

**FEEDING OF INFANTS WITH
PAEDIATRIC HIV/AIDS AT CARE
CENTRES IN GAUTENG**

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ABSTRACT

The paediatric HIV/AIDS population is expanding and speech-language therapists are required to treat these individuals in a range of settings for various complications, including oral-motor difficulties. Increased research and knowledge is essential in the treatment of these young children as this may result in improved service provision and facilitation of successful feeding by the speech-language therapist and caregivers in various settings. The nutritional management, - including diagnosis and management of swallowing disorders - of a young child with paediatric HIV/AIDS is of primary importance as malnutrition predisposes affected children to further opportunistic infections and malabsorption of nutrients.

The main aim of this study was to describe the feeding behaviour of twelve 6 – 36 month-old children with paediatric HIV/AIDS in care centres in Gauteng. The participants were selected from two care centres that cater for children with HIV/AIDS. An exploratory descriptive research design was selected, where observation and assessment were employed to describe the feeding of these young children.

The results of the study indicated that the participants presented with functional feeding skills, with a few individuals presenting with various feeding problems. The results also indicated that the children appear to be functioning well in the care centre environment. In addition, the feeding behaviour of the children was highly individual. Therefore, a number of disciplines should be involved in the intervention in the paediatric HIV/AIDS population, including the speech language therapist in order to provide optimal feeding intervention.

OPSOMMING

Die pediatriese MIV/VIGS populasie is tans besig om toe te neem, en daar word van spraak-taalterapeute verwag om hierdie individue in verskeie kontekste, vir 'n verskeidenheid komplikasies, insluitende oral-motoriese probleme te behandel. Verdere navorsing en kennis word benodig in die behandeling van hierdie jong kinders, om te lei tot verbeterde dienslewering en die fasilitering van suksesvolle voedingsintervensie deur die spraak-taalterapeut en sorggewers in verskillende kontekste. Voedingsintervensie, wat nutrisionele aspekte sowel as die evaluasie en behandeling van slukafwykings insluit by jong kinders, met pediatriese MIV/VIGS, is van belang, omdat wanvoeding en ondervoeding die moontlikheid skep van verdere opportunistiese infeksies en wanabsorpsie.

Die hoofdoel van die studie was om die voeding van 6 – 36 maande oue kinders met pediatriese MIV/VIGS in sorgsentrums in Gauteng te beskryf. Die deelnemers is van twee sorgsentrums wat vir kinders met pediatriese MIV/VIGS sorg geselekteer. 'n Verkennende, beskrywende navorsingsontwerp is geselekteer, waarin waarneming en evaluasie gebruik is, met die doel om die voeding van hierdie kinders te beskryf.

Die verkreeë resultate het getoon dat die deelnemers van die studie funksionele voedingsvaardighede het, maar 'n paar het wel voedingsprobleme vertoon. Die kinders het oënskynlik goed in die sorgsentrumomgewing gefunksioneer. Die resultate het ook aangetoon dat die voedingsgedrag van dié kinders hoogs individualisities is. Daarom behoort 'n verskeidenheid dissiplines betrokke te wees in die intervensie van die pediatriese MIV/VIGS populasie, insluitende die spraak-taalterapeut om optimale voedingsintervensie te verskaf.

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1. INTRODUCTION

“Because there are communication and dysphagia problems that are unique to this disease process, professionals must become knowledgeable about treating children with AIDS” (Pressman, 1992, p.45). The paediatric HIV/AIDS population is expanding and speech-language therapists are required to treat these individuals in a range of settings (Committee on Pediatric AIDS, 2000; Pressman, 1992) for various complications, including oral-motor difficulties.

International literature is available on paediatric HIV/AIDS, however, locally a dearth of research has been identified in the field of communication disorders, including feeding problems in paediatric HIV/AIDS (Bam, Kritzinger & Louw, 2003). It is vitally important that health professionals, including speech-language therapists, become involved in the treatment of young children with paediatric HIV/AIDS in South Africa as research has shown that the prevalence of HIV/AIDS remains alarmingly high in all the provinces and in most age-groups (Department of Health, 1999). A great concern of health care services is that socio-economic factors such as poverty, illiteracy and lack of formal education also contribute to the HIV/AIDS pandemic in South Africa (HIV/AIDS & STD Strategic Plan for South Africa 2000-2005, 2000). Presently government legislation is being amended so that HIV positive pregnant women will be provided with antiretroviral treatment lessening the chance of HIV transmission from mother to child, and hopefully the medication will also become available for the children. With the introduction of antiretroviral treatment the prognosis for children with paediatric HIV/AIDS is much improved (Davis-McFarland, 2000). By implementing early intervention the affected person’s prognosis, as well as quality of life, can be improved (Bobat, Coovadia, Moodley & Coutsooudis, 1999). Therefore, increased research and knowledge is essential in the treatment of young children with paediatric HIV/AIDS (Pressman, 1992) as this may contribute to improved service provision, especially in the areas of speech, language and

facilitation of successful feeding by the speech-language therapist and caregivers in various settings.

Issues related to the feeding process of young children with paediatric HIV/AIDS were identified by conducting a literature review. These issues include the feeding process in normal young children; oral-motor development; the link between feeding and communication; the risk of abnormal development and functioning present in paediatric HIV/AIDS including dysphagia; and the role of the speech language therapist in the team treatment of feeding problems in the paediatric HIV/AIDS population, and will be discussed forthwith.

Successful feeding in young children is a complex and dynamic process that depends on factors such as the child's oral musculature, physical health, oral sensitivity, positioning during feeding, the relationship with the caregiver, and interaction with the environment (Carreto, Topolski, Linkous, Lowman & Murphy, 2000). All these factors contribute to the child's ability to gain adequate nutrition. Good nutrition promotes growth and development of the child in all areas, including cognitive, social and communicative development (Billeaud, 1998). The most critical development period of brain growth and function occurs during the last trimester of pregnancy and the first two years of life, so malnutrition during this period may have long-term developmental consequences for the child (Newman, 2000). The nutritional management of a young child with paediatric HIV/AIDS is of primary importance as malnutrition predisposes affected children to further opportunistic infections and malabsorption (Newman, 2001; Eley & Hussey, 1999; Pressman, 1992). The diagnosis and management of swallowing disorders play an essential role in meeting nutritional needs (Newman, 2001). Growth failure often precedes the onset of opportunistic infections, therefore growth monitoring and appropriate interventions are necessary to limit nutritional deterioration in HIV infection (Eley & Hussey, 1999).

Oral-motor development depends on Central Nervous System (CNS) integrity (Wolf & Glass, 1992). One of the manifestations of paediatric HIV/AIDS disease is CNS dysfunction resulting from encephalopathy. A breakdown in the integrity of the CNS may result in muscle tone abnormalities that may compromise oral-motor development or result in a loss of oral-motor developmental milestones (Davis-McFarland, 2000). Hence, it is possible that HIV-related encephalopathy may result in abnormal oral-motor patterns that are not seen in normally developing children (Davis-McFarland, 2000). Young children with paediatric HIV/AIDS have been found to present with coughing/choking on thin liquids and solids, gagging, slow feeding, possible odynophagia, hypersensitivity, oral defensiveness and oral thrush (Evian, 2000; Pressman, 1992). All these factors may lead to nutritional compromise, reduced endurance for feeding, aspiration and failure to thrive (Hall, 2001; Davis-McFarland, 2000; Pressman, 1992). These abnormal oral-motor patterns and feeding concerns make young children with paediatric HIV/AIDS a unique population requiring special intervention. Young children with paediatric HIV/AIDS present with unique combinations of symptoms and problems and speech-language therapists who treat dysphagia in the paediatric population are required to take note of this. Oral-motor functioning is not only vital to feeding development and behaviour, but also of communication development. Thus, this population requires early intervention by the speech-language therapist, as oral-motor development is the foundation for the development of oral language (Davis-McFarland, 2000).

With regard to the relationship between feeding and communication, there is evidence to suggest that young children pay attention to their environment during and after feeding, which makes feeding time an optimal opportunity for communication with the caregiver. These communication interactions, where the caregiver vocalises and the young child imitates, form an integral part of early communication development (Arvedson & Brodsky, 2002). Satter (1992) indicated that high quality feeding interactions in the first years of life are linked positively to a child's later cognitive and linguistic competence (Crais, 1999).

The young child with paediatric HIV/AIDS may have limited feeding and/or communication opportunities that promote social, cognitive and communication development due to medical circumstances. The young child's opportunities for social contact are often limited, as instead of interactions that promote communication development being prevalent, the contact that is received may be primarily medical in nature (Rossetti, 1996). Environmental factors that may negatively influence the child's potential communication and feeding development are abuse or neglect, the level and type of parental support and parental drug use (Crais, 1999). In South Africa many young children are often placed in care centres due to parents with AIDS being ill or dying and abandonment of unwanted children. Thus, it is likely that these children may have been subjected to these environmental influences (Department of Health, 1999). The child's opportunities for feeding and social interactions that promote oral-motor, cognitive, communication and linguistic development may already be compromised by the environmental factors. In addition, these children are medically at risk due to their HIV positive or AIDS status (Quinn, Ruff & Halsey, 1994), further restricting their potential interactions for the promotion of development. The need for intervention is becoming all the more urgent as, with antiretroviral treatment for young children, their prognosis is much improved and their life expectancy is improved (Davis-McFarland, 2000).

The potential lack of interaction and feeding opportunities indicates a need for intervention in order to assist the development of young children with paediatric HIV/AIDS. Billeaud (1998) states that vegetative functions of the oral mechanism developmentally predate, and form the foundation of later functions of oral communication. It is therefore essential for a speech-language therapist to be a member of the feeding assessment team. Ziev (1999) proposes that the speech-language therapist must share the available expertise regarding successful feeding with the individuals who deal with the child most regularly and intimately. Feeding is the earliest communication between children and caregivers, so a

feeding problem in the neonatal period is usually perceived by caregivers as a significant concern (Arvedson & Brodsky, 2002).

The speech-language therapist has a role to play in the identification of children at risk for swallowing difficulties, and must also educate other health care and education professionals on the impact of swallowing disorders, their complications, symptoms and signs (Newman, 2001). Speech-language therapists are in the unique position to provide information about and evaluate the child's oral-motor skills in the context of a feeding observation (Kedesdy & Budd, 1998). Furthermore, speech-language therapists are able to provide a number of additional services to the child, such as consultation with caregivers and doctors and training of caregivers regarding oral feeding, and other oral-motor activities. These oral-motor abilities are important to the young child as they contribute to the development of co-ordinated movements required for later speech development (Billeaud, 1998). In addition to playing an important role in facilitation of oral-motor development, the speech-language therapist's role also includes sharing information with, and providing guidance to caregivers regarding early communication development, much of which occurs during the child's feedings (Billeaud, 1998).

The importance of the speech-language therapist's contribution in the treatment of young children with paediatric HIV/AIDS cannot be over emphasised. Whether speech-language therapists realise it or not, they are treating these children in all settings (Pressman, 1992) especially as the number of infected children is ever increasing in South Africa. By being knowledgeable about the symptoms that may occur in children with paediatric HIV/AIDS the speech-language therapist may be one of the first team members to suspect HIV positive status or to pick up HIV/AIDS related problems (Davis-McFarland, 2000).

The intervention needs of children with paediatric HIV/AIDS should be addressed in a trans-disciplinary team approach to ensure optimal treatment. A trans-

disciplinary approach is integrative and characterised by role release, and role expansion of a group of professionals, bringing expertise that is useful in the solution of a complex medical problem (Rossetti, 1996). The trans-disciplinary approach is particularly effective in the South African context, as there are insufficient numbers of professionals to treat all the children that require specialised intervention. In the effective treatment of paediatric HIV/AIDS a team approach is vital in addressing the child's diverse medical, psychosocial and developmental needs (Davis-McFarland, 2000). The paediatric HIV/AIDS population is rapidly increasing in South Africa and due to the nature of the problems they experience the speech-language therapist needs to be included in the effective team management of these children.

It is also important to have a co-ordinated team approach, as this has been shown to have tangible advantages for the individuals being treated (Kedesdy & Budd, 1998). In order for the services to be maximally beneficial to the child and the family, the nature and extent of services provided by the various professions involved should be monitored frequently. In early intervention it is essential that the child is treated holistically, and this is most easily accomplished by including professionals from various fields of expertise. This is especially applicable to the treatment of paediatric HIV/AIDS as it is such a complex illness and the effects on the child are pervasive (Davis-McFarland, 2000)

Current literature has indicated that further research is required regarding the functioning of the paediatric HIV/AIDS population, especially regarding oral motor development (Davis-McFarland, 2000). In this study the feeding behaviour of young children with paediatric HIV/AIDS will be described, with the aim of contributing to the service provision by health care professionals. Caregivers often report that young children with HIV/AIDS have no feeding difficulties, yet literature reports indicate that children with paediatric HIV/AIDS are prone to feeding problems (Arvedson & Brodsky, 2002; Hall, 2001; Newman, 2001; Davis-McFarland, 2000; Pressman, 1992). If feeding problems are indeed found to be

present in young children with paediatric HIV/AIDS, caregivers may either be classifying feeding problems incorrectly, or they may not be able to identify feeding problems. The impact of feeding problems on the development of the child was highlighted in the literature review, and it is vital that, if feeding problems are indeed present in this population, they are managed effectively to minimise the potential long-term negative influences.

Based on the above literature review a research problem was identified, and the following research question was formulated namely: *What are the feeding behaviours of young children with paediatric HIV/AIDS in care centres in Gauteng?*

2. METHODOLOGY

2.1 RESEARCH AIMS

The main aim of this study was to describe the nature of the feeding behaviour of twelve 6 – 36 month-old children with paediatric HIV/AIDS in care centres in Gauteng.

The following objectives were formulated to achieve the above-mentioned aim:

- To provide a description of the nature of the feeding behaviour of these young children
- To determine whether the young children with paediatric HIV/AIDS experience feeding problems as determined by the Clinical Evaluation of Paediatric Dysphagia (CEPD) (Hall, 2001).

2.2 RESEARCH DESIGN

The aim of the study was to describe the nature of the feeding behaviour of a group of young children with HIV/AIDS. In order to achieve this aim, a non-experimental, exploratory, descriptive research design was selected. A non-experimental design was selected as it was not possible to describe the feeding behaviour through experimental means (Leedy & Ormrod, 2001); the nature of the information would not allow it, as well as the fact that there was no attempt to make any comparisons in this study. This study is exploratory in that to date and as far as could be determined, no such study has been performed in South Africa, and the researcher was not certain what the results would yield. This descriptive research design was selected as the aim of the study is to describe the feeding behaviour of the paediatric HIV/AIDS population in these care centres, in an attempt to collate South African information to start compiling baseline data. Observation was used to gather data on the feeding behaviour of the participants (Leedy & Ormrod, 2001). An assessment checklist for dysphagia

in infants and children was administered to supplement observational data namely the CEPD (Hall, 2001). The CEPD (Hall, 2001) checklist was selected as it facilitates the evaluation and quantification of behaviours observed (Leedy & Ormrod, 2001).

