THE LIVED EXPERIENCE OF BEING THE MOTHER OF A CHILD WITH CHRONIC FEEDING DIFFICULTIES.

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DECLARATION

I, Ronelle Hewetson, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Date: 15/05/2008

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ABSTRACT

The lived experience of being the mother of a child with chronic feeding difficulties.

This research describes the lived experience of being the mother of a child with chronic feeding difficulties. The study was prompted by questions about how mothers in Cape Town experience their 'caregiving role' and what factors shape their experiences as it relates to the feeding demands of the child. A qualitative phenomenological design was used. Purposive sampling allowed for the identification of information rich participants. Data was collected by in-depth semi-structured interviews with 7 mothers residing in Cape Town. The interviews were transcribed verbatim and together with reflective journal entries analysed as per Colaizzi's phenomenological research method of inductive reduction.

Two categories and seven essences emerged. The first category depicts a deconstructive process characterised by loss and disempowerment. Deconstruction: "A journey of loss and disempowerment", is made up of three essences 1) Losing the mother dream; 2) Everything changes: living on the margins; and 3) Disempowered: from mother to onlooker. The second category describes a very different process. Reconstruction: "Getting through the brokenness" encompasses four essences, namely 4) Letting go of the dream and valuing the real; 5) Self-empowered: becoming the enabler; 6) Facilitating the journey; and 7) The continuing journey: negotiating balance. The phenomenon of being the mother of a child with chronic feeding difficulties was found to encompass two continuing journeys, as the mothers who participated in this study moved between contradictory feelings of acceptance and denial; and engaged in an ongoing process of finding balance between opposing emotions (strength and insecurity) as well as opposing tasks (mothering and caregiving). Positive and/or negative implications of providing home-based care to a child with a chronic feeding difficulty were not mutually exclusive experiences for the mothers in this study, but often co-occurred.

While there is a relatively large body of literature into paediatric feeding difficulties and caregivers' experiences of caring for a child with special needs, very few studies and none in South Africa, have been done of how mothers experience their role as caring for the daily feeding demands of a child with a chronic feeding difficulty. This study should broaden understanding of a mother's experiences as it relates to the contexts of caring for a child with a chronic feeding difficulty at home and while accessing public health care services for that child in Cape Town, South Africa. It is anticipated that this study will provide valuable information for Speech-Language Pathologists and other professionals involved in the care of children with chronic feeding difficulties. This study should furthermore contribute towards a knowledge base to develop more appropriate curriculum in which the needs of mothers are recognised.

GLOSSARY OF TERMS

Audit trail

A record of the research process in which decisions made by the researcher are documented throughout the course of the study enabling evaluation of the rigor of the study by objective parties (Sandelowski & Barrosa, 2003).

Bracketing

A phenomenological technique of holding assumptions and presuppositions in suspension (Holloway & Wheeler, 1996).

Caregiver

For the purposes of this study a caregiver is a person who has primary responsibility for the day-to-day feeding and care of the child.

Chronic feeding difficulty

An ongoing difficulty in the process of intake of food, including both difficulty in food placement and manipulation as well as swallowing of food (American Speech-Language Hearing Association, 2002; Arvedson & Brodsky, 2002).

Dysphagia

"Difficulty moving food from the mouth to the stomach, including all the behavioural, sensory, and preliminary motor acts in preparation for the swallow" (Logemann, 1998, pg. 1).

Enteral feeding / tube feeding

A feeding tube is a medical device used to provide nutrition to patients who cannot obtain nutrition by swallowing. The state of being fed by a feeding tube is called enteral feeding or tube feeding (Kreymann et al., 2006).

Epoche

Epoche is an approach adopted so that the researcher can set aside her/his views of the phenomenon and focus on the views that are reported by the participants. This is achieved by ensuring that nothing is determined in advance and that no philosophical or theoretical position is adopted (Moerer-Urdahl & Creswell, 2004).

Essence

The core or fundamental meaning of a phenomenon (Husserl, 1970).

Gastrostomy tube (G-tube)

"A gastrostomy is a surgically created external stoma in the stomach wall through which a latex or silicone catheter device (G-tube) is implanted so that liquefied formulas can be pumped or infused directly, bypassing the mouth and esophagus" (Thorne, Radford & McCormick, 1997, pg. 89).

Iterative

The iterative approach involves altering the research method in the light of information gained as a research study progresses. The iterative nature of qualitative research requires continuous change of the design and process to discover new perspectives based on preceding steps (Rubin & Rubin, 2005).

Maternal role identity formation

A process directed towards the establishment of an identity that is reflected in maternal behaviours. The process begins during pregnancy and continues into the postpartum period (Mercer, 1995).

Medically fragile

A term often used interchangeably with "technology dependent" when referring to children who are reliant on medical devices that compensate for vital bodily functions such as respiration ventilator dependent and/or who are receiving intravenous nutritional support or other forms of nutritional support (Rehm & Bradley, 2005).

Percutaneous endoscopic gastrostomy (PEG)

The procedure whereby a gastrostomy tube is placed by endoscopy into the stomach, thus bypassing the mouth (Winstock, 2005).

Public health sector

The "public health sector" refers to government departments and institutions performing a public function in the provision, delivery or funding of health services to people in South Africa (www.doh.co.za).

Videofluoroscopic Study (VFS)

A dynamic imaging technique used in the assessment of oral, pharyngeal and upper oesophageal phases of a swallow (Arvedson & Brodsky, 2002).

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CHAPTER ONE

This thesis is organised into seven chapters. Chapter one frames the research by providing an introduction to the phenomenon of interest and positions the researcher in relation to the phenomenon. An outline of the research question and discussion of the need for research within this area is provided. A literature review, which encompasses areas identified in the interviews as having relevance to the experiences of the mothers who took part in this study, is also included in Chapter one. In Chapter two the philosophical and methodological underpinnings of this study are discussed. Chapter three provides an outline of the process followed and the methods used to gather and analyse the data. Participants are introduced in Chapter four. The findings are presented, discussed and linked to potential clinical and theoretical implications in Chapters five and six. Finally, Chapter seven provides a composite summary of the mothers' lived experiences.

1.1. FRAMING THE RESEARCH

The phenomenon of interest in this study is the experience of being a mother and primary home-based caregiver of a child with chronic feeding difficulties and explores this topic from the perspectives of women who are accessing public health care services in Cape Town, South Africa. A search of available literature indicated a paucity on the area of interest, which led to the question: "How do mothers experience their role as the primary home-based caregiver for a child with a chronic feeding difficulty and how is this experience shaped by factors perceived as enhancing or restricting their capacity to cope?"

1.1.1. The researcher

Research procedures are guided by theory which is often based on assumptions about the nature of the world we live in (Hughes, 1997). Researchers enter the research process with their own set of assumptions or world views. The philosophical views held by the researcher about human phenomena and how best to understand experiences, often guide the nature of the methodological approach chosen (Giorgi, 1987).

A philosophical worldview, and the potential impact of such a view on the research process, requires from a qualitative researcher to provide information on his/her personal and professional perspectives and background (Byrne, 2001). Factors such as a researcher's gender, class and ethnicity may play a role in the researcher's approach to a study and potentially bias the findings. It has been argued that "who you are affects what you get told" (Deverell, 1998, p. 29) but this argument can be taken further by realising that a researcher's worldview may affect what is asked during qualitative interviews. In an attempt to reduce interviewer bias, phenomenological research requires that the researcher make known personal assumptions and beliefs about a phenomena to enable bracketing, or suspension of preconceptions, which in turn enables a fuller understanding of the experience and subjective meaning placed by participants on the phenomenon under investigation (Riemen, 1988, in Munhall & Oiler, 1993).

Briefly, I am a 34-year old, female Speech-Language Pathologist working in a private practice in Cape Town. My current work experience, previous employment in a tertiary level public health care hospital, together with previous studies in Psychology has helped me appreciate the enormous task undertaken by mothers of children with special needs and the potential stressors associated with such care. My interest in the meaning that mothers place on their role as caregiver, as it relates to feeding, started while I was conducting an undergraduate research project. The study, which was quantitative in nature, set out to identify the frequency and nature of dysphagia in children with the Human Immuno-Deficiency Virus (HIV) who were receiving antiretroviral medication. During preparation for the study I found quite a large amount of research that reported on the incidence, nature and medical implications associated with paediatric feeding disorders. The aim of my undergraduate study was similarly to identify factors related to the frequency and nature of dysphagia in children. However it was during the pre-evaluation interview with the caregivers that a need to consider their experiences of meeting a child's feeding needs emerged. At that time I became aware of the scarcity of information on how parents and caregivers cope with the demands of adapted feeding strategies.

My experiences while working in the public health care sector also shaped my interest in the phenomenon. After graduating I completed my Community Service as a Speech-Language Pathologist employed at a large tertiary level hospital. I felt well equipped to meet the service delivery needs of a diverse paediatric and adult population that became my caseload; however I often felt ill-prepared during interactions with mothers who were providing specialised care and implementing adapted feeding strategies. I felt familiar with the practical and theoretical aspect of providing a service to these mothers, but often experienced difficulty in understanding some of their reactions to adapted feeding strategies, especially in situations where they appeared to disregard recommendations made by health care professionals. It is possible that my feelings of uncertainty and my perception of my limited understanding of what it meant for these mothers to have a child requiring adapted feeding strategies, stemmed from the fact that I had not yet experienced motherhood myself. However I became increasingly aware that I was not the only health care professional with such uncertainties. My interest in this phenomenon was therefore largely shaped by a personal need to gain an understanding, together with a personally held perception that other health care professionals, involved in the care of children with feeding difficulties, may share my lack of understanding of how mothers experience their role as the primary home-based caregiver.

More recent informal discussions with a mother of a child with cerebral palsy once again highlighted the need to understand what the experience of being the primary caregiver, responsible for the daily feeding needs of a child, is like. Through these discussions it emerged that, being a caregiver may hold different meanings for different people, and may differ from perceptions held by professionals. This, together with a personal commitment to providing family-centred care, led to the realisation that the emotional reaction experienced by a mother who was providing home-based care should be recognised in addition to evaluating therapeutic activities aimed at improving a child's feeding skills.

Qualitative research techniques, and the phenomenological method in particular, aim to describe individual's accounts of particular aspects of their lives and how they construct meaning within a given context. My interest in individual subjective experiences of personal realities was shaped by the philosophical attitude about human phenomena characteristic of the work of Carl Rogers and Victor Frankl. Adopting a Rogerian philosophical approach to the study of phenomena, I set out to observe and truly understand the experience of being the mother of a child with chronic feeding difficulties, not as a spectator but through the eyes of the mother living the experience. It is my hope that this study will enable the reader to share in the experience of truly understanding the mothers who participated.

"What matters, therefore, is not the meaning of life in general, but rather the specific meaning of a person's life at a given moment" (Frankl, 1963, p. 127).

1.1.2. Problem statement and the need for research in this area

Identifying the needs of parents and caregivers from their perspective, which can be achieved through qualitative research, has been identified as essential to inform service delivery (Liley & Manthorpe, 2003). A search of available literature found a number of qualitative studies on how mothers experience their caregiving role, however much less research is available on mothers' experiences of caring for a child with chronic feeding difficulties. The literature that is available on experiences of feeding reports on research which was conducted in countries such as Australia, America and the United Kingdom and all selected participants who were attending specialised support clinics where a multi-disciplinary team provided services. No studies have been conducted in South Africa, which potentially provides a very different context in which mothers are accessing health care services and providing home-based care for children with chronic feeding difficulties, thus highlighting the need for a study to be conducted in Cape Town.

The available literature reported that mothers and caregivers may feel unprepared for the demands of caring for a child who requires adapted feeding strategies (Adams, Gordon &

Spangler, 1999; Craig & Scambler, 2006; Raina et al., 2005). Mealtimes are often described as difficult and ambivalent feelings about oral as opposed to enteral feeding are present (Craig & Scambler, 2006). Inconsistency in advice given and in the techniques taught by professionals, together with the manner in which information is provided, was identified as sources of stress (Hoddinott & Pill, 2000; Liley & Manthorpe, 2003). These findings have implications for Speech-Language Pathologists working in South Africa, who are uniquely concerned with the management of feeding disorders (American Speech-Language Hearing Association, 2002). To support families, and thus promote optimal child outcomes, Speech-Language Pathologists need to be aware of how mothers experience their role as the primary caregiver. Research that adds to the understanding of factors which increase or decrease ability to cope with the demands of feeding a child with a chronic feeding difficulty, will equip service providers to empower individuals, groups or agencies through appropriate information and support provision.

1.1.3. Study aim and objectives

The study aims to describe mothers' personal experiences of caring for the daily feeding needs of their child; to explore how mothers of children with feeding difficulties define their role and identity as a mother; report barriers identified by mothers in terms of their capacity to provide home-based caregiving or that enable their capacity to provide such care; describe perspectives on available services as well as support needs identified by the mothers as it relates to meeting the feeding needs of their children.

1.2. LITERATURE REVIEW

1.2.1. Introduction

The ability to set aside prejudgments is central to phenomenological studies in that a researcher needs to see the phenomenon “freshly, as for the first time” (Moustakas, 1994, pg. 34). It is acknowledged that the benefits of a literature review are numerous, because a researcher undertaking a study can gain focus and support with the assistance of the literature. However phenomenological researchers are cautioned against conducting an in-depth literature review prior to conducting the interviews as it may create a false sense of knowing or preconceived beliefs about what the phenomenon under investigation is going to be like for the participants (Giorgi, 2005; Lopez & Willis, 2004). Conducting an in-depth literature review prior to conducting the interviews may in turn hinder the researcher from exploring the phenomenon in sufficient depth. In order to minimise bias that arises from preconceived beliefs, and that may originate from scrutinizing available literature, it is rather recommended that an in-depth literature review be conducted alongside data analysis and that literature be reviewed in an ongoing manner as new essences emerge from the analysed data (Latham, 2004). I thus conducted several literature reviews throughout the research process, as recommended by Lindseth and Norberg (2004) to illuminate various aspects of the interview text as different themes emerged. As shared themes emerged from the interviews I returned to available literature to frame the mothers’ experiences and provide a composite description of the phenomenon under investigation. An example of a theme that emerged was that frequent interactions with health care professionals in paediatric hospital settings played an important part in shaping a mother’s experience of providing care for a child with a chronic feeding difficulty. A review of available literature on the experiences of mothers in paediatric hospital ward settings was therefore required.

This literature review is divided into seven sections. As stated above, the literature review progressed alongside the data collection and analysis process. The areas considered in this literature review were therefore motivated by the themes that emerged from the mothers' narratives. Firstly, the prevalence and nature of chronic feeding difficulties was reviewed together with different feeding options that may be used (oral, enteral or parenteral). The second section looked specifically at studies that have documented the experience of mothers and/or caregivers in relation to feeding difficulties. The mothers in this study experienced challenges in integrating their ideal perceptions of motherhood with the reality of some of the caregiving tasks that they had to perform. Since this role conflict emerged as a common theme across the interviews a review of studies that explore the link between feeding and maternal role identity formation made up the third section of this review. Perspectives on loss and theories of how people react to and deal with personal loss were reviewed in the fourth section. The fifth section contains a review of literature pertaining to parental experiences of providing care for chronically ill and technology dependent children in the home context. Sections six and seven address issues related to paediatric public health care services. As mentioned earlier, the available literature on caring for children with feeding difficulties originate from countries such as the United Kingdom, United States of America and Australia (Adams et al., 1999; Craig & Scambler, 2006; Craig, Scambler & Spitz, 2003; Franklin & Rodger, 2003; Liley & Manthorpe, 2003), where potentially different services are available. To frame the mothers' experiences within their unique context it was therefore necessary to understand the health care system and services that they were accessing. A brief description of the structure and challenges faced within the South African public health care system was therefore provided in section six followed by a review of literature on parents' experiences during a child's hospitalisation.

1.2.2. Chronic feeding difficulties

A feeding and/or swallowing difficulty, or dysphagia, is a serious and potentially fatal problem, which can lead to the development of complications such as growth failure and aspiration pneumonia if not correctly managed (Darrow & Harley, 1998; Schwarz, Corredor, Fisher-Medina, Cohen & Rabinowitz, 2001). Feeding and swallowing difficulties in children may be related to neurologic, structural, genetic or behavioural factors and may also occur secondary to systemic illness be it respiratory, gastrointestinal or cardiac in nature (Arvedson & Brodsky, 2002). The reported incidence of paediatric feeding and swallowing difficulties is as high as 25% in children who are medically stable; this incidence increases to between 40% and 70% in children with chronic medical conditions (Rudolph & Thompson Link, 2002). Practically any illness can influence a child's motivation and ability to eat, which in turn complicates medical management (Comrie & Helm, 1997; Manikam & Perman, 2000). Though exact incidence data is not available it is estimated that up to 80% of children with cerebral palsy will have swallowing difficulties at some time during their lives (Arvedson & Brodsky, 2002).

Paediatric feeding difficulties include conditions that make it difficult or impossible for children to obtain adequate nutrition, such as food refusal, excessive vomiting, oral-motor dysfunction, gastroesophageal reflux, delayed gastric emptying and dysphagia. Many of these difficulties may be resolved with medical intervention, however about 3% of cases will be chronic in nature and require intensive intervention and hospitalisation (Garro, Thurman, Kerwin & Ducette, 2005).

The presence of feeding difficulties, result in children with medical conditions and those with neurodevelopmental disabilities needing specialised care such as frequent consultations with health care professionals and adapted feeding strategies (Franklin & Rodger, 2003). Adapted feeding strategies may, for example, involve diet modification, diet restriction or enteral feeding (Arvedson & Brodsky, 2002). When a baby or child is unable to take in adequate nutrition orally, or when swallowing has been found to be unsafe, placing the child at risk for aspiration, enteral feeding may be recommended (Winstock, 2005). Enteral feeding may be exclusive, when it is unsafe for a child to take food or liquids orally, or it may be partial where oral intake is safe to continue but a child is unable to meet his/her nutritional needs via exclusive oral intake (Arvedson & Brodsky, 2002). Enteral feeding may be through a nasogastric tube or gastrostomy tube. A nasogastric tube is passed through the nose to the stomach or small intestine and is usually the first method used when a child is not able to eat by mouth. Chronic feeding difficulties may require a gastrostomy tube that is inserted directly into the stomach through a surgical procedure (Winstock, 2005). Parenteral feeding is another means of feeding that is done through an intravenous line (Judson, 2004). Enteral feeding may be temporary or lifelong in the case of chronic difficulties. Should oral feeding improve sufficiently to sustain safe and sufficient oral intake, a gastrostomy tube may be removed resulting in closure of the stoma within 24 to 48 hours though the site may begin to close as soon as six hours after removal (Winstock, 2005).

A multidisciplinary team of professionals including a Speech-Language Pathologist, Dietician and a Paediatrician is recommended to assess and manage childhood feeding difficulties (Trier & Thomas, 1998). It is the role of the Speech-Language Pathologist to perform clinical and instrumental swallowing and feeding evaluations in order to identify if a child's swallowing anatomy and physiology is such that oral intake will be safe. The Speech-Language Pathologist is furthermore responsible for making decisions about how feeding difficulties should be managed and to provide treatment where needed (American Speech-Language Hearing Association, 2001). The Dietician is generally concerned about dietary history in order to evaluate if sufficient nourishment is received as well as to set targets for requirements and intake.

1.2.3. Chronic feeding difficulties and the feeder

Most of the available literature, according to Craig et al. (2003) about chronic feeding difficulties adopt a biomedical emphasis on factors such as weight gain and reduction in incidence of feeding related medical complications, for example aspiration pneumonia and reflux. Relatively few international studies (Craig et al., 2003; Franklin & Rodger, 2003; Liley & Manthorpe, 2003) and none in South Africa, have looked at the everyday experiences of caring for a child with a chronic feeding difficulty and little information is available on factors that enable or hinder a mother's capacity to cope.

Eating is defined as an enjoyable activity with both a nutritional and social dimension (Trier & Thomas, 1998). For some children and their mothers (or primary caregivers) mealtimes are stressful and time consuming. Feeding difficulties in children are enormously significant to mothers and may become a source of considerable distress (Spalding & McKeever, 1998).

The current study interviewed only mothers, as international research shows that mothers are solely responsible for providing nutrition in 90% of families with a child who has a feeding difficulty (Carroll & Reilly, 1996). Statistics of who fulfils the primary responsibility for feeding children are not available for South Africa. The notion of mothers as the "feeders" of their families is embedded in many cultures, as is the underlying or at times explicit belief that if a problem in feeding occurs it is related to a personal failure on the part of the mother (Southall, 2000). A mother's ability to successfully feed a child is therefore imbued with symbolic and emotional significance that transcends the provision of nutrition and may at times be used to reflect on a mother's nurturing skills (DeVault, 1991). Providing for a child's feeding needs is furthermore a key aspect in infant-mother bonding which may be experienced differently by informal caregivers (Arvedson & Brodsky, 2002) in that the feeding relationship is concerned with much more than the act of providing food, it is also central to developing the capacity to share emotional states (Briggs, 2000). A possible causal relationship between persistent feeding difficulties and poor development of an emotional bond between a mother and child has been suggested (Franklin & Rodger, 2003).

While most studies found a link between the ability to feed a child successfully and developing feelings of competence in the mothering role (Pridham, Lin & Brown, 1991), a study conducted by Judson (2004) found that mothers who were unable to feed a child did not necessarily suffer from a loss of self-esteem. The participants in Judson's study were mothers of children who were technology dependent. These mothers were asked to complete questionnaires during their respective children's hospitalisation shortly after being diagnosed with a chronic medical condition. The mothers' ability to remain confident in the mothering role was linked to the degree to which they were participating in the complicated care that their children needed during hospitalisation. They were therefore able to feel confident in their role as mothers because of their ability to perform caregiving tasks unrelated to feeding. Parental experiences in paediatric hospital wards will be discussed further in section 1.2.8. Judson (2004) states, however, that despite feeling confident in their role as mothers, these women experienced some degree of sadness and frustration related to feeding difficulties, findings similar to those of studies which looked at the emotional consequence of not being able to feed a child orally (Spalding & McKeever, 1998; Thorne, Radford & McCormick, 1997).

Enteral feeding via a gastrostomy tube is more often considered appropriate as a temporary option for managing feeding difficulties than in the past, where it was reserved as a long-term solution to a chronic feeding difficulty (Thorne et al., 1997). The increased frequency of gastrostomy use, means that mothers are increasingly expected to manage this technology at home. Though only a small number of studies have evaluated parental experiences of managing enteral feeding at home, what emerged was that home-based enteral feeding is often associated with caregiver burden, perceptions of loss, and that a greater degree of stress is experienced compared to that experienced by mothers of children with disabilities who can still be fed orally (Adams et al., 1999; Spalding & McKeever, 1998; Thorne et al., 1997). The initial decision to have a gastrostomy tube inserted was found to be difficult for mothers to make, a decision which was not necessarily made easier where oral feeding was stressful and difficult (Craig et al., 2003). A link between a mother's perception that she failed in her ability to feed her child orally and the struggle to agree to have a gastrostomy tube inserted was identified by Spalding and McKeever (1998). What also emerged was that a perception of loss surrounding oral feeding persisted, which made acceptance of a gastrostomy tube difficult. Spalding and McKeever (1998) found that it took many years before parents accepted the permanence of the gastrostomy tube and that some mothers in their study were still hoping that oral feeding would be possible even after years of exclusive enteral feeding. Ongoing dissatisfaction with a gastrostomy tube, irrespective of a mother's confidence in managing enteral feeding, was linked to continuing complications such as reflux and bowel disorders, challenging feeding schedules, as well as social isolation in that mothers avoided social gatherings in which they might have to give their child nutrition enterally (Spalding & McKeever, 1998).

The extent to which a chronic feeding difficulty can impact on the primary feeder's life was similarly explored in a study by Franklin and Rodger (2003). They found that the presence of chronic feeding difficulties resulted in a need to make changes to daily routines. The extent of the changes increased both the physical and emotional demands not only on the primary caregiver but on the whole family (Franklin & Rodger, 2003). The need to provide adapted feeding strategies and specialised caregiving should therefore be considered in relation to the impact that it may have on the primary feeder and on the family unit as a whole. Literature that explores the impact of home-based adapted feeding interventions on interfamilial relationships, are limited. Research of home-based care for technology dependent children are more prevalent and provide some insight into the impact of providing specialised care for children in relation to family functioning. Studies report that the impact on interfamilial relationships can be considerable and document an increase in family stress (Patterson, Leonard & Titus, 1992; Teague et al., 1993), behavioural changes in siblings, and marital problems (Jennings, 1990; Teague et al., 1993; Petr, Murdock & Chapin, 1995). O'Brien (2001) conducted a study in which the experience of long-term home based care for technology dependent children from the families' perspective was explored. The sample was made up of 15 families who had been caring for children between the ages of 3 and 12 years for at least one year prior to the interview. The majority of parents in his study reported a change in their relationship with their spouse because of having a child with special needs. Three marriages had dissolved and the women linked this in large part to having a child with special care needs. Similar findings in respect to the adverse effects that home-based caregiving can have on marriages were reported by others, however it also emerged that a strengthening of the relationship between spouses may occur (Heiman, 2002; Taanila, Kokkonen & Jaervelin, 1996).

Areas that required further review emerged in order to gain a greater understanding of the experience of providing care for a child with chronic feeding difficulties, namely how maternal role identity is defined and shaped in relation to feeding, how loss and grief is managed and how a mother experiences her role within the contexts of providing home-based caregiving and accessing health care services for her child.

