

# Oral-motor function for feeding of HIV-exposed and unexposed infants

Ву

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### Abstract

**Background and objective:** HIV-exposed infants are a priority group at-risk for oropharyngeal dysphagia (OPD), yet little is known of their oral-motor functioning during feeding in infancy. This study aimed to compare the oral-motor function for feeding of six-to-twelve month old HIV-exposed infants, to that of HIV-unexposed infants, and to determine whether distinctive oral-motor difficulties existed in the HIV-exposed group.

**Materials and methods:** The oral-motor function during feeding of 75 infants aged six-to-twelve months was evaluated once by a Speech-Language Therapist, using the *Schedule for Oral Motor Assessment*. Data was collected prospectively at a baby-wellness clinic within a low-resourced community. Participants were separated into two groups, according to HIV-exposure status (30 HIV-exposed and 45 HIV-unexposed participants) and subdivided according to age range (six-to-eight and nine-to-twelve months). Significant differences between groups were determined using inferential statistics.

**Results:** Neither group presented with oral-motor dysfunction, or OPD, but the research group (RG) displayed a greater number of difficulties across the food consistencies used. HIV-exposure was strongly associated with the sum of difficulties experienced with semi-solids; solids; chewable solids; soft-bite crackers;

and cup-drinking. Within the six-to-eight month range, no significant differences were found in oral-motor performance of the groups. In the nine-to-twelve month range, the RG displayed greater difficulty when cup-drinking, demonstrating greater liquid loss; choking; and struggling to smoothly coordinate sucking/chewing and swallowing.

**Conclusion:** Older HIV-exposed infants showed more oral-motor difficulties than the younger group, displaying a risk for developing OPD. Oral-motor deficits may become more apparent in older HIV-exposed infants, when the demands for feeding require more advanced oral-motor skill. Further research is required.

**Key words:** HIV-exposed, HIV-unexposed, infants, oral-motor function, oral-motor dysfunction, oropharyngeal dysphagia, Schedule for Oral Motor Assessment

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### **DECLARATION**

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### List of abbreviations

AIDS Acquired Immunodeficiency Syndrome

**ART** Antiretroviral therapy

**ARV** Antiretroviral

**ASHA** American Speech-Language-Hearing Association

**AZT** Zidovudine

**CG** Control group

**CNS** Central nervous system

**HIV** Human Immunodeficiency Virus

MTCT Mother-to-child transmission

**NVP** Nevirapine

OMC Oral motor challenge

PCR Polymerase chain reaction

PHC Primary health care

**PMTCT** Prevention of mother-to-child transmission

**RG** Research group

**RTHB** Road to Health Booklet

**SANDOH** South African National Department of Health

**SLT** Speech-Language Therapist

**SOMA** Schedule for Oral Motor Assessment

**UNAIDS** Joint United Nations Programme on HIV/AIDS

**UNICEF** United Nations Children's Fund

WHO World Health Organization

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### **CHAPTER 1: INTRODUCTION**

### 1.1 Chapter aim and outline

This chapter aims to provide the reader with a critical discussion of the recent and relevant literature pertaining to the development of infants exposed to Human Immunodeficiency Virus (HIV), and the potential implication of their feeding ability during the window period of unconfirmed final HIV-status. This discussion surrounds the HIV-epidemic in the context of South Africa, as well as the management of HIV-exposed infants in the country. Caveats in the current literature are identified within the broader context of the early health and development of infants exposed to HIV, as well as the potential implications on the typical feeding development of these infants. Furthermore, this chapter outlines the rationale for the study, research question, and terminology as used in this dissertation.

### 1.2 Focus of the study

Infancy and early childhood represent a critical period for the successful development of feeding and swallowing ability (Delaney & Arvedson, 2008). Within the first year of life, rapid and crucial development of feeding and swallowing occurs, and is dependent on the successful maturation of the central nervous system [CNS] (Arvedson & Brodsky, 2002). In young infants, the display of typical and effective feeding patterns provides evidence of the infant's overall health, neurodevelopmental well-being and appropriate development of the emerging pathways that underlie subsequent communication skills (Delaney & Arvedson, 2008).

Literature has extensively described the destructive effects of HIV on the developing CNS of infants infected with the virus, often manifesting as static or progressive encephalopathy (Boivin et al., 1995; Pressman, 2010; Strehlau, Kuhn, Abrams & Coovadia, 2016; Van Rie, Harrington, Dow & Robertson, 2007). Predominant early developmental deficits experienced by infants with HIV-encephalopathy include those within the neuro-cognitive and motor domains (Van Rie et al., 2007). Significantly, competency in feeding and swallowing is dependent on the successful progression of neuro-motor development and control (Delaney & Arvedson, 2008). HIV-infected

infants therefore exhibit prominent delays and difficulties in their oral-motor and swallowing development, which are detailed throughout numerous literary sources (Narayanan & Kalappa, 2017; Nel & Ellis, 2012; Pressman, 2010; Rabie et al., 2007).

Recent research findings have determined that infants with prenatal exposure to HIV, who are later found to be uninfected with the virus, evidence subtle neuro-motor delays from as early as four months of age, thereby reflecting possible impairment of the CNS (Alcock, Abubakar, Newton & Holding, 2016; Da Silva, De Sá & Carvalho, 2017; Kerr et al., 2014). This finding suggests that infants who were exposed to HIV may potentially present with feeding difficulties and characteristics that are different from those of infants who are not exposed to the virus. It may therefore be possible that the mere exposure to HIV, and prenatal exposure to antiretroviral therapy (ART), may be reflected in the form of early feeding deficits within the population of infants exposed to HIV. Significantly, a dearth of research exists surrounding this topic, thereby warranting further investigation. Furthermore, infants exposed to HIV display similar, yet less severe developmental delays when compared to HIV-infected infants (Rabie et al., 2007; Strehlau et al., 2016), which may implicate and raise a concern regarding the feeding ability of infants exposed to HIV, as will be discussed later in this chapter.

### Paediatric HIV as an epidemic

Of the extensive preventable conditions currently plaguing the vulnerable paediatric population, HIV is still a core contributor to nearly half of all infant mortalities (United Nations Children's Fund [UNICEF], 2015; World Health Organization [WHO], 2017). Although having accounted for 43% of the global total for new HIV infections in 2016, and remaining the global epicentre of the epidemic, eastern and southern Africa have demonstrated a 56% decline in new HIV infections among children since 2010 (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2018a). Global efforts to minimise mother-to-child transmission (MTCT) of HIV are ever-expansive, rapidly and effectively evolving. Improving interventions employed within the public health sector, as well as increasing accessibility to ART has led to a significant decline in new paediatric HIV infections and a subsequent decline in Acquired Immunodeficiency Syndrome (AIDS)-related paediatric mortality (Rosala-Hallas, Bartlett & Filteau, 2017; UNAIDS, 2017).

In 2015, Cuba became the first country to eliminate MTCT of HIV and syphilis, followed by Thailand, Belarus, Armenia and the Republic of Moldova in 2016 (WHO, 2016a). While South Africa houses the largest HIV epidemic in the world, the country holds the largest treatment programme (UNAIDS, 2018b). By enabling access to ART to over 95% of pregnant mothers who are HIV-positive, MTCT of HIV has been reduced to 1.5% of all infants born to HIV-positive mothers (UNAIDS, 2017). Subsequent to the global and local gains in the prevention of mother-to-child transmission (PMTCT), there has been a substantial and rapid growth in the population of infants exposed to but uninfected with HIV born to mothers who are HIV-positive (Evans, Jones & Prendergast, 2016; Sugandhi et al., 2013).

### HIV-testing and treatment of infants exposed to HIV in South Africa

All infants born to mothers who are HIV-positive, are HIV-exposed. This HIV-exposure is indicated by the presence of vertically-transferred maternal HIV-antibodies in the infant's bloodstream prior to 18 months of age (Nuttall, 2013; South African National Department of Health [SANDoH], 2015). To determine the HIV-infection status of infants exposed to HIV younger than 18 months, an HIV polymerase chain reaction (PCR) test is conducted at birth (SANDoH, 2015). The SANDoH 2015 guidelines recommend that all infants exposed to HIV, regardless of whether they are breast- or formula-fed, receive a six-week course of prophylactic Nevirapine (NVP) initiated immediately from birth. Depending on when maternal ART was initiated during pregnancy, breastfed infants exposed to HIV may instead receive an extended 12week course of NVP or they may be immediately initiated on dual post-exposure prophylaxis, involving NVP with Zidovudine (AZT). A second HIV PCR test is then conducted at 10 weeks, that is, four weeks after completion of NVP, and is used as a confirmatory result of the infant's HIV infection status. For infants receiving the extended 12-week use of NVP/AZT, it is recommended that a confirmatory HIV PCR test be conducted at 18 weeks (four and a half months) of age (SANDoH, 2015).

Due to the risk of MTCT of HIV still being present throughout the duration of breastfeeding, definitive HIV infection status of the infant can only be determined six weeks post-cessation of breastfeeding (Nuttall, 2013; SANDoH, 2015). In this scenario, if the infant is younger than 18 months, it is recommended that they receive

another HIV PCR test. However, if the infant is older than 18 months, an HIV antibody detection test (also referred to as a 'rapid HIV test') is done, to rule out infection six weeks after stopping breastfeeding. Furthermore, it is recommended that all infants exposed to HIV, regardless of their breastfeeding status, receive a Rapid HIV Antibody test at 18 months of age, to establish whether HIV antibodies are still present in their bloodstream, in which case, HIV infection is confirmed, and the infant is immediately initiated onto ART.

Two negative PCR test results indicate that the infant is HIV-negative, and the infant is then considered to be HIV-exposed but uninfected (SANDoH, 2015). Should either of the PCR results be positive, a confirmatory PCR test should be conducted, and the infant should be initiated on ART while awaiting confirmatory results (Gill et al., 2017; SANDoH, 2015). In this dissertation, the term HIV-exposed is therefore used when referring to participants born to HIV-infected mothers, as not all participants had received a confirmatory PCR test to establish whether they were HIV-exposed but uninfected, as they were still being breastfed and were younger than 18 months of age.

Early infant diagnosis and HIV-management, together with the wide-spread and successful PMTCT programme in South Africa, have ensured that 97% of the 300 000 HIV-exposed infants born annually, remain HIV-negative at six weeks of age (Gill et al., 2017; Goga, Dinh & Jackson, 2012). Prompt HIV diagnosis and ART initiation for infants exposed to HIV can reduce the morbidity and mortality associated with HIV (Gill et al., 2017). This may indicate that HIV-exposed infants born under the new PMTCT regimen, may display new and possibly improved, but alternate, health and developmental outcomes compared to the population of infants exposed to HIV born in the pre-ART era. The need for further research into the health and developmental needs of this growing population in resource-limited settings, is thereby prompted (Filteau, 2009).

### The burden of HIV-exposure and environmental risks on early infant development in resource-limited settings

A review of the studies examining the health and developmental outcomes of infants exposed to but uninfected with HIV has asserted that although this group of infants

may have avoided HIV-infection, the mere exposure to HIV and ART in utero may be altering their developmental course (Heidari et al., 2011). A growing body of research has begun acknowledging the compounding developmental effect of environmental and socio-economic risk factors present in resource-limited settings such as South Africa, into which HIV-exposed infants are born (Boivin et al., 2017; Chaudhury et al., 2017; Herrero et al., 2013; Rajan, Seth, Mukherjee & Chandra, 2017; Sughandhi et al., 2013).

Households affected by HIV prominently evidence poverty, increased levels of familial distress, reduced access to health care services and education, maternal and family-related immune suppression and subsequent compromise in caregiving ability, adversely affecting the neurodevelopment of HIV-exposed infants (Boivin et al., 2017; Hair, Hanson, Wolfe & Pollak, 2015; Herrero et al., 2013; Sherr, Skeen, Hensels, Tomlinson & Macedo, 2016; Sugandhi et al., 2013). Additionally, infants exposed to HIV experience greater morbidity consequent to frequent exposure to HIV-related pathogens and opportunistic infections in the household, resulting in poorer health status (Slogrove et al., 2017).

Poverty is one of the main risks for adverse developmental outcomes in early childhood (Hair et al., 2015). Of specific importance, is that 30% of young children in South Africa fall below the food and poverty line, with approximately four million children younger than six years, living in the poorest 40% of households (South African Early Childhood Review, 2017). Infants living in HIV-affected households present with altered structural brain development subsequent to lack of appropriate environmental stimulation, exacerbated by undernutrition (Hair et al., 2015). Effects of deprivation within these areas become clear later in the infants' lives as they demonstrate poorer outcomes in academic functioning (Hair et al., 2015). This may indicate that developmental outcomes of infants exposed to HIV in South Africa may be exacerbated by their exposure to adverse environmental risks during early infancy. These findings signify the complex interaction between the biological risk of prenatal HIV exposure (with associated pre- and peri-natal antiretroviral [ARV] exposure) and the predisposing environmental risks on the health and development of infants exposed to HIV, as opposed to these outcomes resulting from a sole factor.

### Neurological, motor and early development of infants exposed to HIV

The following studies discussing the neurological, motor and early development of infants exposed to HIV will centre around those conducted in resource-limited settings within and similar to South Africa. This is to ensure presentation of research findings that are most applicable to the local population of infants exposed to HIV, as it is assumed that similar environmental risk factors may be present (Filteau, 2009).

Extended and direct prenatal exposure to HIV perturbs an infant's immature CNS, with lasting effects beyond the period of vertical transmission (Locks et al., 2016; Shapiro & Lockman, 2010). Researchers have determined that this exposure may lead to delayed neuropsychomotor development, encephalopathy and alternative forms of neurological sequelae (Da Silva et al., 2017). In sub-Saharan Africa, 40% of young children exposed to but uninfected with HIV presented with general cognitive impairment (Boivin et al., 2017). Compared to young children unexposed to HIV, children exposed to but uninfected with HIV were found to be more likely to experience motor impairments, delayed expressive language and fine motor problems, potentially resulting from HIV- and associated ART exposure (Alcock et al., 2016; Kerr et al., 2014).

Other studies surrounding the development of infants and young children exposed to but uninfected with HIV have, however, yielded conflicting results pertaining to the areas of neurologic, cognitive, and motor development in comparison to HIV-unexposed controls (Chaudhury et al., 2017; Da Silva et al., 2017; Herrero et al., 2013; Hutchings & Potterton, 2014; Kerr et al., 2014; Le Doaré, Bland & Newell, 2012; Rajan et al., 2017; Springer, Laughton, Tomlinson, Harvey & Esser, 2012). These studies strongly postulate that socio-economic and cultural variations, as well as environmental influences play a role in the altered developmental outcomes of infants exposed to HIV, as opposed to solely resulting from HIV- and ARV-exposure. Small sample sizes as well as lack of control of these socio-economic and cultural differences between the study populations, have resulted in such conflicting results (as noted by the researchers of these studies). Certain studies conducted in Brazil, India, Botswana, South Africa, Rwanda and Uganda have demonstrated no significant differences in the motor and neurodevelopment of infants who are HIV-exposed and unexposed, from one month up to two years of age (Chaudhury et al., 2017; Herrero

et al., 2013; Rajan et al., 2017; Springer et al., 2012). Contrastingly, a Zimbabwean study has shown that both HIV-exposed but uninfected, and HIV-infected infants display global developmental delay (i.e. across cognition, receptive and expressive language, gross and fine motor skills) and impaired growth compared to infants who are HIV-unexposed prior to 12 months of age (Hutchings & Potterton, 2014). Other research studies concur with the finding of early deficits in motor, cognitive, expressive and receptive language, although subtle, that manifest in infants exposed to HIV (from four months to 16 years of age) subsequent to neurodevelopmental delay (Boivin et al., 1995; Da Silva et al., 2017; Le Doaré et al., 2012; Sá, Silva, Lima & Carvalho, 2015). Sá et al. (2015) have identified prominent motor delays in the population of infants exposed to HIV at four months of age, and observable cognitive delays at eight months of age, which may indicate delayed acquisition of developmental milestones.

Feeding development, an area which is largely controlled by and dependent on successful neuro-motor control (Arvedson & Brodsky, 2002), may therefore be affected in infants exposed to HIV, considering the cascading effect of developmental difficulties. Considering that infants exposed to HIV have presented with delays in the same developmental areas as infants infected with HIV, it is uncertain whether HIV-exposed infants will display feeding characteristics approximate of infants unexposed to HIV, or if they will fall between those of HIV-unexposed and HIV-infected infants. Early investigation of the oral-motor development for feeding of infants exposed to HIV is therefore warranted.

In order to rationalise deficient feeding characteristics, it is important have an understanding of the complex procession of typical feeding and oral-motor development to identify potential areas where fallouts may occur in this area of HIV-exposed infant development. The following section of the chapter therefore describes the anatomical and physiological changes during the latter half of infancy, necessary for successful feeding and swallowing; within the context of the HIV-exposed infant.

### Typical feeding development of infants from six-to-twelve months as a framework for potential feeding difficulties in infants exposed to HIV

The development of feeding and swallowing is a highly complex and ongoing process involving considerable and rapid anatomic and physiologic changes that begin prenatally and progress through infancy and early childhood (Delaney & Arvedson, 2008). The term "feeding" encompasses anticipatory reactions to receiving food, the placement of food in the mouth, bolus management and transfer into the pharynx (Delaney & Arvedson, 2008). Additionally, "feeding" includes the interactions between the infant and their caregiver during mealtimes (Delaney & Arvedson, 2008).

In order to feed successfully, the infant is required to functionally coordinate sucking, swallowing and breathing. These processes occur in the upper aerodigestive tract and are primarily controlled by - and are dependent on - the maturing CNS for competent neuro- and sensori-motor control (Arvedson & Brodsky, 2002). During the latter half of infancy (i.e. six-to-twelve months), progression of gross and fine motor skills, and neurodevelopmental control of the different phases of swallowing, aid the development of the infant's oral feeding skills, in preparation for transitional feeds (Delaney & Arvedson, 2008; Ramos et al., 2017). Anatomic changes to the oropharynx, including absorption of the sucking pads, enable growth of the oral cavity to facilitate increased movement of oral structures that aid the process of sucking, and are required for spoon feeding (Delaney & Arvedson, 2008). At six months of age, the early pattern of suckling (forward and backward movement of the tongue, with loose approximation of the lips) transitions to a mature sucking pattern (up and down movement of the tongue to extract liquid, with small vertical jaw movements and firm lip approximation), as the infant displays readiness to transition to complementary foods and spoon feeding (Delaney & Arvedson, 2008; Groher & Crary, 2016).

The WHO recommends that from six months of age, complementary solid foods be introduced to infants to supplement their milk feeds and appropriately meet their nutritional demands (Chichero, 2016; SANDoH, 2015). This forms part of the crucial period for introducing a variety of tastes and textures into the diet of the infant, as the infant learns specific oral movements for oral control of varying boluses apart from liquids, which occurs through experience (Delaney & Arvedson, 2008). From six months, developmental gross motor gains allow for improved stability of the trunk, neck and shoulders, enabling the infant to sit upright during feeds and greater movement of the extremities for self-feeding and food exploration (Delaney & Arvedson, 2008; Groher & Crary, 2016). Additional support is provided to the jaw, allowing for more dissociated and precise movements of the lips, tongue, cheek, and palate, for bolus formation and control during mastication and swallowing, once the

teeth begin to erupt from six months of age (Delaney & Arvedson, 2008). Physiological changes subsequent to neurological and motor development facilitate the progression of more efficient jaw, lip and tongue movement during transitional feeding (Arvedson & Brodsky, 2002). Progression from a vertical up and down jaw movement to a circular-rotary pattern facilitates chewing of a greater variety of food textures, while lip strength and movement becomes more defined to remove food from a spoon, maintain the bolus within the oral cavity, and steady the rim of a cup to extract liquid (Delaney & Arvedson, 2008). Tongue movement additionally becomes more coordinated, as less protrusion is noted (compared to a suckling motion), and greater lateral motion occurs to control and transfer the bolus to the pharynx (Delaney & Arvedson, 2008).

As can be seen from these feeding transitions, a link exists between the infant's general motor development and feeding ability, especially when considering that delays in gross motor development and sensory processing problems play a large role in the development of feeding and swallowing difficulties (Delaney & Arvedson, 2008; Ramos et al., 2017). Feeding difficulties arise from a combination of adverse biologic (medical or developmental conditions or delays) and environmental factors (Field, Garland & Williams, 2003). Deficits in feeding and swallowing ability consequently delay the progression of an infant's overall development (American Speech-Language-Hearing Association [ASHA], 2001; Gahagan, 2012). Related sequelae of oropharyngeal dysphagia involve aspiration, malnutrition and increased infant morbidity (ASHA, 2001; Gahagan, 2012), which adversely affect the health and quality of life of the infant (Arvedson & Brodsky, 2002; Ramos et al., 2017). Disruptive mealtime behaviour as well as significant distress on the family and child may additionally result, demonstrating that undiagnosed and unmanaged feeding difficulties have far-reaching consequences (Hall, 2001; Ramos et al., 2017).