One of the advantages of using a checklist is that it is quick to administer (Leedy & Ormrod, 2001). However, checklists are disadvantageous in that they are based on preconceived ideas of what behaviours and factors are expected to be found (Bless & Higson-Smith, 1995). Despite the disadvantages that were identified, the CEPD checklist (Hall, 2001) was selected for this study, as the information that was gained was valuable in that it provided the researcher with an abundance of information. As far as possible the potential influence of the disadvantages was accommodated by the following actions. Firstly, the researcher accompanied a qualified speech-language therapist, specialising in dysphagia assessments, on hospital rounds on three occasions. Six infants were assessed by both the speech-language therapist as well as the researcher, in order for the researcher to become familiar with the assessment material as well as the procedures involved in assessing a young child, in order to make administration of the CEPD more reliable. Secondly, a pilot study was performed (Leedy & Ormrod, 2001) where the applicability of certain items in the checklist (such as prenatal history of the child) to the South African context, were determined.

In addition to observation of feeding behaviour and the use of a checklist, a semi-structured interview was conducted in the pilot study. Semi-structured interviews are specifically suited to determine attitudes and perceptions of people (Leedy & Ormrod, 2001; Neuman, 1997). The interview was conducted in a one-to-one context as this type of interview has the highest response rate and allows the researcher to gauge whether the respondent understands the questions (Neuman, 1997; Stein & Cutler, 1996). The interaction between the researcher and the respondent is especially important when the questions are of a delicate

nature, where the rapport between the researcher and the respondent will determine the nature of the information provided (Neuman, 1997). The information from the semi-structured interview served to describe the feeding process as experienced by the young child with paediatric HIV/AIDS, as well as how the feeding process was perceived by the caregiver.

The advantages of using a semi-structured interview include that the researcher is able to build up rapport with the caregiver (Leedy & Ormrod, 2001), and the flexibility inherent in an unstructured interview allows for aspects to be included that might not have been previously considered. The preconceived ideas of the researcher are not imposed on the caregiver, and the possible answers are unlimited, and additional information can be provided by the caregiver (Malterud, 2001).

One of the disadvantages associated with this type of research is the effect of the preconceived ideas of the researcher on the study. It is impossible to counteract for this form of bias. It is however important to acknowledge its presence in descriptive research (Leedy & Ormrod, 2001). Reduction and control of bias in qualitative research refers to the recognition of the researcher of her fallibility. This recognition leads to the researcher endeavouring to make objective observations, without acknowledging personal values, principles, prejudices or interests (Poggenpoel, Myburgh & Van der Linde, 2001). In this study a second rater was included to limit the possible bias that may enter due to information being obtained by a single assessor. The researcher attempted to be optimally consistent with the interviews and the interactions with the caregivers, to lessen the effect of the bias. Questions employed in the semi-structured interview were open ended, and were phrased as neutrally as possible in order to elicit reflective answers from the caregiver, and not simply have her agree with the underlying implications of the questions (Neuman, 1997; Leedy & Ormrod, 2001). The semi-structured interview regarding feeding behaviour in the pilot study was

supplemented with observations of the feeding behaviour of the participant (Lambert & McKeivitt, 2002).

The non-experimental, exploratory, descriptive research design that was employed in this study was deemed to be most appropriate, as it yields both qualitative as well as quantitative data (Leedy & Ormrod, 2001). When quantitative and qualitative data are combined they complement each other and the validity of clinical evidence can be strengthened (Malterud, 2001).

2.3 PARTICIPANTS

Twelve young children with paediatric HIV/AIDS in care centres in Gauteng, and their caregivers acted as participants in this study, as well as a qualified speech-language therapist who acted as a second rater.

2.3.1 Selection criteria for paediatric participants

The following criteria were applied in the selection of participants:

➤ Age

Participants were required to be between 6 – 36 months of age as children with paediatric HIV/AIDS in this age group are not well described in the literature to date (Davis-McFarland, 2000). Furthermore, this age group was selected as HIV positive status cannot reliably be determined in infants younger than 6 months (Wiznia, Lambert & Pavlakis, 1996). In addition, certain development occurs in this age range, such as changes in the suckling pattern (which disappears after approximately 6 months) as sucking (up and down tongue movement) becomes the most prominent oral pattern (up to approximately 12 months) (Hall, 2001). In this specific age group the introduction of solid (pureed) food should commence between 4 – 6 months through spoon-feeding and cup feeding (Hall, 2001). Self-feeding should also commence approximately between 18 – 24 months (Morris & Klein, 1987). These types of feeding activities were important to observe in order to achieve the objective of the study.

➤ **Geographical area**

The children were to be resident in care centres in Gauteng. This stipulation was made due to logistical constraints pertaining to the collection of data. Additionally, the potential for different approaches, funding and resources in other municipal or provincial areas might have influenced the interpretation of the findings of the study. Further justification for geographical constraints pertaining to the participants are related to the large number of HIV/AIDS centres in Gauteng that accommodate young children with paediatric HIV/AIDS (Department of Health, 1999).

➤ **Care centre**

The participants had to be residents in one of the care centres selected for the study in Gauteng. Children with paediatric HIV/AIDS are currently, in the South African context, most commonly housed in a care centre setting (South African Department of Social Development, 2001), and research in this context may have important implications for caregiving.

➤ **Medical status**

The children had to have a stable medical status and have a confirmed HIV positive diagnosis. This diagnosis was important for the participant selection criteria, as very ill children who were not HIV positive had to be excluded. The participants had to have no known congenital or acquired abnormalities, there had to be no history of a traumatic brain injury or epilepsy. In addition, the participants could not suffer from diabetes, as a systemic illness may influence development and general health (Winter & Miller, 1994).

2.3.2 Medication

➤ **Child medication**

A description of the medications that the children received was obtained, and if any medication had known side effects on feeding abilities, this was taken into account in the interpretation of the data. Medications that were considered

include types that have xerostomia as a side effect, or that influence neuromuscular functioning and development (Kovacs & Oleske, 1994). However, no participant was excluded due to medications, other than those for systemic illnesses, such as diabetes.

2.3.3 Selection criteria for caregiver participants

In order for the caregivers at the care centres to be included in the study, they were required to be permanent staff members and had to be familiar with the children being assessed (Leedy & Ormrod, 2001). This familiarity with the children is important so that the information provided by the caregivers can be seen as reliable and be an accurate reflection of the children in question. The caregivers were required to understand English, as the biographical questionnaire (Hall, 2001) was in English and comprehension of the questions was essential.

2.3.4 Selection criteria for second rater

The second rater was required to be a qualified speech-language therapist, who specialises in dysphagia. The second rater was also required to have experience in assessing the paediatric population with the goal of obtaining descriptive information for the study.

2.3.5 Participant selection procedure

Care centres for children with HIV/AIDS were contacted once the research project was approved by the University of Pretoria's Research Proposal and Ethics Committee (see Appendix C). The managers of the care centres were given information and consent forms to complete (see Appendix D). Thereafter, the centre managers identified caregiver and paediatric participants who complied with the participant selection criteria. Convenience sampling was used in which paediatric and caregiver participants were selected as they were presented to the researcher by mere happenstance (Leedy & Ormrod, 2001).

2.3.6 Description of paediatric participants

Two different care centres in Gauteng were selected for participation in this study in order to obtain a more representative sample, as well as a larger number of participants. The caregivers at the selected care centres were willing to participate in the study.

These two groups of participants from the two care centres are described in Table I. According to Table I, the average ages of the paediatric participants were 21.8 and 23.5 months respectively for Centre A and Centre B. This finding indicated that the total group of participants was relatively uniform regarding the average age, despite the fact that they included participants from two different care centres. This is important as it indicates that different findings between the two centres cannot be attributed to age differences at the two centres.

The average time spent in the respective care centres, namely 5.25 and 5.5 months suggested fairly similar periods of residency in the care centres. These factors make the interpretation of the data obtained from the assessment and observations simpler, in that all the participants can be regarded as a heterogeneous, yet uniform group (Kaplan, 1987) in terms of age and time spent in the care centres. The standard deviations for the average time spent in the care centre, as well as the average age calculations are large (4.2 and 5.2 months for the average time and 10.2 and 8.2 months for the average age). These figures may be due to the limited number of participants in the study. The researcher must take cognisance of such influencing factors when interpreting the data in this study (Malterud, 2001).

Table I: Description of participants (N=12)

	Care centre	Number of participants	Age Range (months)	Number of participants	Time spent at care centre (months)	Average age (months)	Standard deviation (months)	Average time spent in care centre (months)	Standard deviation (months)
	▪ Centre A	2 0 2 1 0 1	▪ 10-14 ▪ 15-19 ▪ 20-24 ▪ 25-29 ▪ 30-34 ▪ 35-39	3 0 2 0 1 0	▪ 0-2 ▪ 3-5 ▪ 6-8 ▪ 9-11 ▪ 12-14 ▪ 15-17	21.8	10.2	5.25	4.2
	▪ Centre B	1 1 1 0 3 0	▪ 10-14 ▪ 15-19 ▪ 20-24 ▪ 25-29 ▪ 30-34 ▪ 35-39	2 2 1 0 0 1	▪ 0-2 ▪ 3-5 ▪ 6-8 ▪ 9-11 ▪ 12-14 ▪ 15-17	23.5	8.2	5.5	5.2
TOTAL		12		12		22.7 months	8.9 months	5.4 months	4.5 months

2.3.7 Description of the second rater

The second rater was selected according to the selection criteria that were compiled. The second rater was a qualified speech-language therapist who is registered with the HPCSA. She has a Master's Degree in Communication Pathology and specialises in dysphagia. She has had more than twelve months of experience in the assessment and treatment of dysphagia. The second rater was deemed to have adequate experience in the field of dysphagia, and could therefore be used to validate the findings of the researcher.

2.4 PILOT STUDY

2.4.1 Aims

A pilot study was performed to achieve the following aims:

- To determine the appropriateness and usefulness of the instrument for data collection, as well as to determine the most relevant procedures for data collection.
- To describe the face validity and content validity relating to the Clinical Evaluation of Paediatric Dysphagia (Hall, 2001), and its applicability in the South African context.
- To determine the viability of the material selected for the study.
- To perform semi-structured interviews with the caregivers in order to enrich the data collection and to determine their perceptions of the feeding process of young children with paediatric HIV/AIDS.

2.4.2 Participants

A single paediatric and a single caregiver participant were selected at Centre C according to the selection criteria described in the methodology. One caregiver was interviewed according to the biographical questionnaire (Hall, 2001), and a semi-structured interview was performed to assess the perceptions and attitudes of the caregiver.

2.4.3 Materials

The material and apparatus that were selected for the pilot study, were the Clinical Evaluation of Paediatric Dysphagia (CEPD) (Hall, 2001), the Biographical Questionnaire (Hall, 2001), a semi-structured interview (Appendix F) as well as a Sony video camera and TDK VHS video cassettes. The semi-structured interview questions were compiled according to guidelines provided by Leedy & Ormrod (2001) namely:

- Open-ended questions were selected as they provide the caregiver with greater opportunity to answer the questions freely, and provide additional information
- Questions were kept as short as possible
- The questions were organised in a logical sequence
- Biased or leading questions were avoided in order to obtain a more representative result

2.4.4 Procedures

The procedures for the pilot study were as follows:

- The care centre manager was contacted and informed consent was obtained for one paediatric participant to be assessed, and one caregiver participant to be interviewed.
- The CEPD (Hall, 2001) was performed on a young child in the care centre, and audio-visual recordings were made of the assessment and of the interviews.
- The researcher assessed the child and additional information was obtained from the caregiver through her completion of a short biographical questionnaire.
- A semi-structured interview was also conducted with a caregiver to determine her perceptions, experiences and attitudes regarding the feeding process as well as with regard to working in a multi-disciplinary team.

2.4.5 Results

The results of the pilot study indicated that minor adaptations to suit the South African context were necessary, namely:

The CEPD (Hall, 2001) was deemed to be an appropriate, comprehensive assessment tool as its clinical application was confirmed, and it provided an abundance of information regarding the feeding process of the child assessed.

The biographical questionnaire in its entirety (Hall, 2001; Form 3-1, Appendix A) was found to have limited applicability to the context of this study, as it required a comprehensive case history of each participant, and no background information was available on the children prior to their admission to the care centres. The participants' parents were not available as the participants were either abandoned or placed in the care centre due to parental ill health and inability to care for the child. Currently this situation with regard to the parents is common in the South African context (South African Department of Social Development, 2001).

The CEPD (Hall, 2001) places a great deal of importance on obtaining a complete case history in order for it to be a thorough assessment. In this study it was not possible, due to children residing in the care centre for varying periods, as well as no case history being available prior to admission. For this reason the assessment needed to be adapted to the South African context, in that less emphasis was placed on the background information and that the focus was mainly on the actual assessment.

The semi-structured interview produced limited results, as it was determined that the caregiver did not consistently feed the same child at every meal. For this reason limited information was obtainable from the caregiver regarding the detailed feeding functions of the child. The caregiver also had very limited time

available for the completion of the interview due, to each caregiver being responsible for the care of at least five children.

It was determined that the caregiver had not previously had the opportunity to collaborate with a speech-language therapist regarding feeding problems with children, and therefore was unable to provide an opinion regarding teamwork.

A barrier to the interview was language, as the caregiver's first language was neither English nor Afrikaans and an interpreter was not available. This language barrier may have led to the caregiver's inability to provide more detailed answers in the interview.

Based on the findings, it was determined that the semi-structured interview did not provide the researcher with valuable information, it was decided to limit the interview to the completion of the biographical questionnaire in its adapted form.

Due to these above-mentioned findings, the original main aim of the study was adapted to primarily focus on the feeding process of children with paediatric HIV/AIDS in care centres in Gauteng, through the use of the CEPD and the biographical questionnaire (Hall, 2001). The researcher no longer attempted to determine the perceptions of the caregivers regarding the feeding process of children with paediatric HIV/AIDS.

2.5 MATERIAL AND APPARATUS

Appropriate assessment material is a critical component of the research study as it affects the validity of the research as well as the data obtained (Neuman, 1997). Various material and apparatus were selected for this study, namely: the Clinical Evaluation of Paediatric Dysphagia, Form 3-2 (CEPD) (Hall, 2001) and the Biographical Questionnaire, Form 3-1 (Hall, 2001). In order to collect the

data, a Sony video camera and TDK VHS video cassettes were used. These are described forthwith.

The Clinical Evaluation of Paediatric Dysphagia (CEPD) (Hall, 2001)

The CEPD (Hall, 2001) was used in this study as a data collection instrument (see Appendix B). This assessment tool was compiled by a panel of experts in the United States of America, who attempted to collate the latest information regarding the assessment and treatment of paediatric feeding and swallowing disorders in a clinician-friendly format (Hall, 2001). The CEPD (Hall, 2001) is considered to be an appropriate assessment tool for paediatric dysphagia (Arvedson & Brodsky, 2002; Hall, 2001).

Furthermore, the CEPD (Hall, 2001) was considered applicable as it includes all aspects required to assess the feeding behaviours of the young children. It is also a comprehensive tool in that broad ranges of factors, which may influence swallowing, are included (Hall, 2001). The areas examined in the CEPD (Hall, 2001) include:

- behaviour / state / sensory integration
- physiologic status
- stress cues during feeding
- general postural control / tone
- respiratory status
- oral / motor / cranial nerve evaluation
- oral structure and function
- feeding / swallowing evaluation (Arvedson & Brodsky, 2002)

The CEPD (Hall, 2001) was adapted according to the findings of the pilot study (see 2.4.5) in order to ensure applicability to the South African context.

