

**Percutaneous Endoscopic Gastrostomy feeding decisions made by caregivers for children with Cerebral Palsy who experience feeding and swallowing difficulties in a public health care setting in Pietermaritzburg, South Africa: An Exploratory Study.**

By  
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## DECLARATION

As the candidate's Supervisor I agree/do not agree to the submission of this dissertation.

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As the candidate's Co-Supervisor I agree/do not agree to the submission of this dissertation.

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### ABBREVIATIONS:

NDD	Neuro-developmental Disabilities
CP	Cerebral Palsy
PEG	Percutaneous Endoscopic Gastrostomy
MDT	Multi-disciplinary Team
GORD	Gastro-oesophageal Reflux Disorder
TB	Tuberculosis
FTT	Failure to thrive
NGT	Nasogastric Tube

### REFERENCING STYLE:

The referencing style used for Chapters' 1, 3 4 and 5 is presented as per the American Psychological Association (APA), 6<sup>th</sup> edition (2010). This referencing style is required as per the submission guidelines from the University of KwaZulu-Natal.

Chapter 2 reflects the manuscript for publication to the Health Expectations Journal and is presented in accordance with the American Medical Association (AMA), 10<sup>th</sup> edition (2007), guidelines. This referencing style was adopted as it is the required format by the Journal for manuscript submission.

## **ABSTRACT**

### **Background**

In South Africa there are no clear guidelines regarding how clinical decisions are made for children with Cerebral Palsy (CP) who require enteral feeds. The incidence of children with CP in KwaZulu-Natal, South Africa is considered the highest (approximately 10:1000 live births under 10 years of age), when compared to the global average (approximately 2:1000 live births). Children with CP are known to present with an increased risk of being malnourished and present with a greater aspiration risk. Chronic malnourishment and aspiration, without timely and effective management can have fatal implications. Enteral feeding options are typically used as a means to ensure that these children are able to maintain safe and adequate nutrition, and are described as supplemental tube feeds that are used for patients unable to maintain their nutritional needs orally. While numerous studies have been conducted exploring clinical decision making in the adult population, there is currently a lack of available research investigating this phenomenon in the paediatric population and more specifically in children with CP. This study thus sought to explore how clinical decisions are made for children with CP who required Percutaneous Endoscopic Gastrostomy (PEG) placements secondary to their feeding difficulties.

### **Objectives**

The study objectives included: (i) Identifying significant individuals involved in the PEG feeding decision making process and their respective roles; (ii) Identifying the factors that affect the decision making process for caregivers of children with CP who require PEG placements and (iii) Exploring the views regarding the decision making process for caregivers' of children with CP with feeding and swallowing difficulties who required PEG placements.

### **Research Design**

This research study is a qualitative explorative study. A single-case research design was used.

### **Setting and Participants**

The research study was conducted at Greys Hospital in the Pietermaritzburg area, KwaZulu-Natal. Caregivers of children with CP who required PEG feeds were selected as participants in this study. Purposive sampling was used to recruit participants and were selected



from the existing population group seen at the hospital. Two participants were selected for the pilot study and two participants were selected for the main study.

### **Data Analysis**

All digital data, from the interviews conducted, was transcribed verbatim and the data was thematically analysed. The transcribed data was coded to: (i) display all the identified themes; (ii) question and verify the data obtained and begin to develop hypotheses from the themes identified and (iii) be able to filter the data obtained and categorize the primary emerging themes. The data was presented in text form with supporting quotes in keeping with the study objectives.

### **Results and Discussion**

Significant individuals involved included doctors, speech therapists, the caregivers' family (familial influence) and God (religious influence). From the excerpts obtained, doctors appeared to be prioritized as key clinical decision makers for the caregivers, who were essentially passive recipients of the decisions made. Interestingly the caregivers appeared to allow for this "paternalistic approach" and actually appeared to endorse it. The distinct power imbalance in the public health care sector in South Africa is still evident despite the laws and policies being developed to discourage this. Factors identified included four primary categories, namely: physiological factors; nutritional factors; financial factors and environmental factors. The caregivers interviewed seem to emphasize either the physiological and/or nutritional factors secondary to the decision to ultimately place a PEG for their child. While environmental and financial factors were also highlighted, they appear to be referenced post the PEG placement and thus not considered prior to the child's surgery. However, both factors do speak to the extrinsic challenges experienced by the caregivers when caring for their children and should thus be adequately explored. Two views were ultimately identified and focussed on the caregivers' intrinsic beliefs regarding the PEG feeding tube and personal feelings experienced. However, here it should be noted that both views were referenced post PEG placement and thus while inferences may be made regarding the caregivers mind-set during the PEG decision making process, it was not explicitly stated as a contributing aspect.

## **Implications**

The results from this study has implications for: (i) clinical decision making and improved management within the paediatric population; (ii) curriculum development at Higher Education Training facilities and (iii) institutional policy changes and/or development.

## **Conclusion**

Clinical decisions are made unilaterally for children with CP who required PEG placements, by health care professionals. Caregivers allowed for this, and considered themselves as active participants within this paternalistic “doctor knows best” health care approach. Physiological and nutritional factors were viewed as chief motivators when considering how clinical decisions were made. These factors serve to appease the agenda of health care professionals primarily and given the novelty of the PEG feeding tube for the caregivers, ultimately facilitated a dependency on the opinions of the health care professionals. Caregivers interviewed also highlighted other significant individuals, factors and views that were not considered prior to the PEG decision but rather acted to speak to the overall mind-set of the caregivers and the extrinsic and intrinsic challenges they experience, which is not being adequately considered by health care professionals. Unless this changes, there will be an increase in the management required for the long term care of these children and a greater dependency on the already resource constrained public health care sector. Greater initiatives are required to adequately educate both caregivers and health care professionals regarding collaborative and inclusive clinical decision making so that more efficient and sustainable decisions may be made.

## **Keywords**

Clinical decision making; Percutaneous Endoscopic Gastrostomy (PEG); Cerebral Palsy (CP).

## CHAPTER 1

### 1.1. Introduction

Globally up to 90 % of children with neuro-developmental disabilities (NDD) present with feeding and swallowing difficulties (Rempel, Colwell & Nelson, 1988, as cited in Schwarz, 2003), many of whom are often malnourished, as reported in several articles (Johnson et al., 2017; Scarpatto et al., 2017; Marchand, 2009). Where oral feeding is not possible, enteral feeding options are usually required to adequately and safely ensure that these children meet their nutritional goals (Marchand, 2009). Enteral feeds are generally used for patients who are unable to adequately maintain their nutrition orally. Common examples of enteral feeding options used include nasogastric tube (NGT) feeds and percutaneous endoscopic gastrostomy (PEG) feeding tubes.

Children with cerebral palsy (CP) are a particular group highlighted under the NDD spectrum of disorders, who present with a greater aspiration and malnutrition risk (Clancy & Hustad, 2011). Aspiration is defined as the inhalation of oropharyngeal and/or gastric material into the larynx and lower respiratory tract (Marik, 2001; Irwin 1999; Cassiere & Niederman, 1998), which if left untreated can develop into an aspiration pneumonia and in some cases, death. Children with CP are categorized as malnourished when they are unable to safely feed for a prescribed period and/or present with high nutrient needs (Kuperminc & Stevenson, 2008)

In South Africa no statistics are currently available regarding the number of children with NDD who present with feeding and swallowing difficulties. In fact, there are no definitive statistics available regarding the total number of children with NDD living in South Africa currently. This is primarily due to the lack of a standardized measuring tool with clear and definitive definitions for the varying diagnoses and methods of data collection to identify these children (DSD, DWCPD & UNICEF, 2012). When considering that children diagnosed with CP in KwaZulu-Natal, South Africa, constitute the highest incidence of the disorder as compared to the global prevalence, the lack of definitive statistics is particularly concerning (Levin, 2006). Globally the incidence of CP ranges between 1.5 to more than 4:1000 live births and the overall prevalence is thought to be approximately 2:1000 live births (Stavsky et al., 2017; Oskoui, Coutinho, Dykeman, Jetté & Pringsheim, 2013; Johnson, 2002). In KwaZulu-Natal, the incidence of CP is thought to be about 10:1000 children under 10 years of age (Couper, 2002, as cited in Levin, 2006).

This chapter presents the background to the study, which addresses issues related to clinical decision making when considering PEG feeding for children with CP. A particular focus here is understanding how clinical decision making is defined in the existing literature and how it is implemented by different health care professionals. It then outlines the rationale and significance of the study, specifically in the public health care sector in Pietermaritzburg, South Africa. However, the findings from the study also has implications for improved patient management in other resource constrained contexts. The study aim, objectives, outline and chapter one synthesis will also be provided.

## **1.2. Background and context**

Clinical decision making may be defined as the process whereby health care professionals use clinical and biomedical knowledge, consider risk-benefits, probabilities, various outcomes and problem-solve within dynamic contexts to make choices to identify an evidence-based course of action (Tiffen, Corbridge & Slimmer, 2014; Hajjaj, Salek, Basra & Finlay, 2010; Smith, Higgs & Ellis, 2008). Essentially it is a tool used by health care professionals to manoeuvre through their everyday clinical lives. Clinical decisions were traditionally made at the discretion of an individual health care professional who was responsible for making all the patient related decisions. Patients were essentially treated passively within this paternalistic “doctor knows best” approach (Manyonga, Howarth, Dinwoodie, Nisselle & Whitehouse, 2014).

This paternalistic approach was facilitated through a distinct power imbalance, where patients and families often perceived health care professionals as being more knowledgeable/authoritative and as a result allowed them to make clinical decisions for them (Nimmon & Stenfors-Hayes, 2016). Joseph-Williams, Edwards and Elwyn (2014) argue that patients often engaged in “covert contracts” with their clinicians where they often felt compelled to adopt the role of the “good patient”, essentially a passive and compliant role. In this “covert contract” patients believed that they should not/ cannot be involved in making clinical decisions often secondary to fear of upsetting the clinician and/or of possible repercussions that may subsequently arise, which include receiving a lower standard of care and being labelled as difficult (Joseph-Williams et al., 2014; Frosch, May, Rendle, Tietbohl and Elwyn, 2012).

Henderson (2003) further argues that this paternalistic approach to clinical decision making was not exclusive to doctors only but extended to nurses also. In that study it was argued that a distinct power imbalance was maintained as the nurses were often unwilling to share their “decision making powers” with their patients (Henderson, 2003). This was done as a method to hold onto their perceived power and control, and because they believed that they “knew best” and viewed their patient’s as lacking in medical knowledge (Henderson, 2003). Furthermore through the use of different strategies health care professionals were able to exert their power, using legitimized training and/or qualification associated language, referent and through the acknowledgement that patients were often reliant on them to provide the services and/or care they required (Bending, 2015 as cited in Nimmon & Stenfors-Hayes, 2016).

However, this approach has since changed and a greater emphasis is placed on collaboration and shared decision making among all stakeholders (de Beer & Brysiewicz, 2017; Rabie, Klopper & Coetzee, 2017; Kanzaria et al., 2015; Couët et al., 2015; Zeuner, Frosch, Kuzemchak & Politi, 2015; Edwards, Jones, Higgs, Trede & Jensen, 2009; Smith et al., 2008; D’Amour, Videla, San Martin-Rodriguez & Beaulieu, 2005). This change is argued in respect to a legal and ethical obligation placed on health care professionals, in response to a patient’s right to self-determination and autonomy. Self-determination and autonomy refers to a patients’ ability to make decisions and control the choices that will affect them (Manyonga et al., 2014). The legal precedence for this, was drafted into South African legislature in 1967 in the case of Richter and another v Estate Hammann (3) SA 226 (C) (1967, as cited in Manyonga et al., 2014; Britz & Le Roux Kemp, 2012) and subsequently in the case of Castell v De Greef 1994 (4) SA 408 (C) (1994).

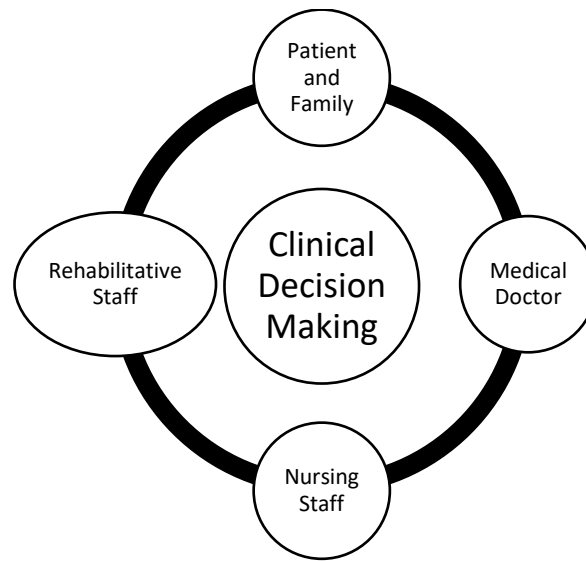
The National Health Act 61 of 2003 (2004) further enforces that all patients have a right to be told about the nature and scope of the treatment option to be used, in a language understood by them and at a level they are able to understand (Manyonga et al., 2014; The National Health Act 61 of 2003, 2004). In countries such as Canada and the United States, this approach to health care appears to have already been recognised and accepted, and multifaceted evidence based interventions, have been adopted in an attempt to implement shared decision making among all concerned parties (Clarke, Harrison, Holland, Kuhn & Barclay, 2013; Stiggelbout et al., 2012). Thus from a legal, ethical and evidence based perspective, the idea of shared clinical decision-making has been encouraged, but it is unclear as to what extent it is being enforced in South Africa in the public health care sector currently.

Within the South African public health care setting, hospitals and clinics are increasingly understaffed, under resourced and under financed (The Green Paper: NHI, 2011), with limited information on the availability and use of a multi-disciplinary teams (MDT) for collaborative decision making. According to the Framework and Strategy for Disability and Rehabilitation services (South African Department of Health, 2015), the availability of a “multi-disciplinary rehabilitation team” in addition to general practitioners and clinical nurse practitioners is emphasized at district, regional and tertiary hospitals. In this report, a core rehabilitation team includes a Speech Therapist, Physiotherapist, Audiologist, Occupational Therapist, Medical Orthotist and prosthetist and other related mid-level health workers. Additional “support team” professionals are also referenced, however as clearly indicated in this report, the ideal MDT does not usually exist within different hospital institutions (South African Department of Health, 2015). The author(s) of this report attribute this to a high vacancy rate of health care professionals, lack of equitable distribution among service providers and a lack of support, and in-experience of junior staff when dealing with complex patient cases (South African Department of Health, 2015).

Barratt and Ogle (2010) argue that despite the presence of a MDT, cross referrals regarding paediatric feeding and swallowing difficulties remain inadequate. Furthermore caregivers of children with feeding difficulties typically experience a significant amount of stress secondary to their child’s malnourishment and difficulty in feeding them orally (Greer, Gulotta, Masler & Laud, 2007; Spalding and McKeever, 1998). Health care professionals are often well placed to provide illness related information, psychosocial support and decrease depression/anxiety in family members (Chien, Chiu, Lam & Ip, 2006 as cited in de Beer & Brysiewicz, 2017; McAdam & Puntillo, 2009 as cited in de Beer & Brysiewicz, 2017), and yet don’t. Despite the apparent increase of children with CP who require PEG placements secondary to their feeding and swallowing difficulties, there is still a distinct lack of knowledge regarding the CP diagnosis, PEG feeding and the MDT personnel’s role. Without MDT collaboration and shared clinical decision making, health care professionals are in effect promoting a unilateral paternalistic approach to health care and subsequently their patients’ dependency on them.

A key consideration when looking at how clinical decisions are made for children with CP, is to explore who comprises the clinical decision making team, their respective roles, and what factors influence their choices. Figure 1 below depicts the four primary decision making

categories included within a MDT, with the individuals within each category being discussed further.



*Figure 1.*

*Diagrammatic representation of key decision making categories of individuals within the multi-disciplinary team (MDT).*

A review of the literature argues for a multifactorial approach to clinical decision making, with the role players being required to consider different variables in their management approaches. Given that practitioners who work independently cannot be assumed to be aware of and independently manage all variables and complications that a child with CP may present with, a proactive and engaging dialogue with other health care professionals is required. This is advocated to ensure that all aspects regarding the child's management are considered and addressed. As such clinical decision making is advocated within a collaborative effort that includes an optimal MDT approach.

Marchand, Motil and the NASPGHAN Committee on Nutrition (2006) describe an optimal MDT as including the following health care professionals: a Physician (medical doctor), Nurse, Speech Therapist, Dietician, Social Worker, Psychologist and Occupational Therapist. Mitchell et al. (2012) further argue that the patient, parents/caregivers and greater family should also be included and respected as integral members within the MDT. According to Marchand et al. (2006) early identification and involvement of the MDT is critical in preventing feeding and swallowing related difficulties. This is supported by Barratt and Ogle (2010), who argued that a collaborative approach among the MDT is required to target the

feeding and swallowing difficulties of these children and reduce the subsequent effects on the child's family. MDT personnel involvement should thus be explored further, particularly with respect to key members of the team and their decisions regarding the overall management of the child.

**1.2.1. Patient and Family.** When considering children who are unable to actively make decisions regarding their own care, and for whom long term management options are required, family members become crucial decision makers. Simply stated, a child's caregivers are responsible for making clinical decisions on their behalf, and are then subsequently required to care for the child and adhere to the implications of the decisions made, thus they form crucial members within a MDT. Kruger and Gericke (2002) argued that caregivers often have inadequate knowledge and that adherence to cultural practices, in rural South Africa, often leads to poor-quality feeding practices among children. They further argued that young mothers often find it difficult to contradict the opinions of their elders and peers (Kruger & Gericke, 2002). Three underlying causes of child malnutrition have been highlighted, namely: inadequate care for children and women, insufficient health services and unhealthy environment, and inadequate access to food (Devereux & Waidler, 2017; UNICEF, 1990). As a result, it is crucial to understand the caregivers nutrition-related and socio-environmental concerns in an effort to improve the overall caregiver's nutritional knowledge regarding the needs required for their child. Ultimately the caregiver is then able to make more informed and sustainable decisions regarding their child.

Food Security is thus important to note when considering a PEG placement. Food security is defined as (i) the availability of safe and nutritious food and (ii) the acquisition of food, of a good quality, in a socially acceptable manner (Labadarios et al., 2011). A socially acceptable manner infers the procurement of food sources that does not violate any social, cultural and/or economic standards. Devereux and Waidler (2017) expand on this understanding and argue food security as four different characteristics, namely: Availability, Access, Stability and Utilisation. Availability is viewed as the total quantity of available food in a particular area at a point in time; Access is viewed both physically, in respect to the distance required for people to travel to obtain food sources, and economically in relation to the affordability of the food for the individual. Stability refers to the seasonal availability/access to food sources over time (Devereux & Waidler, 2017). By adequately understanding food security from the caregiver's perspective, a greater consideration may be given to food



preparation, consistencies that need to be altered for PEG feeds, and whether this is seen as a contributing factor when deciding for a PEG placement.

Various initiatives, in the form of social grants, employment opportunities and supporting small scale agricultural productions, have been used to address food insecurity in South Africa (Devereux & Waidler, 2017; Altman, Hart & Jacobs, 2009). However, despite these initiatives, a real and substantial change with regards to food security in South Africa is still noticeably lacking. Devereux and Waidler (2017) argue that although social grants have shown to have a positive impact on food security, it does not extend to severe malnutrition in children, where the value of the grant received is not sufficient to cover basic food needs. In that study, it was further argued that individuals living in poorer households in South Africa, often pool their income to cover both food and non-food related expenses and not only for the benefit of the beneficiaries whom it is intended for (Devereux & Waidler, 2017). Many families find it increasingly difficult to purchase enough food for all the people within the home to ensure that they follow nutritional diets (Labadarios et al., 2011). Employment opportunities in South Africa have arguably increased, however the income received has not been enough to substantially impact the poverty and subsequent household income for many South Africans (Altman et al., 2009). While food security has been targeted by small scale agricultural initiatives, Altman et al. (2009) argued that this approach seems counter-intuitive in an attempt to promote subsistence within a semi-industrialised economy.

Financial considerations and access to health care services have also been referenced as contributing factors when considered the long-term management required for children with disabilities. The South African public health care sector currently services the majority of the total population in the country (84%) who are largely black African and poor (Naidoo, 2012). When considering children with disabilities, caregivers are often dependant on social grants as their primary source of income to care for their child. According to the South African Social Security Agency (SASSA) caregivers are eligible to receive a monthly social grant of R1600 for their child, should the child be younger than 18 years of age, have a severe disability that requires special, full-time care and not be cared for permanently in a state institution. The caregiver is thus required to use this monthly grant to adequately care for the child, and to transport the child to the hospital for monthly follow-up medical and rehabilitative consultations. Saloojee, Phohole, Saloojee and IJsselmuiden (2007) argued that transportation costs for one way hospital consultations cost caregivers as much as 5% of the family's monthly

income and is often difficult for the caregivers to justify without any spectacular improvements noted for their child.

A study conducted by Grut, Mji, Braathen and Ingstad (2012), argued that despite the establishment of local health clinics for easier access, that patients are still required to walk approximately four hours on narrow gravel roads to their nearest health clinic (Grut et al., 2012). In that study, while public transport was available in the form of small pick-up trucks on main roads, due to the fact that the young adult needed to be accompanied, a fee would also be required for an additional person. Interestingly it was further reported that wheelchairs were only seldom admitted on public transport and people who did not behave in a socially acceptable manner were not admitted at all (Grut et al., 2012). In the absence of a public transportation option, the caregivers in that study elected to use a wheelbarrow to transport their child (Grut et al., 2012). However, given that they were elderly, not physically strong and that the distance to the health care clinic was too far and steep for wheelbarrow access, regular follow-up consultations proved challenging (Grut et al., 2012).

In a study by Spalding and McKeever (1998) the mothers interviewed indicated that the task of feeding their child in many cases was their responsibility exclusively, which resulted in them experiencing feelings of frustration, self-doubt, worry and resentment. While the majority of the caregivers interviewed in that study were initially hesitant to consent to the gastrostomy tube, they eventually agreed due to their exhaustion at the repeated unsuccessful oral feeding attempts or when they believed their child's life was endangered.

Feeding difficulties in children with disabilities are significant to caregivers and a source of considerable distress (Spalding & McKeever, 1998). Feeding has a symbolic representation for many caregivers, who often blame themselves and/or experience blame from others secondary to their child's inability to tolerate oral feeds. As previously alluded to, PEG tubes are often new to caregivers and further compound their distress, as they feel they are required to limit their social activities to ensure that they are available at home to care for their disabled child. Familial fear regarding the child's condition and PEG tube is also a contributing factor toward caregiver isolation. It is therefore important that health care professionals educate and support caregivers regarding PEG placements, and that resources be provided to assist caregivers with the emotional fear and any subsequent isolation they may experience.

Petersen, Kedia, Davis, Newman and Temple (2006) further argued that several caregivers interviewed in their study highlighted the stigma that caregivers of children with CP often experience. The caregivers were concerned that others would view their children with gastrostomies as “things” rather than people. They were further concerned that this could result in their increased isolation, discrimination and stigma, and were worried about how others would perceive the children when watching them feeding via the tube as opposed to the “natural” oral method (Petersen et al., 2006).

According to Crawford, Jeffery, Ball and Brug (2011), socio-cultural factors vary with respect to social roles, cultural factors and social circumstances. Practically, this means that individuals’ have different roles based on the social and/or cultural dynamics present within a particular group. These roles affect how that individual is treated within the group and the degree to which their opinion influences decision making. Socio-cultural patterns specific to societal age groups, gender, racial denominations and relationship patterns are also important to understand and consider (Crawford et al., 2011).

Within a multicultural and diverse country such as South Africa, religion and culture also needs to be considered when exploring decision making. Cultures and religions often have long-held beliefs and behaviours regarding food and eating, that need to be considered in the clinical decision making process. For children with NDD, common feeding challenges include, food refusal, feeding avoidances and behavioural and/or sensory difficulties, which need to be considered (Arvedson, 2008). With respect to religion and culture, managing these difficulties may prove challenging given the dynamics within the family and the preferred method of managing behaviours in children.

Furthermore in South Africa, some cultures have extended family structures where strong links exist between the rural and urban family units, and elder consultation is considered important in family decisions. Depending on the circumstances, a male relative, for example an uncle, grandfather or older cousin, may be consulted (Mohano, 2008). When considering the black African culture especially, a hallmark characteristic is that individual opinion/interest cannot occur without the collective input/interest of the social group being valued (Brysiewicz & Bhengu, 2010). A patient’s social group does not merely include their family but can extend to traditional sources of community support also, such as chiefs and traditional healers, and

should thus be considered and respected by the treating health care professionals (Brysiewicz & Bhengu, 2010).