As mentioned previously, feeding and swallowing difficulties, or oropharyngeal dysphagia of infants infected with HIV, resulting from CNS impairment, are documented in detail. Among the frequently encountered feeding difficulties, infants infected with HIV struggle with oral-motor deficits, and uncoordinated breathing and swallowing which may lead to aspiration (Pressman, 2010; Rabie et al., 2007). Considering the effect of HIV-exposure on the developing CNS, it may be possible that the population of infants exposed to HIV may present with oral-motor difficulties

during feeding, as this group has been identified as being at risk of oropharyngeal dysphagia (Pike, Pike, Kritzinger, Krüger & Viviers, 2016).

As mentioned by Ramos et al. (2017), the estimated prevalence of feeding difficulties among typically developing children falls between 25-45%, and is as high as up to 80% among children with health conditions and/or developmental disabilities. Of concern is that infants exposed to HIV present with and are at greater risk of neurodevelopmental and motor delays than typically developing infants who are HIV-unexposed (Hutchings & Potterton, 2014; Rajan et al., 2017). This finding implicates the possibility of oral-motor feeding difficulties in infants exposed to HIV, which may be more prominent from the six-to-twelve month period, when feeding demands greater neuro-motor coordination and sensorimotor control for transitional feeding (Delaney & Arvedson, 2008). However, the oral-motor development for feeding of HIV-exposed infants has not received attention in research. This poses a concern as the interruption of HIV-exposed infants' growth and development is occurring at a critical time during early development and may result in lifelong impairment if difficulties remain unidentified and unaddressed (Arvedson & Brodsky, 2002).

### Morbidity and mortality of infants exposed to HIV

Recent research has demonstrated that infants who are exposed to but uninfected with HIV present with altered and reduced growth and health outcomes as opposed to infants who are HIV-unexposed in resource-limited settings (Afran et al., 2014; Kuona, Kandawasvika, Gumbo, Nathoo & Stray-Pedersen, 2014; Le Roux, Abrams, Nguyen & Myer, 2016; Locks et al., 2016; Omoni et al., 2017; Springer et al., 2012). Infants who are HIV-exposed but uninfected display increased morbidity and mortality from infectious causes in comparison to infants who are unexposed (Afran et al., 2014; Filteau, 2009; Le Roux et al., 2016; Locks et al., 2016; Springer et al., 2012). This trend has been apparent in both resource-rich and resource-limited settings, although it has been predominantly noted in sub-Saharan Africa (Locks et al., 2016; Ramokolo et al., 2017; Reikie et al., 2014; Ruck, Reikie, Marchant, Kollman & Kakkar, 2016). Altered immune functioning results from placental transfer of proteins from HIV, preventing the immune system from recognising and responding appropriately to the threat of disease (Hoffmann & Green, 2014). Although ART may mediate maternal

transfer of HIV to the infant by supressing the mother's viral load (SANDoH, 2015), variances exist in the duration of exposure to ARV drugs for each infant. This has not been considered in previous studies and may be a contributor to the conflicting results on developmental outcomes of infants exposed to HIV. Infants who are HIV-exposed but uninfected may therefore experience more severe and frequent hospitalisations due to infectious causes, as opposed to infants who are unexposed (Cloete et al., 2015; Hoffmann & Green, 2014; Slogrove et al., 2017).

Impaired immunity may affect gastrointestinal functioning, increasing the risk for fungal infections such as candida, which may be one of the causes of and contributors to feeding problems (Field et al., 2003; Hoffmann & Green, 2014). The most common infections affecting infants who are HIV-exposed but uninfected include: pneumonia, diarrhoea and lower respiratory tract infections, which may all contribute to the development of feeding difficulties (Cloete et al., 2015; Ruck et al., 2016; Slogrove et al., 2017).

Studies conducted in resource-limited settings in Africa have further identified that infants who are HIV-exposed but uninfected present with poorer growth outcomes, in terms of length and weight for age, compared to infants who are unexposed in the first year of life (Omoni et al., 2017). In early infancy, adequate growth and weight gain is used as a primary measure of successful feeding (Arvedson, 2008), which is suggestive of possible feeding problems in infants exposed to HIV. The poorer birth and resultant growth outcomes of infants who are HIV-exposed may pose a developmental risk on the feeding ability of this infant population, which is discussed below.

# Poorer birth outcomes of infants who are HIV-exposed compared to infants who are unexposed

Preterm birth, low birth weight, reduced and early cessation of breastfeeding, pre- and postnatal exposure to maternal infections, and immune compromise have been implicated as contributors to these increasing rates of HIV-exposed infant morbidity and mortality (Locks et al., 2016; Slogrove et al., 2017). Infants who are HIV-exposed but uninfected are commonly born preterm with low birth weight and are often small-for-gestational age in comparison to infants who are not exposed to HIV and ARV

treatments (Dara, Hanna, Anastos, Wright & Herold, 2017; Ramokolo et al., 2017). Intrauterine infection initiates an inflammatory response from the foetus with a consequent triggering of premature labour, additionally contributing to deficient immunity in the infant (Kemp, 2014). Oropharyngeal dysphagia is strongly associated with the neurodevelopmental immaturity and resultant incoordination of the suck, swallow, breathing pattern related to preterm birth and low birth weight (Arvedson, 2008; Goldfield et al., 2010; Pike et al., 2016). Neurodevelopmental delay, CNS impairment, gastrointestinal and airway abnormalities have additionally been implicated as risks for oropharyngeal dysphagia in preterm infants (Pike et al., 2016). It is therefore possible that infants exposed to HIV may present with oropharyngeal dysphagia. The need to investigate the feeding of infants who are HIV-exposed is therefore restated, particularly as exposure to ART may impact the feeding ability of this population.

# The relationship between ART and mitochondrial dysfunction in infants exposed to HIV

Apart from the effects of HIV-exposure, infants exposed to HIV face the compounding effects of pre- and postnatal ARV exposure. Recent research has begun to relate prenatal exposure to highly active antiretroviral therapy and other ARV drugs as affecting the placental environment, with possible resultant low birth weight as well as liver and mitochondrial dysfunction, among other problems (Coelho, Tricarico, Celsi & Crovella, 2017; Hoffmann & Green, 2014). AZT and Tenofovir, which form part of the prophylactic ART and PMTCT programme in South Africa, have specifically been identified as potentially inducing mitochondrial dysfunction in infants exposed to HIV (Tamuzi & Tshimwanga, 2017). Dysphagia and respiratory difficulties have been identified as signs of mitochondrial dysfunction in early infancy (Kisler, Whittaker & McFarland, 2010). Depletion and dysfunction of the mitochondrial DNA hinders the production of the cellular energy required to fulfil basic and critical physiological demands (Perez-Matute, Perez-Martinez, Blanco & Oteo, 2013). Consequentially, the infant's feeding ability may be affected, as the infant may have insufficient energy required for the complex processes of feeding and swallowing. Although perinatal ARV exposure may promote variable negative effects on the infant's health and growth, the benefits of evading HIV-infection outweigh the risks of potential developmental sequelae (Jao & Abrams, 2014; Locks et al., 2016; Ruck et al., 2016). However, the combined effects of preterm birth, low birth weight, and possible mitochondrial dysfunction related to ARV exposure in infants exposed to HIV, may impact their feeding ability. The need to investigate the feeding and swallowing ability of infants exposed to HIV is thereby substantiated in order to identify, treat and prevent further difficulties that may emerge.

# The effect of breastfeeding practices on the health outcomes of infants who are HIV-exposed

Feeding practices have further been considered as contributors to increased morbidity, mortality and reduced growth outcomes in infants exposed to HIV (Locks et al., 2016). Research studies reviewed by Slogrove et al. (2017) have revealed that although infants who were HIV-exposed but uninfected and infants who were HIVunexposed from similar contexts were being breastfed for similar durations, the infants who were HIV-exposed but uninfected experienced greater infectious morbidity. The finding was attributed to frequent exposure to infectious pathogens in the mother's breastmilk, along with delayed functional immune development and deficient acquisition of transplacental maternal antibodies (Slogrove et al., 2017). The above finding is important to note as the national PMTCT guidelines (SANDoH, 2015) in South Africa advise that all mothers, regardless of their HIV status, exclusively breastfeed their infant for six months, and continue breastfeeding for up to one year, provided that the mother is receiving lifelong ART. The WHO (2016b) has since revised and included this recommendation within their guidelines, as opposed to previously recommending exclusive formula feeds for infants exposed to HIV. Exclusive breastfeeding minimises the risk of MTCT of HIV while improving the health, neurodevelopmental and survival outcomes of the infant (SANDoH, 2015). The guidelines further recommend counselling to mothers who are HIV positive regarding the risks of mixed feeding during the first six months of their infant's life as well as how to provide appropriate and exclusive formula feeds should the mother decide against breastfeeding. It is thus important to consider whether or not the infant is being breastor formula-fed, or receiving mixed feeds, in addition to considering the infant's health

history as influencers on the infant's current feeding characteristics. Consideration of the above factors may provide deeper understanding into the nature of the present feeding and swallowing abilities of infants who are HIV-exposed compared to those of infants who are unexposed.

### 1.3 Rationale

Considering that the majority of infants exposed to HIV are born into resource-limited settings, constituting a rising population in countries such as South Africa, the necessity for research studies into the health needs of this population is strongly supported (Le Doaré et al., 2012). Since the risk of HIV-infection has diminished recently, there is a greater demand for a shift in emphasis to provide appropriate interventions for the unique health needs of the population of infants who are HIV-exposed (Evans et al., 2016; Sugandhi et al., 2013).

Mother-to-child HIV-exposure is a lifelong condition and improving the long-term health needs of infants exposed to HIV should be prioritised (Kuona et al., 2014; Sugandhi et al., 2013). Numerous research studies have highlighted core differences between the health and developmental outcomes of infants who are HIV-exposed and unexposed (Afran et al., 2014; Boivin et al., 1995; Da Silva et al., 2017; Kerr et al., 2014; Kuona et al., 2014; Le Doaré et al., 2012; Le Roux et al., 2016; Locks et al., 2016; Springer et al., 2012). Infants who are HIV-exposed are perturbed by the unique exposure to HIV and other pathogenic agents, which infants who are unexposed do not encounter. Infants exposed to HIV display similar, yet less severe developmental delays to infants infected with HIV. Concern is therefore raised regarding the possible resultant implication of the feeding development of infants exposed to HIV, as HIV-exposure may render their oral-motor function for feeding different to those of infants who are HIV-unexposed (Rabie et al., 2007; Strehlau et al., 2016).

Speech-Language Therapists (SLTs) are core team members in the prevention, identification and management of paediatric dysphagia, and more specifically, oropharyngeal dysphagia (ASHA, 2016). It is therefore essential to advocate for and appropriately intervene in the treatment of infants who are HIV-exposed as they may present with unique feeding characteristics not yet described.

Early feeding and swallowing problems in infants vary broadly in manifestation and are defined and described differently according to presenting characteristics and severity across the health care disciplines (Estrem, Pados, Park, Knafl & Thoyre, 2016). Early feeding and swallowing difficulties are therefore difficult to differentiate from typical developmental feeding behaviours/difficulties and are commonly unrecognised by different health professionals, leading to late diagnosis and intervention only after the age of two years (Estrem et al., 2016). Feeding difficulties may be identified prior to to six months of age. However, having reviewed recent literature of motor and cognitive delays in infants exposed to but uninfected with HIV from as early as six months of age (Da Silva et al., 2017), research into the feeding ability of infants exposed to HIV aged six months and older, is prompted. It may therefore be possible that characteristics of oropharyngeal dysphagia may be more prominent in infants exposed to HIV from the six-month period onwards. The six-totwelve month developmental period requires greater advancement of oral-motor coordination for the successful transitioning between oral feeds, suggesting that potential fallouts in oral-motor development may be more prominent during this time (Arvedson & Brodsky, 2002). It is thus possible that distinctive differences may be present in the feeding characteristics and oral-motor ability of infants exposed to HIV within the six-to-twelve month age range compared to that of infants who are unexposed, warranting investigation.

The harmful nature of oropharyngeal dysphagia and its cascading co-morbidities on an infant's overall health, development, and quality of life warrant identification as early as possible, as well as timeous, tailored management. With early identification and management of developmental difficulties, infants exposed to HIV demonstrate the potential for typical development (Rajan et al., 2017). Consequently, comparison between the feeding characteristics of infants who are HIV-exposed and HIV-unexposed (between six and twelve months of age) may assist in identifying whether differences exist in the oral-motor function for feeding and swallowing ability of the HIV-exposed and unexposed infant populations in this age range. By utilising a control group of infants unexposed to HIV, differences in feeding and oral-motor characteristics may be contrasted on the basis of HIV- and ARV exposure. Early identification of signs of oropharyngeal dysphagia by the SLT may thus allow for future appropriate feeding interventions to be designed for the population of infants who are

HIV-exposed. Considering the advantages to furthering investigation into the feeding characteristics of HIV-exposed infants, the following research question was formulated: Do differences exist between the oral-motor function for feeding of infants exposed to HIV (aged six-to-twelve months) with unconfirmed final HIV-status, in comparison to that of infants unexposed to HIV, and furthermore, do infants who are HIV-exposed present with distinctive oral-motor difficulties during feeding in comparison to the group of infants unexposed to HIV?

### 1.4 Terminology as used in dissertation

**Caregiver:** Throughout the dissertation this term is used to refer to the person who accompanied the participating infant(s) in the study. In this study, all participants were accompanied by their primary caregiver, who was either the infant's mother or a family member.

**Dysphagia:** Dysphagia refers to difficulty/impaired swallowing (Arvedson & Brodsky, 2002), and may occur in any of the phases of swallowing. These phases include: the oral phase (preparation of the bolus in the oral cavity and propelling the bolus through the oral cavity to the pharynx), pharyngeal phase (initiation of the swallow to move the bolus through the pharynx to the oesophagus, while maintaining protection of the airway to prevent penetration/aspiration) and the oesophageal phase (peristaltic movement of the oesophageal muscles to transfer the bolus to the stomach (ASHA, 2018). This study primarily focused on difficulties occurring within the oral and/or pharyngeal phases of swallowing, referred to as 'oropharyngeal dysphagia', as the SLT plays a central role in the assessment and management of paediatric oropharyngeal dysphagia.

Feeding and swallowing difficulties: This term is often used synonymously with 'oropharyngeal dysphagia' but encompasses a broader concept related to the processes of feeding and swallowing. Delaney and Arvedson (2008) describe feeding and swallowing difficulties as any difficulty in the anticipation or self-preparation for the reception of food; placement of food in the mouth and management of the bolus; transferring of the bolus into the pharynx; co-ordination of sucking, swallowing and breathing; as well as difficulties in interactions between the infant and caregiver during mealtimes. Considering that the oral-motor processes required for feeding and

swallowing develop through experience, difficulties are typical during early development and may disappear with increased experience (ASHA, 2018). Feeding forms part of the oral phase of swallowing, which involves sucking, chewing and movement of food/liquid into the pharynx (ASHA, 2018). In this dissertation, the term 'feeding and/or swallowing difficulties' is therefore used as a broader term referring to the deficient feeding and swallowing characteristics of the research group, as these included but did not solely revolve around oral-motor behaviours during feeding.

**HIV-exposed and infected:** This term refers to infants who were exposed to HIV prenatally, but upon confirmatory HIV-testing (usually concluded by 18 months of age), have become infected with the virus (either during pregnancy, labour and delivery or breastfeeding) and will require immediate initiation of ART (SANDoH, 2015).

**HIV-exposed but uninfected:** This term refers to infants who were exposed to HIV prenatally, but upon confirmatory HIV-testing, have remained uninfected with the virus (SANDoH, 2015).

HIV-exposed: This term refers to an infant who is born to a mother who is HIV-positive and is at risk of acquiring HIV infection from the mother anytime during pregnancy, labour and delivery, or breastfeeding. An HIV-exposed infant may later be discerned as having merely been exposed to but uninfected with HIV, or being exposed to and infected with HIV, upon confirmatory testing using an age-appropriate HIV PCR or HIV rapid antibody test (SANDoH, 2015). HIV-exposed infants may additionally be exposed to maternal ART prenatally, as well as receive prophylactic ART postnatally.

**Infant:** This term refers to a child who is younger than 12 months of age. In this dissertation, when referring to participants, the term "infant" refers to children who were between the ages of six and 12 months.

Oral-motor dysfunction: The Schedule for Oral Motor Assessment [SOMA] (Skuse, Stevenson, Reilly & Mathisen, 1995) refers to oral-motor dysfunction as difficulty/abnormality in the control of oral-motor movements during feeding (i.e. control of the muscles for movement of the lips, tongue and jaw during feeding), which results in difficulty swallowing, and may therefore be indicative of oropharyngeal dysphagia. When the SOMA was developed in 1995, the term 'oropharyngeal dysphagia' was not widely used in research and clinical contexts; thus in the administration and scoring manual, the term 'oral-motor dysfunction' is used instead (Skuse et al., 1995).

However, recent studies that made use of the SOMA, use the term "oropharyngeal dysphagia" which is inclusive of "oral-motor dysfunction" (Benfer, Weir & Boyd, 2012a; Ko et al., 2011). The oral-motor behaviours that are assessed using the SOMA form part of both the oral and pharyngeal phases of swallowing, therefore; the use of "oropharyngeal dysphagia" encompasses the notion of oral-motor dysfunction. The observed dysfunctional/deficient oral-motor behaviours may indicate the presence of oropharyngeal dysphagia, which requires diagnosis using instrumental assessment, such as by a Videofluoroscopic Swallow Study to determine aetiology of the dysfunctional swallow, to develop an appropriate intervention plan (Benfer et al., 2012a; Ko et al., 2011). As the SOMA was used as the oral-motor assessment tool for this study, 'oral-motor dysfunction' is used when describing deficient oral-motor characteristics observed using the tool.

Oropharyngeal dysphagia: This is the preferred term of use by SLTs when referring to difficulties in the oral and/or pharyngeal phases of swallowing, such as when chewing, initiating the swallow or transfer of the solid/liquid bolus into the pharynx to the oesophagus (ASHA, 2018). In this dissertation, 'oral-motor dysfunction' and 'oropharyngeal dysphagia' are used closely, as difficulties in oral-motor functioning result in difficulty initiating the swallowing process due to improper movement of boluses out of the mouth.

### 1.5 Outline of chapters

**Chapter 1:** Introduction to the research topic, discussion of the rationale of the study, research question, and explanation of terminology as used in this dissertation

Chapter 2: Research methodology used for this study

**Chapter 3:** Research article submitted to the *African Journal of Primary Health Care* and *Family Medicine* 

**Chapter 4:** Summary of the research results, contributions and implications of the findings, recommendations for future research and conclusion

### **CHAPTER 2: METHOD**

### 2.1 Chapter aim and outline

Chapter two aims to comprehensively describe the research methods used to conduct this study. The aim, research design and context of the study, ethical considerations, participants, materials and apparatus as well as procedures followed, are discussed in greater detail than what the journal specifications permitted for the research article contained in chapter three. The approach towards data analysis is furthermore described in addition to reliability and validity of the study.

### 2.2 Study aim

This study aimed to compare the oral-motor function for feeding of six-to-twelve month old infants exposed to HIV to that of infants unexposed to HIV, and to determine whether distinctive oral-motor difficulties during feeding existed in the group of infants exposed to HIV.

### 2.3 Research design

A quantitative, cross-sectional, case-control research design was used for this study (Kaura, 2013). A quantitative approach was selected to enable to the use of a standardised feeding assessment tool, the SOMA (Reilly, Skuse & Wolke, 2000). This tool was specifically selected to obtain and objectively analyse measurable and statistical data pertaining to the oral-motor feeding characteristics of the study population (Leedy & Ormrod, 2014; Maxwell & Satake, 2006). As a form of observational study, a case-control design entailed a single observation and rating of the oral-motor characteristics of participants during a feeding session, and was therefore cross-sectional in nature (Kaura, 2013; Leedy & Ormrod, 2014).

In accordance with a case-control research design, the HIV-exposed participants of the research group (RG) and the HIV-unexposed participants of the control group (CG) were purposively selected and matched as closely as possible (i.e. by age) to ensure similar composition of both groups (Kaura, 2013). By identifying and comparing risk-related feeding and developmental characteristics with the oral-motor performance of each group during feeding, inferences were drawn regarding the impact of HIV-exposure on infant feeding ability (Kaura, 2013). Furthermore, statistical analysis was used to discern whether feeding difficulties occurred more frequently within the research group (RG) than the CG and to determine whether associations existed between HIV-exposure and feeding outcomes.