The Biographical Questionnaire (Hall, 2001)

A Biographical Questionnaire (Hall, 2001) (Appendix A) regarding the developmental history of the child, prenatal history, medications received as well as the feeding and swallowing history was completed by the researcher and the caregiver for each participant.

The specific areas addressed were:

- biographical information
- current status
- social history
- medical history
- motor development
- communication / speech and language history
- description of the child's personality
- feeding and swallowing history

This questionnaire is a comprehensive tool and highlights a broad range of relevant issues related to the current functioning of the child as well as the development of the child in all areas related to successful feeding (Arvedson & Brodsky, 2002).

The material and apparatus employed are summarised in Tables II and III.

Table II: Description of the assessment material

Material	Description	Justification	Source
CEPD Form 3-2 Appendix B	Checklist which assesses: behaviour /state/sensory integration; Physiologic status; Stress cues during feeding; General postural control /tone; Respiratory status; Oral /motor /cranial nerve evaluation; Oral structure and function; Feeding / swallowing evaluation	The CEPD is a comprehensive assessment tool that covers all the relative aspects required to draw conclusions regarding feeding behaviours	Hall (2001)
Biographical questionnaire Form 3-1 Appendix A	A short biographical questionnaire regarding age, medication, and case history was completed	To obtain information regarding the background of the children.	Hall (2001)

Table III: Description of the data collection apparatus

Apparatus	Description	Justification	Source
Video camera	A Sony video camera was used. Model XT 564	To improve objectivity of the data and aid in the interpretation and analysis of data	Leedy & Ormrod (2001)
Video cassettes	TDK VHS cassettes that make high quality recordings were used.	To improve accuracy of data analysis as video tapes may be replayed numerous times	Leedy & Ormrod (2001)

2.6 ISSUES OF RELIABILITY AND VALIDITY IN THE MAIN STUDY

Reliability refers to whether the same data can be obtained at a different time by using the same assessment material, if that is possible then the instrument is reliable (Neuman, 1997). Although it is rare to have perfect reliability (Neuman, 1997; Bless & Higson-Smith, 1995), the highest degree possible should be attempted. A pilot study was performed to improve the reliability of the assessment material, in that the consistency in the results found during the assessment of the children was appraised and interpretations of the questions were evaluated in the participants who took part (Neuman, 1997).

The CEPD (Hall, 2001) is published in a resource guide for clinicians and according to Hall (2001), the development was based on clinical experience and the most recent literature available on swallowing and feeding disorders in the paediatric population. This instrument was deemed to be credible as Hall is internationally recognised as an expert in the field of paediatric dysphagia. As the CEPD (Hall, 2001) was used in such a different context to the mainstream USA context – for which the text was written, it was deemed necessary to determine its applicability to a different context, namely the South African context.

Reliability is also a precondition for measurement validity, (Neuman, 1997), therefore by attempting optimal reliability of the assessment material, the validity

of the material can be increased. There are four types of measurement validity. Face validity is the most basic type of validity (Neuman, 1997), and refers to whether the assessment instrument answers all the research questions using the appropriate language and language level. Face validity was determined for both the CEPD (Hall, 2001), as well as for the interview questions in the pilot study. The CEPD was found to have adequate face validity in that the language was appropriate, despite the fact that all the caregivers were English second language speakers, the information obtained was relevant to the study. The interview questions were deemed inappropriate, possibly due to the caregivers' inability to express themselves in an unstructured fashion due to language limitations. Therefore the interview was limited to the biographical questionnaire (Hall, 2001).

Content validity is a type of face validity (Neuman, 1997), which is a specific consideration of this study. Content validity refers to whether the instrument appropriately and thoroughly assesses the behaviour and perceptions it is intended to measure (Foxcroft, 2000). In most cases content validity is achieved by referring to relevant literature (Bless & Higson-Smith, 1995). The content validity of the CEPD (Hall, 2001) was addressed in that the checklist is based on theory and clinical practice, and includes all the important aspects of the feeding process (Hall, 2001). Content validity for this specific study was addressed in the pilot study, where the content of the CEPD (Hall, 2001) was deemed to be appropriate for the study and it yielded pertinent results.

The other types of validity that were considered in the semi-structured interview were criterion validity and construct validity. Criterion validity is determined by comparing the instrument to another one that is known to be valid (Bless & Higson-Smith, 1995). In this study the open-ended questions included in the interview were not found to be relevant to the South African context (refer to 2.4 Pilot Study). Criterion validity was compromised as no known valid interview questions had been compiled previously. Construct validity, which refers to the

degree to which a construct or concept is actually measured, is achieved by the researcher consulting various guidelines in the literature regarding construction and types of questions (Foxcroft, 2000). The language barriers prohibited the use of open-ended questions in a meaningful manner. The interview was therefore limited to the completion of the biographical questionnaire

A second rater was employed to corroborate the findings of the study. In order that deductions can be made from observational data it is imperative that at least two individuals observe the behaviour independently (Graziano & Raulin, 2000). An agreement of 85% between the researcher and the second rater is deemed to be acceptable (Bernard, 1982). The number of assessed items on which the data collectors agreed were noted and produced 80% agreement. The forms that were completed by the researcher were given to the second rater who was required to make note of discrepancies. All the relevant questions were numbered and the discrepancies were counted and then converted into percentage values. The 80% agreement was deemed to be sufficient, as it was merely 5% below the required percentage (Bernard, 1982). The discrepancies between the researcher and the second rater may have been due to various reasons. Firstly, due to individual opinion as some of the observations were subjective. Secondly, due to differing training in the administration of the assessment tools (Leedy & Ormrod, 2001), as the researcher had previous experience in the administrative procedures. The second rater was used to improve the reliability of the study as high inter-rater reliability indicates high overall reliability (Neuman, 1997).

Reliability and validity are central scientific measurement in research (Neuman, 1997). A high degree of both must be attained in order for the results of the research to be credible. In an attempt to improve the reliability and validity of the findings further, a second rater was included in order to corroborate the findings (Neuman, 1997). In order to achieve high degrees of both in this study, extensive literature was consulted in order to ensure that the study was based on

sound theoretical underpinnings. A pilot study was also performed in which the appropriateness of the method and measurement instrument was assessed (Neuman, 1997; Mouton, 1996; Bless & Higson-Smith, 1995).

2.7 ETHICAL CONSIDERATIONS

Ethical considerations are essential to every research attempt, especially when humans are involved (Foxcroft, 2000). The ethical considerations regarding anonymity, as well as the confidential nature of HIV positive diagnosis were noted and explained in the application forms completed for the Research Proposal and Ethics Committee, Faculty of Humanities, University of Pretoria. The Committee granted approval of the study and the approval letter is included in Appendix C.

In ethical research, the researcher must respect the rights of the participants, who must make informed decisions when agreeing to partake in a study (Leedy & Ormrod, 2001; Graziano & Raulin, 2000). An information letter (Appendix E) was provided to the managers of the care centres. These managers participated in the study by suggesting suitable participants for the study who were residing in their care centres, as well as caregiver participants who looked after the potential paediatric participants. A letter of consent (Appendix D) and a covering letter (Appendix E) regarding what the study was about were given to the caregivers. In the letter of consent the exact procedures were set out and the caregivers were assured of their anonymity (Graziano & Raulin, 2000), and the value of their participation in the study was emphasised, as this improves co-operation on the part of the caregivers (Leedy & Ormrod, 2001). In the covering letter the process of the observation and assessment, as well as the aim of the interviews, was explained to the caregivers and the goal of the study was clarified (Appendix E).

2.8 PROCEDURE FOR THE MAIN STUDY

2.8.1 Data collection procedures

- The first step in the research process was to obtain permission from the care centres to perform the study as well as to receive ethical clearance from the Research Proposal and Ethics Committee, Faculty of Humanities, University of Pretoria (see Appendix C).
- The caregivers were required to complete a biographical questionnaire (see Appendix A). The caregiver who was responsible for the child on a regular basis completed the form with the assistance of the researcher. This information was important for purposes of selection and inclusion and exclusion criteria as well as for biographical information.
- The assessment of the participants, using the Clinical Evaluation of Paediatric Dysphagia (CEPD) (Hall, 2001) was completed as the researcher filled in the relevant forms (see Appendix B). The caregivers were instructed to ignore the researcher and to continue feeding the child as they normally would. Observation of their feeding practices was recorded on the CEPD (Hall, 2001) score sheet and audio-visual recordings were made. The researcher completed the rest of the assessment as instructed by the CEPD (Hall, 2001). The young children were assessed at different times depending on their sleep / wake cycles and feeding times (Rossetti, 1996).
- A second rater viewed the completed assessment forms, as well as the audio-visual recordings of the assessment and the interviews and then provided her interpretation of the findings. These were then compared to the findings of the researcher and discrepancies were noted. Inter-rater reliability was determined to be an 80% agreement, and was improved according to the guidelines set out in Neuman (1997) as well as according to the findings of the pilot study.

2.8.2 Data recording

For the paediatric dysphagia evaluation, the researcher recorded the data manually. The CEPD assessment forms were completed according to the information gained from the direct dysphagia assessment (Hall, 2001). Audio-visual recordings of the assessments were performed.

2.8.3 Data analysis

Once the data were collected, data analysis was carried out. The CEPD (Hall, 2001) forms were analysed and scored according to the Pediatric Dysphagia Resource Guide (Hall, 2001) as well as in terms of which behaviours were expected and which were actually present for the child's age as per instructions.

The audio-visual recordings from the assessment as well as the completed CEPD forms were given to the second rater who was experienced in the field of dysphagia. The written instructions required the rater to indicate where she found areas of disagreement or discrepancies in the rating sheet. The discrepancies were counted and then converted into percentage values. An overall agreement of 80% was found and deemed to be appropriate. Areas of disagreement were noted for later analysis in order to ensure inter-rater reliability (Neuman, 1997).

The results obtained were then analysed using descriptive statistics and depicted in the form of histograms and tables (Neuman, 1997). The mean and standard deviations were determined for the ages of the children as well as for the length of time spent at the care centre (Kaplan, 1987). Frequency distribution tables (Kaplan, 1987) were compiled in order to determine whether there was any correlation between the various findings. Descriptive statistics were considered to be most appropriate for the study as a description will be compiled (Leedy & Ormrod, 2001), and there is no normative data for young children with paediatric HIV/AIDS for the specific dysphagia instrument (CEPD) (Hall, 2001).

Inferential statistical analysis of the data was performed, however, one of the major limitations in the statistical analysis was the small number of participants (N=12), as the analysis usually requires a larger number to provide more reliable results. When interpreting the findings of the statistical analysis, the small number of participants must be kept in mind, in that generalisations cannot be made (Leedy & Ormrod, 2001). A Fisher's Exact Test (Kaplan, 1987) was performed on the data, as the Chi-Square was not valid due to the values being too small.

3. RESULTS AND DISCUSSION

The results are presented and discussed according to the stated aims and objectives of the study. The following results were obtained from the feeding observations and assessment conducted on a group of twelve participants in two care centres for abandoned and HIV positive children in Gauteng. The results were analysed and are presented in the following format.

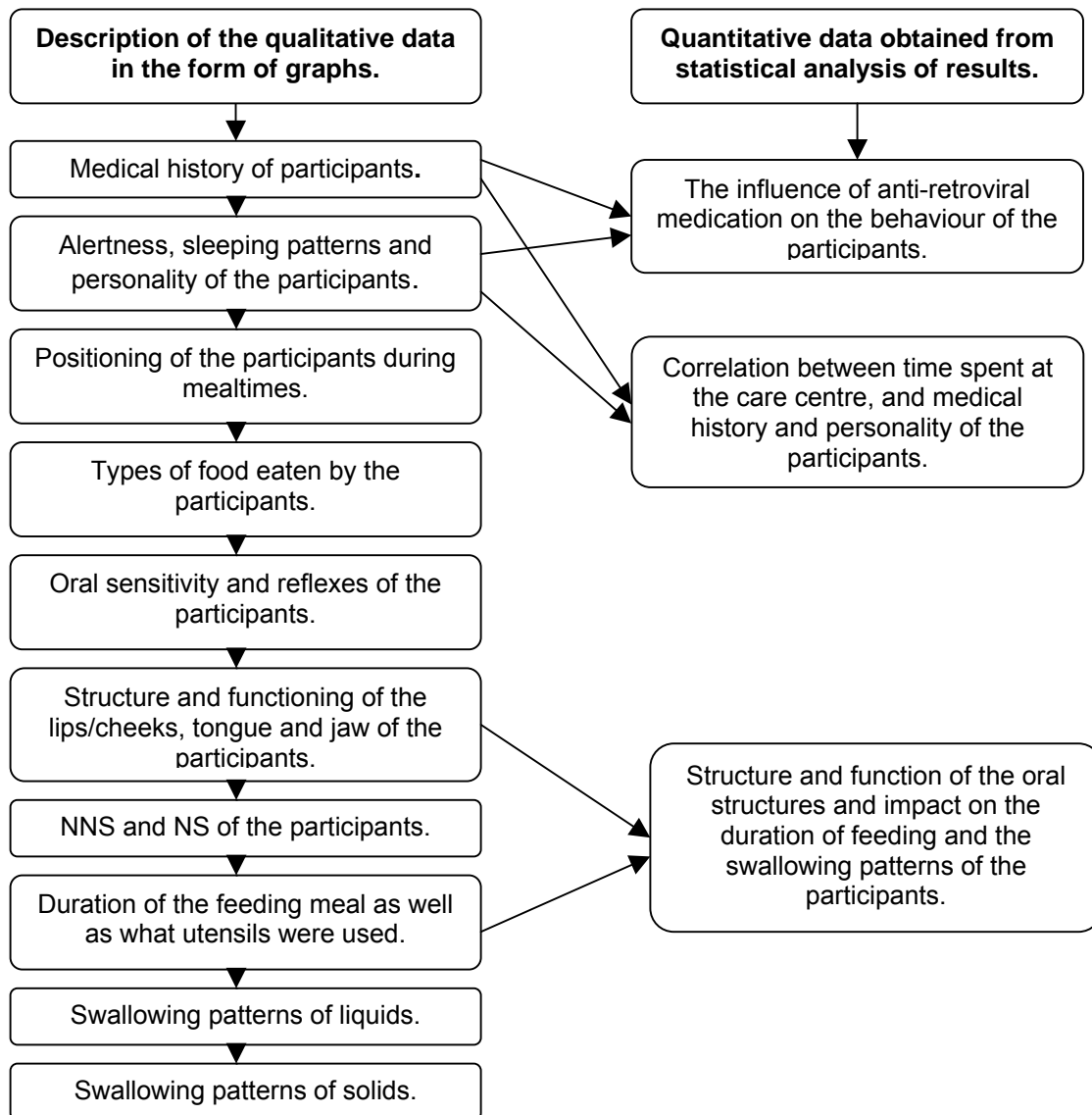


Figure 1: Presentation of sequence of the results

3.1 MEDICAL HISTORY

A medical history of the twelve participants was obtained from the caregivers, who provided the information required according to the relevant sub-sections of the Biographical Questionnaire and CEPD (Hall, 2001), Form 3-1 and Form 3-2 (See Appendices A and B respectively). The primary caregivers in this study were the care workers at the care centres and not the parents of the participants. The participants' parents were not available as the participants were either abandoned, or were placed in the care centre due to parental ill health and inability to care for their child; situations that are relatively common in the South African context (South African Department of Social Development, 2001). Optimal and traditional care environments are often lacking in the South African context as the incidence and prevalence of HIV/AIDS are increasing (Evian, 2000).

