Practitioners, 2001, revised 2006). It is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects. This ideology was closely adhered to during the conduction of this study.

Principles that guide the ethics of research are *respect for persons, beneficence* and *non-malfeasance* as well as *distributive justice* (Leedy & Ormrod, 2004: 103).

- **Respect for Persons**

Respect for the privacy and confidentiality of all those children whose hospital records were analysed during data collection was enforced. No personal particulars were recorded, and records were analysed without prejudice. Records were analysed over weekends or at times when the clinic was not actively assessing and treating pediatric patients, and records were not accessed by anyone other than the researcher during the data collection process. Due to the

fact that this study is largely retrospective, it was not be possible to gain informed consent from parents and caregivers to access personal files.

- **Permission and Consent**

Permission was required in writing from the Chief Executive Officer (CEO) of the hospital where the study took place, as well as permission to access hospital records of the pediatric HIV/AIDS population. This was achieved once ethical clearance was granted by the Research Ethics and Proposal Committee, Faculty of Humanities, University of Pretoria. Hospital procedure states that ethical clearance from the respective training institution is required prior to submission to the hospital CEO. Approval from the Gauteng Department of Health was also obtained (see Appendix B, C and D for letters in this regard). Informed consent was obtained from the medical doctors before completing the questionnaires (see Appendix E). An informed consent form describing the nature of the research project, as well as the nature of the doctors' participation in it was provided to each doctor completing the questionnaire. This information was necessary to adequately inform the participants as well as to ensure their right to chose to complete the questionnaire, as participation was voluntary (Leedy & Ormrod, 2005: 101).

- **Beneficence and Non-maleficence**

This study utilized a cross-sectional, non-experimental descriptive design, and was largely retrospective in nature (Leedy & Ormrod, 2005: 179-183). Participants were not directly involved and therefore not exposed to any direct risks. There were no physical, psychological, social or any other risks involved in the medical doctors' participation of this study, thus allowing for a favourable risk-benefit balance for participants (Leedy & Ormrod, 2005: 101).

- **Distributive Justice: Inclusion and Exclusion Criteria**

The outreach clinic records of those children between the ages of 0 to 5 years 11 months were used in the study. No additional criteria for selection were used and therefore no records were unfairly or unjustly excluded during the data collection process.

- **Relevance of research**

HIV/AIDS is probably the most challenging medical phenomenon of modern times. It has caused devastation on compounding levels. With no cure currently available, the only potential for providing this at risk population with hope is the idea of comprehensive, multidisciplinary care. The Speech-Language Therapist and Audiologist is a key role-player in such a multidisciplinary team. It is only through an in-depth understanding of the medical and developmental characteristics of HIV/AIDS infected children within the South African context that Speech-Language Therapists and Audiologists can bring about the necessary change in these children's lives. Research serves as the gateway to such improvement. Due to the lack of locally relevant research involving the Speech-Language Therapist and/or Audiologist and the pediatric HIV/AIDS population, this research study may assist in the process aimed towards the development of context appropriate assessment and intervention material to be used within the clinical framework.

3.5 RESEARCH CONTEXT

The context selected for data collection for this study was a large regional hospital in Gauteng province. Tembisa consists of over fifty sections (www.tembisa.co.za) and is the single regional township between Pretoria and Germiston. It is estimated that more than 16% of the population have no income, and 44% have an annual income of less than R19 200,00 or R1600,00 a month

(Environmental Management Framework Report**,** 2007: 81). The hospital itself houses approximately 800 beds, services a large population, and is home to one of only few official HIV/AIDS treatment centers within the area, thus making this the ideal research context for the conduction of this study.

The outreach clinic functions within the hospital but as a separate entity. Children with suspected and confirmed HIV/AIDS diagnoses are referred to the clinic from both the pediatric in- and outpatient departments by medical doctors. These children and their families' and/or caregivers are followed up at the outreach clinic at various intervals depending on their individual needs. The permanent clinic staff consists of Medical Doctors, Nurses, Counselors, a Social worker and a Dietician. It is important to note that the outreach clinic is not exclusively pediatric in nature and that adolescents and adults across the age spectrum are also treated at the clinic.

3.6 SAMPLE

Nonrandom, purposive sampling was used in order to focus on the attributes of the pediatric HIV/AIDS population (Maxwell & Satake, 2006: 97). The main advantage of implementing purposive sampling within this research study was that subjects who presented with the major attributes that the researcher wishes to study could be selected. Purposive sampling may, however, pose the disadvantage of not representing the population as intended (Maxwell & Stake, 2006: 97). Characteristics of the sample that was chosen for the study are discussed below, with reference to population, sampling design, participation selection criteria and sample size.

- **Population**

The population from which the sample was selected included the pediatric population infected with HIV/AIDS within the hospital's outreach clinic. The clinic

records of HIV/AIDS infected children between the ages of 0-5 years were selected for data collection. Purposive sampling was used during population selection in order to target those children infected with HIV/AIDS (Leedy & Ormrod, 2001: 206).

- **Participation Selection Criteria**

The pediatric HIV/AIDS population within the hospital's outreach clinic was required to meet the following criteria for selection in order for their hospital records used within the outreach clinic to be included as part of the study: HIV/AIDS infected children from birth to 5 years 11 months of age were included in the study. Children within the above-mentioned age group who had been diagnosed and confirmed as HIV positive (by both the RAPID and ELISA methods as proposed by the Department of Health and not based exclusively on clinical presentation) within the pediatric caseload referred to the hospital's outreach clinic, which had to be documented in the child's outreach clinic records. Permission to conduct the study was obtained from the hospital CEO, as well as ethical clearance by the Research Proposal and Ethics Committee, Faculty of Humanities, University of Pretoria. Doctors working with the pediatric HIV/AIDS population within the outreach clinic were targeted for the completion of the questionnaire. Informed consent was obtained from the medical doctors before completing the questionnaires.

- Description of Pediatric HIV/AIDS population

Two hundred and three were those children infected with HIV/AIDS who were between the ages of birth to 5 years 11 months. Gender distribution as acquired during data collection, is documented in Figure 3.3. Results show 55.70% male (113 children) and 44.30% female (90 children), showing relatively even gender distribution amongst HIV/AIDS infected children seen at the outreach clinic.

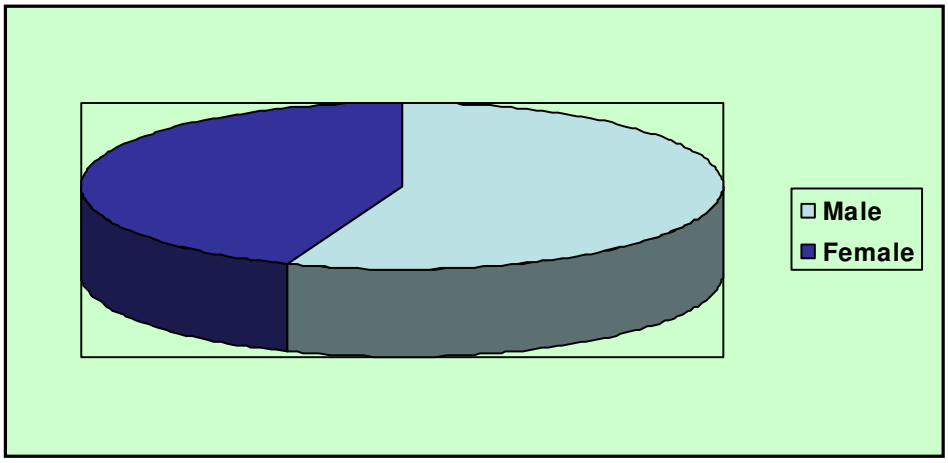

Figure 3.3 Genders of sample used in the study (n=203)

Age distribution in months is described in Figure 3.4 below. All age groups between birth and 5 years 11 months were represented in the sample, with the majority of infected children presenting between the ages of 12-35 months.

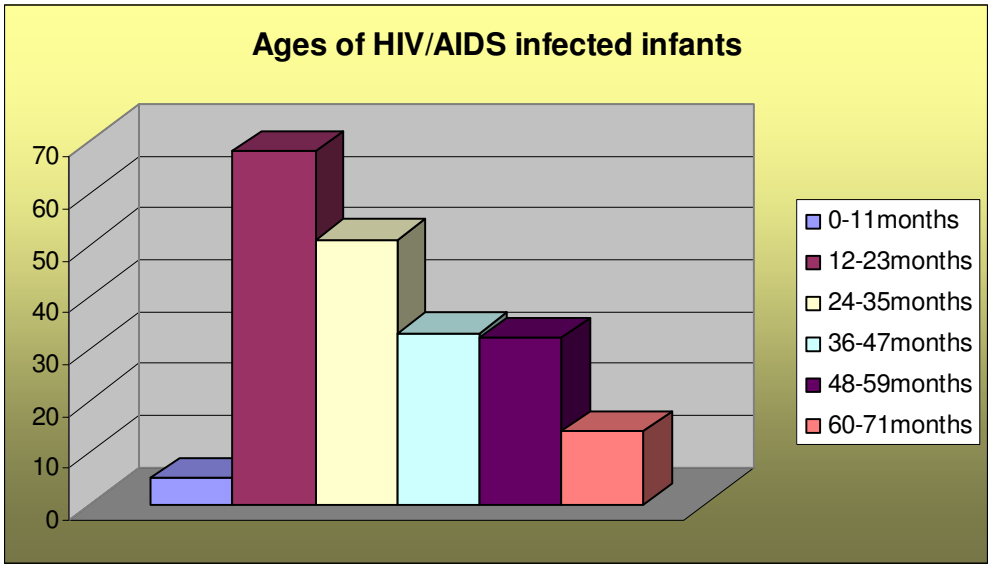

Figure 3.4 Ages of children infected with HIV/AIDS at outreach clinic (n=203)

- Description of Medical Doctors as Respondents

At the time the study was conducted, 7 medical doctors treating the hospital's pediatric population were practicing within the outreach clinic. Of the 7 questionnaires sent out, 4 were returned, and the remaining 3 could not be retrieved due to reasons such as time constraints. Table 4 below describes the salient characteristics of the respondents.

Table 4: Description of Respondents (n=4)

DEMOGRAPHICS	SAMPLE	PERCENTAGE (%)	TOTAL (N)
Gender	• Female • Male	75% 25%	3 1
Ethnicity	• Black • Coloured • Indian • White	50% 0% 25% 25%	2 0 1 1
Age	• 29 years • 33 years • 45 years	50% 25% 25%	2 1 1
Years of Experience working with the pediatric HIV/ADS population	• 8 months • 13 months • 30 months • 48 months	25% 25% 25% 25%	1 1 1 1
Years of Experience working with the pediatric HIV/AIDS population at the outreach clinic in question	• 8 months • 13 months • 30 months • 48 months	25% 25% 25% 25%	1 1 1 1

3.7 MATERIAL AND APPARATUS

The material and apparatus designed and used for the collection, recording and analysis of data obtained form hospital records in this study will be described below:

3.7.1 Checklist

A checklist was developed for the process of data collection for this research study. Use of a checklist allowed for the characteristics of the HIV/AIDS infected children to be simplified and quantified (Leedy & Ormrod, 2001: 187), and prevented researcher bias. Both evaluation and quantification are yielded through the use of a predesigned checklist (Leedy & Ormrod, 2001: 185).

The checklist was compiled from locally relevant literature regarding the pediatric HIV/AIDS population's medical characteristics (Marais et al., 2006, 1 and 2), as well as from international and local literature regarding social, communicative and developmental characteristics of children with HIV/AIDS. The use of a predetermined checklist allowed the researcher to obtain geographical, medical as well as social and developmental information regarding each HIV/AIDS infected child. The checklist was developed in the form of an electronic data collection sheet in collaboration with a statistician. The data sheet was used in paper format for the process of data collection. The data collection sheet was used when gathering data form the target population's outreach clinic records, allowing for all necessary data to be captured. The captured data regarding the characteristics of the HIV/AIDS infected children from the completed checklist was transferred to the Microsoft Excel spreadsheet for evaluation purposes. The researcher consulted with a statistician, where the results from the checklist were evaluated through the use of the statistical analysis system (SAS).