1.2.4. Maternal role identity

It was necessary to investigate the process of developing a maternal identity and the factors which could influence this process as the mothers in the current study spoke of times when they struggled to define their role as a mother. Literature on maternal identity formation is plentiful and diverse, therefore, this section of the literature review is limited to feeding and feeding related difficulties as a factor that influences maternal identity formation.

Perceptions of motherhood and mothering practices are socially defined and are constantly reconstructed over the course of time (Ambert, 1994). Douglas and Michaels (2004) conducted a study in which they evaluated images of motherhood portrayed in the media including film, television and print and they concluded that women are bombarded with such images. Images of mothers portrayed in film and television in the 1970's began to deviate from the traditional stay-at-home mother however they found that this changed again in the 1980's and 1990's where women were once again portrayed as happiest in a stay-at-home capacity. The joys of motherhood and an absence of images that would portray the anxiety and confusion that some mothers experience became common in magazines aimed at the new mother market.

Simon (1995) found that women internalise "wife" and "mother" together with the responsibilities associated with these roles as their principal identities. Women were found to experience a greater perception of personal responsibility for the overall functioning of the family when compared to men. Feelings of guilt may emerge when women are not able to meet the standards they prescribe for themselves in relation to being a "mother" (Cassidy & Davies, 2003). Simon (1995) furthermore found that cultural expectations of a woman's role in relation to being a stay-at-home mother resulted in feelings of guilt and perceptions that they let their families down in their emotional support role by attempting to combine work and family. Maternal role identity formation appears to be closely related and influenced by the concepts of the "ideal" or "good mother". Woodward (1997) described how the "ideal mother" is frame their difficulties as personal inadequacies stemming from an underlying belief that women should have instinctive knowledge of how to be a mother. This belief, closely linked to the concept of a good mother, may be damaging when unattainable. A perception of inadequacy may therefore arise when a mother feels overwhelmed or unable to meet her child's feeding needs (Brown, Lumley, Small, & Astbury, 1994).

Marshall et al. (2007) furthermore found that the reactions of significant others in relation to difficulty with breastfeeding and/or a child struggling to gain weight, played an important part in the mother's self perception of ability to fulfil the ideal concept of a good mother. When children failed to thrive, regardless of the mode of nutrition, the mothers reported feeling distress at the perception that family members were judging their feeding practices (Spalding & McKeever, 1998; Thorne et al., 1997).

What also emerged was that a women's perception of herself as a good mother is influenced by the nature of her interactions with health care professionals. Where mothers experience difficulty in breastfeeding, conflicting information and inadequate support offered by health care professionals in relation to breastfeeding are often documented as barriers to a mother's capacity to cope (Marshall et al., 2007). The majority of studies that address the issue of parent-professional interactions in relation to breastfeeding appear to be in the context of parents' experiences during a premature infant's hospitalisation. Though none of the children in this study were born prematurely two of them experienced birth trauma resulting in prolonged hospitalisation in neonatal intensive care units (NICU) where the mothers struggled to breastfeed their newborn infants. A mother of a preterm or medically fragile infant will generally spend some time in an NICU which is characterised by care provided by many health care professionals and the use of highly technical equipment. The physical barrier created by medical equipment used in an NICU makes it difficult for mothers to cuddle their children in a similar manner to parents of full term and healthy infants. This, together with a sense of inability to meet a child's feeding needs result in mothers questioning their own ability to assume the role as primary caregiver upon the child's discharge (Flacking et al., 2007). Flacking et al. found that mothers of premature infants experience breastfeeding as being non-reciprocal in that they were only meeting the infant's needs without similarly gaining from the experience through establishing an emotional bond. It has been proposed that breastfeeding may take on the properties of labour for mothers if health care professionals focus on the mechanics and duration of feeding, without acknowledging the emotional interplay that occurs during breastfeeding and the potential impact that the inability to establish an emotional bond through feeding may have for the mother (Dykes, 2005; Flacking et al., 2007).

During analysis of the interview data it emerged that the mothers were not only involved in a process of creating a maternal role identity but that they also had to construct an identity for their respective children based on their perceptions of the "ideal child". The concept of relating to a "different child" was discussed in a study by Guerriere and McKeever (1997). Their study explored how mothers came to terms with changes that occurred in their children following traumatic brain injuries through a process of reconsidering notions of an ideal child and learning to relate to a different child (Guerriere & McKeever, 1997). The participants in their study spoke of multiple changes that occurred in their children after sustaining brain injuries, which resulted in the children being viewed as different children, who often could not interact with the mother as before. Serious brain injuries often result in changes in a child's appearance, abilities and behaviour. A review of literature on how mothers experience a sudden change in their child was relevant in the current study as the onset of feeding difficulties of three of the children was acute in nature and resulted in a complete loss of oral feeding ability following years of independence in ability to eat. In their qualitative study of seven mothers whose children had sustained serious brain injury, Guerriere and McKeever (1997), found that feelings of grief and loss were related to the profound differences observed in their children. The mothers in their study reported that they had become mothers of different children and that this forced them to construct a new view of the child. Further evaluation of perceptions of loss was required as the experience of loss emerged as a powerful theme for the mothers in the current study.

1.2.5. Perspectives on loss

In analysing the data in the current study it emerged that the mothers experienced both positive and negative outcomes in relation to caring for a child with a chronic feeding difficulty. In order to gain an understanding of these seemingly contradictory experiences a review of literature focusing on how people react to and deal with loss, the grieving process and coping strategies was conducted. Three theories addressing the process of grieving and the reaction to loss were identified as particularly relevant to the experiences that emerged from the interviews, namely "chronic sorrow", "cyclical grief" and "post-traumatic growth".

Grief is a natural human reaction to loss which can have emotional, physical, behavioural, cognitive and philosophical dimensions (Stroebe & Schut, 2001). Losses range widely from loss of possessions, employment, hearing or sight, to loss of a person who was cared for through separation or death (Parkes, 2001). Grieving encompass more than an experience of sadness to include a range of emotions that are experienced as a person attempts to accept a change, loss, disappointment or death (Wurzbach, Lesniak & Wilson, 1988)

Some studies (Bowlby, 1960; Kübler-Ross, 1969; Parkes, 1996) focused on distinct stages associated with the grieving process. Notable among these is the work of Elizabeth Kübler-Ross who in her book, "On Death and Dying" (1969), outlined five stages in the grieving process. The stages are presented in sequential order starting with denial, then anger, bargaining, depression and finally acceptance. The linear nature of her theory is reportedly often misinterpreted as encompassing a rigid progression through pre-determined emotional reactions, however Kübler-Ross noted that the stages do not always follow the same order and may not all be experienced by everybody following loss (Silverman, 2001). Nevertheless, stage theories of grief focus on the benefits of moving through stages characterised by a particular emotional reaction, towards eventually reaching a stage of acceptance, which is considered to demonstrate emotional stability (Silverman, 2001).

Other studies have moved away from stage theories of grief in recognition that people do not always move through an orderly, predictable series of responses to loss. The concept of "chronic sorrow" was first introduced by Simon Olshansky (1962) as an all-encompassing and persistent emotional response experienced by parents of children with an intellectual disability. What sets chronic sorrow apart from other theories of loss is that Olshansky postulated that the persistent nature of the grief is a normal response, as the loss of dreams for the child cannot be grieved in the same manner as grieving for someone who has passed away. Chronic sorrow is therefore not resolvable as the loss is continuing and the parent experiences multiple losses over time as long as the child continues to live. The implication of Olshansky's work is that professionals cannot expect parents to resolve their grief in a time-bound manner as is postulated in stage theories of grief. Periodic resurgence of intense grief is to be expected and is a natural rather than pathological reaction to the ongoing experiences of loss in the face of chronic illness or disability (Summers, Behr & Turnbull, 1998). The presence of a pervasive, persistent sorrow have been documented in parents of children with a wide range of challenges including intellectual impairment (Wikler, Wasow, & Hatfield, 1981), developmental disability (Mallow & Bechtel, 1999), prematurity (Fraley, 1986), Down syndrome (Damrosch & Perry, 1989), chronic mental illness (Eakes, 1995) and chronic medical conditions (Hobdell, 2004; Northington, 2000). Teel (1991) further defined chronic sorrow by recognizing the persistent but also potentially progressive nature of the experience of sadness which is different from the linear and time-bound grief reactions that follow the death of a loved one. Whereas grief ultimately reaches resolution, chronic sorrow is persistent, however it is set apart from depression, as the presence of chronic sorrow does not necessarily interfere with daily functioning (Burke, Hainsworth, Eakes, & Lindgren, 1992).

Grieving that occurs following the loss of an ideal, as opposed to a tangible object was reported by Betman (2006) who looked at the experiences of parents whose children had a chronic-illness. In his study the lost ideal was that of having a healthy child. The premise that parents grieve the loss of their ideal or "dream child" was first reported by Moses (1983). An ongoing incongruence between ideals and the reality of caring for a child with a chronic medical condition or disability was identified as the antecedent to chronic sorrow (Eakes, Burke & Hainsworth, 1998).

"Cyclical grieving" is a term that was coined by Joan Blaska (1998) to describe the cyclical or recurring nature of emotions associated with the grieving process experienced by parents who have children with disabilities. This theory of grieving differs from the ongoing experience of sadness which is characteristic of chronic sorrow to acknowledge that people move in and out of grief. Grief recurs throughout the life cycle of the family; however the duration and intensity of feelings diminish with the passage of time. Parents in Blaska's study (1998) identified a number of events which caused the feelings of grieving to reoccur. Grieving reoccurred and was triggered by events such as a child not reaching an expected developmental milestone, events in which a child was identified as different or excluded such as from children's birthday parties, when considering future care needs and the possibility of residential placement, and during seemingly irrelevant situations such as seeing a non-disabled child of similar age. Another example of a theory of grief that describes grieving as cyclical is the Dual-Process-Model proposed by Stroebe and Schut (2001). The Dual-Process-Model proposes that two states are present and that people move between these two states in an ongoing manner. There is either a focus on "loss" or on "restoration". An example of "restoration-focus" might be when a parent performs various restoration oriented tasks such as preparing food or requesting information about a child's condition, while a focus on loss might be present when time is spent thinking about the loss for example when a parent is reminded of previously held ideals for a child.

Other researchers (Wikler et al., 1981) have questioned the application of concepts of chronic sorrow and cyclical grieving to all parents caring for a child with a disability or chronic medical condition. Though they do not dispute the value of the concepts to describe the emotional state of many parents, there is a concern that it does not describe parents' full experience. A number of studies have focussed on the possible benefits of caring for a family member within a home-based context and on the positive emotions experienced by such caregivers (Boerner, Schulz & Horowitz, 2004; Cohen, Colantonio

& Vernich, 2002; Kramer, 1997; Louderback, 2000). A theme that emerged from such studies was that people with disabilities or who require assistance with daily caregiving have the potential to enrich and enhance the quality of life of those close to them who are performing caregiving tasks. Blaska (1998) also acknowledged that the occurrence of cyclical grieving does not necessarily prevent parents from identifying positive consequences of having a child with a disability and that they also experience joy from their respective children's achievements.

The reported experience of positive outcomes associated with caregiving is closely linked to research into the positive changes that often occur when people experience intense feelings of loss or following trauma. The idea that positive change may follow stressful events is not new and has been documented in philosophical and religious writings (Calhoun & Tedeschi, 1998). Different terms are used to describe the phenomenon of positive coping following a crisis or trauma, such as "thriving" (O'Leary & Ickovics, 1995), "positive psychological changes" (Yalom & Lieberman, 1991), "perceived benefits" (Calhoun & Tedeschi, 1998), "adversarial growth" (Linley & Joseph, 2004), "stress-related growth" (Park, Cohen and Murch, 1996) and "post-traumatic growth" (Tedeschi, Park & Calhoun, 1998). Research has shown that a personal crisis may act as a catalyst resulting in enhanced personal resources and the development of new coping skills (Schaefer & Moos, 1998). The key feature in identifying post-traumatic growth (PTG) is that something is gained, or a higher level of coping capacity reached. Growth is generally reported in three domains: changed perception of self, changed relationships with others and a changed outlook on life that often includes a deeper appreciation for life and the setting of new priorities (Tedeschi et al., 1998). Recent literature has examined the factors that may contribute to the phenomenon in which an individual is not merely changed by a traumatic experience but thrive under such conditions (Cadell, Regehr & Hemsworth, 2003). Cadell et al. conducted a study in which they examined the potential contribution to PTG made by the presence of three variables: spirituality, social support and stressors or factors that cause stress. They found that individuals who had the strongest spiritual and/or religious beliefs and who had the greatest amount of support demonstrated the most benefit after trauma. Contrary to their initial hypothesis they found that stressors had a significant positive effect on PTG. Individuals who experienced the highest levels of distress were therefore more likely to demonstrate growth (Cadell et al., 2003).

Noting different theories on the process of grief and the potential impact of experiencing intense feelings of loss is valuable, as it creates an understanding of the different emotions that may be experienced by the mothers in this study. In presenting the above theories it is hoped that the reader will set aside predetermined expectations and recognize the possibility that both positive and negative consequences of caring for a child with a chronic feeding difficulty, may emerge from the mothers' stories.

1.2.6. Experiences of home-based care

A phenomenological study aims to understand a human experience within a given context. An analysis of the data revealed that two specific contexts were present and significant in shaping the mothers' experiences, namely providing care within the home and accessing public health care services during a child's hospitalisation.

The mothers in the current study differed in relation to the type of feeding provided (oral, combination of oral and enteral, exclusively enteral) as well as in the nature of the onset of a feeding difficulty (progressive and acute) however they shared the experience of providing adapted feeding within a home-based context. All the mothers in the current study were the primary home-based caregivers for their children. A review of literature into home-based caregiving was therefore conducted as the analysis of the data revealed that maternal role identity was influenced by how the mothers made sense of the need to become home-based caregivers.

The number of children with complex medical needs being cared for at home is increasing throughout the world largely due to medical and technological advances resulting in portable equipment that is suitable for use in the home (Glendinning, Kirk, Guiffreda & Lawton, 2001; McIntosh & Runciman, 2007; Wang & Barnard, 2004).

With this move from hospital to community-based care, families are also taking on greater responsibility in managing adapted feeding strategies at home (Liley & Manthorpe, 2003). Research shows that caring for a child with a disability or medical condition at home involves many time consuming and complex tasks, but there is evidence that managing chronic feeding difficulties at home are especially challenging for parents (Cameron, Snowdon & Orr, 1992; Spalding & McKeever, 1998). Past research found that those who perform home-based care may experience a feeling of loss of identity or sense of self (Skaff & Pearlin, 1992). Wilson, Morse and Penrod (1998) found that mothers experience a conflict between their role as mother versus that of nurse, which in their words, required a shift from caring about a child to caring for a child. Their stories also revealed issues surrounding the role conflict that occurs when a mother has to take on the role of nurse or caregiver and with that the responsibility of caring for the medical needs of a child at home.

In order to understand the challenges encountered by parents who are providing home-based care, studies were reviewed that identified parental needs after a child is discharged from hospital. Children, because of the presence of parents who can provide care, are often discharged from hospital at an earlier stage than adults would have been even if they present with comparable medical conditions and needs (Smith & Daughtrey, 2000). In surveys conducted in the United Kingdom it was found that the needs of families who provide home-based care for children are often unknown and that the transition from accessing care at the tertiary hospital to accessing services at a community level may not be seamless (Thornes, 1993; Winter, 1997). Thornes (1993) states that for seamless, continuous care to be provided, closer liaison between doctors at specialist centres and community health care services need to be ensured through a planned discharge process. Not being kept informed on discharge decisions is a source of frustration for parents with hospitalised children (Smith & Daughtrey, 2000). To ensure quality service for these families it is important for health care professionals and parents to establish a discharge plan that includes aspects such as modifying the home environment, ordering of medical equipment and ensuring that home-based assistance is set in place prior to discharge (Heywood, 2002; Stephens, 2005). A planned discharge has been shown to result in a reduction in parental anxiety about assuming the role of primary care provider at home (Smith & Daughtrey, 2000).

The World Health Organization Classification of Functioning, Disability, and Health framework highlights the important relationship that exists between the health of the caregiver and the health of the child (World Health Organization, 2001). The importance of considering the caregiver is reflected in studies that aimed to document the emotional reactions that parents experience in relation to providing home-based care. Past research has identified a myriad of emotions experienced by parents who care for a chronically ill or technology dependent child at home including fear, anger (Brunier & McKeever, 1993); uncertainty (Cohen, 1993) and sorrow (Hobdell, 2004). The daily demands of caring for a child with special needs have been shown to lead to "caregiver burden" in some, which is defined as the strain experienced by a person who cares for a chronically ill, or disabled person that may be related to both the nature of caregiving tasks as well as to subjective experiences of stress (Stuckey, Neundorfer & Smyth, 1996). Mothers who have children with disabilities have been found to experience more stresses and to be less able to cope with stress than mothers of children without special needs (Cuskelly, Pullman & Hayes, 1998; Leonard, Brust & Nelson, 1993; Patterson et al., 1992). In particular, mothers of children with disabilities have been found to be more likely to experience depression and to feel pessimistic about the future compared to mothers of children without disabilities (Brehaut et al., 2004). The degree of change that occurred to life areas such as finances and career roles of parents who have a child with chronic medical difficulties was found to increase the level of stress experienced by the parents (Garro et al., 2005).

Kirk (1998) reviewed past studies on families' experiences of caring for a technology-dependent child at home, which included children reliant on enteral feeding. The reviewed studies documented extensive social restrictions that resulted from caring for a technology-dependent child, with some parents literally becoming house-bound (Bradley, Parette & Van Bierliet, 1995; Clarke, 1995; McKeever, 1991). In his review of studies conducted in the United Kingdom and the United States of America, Kirk (1998) found that parents report difficulties in finding respite care for a child who requires specialised care (Diehl, Moffitt & Wade, 1991; McKeever, 1991) which restricted their ability to leave the home. In addition to social isolation, parents providing home-based care for a child with a feeding difficulty have also been found to experience feelings of fear for a child's survival (Franklin & Rodger, 2003). Franklin and Rodger (2003) conducted a study in which they investigated parents' experiences and perceptions related to the demands of providing home-based care for medically compromised children with particular focus on feeding dynamics. Following in-depth interviews and mealtime observations it was found that feeding difficulties had an emotional impact on a parent in that they often feared for their child's survival. Though a link between caregiving burden and caregiver physical and psychological well-being has been demonstrated, it is not fully understood why some caregivers cope and others do not (Raina et al., 2005).

Contrary to findings of negative implications of home-based care on the caregiver other studies document positive outcomes. In an evaluation of Canadian parents' experiences of caring for a child with a disability at home it was found that parents also identified positive gains of caring and described their experiences as rewarding and satisfying (Roeher Institute, 1999). In a study by Scorgie and Sobsey (2000) it was found that mothers who have children with disabilities were experiencing positive outcomes associated with caring for a child with special needs, including a larger social network with many meaningful relationships. Following parental interviews, O'Brien (2001), described the experience of providing long-term home care for technology dependent children as "living in a house of cards". The families experienced their lives as characterised by frequent change and uncertainty. Despite the presence of uncertainty these families actively sought and gained stability by adopting effective coping strategies such as reframing their beliefs and priorities to be able to identify positive aspects of their lives. What emerges from these two studies is that parents appear to be enabled in their capacity to provide home-based care where social support is present and when they are able to develop coping strategies that involves a redefinition of their priorities and how they construct meaning in order to identify positive aspects in their lives.

Insight into enabling factors can also be deduced by reviewing the needs identified by parents as their capacity to cope would be increased by addressing such needs. In their study, Smith and Daughtrey (2000) identified a number of needs that parents who provide home-based care for children with complex medical conditions have. They found that parents need information about their child's medical condition and about the specific care tasks that they have to perform at home. Parents reported that they left the hospital setting with unanswered questions which they attributed to difficulties they had in asking health care professionals; who appeared too busy with their work. Another possible reason for unmet information needs and feelings of being ill prepared to assume caregiving on discharge, may be a difficulty in learning or accepting new information in the hospital setting when multiple stressors are present (Bailey & Caldwell, 1997; Snowdon & Kane, 1995). Apart from information needs, the parents also expressed the need for support as they experienced intense anxiety at the perceived total responsibility that they had to assume for the child's care. Isolation was a theme that emerged as parents felt that professional support was often not accessible. A final need that was identified was that parents require reassurance from health care professionals that what they are doing is correct and that the manner in which their child responds is normal (Smith & Daughtrey, 2000).

A number of coping strategies have been identified in studies looking at families who care for chronically ill children at home. Sharing caregiving tasks with a family member; seeking information and acquiring skills; seeking spiritual support; seeking out others in similar circumstances; and finding opportunities to talk about difficulties were the most frequently reported stress management strategies (Ireys, Chernoff, DeVet & Kim, 2001; Sterling, 1990). The context of providing home-based care for a child with a chronic feeding difficulty was the first of two important environments that influenced the experiences of the mothers in the current study. The second context, which continuously emerged in the mothers' stories, was that of experiences during times of accessing public health care.

1.2.7. Public health care in South Africa

In order to describe the phenomenon of being a mother of a child with a chronic feeding difficulty in depth it was necessary to gain an understanding of a very specific milieu, namely the public health system of South Africa. A brief overview of the public health care system in South Africa and the philosophical and political policies that guide service provision will be provided in this section. Prior to 1994 South Africa was a country divided which resulted in a highly fragmented health system that deprived the majority of the population of access to health services. Health care services were restructured after a democratically elected government came into power in 1994. The restructuring was based on a vision of creating a unified health system that would be capable of delivering quality health care to all citizens in line with primary health care (PHC) goals as outlined in the Alma Ata declaration (African National Congress, 1994, pg. 19). Alma Ata was based on the belief that health is a basic human right encompassing mental, physical and social wellbeing (www.who.int/archives/hfa). Primary health care (PHC) "embodies the concept of community development, and is based on full community participation in the planning, provision, control and monitoring of services which aims to reduce inequalities in access to health services" (African National Congress, 1994, p. 19).

The National Health Plan, proposed in 1994, was based on the PHC approach and envisioned that district health services would be the building blocks to attain equality in access to health services through community participation. Each province in South Africa would thereby be divided into districts with their respective District Health Services (http://www.doh.gov.za/docs/policy/norms/full-norms.html). All the mothers who took part in this study fell within the boundaries of the Cape Town Metro District, which is in the Western Cape Province.

At present the South African health system consists of a large public sector delivering services to about 80% of the population. South African public hospitals are managed by provincial departments of health with the national Department of Health (DoH) assuming responsibility for channelling funding to these provincial departments. The public health system is divided into levels of care, providing different services, with each level providing more specialised care than the level below it (Von Holdt & Murphy, 2007). Services vary from basic health care provided at primary level community clinics to highly specialised health services available at tertiary level hospitals. A patient is required to first access the primary or clinic level from where they are then referred upwards as required (Von Holdt & Murphy, 2007).

Despite efforts to restructure the South African public health care system in such a manner that greater equity of access will be possible, service-delivery challenges are still present. The public health care system is still characterised by some apartheid era legacies; in particular a vast language divide between health care professionals and the majority of patients exist. South Africa has eleven official languages, yet the majority of South African health care professionals are proficient in only English and/or Afrikaans (Drennan & Swartz, 2002). Apart from the challenge posed by language differences, the different levels of care that are operational in South Africa have also been described as being under-resourced (Hall & Roberts, 2006). The expansion of infrastructure following the adoption of the PHC objective of greater access to healthcare, in particular the establishment of more primary level community clinics, was not matched by an equivalent increase in health professional training and employment, most notably of nurses (Chabikuli, Blaauw, Gilson & Schneider, 2006). Universities and nursing colleges have been facing a decline in new student registrations. The shortage of nurses together with an expansion of their scope of practice increased the workload of nurses and, in so doing, negatively impacted on PHC service delivery (Chabikuli et al, 2006). In addition to declining numbers of trained health professionals, a survey by Penn-Kekana, Blaauw and Schneider (2004) of nurses working in maternal health services found that they present with very low morale. A decline in the availability of both doctors and nurses has been reported between 1996 and 2003 resulting in a shortage of about 46 000 personnel in the health system in 2005 (Day & Gray, 2005). Occupation specific statistics are not available on the number of posts that are vacant in the public health care system, however in 2007 it was found that a total of 18,7% of all health professional posts were vacant in the Western Cape. Statistics compiled in July 2007 show that doctors have to see an average of 56 patients per clinical work day in the Western Cape (District Health Information System Database, 2007). Following interviews conducted in eight South African public hospitals it was found that most doctors and nurses believed that staff shortages played a major part in compromised patient care. One senior nurse commented: "Everything is done in a rush, and staff are left exhausted. The result is a reduction in the quality of care and avoidable morbidity and mortality" (Von Holdt & Murphy, 2007, pg. 3). The study concluded that public hospitals in South Africa are "highly stressed institutions" due to unmanageable workloads and inadequate patient care which was similarly found by others (Schneider, Barron, & Fonn, 2007). This shortage of health care professionals was furthermore identified as a significant constraint to improving health care in South Africa.