#### 2.4 Ethical considerations

Specific ethical principles were employed throughout the execution of this research study to ensure that all aspects were ethical, respectful, culturally-sensitive, fair and protective of the rights and safety of participants, and accurate in the reporting of results (Nelson, 2013). Ethical clearance was obtained from the Research Ethics Committee of the Faculty of Humanities of the University of Pretoria (Appendix A). Permission was obtained from the Tshwane Research Committee (Appendix B) and the facility manager of the primary health care (PHC) clinic (Appendix C), to conduct the study at the baby-wellness clinic and to access and use information from the Road to Health Booklets (RTHB) of participants. The following research ethical principles and standards were adhered to:

### 2.4.1 Beneficence, justice and non-maleficence

All data collection procedures ensured that participants and their caregivers would maximally benefit from participation in the study, without the risk of harm (physical/psychological) befalling them (Department of Health, 2015). As data collection was conducted within the baby-wellness clinic, caregivers were able to partake in the study after completion of their infant's medical appointment at the clinic, without losing their space in the waiting line or having to move to an alternate venue, proving to be highly convenient. Participation in the study offered caregivers the opportunity to receive valuable information regarding their infant's feeding ability and development after data collection. When feeding or general developmental difficulties were identified, the participants were referred for treatment to the appropriate health

professionals at the clinic, and verbal feedback and guidance was immediately provided to the caregivers on how to presently manage the difficulties at home. Each caregiver was further offered a written handout containing activities to stimulate their infant's speech and language development, relative to their infant's age (Appendix I and J), and a small gift of appreciation was offered as gratuity to the participating caregivers for their time and participation. To ensure the safety of the participant throughout the feeding assessment, precautions were taken by the researcher (a registered student SLT at the Health Professions Council of South Africa) to prevent aspiration during feeding. Food items were also not presented when food allergies were noted by the caregiver. To avoid stigmatization of caregivers or participants with HIV-exposure or infection, all caregivers with infants within the specified age range were approached for voluntary participation, regardless of maternal HIV-status. The HIV PCR results were therefore obtained from participants' Road to Health Booklets to identify the HIV-status of participants, and no caregiver was asked to disclose their HIV-status verbally to the researcher.

### 2.4.2 Dignity, autonomy, and informed consent

All caregivers and participants were treated with respect, dignity and cultural and linguistic sensitivity throughout the data collection process. All caregivers with infants between the specified age range were offered the opportunity to decide whether they would like their infant to participate in the study once they had been informed of the nature of the study (Leedy & Ormrod, 2014). A parent/caregiver information sheet and informed consent form (Appendix D, E, or F) was provided to potential participating caregivers. This form detailed the nature of the study, the type information required from them, the procedures for the feeding assessment of their infant, how the information may be used, and their own and their infant's rights regarding participation. Many of the residents in the township do not speak English as a first language (2.08% of the population), therefore, the parent/caregiver information sheet and informed consent form were translated into the two most common first languages of the townships' population: Northern Sotho (spoken by 42.35%) and isiZulu (spoken by 12.15%) (Frith, 2011). Linguistic sensitivity was thereby ensured by providing a parent/caregiver information sheet and informed consent form in the preferred

language of choice of the caregiver i.e. English (Appendix D), Northern Sotho (Appendix E), or isiZulu (Appendix F). This ensured that the caregiver would be able to fully understand the nature of the study before deciding to provide consent to participate (verbal or written consent), if he/she struggled to communicate effectively with the researcher in English. Prior to providing informed consent, caregivers were given the opportunity to question the researcher about the study and were informed that they could withdraw participation from the study at any stage, should they decide to, with no negative influencing of their treatment at the PHC clinic. All HIV-specific information was handled sensitively, respectfully and confidentially by the researcher and cultural/religious considerations were sensitively and respectfully upheld in the researcher's response to caregiver questions and in treatment recommendations. All caregivers in the study were competent in the primary language of the researcher and were able to provide written informed consent prior to data being collected.

### 2.4.3 Scientific integrity

To ensure scientific integrity, all findings were represented accurately and ethically; and to avoid misinterpretation of findings, all incomplete/unclear/incorrect/unreliable information and/or results (from the caregiver, RTHB or SOMA) were excluded from the dissertation and research article (Department of Health, 2015). To avoid plagiarism, all authors and researchers whose work and findings are represented in this study, have been referenced accurately and appropriately throughout.

### 2.4.4 Fair selection of participants

Participant selection was solely based on the age range of the infants (i.e. between six and twelve months), in order to ensure that no infant/caregiver was unfairly discriminated against or excluded from the study on the basis of race, gender, educational level or HIV-status (Nelson, 2013). All caregivers of infants within the required age range were approached for voluntary participation as long as the caregiver was over the age of 18 years, to provide informed consent for their infant to participate in the study. As data collection was conducted over a period of two and a half months, only caregivers present at the clinic within that time frame were

approached for participation and included in the study. To prevent exclusion on the basis of a potential language barrier, the translated parent/caregiver information sheet and informed consent forms (Appendix D, E, and F) provided the opportunity for mothers of different primary languages to fairly participate as well. In the event that the caregiver was illiterate, verbal informed consent may have been provided, following ethical and accurate explanation of the study, by the researcher. However, all caregivers were literate and provided written informed consent.

### 2.4.5 Privacy and confidentiality

To protect the identity and ensure confidentiality of the personal information of participants and their caregivers, each participant was assigned a numerical code, which was used to refer to the participants' information, instead of their name (Leedy & Ormrod, 2014). Privacy was furthermore ensured throughout data collection as all procedures were conducted in a private space within the baby-wellness clinic. The names of participants' caregivers were only held in hardcopy in their consent form, to which only the researcher had access, and was handled confidentially. The collected data was imported into a spreadsheet on a password-protected laptop computer, using the numerical code assigned to each participant. In addition to the researcher, the supervisors of the study and the statistician were able to access the data depicted on the spreadsheet, and this was handled privately and confidentially. The caregivers of participants were informed of these measures and assured that anonymity of their information in the reporting of results in the research article and dissertation. Participants who were exposed to HIV would not have been isolated and identifiable to other patients in the baby-wellness clinic, as all participants' RTHB were perused for HIV-status and medical information. In accordance with the University of Pretoria's data storage guidelines, the hard copies of the data and electronic data collected in this study are securely stored in room 2-12 in the Department of Speech-Language Pathology and Audiology for 15 years.

### 2.5 Research context

Data collection was conducted at the baby-wellness clinic of a PHC clinic in an urban township in the Tshwane district of Gauteng, South Africa. The township is predominantly a Black African community, encompassing a spectrum of socio-economic classes and living conditions, ranging from permanent residential areas to extensive informal settlements with self-constructed houses (Mashigo, 2012). Of the approximately one million people residing in the township, most use PHC clinics such as the selected clinic, as their initial point of access to health care services (Darkey & Visagie, 2013; Schoeman, Swanepoel & Van der Linde, 2017). The baby-wellness clinic offered services such as: immunisations; family planning; HIV-testing and counselling; PMTCT services; ante- and post-natal maternal care; and general health care services for neonates and infants. The baby-wellness clinic therefore proved an effective site for participant recruitment, as a significant number of caregivers frequented the clinic on a daily basis to attain these services.

### 2.6 Sampling

A sample of 75 participants (30 HIV-exposed and 45 HIV-unexposed) were included. All 30 HIV-exposed participants were confirmed HIV-exposed but uninfected as of their latest PCR test result. Maxwell and Satake (2006) denote that a smaller sample size is appropriate to describe and compare the characteristic of interest between the RG and CG when the population is more alike. In this scenario, the study's sample size proved appropriate as all participants displayed similar demographic and socioeconomic characteristics, enabling appropriate comparison of their feeding characteristics.

A purposive, non-probability, convenience sampling strategy was implemented to recruit participants. The use of purposive sampling enables the unique selection of participants who will be particularly informative to the research study; while non-probability convenience sampling allows for the recruitment of participants who are readily available and willing to participate in the study at a given point in time (Leedy & Ormrod, 2014; Maxwell & Satake, 2006). This strategy proved effective as all caregivers attending the baby-wellness clinic throughout the two and a half months of data collection were approached for voluntary participation in the study and were

included, provided they met the inclusion criteria. This sampling strategy is broken down in Figure 1, which summarises the composition of the RG and CG.

### 2.6.1 Inclusion and exclusion criteria

All infants within the specified age range (six-to-twelve months) were included in the study, provided that their caregiver was over the age of 18 years, to provide consent for their participation. Exclusion was based on confirmed HIV-infection of the participants, and the presence of co-occurring congenital conditions or syndromes, as this would have yielded inaccurate feeding results. One participant was excluded from the study as they had presented with confirmed HIV-infection. No participants displayed congenital conditions or syndromes.

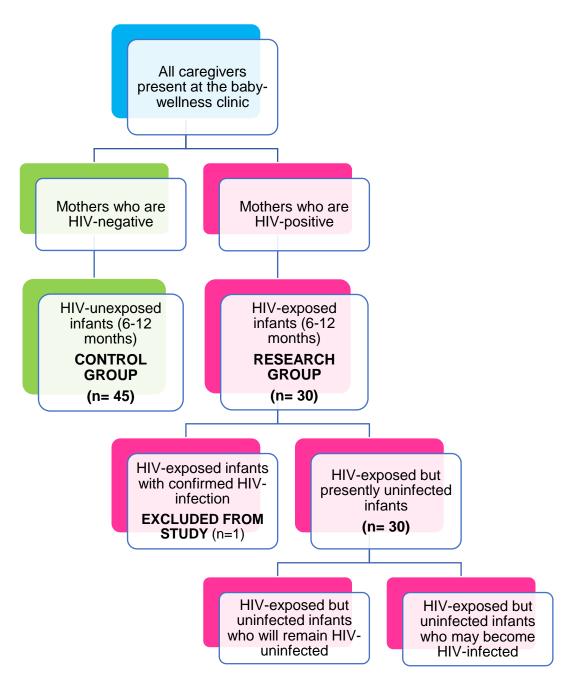


Figure 1. Summary of the research and control groups of the study (n=75)

### 2.7 Participant description

Both the RG and CG displayed a similar composition of participants, with regard to age, gender, gestational age, and birth weight, with no statistically significant differences between the groups (Table 1). The mean age of participants was 8.69 months (Standard deviation [SD]: 2.24).

Table 1. Participant and maternal characteristics (n=75)

Characteristic			RG n=30	CG n=45	p-value
Gender	Male		15	23	1
Geriaei	Female		(50%)	(51.11%)	
			15	22	
			(50%)	(48.89%)	
Age division	6-8 months		14	20	0.980
			(46.67%)	(44.44%)	
	9-12 months		16	25	
			(53.33%)	(55.56%)	
Gestational age (weeks)	Full term	(38-41)	19	32	0.912
			(63.33%)	(71.11%)	
		-late preterm	6	5	
	(33-37)		(20%)	(11.11%)	
	Extremely preterm (28-32)		2 (6.67%)	3 (6.67%)	
	Post mature (>42)		3	5	
			(10%)	(11.11%)	
Birth weight (kg)	Normal (±3.2-3.8)		17	23	0.807
			(60.71%)	(52.27%)	
	Low (±1.5-2.5)		11	21	
			(39.29%)	(47.73%)	
Weight gain (from birth-	Typical		26	38	0.734
data collection)			(89.66%)	(86.36%)	-
	Atypical	Underweight	4 (13.33%)	3 (6.67%)	
		Overweight	-	3 (6.67%)	
Maternal age (years)	Minimum age		22	18	0.002*
	Maximum		42	41	
	Mean (SD)		33.13	28.27	
			(5.95)	(7.25)	
Maternal educational level	No formal schooling		11	5	0.003*
			(37.93%)	(11.11%)	1
	Below grade 8		1 (3.44%)	-	
	Grade 9-10		-	4 (8.89%)	
	Grade 11-12		(49.270/)	21	
Tortion, advantion		(48.27%)	(46.67%) 15		
	Tertiary education		(10.34%)	(33.33%)	
Maternal employment	Employed		7	11	1
Material employment			(23.33%)	(24.44%)	
	Unemployed		23	34	
			(76.67%)	(75.56%)	
· *Indicates a statistically signific	ant difference	o ka – Kiloarom			

<sup>\*</sup>Indicates a statistically significant difference. kg = Kilogram; SD = Standard deviation

All participants were accompanied by their primary caregiver; 72 of whom were participants' mothers and three were family members who provided maternal-related information. The mothers of the RG tended to be older than the mothers of the CG

participants with a mean age of 33.13 years (SD: 5.95) and had lower levels of education (high school and below) than mothers of the CG. These two variables differed significantly between the groups (Table 1). Of the HIV-positive mothers, approximately half (51.72%) had initiated ART prior to pregnancy, whereas 42.28% had initiated ART during pregnancy. As discussed in chapter 1, pre- and post-natal ARV exposure may affect an infant's feeding effectivity (Kisler et al., 2010). HIV-exposed infants born to mothers who initiated ART during pregnancy, require extended post-natal exposure to AZT/NVP as a prophylactic measure (SANDoH, 2015), which may have implications on their feeding ability. None of the caregivers of the RG, however, reported any associated complications, health/developmental alterations of their infants who had all been exposed to ARV's (in the past, or with current exposure).

# 2.8 Materials and apparatus

The SOMA (Reilly et al., 2000) (Appendix H) was selected as the oral-motor feeding assessment tool for the study. The SOMA is a standardised and sensitive assessment tool which allows for the objective evaluation of oral-motor functioning (sucking, chewing and swallowing) in preverbal infants between the ages of eight and 24 months (Reilly et al., 2000; Skuse et al., 1995). It has been proven to be a valid and reliable measure for distinguishing normal feeding skills from clinically significant characteristics of oropharyngeal dysphagia from as early as six months to 24 months of age, and was therefore applicable for use in this study (Benfer et al., 2012a; Ko et al., 2011; Reilly et al., 2000; Skuse et al., 1995).

As reviewed in chapter 1, infants exposed to HIV are at risk for motor delays, which may implicate their oral-motor development for feeding (Boivin et al., 1995; Da Silva et al., 2017; Le Doaré et al., 2012; Sá et al., 2015). In a study conducted by Benfer et al. (2012b), the SOMA proved effective in detecting and relating oropharyngeal dysphagia to the severity of gross motor impairment exhibited by infants with neurological impairment. This provides further motivation for the use of the SOMA to detect characteristics of oral-motor dysfunction and associated oropharyngeal dysphagia in the RG who are at risk of such difficulties. The SOMA additionally enabled the researcher to assess the participants' posture and degree of support

required during feeding, which assisted in identifying whether these motoric aspects were implicated in the RG and if they were a contributor towards the presenting feeding characteristics.

The SOMA involves the provision of various food tastes, textures and consistencies to the infant, to elicit specific oral-motor behaviours, providing important information about the infant's sensorimotor and swallowing abilities (Benfer et al., 2012a). Table 2 illustrates the various oral-motor behaviours that are rated using the SOMA.

Table 2. Summary of the discrete oral-motor behaviours rated in the SOMA

Oral-motor behaviour category	Discrete oral-motor behaviours rated included:
Initiation/reaction to food stimulus	Head/body/trunk movement towards the spoon or drink presented and initiating the sequence within the oral cavity within two seconds.
Drooling	If drooling occurs >25% the time during the sequence, leading to loss of food/liquid.
Sequencing of actions	Executing a smooth sequence by coordinating and integrating ± three suck-swallows, munching/chewing actions and swallows. Panic reactions and choking are also assessed.
Lip movement/functioning	Activation of the upper and lower lip to assist in removing food from the spoon; holding food/liquid within the oral cavity and cleaning food from the lips. Active involvement of the lips during sucking/munching/chewing; forming a consistent and complete seal when required, and lip closure during swallowing.
Tongue movement/functioning	Interference of tongue protrusion throughout sucking/munching/chewing/swallowing. Symmetrical positioning and tongue movement is rated, along with the presence of tongue thrusting at rest or during feeding.
Jaw movement/functioning	Graded jaw opening; internal jaw stabilisation; presence of associated jaw/head movements; vertical excursions; jaw alignment during feeding and jaw clenching are rated. Breaking or transferring food in the mouth using fingers, is also rated.
Bite movements	Controlled and sustained biting, and graded jaw opening are evaluated, along with only mouthing a food stimulus.
Swallowing of food/liquid presented	Jaw alignment during swallowing is rated, as well as if panic reactions/gagging occur in response to food presentation, and if gravity/head extension is used to assist in swallowing.

Table compiled from *The Schedule for Oral Motor Assessment: Administration Manual (Reilly et al., 2000)* 

Assessment of these specific behaviours provided information on the areas of oral-motor ability, which were deficient in the RG and CG. Following provision of the food consistency, the researcher observed and rated each specific oral-motor behaviour within each oral motor challenge (OMC) category. If the trial was rateable, the behaviour would receive a YES/NO, indicated on the score sheet (Appendix H), and the sum of the shaded boxes (indicating deficient oral-motor behaviours) would reveal the presence of oral-motor dysfunction within the specific OMC category. Table 3 displays the OMC categories assessed.

The SOMA has been identified as the most suitable measure to use in a research context as it provides the researcher with valuable information to support clinical decision making regarding the infant's feeding ability (Benfer et al., 2012a), thereby supporting its use in this study. The SOMA further accommodates the substitution/adaption of foods in each OMC category so that they are culturally appropriate and suitable for the study population (Reilly et al., 2000). Specific food adaptations were made so that they were culturally appropriate for the South African context, and each item that was used is displayed in Table 3.

Table 3. OMC categories assessed in the SOMA and apparatus used for each

OMC category	Food item(s) used	Apparatus required for administration
Puree	Smooth strawberry yoghurt	Plastic baby spoon and bowl
Semi-solids	Cerelac porridge (honey flavoured)	(Baby Things: 6+ months)
Solids	Steamed cubes of butternut	
Chewable solids	Dried apricot	No apparatus required
Cracker: Soft-, medium-, and hard-bite	<ul> <li>Soft-bite: Marie biscuit</li> <li>Medium-bite: Boudoir biscuit</li> <li>Hard-bite: Nuttikrust biscuit</li> </ul>	
Liquids: Bottle, trainer cup, and open cup	Water (50 ml)	<ul> <li>Nuk baby bottle with narrow teat and small hole</li> <li>Baby Things Trainer Cup</li> <li>Open cup</li> </ul>

Table compiled from *The Schedule for Oral Motor Assessment: Administration Manual (Reilly et al., 2000)* 

A data collection sheet (Appendix G) was compiled using aspects of the Risk Assessment (Kritzinger, 2012) and the Oral-Motor and Feeding Evaluation (Arvedson & Brodsky, 2002), to obtain demographic, health and developmental information from participants' caregivers prior to the feeding assessment. The aim of this was to enable identification of contributing factors towards the participants' feeding characteristics.

#### 2.9 Procedures

# 2.9.1 Pilot study

A pilot study was conducted prior to commencing data collection for the study. The aim was to determine whether the proposed research procedures and selected tools would be effective in answering the research question, in addition to identifying aspects that required alteration prior to data collection (Leedy & Ormrod, 2014). Certain variables were identified and controlled for during this process, to ensure that they remained consistent throughout the execution of the procedures during data collection, improving internal validity of the study (Maxwell & Satake, 2006). These variables included: the researcher remaining the sole person explaining the study to the caregivers of potential participants, ensuring accurate conveyance of information; utilising a private space within the baby-wellness clinic for the assessment procedures; and all participants were seated across from the researcher, positioned on their caregiver's lap during the feeding assessment. The researcher was furthermore responsible for the administration and rating of each food trial for each participant. In instances where the participant refused feeding by the researcher, the researcher provided standard instructions to the caregiver on how to provide the food stimulus without compromising the outcomes of the infant's oral-motor behaviours. All food and liquid items remained consistent across size, portion and presentation to all participants, and the researcher ensured to used standardised apparatus for each trial (Table 3).

The researcher conducted the pilot study on the first day of data collection at the baby-wellness clinic. One participant from the RG and one from the CG were included to determine the feasibility of the research procedures. No difficulties were encountered in retrieving the necessary information required for the data collection sheet, or in the administration of the SOMA. The only necessary adjustment was in the allotted time

required to administer the SOMA, as the participants were unfamiliar with certain foods (i.e. the butternut and medium- and hard-bite biscuits) as they had not been introduced to them before, therefore requiring additional time to familiarise themselves with the foods before accepting it. Caregivers were thereafter informed that the entire data collection process would require an average of 40 minutes (as opposed to the proposed 30 minutes) of their time, dependent on their infants' respondence to the food stimuli. As no other significant adjustments were made, the results of these two participants were included in the study, as the results obtained during the pilot study were viable.

### 2.9.2 Data collection

Following the identification of potential participants within the age range of six-to-twelve months, the caregivers of these participants were approached and provided voluntary informed consent, after completion of their infant's medical appointment at the clinic. Caregivers were informally questioned to provide demographic and background information, and the participants' RTHBs were perused to obtain developmental, health- and HIV-specific information (Appendix G). This included: socio-economic status; maternal characteristics and complications during pregnancy, labour and delivery; maternal and infant HIV-status and adherence to ART; and participant feeding and developmental history.

Each participant's oral-motor ability during feeding was then assessed once, using the SOMA (Reilly et al., 2000), by the researcher, within a private area in the baby-wellness clinic. When applicable, each participant was provided with two-to-three trials of each food stimulus, provided that they did not refuse the trial, and the second trial was rated. If three trials could not be administered, the trial that was accepted was then rated. In instances where the trial in the OMC category was not applicable to the participant, the trial was omitted and therefore not rated, for e.g. liquids administered via a bottle were omitted if the participant was not being bottle-fed. After the feeding assessment, the caregivers were provided with feedback regarding their infant's feeding ability, and they received guidance if necessary. Referrals were made to a SLT or dietician at the PHC clinic if feeding or nutritional difficulties were identified.

## 2.9.3 Data analysis

Data analysis was conducted using SPSS version 25 by a statistician. Descriptive statistics were used to describe the characteristics of the two groups of infants, and to identify differences between groups. To determine the statistical significance of the differences between the findings of the HIV-exposed and HIV-unexposed infant groups, and to identify the age group in which the greatest differences in feeding ability occurred, the infants in each group were further divided and compared within their age categories (i.e. six-to-eight or nine-to-twelve months). To determine the statistical significance of the differences between variables, Pearson's chi-square test, Fisher's exact test, and the Mann-Whitney U test were used. All statistical tests were two-sided, and findings were considered statistically significant if p< 0.05. Spearman's correlation coefficients were used to determine the associations.