The checklist consisted of four sections (refer to Appendix F), which were included so as to fulfill the above-mentioned objectives:

- **Section A, I – 4 : Geographical Information**

The purpose of this section was to obtain biographical information regarding the pediatric HIV/AIDS population, namely age, gender, and social care status of the child. Such information would be purposeful for the compilation of guidelines for working with the pediatric HIV/AIDS population, as it is representative of the current social situation within the local setting. This information is important for the description of the data sample in the study (Leedy & Ormrod, 2004: 199), and allows for the collection of data to fulfill the first sub aim of the study, which is to explore the prevalence of children infected with HIV/AIDS within the hospital's pediatric caseload.

- **Section B, 1 – 5.3 : Medical Information**

The inclusion of this section was aimed at the fulfillment of the second objective of the study, which was to describe the current medical conditions of those children infected with HIV/AIDS within the hospital's pediatric caseload. This is essential in order to provide a holistic description of the pediatric population in question. International literature (Screen & Lee-Wilkerson, 2007; Davis-McFarland, 2000) has revealed a casual link between the HIV-infected child's medical condition and his/her communication development. Davis-McFarland (2002: 2) states that there is a difference in terms of communication outcomes when infected children receive the appropriate medication. As the health status of these infected children improves, so do their communication skills. It is also important to understand the side effects associated with each drug regime, and its possible effect on a child's ability to function appropriately. Thus, a comprehensive medical description is a pertinent guide to the compilation of a communication profile.

- **Section C, 1 – 2 : Communication**

The aim of this was to provide information regarding the communication development of HIV/AIDS infected children seen at the outreach clinic as is documented in their clinic records. In order to develop a contextually appropriate model for ECI service delivery for the pediatric HIV/AIDS population, a better understanding was required as to how the infected child presents when included in an ECI caseload (Louw, 2004). The collection of data on the nature of communication disorders presenting in infected children in Gauteng will inform the issue of contextually appropriate service delivery in the South African context. The construction of a communication profile will assist in directing assessment and treatment of this vulnerable population and allow for an optimum continuity of care for Speech-Language Therapists and Audiologists within the South African context (Louw, 2004). It is also necessary to determine whether doctors and other professionals involved with HIV/AIDS infected children are able to identify the presence of delays and/or disorders in communication development in this population.

- **Section D, 1 - 4 : Team Involvement**

The aim of the inclusion of this section in the checklist was to determine what the level of team involvement was at the outreach clinic when working with the pediatric HIV/AIDS population. A multidisciplinary approach to working with individuals infected with HIV/AIDS is the optimal mode of service delivery (Van Dyk, 2005: 145). Inclusion of information regarding teamwork involved in the assessment and treatment of the HIV/AIDS infected child within the local setting would allow for appropriate recommendations regarding communication intervention within a team approach.

3.7.2 Questionnaire

A questionnaire was compiled to survey the medical doctors' perceptions and practices regarding the general and communicative development of the pediatric HIV/AIDS population within the outreach clinic (see Appendix G). The use of questionnaires allows the participants to respond to questions with the assurance that their responses will remain anonymous, thus they can be more truthful than if a direct interview was conducted (Leedy & Ormrod, 2005:185). The self-administered questionnaire ensures that the same set of questions is presented to each respondent and that interview bias is avoided (Leedy & Ormrod, 2001: 209). Medical doctors working with the pediatric HIV/AIDS population are often the first professionals within the team to assess and provide treatment to this population. Therefore, receiving information from these professionals was deemed as a useful and necessary undertaking.

- **Development of the Questionnaire**

The questionnaire compiled for use in this study consisted of a variety of question types, namely open and closed-ended questions, partially open and matrix questions. The response format included nominal and yes/no scales as well as statements. (Leedy & Ormrod, 2004: 192). Typically questionnaires often yield a low return-rate.

The questionnaire included a cover letter with instructions for completion of the questionnaire. A letter of informed consent was also attached and the respondents were entitled to keep a copy thereof (see Appendix E and G).

The following aspects were included in the questionnaire:

- **Question 1- 5: Biographical Information**

The purpose of including this section in the questionnaire was to obtain biographical information from the respondents, namely gender, age, years of experience in pediatrics as well as the respondent's current level of experience in working with HIV/AIDS infected children. Biographical information provides a better understanding of the respondents' background and allows the researcher to interpret the responses more insightfully (Neuman, 2005: 53). This section was placed at the beginning of the questionnaire because the questions were easily-answered and nonthreatening.

- **Question 6-20: Observed phenomena and professional opinion**

Questions in this section were included to obtain information pertaining to the medical doctors' assessment and treatment periods, as well as professional opinions regarding possible causes for general and communicative delays in the target population. It is of importance and value to note the observed phenomena and professional opinions of medical doctors working with the pediatric population within the hospital's outreach clinic with regards to the pediatric HIV/AIDS population. This information may help to shape guidelines for service delivery for the Speech-Language Therapist and Audiologist with regard to ECI practices with the pediatric HIV/AIDS population within a multidisciplinary team model.

3.8 PILOT STUDY

A pilot study was conducted to refine the checklist and questionnaire and determine the feasibility of its use during the study. A pilot study was a necessary and useful way to determine the feasibility of the data collection materials that were used in this study (Leedy & Ormrod, 2005: 110).

- **Aim:**

The aim of the pilot study was to ensure the content and construct validity of the checklist as well as the questionnaire so as to increase the reliability of the results obtained during the main study (Leedy & Ormrod, 2005: 111). It was also a practical way in which to save time and to ensure that any problems could be addressed before the main study commenced. By conducting the pilot study, the researcher was able to ensure that both the devised checklist and questionnaire were practical and user-friendly. The pilot study was necessary to ensure that the checklist captured relevant information available in the clinic records of HIV/AIDS children at the outreach clinic. The pilot study assisted the researcher to assess the functionality of the questionnaire. In addition, the conduction of the pilot study provided an opportunity for the researcher to become familiar with the data collection process.

- **Sample - Checklist:**

The hospital records of children aged between birth and 5 years 11 month who had been diagnosed and confirmed as HIV positive were targeted for the pilot study. These criteria are the same criteria as those implemented in the main study, as these criteria form the salient characteristics of the population targeted during the study. The clinic records of ten children were assessed using the checklist. These records were not included in the main study's data that was used for analysis.

- **Sample - Respondents:**

Medical doctors at the same regional hospital as the main study were targeted as respondents for the pilot study. Two medical doctors working in the pediatric out patient department within the hospital were requested to complete the questionnaire and provide any necessary feedback regarding its completion. Respondents in the pilot study were not included in the main study.

- **Procedure followed during the pilot study**

The procedure followed during the pilot study is described below.

- The researcher used the checklist developed to obtain information from the clinic records of ten children infected with HIV/AIDS. The first ten records where the child was between the ages of birth to 5 years 11 months were used for data collection. The appropriateness of each section of the checklist as well as it's ease of use was assessed by the researcher.
- The questionnaire developed was hand–delivered to two medical doctors working in the hospital's pediatric out patient department. Informed consent was obtained from both doctors participating in the pilot study. The respondents were asked to report on any ambiguous questions or any areas of the questionnaire that they felt may need revision. The completed questionnaires were retrieved from the two doctors.
- Results of the pilot test for the checklist and questionnaire were analysed.

- **Results of the pilot study**

No changes were made to the data collection materials used in the main study; however, recommendations for adaptations during the data collection process were recorded. Table 5 documents the adaptations that were noted from the

pilot study that would be implemented in the main study. Implementation of the pilot study was functional and necessary and the conclusion was reached that the data collection material to be used in the main study would be effective and user-friendly, allowing for the optimal collection of data.

Table 5: Recommendations from pilot study

Checklist	Questionnaire
The researcher recorded information from the clinic records onto the checklist in paper format. It was decided that the data would then be transferred to an electronic version after the data collection process was completed. This was done so due to practical reasons and ease of use within the outreach clinic.	No changes were made as the respondents from the pilot study indicated that the questionnaire was user-friendly and they felt that all questions included were appropriate and perfunctory.
It was decided that the child's clinic record file number would be recorded on the checklist to allow for accurate record keeping during the main study.	

3.9 RESEARCH PROCEDURE

A detailed account of the data collection and analysis procedure follows:

3.9.1 Data collection and recording procedures

- Permission was received in writing from the Chief Executive Officer (CEO) of the hospital where the study took place, as well as permission to access hospital records of the pediatric HIV/AIDS population. This was achieved once ethical clearance was authorised by the Research Ethics and Proposal Committee, Faculty of Humanities, University of Pretoria. Approval from the Gauteng Department of Health was also received, as well as from the University of Pretoria Research Ethics Committee (see

Appendix B, C and D for letters in this regard). Informed consent was obtained from the medical doctors before completing the questionnaires (see Appendix E).

- A pilot study was conducted to determine whether the checklist and questionnaire developed for use in the study were reliable and accurate.

- The clinic records of HIV/AIDS infected children at the outreach clinic were targeted. Five hundred and seventeen records belonging to children below the age of 18 years of age within the outreach clinic were accessed, of which 203 were those of children infected with HIV/AIDS who were between the ages of birth to 5 years 11 months. The researcher used a devised checklist to manually record the predetermined data from the clinic files of the 203 children that matched the criteria for inclusion.

- Questionnaires were sent out to the medical doctors practicing at the outreach clinic. Respondents completing the questionnaire were contacted before the questionnaire was hand delivered to the outreach clinic during clinic hours. Contact was maintained and questionnaires were collected at a time convenient for both the respondent and the researcher. This was done to improve the questionnaire return rate. A total of 4 out of 7 completed questionnaires were returned to the researcher for analysis.

3.9.2 Data analysis procedures

The data analysis procedure followed in this study is explained below:

- Once data recorded from the checklist that was manually completed had been captured and entered into a Microsoft excel data sheet, a statistician conducted statistical analysis through the use of a statistical analysis system (SAS). SAS is a powerful statistical analysis package, which

allowed for the researcher to describe the characteristics of the pediatric HIV/AIDS infected children within the outreach clinic from the results obtained from the data collection process in an outlined, detailed fashion (Cabrera & McDougall, 2002: 331).

- The PROC FREQ data provided a frequency count of the values each variable represented of the total data. Although PROC FREQ is the simplest level of statistical analysis, it provided the necessary data to fulfill the main aim of the study, which was to describe the characteristics of a group of children infected with HIV/AIDS.

- A frequency value was provided for each characteristic recorded from the child's hospital record, as well as the percentage of the total sample size this represented. It was not necessary, for purposes of this study, to draw inferences between variables.

3.10 RELIABILITY AND VALIDITY

The research design used in this study was quantitative in nature. In order for the research process used in this study to be accurate and consistent, thus ensuring reliability and validity, several necessary steps were enforced, and are discussed below.

3.10.1 Reliability

According to Leedy and Ormrod (2001: 93) the reliability of a measuring instrument is the extent to which it yields consistent results.

The following aspects were implemented in order to ensure a high level of reliability:

- Language and phrasing used in the questionnaire were concise, unambiguous and free from slang and/or jargon. Furthermore, questions and responses were worded in such a way as to avoid giving cues about preferred or desirable responses (Leedy & Ormrod, 2001: 190).
- A pilot study was conducted on a smaller but representative sample of the target sample for both the checklist and questionnaire, thus increasing the measuring instruments' reliability.
- A single person (the researcher) was responsible for the collection of data, as well as the transferring of this data to the Microsoft Excel spreadsheet. Research bias was overcome by ensuring that the developed checklist was followed consistently during the recording of data.

The measuring instruments used in this research study can be viewed as accurate and reliable.