According to Kruger and Gericke (2002), an overlap occurs with regards to food preparation, choices and allocation to different family members. This may manifest in a paternal matriarch receiving more food than a young child in the family, highlighting that an adequate quantity of food in a home does not necessarily equate to adequate nutrition for all individuals. Thus exploring how caregivers consider food access and cultural rules within the family is relevant, particularly when, managing paediatric feeding and swallowing difficulties.

**1.2.2. Medical Doctor.** When considering patients who are at the end of life; critically ill; cognitively disorientated; minors with severe disabilities or where families have actively elected for doctors to assume the primary decision making role, the shared clinical decision making among all health care professionals becomes more difficult to enforce (Kanzaria et al., 2015). Kanzaria et al. (2015) argued that while medical doctors are more informed regarding the importance of shared clinical decision making, and advocate for the potential benefits of this approach, that the clinical decision making within an emergency room environment is often at the discretion of the doctors exclusively. This occurs because the clinical environments may often involve unscheduled acute care, emotionally charged environments and time constraints that cause the medical doctors to feel pressurised into making rapid unilateral decisions.

Calis et al. (2008) argued that children with severe generalised CP and Intellectual Disabilities (ID) present with numerous dysphagia related difficulties, secondary to their neurological conditions. Dysphagia may commonly be described as disordered swallowing with difficulties commonly occurring in the oral, pharyngeal and oesophageal phases. All these difficulties are thought to be caused as a result of anatomical abnormalities, neurological immaturity, oral-motor dysfunction, oral sensory impairments and oesophageal motility disorders which may be progressively worsened due to GORD (Calis et al., 2008). Thus the timeous identification and management of these difficulties is important as it reduces the health risks and enhances the overall nutrition for the child (Calis et al., 2008).

Malnutrition is increasingly common in patients with neurological conditions and may constitute a multifactorial cause (Stavroulakis & McDermott, 2016). The patients that are at

risk for being malnourished include those diagnosed with strokes, dementia, motor neuron diseases, Parkinson's and Alzheimer's disease (Stavroulakis & McDermott, 2016). In a younger demographic, malnourishment is increasingly common in children with neurological conditions, such as CP and Autism. Feeding and Swallowing difficulties are increasingly common in this population, with difficulties ranging from sensory related aversions to physical related challenges (Stavroulakis & McDermott, 2016). Metabolic related difficulties can also be a problem, and can result in malnutrition to the extent that would impair their immunity, muscle strength, psychological willpower and wound healing (Stavroulakis & McDermott, 2016; Stroud, Duncan & Nightingale, 2003), with enteral feeds being typically prescribed for patients when this occurs (Stroud et al., 2003). Under these circumstances medical doctors generally make the decision to provide enteral feed placement for their patients, especially when their prognosis is uncertain (Bell, Somogyi-Zalud, Masaki, Fortaleza-Dawson & Blanchette, 2008).

Unilateral medical doctor related decisions are often intrinsically and/or extrinsically motivated (Bell et al., 2008), with Hajjaj et al. (2010) arguing that patient, clinician and practice related non-clinical factors may also influence the clinical decision making process. Patient related factors include their socioeconomic status, age, race, preferences, behaviour, attitudes, gender, medical/non-medical concern, adherence to treatment, personal characteristics, inappropriate behaviours that may influence treatment adherence, familial /friend influences, quality of life and religion and/or culture (Hajjaj et al., 2010). Physician-related factors include the physicians' time, work constraints, age, faith, race, culture, and professional interactions (Hajjaj et al., 2010). The final category presented is practice-related factors, which include the type, size and resource availability of the practice (health care institution), as well as the availability of resources, management policies and treatment costs (Hajjaj et al., 2010).

In the retrospective study conducted by Mahant, Jovcevska and Cohen (2011), the process by which decision making was done is highlighted as a key consideration. Parents interviewed in that study reported that the information provided to them throughout the decision making process was inadequate, and that insufficient support from the different health care professionals was provided. Patients and families often reported that health care practitioners typically only discussed procedural risks with them and no other components of the patient's care were commented on, with enteral feeds being a foregone conclusion (Shega, 2010). They also reported the amount of time given to them to make different decisions was

not adequate, and that they often felt pressurised and rushed to make decisions quickly. Collectively, the parents felt that these, and other factors, influenced their experiences of the PEG process and ultimately their decisional conflict.

**1.2.3. Nursing Staff.** Nurses are another important discipline to engage when making clinical decisions for patients, given that they are ultimately the health care professionals responsible for managing and caring for the patient on a daily basis (Thompson, Aitken, Doran & Dowding, 2013). When considering enteral feeds, the nursing staff have a significant role within the MDT. They are responsible for monitoring the patient to observe whether or not the enteral feeds are tolerated once initiated. Nurses are responsible for observing the patient's abdomen for any gastric distention, rigidity, abdominal pain and/or vomiting, as well as their general adaptation to such means of nutrition consumption (Houston & Fuldauer, 2017).

**1.2.4. Rehabilitation Services.** When considering enteral feed decisions and patients with long-term nutritional requirements, other significant health disciplines to include are Speech Therapists, Dieticians, Psychologists, Social Workers Physiotherapists and Occupational Therapists, all of whom contribute to the overall well-being of the patient.

**1.2.4.1. Speech Therapists** are responsible for evaluating the safety of the swallow for the patient (Farneti & Consolmagno, 2007), as they are able to assess the feeding and swallowing skills of a patient and make recommendations thereafter regarding oral and/or enteral feeds. For patients who present with an increased aspiration concern, enteral feeds are typically recommended to ensure safe and adequate nutrition for the patient (Opilla, 2003). This decision is done in consultation with the MDT, which is particularly important when considering enteral feeding options. In their evaluation of the patient's feeding and swallowing ability, speech therapists are required to be sensitive to both the patient and family's cultural and social influences. Once the swallowing ability of the child is assessed and enteral feeds prescribed, ensuring adequate nutrition becomes important and dieticians then provide a key role.

**1.2.4.2. Dieticians** are responsible for evaluating the nutritional needs for a patient and ensuring that nutritional support is provided timeously. According to The National Institute for Health and Care Excellence (NICE) (2006) nutritional support is often provided to patients who are malnourished, namely those who present with a Body Mass Index of less than 18.5

kg/ m<sup>2</sup> or have an unintentional weight loss greater than 10 % within the last 3 – 6 months (in hospital). Patients are considered at risk for malnutrition when: i) they have eaten little/nothing for more than 5 days and/or likely to eat nothing for the next 5 days, and ii) have high nutrient losses and/or high nutritional needs (NICE, 2006).

One of the primary concerns for children with neurological impairments is malnutrition (Marchand, 2009). Due to the lack of information regarding the growth patterns for these children, it becomes increasingly difficult to adequately ensure the energy needed for the children is maintained (Marchand, 2009). Thus the need to monitor the children's weight particularly after the initiation of an enteral feed is established. Based on the child's age, dieticians often consider the child's enteral access, caloric needs, daily activity requirements and tolerance to feeds (Marchand, 2009). Depending on the child's individual needs, formula feeds may also be encouraged to ensure that the child's micronutrients are also adequately considered (Marchand, 2009). Formula feeds do not replace bolus enteral feeds and caregivers should be educated of this prior to their child's PEG placement. Furthermore, children with CP frequently present with numerous feeding and swallowing difficulties which include oral and pharyngeal phase swallowing difficulties (Arvedson, 2013). These may possibly contribute to the child's apparent dislike and/or refusal of food prior to a PEG placement and should be considered during the caregiver's decision making process. Therapy to assist with the child's food refusal and/or inability to tolerate feeds should thus be implemented to assist with improving the child's feeding and swallowing where possible. Dieticians are typically requested to monitor the child's nutritional needs and to advise accordingly regarding supplemental feeds for the child. Furthermore, PEG feeds require that the caregiver present a blended bolus to the child as other consistencies will not be tolerated by the child, via the PEG feeding tube. While increasingly familiar, malnutrition should not be accommodated in children with CP.

**1.2.4.3. Psychologists** are essential to investigate the cognitive capacity of the patient to be able to actively participate in the clinical decision making process. The study conducted by Politi, Dizon, Frosch, Kuzemchak and Stiggelbout (2013) argued that many health professionals often assume that patients do not want to/are not able to participate in the decision making process, and thus often exclude the patients. Not only was this proven inconsistent with the contemporary and evidence based models of care, but the research available in this area

argued that patients who were more involved in the decision making process had an improved overall understanding, satisfaction and confidence in the choices made (Politi et al., 2013).

**1.2.4.4. Social Workers** are arguably one of the key role players within the clinical decision making MDT when considering enteral feeds for a child with CP. Social workers provide a crucial role in that they are often recruited to assist caregivers and families to ensure that resources are available to support them in the management of their child. Home based enteral feeding options are often encouraged among health care professionals as they are known to assist with weight gain, reduce the patients overall number of hospital admissions and decrease the overall health care costs for the patient and health care institutions. As in the case with PEG's, patients are able to be discharged home once the feeding tube is placed, thereby reducing their risk of acquiring infectious complications (Ojo, 2015). However, one key consideration is that home based enteral feeds often requires funding to ensure that feeds are delivered to the patient and that the PEG related accessories and/or any complications, such as the pump and stoma site are timeously managed (Ojo, 2015). These are typically cited as challenges within developed countries, such as the United States of America (USA) and Europe. In developing countries like India, Pakistan and Bangladesh, home based enteral feeds are generally not common due to the financial and resource constraints (Ojo, 2015). Another key considerations is that rehabilitative services are often unavailable within developing countries which further places a challenge on the decision making process.

**1.2.4.5. Physiotherapists and Occupational Therapists** aim to mobilise patients and increase the functional movement and activities for their patients, which is particularly important for children with CP. When considering enteral feeds in this population group, adequately ensuring postural support during and after feeds is important and physiotherapists and occupational therapists have an invaluable role here. According to Chiarello, Palisano, Bartlett and McCoy (2011) physiotherapists and occupational therapists have various different roles when considering the management of children with disabilities. They are encouraged to provide rehabilitative "hands-on" therapy, such as joint and soft tissue mobilisation and positioning, in addition to providing caregivers and families of children with disabilities with the skills needed to enable the child's participation within their respective environments/communities (Anaby et al., 2011). This was further supported by Andrade, Ferreira, Mendonça and Haase (2012), who argued that physiotherapists and occupational therapists are very relevant professionals to conduct rehabilitation services for children with



disabilities, given their comprehensive assessments and management of these children. When considering children with CP and long-term decisions that affect them and their management, occupational therapists and physiotherapists should be contacted and therapy timeously implemented.

### **1.3. Rationale and Significance**

According to UNICEF South Africa (2013) malnutrition contributes to approximately 64% of the total fatalities of children under five years of age. Despite this, there are no procedural guidelines available to indicate how clinical decisions should be made to ensure timeous management for these children. While a significant portion of the available literature currently investigates PEG feeding decision making in the adult population with diagnoses that range from alzheimers, acute strokes, amyotrophic lateral sclerosis, head and neck cancer, cystic fibrosis and critically ill patients, very little literature is available in the paediatric population and no literature is available regarding children with CP. This is particularly concerning given that CP is considered the most common cause of physical disability in children globally (Donald et al., 2014). The majority of the South African population is dependent on public health care services, including children with CP who have feeding and swallowing difficulties. The public health care sector in South Africa is currently over-burdened due to a lack of available resources and skilled professionals which often leads to a decrease in the services they are able to provide. Without timeous, efficient, and comprehensive clinical decisions being made, the long-term implications required for these children from the public health care sector will be exponentially increased. The rationale and significance of this study is thus established, where the ultimate goal envisioned is to i) contribute to the existing literature in this area and ii) assist with operational policy development toward cultivating a functional multi-disciplinary approach to health care, particularly in cross- cultural and resource constrained environments. In this way, sustainable and practical measures may be implemented to ultimately benefit this at risk population group and to prevent the continued wastage of resources due to a fundamental lack of proper management of these children. The current system is not working and a continuation of the current practices will ultimately lead to a further wastage of resources within the public health care sector which benefits neither the professionals or the patients; impairs the long-term management required for these children or in severe cases can contribute to the child's death as a result of lack of understanding among stakeholders, that can be prevented.

#### **1.4. Research Question**

How are Percutaneous Endoscopic Gastrostomy (PEG) feeding decisions made by caregivers for children with Cerebral Palsy (CP) who experience feeding and swallowing difficulties in a public healthcare setting in Pietermaritzburg, South Africa: An exploratory study.

#### **1.5. Aims and Objectives**

##### **1.5.1. Main Aim**

To investigate how Percutaneous Endoscopic Gastrostomy (PEG) feeding decisions are made by caregivers for children with Cerebral Palsy (CP) who experience feeding and swallowing difficulties, in a public health care setting in Pietermaritzburg, South Africa.

##### **1.5.2. Research Objectives**

- Objective 1:** To identify significant individuals involved in the PEG feeding decision making process and their respective roles.
- Objective 2:** To identify the factors that affect the decision making process for caregivers of children with CP who require PEG placements.
- Objective 3:** To explore the views regarding the decision making process for caregivers of children with CP with feeding and swallowing difficulties who required PEG placements.

#### **1.6. Outline of study**

The study is presented in the following chapters:

**Chapter 2:** *Manuscript.* “How are Percutaneous Endoscopic Gastrostomy (PEG) feeding decisions made by caregivers for children with Cerebral Palsy (CP) who experience feeding and swallowing difficulties in Pietermaritzburg, South Africa: An exploratory study”. This manuscript is being prepared for submission to the journal, Health Expectations. The manuscript format subscribes to the AMA format as detailed by the Health Expectations Journal and not to University of KwaZulu-Natal guidelines for submission. Similarly the figures used in the manuscript will differ, and follow the prescribed guidelines as detailed for the AMA

format. Chapter 2 should be viewed as a stand-alone chapter in this dissertation.

**Chapter 3: *Methodology.*** The research design, data collection methods and processes are described, as well as the data analysis and management methods. Furthermore the reliability, validity and ethical considerations adhered to are also discussed. Chapter 3 should be viewed as a continuation from the methodology section in chapter 2. The aim of this chapter is not to repeat the information presented in chapter 2 but rather to augment and elaborate some of the methodological sub-sections highlighted previously.

**Chapter 4: *Results and Discussion.*** The results are presented with respect to each of the three study objectives, and are discussed.

**Chapter 5: *Conclusion.*** This chapter evaluates the extent to which the research problem was addressed, the research question answered and the aim achieved by reviewing the findings of each objective. It outlines the significance of the study, its limitations and recommendations for future research and application in the public health care setting in South Africa.

### **1.7. Chapter synthesis**

This chapter primarily aimed to introduce the study and to detail the key aspects included. A presentation of the available literature in this area was also given to support the intent of the study and to explore similar studies and their contributing factors related to this topic further. Clinical decision making regarding enteral feeding cannot be viewed in isolation but rather as a collaboration of different variables. Each variable needs to be adequately explored, in order to provide an understanding thereof and insight into understanding how decisions are made for children with CP who require enteral feeds.

As previously alluded to, one of the main goals from this study is to assist with operational policy development and multi-disciplinary education and awareness. As a result, it was important to present the study and the results obtained to a global audience. Chapter two details the manuscript submitted to the Health Expectations Journal. This journal was selected for submission due to its core principles which include public-participation in health care and health policy development. The publication is also accessible to a multi-disciplinary and international audience, which allows for a greater variation of professional input and growth

and is important given that clinical decision making is not exclusive to any specific professional discipline.

## CHAPTER 2: RESEARCH MANUSCRIPT

**Article: Percutaneous Endoscopic Gastrostomy feeding decisions made by caregivers for children with Cerebral Palsy: An exploratory study.**

**Authors:** Ms. Lavanya Naidoo, Associate/Professor Mershen Pillay and Ms. Urisha Naidoo

### **Abstract**

#### **Background**

In South Africa there are no clear guidelines regarding how clinical decisions are made for children with Cerebral Palsy (CP) who require enteral feeds. Without timeous and effective management, the implications for these children can be fatal.

**Objectives.** To identify the significant individuals, factors and views involved in the percutaneous endoscopic gastrostomy (PEG) decision making process for caregivers of children with CP.

**Research Design.** A single-case research design was used in this qualitative explorative study.

**Setting and Participants.** This study was conducted at a public health care tertiary hospital in Pietermaritzburg, KwaZulu-Natal. Purposive sampling was used to recruit participants and two participants were selected for the study.

**Main Results.** Four primary individuals were ultimately identified, namely: Doctors, Speech Therapists, the caregiver's family and God. Two factors were identified as extrinsically motivating for the caregivers namely: physiological and/or nutritional benefits. No views were explicitly stated as intrinsically motivating for the caregivers.

**Discussion and Conclusion.** PEG feeding decisions are made unilaterally by health care professionals for children with CP. Caregivers allow for this and are dependent on their medical doctors, who they perceived as more knowledgeable. More operational policies and initiatives are required to empower health care professionals and caregivers to change this paternalistic approach to health care.

**Keywords.** Clinical decision making; Percutaneous endoscopic gastrostomy (PEG); Cerebral palsy (CP)

## **Introduction**

The prevalence of children diagnosed with Cerebral Palsy (CP) in KwaZulu-Natal, South Africa is estimated at 10:1000 live births under 10 years of age<sup>1</sup>. This statistic is thought to be the highest in the world, with other countries ranging between 1.5 to more than 4:1000 live births and the overall prevalence is thought to be approximately 2:1000 live births<sup>2-6</sup>. Of these children, it is argued that a greater majority will have some form of feeding and/or swallowing difficulty. The prevalence of feeding and swallowing difficulties in children with neuro-developmental disabilities (NDD) is estimated to range between 33% and 90%<sup>7-8</sup>.

Children with CP present with a greater aspiration and malnutrition risk, due to their presenting feeding and swallowing difficulties<sup>9</sup>. This risk may possibly be attributed to the child's sensorimotor impairments, cognitive and/or communication deficits, and gross and fine motor limitations<sup>37</sup>. Aspiration is defined as the inhalation of oropharyngeal and/or gastric material into the larynx and lower respiratory tract<sup>10-12</sup>, which if left untreated can develop into an aspiration pneumonia and in some cases, death. Children with CP are categorized as malnourished when they are unable to safely feed for a prescribed period and/or present with high nutrient needs<sup>38</sup>. Enteral feeds are typically recommended using either a nasogastric tube or a percutaneous endoscopic gastrostomy (PEG) feeding tube<sup>13</sup>. Enteral feeding options are known to improve the patients' safety of swallowing, nutrition, growth and reduce feeding times<sup>14</sup>. Thus, given the nutritive and at times life-preserving role that enteral feeding has for these children, there is a need for timeous and collaborative clinical decision making. Despite this, no literature and/or prescribed guidelines are available regarding clinical decision making for children with CP who require PEG feeds, with a vast majority of the available literature currently focussed almost exclusively on adult patients.

Clinical decision making is defined as the process whereby health care professionals use clinical and biomedical knowledge, consider risk-benefits, probabilities, various outcomes and problem-solve within dynamic contexts to make choices<sup>15-16</sup>. Clinical decisions were traditionally made at the discretion of an individual health care professional who was responsible for making all the patient related decisions. Patients were essentially treated passively within this paternalistic "doctor knows best" approach<sup>17</sup>.

A hallmark of this paternalistic approach was the distinct power imbalance between the “superior”, “authoritative” and “all-knowing” health care professional on one end of the spectrum and the patient and their families, on the other. Health care professionals arguably promoted this approach in their use of different power enforcing strategies, such as using legitimized training and/or qualification associated language, referent and through the acknowledgement that patients are often reliant on them to provide the services and care they require<sup>18</sup>. However this paternalistic approach was also advocated by the patient and their families where health care professionals were often perceived as being more knowledgeable and authoritative, and as a result allowed them to make clinical decisions on their behalf<sup>18</sup>. Patients often engage in “covert contracts” with their clinicians where they often feel compelled to adopt the role of the “good patient”, essentially a passive and compliant role<sup>19</sup>. In this “covert contract” patients believed that they should not/ cannot be involved in making clinical decisions often secondary to the fear of upsetting the clinician and of possible repercussions that may subsequently arise which includes receiving lower and/or less care and being labelled as difficult<sup>19</sup>.

This paternalistic approach to clinical decision making has since changed, with new legislation and policy development. Health care professionals are now required to engage in proactive and collaborative discussions among all stakeholders in an attempt to make more informed and sustainable clinical decisions<sup>16-28</sup>. An optimal Multi-Disciplinary Team (MDT) is viewed as the inclusion of the following health care professionals: a Physician (medical doctor), Nurse, Speech Therapist, Dietician, Social Worker, Psychologist and Occupational Therapist<sup>26</sup>. It is further argued that the patient, parent/caregivers and greater family should also be included and respected as integral members within the MDT<sup>27</sup>. Early identification and involvement of the MDT is thus critical in preventing feeding and swallowing related difficulties<sup>26</sup>.

However, the enactment of these laws is still not being practically enforced, and MDT cross referrals regarding paediatric feeding and swallowing difficulties remain inadequate<sup>28</sup>. The increased need for collaboration among all stakeholders within the MDT, is still emphasized<sup>28</sup>. Within the South African public health care sector, hospitals and clinics are increasingly understaffed, under resourced and under financed<sup>29-30</sup>, with limited information on the availability and use of MDT’s for collaborative decision making. Caregivers of children with feeding difficulties typically experience a significant amount of stress secondary to their child’s malnourishment and difficulty in feeding orally<sup>31-32</sup>. Health care professionals are often well

placed to provide illness related information, psychosocial support and decrease depression and anxiety in family members<sup>20</sup>. However, this often does not occur and clinical decisions are often unilaterally made for caregivers and their children by the health care professionals exclusively. For many families, clinical decisions for their loved ones are often required quickly post a sudden hospitalization, with an understanding that the patient may be severely disabled and/or die<sup>20</sup>. Against these psychological implications, the family may lack the ability to adequately cope with the situation<sup>20</sup> and this essentially links to a dependency facilitated on their health care professionals. In South Africa there is a need for more practical and collaborative MDT initiatives particularly in cross-cultural and resource constrained environments, to help empower both caregivers and health care professionals, and in so doing improve the management received for these children.

## **Method**

### **Research Ethics**

Permission to conduct the research study was obtained from the University of KwaZulu-Natal Biomedical Research Ethics Committee (BREC), the KwaZulu-Natal Department of Health and by the Medical Manager at the hospital where the study was conducted.

### **Research Setting**

The research study was conducted at a public health care tertiary hospital in the greater Pietermaritzburg area, KwaZulu-Natal. This hospital was specifically selected given that most PEG placements are done at this hospital within the greater northern KwaZulu-Natal area.

### **Research Design**

A single-case research design was used, as it allowed for more in-depth and varied data to be obtained.

### **Participants and recruitment**

A purposive criterion sampling method was used in this study, and caregivers of children with CP who required PEG placements secondary to their feeding difficulties were selected as the target participants. The inclusion criteria included caregivers of children with CP who required a PEG and i) elected not to place the PEG, ii) had already received a PEG or iii) had since had their PEG removed. Furthermore the respective children were required to be between 2 – 6 years of age at the time of the PEG decision, and the caregivers themselves were required to



be actively involved in their child's management; have stayed with their child throughout their hospital admission and be proficient in either English and/or isiZulu. Caregivers of children with CP with additional structural abnormalities or neurological conditions linked to their feeding difficulties and children who were not considered for a PEG placement were excluded from the study. Caregivers who did not give consent to participate in the study were also excluded from the study. Two participants were ultimately selected for the main study and two participants were interviewed for the pilot study.

### **Data Collection Tools**

**The Semi-structured Interview Schedule.** The Semi-structured interview was the data collection tool used in this study. The researcher developed the interview schedule which was adapted and changed based on the responses obtained from the participants during the pilot study. The interview schedule was developed with specific key considerations, and divided according to four sections, namely: (i) Biographical details; (ii) Significant Individuals involved in the decision making process (objective 1); (iii) Caregiver factors (objective 2) and (iv) Caregiver Views (objective 3).

**Critical Incident Vignettes.** For the purposes of this study, critical incident vignettes were used as a method to facilitate a dialogue with the participants and **not a data collection tool**. The vignettes were presented to the participants either (i) by written text or (ii) verbally with the assistance of an interpreter, where necessary. All three vignettes focused on a child with CP aged between 4-6 years old, but differed in respect to their socio-economic status, familial support/influence and home environments. The context for PEG placement also differed in each vignette, namely in vignette 1, the child is being currently fed via a PEG, vignette 2 the child is being considered for a PEG placement and vignette 3 the child's PEG has since been removed.