# 2.10 Reliability and validity

The reliability of the study was initially enhanced by using a pilot study to ensure that data collection procedures were viable to yield the results required and would remain consistent once data collection began (Leedy & Ormrod, 2014). Reliability was further supported through the use of the SOMA, which is a published and broadly recognised research assessment tool that has received validation in terms of its procedures and reliability (Reilly et al., 2000; Skuse et al., 1995). The SOMA has successfully been used to assess the oral-motor skills of infants in previous studies, to identify areas of deficient oral-motor functioning (Benfer et al., 2012a; Benfer et al., 2012b; Ko et al., 2011; Skuse et al., 1995), and its use in this study proved effective for this purpose. The researcher was solely responsible for data collection, and therefore ensured that all procedures were conducted in the same manner for all participants. Data was collected prospectively, allowing for a complete set of results to be collected based on direct observations during the feeding assessment.

The SOMA has been validated with high criterion validity, and over 85% sensitivity to detect and distinguish infants who present with clinically significant oral-motor dysfunction, from infants with normal oral-motor ability during feeding (Skuse et al., 1995). Face validity was addressed throughout the study as the researcher informed all participating caregivers of the purpose of the study and the supporting information

being collected from them, ensuring cooperation of participants through their subjective judgement (Leedy & Ormrod, 2014). The use of the SOMA ensured content validity, as each aspect served the purpose of the study and enabled comparison and description of the oral-motor characteristics during feeding of the RG and CG.

# **CHAPTER 3: ARTICLE**

The following article was submitted to the *African Journal of Primary Health Care and Family Medicine*. The format and style differ from the rest of the dissertation, as the article was compiled according to the journal's guidelines and style.

## Oral-motor function for feeding of HIV-exposed and unexposed infants

Mishkaya Lalbahadur, Esedra Krüger, Alta Kritzinger, and Marien Graham

#### **Abstract:**

**Background:** HIV-exposed infants are highlighted as a priority group at risk for oropharyngeal dysphagia (OPD), yet little is known of their oral-motor functioning during feeding in infancy.

**Aim:** To compare the oral-motor function for feeding of HIV-exposed infants to that of unexposed infants.

**Setting:** The study was conducted at the baby-wellness clinic of a primary health care clinic in Gauteng province, South Africa.

**Methods:** Oral-motor function during feeding of 75 infants aged six-to-twelve months (Mean: 8.69; Standard deviation: 2.24), was prospectively evaluated using the Schedule for Oral Motor Assessment in this cross-sectional, case-control study. Participants were separated into two groups, according to HIV-exposure status (30 HIV-exposed and 45 unexposed participants) and subdivided according to age range (six-to-eight and nine-to-twelve months).

**Results:** Neither group presented with oral-motor dysfunction. The research group (RG) displayed a significantly greater number of difficulties across the food consistencies. HIV-exposure was strongly associated with the sum of difficulties experienced with semi-solids; solids; chewable solids; soft-bite crackers; and cup-drinking. No significant differences were found in oral-motor performance of the groups in the six-to-eight months range. In the nine-to-twelve month range, the RG displayed significantly greater difficulty when cup-drinking,

compared to the control group. The RG showed liquid loss when cup-drinking, choking, and struggled to smoothly coordinate sucking/chewing and swallowing.

**Conclusion:** Older HIV-exposed infants showed more oral-motor difficulties than the younger group, displaying a risk for developing OPD. Oral-motor deficits may become more apparent in older HIV-exposed infants, when the demands for feeding require more advanced oral-motor skill. Further research is required.

Key words: HIV-exposed, infants, oral-motor function, oropharyngeal dysphagia, SOMA

## Introduction

In the absence of Human Immunodeficiency Virus (HIV) infection, prenatal exposure to the virus still poses a risk to infants' early development.<sup>1</sup> Maternal adherence to antiretroviral therapy (ART) throughout pregnancy and breastfeeding, significantly reduces the risk of mother-to-child transmission of HIV, ensuring that infants who are HIV-exposed remain HIV-uninfected.<sup>2</sup> Vertically transferred HIV-antibodies in the bloodstream of infants exposed to HIV younger than 18 months, can be detected by HIV polymerase chain reaction (PCR) testing, temporarily discerning HIV-status, until six weeks post-cessation of breastfeeding, or until 18 months.<sup>3</sup> In South Africa, where breastfeeding is encouraged for up to two years for all infants regardless of HIV-exposure, a considerable period exists before the final HIV-status may be confirmed.<sup>2</sup> Research about the development of infants exposed to HIV within this window period is lacking, and it is uncertain whether these infants are at risk for oropharyngeal dysphagia (OPD).

Infants who are HIV-exposed evidence early neuro-motor developmental delays, reflecting impairment of the central nervous system.<sup>4</sup> In sub-Saharan Africa, infants and young children who are HIV-exposed but uninfected demonstrate subtle delays in neuro-cognitive, motor, and language development as early as four-to-six months of age, compared to infants who are unexposed.<sup>4,5</sup> An essential developmental area demanding attention in research, is the feeding ability of infants exposed to HIV.

During the latter half of infancy, successful maturation of the central nervous system enables rapid development of gross- and sensori-motor skill and neurodevelopmental control for feeding and swallowing, facilitating the transition to solid foods.<sup>6</sup> Neuro-motor delays exhibited by infants who are HIV-exposed may suggest delays in oral-motor development and,

subsequent feeding difficulties.<sup>7</sup> Although no differences were identified in the feeding skills of neonates exposed to HIV,<sup>8,9</sup> it remains uncertain whether differences may exist in older infants who are HIV-exposed, who require greater oral-motor skill for transitional solid feeds after six-months, when oral-motor deficits may become more prominent. Infants who are HIV-exposed may therefore present with oral-motor characteristics different from unexposed counterparts.

Infants exposed to HIV display similar yet less severe developmental delays to infants infected with HIV, which may implicate their oral-motor function for feeding. Literature extensively describes OPD affecting infants infected with HIV, yet little is known of the feeding ability of infants exposed to HIV. Neurodevelopmental immaturity secondary to preterm birth and low birth weight results in incoordination of swallowing and respiration, posing a risk for OPD in infants exposed to HIV, who are predisposed to these factors. Furthermore, exposure to Zidovudine and Tenofovir as part of the prevention of mother-to-child transmission (PMTCT) programme, may induce mitochondrial dysfunction in infants who are HIV-exposed, potentially manifesting as dysphagia and respiratory difficulties. 14,15

Infants who are HIV-exposed may therefore display complicated and different oral-motor function for feeding to infants unexposed to the virus, resulting from multiple factors influencing their developmental outcomes. Early feeding and swallowing problems vary in manifestation and are detrimental to all aspects of infants' development, warranting early identification and appropriate management. Determining the presence of delayed oral-motor development during the transitional feeding period may enable future design of tailored interventions for infants exposed to HIV. This study aimed to investigate the oral-motor function for feeding of HIV-exposed infants (of unconfirmed HIV status) within the six-to-twelve month developmental period as compared to an unexposed group.

### Research methods and design

Data was collected prospectively at the baby-wellness clinic of a primary health care clinic (PHC) within an urban township in Gauteng Province, South Africa, using a cross-sectional, case-control design<sup>17</sup>. Caregivers of potential participants were approached for participation at the clinic and informed consent was obtained. Predominantly a Black African community, the township encompasses a spectrum of socio-economic classes and living conditions, ranging from residential areas to extensive informal settlements.<sup>18</sup> The majority of residents access

PHCs as the initial health care access point,<sup>19</sup> obtaining services such as: immunisations; family planning; HIV-related and PMTCT services; ante- and post-natal maternal care; and general health care services for neonates and infants.

## Study population and sampling strategy

Seventy-five participants (six-to-twelve months) were purposively selected. Exclusion was based on confirmed HIV-infection, and the presence of co-occurring genetic conditions. A research group (RG) of 30 infants exposed to HIV was compared against a control group (CG) of 45 infants unexposed to the virus. Participants were matched for age (six-to-eight and nine-to-twelve months). All 30 HIV-exposed participants were confirmed HIV-exposed but uninfected as of their latest PCR result. All participants were accompanied by their primary caregiver; seventy-two of whom were participants' mothers and three were family members, providing maternal-related information. Table 1 summarises participant and maternal characteristics.

**TABLE 1:** Participant and maternal characteristics (n=75)

Characteristic		RG (n=30)	CG (n=45)	p-value
Gender	Male Female	15 (50%) 15(50%)	23 (51.11%) 22 (48.89%)	1
Age division	6-8 months 9-12 months	14 (46.67%) 16 (53.33%)	20 (44.44%) 25 (55.56%)	0.980
Gestational age (weeks)	Full term (38-41) Moderate-late preterm (33-37) Extremely preterm (28-32) Post mature (>42)	19 (63.33%) 6 (20%) 2 (6.67%) 3 (10%)	32 (71.11%) 5 (11.11%) 3 (6.67%) 5 (11.11%)	0.912
Birth weight (kg)	Normal (±3.2-3.8) Low (±1.5-2.5) Very low (<1.5) Extremely low (<1)	17 (60.71%) 11 (39.29%) -		0.807
Weight gain (from birth-data collection)	Typical Atypical Underweight Overweight	26 (89.66%) 4 (13.33%)	38 (86.36%) 3 (6.67%) 3 (6.67%)	0.734
Maternal age (years)	Minimum Maximum Mean (SD)	22 42 33.13 (5.95)	18 41 28.27 (7.25)	0.002**
Maternal education	No formal schooling Below grade 8 Grade 9-10 Grade 11-12 Tertiary education	11 (37.93%) 1 (3.44%) - 14 (48.27%) 3 (10.34%)	5 (11.11%) - 4 (8.89%) 21 (46.67%) 15 (33.33%)	0.003**
Maternal employment	Employed Unemployed	7 (23.33%) 23 (76.67%)	11 (24.44%) 34(75.56%)	1

kg, Kilogram; SD, Standard deviation.

No significant differences between age, gender, gestational age, birth weight, and subsequent weight gain of the two groups were found. Significant differences were noted in the age and education level of participants' mothers. Mothers of the RG were older, with lower levels of education than mothers of the CG. The majority of mothers were unemployed. Approximately half (51.72%) of the mothers who were HIV-positive had initiated ART prior to pregnancy, whereas 48.28% had initiated ART during pregnancy.

### **Data collection**

Relevant demographic and background information was obtained from caregivers. Participants' Road to Health Booklets were used to retrieve developmental and health-specific information, and HIV-exposure status as of the latest PCR test.

Each participant's oral-motor function during feeding was assessed once, by a Speech-Language Therapist (SLT), using the Schedule for Oral Motor Assessment (SOMA)<sup>20</sup>. The

<sup>\*\*,</sup> p≤0.01, indicates a statistically significant difference between the groups.

SOMA is a valid and reliable tool used to assess oral-motor functioning during infancy.<sup>20</sup> A pilot study was conducted using the first two participants, who were included in the study as no alterations were made to data collection materials and procedures. Participants were provided with two-to-three trials of varying tastes and textures of culturally adapted foods, to elicit an extensive range of oral-motor behaviours (i.e. lip, tongue and jaw movements during sucking, chewing and swallowing), while seated on their caregiver's lap. These behaviours were scored on the second trial, according to the SOMA criteria, enabling the distinction of oral-motor dysfunction within a specific oral-motor challenge (OMC) category. 'Oral-motor dysfunction' incorporates difficulty/abnormality in controlling oral-motor movements during feeding, which may lead to OPD.<sup>21</sup> The OMC categories were assessed using the food/liquid in Table 2.

**TABLE 2:** Food/liquid items used for the SOMA

OMC category assessed		Food/liquid presented
Puree		Smooth strawberry-flavoured yoghurt
Semi-solids		Maize-meal soft porridge
Solids		Steamed cubes of butternut
Chewable solids		Dried apricot
Crackers:	Soft-bite:	Marie Biscuits
	Medium-bite:	Boudoir Biscuits
	Hard-bite:	Nuttikrust Biscuit
Liquids presented in:	Nuk bottle with narrow	Water
	teat and small hole	
	Trainer cup	
	Open cup	

Source: Food/liquid items were adapted from the SOMA (Reilly et al.<sup>20</sup>).

Participants' behaviour and caregiver-interaction patterns; posture; head positioning and degree of support required during feeding were noted. Caregivers received feedback about their infant's feeding ability and guidance if necessary. Referrals were made to a SLT or dietician when feeding difficulties were identified.

## **Data analysis**

The SOMA was scored using a binary method (yes/no) to rate observable oral-motor behaviours for the OMC categories.<sup>20</sup> The presence of certain behaviours identified as dysfunctional/abnormal, are indicated by a yes/no, the sum of which indicates oral-motor dysfunction within an OMC category, differing for each subsection of the SOMA. Data

analysis was conducted using SPSS (version 25). Participant characteristics and feeding history were compared across the six-to-twelve month range, and the SOMA results were compared per age division (i.e. six-to-twelve, six-to-eight, and nine-to-twelve months). Significant differences between groups were determined using Pearson's Chi-square, Fisher's exact tests and the Mann-Whitney U test. All tests were two-sided, and findings were considered statistically significant if  $p \le 0.05$ . Spearman's correlation coefficients were used to determine associations.

## **Ethical considerations**

Ethical clearance and permission to conduct the study was obtained from the Tshwane Research Committee and the Research Ethics Committee of the Faculty of Humanities of the University of Pretoria (Reference number GW20180113HS). Caregivers of participants provided voluntary written informed consent prior to data collection, after the researcher explained the aims and procedures of the study. Caregivers were ensured that all personal and participant information would be reported anonymously when writing the research findings. Caregiver information sheets and informed consent forms were available in English, Northern Sotho, or isiZulu, the most common primary languages of the caregivers.

#### **Results**

### Infant and maternal factors associated with HIV-exposure

A strong correlation was identified between HIV-exposure and low birth weight (p=0.025). HIV-exposure was not significantly associated with preterm birth (p=0.676). Four participants who were HIV-exposed and five who were unexposed were referred to the dietician, due to atypical weight gain. Table 3 summarises participants' feeding history.

**TABLE 3:** Participant feeding history (n=75)

Characteristic		RG (n=30)	CG (n=45)	p-value
Feeding difficulties after birth		1 (3.33%)	3(6.67%)	0.651
Currently breastfeeding		25 (83.33%)	42 (93.33%)	0.254
Current breastfeeding difficulties		1 (3.33%)	1 (2.22%)	1
Mean duration of breastfeeding	6-8 months	5.09 (3.24)	5.70 (4.23)	0.007**
(months), SD	9-12 months	6.64 (6.09)	9.92 (2.80)	0.004**
Mixed feeds (breastmilk and formula)		1 (3.33%)	9 (20%)	0.079
Currently bottle-feeding		6 (20%)	22(48.89%)	0.015*
Mean age of introduction of bottle (months), SD		3.30 (6.75)	2.96 (8.36)	0.718
Mean age of introduction of cup (months)	, SD	6 (3.69)	5.64 (6.82)	0.766
Solids have been introduced into diet	6-8 months	2 (6.67%)	4 (8.89%)	1
	9-12 months	6 (20%)	5 (11.11%)	0.287
Mean age of introduction of solids	6-8 months	6 (1.26)	5.25 (0.80)	0.644
(months), SD	9-12 months	6.5(1.57)	7.4 (1.32)	0.479

SD. Standard deviation.

Almost all participants had been breastfed, although the CG was breastfed for significantly longer (p=0.000). Significantly more CG participants were bottle fed (p=0.015) and received mixed feeds (p=0.079) compared to the RG, as there was no risk of vertical HIV-transmission. Only seventeen participants (22.67%) had been introduced to solids, of which eight (47.06%) were exposed to HIV. The mean ages of solid food introduction did not differ significantly between the groups. Caregivers of the CG introduced solids earlier as well as later than the RG, and not at the recommended age of six months. Significantly more caregivers of the CG thus demonstrated limited knowledge regarding timing of transitional feeding, and raised concern of their infant's feeding and weight gain (p=0.019). Two participants who were HIV-exposed and four who were unexposed, reportedly required longer than 30 minutes to complete a feeding.

# Comparison of feeding using the SOMA

All participants were seated upright upon presentation of the food trials, either requiring minimal trunk or back support, or seated independently. Participants did not require external support during feeding, and no abnormalities in head positioning or caregiver-interaction were observed.

Neither group displayed oral-motor dysfunction across any of the OMC categories of the SOMA. This implies that neither group experienced abnormal functioning of the oral-musculature/structures required for feeding. However, the RG performed significantly poorer

<sup>\*,</sup> p≤0.05, indicates a statistically significant difference; \*\*, p≤0.01, indicates a statistically significant difference.

on specific OMC categories, displaying significantly more deficient oral-motor behaviours compared to the CG (Table 4). Deficient oral-motor behaviours may lead to feeding difficulties, involving problematic behaviours when eating, and with caregiver-interaction during the mealtime.

**TABLE 4:** Oral-motor areas of greatest difficulty of the RG compared to the CG (n=30)

Age divisions	OMC categories with most errors (RG)	p-value	Oral-motor areas of greatest difficulty (RG)	p-value
6-12 months	Semi-solids	0.014*	Sequencing sucking/munching/chewing	0.039*
	Solids	0.013*	and swallowing	
	Liquids (cup)	0.018*	Profuse liquid loss	0.026*
6-8 months		No differen	ce compared to the CG	
9-12 months	Liquids (cup)	0.022*	Profuse liquid loss and choking	0.013* 0.032*

<sup>\*,</sup> p≤0.05, indicates statistically significant difficulty compared to the CG.

The RG experienced significantly more errors when coordinating and executing the oral-motor behaviours rated within the categories for semi-solids, solids, and liquids from a cup. When presented with semi-solids and chewable solids (p=0.018), the RG exhibited significantly more errors in smoothly sequencing the oral-motor behaviours for sucking/munching/chewing and swallowing. When cup-drinking, a greater number of RG participants experienced profuse liquid loss from the mouth, demonstrating possible immaturity with this developmental feeding skill. Table 5 shows the oral-motor difficulties experienced per age group.

**TABLE 5:** Number of oral-motor behaviour errors of the RG and CG participants (n=75)

Oral-motor behaviours	Frequency of errors			
	RG (n=30)		CG (n=45)	
	6-8 months (n=14)	9-12 months (n=16)	6-8 months (n=20)	9-12 months (n=25)
Initiation/reaction to food stimulus	3	2	1	0
Drooling	7 <b>†</b>	2	1	0
Sequencing of actions	15†	11	10	1
Lip movement/functioning	7†	6	4	1
Tongue movement/functioning	2	16†	0	0
Jaw movement/functioning	4	12†	3	4
Bite movements	1	3	7†	6
Swallowing of food/liquid presented	6†	1	1	0
Total number of errors	45	<b>53</b> †	27	12

<sup>†,</sup> indicates the highest number of errors across both groups, across the age ranges.

The RG displayed a higher number of oral-motor errors involving tongue, lip and jaw functioning, particularly from nine months, substantiating the overall oral-motor difficulties observed. Interfering tongue protrusion and slight discoordination of tongue movement was noted. Difficulty using the lips to hold boluses in the mouth and form an effective seal, leading to food/liquid loss was also observed. The RG displayed greater difficulty with oral-motor behaviours required for extracting and controlling food/liquid boluses in the mouth but did not exhibit many errors when swallowing. This indicates potential deficits in the oral rather than the pharyngeal phase of swallowing. Thirteen (28.89%) of the CG tended to mouth all the crackers, which is rated as difficulty with biting. However, the CG displayed significantly fewer errors in other domains of oral-motor movement.

Statistically significant correlations were identified between HIV-exposure and the sum of oral-motor difficulties for semi-solids (p=0.008); solids (p=0.010); chewable solids (p=0.047); soft-bite crackers (p=0.039); and liquids from a cup (p=0.011). This indicates a relationship between HIV-exposure and the number of oral-motor difficulties experienced within these OMC categories irrespective of participants' ages.

The CG displayed a higher number of food refusals compared to the RG, particularly in the nine-to-twelve month age group, however, both groups mostly refused chewable solids and medium-bite crackers. Unfamiliarity with these foods may explain this finding.

When compared across age divisions, the six-to-eight month CG and RG displayed similar oral-motor performance. In the nine-to-twelve month division, the RG performed significantly worse with liquids in a cup. This group experienced significantly worse liquid loss from the mouth and choking. Ten (33.33%) RG participants used their fingers to transfer all crackers around the inside of the mouth, indicating abnormal jaw function, according to the SOMA. The nine-to-twelve month RG exhibited the highest number of deficient oral-motor behaviours (Table 5), suggesting a potential risk for the development of OPD.