3.10.2 Validity

It is essential to determine the accuracy, meaningfulness and credibility of a research study as a whole. The validity of this research study was assured. The internal validity refers to the extent to which the research design and data collected in this study allow the researcher to draw accurate conclusions about relevant relationships (Leedy & Ormrod, 2001: 97).

Content validity is the extent to which the checklist and questionnaire cover the topic of the medical practices and characteristics of, as well as general and communicative development of HIV/AIDS infected children (Leedy & Ormrod, 2001: 92). In order to obtain a high content validity, both the checklist and the questionnaire were developed with the use of local and international data

relevant to pediatric HIV/AIDS and Early Communication Intervention. The pilot study assisted with the determination of the content validity of the checklist and questionnaire. Anonymity of both the respondents completing the questionnaires, as well as the HIV/AIDS infected children whose clinic records were assessed, was ensured throughout both the pilot study and main study. In terms of face validity (Leedy & Ormrod, 2001: 92), the developed questionnaire appeared to be a reasonable manner in which to collect data from the respondents regarding perceptions and practices when working with the HIV/AIDS infected children within the outreach clinic. The questionnaire seemed to reflect the variables that it was designed to measure.

The validity of this research study was further improved by ensuring that the quantitative data collected was reviewed a number of times. This ensured that inaccurate reporting of results was avoided.

3.11 CONCLUSION

The research problem highlighted in this study was addressed by the development and use of a predesigned checklist in order to describe the characteristics of a group of HIV/AIDS infected children, and questionnaire to describe the perceptions and practices of medical doctors working with these HIV/AIDS infected children. Both the checklist and questionnaire were designed stringently according to the most updated local and international literature regarding pediatric HIV/AIDS. The method of data collection and analysis used was suitable for the purposes of this study as it provided descriptive information. The results of this study may potentially serve in the development of a locally relevant description of HIV/AIDS infected children, and in so doing, provide grounds for a research based ECI protocol for use in South Africa.

3.12 SUMMARY

The justification for the selection of the research design used in the research study was described in this chapter. The process of developing the materials used for this study was explained. Information regarding this study's complete research process was clearly discussed. The ethical considerations, sample selection and description, material and apparatus used during the study, as well as the methods used for data collection and analysis were described. Issues relating to reliability and validity were discussed. The results obtained as well as a discussion of the results will be described in the following chapters.

CHAPTER 4

RESULTS AND DISCUSSION

Aim: The aim of this chapter is to present and discuss the results obtained from the study, which have been displayed through the use of figures and tables.

4.1 INTRODUCTION

Children infected with HIV/AIDS in South Africa require ECI services in keeping with best practice guidelines (Rossetti, 2001: 254). The Speech-Language Therapist and Audiologist working with the pediatric HIV/AIDS population, particularly in the clinical setting, may have limited knowledge of, and experience with, providing services to this population. Therefore, there is a dire need for locally relevant, research-based literature describing the pediatric HIV/AIDS population and the effects of the disease on development in the infected infant. To address this need, this study aimed to describe the characteristics of a group of children between 0-5 years infected with HIV/AIDS, at a regional hospital in Gauteng.

A retrospective, descriptive study was conducted in order to describe the characteristics of a group of children infected with HIV/AIDS at a regional hospital in Gauteng. The results from this study provide locally relevant data regarding the pediatric HIV/AIDS population, with particular reference to the role of the Speech-Language Therapist and Audiologist in ECI service delivery. The characteristics of HIV/AIDS infected children at the outreach clinic are described and discussed. Perceptions and practices of medical doctors treating the pediatric HIV/AIDS population are explored. The data is presented in figures and tables in order to answer the research question posed: *What are the medical and*

developmental characteristics of a group of HIV/AIDS infected children aged 0 – 5 years in a large regional hospital in Gauteng?

4.2 PREVALENCE OF HIV/AIDS INFECTED CHILDREN

The first objective of the study was to determine the prevalence of HIV/AIDS infected children within the outreach clinic's caseload. The prevalence of HIV/AIDS infected children between 0-5 years was measured in accordance with the total patient load (adults and children) within the outreach clinic. At the time the data was collected, a total of 1356 patient records existed within the outreach clinic. A total of 517 of these records were of children aged below 18 years, with 203 of these records belonging to children between the ages of 0 – 5 years 11 months. Figure 4.1 represents the prevalence of HIV/AIDS infected infants within the outreach clinic's total caseload.

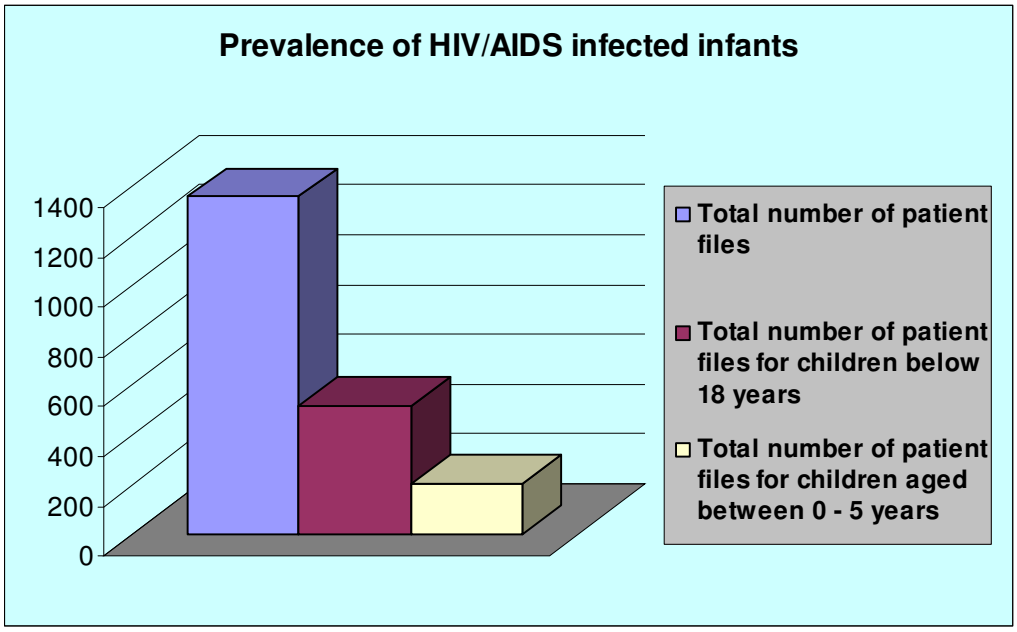

Figure 4.1 Prevalence of HIV/AIDS infected infants (n=1356)

Results suggest that the majority of patients being managed within the outreach clinic are adults; however, there are a substantial number of children within the caseload as well. This is a positive indication that HIV/AIDS infected children are indeed being treated within the outreach clinic, and that they have access to the necessary management and care that they require. This is in keeping with the UNAIDS Declaration of Commitment on HIV/AIDS (2008), aimed at ensuring that the well-being of children remains at the heart of the global response to HIV/AIDS.

The above results thus indicate that the pediatric HIV/AIDS population constitutes a significant portion of the total patient caseload within the outreach clinic. Children infected with HIV/AIDS warrant special attention, due to the far-reaching effects of the disease on the infected child's health and development.

4.3 MEDICAL CHARACTERISTICS OF HIV/AIDS INFECTED CHILDREN

The data for the description of the medical conditions of the HIV/AIDS infected children was obtained from the Medical and Biographical Information sections of the checklist.

4.3.1 Clinical and Immunological Staging and HAART

The stages of HIV/AIDS infection of the target children is plotted in Figure 4.1.

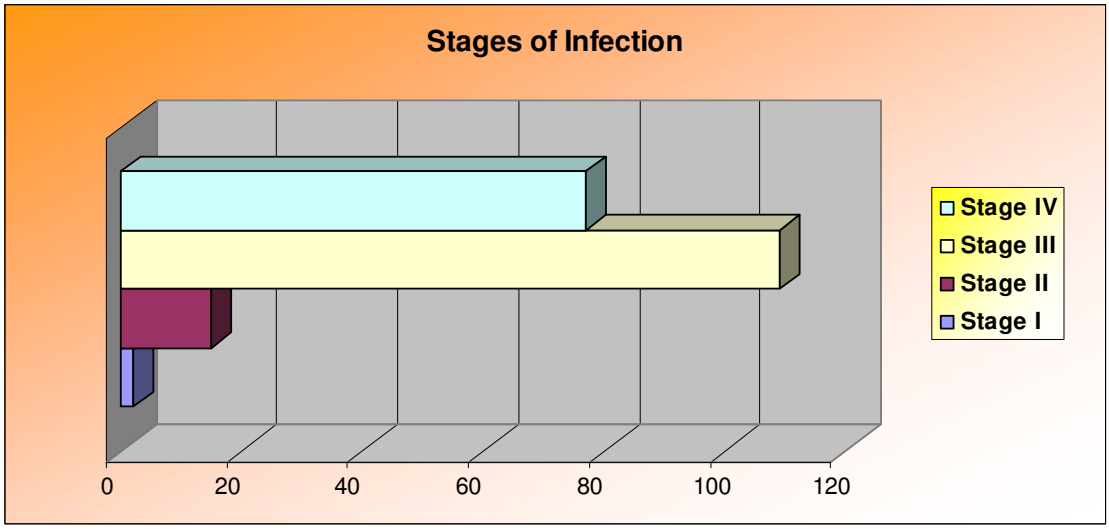

Figure 4.2 Stages of infection of HIV/AIDS infected children (n=203)

Of the 203 children whose medical records were assessed, results indicate that the majority of children with HIV/AIDS infection being treated at the outreach clinic, were in the WHO (2005) clinical Stage III and Stage IV categories of HIV/AIDS infection. Clinical staging of HIV/AIDS allows the clinician to categorise a child's HIV/AIDS infection from Stage I to Stage IV, according to disease progression (Rabie et al., 2006:56). It is expected that the majority of children at the outreach clinic present as Stage III and Stage IV, as infants in these two stages qualify for antiretroviral treatment (WHO, 2005), and would likely be referred for management more readily than HIV/AIDS infected children in Stage I and Stage II. HIV/AIDS as these are Figure 4.3 documents the CD4% of the target children at the outreach clinic. Clinical and immunological staging of HIV disease in children are a fundamental component of the accurate management of children with HIV/AIDS infection, providing essential prognostic information (Rabie et.al, 2006: 56). Results are a clear indication that all the children being treated at the outreach clinic between birth and 5 years 11 months were immunologically compromised, with the majority of these children falling into the WHO (2005) advanced and severe suppression stages.

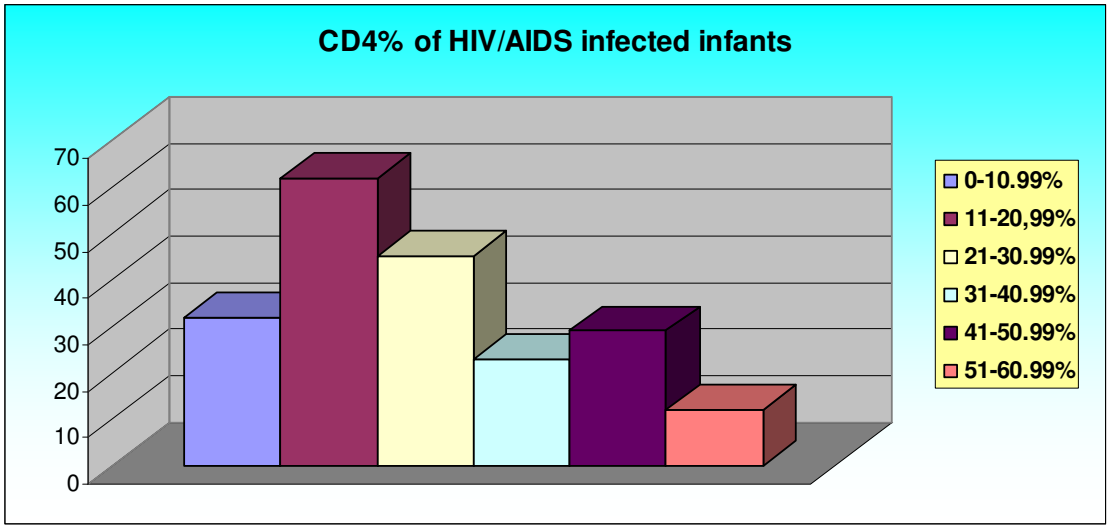

Figure 4.3 CD4% of HIV/AIDS infected children (n=203)

Indications for treatment initiation in the HIV/AIDS infected child are based on clinical as well as immunological staging, derived from the South African Department of Health's guidelines for treatment initiation (2005). Clinical and immunological staging are key components in the management of HIV/AIDS infected children, as accurate staging provides valuable prognostic information (Rabie et al., 2006: 56). It also identifies HIV/AIDS infected children who require HAART and those who experience treatment failure, both of which are likely to have a significant effect on a child's general and communicative development. This is essential information for the Speech-Language Therapist and Audiologist to consider when providing ECI services to the HIV/AIDS infected child.