### **Data Collection Procedure.**

This study required the participants to be proficient in either English and/or isiZulu, and the use of an interpreter was indicated as the primary researcher was not proficient in isiZulu. Prior to the onset of the study the interpreter was trained by the researcher regarding the study procedure to be used. During the interpreter training, specific reference was made to the translation of concepts to the participant and not necessarily a word-by-word translation. During the interviews conducted the interpreter was also requested to check for understanding

of concepts from the participants before moving on to other concepts. An audio recorder was used throughout the interview to record participant responses.

### **Data analysis**

After the data collection was completed, the digital data on the voice recorder was transcribed verbatim and the data was thematically analysed. The transcribed data was coded to: (i) display all the identified themes; (ii) question and verify the data obtained and begin to develop hypotheses from the themes identified and (iii) be able to filter the data obtained and categorize the primary emerging themes. The data was presented in text form with supporting quotes in keeping with the study objectives.

### **Validity and Reliability**

Trustworthiness was ensured by establishing the research credibility, transferability, dependability and conformability<sup>33</sup>. Each principle was upheld and maintained throughout the research study conducted.

Credibility refers to the extent to which the study accurately and confidently measures what was actually intended<sup>33</sup>. Credibility was maintained throughout the study through: i) a reflective and iterative line of questioning throughout the interviews conducted; ii) a prolonged engagement through the use of a pilot study; iii) participant honesty measures; iv) communicating the independent status of the researcher and interpreter to the participants prior to the onset of the study; v) frequent researcher-supervisor debriefing sessions; vi) peer scrutiny; vii) reflective commentary and viii) member checks.

Transferability refers to the extent to which the research results may be relevant and valid to other contexts/situations and population groups<sup>33-34</sup>. A thick description was utilised here as a means to ensure the transferability of the research results<sup>33</sup>. Furthermore, the study boundaries were also communicated to the participants prior to the onset of the study to further ensure the transferability of the results obtained<sup>34</sup>.

Dependability within a research study is upheld, if similar results would be yielded, should the research design be repeated in a similar context and when using similar research methods and participants<sup>34</sup>. Dependability in this study was upheld by ensuring that the data collection

processes were detailed, and thus ensured that similar results would be obtained, even if conducted by another researcher<sup>34</sup>.

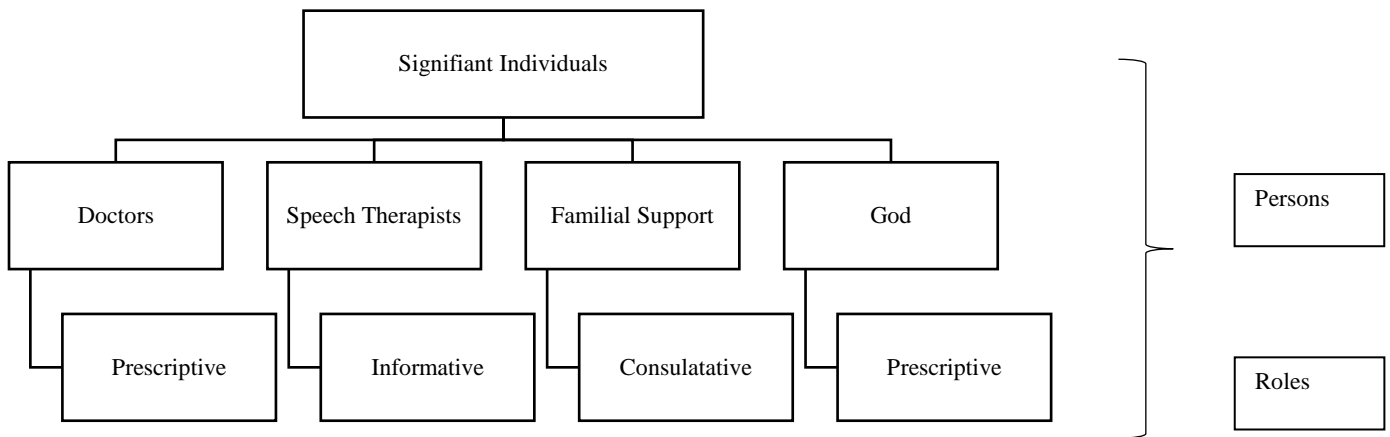
Conformability refers to the extent to which the study results are influenced by the participant responses and not by the researcher<sup>33</sup>. To this extent, conformability was maintained throughout this study by ensuring “reflective commentary” from the participants<sup>34</sup>. By transcribing the recorded interviews and subsequently coding for different themes, the researcher further ensured the conformability of the data obtained by establishing an “audit-trail”<sup>34</sup>. This may be used by independent researchers wanting to verify the participant responses<sup>34</sup>.

## **Results and Discussion**

The findings are presented here in respect to two objectives from this study, these being an identification of significant individuals involved in making clinical decisions, and the identification of the factors involved in the decision making process for the caregivers. The third objective aimed to explore the caregivers’ views that were intrinsically valued by them when considering the PEG decision for their children. While two views were highlighted, both essentially spoke to the caregiver’s views post PEG placement for her child, and as a result the views will not be elaborated on in this manuscript.

### **Significant individuals involved in the PEG feeding decision making process and their respective roles.**

Throughout the interviews, the caregivers identified four groups of individuals, as being significant. These include: doctors, speech therapists, family members and God, each with their respective roles (figure 1).



**Figure 1.** Hierarchical depiction of significant individuals and their roles

**Doctors.** For one caregiver interviewed, the child’s doctors were the first to recommend a PEG placement for her child. In this way it may be argued that the doctor’s role is prescriptive, as no evidence was identified to support a collaborative, shared dialogue between the health care professional and the caregiver. Interestingly, when analysing this quote further the caregiver states that, as explained to her the PEG would help with “this and this and this”. The repetition of the word “this” implies a distinct lack of knowledge regarding the benefits of the PEG feeding tube and despite this the caregivers agreed to the recommendation of their doctor, on whom a dependency was cultivated.

P1: (line 151) “They (the Doctors) all told me the PEG would help him with this and this and this”.

Both caregivers interviewed reported that their respective children received nasogastric tube (NGT) feeds upon admission to the hospital prior to their respective PEG placements. One caregiver understood that the NGT was placed due to her child’s difficulty in tolerating oral feeds and to ensure that the child would have adequate nutrition. From the doctors, the caregiver understood that her child was vomiting secondary to him aspirating the oral feeds she gave him, and as a result, the child needed the PEG placed. The power imbalance between the health care professional and caregiver is reiterated, where the health care professionals were viewed as more knowledgeable and authoritative as compared to the caregiver. Ultimately this acts to re-inforce the caregiver-doctor dependency dynamic and enables doctors to unilaterally make decisions for their patients.

P1: (line 165) “They (the doctors) told me that he was vomiting because when I feed him through the mouth, then food goes into the breathing tube. At this time he had a tube through his nose to help him eat. That is why he needed a PEG placed. Before that he was coughing a lot and then vomiting....”

Despite an MDT approach to health care being widely publicized and encouraged as a standard of care among all health care professionals, when considering the transcribed data in this study, one caregiver repeatedly use the word “they”. “They” referred to the medical doctors involved in the PEG and tracheostomy placements for the child, and were viewed as capable of prolonging life through their clinical decisions. The continued use of this word, would indicate that the caregiver allowed for external individuals to make decisions for her and her child, and would support the lack of involvement the caregiver experienced, being part of the MDT. Linguistically, the use of the word “we” would denote caregiver inclusion as opposed to “they” which infers that the caregiver felt excluded from the clinical decision making MDT. Ultimately, this further links to the caregiver and child being seen as passive recipients for whom decisions are made.

P1: (line 12) “Yes, for S (child), when they put the PEG and the trachey stoma everything was fine. It looked like **they** were giving him a second chance to live. I’m fine with everything that has happened with him because I am used to it now”.

P1: (line 75) “Here at (the hospital), **they** told me everything, because it is easier to know the truth than to know nothing... I didn’t want the doctor to just come and write in the file, so I just said “No no no what has happened? What is happening with my child? Is there something wrong or what?” **They** always told me because I was asking a lot about what was happening”.

**Speech Therapists.** The role of the speech therapist, as was indicated by one participant, was informative and stated in relation to providing caregiver training regarding the PEG procedure and management post placement. This was done through the use of a DVD that was provided and played by the speech therapist. The caregiver further reported that this method of training was helpful in adequately understanding the PEG more.

P2: (line 27) “They (speech therapists) taught us before they put the PEG in about what is going to happen. We watched a DVD and that helped to explain everything about the PEG”.

**Familial Support.** Family support was referenced as being important when making clinical decisions for both caregivers. The family was referenced in a consultative function and valued by the caregivers interviewed. One of the caregivers stated how during the PEG decision making process, the child’s maternal grandmother was consulted, as it was important for her, to discuss the child’s condition prior to consenting to the PEG placement for her child. This alludes to cultural practices being observed, namely that respect for the elders in the family be demonstrated and ultimately speaks to the important role and value the child’s family has when making decisions for this child. The child and caregiver is ultimately viewed as a part of the extended family nucleus, and the caregiver does not view herself in isolation as the sole party responsible for making decisions for her child.

P2: (line 40) “L’s (child) grandmother also lives with them and they all had to make the decisions together”.

**God.** One caregiver repeatedly referred to the influence of religious motivation on her decision making ability, and was perceived as a key entity when considering the decision to place a PEG for her child. For many patients, religion provides a consoling and often prescriptive method of dealing with stress, trauma and anxiety among many other emotions. One caregiver reported her child’s need for a PEG stemmed from her intrinsic belief that this was “God’s plan” for her child. While this belief is completely plausible, it could also be underpinned by her lack of overall PEG knowledge. The caregiver equated her child’s need for a PEG placement with a “divine plan” for her child and not merely as a method to ensure nutrition. A dependency on God is thus cultivated by the caregiver, as a method to understand and rationalise her child’s difficulties and proposed enteral feeding plan.

P1: (line 22) “I can remember the day they put the PEG...I kept telling myself it was all the plan of God...”.

P1: (line 218) “I just pray to God to keep us and keep us carrying on”.

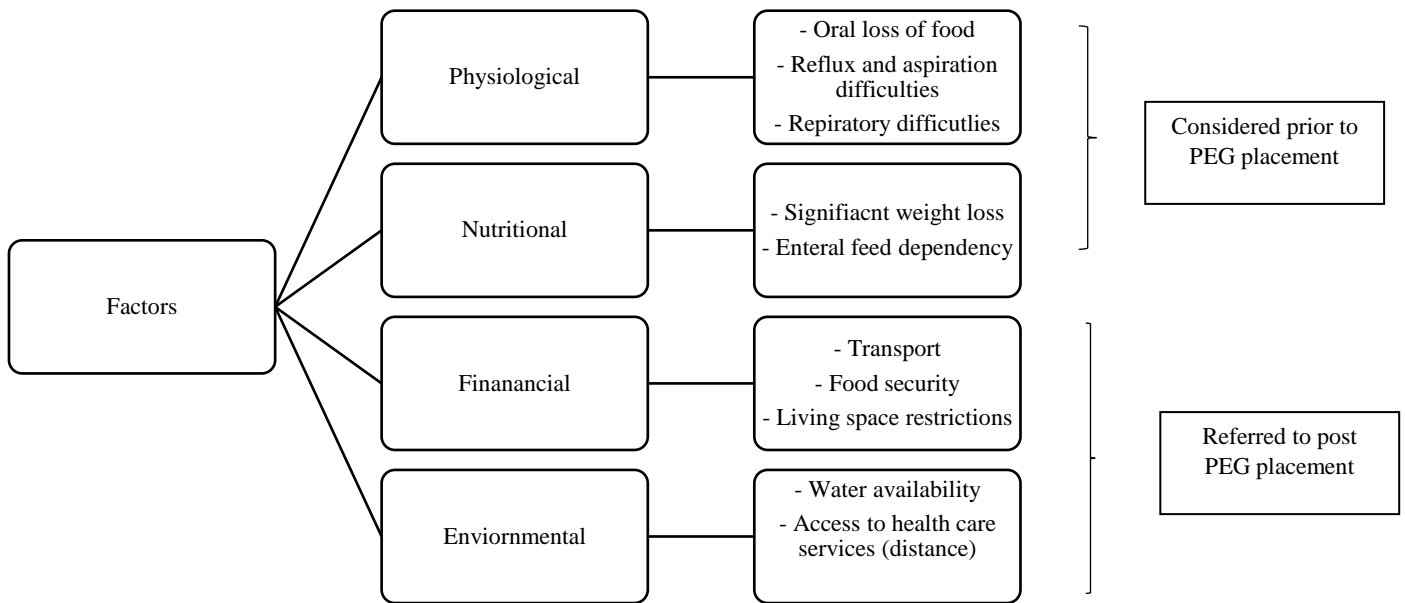
Irrespective of religious affiliation, it is important that health care professionals acknowledge this aspect, and adequately explore their patient's religious and cultural beliefs before deciding on the PEG placement. Family members and/or secondary caregivers should also be consulted, where possible, given the effects that this can have on the decision making process and subsequent management of the child.

### **Factors affecting the decision making process for caregivers**

The following section presents how extrinsic factors affected the decision making process for the caregivers. Extrinsic factors are regarded as external motivators, for example when caregivers decide to have a PEG placed for their child in an attempt to obtain external benefits, such as improved medical symptomatic management for their children.

On review of the participants' transcripts, four primary categories were identified, namely: physiological, nutritional, financial and environmental factors. Environmental factors constituted three (30%) of the total number of themes identified; nutritional factors constituted two themes (20%); financial factors constituted three themes (30 %) and environmental factors constituted two themes (20%). Based exclusively on the number of the themes identified per category, it would be argued that significant themes for the caregivers interviewed included physiological and financial factors primarily.

However, it should be noted that from the excerpts obtained, that the caregivers referred to the financial and environmental factors post PEG placement and thus did not directly state these two categories as contributing factors when considering the PEG placement for their child. Financial and environmental factors will thus not be discussed in the content of this manuscript, given that the aim of the study sought to explore the factors involved in the clinical decision making process for the caregivers when considering a PEG for their children. All four factors have been graphically represented in figure 2 below, in an attempt to maintain transparency regarding all factors identified.



**Figure 2** Hierarchical depiction of caregiver factors that extrinsically affect their decision making process.

### Physiological Factors

**Oral Loss of Food.** For one caregiver, oral loss of food was indicated as the reason for requiring a PEG placement for her child, this being the loss of all food given via the child’s mouth. Oral loss of food was reported for all consistencies given and subsequent weight loss was also noted.

P1: (line 5)“...he can’t eat with the mouth. Every time he eats with the mouth, everything comes out. So that is why they put a PEG”

**Reflux and Aspiration Concerns.** Both caregivers interviewed indicated that vomiting and/or coughing were the initial feeding difficulties noted with their respective children. One caregiver stated that the PEG feeding decision was made after the child experienced increased coughing and vomiting and appeared to have been told that the oral feeds given to her child was entering the “breathing tube”. The caregiver further referenced how all the feeds she would give her child was vomited, and how the child physically looked thinner.

P1: (line 17) “Before the PEG, all the food I was giving him would be vomited. He was getting so thin. But when they put all the things, yes S (child) was alright”.



P1: (line 16) “They told me that he was vomiting because when I feed him through the mouth, then food goes into the breathing tube. At this time he had a tube through his nose to help him eat. That is why he needed a PEG placed. Before that he was coughing a lot and then vomiting”.

P2: (line 15) “He was coughing all the times when he eats and then I decided to take the child to the hospital and then was sent to (the hospital). At (the hospital) they started checking about what was happening and then he vomited all the food”.

Reflux and aspiration at its basis are medical/ physiological related conditions that caregivers have very little control over and furthermore from the excerpts obtained, it appeared that the caregivers had very little knowledge regarding the extent of their child’s difficulties, yet they still chose to have the PEG placements done for their children, at the recommendation of their doctors. This passive adoption of the doctors’ recommendation, acts to further re-inforce the dependent relationship cultivated from the caregivers onto the doctors.

**Respiratory Complications.** One caregiver reported that her child’s respiratory and feeding difficulties occurred simultaneously and understood the difficulties as an amalgamation of feeding and breathing. This may possibly be due to both the tracheostomy and PEG being placed simultaneously.

P1: (line 87) “Yes they both happened at the same time” (in response to a question regarding whether or not both the PEG and tracheostomy occurred simultaneously”.

When considering additional excerpts from the caregivers’ transcript regarding the child’s respiratory complications, the respiratory complications are stated in relation to how the caregiver experienced feelings of possible embarrassment and emotional pain due to the fact that while in hospital her child had become a visual form of entertainment for others in the ward.

P1: (line 158) “S (child) was not breathing well. Even when someone was walking past the room, they would come back when they heard his breathing, it was so bad. It was so painful, even in the ward, when other people were visiting they would often forget

to go to their relatives and instead come to S to ask who this child was. It was painful because I was like a video or TV (television)...”.

The child’s weight gain was reported secondary to his respiratory difficulties which could possibly infer that the caregiver elected to have the PEG placed secondary to the respiratory complications and not exclusively the nutritional benefits.

P1: (line 17) “Yes, and even his weight, he started gaining because he was even suffering to breathe”.

This excerpt re-enforces the understanding that the caregivers perhaps did not understand the PEG feeding tube completely, and despite this lack of understanding, they elected to have the PEG placed for their children. The simultaneous respiratory and nutritive complications ultimately speaks to the child’s need for prompt and timeous clinical decisions to be made by the caregiver.

### **Nutritional Factors**

**Significant weight loss.** Significant weight loss was reported by both caregivers and considered to be a contributing factor when deciding on the PEG placement for their respective children. For one caregiver, the significant weight loss was reported due to the child’s inability to take feeds orally without subsequently vomiting. The other caregiver quantified her child’s weight loss, stating that at three years of age, her child weighed 9kg’s. These clinical signs were validated in the available literature where it was reported that while parents may not be able to identify specific feeding and swallowing difficulties, that many are able to reference their child’s increased feeding time and/or weight loss<sup>37</sup>.

P1: (Line 17) “Yes, and even his weight, he started gaining.... Before the PEG all the food I was giving him would be vomitted. He was getting so thin...”.

P2: (line 6) “There was no development or weight gain before the PEG and then afterward he started gaining weight....He weighed almost 9kg’s at 3 years old before the PEG”.

**Enteral Feed Dependency.** Both caregivers interviewed reported that their respective children received nasogastric tube (NGT) feeds upon admission to the hospital prior to their respective PEG placements. This was done secondary to their child’s difficulty in tolerating oral feeds and to ensure that the child would have adequate nutrition. The caregivers believed that the enteral feeding options allowed for their children to feed safely.

P1: (line 165) “They told me that he was vomiting because when I feed him through the mouth, then food goes into the breathing tube. At this time he had a tube through his nose to help him eat. That is why he needed a PEG placed. Before that he was coughing a lot and then vomiting. He tried a lot to tell me that there is something painful when he is eating”.

P2: (line 127) “Yes, he had a nose pipe to help him eat”

### **Critical Appraisal**

**Strengths.** This research study is unique in that no other study, exploring enteral feed decisions within the CP population has been conducted before. Thus, the results obtained have implications for operational policy development, caregiver and health professional empowerment, MDT advocacy for clinical decision making, practical service delivery initiatives and ultimately, a precedence is now argued that health care services at public hospitals in South Africa, need to be changed from the outdated paternalistic approach to a family-centred approach that prioritizes MDT involvement and considers all caregiver related factors and views. In this manner, sustainable and positive clinical decisions may be made to ultimately improve quality of life for thousands of children currently living in South Africa and affected by CP.

**Limitations.** The primary limiting factors in this study included: the relatively small population sample size used; the reduced variation within the sample and that participants were recruited from one hospital only.

### **Conclusion**

The results from this study confirm that clinical decisions are still unilaterally made by health care professionals for children with CP who require PEG feeds. Caregivers are often dependent on the decisions of their health care professionals and essentially passively adopt this approach

to their child's management. Despite the laws and policies implemented, encouraging collaborative and shared clinical decision making among all stakeholders, the reality is that this is not practically implemented. With the prevalence of CP increasingly in South Africa, the results of this study has implications for operational policy development and further research in the area of clinical decision making within the paediatric population. If this paternalistic "doctor knows best" approach to healthcare continues. the increased impact on service delivery, wastage of resources, litigation cases and unnecessary fatalities within the public health care sector is inevitable. In a developing country like South Africa, where access to information is so readily available, this approach to health care seems so outdated and contradictory to the ethos of this multi-cultural, diverse and socially opinionated country, surely these children and their caregivers deserve better. "When we know better- we do better".

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## CHAPTER THREE: METHODOLOGY

### 3.1. Introduction

This chapter describes how the study was conducted, and outlines the study design, location, population and sample. It then details the data collection tool, pilot study, participant description, data collection, data analysis, data management, reliability and validity, and research ethics. The method is described with respect to the three study objectives that were intended to address the aim of the study. Chapter 3 is presented in accordance with the APA submission guidelines as requested from the University of KwaZulu-Natal and primarily seeks to augment/support the methodological aspects highlighted in chapter 2, and not to unnecessarily repeat items. Please refer to chapter 2 for any methodological sections not referenced in chapter 3.

Objectives		Methods
1	To identify significant individuals involved in the PEG feeding decision making process and their respective roles.	Semi-structured interview
2	To identify the factors that affect the decision making process for caregivers of children with CP who require PEG placements.	
3	To explore the views regarding the decision making process for caregivers' of children with CP with feeding and swallowing difficulties who required PEG placements.	

*Table 1: Study Objectives and Method*

### 3.2. Research Aim

To investigate how Percutaneous Endoscopic Gastrostomy (PEG) feeding decisions are made by caregivers for children with Cerebral Palsy (CP) who experience feeding and swallowing difficulties in a public health care setting in Pietermaritzburg, South Africa.

### **3.3. Research Study Design**

Given the explorative nature of this study, a qualitative research design was selected as it allowed for greater understanding of individual situations, perspectives and contexts (Kaplan & Maxwell, 2005, as cited in Anderson & Aydin, 2005). Furthermore according to Kaplan and Maxwell (2005, as cited in Anderson & Aydin, 2005) qualitative research is advocated as a helpful tool in that it allows for the emergence and development of different hypothesis and processes as opposed to presupposed ideas and outcomes. Given the lack of literature currently available on this topic and the relatively small population sample used in this study, a single-case research design was ultimately used, given that it allows for more in-depth and varied data to be obtained (Baxter & Jack, 2008). A single case research design is further encouraged as it allows for a greater understanding of the phenomenon being explored and for an exploration of new theoretical considerations (Gustafsson, 2017).

### **3.4. Research Setting**

The research study was conducted at a public health care tertiary hospital in the Pietermaritzburg area, KwaZulu-Natal. The facility services patients who cannot afford private health care and who are referred from regional and/or district level hospitals, with the hospital receiving referrals from the Pietermaritzburg region, Midlands (28.1 km), Ladysmith (159.5 km), Newcastle (264.6 km) and Northern Zululand (298.32 km). At this hospital all types of patients are seen, such as neonates, infants, paediatrics, young adults, older adults, and geriatric patients, for a variety of different medical conditions. A range of health care disciplines currently work at the hospital and includes: medical doctors, nurses, speech therapists, dieticians, psychologists, physiotherapists and occupational therapists among others. An MDT approach is thus adopted when managing patients at the hospital.

At this institution, children are admitted to either: the paediatric neurological ward (27 beds available); paediatric surgical ward (28 beds available) or the paediatric cardiac/ renal ward (12 beds available). Children with CP who require a PEG placement secondary to their feeding and swallowing difficulties would thus be admitted to one of these three wards first, pending a bed availability. These children are seen for an (i) initial consultation prior to their hospital admission by the MDT which also includes a paediatric surgeon; (ii) consultations during their hospital admission up until their PEG placements and for (iii) follow-up consultations post discharge as out-patients. In the ward there are no beds available for the accompanying caregiver, and they are required to stay in the hostel facilities available in

another building on the hospital premises. However, some caregivers are allowed to sleep on chairs/benches placed next to the child's bed if the child is critically ill and/or the child has specific feeding requirements that need to be regularly maintained. Once discharged from the hospital, the child is referred to their base hospital/clinic for continued care. A follow up-consultation at the hospital may be booked if required.

### **3.5. Study population and size**

Children who are not able to safely tolerate their feeds orally are admitted to the hospital to ensure that their nutritional needs are safely and adequately maintained via enteral feeds. Children are typically brought to the hospital, by a primary caregiver who stays with the child throughout their admission, where possible. Caregivers of children with CP who required PEG placements secondary to their feeding difficulties were selected as the target population group used in this study.

Initially a total of eight caregivers were hoped to be recruited for the study, namely three caregivers for the pilot study and five for the main study. However numerous logistical challenges were experienced that resulted in only two caregivers being selected and interviewed for the pilot study and two for the main study. The hospital site used was a public health care tertiary level hospital and patients were often discharged from the hospital once effectively managed back to their base hospitals for continued care. As such, accessing the hospital for the interview exclusively was challenging for some of the caregivers.