#### **Discussion**

Significant differences were identified between the oral-motor function for feeding of the HIV-exposed and unexposed participants. Although no participants exhibited oral-motor dysfunction according to the SOMA, the RG displayed significantly more deficient oral-motor behaviours than the CG, indicating qualitative differences in oral-motor function. Across the six-to-twelve month range, HIV-exposure strongly correlated with a higher total of deficient oral-motor behaviours across semi-solids, solids, chewable solids, soft-bite crackers and liquids from a cup. With the introduction of spoon-feeding at six months, these food consistencies are meant to be gradually introduced into infants' diets, as more complex oral-motor skills emerge with the progression of gross motor skills, to facilitate a toddler diet of table foods by twelve months. This finding indicates difficulty of the RG to progress to food consistencies requiring the use of complex and developed oral-motor skills, which are potentially delayed in emerging. Delayed emergence of these skills may inhibit further attainment of feeding milestones, hindering progression to solid consistencies expected by twelve months, possibly leading to malnutrition and growth faltering.

The RG frequently struggled to smoothly sequence the oral-motor behaviours for sucking/chewing and swallowing, and exhibited difficulty controlling liquid in the mouth, leading to profuse spillage during cup-drinking. Noticeable oral-motor deficits included uncoordinated and protruding tongue movement, difficulty using the lips to remove food/liquid from the spoon/cup, and maintain/control the bolus in the mouth, leading to spillage. These oral-motor difficulties are early signs of deficits in the oral phase of swallowing, and are frequently observed in infants infected with HIV who present with OPD. 11,23 These findings concur with that of Sa, Silva, Lima and Carvalho<sup>24</sup>, who identified motor delays in infants exposed to HIV between six and 18 months. In this study, oral-motor deficits were evident in

the nine-to-twelve month RG, suggesting that motor development of older infants exposed to HIV may be impaired. No standardised assessment of motor development was conducted in this study, and further research is warranted. The present study also had a small sample, with a cross-sectional design, and its findings cannot be generalised to the population of infants exposed to HIV, at large.

Clinicians working with infants who are HIV-exposed should adopt a transdisciplinary approach, acknowledging the risk for oral-motor dysfunction and OPD in HIV-exposed infants. SLTs and primary health care practitioners should be vigilant of early signs of OPD including prolonged mealtimes, ineffective nutritional intake and inappropriate weight gain, <sup>25</sup> as were observed in the participants referred to the dietician. Assessment of infants exposed to HIV should include a thorough evaluation of oral-motor functioning for feeding, by an SLT, whose speciality involves assessment and treatment of OPD. <sup>26</sup> Early feeding interventions can be implemented when necessary, minimising the harmful effects on infants' development, ensuring as typical development as possible. <sup>27</sup>

The CG refused food trials more often than the RG and tended to mouth crackers instead of biting them. This is attributed to possible unfamiliarity with the foods presented, rather than representing deficient behaviours. The SOMA has not been used widely in practice in South Africa, and although the foods were adapted for the study population, they still appeared unfamiliar to participants which may have altered infant performance. In the nine-to-twelve month RG, a few participants were identified with abnormal jaw function according to the SOMA, as they used their fingers to assist with moving the bolus inside the mouth. This behaviour is typical of infants aged eight-to-ten months.<sup>28</sup> It is therefore possible that certain behaviours of the RG that were rated as abnormal in the SOMA, may be characteristic of typical development, as developmental differences according to age are not taken into account when scored.<sup>22</sup> Further investigation into the oral-motor functioning of infants exposed to HIV using larger samples is necessary.

Only 17 infants had been introduced to solids at the appropriate time. The majority of participants were therefore not exposed to varying tastes and textures of boluses during the sensitive period in which sensory tolerances develop with an increase in oral-motor skill.<sup>29</sup> The oral-motor skills for feeding and swallowing develop through a process of motor learning. The specific oral-motor movements and sequences required for transitional feeding become more precise with increased exposure to a greater variety of boluses.<sup>29</sup> This implies that both groups

had less experience with solid boluses, displaying a limited range of oral-motor function, which appeared deficient in the RG. As oral-motor skills required for spoon-feeding and cup-drinking advance with repeated attempts, it may be possible that the deficient oral-motor behaviours of the RG may decrease with experience. A longitudinal study may be beneficial, involving follow-up of final HIV-status, to accurately deduce the effect of HIV-exposure on oral-motor function. Improved caregiver education regarding timing of complementary feeding is necessary.

When compared across the age divisions, the six-to-eight month RG displayed similar oral-motor function compared to the CG, indicating a more typical pattern of feeding development than the nine-to-twelve month RG. The nine-to-twelve month RG expressed significant difficulty with cup-drinking and showed choking throughout the trial. Choking is an indication of improper airway closure, and difficulty coordinating breathing and swallowing, and is commonly found in infants infected with HIV.<sup>11</sup> This finding suggests that the RG is at risk for aspiration, which may lead to pneumonia and respiratory tract infections, which infants exposed to HIV commonly present with.<sup>30</sup> SLTs should conduct instrumental assessments with infants exposed to HIV displaying symptoms of aspiration, to determine the cause of possible swallow dysfunction.

HIV-exposure was associated with low birth weight in this study, as also found by Ramokolo et al.<sup>31</sup> Although the differences in gestation and birth weight were not significant between the groups, neurodevelopmental immaturity associated with preterm birth and low birth weight leads to incoordination of swallowing and respiration<sup>8</sup>, which was prevalent in the RG.

Environmental factors associated with feeding difficulties were not directly examined and should receive greater attention in future studies. Maternal age, educational level and employment status did not correlate with feeding difficulties in this study, although they are factors known to influence feeding practices.<sup>32</sup>

Having displayed a risk for the emergence of OPD after the ninth-month, further research is required to determine whether older infants who are HIV-exposed may be experiencing OPD. Early identification and transdisciplinary management of this population by SLTs, primary health care nurses and dieticians is essential in ensuring improved developmental and health outcomes.

#### Conclusion

Infants exposed to HIV, aged six-to-twelve months may evidence altered and delayed oral-motor function for feeding compared to infants who are unexposed, as measured by the SOMA. During the period of transitional feeding, when feeding demands greater oral-motor control, nine-to-twelve month old infants exposed to HIV displayed a greater risk for OPD. However, the findings are not conclusive and larger scale studies also focusing on toddlers (>12 months) is required to confirm the effect of HIV-exposure on the oral-motor functioning of infants who are HIV-exposed.

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## **Competing interests**

The authors declare that they have no financial or personal relationships which may have inappropriately influenced them in writing this article.

#### **Author contributions**

M.L. was responsible for collecting the data for the research study. E.K. and A.K. supervised the study and were responsible for conceptualising the methodology. M.L., E.K., and A.K. were co-authors of the research paper, and M.G. contributed to the statistical analysis and interpretation of the data.

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## **CHAPTER 4: IMPLICATIONS AND CONCLUSIONS**

## 4.1 Chapter aim and outline

This chapter aims to highlight the most important results of the study, as well as the study's contributions and implications. The strengths and limitations of the study are critically evaluated, and recommendations for future research directions are discussed. The chapter concludes with a summary of the current research study's findings.

# 4.2 Discussion of selected findings

This section provides a further discussion of selected results of the present study which warranted deeper discussion. Significant differences were identified between the oral-motor function for feeding of the HIV-exposed and unexposed participants. Although no participants exhibited oral-motor dysfunction according to the SOMA, the RG displayed significantly more deficient oral-motor behaviours than the CG, indicating differences in oral-motor functioning for feeding.

The most important finding of the present study showed that when compared across the age divisions, the six-to-eight month RG displayed similar oral-motor function compared to the CG, indicating a more typical pattern of feeding development than the nine-to-twelve month RG. Narayanan and Kalappa (2017) also found that the oral-motor difficulties of infants infected with HIV became more apparent at a later stage in childhood, when the demands for feeding were increased. A similar pattern was observed in the present study's RG, whose oral-motor difficulties were more distinct in the older group of infants (nine-to-twelve months). Figure 2 summarises the oral-motor deficits observed in the RG.

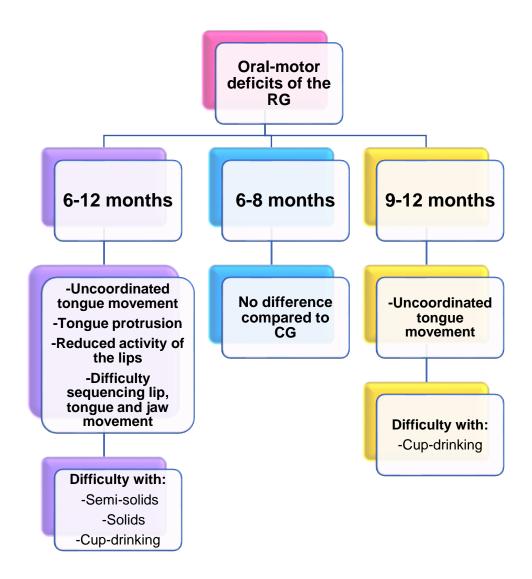


Figure 2. Summary of the oral-motor deficits of the RG compared to the CG (n=30)

As seen in Figure 2, the RG demonstrated significant difficulty with consistencies and boluses that required more complicated oral-motor functioning, and coordination. The RG frequently struggled to smoothly sequence the oral-motor behaviours for sucking/chewing and swallowing, and exhibited difficulty controlling liquid in the mouth, leading to profuse spillage during cup-drinking. Noticeable oral-motor deficits included uncoordinated and protruding tongue movement, difficulty using the lips to remove food/liquid from the spoon/cup, and maintain/control the bolus in the mouth, leading to spillage. These oral-motor difficulties are early signs of deficits in the oral phase of

swallowing, and are frequently observed in infants infected with HIV who present with oropharyngeal dysphagia (Nel & Ellis, 2012; Pressman, 2010). These deficits were apparent across the consistencies, and although the sum of these oral-motor difficulties did not indicate oral-motor dysfunction within any specific OMC category on the SOMA, their presence throughout feeding may indicate that infants exposed to HIV may be at risk for the development of oropharyngeal dysphagia.

In the nine-to-twelve month RG, a few participants were identified with abnormal jaw function according to the SOMA, as they used their fingers to assist with moving the bolus inside the mouth. However, this behaviour is typical of infants aged eight-to-ten months (Carruth & Skinner, 2002). The SOMA does not account for developmental differences according to age when it is scored, and it may therefore be possible that certain behaviours rated as abnormal in the SOMA may be characteristic of typical development for the child's developmental stage (Delaney, 2010).

Table 4 highlights another important finding of this study, showing that only 17 participants (22.67%) had been introduced to solids at the time of data-collection. There were no significant differences between the number of infants from the RG and CG who were introduced to solids (eight from the RG and nine from the CG). The mean age of introduction of solids did not differ significantly between the groups. Caregivers of the CG introduced solids earlier as well as later than the RG, and not at the recommended age of six months, possibly demonstrating limited knowledge of the timing of transitional feeding. Food security could have been another possible contributing factor to the delay in the introduction of solid foods.

**Table 4.** Participant feeding history regarding introduction of solids (n=75)

Characteristic		RG n=30	CG n=45	p-value
Solids have been introduced into diet	6-8	2	4	1
	months	(6.67%)	(8.89%)	
	9-12	6	5	0.287
	months	(20%)	(11.11%)	
Mean age of introduction of solids	6-8	6	5.25	0.644
(months), SD	months	(1.26)	(0.80)	
	9-12	6.5	7.4	0.479
	months	(1.57)	(1.32)	

Similar feeding practices were identified between the groups regarding the first solid foods introduced, which included butternut/sweet potato/potato, and were introduced using a spoon (n=15; 88.24%) or the caregiver's hand (n=2; 11.76%). Limited research surrounds the cultural/traditional feeding practices of mothers in South Africa, yet it is known that such practices may influence complementary feeding practices, rendering them suboptimal (Sayed & Schönfeldt, 2018). In the review of complementary feeding practices in South Africa by Sayed and Schönfeldt (2018), it was clear that maternal knowledge of complementary feeding during the transitional feeding period, varies, and that dietary diversity is poorer in older infants. The findings of the present study support these notions, as atypical weight gain was observed in the two HIV-exposed and four unexposed participants referred to the dietician. This was likely due to the inability to meet their nutritional goals during their prolonged mealtime, all of which are early signs of oropharyngeal dysphagia (Narayanan & Kalappa, 2017).

Late introduction of solid foods was found to be a causal factor for the development of feeding difficulties in infants (Ramos et al., 2017). This late introduction may lead to difficulty transitioning to different textures/consistencies of solids, which could be related to delays in oral-motor development and sensory processing, associated with feeding and swallowing difficulties (Ramos et al., 2017). This is noteworthy as the majority of the study sample (77.33%) had not been exposed to solids at the time of data-collection. The presenting oral-motor difficulties observed in the RG may have been indicative of potential delays in oral-sensorimotor development, secondary to late introduction of solids. It is therefore difficult to discern whether HIV-exposure alone could have contributed to the differing oral-motor function of the RG, or whether the difficulties can be attributed to a combination of HIV-exposure, prenatal ART exposure, and improper feeding practices. Further research is warranted in this regard.

Feeding and swallowing is a process of skill acquisition, occurring through motor learning, and maturing with increased experience with food consistencies (Sampallo-Pedroza, Cardona-Lopez & Ramirez-Gomez, 2014; Van den Engel-Hoek, Van Hulst, Van Gerven, Van Haaften & De Groot, 2014). Oral-motor sequences for feeding become more refined and precise with repeated exposure and experience with varying boluses, to facilitate effective and different swallowing patterns required for liquids, semi-solids and solids (Sampallo-Pedroza et al., 2014). The nine-to-twelve month RG expressed significant difficulty with cup-drinking and struggled to control the liquid in

the mouth, resulting in choking. Choking is an indication of improper airway closure, and difficulty coordinating breathing and swallowing, and is commonly found in HIV-infected infants (Pressman, 2010). Similar to the findings of Nel and Ellis (2012), this incoordination of breathing and swallowing may be occurring as a result of a 'functional disturbance' rather than structural abnormalities of the oral-musculature. This finding suggests that the RG is at risk for aspiration, which may lead to pneumonia and respiratory tract infections, which infants exposed to HIV commonly present with (Cloete et al., 2015). It is imperative that SLTs working with infants who are HIV-exposed conduct instrumental assessment with those infants displaying symptoms of aspiration, to determine the cause of possible swallow dysfunction and generate an appropriate management plan (ASHA, 2018).

Considering that spoon-feeding and cup-drinking are skills acquired through motor learning (Delaney & Arvedson, 2008; Van den Engel-Hoek et al., 2014), it may be possible that the deficient oral-motor behaviours (lip, jaw and tongue movements) of the RG may decrease with experience. Both groups were similar in the composition of factors which are known to influence feeding ability; including age, gestational age at birth, birth weight and number of participants exposed to solid foods. The significant differences in oral-motor function of the RG may therefore have resulted from a combination of HIV-exposure as well as the compounded effect of improper complementary feeding practices. Findings are interpreted with caution due to the small sample, and therefore further research is required.

A close relationship exists between the rapid neurological development occurring throughout the transitional feeding period (i.e. six-to-twelve months) and the subsequent gross motor gains that facilitate the emergence of more mature oral-motor skills (Van den Engel-Hoek et al., 2014). These findings suggest a potential delay in the emergence of more complex oral-motor skills of the RG compared to the CG, which may inhibit further attainment of feeding milestones and progression to solid consistencies expected by 12 months. It may therefore be possible that the motor development of older infants who are HIV-exposed may be impaired, which could be reflected in the form of difficulty transitioning to solid foods in later infancy, when the demands for feeding increase.

In summary, statistically significant differences existed between the oral-motor function for feeding of infants exposed to HIV compared to infants unexposed to HIV. In comparison to the unexposed infants, the infants exposed to HIV displayed distinctive oral-motor difficulties during feeding, requiring further investigation in larger scale studies.

## 4.3 Theoretical and clinical implications of the study

The substantial increase in the South African population of infants exposed to but uninfected with HIV, bears testament to the successful implementation of the PMTCT programme in the country (UNAIDS, 2017). Widespread and improved access and adherence to maternal ART may propose a different future for the majority of infants exposed to HIV, ensuring that they will remain uninfected, with the possibility of improved health and developmental outcomes (Filteau, 2009; Le Doaré et al., 2012). The findings of this study contribute to the pool of research regarding the early developmental outcomes of this growing vulnerable population of infants with uncertain health needs. In doing so, the study was able to identify that oral-motor function for feeding, which is a core developmental area, may be different in infants exposed to HIV, during the critical period of transitional feeding (six-to-twelve months). The study was able to identify and describe core areas of oral-motor functioning, which appeared deficient in the study sample that may aid clinicians working with infants exposed to HIV, in identifying early signs of feeding and swallowing difficulties.

In the study sample, the group of younger infants exposed to HIV (six-to-eight months) presented with a more typical pattern of oral-motor functioning. The older group (nine-to-twelve months) exposed to HIV displayed significant differences and atypical oral-motor behaviour during feeding, compared to unexposed infants, placing them at risk for the development of oropharyngeal dysphagia. This finding may have implications for clinical practice as it has not previously been identified that infants exposed to HIV are at risk for oropharyngeal dysphagia when the demands (neurological and sensorimotor) for feeding increase through infancy. All clinicians working with infants who are HIV-exposed should be made aware that in addition to the impaired areas of neurological, motor and language development, feeding development is now also of concern in this infant population.

The descriptions of oral-motor function provided by this study may particularly be of value to practising SLTs, who are primarily involved in the assessment and management of paediatric oropharyngeal dysphagia and may serve as 'red flags' to look out for when treating infants exposed to HIV. Further research, with a larger study sample and longitudinal design is necessary to confirm the effect of HIV- and associated ARV-exposure on the oral-motor function of HIV-exposed infants. The findings of this study are not conclusive, but suggest that older infants who are HIV-exposed may be at a greater risk of oropharyngeal dysphagia, due to the increase in demands for feeding, requiring investigation and vigilance in practice. SLTs should therefore be made aware of the risk for oral-motor dysfunction and oropharyngeal dysphagia in infants exposed to HIV, and should advocate for developmental monitoring of HIV-exposed infants, and coaching of their parents within their clinical settings.

When considering the nature of feeding and swallowing difficulties, it becomes clear that the causes are multifactorial, and therefore its treatment will require transdisciplinary collaboration among various health professionals (Arvedson & Brodsky, 2002; Groher & Crary, 2014). In this study, inappropriate complementary feeding practices may have been a core contributor to the presenting oral-motor difficulties displayed by both groups. Considering that solid foods had not been introduced into the diets of the majority of participants in both groups, the additional oral-motor deficits of the RG may not have been solely due to the delayed introduction of solids. It may be possible that the RG could have been experiencing some degree of neurological delay as a result of HIV-exposure, which may have delayed emergence of specific and more complex oral-motor behaviours, compared to the CG. Improved caregiver education by PHC nurses or dieticians regarding timing of complementary feeding and favourable practices, may help to minimise the negative effects of delayed introduction on solids on the oral-motor development for feeding of all infants.

Feeding offers the platform for the development of active social interactions between caregivers and their infant (Van den Engel-Hoek et al., 2014). Feeding difficulties and problematic behaviour during mealtime in early infancy may place strain on the relationship between the caregiver and the infant, which may affect mother-infant attachment. Difficulties in mother-infant attachment may lead to communication difficulties in the infant later on (Rossetti, 2001). Older infants exposed to HIV (eight-

fifteen months) have been found to present with deficits in early expressive and receptive language (Alcock et al., 2016). Additionally, infants exposed to HIV are further exposed to the environmental risks associated with living in an HIV-affected household, such as poverty, and lack of developmentally appropriate stimulation (Hair et al., 2015). By identifying and minimising environmental risks by improving caregiver knowledge (Ramos et al., 2017), the compounded effects on the infant may be reduced. It is therefore important to holistically consider the early risks associated with feeding difficulties in the population of HIV-exposed infants, as well as the cascading effects if left undiagnosed and untreated. Infants exposed to HIV evidently display a unique profile of development. Intervention by an SLT may not necessarily be required for HIV-exposed infants, however, continuous developmental monitoring is warranted.

PHC nurses are often the health care workers with which caregivers of infants exposed to HIV have frequent contact. These nursing sisters should specifically be vigilant of early signs of feeding and swallowing difficulties in infants exposed to HIV, to make the appropriate referrals. Signs of such difficulties observed in this study included: prolonged mealtimes, ineffective nutritional intake, inappropriate weight gain, and disruptive mealtime behaviour (Ramos et al., 2017). Transdisciplinary management of infants exposed to HIV, should therefore occur between SLTs, PHC nurses and dieticians. This may ensure holistic and tailored intervention for this vulnerable population, as early as possible.

Training of undergraduate SLT students should begin to include the developmental risks to which infants exposed to HIV are predisposed, as well as how to holistically assess, manage and minimise the potential feeding difficulties/oropharyngeal dysphagia of this at-risk population. Understanding the specific environmental risks that HIV-exposed infants experience, and their role in the development of feeding and swallowing difficulties should also be emphasised in the undergraduate curriculum. The findings of this study show that HIV- and maternal-related factors may be contributing to the oral-motor functioning of infants exposed to HIV, and should be investigated further.