Determining the medical history of each of the participants was considered to be important for this study, as health status plays a crucial role in children that are HIV positive (Evian, 2000). Opportunistic infections may have a considerable influence on all areas of functioning (Evian, 2000), and young children with paediatric HIV/AIDS are more susceptible to opportunistic infections than adults, due to their immature immune systems (O'Flaherty & Gerber, 1991).

An important consideration in this population is length of time exposed to an illness or time of ill health. A typical symptom of HIV infection is recurrent infections (Evian, 2000). However, in this study it was not possible to determine length of illness for two reasons. Firstly, participant case history prior to admission to the care centre was unobtainable as a number of the participants were abandoned. Secondly, the participants were assessed on a single occasion, thus long-term health status could not be determined. Information regarding duration of illness after admission to the care centre was provided by the caregivers. However, even this information was limited as the length of time

spent at the care centre varied for each participant. These two factors are important when interpreting the study's findings. The length and recurrence of any illness experienced may well negatively influence all areas of functioning, including feeding (Evian, 2000).

Variations in the time spent at the care centre may also have influenced caregivers' familiarity with the participants' medical status. As mentioned previously, no information was available regarding the participants' health prior to their arrival at the care centre. The findings relating to the medical history of the participants are presented in Figures 2 and 3.

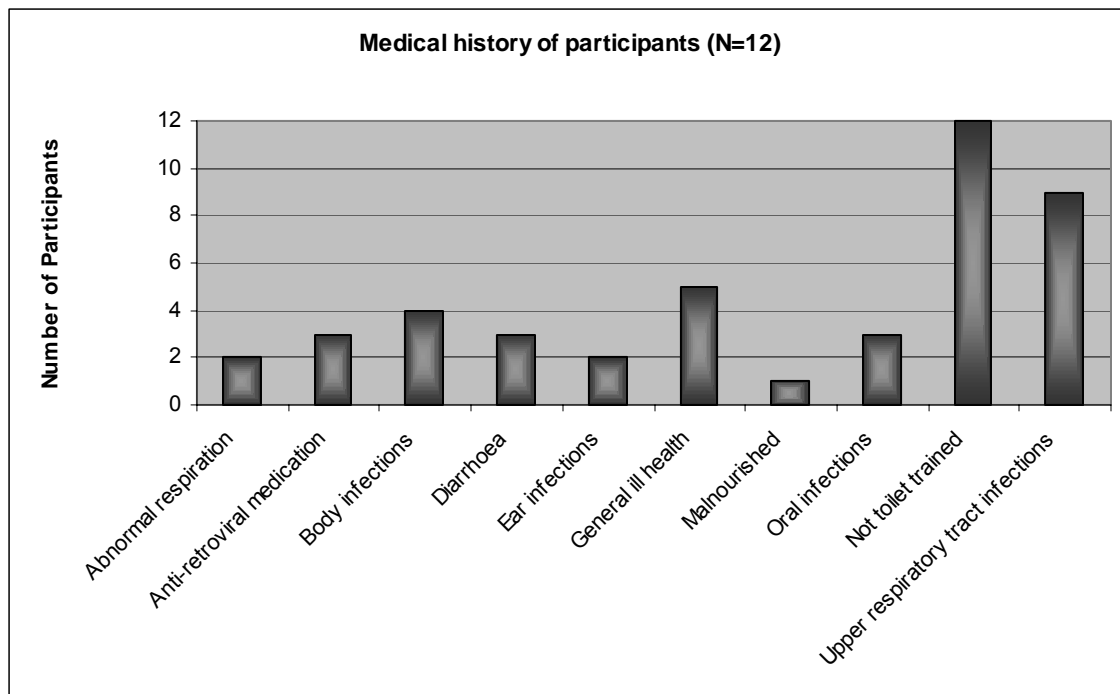


Figure 2: Medical History of Participants (N=12)

Figure 2 indicates that nine participants were suffering from upper respiratory tract infections at the time of the assessment, and five participants showed evidence of general ill health. At the time of assessment, six of the participants suffered from other infections namely diarrhoea, body and oral infections as well as ear infections. The prevalence of body and oral infections is consistent with the nature of infections present in the paediatric HIV/AIDS population (Evian,

2000; O'Flaherty & Gerber, 1991). However, it was not possible to determine whether these infections were purely the result of the participants' susceptibility to infections due to the presence of HIV/AIDS, or partly the infections that affect young children generally.

The most common illness that participants presented with was upper respiratory tract infections (see Figure 2), which resulted in nasal congestion in the affected participants. Upper respiratory tract infections are typically found in children who are HIV positive (O'Flaherty & Gerber, 1991). This finding was considered to be important as it was thought to contribute to the participants who were oral breathers, namely, participants three, eight and nine (Hall, 2001). Nasal congestion may contribute to oral breathing, which in turn, may affect the participants' feeding abilities, as the oral cavity is primarily used for respiration, thus interfering with their feeding abilities. The incidence of upper respiratory tract infections and general ill health in the participants appeared to be inversely proportioned to the duration of time spent at the care centre ($p < 0.05$, $p = 0.03$), which suggests that the environment has a positive influence on the health of the participants. This is an important finding, especially in the South African context, as increasing numbers of children with paediatric HIV/AIDS are being placed in care centres.

Thus, although the South African Department of Social Development (2001) indicates that children should preferably stay with their parents or be placed in foster care, depending on the stipulated circumstances, this finding suggests that care centres may also be an option for consideration in the South African context. That is, as the number of HIV/AIDS orphans increases, care centres may be a valuable alternative for childcare when fostering is not an option (Population Reports, 2001).

It has been noted in the literature that otitis media occurs frequently in the paediatric HIV/AIDS population (Newman, 2001; Davis-McFarland 2000;

O’Flaherty & Gerber, 1991). In a previous local study, the incidence of otitis media was found to be significantly higher in the paediatric HIV/AIDS population than in the control group (Swanepoel, 2000). However, in this study, only two out of the twelve participants namely, participants eleven and twelve were reported to suffer from middle ear infections. This discrepancy may be due to insufficient training of caregivers in the identification of middle ear infections. Furthermore neither caregivers, nor the researcher had access to the participants’ medical history prior to admission to the care centre. Hence it is possible that the participants suffered from middle ear infections prior to admission to the care centre. On the other hand, this participant group may simply not have been prone to suffer from ear infections. This trend may have been enhanced by the fact that the number of participants is small and the field work was conducted during the summer months, when the prevalence of otitis media is usually lower than in winter (Louw, Hugo, Kritzinger & Pottas, 2002). In this study the latter two reasons appear to be the most probable explanations, and the findings can be regarded as reliable as a paediatrician sees the participants on a regular basis for check-ups.

As depicted in Figure 2, of the twelve participants only three (participants one, two and four) were receiving anti-retroviral medication. These three participants were resident at Centre A, where members of the public voluntarily sponsor the cost of the participants’ anti-retroviral medication. The remainder of the participants were not receiving anti-retroviral medications due to lack of private and public funding.

Although the number of participants is too small to make generalisations from the findings, an interesting correlation was noted in the three children on the anti-retroviral medication, regarding their demeanour. It was observed, according to the results of the relevant sub-section in Form 3-1 of the Biographical Questionnaire (Hall, 2001) in Appendix A, the children on the anti-retroviral medication appeared to be more pleasant than the other participants ($p < 0.05$;

$p=0.045$). This correlation may either be due to personality variables, or to the fact that the children on the anti-retroviral medication experience fewer illnesses as they are less susceptible to opportunistic infections. Thus, they may feel better, and are more pleasant when interacting with others (Evian, 2000). This may well be an additional justification for providing children with HIV/AIDS with anti-retroviral medication, as their quality of life is improved. However, in South Africa, governmental policies and costs are currently major obstacles to the provision of this medication (Evian, 2000). It is important that everyone involved in caring for children with HIV/AIDS addresses these obstacles, as they must be provided with the best care and medication available to improve their quality of life (Evian, 2000) and their life expectancy.

According to Figure 2, three of the participants experienced oral infections, namely participants two, three and eleven. Davis-McFarland (2000) reported that a number of children with paediatric HIV/AIDS experience frequent oral infections such as oral thrush. Oral thrush is common in young children under one year of age, however, it is much more severe in immunosuppressed children (Davis-McFarland, 2000). According to Braeggens, Albisette and Nadal (1995) 30 to 40% of children infected with HIV/AIDS experienced one or more types of oral lesions during the course of the infection. A compromised immune system is unable to maintain a healthy balance in the microflora present in the oral environment, resulting in infection (Larsen, 1998). In this study the number of participants suffering from oral infections was relatively small. It is possible that some oral infections went unnoticed, and if they did not interfere with the feeding, the caregivers may not have been aware of the infection. Alternatively, the children in this study may simply not have suffered from oral infections.

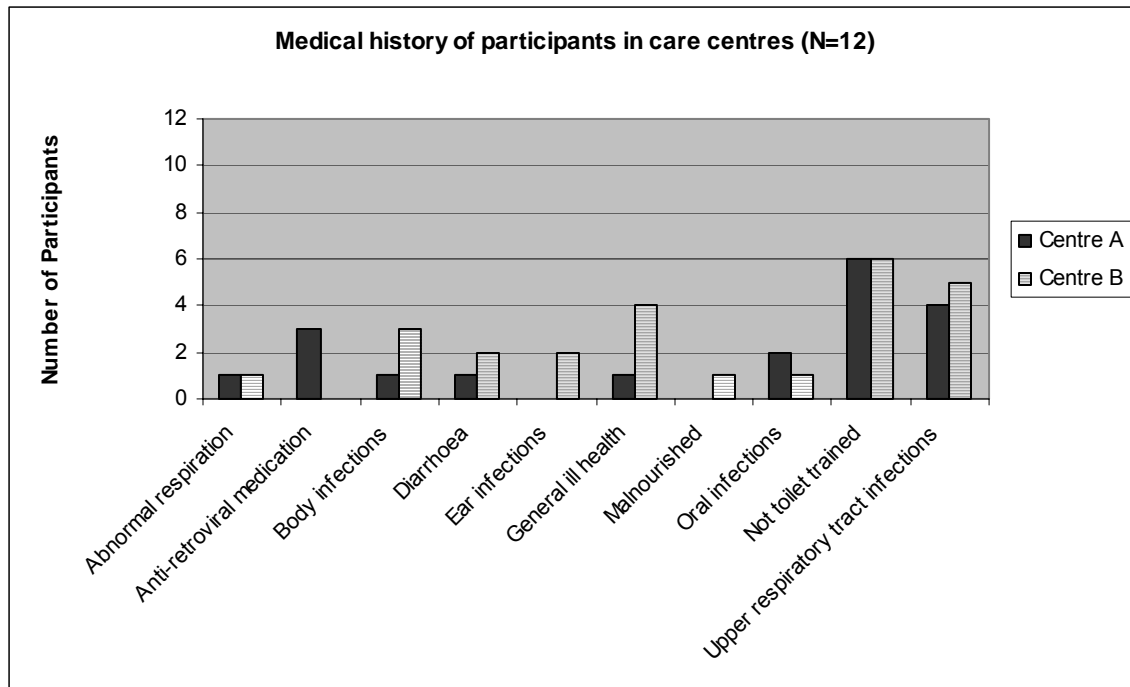


Figure 3: Medical history of participants in care centres (N=12)

On inspection of Figure 3, where the two groups at the two care centres are depicted separately, there appeared to be few differences regarding the nature of the illnesses of the participants in the two care centres. However, the children in Centre B seemed to experience more illnesses than the children in Centre A. The reason for this difference is not known, as the sample size is too limited to make any inferences. It appears that Centre B had more sickly children at the time of the study, thus explaining the greater number of illness experienced by the participants that reside at Centre B. There were no environmental factors that could be identified by the researcher, which could account for the difference in general health between the two centres.

In general, the results indicated that according to the medical history the participants experienced a range of illnesses that are consistent with those experienced by the general paediatric HIV/AIDS population (Davis-McFarland, 2000; Evian, 2000; Braeggens et al., 1995). Determining the medical history of the participants was an important component of the study, as illnesses experienced may contribute to the feeding behaviour and functioning of a child

(Davis-McFarland, 2000). Despite the information being limited to the duration of the participants' stay at the care centres, the information was valuable in describing the health conditions of the participants, as a range of illnesses were noted by the caregivers. As children with HIV/AIDS are especially susceptible to infections, medical history provides insight into the ability of the child to function under varying health conditions (Hall, 2001).

3.2 ALERTNESS, SLEEPING PATTERNS AND PERSONALITY

Information regarding the personality and the sleeping patterns of the participants was obtained from the caregivers, who were required to answer the questions in the relevant sub-section of the Biographical Questionnaire (Form 3-1) (Hall, 2001) and are provided in Appendix A. The information obtained from the caregivers was supplemented by the observations of the researcher made during the feeding assessment of each participant. The researcher assessed the alertness of the participants during either breakfast or lunch. The findings from the mealtime assessments are presented in Figure 4.

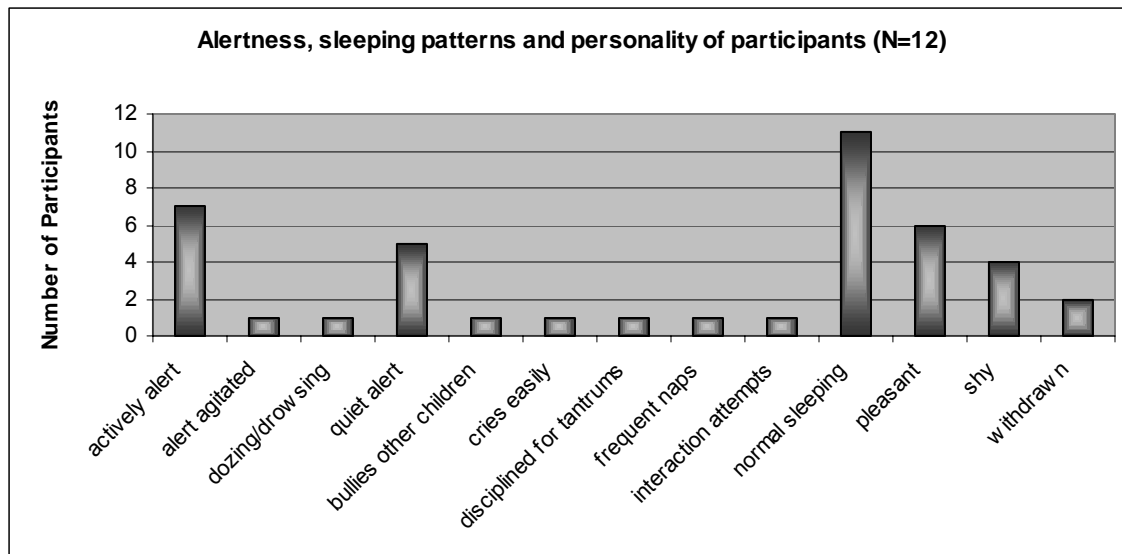


Figure 4: Alertness, sleeping patterns and personality of participants during mealtimes (N=12)

Seven participants (numbers one, three, four, six, eight, eleven and twelve) were actively alert during feeding, while five participants (numbers two, five, seven, nine and ten) were quietly alert. The behaviour of three participants (numbers eight, five and nine) ranged from crying easily during feeding, to bullying other children, to taking frequent naps during the meal.