Financial difficulties were cited, by the caregivers, as another reason preventing attendance to participate in the study. A re-application was done to amend the initial study proposal to provide for a transport fee to participants (Appendix J). Furthermore, attempts to contact participants telephonically to schedule interviews proved unsuccessful as many of telephone numbers provided were incorrect. This is not uncommon in qualitative research, as argued by Newington and Metcalfe (2014), where a study conducted in London revealed that logistical challenges, such as language barriers and long journey times, are often considered negative influences to recruiting participants.

### **3.6. Participant Sampling Technique**

A purposive criterion sampling method was used in this study, which is based on a specific criteria, from which variables may be identified and deductions made (Palinkas et al.,

2015; Meline, 2010; Miles & Huberman, 1994). Prospective caregivers were screened prior to participating in the study using a participant screener (Appendix A). The participant screener used included biographical information about the prospective participants, namely the child's name, age, gender, language proficiency, medical diagnosis, date of admission and discharge. Information regarding whether the PEG was placed prior or during the child's admission was also noted. Participants for whom a PEG recommendation was made, but who elected not to have a PEG placed for their child, were also noted. An inclusion and exclusion criteria was adhered to when selecting participants, and has been previously detailed in chapter 2.

### **3.7. Data Collection Tools**

**3.7.1. Semi-structured Interview Schedule.** As previously alluded to, a semi-structured interview was used as the primary data collection tool in this study (Appendix C). Semi-structured interviews are advocated in qualitative research, as it allows the researcher the opportunity to alter the wording and change the questions posed if required (Jamshed, 2014). This was done on condition that certain standards were maintained and adhered to during the interview (Bennett & Ritchie, 1975 as cited in Davison, 2000). Ultimately, this approach was used as it allowed for some structure to the interviews conducted, but still allowed for flexibility from the researcher and interview process (Gall, Gall & Borg, 2003, as cited in Turner, 2010). The interview schedule was developed with specific key considerations, divided into four sections, namely:

- Biographical details of the caregiver and child: the child's age and gender; the caregivers home address; the caregivers relation to the child; preferred language; the child's medical diagnosis and the date of the child's hospital admission and discharge.
- Objective 1: Significant Individuals involved in the decision making process.  
MDT personnel involvement: By exploring the significant individuals who the caregivers considered as important, a greater understanding would be facilitated regarding valued health care professionals and their specific roles.
- Objective 2: Caregiver factors  
Contextual factors: Socio-cultural environmental factors were highlighted here, exploring how the caregivers understood familial input/support, religion, culture and access to a hospital/clinic, when considering the PEG feeding decision.

Economic factors: Food security was highlighted here, namely the types of foods that caregivers understood as important to have access to and how they perceived the importance of working especially when considering a child who requires enteral feeds. Social grants were also referred to, namely how the caregivers perceived the importance of social grants when accessing food for their child, and legal factors, namely who they felt should represent them when considering the decision making process and what emotions were experienced throughout the decision making process.

Temporal factors: The caregivers were also asked about what decision was made first regarding the child's feeding and swallowing difficulties, when the PEG decision was made and whether or not they agreed/disagreed with the decisions made.

- **Objective 3: Caregiver Views**

Inherent factors: During the interviews, the caregivers were also asked to explain how they understood the child's CP (medical diagnosis) and associated feeding difficulties. They were also asked to reflect on the biggest challenge they have personally experienced or are aware of, when caring for a child with CP.

**3.7.2. Critical Incident Vignettes.** Barter and Reynold (2004 as cited in O'Dell, Crafter, Abreu & Cline, 2012) advocated using vignettes as a means to explore topics/issues with participants without being insensitive or forcing the participants to disclose personal information. For the purposes of this study, the vignettes were used as a method to facilitate a dialogue with the participants and not as a data collection tool.

### **3.8. Pilot study**

By conducting a pilot study, the researcher was allowed the opportunity to evaluate the suitability of the data collection tool used (van Teijlingen & Hundley, 2001). For the purposes of this pilot study, the semi-structured interviews and critical incident vignettes were evaluated. The researcher made changes, where necessary, this being particularly important within the context of this study as similar research studies are limited in this area. An interpreter was made available during the pilot study to assist participants who preferred communicating in isiZulu. Some amendments made to the main study after conducting the pilot study, included: i) Study Logistics - Participants were contacted telephonically and appointments scheduled. Telephonic reminders were also done the day before to the interview. This was done in an effort to

maximize the available time for each interview and to prevent any overlap between interviews, as was a challenge noted during the pilot study; and (ii) Greater need for interpreter training - This was done as it allowed for the interpreter to facilitate discussion with the participants independently of the researcher. This is also encouraged, as it assists with continuing the discussion and not interrupt the flow of conversation, as was noted during the pilot study conducted.

### **3.9. Participant Description**

The participants included in this study were required to be caregivers' of children with CP who required a PEG and i) elected not to place the PEG , ii) had already received a PEG or iii) had since had their PEG removed. Furthermore the respective children were required to be between 2 – 6 years of age at the time of the PEG decision, and the caregivers themselves were required to be actively involved in their child's management. The caregivers' identified were also required to have stayed with their child throughout the child's hospital admission and be proficient in either English and/or isiZulu. Age, race, gender and socio-economic status were not included as excluding participant demographic factors.

### **3.10. Data Collection Process**

The semi-structured interviews were conducted at the Speech Therapy Department of the hospital on the days when the participants had additional out-patient consultations at other departments. This was done as both caregivers did not live in Pietermaritzburg and were therefore required to travel to the hospital.

Given that this study required the participants to be proficient in either English and/or isiZulu, the use of an interpreter was indicated. The interpreter recruited was required to submit proof of her accreditation and proficiency in both English and isiZulu, prior to her involvement in the study. She was also asked to sign a confidentiality agreement. Prior to the onset of the study the interpreter was trained by the researcher regarding the study procedure to be used. Time was allocated during the researcher-interpreter training to allow for clarification and greater understanding from the interpreter. During the interviews conducted the interpreter was also requested to check for understanding of concepts from the participants before moving on to other concepts.

- All identified participants were verbally presented with one critical incident vignette, from a choice of three. The vignette presented was selected at the researchers' discretion.
- The interpreter was available here to present the case verbally to the participants who elected to use isiZulu as opposed to English.
- Time was allocated for the participant and interpreter to complete the biographical information section which was read to those who were illiterate.
- The participants were allowed to clarify any terms or ask any questions regarding the vignette to the interpreter, when isiZulu was selected as the preferred language of communication. The researcher was available to provide clarity when anything was unclear or required further explanation.
- The audio recorder was switched on and adequately positioned (permission was obtained from the participants prior to this).
- The semi-structured interview was then conducted by the researcher for participants who preferred to use English and the interpreter for participants who preferred to use isiZulu.

### **3.10.1. The Interview Schedule**

- One hour was scheduled for each interview and for questions posed after to the researcher by the participants. This time frame did not include the initial introduction; completion of the participants biographical information; brief description of the purpose of the interview; terms of confidentiality; format of the interview process; length of the proposed interview; methods of redress and questions posed prior to the interview. An additional thirty minutes was allocated here to accommodate these tasks. Participants were informed of this one hour and thirty minute time frame and each interview was scheduled accordingly.
- Throughout the interview schedule prompts were provided, as required.
- All the interview data obtained was recorded, transcribed and analysed as follows: (i) Audio recordings from the participants were saved (pending participant consent); (ii) recordings were transcribed into text; (iii) the transcribed texts were then subsequently edited and coded by the researcher to assist with data analysis.



### **3.11. Data Analysis**

After the data collection was completed, the digital data on the voice recorder was transcribed verbatim and the data was thematically analysed. The transcribed data was coded to: (i) display all the identified themes; (ii) question and verify the data obtained and begin to develop hypotheses from the themes identified and (iii) be able to filter the data obtained and categorize the primary emerging themes. The data was presented in text form with supporting quotes in keeping with the study objectives. The emerging themes were then reviewed and compared in respect to overlap of common ideas, arguments and re-categorized were necessary. The identified themes were subjectively categorized by the primary researcher initially and then subsequently discussed with the research supervisors to ensure objectivity in the emergent themes. Ultimately all the emerging themes were categorized in respect to the objectives of the study and the results obtained have been discussed in Chapter 4.

### **3.12. Data management**

According to Seidman (2013) ensuring the security of all participant data sources throughout the research process is of increasing concern. These included: (i) keeping track of participant information forms, (ii) ensuring participant consent forms were safely and securely stored, (iii) accurately labelling audio recorded tapes and (iv) ensuring the overall management of the participant transcripts. All participant data sources obtained in this study, namely: the participant consent forms; participant screener; biographical details; audio recorded tapes; interview transcript and coded transcripts will be collectively stored in a locked file cabinet by the researcher. All electronic data sources with patient information were printed and will be stored securely in the locked file cabinet at the University of KwaZulu-Natal, Speech Therapy Department with all the other data for this study for the required period of 5 years.

### **3.13. Validity and Reliability**

Trustworthiness in the research study was ensured by establishing the research credibility, transferability, dependability and conformability (Lincoln & Guba, 1985). Each principle will be discussed further:

Credibility refers the extent to which the study accurately and confidently measures what was actually intended (Shenton, 2004; Lincoln & Guba, 1985). Credibility was maintained throughout the study through: i) a reflective and iterative line of questioning throughout the interviews conducted and ii) the use of a similar data collection tool when compared to similar

qualitative studies conducted. By conducting a pilot study, a prolonged engagement was attained and the researcher was able to develop an early familiarity with the operations and culture of the hospital setting and to build a rapport with the hospital staff prior to the first interview being conducted for the main data collection. Shenton (2004) advocated tactics to ensure participant honesty when contributing data, as an additional measure to ensure credibility. This was advocated by ensuring that participants be given the opportunity to refuse participation in the study so as to include participants who are willing to partake in the study and provide data voluntarily. Throughout the study the caregivers were reminded of the voluntary nature of their participation in the study and the method to use should they wish to recuse themselves at any point. Furthermore another attempt to ensure credibility is the researchers' effort to build rapport with the participants prior to the onset of the study and an emphasis on an iterative dialogue with no right/wrong answers expected and one that allows the researcher to return/reflect on/ rephrase previously discussed questions and/or answers. The participants included in the study were also informed of the independent status of the researcher and interpreter, namely that they were not affiliated to the hospital and in that manner allows the participants the opportunity to share their experiences/views without anxiety/fear of losing credibility from the managers of the institution, as was advocated by Shenton (2004).

Credibility of the data obtained was also upheld through frequent debriefing sessions between the research and supervisors as a method to broaden the goal and perspective envisioned for the study; to discuss alternative approaches to challenges experienced; highlight prospective flaws in the study; assist with developing ideas and to prevent researcher preferences and/or bias (Shenton, 2004). To this extent, frequent debriefing sessions were conducted between the researcher and supervisors and an audit trail is available on request to verify the items discussed and proposed action plan. Peer scrutiny is also encouraged by colleagues, academics and peers, as it allows the researcher the opportunity to challenge assumptions made, where the researcher may not be able to, due to their attachment/closeness to the study (Shenton, 2004). The researcher has continuously reviewed the research methods with others and engaged in reflective commentary, in an attempt to ensure the credibility of the research design and strengthen the arguments made throughout the study.

Member checks were continuously employed throughout the study to further encourage the studies' credibility and has been advocated by Guba and Lincoln (1985) as an important

measure. Throughout the interviews conducted, participants were asked to verify the responses with their intended meaning. This was done using prompts such as, “Did I understand you correctly?” and “Can you give me an example?” Participants were also given the opportunity to change responses throughout the interviews and/or correct themselves as required.

Transferability refers to the extent to which the research results may be relevant and valid to other contexts/situations and population groups (Merriam, 1998 as cited in Shenton, 2004; Lincoln & Guba, 1985). Given the small number of participants used in this study and the lack of similar studies conducted, conventional generalisability proved difficult, however a hallmark of qualitative research is that each case is considered unique and ultimately an example within a broader context, and as result the transferability of the results obtained cannot be completely rejected (Stake, 1994 as cited in Shenton, 2004; Denscombe, 1998 as cited in Shenton, 2004). A thick description was utilised here as a means to ensure the transferability of the research results. A detailed account of the emerging themes as transcribed from the experiences of the caregivers was provided throughout the research study, and in this manner the transferability of the conclusion decided on allows other researchers to apply the research findings to other contexts and population groups (Lincoln & Guba, 1985). This was further advocated by Shenton (2004) where it was argued that the boundaries of the study must be communicated to the participants prior to the onset, some areas include: the number of participants involved in the study; the number and length of the data collection sessions; the time period of the data collection; restrictions on participants; the number of organisations participating in the study, the research study location and the data collection methods used in the study. This is advocated at the onset as a means to ensure transferability of the data obtained later when discussing the results obtained. In this study, all the above mentioned information was disclosed to the participants prior to their interviews.

Dependability with a research study is upheld, if the similar results would be yielded, if the research design were repeated in a similar context, using a similar research method and with similar participants (Shenton, 2004). Dependability in this study was upheld by ensuring that the data collection processes were detailed, thereby ensuring that similar results would be obtained, even if conducted by another researcher (Shenton, 2004). Shenton (2004) further argues that when detailing this “prototype model” for other researchers, an understanding of the studies’ effectiveness and methods may be cultivated and as such this model should include:

the research design and implementation; the data collection process and a reflective appraisal of the study.

Conformability refers to the extent to which the study results are influenced by the participants' responses and not by the researcher (Lincoln & Guba, 1985). To this conformability was maintained throughout this study by ensuring "reflective commentary" from the participants (Shenton, 2004). As previously alluded to, throughout the interviews conducted the participants were verbally prompted to reflect on their responses and confirm if their verbal responses accurately reflected their intended meaning. They were also asked to elaborate on different points to further confirm the accuracy of their responses. By transcribing the recorded interviews and subsequently coding for different themes, the researcher further ensured the conformability of the data obtained by establishing an "audit-trail" that may be used by independent researchers wanting to verify the participants' responses (Shenton, 2004). Using a data-orientated approach, the researcher was able to demonstrate the identification of different themes and formation of recommendations as obtained from the participant responses thereby further ensuring the conformability of the study (Shenton, 2004).

A semi-structured interview was used as the primary data collection tool in this study, and was used as it allowed the researcher the flexibility to change the structure of the interview and change questions posed to the participants throughout the interview. Furthermore critical incident vignettes were used to help facilitate the semi-structured interviews but not to dictate the dialogue to the participants. Participants were given the option to either read through the critical incident vignettes themselves or have it read to them. An interpreter was also used to ensure that participants were able to communicate in their preferred language throughout the interview. In this manner the conformability of the data obtained may be argued, as similar results were obtained from both interviews conducted. In this manner triangulation was achieved, in that different methods of data collection were utilized in support of the semi-structured interviews.

### **3.14. Research Ethics**

The following ethical considerations were adhered to throughout the study:

- **Informed consent.** All recruited participants were informed of the study; the purpose of the study; the data collection tool to be used; the data collection procedure and why they were selected as a participant for the study. They were also informed that their

participation in the study was voluntary and that should they wish to withdraw from the study at any point, that they would be able to do so.

- **Confidentiality.** Participants were assured of their confidentiality throughout the study, what would happen to their data and how the findings would be reported and to whom. They were assured that their responses would not in any way affect the service that they would receive at any public health care facility as their name and other personal details would not be provided to anyone.
- **Autonomy and Veracity.** Time was allocated for participants to ask questions prior to the study and throughout the data collection process. A translator was made available throughout the interviews to ensure that the participants were able to clarify and/or ask questions in their preferred language. In this manner, respect for the participant's autonomy and study veracity (truthfulness) was maintained.
- **Ensuring privacy and respect for vulnerable persons.** Given the sensitivity of the topic, ensuring participant privacy and confidentiality was critical. All additional personnel involved in the study namely the interpreter and translators were required to sign confidentiality agreements prior to their involvement in the study. Furthermore each interview conducted was done face-to face and individually, and with no other hospital staff member present. The audio recordings of the interviews conducted were transcribed using a coding system and participant names were excluded. Upon completion of the study all the information relevant to the participants was securely stored and only the researcher was allowed access to it.
- **Beneficence (benefit for others).** Beneficence refers to the responsibility of the researcher throughout the research process to (i) uphold the well-being of their research participants; (ii) to do no harm to the identified participants; (iii) to maximise the benefit received by the participants and (iv) to minimize the potential risks to the participants (Meline, 2010; Orb, Eisenhauer & Wynaden, 2001). The intended aim from this study was to generate valuable information into how everyday clinical decisions are made and to contribute to the existing body of knowledge in this area. The hope is that all who participated and all who read the results will benefit from the findings. It is further hoped that they would empower themselves to make more well informed decisions regarding the assessment and management of different paediatric feeding and swallowing related difficulties. The results of the study will be made available to the health community through conference presentations and journal articles. A presentation

to the medical, nursing and rehabilitative staff at the hospital where the research was conducted at, will also be held.

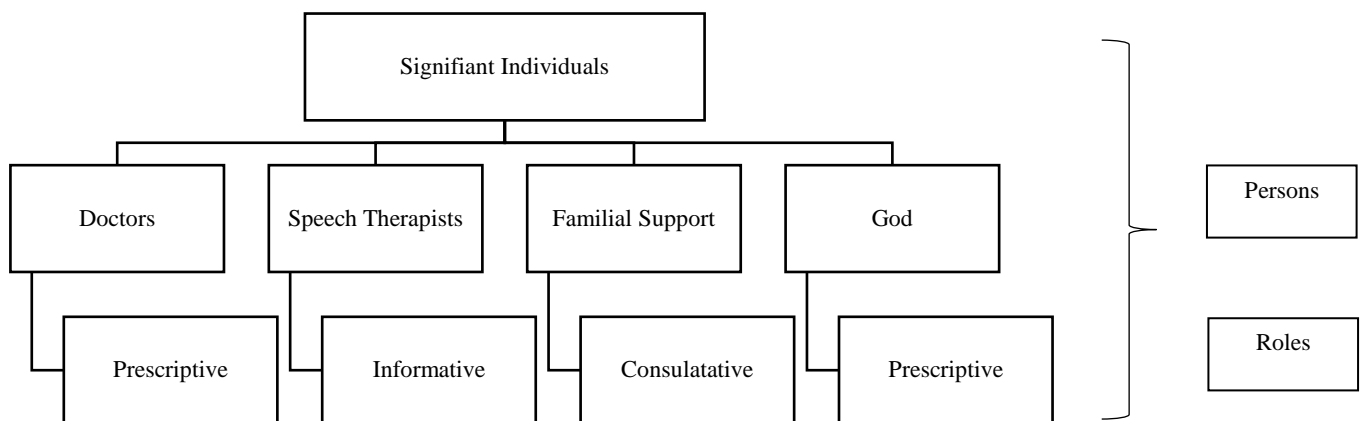
## **CHAPTER 4: RESULTS AND DISCUSSION**

### **4.1. Introduction**

According to Arvedson (2013) children with CP commonly present with feeding and swallowing difficulties that in many cases reduce their overall nutritional status and increase their risk for aspiration. Depending on the severity of the presenting feeding and swallowing difficulty, a PEG may also be considered as a long-term enteral feeding option to ensure adequate nutrition (Zelante, Sarori & Trevisani, 2015). While the advantages of PEG placements are widely reported, complications can frequently co-occur and should thus be adequately considered prior to the placement (Milkes, 2002). Globally, there is a lack of literature exploring how PEG decisions are made for children with CP who have feeding difficulties. Given that the study was conducted within the South African public health care sector, the results obtained have implications particularly for improved service delivery in this sector. The results presented in this chapter are the responses from the two caregivers, these being discussed within each section. The findings are presented here in respect to the three objectives from this study, these include, first to identify the significant individuals involved in making clinical decisions, the second being identifying the factors involved in the decision making process for the caregivers and the third being exploring the caregivers views.

### **4.2. Objective 1. To identify significant individuals involved in the PEG feeding decision making process and their respective roles.**

This section explores the people, who the two caregivers identified as being significant throughout their PEG decision making process. Throughout the interviews, the caregivers identified four groups of individuals, these being: doctors, speech therapists, their family members and God, each with their respective roles (Figure 1).



*Figure 1:*  
*Hierarchical depiction of significant individuals and the roles they perform as indicated by the caregivers interviewed.*

One caregiver interviewed also referenced the tracheostomy team as being influential when considering her decision for a PEG, given her child’s respiratory related difficulties. The other caregiver reported that her child attends physiotherapy out-patient consultations, although no additional reference to physiotherapists was made. The caregivers were also asked to indicate what role the significant individuals played in assisting them with the PEG placement decision.

**4.2.1. Doctors.** Doctors are typically the first to recommend PEG placements secondary to a child’s feeding and swallowing difficulties, and in this way this clinical decision may be seen as prescriptive in its presentation. This recommendation is often supported, given the PEG’s effectiveness as a long term enteral feeding option for patients and due the fact that it is a relatively safe, routine and uncomplicated surgery (Zelante et al., 2015; Milkes, 2002). Furthermore, in public hospitals, where out and in-patient facilities are often over-burdened, under-staffed and under-resourced there is a need to maximise patient discharges, with PEG placements often being encouraged secondary to earlier patient discharges. When considering clinical decision making, the benefits of early collaboration among all stakeholders is encouraged. The caregivers interviewed felt as though their doctors included them and informed them of the PEG and how it would work. One caregiver understood the doctor’s roles prescriptively and unilaterally, and that the PEG placement would help her child. She



repeatedly stated “help with this and this and this”, which alluded to a lack of additional caregiver understanding regarding the PEG. The repetition of the word “this” infers a lack of understanding from the caregiver regarding the function of a PEG and/or regarding the information communicated to her by the doctor. In this scenario this lack of understanding from the caregiver acts to encourage a dependency on the health care professional and appears to re-inforce the development of a power imbalance between the two parties.

P1: (line 151) “They (the Doctors) all told me the PEG would help him with this and this and this”.

Both caregivers interviewed reported that their respective children received nasogastric tube (NGT) feeds upon admission to the hospital prior to their respective PEG placements. This was done secondary to their child’s difficulty in tolerating oral feeds and to ensure that the child would have adequate nutrition. From the doctors, one caregiver understood that her child was vomiting due to his aspiration of the oral feeds, that she gave him, which ultimately resulted in the child needing a PEG. The distinct power imbalance between the health care professional and caregiver is reiterated here, where the health care professionals were viewed as more knowledgeable and authoritative as compared to the caregiver. Ultimately this acts to re-inforce the caregiver-doctor dependency dynamic and enables doctors to unilaterally make decisions for their patients.

P1: (line 165) “They told me that he was vomiting because when I feed him through the mouth, then food goes into the breathing tube. At this time he had a tube through his nose to help him eat. That is why he needed a PEG placed. Before that he was coughing a lot and then vomiting. He tried a lot to tell me that there is something painful when he is eating”.

P2: (line 127) “Yes, he had a nose pipe to help him eat”

Despite an MDT approach to health care being widely publicized and encouraged as a standard of care among all health care professionals, when considering the transcribed data in this study, one caregiver repeatedly used the word “they”. “They” referred to the medical doctors involved in the PEG and tracheostomy placements for the child, and were viewed as capable of prolonging life through their clinical decisions. The continued use of this word,

would indicate that the caregiver allowed for external individuals to make decisions for her and her child, and would support the lack of involvement the caregiver experienced, being part of the MDT. Linguistically, the use of the word “we” would denote caregiver inclusion as opposed to “they” which infers that the caregiver felt excluded from the clinical decision making MDT. Ultimately, this further links to the caregiver and child being seen as passive recipients for whom decisions are made.

P1: (line 12) “Yes, for S (child), when they put the PEG and the trachey stoma everything was fine. It looked like **they** were giving him a second chance to live. I’m fine with everything that has happened with him because I am used to it now”.

P1: (line 75) “Here at (the hospital), **they** told me everything, because it is easier to know the truth than to know nothing... I didn’t want the doctor to just come and write in the file, so I just said “No no no what has happened? What is happening with my child? Is there something wrong or what?” **They** always told me because I was asking a lot about what was happening”.

**4.2.2. Speech Therapists.** The role of the speech therapist was argued as informative, as one caregiver stated that the speech therapists offered her training/information regarding the PEG procedure and management required post placement. This was done through the use of a DVD that was provided and played by the speech therapist.

P2: (line 27) “They (speech therapists) taught us before they put the PEG in about what is going to happen. We watched a DVD and that helped to explain everything about the PEG”.

The caregiver further reported that this method of training was helpful in adequately understanding the PEG more. In this way, the speech therapists’ role, as understood by the caregivers, was informative.