Currently all South African children under the age of six have the right to free health care at community level clinics in the public health care sector. When a child accesses secondary or tertiary level facilities, a payment in accordance with a sliding scale linked to parental income is required (King, Mhlanga & de Pinho, 2006). Despite adopting a human rights-based framework for public health service delivery evidence shows that the health needs of children are often not met largely due to difficulty in accessing services especially in rural areas (King et al., 2006). Robertson (2006) identified the lack of transportation to and between hospitals as a major obstacle in the public health care system's ability to ensure equity of access to services offered at different levels of care.
It is estimated that about twenty per cent of South African children suffer from a chronic condition, also sometimes referred to as a Long Term Health Condition (LTHC), for which ongoing care is needed (Robertson, 2006). Disease and impairments such as cerebral palsy, epilepsy, congenital heart disease, developmental delay and HIV infection are examples of frequently occurring childhood conditions that will not only require ongoing management over a long period of time but often requires comprehensive health care provided by different professionals who may be at different levels of health care (Robertson, 2006). The "Implementation Framework for the Management of Children with Long Term Health Conditions" was drafted in 2002. This framework outlines standards for the development of services offered to children with LTHC. The

framework emphasises the need for family oriented multi-disciplinary services to be provided at each level of service provision. In order to ensure individual and appropriate case management, the framework calls for the establishment of a liaison person to manage referrals and for inter-sectoral collaboration with community organisations, social and educational bodies (Robertson, 2006). No information could be found on the extent to which these recommendations have been implemented, if at all, within the Western Cape Province.

When reviewing service provision within the South African public health care system for children with disabilities and their families it was found that although a range of services are being provided, the focus often tends to be almost exclusively on the medical needs of the child with little attention given to the family's needs (Philpott, 2006). Barriers to access have also been identified including a lack of information about support options that are available at different hospitals, fragmentation of services between the different levels of health care and a lack of transportation which make it difficult for families to access the services. Ignorance on the part of health care professionals regarding the type of support that a disabled child and their family may need, a lack of knowledge about available services as well as about the procedures for referral to support services have been documented (Bornman & Alant, 2002; Clacherty, Matshai & Sait, 2004).

1.2.8. Parental experiences of paediatric hospitals and interactions with health care professionals

As the mothers' stories contained many references to their experiences in paediatric hospital wards, literature relating to parental experiences of paediatric hospitals was reviewed. The degree of participation in providing care to their respective children and the nature of the interactions with health care professionals emerged as significant during analysis of the data.

The role and degree of participation of parents in paediatric hospitals have been examined by several researchers (Connell & Bradley, 2000; Ygge, 2004) resulting in different terms and descriptions of what is intended by the concept of parental participation, which may also be referred to as parental involvement or family centred care. Participation has been described as "being an integral and essential part of the child's hospital experience" (Darbyshire, 1994, p. 1671), and as the right to be listened to and having ones viewpoints treated with respect (Cashmore, 2001). Research found that parental participation in care tasks has benefits for the child, such as improved health outcomes, as well as for the parent providing such care, such as greater family satisfaction (American Academy of Pediatrics Policy Statement, 2003). Such findings support a shift from child-centred to family-centred care that recognises the crucial role of the primary caregiver and/or family in the child's development and well being (American Academy of Pediatrics Policy Statement, 2003). Family-centred care, like parental participation, is a concept that is not clearly defined. Connell and Bradley (2000) describe family-centred care as the sharing of power, provision of information and empowerment of the family. Baksi and Cradock (1998) define empowerment as the ability to improve one's quality of life based on knowledge, skills and self-awareness gained. Empowerment as it is used within the health care system is vague and a definitive definition could not be found in the literature reviewed. Gibson (1995) provides some insight into parental empowerment by stating that the full participation of parents in a child's care during hospitalisation is a crucial determinant to becoming empowered.

The benefits of family-centred care and parental participation within the health care context in relation to children with chronic feeding difficulties, was demonstrated in a study by Garro et al. (2005). They examined changes in levels of stress of 37 mothers/caregivers of children with chronic feeding problems. The participants were recruited from an inpatient unit of a paediatric rehabilitation hospital in a large American city. They were all enrolled in a feeding program that was staffed by a multi-disciplinary team of Physicians, Nurses, Speech-Language Pathologists and Occupational Therapists. The mean length of time spent in the feeding program was 40.4 days. Parental stress data was collected at three transition points or stages of the child's hospitalization, namely at the time of admission, at the first progress point (when the child completed 12 of 15 therapist-facilitated feeding sessions with at least 80% food acceptance), and at the time of discharge. It was found that stress related to self-perception and social isolation significantly decreased from the time of the child's admission to the time of discharge. The study identified factors that may have contributed to the decreased stress levels such as receiving confirmation of perceptions regarding the feeding problem, clarification of specific medical conditions, the provision of support that was not previously in place and parental participation during feeding sessions and multi-disciplinary discussions. This finding suggests that hospital-based intensive intervention services can reduce stress levels in parents where they are empowered through participation.

In a study of 50 parent Balling and McCubbin (2001), described parents' desired degree of participation in the care of their chronically ill child when the child was hospitalised. They reported that parents wanted a high degree of participation in the care of their child with information sharing about their child's condition and treatment plan, identified as the area in which parents wanted the highest degree of participation.

Though the benefits of family-centred care have been demonstrated, and despite parental expressions of desire to support the child during hospitalisation, the reality is that it is not always implemented (Judson, 2004). Newton (2000) identified two challenges to the implementation of family-centred care within a health care context, namely role uncertainty and power imbalances between parents and professionals. Family-centred care is characterised by the sharing of power, provision of information and empowerment in terms of skill acquisition (Connell & Bradley, 2000). It requires the fostering of open, honest dialogue with a family and its success is therefore largely dependent on the professional (Irlam & Bruce, 2002). Parents report uncertainty as to their role during a child's hospitalisation and cite a lack of information provided by health care professionals that would define their role, as a reason (Connell & Bradley 2000; Kristensson-Hallström & Elander 1994).

A review of the literature found that common sources of stress are often present in parents of hospitalised children. Heuer (1993) identified sources of stress as including the unfamiliar environment of hospital wards, unfamiliarity with procedures performed, relinquishment of parental role and communication with health care professionals; while Thompson, Hupcey and Clark (2003), report a lack of privacy and not being kept informed or included in decision making as additional sources of stress. Kirk (1998) reviewed a number of studies that looked at parent-professional relationships and found factors that play a role in the experience being perceived as either positive or negative by the parent. Positive interactions with health care professionals were found to be characterised by professional willingness to collaborate with and to acknowledge parental competence. A similar finding was reported by Meyer, Snelling and Myren-Manbeck (1998) who reported that the creation of a trusting parent-professional relationship was positively related to a health care professional's ability to recognise the importance of the parent's role in the child's care. Parental needs during a child's hospitalisation frequently include an intense need to trust health care professionals (Meyer et al., 1998). The development of parental trust has been related to the quality of care provided (Patterson et al., 1992), to honest information provision (Heuer, 1993) but even more significantly to the health care professional demonstrating genuine concern for the child and family (Meyer et al., 1998). A health care professional's ability to demonstrate respect, warmth and concern during interactions with patients has similarly been found to be valued attributes (Davies & Hall, 2005).

Problematic interactions were characterised by issues surrounding professional control, a lack of trust in parental competence and a lack of respect (Kirk, 1998). Parents often have to relinquish their caregiving role when entering the hospital setting (Leahey & Harper-Jaques, 1996). Despite research showing that parents who care for children with a chronic illness at home develop expertise in caring for their children, such expertise may receive little recognition by health care professionals (Leahey & Harper-Jaques, 1996). Thompson, Hupcey and Clark (2003) found that not enabling a parent to assist in caregiving tasks such as feeding and bathing, and expecting parents to provide care that they are not comfortable with, can also inhibit the establishment of trust.

One explanation for the difficulty in establishing a partnership is offered by McIntosh and Runciman (2007) who found that the creation of a parent-professional partnership is knowledge, skill and resource intensive on the part of the health care professional. The establishment of such a partnership is therefore complex and time consuming as parents' trust has to be gained and information and skills tactfully imparted. Another possible reason why a partnership is difficult to establish may be related to incongruence between perceptions of needs. A study by Scott (1998) of paediatric nurses and the parents of hospitalised children, found that a mismatch between perceived needs may occur. In his study parents listed the need to see that health care professionals cared about their child as their number one need. Nurses held the perception that a parent's number one need would be information about the child's medical treatment and only listed the parents need to experience caring interactions as the tenth most important need.

Dixon (1996) identified changes that occur in the nature of the parent-professional relationship over time. He concluded that as parents increase their knowledge and confidence in performing various caregiving tasks decision making progresses from being professionally dominated to becoming collaborative. A similar finding was reported by McKeever (1991) who found that mothers become less compliant with time due to an increase in confidence. Contrary to Dixon's finding that the degree of parent-professional collaboration in decision making increases with time, McKeever found that professionals often adopt a more coercive interaction style and that they may avoid contact with a parent as the parent's knowledge and expertise increases (McKeever, 1991). Establishing and maintaining relationships between parents and health care professionals was found to be an evolving process that progresses through the stages of naive trusting, disenchantment, and guarded alliance (Thorne & Robinson, 1989). There is often an initial trust that health care professionals will hold the child's best interest as paramount, however mistrust can arise should parents identify mistakes or inappropriate decisions on the part of the health care professional (Thornes, 1993).

CHAPTER TWO

2.1. RESEARCH METHODOLOGY

Chapter two provides a description and discussion of the philosophical underpinnings of this study together with comments by key authors such as Husserl, Moustakas and Frankl as they shaped the process of selecting a methodology. The historical evolution and philosophical basis of phenomenology is therefore provided together with a rationale for choosing this method for the current study. As Phenomenology has been described to be essentially an orientation to enquiry which can be "elusive" or difficult to define (Merleau-Ponty, 2002), it is hoped that this chapter will provide insight into the nature of conducting a phenomenological study and why it was deemed appropriate.

2.1.1. Qualitative research

The goal of research in Speech-Language Pathology is to provide evidence that informs practice. While outcome measures and cause-and-effect research can enhance the quality of service provision, much of what constitutes care in the health care and allied health professions cannot be examined by the purely hard sciences of positivist research (Lindseth & Norberg, 2004; Plack, 2005). Positivist research provides information about causality, however it fails to generate an understanding of human nature and its impact on health (Gibson & Martin, 2003). Michell (1999) states that many things that have the potential to act as barriers to a given intervention may not be measurable, thus necessitating the use of research methods that can clarify factors that fall outside of the biophysical. While evidence-based practice is, and should be, valued by health care professionals, the evidence is incomplete unless voice is given to complex phenomena such as human behaviour which can only be gained by considering the lived experience of participants (Maxwell, 2004).

Since this study aimed to describe mothers' experiences of caring for a child with a chronic feeding difficulty a qualitative research design was suitable (Creswell, 1998).

Qualitative research encompasses methods used to understand phenomena as they occur within a given context (Lincoln, 1992). For the field of Speech-Language Pathology to show efficacy of management, the importance of contextual considerations cannot be ignored. It is proposed that a true understanding of mothers' needs can only be gained by what Baum (1995) terms the adoption of strategies for understanding rather than measuring. As such, a qualitative study has the potential to make contributions to evidence-based practice (Whalley Hammell & Carpenter, 2004) and was thus chosen as the most appropriate design for this research.

The results obtained in this study do not allow for generalisation or statistical projections across a target population as the sample was not selected at random. Though qualitative methods do not claim to generalise findings they nevertheless allow for what Myers (2000) terms partial generalisation, in that findings may be applied to others in similar contexts. The research method chosen in this study was deemed suitable, as the purpose of this study was not to predict outcomes but rather to gain insight into mothers' unique experiences within a given context, as is appropriate within a qualitative design (Malterud, 2001). Mothers in other contexts are likely to have different support services in place resulting in potentially different experiences. The study aimed to broaden understanding of a mother's experiences as it relates to the contexts of caring for a child with a chronic feeding difficulty at home and while accessing public health care services for that child in Cape Town, South Africa. It is hoped that an in-depth understanding of this phenomenon will guide client-centred interventions for others in similar contexts (Valliant Cook, 2001).

2.1.2. Phenomenology

This study aimed to describe the essence of being a mother as it relates to a child with chronic feeding difficulties. A phenomenological approach was therefore appropriate as it sets out to provide an in depth description of how people experience a given phenomenon, and ascribe meaning to experiences (Holloway & Wheeler, 1996). Phenomenological research required a shift of focus from cause-effect analyses to human subjectivity in which the unique dimension of humanity is to be understood (Miller & Crabtree, 2000).

Phenomenological philosophy as a school of thought and as a research method arose in Germany in the late nineteenth century as a result of growing dissatisfaction with positivism which was not able to supply answers to many human concerns (Cohen, 1987). Two different approaches to conducting a phenomenological study are available, however both draw on German philosophy related to understanding human experience (Laverty, 2003). The choice of approach for the current study was guided by the method that was felt to be best suited to both the research question as well as the researcher.

The two broad fields of Phenomenology is Husserlian Transcendental (eidetic or descriptive) and Heideggerian Hermeneutic (interpretive). The two approaches represent different, though often overlapping assumptions about how data should be organised and analysed (Moerer-Urdahl & Creswell, 2004). The approaches furthermore differ in their historical advocates and current proponents. Husserl, Moustakas, Colaizzi and Giorgi are generally associated with Transcendental Phenomenology while Heidegger and van Manen are proponents of Hermeneutic Phenomenology (Laverty, 2003).

Husserl based his philosophy of Phenomenology on a critique of positivism as he believed that science needed a philosophy that could come in contact with deeper human concerns (Cohen, 1987). For Husserl, a clear understanding of the essential nature of reality could only be discovered through the study of lived experience and a systematic description of the phenomena encountered by humans in their everyday lives (Lindseth & Norberg, 2004). He described his approach as transcendental, as the purpose was to transcend the traditional scientific notion, that only that which can be measured is valid knowledge (Giorgi, 2005). In a transcendental study the researcher sets aside prejudgments as much as possible and uses systematic procedures for analysing data. The process of setting aside prejudgments is called "epoche" stemming from a Greek word meaning to refrain from judgment. The process has therefore been termed transcendental because the researcher needs to see the phenomenon as for the first time in a manner which is characterised by being "open to its totality" (Moustakas, 1994, p. 34). In order to set aside prejudgments, Moustakas emphasised the need for the researcher to start the research process by describing his or her own experiences with the phenomenon. In this regard the researcher provided information on her background, work experience and perceptions concerning family-centred care in Chapter one. The data analysis process in a transcendental research study should follow a systematic process of identifying significant statements in the data, clustering the statements into themes and then synthesising the themes into a description of the individual's experiences.

Martin Heidegger, a former student of Husserl, became his intellectual adversary after publishing his early work, "Being and Time", which differed from the ideological beliefs encapsulated in Transcendental Phenomenology (Walsh, 1996). In Heideggerian or Interpretive Phenomenology the researcher also focuses on participants' everyday practices as they are revealed in narratives; however the researcher then interprets these experiences in a process of interpretation called Hermeneutics (Lindseth & Norberg, 2004). Interpretive Phenomenology sets out to analyse what the participants' descriptions of their lived experiences 'really' mean through a process of reflective interpretation. The analysis and interpretation of the data incorporates the researchers own perspectives based on personal experiences which sets it apart from Husserlian Phenomenology that emphasizes objectivity (Moerer-Urdahl & Creswell, 2004).

Transcendental Phenomenology was chosen, and deemed appropriate, as this study set out to describe the essence of being a mother of a child with chronic feeding difficulties. Transcendental Phenomenology was furthermore appropriate as the researcher has not herself had a "lived experience" of providing care for a child with a chronic feeding difficulty. By not having experienced the phenomenon under investigation the researcher was better able to achieve objectivity or to set aside preconceptions, as is called for in Transcendental Phenomenology (Lopez & Willis, 2004). Phenomenological reduction or bracketing is an important concept in Husserl's phenomenological philosophy (Cohen, 1987) as there is a need to hold presuppositions in abeyance in order to see beyond the 'taken for granted', thereby finding the essence of an experience (Giorgi, 2005).

"It is what we know already that often prevents us from learning." (Bernard, 1949). The above quotation by Claude Bernard summarises the Husserlian philosophy of engaging in research without preconceived ideas of what it is like to be a mother of a child with a chronic feeding difficulty. A misperception of Transcendental Phenomenology is that the researcher should be able to become like a blank slate, thereby setting aside all previous knowledge and personal experiences. Transcendental Phenomenology calls for the discovery of essences that capture the subjective experiences of participants, which is only possible where no truths are presupposed by the researcher (Moustakas, 1994). Though the methodology focuses on exploring subjective experiences it requires positivist values of thinking and reflecting (Moustakas, 1994). Husserl did not require the setting aside of all presuppositions, but rather a guarding against acceptance of unverified presuppositions (Spiegelberg, 1980). Bracketing allows the researcher to set aside notions about potential implications of an experience that may have been considered as truths before immersion in the data. Any theory or philosophical belief held by the researcher that could potentially interfere with the researcher's ability to explore or revisit the phenomenon openly, should therefore be bracketed (acknowledged) and set aside (Koestenbaum, 1975), as was done in Chapter one.

Yet another misperception of Transcendental Phenomenology is that the researcher merely provides a summary of the concrete descriptions provided by participants. The description should, according to Moustakas (1994), result in the identification of essences that make up the phenomenon, which requires the ability to explicate the phenomenon in terms of its possible meanings. In this regard a degree of researcher intuition is required in a process called eidetic reduction. For Husserl, the purpose of phenomenological analysis was not to provide a verbatim description of an experience, but rather to understand the demarcation between what is happening and what is potential in a person's experience. Husserl spoke of eidetic reduction as the process whereby we reduce facts presented by participants to general essences. The process allows the researcher to focus on the essential meaning of an experience (Sokolowski, 2000). Eidetic reduction requires from the researcher to remove herself from the interview so that the phenomenon in question can be observed from a distance or what is referred to as a state of reflection (Koestenbaum, 1975). The use of open-ended questions during the interviews allowed participants in this study to share and reflect on experiences that emerged in their minds as significant, thereby removing potential researcher influence as what might occur during a structured interview or questionnaire. Husserl's reductions refer to a change in attitude, through which we learn to see the experience in a different way, which allows for a deepened understanding of the phenomenon (Moustakas, 1994).

Another concept described by Husserl, of relevance to the current study, relates to the inter-subjective experience of the world or Lebenswelt, which is the everyday life world of ordinary people (Van Heerden, 2000). In this regard Husserl acknowledged that the world is a shared space or context which cannot be ignored as it plays an important part in shaping the individual's experience of a given phenomenon (Moustakas, 1994). Individuals have subjective beliefs about the meaning of the context or space in which they live (Sokolowski, 2000). Space has been defined as "the medium in which people act, intersect, move and locate themselves" (Freund, 2001, p. 695). Sack (1993, p. 328) states that "people are always in a place, and places constrain and enable". From these statements it must be acknowledged that a person's experience does not only occur within a particular space but that the nature of that space has the capacity to shape how a phenomenon is experienced. It therefore becomes important to understand the context within which the individual lives and interacts with others and the unique experience of this world, which in turn may illuminate the role played by such a context in how meaning about a given phenomenon is constructed (Van Heerden, 2000).

"Phenomenology is an attempt to describe the way in which man understands himself, in which he interprets his own existence..." (Frankl, 1988, p. 7). This study was guided by the philosophical views of Husserl and Moustakas which are summarised in the above quotation by Victor Frankl. The researcher set forth to create knowledge that is unique to the mothers who took part in this study in order to offer a portal of insight into their personal experience of being the mother of a child with chronic feeding difficulties, which is in line with what Transcendental Phenomenology aspires to achieve (Laverty, 2003).

CHAPTER THREE

The following chapter will outline the process followed and the methods used to gather and analyse the data. Ethical considerations pertaining to the research are also discussed. The final section addresses rigor and trustworthiness.

3.1. RESEARCH METHOD

3.1.1. Participant selection

3.1.1.1. Inclusion criteria

Participants were required to meet the following criteria:

- be the mother and primary caregiver of a child with a chronic feeding difficulty.
- be conversant in English or Afrikaans. The data from this study was derived from interviews in which ideas were expressed through words. To reduce potential misinterpretations, related to different understandings of terms and words used during the interview, it was considered appropriate that only the languages in which the researcher is proficient be included. Though translators may have enabled me to include participants who speak a language other than English or Afrikaans some contamination of the participants' responses may have occurred making it difficult to ensure that the essence of their experience is captured (Patton, 2002).
- reside in the same geographic setting, which for the purpose of this study was mothers residing in Cape Town, South Africa.
- access public health care services. The inclusion of participants who live within one area and have access to the same health care and support services was important to ensure comparability of experiences. Mothers in other contexts would be likely to have different support services in place resulting in potentially different experiences.

3.1.1.2. Sampling

Sampling in this study was purposeful (Miles & Huberman, 1994) in that participants considered to be information rich, who met the inclusion criteria of having experienced the phenomenon of caring for a child with a chronic feeding difficulty, were selected. Information rich participants are defined by Patton (2002) as participants who will yield detailed understanding about the issue under study. A purposeful sampling strategy, in which the researcher consciously selects participants, was suitable for this study as the participants in a phenomenological study need to represent those who have experienced a specific phenomenon (Creswell, 1998).

A snowball sampling method was used, as a network of mothers was believed to be the best source for identification of potential participants (Neuman, 2006). This method was suitable for this study as it enabled me to locate information rich participants. The initial "key informant" (Miles & Huberman, 1994) was a mother known to me who was in a position to identify other mothers who met the inclusion criteria, thus starting a chain of potential participants (Patton, 2002). The two participants recruited through the initial key informant did not however have contact with other mothers in similar situations and were not able to identify further potential participants. For this reason another key informant was approached who was in a position to identify mothers who met the inclusion criteria. A further three participants were recruited through the second key informant.

Qualitative research methods are often defined as emergent in nature (Patton, 2002) in that the selection of participants and the sample size is guided by initial analysis of the data. It became evident that the initial five participants recruited shared a great degree of inter-relationships, thereby reducing representativeness to other mothers who met the inclusion criteria. I therefore actively looked for mothers not connected to the networks that I had already tapped into (Van Meter, 1990). A further two participants were recruited through a third key informant. As the first five participants were similar in terms of the method of feeding used (enteral only or a combination of enteral and oral) two participants were recruited who could provide insight into mothers experiences who used exclusive oral feeding. In this regard sampling for dissimilarity was employed in an attempt to see if the themes that emerged following initial analysis of the first five interviews would be universal or shared by mothers who had children with chronic feeding difficulties who were still able to take nutrition orally (Rubin & Rubin, 2005).

3.1.1.3. Sample size

The sample size in this study was based on a minimum sampling strategy as recommended by Patton (2002). A minimum of six participants is recommended by Sandelowski (1995) to obtain the essence of the phenomenon under investigation. A relatively small sample size was appropriate for this study since qualitative research aims to describe experiences in-depth. The analysis of large numbers of interviews may have limited my ability to efficiently analyse large quantities of data (Ritchie & Lewis, 2003). The final sample size was furthermore guided by sampling adequacy evidenced by replication of categories in order to ensure verification and completeness (Patton, 2002). A total of seven mothers participated in this study.

3.1.1.4. Recruitment procedure

Participant recruitment commenced as follows:

- Key informants were approached. Information on the purpose of the research and the procedures was provided in a document called the "Research Information Sheet" which was available in English (Appendix A) or Afrikaans (Appendix B) to accommodate participants who were proficient in either of these languages. The Research Information Sheet provided participants with information about:
    - the researcher;
    - the aim of the research;
    - the nature of the research in terms of what would be required of participants;

  - potential benefits of the research;
  - the assurance of confidentiality;
  - the right to voluntary participation; and
  - the right to withdraw from participating at any time without penalty.

- The key informants were asked to identify potential participants based on that person's ability to share and reflect upon their experience of being the mother of a child with chronic feeding difficulties with me.

- Information rich participants, based on the specified inclusion criteria, were identified by the key informants, who informed them of the study and supplied them with my telephone number and email address. If they were interested in finding out more about the study they were asked to notify me, which facilitated confidentiality and reduced pressure to participate.

- Once I had been notified that a potential participant may be contacted, written information regarding the nature and procedure of the study was provided as outlined in the Research Information Sheet.

- Mothers who, following review of the information, agreed to participate in the study were asked to give written informed consent and were given the opportunity to ask questions regarding the study. The "Participant Consent Form" (Appendix C) was available in English or Afrikaans in order to accommodate participants who are proficient in either of these languages. The consent form asked participants to indicate that the nature of the research; the right to voluntary participation; and to withdraw from participation without penalty, were explained to them.

- Initial analysis of the interviews guided the process of participant selection in that data saturation was not reached by the 5th interview, thus necessitating further recruitment.

3.1.2. Data collection

This section will outline the methods used to gather the data namely qualitative interviews, reflective journal writing and a biographical questionnaire.

3.1.2.1. Qualitative interviews

In-depth semi-structured interviews (Rubin & Rubin, 2005) were used, which allowed me to gain an understanding of the lived experience of being the mother as it relates to caring for a child with a chronic feeding difficulty. The use of in-depth semi-structured interviews was an appropriate method of data collection for this study as it evoked personal experiences and provided insight into perspectives held by participants (Patton, 2002). The aim of this study was to obtain personal experiences, which might have been difficult for some participants to share in another qualitative method of enquiry, such as a focus group method. The focus group approach might have limited the information gained, and was thus not chosen for this study (Kritzinger, 1995).

In-depth semi-structured interviews were furthermore better suited to this study than fixed response questionnaires, which are not able to capture the individual participant's perceptions and experiences (Patton, 2002). Though the informal conversational interview, as defined by Patton, would also have enabled me to understand the essence of being a mother as experienced by participants, it requires a greater degree of interviewer skill. To limit potential biases that may have emerged from this approach being used by a researcher who is a novice to the field of qualitative research, it was not considered appropriate for the current study.