During the mealtime the participants were in various normal stages of alertness (Rossetti, 1996), with only two children being either agitated or dozing. One infant (participant two) was orally hypersensitive due to oral thrush (Evian, 2000). In addition, she was agitated and fretful during the feeding, which was most likely due to eating being painful (Davis-McFarland, 2000). Once medication was administered to relieve the pain, she was willing to eat a few mouthfuls. It is a normal reaction that children will refuse to eat if they are feeling unwell or are in pain (Evian, 2000).

The length of exposure to the infection may be significant in accurately determining whether oral thrush was influencing participant two's functioning or comfort during feedings. In children with paediatric HIV/AIDS recurrent oral thrush is typical, and if this was the case for participant two then oral thrush was likely to impact her feeding abilities negatively (Evian, 2000). However, participant two received anti-retroviral medication, and if this medication was able to limit the oral infections to short, infrequent bouts, she should have been able to maintain adequate feeding behaviour and her quality of life could improve (Evian, 2000).

According to Figure 4, the sleeping patterns of the participants were in keeping with expectations of children of this age, with no apparent overt sleeping difficulties, as reported by the caregivers. It was observed that participant nine dozed during mealtimes. This behaviour may be accounted for by the suspicion of caregivers that participant nine presented with mental retardation. However, no formal diagnosis of this nature had been made at the time of assessment.

Mental retardation or even HIV-encephalopathy might account for his abnormal sleeping pattern during feeding (Davis-McFarland, 2000). Neurological complications often affect appropriate state / wakefulness throughout the day. Kastner (1988) asserted that HIV infection in infants and children can be a cause of mental retardation and mental disability. It is important that this participant receives holistic treatment in this respect, as neurological complications influence all areas of functioning.

The group of twelve participants at the two care centres appeared to exhibit a normal range of personalities (Louw, van Ede & Louw, 1998). Six of the total group (participants three, four, five, seven, nine and twelve) were shy or withdrawn, while the other six (participants one, two, six, eight, ten and eleven) were pleasant and more outgoing. An interesting finding was the correlation determined between the length of time spent at the care centre and the demeanour of the children. Analysis indicated that the children who had been at the care centre longer were more pleasant ($p < 0.05$; $p = 0.05$). Although the findings cannot be generalised, this is an important finding regarding the placement of young children with paediatric HIV/AIDS. As was noted earlier with regard to the presence of illnesses, this finding appears to support the notion that placement of the affected children in a care centre may contribute positively to the children's demeanour. That is, children may gain various benefits from the care and attention provided by the caregivers. Thus, alternative care of children with HIV/AIDS in the South African context should be examined further.

It is apparent that the participants were not a uniform group, and that each individual should be treated according to his or her own needs and personality. Holistic treatment is the key to providing these children with the care they need to reach their optimum potential (Evian, 2000). Alertness during mealtime, as well as personality traits of the individual, may positively or negatively affect that particular person's feeding interactions. Professionals and caregivers who work with the paediatric HIV/AIDS population must promote active alertness in the

children, as this is conducive to successful feeding (Hall, 2001) with implications for growth and development.

3.3 POSITIONING OF PARTICIPANTS DURING MEALTIME

The participants were positioned differently according to their age, as well as depending on their ability or inability to feed themselves. The findings are depicted in Figures 5 and 6 below.

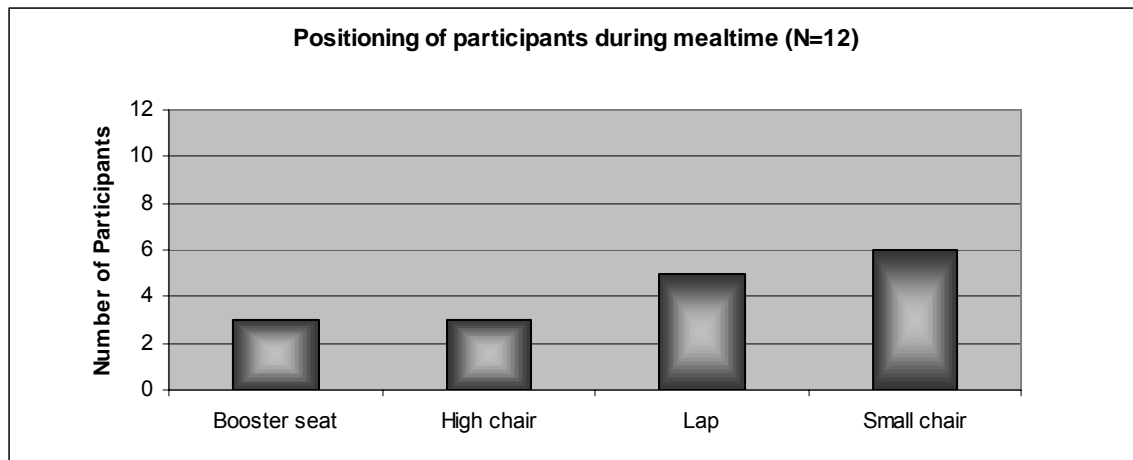


Figure 5: Positioning of participants during mealtime (N=12)

Six participants (four, five, six, ten, eleven and twelve), between the ages of two and three years, were seated in small chairs at tables during meals. This positioning was judged to be appropriate for this age group, particularly for self-feeding (Arvedson & Brodsky, 2002). According to Figure 5, three participants were fed while positioned on a booster seat (participants one, two and three) while participants seven, eight and nine were fed while seated in high chairs.

According to Figure 6, different positioning was noted as the only variation between the two groups. At Centre A, some participants (one, two and three) were fed while positioned in a booster seat, whereas at Centre B participants seven, eight and nine were fed in high chairs. Booster seats provide more stability for the child as he/she has a stable base, which makes it easier to

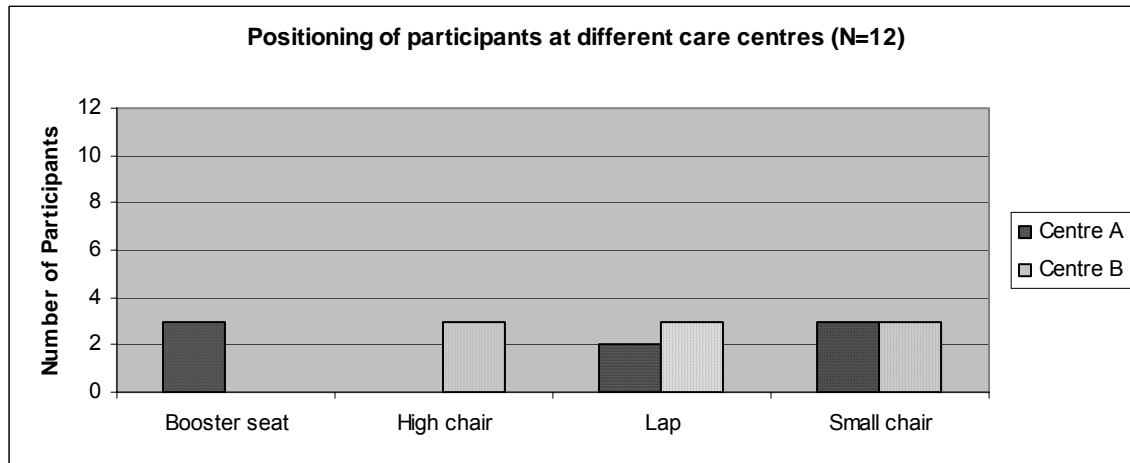


Figure 6: Positioning of participants at different care centres (N=12)

concentrate on eating and swallowing (Arvedson & Brodsky, 2002; Davis-McFarland, 2002). Financial constraints are likely to have contributed to the differences in the use of feeding equipment such as a booster seat during meals, as Centre A receives private funding, and Centre B is state funded. No other differences between the two groups were noted regarding the positioning of children during mealtimes. Positioning of the child affects the stages of swallowing, and proper positioning is required to establish stability and mobility of the lips, cheek, jaw and tongue (Hall, 2001; Schubert, 1994). The positioning of the participants was deemed to be adequate, keeping the equipment constraints in mind.

3.4 TYPES OF FOOD FED TO THE PARTICIPANTS

The types of food the participants in the two groups were fed during mealtimes were noted. The findings indicated that the participants were fed a range of different food types depending on their age and capabilities. The findings are provided in Figures 7 and 8 and Table II.

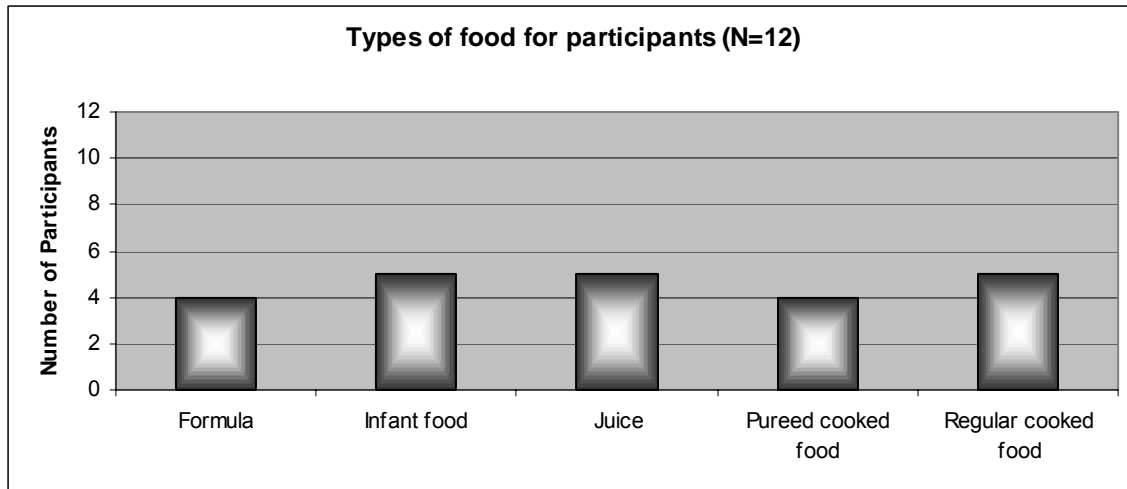


Figure 7: Types of food fed to participants (N=12)

Age considerations may account for different food types being given to the children. For example, participants one and eight ate infant food (Purity™) and pureed cooked food. This is age appropriate, as infants of this age (10 months and 13 months old respectively) normally still eat infant food as well as pureed cooked food (Hall, 2001).

Table IV: Clarification of different food types fed to participants (N=12)

Participant number	1	2	3	4	5	6	7	8	9	10	11	12
Types of Food												
<i>Formula</i>	X	X					X	X				
<i>Infant food</i>	X	X					X	X	X			
<i>Juice</i>			X	X	X	X			X			
<i>Pureed cooked food</i>	X	X	X					X				
<i>Regular cooked food</i>			X	X	X	X				X	X	X

Participant nine (20 months old) did not eat age appropriate food and only ate infant food, as can be seen in Table IV. Children with HIV/AIDS often do not receive age-appropriate foods due to their frequent illness and developmental delay (Pressman, 1992). He could not tolerate any food with a thicker or grainier

consistency, and refused to eat this type of food. This refusal and/or sensitivity to thicker consistencies may have been due to neurological influences that were observed in this participant. Children with mental retardation and cerebral palsy frequently do not tolerate thicker consistencies well (Davis-McFarland, 2000).

Participant nine required individual attention in order to correct his eating patterns, as prolonged feeding of soft foods to children with disabilities commonly occurs, which may be detrimental to oral health and limit the intake of essential nutrients (Faine, 1994). Thus, participant nine should gradually have been introduced to different textures of infant food (Morris & Klein, 1987), including vegetable puree. It is possible that he was refusing the pureed cooked food, as it was not sweet, whereas the Purity™ is sweet and smooth in consistency. He may have been averse to change in his diet, and if change is attempted it needs to be done gradually (Hall, 2001).

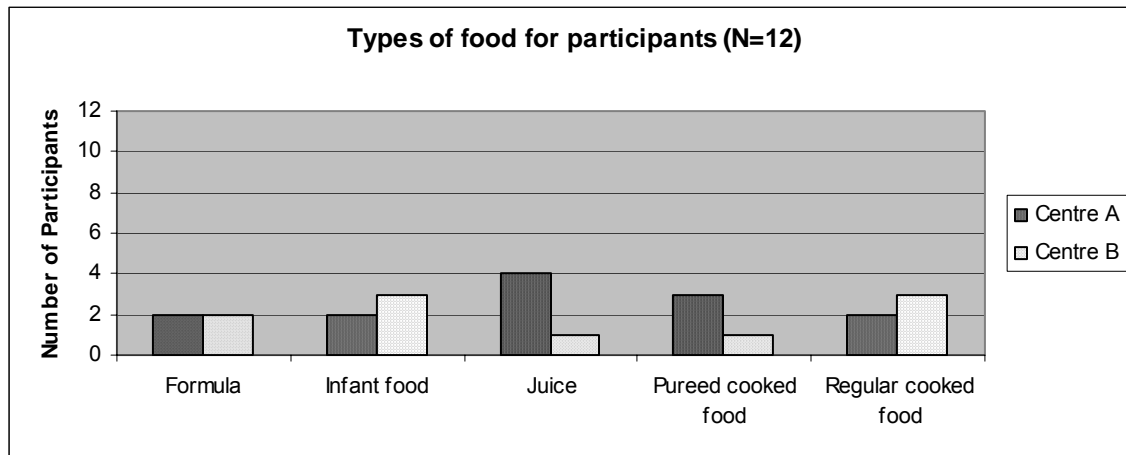


Figure 8:Types of food presented to the participants at different centres

From Figure 8 it was noted that the children from Centre B were given less juice than those from Centre A. This finding may be attributed to the fact that some of the children at Centre B were assessed during breakfast where they were given milk to drink instead of juice. It is likely that at lunchtime they would have also received juice. The different times of observation were due to logistical constraints in collecting the data.

It is vitally important that children with paediatric HIV/AIDS receive adequate nutritional intake, as decreased dietary intake, intestinal malabsorption, increased excretion of nutrients and increased energy requirements are responsible for the growth failure and malnutrition in HIV infection (Evens, 2002). Many essential nutrients become deficient, which may compound immune deficiency, and declining immune function then allows for infections such as diarrhoea and respiratory infections to become recurrent, which adds to the growth failure and malnutrition (Eley & Hussey, 1999).

In an optimal environment it would be advisable that the children receive individual attention regarding their feeding likes and dislikes. However, in the care centre environment this was not possible, as the care worker child ratio was too large and did not allow for catering for individual food preferences. Nevertheless the care workers did ensure that the children received sufficient sustenance.

3.5 THE ORAL SENSITIVITY AND REFLEXES OF THE PARTICIPANTS

The oral sensitivity and the oral reflexes of the participants were assessed where possible. Four participants (number two, four, five and nine) were uncooperative during the oral peripheral examination, which resulted in limited information regarding their oral sensitivity and reflexes. However, information regarding these aspects was supplemented from observations during the mealtimes of the participants. The findings are presented in Figure 9.