**4.2.3. Familial Support.** Family support was referenced as being important in making the clinical decisions for both caregivers. One of the caregivers referenced how during the PEG decision making process, the child’s maternal grandmother was consulted, as it was important

to her to contact her family and discuss the child's condition prior to consenting for the PEG placement for her child.

P2: (line 40) "L's (child) grandmother also lives with them and they all had to make the decisions together".

In this instance the familial support structure constitutes a consultative role for the caregiver and alludes to greater cultural practices being observed. Respect for the elders in the family must be adhered to, as they are seen as integral when considering the clinical decision making process for the caregiver. The caregiver did not want to make the decision without consultation with her family first. This traditional view and practice is increasingly relevant where, despite an apparent shift toward urbanisation, these practices are still being adhered to. Furthermore families, grandparents and older males in the family are afforded opinions regarding the child's care, despite not actually being the child's primary caregiver. According to Mohonoe (2008), while changes in urban families occur secondary to housing challenges, urbanization, political factors, poverty and economic underdevelopment, most nuclear families form part of an extended family. Within these units, respect and obedience for parents and grandparents are seen as crucial when considering the care for any family member. Thus the role of the grandparents and extended family are seen as an important source for consultation, for the caregiver prior to making the PEG decision. The child and caregiver is viewed as a part of the extended family nucleus, the caregiver does not view herself in isolation as the sole party responsible for making decisions for her child.

P2: (line 43) "They (the family) saw that it is the only way to help the child".

**4.2.4. God.** One caregiver referred to the influence of religious motivation on her decision making, and God was perceived as a key entity when considering the decision to place a PEG for her child. PEG placements are traditionally placed secondary to an individual's inability to safely and adequately tolerate oral feeds (Zelante et al., 2015). The decision to place a PEG should be carefully considered in relation to aspects, such as the individuals cultural, religious, emotional and social values (Schwartz et al., 2014).

According to Ross (2010), when considering health, disability, illness and healing, two approaches traditionally exist, these being the traditional and medical approaches/paradigms.

The traditional approach functions as an extension of the indigenous belief systems as opposed to the medical approach, which adopts the Western Medical approach to healthcare, with a focus on diseases, disorders and medical management (Ross, 2010). Given that approximately two-thirds of the global population rely on traditional or alternative forms of medicine, this factor cannot be excluded when considering how decisions are made.

The article by Beaulieu et al. (2012), advocated for the use of a PEG from the perspective of the Catholic Church, with tube feeding being considered as ordinary care and subsequently morally obligatory. They further advocated a step-by-step procedure to assist with decision making regarding PEG placements (Beaulieu et al., 2012). For many patients, religion provides a consoling and often prescriptive method of dealing with stress, trauma and anxiety among many other emotions. One caregiver reported that her child's need for a PEG stemmed from her intrinsic belief that this was "God's plan" for her child. While this belief is completely plausible, it could also be underpinned by her lack of overall PEG knowledge. The caregiver was equating the PEG placement with a prescriptive divine link and plan for her child and not merely as a method to ensure nutrition. This caregiver also possibly used her faith as a means to cope with her child's difficulties and to rationalise the PEG placement for herself.

P1: (line 22) "I can remember the day they put the PEG...I kept telling myself it was all the plan of God. God was wanting me to be a mother who is not full of something but wanted me to stay with S (child) all this time".

P1: (line 218) "I just pray to God to keep us and keep us carrying on".

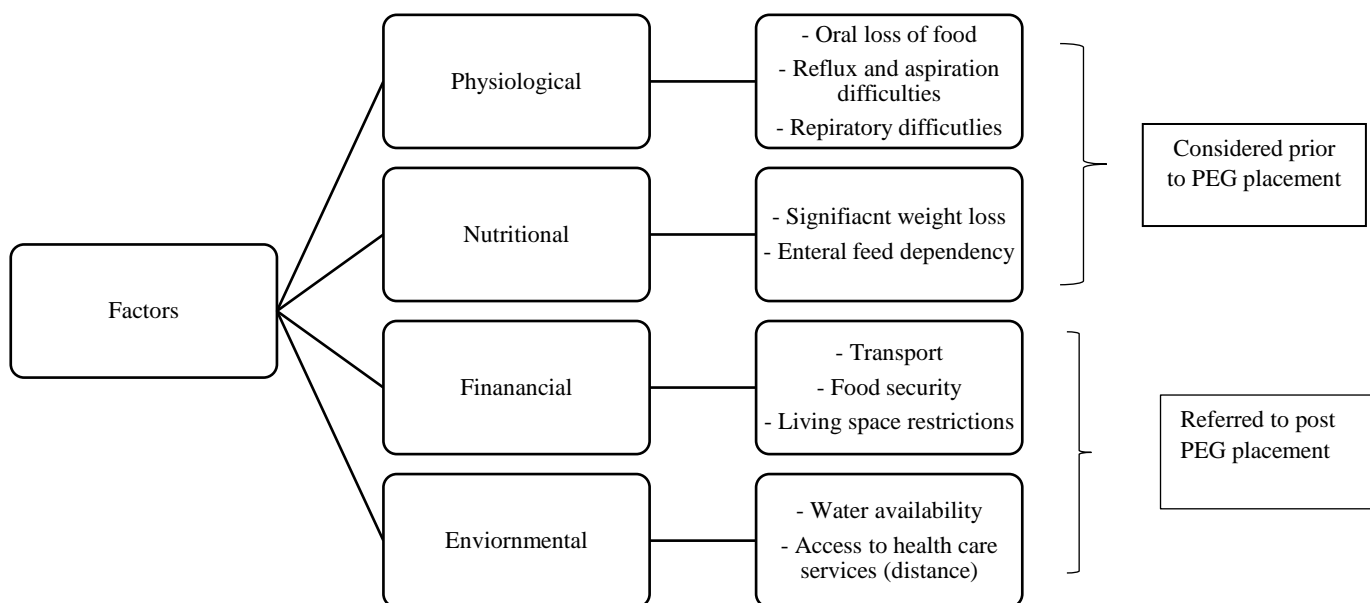
Irrespective of religious affiliation, it is important that health care professionals acknowledge this aspect, and adequately explore religion and culture before deciding on the PEG placement. Where possible, family members/secondary caregivers should also be consulted, given the effects that this can have on the decision making process and subsequent management of the child.

#### **4.3. Objective 2. To identify the factors that affect the decision making process for caregivers of children with CP who require PEG placements.**

The following section presents how extrinsic factors affected the decision making process for the caregivers. Extrinsic factors are regarded as external motivators, for example when caregivers decide to have a PEG placed for their child in an attempt to obtain external benefits, such as improved medical symptomatic management for their children.

On review of the participants' transcripts, four primary categories were identified, namely: physiological, nutritional, financial and environmental factors. Environmental factors constituted three (30%) of the total number of themes identified; nutritional factors constituted two themes (20%); financial factors constituted three themes (30 %) and environmental factors constituted two themes (20%). Based exclusively on the number of the themes identified per category, it would be argued that significant themes for the caregivers interviewed included physiological and financial factors primarily.

From the excerpts obtained, the caregivers referred to the financial and environmental factors post PEG placement and thus did not directly state these two categories as contributing factors when considering the PEG placement for their child. However, the data obtained from these categories infers significant plausible hypotheses regarding the mind-set of the caregivers and challenges/concerns experienced during this period and thus may be argued as possible contributing factors to be explored further.



*Figure 2:*  
*Hierarchical depiction of caregiver factors that extrinsically affect their decision making process.*

### **4.3.1. Physiological factors**

**4.3.1.1. Oral loss of food.** For one caregiver, oral loss of food was indicated as the reason for requiring a PEG placement for her child, this being the loss of all food given via the child’s mouth. The oral loss of food is clinically indicative of difficulties in the oral preparatory and/or oral phase of swallowing (Arvedson & Brodsky, 2002). The results obtained here were similar to a study conducted by Ghayas and Sulman (2013), where the majority of caregivers interviewed indicated that oral feeding difficulties were typical of their children also. That study aimed to investigate how caregivers perceived oromotor impairments related to feeding difficulties in children with CP (Ghayas & Sulman, 2013). Specific oral phase difficulties highlighted, included: sucking difficulties; oral motor dysfunction; drooling; extensor dystonia during feeding; reduced tongue lateralization and hypotonic lingual movements (Ghayas & Sulman, 2013). All of these difficulties could result in increased anterior spillage or oral loss of food. However, the study conducted by Ghayas and Sulman (2013) differed from the current study in that it included a larger population size (122 caregivers of children with CP), with the average age of the children being 9.4 years of age.

P1: (line 5)“...he can't eat with the mouth. Every time he eats with the mouth, everything comes out. So that is why they put a PEG”.

Petersen et al. (2006) reported that oral feeding is seen as the natural/normal method of eating, and that the child who has to obtain nutrition through a PEG is considered “less human” as they are unable to feed orally. Additional concerns included a lack of maternal experience in feeding the child via a PEG, which was perceived as a failure on the part of the caregiver. The child's physical inability to take feeds orally is a contributing factor for the caregiver, affecting her decision to place the PEG for her child. Caregivers in that study also perceived oral feeding as a means to enjoy eating and that the lack of oral feeding reduced the positive meal experience for the child and caregiver and subsequently the overall familial bonding (Petersen et al., 2006). It is important to consider a range of factors in addition to the clinical presentation of the oral loss of foods when deciding about a PEG placement for a child.

**4.3.1.2. Reflux and Aspiration Concerns.** Both caregivers interviewed indicated that vomiting and/or coughing were the initial feeding difficulties noted with their respective children. One caregiver stated that the PEG feeding decision was made after the child experienced increased coughing and vomiting. According to Sullivan (2013) children with CP typically present with gastro-oesophageal reflux disorder (GORD) and delayed gastric emptying due to their foregut dysmotility which further impacts their overall nutritional status and should thus be adequately discussed when considering to place a PEG. Furthermore, the caregiver appeared to have been told that all the oral feeds given to her child was entering the child's “breathing tube”.

P1: (line 16) “They told me that he was vomiting because when I feed him through the mouth, then food goes into the breathing tube. At this time he had a tube through his nose to help him eat. That is why he needed a PEG placed. Before that he was coughing a lot and then vomiting”.

The caregiver further referenced how all the feeds she would give her child was vomited, and how the child physically looked thinner.

P1: (line 17) “Before the PEG, all the food I was giving him would be vomited. He was getting so thin. But when they put all the things, yes S (child) was alright”.

Reflux and aspiration at its basis are medical related conditions that caregivers have very little control over, yet this caregiver chose to interpret these extrinsic events as a primary motivating factor for her child's PEG placement. This extrinsic motivation appears to have been re-enforced by the child's doctors who appear to have used professional knowledge to inform the caregiver about her child's difficulties. This ultimately acted to re-enforce the existing power dynamic and level of dependency facilitating onto the doctors, by the caregivers.

**4.3.1.3. Respiratory Complications.** One caregiver reported that her child's respiratory and feeding difficulties occurred simultaneously and understood the difficulties as an amalgamation of feeding and breathing. This may possibly be due to the child receiving a tracheostomy and PEG simultaneously.

P1: (line 87) "Yes they both happened at the same time" (in response to a question regarding whether or not both the PEG and tracheostomy occurred simultaneously").

When considering additional excerpts from the caregivers' transcript regarding the child's respiratory complications, she appears to compare the child's respiratory complications to feelings of possible embarrassment and emotional pain due to the fact that while in hospital her child had become a visual form of entertainment for others in the ward.

P1: (line 158) "S (child) was not breathing well. Even when someone was walking past the room, they would come back when they heard his breathing, it was so bad. It was so painful, even in the ward, when other people were visiting they would often forget to go to their relatives and instead come to S to ask who this child was. It was painful because I was like a video or TV (television)...".

The child's weight gain was reported secondary to his respiratory difficulties which could possibly infer that the caregiver elected to have the PEG placed secondary to the child's respiratory complications.

P1: (line 17) "Yes, and even his weight, he started gaining because he was even suffering to breathe".



While respiratory complications and feeding difficulties are traditionally considered independently, the last quote alluded to how the caregiver believed that the child's weight gain was secondary to an absence of respiratory difficulties. Keeping in mind that the PEG and tracheostomy were placed simultaneously, the most obvious attribute regarding the child's weight increase would probably be due to the PEG placement. However, the caregiver is validated here as children with CP are more susceptible toward acquiring respiratory complications secondary to the oral-motor dysfunction. Ghayas and Sulman (2013) reported that feeding difficulties have been reported as the cause of most chronic respiratory disease in children with CP.

#### **4.3.2. Nutritional factors**

**4.3.2.1. Significant weight loss.** Significant weight loss was reported by both caregivers and considered to be a contributing factor when deciding on the PEG placement for their respective children. For one caregiver, the significant weight loss was reported due to the child's inability to take feeds orally without subsequent vomiting. The other caregiver quantified her child's weight loss, stating that at three years of age, her child weighed 9kg's. These clinical signs were validated by Arvedson (2013) who reported that often parents may not be able to identify specific feeding and swallowing difficulties but that many are able to reference their child's increased feeding time and/or weight loss, which should be adequately considered when considering a PEG placement. Arvedson (2013) indicated that these difficulties were typically noted in young children under two year of age. Significant weight loss should also be considered in conjunction with stressful mealtimes and respiratory conditions secondary to aspiration (Arvedson, 2013).

P1: (Line 17) "Yes, and even his weight, he started gaining because he was even suffering to breathe. Before the PEG all the food I was giving him would be vomitted. He was getting so thin. But when they put all the things, yes S (child) was alright".

P2: (line 6) "There was no development or weight gain before the PEG and then afterward he started gaining weight....He weighed almost 9kg's at 3 years old before the PEG".

**4.3.2.2 Enteral Feed Dependency.** Both caregivers interviewed reported that their respective children received nasogastric tube (NGT) feeds upon admission to the hospital prior

to their respective PEG placements. This was done secondary to their child's difficulty in tolerating oral feeds and to ensure that their children would have adequate nutrition. The caregivers believed that the enteral feeding options allowed for their children to feed safely.

P1: (line 165) "They told me that he was vomiting because when I feed him through the mouth, then food goes into the breathing tube. At this time he had a tube through his nose to help him eat. That is why he needed a PEG placed. Before that he was coughing a lot and then vomiting. He tried a lot to tell me that there is something painful when he is eating".

P2: (line 127) "Yes, he had a nose pipe to help him eat".

### **4.3.3. Financial Factors**

Financial factors were not explicitly stated by the caregivers as a contributing factor considered when deciding for the PEG placement, but were indirectly inferred from the references made to transport difficulties, food security and living space restrictions. These financial factors are discussed as they speak to the mind-set of the caregivers and the specific on-going challenges/concerns they experience. Transport difficulties were reported in relation to accessing the health care institutions. Food security was reported in relation to the difficulties the caregivers experienced in obtaining nutritious foods in a safe manner for their child. Living space difficulties were reported in relation to not being able to afford adequate space for her child and having to live with her extended family in a small space, with all three factors being detailed below.

**4.3.3.1. Transport Difficulties.** One caregiver interviewed was dependent on a monthly social grant to be financially able to care for her child. A primary financial concern for the caregiver was that in addition to the groceries and insurance she contributed towards monthly, she was also required to save towards paying for private transportation costs to access the hospital for her child's follow-up consultations, as public transportation was not a feasible option for her child. This meant that approximately 20% of the family's total monthly income was spent paying for each trip to the hospital. Similar arguments were referenced by Saloojee et al. (2007) who argued that private transportation is often required for children with disabilities given that public transportation does not accommodate them.

P1: (line 109) "...Sometimes things are bad because I'm not working and I'm dependent on a social grant for S (child)...When I receive the grant for S (child), I must give R400 for groceries, then I must give money for insurance for S (child) and I. I also have to save to come here. I can't come with the taxi because they won't take us from the road. If I come with the taxi I have to pay for me, for the chair, for the person coming with us because I must give S (child) to that person when getting into the taxi. I can't stop the taxi when we getting in. I can't give another person to hold him because he will be so scared. But now I hire the taxi car for R200 to go. Even to attend the CP clinic I must hire that care with that money. Even with that money I have to get S something to eat and dress and even for me".

Another quote, highlighted one caregivers need to understand more regarding the PEG and how it was placed, which was done on their first visit, as a follow-up consult would be difficult given that the family lived far away from the hospital. This speaks to the caregiver's concern regarding financial challenges, as she would be unable to access the hospital regularly if there were difficulties experienced with the PEG feeding tube. This acts to support the point raised earlier, namely that caregivers incurred increased financial challenges in their attempt to access health services. To avoid this, the caregiver decided to seek out health education to empower herself. While it was commendable to note the caregivers decision to enquire and educate herself further, one cannot help but consider other caregivers who do not do so, and how that may affect their decisions. Thus, a practical method for caregivers and their children to access therapy sessions regularly needs to be established. Saloojee et al. (2007) argued that further research is required into the impact that transport subsidies may have when considering healthcare access for disabled children.

P1: (line 68)"...I told the doctor I want to see how it is being put in and how it is done because it is too far for me to come here again. When they were doing it, I could see that this thing is not that difficult. I just needed to be strong"

**4.3.3.2. Food Security.** One caregiver alluded to food avoidances that her child had possibly due to a food refusal and/or the child's inability to tolerate certain feeds orally. The caregiver reports that she received some feeds for the child via her base hospital but that she needed to buy additional feeds for the child. This is linked to the increased financial challenges

experienced by the caregiver when having to care for her child, and the concern associated with accessing feeds.

P1: (line 129) “Yes, because S (child) is not eating every kind of food. Some food I take from the provincial hospital but I still need to buy him something to eat. Sometimes when the foods are not available I have to buy the food myself...”

**4.3.3.3. *Living Space Restrictions.*** Taking care of children with disabilities is arguably demanding and challenging for caregivers, particularly for single-parent families, where the child’s disability grant constitutes the only income. However, with increased expenses for child care, affording alternate accommodation options often became an increased financial burden that the caregivers simply cannot afford. One caregiver attributed her lack of financial resources to her inability to provide her child with the space she believed he required for his care. Furthermore, the caregiver’s inability to assist her family financially and the lack of socialisation for her and her child within her family was also reported.

While not directly linked to the PEG decision making, this theme does appear to indirectly be linked with the caregivers’ belief regarding the importance of her environmental and financial challenges. Thus it can be argued that this may have been a contributing thought process for the caregiver when considering the PEG placement for her child, a new and traditionally unfamiliar method of feeding her child.

P1: (line 176) “Yes, the part about them living far away with no water or nothing, water is so important. For me I have water, but sometimes I wish I had a space for S (child). We are full at home. We even share the bed. We are 9 or 10 of us in a 6 room house. S and I sleep in one room and it’s hard because they can’t sleep with us. I wish I had space for myself but how can I because I don’t have money. My grandfather goes to the bathroom outside so he can give S (child) and I space. My family tries a lot to help”.

#### **4.3.4. Environmental Factors**

**4.3.4.1. *Water availability.*** Similarly to the category referenced above, the caregivers did not explicitly refer to environmental factors as a contributing factor when considering the PEG placement for their children. However on review of the excerpts related to environmental

factors, it may be argued that these considerations are valid and need to be explored given that they relate to broader, functional concerns for the caregivers when caring for their children. One caregiver highlighted the importance of having access to water in the home environment to assist with child care and general hygiene, specifically with reference to the vignette presented. This particularly speaks to how people living in rural areas are able to acquire water in contexts where it is not readily available or accessible. When considering PEG placements for children, it is therefore important to adequately consider the family environment and context.

P2: (line 60) “Yes, it is important because for them for example, they are from the rural areas, so sometimes they have to take water from the (rivers), any kind of water, because they don’t have taps. Sometimes they need to take water from the river etc. so it is really important to consider the environment for such places especially”.

#### ***4.3.4.2. Access to health care services.***

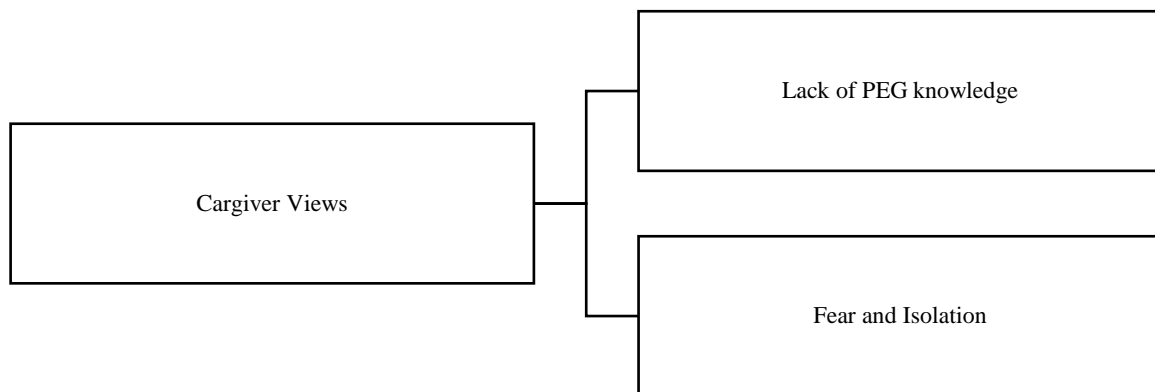
One caregiver referred to the fact that she and her child lived far away from the hospital and further elaborated that the level of care they received at this hospital is different from the care they received at their local hospital. While this distance was not referred to as a contributing factor for the caregiver when considering the PEG placement, the inference here is that for the caregiver, the health care services that her child receives elsewhere is “not the same”. Thus the plausible assumption here in relation to the PEG, was that the caregiver possibly felt as though the PEG tube, could require additional medical monitoring which was inaccessible for her and her child. The researcher acknowledges that this is was not explicitly stated by the caregiver and that this section is reliant on inferences however, one undisputed point here is that doctors at the preferred hospital have cultivated a level of dependency from the caregiver and interestingly have adopted almost a parental role for the caregiver and child.

P1: (line 109) “I even told them (doctors) that sometimes I wish that I lived her and didn’t live so far away, because they treated us like their own children. Even when I have questions, I can ask here, when we go home it’s not the same...”

**4.4. Objective 3. To explore the views regarding the decision making process for caregivers’ of children with CP with feeding and swallowing difficulties who required PEG placements.**

This objective aimed to explore how caregivers were intrinsically (internally) motivated in their decision making process regarding their child’s need for a PEG placement. Intrinsic motivators are understood as decisions made that are personally rewarding to the caregivers. Despite there being a distinct lack of literature in this area, the few international studies that investigated decision making factors in caregivers of children with CP who required PEG feeds, highlighted a multitude of different intrinsic motivations. These included, dealing with stigma, loss of maternal competence, attitudinal barriers, disappointment, relief and considering the enteral feeds as “unnatural” (Backx, 2008; Petersen et al., 2006; Spalding & McKeever, 1998). As a result it is increasingly important to adequately consider all the emerging caregiver views as expressed in the interviews conducted.

Two caregiver views were ultimately identified from the analysed participant transcriptions, and are indicated in figure 3 below.



*Figure 3:  
Hierarchical depiction of caregiver views that intrinsically affect their decision making process.*

#### **4.4.1. Lack of PEG Knowledge**

One of the key themes identified for both caregivers interviewed, was that the PEG was “new” and unfamiliar, and that they had a lack of PEG knowledge prior to their children receiving a PEG. Both caregivers reported how they had not been exposed to anyone else in their families and/or environments who required a PEG previously. This novelty thus contributed to the fears personally experienced by the caregivers as well as their families at home due to overall lack of knowledge regarding the PEG.

When considering children with CP who have feeding and swallowing difficulties, enteral feeding options are frequently being recommended as a management option (Backx, 2008). Given the fact that caregivers are primarily responsible for their children, understanding their perceptions was important, given the implications of the PEG and subsequently the need to adhere to management recommendations (Backx, 2008; Petersen et al., 2006). Backx (2008) conducted a review of studies in an attempt to explore the perceptions of gastrostomy tube-feeding in caregivers of children who have CP. While the studies reviewed differed from the current study in respect to their methodology, they had similar themes regarding the need for a greater understanding of PEG’s and of how it would fit into the families’ daily life.

P1: (line 53) “This situation for S (child), it was even the uncle at home with the same with the brain affected but not like this, with the PEG and trachey, was a new thing”.

P2: (line 52) No, no one (in response to question regarding whether there were other children at home with similar difficulties and needed a PEG)

P1: (line 64) “There was one time when the PEG came out and I went to the (base hospital) and I was afraid because I didn’t know what to do. What if it closes? They will have to do another operation...”

P2: (line 48) “It was new and they didn’t know about it but it got better”.