The general interview guide approach, as outlined by Patton (2002) was used and was appropriate for this study as it enabled me to focus on specific areas with a number of different participants. The general interview guide approach also allows for flexibility, which enabled me to explore issues raised during the interviews which would not have been possible using a standardised open-ended interview (Patton, 2002). In an attempt to obtain sufficient detail and depth, which is defined as "thick descriptions", a main question and probe or follow-up questions were used (Rubin & Rubin, 2005). While the interview guide served a role in focusing on the original question it was used flexibly and not as a fixed itinerary. I started each interview in the same manner, by asking the main question: "Please tell me as fully as you can about your experiences of being the mother of a child with chronic feeding difficulties. In answering this question think about the things that have played a role in how you experience your role as the mother." When needed, I used probe questions (Patton, 2002) to ensure greater depth of responses. The use of probes were appropriate for this study as it enables a researcher to request detail and to clarify ideas that emerge during the interviews that may not have been anticipated during the construction of the interview guide (Rubin & Rubin, 2005). Questioning during the interviews was often guided by themes that seemed most salient to the participant. The preliminary analysis that followed each individual interview enabled me to identify themes that in turn influenced questioning in subsequent interviews, in line with the emergent design adopted by this study. The flexible nature of the interview guide was an important aspect of this study as it enabled me to provide participants with the space to tell their story. Interviewing was guided by Kvale (1996) who stated that it is the researcher's responsibility to provide the person being interviewed with sufficient freedom to enable the telling of their story, which can only be achieved by limiting the researcher's participation during the interview.

This flexibility reflects the iterative process of this study, in that the interview focus was adapted following the initial analysis of each interview based on essences that emerged. The themes that emerged from the initial five interviews resulted in an active search and recruitment of two mothers who were able to reflect on a specific aspect of the lived experience of being a mother, namely providing care for a child with a chronic feeding difficulty who is still able to take food orally. Another iteration involved a change in focus of the interview guide, away from the everyday tasks involved in feeding a child to a focus on the process of role definition and role change that emerged as an essence after analysis of the initial interviews.

3.1.2.2. Reflective journal

Personal field notes were kept in a journal which was both descriptive and reflective. Descriptive notes stemming from observations made during each interview were documented. In addition reflective ideas that evolved following each interview and during analysis of the data were documented in an ongoing manner. Journal entries enable a researcher to identify potential biases that emerge because of personal assumptions (Holloway & Wheeler, 1996). I documented decisions made throughout the study, which served as an audit trail (Sandelowski & Barrosa, 2003). Examples of reflective journal entries are presented in Appendix D.

3.1.2.3. Pilot interview

A pilot interview was conducted to identify potential difficulties with the proposed research, to establish if modifications needed to be made to the methodology as well as to familiarise the researcher with the research process (Van Vuuren & Maree, 1999 in Terre Blanche & Durrheim, 1999). Though some (Holloway, 1997) argue that pilot studies are not needed in qualitative research, Frankland and Bloor (1999) note that piloting provides the qualitative researcher with a clear focus and enables narrowing the spectrum of potential categories to be explored in depth and was thus deemed appropriate to use in this study.

One in-depth interview using the interview guide that had been developed was conducted with a mother who met the inclusion criteria and who was therefore similar to the participants who were selected. Critical evaluation of the transcribed interview highlighted the need to probe future participants to a greater extent as some of the responses were superficial and the data obtained from this pilot interview was thus not reported on in the main study. In order to ensure rich data I therefore spent time evaluating and refining my interview skills. The iterative process of this study enabled me to make adjustments to the interview guide following the pilot interview and in effect following each interview as themes emerged which were not anticipated.

3.1.2.4. Data collection tools

The following tools and forms were used in this study:

Biographical questionnaire

A biographical questionnaire (Appendix E) provided information on the:

- mother's marital and employment status;
- household composition;
- child's age, nature of physical and/or intellectual difficulty, nature of feeding difficulty, and the feeding method used (oral, enteral, combination of oral and enteral);
- support and assistance received as it related to the daily feeding needs of the child.

Interview guide

An interview guide consisting of open-ended questions was used (Appendix F). The selection of questions was based on the relevant literature, the purpose of the study and on themes identified in the preliminary analysis following each interview. Open ended questions were used that allowed the participants to describe aspects of the phenomenon in their words, which was appropriate as it enabled me to indentify experiences viewed as significant by the mothers without imposing predetermining ideas (Patton, 2002).

The questions selected for the interview guide encompassed three distinct levels of enquiry or types of questions as outlined by Patton (2002), and were specifically chosen to obtain depth of information.

- Experience and behaviour questions were posed in order to describe the activities and experiences that form part of feeding the child.

- To gain insight into and thereby describe mothers' expectations and wishes, especially related to support services, opinion and value questions were used.

- Feeling questions were included in order to describe emotional responses of mothers in respect of their experiences and thoughts surrounding the demands of caring for a child with a chronic feeding difficulty.

3.1.2.5. Data collection process

- Participants were given a choice of interview location, either in their homes or at an alternative quiet venue. All the participants chose to be interviewed in their homes.

- The interviews were audiotaped for which informed consent was obtained. A good quality audiotape was used to enable accurate transcription of the interviews.

- The audiotaped interviews were transcribed and field notes taken immediately after each interview thus ensuring that nuances such as body language were recorded accurately. The transcriptions were done by myself to ensure that valuable non-verbal interactions were not omitted as may occur when using an independent transcriber. Each taped interview and transcription was labelled with a participant number to ensure confidentiality.

- A reflective journal entry was made immediately after the interview detailing thoughts about the interview and my impressions of the process.

- After initial analysis of the data the participants were asked to review a brief summary of themes that emerged during their interview. They were given the opportunity to indicate whether their experience was accurately portrayed and/or to make amendments and additions.

3.1.3. Data analysis

This section is concerned with showing the process followed in data analysis more clearly. The method chosen and steps that were followed are described in detail to add to the rigor of this study.

The data analysis process followed in this study is an adaptation of Colaizzi's (1978) seven steps to analyzing data; and was influenced by concepts outlined by Giorgi (1997) that deal with reduction of data in order to search for essences which are then described in depth. The following steps were taken:

- The recorded interviews were listened to several times and verbatim transcriptions made which were read a number of times. At this stage I attempted to hear the stories as if I was the mother, rather than as a spectator. This step of the analysis process also referred to as data immersion, facilitated intimate familiarity with the content of each interview (Ulin, Robinson & Tolley, 2005). I started immersing myself in the data immediately following each interview which ensured that no detail about the interview was lost as may occur if an interview is only transcribed at a later time.

- Phrases or sentences that were directly related to the research question were identified and extracted from the transcripts, a process referred to as extracting significant statements. In order to extract significant statements I identified specific statements in the transcripts that provided information about the experiences of the participants. These significant statements are simply gleaned from the transcripts and identify the range of perspectives about the phenomenon (Moustakas, 1994). Each of these significant statements was related to a particular concept or aspect of the experience.

- The next step, defined by Colaizzi as formulated meanings, involved reflecting on the significant statements extracted and then defining a meaning for each of these significant statements. This step necessitated a move from the literal words used by the mothers, to grasping what was meant by the words.

- The formulated meanings derived from each interview were then assigned a preliminary theme. I then examined all of the identified preliminary themes as a whole in order to delete or merge themes that overlapped in meaning. Finally the preliminary themes were clustered into what is referred to as meaning units (Moerer-Urdahl & Creswell, 2004). The preliminary themes were therefore grouped into clusters of themes as per recurrent meanings. In this step there was a search for commonality between interviews.

- A description of the phenomenon under investigation followed, which entailed integrating the themes and quoted statements from the participants.

- At this point in the data analysis an adaptation was made to Colaizzi's method by changing the sequence of steps six and seven. In his approach, step six provides a final comprehensive statement of the phenomenon followed by checking and validating. As I wanted to be open to potential alternative interpretations of the text it was decided to first undertake methods to validate the analysis process before generating a final descriptive statement of the phenomenon. In this regard Colaizzi's step six, or the final comprehensive statement of the phenomenon, became step seven in my analysis process.

Two approaches to check and validate the process were followed. Firstly, I returned to the participants for confirmation and clarification that my interpretation of their lived experience was accurate. Though reflection and clarification occurred during and at the end of each interview to establish if I gained an accurate understanding of the participant's experiences, they were also asked to read a preliminary analysis of the data which contained a summary of the themes that emerged from their interview. The participants were asked to provide feedback regarding the accuracy of portrayal of their experiences and elaborate if they so wished. All of the participants agreed that their experiences were accurately portrayed and some of the participants offered additional information in terms of service delivery needs that they had thought about since the interview.

Secondly, validation of the process was further ensured by incorporating a multiple coding analysis strategy. A multiple coding analysis strategy allowed for the cross checking of interpretation of segments of data by independent coders (Barbour, 2001). Ten independent coders participated in this process all of whom were in the process of conducting post-graduate research in the fields of Speech-Language Pathology and Audiology. They were each given a segment of data that contained direct quotations taken from the interviews to interpret. Following this task they were asked to pair the quotations that they interpreted to an essence that was described by the researcher, which is a consistency check strategy described by Erlandson, Harris, Skipper and Allen (1993). A benefit of using this strategy is that potentially competing interpretations may emerge (Barbour, 2001). The independent coders provided interpretations that closely matched mine. Even though competing interpretations did not emerge, the process had value as it provided insights into the data which will be identified in the results and discussion section of this study.

- The final step entailed formulating a descriptive summary statement which comprehensively described the phenomenon. The descriptions of the experiences were synthesized to form a composite description of the phenomenon or the ultimate "essence" which captured the meaning ascribed to the experience.

The above steps outline the data analysis process that was implemented and is represented diagrammatically in Appendix G. The following section provides further information on how the above process unfolded and what factors shaped my decisions within the process. Information on the rationale for how the findings are presented and discussed will also follow. It is hoped that this additional information will assist the reader in terms of following the decision trail of this study.

3.1.3.1. The preliminary analysis

This part of the data analysis process involved analyzing each interview separately. Sections of text, words and phrases, in each interview, that shared similar ideas, or addressed a particular concept were grouped and became preliminary themes.

3.1.3.2. The analysis

The preliminary themes identified in each individual interview were taken and then compared with themes that emerged in other interviews to identify common or shared meanings between the participants. Data analysis, as outlined by Lincoln and Guba (1985), was inductive in that it occurred concurrently with the collection of data. Following the fifth interview it became apparent that some unique themes were emerging, which were not universal to all the participants. An example of a unique theme that emerged from Kathy's story was the positive impact that the ability to feed her son orally, after a period of time when she was not able to do so, had for her as a mother. As the first four participants were feeding exclusively via gastrostomy tubes, I decided to actively recruit mothers who were exclusively or predominantly feeding their children orally. The aim set forth by this research study was to provide an in-depth description of what it means to be the mother of a child with a feeding difficulty which was not delineated by the means of feeding. What emerged in the analysis was that the essence of the mothers' experience remained the same irrespective of mode of feeding; however it would have been evidence of researcher bias had mothers who represented the different means of feeding a child not been recruited.

By the seventh interview no new themes emerged and a point of data saturation was reached. It should be noted that variations on themes occurred. Where such differences emerged they were documented in the results section together with the reason why it was decided to identify them as variations rather than as separate themes. The variations that emerged were often attributed to temporal aspects, i.e. timing of the interview relative to time elapsed since the diagnosis of a feeding difficulty or since the insertion of a gastrostomy tube. For example, a difference in level of confidence in handling a gastrostomy tube was experienced in relation to the length of time that the task had been performed. In the above example, a mother (Tanya) who felt confident in handling gastrostomy tubes at the time of the interview reported that she experienced initial difficulty. Tanya's experience of competence in handling a gastrostomy tube therefore differed from that of Sumaya and Rita who at the time of the interview reported struggling; however they had all shared an experience of initial difficulty with a gastrostomy tube.

3.1.3.3. Development of two categories

In describing the experience of being the mother of a child with chronic feeding difficulties the need to represent the data in two separate categories emerged. On the one hand, the mothers' experiences spoke powerfully about their struggle in defining themselves as mothers, adjusting to the care needs of their children and their disempowering experiences with the public health care sector. What also emerged from the mothers' words was that growth and adaptation occurred as they redefined their role as mother and became enabled (endowed with power). Deconstruction and reconstruction stand apart and not in a linear relationship as there was not necessarily a move away from the experiences outlined in the "journey of loss and disempowerment" towards those discussed in "getting through the brokenness". A decision was therefore made to group the essences into two categories representing two separate journeys that ebb and flow rather than follow a linear path towards a known destination.

All the preliminary themes that depicted a deconstruction of self, reduction in perceptions of competence and coping ability, were identified and grouped into the first category. Deconstruction: "A journey of loss and disempowerment", is made up of three essences 1) Losing the mother dream, 2) Everything changes: living on the margins, and 3) Disempowered: from mother to onlooker.

The second category documents a very different path. Reconstruction: "Getting through the brokenness", encompasses four essences, namely 4) Letting go of the dream and valuing the real, 5) Self-empowered: becoming the enabler, 6) Facilitating the journey, and 7) The continuing journey: negotiating balance. Tables 1 and 2 provide a visual representation of the two categories together with their respective essences and sub-themes. Direct quotations from the interviews are provided in support of the selection of sub-themes.

Table 1: Deconstruction: "A journey of loss and disempowerment"

Essence 1	**Sub-themes**	**Significant statement**
Losing the mother dream	Motherhood ideal and conflicting reality	A mother should naturally be able to feed her child that's what mothers do
	Bonding versus task	I tried to make the task of putting milk through a tube as personal as what I could, so I held him and talked to him.
	Questioning competence	For me the breastfeeding thing was I should at least be able to do it
	Not letting go of the dream	[1]Ek het 'n sterk belief gehad dat hy gaan weer kan eet.
Essence 2	**Sub-themes**	**Significant statement**
Everything changes: living life on the margins	Changes to family interactions	[2]...jy en jou kind sit alleen, almal is bymekaar anderkant.
	Changes to lifestyle	You can't go for a picnic because where do I warm her food.
	Changes in employment status and to future plans	We haven't been away since she was born. Our concern is for the future.
Essence 3	**Sub-themes**	**Significant statement**
Disempowered: from mother to onlooker	Expected versus enabled to cope	[3]Hulle verwag ons goeters te doen waarvoor ons nie geleerd is nie.
	Disempowering professional interactions	I felt like he picked up a club and let's give her another klap [smack].
	Disempowering public health system	[4]Ek verstaan nie hoekom ons nie alles op een plek kan doen nie
	Unanswered questions and unmet needs	[5] Jou vrae is nooit beantwoord nie.

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[1] I had a strong belief that he would eat again.

[2] You and your child sit alone, everybody else is together elsewhere.

[3] They expect us to do things for which we are not trained.

[4] I don't understand why we can't do everything at one place.

[5] Your questions are never answered.

Table 2: Reconstruction: "Getting through the brokenness"

Essence 4	**Sub-themes**	**Significant statement**
Letting go of the dream and valuing the real	Redefining 'mother'	You stop being a mother and you stop mothering in the traditional sense, you become a caregiver.
	Celebrating the positives	When I say now that it is so well done that she coughs so nicely, people look at me and ask: She coughs well? But for me it is such a big thing.
Essence 5	**Sub-themes**	**Significant statement**
Self-empowered: becoming the enabler	Finding information and support	You have to ask and people have to tell you.
	Acquiring skills	I mean there is a lot of things that I learnt. What nurses do I can do.
	Empowering others	It has also been wonderful to be able to give other mothers support.
	Challenging and advocating	You fight for him and whatever handicapped child till the end.
Essence 6	**Sub-themes**	**Significant statement**
Facilitating the journey	Facilitating home-based caregiving	That we are walking this thing together that is enormously comforting for me.
	Facilitating ability to cope within the public health care sector	I was very fortunate that my doctor spent a lot of time explaining things to me.
	The importance of being heard and offered hope	I go and talk to them that's the way I feel better.
Essence 7	**Sub-themes**	**Significant statement**
The continuing journey: negotiating balance	A philosophical, emotional and spiritual journey	I've also got a change in outlook, at how I look at the world where materialism becomes so apparent

3.1.3.4. Representation of the data

A well written qualitative report should paint a vivid picture for the reader of the phenomenon through the use of thick descriptions that outline the context in which the phenomenon is experienced and describe the meanings that the experience holds for the participant (Miller & Crabtree, 2000). Throughout this thesis the participant's words are provided in quotation marks to foreground their voices while information that is needed to contextualise or make sense of the quotes are placed in brackets. The researcher's words used during the interviews are written in bold and also placed within brackets.

The concrete descriptions of the mothers' experiences were initially presented separately from my discussion about the emerging essences. This method of separating the results from the discussion created distance from the mothers' words and it was felt that much of the depth of their experiences was lost. In an attempt to provide the reader with the opportunity to become immersed in the phenomenon it was decided to merge the results (concrete description in participants' words) and the discussion (description of emerging essences in researcher's words). Many direct quotations were provided to enable the reader to evaluate my decision making process in terms of essence selection. Where mothers spoke Afrikaans, direct quotations in Afrikaans are used and translations included as foot notes to once again enable the reader to evaluate my selection of essences. In order to provide a composite picture of the data each sub-theme was then discussed in relation to past research studies. A summary of each essence follows the discussions, which contains clinical and research implications that emerged. Chapter eight provides a summary statement of the lived experience of being a mother of a child with chronic feeding difficulties.

3.2. ETHICAL CONSIDERATIONS

Ethical approval for this research was obtained from the University of Cape Town's Faculty of Health Sciences Research Ethics Committee prior to commencement of the study. This research adhered to ethical principles as outlined in the World Medical Association Declaration of Helsinki (www.wma.net, 2000). Ethical issues addressed included:

3.2.1. Non-maleficence

Participation in the study did not cause the participants discomfort or harm them in any way. It was not anticipated that the subject matter would be overly emotive but if a need was expressed by participants I would have assisted them to find counselling services.

3.2.2. Beneficence

Though participants would not gain immediate, direct benefit from participating in the study it was explained how insights obtained would enable Speech-Language Pathologists and other health care professionals involved in the management of children with feeding difficulties to provide more appropriate services to the child and family.

3.2.3. Autonomy

Participants were fully informed about the nature of the research and understood that their participation was entirely voluntary and that they could withdraw at any time without penalty. I also informed participants that should they request at any point during the interview or when reading the preliminary analysis, not to have information provided used in the study, they may do so.

3.2.4. Confidentiality

The names of participants and their family members were not recorded on the transcriptions; rather they were allocated a participant number. Similarly, the

Biographical Questionnaire allowed for the recording of a participant number, which corresponded to the number recorded on the transcript of their interview. In this regard participants' names were not recorded on the transcriptions nor on the questionnaire in order to ensure confidentiality (Medical Research Council, 1993). Although only numbers were recorded, I assigned a pseudonym for each participant and for family members who were named during the interviews for reference and continuity. The dissemination of findings from this study involved a written thesis. Participants were made aware that quotes from their interviews may be used in the final thesis however that every effort would be made to choose quotes that in no way identified the participant or the participant's child.

3.3. RIGOR AND TRUSTWORTHINESS

The criteria for validity and reliability hold a different meaning in phenomenological research as what is commonly understood. Validity and reliability are generally understood to refer to the confidence that one has in a particular instrument to measure a given variable. In this regard validity is proven if an instrument measures the variable that it is supposed to measure while it is reliable if it can obtain the same outcome consistently (Polkinghorne, 2003). In phenomenological research the scientific criteria of validity and reliability is linked to remaining faithful to the phenomenon. Faithfulness is understood as the ability to describe a given phenomenon in a manner that truly captures the essence (Giorgi, 1987). Trustworthiness or faithfulness exists when the findings of a study are found to be credible, dependable and transferable (Koch, 1994). The terms validity and reliability are therefore replaced in phenomenological research by concepts that address credibility, dependability and transferability. In an attempt to ensure the trustworthiness or rigor of this study the following was done:

3.3.1. Credibility

- Triangulation was implemented by using different methods of data collection, namely in-depth semi-structured interviews, field note observations and reflective journal notes. Triangulation yielded depth of insight about the phenomenon and increased the credibility of findings (McMillan & Schumacher, 2001). Theoretical triangulation was also used and is defined by Creswell (1998) as reviewing relevant literature to furthermore enhance the credibility of interpretations.

- Member checking, a process through which participants confirm data and the interpretations thereof (Savin-Baden & Fisher, 2002) was used. I asked participants to verify the accuracy of the themes identified as a true reflection of their experience. This strategy also minimised researcher bias (Lincoln & Guba, 1985).

- Credibility of data analysis was furthermore achieved by implementing a multiple coding analysis strategy. Ten independent coders, all of whom were post-graduate research students within the fields of Speech-Language Pathology and Audiology, interpreted segments of data comprising of direct quotations from the interviews. Following their interpretations of the data they were asked to pair the quotations to an essence that was described by the researcher, a process known as consistency checking. The independent coders provided interpretations that closely matched mine.

- The interviews were recorded and verbatim transcriptions made to ensure accuracy and detail of recall. Verbatim quotations were used in the presentation of the data to allow the reader to gain a deeper understanding of the findings, thus adding to the credibility of my interpretations.

3.3.2. Dependability

- Dependability is defined as the ability of the reader to follow the research process (Lincoln & Guba, 1985). Dependability was ensured through an audit trail in which a step by step description of the data collection and data analysis process was provided. The audit trail should enable the reader to evaluate both methodological and analytical decisions that I made. Methodological evidence encompassed research design decisions, which is of particular importance in a qualitative study in which an emergent research design is used (Sandelowski & Barrosa, 2003). Decisions made during data analysis in terms of coding and categorising choices provided the analytic evidence for this study (Sandelowski & Barroso, 2003).

3.3.3. Transferability

- Transferability relates to the ability of others to apply the findings of this study to those in similar contexts. "Thick description" (Patton, 2002) was used to ensure transferability in that detailed descriptions of the experiences of the participants were provided. By defining the context of the study the reader can gain insight into what it is like to be the mother of a child with a chronic feeding difficulty within a specific context, namely mothers who are providing home-based care and who access public health care services in Cape Town. By providing thick descriptions of the participants' experiences and relating these experiences to specific contexts transferability of findings was ensured.

CHAPTER FOUR

4.1. PROFILE OF THE MOTHERS WHO PARTICIPATED

Below follows a brief profile of each of the mothers who participated in this study. The intention of the profile is to provide the reader with context or an understanding of the space in which these mothers live. According to the phenomenological principle of "being in the world" (Heidegger, 1967) humans are always in a certain context and act or function in relation to that context. Life events must therefore be understood within specific contexts which could include the physical, temporal and interpersonal spheres within which a person lives. Truly understanding the essence of an experience is therefore dependent on understanding the context in which it occurs (Reason, 1998).

The women who participated in this study were from different physical, social and economic contexts. They were diverse in their age, race, religious beliefs, education, work and marital status. The onset and nature of their respective children's feeding difficulties together with the type of adapted feeding strategies required by the children also varied. Though the participants were not homogenous in the spaces they occupied they all shared the experience of being a mother who was providing home-based care to a child with a chronic feeding difficulty for whom health care services had to be accessed within the public health care setting of Cape Town, South Africa. I initially considered a narrower delineation of selection criteria, however after a brief review of available literature it emerged that children who present with chronic feeding difficulties and their families are diverse (Roeher Institute, 1999), a diversity of participants was therefore appropriate.

All of the participants' names and the names of family members are pseudonyms to ensure anonymity as outlined in the ethical considerations. It was my desire for the women who participated in this study to have presence as real people rather than as faceless participants. In an attempt to provide the reader with an opportunity to become immersed in their stories the women are either referred to by their pseudonym or collectively as "the mothers" rather than as "the participants" or by an arbitrary number.

4.1.1. Margaret

45-year old Margaret is a married mother of four who lives in a 3-bedroom home. At 3-months of age her youngest son had an epileptic seizure which left him with multiple disabilities. Her son was breastfeeding well after birth but feeding became a battle following his seizure. After many episodes of aspiration pneumonia a decision was taken that oral feeding should stop. Now, at age 13, her son is receiving all his nutrition enterally. Margaret has three older children (14, 18 and 20 years respectively). For the first nine years she was solely responsible for her son's care but is now being supported by her grown daughter. She recently resumed part time employment and her son attends a day care facility on the days that she is at work. The interview took place in the family living room. Margaret struck me as a confident woman who spoke out passionately about the rights of children with disabilities. She did not always find it easy to talk about the early days and about her own needs. There were moments when she let me see her true feelings but as she herself stated in the interview, she has become very good at hiding these from the world, becoming "like a rock".

4.1.2. Kathy

39-year old Kathy lives in a 3-bedroom house with her husband and six children. Her husband sat in during part of the interview and the close bond between husband and wife was immediately visible. He is employed full time in a family owned business. Kathy was standing outside her home waiting for me on the day of the interview. Three of her children were playing in their small front yard. She kept the front door open throughout the interview and sat where she could keep an eye on the children playing outside. Her need for constant vigilance started when her 10-year old son was knocked off his bicycle close to the house, less than a year before. The accident left him with marked physical impairments and difficulty communicating. Her son was sitting in his wheelchair in the family room eating chips when I arrived. After his accident and following months of attempting oral feeding a recommendation was made that nutrition should only be given enterally and a PEG was placed. Kathy never accepted this and through continual attempts on her part, her son is now almost exclusively fed orally. A PEG is still in place. Kathy and her husband openly and easily shared their experiences and feelings.