From the findings of this study, it is clear that the oral-motor characteristics of the HIV-exposed group bore similar resemblance to the difficulties experienced by infants infected with HIV, as well as those unexposed to HIV. This may suggest that HIV-

exposure possibly influences oral-motor and feeding development, albeit to a lesser extent than HIV-infection. The similarity with the feeding profile of the HIV-unexposed infants, is promising, as this may suggest the potential for continued typical development with appropriate early intervention by clinicians (Rajan et al., 2017). Further research is needed to determine the degree to which feeding and swallowing development may be affected. The oral-motor deficits of the RG in this study should not be overlooked, but should serve as a motivation for the further investigation into the feeding and oral-motor development of older infants exposed to HIV. By determining a profile of deficient oral-motor behaviours, SLTs may be able to better develop and employ the earliest interventions possible, to minimise the detrimental sequelae on HIV-exposed infants' development, and ensure as typical development as possible.

# 4.4 Strengths and limitations of the study

## Strengths of the study:

- Both groups were similar in age, gestational age at birth, and birth weight, all of
  which are factors that influence feeding (Jadcherla, 2016). The similarity of these
  factors therefore limited the possibility of inaccurate presentation of feeding
  difficulties in either group due to these factors.
- Further comparison of the RG and CG per age division (six-to-eight or nine-to-twelve months) provided a more accurate description of the oral-motor function and subsequent difficulties experienced by each group. Considering that the developmental differences between infants of six and twelve months are substantial, feeding ability cannot be accurately compared across such a wide age division. By narrowing the age divisions, infants were compared against their peers who were assumed to have attained similar developmental gains for feeding.
- The SOMA is a standardised, valid and reliable feeding assessment tool specifically designed for the transitional feeding period (Delaney, 2010; Reilly et al., 2000). Its use in this study therefore ensured the outcome of valid and reliable results, and proved effective in identifying the characteristics of oral-motor function of both groups, as well as in determining areas of deficient oral-motor functioning of the RG. Participants were provided with the same standard feeding apparatus

and amount of food/liquid stimuli for each trial in the SOMA, strengthening the reliability of the results. Furthermore, the information collected with the data collection sheet supplemented the oral-motor results obtained from the SOMA, and was able to provide the researcher with a holistic view of the infants' feeding and developmental history. This information proved useful in identifying contributing factors, which may have contributed to the infants' deficient oral-motor function during feeding.

# Limitations of the study:

- This study had a small sample size, which limited generalisability of its findings.
   The cross-sectional nature made it difficult to confirm the effect of HIV-exposure on oral-motor functioning of the RG, particularly as no follow-up could be done of the infants' final HIV-status, due to time constraints of the study.
- The SOMA has not been widely used in practice in South Africa. Even though the
  foods used were adapted for applicability and cultural appropriateness of the study
  sample, the foods still appeared unfamiliar to participants. This may have
  influenced their behaviour during the assessment, yielding inaccurate results of
  oral-motor performance.
- The study did not make use of a second rater. Having a second rater present during the assessment could have improved reliability of the findings.
- The feeding assessment did not occur in a natural setting for participants, particularly as they were being fed by an unfamiliar person (the researcher), which may have indirectly influenced their behaviour during the assessment, not presenting an accurate image of their typical feeding patterns. It could have been beneficial to have observed the oral-motor behaviours in a typical feeding session with their caregiver, however, this was not possible in the context of this study. Observation of a single feeding session may not be sufficient to draw conclusions about an infant's feeding ability, and repeated assessment/observation should have been conducted.
- Environmental and maternal factors associated with feeding were not directly examined in the study. This could have assisted in identifying relationships between maternal health/stage of HIV disease, poverty, feeding practices, and

other factors, which may have affected the oral-motor and feeding function of participants. However, this was not the main aim of the study.

## 4.5 Recommendations for future research

To the author's knowledge, no other research studies have investigated the oral-motor function for feeding of infants exposed to HIV, during the transitional feeding period. This study therefore aimed to provide information regarding the oral-motor characteristics of this population. The results raised a few points that require further investigation.

- Future research studies should include larger samples of infants exposed to HIV and compare the feeding and oral-motor development of HIV-exposed infants in contrast to those of infants unexposed to HIV. This may strengthen the reliability and generalisability of findings. Studies should include older infants and toddlers (>12 months), to determine whether genuine oral-motor deficits emerge as infants exposed to HIV age and require advanced skills in oral-motor function for feeding. Alternative assessment measures should also be used, apart from the SOMA, such as Videofluoroscopic Swallow Study, which may provide a more comprehensive description of the infants' oral-motor and swallowing mechanisms.
- In order to truly determine the impact of HIV-exposure on oral-motor function and feeding development in general, it is recommended that longitudinal studies be conducted with infants exposed to HIV, involving multiple observations and assessments of feeding, and follow-up of final HIV-status at 18 months, or sixweeks post-cessation of breastfeeding.
- Comparison studies of infants exposed to HIV, should be conducted against control groups of both infants unexposed to HIV, and those infected with HIV, throughout and beyond the transitional feeding period. Comparison between these groups may assist in identifying the degree of oral-motor impairment as a result of HIV-exposure.
- The perceptions of mothers of HIV-exposed and unexposed infants regarding complementary feeding practices, is an area requiring further investigation. This information may help in identifying gaps in maternal knowledge that may be contributing to feeding difficulties of the infants in the country.

Since there is close relationship between the developmental pathways for feeding and subsequent communication skills (Delaney & Arvedson, 2008), and considering that infants exposed to HIV have demonstrated delay in expressive language (Alcock et al., 2016), it may be valuable to investigate the link between these areas. It may also be valuable to investigate whether early oral-motor deficits that are present during feeding are also present during speech production of infants exposed to HIV.

### 4.6 Conclusion

In comparison to the unexposed participants, the participants who were HIV-exposed aged nine-to-twelve months displayed altered and deficient oral-motor function for feeding, as measured by the SOMA. This study highlighted the early differences in oral-motor function of HIV-exposed infants, which place them at risk for the development of oropharyngeal dysphagia in later infancy. Findings revealed a complex and unique feeding profile of the infants exposed to HIV, which encompasses characteristics of both typical development of HIV-unexposed infants, as well as concerning oral-motor deficits similar to that of infants infected with the virus. It is clear that infants exposed to but uninfected with the virus may experience an array of developmental difficulties resultant of their prenatal HIV-exposure (Boivin et al., 1995; Da Silva et al., 2017; Le Doaré et al., 2012; Sá et al., 2015). Ineffective complementary feeding practices may have influenced the research findings, as the majority of the sample had not been exposed to solid foods. Further research is thus required to improve understanding of the early feeding development of this at-risk population of HIV-exposed infants. Early identification and transdisciplinary management of the potential feeding and swallowing difficulties of this growing population is essential, to minimise the harmful effects on their development.

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### **APPENDICES**

**APPENDIX A:** Ethical clearance letter from the Research Ethics Committee of

the Faculty of Humanities

**APPENDIX B:** Clearance certificate from the Tshwane Research Committee

**APPENDIX C:** Letters of permission from the Manager of the PHC clinic

**APPENDIX D:** Parent/caregiver information sheet and informed consent form

(English)

**APPENDIX E:** Parent/caregiver information sheet and informed consent form

(Northern Sotho)

**APPENDIX F:** Parent/caregiver information sheet and informed consent form

(isiZulu)

**APPENDIX G:** Data collection sheet

**APPENDIX H:** Schedule for Oral Motor Assessment (scoring sheets)

**APPENDIX I:** Speech and language stimulation handout (6-9 months)

**APPENDIX J:** Speech and language stimulation handout (9-12 months)

**APPENDIX K:** Proof of article submission to the *African Journal of Primary* 

Health Care and Family Medicine

# APPENDIX A: Ethical clearance letter from the Research Ethics Committee of the Faculty of Humanities



Faculty of Humanities Research Ethics Committee

18 April 2018

Dear Ms Lalbahadur

Project:

Feeding characteristics of HIV-exposed infants

Researcher:

M Lalbahadur

Supervisors:

Ms E Krüger and Prof A Kritzinger

Department:

Speech-Language Pathology and Audiology

Reference numbers: 2

21013374 (GW20180113HS)

Thank you for your response to the Committee's correspondence of 9 March 2018.

The Research Ethics Committee notes that the outstanding permissions from the *Tshwane Research Committee and Stanza Bopape Hospital* were submitted as requested. Final ethics approval for the above application was granted at an *ad hoc* meeting on18 April 2018. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely

Prof Maxi Schoeman

Deputy Dean: Postgraduate and Research Ethics

**Faculty of Humanities** 

UNIVERSITY OF PRETORIA e-mail: PGHumanities@up.ac.za

cc: Prof A Kritzinger and Ms E Krűger (Supervisors)

Dr J van der Linder (HoD)

Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean); Prof KL Harris; Dr L Blokland; Dr K Booyens; Ms A dos Santos; Dr R Fasselt; Ms KT Govinder; Dr E Johnson; Mr A Mohamed; Dr C Puttergill; Dr D Reyburn; Dr M Soer; Prof E Taljard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

### APPENDIX B: Clearance certificate from the Tshwane Research Committee



Enquiries: Dr. Lufuno Razwiedani Tel: +27 12 451 9036 E-mail: <u>lufuno.razwiedani@gauteng.gov.za</u>

TSHWANE RESEARCH COMMITTEE: CLEARANCE CERTIFICATE

MEETING: 02/2018

PROJECT NUMBER: 26/2018

NHRD REFERENCE NUMBER: GP 201803 025

TOPIC: Feeding characteristics of HIV-exposed and HIV-unexposed infants

Principal investigator:

Mishkaya Lalbahadur

Supervisor:

Mrs Esedra Krüger

Co-supervisor:

Professor Alta Kritzinger

Facility:

Stanza Bopape CHC

Name of the Department:

University of Pretoria

NB: THIS OFFICE REQUEST A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE AND

NOTE THAT RESUBMISSION OF THE PROTOCOL BY RESEARCHER(S) IS REQUIRED IF THERE IS DEPARTURE FROM THE PROTOCOL PROCEDURES AS APPROVED BY THE COMMITTEE.

DECISION OF THE COMMITTEE:

**APPROVED** 

Dr. Robert Oyedipe

Acting Chairperson: Tshwane Research Committee

Date: 13.04 2018

Mr. Pitsi Mothomone

Chief Director: Tshwane District Health

Date: Lot 9-ole 13

### **APPENDIX C:** Letters of permission from the Manager of the PHC clinic

GAUTENG PROVINCE  MEALTH  REPUBLIC OF SOUTH AFRICA
Annexure 1
Declaration of intent from the clinic manager or hospital CEO
I give preliminary permission to Mishkaya Lalbahadur to do her
research onFeeding characteristics of HIV-exposed and HIV-unexposed infants in
Stanza Bopape CHC
I know that the final approval will be from the Tshwane Regional Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.
Other comments or conditions prescribed by the clinic or CHC manager or hospital CEO:
Signature Clinic Manager/CHC Manager/CEO  16 - 03 - 20/8  Date



### Faculty of Humanities

Department of Speech-Language Pathology and Audiology

9 March 2018

Facility Manager of Stanza Bopape Community Health Centre, Mamelodi

Dear Mr Otsheleng,

## RE: PERMISSION TO CONDUCT A RESEARCH PROJECT AT STANZA BOPAPE COMMUNITY HEALTH CENTRE

I am a Master's student at the University of Pretoria and as a requirement for my degree in Speech-Language Pathology I am conducting a research project entitled "Feeding characteristics of HIVexposed and HIV-unexposed infants". The project aims to identify and describe the feeding characteristics of infants who are HIV-exposed in comparison to infants who are HIV-unexposed.

Limited research has been conducted on the health needs of the growing population of HIV-exposed (HE) infants born to HIV-positive mothers in South Africa. There is an increasing need to determine whether HE infants present with possible feeding difficulties and the extent thereof in comparison to the feeding patterns of infants who are HIV-unexposed. Demographic information gathered from the parent/primary caregiver through informal questioning and a clinical feeding assessment of their infant may help to determine differences between the feeding patterns of the two groups of infants; and identify if feeding problems do exist in infants exposed to HIV. This will allow for future, early and effective treatment of these problems by speech-language therapists and other health professionals.

In order to conduct my study, I will require the participation of infants from six to 12 months of age and their parent/primary caregiver. I would like to involve all infants within this age range, regardless of their own and their mother's HIV status. This will ensure that the participants who are HIV-positive, are not marginalised, as their HIV status will not be made known to anyone else, or asked to be disclosed to the researcher.

I would like to kindly request permission to approach these patients from the baby-wellness clinic at Stanza Bopape CHC and request voluntary participation from their parent/primary caregiver for my research project. This will not influence the running of the baby wellness clinic, nor will it interfere with the work of the doctors or sisters. I would also like to request whether I may work in a quiet room or other private space in the clinic.

Prior to commencement of the study, I will obtain ethical clearance from the Faculty of Humanities of the University of Pretoria and the Tshwane Research Committee; however, I require permission from the CHC to conduct my research on site, before I am able to obtain ethical clearance. I would like to kindly request permission to do so. The data I require will be obtained through brief questioning of the infant's caregiver and a clinical feeding assessment of the infant, either conducted by myself or by the parent/caregiver (with appropriate guidance). Furthermore, I would like to kindly request permission to

Fakulteit Geesteswetenskappe Departement Spraak-Taalpatologie en Oudlologie Lefapha la Bomotho Kgoro ya Phatholotsi ya Polelo-Maleme le Go kwa access the participating infants' patient files and Road to Health Booklets to use relevant birth, medical, and HIV-related history.

All participants' identifying information and results from the study will be reported anonymously and handled with the strictest confidentiality. Participants will also not be exposed to any risk or discomfort for the duration of the study and any infants presenting with feeding difficulties with be referred appropriately. The participants may also withdraw at any stage during the study, should they wish to do so, without any negative consequences. No direct benefits or rewards will be offered to participants for their involvement in the study, however; the parent/caregiver will be allowed to keep any food items that may have been used during the feeding assessment. Information will also be provided to the infants' mothers/primary caregivers should they require any.

The results from this study will be stored at the Department of Speech-Language Pathology and Audiology at the University of Pretoria for 15 years; will be reported in the form of a scientific article and dissertation, made available to professionals in the field of Speech-Language Pathology, and may be used for future research. I would greatly appreciate your permission to approach the patients at your baby wellness clinic and their caregivers and I hope that my intentions meet your approval. Kindly complete the following letter of consent if you are willing to allow me to conduct my research at the clinic. Thank you for your time and consideration.

Please do not hesitate to contact me should you have any questions or concerns regarding my research study.

Yours sincerely.

Mishkaya Lalbahadur Student Researcher

Tel: 072 027 1292

Email: mishkayal@gmail.com

Mrs Esedra Krüger Research Supervisor

Tel: 012 420 4910

Email: esedra.kruger@up.ac.za.com

Professor Alta Kritzinger

Research Supervisor Tel: 012 420 2949

Email: alta.kritzinger@up.ac.za

Dr Jeannie van der Linde

Head of Department of Speech-Language Pathology and Audiology

Tel: 012 420 2355 (x2948)

Email: jeannie.vanderlinde@up.ac.za

PERMISSION TO CONDUCT THE ABOVE-MENTIONED RESEARCH AT THE BABY WELLNESS

CLINIC AT STANZA BOPAPE COMMUNITY HEALTH CENTRE

, Manager of Stanza Bopape CHC, give my consent that

Mishkaya Lalbahadur may conduct data-collection for the research project entitled "Feeding

characteristics of HVV exposed and HIV-unexposed infants".

Signature of Manager

Date:

# APPENDIX D: Parent/caregiver information sheet and informed consent form (English)



### **Faculty of Humanities**

Department of Speech-Language Pathology and Audiology

9 March 2018

Dear Parent/Caregiver,

#### PARENT/CAREGIVER INFORMATION SHEET & INFORMED CONSENT

Title of the research study: Feeding characteristics of HIV-exposed and HIV-unexposed infants

### INTRODUCTION

I (Mishkaya Lalbahadur) am doing a research project for my Masters degree in Speech-Language Pathology at the University of Pretoria, and I would like to kindly invite you and your baby to take part in my study. My research aims to identify and describe whether HIV-exposure can change a baby's feeding ability. This information sheet will help you understand what will happen during this study and will help you decide if you would like to take part. If you have any questions that are not explained in this sheet, please feel free to ask me.

### WHAT IS THE PURPOSE OF THIS RESEARCH?

Feeding problems can change a baby's health and growth. There are many babies who were exposed to HIV but they are not yet HIV-positive. We are unsure if they may have problems with feeding, swallowing and growing. If these babies have problems with feeding and swallowing, they may be helped early to solve these problems as soon as possible. I would like to learn about the feeding skills of babies under one year. You and your baby may give me very important information that may help me understand how to help babies with feeding problems.

### WHY HAVE MY BABY AND I BEEN CHOSEN?

I would like to invite all babies at the baby wellness clinic who are:

- Between the age of six to 12 months
- Whose parent/caregiver can understand and speak English
- Whose parent/caregiver is older than 18 years

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### WHAT WILL WE DO, IF WE DO TAKE PART?

I will ask you about yourself and your baby's feeding and I will also look in your baby's file to see their HIV status and health.

Please know that if you do feel uncomfortable answering any of the questions, you do not have to, and you will not be forced to do so.

I will then check your baby's feeding skills and see if they are having any problems with eating. If your baby does not want me to feed them, I will ask you to feed them, but I will help you on how to do this so that we can get the right information. You are free to ask me for advice or information if you would like.

### WHERE WILL WE NEED TO GO AND HOW LONG WILL IT TAKE?

I will ask you the questions and check your baby's feeding while you are waiting at the well-baby clinic. If you want to take part after your baby sees the doctor or the sister, or if you want to leave your space in the waiting line, we can check your baby's eating skills in a separate room next to the baby wellness clinic. This will take about 20 minutes.

### WHAT ARE THE POSSIBLE RISKS TO MY BABY AND ARE THERE ANY BENEFITS IF WE TAKE PART?

You and your baby will not feel uncomfortable; all parts of the study are safe. You will not be paid if you do choose to take part; but if your baby has any feeding problems, I will tell you where to go for help. After I finish checking your baby's feeding, you will also be able to keep any of the food items that I have used to check your baby's feeding (yoghurt, biscuits or dried fruit).

### DO MY BABY AND I HAVE TO TAKE PART AND CAN WE WITHDRAW FROM THE STUDY?

You can choose if you and your baby would like to take part in the study or not and you can also choose to refuse. You may also stop taking part at any point if you want to, and nothing bad will happen to you and your baby in any way. Your services at the well-baby clinic will still continue as normal either way.

### **HOW WILL THE RESULTS BE SHARED?**

The results from the study will be stored at the Department of Speech-Language Pathology and Audiology at the University of Pretoria for 15 years, and will be used for a scientific article and dissertation for my degree. These will be made available to other health professionals in the field of Speech-Language Pathology and may be used for other research. If you would like a summary of the findings from this study, I can make a copy for you when the project is finished.

### WHAT ABOUT CONFIDENTIALITY AND PRIVACY OF OUR INFORMATION?

All your personal information from the questions I ask you and the results from the feeding test will be kept secret (your names will not be used so no one will be able to identify you) in the reporting of the results. Only my supervisors and I will be able to see your personal information.

#### **CONTACT DETAILS**

If you have any questions or are unsure about anything to do with the study, please feel free to contact me or my supervisors:

Ms Mishkaya Lalbahadur: 072 027 1292 / mishkayal@gmail.com Mrs Esedra Krüger: 012 420 4910 / esedra.kruger@up.ac.za Professor Alta Kritzinger: 012 420 2949 / alta.kritzinger@up.ac.za

If you have any further questions about this research study, you are welcome to phone me, Ms Mishkaya Lalbahadur, at 072 027 1292.

If you are willing to participate in my research study, please sign the attached consent form.

Yours sincerely,

Ms Mishkaya Lalbahadur Student Researcher

Mrs Esedra Krüger Research Supervisor **Professor Alta Kritzinger** Research Supervisor

Dr J. van der Linde

Head: Department of Speech-Language Pathology and Audiology

### WRITTEN INFORMED CONSENT

I hereby confirm that I have been informed by Ms Mishkaya Lalbahadur about what the study called "Feeding characteristics of HIV-exposed and HIV-unexposed infants" involves. I understand that we will not be paid to take part and that there are no risks to me or my baby. I have received, read and understood the *Parent/caregiver information sheet & informed consent*. I have been given enough time to ask questions and I am happy that they have been answered completely. I understand that I will be asked a few questions and that my baby will have a feeding test done and that information will be used from my baby's clinic file. I understand that I am free to participate and that if I choose not to participate, it will not change the treatment of my baby and me. I understand that our information will be kept confidential at all times and that our information will be used anonymously for a research report and that this may be used for other research and will be stored.

I understand that I may stop participating in the study at any time if I choose do so and it will not change my baby's treatment in any way and I know who to contact if I have any questions. I hereby give my consent for myself and my baby to participate in this study.