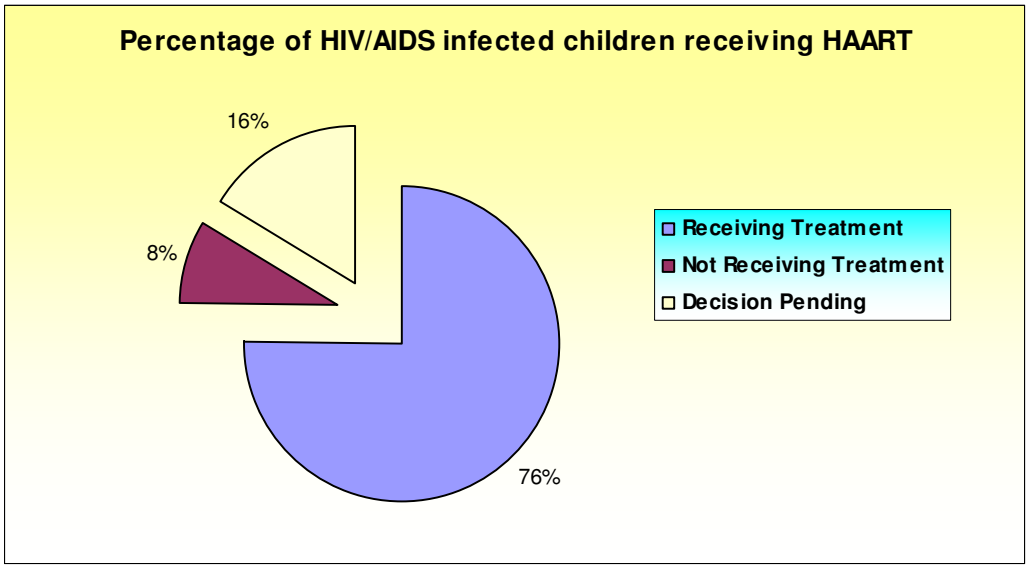

Figure 4.4 HIV/AIDS infected children receiving HAART (n=203)

Results regarding children receiving HAART are detailed in Figure 4.4. A total of 153 of the 203 HIV/AIDS infected children at the outreach clinic were receiving HAART at the time the data was collected. Children not receiving treatment likely did not yet qualify for treatment according to clinical and immunological staging. Those children where treatment initiation was pending, were likely in the process of treatment preparation, as the outreach clinic necessitates parents/caregivers to attend at least 3 counseling sessions before initiating HAART. The value of HAART is that ARV's from different classes are combined to achieve maximum and prolonged suppression of viral replication, which has brought about a significant reduction in the morbidity and mortality associated with pediatric HIV/AIDS (Rabie et al., 2006: 54-55). This is also likely to have an impact on the HIV/AIDS infected child's communication development, as their general health improves, allowing for increased social interaction and communication.

- **Summary**

The majority of HIV/AIDS infected children being managed within the outreach clinic presented with significant immunosuppression, with most children being categorized with Stage III or Stage IV HIV/AIDS infection, with low CD4%. A large number of children were receiving HAART at the time the data was collected. This is in keeping with WHO (2005) guidelines as well as the Millennium Development Goals as set out by The South African Department of Health. Children infected with HIV/AIDS being treated at the outreach clinic are thus receiving the necessary medical care in compliance with government guidelines.

4.3.2 Opportunistic Infections

Table 4.1 documents the frequency of opportunistic infections in the target HIV/AIDS infected children in this study, which are further discussed.

Table 4.1 Presence of Opportunistic Infections in HIV/AIDS infected children

Category	Opportunistic Infection	Number of Children Diagnosed with Opportunistic Infection
Bacterial Infection	• Streptococcal pneumonia • Klebsiella pneumonia • Klebsiella pneumonia and Staphylococcus aureus	• 2 • 1 • 2
Viral Infection	• Influenza	• 4
Fungal Infection	• Pneumocystis jiroveci (PCP – Plasma Cell Pneumonia)	• 33
Mycobacteria	• Mycobacterium Tuberculosis	• 78
Candida	• Oral candida • Oral and pharyngeal candida	• 47 • 1
Other	• Chronic Respiratory infection • Cardiomyopathy • Herpes Simplex • Chickenpox • Molluscum contagiosum • Meningitis • Herpes Zoster • *Immune reconstitution inflammatory syndrome (IRIS)*	• 2 • 1 • 1 • 1 • 1 • 8 • 6 • 4

The above-mentioned categories are discussed below:

- **Bacterial Infections**

In the current study, 2 cases of streptococcal pneumonia were recorded, with 1 case of Klebsiella pneumonia and 2 cases of Klebsiella pneumonia with co-occurring staphylococcus aureus being documented (Table 4.1). This is a slightly lower than expected finding, as the incidence of bacterial infections is

significantly greater in children with HIV/AIDS infection compared with uninfected children (Abrams, 2000:85), although precise prevalence statistics are unknown. Streptococcus pneumonia is the most common bacterial pathogen isolated from HIV/AIDS infected children with severe pneumonia.

- **Fungal Infections**

As was recorded in Table 4.1, 33 cases of Pneumocystis jiroveci pneumonia (PCP) were documented in the current study. This is significantly higher than the presentation of bacterial infections discussed above, which is an expected finding, correlating with literature regarding PCP in infants with HIV/AIDS. PCP is the hallmark opportunistic infection of the pediatric AIDS epidemic (Abrams, 2000: 80). PCP is frequently the first serious illness encountered by the HIV/AIDS infected infant who is not on cotrimoxazole prophylaxis. Cotrimoxazole prophylaxis is a fixed-dose, broad spectrum antimicrobial agent that targets a range of aerobic gram-positive and gram-negative organisms, fungi and protozoa (WHO, 2006: 7). It seems as if cotrimoxazole prophylaxis protects against severe disease rather than infection. PCP remains an exceedingly common cause of death among HIV-infected children in Africa (Marias et al., 2006: 54).

- **Mycobacterium Tuberculosis (TB) and Immune Reconstitution Inflammatory Syndrome (IRIS)**

Bacterial infections are the most common cause of respiratory deaths in children in Africa (Marais et al., 2006: 52). TB, as an opportunistic infection, presented in 78 children in this study (Figure 4.1). This result is an expected finding, as a recent report indicated that children <13 years of age contribute 13.7% of the total TB disease burden in South Africa, with a calculated TB incidence rate of more than 400/100 000/year (Marais, Rabie, Schaaf & Cotton, 2006: 260). The TB epidemic is typically sustained in conditions of poverty and crowding, where

both exposure to the organism and the vulnerability to progress to disease following infection, are increased. In sub-Saharan Africa, it is fuelled by the immune compromise that results from HIV/AIDS infection (Marais et al., 2006: 55).

IRIS refers to the temporary worsening of TB symptoms (for example, lymph node enlargement) that may occur when HAART is first introduced in the HIV/AIDS infected infant. It usually manifests within 2-6 months after the initiation of HAART, and subsides spontaneously (Marias et al., 2006: 56). IRIS was documented in 4 of the HIV/AIDS infected children in this study, which is a relative finding, given that IRIS may or may not temporarily present in the HIV/AIDS infected infant with TB, who is receiving HAART.

- **Candida**

Forty-seven findings of oral candidiasis were documented, as well as 1 case of oral and pharyngeal candidiasis in the current study. This finding is to be expected, as oral candidiasis is the most frequent oral manifestation in HIV/AIDS infected infants and children (Rabie et al., 2007: 43). In HIV/AIDS infected children candida infections are not restricted to infancy, may cause extensive and persistent (or recurrent) infections and may spread to the oesophagus and larynx as well (Rabie et al., 2007: 42). Severe oral candidiasis may be the first clinical indication of HIV/AIDS infection in HIV-exposed children (Abrams, 2000: 95). The presence of oral and/or pharyngeal candidiasis may result in feeding and/or swallowing problems in the HIV/AIDS infected infant, necessitating the need for intervention by the Speech-Language Therapist.

- **Herpes Simplex Virus**

Primary infection with herpes simplex virus (HSV 1) commonly results in extensive, but self limiting, gingivostomatitis in immune competent children. Only one case of HSV 1 was documented in the current study, which is a lower than

expected finding. Although precise prevalence statistics are unknown, the high rate of children receiving HAART in this study may have contributed to the low rate of HSV 1 presentation. HIV/AIDS infected children experience similar extensive gingivostomatitis, but often with extensive presentation before healing (ulcers persisting for longer than four weeks is an AIDS defining condition) and painful recurrences are not uncommon (Marais et al., 2006: 41).

- **Chickenpox and Varicella Zoster**

In the current study, 1 case of chickenpox was documented and 6 cases of varicella zoster virus (VZV), which is a relatively low presentation, although the prevalence statistics for HIV/AIDS infected children and chickenpox/VZV is unknown. Chickenpox and zoster are different disease manifestations caused by the same virus. A wide range of clinical manifestations of VZV have been described in children with HIV/AIDS infection. Children with advanced immunosuppression seem to be at increased risk for recurrent disease and more severe manifestations of VZV (Abrams, 2000: 101).

- **Meningitis**

In the current study, 8 cases of meningitis were recorded. This is an expected finding, as meningitis affects between 30-60% of HIV/AIDS infected children (Mubaiwa, 2008: 1). Meningitis in the HIV/AIDS infected child has far-reaching effects on development, with approximately 80% of children suffering cognitive impairment as a result (Mubaiwa, 2008: 2). Multidisciplinary assessment and treatment is essential in the management of meningitis in children and children infected with HIV/AIDS (Mubaiwa, 2008: 5), due to the broad spectrum of disabilities resulting from subsequent neurological damage. Referrals to Speech-Language Therapists and/or Audiologists in these 8 cases would have been necessary.

➢ **Summary**

The data obtained in the current study appears to be a representative sample of the opportunistic infections documented in the pediatric HIV/AIDS population in South Africa in general, according to local literature (Rabie et al., 2007; Marais et al., 2006; Mubaiwa, 2008). A significant percentage of the HIV/AIDS infected children being treated at the outreach clinic present with the most common characteristics of HIV/AIDS infected children, namely TB, meningitis and candida.