It is important for all health care professionals to understand and explain all the factors regarding a PEG to a caregiver prior to placement. Despite PEG placements becoming more popular, for caregivers it can be a relatively new procedure, particularly when not previously exposed to a PEG in their social context. Enteral feeds essentially altered the caregivers

perceptions about how feeding could occur, forcing them to use an alternate, and in many cases socially, unfamiliar method of feeding. It is therefore essential that health education and support be provided to these caregiver prior to, during and post PEG placement.

#### **4.4.2. Fear and Isolation**

Caregiver fear and social isolation/stigma appeared to be linked to the caregivers' lack of familial support (isolation), personal fears and community based fears. Furthermore, one caregiver appeared to present herself in an optimistic and happy manner to ensure that her child and his PEG was accepted by her family. This inferred feelings of isolation, fear and personal anxiety, as she believed that if she showed her family and others in her community that she was sad/unhappy, her child would not be accepted and would be socially stigmatised.

These results resonated with the study conducted by Spalding and McKeever (1998) where mothers reported that the task of feeding their child in many cases was their responsibility exclusively, which resulted in them experiencing feelings of frustration, self-doubt, worry and resentment. The majority of the caregivers interviewed in that study, reported being initially hesitant to consent to the procedure. They eventually consented due to their exhaustion at the repeated unsuccessful oral feeding attempts or when they believed their child's life was endangered. An important difference between the study by Spalding and McKeever (1998) and this research is they focussed on children with disabilities rather than children with CP.

Petersen et al. (2006) further argued that several caregivers with children with CP interviewed in their study highlighted the stigma they often experienced. The caregivers were concerned that people would view their children with gastrostomies as "things" as opposed to people. They were further concerned that this could result in increased isolation, discrimination and stigma, which would serve to isolate them as caregivers (Petersen et al., 2006). The caregivers also worried about how others would perceive the children when watching them feed via the tube as opposed to the "natural" oral method (Petersen et al., 2006). The study differed from the current research in that it had a greater number of participants and another medical diagnosis, namely not CP.

P1: (line 144) "Because I was alone here, I had to make the decision myself. I think I if didn't make the decision, I don't think S would be alive. I didn't tell anyone, I just told



my mother that they (the Doctors) put this thing and this is what happened and when I came home they (the family) saw it. They (the family) were scared of it but they accepted it. I always made sure that in front of them I was happy and fine. They accepted the decision because I was fine and they were looking at me, like how I was feeding him”.

P1: (line 47) “Yes, and every time as the mother you have to be strong to show them (other people) that there is nothing wrong. Even if you see that there is something wrong, you must tell yourself to be strong. For me, when something was wrong, no one at home saw me crying. I always went out of the house to cry and wiped my face before going back into the house. I was worried what would happen to S (child) if I cried in the house”.

P1: (line 215) “I told myself not to be scared and that all the time must be happy. Even when something is wrong I must smile and I always smile and then the people look at S (child) and say “he’s so big, he is so beautiful with so nice clothes” and then they just forget about the trachey and all this stuff. I just pray to God to keep us and keep us carrying on”.

P1: (line 210)” Sometimes our children are not recognised by people because people are scared of our children sometimes but when there is education for the mother, then they (the people) look at her and say “she’s a strong one” and I try when something is wrong with S (child).

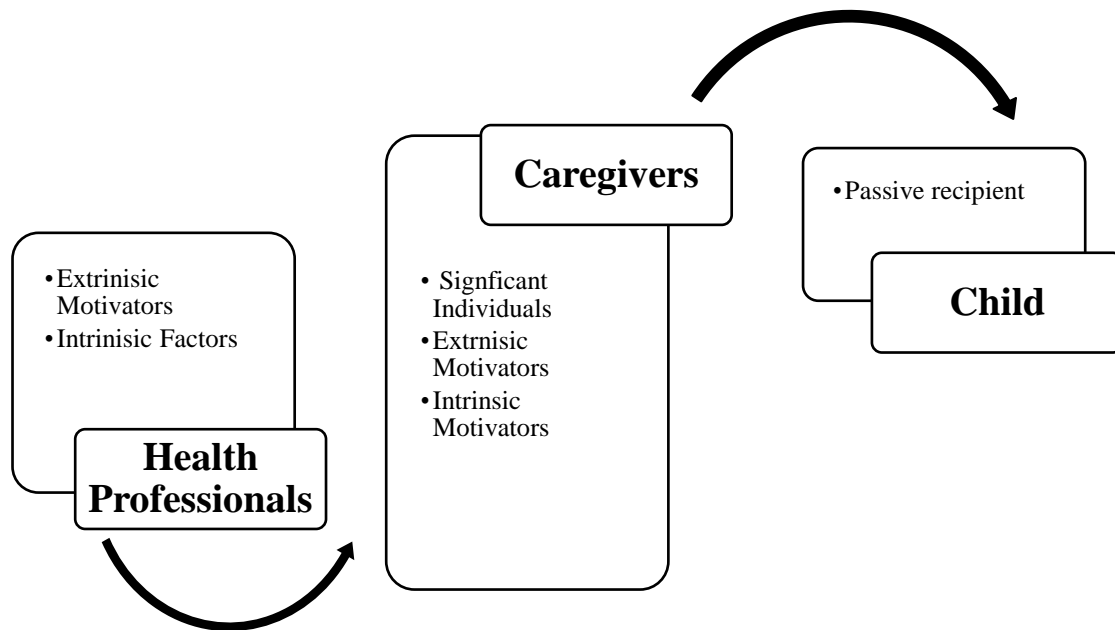
P1: (line 184) “Yes, I try because even when I need to go out I go quickly and come back I don’t stay out to long...”.

According to Spalding and McKeever (1998), feeding difficulties in children with disabilities were a source of considerable distress for the caregivers. Feeding had a symbolic representation for many caregivers, who often blamed themselves and/or experienced blame from others due to their child’s inability to tolerate oral feeds. As previously alluded to, PEG’s are often new to the caregivers, which further compounded their distress. They felt as though they were required to limit their social activities to ensure that they were available at home to care for their children. Familial fear regarding the child’s condition and PEG was also a

contributing factor towards the caregivers' isolation. Health care professionals need to educate and support caregivers regarding PEG placements and ensure that resources are provided to assist them with the emotional fear and any subsequent isolation they may experience. As previously alluded to, the decision to place the PEG was possibly prescriptive in its approach.

#### **4.5. How clinical decisions are made**

Theoretically the global consensus regarding clinical decision making encourages collaboration among all stakeholders while adequately considering all contributing factors. This is being done in an attempt to optimize and maintain the interventions implemented. However practically, clinical decisions for children are still largely made at the discretion of a single health care discipline and are often motivated from a paternalistic approach. Health care professionals are often influenced by their own intrinsic and extrinsic motivators that affect their clinical decision making (Hajjaj et al., 2010). The study conducted by Pain et al. (2016) argued that health care professionals (medical, nursing and allied health professionals) make unilateral decisions for their patients and consult/use other allied health care professionals' notes when attempting to obtain specific pieces of information to support their own professional needs. While this approach explores specific aspects of their patients' functioning it does not consider them holistically (Pain et al., 2016). This was supported in the current study, where the primary motivation focussed on medical benefits for the child (improved nutrition, weight gain, reduced aspiration risk etc) and not holistic management. Caregivers are also motivated by their own intrinsic and extrinsic motivators which are not adequately considered by health professionals. The caregivers appear to have made decisions for their child based on the health care professionals' recommendations. The children in the study were seen as passive recipients for whom caregivers made decisions for, as the child was unable to actively participate in the decision making process. Figure 4 below depicts the decision making process, with the "more knowledgeable" health care professionals informing the caregivers on the various and "best options" for the child. The caregivers then need to make the final decision about what should happen to their child.



*Figure 4*

*Flow-chart representation of how clinical decisions are made.*

Children with persistent feeding and swallowing difficulties are often at risk for developing complications, for which they may require medical management. On admission to a health care facility, these children are seen by health care professionals, usually doctors and nurses, with the former being responsible for making the initial clinical decisions regarding the child and subsequent referrals. These clinical decisions are often made at the discretion of the doctors extrinsic and intrinsic motivators (Hajjaj et al., 2010). Some of the extrinsic motivators highlighted include: the child’s medical difficulties; feeding and swallowing difficulties and/or prognosis; symptoms; hospital policies and procedures; bed occupancy; financial implications and legal/ethical guidelines (Hajjaj et al., 2010). Intrinsic motivators include: the health professionals’ age, gender, personal beliefs/preferences and religious beliefs (Hajjaj et al., 2010).

Doctors generally make the clinical decision for a child with CP to have a PEG placed, which may be made in consultation with other health care professionals. At this point, the doctors and rehabilitation professionals may advise this option to the caregiver. From the results of this study, it appeared that the current medical difficulties and PEG benefits regarding this aspect were discussed with the caregivers, who appeared to make their decision largely based on this recommendation. No consideration appears to have been given by the health care professionals, to the caregivers regarding influences such as: religious factors; environmental

resources and/or challenges; financial difficulties associated with health care access and food security, and family understanding and support post PEG placement. It also did not include the caregivers own personal related factors, namely: their emotional reactions associated to their child requiring a PEG placement. Without adequately considering these aspects, the decision to place a PEG may be prolonged and/or resisted completely by the caregiver, which affects the long term management for the child.

This is particularly relevant when considering the mission of the South African Department of Health Strategic plan 2014/15 -2018/19 namely to improve health through the prevention of illness and disease, the promotion of healthy lifestyles, and to consistently improve the health care delivery system by focusing on access, equity, efficiency, quality and sustainability. PEG placements, not adequately cared for, may contribute to the child developing subsequent complications which ultimately acts to re-direct the child to the hospital and doctors and increases the health care demands for the child, caregiver, health care professionals and hospital.

The child in the clinical decision making process is ultimately a passive recipient of the PEG placement, and may not be involved in the clinical decision making process. Depending of the severity of their CP, they may also experience communication difficulties that prevents them from verbally expressing themselves. Ultimately, they are then viewed as the legal responsibility of their caregiver. It is important to note that CP is a motor (movement) disorder and that with adequate support, the child should be assisted to achieve their highest level of individual functioning and not be merely a passive recipient. They should therefore be included in the decision making process as much as possible, with the social, spiritual and emotional needs of the caregiver also being accommodated.

## CHAPTER 5: CONCLUSION

### 5.1. Introduction

The aim of this study was to explore how clinical decisions are made for children with CP who required PEG placements secondary to their feeding difficulties. By reviewing the findings of each objective, the extent to which the study problem was addressed and the aim achieved, will be evaluated further in this chapter. This is followed by the study limitations, the significance of the findings, and recommendations for further research.

The study aimed to investigate how PEG feeding decisions are made by caregivers for children with CP who experienced feeding and swallowing difficulties, in the public health care sector in KwaZulu-Natal, South Africa. The results obtained would argue that this aim was achieved. Clinical decision making for caregivers does not occur in a vacuum, but rather as a result of the input received from different individuals, and the extrinsically valued factors and intrinsically valued views that the caregivers innately perceive. The aim of the study was envisioned through an exploration of the different objectives in an attempt to investigate the success of the research study further. Each objective will now be highlighted and significant findings for each detailed, in respect to how they ultimately support the research aim.

Objective one provided insight into the significant individuals identified by the caregivers and their specific roles in the decision making process. It is interesting to note the degree of importance the caregivers placed on the input provided by their doctors especially, and how dependent they are to their recommendations. The distinct lack of input from other health care professionals was also interesting to note, despite the valued contribution that they theoretically provide. The caregivers may also be part of an extended family where importance is given to the input/support from others when making decisions, which may not always be possible in high-intensity environments, like hospitals, where clinical decisions are required quickly. Religious influence is valued differently, by caregivers, and it is thus important for all health care professionals to be aware and respectful of this for their patients. By investigating significant individuals involved in the clinical decision making process for the caregivers, and the influence they have, a greater degree of MDT input and education, policy development, patient management and service delivery can be achieved.

When considering Objective two, namely the caregiver factors involved in the decision making process, the resounding motivator appeared to be the child's medical improvements. However, this was not the only factor referenced, with nutritional factors, financial difficulties, and environmental concerns also being highlighted. When discussing the enteral feeding option with caregivers, it is important for health care professionals to consider different factors that may be relevant and not just the medical benefits for the child, as this ultimately has implications for how decisions are made.

Objective three explored the views that intrinsically motivated the caregivers' decision making process. Caregivers are often exclusively responsible for their child, and for making major decisions without adequately understanding all the information and surgical procedures required. PEG feeding tubes, while increasingly common place within the health care context is often exceedingly new and unfamiliar for caregivers, and health care professionals should thus be considerate and respectful of this when managing children in their care. Furthermore caregivers of children with CP often experience feelings of fear and isolation for both their child and themselves. It is thus very important that health care professionals be mindful and considerate of these views as they collectively affect how the caregiver will ultimately make a decision.

The results of the study were hoped to: positively contribute to available research in this area; assist with developing initiatives and policy to improve service delivery and patient management in the public health care sector and to further assist with understanding clinical decision making, particularly when considering children with CP who required PEG placements. Prior to this study, limited research was available in this area and no similar research was available from a public health care perspective in KwaZulu-Natal. The results from the study provide valuable insight into the factors and views considered by public health care patients and in particular caregivers of children with feeding and swallowing difficulties. Health care professionals have the responsibility to educate themselves and empower their patients to make informed and collaborative decisions, and to improve the health care services provided.

Furthermore, by dispelling inaccuracies and educating caregivers regarding the medical advantages and disadvantages of the PEG, managing caregiver concerns becomes easier. By identifying factors that extrinsically motivate or create feelings of stress and/or despondency

among caregivers, a greater attempt toward creating sustainable initiatives that increase health care access for caregivers and create independence regarding enteral feeds may be acquired. In utilising this approach, a culture of proactive caregivers and health care professionals, who are actively involved in the child's management, may be cultivated. In this way caregivers are empowered in respect to implementing the management goals for their child.

One emerging theme that needs to be highlighted here, is that despite the health care initiatives and improvements that have been implemented to assist patients, caregivers of children with disabilities still experience a great deal of social stigma and isolation due to their child's condition. Caregivers who do not adequately understand all the aspects involved with their child's condition cannot be expected to implement management goals successfully, thereby resulting in recurrent diseases and difficulties that would otherwise be avoidable. Health promotion is thus vital and the need for caregiver, family and community education is raised, given the fact that without it, the demands placed on all stakeholders, including the public health care sector in the future will continue to increase. Health education is primarily conducted by communicating with others and can be done in a variety of different settings, namely hospitals, clinics and schools. Through health promotion/ education initiatives, the hope is that a greater degree of awareness, learning and education regarding the roles and responsibilities of the different team members may occur. This is ultimately done in an attempt to improve the services offered and acknowledge all stakeholders involved.

## **5.2. Critical Appraisal**

**5.2.1. Strengths.** This research study is unique in that no other study, exploring enteral feed decisions within the CP population has been conducted before. Thus, the results obtained have implications for operational policy development, caregiver and health professional empowerment, MDT advocacy for clinical decision making and practical service delivery initiatives. Ultimately, a precedence is now argued that health care services at public hospitals in South Africa, need to be changed from the outdated paternalistic approach to a family-centred approach that prioritizes MDT involvement and considers all caregiver related factors and views. In this manner, sustainable and positive clinical decisions may be made to ultimately improve the quality of life for thousands of children currently living in South Africa and affected by CP. It is thus hoped that by conducting this study and encouraging similar research studies that more can be done for these children and their families. This study has thus provided an excellent basis for such research advocacy and as the primary researcher, I feel proud of the

research study conducted and confident that this study will contribute to positive literature and initiative development in the future.

**5.2.2. Limitations.** The biggest limiting factor in this study was the population sample size and the reduced variation within the sample, with reasons for this including: (i) The participants were recruited from one hospital only; (ii) Incorrect and/or discontinued contact numbers were often provided by some of the caregivers who could then not be contacted; (iii) Where correct contact numbers were available, no follow-up consultations were reported; (iv) Financial difficulties were reported by the caregivers as preventing them from coming back to the hospital for the interviews and (v) Some caregivers did not disclose additional appointments they had on the same day that resulted in them not attending the interview.

### **5.3. Implications and Recommendations**

The aim of the study sought to investigate how clinical decisions were made by caregivers for their children with CP who required PEG placements. While the aim links specifically to a particular population group, the implications for clinical decision making in general, for all health care professionals within the paediatric population may be argued. The results obtained particularly highlighted the need for a more comprehensive MDT approach when managing these children, which includes the caregiver's involvement.

Medical doctors appear to be prioritised within the clinical decision making team and this needs to change in the public health care sector in South Africa. Clinical decisions cannot be made at the discretion of a single health care professional discipline as it simply not sustainable, and often results in an increased burden placed on health care services, and in the long term management required for these children. Children with CP who require PEG placements need to be managed within an MDT approach, where different aspects of the child's physical, emotional and social abilities are considered. The child's physical difficulties cannot be viewed in isolation or as more important, but should rather be seen as a part of a comprehensive whole. As a result greater initiatives should be conducted at Higher Education Training Facilities, in the form of curriculum development at an undergraduate level, to educate health care professionals regarding other disciplines and the roles they play within the management of these children. Further health initiatives should also be encouraged regarding the need for collaborative clinical decision making among all stakeholders, given that legal and ethical implications for all health care professionals in South Africa. Litigation and service



delivery challenges, particularly in the public health care sector is also a growing concern when considering children with CP who require PEG placements, thereby emphasizing the need for improved caregiver and family education.

Within a public health care setting, health care professionals are required to adhere to different policies as approved by the National Department of Health. While a collaborative MDT approach is nationally recommended, the implementation and enforcement of this is arguably lacking, as demonstrated in the study. In light of this, the results of the study thus have implications for institutional policy changes and/or development. Without the proper planning and implementation of policies and guidelines, health care professionals will continue to function in isolation thereby ultimately increasing the service delivery demands for the institution.

The results from the study has recommendation for further policy development and implementation from a national level. Subsequently at provincial level, more support needs to be provided regarding the provision of resources (funding, procurement and infrastructure) and supporting district health care institutions. At a local government level, namely district health care institutions and clinics, more education initiatives need to be conducted to encourage patient education and empowerment. Education with health care professionals should also be encouraged. Furthermore follow-up consultations should also occur as a means to ensure the success, compliance and implementation of previous training initiatives. Outreach activities at local hospitals and clinics should also occur and actively supported where possible.

#### **5.4. Conclusion**

More research in the area of clinical decision making needs to be encouraged, particularly within the paediatric population. In a developing country like South Africa, with access to research and resources, it seems inconceivable that unilateral clinical decisions still occur. This is not in keeping with the Vision and Mission of Health Care in South Africa, and simply stated it is not sustainable. Children with NDD who present with feeding and swallowing disorders are increasing. In a country plagued by poverty, unemployment and co-morbid conditions like HIV/Aids and Tuberculosis (TB) improved service delivery initiatives are crucial.

While numerous guidelines and policies have been recommended and encouraged regarding a collaborative MDT approach, the reality particularly in the public health care sector in KwaZulu-Natal, South Africa is that this is not practiced. Health care professionals and medical doctors in particular are still unilaterally making clinical decisions for these children and their caregivers. Furthermore, social, cultural and environmental influences for caregivers are not being adequately considered enough by health care professionals when making clinical decisions and caregivers are often not sufficiently included within a comprehensive MDT. If this continues, the increased impact on service delivery and wastage of resources within the public health care sector is inevitable. Greater health promotion initiatives targeted at improving caregiver education and proactive clinical decision making needs to be encouraged. By including caregivers in the management of their children and listening to their concerns, better sustained clinical decisions can be made, which ultimately improves the quality of life for all involved.

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## APPENDICES

### Appendix A: Participant Screener

Number:	Childs' initials:	Age:	Genders:	Language:	Medical diagnoses:	Date of admission:	Date of discharge:	Inpatient enteral feeds:	Placement of PEG prior to admission:	Placement of PEG during hospital admission:	PEG placement recommended but not placed:	Additional comments:

## **Appendix B: Critical Incident Vignette's to be used during the semi-structured interviews (English version)**

### **Critical Incident Vignette: One**

Nhlakanipho Dladla is a 5 year old boy with Cerebral Palsy (CP). CP is described as a difficulty with the child's brain that is caused by different reasons and affects the child's ability to move, to talk and to eat. Nhlakanipho has difficulty moving his arms and legs and they almost appear to be stuck. According to his aunt, Nhlakanipho coughs when he drinks liquids (like water or juice); he eats porridge and soft foods (mashed potatoes or butternut) but vomits every time after eating. Nhlakanipho is currently being fed with a feeding tube. Nhlakanipho's feeding tube is called a PEG feeding tube and is placed directly into his stomach, through which he gets his food, to help him to eat safely. Currently Nhlakanipho lives with his aunt (his mother's sister) and 2 cousins (aged 3 and 5 years old respectively). The family receives a monthly grant for Nhlakanipho as his aunt currently does not work. Nhlakanipho has never attended school or crèche and the family does not have clean running water or electricity. They currently live in a rural village that is 2 hours from their nearest clinic and 3 hours from their closest hospital.

### **Critical Incident Vignette: Two**

Princess Mkoba is 6 year old little girl with Cerebral Palsy (CP). CP is described as a difficulty with the child's brain that is caused by different reasons and affects the child's ability to move, to talk and to eat. Princess is unable to sit by herself or walk and needs a special wheelchair to help her to move around. Both Princess's hands and legs are difficult to move and they look almost stuck. Every time Princess eats, she coughs and vomits after. Princess is currently in hospital and because of her problems with eating food, she is getting her food through a feeding tube. Princess's feeding tube is called an NGT and is placed through her nose and into her stomach to help her eat safely. Princess's doctor is advising her family now about a PEG feeding tube. A PEG feeding tube is described as a tube that is placed into the child's stomach, through which she would get her food, to help her to eat safely. Princess currently lives with her mother and younger brother (3 years old). Her mother is currently not working and is dependent on Princess's monthly grant to help her care for the family. Princess has never attended school/crèche and the family stay in a rural area that is about 4 hours away from the closest hospital. They do not have clean running water or electricity at home.



### **Critical Incident Vignette: Three**

Lindo Zuma is a 4 year old boy with Cerebral Palsy (CP). CP is described as a difficulty with the child's brain that is caused by different reasons and affects the child's ability to move, to talk and to eat. He currently lives with his mother and older brother (9 years old). Lindo is currently attending his follow up Speech Therapy, Occupational Therapy, Physiotherapy and Dietetics consult at the hospital. He previously had a PEG feeding tube placed because he had difficulty eating all food types. A PEG feeding tube is placed into the child's stomach, through which he gets his food, to help him to eat safely. Every time Lindo would eat he would cough. He was also unable to sit by himself or walk and was losing weight. Every time Lindo would eat food he would cry and it was very difficult for his mother to feed him. After his PEG placement Lindo's weight increased. After a while Lindo started eating from his mouth again and improved enough for his PEG to be removed. He is now able to maintain his weight properly and meal times are now more enjoyable for both Lindo and his mother. He is also starting to learn how to sit and move himself around. Lindo's father works and his mother stays at home to look after him. His older brother is in grade 3 at a nearby school. Lindo's family lives about 15 minutes away from the hospital and his mother is able to bring him every month for his follow-up appointments.

### **Appendix B: Critical Incident Vignette's to be used during the semi-structured interviews (isiZulu version)**

#### **Isimo esibucayi: Esokuqala**

UNhlakanipho Dladla ungumfana omncane oneminyaka eyi-5 onesifo ekuthiwa iCelebral Palsy (CP). ICP ichazwa njengobunzima obukwingqondo yengane ebangelwa izizathu ezahlukene futhi zithikameza ukuba ingane ingakwazi ukunyakaza, ukukhuluma, kanye nokudla. UNhlakanipho unobunzima ekugwinyeni nasekudleni. Ubuye angakwazi ukunyakazisa ingalo kanye nezinyawo futhi zibukeka zibambekile. Ngokusho kuka-Anti wakhe, uNhlakanipho uyakhwehlela mayephuza izinto eziwuketshezi (ezifana namanzi/ijusi). Uyalidla iphalishi kanye nokudla okuthambile (amazambane abhucwiwe noma ithanga) kodwa aphilaze ngaso sonke isikhathi mayeqeda ukudla. UNhlakanipho okwamanje udla ngepayipi ekuthiwa iPercutaneous Endoscopic Gastrostomy (PEG). iPEG ichazwa njengepayipi kumbe ishubhu elifakwa esiswini sengane elimsiza ukuthi adle kangcono. Okwamanje UNhlakanipho uhlala no-Anti wakhe kanye nabazala ababili (eneminyaka emithathu (3) nemihlanu (5) ngokulinganisa). Umndeni uyayithola imali yesibonelelo nyanga zonke njengoba Anti wakhe engasebenzi. UNhlakanipho akakaze afunde iskole/inkulisa futhi umndeni wakhe awunawo amanzi ahlanzekile nogesi. Bahlala endaweni esemakhaya okuthatha amahora amabili ukuya eMtholampilo oseduze kanti amahora amathathu ukuya esibhedlela esiseduze.