4.1.3. Tanya

35-year old Tanya lives with her husband in a double-story home. Her 3-year old son was born with mitochondrial disease, a rare condition which has resulted in severe physical and intellectual impairments and complicated medical issues. She also has an 8-month old daughter. Tanya gave up full time employment to look after her son. For the first two and a half years of his life she did this alone, but has since employed a part time caregiver to help her at home. The interview took place in the living room where both children were sleeping at the time. The room contained many toys and photos of the children and the smells of home cooked food filling the house. My first impression of Tanya was that of an intelligent, well spoken woman who appeared to embrace her role as a mother with ease. In her interview she told me how oral feeding was a battle from birth. Her son was not able to gain sufficient weight via oral feeding and by 12 months of age oral feeding was no longer safe. Enteral feeding is now done exclusively. Though a full time mother now, she was actively involved in establishing and continues to run a support group in her neighbourhood for mothers with children who have special needs.

4.1.4. Rita

28-year old Rita lives in a one-bedroom brick and zinc home with her two children, her mother, brother and his girlfriend. The community was described as poor but her home had electricity and water supplied. Her 4-year old son was shot outside the front door in a gang related shooting seven months prior to the interview, resulting in severe physical and intellectual impairments. Oral feeding was attempted during his stay in the hospital but found to be unsafe. At present her son is receiving all nutrition enterally. She also has a 5-year old son. Rita is not married and the children's father is not involved in raising or supporting them. Rita's mother is employed and her income supports the family. I drove down the gravel and at times sand road that led to the house. The community is relatively new and though quite a few brick homes have been built, there were mostly homes built out of zinc and timber. I was met by Rita and her mother who both took part in the interview as they both share equal responsibility in caring for her son since the accident. I picked up on emotions of uncertainty and a feeling of isolation even as the two women stood together and provided support to each other.

4.1.5. Sumaya

22-year old Sumaya lives in a two-bedroom house with her parents and two sisters. Her parents are both employed full time and she has been solely responsible for the care of her son. She is married but her husband was serving a prison sentence at the time of the interview. Her son sustained traumatic brain injury when he was knocked over by a car at the age of 3, six months prior to the interview. The accident left him severely physically and intellectually impaired. During the time that he spent in the hospital his swallowing was assessed and found to be unsafe. A PEG was placed and he is now only receiving nutrition enterally. Sumaya also has a two and a half year old daughter. Sumaya earns a living from a [6]'spaza shop' run from her home selling snacks to the local community. She is a petite woman with a ready smile which almost hides the tiredness which I became more and more aware of as the interview progressed. She spoke easily of her life and shared her thoughts openly. There were many times during the interview that her eyes welled up with tears and she did not try to hide these moments from me.

4.1.6. Agnes and Stephanie

I was contacted by Stephanie who expressed interest in the study. She told me the story of her daughter who passed away during delivery of her granddaughter and how Agnes, who was working for the family at the time, assumed the role of mother. Initially I was unsure about selecting Agnes as a participant as she was not the little girl's biological

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[6] A spaza shop refers to a small, home industry where items such as sweets, chips and cool drinks are sold from ones home to the people living in the neighbourhood.

mother. Having gone ahead with the interview though, I soon realized that she truly was a mother to the child. Now 12 years of age, the girl sustained birth trauma which left her with intellectual and physical disabilities. Her father passed away a couple of years ago in a car accident and since then she has been living with Agnes as part of her family. Both Agnes and Stephanie took part in the interview. Though initial difficulties were experienced with oral feeding, she is now getting exclusive oral feeding. When I arrived for the interview at the three-story townhouse I found Agnes and Stephanie singing songs with the girl while Agnes's 14 year old son was playing his saxophone. The two women spoke often of their journey together, of their faith and how they have taken turns in being each other's strength. Frequent accounts of disappointment with their interactions with health care professionals dominated the interview which resulted in the family "doing it on their own".

4.1.7. Rehana

33-year old Rehana is married and she and her husband were living with her mother while their house was being renovated at the time of the interview. They have only one daughter and although Rehana would like another child the couple have decided against it so that all their energy can be spent on their daughter. Rehana's daughter is 3 years old and was born following a full term pregnancy. However last minute complications during the delivery necessitated admittance to a paediatric intensive care unit where she spent 30 days. Her daughter was on life support for the first week following delivery and the family were told to expect the worst and that the baby would not live. All feeds were through nasogastric tube for the first couple of weeks and there were difficulty getting her to breastfeed. Through persistence on the parents' part she eventually took milk via a bottle. At present all nutrition is given orally. Rehana came across as a self-assured woman who was very in control of her life and her daughter's daily needs. For the first year she was solely responsible for her daughter's care, but after returning to work full time (a difficult decision for her), a part time caregiver was employed to help. She spoke often of her husband and the strength that they give each other. Despite the orderliness of her life, there were many moments during the interview that she found it difficult to control her emotions.

Table 3: Profile of the mothers who participated

Participant	Mother's age	Marital status and children	Employment status	Child's age	Child's Diagnosis	Nature of disabilities	Type of nutrition
Margaret	45	Married with four children	Part time	13	Cerebral palsy Epilepsy	Physical and intellectual disabilities	Enteral only. Since six months of age.
Kathy	38	Married with six children	Unemployed	10	Traumatic brain injury	Physical disabilities	Enteral and oral. Past eight months.
Tanya	34	Married with two children	Unemployed	3	Mitochondrial disease	Physical and intellectual disabilities	Enteral only. Since six months of age.
Rita	28	Single with two children	Unemployed	4	Traumatic brain injury	Physical and intellectual disabilities	Enteral only. Past seven months.
Sumaya	22	Married with two children	Home industry	3	Traumatic brain injury	Physical and intellectual disabilities	Enteral only. Past six months.
Agnes	40	Single with two children	Employed as caregiver	12	Cerebral palsy following birth trauma	Physical and intellectual disabilities	Oral only. Since two months of age.
Rehana	33	Married with one child	Full time	3	Cerebral palsy following birth trauma	Physical and intellectual disabilities	Oral only. Since one month of age.

CHAPTER FIVE

5.1. RESULTS AND DISCUSSION: CATEGORY ONE

In describing the experience of being a mother of a child with chronic feeding difficulties, the need to present the data in two separate categories, representing two separate journeys that ebb and flow, emerged. The two categories stand apart as there is not a linear relationship in terms of moving away from the experiences outlined in Deconstruction: "A journey of loss and disempowerment" towards those discussed in Reconstruction: "Getting through the brokenness". Seven essences central to the mothers' experience emerged. Each sub-theme within an essence will be discussed in relation to other research studies to offer a composite picture of the data. A summary of the essences is then provided which includes practical and research implications.

This chapter describes and discusses the first of the two categories, namely Deconstruction: "A journey of loss and disempowerment". Three essences emerged that depicted a deconstruction of self, reduction in perception of competence and difficulty coping with the demands of caring for a child with a chronic feeding difficulty. A concrete description of each of the three essences, namely 1) Losing the mother dream, 2) Everything changes: living on the margins, and 3) Disempowered: from mother to onlooker, is provided, followed by a discussion that draws on academic literature. As mentioned previously the results and discussion sections of this thesis are integrated in an attempt to remain close to the mothers stories while simultaneously framing their experiences within the researcher's language.

DECONSTRUCTION: A JOURNEY OF LOSS AND DISEMPOWERMENT

The mothers in this study shared many emotional and practical challenges as a direct result of being the mother of a child who has a chronic feeding difficulty. The term "deconstruction" was chosen as there emerged to be a breaking down of their identities as mothers, sense of social connectedness as well as perceptions of competence as mothers. Losing the mother dream was the first experience in a journey which challenged their capacity to cope.

ESSENCE 1: LOSING THE MOTHER DREAM

> "Before he got sick he was fine. I was breastfeeding and he was eating and he started to walk, you know when you hold him up just pushing down with his legs. But after that, after he got sick...I don't know. It was really tough in the beginning. You know I will look at him now (looks at her son sitting in his wheelchair in the room). I mean look at him!" (Margaret, pg. 4, L 91).

Most mothers create images of themselves and their child, which are often based on the ideal or the traditional image of motherhood that is portrayed in popular media (Rokach, 2004). Television advertising, magazines for mothers and other printed media aimed at preparing women for motherhood are filled with images that portray the miracle of pregnancy and the ideal baby. The term "mother dream" is used in this context to encapsulate the ideal, that was present in the mothers stories, of what it should have been like to be a mother and what a child should have been like.

Motherhood ideal and conflicting reality

The mothers shared their experiences of having to deal with an incongruity between ideal constructions of motherhood and their disparate reality. Most women have personal constructs of the ideal mother and a perfect child, which are challenged when a child is diagnosed with a disability (Ypinazar, 2003). The previous quotation by Margaret shows her difficulty in accepting the lost dream of what her son should have been like. Other mothers also spoke of feelings of loss that emerged when there was a realisation that their respective children were not able to interact with them as they expected.

> "You look at the life they have and at the quality. Is this quality of life? At least with some of the other moms their kids can move around and interact with their world. They have that experience, but I don't." (Tanya, pg. 13, L 285)

The mothers' stories illustrated how socially created images shaped their own beliefs about what motherhood should be like. What featured prominently in the stories was that a mother should be able to feed a child. The ideal of motherhood was therefore closely linked to feeding ability. The loss of ability to feed became a conflicting reality for the mothers in this study.

> "So yes, there is a perception of what, or what society thinks a mother is, and a good mother is a mother who is able to provide for her children, who is able to make sure that her children get enough food and enough of the right food. So that's why it was very important for me to keep on trying [with oral feeding]." (Tanya, pg. 5, L 103)

> "A mother should naturally be able to feed her child, that's what mothers do, that's what mothers are, they feed and they look after their children." (Tanya, pg. 5, L 92)

A theme that emerged from Tanya's story was her perception of how mothering and feeding are inextricably linked. After three years of battling with oral feeding with her son, her daughter was born. It was only in the success she experienced with feeding her daughter that she started to define herself as a mother.

> "I remember the one day feeding my daughter. I looked down at my shirt and it was full of pumpkin and I giggled because I thought: now I'm a mother." (Tanya, pg. 5, L 100)

Reconciling the image of motherhood with the reality of struggling with oral feeding was more prominent in the stories of mothers whose first child had a feeding difficulty or where no other experiences of successful feeding was present, as was the case for

Rehana. In her interview she questioned whether it would not be easier for mothers who had already experienced success in oral feeding with another child to adapt to the struggles of a feeding difficulty.

> "…first time moms have nothing to compare to." (Rehana, pg. 8, L 257)

The mothers also spoke of difficulty in reconciling expected nurturing activities with the reality of having to execute tasks that were uncomfortable or painful for the child.

> "I made myself absolutely hard against what I was seeing and what I was going to have to deal with so I just went in and I did it and I pushed it in [reinserting a gastrostomy tube]. I couldn't believe I did it because initially in the hospital I thought there was no ways, that I would never be able to. It is similar to the suctioning. I have a suctioning machine here for him when he cannot swallow his saliva. Initially this was also something that the people in the hospital just expected me to be able to deal with but it was hard initially... and I can see it is sore and uncomfortable for him when I'm doing it, but I make myself hard because I know it has to be done." (Tanya, pg. 8, L 171).

Four mothers spoke of the need to steel themselves in such moments in order to be able to cope with what was required of them.

> "I've come to this point now where I feel like a rock. I feel like a rock, that's the way I feel." (Margaret, pg. 13, L 385)

Rehana's words below, illustrated how socially created images of being a good mother also influenced medical professionals' expectations of mothers. She recalled a desire to breastfeed her baby while in the neonatal intensive care unit (NICU). The conflicting reality for her was that her daughter was not able to suck and struggled to coordinate sucking and swallowing. In spite of repeated attempts Rehana experienced continual failure in her ability to breastfeed her baby. The health care professionals in the NICU had a policy of insisting that new mothers breastfeed, thereby reinforcing the perception that this task should be manageable for all mothers.

> "She was attached to the oxygen and a heart rate monitor, so in trying to breastfeed her you had to watch her oxygen levels go down her heart rate go up and she goes into a panic, I go into a panic. In the end it was sort of, what's the use of this? There has to be another way! It is the nurses' priority to make sure the mother breastfeeds. What is the difference between putting the breast milk into a bottle and breastfeeding?" (Rehana, pg. 1, L. 22)

Discussion of sub-theme: Motherhood ideal and conflicting reality

The mothers shared their stories of having to deal with an incongruity between ideal constructions of motherhood and a different reality. Pregnancy is described as a time when women start to develop dreams and ideals of what motherhood will be like (Greenberg, Kroll & Grill, 2002). Adjusting to the conflict between expectations and reality is seen as one of the most stressful challenges new mothers face (Tiemann, 2006). Four women who took part in this study were given the diagnosis that chronic medical and feeding difficulties were present in their babies either at birth or within the first three months following birth. These mothers experienced loss related to incongruence between their dreams and the reality of struggling to feed their babies. What emerged from all of the stories was that the experience of loss of an ideal about what motherhood should be like, was universal irrespective of the time of onset of feeding difficulties. Three children sustained traumatic brain injuries resulting in severe and multiple impairments. Two of these children were toddlers (three and three and a half years of age respectively) and one was a child of nine years. The reality for these mothers was that they had to learn how to feed their children again as the children lost their ability to feed independently. These mothers experienced a loss of maternal ideals similar to the mothers who had newborn babies.

Motherhood was understood in relation to what an ideal mother should be like but also in relation to what a child should be like. A deconstruction of the ideal child occurred, which was in line with the theme "relating to a different child" identified in a previous study which explored how mothers came to terms with changes that occurred in their children following traumatic brain injuries (Guerriere & McKeever, 1997). The participants in their study spoke of multiple changes that occurred in their children after sustaining brain injuries, which resulted in the children being viewed as "different", and not able to interact with the mother as before.

The current study showed that for the mothers, the ideal image of motherhood was closely linked to the ability to feed a child. Tanya's mention of only regarding herself as a mother when she was able to feed her daughter is an example of how the mothers in the current study equated the inability to feed a child with failing to be an ideal or good mother. Woodward (1997) described how the "ideal mother" is inscribed within western culture, constructed within a moral context, and yet also somehow assumed as a biological product, as if giving birth transforms a woman into the ideal mother. The construct of an ideal mother is closely related to a theme of "Maternal Failure" identified in a study by Thorne et al. (1997). The participants in their study identified feeding as a quintessential mothering act symbolizing the loving role associated with being a mother.

Having to perform potentially painful tasks on their children, such as suctioning the airway and removing a gastrostomy tube to clean it (discussed in detail under the sub-theme of "Bonding versus task"), further separated the ideal of being a caring mother from the reality. Their stories revealed a battle to find congruence between their image of the mother figure and the need to fulfil these tasks. *Motherhood ideal and conflicting reality* outlines the conflict that emerged as the mothers struggled to match their reality to their ideal of motherhood. Reconciling the image of motherhood with the reality of struggling with oral feeding was more prominent in the stories of mothers' whose first child had a feeding difficulty. The inability to feed their children with ease and to meet their ideal constructions of what it means to be a mother resulted in questioning of their competence.

Questioning competence

> "Everybody speaks about it [breastfeeding] as if it is the most natural thing in the world, and the easiest thing in the world and people have been doing it for centuries and people in the jungle are doing it so why should these people in the modern city not be able to. For me the breastfeeding thing was: I should at least be able to do it, I can do nothing else for her, I should be able to feed her properly." (Rehana, pg. 4, L 105)

The ability to breastfeed a baby with ease reflects an ideal image of the mother. For three women in this study this image was unattainable. Rehana's words show how the inability to meet an ideal of motherhood resulted in a questioning of her own competence as a mother. Tanya experienced similar feelings following challenges in getting her son to breastfeed. She recalled spending hours with her son at her breast.

> "So I breastfed him for two months and struggled. It got to a stage where I remember lying on the couch with him permanently attached to my breast. It took so long." (Tanya, p. 2, L 34)

Questioning of competence extended beyond difficulties with breastfeeding. Other mothers also made reference to times when they doubted their own competence as mothers, which seemed to be most powerfully felt in relation to the inability to feed a child. Only one mother made reference to questioning of competence in terms of physical handling of her child.

> [7]"Ek dink nie ek gee die oefeninge reg vir hom nie. Ek doen dit maar miskien doen ek dit nie reg nie. Ek sit hom in sy stoel dan sit hy reguit maar as hy lê dan raak sy nek styf. Ek weet nie of ek sy nek mag beweeg nie." (Rita, pg. 6, L 141)

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[7] I don't think that I am doing his exercises the way I should. I do it, but maybe I am not doing it in the right way. He sits upright when I place him in his chair but his neck gets stiff when he is lying down. I don't know if I am allowed to move his neck.

No other mothers mentioned questioning their competence in terms of other caregiving tasks such as bathing, dressing or positioning. Their stories demonstrated the extent to which difficulty in feeding a child orally, resulted in feelings of inadequacy as mothers. Feelings of being ineffective "feeders" emerged again in cases where oral feeding was lost and the mothers had to learn how to give nutrition enterally.

> "So initially we started off with NG [nasogastric] feeding and he was on that for about a month. Then it just became too much, because his nose got sore and the stress of having to test constantly that it is in his stomach and not in his lungs. So I went back to my doctor and I said that I would consider PEG placement and at that stage they arranged that I could see a little baby who had one in place and for me that was unbearable. I felt absolutely shocked and horrified and I couldn't imagine that that would ever be done to my child and that I would need to take care of it. But we went ahead and there were initially days that I felt completely out of my depth and unprepared to deal with what was expected of me..." (Tanya, p. 6, L 117)

When a child was moved from oral to enteral feeding the mothers had to be taught by others how to feed their respective children. An ongoing feeling of challenge to competence as a mother was a reality for some mothers who continued to feel unsure about their ability to deal with challenges surrounding enteral feeding.

> [8]"Ek was net bly dit [nasogastric tube] is uit sy neus uit, maar ek het nie gedink dat dit so moeilik sal wees met die PEG nie." (Sumaya, pg. 6, L 160)

> [9]"Ons is nog nie gemaklik met die PEG nie. Ek is ook nie verseker of die melk nou reg afgaan nie en of dit [PEG] nou reg in is nie." (Rita, pg. 4, L 79)

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[8] I was just happy that the nasogastric tube was out of his nose but I never imagined that the PEG would be so difficult.

[9] We are still not comfortable with the PEG. I am also not sure if the milk is going down the right way and if the PEG is placed correctly.

Questioning competence was a very powerful theme that emerged in Tanya's story and led to a need to be validated by professionals, or to be reassured that her son's difficulty in taking food orally was not due to her inability to feed him properly.

> "I remember going to them [Speech-Language Pathologists] to watch me feed Kevin because I needed to know if I was doing anything wrong. But they said that I was doing everything right but he just couldn't. I felt a great relief that it wasn't me, I wasn't doing anything wrong." (Tanya, pg. 12, L 253)

Despite professional validation, Tanya's earlier difficult experiences with oral feeding were powerful, resulting in a fear for feeding that challenged her perceptions of competence and persisted when her second child was born.

> "When I gave food to my little one here [her daughter, second born] I had a phobia, I said I can't do this I can't feed her." (Tanya, pg. 2, L 41)

Tanya's story also revealed how she continued to battle with questions regarding competence as a mother until she experienced success in oral feeding. It was in being able to feed her daughter that she finally 'felt better' and competent as a mother.

> "Now she obviously, she is really great now in feeding [laughs], so I feel a lot better." (Tanya, pg. 2, L 43)

Discussion of sub-theme: Questioning competence

The mothers in this study experienced feelings of incompetence as a result of their perceived inability to meet the standards associated with being a "good mother". Similar findings emerged in a study by Cassidy and Davies (2003) who found that women internalise perceived inadequacies as personal failures. The inability to meet the ideal of motherhood as it related to feeding the child resulted in a *questioning of competence*. This was done in relation to breastfeeding, oral feeding and enteral feeding. Other studies have documented a similar link between successful feeding and a feeling of competence in the role of mother (Pridham et al., 1991; Rubin & Rubin, 2005). Rehana's struggle with breastfeeding, for example, and in particular her frustration with the perception that breastfeeding should come naturally for all women, was similar to findings of other studies that identified a link between performance in breastfeeding and a woman's representation of being a "good mother" (Flacking et al., 2007; Hauck & Irurita, 2002; Marshall et al., 2007). Other studies, however, have found that when mothers are allowed to be actively involved in complex caregiving within a hospital context, they feel more competent in their caregiving role (Judson, 2004). It is therefore possible that the mothers in the current study did not feel empowered to take on complex caregiving tasks at an early stage, resulting in feelings of incompetency. This finding may have implications for clinicians and how they view the role of parents in the hospital setting, which will be discussed in further detail when looking at the third essence within Category one.

Bonding versus task

Mother-infant bonding or attachment refers to a significant emotional relationship or connectedness which is established in the first couple of years of a child's life and which endures over time (Holmes, 1993). Research shows that where such an attachment fails to form, a child may struggle to regulate emotions and the development of future inter-personal relationships may be adversely affected (Holmes, 1993).

Bonding was a concept that the mothers in this study were familiar with. They all made reference to bonding that happens when a mother feeds her child and how the opportunity to form a close bond with a child is somehow lost with the loss of oral feeding. Tanya spoke of showing affection through preparation of food and Sumaya thought that special treats are one way to steal a child's heart.

> "Cause that's really what makes feeding your child such a big part of being a mother there is the closeness between a mom and a child during feeding." (Tanya, pg. 7, L 142)

> "…and even in terms of older children and the family the moms place is often in the kitchen preparing food for her family that's how she shows her affection." (Tanya, pg. 5, L 95)

> [10]"Of klaar gevoer is dan hier is jou pakkie chips. Jy weet, net om jou kind se hart so te steel." (Sumaya, pg. 3, L 86)

The sharing of a special moment through feeding was also lost for other members of the family. In particular Rita's mother also experienced a sense of loss at not being able to spoil her grandchild with something to eat, as this is what grandmothers traditionally do.

> [11]"Dis verskriklik hartseer vir my. Net die fyt dat hy kan nie 'n lekkertjie kou nie. Dis nogal baie hartseer vir my wat ouma is." (From Rita's interview, pg. 2, L 50)

The mothers recalled small rituals and playful interactions that were centred on food, which were seen as opportunities for them to interact and bond with their children. Sumaya in particular struggled with the loss of small eating rituals as she runs a [12]"spaza shop" from her home selling chips and sweets to the community. The times that she caught her son "stealing" a sweet from the shop were recalled with sadness at the loss of such moments.

> [13]"Hy was enige tyd dan sit hy daar met sy hande agter sy rug en glimlag. Wat het jy gevat daar? Dan wil hy my nie wys nie dan is dit 'n klomp bubblegums of miskien 'n lekker." (Sumaya, pg. 3, L 68)

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[10] Or, finished feeding then here is your packet of chips. You know, just to steal your child's heart like that.

[11] It is extremely sad for me. Just the fact that he cannot eat a sweet. It is actually very sad for me as grandmother.

[12] A spaza shop refers to a small, home industry where items such as sweets, chips and cooldrinks are sold from ones home to the people living in the neighbourhood.

[13] He would often sit there with his hands behind his back smiling. Then I would ask: What did you take? He wouldn't want to show me. Then it is bubblegum or maybe a sweet.

Oral feeding was described using words such as "closeness" and "bonding". In contrast to such descriptions were experiences of giving enteral feeds which was seen as a job that had to be done. From Sumaya, Kathy and Tanya's stories it emerged that they did not equate the giving of enteral feeds with feeding and that it was seen as an impersonal task.

> [14]"Dis swaar, want al waarop ek kan lewe is 'n feeding wat nie eers kos is nie dis net melk en daai is 'n moeilike ding want jy het vir hulle van borsvoeding af kos in hul mond gegee. Dis net 'n feeding wat jy moet gee alles is net feeding." (Sumaya, pg. 3, L 84)
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> [15]"Ek gebruik die pyp [PEG]. Maar ek gebruik dit nie aanhoudend nie. Ek gebruik dit in die oggend en in die aande. Maar deur die dag gee ek vir hom kos." (Kathy, pg. 1, L 20)
>
> "You know when he first got the PEG I would still hold him next to me, against my breast while I was putting the feed in because I felt this need to be close to my child, to bond with him. I tried to make the task of putting milk through a tube as personal as what I could so I held him and talked to him." (Tanya, pg. 7, L 138)

A strong need for a mother to experience bonding that is associated with oral feeding was clearly reflected in Tanya's words. Where the ability to feed orally was lost the mothers felt that there were fewer opportunities to bond with their children. Even though a mother would still be fulfilling a nurturing role by providing her child with nutrition enterally it was described as a task to be performed. Pleasurable, bonding opportunities were therefore lost and replaced by interactions in which many of the mothers felt unsure of themselves, and even experienced fear of handling feeding tubes.

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[14] It is difficult, because all I can live on is a feeding that is not even food it is just milk and that is the difficult thing because you fed them orally from breastfeeding. It is just a feeding that you have to give, everything is just feeding.

[15] I use the pipe [PEG] but I don't use it continuously. I use it in the mornings and evenings. But in the day I give him food.

> "They showed me how to take it [PEG] out and clean it. But I'm scared of this one." (Margaret pg. 6, L 158)

At the time of the interviews Sumaya was the only mother who did not have daily assistance in preparation and giving of enteral feeds, nor with the tasks surrounding cleaning the gastrostomy tube and the stoma site. The challenges of enteral feeding dominated her story. Again her use of the word "job", when referring to enteral feeding, illustrated the meaning the mothers attached to adapted feeding strategies. A clear distinction was evident between the nurturing role of oral feeding as opposed to the task of providing enteral nutrition which was also tiring.