4.3.3 HIV/AIDS Associated Conditions

Several conditions are associated with HIV/AIDS infection, often with significant consequences to the developing infant and child (Rabie et al., 2007: 19). The findings in the current study will be discussed hereafter:

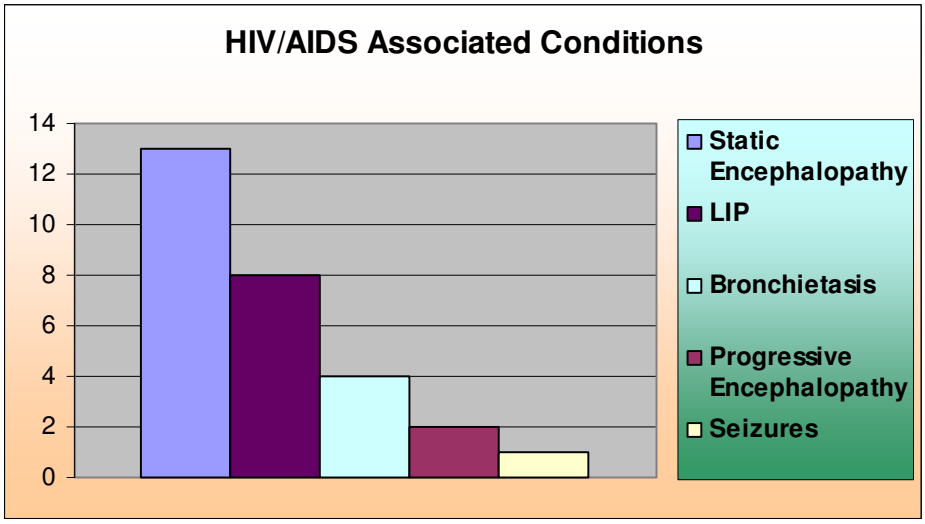

Figure 4.5 HIV/AIDS Associated Conditions in HIV/AIDS infected children (n= 30)

- **Static and Progressive Encephalopathy**

In the current study, 13 cases of static encephalopathy and 2 of progressive encephalopathy were noted (Figure 4.5). Thus, a total of at least 15 children from the current study qualify for ECI services, due to the presence of static or progressive encephalopathy. This is an expected finding, as HIV encephalopathy is the most common neurological manifestation of HIV/AIDS in children, which in many cases may be the primary presenting feature (Rabie et al., 2007:19). Feeding difficulty, especially nasopharyngeal incoordination, may be an important pointer to neurological illness and may lead to other co-morbidities such as malnutrition and/or aspiration with chronic lung disease (Rabie et al., 2007: 19). Developmental regression in HIV/AIDS encephalopathy has been noted over all areas of development; motor, cognitive, socio-emotional, language, vision and hearing (Mubaiwa, 2008: 1). The Speech-Language Therapist and Audiologist thus should provide assessment and intervention services which are essential to this population.

- **Lymphoid Interstitial Pneumonia (LIP)**

Figure 4.5 documents the presence of HIV/AIDS Associated Conditions in the current study. 8 cases of LIP were recorded, which is an expected finding, as LIP represents 25 - 40% of the pulmonary disease burden in HIV/AIDS infected children. (Rabie et al., 2007: 20).

- **Bronchietasis**

In the current study, 4 cases of Bronchietasis were documented (Figure 4.5), which is anticipated, as Bronchietasis occurs in up to 16% of children with HIV/AIDS infection. HIV/AIDS infected children are vulnerable to develop bronchiectasis for a number of reasons, namely; recurrent and/or severe pulmonary infections resulting from impaired immunity, as well as compromised

local defense mechanisms; LIP; and neurodevelopmental abnormalities/ oesophagitis that may lead to repeated aspiration (Rabie et al., 2007: 20). In this study, 8 children presented with LIP, which may thus have contributed to the occurrence of Bronchietasis.

- **Seizures**

Seizure activity was recorded in only 1 case in the current study. This finding correlates to literature regarding seizure presentation in the HIV/AIDS infected child, emphasising that seizures are not usually associated with HIV related CNS disease, as HIV/AIDS primarily affects the white matter of the brain. However, simple febrile seizures may occur (Rabie et al., 2007: 19), which may be the case in this study.

- **Summary**

The results obtained in the current study appear to be a representative sample of the HIV/AIDS associated conditions in the pediatric HIV/AIDS population in South Africa in general, according to local literature (Rabie et al., 2007; Marais et al., 2006; Mubaiwa, 2008), with static encephalopathy presenting as the most common medical condition. These opportunistic infections and associated conditions are likely to have a pervasive effect on the HIV/AIDS infected childrens' general development.

4.3.4 HIV/AIDS Associated Failure-to-Thrive (FTT)

The prevalence of FTT amongst the target sample is graphically presented in Figure 4.6 below:

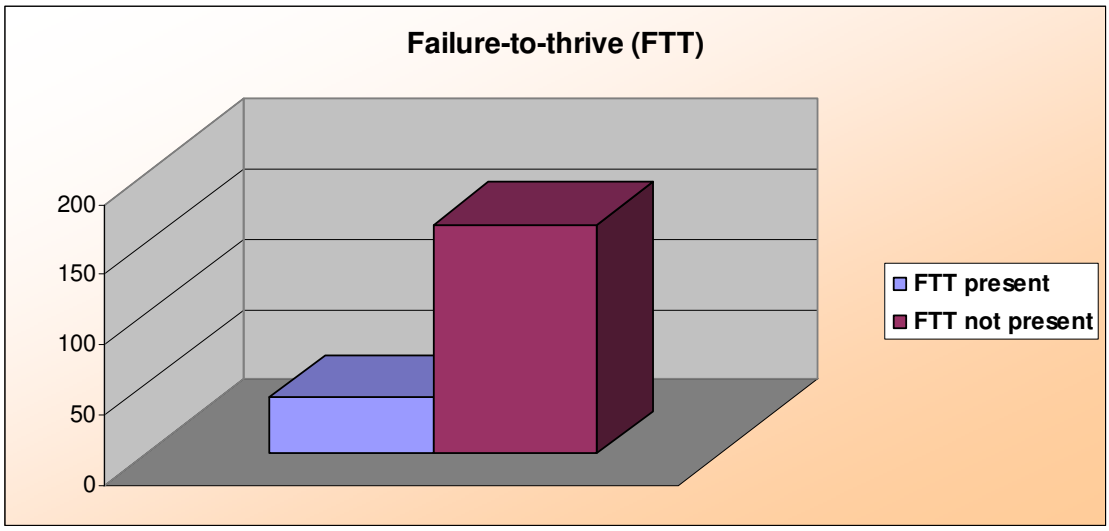

Figure 4.6 Failure-to-thrive (FTT) in HIV/AIDS infected children (n=203)

FTT was a presenting feature in 40 of the children in the current study, which is an anticipated finding. According to Van Kooten Niekerk et al., (2005: 10), failure-to-thrive is a major predictor for death in HIV/AIDS infected children, and should be considered for a classification system of disease severity in African children. Conversely, in a study by De Lange (2003), the majority of HIV/AIDS infected children seen at a care centre in Gauteng did not display signs of FTT, although it was noted that this is not representative of the pediatric HIV/AIDS population according to relevant literature. It appears that the HIV/AIDS infected infants in this study present with FTT as a significant feature, in keeping with relevant literature.

4.3.5 Caregivers

Figure 4.7 below describes the primary caregivers of the children with HIV/AIDS at the outreach clinic:

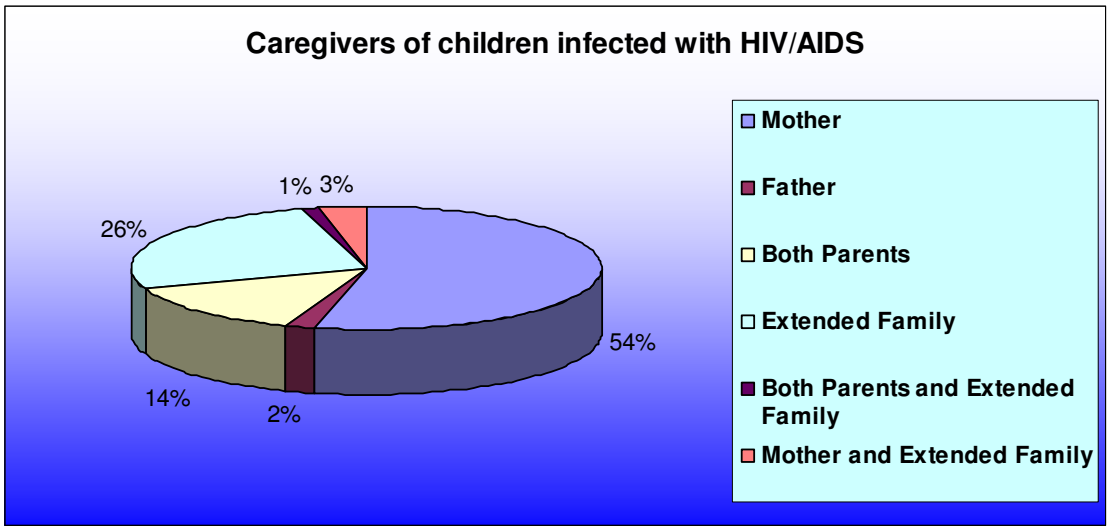

Figure 4.7 Caregivers of HIV/AIDS infected children (n=203)

According to Figure 4.7, the majority (54%) of the HIV/AIDS infected children at the outreach clinic are in the care of their mother (as a single parent), with no other adult family member residing in the same home. Fifty-three children are in the care of their extended family alone and not in the care of either biological parent. This may be contributed to the increasing social impact of HIV/AIDS within the South African context, with an estimate of 1,91 million children orphaned by HIV/AIDS by 2009 (www.statssa.gov.za), leaving extended family members (usually grandparents) to take on the role as primary caregiver (Mamaila, 2005: 3). This finding concurs with that of Van Kooten Niekerk et al., (2005), where mothers as primary caregivers were by far in the majority. This has further implications, as most children acquire HIV/AIDS through vertical transmission, the majority of these mothers will themselves be infected with

HIV/AIDS. With the likelihood of reduced health, the possibility of primary caregiver having to fall on the extended family is increased. This is likely to impact on the HIV/AIDS infected child's general and communicative development, with increased demands being placed on caregivers, with the potential for reduced stimulation and for interaction between child and caregiver.

Social demographics of the HIV/AIDS infected children in the current study seem to be in keeping with the demographics of the HIV/AIDS infected children in at least one other locally relevant study.

4.4 PRESENCE OF COMMUNICATION DISORDERS IN THE PEDIATRIC HIV/AIDS INFECTED POPULATION AT THE OUTREACH CLINIC

The description of the presence of communication disorders within the HIV/AIDS infected children was taken from the Communication Disorders section of the checklist and is described below.

4.4.1 Associated Factors affecting Communication Development

Figure 4.8 represents the associated factors affecting communication development that were documented in the hospital records of the HIV/AIDS infected children being managed at the outreach clinic:

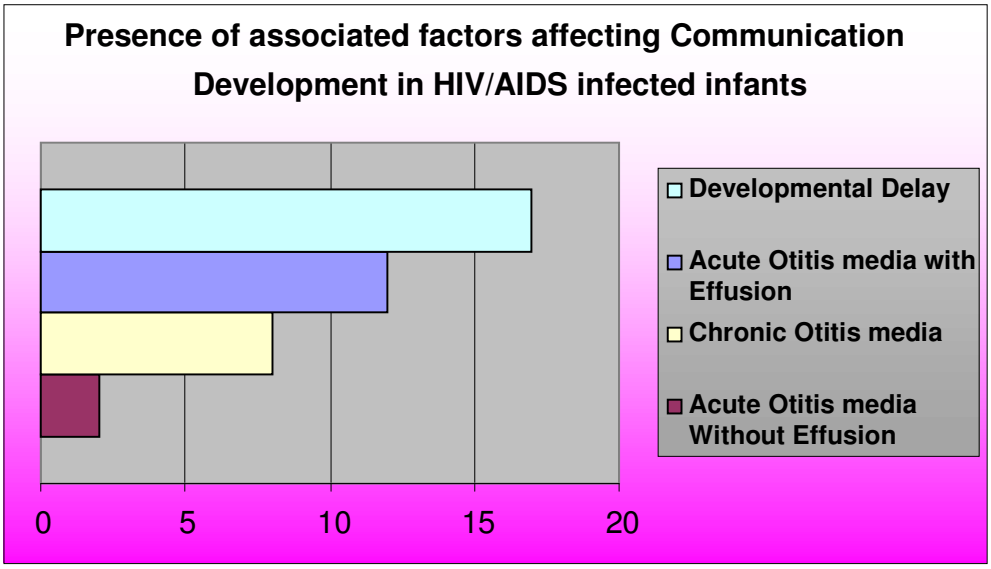

Figure 4.8 Presence of associated factors affecting Communication Development in HIV/AIDS infected children (n=39)

- **Developmental Delay**

According to Figure 4.8, 17 children were indicated as presenting with developmental delay in the current study. Results obtained from the medical characteristics of the children, would imply a greater number of children presenting with a delay in development than the 17 recorded, as the majority of the HIV/AIDS infected children were Stage III and Stage IV disease progression with low CD4%. The predominant developmental feature of pediatric HIV/AIDS is a pattern of developmental delay in infancy. Developmental delays are present in the majority of symptomatic children infected with HIV/AIDS, with reports of involvement ranging from 60 to 90% of children (McNeilly, 2005: 305). It is not clear whether the HIV/AIDS infected children being treated at the outreach clinic indeed did not present with developmental delay, or whether no record was made regarding the developmental status of the remaining 186 children within the total sample, even if developmental delay was a presenting characteristic.