**Isimo esibucayi: Esesibili**

UPrincess Mkoba intombazane encane eneminyaka eyi-6 unesifo ekuthiwa iCerebral Palsy (CP). ICP ichawa njengobunzima obubasengqondweni yengane okubangelwa izizathu ezahlukene futhi zithikameza ingane ukuba ingakwazi ukunyakaza, ukukhuluma kanye nokudla. UPrincess akakwazi ukuzihlalela, nokuzihambela futhi udinga inqola yokuhamba ukuze akwazi ukwenza into ayithandayo. Izinyawo nezandla zikaPrincess kunzima ukunyakaza futhi zibukeka zibambekile. Njalo mangabe edla uyakhwehlela futhi uyaphalaza. UPrincess okwamanje usepayipini iNasogastric Tube (NGT) INGT ishuhu elingena emakheleni engane bese liya esiswini ukuze limsize adle. Udokotela kaPrincess ululeka umndeni manje mayelana nePercutaneous Endoscopic Gastrostomy (PEG) okumele ifakwe. iPEG ichazwa njengeshubu elifakwa esiswini sengane ukumsiza adle kangcono. UPrincess Mkoba uhlala nomama wakhe kanye nobhuti omncane (oneminyaka emithathu). Umama kaPrincess akasebenzi kanti uphiliswa imali yesibonelelo kaPrincess Mkoba ayithola njalo ngenyanga. UPrincess Mkoba akakaze afunde isikole/inkulisa kanti futhi umndeni wakhe uhlala endaweni eyamakhaya okuthatha amahora amane ukusuka lapho uya esibhedlela esiseduze. Abanawo amanzi ahlanzekile kanye nogesi ekhaya.

**Isimo esibucayi: Esesithathu**

ULindo Zuma ingane yomfana eneminyaka emine enesifo ekuthiwa iCelebral Palsy (CP). ICP ichazwa njengobunzima obukwingqondo yengane okubangelwa izizathu ezahlukene ezithikameza ukuba ingane ingakwazi ukunyakaza, ukukhuluma, kanye nokudla. Uhlala nomama wakhe kanye nobhuti wakhe omdala (oneminyaka eyisishiyagalolunye). ULindo Zuma uhamba abamfundisa ngokukhuluma kanye nabaluleka ngokudla khona lapha esibhedlela. Ubeyifakile iPercutaneous Endoscopic Gastrostomy (PEG) ngoba enobunzima bokudla yonke inhlobo yokudla. iPEG ichazwa njengeshubhu elifakwa esiswini sengane ukuze limsize adle kangcono. Njalo mangabe ezodla uyakhwehlela. Ubengakwazi ukuzihlalela ngokwakhe kumbe azihambele kantifuthi ubesenciphile nasemzimbeni. Njalo mangabe esezodla uyakhala, bekunzima mangabe umama wakhe sekumele amfunze. Ngesikhathi esefakiwe iPEG, uLindo Zuma wakhuluphala nasemzimbeni. Ngemva kwesikhathi uLindo Zuma wabe esezidlela ngomlomo wakhe futhi, ngalendlela yokuthi kwaze

kwakhishwa iPEG Useyakwazi manje ukugcina isisindo sakhe ngendlela efanele kanye nokudla ngesikhathi sebeyakuthokozela bobabili uLindo nomama wakhe. Useyazama nokuzihlalela aphinde azenzele izinto. Ubaba kaLindo uyasebenza kanti umama wakhe uhlala ekhaya ukuze amnakekele. Ubhuti wakhe omdala ufunda ibanga lesi- 3 esikoleni esiseduze. Umndeni kaLindo uhlala maduzane

nesibhedlela okuthatha imizuzu eyishumi nanhlanu yingakho umama wakhe ekwazi ukumuletha njalo ngenyanga ezolandelela ukusizwa kwakhe.

## Appendix C: Interview Schedule and Prompts

### **Interview Schedule:**

#### **Biographical Information**

Parent/Caregiver's name:

Child's age:

Child's gender:

Address:

Date of admission:

Child's name:

Relation to child:

Language:

Medical diagnoses:

Date of discharge:

#### **General:**

##### **1) Introduction and welcome**

##### **2) Overview of the study**

My name is Lavanya Naidoo and I am currently a Masters Student at the University of KwaZulu-Natal. I am interested in conducting a study looking at how decisions are made for children with Feeding and Swallowing Difficulties. For this study I am interested in looking at how decisions are made for children with CP who require PEG placements.

Five caregivers have been selected to participate in this study. The purpose of this interview is to understand all the factors involved in the decision making process and hopefully to improve decision making for all involved. All the information you provide will be kept confidentially and stored safely by the researcher. All names and personal details will be removed once the study has been completed and only the researcher will have access to the information presented here.

1 hour and 30 minutes has been scheduled for each interview and there will be time for questions before and after the interview. During the interview you will be given a case and questions will be asked based on the case. The cases will either be given to you to read or will be read out to you (according to what you prefer). An interpreter will be available to repeat or clarify any information regarding the case for you. You are welcome to ask questions at any point throughout the interview to either the researcher and/or interpreter. At any point during the interview should you wish to stop the interview, please know that you are free to do so and will not be disadvantaged in any way.

With your permission, the interview will be recorded using a tape recorder. The recordings are meant only to help the researcher with collecting information and later to understand all the information obtained from all the interviews conducted. All recordings collected will be kept confidential and stored safely. At the end of the research study, a copy of all the findings will be made available for you and should you wish to contact the researcher regarding the interview conducted, contact details will be provided.

##### **3) Informed consent for the study:**

All participants will be given informed consent forms to sign prior to their initiation in the study. All consent forms will be provided in written format for the participants to read and sign. An interpreter will be available to assist any participants or to help with any questions any of the participants may have.

## **Interview Schedule Continued:**

### **4) Discussion of core construct: Decision Making in Paediatric Feeding and Swallowing Difficulties**

The core construct will be explored through this semi-structured interview and include the following considerations where relevant.

#### **4.1) Key Considerations/factors of the Critical Incident Vignette**

- What are some of the main points that you consider important from the case?

#### **4.2) Key decisions made in Critical Incident Vignette**

- When reading/listening to the case what are some of the important decisions you think that were made?

#### **4.3) Multi-disciplinary team (MDT) personnel involvement**

- During the case who do you think were some of the people involved in making decisions in the case?
- Do you think these people are equally important in the management of the case? If not, who is the most important? and why?
- Do you think the caregivers (mother/aunt) in the cases provided were included in making decisions for their child?

#### **4.4) Contextual factors**

##### **Socio-cultural environmental factors**

- Do you think it is important to consider the child's family when thinking about decision making regarding their feeding and swallowing difficulties and PEG placement? And why?
- Do you think the child's home environment is important to consider when thinking about a PEG placement for this child? And why?

##### **Religion and Culture**

- Do you think that it is important to consider the families religion when looking at decision making and possible PEG placements? And why?
- Do you think it is important to consider how far the child lives from the clinic or hospital when deciding about a PEG placement? And why?

## **Interview Schedule Continued:**

### **Economic Factors continued...**

#### **4.5) Economic factors**

##### **Food Security:**

- Do you think it is important to consider whether the caregiver is working or not and whether the family receives a grant for the child? And why?
- Do you think the types of foods the caregivers have access too is important for the child? Why?

##### **Legal factors:**

- Who do you think should be representing the caregivers and why?
- How included do you think the caregiver feels in the decision making process?

##### **Inherent factors:**

- How do you understand the child's CP diagnosis and their feeding and swallowing difficulties? What do you feel are the biggest challenges both in this case and in your own experience?
- Do you know about any other problems/difficulties associated with children with CP that could result in feeding and swallowing difficulties?

#### **4.6) Temporal factors**

- When considering this case, in your opinion, what decision regarding the child's feeding and swallowing was considered first?
- At what point was a PEG consideration made? Do you agree with this decision when thinking about your own case?

#### **4.7) Prompts to use throughout the interview**

- "Why..."
- "Tell me more..."
- "Did I understand you correctly?..."
- "Can you give me an example..."
- 

**Thank you. This concludes our interview. Please let me summarize a few key points and please help me to understand if I have understood you correctly.**

**Thank you for your participation in this study**

**Questions**

## Appendix C: Ukumiswa kwesivivinyo kanye nokulindelekile

### Ukumiswa kwesivivinyo:

#### Uminingwane:

Igama lomzali/ umnakekeli:  
Iminyaka yengane:  
Uyini umntwana:  
Ikheli:  
Usuku angene ngalo:

Igama lengane:  
Ubudlelwane nengane:  
Ulimi:  
Unasiphi isifo:  
Usuku aphume ngalo:

#### Okujwayelekile:

- 1) **Isingeniso nokubingelela**
- 2) **Okunye mayelana nocwaningo**

Igama lami ngingu Lavanya Naidoo ngenza iziqu zeMasters Esikhungweni Semfundo Ephakeme iKwaZulu-Natali. Nginesifiso sokwenza ucwaningo ngibheke ukuthi zithathwa kanjani izinqumo ezinganeni ezingakwazi ukugwinya, ngibheke kakhulu izingane ezinesifo iCerebral Palsy (C.P). ezifika nobunzima bokugwinya nokudla okuzodingeka zifake iP.E.G. Abanakekeli abahlanu abazodingeka bazobamba iqhaza kulolu cwaningo. Injongo yalesi sivivinyo ukuqonda izinto ezihlangene nokuthathwa kwezinqumo kanye nokunyusa izinga lokuqwashisa ngokufakwa kweP.E.G. Yonke iminingwane ozoyiletha izoba yimfihlo futhi izogcinwa iphephile ngumcwaningi. Wonke amagama abantu azosuswa mangabe sekuqedliwe ngalokhu, futhi umcwaningi kuphela ozoba nelungelo lokungena kulokhu okunikeziwe.

Ihora nemizuzu eyishumi nantathu elibekelwe le nhlolokhono futhi kuzoba nesikhathi semibuzo ngaphambi kwesivivinyo nangemuva kwayo. Ngesikhathi sesivivinyo uzonikezwa indatshana futhi imibuzo izobuzwa ngayo leyo ndatshana. Izindatshana lezo nizonikezwa nizifunde noma nizofundelwa zona (kuzoya ngokuthi ufunani wena) futhi notolika uzobe ekhona ukuniphindela, anichazele futhi anicacisele noma ikhuphi la enithanda khona. Kunoma isiphi isigaba sokuvivinywa umangabe usufuna ukuyeka, sicela wazi ukuthi uvumelekile futhi ngeke ubukelwe phansi ngokwenza lokho.

Ngemvume yakho, isivivinyo sizoqoshwa. Umqopho lowo owokusiza umcwaningi ngale mininingwane ayiqoqile futhi ngokuhamba kwesisikhathi aqonde ngayo yonke iminingwane ayitholile. Konke okuqoshiwe kuzogcinwa kuyimfihlo futhi kuzobekwa endaweni epephile. Ekugcineni kophenyo uzonikezwa umfaniswano kumbe ikhophi ukuthi nawe ubenayo besekuthi modinga ukuxhumana naye umcwaningi, inombolo yocingo uzoyithola ekugineni kwesivivinyo.

### **3) Ukwaziswa kwemvume yalokhu**

Bonke ababambe iqhaza bazonikezwa amafomu abazowa sayina ngaphambi kokuthi babe ingxenye yalokhu. Wonke amafomu azobe ebhaliwe ukuze ababambe iqhaza bazowafunda bawasayine, futhi utolika uzobe ekhona ukusiza abangafundile kumbe asize ngemibuzo enizobe ninayo.

### **Kuqhutshekwa okuphathelene nesivivinyo:**

#### **4) Umongo nezixazululo: Ukuthathwa kwezinqumo mayelana nezingane ezinenkinga yokugwinya umongo nezixazululo kuzokwenziwa ngaphansi kwalokhu kuvivinywa kuzobala lokhu okulandelayo okusemqoka.**

##### **4.1) Izinto eziphathelene nezimo eziphuthumayo.**

- Yimaphi amaphuza asemqoka okumele siwabhekisise kulokhu?

##### **4.2) Amaphuzu asemqoka ekuthatheni izinqumo kwizimo ezibucayi**

- Uma ufunda noma ulalele indatshana yimaphi amanye amaphuzu abalukile ekuthathweni kwezinqumo ocabanga ukuthi ashiwo?

##### **4.3) Abanakekeli bezempilo kuyo yonke imikhakha kumele babandakanywe**

- Ngalesi sikhathi kwenziwa yonke lento ubani ongathi ubekhona ekuthathweni kwezinqumo.
- Ucabanga ukuthi la bantu bonke bebalulekile ekuthathweni kwezinqumo? Uma kungenjalo, ucabanga ukuthi ubani obaluleke kakhulu?
- Ucabanga ukuthi onompilo (umama/mamekazi) babaliwe ekuthathweni kwezinqumo mayelana nezingane zabo?

##### **4.4) Izici zesimo**

###### **Okuphazamisa ukusimama kwemvelo**

- Ucabanga ukuthi kubalulekile yini ukubuka umndeni womntwana mangabe uzokwenza isinqumo mayelana nokudla Kanye nokugwinya kanzima uphinde ufake iP.E.G? Ngobani?
- Ucabanga ukuthi kubalulekile yini ukubheka indawo lapho ingane ihlala khona mangabe izofakwa IP.E.G? Ngobani?

###### **Inkolo namasiko**

- Ucabanga ukuthi kubalulekile yini ukubheka inkolo Yomndeni womntwana mangabe izofakwa IP.E.G? Ngobani?
- Ucabanga ukuthi kubalulekile yini ukubheka ukuthi ingane ihlala kude kangakanani nomtholampilo kumbe isibhedlela mangabe kumele ifakwe iP.E.G? Ngobani?



#### **4.5) Ukuvikeleka kokudla**

##### **Ukudla Security**

- Ucabanga ukuthi kubalulekile ukubheka ukuthi unompilo yasebenza yini nokuthi umndeni yayithola imali yesibonelelo yomntwana? Ngobani?
- Ucabanga ukuthi izinhlobo zokudla ezitholwa onompilo zibalulekile? Ngobani?

##### **Amaphuzo asemthethweni**

- Ucabanga ukuthi ubani okufanele asekele onompilo futhi ngobani?
- Ucabanga ukuthi onompilo bazizwa kanjani ekuthathweni kwezinqumo?

##### **Amaphuzo atholakele**

- Ucabangani ngeCerebral Palsy eyisifo esitholokala enganeni kanye nobunzima bokudla nokugwinya? Ucabanga ukuthi yiziphi izingqinamba ngokwalokhu kanye nokwazi kwakho?
- Zikhona ezinye izinkinga ozaziyo/ubunzima obuhlangabezana nezingane ezineC.P. ezingase zibe umphumela wobunzima wokudla Kanye nokugwinya?

#### **4.6) Amaphuzo esikhashana**

- Mangabe ubheka lokhu, ngokwakho isiphi isinqumo esithathwe kuqala mayelana nokudla kumbe nokugwinya komntwana.
- Ukufakwa kweP.E.G. kwacatshangwa kusiphi isigaba? Uyavumelana nalesi sinqumo mawuzicabangela ngokwakho?

#### **4.7) Ongakusebenzisa kuze kuphele isivivinyo:**

- “Ngobani...”
- “Ngitshele okunye...”
- “Ngikuzwe kahle...”
- “Ungakwazi ukunginika isibonelo...”

**Ngiyabonga. Siphela lapha isivivinyo sethu. Ngicela ukufingqa okubaulekile bese ungisiza ekutheni ngiqonde ngikuzwe kahle.**

**Ngiyabonga ngokubamba kwakho iqhaza kulokhu.**

**Imibuzo**

**Isiphetho.**

## Appendix D: Participant Informed Consent Form



**UNIVERSITY OF  
KWAZULU-NATAL**

DISCIPLINE OF SPEECH-LANGUAGE  
PATHOLOGY  
SCHOOL OF AUDIOLOGY & SPEECH-  
LANGUAGE PATHOLOGY  
FACULTY OF HEALTH SCIENCES

Research Administration Contact:

Anusha Marimuthu

Phone: 031 260 4769 Fax: 031 260 4609

E-Mail: [Marimuthu@ukzn.ac.za](mailto:Marimuthu@ukzn.ac.za)

### Information Sheet and Consent to Participate in Research

Date:

Greetings

My name is Lavanya Naidoo and I am currently a Masters student in the Speech-Language Pathology programme at the University of KwaZulu- Natal, Westville Campus.

You are being invited to consider participating in a study that involves research looking at how decisions are made for children with Cerebral Palsy (CP) who have feeding and swallowing difficulties, and who require a Percutaneous Endoscopic Gastrostomy placement (PEG). CP is described as a disorder with the child's brain that is caused by different reasons while it is still being developed and affects the child's ability to move their body and coordinate their muscles for talking and eating. A PEG is described as a tube that is placed into the child's stomach, through which they are able to eat safely. A PEG is particularly used for children who have difficulty with feeding and swallowing.

The study is expected to include 5 participants in total and will be conducted at One Hospital site only, namely Greys Hospital, Pietermaritzburg. This study will involve the following procedure:

1. All participants in this study will be interviewed by the researcher at a venue at Greys Hospital and at specific times. Participants will be telephonically informed of the venue and time prior to their interview.
2. The duration of your participation if you choose to enrol and remain in the study is expected to be approximately 1 hour and 30 minutes per interview.

3. During the interview you will be presented with a case and the researcher will ask questions based on the case. You will either be given the case to read or will be read out to you. An interpreter will be available to repeat, clarify and explain any information of the case that you would like.
4. With your permission the interviews conducted will also be audio recorded to assist the researcher with later review.

The hope of the intended study is to gain greater understanding regarding how decisions are made regarding children with CP who require PEG placements, and in so doing add to the existing knowledge in the area and improve the practical implementation (assessment and management) and understanding for all concerned.

The research study has been reviewed and approved by the Biomedical Research Ethics Committee of the University of KwaZulu Natal (UKZN) (approval ethics number: BE 424/25), the Department of Health, and the Hospital Manager of Greys Hospital for you to participate, should you agree.

In the event of any problems or concerns/questions you may contact the researcher, or the UKZN Biomedical Research Ethics Committee, contact details as follows:

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

Private Bag x 54001

Durban

4000

Kwa-Zulu Natal, South Africa

Tel: 27 31 2604769

Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

Please be advised that your participation in this study is voluntary and you may withdraw at any time without any penalty. Furthermore in the event of withdrawal from the study, you will not incur penalty or loss of treatment or any other benefit to which you are normally entitled. Should you wish to withdraw at any point during the study, please inform the researcher or interpreter of this either verbally or in writing and you will be allowed to withdraw from the study immediately.

All participants will be required to attend the interviews scheduled. No incentives or reimbursements will be provided for participation in this study.

All participant data sources obtained in this study, namely the participant consent forms, research screening tool, participant biographical details, participant audio recorded tapes, participant interview transcripts and all participant coded transcripts will be collectively stored in a locked file cabinet by the researcher. All electronic data sources with patient information will be printed and stored securely in the locked file cabinet and all electronic data will subsequently be deleted. Furthermore, prior to storage all the audio recordings will be numbered as a means to further ensure the participants confidentiality. Only the researcher will have access to the locked filing cabinet. All physical data sources will be kept and destroyed after a period of 5 years.

For any further queries please do not hesitate to contact the Researcher, Ms. Lavanya Naidoo or the Research Supervisors, A/Prof. Mershen Pillay or Ms. U. Naidoo at the numbers provided below. Should you choose to participate, please indicate this by completing the permission slip below.

Thank you sincerely,

Kind regards,

---

Ms. Lavanya Naidoo

Researcher

033 395 4598

---

Date:

---

A/Prof. Mershen Pillay

Supervisor

031 260 8190

---

Date:

---

Ms. U. Naidoo

Co-Supervisor

031 260 7140

---

Date:



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FACULTY OF HEALTH SCIENCES

Research Administration Contact:

Anusha Marimuthu

Phone: 031 260 4769 Fax: 031 260 4609

E-Mail: [Marimuthu@ukzn.ac.za](mailto:Marimuthu@ukzn.ac.za)

## Participant Consent Forms

### (Consent forms to be used for Pilot Study and Main Study)

I \_\_\_\_\_ (insert name) have been informed about the study entitled, Percutaneous Endoscopic Gastrostomy Feeding Decisions made for Children with Cerebral Palsy: An Exploratory Study, by the researcher, Ms. L. Naidoo.

I understand the purpose and procedures of the study.

I have been given an opportunity to ask questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at the details provided below.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

Private Bag x 54001

Durban

4000

Kwa-Zulu Natal, South Africa

Tel: 27 31 2604769

Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date



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FACULTY OF HEALTH SCIENCES

Research Administration Contact:

Anusha Marimuthu

Phone: 031 260 4769 Fax: 031 260 4609

E-Mail: Marimuthu@ukzn.ac.za

### **Iphepha le mininingwano kanye nemvume yokubambha iqhaza ekwenzeni ucwaningo**

Usuku:

Sawbona

Igama lami nginguLavanya Naidoo okwamanje ngingumfundi owenza iziqu zeMasters kwezokhuluma – Kanye nolimi ekululekeni khona Esikhungweni Semfundo Ephakeme iKwaZulu-Natal eWestville Campus.

Uyamenywa ekutheni ubambe iqhaza kucwaningo olubeka ukuthathwa kwezinqumo mangabe kusizwa izingane ezineCerebral Palsy (CP), ezidinga iPerctaneous Endoscopic Gastrostomy (PEG). ICP ichazwa njengobunzima bengqondo obutholakala kwingane okubangwa izizathu ezahlukene ngesikhathi isakhula bese ithikameza umzimba wengane ukuthi unganyakazi ngokukhuluma Kanye nokudla. IPEG ichazwa njengeshubhu elifakwa esiswini sengane, okuyilona abadla ngalo kangcono. IPEG isetshenziselwa kakhulu izingane ezinobunzima bokudla kanye nokugwinya.

Lokufunda kulindeleke kufake ababambiqhaza abahlanu ngokwesibalo abazothathwa ezibhedlela kuphela, okuyisibhedlela iGreys, eMgungundlovu. Lokhu kufunda kuzobala lokhu okulandelayo.

- 1) Bonke ababambiqhaza bazovivinywa ngezikhathi ezithile umcwaningi esibhedlela iGreys. Abazobambiqhaza bazokwaziswa ngocingo ngendawo kanye nesikhathi sesivivinyo.
- 2) Mangabe uzobambiqhaza kungathatha isikhathi esingangehora nemizuza eyishumi nantathu mangabe uzobhalisa uphinde ubeyingxenywe yesivivinyo.

- 3) Ngesikhathi sokuvinjanywa uzonikezwa indatshana bese umcwaningi akubuze imibuzo mayelana nayo. Kungezeka unikezwe kumbe ufundelwe. Utolika uzobe ekhona ukuphinda bese eyachaza lapho othanda akuchazele khona.
- 4) Ngemvume yakho isivivinyo sizoqoshwa ukuze kusizakale umcwaningi mangabe esebukisisa okanye elalelisisa ngokuhamba kwesikhathi.

Ngethemba lalokhu kufunda uthola ukwazi kangcono kumbe ukuqonda indlela okuthathwa ngayo izinqumo mayelana nezingane ezineCP ezidinga ukufakwa iPEG, ngokwenza njalo siqwashisa ngolwazi endaweni siphinde sithuthukise ukufakwa (ngokuhlola kanye nokusiza) kanye nokwazi kuzona zonke izingxenye.

Imvume yokufunda lolu cwaningo silunikezwe yiKomidi Locwaningo Lwezokugula Esikhungweni Semfundo Ephakeme iKwaZulu-Natal (UKZN) (inamba yokuthathwa: BE 424/15, uMnyango wezempilo, kanye noMphathi wesibhedlela saseGreys ukuthi ubambiqhaza, mangabe uvuma.

Mangabe kubakhona izinkinga kumbe imibuzo/ukukhathazeka ungathintana nomcwaningi, kumbe iKomidi Locwaningo lwezokugula, imininingwane yocingo iyalandela:

### **BIOMEDICAL UCWANINGO KWEZOKWELAPHA**

Research Office, Westville Campus

Govan Mbeki Building

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4000

Kwa-Zulu Natali, Ningizimu Afrika

Ucingo: 27 31 2604769

Isihlanzandaba: 27 31 2604609

i-Email: [PREC@ukzn.ac.za](mailto:PREC@ukzn.ac.za)

Uyaziswa ukuthi ukubambiqhaza kwakho kulokhu ukuzikhethela kwakho futhi ungacela ukuhoxiswa noma yinini ngeke ubekwe icala. Okunye okungavela kulokhu, angeke uncishwe ilungelo lokuthola usizo noma ngabe yiluphi usizo, sicela uthinte umcwaningi kumbe utolika ngokubhala kumbe uzisholo wena futhi uzovunyelwa ukuhoxa ngaleso sikhathi.