> "[16]Dit is eintilik 'n tiring job want jy moet sorg dat die feeding gemaak moet word. Eleven o'clock is die laaste feeding wat ek in die aand gee en ek kan nie deur die dag slaap nie want ek voel ek moet hom dophou." (Sumaya, pg. 4, L 100)

Another theme that emerged was that the loss experienced by the mothers in relation to bonding with a child through feeding, was ongoing. The mothers made reference to an awareness of their respective children's loss of pleasurable eating experiences and how they as mothers continued to experience the desire to provide more than mere nutrition.

> "I've learned to accept it that he can't eat stuff that they are eating [other children]. But sometimes I'll take a lollipop and take it to him. And if they are eating ice cream I'll take a little on a straw just to give him a taste." (Margaret, pg. 8, L 221)

Margaret's words show an acceptance that she had developed over the years of what her son was not able to eat. Even though she claims to have accepted the loss of oral feeding, she spoke of letting him at least taste certain things. The need to be able to give their children something enjoyable to eat was echoed by other mothers. Sadness in relation to the child's loss of enjoyment that comes with food was a common theme.

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[16] It is actually a tiring job because you have to ensure that the feed is made. I give him his last feeding at eleven o'clock at night and I can't sleep in the day because I feel that I have to keep watch over him.

Tanya recalled her frustration with another mother who did not allow her child to experience different tastes and textures, despite being physically able to, preferring rather to stick to easy, tried and tested foods such as pumpkin. Her emotive reaction to the mother's reluctance to give her child the opportunity to explore tastes alludes to Tanya's intense wish that she could offer her son such opportunities.

> "I get so angry with her, because she insists on only feeding her child pumpkin and spinach. If it was my child I would want him to experience tastes. I mean I love food and if you see the way my little girl loves tastes then you would give that child the experience if you could." (Tanya, pg. 11, L 244)

Discussion of sub-theme: Bonding versus task

This sub-theme summarized the disparity that emerged between the notion that feeding would serve as an opportunity to bond with a child; and the reality of feeding taking on negative connotations. Once again the essence of losing the mother dream, or the perception of what motherhood should be like, emerged. The mothers spoke of a loss of pleasurable, bonding opportunities associated with oral feeding which were replaced by tiring, challenging and at times frightening moments in which they questioned their competence. In contrast to pleasurable oral feeding rituals, enteral feeding was regarded as an impersonal, physically demanding task. Judson (2004) found similar reactions of mothers giving parenteral nutrition. In her analysis of interviews with nineteen mothers, she found that they placed great value on the ability to feed a child orally and that they felt helpless and frustrated when oral feeding was not possible. Franklin and Rodger (2003) described the difficulty experienced by mothers in establishing an emotional bond with their children as being caused by extreme feelings of stress and a fear for the child's survival during feeding interactions. In recalling experiences with enteral feeding, the mothers in the current study also indicated that stress and fear formed part of the feeding interaction with their respective children. The researcher's identification of *bonding versus task* as an emerging theme was validated during a discussion with independent coders who also recognized how the act of feeding was transformed from an enjoyable activity into a planned task imbued with feelings of fear and uncertainty for the mothers in this study.

Not letting go of the dream

> "I just want it to be okay and everyone would be okay again, how one naturally wants to deal with stuff when it seems to be out of line." (Agnes, pg. 1, L15)

The stories revealed an ongoing desire to regain or to achieve the envisioned ideal belief of what a mother and child should be like as opposed to the disparate reality. To be able to hold onto the motherhood dream various attempts were made to normalise the reality of feeding difficulties. Tanya spoke of a strong need for normality in terms of seeing her son achieve developmental milestones for feeding. She recalled how important it was for her that her son "progressed" from liquid to solid consistencies.

> "It was so important for me that Kevin take solid food that I made his porridge thin enough for it to be taken via bottle. I had an incredible need for him to eat normal food." (Tanya, pg. 4, L 81)

The mothers also attempted to normalise feeding by, for example, including the child in normal family mealtimes.

> "We always include him in family meal times and special occasions. His pram will be put up next to the table and he will get his feeds when we all eat, so we do include him in everything." (Tanya, pg. 14, L 305)

Where oral feeding was "lost" the mothers spoke of a strong desire for it to be regained. Four of the five mothers, who were giving nutrition enterally or where a combination of enteral and oral nutrition was given, expressed a wish for oral feeding to be possible again.

> [17]"Want ek het 'n sterk belief gehad dat hy gaan weer kan eet. En ek kan dit sien dat daar sal 'n vordering kom. En dis hoekom ek aangehou het daarmee [per mond voeding]." (Kathy, pg. 2, L 31)

Some mothers spoke of observations they had made in terms of improvement in oral motor activity which perpetuated the hope.

> [18]"Maar vir my lyk dit hy sal weer kan eet want aan die begin het hy gekwyl en lately doen hy nie meer daai nie en hy maak geluide en speel so met sy tong. Ek glo nie hy gaan daai PEG die heeltyd in hê nie." (Sumaya, pg. 11, L 324)

Other mothers adopted a more active part in trying to get their children to take food orally again by attempting to train them.

> [19]"Ek probeer hom so train by die huis, ek weet nie of dit reg is nie, maar dis wat ek van my kant af doen. Ek vat 'n droë lepel dan sê ek maak oop vir mamma dan probeer ek hom train." (Rita, pg.2, L 28)

A theme that emerged from Kathy's story was a refusal to accept the loss of oral feeding. She recalled how she was told by health care professionals that oral feeding was unsafe and how they did not seem to understand her desire to keep trying. She did not want to let go of the belief that her child would be able to take food orally again. Her motivation to continue trying also stemmed from necessity as she was not always able to get feeds.

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[17] I had a strong belief that he would eat again. And I see that there will be improvement and that is why I continue trying [with oral feeding].

[18] It looks to me that he will be able to eat again because he used to drool in the beginning but not anymore and he makes sounds and plays around with his tongue now. I don't believe that he will have the PEG forever.

[19] I try to train him at home, I don't know if what I'm doing is right but it is what I can do from my side. I take a dry spoon and ask him to open his mouth then I try to train him.

> [20]"Die hospitaal wil nie gehê het dat ons vir hom kos moet voer nie. Maar ek het nie hulle dinge gedoen nie, ek het net self probeer. Ons het baie getry met hom. Ons gee vir hom dan kyk ons hoe werk dit." (Kathy, pg. 1, L 4)

> [21]"Ons gaan na die dag hospital vir melk, en hulle het nie altyd nie, dit is dalk ook hoekom ons maar probeer met die voer." (Kathy, pg. 3, L 76)

The wish to hold onto the dream of oral feeding was highlighted in the mothers' initial reactions to the suggestion of a gastrostomy tube. They used words such as "horrified" and "traumatic" to describe their initial feelings. All of the mothers reported that they had no previous knowledge about enteral nutrition. A shared theme that emerged from the stories of the mothers giving nutrition enterally was that despite struggling with oral feeding they were resistant to moving onto enteral nutrition. Their beliefs about a PEG highlighted fears that their children may not improve in feeding ability. There remained a strong desire that the tube would be removed and that it would not be permanent.

> "Initially I was resistant to the idea [to have a PEG placed] because it sort of felt like that was the end you know, only very sick people or people close to death goes onto tube feeding." (Tanya, pg. 6, L 115)

All of the mothers spoke of times when they were reminded of what was lost. Their ability to let go of the dream of motherhood and in particular the wish for oral feeding to return, or to be experienced as a carefree interaction with the child was challenged at such times. The loss of oral feeding was constantly recalled in everyday situations.

> "And a lot of little things were lost when Kevin was not able to eat orally anymore. And I do get sad sometimes when I am in the kitchen making nice home cooked food for my daughter and knowing that he can't have it." (Tanya, pg. 5, L 97)

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[20] The hospital did not want us to feed him but I didn't do their thing, I just tried myself. We tried a lot with him. We give him something and see how it works.

[21] We go to the day hospital for his enteral feeds but they don't always have which is also why we kept on trying to feed him orally.

> "I see people in shopping centres and they just open a jar of Purity [baby food] and feed the child sitting in the trolley and I can't do that." (Rehana, pg. 7, L 186)

Rita spoke of times when the family would feel guilty for eating something enjoyable in front of her son. What made this difficult was the presence of other children in the home, for whom she still wanted to provide special food. At such times she recalled foods her son used to like, and for her there was a loss of who her child was as a unique person.

> [22]"Maar dis nogal baie hartseer, want somtyds dan het ons iets wat ons eet dan kan hy dit nie eet nie hy lê net daar. Sy broer is ouer, hy is 5 jaar oud. Dit maak dit ook moeilik as hy nou iets lekker sit en eet. En dit as ons weet watter tipe kind hy is en waarvan hy hou." (Rita, pg. 2, L 32)

Discussion of sub-theme: Not letting go of the dream

For the mothers there remained an ongoing longing for oral feeding to return or for feeding to be an easier activity, thereby demonstrating their difficulty in *letting go of the dream* of motherhood. Difficulty in accepting the loss of oral feeding might be related to the meaning that these mothers attached to feeding. The mothers' words revealed that they regarded feeding and food as much more than a means of providing nutrition which is in accord with other studies that define eating as having both a nutritional and social dimension (Trier & Thomas, 1998). As reported by Spalding and McKeever (1998), the mothers in the current study also placed enormous significance on their ability to feed orally and how the loss of feeding opportunities were experienced as a source of considerable distress. Feeding and food became enmeshed with emotional bonding and social participation and was linked to a child's unique personality.

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[22] But it is very sad because sometimes we have something that we eat then he cannot eat it, he just lies there. His brother is older, he is 5 years which also makes it hard when he is sitting eating something nice. And this when we know what type of child he is, what he likes.

Craig et al. (2003) found that experiences of stressful oral feeding do not necessarily increase the willingness to proceed towards a surgical solution. An essence that emerged from a study by Spalding and McKeever (1998) was that of "Giving in to the G-tube" (gastrostomy tube). These findings were affirmed in the current study where the mothers, despite battling with oral feeding, showed resistance to move onto enteral feeding and maintained a strong desire that the gastrostomy tube would be removed. The persistent, continuing feelings of sadness and loss experienced by the mothers in relation to exclusive enteral feeding have also been reported in other studies (Judson, 2004; Spalding & McKeever, 1998; Thorne et al., 1997).

While some mothers in the current study merely held a strong wish for oral feeding to return other mothers adopted a more active part in trying to re-establish oral feeding, despite medical recommendations against it, which was similarly reported by Spalding and McKeever (1998). What emerged when reviewing their study was that the continual attempts to re-establish oral feeding were largely motivated by a wish to disprove professional predictions that enteral feeding would be permanent. Some differences emerged in the current study. Kathy shared similar motivations as reported by Spalding and McKeever in that she too wanted to demonstrate her ability to feed her child orally and thereby disprove professional claims that swallowing was unsafe. An additional motivation to continue trying to re-establish oral feeding emerged from her story. Kathy reported that she was forced to attempt oral feeding because she was not always able to get enteral feeds at the primary level hospital due to limited resources. Rita and Sumaya's need to re-establish oral feeding appeared to be primarily related to uncertainty and fear of handling gastrostomy tubes while Tanya's desire to continue trying with oral feeding seemed to be related to an emotional need to feed her child and to see him reaching developmental milestones characteristic of "normal" children or the ideal child.

Difficulty in letting go of the dream was seen in attempts to normalise feeding, irrespective of the mode of nutrition, such as holding a child against the breast while giving enteral feeds, attempting to reach developmental oral feeding milestones and in the need to include a child at mealtimes by giving enteral feeds while the rest of the family were eating a meal . The concept of normalising also emerged in other studies. These studies found that parents valued activities that symbolised normal family interactions, such as oral feeding, very highly and that they would attempt to continue with such activities for as long as possible (Judson, 2004; Thorne et al., 1997). The mothers who took part in this study reported that their ability to let go of the dream of oral feeding was challenged at social gatherings, when recalling what their child used to enjoy, and when observing other mothers feeding with ease.

Summary of Essence 1: Losing the mother dream

In summarising the essence of what it meant to lose the mother dream, it emerged that the mothers in this study experienced an initial feeling of loss in relation to the incongruence of expectation versus the reality after their child was diagnosed with a feeding difficulty. The incongruence between expectation and reality was most strikingly experienced in the inability to feed a child, as well as having to perform uncomfortable or painful tasks on a child. Losing the mother dream emerged to be an ongoing experience as the mothers in this study struggled to let go of their ideals and dreams. The inability to reach dreams of what it means to be a mother, resulted in a questioning of competence most powerfully experienced in relation to feeding. Their stories highlight a difficulty in accepting the loss of oral feeding. Strong feelings of loss were re-experienced at times when the mothers were reminded of the loss of their ability to bond with their child, when they saw other women performing mothering tasks, and when their child was unable to participate in eating routines.

Stress related to incongruence between expectation and reality of motherhood is experienced by many women, even following full term pregnancies where no infant complications are present (Maushart, 1999). However the persistent nature of the experience of loss identified by the mothers in this study seems to set them apart. A universal, persistent experience of loss was therefore present which was strongly felt in relation to their ideals of motherhood but extended further to a loss of bonding opportunities. It has been found that caregivers face an "ambiguous loss" when a family member is changed following a sudden incident (Boss, 1991). Boss explains that the ambiguity emerges because the family member does not die, which means that the loss is seldom given public validation and the grieving process cannot be ritualised as would occur following death. The current study found a similar trend in the ongoing experience of losing the mother dream, as the mothers recalled repeated and persistent experiences of grief at the loss of previously held ideals of motherhood and the notion of an ideal child.

Implications

An understanding of the pervasive and persistent feelings of loss due to the inability to feed a child orally or with ease has implications for mothers, family members as well as for health care professionals and others involved in the care of children with chronic feeding difficulties.

a. Implications for mothers and family members
   i. An awareness of the ambiguous and persistent nature of loss may equip mothers and family members to understand emotional reactions and potentially reduce distress associated with ongoing questioning of maternal competence.
   ii. Mothers can be counselled regarding changed expectations and dreams and prepared for a potentially different reality in which difficulties in coping are to be expected.
   iii. Mothers and family members would benefit from information and experiences with different mechanisms to enhance bonding such as inclusion of a child at mealtimes and incorporating physical closeness during enteral feeding.
   iv. Mothers could also be prepared for the periodic resurgence of intense sorrow and would be enabled in their capacity to cope with such feelings if they understood that it is a normal not pathological reaction to mothering a child with a chronic feeding difficulty.
   v. An awareness of the prevalence of feelings of fear and reduced competence associated with enteral feeding may potentially reduce maternal distress as would strategies aimed at managing enteral feeding.

b. Implications for health care professionals

i. Professionals involved in the care of children with chronic feeding difficulties should be aware of the feelings of loss experienced by mothers and implications for ongoing management and referral for counselling. In this regard health care professionals could anticipate the kind of support a mother will need and focus on preparing them for the potential emotional crisis that may arise from loss of oral feeding.

ii. Health care professionals would be assisted in their management through an understanding that resistance to enteral feeding stems from different sources and that a strong wish to re-establish oral feeding may be present which could have a direct impact on acceptance of and adherence to professional recommendations. Sources of resistance that emerged from this study included:

- Fear that oral feeding may never be regained.
- Sorrow that a child will not have pleasant eating experiences.
- Perceptions of personal failure as a mother.
- Confrontation with and a need to accept that a child is really ill or have a poor prognosis for future development.

c. Future research

i. The systemic barrier associated with public health care service delivery that emerged in this essence was the lack of available resources (enteral feeds), at a community clinic level. A potential closer collaboration between the different levels of health care in relation to obtaining resources at short notice may also have resolved this particular difficulty. Future research that could provide statistics on the number of children who are dependent on enteral nutrition in relation to the community level clinic that they would be expected to access would be beneficial in this regard.

ESSENCE 2: EVERYTHING CHANGES: LIVING LIFE ON THE MARGINS

In describing the early days of finding out about their child's feeding difficulty, mothers used words such as "chaos, mayhem, tragedy, harshness, a struggle, so hurt and so broken." Their stories depicted an intensity of emotions and a struggle to create meaning and order. All but one of the mothers spoke of how they never imagined that a feeding difficulty could impact and change their entire life. Kathy was the only mother who reported that life was much as it was before and that the family was still able to enjoy most activities that were part of their lives before her son's accident. The amount of support and validation that Kathy received from her husband set her apart from the other mothers. Their family life following her son's accident was characterised by a sharing of caregiving tasks between herself and her husband and a determination to continue to engage in activities that the family use to enjoy, which might account for a difference between her and the other mothers.

> [23]"Ons doen nog meeste dinge nes voorheen. Ons vat hom saam na die winkels, na vriende en laas naweek na die strand. Enige plek waar ons sy stoel kan in vat neem ons hom." (Kathy, pg. 2, L 41)

A powerful theme that emerged from the other six mothers' stories was a sense of living on the margins, feeling invisible and not quite part of their families and society anymore. The sense of being marginalised was experienced in a wide range of contexts, including within a health care setting, during family interactions and in social settings.

"Everything changes: living on the margins" was chosen to capture the essence of how the mothers experienced an all encompassing change in their lives as a direct result of being the mother of a child with a feeding difficulty and how these changes resulted in feelings of isolation.

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[23] We still do most things as we use to before. We take him with to shops, to friends and last weekend we took him with to the beach. We take him any place where his wheelchair will fit.

Three sub-themes were identified within this essence which relates to changes that occurred in different spheres of the mothers' lives; namely the family, society and the workplace. Changes to future plans also occurred which initially formed a fourth sub-theme. However, changed future plans and changes in employment status were grouped together as altered future plans were often related to changes in financial resources.

Changes to family interactions

Caring for a child who needs adapted feeding strategies at home impacted on the mothers' relationships with their spouses in various ways. Rehana and Kathy spoke about a strengthened bond with their spouses while Margaret experienced marital stress as she felt that her husband was not able to accept their son.

> "My life has changed quite a lot. My husband doesn't support me with my son. It's like my son does not exist. He won't talk to him. It is hard, but I just totally switch off. I told him that I don't worry about my marriage but my son comes first. If he is not important to your life, he is important to my life. He can't do nothing, so why don't you accept him? I mean it is not somebody else's child, it is his child!" (Margaret, pg. 6, L 180)

What emerged from the stories and what might set Rehana and Kathy apart from the other two married mothers was the degree of paternal participation in caregiving tasks. Both Rehana and Kathy spoke about their husbands as active partners in caring for their children and how they took turns providing care or assumed different roles.

> [24]"Husband: My vrou doen al die werk, sy werk elke liewe dag met hom. Hulle doen sy oefeninge en party aande dan sal ek sit en sy lees oefen. Hy lees goed, as jy vir hom twee woorde wys en een lees dan wys hy daarna. Wife: Ja, ons vat so

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[24] Husband: My wife does all the work. She works with Ronald every day. They do his exercises and some nights I will sit and practice his reading. He reads well. If you show him two words and read one out loud he is able to point to the right word. Wife: Yes, we take turns and help each other with everything that needs to be done but it is not such a big adjustment as what we imagined.

> beurte en help mekaar met alles wat gedoen moet word, maar dis nie so 'n groote aanpassing as wat ons gedink het nie." (Kathy, pg. 3, L 50).

> "I still come home to bath her and give her supper. Her dad gives her her last bottle and puts her down." (Rehana, pg. 12, L 336)

In contrast, Margaret assumed sole responsibility for caregiving tasks.

> "I did it [caregiving tasks] all. I had a girl here for a little while who helped me but she moved away then I had to do it alone again." (Margaret, pg. 4, L. 104)

Although Tanya did not speak directly of her husband and her son's grandparents, she described them as being unable to assist her in taking care of her son's gastrostomy tube which resulted in her providing sole care until she was able to employ and train a part time caregiver to assist her.

> "In the early days, for two years, it was just me doing everything. My family was very supportive but Kevin's grandmothers and even his father can't watch when the PEG has to come out or when I have to suction." (Tanya, pg. 8, L 181)

> "Even his dad cannot cope with some of the things I have to do, it is down to the mother." (Tanya, pg. 14, L 310)

Extended family was often referred to as supportive however they were also described as not always understanding of the manner in which care tasks had to be performed. The following quotes from Rehana's story shows how even after she had provided her family with extensive information on the reasons why tasks had to be performed in a certain way there were still times when her advice was not followed. What also emerged was how the lack of understanding demonstrated by extended family members created a degree of discord between Rehana and her family which may in turn have added to feelings of isolation.

> "But some of the family obviously still don't quite get it. They don't see us enough, maybe they don't ask questions and maybe we don't say." (Rehana, pg. 5, L 143)

> "They [extended family members] don't always understand. I think sometimes it is a bit of like hiding, not wanting to face the full reality of it. But, sometimes they do." (Rehana, pg. 7, 207)

> "I know my sister- and brother-in-law are very much not schedule people with their kids. They think that I am anal and ask me why can't we do this, or do that." (Rehana, pg. 13, L 371)

The mothers spoke of how the presence of a feeding difficulty impacted family interactions especially during family gatherings. They experienced feelings of isolation at family gatherings because they were not able to participate in the same way as they did before their children were diagnosed with feeding difficulties.

> "I will sit one side where it is quiet and feed her while the others are sitting eating somewhere else, having their Sunday lunch." (Rehana, pg. 6, L 108)

Special occasions such as religious holidays lost their "specialness" for the mothers. Most religious holidays are celebrated through the sharing of a meal between family members. It is mostly around a table and over specially prepared dishes that families celebrate their religious beliefs or their bond as family members.

> [25]"...jy en jou kind sit alleen, almal is bymekaar anderkant. Christmas is nie meer dieselfde nie, niks is dieselfde nie" (Sumaya, pg. 7, L 202)

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[25] You and your child sit alone, everybody else is together elsewhere. Christmas is not the same anymore, nothing is the same.

> [26]"Ons het gegaan [New Year's Day celebration at the beach] maar dit is nie soos ons gesien het hoe die ander mense dit geniet het nie. Ons moes vir Ben deur daai ding voer [PEG]. Ons moes daar by hom sit. Ons kon nie vir ons enjoy nie." (Rita, pg. 8, L 206)

Rita recalled an occasion where family travelled from afar to gather in Cape Town. It was the first time that the family would see her son after his accident. They brought things for her son to eat and Rita had to explain to them that he was no longer able to eat orally, which was difficult for the family to understand.

> [27]"So dit is baie hartseer vir die family om hom so te sien. Want hulle het nogal vir hom 'n juice en yoghurts gebring van Knysna [coastal town about 400km from Cape Town] af kort na die ongeluk. Toe sê ek vir hulle, nee hy kan niks eet nie. Hulle het nog gedink hy kan darem eet. Toe vra hulle kan ek dit nie deur die pypie [PEG] gee nie. Ek moes nee sê." (Rita, pg. 6, L 150)

Discussion of sub-theme: Changes to family interactions

The reality of being a mother of a child with a feeding difficulty was that *changes to family interactions* occurred. Marital stress and breakdown was found by O'Brien (2001). This was however not the case with everyone who took part in the current study. Findings from this study seem to suggest that paternal participation in caregiving tasks as well as the extent to which a spouse validates the mother's efforts, can strengthen the relationship between spouses. Where a father assumed responsibility for some of the tasks a greater degree of support was perceived to be present and it was these relationships that were described as close. Where such support and acknowledgement

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[26] We went [New Year's Day celebration at the beach] but it was not as we expected and how we saw the others enjoying themselves. We had to feed Ben through that thing. We had to sit there with him. We could not enjoy ourselves.

[27] So it is very sad for the family to see him like this. Because they brought him a juice and yoghurts from Knysna [coastal town about 400km from Cape Town] shortly after the accident. Then I told them, no he cannot eat anything. They thought he can at least eat. They asked me if I cannot give it through the PEG but I had to say no.

was not present, as for Margaret, a breakdown of the marital relationship seemed to occur. Altered family dynamics, including marital stress has been found (O'Brien, 2001; Petr et al., 1995) to be a challenge faced by families caring for children who have chronic medical conditions. O'Brien's (2001) study examined the experience of long-term home care for technology dependent children, from the families' perspective. The majority of parents in his study reported a change in their relationship with their spouse because of having a child with special needs. Some marriages had dissolved and the women linked this in large part to having a child with special care needs. Unfortunately, O'Brien's (2001) study did not provide further insight into the characteristics that set the participants apart in relation to those who were able to maintain a strong relationship with their spouses and those whose relationships dissolved.

The mothers experienced feelings of isolation at family gatherings because they were not able to participate in the same way as before. Special occasions such as religious holidays lost their "specialness". These occasions had to be carefully planned, arrangements had to be made to allow their children to participate and the mothers had to be vigilant in what was offered to eat during family gatherings.

Changes to lifestyle

The mothers spoke about changes that had to be made to their lifestyle. Sumaya, the only mother without support at home, felt the impact of these lifestyle changes to the greatest extent. She spoke of becoming isolated and unable to leave her house. Her son's specialised feeding needs made her feel captive and this, more than his physical disability following the accident, was what limited her social interaction with others.

> [28]"Ek wil nie uitgaan nie waarheen moet ek gaan as my kind in so 'n toestand is. Ek is net in die huis. Ek kan nêrens gaan nie. Ek kan nie vir iemand vra om hom

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[28] I can't go out, where must I go with my son in such a condition. I am just at home, I can't go anywhere. I cannot ask anyone to watch him. There is nobody who can give his feeding. It is the feeding which keeps you away from many things.