- **Otitis media**

A total of 12 cases of acute otitis media with Effusion, and 2 cases of acute otitis media without, were documented in this study (Figure 4.8). A further 8 cases of chronic otitis media were recorded in the hospital records of the HIV/AIDS infected children being managed at the outreach clinic. HIV/AIDS is a known risk factor for otitis media (Swanepoel et al., 2004: 635). Although exact prevalence data regarding otitis media and HIV/AIDS infected children does not exist, otitis media with risk for hearing loss is a frequent manifestation of HIV/AIDS infection (Gold & Tami, 1998: 165). Conductive hearing losses are seen in 50% of HIV/AIDS infected infants and children, and 5% have severe to profound sensorineural hearing losses (McNeilly, 2005: 305). It is therefore likely that a significant percentage of HIV/AIDS infected children in this study would present with hearing loss. No information regarding the presence of hearing loss, or suspected hearing loss was recorded in the hospital records of the HIV/AIDS infected children in the current study.

- **Summary**

The presence of disorders affecting communication development detailed in the clinic records of HIV/AIDS infected infants was lower than expected. This finding may have a significant impact on the provision of ECI services to this population, as the potential for communication delays and/or disorders are not identified by medical doctors treating these children within the outreach clinic.

4.4.2 Aspects of Communication Development

Results regarding aspects of communication development in the pediatric HIV/AIDS population being managed at the outreach clinic were taken from the Communication section of the checklist, and are discussed below.

- **Language and Speech Development**

Information regarding the speech production and speech development of HIV/AIDS infected children being managed at the outreach clinic was not documented in the children' hospital records. The records of 5 children indicated that their expressive language use was on a single word level. These 5 children were aged between 16 and 27 months. No other data regarding the development of speech and language in the pediatric HIV/AIDS population being managed at the outreach clinic was documented in the children's hospital records. It is unclear whether speech and language development is an area included in the screening procedure of the medical doctors working with the pediatric HIV/AIDS population within the outreach clinic. According to McNeilly (2005: 306) language development deficits occur frequently within the pediatric HIV/AIDS population. Further international literature documents numerous types of speech and language problems occurring in the infant infected with HIV/AIDS (Screen & Lee-Wilkerson 2007; Mc-Farland, 2000; McNeilly, 2000). These include phonological errors, raspy and strained vocal quality, exacerbated with candidiasis in the oral-laryngeal cavity, expressive language delays, and receptive language delays. It is thus likely that many of the HIV/AIDS infected children being managed within the outreach clinic would present with delayed and/or disordered speech and language development, and were likely not receiving the necessary ECI services.

- **Feeding and Swallowing**

Feeding difficulties, such as nasopharyngeal incoordination, frequently occur in the pediatric HIV/AIDS population, and are an important pointer to neurological illness (Rabie et al., 2007:19). Although the prevalence of swallowing disorders and gastro-oesophageal reflux disease (GORD) within the pediatric HIV/AIDS population is poorly quantified, they are frequently encountered in clinical practice. Swallowing disorders may contribute significantly to morbidity in HIV/AIDS infected children (Rabie et al., 2007: 23). No information regarding

swallowing and/or feeding were recorded in the hospital records of HIV/AIDS children being managed at the outreach clinic, nor was the presence of a disorder in these areas documented. It is unclear whether feeding and/or swallowing are screened by medical doctors during the HIV/AIDS infected infant's initial and/or follow-up visits. The presence of feeding and/or swallowing disorders in the pediatric HIV/AIDS population necessitates the services of the Speech-Language Therapist (McNeilly, 2005: 306; Rabie at al., 2007: 23). Therefore, it is likely that feeding and/or swallowing difficulties indeed did occur in the pediatric HIV/AIDS population being treated at the outreach clinic, but that these children did not receive the necessary Speech-Language Therapy assessment and intervention services they require,

- **Summary**

Information obtained from the checklist regarding the communication development and presence of communication disorders within the pediatric HIV/AIDS population being managed at the outreach clinic was discussed. Information regarding the level of expressive language development was documented in 5 of the children. No further information regarding the communication development and/or presence of communication disorders was documented. It is not clear whether communication is an area that is screened by the medical doctors during the initial and/or follow-up visits of HIV/AIDS infected children being managed within the outreach clinic.

4.5 CURRENT PRACTICES SURROUNDING TEAM INVOLVEMENT WITH HIV/AIDS INFECTED CHILDREN AT THE OUTREACH CLINIC

The data for the description of the current practices surrounding team involvement with HIV/AIDS infected children was taken from the Team Involvement section of the checklist.

4.5.1 Referrals to other professional disciplines

Figure 4.9 graphically represents the referrals made by medical doctors treating HIV/AIDS infected children at the outreach clinic, to other professional disciplines.

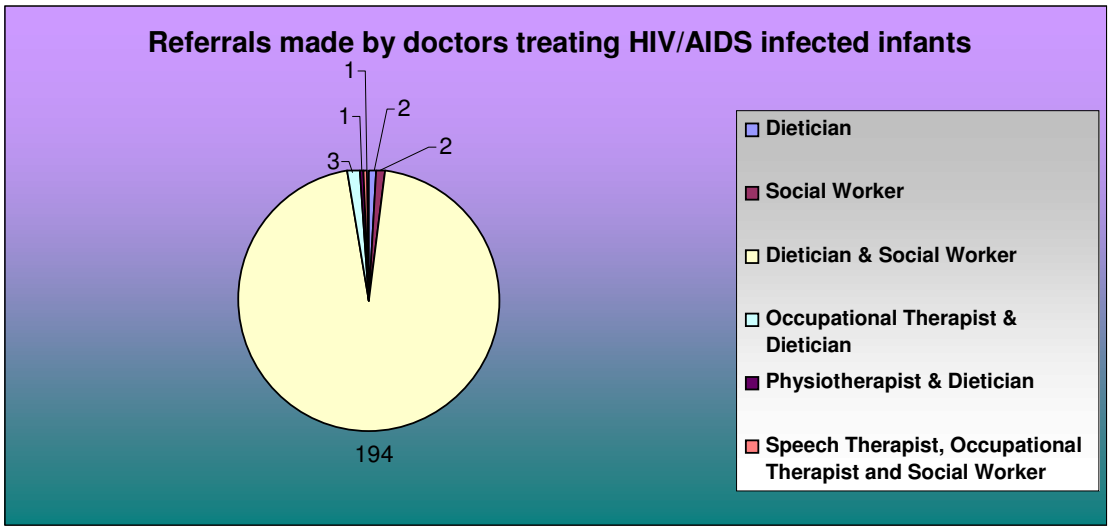

Figure 4.9 Referrals made to other professional disciplines

According to the Figure 4.9, almost all (194) of HIV/AIDS infected children being managed at the outreach clinic were referred to a Dietician and Social Worker for further management. The outreach clinic targeted in this study had a full time Dietician and Social Worker employed within the clinic at the time the data was collected. It can therefore be noted that the vast majority of children were receiving nutritional support as well as assessment and management of social aspects within the outreach clinic. Children depend on parents and/or caregivers to bring them to the outreach clinic, as well as administer and manage their medication. A stable social circumstance and the identification of a reliable caregiver are therefore essential (Rabie et al., 2006: 55). Malnutrition is a common feature in many HIV/AIDS infected children, particularly those under 2 years of age (Van Kooten Niekerk, 2005: 9). It is therefore essential that

HIV/AIDS infected children receive nutritional management in order to optimize their nutritional status. 3 of the HIV/AIDS infected children being managed at the outreach clinic were referred to an Occupational Therapist as well as a Dietician.

3 of the children with HIV/AIDS infection were referred to an Occupational Therapist as well as to a Dietician, and a further 1 referred to a Physiotherapist as well as a Dietician. According to Schaaf, Sherwin and Youngblood (1997: 65), HIV/AIDS infected children with progressive encephalopathy, which usually includes motor dysfunction. Progressive motor dysfunction involves impairment of upper motor neuron pathways and may also encompass disruption of other areas of motor control including tone and posture, spatial orientation and balance. Children demonstrate deterioration of fine motor function, hypertonia of the lower extremities, tonal abnormalities, truncal hypotonia and poor head control. Those HIV/AIDS infected infants and children with static encephalopathy present with static motor dysfunction (Schaaf et al., 1997: 65). With 13 and 2 children in this study presenting with progressive and static encephalopathy respectively, the need for Physiotherapy and Occupational Therapy services to this population is highlighted. It is unclear whether further children infected with HIV/AIDS, that were being managed at the outreach clinic, were referred for Physiotherapy and Occupational Therapy services and this was merely not documented in their hospital files, or whether these referrals were indeed not made.

A mere 1 infant infected with HIV/AIDS being managed at the outreach clinic was referred for Speech-Language Therapy and/or Audiological assessment and intervention. As previously mentioned it is unclear whether further children infected with HIV/AIDS that were being managed at the outreach clinic, were referred for Speech-Language Therapy and/or Audiological assessment and intervention services and this was merely not documented in their hospital files, or whether these referrals were indeed not made. Results obtained regarding the medical characteristics of the children infected with HIV/AIDS in this study clearly

indicate the high risk for delay and disorder in the communication development of this population.

4.5.2 Team Approach within the outreach clinic

The team approach being implemented within the outreach clinic, with regards to the assessment and management of the pediatric HIV/AIDS population at the time of the current study, was not documented within the hospital records of the children. Although the exact team approach followed within the outreach clinic is unclear, the conclusion can be drawn from the above results that there was indeed a referral system in place, but not all necessary professional disciplines were being utilized. The assumption is made that teamwork exists, at best, on an interdisciplinary level when working with the pediatric HIV/AIDS population. According to Rossetti (2001: 118), the transdisciplinary approach to ECI service delivery involves the clear and goal-directed exchange of information, as well as group decision making regarding all areas of intervention.

4.5.3 Summary

The results regarding teamwork and referrals made to other professional disciplines, obtained from the current study, were documented and discussed. A large percentage of the children with HIV/AIDS being managed within the outreach clinic were referred to a Social Worker as well as Dietician. This is likely due to the social concerns involved in the initiation of HAART, as well as the necessity for adequate nutrition (Department of Health, 2005). Referrals to other disciplines namely Speech-Language Therapists, Physiotherapists and Occupational Therapists, were documented in only 2.46% of the total sample, despite the pediatric HIV/AIDS population's need for such intervention services as highlighted in local and international literature (McNeilly, 2005; Rabie et al., 2007; Schaaf et al., 1997; Louw 2004; Swanepoel et al., 2004). The model of

teamwork being implemented within the outreach clinic at the time of data collection was unclear, although the assumption could be made that teamwork existed on a multidisciplinary level.

4.6 PERCEPTIONS AND PRACTICES OF MEDICAL DOCTORS WORKING WITH THE PEDIATRIC HIV/AIDS POPULATION WITHIN THE OUTREACH CLINIC

Data concerning the perceptions and practices of medical doctors, working with the pediatric HIV/AIDS population within the outreach clinic, was taken from the questionnaires completed by the respondents. Results are discussed below.