Most of the participants (n=10) presented with normal oral sensitivity and reflexes. This indicates that their oral sensitivity and reflexes were not negatively impacting on their feeding behaviour, and any feeding difficulties that were noted were likely to be due to another cause. Participants two and nine displayed

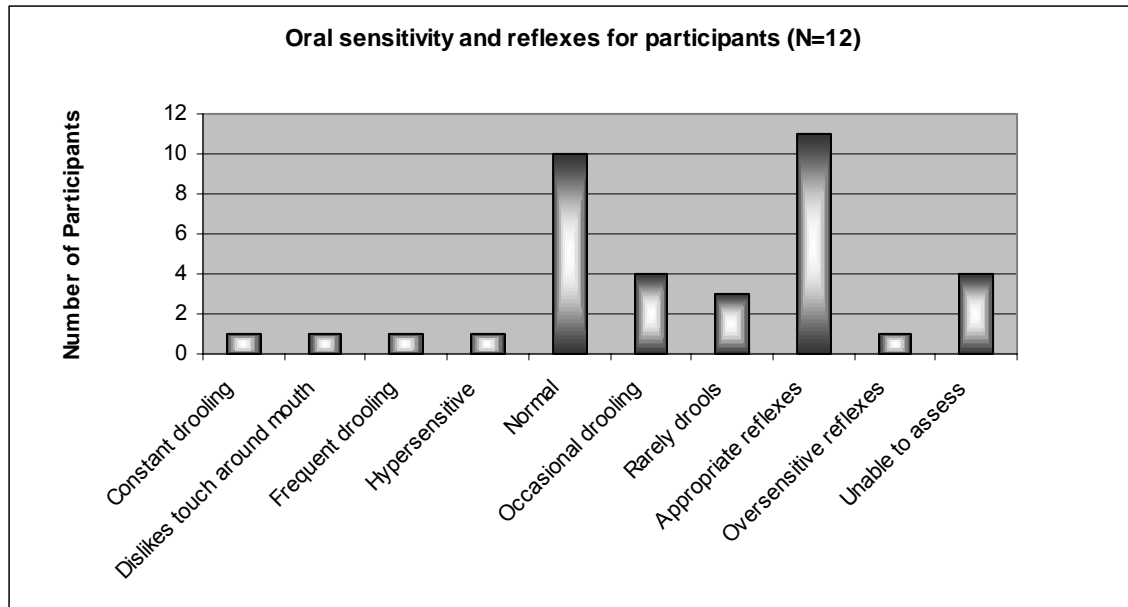


Figure 9: Oral sensitivity and reflexes of the participants (N=12)

heightened oral sensitivity and oral reflexes. As previously mentioned, participant two was orally hypersensitive due to oral thrush, and she was unwell at the time of assessment. She also had an oversensitive gag reflex that was elicited by touching the lips during the oral peripheral examination. It would have been valuable to assess her on another occasion, in order to determine whether the oral sensitivity and reflexes returned to normal once the infections cleared up, or whether the sensitivity remained. If the hypersensitivity had remained, it may have been indicative of additional problems, such as a central nervous system dysfunction such as encephalopathy (Davis-McFarland, 2000). HIV-related encephalopathy can cause abnormal oral motor patterns not usually seen in normally developing children (Morris & Klein, 1987). Participant nine also presented with abnormal oral reflexes, which were attributed to a possible neurological involvement (suspected mental retardation) (Davis-McFarland, 2000).

Nine participants (number one, two, five, seven, eight, nine, ten, eleven and twelve) displayed various degrees of drooling, which could have been accounted for by the fact that a number of the participants were teething at the time of the

assessment. However, in the case of participants two and eight oropharyngeal lesions could have resulted in excessive drooling, as the lesions inhibit a child's ability to control saliva (Davis-McFarland, 2000). Though no oral thrush was noted in participant eight, the possibility exists that he was suffering from pharyngeal lesions that were not easily visible on visual inspection of the oral cavity.

As mentioned previously, four participants displayed some unwillingness to allow the researcher to perform an oral examination. The participants may have been uncooperative due to the researcher being unfamiliar, as well as the fact that many of the participants were teething at the time of the assessment. The unwillingness may also have been due to the fact that most of these children were suffering from upper respiratory tract infections (refer to 3.1), and that the oral examination hampered their breathing, making them uncomfortable, irritable and uncooperative.

The information gleaned from the oral peripheral examinations was valuable in obtaining a more accurate description of the feeding process of the participants, despite the fact that not all participants were co-operative during the assessment.

3.6 STRUCTURE AND FUNCTIONING OF LIPS/CHEEKS, TONGUE AND JAW

The structure and functioning of the oral structures, namely the lips, cheeks, tongue and jaw were also assessed during a brief oral peripheral examination, which formed part of the CEPD (Hall, 2001). The findings are presented in Figure 10.

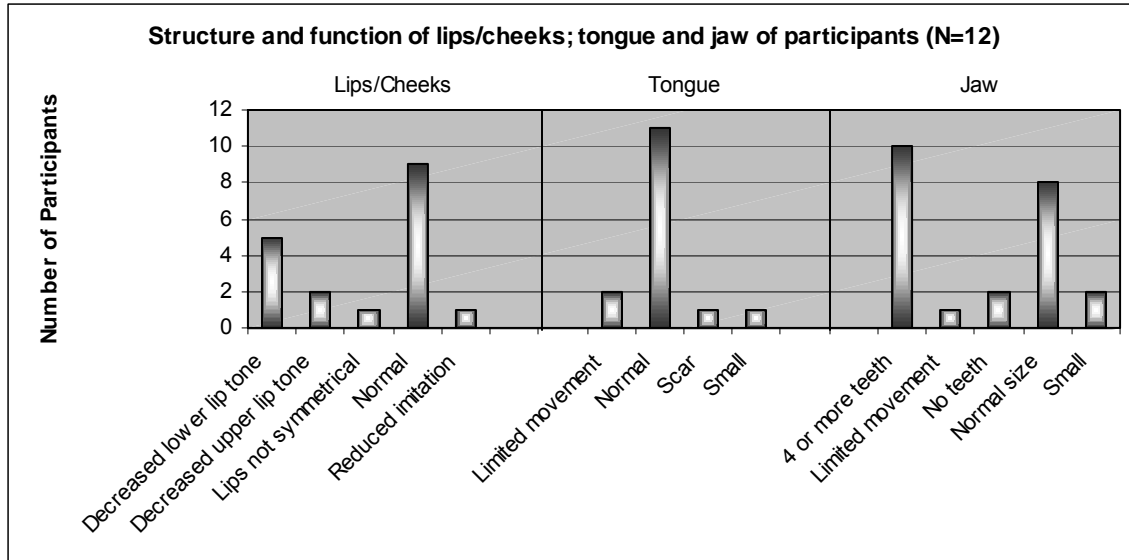


Figure 10: Structure and functioning of the oral structures (N=12)

Between eight and eleven of the participants presented with normal size lips/cheeks, tongue and jaw (Hall, 2001). Six participants (two, three, five, six, eight and eleven) presented with decreased muscle tone in the lips, especially the lower lip. It is interesting to note that five of these children with decreased muscle tone in the lips were from Centre A. The researcher initially assumed that upper respiratory tract infections may be the cause of the decreased muscle tone, due to compensatory breathing (Hall, 2001). However, this was not the case, as nine participants from both care centres suffered from these infections, whereas mainly children from Centre A presented with decreased muscle tone in the lips. Therefore, individual differences may have accounted for this finding of decreased muscle tone.

Participant five from Centre A presented with limited tongue and jaw movement, which negatively influenced his drinking abilities (Hall, 2001). No obvious explanation could be found in his medical and case history.

No major structural anomalies were noted in the participants' oral structures. Only participant five presented with a functional problem of the oral structures.

The decreased muscle tone in the lips was observed to be the only structural difference in the rest of the participants. According to Iosub, Bamji, Stone, Gramisch and Wasserman (1987) some children with HIV/AIDS may present with dysmorphic features, specifically a distinctive head shape. In addition, Iosub et al. (1987) did not report oral structural abnormalities in their study. This finding is in keeping with the results of the present study, where none of the participants presented with oral structural abnormalities.

3.7 NON-NUTRITIVE AND NUTRITIVE SUCKING

Non-nutritive sucking (NNS) and nutritive sucking (NS) were assessed in the participants for whom it was age appropriate, (participants one, two, seven and eight) namely till approximately 12 months of age (Arvedson & Brodsky, 2002). The results are depicted in Figure 11.

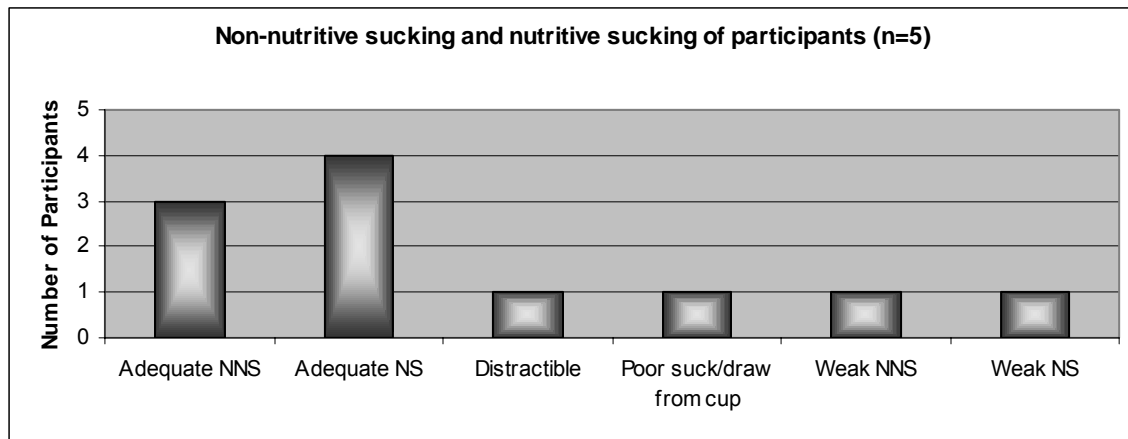


Figure 11: Non-nutritive and nutritive sucking of participants (n=5)

The infants in the care centres were not provided with pacifiers so the possibility of NNS was limited, except if they sucked their fingers or toys. It appears as if NNS was not encouraged by the caregivers, and it may have been valuable to inform the caregivers of the value of NNS in stimulating adequate NS (Arvedson & Brodsky, 2002). For the participants for whom it was appropriate (one, two, seven and eight) their sucking movements appeared to be adequate.

Participant five was assessed regarding his drinking abilities from a cup as he was already 28 months old, and no longer drank from a bottle. Participant five was noted to have a poor suck/draw action from a cup, which could be related to a limited tongue and jaw movement recorded in the previous section. It was noted that participant one was distractible, which may simply be related to her individual personality traits (refer to 3.2).

Participant seven from Centre B, presented with adequate to weak NNS and NS, as she was unable to latch onto the nipple or the researcher's finger, and was not able to maintain the sucking behaviour. This may have been due to illness as she was unwell at the time of the assessment. She was reportedly struggling to gain weight, and it would have been advisable to stimulate NNS to prevent the loss of her sucking capabilities while she was ill (Hall, 2001).

Non-nutritive sucking has been proven to stimulate NS (Arvedson & Brodsky, 2002) as well as calming infants and giving them a feeling of security (Comrie & Helm, 1997; Wolf & Glass 1992). This is important in children, especially in a care centre environment, which attempts to simulate the home environment. These advantages need to be explained to the caregivers so that more children in their care can reap the benefits of NNS.

3.8 DURATION OF MEALTIME

The length of time that it took the participants to complete a meal was noted, as well as the utensils with which they fed themselves or with which they were fed. The findings are depicted in Figures 12 and 13.

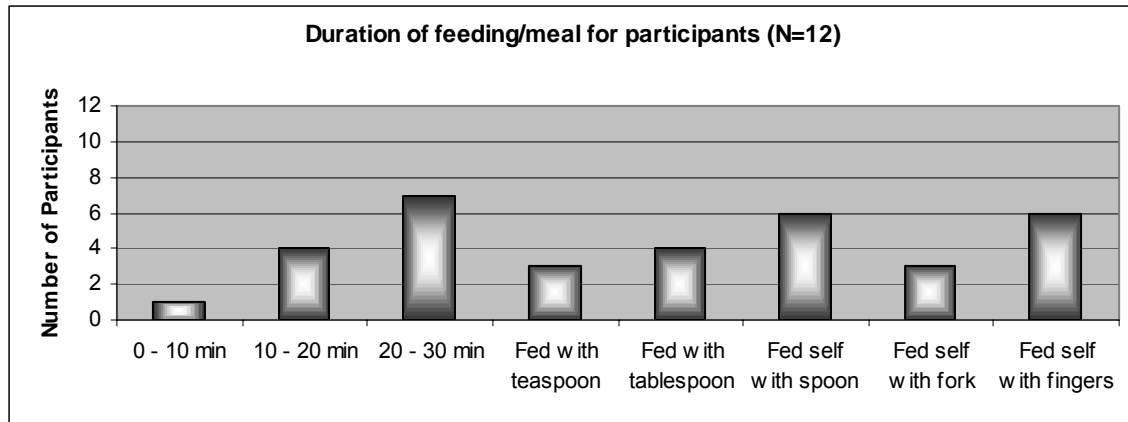


Figure 12: Duration of the mealtimes of the participants (N=12)

It was noted that seven of the participants took 20-30 minutes to complete a meal, which, according to Arvedson and Brodsky (2002), is an average-to-long time. The duration of the meals could not be explained by the fact that some children were fed by caregivers while others fed themselves, as the times varied across these confines. It was observed that participant twelve (32 months old) completed his meal in less than 10 minutes in order to get a second serving of food. This finding may be attributed to the fact that if participant twelve ate at a slower pace, there would not be any food left for a second serving.

An interesting finding was that five participants, namely participants one, three, six, ten and twelve had normal tongue movement for swallowing of solids, and it took them under 20 minutes to complete a meal. Of the seven participants that took between 20-30 minutes to complete a meal, four of them, namely participants two, four, seven and nine displayed irregular tongue movement; either food residue not being cleared by the tongue or tongue protrusion/thrusting for the swallowing of solids. This finding suggests that those participants who took a longer period of time to complete their meal, had irregular tongue functioning ($p \leq 0.1$; $p = 0.08$).