Parent/caregiver's name:	———— (Please print)
Parent/caregiver's signature:	
Researcher's name: Ms Mishkaya Lalbahadur	
Researcher's signature:	
Witness's name:	_ (Please print)
Witness's signature:	_
Date:	

## VERBAL PARENT/CAREGIVER INFORMED CONSENT (if parent/caregiver is unable to read/write)

I, the undersigned, Ms Mishkaya Lalbahadur, or a translato	r, have read and have fully explained to
the parent/ caregiver, named	and his/her relative, the
Parent/caregiver information sheet & informed consent, wh	ich has indicated the nature and purpose
of the study in which I have asked the participant to take pa	art. I have explained the risks and benefits
of the study and exactly what will be expected from the part	ticipant for the study. The parent/caregiver
has indicated that he/she understands that he/she is free to	
any reason and that this will not affect the treatment of him	
been given enough time to ask questions and he/she is sat	
appropriately. The participant understands that he/she is from	
participate, it will not affect his/her baby's treatment in any	
storage of information from the study and understands that	
anonymously and they know who to contact if they have an	• •
participant has consented to his/her own and his/her baby's characteristics of HIV-exposed and HIV-unexposed infants'	
characteristics of this-exposed and this-difexposed infants	•
Parent/caregiver's signature:	
Researcher's name: Ms Mishkaya Lalbahadur	
Researcher's signature:	
Interpreter's name:	_ (Please print)
Interpreter's signature:	
Witness's name:	(Please print)
Witness's signature:	
Date:	

# APPENDIX E: Parent/caregiver information sheet and informed consent form (Northern Sotho)



## **Faculty of Humanities**Department of Speech-Language Pathology and Audiology

9 Matšhe 2018

Thobela Motswadi/Mohlokomedi

#### LEPHEPHE LA BOHLATSE BJA MOTSWADI/MOHLOKOMEDI LE TUMELELO

Hlogo ya nyakišišo thuto: Dika tša phepo tša HIV di tšwetše kgakala le bana bao ba hlokago HIV.

#### Matseno

Nna (Mishkaya Lalbahadur) ke dira porojeke ya nyakišišo ya dithuto tša ka tša Master's ya Bolela-Polelo Phatholotši kua Yunibesithi ya Pitori, ebile ke rata go le mema le bana ba lena gore le tšee karolo dithutong tša ka. Tebanyo ya nyakišišo ya ka ke go netefatša gore na phatlalatšo ya HIV e ka fetola bokgoni bja go fepa ngwana. Bohlatse bjo, mo godimo ga pampišana ye, bo tlo le thuša gore le kwešiše gore go tlo direga eng mo thutong ye. Ka yona tsela yeo le tlo kgetha gore la nyaka goba karolo ya thuto ye goba bjang. Ge le na le dipotšišo mabapi le yona taba ye, le amogetšwe gore le ka botšiša nna. Mo nyakišišong ye, ke hloka go akaretša bana bao ba belegilwego ke batswadi ba go ba le HIV le bao ba belegilwego ke ba go hloka HIV.

### NA MORERO WA NYAKIŠIŠO YE KE ENG?

Mathata a phepo a ka fetola go hlweka le go gola ga ngwana. Go na le bana ba bantši bao ba belegilwego ke batswadi ba go ba le HIV efela ga ba na bolwetši bjoo. Ga re na bohlatse gore ba ka le bothata bja fepa, go metša le go gola. Ge e le gore bana ba ba na le bothata bja phepo le go metša, ba ka thušwa ka pela go rarolla mathata ao. Nka rata go ruta ka ga mabokgoni a phepo ya bana ba ka fase ga ngwaga o tee. Lena le bana ba lena le ka mpha bohlatse bja bohlokwa kudu bjoo bo nka thušago go kwešiša gore bana ba go ba le mathata a phepo nka ba thuša bjang.

### KE KA BAKA LA ENG NNA LE NGWANA WA KA RE KGETHILWE?

Nka rata go mema bana bohle bao ba latelago kliniking ya tša hlwekišo:

- Bana bao bego le dikgedi tše tshela go iša go tse lesomepedi
- Ke Motswadi/Mohlokomedi ofe yo a kwešišago Seisemane
- Ke Motswadi/Mohlokomedi ofe yo a bego le mengwaga ya go feta ye masomeseswai

### RE KA DIRA ENG, GE RE KA TŠEA KAROLO?

Ke tlo botšiša ka ga wena le ka ga phepo ya ngwana wag ago. Ke tlo lebelela gare ga faele ya ngwana wag ago gore ke kgone go bona maemo a ngwana wa gago a HIV le gore o hlwekile na. Tseba gore ga se kgapeletšo go araba dipotšišo tše, ebile o ka se gapeletšwe. Ke tlo lekola mabokgoni a phepo ya ngwana wa gago gore ke kgone go bona ge ba na le mathata a go ja. Ge bana ba lena ba sa nyake ke ba fepa, ke tlo le kgopela gore lena le ba fepe, efela ke tlo le thusa go dira se gore re hwetše bohlatse bja nnete. Le amogetšwe go mpotšiša ge le nyaka dikeletšo.

### NA RE TLO HLOKA GO YA KAE LE GONA E TLO RE TŠEA NAKO YE KAAKANG?

Ke tlo le botšiša dipotšišo le go lekola phepo ya ngwana wa lena ge le sa eme klininking ya hlokomelo ya bana. Ge o nyaka go tšea karolo morago a gore ngwana wa gago a bone ngaka goba mooki, go dumeletšwe go dira seo, goba o ge o nyaka go tlogela sekgoba boemalaene , re ka kgona go lekola mabokgoni a go ja a ngwana wa gago mo kamoreng ye nngwe gauswi le kliniki ya hlokomelo ya bana. Se se tlo tšea metsotso ye masomepedi.

### NA KE DIKOTSI DIFE TŠEO DI KA HLAGALELAGO NGWANA WA KA, KE TLO KGOLEGA BJANG GE KE TŠEA KAROLO?

Wena le ngwana wa gago le ka se gobatšwe, dikarolo ka moka tša thuto di bolokegile. O ka se lefelwe ge o ka kgetha go tšea karolo; efela ge eba ngwana wa gago o na le mathata a phepo, ke tlo go botša gore go ye kae gore o hwetše thušo. Ge ke fetša go lekola phepo ya ngwana wa gago, o tlo šala le dijo tšeo ke bego ke di šomiša go fepa ngwana wa gago (yoghurt, biscuits or dried fruit).

### NA NNA LE NGWANA WA KA RE SWANETŠE GO TŠEA KAROLO, RE KA KGONA GO TSWA MO THUTONG YE?

Go ka kgetha ge eba wena le ngwana wag ago le ka rata go tšea karolo mo thutong goba go se tšea karolo. Go ka emiša go tšea karolo nako ye nngwe le ye nngwe ye go ratago ebile ga go na selo se sebe seo tlogo diragalela wena le ngwana wag ago. Tirelo ya gago kliniking ya hlokomelo ya bana e tla no tšwela pele go no swana le ka mehla le ge go ka tšea sephetho sa go se tšee karolo mo thutong ye.

### NA KABO YA DIPOELO E TLO BA BJANG?

Dipoelo go tšwa thutong ye, di išwa kgorong ya Bolela-Polelo Phatholotsi le Theeletšo kua Yunibesithi ya Pitori tekanong ya mengwaga ye masomehlano ebile di tlo šomišwa taodišong ya saense le pampering ya ka ya tikiri. Taodišo ye e bewa pepeneng gore bašomi ba bangwe ba tša maphelo ba kgone go e šomiša nyakišišong tše dingwe. Ge o nyaka kakaretšo ya poelo go tšwa mo thutong ye, ke tla gatiša pampišana yeo gomme ka go fa ya gago morago ga porojeke ye.

### NA DITABA TŠA RENA DI BOLOKEGILE?

Ditaba tša lena ka moka ga tšona, tšeo ke tlabego ke le botšiša, ke sephiri sa ka le lena, nka se botse motho (maina a lena a ka se somišwe, ka fao ga o na motho yoo a tlogo le tseba) ge ke tšweletša dipoelo. Ke nna le bahlahli ba ka fela bao re tlogo bona ditaba tša lena tša bomotho.

### **DINOMORO TŠA MOGALA LE EMEILE**

Ge o na le dipotšišo ka ga se sengwe le se sengwe mabapi le thuto ye, ke kgopela o founele/letšetše nna goba bahlahli ba ka:

Ms Mishkaya Lalbahadur: 072 027 1292 / mishkaya@gmail.com Mrs Esedra Krüger: 012 420 4910 / esedra.krüger@up.ac.za Professor Alta Kritzinger: 012 420 2949 / alta.kritzinger@up.ac.za

Ge o na le dipotšišo tše dingwe mabapi le nyakišišo ye, lokologa go mphounela, nna Mishkaya Lalbahadur, mo go 072 027 1292

Ge eba o na le kgahlego ebile o ka rata go tšea karolo mo nyakišišong ye, ke kgopela o saene foromo ya tumelo / ya go dumela

Egbellyslimper a.W.W

Wa lena

**Ms Mishkaya Lalbahadur** Moithuti wa go nyakišiša

**Mrs Esedra Krüger** Mohlahli wa nyakišišo Professor Alta Kritzinger Mohlahli wa nyakišišo

Dr J. van der Linde

Hlogo: Kgoro ya Bolela-Polelo Phatholotši le Theeletšo

### **TUMELELANO YE E NGWADILWEGO**

Nna ke netefatša gore ke tsebišitšwe ke Mishkaya Lalbahadur ka ga thuto ya go bitšwa "Feeding characteristics of HIV-exposed and HIV-unexposed infants" involves. Ke a kwešiša gore re ka se lefelwe ge re tšea karolo ebile rena le bana ba rena re bolokegile. Ke amogetše, ke badile ebile ke kwešišitše pampišana ya tumelelo ya Motswadi/Mohlokomedi. Ke filwe sebaka sa go botšiša dipotšišo ebile ke thabile gore dipotšišo tšeo di arabilwe ka moka. Ke a kwešiša gore ke botšišwa dipotšišo tša nnyane fela ebile go tlo dirwa teko ya phepo godimo ga ngwana wa ka. Bohlatse bjo bo tlo somiswa faeleng ya kliniki ya ngwana wa ka. Ke a kwešiša gore ke lokologile go tšea karolo ebile, ge ke sa nyake go tšea karolo, se se ka se fetole kalafo ya ka le ngwana. Bohlatse bja rena bo tlo šireletšwa ya ba sephiri ka di nako ka moka ebile ga go na motho yo a tlogo tseba ka taba tse.ke a kwesisa gore nka tlogela go tšea karolo nako ye nngwe le ye nngwe ge ke rata, ebile se se ka se fetole kalafo ya ngwana w aka. Ke a tseba gore ke swanetše ke founele mang ge ke na le dipotšišo. Nna le ngwana wa ka re dumela go tšea karolo mo thutong ye.

Leina la Motswadi/Mohlokomedi:	_
Mosaeno wa Motswadi/Mohlokomedi:	
Leina la Monyakišiši: Ms Mishkaya Lalbahadur	
Mosaeno wa Monyakišiši:	
Leina la hlatse:	
Mosaeno wa hlatse:	
Letšatšikgwedi:	

## TUMELELO KA MOTSWADI/MOHLOKOMEDI KA GO BOLELA (ge motswadi a sa kgone go bala le go ngwala)

Nna, mosaeni, Ms Mishkaya Lalbahadur, goba toloki, ke badile ebile ke hlathollotse ka botlalo go motswadi/mohlokomedi, leina ke
Mosaeno wa Motswadi/Mohlokomedi:
Leina la Monyakišiši: Ms Mishkaya Lalbahadur
Mosaeno wa Monyakišiši:
Leina la toloki:

Mosaeno wa toloki:

Mosaeno wa hlatse: \_\_\_\_\_\_

Letšatšikgwedi: \_\_\_\_\_

Leina la hlatse: \_\_\_\_

# APPENDIX F: Parent/caregiver information sheet and informed consent form (isiZulu)



### **Faculty of Humanities**

Department of Speech-Language Pathology and Audiology

#### IPHEJI LEMINININGWANE YOMZALI/UMNAKEKELI WENGANE KANYE NEMVUME.

Isihloko socwaningo:izidlela zokupha ingane ukudla ezisemathubeni okutheleleka ngegciwane lesandulela sengculaza nezingekho emathubeni okutheleleka ngegciwane.

### **ISINGENISO**

Igama lam ngiwu Mishkaya Lalbahadur, ngenza ucwaningo malunga neziqu zenfundo yam ephakeme kuhlelo lokufunda ngendalo,imvelaphi,inqubekela phambili, Kanye nembangele yezifo kumkhakha wezokukhuluma nolwimi. Ngingathanda ukunimema kanye nengane yenu ukuba nibe ingxenye yaloncwaningo. Ucwaningo lwami luhlose ukuhlola ukuba igciwane lengculazi lingaba namthelela muni ekunceliseni noma ukudlisa ingane yakho.

Lolulwazi olubhalwe ngezansi luzokusiza ukuqonda kabanzi ngokuzokwenzeka kulocwaningo nokuzokusiza ukuba ukwazi ukuthatha isinqumo ngokuzibandakanya nalolucwaningo. Uma unemibuzo engacaciselekile kulombhalo,ngicele uthintane nami.

Kulolucwaningo ngizodinga izingane ezazalwa ngomama abanesandulela segciwane lengculaza Kanye nalabo abazalwa ngomama abangenaso isandulele segciwane lengculaza.

### IYINI INTLOSO YALOLUCWANINGO

Ukuncelisa okanye ukudlisa untwana wakho kungayishintsha indlela akhula ngayo. Kunabantwana abazalwa ngomama abanesandulela gculaza kodwa bakwazi ukuvikeleka kuleligciwane. Asinaso isiqiniseko sokuthi kungenzeka babe nezingqinamba ekudleni, ekuginyeni nasekukhuleni kwabo.uma labantwana benezinezinkinga zokudla, nokugwinya bangakwazi ukusizakala ngokushehsa. Ngingathanda ukufunda ngokuncelisa/ukudlisa kwabantwana abangaphantsi konyaka.

Nginethemba lokuba wena nomntwana wakho ningaba usizo olukhulu ekuthuthukiseni ulwazi olungaba usizo ngikwazi ukugonda ukuba bangasizakala kanjani abantwana abanalenkinga.

Fakulteit Geesteswetenskappe Departement Spraak-Taalpatologie en Oudiologie Lefapha la Bomotho

Kgoro ya Phatholotši ya Polelo-Maleme le Go kwa

### KUNGANI KUKHETHWE MINA NENGANE YAMI

Ngithand ukumema bonke abantwana abasemitholampilo abanalokhu okulandelayo:

- Abaphakathi kwezinyanga eziyisithupha kuya kweziyishumi nambili bezelwe
- Abazali okanye abanakekeli babo abaluqondayo ulwimi lwesingisi
- Abanabazali /abanakekeli abangaphezu kweminyaka eyishumi nesishiyagalo mbili

### YINI ELINDELEKE KITHI UMA SIZIBANDAKANYA NALOLUCWANINGO

Uzobuzwa imibuzo malunga nawe Kanye nokuncelisa/ukudlisa umntwana wakho, nefayela lomntwana wakho liyobukwa ukuthola ulwazi nesimo sakhe ndegciwane lesandulela gculaza Kanye nendlela akhula ngayo. Uma kungakuphathi kahle ukuphendula lemibuzo, awuphoqelekile futhi awusoze waphoqwa. Kuyobukwa nendlela oncelisa/odlisa ngayo umntwana wakho, ukuthi kunawuphi umthelela uma idla. Uma umntwana wakho enqaba ukuceliswa/ukudliswa imina, ngiyocela kube uwe omncelisayo/dlisayo, kodwa ngiyobe ngiseduze kwakho ukukusiza ukuze sithole iziphumo ezikahle. Uvumelekile ukungibuza imibuzo noma ufuna ukululwekwa ngokuthile.

### MHLAWUMBE EZIPNI IZINDAWO OKODINGEKA SIYE KUZO FUTHI KOTHATHA ISIKHATHI ESINGAKANANI?

Uyoqalwa ngokubuzwa imibuzo kuhlolwe nendlela oncelisa/odlisa ngayo umntwana wakho, ngesikhathi usalindile emtholampilo wezingane. Uma ufisa ukuba yingxenye yalokho emva kokuthi ingane ibonwe udokotela okanye umhlengikazi,okanye uma ufuna ukugcina indawo yakho emigceni yokulindela, thina sibe siqhubeka nokuhlola indlela encela/edla ngayo ingane yakho kwindlu esecaleni maduze nomtholampile wezingane. Kuyothatha imizuzu emgamashumi amabili nje kuphela.

### YINI ENGABA INGOZI KUMNTWANA WAM NGALOLUCWANINGO FUTHI NGABE KUKHONA ESIYOKUZUZA NGOKUBA INGXENYE

Akukho okuyongakuphathi kahle wena nomntwana wakho; zonke izintlelo zocwaningo ziphephile.

Akukho oyokukhokhelwa ngokuba ingxenye yalocwaningo; uma umntwana wakho inezinkinga ngokuncela/ukudla kwakhe ,uyolulekwa ngezindawo ongaya kuzo ukuyothola isizo. Uma sengiqeda ukuhlola indlela umntwana wakho adla ngayo, konke ukudla okuyobe kusetshenziswa kumntwana wakho ngesikhathi socwaningo uvumelekile ukukugcina(iyogathi, amabhisikidi nezithelo ezomisiwe).

### NGINGAKWAZI MINA NOMNTWANA WAMI UKUHOXA KUCWANINGO?

Ungakwazi ukukhetha ukuba wena nomntwana wakho nizibandakanye kulolucwaningo noma cha futhi unelungelo lokunqaba. Ungakwazi ukuhoxa ngisho noma ucwaningo seluqalile, akukho okubi okuyokwenzeka kuwe nomntwana wakho. Usizo oluthola emtholaphilo wabantwana luyoqhubeka njengenjwayelo noma ngabe uthathe esiphi isingumo.

### **IZIPHUMO ZIYOKWAZISWA KANJANI?**

Iziphumo zocwaningo ziyogcinwa Kumnyango wezokufunda ngezolwimi nokukhuluma enyuvesi yase Pitoli iminyaka eyishumi nesihlanu,futhi iyosetshenziswa kushicilelo lezobuchwepheshe bososayensi nemiphumela yeziqu zami. Iyophinde itholakale kubazebenzi abaqeqeshiwe kwezempilo kuhlelo lwezokufunda kabanzi ngokukhuluma nangolwimi futhi ingasetshenziswa uma kwenziwa olunye ucwaningo.uma ungathanda ukuthola imiphumela yalolucwaningo, ngingakwenzela umfanekiso weziphumo uma loluhlelo seluqediwe.

### IYOQINISEKISWA KANJANI IMIPHUMELA EYIMFIHLO

Yonke imininingwane yakho kumqulu wemimizo oyobuzwa yona, Kanye nemiphumela malunga nokuhlolwa kwendlela umntwana wakho adla ngayo kuyogcinwa kuyimfihlo (ngeke lisetshenziswe igama lakho ngakho akukho noyedwa oyokwazi ukuba ubuyingxenye yocwaningo) kwimininingwane yemiphumela. Umuntu oyoba nelungelo lokubona imininingwane yakho imina Kanye nomphathi wami.

### **IMINININGWANE YOKUXHUMANA**

Uma unemibuzo okanye udinga ukwazi kabanzi ngokuzokwenzeka kulolucwaningo, ngicela uxhumane name okanye umphathi wami.

Ms Mishkaya Lalbahadur: 072 027 1292 / mishkayal@gmail.com

Mrs Esedra Krüger: 012 420 4910 / <a href="mailto:esedra.kruger@up.ac.za">esedra.kruger@up.ac.za</a>

Professor Alta Kritzinger: 012 420 2949 / alta.kritzinger@up.ac.za

Uma unemibuzo malunga nalolucwaningo,ungafonela mina, Ms Mishkaya Lalbahadur, at 072 027

1292.

Uma ufisa ukuba ingxenye yalolucwaningo ngicela usayine ifomu eliyisivumelwano elishuthekiwe.

Ozithobile

Ms Mishkaya Lalbahadur

Mrs Esedra Krüger

**Professor Alta Kritzinger** 

Student Researcher

Research Supervisor

Research Supervisor

Dr J. van der Linde

Head: Department of Speech-Language Pathology and Audiology

### **IFOMU LESIVUMELWANO**

Ngiyavuma ukuba u Ms Mishhkaya Lalbahagur ungazisile malunga nocwaningo ngezindlela, nemithelela yokuncelisa/ukudlisa komntwana osemathubeni okutheleleka ngesandulela ngculaza nalowo onganamathuba okutheleleka. Ngiyaqonda ukuthi ayikho inkokhelo eyokwenziwa ngokuba ingxenye yaloluncwaningo, nangokuthi akukho okungaba ingozi kimi okanye kumntwana wami. Ngiyitholile futhi ngayifunda ngayiqonda yonke imininingwane ebhaliwe Kanye ifomu lesivumelwano yomzali/umnakekeli womntwana.ngisinikiwe isikhathi esanele sokubuza imibuzo futhi ngijabulile ukuthi iphendulwe yonke. Ngiyaqonda ukuba ngiyobuzwa imibuzo embalwa, nanokuthi umntwana wam uyokuba kuhlelo lokuhlolwa indlela adla/ancela ngayo. Imininingwane eyosetshenziswa iyothathwa kwi fayela lomntwana lasemtholampilo. Ngiyaqonda ukuba nginelungelo lokukhetha ukuzibandakanya nalolucwaningo. Uma ngikhethe ukungabi ingxenye yalo akukho okuyoshinstha kwimpatho phakathi kwami nomntwana wami. Ngiyaqonda ulwazi oluyotholakala emva kocwaningo luyongcinwa luyimfihlo ngasosonke isikhathi nanokuthi ankeke adalulwe amagama ethu uma sekushicilelwa imiphumela.futhi imininingwano iyogcinwa iphinde isetshenziswe kolunye ucwaningo.