4.6.1 Time spent during initial assessment

Figure 4.10 documents the approximate time spent by medical doctors on the initial assessment of each child with HIV/AIDS being managed within the outreach clinic.

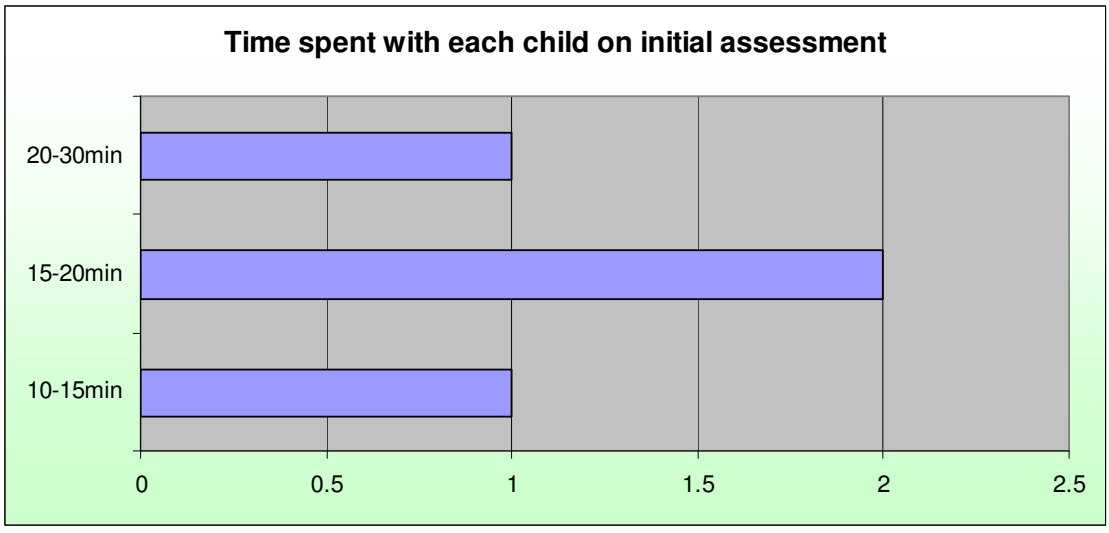

Figure 4.10 Time spent by medical doctors during the initial assessment of a child infected with HIV/AIDS (n=4)

The medical doctors' initial assessment of the HIV/AIDS infected child at the outreach clinic was between 10 and 30 minutes. Factors affecting the amount of time spent with each child are not documented, but possible influential factors include; large daily caseloads as well as several medical areas of assessment to be addressed during the initial assessment. This may be a likely reason that referrals to the necessary professional disciplines are not routinely made when necessary, as time constraints do not allow for a holistic developmental assessment/screening to be performed by the doctor.

4.6.2 Time spent during follow-up visit

Results taken from the questionnaire regarding the time spent on each HIV/AIDS infected child during a follow-up visit are graphically represented in Figure 4.11.

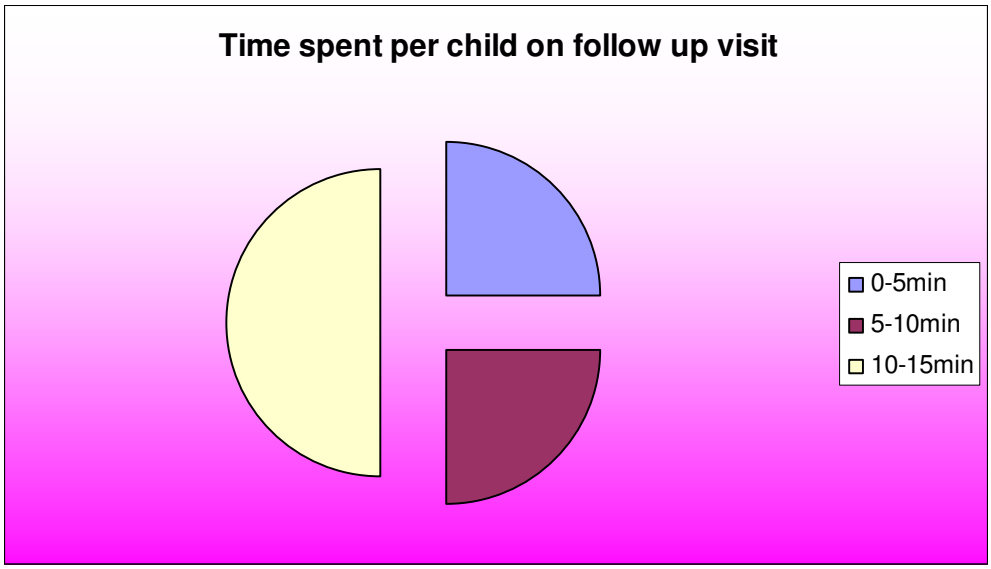

Figure 4.11 Time spent by medical doctors during an HIV/AIDS infected child's follow-up visit to the outreach clinic (n=4)

Follow-up visits to the outreach clinic were between 0 to 10 minutes. Similarly, a primary factor affecting the length of follow-up visits is likely to be high patient loads per medical doctor working within the outreach clinic. The protocol followed during each child's follow-up visit is unclear and hence the appropriate length of time per follow-up visit could not be determined.

4.6.3 Medical Doctors perceptions regarding pediatric HIV/AIDS and delays and/or disorders in communication development

The perceptions of medical doctors working within the outreach clinic regarding HIV/AIDS infected children, and the presence of communication disorders is tabulated in Table 4.2. The majority of the respondents observed that children infected with HIV/AIDS being managed at the outreach clinic often presented with general developmental delays. Delays in language development as well as feeding and/or swallowing difficulties, were sometimes noted, but only indicated as being a frequent characteristic of the HIV/AIDS infected child by one of the respondents. Cognitive difficulties were only noted as sometimes being present by all of the respondents.

Table 4.2 Perceptions regarding the HIV/AIDS infected population and communication disorders

	Sometimes	Often
General Developmental Delay		**4**
Delay in Language Development	**3**	**1**
Cognitive Difficulties	**4**	
Feeding and/or Swallowing Difficulties	**3**	**1**

Table 4.3 indicates the comparison between HIV/AIDS infected children being managed at the outreach clinic and children from the general population. All of the respondents indicated that the presence of general developmental delay occurs more frequently in the HIV/AIDS infected pediatric population being managed at the outreach clinic, compared to children in the general population. Half the respondents perceived the presence of language delays, cognitive difficulties as well as feeding and/or swallowing difficulties to be more of a problem in the pediatric HIV/AIDS population when compared to children in the general population. The remaining half did not perceive a difference in the presence of these disorders within HIV/AIDS infected children when compared with children from the general population.

Table 4.3 Comparison between HIV/AIDS infected children at the outreach clinic and children from the general population

	The same	More of a problem
General Developmental Delay		**4**
Delay in Language Development	**2**	**2**
Cognitive Difficulties	**2**	**2**
Feeding and/or Swallowing Difficulties	**2**	**2**

Table 4.4 documents the respondents' perceptions regarding the likely reasons for the presence of delays in communication development. All of the respondents cited reduced stimulation by caregivers, malnutrition, poor socioeconomic status, compromised neurological status and presence of opportunistic infections as likely reasons for a child infected with HIV/AIDS to present with general developmental delay. 2 of the respondents cited recurrent otitis media as a likely cause for the presence of delayed language development. The reason for lack of documented referrals for Speech-Language Therapy and/or Audiological intervention services for the pediatric HIV/AIDS population being managed within

the outreach clinic is thus unknown, as at least half of the respondents are aware of the high risk for hearing loss and communication delay posed by chronic otitis media.

Table 4.4 Likely reasons for delays in communication development

	Reduced Stimulation by Caregivers	Malnutrition	Poor Socioeconomic Status	Compromised Neurological Status	Presence of Opportunistic Infections
General Developmental Delay	4	4	4	4	4
Cognitive Difficulties		3	3	3	2
Delayed Language Development	2	2		3	1
Feeding and/or Swallowing Difficulties		1	1	2	1

The respondents' perceptions regarding the need for Speech-Language Therapy and/or Audiological intervention services for the pediatric HIV/AIDS population is detailed in Table 4.5. Only 1 of the respondents felt that it was always necessary for children infected with HIV/AIDS to receive Speech-Language Therapy management, and that these children would indeed benefit from such assessment and intervention services. Half of the respondents perceived Audiological intervention to be a necessary service in some cases, in which they felt that only some children would benefit from audiological intervention. All respondents were in agreement that a team approach to intervention, when working with the pediatric HIV/AIDS population, is more often than not a valuable service to children infected with HIV/AIDS. These results highlight the respondents' perception that Speech-Language Therapy and Audiological intervention services are often a necessary and beneficial part of the management of the HIV/AIDS infected child. It is unclear as to the low rate of

document referrals made to Speech-Language Therapists and Audiologists as professional disciplines.

Table 4.5 Perceptions regarding Communication Intervention services for the HIV/AIDS infected population

	Sometimes	Often	Always
Requires Speech-Language Therapy	**1**	**2**	**1**
Would benefit from Speech-Language Therapy	**1**	**2**	**1**
Requires Audiological Intervention	**2**	**2**	
Would benefit from Audiological Intervention	**2**	**2**	
Would benefit from a Team Approach to Intervention		**3**	**1**

All of the respondents were of the opinion that doctors are not always sufficiently aware of the impact that delayed assessment of general, language, cognitive and feeding and/or swallowing disorders may have on the HIV/AIDS infected child. This supports the very low referral rate of HIV/AIDS infected children to the Speech-Language Therapist and Audiologist documented in this study.

4.6.4 Summary

Results obtained from the questionnaires, completed by the medical doctors working with the pediatric HIV/AIDS population within the outreach clinic, were documented and discussed. The respondents appeared to perceive general developmental delay within the pediatric population as the main disorder present in children infected with HIV/AIDS, and yet only 8.37% of the total sampled children were documented as having general developmental delay. Respondents also appeared to be aware of the possible presence of delays in language and cognitive development in the HIV/AIDS infected population. It is thus not clear why such low rates of speech, language and cognitive delays and/or disorders were documented in the hospital records of those children infected with HIV/AIDS, who were being managed at the outreach clinic. It is also not clear as to the reason for the low referral rate to Speech-Language Therapists and Audiologists, as documented in the study. Possible reasons may be attributed to the lack of locally relevant, researched-based literature regarding the communication development of children infected with HIV/AIDS available, as well as the lack of training that medical doctors receive, regarding the role of the Speech-Language Therapist and Audiologist in the assessment and treatment of the HIV/AIDS infected child.

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

Aim: The aim of this chapter is to draw relevant and appropriate conclusions from the results obtained in this study, as well as provide a critical evaluation of the study as a whole. Recommendations for further research are presented and discussed.

5.1 INTRODUCTION

The impact of HIV/AIDS on the most affected countries has meant that life expectancy has dropped by almost 20 years, poverty has increased and economies have been drastically affected (UNAIDS: 2008: 13). For countless infants and children, the presence of HIV/AIDS has drastically changed the manner in which they are being forced to grow up (UNAIDS: 2008: 2). HIV/AIDS has been shown to have significant effects on the global development of an infected child, with particular delays and disorders noted in speech, language, hearing and overall communication (Screen & Lee-Wilkerson 2007; Mc-Farland, 2000; McNeilly, 2000). There is, however, a lack of locally relevant research based literature regarding HIV/AIDS and communication development in the infected infant.

Research based literature for the Speech-Language Therapist and Audiologist allows for the support of clinical decisions when working with a given population (Kahmi, 2006:255). This research study may serve as a precursor for further research, assisting with the maintenance of Evidence-Based Practice when working with the pediatric HIV/AIDS population.