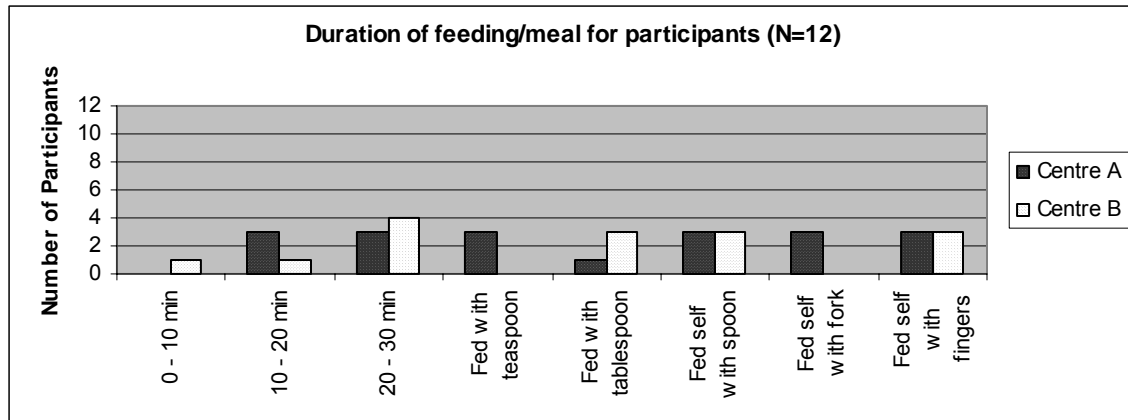


Figure 13: Duration of the mealtime for participants from both centres (N=12)

According to Figure 13, a difference between the utensils used to feed the children, as well as those used by the children to feed themselves was evident between the two groups. At Centre B the younger children were fed with plastic tablespoons and the older children also ate with tablespoons. At Centre A the younger children were fed with teaspoons and the older children fed themselves with spoons and forks. Eating with utensils during mealtimes provided them with the opportunity to gain familiarity with various utensils. It is advisable to expose the children to various feeding utensils, as this contributes to socially appropriate eating behaviour (Arvedson & Brodsky, 2002). However, the lack of feeding utensils at Centre B may be due to financial constraints.

It would, however, have been advisable to feed the younger children with teaspoons rather than tablespoons, as the size of their mouths did not adequately accommodate the larger spoon. As eight participants had poor lip closure during feeding (refer to 3.6), feeding with a teaspoon may have encouraged more normal oral functioning and facilitated lip closure while eating (Hall, 2001). However, the presence of upper respiratory tract infections in participants may also have contributed to the poor lip closure (refer to 3.1).

These findings suggest that irregular tongue movement in four participants, as well as whether the child fed him/herself or was fed by a caregiver, influenced duration of a meal. A difference that was noted between the two care centres was that different utensils were used, which may have negatively influenced the lip closure of the younger participants.

3.9 SWALLOWING PATTERNS OF LIQUIDS

The swallowing patterns of liquids were observed and assessed for each of the participants individually. These patterns were assessed by considering the oral structures in three structural regions, namely lips/cheeks, tongue and jaw. Each of these regions was assessed and could either be functioning normally, or one or more aberrant movements could be indicated. The results are presented in Figure 14.

During the swallowing of liquids it was observed that the lip and cheek functioning of seven participants was compromised. Tongue and jaw functioning for the swallowing of liquids was judged to be in the range of normal. Loss of liquid from the lips was noted in five of the participants due to poor lip functioning. Participants one, two and seven experienced liquid loss while drinking from a bottle, and participants ten and twelve experienced liquid loss while drinking from a cup. The bilateral liquid loss observed in participants ten and twelve may have been due to them drinking from cups with no lids, whereas the participants of similar age from Centre A drank from tippy cups – from which it is easier to drink without spilling (Arvedson & Brodsky, 2002; Hall, 2001). Furthermore some individual differences can be attributed to the fact that the children were of various ages and personalities (see 3.2).

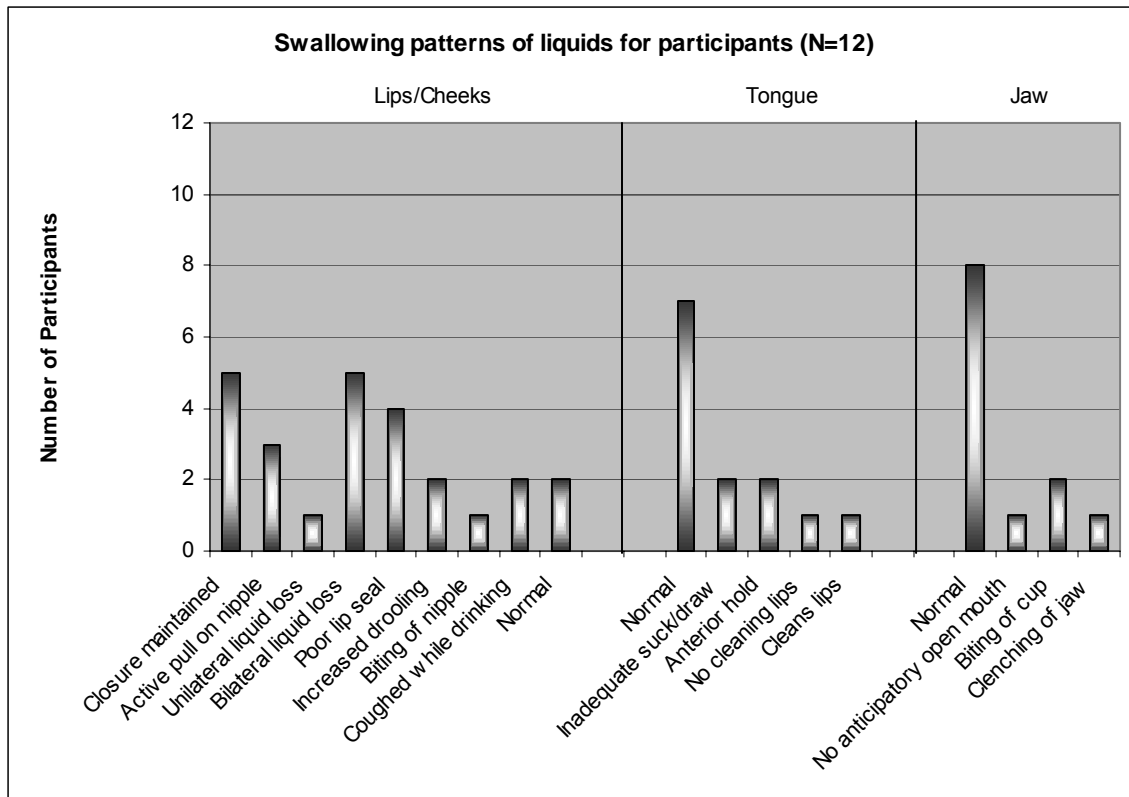


Figure 14: Swallowing patterns of liquids for participants (N=12)

In seven participants (participants one, two, three, seven, nine, ten and twelve) compromised lip and cheek functioning was noted. Only one of the seven participants did not experience frequent upper respiratory tract infections. It appears that the children with upper respiratory tract infections were more prone to compromised lip and cheek functioning during swallowing of liquids, as this jeopardised their breathing mechanism, that is, their mouth.

As mentioned previously, the older children at Centre A drank their juice from tippy cups whereas the same age group at Centre B drank from cups with no lids. This may account for the fact that two of these participants from Centre B had bilateral liquid loss, while the children at Centre A were able to drink without spilling. It is age appropriate for children between 18 – 36 months of age to drink from tippy cups (Morris & Klein, 1987). A possible reason for the discrepancy

between the two centres may once again be financial, as tippy cups are more expensive and Centre B has more financial restrictions than Centre A.

3.10 SWALLOWING PATTERNS OF SOLIDS

The swallowing patterns of solids were observed during mealtimes, where the participants were either fed by a caregiver or fed themselves. The patterns were separated into normal or aberrant, where one or more aberrant patterns could be present in either lip/cheek, tongue or jaw functioning. The findings are depicted in Figure 15.

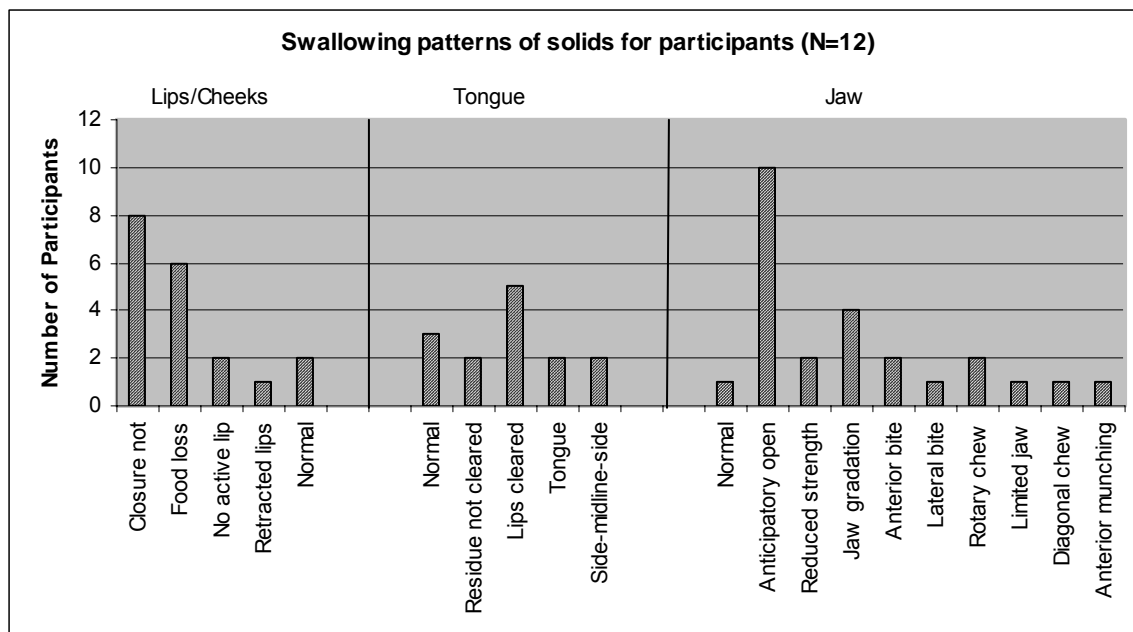


Figure 15: Swallowing patterns of solids for participants (N=12)

According to Figure 15, the most evident observation was that nine participants (number two, three, four, five, six, seven, eight, eleven and twelve) either did not maintain lip closure while eating solids or experienced loss of food. Of these nine participants, participants two, three, four, five, seven, eight and twelve experienced upper respiratory tract infections. In their case, a relationship may exist between the fact that it was difficult for them to breathe while eating as their primary breathing apparatus, the nose, was congested (Hall, 2001). This nasal

congestion would explain why there was a need to keep the mouth open while eating in order to breathe between chewing mouthfuls.

In the two participants who did not maintain closure (participants six and eleven), and did not experience upper respiratory infections, a different explanation is required. Their behaviour may be attributed to the fact that this was a learnt pattern, and had become a habit (Arvedson & Brodsky, 2002). Although participants six and eleven were not noted as having upper respiratory infections at the time of the assessment, this does not mean that they did not still experience frequent upper respiratory infections, and had become accustomed to mouth breathing. Some of the participants may in fact have had compromised lip and cheek muscle functioning, which would then explain their inability to maintain lip closure while eating (Hall, 2001). However, a congested airway may still contribute to this pattern, so direct causation is difficult to determine, and only possible contributing factors were described here. The participants seemed to eat well and no further problems were noted that applied to the whole group. Individual differences occurred, however, there was a general progression of normal feeding and the children still managed to adhere to the requirements of normal swallowing according to this progression (Hall, 2001).

The participants from the two groups seemed to be able to eat solids well enough. Where problems with eating were present, it was likely that the participants compensated adequately. It is a positive sign that no major swallowing problems were present in the participants, as failure to thrive (FTT) is a very common condition in children with paediatric HIV/AIDS (Evian, 2000). A number of explanations may account for this finding. Firstly, long-term assessments of the participants may be warranted in order to precisely ascertain the presence or absence of FTT. In this study, assessment occurred on one occasion and case history was limited (refer to 3.1), therefore growth and weight could not be monitored over a period of time, which is necessary for determination of FTT (Kessler, 1999; Lopez, 1997). Secondly, as the number of

participants in this study was limited, these specific children may simply exhibit adequate nutrition. However, this does not exclude the possibility that a number of children with HIV/AIDS in Gauteng do exhibit signs of FTT.

The results of this study highlight the fact that the paediatric HIV/AIDS population in the specific care centres in Gauteng is a unique group, with specific needs, requiring a holistic approach. It is vital to take differing environments and situations into account when attempting to work with this population. Especially when endeavouring to apply principles of intervention for the paediatric HIV/AIDS population, found in international literature.

4. CONCLUSIONS

In accordance with the main aim of the study, the nature of the feeding behaviour of 6 – 36 month-old children with paediatric HIV/AIDS in care centres in Gauteng was described. Based on the results of each of the study's objectives, the following **conclusions** were drawn.

The following information assisted in the **description of the nature of the feeding behaviour** of these young children. According to the medical history obtained, the participants experienced a range of illnesses, which were consistent with those experienced by the general paediatric HIV/AIDS population (Davis-McFarland, 2000; Evian, 2000; Braeggens et al., 1995). It was important to determine the medical history of the participants as children with HIV/AIDS are very susceptible to infections; and illnesses experienced may contribute to the feeding behaviour and functioning of a child (Davis-McFarland, 2000), such frequent upper respiratory tract infections. Medical history provides insight into the ability of the child to function under varying health conditions (Hall, 2001).

The findings indicated that the incidence of upper respiratory tract infections and general ill health in the participants appeared to be inversely proportional to the duration of time spent at the care centre, suggesting that the environment has a positive influence on the health of the participants. It was also noted that the placement of the affected children in a care centre contributed positively to the children's demeanour. That is, children may have gained various benefits from the care and attention provided by the caregivers. These are important findings, especially in the South African context, and may even be a motivation to provide these care centres with additional funding as it is more feasible to place children with paediatric HIV/AIDS in a care centre than arrange foster/adoptive parents for all of them (Population Reports, 2001).

The results further indicated that the participants were not a uniform group with regards to their feeding capabilities, and that each individual needs to be treated according to his or her own needs and personality. Holistic treatment is the key to providing children with paediatric HIV/AIDS with the care they need to reach their optimum potential (Evian, 2000). Individuals who work with these children must promote active alertness in the children, as this is conducive to successful feeding (Hall, 2001). Alertness and successful feeding both have implications for growth and development (Rossetti, 1996).

This study illustrated that Centre A employed different methods of positioning during mealtimes in comparison to Centre B. The different methods of positioning employed at the respective care centres were noted as positioning influences swallowing, in that if a child is provided with a stable base, that is when placed in a booster seat, it is easier for the child to concentrate on eating and swallowing (Arvedson & Brodsky, 2002; Davis-McFarland, 2002). The positioning of the participants during mealtimes was deemed to be adequate, keeping the financial and equipment constraints of Centre B in mind. Positioning of the child affects the stages of swallowing, and proper positioning is required to establish stability and mobility of the lips, cheek, jaw and tongue (Hall, 2001; Schuberth, 1994)

The information gleaned from the oral peripheral examinations was valuable in obtaining a more accurate description of the feeding process of the participants, despite the fact that not all participants were co-operative during the assessment. No major structural anomalies were noted in the participants' oral structures.

It was noted that non-nutritive sucking (NNS) was not actively encouraged in the infants assessed at the respective care centres. Non-nutritive sucking has been proven to stimulate nutritive sucking (Arvedson & Brodsky, 2002) as well as calming infants and giving them a feeling of security (Comrie, 1996; Wolf & Glass 1992). This is important in young children, especially in a care centre

environment, which attempts to simulate a secure home environment. These advantages need to be explained to the caregivers so that more young children in their care can benefit from NNS.