> te watch nie en daar is niemand wat die feeding kan gee nie. Die feeding is eintlik die ding wat jou weghou van baie dinge af." (Sumaya, pg. 7, L 210)

Activities that were engaged in with ease before became difficult or impossible because of the presence of a feeding difficulty and the caregiving tasks related to it. The mothers experienced feelings of social isolation when interacting with friends. Joining friends for lunch, going on a picnic or even spending time on the beach all had to be planned around feeding schedules and were often avoided.

> "You can't go for a picnic because where do I warm her food. You can't go out or stop somewhere to buy food because she won't eat it. So I can't just say let's go and have lunch." (Rehana, pg. 6, L 171)

Tanya felt that her friends lacked an awareness of the needs of children requiring adapted feeding strategies as opposed to children with other medical conditions.

> "What really annoys me is when my friends say let's go shave our heads for cancer or let's give money for HIV. I just feel that these type of kids are invisible, the world does not, or this country does not always see them..." (Tanya, pg. 12, L 292)

Tanya's words highlight how she experienced being isolated from others in the sense that people were perceived to lack awareness of the needs of children with feeding difficulties. She felt that South Africans did not advocate for the rights of children with feeding difficulties, possibly due to a lack of awareness of these children who suffer from a less well-known (and less understood) condition. This theme was echoed by Rehana when recalling a time when she was trying to find diapers for her three year old daughter.

> "I was asking this woman in a shop: Don't you have further than age two [diapers]? She said: Why do you need it? Kids are supposed to be potty trained by two. And I thought, well I am not going to answer you, you are not considering, but then I thought maybe she never had to think about it." (Rehana, pg. 14, L 407)

Children's birthday parties was another difficult social situation for the mothers and served as a reminder of what was lost. Special arrangements had to be made and the mothers had to be vigilant in what was offered to eat.

> "Things like Party Packs [containing toys and sweets] at kids birthdays. They are full of things that she can't eat. My sister will make up a pack with things that she can eat like teddy chocolates, yoghurt things that she can eat. Not the other things that kids normally eat. Or they will want to give her something and I would have to say, but she can't, she does not just eat chocolate cake." (Rehana, pg. 5, L 145)

The time needed for altered feeding also impacted on the mothers' lifestyle adding considerably to a sense of burden. This was true for both mothers who were giving nutrition orally as well as those doing exclusive enteral feeding. For both groups feeding was often described as a time consuming activity.

> "But you just have to be so so patient. And then you sort of have this 20 minutes 30 minutes and I'm watching the clock, do I give up now [with oral feeding] or carry on trying. That's what I did in the beginning I would sit for a whole hour and the child had not eaten half the lunch yet." (Rehana, pg. 13, L 280)

> [29]"Dit [giving enteral feeds] is eintlik 'n tiring job want jy moet sorg dat die feeding gemaak moet word. Eerste moet ek die water kook en dan laat ek dit afkoel. Eleven o'clock is die laaste feeding wat ek in die aand gee en ek kan nie deur die dag slaap nie want ek voel ek moet hom dophou." (Sumaya, pg. 4, L 100)

Another theme that emerged was the need for the mothers to organise their lives around feeding schedules. Mothers who were giving exclusive oral feeding faced challenges in organising their lives around mealtimes.

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[29] Giving enteral feeds is actually a tiring job because you have to ensure that the feed is made. First I have to boil the water and then it has to cool. At eleven o'clock I give him his last feed and I can't sleep during the day because I feel that I have to keep watch over him.

> "If my husband says lets go to the beach I will say it is fine but I will go in my own car so that I can come home and feed her. Or I have to go after lunch. At four o'clock she has some chips and I can give her that at the beach if need be but then we have to be home for supper..... So I have to make sure that I have to be somewhere that is appropriate for her." (Rehana, pg. 6, L 181)

Not only did the mothers have to organise the day around a feeding schedule but they often had a separate medication schedule to follow as well.

> [30]"Dan raak ek so moeg. Want ek moet daai feeding gee en in between moet ek sy pille gee. En ek moet hulle eers fynkap. So sê maar 8am kry hy feeding en pille, dan gee ek weer 11am feeding, dan weer 1pm sy pille en 2pm sy feeding, 5pm sy feeding en pille, 8pm sy feeding, 11pm sy pille. Dit is 'n werk. Dis worse as iemand wat 'n werk het." (Sumaya, pg. 15, L 444)

Additional considerations were present for mothers who were giving enteral nutrition including having to make arrangements to collect feeds at the nearest community day hospital. Two mothers were reliant on public transport which made getting the feeds difficult. The need to collect feeds and to make arrangements for transportation increased the amount of planning and time required to feed a child and thereby impacted on the mothers' lifestyles.

> [31]"Dit is moeilik om die melk te kry. Ek moet dit gaan haal by die dag hospitaal. Dis twee bokse, miskien 30 blikke in. Dit kos vir my mense te vra om my te vat. En mense wil nie altyd iets verniet doen nie." (Sumaya, pg. 4, L 107).

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[30] I get so tired because I have to give medicine in between giving feeds and I first have to crush the pills. So he gets feed and pills at 8am, then at 11am feeding, then again 1pm his pills and 2pm his feed, 5pm his feeding and pills, 8pm his feed, and 11pm his pills. It is work. It is worse than someone who has a job.

[31] It is difficult to get the milk. I have to fetch it at the day hospital. It is two boxes full of maybe 30 tins. It means that I have to ask people to take me and people do not always want to help you for free.

Restriction of social participation also appeared to be related to societal barriers in the form of limited adaptations made to public transport and public places that would enable children who use a wheelchair to access them with ease. Dependency on others for transportation, challenges in making use of public transport and barriers created to engagement through poorly planned buildings that were not designed to provide easy access for disabled people all contributed to social isolation.

> "I just have a problem when I want to go somewhere. I need to take the train but it is awkward because you have to carry him [her son]. And there are steps all over the place. So I must just get somebody who has a car or whatever to take us." (Margaret, pg. 8, L 211)

> [32]"[name of hospital] het vir my 'n pram gegee, maar die pram is te groot. Dit kan nie in 'n taxi in nie. So ek moet vir Ben dra, maar mens kan nie vir hom so regop hou nie want dan gooi hy op." (Rita, pg. 4, L 91)

Popular media was another context in which the mothers felt poorly represented. Rehana's words indicate that she was not able to identify with mothering practices as represented through television programs or in printed media.

> "There is a TV program all about feeding; you know that program on TV? So they go through talking to all kinds of specialists, all sorts of moms, all ages but there is not a single thing on feeding a special needs child." (Rehana, pg. 13, L 393)

> "I think just the fact that you have to go and look for information yourself, where for all other moms the books are just there. You know you get these books about caring for a baby and I thought, great doesn't help me one bit! Other moms can walk into any shop and buy a book. But you can't." (Rehana, pg. 14, L 420)

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[32] [name of hospital] gave me a pram but the pram is too big because it cannot fit into a taxi. So now I have to carry Ben, but you can't carry him upright because he vomits.

Discussion of sub-theme: Changes to lifestyle

A *change to lifestyle* was a reality for the mothers in this study. Activities that were engaged in with ease before the diagnosis of a feeding difficulty became difficult or impossible because of the practical implications of adapted feeding strategies. The change in lifestyle that was found in the current study was similarly documented in a study by Franklin and Rodger (2003). They too, found that chronic feeding difficulties necessitated changes to daily routines and that it increased both the physical and emotional demands on those caring for a child with a feeding difficulty (Franklin & Rodger, 2003). In the current study mothers experienced adapted oral and enteral feeding as time consuming activities that had to be planned carefully within a daily schedule of tasks. In planning their daily routines the mothers had to consider feeding and medication schedules as well as hospital visits for medical management and for the collection of medication and enteral feeds. The mothers made reference to non-feeding tasks associated with caring for their child that had to be done however it was the challenges of managing a chronic feeding difficulty within their everyday lives that was especially demanding, a finding similarly reported by Spalding and McKeever (1998).

When comparing the current study's finding, that the presence of a feeding difficulty restricts social participation, to past research, it emerged that families caring for technology-dependent children at home experienced similar social restrictions. Kirk (1998) reviewed research on families' experiences of caring for a technology-dependent child at home and found that extensive social restrictions resulted with some parents literally becoming house-bound. This finding is in line with Sumaya's experience of feeling captive in her own home. Guerriere and McKeever (1997) found that mothers of children with traumatic brain injuries made changes to their lifestyles and reduced leisure activities because of the time and energy required to meet their children's many physical needs. The participants in OBrien's study (2001) also reported finding it difficult to make time for family activities because of the time consuming nature of caregiving tasks. In the current study, mothers similarly reported that caregiving tasks reduced opportunities for social interactions with friends.

When there was no support with the child's daily care, restrictions on activities were experienced most intensely resulting in a feeling of captivity as some mothers become literally unable to leave the home. Sumaya attributed her difficulty in leaving the home to the absence of respite carers who were trained in adapted feeding methods. The shortage of respite options documented in this study is not unique to South Africa as parents in the United Kingdom and the United States of America report similar difficulties in finding respite care for a child who requires specialised care (Diehl et al., 1991; McKeever, 1991; Petr et al., 1995). A shortage of adequately trained caregivers who are able to provide for the specialised care needed by technology dependent children was identified as the primary reason why parents were not able to obtain respite.

Changes in employment status and to future plans

It was not only changes to family interactions, daily routines and social participation that emerged in the mothers' stories, but also the change in employment status and to future plans, as they assumed the role of primary home-based caregiver.

Three of the mothers were employed full time before the birth of their children. Tanya made the decision to give up her job to care for her son full time. She acknowledged that she was fortunate as her husband was able to support them financially. Tanya attributed her son's improved physical health to her decision to care for him as a primary home-based caregiver, which indicates that she had made sense of her decision to leave the workforce based on the positive outcome for her son.

> "Initially I thought that I would go back to work and that he would go to crèche, because we were under the impression that he's just a dwarf so, unbeknown to us, he shouldn't really get sick. In the two months that he was in crèche he was hospitalised three times. When he was five months old he got a respiratory virus or something, and he battled to recover from it. There and then we [husband and wife] decided that I should stop working and try to help him. And we were in a

> fortunate position that I could. Then at eleven months, I think because I stayed at home with him, he was much healthier." (Tanya, pg. 3, L 48)

Margaret initially gave up employment to look after her son but was able to enrol her son in a daycare program so that she could return to work on a part-time basis. She spoke of how she valued the ability to work as it offered opportunities for her to gain emotional support from colleagues.

Both Tanya and Margaret were comfortable with the changes that they made in their employment status and were able to make the changes without any sense of guilt, a theme that emerged from Rehana's story. She spoke about the guilt she felt at the thought of not returning to work after being granted 12 months maternity leave to take care of her daughter, while at the same time experiencing guilt at the thought of not being able to spend every minute with her daughter. After a year she made the decision to return to work full-time but was still had guilt feelings at the time of the interview. Her choice to return to work was jointly decided on by her and her husband and based on the need to be able to provide her daughter with every possible opportunity.

> "There is guilt of going back to work and not being there [at home]. But at the same time to be able to provide everything that she needs it is better for both of us to work. So I feel guilty when I'm not at work and I feel guilty when I am not at home." (Rehana, pg. 11, L 314)

Being the mother of a child with a feeding difficulty resulted in an inability to seek employment for Sumaya and Rita as they were the primary caregivers of their respective children and lacked the financial resources to employ part time caregivers to assist them. In her interview, Sumaya spoke about how she would have liked to study towards becoming a nurse to provide better for her children, but that this would not be possible now, both financially and in terms of the amount of time she needed to spend meeting her child's special needs.

> [33]“En vir my was dit net swaar want ek kan nie gaan werk en vir hulle sê: Mammie het die vir jou gekoop mammie het daai vir jou gekoop nie.” (Sumaya, pg. 4, L 95)

Sumaya and Rita also spoke of the financial burden created by the need to remain at home to care for their children. There were additional expenses such as travelling to the hospital with public transport and buying specialised seating which resulted from having a child with a chronic feeding difficulty. They spoke of various items that they felt their children would need but that they were not able to afford. For Rita there was an urgent need to buy another bed.

> [34]“Toe Ben huis toe kom toe is hier net een kooi. Die kot het ‘n meisie solank vir ons geleen. Hy kan nie eintlik op die kooi slaap saam met ons nie, want ons is bang dat die PEG kan uitval. Ons het nie geld dat ons kan sê: Hy kom môre huis toe so gaan winkel toe en koop alles wat hy nodig het nie.” (Rita, pg. 7, L 183)

Changes to future plans extended beyond employment related options to a variety of contexts. The mothers acknowledged that they lived their lives differently than they would have if their children did not have a chronic feeding difficulty. For Rehana and her husband future plans related to travelling and home renovations had to be altered as their daughter’s needs took priority.

> “My husband and I travelled quite a bit. We haven’t been away since she was born.” (Rehana, pg. 8, L 215)

> “Our concern is the future. Like the house we are busy renovating will have ramps and her bedroom has to have space for all her therapy stuff. Because that is the future she is getting bigger and older.” (Rehana, pg. 10, L 306)

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[33] It was difficult for me because I can work and say to my children: Mommy bought this or that for you.

[34] When Ben came home from the hospital we only had one bed. The cot he is using was lent to us. He cannot really share the bed with the rest of us because we are scared that the PEG might fall out. We don’t have money to say: He is coming home tomorrow so let’s go to the shop and buy everything he needs.

Rehana and her husband also decided against having another child. They made this decision; even though Rehana's words indicated a desire to do so; based on the premise that her daughter needed all the resources that they could offer her.

> "She is the first [child] and probably the last if it is up to her father. I wouldn't mind, but I understand his reasoning as well. Our focus is on her, and the time we spend doing everything for her." (Rehana, pg. 4, L 97)

Discussion of sub-theme: Changes in employment status and to future plans

A need to make *changes in employment status and to future plans* emerged as a direct consequence of being a mother of a child with a chronic feeding difficulty. A Canadian study of families caring for children with disabilities at home also found that parents faced challenges related to employment (Irwin & Lero, 1997). Often one parent would have to leave the workforce in order to care for the child and this parent was most frequently the mother. A number of reasons why continued employment become difficult was identified in research conducted by the Roeher Institute (1999), a Canadian organization that generates information related to disability. The research identified both caregiver- and workplace-related barriers to employment. Barriers included the amount of time needed to care for the child, the unpredictable nature of the child's need to access medical care, employers lack of willingness or ability to offer flexible working schedules and the parents physical and emotional ability to care for a child in addition to working outside the home. Caregiver-related barriers were present and most notable for the mothers who were not able to afford the services of part time caregivers thereby making it impossible for them to either continue with, or seek employment. Workplace-related barriers were not identified by the mothers in the current study as both Margaret and Rehana made reference to their employers as being supportive and understanding.

The degree of change that occurred in areas such as finances and career roles of parents who had a child hospitalised for a chronic feeding difficulty was found to increase the level of stress experienced by the parents (Garro et al., 2005). Distress caused by changes in employment status and future plans was not a universal experience in the current study. Varied emotions about changes in employment status were evident, possibly related to the mothers' degree of financial stability. The mothers who remained unemployed by choice and were financially able to do so because they had alternate sources of income, did not experience the distress experienced by those who were overwhelmed by the additional financial implications of their child's special care needs. Margaret valued the ability to continue working, seeing it as an opportunity to gain emotional support from colleagues and as respite from care demands. For Rehana, leaving her child in another person's care while she worked was distressing and created feelings of guilt. Her experience of guilt was closely related to findings reported by Simon (1995) that women often experience guilt and a sense that they let their families down when they attempt to combine mothering and employment outside of the home. The mothers in the current study also made changes to some of their future plans, which had to place the child's care at a priority. O'Brien (2001) found that being a parent of a technology dependent child influenced decision-making related to having other children, with some parents making a conscious decision not to, noted in Rehana's story.

Summary of Essence 2: Everything changes: living life on the margins

The universal experience of loss described in 'Losing the mother dream' continued as a thread throughout 'Everything changes: living on the margins'. Living on the margins was chosen to describe the feeling of isolation that the mothers experienced within their communities and even within their extended families. The mothers spoke about how being the mother of a child with chronic feeding difficulties had resulted in changes that impacted every aspect of their lives. Their stories show a loss of ability to participate in family gatherings, social interactions and full time employment. Marital relationships were influenced positively for some mothers but other marriages were negatively impacted which appears to be related to the degree of paternal participation in caregiving tasks and the extent to which the mother's role as caregiver was acknowledged by a spouse. The demands of feeding related tasks were felt most powerfully and played the greatest role in the changes that had to be made to the mothers' lives, more so than the physical difficulties with which their children presented. Demanding feeding schedules as well as the nature of adapted feeding strategies resulted in the mothers spending much of their time planning their lives around mealtimes. The experience of loss that was so strongly felt in relation to their ideals of motherhood, extended further to a loss of social participation and to future options.

Implications

The implication that emerged from this essence is that mothers will require strategies and assistance that could potentially reduce the extent to which isolation is experienced.

a. Implications for mothers and family members
    i. The ability to cope with the demands of providing home-based caregiving would be increased when mothers adopt a number of coping strategies identified within this study, namely:
        - Acknowledging the need for both practical and emotional support.
        - Obtaining support in providing for the physical needs of a child, ideally through sharing of caregiving tasks.
        - Continuing to engage in activities that were part of the family's life prior to a child being diagnosed with a chronic feeding difficulty.
        - Actively seeking opportunities to socialize with others and to foster broader social networks.
    ii. Spouses and other family members should ideally be included during skills demonstration, which would empower them to assist the mothers during home-based caregiving tasks and potentially to provide respite. Spouses could be involved positively in a child's management by for example engaging in activities such as bathing, settling a child in for sleep, preparing and giving feeds.
    iii. Skills regarding time management and organisation of daily schedules are important to develop.

ESSENCE 3: DISEMPOWERED: FROM MOTHER TO ONLOOKER

The word disempowered is used in this study to refer to a stripping or depriving of power and strength. The mothers in this study all spoke of times when they experienced a sudden loss of ability to cope. What also emerged from their stories was a lack of opportunities in which they could feel empowered.

Expected versus enabled to cope

The mothers recalled many situations in which they perceived family members and health care professionals as expecting them to be able to cope. The expectation to cope was experienced when a diagnosis or prognosis was made; and when they were shown how to perform caregiving tasks, in particular feeding related tasks. The stories showed that the mothers felt that they were expected to cope emotionally with their changed lives and changed children in some cases, as well as in their ability to perform the physical tasks associated with providing home-based care.

> "You are expected to do a lot of things that I think most people would not be able to cope with if they were in a similar situation. But everybody just expects that you must be able to do it because you are the mother, um, feed your child you are the mother, make him pick up weight you are the mother." (Tanya, pg. 9, L 186)

> "My family was very supportive but Kevin's grandmothers and even his father can't watch when the PEG has to come out or when I have to suction." (Tanya, pg. 8, L 182)

> "I've had that before when Kevin was losing so much weight, where people will look at me or family will look at me and say: What is going on are you wanting your child to die?" (Tanya, pg. 13, L 282)

b. Implications for health care professionals

  i. Health care professionals should be aware of the need for respite and can play an important role in providing mothers with information on agencies that offer home-based care services.
  ii. Social workers within the public health care system should be involved as part of a multi-disciplinary team. Counselling in respect to potential feelings of isolation, marital counselling and providing information on financial assistance offered by the state would benefit mothers.
  iii. Health care professionals can reduce the amount of time that a mother spends administering medication and giving feeds by considering ways to better combine feeding and medication schedules.
  iv. Home-based caregivers employed by the public health care system as well as non-governmental organisations, who provide informal caregiving assistance, should empower caregivers through skills development in relation to adapted feeding needs of children with chronic feeding difficulties. Speech-Language Pathologists, who are uniquely concerned with feeding interventions, could play an important role in terms of training provided to informal caregivers.

c. Future research

  i. During review of literature I was not able to identify any studies that document the financial expenditure incurred by families who are providing home-based care in South Africa. Research in this area would be valuable as it may influence governmental policies in relation to financial and other assistance provided.
  ii. Research on the potential benefit of empowering extended family members in providing specialised feeding as a source of support and respite to mothers who have children with chronic feeding difficulties should also be evaluated.
  iii. As noted in the literature review research that explores the impact of home-based adapted feeding interventions on interfamilial relationships is limited. The variations in spousal relationship changes that emerged in the current study necessitates further evaluation of factors that impact on marriages where a child with a chronic feeding difficulty is cared for in the home.

The mothers in this study assumed primary, and often sole responsibility for providing care. As mentioned earlier, the initial topic was to understand the lived experience of a caregiver, be that a mother, father, grandparent or non-related caregiver. An interview was conducted with a grandparent (pilot study –not included in the results reported in this study) who shared many experiences with the mothers who took part in this study, however she experienced less externally and internally created pressure and fewer expectations of competency to cope with caring for the child. Agnes was the only mother in this study who was not the child's biological mother. What emerged from her story was that Agnes also had no experience of societal pressures about the "good mother". Agnes was the only [35]African Black mother and her cultural background may account for the variation. An observation made by Stephanie during the joint interview with both women alludes to a cultural difference in dealing with disability although this was not expressed by Agnes herself.

> "But maybe it is the black community. Agnes takes it in her stride. We [reference to white community] are so closeted in our little worlds. I never knew anyone with a disability growing up. And Agnes has got a greater capacity to carry it than me, it's fascinating that." (Stephanie from Agnes's story, pg. 8, L 198)

A powerful theme that emerged from the remaining six mothers' stories was that they experienced a sense that others expected them to be able to cope with providing home-based care. Some of the challenging care demands that the mothers were expected to fulfil included suctioning of the airway, removing a gastrostomy tube to clean it and one mother was cauterising around her child's stoma site. All of these activities are potentially uncomfortable or painful for a child. As mothers they were expected to cope with tasks that were perceived as a direct contradiction of what a mother is believed to embody, i.e. caring and someone who would never hurt a child. The mothers' stories revealed a struggle to find congruence between the image of the mother figure and the requirement to fulfil these tasks. They all felt unprepared for what was expected of them.

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[35] In South Africa the continued use of racial terms is necessary in terms of equal service provision and does not necessarily denote internal characteristics.

> "Initially this [suctioning] was also something that the people in the hospital just expected me to be able to deal with, but it was hard initially." (Tanya, pg. 8, L 176)

Specialised care tasks were often demonstrated by health care professionals, but the mothers experienced a sense that it was up to them to cope. Not one of the mothers recalled a health care professional who made reference to the fact that it may take time to feel competent in managing new skills. The mothers reported that very little time was spent in demonstrating new skills after which they were expected to perform the tasks on their own.

> [36]"Hulle verwag ons goeters te doen waarvoor ons nie geleerd is nie. Kyk 'n nurse of 'n dokter vat miskien 'n paar maande of 'n jaar om dit te leer [care of a gastrostomy tube]. Ons moet dit nou net in 'n split sekonde in ons in onse brein moet hou." (Rita, pg. 8, L 213)

Sumaya recalled the day she was shown how to cauterise the skin around her son's stoma. Her experience was that she was expected to do it and cope even though the thought of having to do something painful to her child was traumatic for her.

> [37]"Ek het nog nie begin brand nie toe leer hulle vir my hoe daai dag. Nie eers geleer in 'n uur of 'n half uur nie, sommer net vinnig. Toe kos dit vir myself om my hier by die huis te leer en om my plak vas te maak om dit te doen. Toe sê sister: Sien jy hier steek die vet nou uit so jy moet dit brand. Toe sê ek: Sister, ek moet my eie kind brand?" (Sumaya, pg. 14, L 399)

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[36] They expect us to do things for which we are not trained. You see nurses or a doctor may take a couple of months or even a year to learn [how to take care of a gastrostomy tube]. We have to learn how to do it in a split second and try to remember it.

[37] I had not started cauterizing so they taught me that day. Not in an hour or even half an hour just quickly. So it meant that I had to teach myself at home and to make myself hard to the thought of it. The sister said: Do you see here the fat is sticking out so you must burn it. I said to her: Sister I have to burn my own child?

> what are you doing wrong, why is your child not gaining weight why is he losing weight." (Tanya, pg. 4, L 85)

> [40]"Ek het gistraand heel nag wakker gesit. Ek moes vanoggend gaan werk het. Om net te dink het Rita daai ding reg ingesit. As dit nie reg ingesit is nie dan staan ons op en die kind is stokstyf. Vir wie gaan die dokters blame? Vir ons. Maar ons is mos nie dokters nie. Hulle gaan vir ons blame." (Rita's mother, pg. 8, L 212)

A powerful theme that emerged was the emotional reaction to performing newly acquired caregiving tasks on one's child. Whereas practical demonstrations were given in performing the tasks no emotional support was evident. Tanya described herself as a strong woman who felt that she coped well with her son's initial diagnosis of mitochondrial disease as well as subsequent specialised care needs that had to be fulfilled. The following quote from her story showed how her outward appearance of strength and ability to cope disguised difficulty in dealing with news of additional medical complications. Again the theme of others' expectations that a mother should be able to cope emotionally, became apparent.