The current study aimed to address the lack of appropriate local literature regarding pediatric HIV/AIDS and communication development through a retrospective record review. The characteristics of a group of HIV/AIDS infected children at a regional hospital in Gauteng were described and discussed. The perceptions and practices of the medical doctors working with the pediatric HIV/AIDS were also discussed. This chapter highlights and discusses conclusions that can be drawn from the current study. A critical review of the study is made. Areas for future research are introduced and discussed, aiming for the continuation of research into the field of pediatric HIV/AIDS and communication development.

5.2 CONCLUSIONS

The conclusions regarding the results obtained in this study are discussed below:

Results obtained regarding the medical characteristics of the pediatric HIV/AIDS population being managed at the outreach clinic showed that 91.62% of the children aged 0-5years 11months were diagnosed as either Stage III or IV HIV/AIDS, with all infants presenting with a CD4% of less than 60. The majority of these children (75.37% of the total sample) were receiving HAART at the time the data was collected. This is a positive sign, as it implies that outreach clinics within South Africa are well on their way to implementing treatment initiation for HIV/AIDS infected infants as stated by WHO (2008) and the Department of Health.

HIV/AIDS infected children being managed at the outreach clinic presented with several opportunistic infections, with 38.42% of the total sample having been diagnosed with TB. A total of 8 children were diagnosed with meningitis. According to Mubaiwa (2008) at least 80% of HIV/AIDS infected infants and children with meningitis will require multidisciplinary assessment and intervention due to the subsequent cognitive difficulties caused by the meningitis.

Furthermore, HIV/AIDS associated conditions such as Static and Progressive Encephalopathy were present in 12 and 2 infants respectively.

This study also investigated the HIV/AIDS infected children's primary caregiver as was recorded in each child's hospital records. Results show that the majority of children (53.69% of the total sample) were in the care of their mother. This is in keeping with other local literature which shows the mother as the primary caregiver (Van Kooten Niekerk et al.,:2005). A total of 53 children were in the care of their extended families, which is likely due to the loss of their parents to HIV/AIDS, although this cannot be confirmed.

In the current study, 8.37% of the total sample were recorded as presenting with general developmental delay. It is expected, however, that developmental delay present as the predominant feature in HIV/AIDS infected infants (McNeilly, 2005: 305), and therefore the lower than expected presentation of developmental delay recorded in this study is not in keeping with international literature. Fewer than 25 individual cases of otitis media were recorded within the total sample, even though at least half of infants and children with HIV/AIDS present with conductive hearing loss, with middle ear infection as a predominant feature (McNeilly, 2005: 305; Gold & Tami, 1998: 165).

The model of teamwork being enforced at the time of the study was unclear. 95.57% of the total sample had been referred to a Dietician and Social Worker, both of which are full-time employees within the outreach clinic. Very few children were referred to other professionals, with only 0.49% of the total sample being referred for Speech-Language Therapy and Audiology (1 child). With a high percentage of the HIV/AIDS infected children presenting with opportunistic infections and/or associated conditions, the conclusion can be reached that several, and ideally all of the HIV/AIDS infected children being managed at the outreach clinic should have been referred for ECI assessment and intervention services. It is unclear whether referrals to other professionals were indeed made

but not recorded in the children's hospital records, or whether the minimal referrals are a true reflection of the referral process at the time the data was collected.

All of the medical doctors working within the outreach clinic identified that children infected with HIV/AIDS presented with general developmental delay, and that this was more prevalent in the pediatric HIV/AIDS population when compared to the general pediatric population (McNeilly, 2005: 305). However, not all of the respondents thought that the pediatric HIV/AIDS population as a whole required Speech-Language Therapy and Audiology intervention services, and that they would indeed benefit from such services. Respondents were in agreement that medical doctors are not always adequately trained regarding the speech, language and hearing development of the HIV/AIDS infected child.

The results obtained in this study allowed for the research question posed to be answered. The medical characteristics of the children infected with HIV/AIDS were described and discussed. The developmental characteristics of the children infected with HIV/AIDS could not, however, be fully described, as data relied on the perceptions and practices of respondents, as well as the data collected from the children's clinic records.

5.3 CRITICAL EVALUATION OF THE STUDY

A critical evaluation of this study was necessary, allowing the researcher to identify several limitations and strengths of the study. Kahmi (2006: 256) highlights the need for research to be critically reviewed in order for reliable clinical decisions to be reached. Limitations and strengths identified in this study are discussed.

5.3.1 Limitations of the study

- A limited sample of respondents in this study implies that results obtained may not be representative of the perceptions and practices of the total population of medical doctors working with the pediatric HIV/AIDS population within the outreach clinic (Leedy & Ormrod, 2005: 207). The questionnaires sent out to the medical doctors within the outreach clinic were only completed and returned by 4 doctors.
- The retrospective nature of this study allowed for results regarding the characteristics of the pediatric HIV/AIDS population being managed at the outreach clinic to be based entirely on the data collected from the children's clinic records. Therefore conclusions were based on data either present or absent from the children's records and could not account for any information that may not have been recorded but may have indeed been present/have occurred. This is also true for information regarding teamwork and referrals made to other professional disciplines. In order to obtain more detailed information, a longitudinal study may be optimal, where characteristics of the pediatric HIV/AIDS population are collected at different times (Leedy & Ormrod, 2005: 183), allowing for a more comprehensive research process.

5.3.2 Strengths of the study

- Data collected regarding the characteristics of children infected with HIV/AIDS is useful, as it was taken from clinic records and provides information in a collated format to the hospital. This information can be expanded on in the future, allowing for an updated database at the hospital in question.
- Data collected regarding the characteristics of the HIV/AIDS infected infant provides much needed locally relevant research based information. This can serve as groundwork for future research which may be extended

into larger, more representative samples (if ethical clearance is obtained) surrounding the HIV/AIDS infected infant and the Speech-Language Therapist and Audiologist's involvement in assessment and management of this population.

Limitations and strengths of this study were identified and discussed, with Evidence-Based Practice as the rationale for the critical evaluation (Kahmi, 2006: 256).

5.4 CLINICAL IMPLICATIONS OF THE STUDY

The current study aimed to describe the characteristics of a group of children infected with HIV/AIDS who were being managed at an outreach clinic within a regional hospital in Gauteng. Implications of the results of this study will be discussed below:

It can be concluded that several children infected with HIV/AIDS being treated at the outreach clinic at the time this study was conducted, present with opportunistic infections and/or HIV/AIDS associated conditions. The presence of such infections and/or conditions is such that several children would require ECI services, due to the impact on normal speech, language and hearing development (Screen & Lee-Wilkerson 2007; Mc-Farland, 2000; McNeilly, 2000).

The predominant feature obtained from this section of results is that very few children with HIV/AIDS being managed at the outreach clinic were recorded as presenting with delays and/or disorders in speech, language and hearing. This has a direct impact on the Speech-Language Therapist and Audiologist. By implication, several children infected with HIV/AIDS may not be provided with the essential ECI services as they were not identified as candidates for assessment and intervention by the Speech-Language Therapist and Audiologist (Rossetti, 2001:33). It is not clear whether these children, according to the medical doctors

treating them within the outreach clinic, indeed did not present with delays and/or disorders in communication, or whether they were identified as candidates for ECI services but this was not recorded in their medial records. It is thus the responsibility of the Speech-Language Therapist and Audiologist working within the clinical setting to advocate the role of ECI service delivery to the pediatric HIV/AIDS population. This can only be achieved through further, locally relevant research (Louw, 2004), which would provide useful information for both the Speech-Language Therapist and Audiologist as well as medical and allied professionals regarding communication development and ECI service delivery to the pediatric HIV/AIDS population. HIV/AIDS infected children present with several family dynamics (Mamaila, 2005), impacting on their social situations. The Speech-Language Therapist and Audiologist needs to be aware of the social dynamics involved in the HIV/AIDS infected child's home and family situation.

Results further highlight the need for the Speech-Language Therapist and Audiologist to be more actively involved in the team responsible for the management and care of children with HIV/AIDS being treated at outreach clinics (McNeilly, 2005: 307). Where resources allow it, ECI assessment and intervention services should ideally be carried out within the outreach clinic itself, and all HIV/AIDS infected children and their families' and caregivers should be provided with ongoing ECI service delivery parallel to medical care and management.

There is a probable link between the doctors' knowledge regarding pediatric HIV/AIDS and communication development and the low referral rates to the Speech-Language Therapist and Audiologist. This has implications for future research projects which would allow for the improvement of professional relationships and team participation when working with the pediatric HIV/AIDS population. The results from this study clearly identify the dire need for medical doctors and other allied health care professionals to be provided with locally relevant literature and/or training regarding the communication development of

the HIV/AIDS infected child. In clinical settings where it is not possible for the Speech-Language Therapist and Audiologist to provide full-time services from the outreach clinic, ECI service delivery to the pediatric HIV/AIDS population will depend largely on referrals from other professionals. It is thus likely that HIV/AIDS infected children requiring ECI services will either not have access to them, or not receive them timeously.

5.5 RECOMMENDATIONS FOR FUTURE RESEARCH

Several areas requiring further research were identified in this study. Recommendations in this regard will be discussed below:

- It is recommended that the research design implemented in this study be repeated in other clinical settings within the South African context to allow for a comprehensive description of the characteristics of the pediatric HIV/AIDS population. This study only allowed for a small sample of children infected with HIV/AIDS to be targeted (Leedy & Ormrod, 2005: 207), therefore results cannot be generalised to the larger population. A longitudinal study may be optimal for further research (Leedy & Ormrod, 2005: 183), allowing for more comprehensive data regarding the characteristics of the pediatric HIV/AIDS population within South Africa.
- The assessment and description of communication development in infants and children infected with HIV/AIDS should be researched within the South African context (Louw, 2004). The current study did not allow for the communication development of the children infected with HIV/AIDS to be assessed by a Speech-Language Therapist and Audiologist. A description of communication development both in infants and children who are receiving HAART and those not receiving antiretroviral therapy, would further impact the quality of ECI services provision to this population. The Speech-Language Therapist and Audiologist would be provided with locally relevant information regarding the medical aspects of the HIV/AIDS

infected child, allowing for a holistic approach to intervention. It is essential that the Speech-Language Therapist and Audiologist be knowledgeable regarding the treatment regimen children infected with HIV/AIDS, as well as the effects on aspects of development (McNeilly, 2005: 307).

- The communication development of HIV/AIDS infected infants who have been orphaned by HIV/AIDS should be profiled against HIV/AIDS infected infants who are in the care of their biological parent/s. The current study did not allow for the comparison between the characteristics of orphaned children and children living with one or both parents. This will allow the Speech-Language Therapist and Audiologist to provide appropriate ECI services to HIV/AIDS orphans.
- Future research into the development of a communication screening tool to be used by medical doctors working with the pediatric HIV/AIDS population is necessary. The use of such a tool could assist medical doctors and other professionals in the identification of those infants who are high-risk for delayed and/or disordered speech, language and hearing development. This would aid necessary referrals, and thereby ensure that timeous ECI assessment and intervention services can be provided to the pediatric HIV/AIDS population.

The need for future research which investigates the perceptions and practices of other allied professionals such as Occupational Therapists, Dieticians and Social Workers is highlighted

5.6 FINAL COMMENTS

With very few appropriate referrals being made to the Speech-Language Therapist and Audiologist in this study, it is clear that both the medical profession, as well as the profession of Speech-Language Therapy and Audiology, are in dire need of locally relevant research based literature. This study aimed to provide information regarding the characteristics of a group of children infected with HIV/AIDS, answering the call for locally relevant literature regarding this population. Optimal ECI service delivery to the pediatric HIV/AIDS population can only be achieved by the ongoing clinical research within the Speech-Language Therapy and Audiology profession, in order to increase and improve knowledge and skills. Only then can ECI services to the pediatric population reach the necessary standard of best practice (Rossetti, 2001: 266).

"The global HIV/AIDS epidemic is an unprecedented crisis that requires an unprecedented response. In particular it requires solidarity -- between the healthy and the sick, between rich and poor, and above all, between richer and poorer nations. We have 30 million orphans already. How many more do we have to get, to wake up?" Kofi Anan

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