Ngiyaqonda ukuba nginelungelo lukuhoxa kucwaningo noma kunini uma ngifuna, futhi loko ngeke kushintshe indlela aphathwa ngayo umntwana wami, ngiyazi ukuthi ubani ekumele ngixhumane naye uma nginemibuzo.

Ngiyavuma ukuba mina nomntwana wami sibe ingxenye yalolucwaningo.

Igama lomzali/umnakekeli:	(sicele uphilinte)
Isiginisha yomzali/umnakekeli:	
Igama lomcwaningi: Ms Mishkaya Lalbahadur	
Isiginisha yomcwaningi:	
Igama lofakazi:	(sicela uphilinte)
isiginisha lofakazi:	
Umhla:	
IFOMU LESIVUMELWANO	LOMZALI/UMNAKEKELI
(uma umzali/umnakekeli engakwa	azi ukufunda okanye ukubhala)
Mina Ms Mishkaya Lalbahadur okanye utolikala,ngiy malunga nocwaningo, nefomu lesivumelwano somza igamakubazali nezil nakokonke okuqulethwe ilolucwaningo engicele kulo nagokubi bocwaningo, nangezinto ezilindeleke ukub uyaqonda ukuba uvumelekile ukuhoxa kucwaningo rangeke kuphazamise indlela aphathwa ngayo yena isikhathi esanele sokubuza imibuzo,ugculisekile ngo Umhlanganyeli uyaqonda ukuba unelungelo lokuziba nalomcwaningo loko ngeke kuphazamise indlela aphaye.umhlanganyeli uvumelene nokusetshenziwa Kafuthi uyaqonda ukuba imininingwane yakhe iyogcinwa nobani uma benemibuzo Ngiyaqinisekisa ukuba un yocwaningo kanye nomntwana wakhe olubizwa. "Incabasemathubeni/abangekho emathubeni okutheleleki	ali/umnakekeli ————————————————————————————————————
Isiginisha yomzali/umnakekeli:	
Igama lomcwaningi: Ms Mishkaya Lalbahadur	
Isiginisha yomcwaningi:	
lgama likatolika:	(sicela uphilinte)
Isiginisha katolika:	
lgama lofakazi:	(sicela uphilinte)
Isiginisha yofakazi:	<u></u>
Umble	

### **APPENDIX G:** Data collection sheet

### **DATA COLLECTION SHEET**

The following information is to be obtained from the caregiver accompanying the infant on the day of the assessment or from the Road to Health Booklet.

	RTICIPANT IMBER:							
	te of feeding sessment:							
CA	REGIVER INFORM	ATION						
1.	Relation to the infant:	Mother	Mother Father					
		Family n	nember	ber Non-related caregiver of the infant				
2.	Age as of last birthday:							
3.	Age of the infant's mother as of her last birthday:							
4.	Home language:	English	Sepedi	IsiZulu	Afrikaans	IsiXhosa	IsiNdebele	
		Sesotho	Setswana	Siswati	Venda	Xitsonga	Other (specifiy)	
5.	Highest level of education of the	Unk	known	No formal schooling Below grade 8				
	caregiver:	Grad	de 8-10	Grade 11-12 Diploma/Degree				
		Postgraduate						
6.	Highest level of education of the	Unk	known	No formal schooling Below grade 8			w grade 8	
	infant's mother:	Grad	de 8-10	Grade 11-12 Diploma/Degree				
				Pos	tgraduate			
		Unk	known	No formal schooling Below grade 8				

7.	Highest level of education of the	Grade 8-10			11-12	Di	ploma/Degree		
	infant's father:			Postgr	aduate				
8.	Infant's primary caregiver during the	Mother	Fa	ather	Both parent		Grandparents		
	day:	Other family		oster	Daycar	е	Other		
		members	pa	rents			(specifiy)		
9.	Employment status	Employed Unemployed					ployed		
	of the primary caregiver:								
10.	Number of children								
	the infant's mother								
11	has given birth to: Number of living								
	children the mother								
	currently has:				ı				
12.	Complications surrounding	Ye	Yes No						
	pregnancy:	Specify complic	cation	(pre-,peri,	 , postnatal):				
	, ,	,							
13.	Mother's current HIV status:	Posi		Negative					
14.	ART was initiated:	Prior to		uring	Post- Not initi		Not initiated		
		pregnancy	pre	gnancy	pregnancy				
15.	Adherence to ART	Ye	es	No					
16	during pregnancy:  Is the mother	Yes (Specify ty	ma of Λ	ART plan No			lo.		
10.	currently taking	followed/type of	-	-	140				
	ARV's:	,,		,					
17.	Adherence to	Ye	es		No				
12	current ART plan: Area of residence of								
10.	the infant:								
PR	E- AND POST-NATA	L INFANT INFO	RMA	ΓΙΟΝ					
19.	Date of birth (dd/mm/yy)								
20.	Current age								
0.4	(months)	B. #	.1.						
21.	Gender	Ма	aie			⊢er	nale		
22.	Gestational age								
	(weeks)								

23. Manner of delivery:	Va	iginal	Caesa		area	n		Bree	ch	
24. Birth weight:										
25. Current weight/weight for height:										
26. Weight gain and weight for height:	Typical Atypical (specify reason)									
27. Infant's current HIV status		Positi	ve					Ne	egative	
28. Current receival of ARV treatment (infant)	Yes (specify type)								No	
29. Adherence to ART plan:	Yes								No	
30. Present reason for visit to the clinic	Immunisations Check-up doc						Other (specify)			
31.Immunisations obtained at:	Birth	6 weeks	w	10 reeks		4 6 eks months			9 months	12 months
32.General health of the infant	Appropriate					Ina	pprop	riat	e (specify	reason)
33. General development of the		Typic	al					A	typical	
infant (attainment of milestones)	Areas of	concerr	ı (sp	pecify):						
34. Presence of co- occurring conditions or syndromes	Yes (specify):								No	
INFANT FEEDING HIST	ORY									
35. Presence of feeding difficulties after birth	Yes  (e.g. latching/sucking on breast; falling asleep too soon at breast, vomiting, colicky)  Other (specify):								No	
36. Required stay in the hospital for an	Yes (specify reason):								No	

extended time after birth:										
37. Receival of tube feeds while in the	Yes					No				
hospital:	Orogastric Nasogastric									
	Duration:									
38. Breastfeeding received straight after birth:			es					N		
39. Previous receival of breastmilk (direct or expressed) and manner of receival:		Y	es			N	lo, fo	ormula	fee	eds via:
	Breast	Cı	up	В	ottle	Brea	ast	Cu	ıp	Bottle
40. Any difficulties with breastfeeding:		Y	es					No	0	
41. Type of feeding difficulty:	Latching onto nipple Sucking on bre					ast				
	Falling asleep too soon during feed  Other (specify					ecify):				
42. How long the infant has been breastfed for (months):						,				
43. Receival of both breast and formula milk:		Y	es					N	0	
44. How long the infant has been using a	Cup							Bot	tle	
cup/bottle & when it was first introduced:	Duration of use:			when oduced:		Duration of use:		f	Age when introduced:	
45. Other liquids the infant drinks apart from milk:	Water		Tea Fruit juice Co				Col	d drink	d drinks Other (specify)	
46. Food consistencies the infant currently	Pur	ee			Semi-	solids			S	olids
eats:	Biscuits/o	crack	ers		Liqu	uids		Ot	her	(specify)
47. Solid foods were first introduced at (age in months):										

48. First solid food that was introduced:						
49. Method used to introduce solids:	Caregiver's ha	Caregiver's hand Spoon Other (spec				
50. Duration of feeding sessions:	Duration:	Breast		Bottle		Solids
	5 – 10 min					
	15 – 20 min					
	25 – 30 min					
	Other (specify)					
51. Caregiver concerns about the infant's	Y	es			Ν	lo
feeding and/or weight gain	Concerns (spec	cify):				

### **APPENDIX H:** Schedule for Oral Motor Assessment (scoring sheets)

## **SOMA OMC** category: purée

Name:	Examiner:	
Date of birth:	Diagnosis:	***************************************
Date of assessment:	0,000	
Age:		
Body position:		
Support required:	Head position:	

	Purée		
Fromage fra	s Mousse Puréed fruit Other (Circl	e choice)	
	Non-rateable	Rate	able
R	efused Omitted Not observed	Yes	No
React I	Head orientation to spoon	у	n
Sequence 1	Smooth rhythmic sequence		n
Lip I	Lower lip draws inwards around spoon	у	n
Lip 2	Upper lip removes food from spoon	у	n
Lip 3	Lower/upper lip assists in cleaning		n
Lip	Lower lip active during suck/munch/chew		n
Tongue II	Consistent/considerable protrusion	у	n
Tongue 12	Protrusion beyond incisors		n
law I	Graded jaw opening		n
	Sum of shaded boxes	-	
Cutting score	: > 3 indicates oral motor dysfunction < 3 normal oral motor function		

## **SOMA OMC** category: semi-solids

Name:	Examiner:
Date of birth:	Diagnosis:
Date of assessment:	
Age:	
Body position:	
Support required:	Head position:

	Semi-solids		
Peas Baked beans Cottage cheese Other (Circle choice)			
	Non-rateable Rateable		
Refused Omitted Not observed Yes		No	
Drool I Consistent/considerable drooling y n			n
Sequence I	e I Smooth rhythmic sequence y n		n
Initiation I	Sequence initiated within 2 seconds		n
Lip 13	Lips closed during swallow y		n
Jaw I	aw I Graded jaw opening		n
Jaw 2	Internal jaw stabilisation y		n
Jaw 3	w 3 External jaw stabilisation required 100%		n
Jaw 10	Associated jaw movements		n
	Sum of shaded boxes		
Cutting score	: > 4 indicates oral motor dysfunction	······································	
	< 4 indicates normal oral motor function		

## **SOMA OMC** category: solids



Name:	Examiner:
Date of birth:	Diagnosis:
Date of assessment:	
Age:	
Body position:	
Support required:	Head position:

Solids			
Potato salad	Fruit salad Other (Circle choice)		
Non-rateable		Rateable	
Refused Omitted Not observed		Yes	No
Food loss I	None/trivial	у	n
Drool I	Consistent/considerable drooling		n
Sequence I	Smooth rhythmic sequence	у	n
Lip I	Lower lip draws inwards around spoon	у	n
Lip 2	Upper lip removes food from spoon		n
Lip 4	Lower lip behind upper teeth/sucking		n
Lip I I	Lower lip active during suck/munch/chew		n
Tongue 10	10 Transient/minimal tongue protrusion		n
Jaw I	Graded jaw opening		n
	Sum of shaded boxes		
Cutting score	: > 4 indicates oral motor dysfunction < 4 indicates normal oral motor function		

## **SOMA OMC** category: cracker

Name:	Examiner:
Date of birth:	Diagnosis:
Date of assessment:	
Age:	
Body position:	
Support required:	Head position:

	Cracker		
Non-rateable Rateab		eable	
Refused	Omitted Not observed	Yes	No
Food loss 1	Profuse/marked food loss	у	n
Drool I	Profuse/marked drooling	у	n
Initiation I	Sequence initiated within 2 seconds	у	n
Lip 4	Lower lip behind upper teeth to suck	у	n
Lip 7	Lips close around stimulus during bite	у	n
Lip 9	Lips close intermittently during suck/munch/chew	у	n
Tongue 10	Transient minimal tongue protrusion	у	n
Tongue 11	Considerable/consistent tongue protrusion	у	n
Tongue 12	Protrusion beyond incisors	у	n
Tongue 13	Tongue 13 Protrusion beyond lips		n
Jaw 2	Internal jaw stabilisation established	у	n
Jaw 3	Variable stabilisation (not fully established)	у	n
Jaw 4 External stabilisation required y		n	
Jaw 5 Vertical movements y n		n	
Jaw 8 Wide vertical excursions y n		n	
Jaw 9 Small vertical excursions y n		n	
Jaw 11	Associated head movements to bite	у	n
Jaw 12	Uses fingers to transfer food	у	n
Swallow 9	Gagging	у	n
Bite 5	Controlled sustained bite	у	n
Bite 8	Graded jaw opening	у	n
Bite 12	Mouthes cracker only	у	n
Sum of shaded boxes			
Cutting scor	e: > 9 indicates oral motor dysfunction		
	< 9 indicates normal oral motor function		

## **SOMA OMC** category: bottle

Name:	Examiner:
Date of birth:	Diagnosis:
Date of assessment:	_
Age:	
Body position:	
Support required:	Head position:

	Bottle			
Indicate liqui	d administered:			
	Non-rateable		Rateable	
Refused	Omitted Not observed	Yes	No	
React 2	Anticipatory mouth opening	у	n	
React 4	No liquid enters mouth	у	n	
Accept 2	Accepts liquid within 2 seconds	у	n	
Lip 3	Upper lip firmly seals around teat	у	n	
Lip 5	Intermittent/incomplete upper lip contact/seal	У	n	
Lip 6	Intermittent/incomplete upper lip contact/seal	У	n	
Lip 7	Lip closure during swallow	у	n	
Jaw I	Small vertical movements	у	n	
Sequence I	Smooth rhythmic sequence	у	n	
	Sum of shaded boxes			
Cutting score	e: > 5 indicates oral motor dysfunction < 5 indicates normal oral motor function			

## **SOMA OMC** category: trainer cup



Name:	Examiner:
Date of birth:	Diagnosis:
Date of assessment:	_
Age:	
Body position:	
Support required:	Head position:

	Trainer cup		
Indicate liqui	d administered:		
	Non-rateable	Rateable	
Refused	Omitted Not observed	Yes	No
Liquid loss	Profuse/marked liquid loss	у	n
Sequence 2	Panic reactions when liquid presented	у	n
Sequence 3	Choking	у	n
Tongue 10	Tongue thrust	у	n
Tongue 11	Asymmetry	у	n
Jaw I	Small vertical movements	у	n
Jaw 6	Jaw alignment during drinking	у	n
Jaw 10	External jaw stabilisation required 100%	у	n
Jaw 12	Internal stabilisation	у	n
Swallow I	Jaw alignment	у	n
Swallow 4	Panic reactions during/after swallow	у	n
Swallow 5	No swallow observed	у	n
Swallow 6	Uses gravity, e.g. head extension	у	n
Swallow 7	Numerous attempts to initiate swallow	у	n
-1000	Sum of shaded boxes		
Cutting score	: > 5 indicates oral motor dysfunction		
	< 5 indicates normal oral motor function		

## **SOMA OMC** category: cup

Name:	Examiner:
Date of birth:	Diagnosis:
Date of assessment:	
Age:	
Body position:	
Support required:	Head position:

		Cup			
Indicate liquid administered:					
Non-rateable		Rateable			
Refused	Omitted	Not observed	Yes	No	
Accept 2	Accepts wit	hin 2 seconds	у	n	
Sequencing 2	Panic reactions when liquid placed in mouth		y	n	
Sequencing 3	Choking		У	n	
Liquid loss	Profuse/marked liquid loss		у	n	
Tongue 10	Tongue thru	ust	у	n	
Tongue II	Asymmetry		у	n	
Jaw I	Small vertic	al movements	y	n	
Jaw 4	Jaw clenchii	ng	у	n	
Swallow 9	Gagging		у	n	
	1	Sum of shaded boxes			
Cutting score		es oral motor dysfunction es normal oral motor function			

### **APPENDIX I:** Speech and language stimulation handout (6-9 months)

# Activities to stimulate speech and language: 6-9 months Meralokwana go hlohleletsa, puo le puo le leleme 6-9 months

- 1. Make silly syllables. When facing your baby say, "ahboo, babo, ooh bee" or other syllables.
  - Dira mantšu a go silikiša, ge o lebeletše ngwaka wa gogo ere "ahboo, babo, vow bee" goba montšu a mangwe.
- 2. If your baby makes a sound or babbles different syllables, repeat them as reinforcement.
  - Ge a dira medumo goba o bolela mantšu a fafanego o boeletše go a gatelela.
- 3. Let your child experience music often play a variety of music (TV, radio, tapes and match his response).
  - Dira gore ngwana a tlwaele mmino, mo ralokele mmino wa go fapana-fapana (television, radio, teipi).
- 4. Hold the mirror that he can see his reflection and say, "I see...; Where is...; Find...; Look at...".
  - Swara seipone fa pele gagwe go ippna, ore bona, wa ipona, ipone.
- 5. Listen to the baby's vocalisations while he is in his cot, chair, on the carpet. When he combines different syllables be sure to reinforce the behaviour by praising, touching and repeating the syllable immediately after they are said. Utwella polelo ya ngwana ge a le ka mmetong wa gagwe goba setulong goba a dutše fase, ge a kopanya maletere a a fapanego, mohlohleletse ka go mo tumiša o moswase o boletše polelelo ya gagwe ge a fetsa.
- 6. Pair sound with a motor action, e.g. bye (wave), soo big (raise arms), mmm good (rub tummy), pat-a-cake (clapping), oops (falling).

  Dira medumo gomme a go ekiše mohlala (bye-bye) o mo supetše ka lesogo godira (bye-bye) emisa letsogo (raise arms) phaphatha metsogo, forohla mala.
- 7. Play finger games, e.g. "This little piggy..." Let him say "wee wee wee". Raloka moralokwana ya diatla.
- 8. Use words and sounds that go naturally with an activity, e.g. "zoom, boom". Dira mantšu le medimo yeo e sepelelanago ka hlago.
- 9. Play games like peek-a-boo and exaggerate the pattern when saying it. Raloka meralokwa yago hlaletša.
- 10. Let him imitate sounds such as tongue, click, cough, ppp, ah, lip smacking. Dira gore a ekiše medumo ya go swana le lelema, go gothola.
- 11. Let him imitate gestures and facial expressions, e.g. sniff a flower, raise arms above head, wave, point, lick lips, bang blocks together, hand on mouth.

  Dira gore a ekiše dika tsa mmele le sepahlego, e.g. nkgehlele letšoba, emisa matsogo godimo ga hlogo, supa, latšwa, seatla molomong.

Compiled by B. Louw and A. Kritzinger, University of Pretoria

### **APPENDIX J:** Speech and language stimulation handout (9-12 months)

### Activities to stimulate speech and language: 9-12 months

### Meralokwana yago hlohleletsa, puo le leleme le leleme 9-12 months

- 1. When he is babbling, choose a sound that he has made and say it yourself and laugh. Sometimes he will laugh, too, and say the sound again. Repeat this several times. Ge a buduletša, kgetha modumo oo a o dirago gomme o o dire a sege ka nako e nnawe o tla tshega le yena, gomme a dire modumo o gape. Busuletša gangwe le gangwe.
- 2. Choose a simple sound which you have not heard him make before and see if he imitates the new sound.
  - Kgetha modungwana yoo a sekego a o dira, o tle o bone gore a ka o dira.
- 3. Wave and say "bye-bye". Motataise "bye-bye".
- 4. Say "hello" when someone comes into the house and to him when you see him. Modumediše o re "hello" ge motho a tsena ka ntlong le ge o mmona.
- 5. Using a toy phone, pick it up and say "hi". Encourage him to imitate you. Somiša founo ya go, bapala, e kuke ore "hi" mo hlohletše go go ekiša.
- 6. Play "bouncy-bouncy" by bouncing him up and down as you sit and he will imitate. Say the words; he will soon bounce simply on hearing the words.

  Moralokiše, o mo iša godimo le fese, o mo hlaletša o dirisa mafoko o tra bona a go ekiša.
- 7. Pretend to drink from a toy cup; give him the cup to drink. Dira o kare o nwa ka komiking yago o mofe a nwe.
- 8. Hold a block in each hand and hit them together. Let him try. Swara diboloko matsogong a mabedi gomme o di thulonganye, o mofe le yena a leke.
- 9. Put some blocks in a container and shake it to make noise. Lokela boloka ka gore ga thini o sikinye go dira modumo.
- 10. Play peek-a-boo. Show him how to hide behind his hands.

  Mmontše go raloka meralokwang ya go iphihla, o mmitše gore e yena a iphihle.
- 11. Show him how to make smacking noises and then kiss him on the cheek. Put your cheek against his mouth and see if he kisses your cheek.

  Mošuwe lerameng gomme o bone gore le yena o tla go suna lerameng.
- 12. Play "this little piggy went to market" with his toes. Let him have turn pointing to your toes. Molaetše go ralokiša menwana ya maoto.
- 13. Put your finger over your mouth and say <u>shhh</u>. When he is listening, tell him to listen for some noise around the house, such as somebody coming in the door, the TV, water running, the dog barking, kids yelling outside.

  Beya mongwana molomong go mo didimatše, mmotse go theeletša medumo ka ngwakong. A theeletse modumo wa mpsa yeo e gobang.
- 14. Have toys that require pulling a string to move them. Many will make a noise, such as a duck saying "Quack-Quack". Encourage him to make the sound while pulling.

  Dinra di papadišane gomme o di swaraganye ka thapo tše dingwe di tlo dira lešata go swana le pidipidi "gwa gwa".

Compiled by B. Louw and A. Kritzinger, University of Pretoria

# APPENDIX K: Proof of article submission to the *African Journal of Primary*Health Care and Family Medicine

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