Bonke ababambe iqhaza bazodingeka ukuthi bavele kwizivivinyo. Azikho izibonelelo kanye nokubuyiselwa okuzonikezwa laba ababambiqhaza kulokhu kufunda.

Konke lokhu okuzonikezwa ababambiqhaza kulokhu kufunda, sibala ifomu le mvume, amathuluzi azosetshenziswa, okuqoshiwe, okutholwe kwisivivinyo kanye nokubhaliwe yilaba ababambiqhaza kuzoqoqwa umcwaningi kugcinwe endaweni ekhiyekayo. Konke okuthunyelwe ngezokuxhumana kweziguli kuzogcinwa endaweni ekhiyekayo bese kuyalahlwa okungasadingeki. Okunye futhi, kulokhu okugciniwe ngokuqoshwa kuzobhalwa bese kutshengiswa abanikazi ukuthi kuhleli endaweni ephephile. Umcwaningi kuphela ozoba nelungelo lokuvula lapha kugcinwe khona lokhu. Ngemuva kwesikhathi esingange minyaka eyi-5 kuzolahlwa konke okugciniwe.

Mangabe kukhona ofuna ukukwazi, sicela ungangabazi ukuthinta umcwaningi, uNksz Lavanya Naidoo, kumbe umcwaningi owuchwepheshe uMershen Pillay noma uNkk Urisha Naidoo kulezi zinombolo ezingezansi ezinikeziwe. Mangabe ufuna ukubambiqhaza, sicela ucacise ngokugcwalisa imvume engezansi.

Siyabonga ozithobayo

---

uNksz Lavanya Naidoo  
Umcwaningi  
033 395 4598

---

Usuku:

---

Uchwepheshe Mershen Pillay  
Umphathi  
031 260 8190

---

Usuku:

---

Nksz U. Naidoo  
Sekela-Mphathi  
031 260 7140

---

Usuku:



UNIVERSITY OF  
KWAZULU-NATAL

DISCIPLINE OF SPEECH-  
LANGUAGE PATHOLOGY  
SCHOOL OF AUDIOLOGY &  
SPEECH-LANGUAGE  
PATHOLOGY  
FACULTY OF HEALTH  
SCIENCES

Research Administration Contact:

Anusha Marimuthu

Phone: 031 260 4769 Fax: 031 260  
4609

E-Mail: Marimuthu@ukzn.ac.za

### **Ifomu lemvume yobambiqhaza**

#### **(Ifomu lokuhlolelwa ukufunda elizosethshenziselwa ucwaningo)**

Mina, \_\_\_\_\_ (faka igama) ngazisiwe ngalokhu kufunda okubizwa, IPercutaneous Endoscopic Gastrostomy yokudla eyenzelwe izingane ezineCerebral Palsy: Ucwaningo lokufunda, ngokuka mcwaningi, uNksz L. Naidoo.

Ngiyayiqonda injongo nenqubomgomo yalokhu kufunda.

Nginikeziwe ithuba lokubuza imibuzo ngalokhu ngase nginikezwa izimpendulo ezigculisayo.

Ngiyazi ukubamba kwami iqhaza kulokhu kufunda ukuzithandela kwami futhi ngingahoxa noma yinini ngaphandle kokuthikameza usizo kumbe ukululekwa enginelungelo ukuthi ngiluthole.

Ngazisiwe ngokuthola isinxephezelo kumbe usizo lokululeko mangabe ngilimala okungumphumela ohambelana nenqubomgoma yokufunda.

Mangabe nginemibuzo/ukukhathazeka mayelana nalokhu ngiyaqonda ukuthi kumele ngixhumane nomcwaningi obhalwe ngeszansi.

Mangabe nginemibuzo kumbe ukukhathazeka ngamalungelo wami njengombambiqhaza kulokhu kufunda, ngingaxhumana ne:

**BIOMEDICAL UCWANINGO KWEZOKWELAPA**

Research Office, Westville Campus

Govan Mbeki Building

Private Bag x 54001

Durban

4000

Kwa-Zulu Natali, Ningizimu Afrika

Ucingo: 27 31 2604769

Isihlanzandaba: 27 31 2604609

i-Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

**Obambiqhaza**

Osayinile \_\_\_\_\_ (osayinile)

Igama \_\_\_\_\_ (faka igama ngokugcwele)

Usuku \_\_\_\_\_ (faka usuku)

**Ufakazi Wokuqala**

Osayinile \_\_\_\_\_ (osayinile)

Igama \_\_\_\_\_ (faka igama ngokugcwele)

Usuku \_\_\_\_\_ (faka usuku)

**Ufakazi Wesibili**

Osayinile \_\_\_\_\_ (osayinile)

Igama \_\_\_\_\_ (faka igama ngokugcwele)

Usuku \_\_\_\_\_ (faka usuku)

## Appendix E: Gate-keeper letter: Greys Hospital CEO



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KWAZULU-NATAL

DISCIPLINE OF SPEECH-  
LANGUAGE PATHOLOGY  
SCHOOL OF AUDIOLOGY &  
SPEECH-LANGUAGE  
PATHOLOGY  
FACULTY OF HEALTH  
SCIENCES

Research Administration Contact:

Anusha Marimuthu

Phone: 031 260 4769 Fax: 031 260  
4609

E-Mail: [Marimuthu@ukzn.ac.za](mailto:Marimuthu@ukzn.ac.za)

### Request to conduct a Masters Research Study

#### For Attention:

Dr. L. Naidoo

Senior Manager-Medical Services

Greys Hospital

Date:

Dear Sir

#### RE: Permission to conduct research study at Greys Hospital

I am currently a Masters student at the University of KwaZulu- Natal intending to conduct a research study in the field of paediatric feeding and swallowing difficulties. My research study is titled: Percutaneous Endoscopic Gastrostomy Feeding Decisions made for Children with Cerebral Palsy: An Exploratory Study.

This exploratory study seeks to analyse how feeding decisions are made regarding children with CP who require PEG placements secondary to their feeding and swallowing difficulties. Children with CP are frequently known to present with feeding and swallowing difficulties<sup>9</sup>. If left untreated these complications can result in child mortality, GORD and respiratory complications. Enteral feeds are typically recommended as an alternative to adequately and safely feed these children, however this is not always the management option selected. By exploring the decision making process, different variables may be identified and a greater understanding regarding how decisions are made in the context of paediatric feeding and swallowing difficulties may be deduced. Currently

there is a lack of available research in this area and ultimately the research study thus seeks to contribute to the available research in this area and provide practical implications for all stakeholders.

The University of Kwa-Zulu Natal's Biomedical Research Ethics Committee (BREC) has granted me provisional approval (BREC reference number: 424/15) pending approval from gatekeepers.

I request permission from you to:

- Screen paediatric patients at Greys Hospital for a period of 1 month for feeding and swallowing difficulties by means of a file review. No patients will be directly involved during the screening and all the information retrieved will be securely stored and treated as confidential. 8 cases in total cases will then be selected (3 cases will be used for the pilot study and 5 cases will be used for the main study data collection). The respective caregivers will then be contacted and interviews with them scheduled. Informed consent will be obtained by all participants.
- The proposed interviews will be scheduled at Greys Hospital and the total data collection process will be conducted over a period of 3 days (1 day is allocated for conducting the participant screening; 1 day is allocated for conducting the pilot study and 1 day has been allocated for the main study).

Please be advised that:

- All participant data sources obtained in this study, namely the participant consent forms, research screening tool, participant biographical details, participant audio recorded tapes, participant interview transcripts and all participant coded transcripts will be collectively stored, in a locked file cabinet, by the researcher at the University of KwaZulu-Natal, Speech Therapy Department.
- All electronic data sources with patient information will be printed and stored securely in the locked file cabinet and all electronic data will subsequently be deleted. Furthermore, prior to storage all the audio recordings will be numbered as a means to further ensure the participants confidentiality. Only the researcher will have access to the locked filing cabinet. All physical data sources will be kept and destroyed after a period of 5 years.
- All translators (Appendix G) and interpreters (Appendix H) affiliated to this research study will be required to sign confidentiality agreements prior to their commencement in this study, as a means to further ensure that patient confidentiality is upheld.

For any further queries please do not hesitate to contact the Researcher, Ms Lavanya Naidoo or the Research Supervisors A/Prof. Mershen Pillay or Ms. Urisha. Naidoo at the numbers provided below.

Thank you sincerely,

Kind regards,

\_\_\_\_\_  
Ms. Lavanya Naidoo  
Researcher  
033 395 4598

\_\_\_\_\_  
Date:

\_\_\_\_\_  
A/Prof. Mershen Pillay  
Supervisor  
031 260 8190

\_\_\_\_\_  
Date:

\_\_\_\_\_  
Ms. U. Naidoo  
Co-Supervisor  
031 260 7140

\_\_\_\_\_  
Date:

Please sign and complete below if permission is granted.

I \_\_\_\_\_, Senior Manager-Medical Services of Greys Hospital, hereby grant permission for the study (Percutaneous Endoscopic Gastrostomy Feeding Decisions made for Children with Cerebral Palsy: An Exploratory Study) to be conducted at Greys Hospital. The nature and purpose of the study has been explained to me and I have had the opportunity to ask questions to gain more information.

Signature .....

Date.....

## Appendix F: Gate-keeper letter: KZN Department of Health



UNIVERSITY OF  
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DISCIPLINE OF SPEECH-LANGUAGE  
PATHOLOGY

SCHOOL OF AUDIOLOGY & SPEECH-  
LANGUAGE PATHOLOGY

FACULTY OF HEALTH SCIENCES

Research Administration Contact:

Anusha Marimuthu

Phone: 031 260 4769 Fax: 031 260 4609

E-Mail: Marimuthu@ukzn.ac.za

### Request To Conduct a Masters Research Study

KwaZulu-Natal Department of Health

Umgungundlovu District

District Office

Date:

Dear Sir/Madam

#### **RE: Permission to conduct research study at Greys Hospital**

I am currently a Masters student at the University of KwaZulu- Natal intending to conduct a research study in the field of paediatric feeding and swallowing difficulties. My research study is titled: Percutaneous Endoscopic Gastrostomy Feeding Decisions made for Children with Cerebral Palsy: An Exploratory Study.

This exploratory study seeks to analyse how feeding decisions are made regarding children with CP who require PEG placements secondary to their feeding and swallowing difficulties. Children with CP are frequently known to present with feeding and swallowing difficulties (Clancy & Hustad, 2011). If left untreated these complications can result in child mortality, GORD and respiratory complications. Enteral feeds are typically recommended as an alternative to adequately and safely feed these children, however this is not always the management option selected. By exploring the decision making process, different variables may be identified and a greater understanding regarding how decisions are made in the context of paediatric feeding and swallowing difficulties may be deduced. Currently there is a lack of available research in this area and ultimately the research study thus seeks to contribute to the available research in this area and provide practical implications for all stakeholders.

The University of Kwa-Zulu Natal's Biomedical Research Ethics Committee (BREC) has granted me provisional approval (BREC reference number: 424/15) pending approval from gatekeepers.

I request permission from you to:

- Screen paediatric patients at Greys Hospital for a period of 1 month for feeding and swallowing difficulties by means of a file review. No patients will be directly involved during the screening and all the information retrieved will be securely stored and treated as confidential. 8 cases in total cases will then be selected (3 cases will be used for the pilot study and 5 cases will be used for the main study data collection). The respective caregivers will then be contacted and interviews with them scheduled. Informed consent will be obtained by all participants (Appendix D)
- The proposed interviews will be scheduled at Greys Hospital and the total data collection process will be conducted over a period of 3 days (1 day is allocated for conducting the participant screening; 1 day is allocated for conducting the pilot study and 1 day has been allocated for the main study).

Please be advised that:

- All participant data sources obtained in this study, namely the participant consent forms, research screening tool, participant biographical details, participant audio recorded tapes, participant interview transcripts and all participant coded transcripts will be collectively stored, in a locked file cabinet, by the researcher at the University of KwaZulu-Natal, Speech Therapy Department.
- All electronic data sources with patient information will be printed and stored securely in the locked file cabinet and all electronic data will subsequently be deleted. Furthermore, prior to storage all the audio recordings will be numbered as a means to further ensure the participants confidentiality. Only the researcher will have access to the locked filing cabinet. All physical data sources will be kept and destroyed after a period of 5 years.
- All translators and interpreters affiliated to this research study will be required to sign confidentiality agreements prior to their commencement in this study, as a means to further ensure that patient confidentiality is upheld.

For any further queries please do not hesitate to contact the Researcher, Ms Lavanya Naidoo or the Research Supervisors A/Prof. Mershen Pillay or Ms. Urisha. Naidoo at the numbers provided below.



Thank you sincerely,

Kind regards,

---

Ms. Lavanya Naidoo

Researcher

033 395 4598

---

Date:

---

A/Prof. Mershen Pillay

Supervisor

031 260 8190

---

Date:

---

Ms. U. Naidoo

Co-Supervisor

031 260 7140

---

Date:

## Appendix G: Confidentiality agreement between the Researcher and Translator



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DISCIPLINE OF SPEECH-LANGUAGE  
PATHOLOGY

SCHOOL OF AUDIOLOGY & SPEECH-  
LANGUAGE PATHOLOGY

FACULTY OF HEALTH SCIENCES

Research Administration Contact:

Anusha Marimuthu

Phone: 031 260 4769 Fax: 031 260 4609

E-Mail: Marimuthu@ukzn.ac.za

### Translator Confidentiality Agreement

Date:

Dear Sir/Madam

RE: Translator confidentiality throughout the research study conducted

Thank you for your willingness to participate in this research study.

I am currently a Masters candidate in the School of Health Sciences at the University of KwaZulu-Natal. My research study is titled: Percutaneous Endoscopic Gastrostomy Feeding Decisions made for Children with Cerebral Palsy: An Exploratory Study.

For the purposes of this study:

- 1) All prospective participants are required to be proficient in either English and/or isiZulu.
- 2) Translators are required to translate all informed consent documents and any additional information, from English to isiZulu, pertaining to the study that is relevant to the participants (pending approval from the Biomedical Research Ethics Committee).
- 3) Translators are required to provide the researcher with proof of their accreditation by means of a certified document and/or signed affidavit prior to their participation in the study.
- 4) For this study 2 different translators will be recruited. Translators will be allocated a Translator One or Translator Two status by the researcher only.

5) Role of the translators:

One translator will be asked to translate an English version of a respective document into isiZulu and the second translator will then be asked to translate the isiZulu translation as retrieved from translator one, back to English.

6) Both translators will not be permitted to discuss the translations obtained and the researcher will then compare the original English version as given to translator one and the second English version as retrieved from translator two.

7) Both translators will be required to keep all the information related to this study and any information retrieved from the participants (biographical information and/or interview information) confidential.

8) The translators will be required to sign this confidentiality agreement prior to their study participation and training.

The research study has been granted permission from the Biomedical Research Ethics Committee of the University of KwaZulu-Natal, the Department of Health (Ethics Number: BE 424/15).

For any further queries please do not hesitate to contact the researcher, Ms Lavanya Naidoo or the research supervisors A/Prof. Mershen Pillay or Ms. Urisha. Naidoo at the numbers provided below.

Thank you sincerely,

Kind regards,

---

Ms. Lavanya Naidoo  
Researcher  
033 395 4598

---

Date:

---

A/Prof. Mershen Pillay  
Supervisor  
031 260 8190

---

Date:

---

Ms. U. Naidoo  
Co-Supervisor  
031 260 7140

---

Date:

**Appendix H: Confidentiality agreement between the Researcher and Interpreter**



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KWAZULU-NATAL**

DISCIPLINE OF SPEECH-  
LANGUAGE PATHOLOGY  
SCHOOL OF AUDIOLOGY &  
SPEECH-LANGUAGE  
PATHOLOGY  
FACULTY OF HEALTH  
SCIENCES

Research Administration Contact:

Anusha Marimuthu

Phone: 031 260 4769 Fax: 031 260  
4609

E-Mail: Marimuthu@ukzn.ac.za

**Interpreter Confidentiality Agreement**

I, \_\_\_\_\_ (insert your name) agree to participate in a Masters research project entitled: Percutaneous Endoscopic Gastrostomy Feeding Decisions made for Children with Cerebral Palsy: An Exploratory Study.

I also understand that ALL information pertaining to this research study will be kept confidential and that no information regarding any aspect of this study should be discussed with anyone outside the construct of this study.

Translator \_\_\_\_\_

Signed \_\_\_\_\_ (signature)

Name \_\_\_\_\_ (print name)

Date \_\_\_\_\_ (insert date)

Qualifications

---

---

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Witness one

Signed \_\_\_\_\_ (signature)

Name \_\_\_\_\_ (print name)

Date \_\_\_\_\_

## Appendix I: Approval letters from the Biomedical Research Ethics Committee (BREC)



11 February 2016

Ms L Naidoo (215080539)  
Discipline of Speech-Language Pathology  
School of Health Sciences  
[naidoo.lavanya@gmail.com](mailto:naidoo.lavanya@gmail.com)

**Protocol:** Percutaneous endoscopic gastrostomy feeding decisions made for children with cerebral palsy: An exploration study.  
**Degree:** M Speech-Language Pathology  
**BREC reference number:** BE424/15

### EXPEDITED APPLICATION

The Biomedical Research Ethics Committee has considered and noted your application received on 25 September 2015.

The study was provisionally approved pending appropriate responses to queries raised. Your responses dated 08 February 2016 to queries raised on 28 January 2016 have been noted and approved by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval.

This approval is valid for one year from 11 February 2016. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

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

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

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

The sub-committee's decision will be **RATIFIED** by a full Committee at its meeting taking place on 08 March 2016.

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

Yours sincerely

Professor J Tsoka-Gwegweni  
Chair: Biomedical Research Ethics Committee

cc: supervisor: [pillaym1@ukzn.ac.za](mailto:pillaym1@ukzn.ac.za)

---

Biomedical Research Ethics Committee  
Professor J Tsoka-Gwegweni (Chair)  
Westville Campus, Govan Mbeki Building



UNIVERSITY OF  
KWAZULU-NATAL

INYUVESI  
YAKWAZULU-NATALI

RESEARCH OFFICE  
Biomedical Research Ethics Administration  
Westville Campus, Govan Mbeki Building  
Private Bag X 54001  
Durban  
4000  
KwaZulu-Natal, SOUTH AFRICA  
Tel: 27 31 2604769 - Fax: 27 31 2604609  
Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

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

23 February 2017

Ms L Naidoo (215080539)  
Discipline of Speech-Language Pathology  
School of Health Sciences  
[naidoo.lavanya@gmail.com](mailto:naidoo.lavanya@gmail.com)

Dear Ms Naidoo

Protocol: Percutaneous endoscopic gastrostomy feeding decisions made for children with cerebral palsy: An exploration study.  
Degree: M Speech-Language Pathology  
BREC reference number: BE424/15

### RECERTIFICATION APPLICATION APPROVAL NOTICE

Approved: 11 February 2017  
Expiration of Ethical Approval: 10 February 2018

I wish to advise you that your application for Recertification received on 15 February 2017 for the above protocol has been noted and approved by a sub-committee of the Biomedical Research Ethics Committee (BREC) for another approval period. The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

This approval will be ratified by a full Committee at its meeting taking place on 14 March 2017.

Yours sincerely

Mrs A Marimuthu  
Senior Administrator: Biomedical Research Ethics

cc supervisor: [pillaym1@ukzn.ac.za](mailto:pillaym1@ukzn.ac.za)

## Appendix J: Approval letter from BREC regarding study amendments



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INYUVESI  
YAKWAZULU-NATALI

RESEARCH OFFICE  
Biomedical Research Ethics Administration  
Westville Campus, Govan Mbeki

Building

Private Bag X 54001  
Durban  
4000

KwaZulu-Natal, SOUTH AFRICA  
Tel: 27 31 2604769 - Fax: 27 31 2604609  
Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

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

12 July 2016

Ms L Naidoo (215080539)  
Discipline of Speech-Language Pathology  
School of Health Sciences  
[naidoo.lavanya@gmail.com](mailto:naidoo.lavanya@gmail.com)

Dear Ms Naidoo

**Protocol:** Percutaneous endoscopic gastrostomy feeding decisions made for children with cerebral palsy: An exploration study.

**Degree:** M Speech-Language Pathology

**BREC reference number:** BE424/15

Your letter received 07 June 2016 submitting an Application of Amendments to include a transport fee and provide refreshments to participants for the above study has been **noted and approved** by a sub-committee of the Biomedical Research Ethics Committee.

The sub-committee's decision will be **RATIFIED** by a full Committee at its meeting taking place on **16 August 2016**.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Mrs A Marimuthu'.

Mrs A Marimuthu  
Senior Administrator: Biomedical Research Ethics Committee

cc supervisor: [pillaym1@ukzn.ac.za](mailto:pillaym1@ukzn.ac.za)



## Appendix K: Approval letter from the Greys Hospital CEO to conduct study



health

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

**GREYS HOSPITAL  
OFFICE OF THE CEO**  
Private Bag X 9001, Pietermaritzburg, 3200  
Town Bush Road, Chase Valley, Pietermaritzburg, 3201  
Tel.: 033 – 897 3321 Fax.: 033 - 8973398  
www.kznhealth.gov.za

<b>To:</b> Ms. L. Naidoo Dept. of Speech Therapy – Edendale Hospital
<b>From:</b> Dr. K. B. Bilenge CEO - Greys Hospital
<b>Date:</b> 26 November 2015
<b>Re:</b> Request for permission to conduct research at Grey's Hospital: <i>Percutaneous endoscopic gastrostomy feeding decisions made for children with cerebral palsy: An exploration study</i>

Dear Ms. Naidoo

Your request to conduct research at Grey's Hospital refers.

Permission to conduct the above study is hereby granted under the following conditions:

- Your provisional ethics approval and research protocol are assumed to be valid and final ethics approval is a prerequisite for conducting your study at our hospital. Once obtained from BREC, please submit a copy of the full ethics approval;
- You are also required to obtain approval for your study from the Provincial Department of Health KZN Health Research Unit prior to commencing your study at Grey's Hospital. You will find more information on their website: <http://www.kznhealth.gov.za/hrkm.htm>
- Confidentiality of hospital information, including staff and patient medical and/or contact information, must be kept at all times; Patient records are **not** to be removed from the hospital premises nor are you allowed to photocopy/ photograph them.
- You are to ensure that your data collection process will not interfere with the routine services at the hospital;
- You are to ensure that hospital resources are **not** used to manage your data collection, e.g. hospital staff collating data; photocopying; telephone; facsimile, etc.;
- Informed consent is to be obtained from all participants in your study, if applicable;
- Policies, guidelines and protocols of the Department of Health and Grey's Hospital must be adhered to at all times;
- Professional attitude and behaviour whilst dealing with research participants must be exhibited;
- The Department of Health, hospital and its staff will not be held responsible for any negative incidents and/or consequences, including injuries and illnesses that may be contracted on site, litigation matters, etc. that may arise as a result of your study or your presence on site;
- You are required to submit to this office a summary of study findings upon completion of your research.
- You are requested to make contact with the **HoD of our Speech Therapy & Audiology Department, Mrs. Y. Naidoo**, at Grey's Hospital once you are ready to commence data collection.

Recommended by:

Dr L. Naidoo  
Senior Manager: Medical Services

Approved by:

  
Dr/ K. B. Bilenge  
Hospital CEO

uMnyango Wezempilo . Departement van Gesondheid

*Fighting Disease, Fighting Poverty, Giving Hope*

## Appendix L: Approval letter from the KZN- Department of Health to conduct study.



**health**  
Department:  
Health  
PROVINCE OF KWAZULU-NATAL

330 Langalibalele street,  
Private Bag X9051 PMB, 3200  
Tel: 033 395 2805/3189/3123 Fax: 033 394 3782  
Email: [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)  
[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

DIRECTORATE:

Health Research & Knowledge  
Management (HKRM)

Reference: HRKM361/15  
KZ\_2015RP19\_886

10 December 2015

Dear Ms L Naidoo  
(University of KwaZulu-Natal)

**Subject: Approval of a Research Proposal**

1. The research proposal titled '**Percutaneous Endoscopic Gastrostomy Feeding Decisions made for Children with Cerebral Palsy: An Exploratory Study**' was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

The proposal is hereby **approved** for research to be undertaken at Greys Hospital.

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

For any additional information please contact Ms G Khumalo on 033-395 3189.

Yours Sincerely

Dr E Lutge

Chairperson, Health Research Committee

Date: 11/12/15

Fighting Disease, Fighting Poverty, Giving Hope