Regarding the eating utensils employed by the children, it is important to be aware of various eating utensils used, as the children at Centre B were only exposed to tablespoons (due to financial constraints). Nonetheless, teaspoons are more suitable for infants and the older toddlers should be starting to use forks to eat (Morris & Klein, 1987). In a future study it may be interesting to note whether the utensils used by the children during their mealtimes influenced the duration of the mealtime. If this was found to be the case it might be valuable to provide all care centres with the various eating utensils such as teaspoons, tablespoons and forks in order for the children to develop appropriate eating behaviour.

A great wealth of information was obtained from the assessments of the feeding of the young children in this study, and it was possible to compile a detailed description of the nature of the feeding of these children.

An expansion of the previous objective was to **determine whether the young children with paediatric HIV/AIDS experience feeding problems**, the following factors were highlighted. In these specific care centre environments (both centre A and B) the children did not receive individual attention regarding their feeding likes and dislikes due to the caregiver-child ratio being too large. As a result, the situation did not allow for catering of individual food preferences. Nevertheless, the caregivers ensured that the children received sufficient sustenance during a meal. With regard to food preferences, caregivers should take note when children do not eat certain foods, and then determine whether this is due to intolerance of the texture or due to individual preference on the part of the child. If it is intolerance or an aversion to a specific type of food, this must be noted and an explanation must be attempted. For example, a sudden

aversion may indicate an oral infection, which is very common in the paediatric HIV/AIDS population (Evian, 2000), and must be treated as soon as possible (Davis-McFarland, 2000).

The findings indicated that nine of the participants either did not maintain lip closure while eating or experienced loss of food. These concerns may have been due to upper respiratory tract infections, which compromise the free use of the nose as an airway, making the mouth the primary breathing mechanism. A possible solution to this problem would be to clear up the upper respiratory infections of the children, thus, restoring the normal integrity of the respiratory system, which should enable them to maintain lip closure during meals and avoid food loss (Evian, 2000). Two participants who displayed poor lip closure and food loss were not noted as having upper respiratory infections at the time of the assessment. However, they may have experienced frequent upper respiratory infections previously, and had become accustomed to mouth breathing. In this case, the habit should be changed so that a more appropriate form of eating can be adopted, and food loss can be avoided. The findings suggested that participant five appeared to have limited tongue and jaw movement. No explanation for the limited mobility could be found in the medical history or limited background information available. This limited mobility may possibly be due to individual differences, however a further, more detailed investigation may well be warranted as this does influence his feeding capabilities, especially his drinking abilities.

The participants from the two groups seemed to be able to eat solids adequately according to their age and development. Where problems with eating were present, it was likely that the participants compensated adequately. It is a positive sign that no major swallowing problems were present in the participants, as failure to thrive (FTT) is a very common condition in children with paediatric HIV/AIDS (Evian, 2000). In this study one could draw the conclusion that these specific children with paediatric HIV/AIDS do not exhibit signs of FTT, contrary to

reports in the literature that FTT frequently occurs in this population (Evian, 2000; Pressman, 1992). However, this does not exclude the possibility that a number of children with HIV/AIDS in Gauteng do exhibit signs of FTT.

From the results it was clear that the participants displayed individual, yet functional feeding skills. However, some individuals did present with some feeding problems, which should be addressed by the care workers as well as by professionals involved in caring for these children.

A **critical evaluation** of this study was performed in order to reflect on the value and limitations of the results. Due to the environmental and family situations discussed previously, the case history available for each of the participants was limited. It was noted that a more detailed background for each of the paediatric participants would have been valuable in describing their medical status over the long-term and describing their feeding behaviour more accurately. This study, however, illustrates the conditions as they are presently in the South African context. One of the major adaptations made to the assessment tool in order to increase its applicability to the South African context, was that less emphasis was placed on the interpretation of the participant's background information and more emphasis was placed on the information obtained from the direct assessment. This shift in emphasis may be considered as a limitation of the study; at the same time it may be considered a strength, as it is more reflective of the South African context.

The reliability of the study may have been affected by the fact that the caregivers fluctuated between assessments and they were not always extensively familiar with the child being assessed, as the children were resident at the care centres for varying amounts of time. Another factor, which may have influenced the study, was the fact that English was not the caregivers' first language, so misunderstandings may have occurred during the completion of the assessment. Despite these obstacles similar data was obtained from the two different care

centres, indicating some degree of reliability. The results were also determined to be valuable in that a wealth of information regarding the feeding process of this group of participants was obtained. Again scientific purists may consider the caregivers' linguistic factors to be flaws in the reliability. However, the research process was embedded in a realistic context, one in which laboratory conditions could not be replicated. In addition, attempts to force laboratory or scientifically rigid conditions on these participants would have resulted in the deliberate discarding of the wealth of data.

The results have important **clinical applications**. Firstly, the adaptations made to the assessment material are noteworthy (Biographical questionnaire, Form 3-1) (Hall, 2001). It is especially important to consider what adaptations are required when assessment protocols from the United States of America are being considered for use in the South African context. The adaptations suggested in the Methodology may be used successfully in the South African context. Furthermore, the CEPD (Hall, 2001) was a lengthy assessment tool, which provided the researcher with a wealth of detailed information. However, clinical application of the CEPD (Hall, 2001) in South Africa appears to be limited as it is very time consuming. The dearth of speech-language therapists in South Africa necessitates screening instruments, and once problems have been identified, the CEPD (Hall, 2001) may be applied.

A further clinical implication relates to the importance of continued monitoring of children with paediatric HIV/AIDS regarding their feeding abilities. This study, and the literature indicates that their feeding abilities as well as their general functioning varies according to the state of their health, and whether they are presently suffering from infections, such as upper respiratory tract or oral infections (Evian, 2000; Pressman, 1992). As has been stated previously, prompt intervention is likely to lessen the potentially negative impact of feeding problems on the functioning of the child, such as feeding problems that may lead

to malnutrition which in turn compromises the child's ability to develop optimally (Evens, 2002).

A final clinical implication of the study relates to the role of the speech-language therapist in children with paediatric HIV/AIDS. The speech-language therapist has much to offer the children with paediatric HIV/AIDS as well as their caregivers in terms of sharing of knowledge. For example, the caregivers should be informed that mealtimes are suitable opportunities to stimulate language and communication development, as natural interaction occurs between the caregiver and the child at this time (Arvedson & Brodsky, 2002; Davis-McFarland, 2000). Caregivers should always attempt to make mealtimes a pleasant experience so that the children make a positive association with food, and eating in order to lessen the chance of possible malnourishment developing due to disinterest in food (Kessler, 1999)

In terms of further **research implications**, it is suggested that a similar study is conducted, possibly on a national scale where a larger number of young children are assessed. This will enable one to make generalisations about the feeding of children with Paediatric HIV/AIDS in South Africa, and provide guidelines for the effective care of these children. It may also be of value to conduct a detailed study on the influence of the care centre environment on the functioning of young children with paediatric HIV/AIDS as this study highlighted the finding that the children were benefiting from the care centre environment.

In this study only three out of the twelve participants were receiving anti-retroviral medication. It was noted that they had an improved demeanour in comparison with the rest of the participants. Anti-retroviral medication has been shown to have numerous benefits for the adult population (Evian, 2000). A further study may be warranted which explores the exact influence the anti-retroviral medication has on the functioning of the child in the care centre in the South African context. This may then possibly lead to the identification of factors

motivating the provision of this medication for all children with HIV/AIDS. The long-term implications for the health, well-being and education of the child are obvious.

Another research implication relates to the positioning of the child during meals. Positioning of the child affects the stages of swallowing, and proper positioning is required to establish stability and mobility of the lips, cheek, jaw and tongue (Hall, 2001; Schuberth, 1994). Regarding the different positioning employed by the various care centres during mealtimes, firstly, a further study may be of value to compare the feeding of the same child when positioned differently. The different positions for feeding then highlight concerns that may not be obvious when assessing different children, as feeding capabilities of a specific child can be assessed when positioned on the caregiver's lap, in a booster seat or in a high chair. Booster seats provide more stability for the child as he/she has a stable base, which makes it easier to concentrate on eating and swallowing (Arvedson & Brodsky, 2002; Davis-McFarland, 2002). Secondly, a long-term study may be of value where gradual inclusion of various food textures is attempted in one child with a feeding concern in order to illustrate to caregivers how to go about integrating various food textures into the children's diet. This study would be of value as it is important to promote feeding skills that approximate the norm, especially with regard to the inclusion of different textures (Morris & Klein, 1987).

In **conclusion**, the participants of this study presented with functional feeding skills, with a few individuals presenting with various problems. The children seem to be functioning well in the care centre environment, which is an encouraging finding. The paediatric HIV/AIDS population is unique and this study has illustrated the importance of investigating the characteristics of specific participants, as the literature does not always present a true reflection of the population. The South African situation differs significantly from those described in the international literature due to financial and familial circumstances as well as child care in the care centres of children with paediatric HIV/AIDS (Bam et al.,

2003). For this reason one cannot simply apply the findings of international data to this population. When considering intervention in the paediatric HIV/AIDS population it is therefore important to consider the inherent individuality of each child in mind. In order to make the conditions available to the child that will promote a positive quality of life, a number of disciplines should be involved in their intervention. The speech-language therapist has an important role to play in the identification of feeding problems in this population. It is vital that the speech-language therapist liaises with the caregivers in this respect in order to provide the children in their charge with optimal feeding intervention.

The importance of the current study and its findings can be summarised in the following quote from McNeilly (2000, p 74):

“ As medical and pharmacological advances continue to be made, health care professionals will continue to see more children living with HIV. Many of them will present with feeding and communicative disorders that require the services of competent, caring speech-language pathologists.”

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6. APPENDICES

Appendix A: Biographical Questionnaire (Hall, 2001)

Appendix B: Clinical Evaluation of Pediatric Dysphagia (Hall, 2001)

Appendix C: Ethical Clearance forms

Appendix D: Informed consent form

Appendix E: General information form

Appendix F: Questions used in the semi-structured interview

Appendix A: Biographical Questionnaire (Hall, 2001)

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Appendix B: Clinical Evaluation of Pediatric Dysphagia (Hall, 2001)

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Appendix C: Ethical Clearance forms

Appendix D: Informed consent form

Appendix D

Dear Participant,

As a Master's student in the Department of Communication Pathology at the University of Pretoria, I am conducting a research project to determine: **The feeding of infants with paediatric HIV/AIDS in care centres in Gauteng.** Information will be gathered from assessment of the infants as well as from interviews with the caregivers. Feeding and nutrition issues affect the general development of infants and warrant the earliest intervention possible. The paediatric HIV/AIDS population is also increasing and health professionals need to know the exact extent of the problems that these children are dealing with. Your contribution can be very useful in providing additional information as well as improving the quality of service provided.

I realise that you have a very busy schedule, and greatly appreciate the time taken to participate in the interview. The information obtained from the interviews and the assessment will provide the speech language therapist and various other team members with valuable insight for the improved treatment of feeding problems in infants with HIV/AIDS.

I would appreciate it if you could take part in the interview and collaborate in the assessments of the infants. Attached please find an informed consent form, of which you are entitled to retain a copy. Your anonymity is assured, and your participation is highly regarded.

Thank you.

Yours sincerely,

Ms. Jacqueline de Lange
M. Communication Pathology IV
Department of Communication Pathology
University of Pretoria

Professor Brenda Louw
Supervisor

Appendix D

Participant's name: _____

Date: _____

Principal Investigator: **Jacqueline de Lange**
Communication Pathology Department
University of Pretoria

Informed Consent

1. *Title of study:* Feeding of infants with paediatric HIV/AIDS in care centres in Gauteng.
2. *Purpose of the study:* The purpose is to compile a feeding profile of the infants highlighting any problems they may experience as well as whether and how a speech-language therapist may be included in the service provision.
3. *Procedures:* I will be asked to take part in an assessment of the infants as well as an interview regarding the above-mentioned aspects. The interview will take approximately 15 minutes to complete. The interview will be scheduled at my convenience.
4. *Risks and discomforts:* There are no known medical risks or discomforts associated with this project.
5. *Benefits:* The results of this study will help other professionals and students to gain a better understanding of the feeding experience of infants with HIV/AIDS and how to deal with any difficulties effectively.
6. *Participant's rights:* I may withdraw from participating in the study at any time.
7. *Confidentiality:* In order to record exactly what I say during the interview a video recorder as well as a tape recorder may be used. The tapes will be viewed only by the Principal Investigator and authorised members of the research team at the University of Pretoria. I understand that the information will be kept confidential unless I ask that it be released.
8. If I have any questions or concerns, I can call the Principal Investigator, Jacqueline de Lange, at 072 1388736 at any time.

I understand my rights as a participant, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Participant's signature

Date

Signature of Investigator

Signature of Supervisor

Appendix E: General information form

Appendix E

Jackie Schoeman
Cotlands Baby Sanctuary
Turfontein

Dear Ms Schoeman

Request for permission to include infants under 12 months with HIV/AIDS and caregivers in research

As a Masters student in the Department of Communication Pathology, University of Pretoria, I would like to perform a research project including the infants with paediatric HIV/AIDS and their caregivers. In this project the feeding functions and the experience of the feeding interaction will be investigated.

The research methodology will consist of an assessment to be completed by the researcher and an interview will be conducted with the caregivers. It will take approximately 10 - 15 minutes per interview. If possible I would like to assess as many infants as possible to obtain a representative sample. Caregivers who take part in the study will remain completely anonymous.

The aim of this project is to facilitate collaboration between Speech - Language therapists and the caregivers, in order to provide the infants with optimal care regarding the resolution of feeding problems. Caregivers play a vital role by interacting most intimately with these infants, for these reasons collaboration is extremely important. The Speech - Language therapist is in a unique position to provide input regarding the lasting impact and optimal application of various feeding techniques. Upon completion of the research a copy of the research report will be made available to you and the caregivers that participated in the study.

I hope that this request to involve the infants in your care and their caregivers in my research will meet with your approval.

Yours sincerely,

Jacqueline de Lange
M. Communication Pathology IV
Department of Communication Pathology
University of Pretoria

Professor Brenda Louw
Supervisor

Appendix E

Tikie de Vos
Mohau
Kalafong Hospital

Dear Ms de Vos

Request for permission to include infants 6 - 12 months with HIV/AIDS and caregivers in research

As a Masters student in the Department of Communication Pathology, University of Pretoria, I would like to perform a research project including the infants with paediatric HIV/AIDS and their caregivers. In this project the feeding functions and the experience of the feeding interaction will be investigated.

The research methodology will consist of an assessment to be completed by the researcher and an interview will be conducted with the caregivers. It will take approximately 10 - 15 minutes per interview. If possible I would like to assess as many infants as possible to obtain a representative sample. Caregivers who take part in the study will remain completely anonymous.

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I hope that this request to involve the infants in your care and their caregivers in my research will meet with your approval.

Yours sincerely,

Jacqueline de Lange
M. Communication Pathology IV
Department of Communication Pathology
University of Pretoria

Professor Brenda Louw
Supervisor

Appendix F: Questions used in the semi-structured interview

INTERVIEW SCHEDULE

A: Caregivers

- Experience in feeding infants (length of time)
- Length of time employed at care centre?
- What training has been received regarding feeding and caring for infants?

B: Feeding circumstances

- How many feeds does the infant receive?
- Does one caregiver consistently feed the same infant?
- Where does feeding occur? Please describe the environment.
- Who supervises the feeding of the infants?