> "I don't want my doctor to tip toe around me, you know I want her to tell me things straight. But at the same time, there are those times when I wouldn't mind a little bit of sympathy being shown, so .... it is almost as if they feel, when breaking bad news to you. Let's say there is something else that is wrong, for example Kevin started having seizures quite recently. And it is almost like when they give you that news, you know well, you've coped with so much already or you already have so much wrong with your child that what is a diagnosis of one more thing on top of that. Whereas if they would have to give that news to another mother she would be devastated I am just expected to deal with it and move on because what is another thing." (Tanya, pg. 10, L 217)

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[40] I was lying awake the whole night last night. I had to go work this morning. Just to think if Rita put that thing in the right way. If it is not in the right way then we will wake up to find the child dead. Who will the doctors blame? They will blame us, but we are not doctors. They will blame us.

Again the theme of being expected to cope emerged following a brief demonstration of a new skill. Similar experiences related to gastrostomy care were recalled by mothers providing enteral nutrition. Some mothers felt that professionals did not prepare them adequately, emotionally or practically, for enteral feeding and assumed that the mothers would be able cope with it. The focus during these times was mostly on the mechanics of enteral feeding and cleaning of the gastrostomy tube with little opportunity given for mothers to express their fears and uncertainty.

> [38]"By [name of hospital] wys hulle vir jou op 'n pop. Luister net gou hier, maar dis mos nou jou eie kind, jou eie kleinkind. Kyk ons is mos nie geleerd soos nurses en dokters nie." (Rita's mother, pg, 3, L 61)

> [39]"Hulle het my eers op die pop geleer. Dit was maklik op die pop [ma lag] toe dink ek haai is die nou al. Maar toe ek dit op hom sien, toe huil ek. Maar op 'n pop lyk dit net normaal. En toe dink ek ag dis maklik wat is die groot ding, maar toe ek my kind sien met daai ding [PEG] in toe huil ek. Dit is nie lekker om jou kind so te sien nie. En veral om dit skoon te maak, om op jou eie kind te werk dis erg. Maar wat dan anders." (Sumaya, pg. 8, L 238)

Where the mothers struggled to fulfil the new tasks a sense of being judged by others was evident in their stories.

> "At that stage he was losing a lot of weight his ribs were showing, and there was sort of a feeling that I was doing something wrong. [Hospital staff or people in your life?] Well both. It felt as if they were judging me, there was a feeling of

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[38] At [name of hospital] they show you on a doll [how to insert a gastrostomy tube]. But listen here, it is your own child, your grandchild. You see we are not learned like nurses and doctors.

[39]" They first taught me on a doll [how to insert a gastrostomy tube]. It was easy on the doll so I thought is this all? But when I saw it on my child I cried. But on a doll it looks normal and I thought this is easy, what is the big issue. But when I saw my child with that thing [PEG] in I cried. It is not nice to see your child like this and especially to clean it, to have to work on your own child is terrible but what else can you do.

Tanya's experience alludes to a perception held by health care professionals that mothers who are already caring for a child with complicated medical needs are able to accept additional bad news and that they therefore require less empathy or opportunity to express feelings of loss and uncertainty.

Several possible reasons for the absence of empowering interactions and the subsequent experience of being "expected to cope", emerged from the stories. The mothers made references to limited time spent by health care professionals in demonstrating new skills which might have been related to staff shortages and high patient loads.

> [41]"Want daai dag het sy [verpleegster] my so aangejaag en gesê sy het baie pasiente om te sien. Sy het hom net gebrand [cauterised] en toe loop sy." (Sumaya, pg. 14, L 409)

The mothers also described health care professionals as appearing frustrated and lacking the desire to engage with parents. Opportunities to ask questions appeared to be discouraged.

> [42]"Almal [mediese personeel] is in hulle eie wêreld en frustrated. Jy is nie 'n dokter nie, jy is nie 'n nurse nie jy weet nie wat om te doen nie, nou lyk dit jy phone onnodig die susters en dan is hulle so vol nonsense oor die phone." (Sumaya, pg. 17, L 488)

> [43]"Soms het jy net 'n bietjie airtime en dan bel jy en hulle [verpleegsters] sit daai phone net neer en jy hoor hoe staan hulle en praat hulle storie eers in die

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[41] She [nurse] rushed me that day and said that she had many patients to see. She just cauterised him and then she left.

[42] Everybody [health care professionals] is in their own worlds and frustrated. You are not a doctor or a nurse and you don't know what to do but it looks as if you are phoning the sisters unnecessarily and then they can be so full of nonsense on the phone.

[43] Sometimes you only have a little bit of airtime [credit] on your phone and then when you phone the they [nurses] will put the phone down and you can hear them talking about their own things in the background. Their job is to be there for you. You are the mother and you don't know what to do. But it is almost as if you just have to wait because you need their help.

> agtergrond. Hulle werk is om daar te wees vir jou. Jy is die ma en jy weet nie wat om te doen nie. Maar dit is amper soos: jy hou net aan want jy het ons hulp nodig so jy sal nou maar net moet wag." (Sumaya, pg. 17, L 498)

> "And they [reference to health care professionals] don't make mothers part of discussions they just say because they are the doctors." (Margaret, pg. 15, L 425)

Few opportunities were provided in which the mothers could talk about their emotional reactions to providing home-based care.

> "Every time when he is sick and the doctor tells me this and that I feel this anger again cause you know they are not there to support you." (Margaret, pg. 4, L 92)

> "She [Speech-Language Pathologist] only asked if he is eating. And I said: No I'm not feeding him through the mouth. And then that was it, she didn't give another appointment." (Margaret, pg. 11, L 305)

> "The Physiotherapist we went to, she was very nice, I mean she was a Christian, but I think she was bringing all her theory. Rose use to scream and scream so Stephanie said no more and we took Rose and left." (Agnes, pg. 5, L 125)

Parents' tendency to avoid initiating discussions may also play a part in the process through which they are expected rather than enabled to cope.

> "But some of the family obviously still don't quite get it, they don't see us enough, maybe they don't ask questions and maybe we don't say." (Rehana, pg. 5, L 143)

What emerged during the analysis of the mothers' stories was that they often appeared to be coping, either because they felt the need to appear strong or because they themselves did not engage with family members and health care professionals to make their needs known.

[44]"Daar is ma's wat nie baie praat of vrae vra nie, dan word hulle huis toe gestuur met vrae wat nie beantwoord is nie." (Sumaya, pg. 12, L 354)

[45]"Ons [moeders] almal lyk happy by die hospitaal. Jy sit en smile die hele dag daar by die hospitaal maar die moment wat jy van daai kind af loop huis toe dan huil jy." (Sumaya, pg. 14, L 460)

[46]"Dan is daar tye wat mense kom. Dan vra hulle my hoe kan jy dit handle? Dan sê ek: Nee ek kon nie gewerk het aan die PEG aan die begin nie maar toe raak ek gewoond aan dit. Dan moet ek my sterk hou voor hulle." (Sumaya, pg. 8, L 217)

"And they say: No Margaret you won't say it because you just smile, you never look down. And I say: No, why must I be like that I just take every day as it comes." (Margaret, pg 10, L 204)

Discussion of sub-theme: Expected versus enabled to cope

Expected versus enabled to cope was a reality as the mothers experienced pressure from family members and health care professionals to cope with the diagnosis of a feeding difficulty, together with the practical and emotional implications of such a diagnosis. The mothers recalled times when they experienced feelings of being judged in terms of their ability to provide care for a child. A sense of feeling judged was experienced most intensely during interactions with health care professionals. These feelings may potentially be linked to self-perceptions of their own competence or inability to meet the ideally held view of motherhood. The traditional image of who a mother ought to be may result in mothers judging their own behaviour through standards prescribed by

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[44] There are mothers who do not talk or ask many questions then they are sent home with unanswered questions.

[45] We [mothers] look happy at the hospital. You sit and smile the whole day there at the hospital but when you go home you cry.

[46] Then there are times when people come and ask me how can I handle it? Then I say: No I could not work with the PEG in the beginning but now I am getting use to it. Then you have to appear strong in front of them.

"experts" (Arnold, 2003). Apart from self-perceptions of competence the stories also revealed that the brusque manner in which health care professionals imparted information and skills was construed by the mothers as expectations for them to be able to meet the care needs of their respective children with ease.

Specialised care tasks such as suctioning and removing a gastrostomy tube were demonstrated by health care professionals, but little or no reference was made to the possibility that time may be needed to feel competent in acquiring the new skills. With reference to enteral feeding the mothers felt unprepared for what was expected of them, reported few opportunities to express their uncertainty and when struggling to fulfil the new tasks experienced a feeling of being judged. When children failed to thrive, regardless of the mode of nutrition, the mothers reported feeling distressed as they perceived family members and health professionals to be judging their feeding practices which was also reported in a study by Spalding and McKeever (1998) and by Thorne et al. (1997). Guerriere and McKeever (1997) found that, in addition to feeling judged by others, mothers of children who had sustained traumatic brain injury went through a continual process of self-blame and judging themselves as ineffective in fulfilling maternal role expectations of ensuring a child's well-being. A sense of self-blame emerged in Sumaya's words "dit is jou straf nou" (this is your punishment), which is possibly related to the fact that she was present when her son sustained a head injury.

The experience of the mothers in this study was that they were not empowered by others in either their emotional ability to cope, nor in their physical ability to perform certain caregiving tasks. Inadequate time for practicing new skills was provided; few if any opportunities were created for the mothers to discuss emotional reactions to the demands of home-based care; and assumptions were made that the mother would be able to perform the care tasks without continued support. A focus on skill demonstration as opposed to enabling parents to feel competent in these skills through practice and discussion of concerns dominated the interactions with health care professionals, a theme that will be discussed further in "Disempowering professional interactions". Family-centred care has the goal of bringing the family into a central or powerful role in the care of the child (Brooks, 1997). To achieve this goal parental competencies should be developed related to knowledge and skills (Fisher, Bullock, Rotenberg & Raya, 1993). The universal feeling of expectations to cope following insufficient opportunity to master new skills that emerged from the current study highlights a shortcoming of the professionals who were involved in meeting the aims of family-centred care. The mothers' stories highlighted a need for others to provide more practical and emotional support in order to empower them to develop a feeling of competence and emotional capacity to perform specialised care tasks and to deal with their own feelings.

When evaluating why the mothers were not enabled to cope it emerged that the mothers themselves also played a part in the lack of empowerment opportunities by not making their needs known to others. The mothers asked few questions of health care professionals in the first couple of months following a diagnosis of a feeding difficulty. They also presented a facade of being in control both during a child's hospitalisation as well as during interactions with friends and family members.

Disempowering professional interactions

The mothers made many references to instances where they felt disempowered in their interactions with health care professionals. The situations were related to receiving a diagnosis and prognosis, the manner and place in which information was shared or not shared, treatment and discharge decision making, and degree of sensitivity to their emotional needs.

Receiving the initial diagnosis was challenging for many of the mothers as they spoke of health care professionals who were perceived as insensitive to a parent's need to know what was happening with their child. When considering the quotations below it appeared that both cases may not have been easy for a health care professional to diagnose, however this was not clearly communicated to the mothers, resulting in perceptions that health care professionals lacked sensitivity and that they even appeared ineffective.

> "When I was pregnant I was told that he was going to be a dwarf. After a lot of soul searching we decided to keep him. The doctors said terminate, and we asked is there anything else wrong and they said no nothing else wrong. When he was born he had trouble sucking and had an extremely high palate. We kept on saying to the doctors: Why does he have such a high palate? He had features of a dwarf, but didn't fit into any category. The doctors kept on saying: Ag maybe he's this, or maybe he's that. (Tanya, pg. 2, L 26)

> "I took him to [name of hospital] and then the doctor there told me he is stubborn and that it is breath holding attacks, that he has a blocked nose. But it wasn't, it was a fit at that time already. Then I took him to a private doctor who told me I had to go back to [name of hospital] for tests. And then only did they keep him overnight and they did tests and only then did they tell me it is cerebral palsy and epilepsy. But I mean up and down, and the doctors don't do it the first time. But maybe if they found out before then maybe they could have done something to prevent him from getting worse. But they didn't. One day I went for a check-up and I saw that same doctor and I told the doctor: I'm sorry I don't want to see you because that hatred was in me, because why didn't you acknowledge it the first time already." (Margaret, pg. 3, L 60)

Difficulties in diagnosing the problems add to parental concerns and stress preventing (good) decision-making which resulted in a delay in appropriate management.

All the mothers spoke of deconstructive or disempowering professional interactions related to information sharing. The manner in which they were provided information was problematic with respect to the medical prognosis as well as expectations for the child's future health and development.

> [47]"Soos ek leer nou eers dat altwee kante van sy brein beskadig is. Toe dink ek maar julle moes my al daai tyd gesê het sy hele brein is gedamage. By [naam van hospitaal] moes ek dokter gaan vra het. Julle het nog nooit vir my gesê wat is gedamage nie. Hy sê toe: Jammer om vir jou te sê maar altwee kante van sy brein is beskadig so jy moet nie daai hope vir hom hê nie." (Sumaya, pg. 11, L 303)

In some instances, the mothers did not necessarily feel disempowered by the manner in which information was provided but rather, their difficulty in dealing with the information was disempowering.

> "I think for me, every time I left the paediatrician I left there, it wasn't his fault, he obviously had to give us the facts, but I felt like he beat me over the head every time. I felt like he picked up a club and let's give her another klap [smack]. (Stephanie, from Agnes's interview, pg. 5, L 128)

> "Because we were told that her brain was completely destroyed. They [doctors] basically just said that she would never do anything, she would never be anything. That was a very dark moment for me." (Agnes, pg. 3, L 53)

The mothers also spoke about the fact that they felt that professionals were insensitive to a mother's need for privacy and that sensitive and personal information was provided in public places in front of strangers.

> [48]"Toe sê dokter vir my laat nature sy course vat, in die saal, voor almal. Ek het gehuil want ek het gedink gaan die kind dan nou nie lewe nie? Ek gee nie om hoe hy gaan wees nie ek wil net hê hy moet lewe." (Sumaya, pg. 10, L 285)

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[47] I only learned recently that both sides of his brain is damaged. I thought to myself: but you should have told me that his entire brain is damaged before. At [name of hospital] I had to ask the doctor. They never told me what was damaged. Then the doctor said to me: Sorry to tell you but both sides of his brain is damaged so you must not have hope for him.

[48] Then the doctor told me to let nature take its course, in the ward, in front of everybody. I cried because I thought my child would not live, but I wanted him to live I did not care how he would be only that he lived.

The focus during parent-professional interactions, according to the mothers in this study, was mostly on the negative implications of the medical diagnosis during which little hope of improvement was provided and in fact such hope was actively discouraged.

> "The way she explain! But they don't tell you in the right time, they do it you know while you are sitting there and you are hoping for a recovery for your child. They tell you something and they want you to, you know just to give up." (Margaret, pg. 1, L 8)

> "I think she [Physiotherapist] obviously sensed the hope in me and thought, well I'll sort out this hope. She used to say to me, somehow every day: Do you realize how seriously disabled Rose is? And I'd get in the car and I'd just cry. In a way she helped me, but I mean it was brutal. I'll just knock some sense into her. She was that forthright type of person, so here's hope in her, I mean she is deluded so let's just knock delusion out of her." (Stephanie from Agnes's story, pg. 3, L 77)

Margaret and Stephanie's need to hear something positive ("hoping for a recovery for your child") during interactions with professionals or for a health care professional to show interest in changes that may have occurred in a child, was echoed by other mothers.

> [49]"Ek sê toe vir hulle [verpleegsters]: Maar die dokter het nie eers my kind ondersoek nie, hy het nie eens gevra wat is nuut met die kind nie. Hy het nog nooit eers vir my gesê, miskien sy been is 'n bietjie beter nie, hy het nie eers na hom gekyk nie." (Sumaya, pg. 5, L 143)

A lack of interest exhibited by health care professionals also emerged in Margaret and Agnes's stories.

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[49] I said to them [nurses]: But the doctor has not even examined my child, he has not even asked what is new with my child. He has never even said that maybe his leg is a bit better; he did not even look at my son.

> "I mean it is a life. Don't think you are going to waste your time, and it is not going to help. Now that attitude! It is really sad." (Margaret. pg. 15, L 422)

Agnes's story revealed how interactions with health care professionals left her feeling that there was little interest in the child and that doctors were merely doing a job. Her words illustrated a need, reflected in the other mothers' stories, for health care professionals to demonstrate true understanding and empathy.

> "No because they are just working all the time. That is not love. A money game not a heart game." (Agnes, pg. 5, L 119)

The mothers perceived health care professionals to lack interest in their children. Furthermore, what emerged from their stories was that they also perceived the professionals to lack interest in them as mothers and their needs. Margaret and Rehana spoke of their frustrations with health care professionals who did not appear to want to speak to them nor to want to understand what it was like for someone in their situation.

> "Because you know you [reference to doctors] don't speak to me, you don't know what is my situation with a child like that." (Margaret, pg. 1, L 22)

> "Maybe it is something that the nursing staff or doctor they feel that is not their department, it is somebody else's department. There is not that department [laughs]. And they are just kind of saying, they will just say that you must go to a psychologist." (Rehana, pg. 9, L 262)

The above quotes illustrated a desire that the mothers have for health care professionals to focus on both the physical needs of the child as well as on the emotional well-being of the mother. By not exploring the mothers' needs, health care professionals at times made assumptions that were not accurate and served to further alienate the mother from the professional. As the preconceptions were often erroneous they created a barrier to the establishment of an empowering doctor-patient relationship.

> "The one doctor, an old lady doctor, she told me once why don't you put him in a home. So I told her: why should I put him in a home. She said: It will be better for me. So I said: Why must I do it. I mean if I can look after him still then I must look after him. But she wasn't happy with my answer." (Margaret, pg. 4, L 96)

> "And she [doctor] said, but you must learn to accept. So I said what must I accept? Like they say you must prepare yourself for when he dies. So I say: But I can die before him why must I prepare myself? So she made an appointment with the social worker to speak to me because it looks like I don't accept." (Margaret, pg, 12, L 354)

Not only did the mothers experience a lack of sensitivity in the manner and place where information was shared, as well as a lack of interest in understanding their needs, they also felt excluded from discussions and decisions made about their respective children. Some of the mothers recalled instances in the hospital where they overheard health care professionals discussing their child without including them.

> [50]"Hulle [mediese personeel] het my nie deel gemaak van besluite nie. Ek sal maar net hoor dis so of so terwyl ek daar [in die hospitaal] sit." (Sumaya, pg. 8, L 232)

> "It's like she [doctor] said: I am in charge here, and sorry you are useless." (Agnes, pg. 8, L 225)

Their words highlight a power difference between professionals and mothers, which was strongly experienced. A shared theme that emerged from the mothers' stories was the frustration they experienced at having to ask professionals for information rather than being included in discussions.

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[50] They [health care professionals] did not include me in decision making. I would sit in the ward and overhear them talking.

> [51]"Nou dink ek by myself, as ek nou nie gevra het nie, dan wat sou hulle vir my gesê het. En hoekom moet ek vra? Julle is die dokters, julle is die therapists. En daar is ma's wat nie baie praat of vrae vra nie, dan word hulle huis toe gestuur met vrae wat nie beantwoord is nie, hulle sukkel by die huis." (Sumaya, pg. 12, L 252)

For Kathy, not being included when her son's swallowing was evaluated made it difficult for her to accept that oral intake was unsafe. She felt frustrated at not being included and reported that she felt that the evaluation was deliberately done behind her back. The result was that she disputed the findings and upon her son's discharge from the hospital she started trying to feed him orally.

Not being included in decision-making during hospitalisation also disempowered the mothers who took part in this study. Rita and her family were not kept informed of her son's discharge plans which resulted in difficulty making arrangements for caring for him at home at short notice.

> [52]"Toe Ben huis toe kom toe is hier net een kooi. Daai kot het 'n meisie solank geleen. As hulle vir ons gesê het prepare vir julle Ben kom nou huistoe. Ons het nie geld dat ons kan sê: OK Ben kom môre huis toe, ek kan winkel toe gaan en alles koop nie." (Rita, pg. 7, L 179)

Tanya also spoke about the need for health care professionals to consider a mother's financial capacity before making recommendations.

> "I think one of the things that I would tell professionals is that they need to be sensitive to the financial ability of parents. You want the best for your child and you want to have everything done for your child. They will often give you a list of

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[51] So I thought to myself, what would they have told me had I not asked. And why must I ask? You are the doctors, you are the therapist. And there are mothers who don't ask questions then they are sent home with unanswered questions having to struggle at home.

[52] When Ben came home we only had one bed and had to borrow a cot from another lady. If they could have told us to prepare ourselves that Ben is coming home. We don't have money. We can't just say: OK Ben is coming home tomorrow let us go to the shop and buy everything we need.

> things which they feel should be done but it is just often financially not possible for parents. (Tanya, pg. 10, L 210)

Despite unhappiness with professional interactions most of the mothers tolerated it and even though they wanted to confront the professional decided not to. They often reported feeling powerless to speak up because they lacked knowledge about medical issues and treatment options.

> [53]"Ons betaal hulle salaries en dan behandel hulle ons asof hulle vir ons 'n guns doen. Maar ons kla nie en het niks gesê nie." (Kathy, pg. 4, L 91)

> "I went in that room with her and I thought, I'm alone with her [doctor] now why don't I do something? But I'm thinking of my child. I can't say anything to this doctor because I need her help." (Margaret, pg. 1, L 13)

> [54]"En toe laat sy [verpleegster] my voel ek lieg, en sy het mos haar degrees en whatever sy gedoen het en ek moet net stil bly, ek is net die ma." (Sumaya, pg. 14, L 416)

The consequence of the breakdown in communication between professionals and some mothers in this study was that a degree of distrust developed. Anger and distrust towards health care professionals were feelings expressed by five of the seven mothers. These feelings resulted in the mothers adopting a stance of vigilance during periods of hospitalisation as they felt that they needed to check up on the health care providers.

> "So whenever he is admitted I sit there. I don't worry about the work I sit there, I watch them and I ask them what are they giving him." (Margaret, pg. 10, L 282)

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[53] We pay their salaries and then they treat us as if they are doing us a favour. But we don't complain and said nothing.

[54] And then she [nurse] made me feel as if I was lying. She is the one with the degrees and I had to be quiet, I am just the mother.

> [55]"Dan is daar tye wat ek daar [by die hospitaal] gekom het dan was hy sopnat in die kooi en hy het so 'n rash op sy vel gekry. Hulle was nurses, hoe kan hulle so iets laat gebeur? Dan het ek ontsteld geraak want hulle was nalatig met hom dan wil ek hê hy moes huis toe kom. En dan partykeer het hulle nog nie sy feeding gegee nie dan het een vergeet of een is nog op training of het dalk sy feeding gegee maar het nie vir my in kennis gestel nie dan gee ek ook 'n feeding dan is dit dat hy twee keer nou gekry het en dit is te veel." (Sumaya, pg. 2, L 35)

> [56]"Hulle [verpleegsters] stry vir jou in die gesig want jy is die een wat kom na hulle so jy moet maar net geduldig wees. Daar is baie tye wat die ma's voel hulle belieg vir hulle dan dink ek: Maar vir wie moet ons dan vertrou by die hospitaal? Dan cause dit so wrywing dat hulle jou kind afskeep." (Sumaya, pg. 14, L 112)

Negative experiences of health care professional interactions also created distrust of health care professionals in Agnes and resulted in a decision to avoid further interactions.

> "In the end I said: OK we don't need any of these people in our lives, we don't need the negatives, let's get on with it ourselves, which is what we did." (Agnes, pg. 5, L 129)

> "I just feel like it is just all of these professionals with their point of view and I don't actually feel like anybody else's point of view about Rose quite honestly. I found what I do is I just don't go near any of them." (Stephanie, from Agnes's story, pg. 6, L 141)

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[55] And then there were times when I arrived [at the hospital] to find him soaking wet in the cot and he got a skin rash because of it. They were nurses, how could they let such a thing happen? I became upset because they were negligent and I wanted to take him home. And sometimes when I arrived there they had not yet given him his feeds because somebody forgot or was still training or maybe they gave the feeds but would then forget to tell me resulting in me feeding him again and giving him too much.

[56] They [nurses] will argue with you because you are the one coming to them for help so you just have to be patient. There were many times when the mothers felt that the nurses lied to them, then I use to think: Who are we suppose to trust at the hospital? Then it causes so much friction that they end up neglecting your child.

The same mothers who recounted times during the early months of their child's illness when they did not take action or speak up when they were unhappy with health care professionals, also spoke of times when they challenged the manner in which information was provided and treatment decisions made. Such recollections were more prominent in the mothers who had been providing home based care for a longer period of time and illustrated a need to protect themselves and their child from disempowering and negative interactions with health care professionals.

> "And the one doctor said: Is he retarded? So I said: Sorry doctor, how can you say something like that? So he said: Is he always like that? So I said: No, he is not always like that. He is sick." (Margaret, pg. 10, L 269)

Discussion of sub-theme: Disempowering professional interactions

Disempowering professional interactions occurred, which reduced the mothers' feelings of competence and created a barrier to the establishment of an empowering doctor-patient relationship. Aspects of professional interactions that reduced the mothers' capacity to cope included professionals' insensitivity in the manner and place in which information was shared; when no hope of improvement was provided; when inaccurate assumptions about the mothers' needs were made; when they failed to demonstrate a true interest in the child or the mother; and excluded mothers from decision making, discharge planning and discussions. Negative interactions left the mothers feeling that health care professionals were only interested in the medical needs of the child and not in the emotional needs of the family. The disempowering experiences recalled by the mothers in this study predominantly centred on the manner in which the health care professional interacted with them as mothers, which was perceived as brusque, disinterested and not encouraging of a partnership.

During analysis of the interviews the words of Dr. Frances Peabody came to mind and the realisation that the mothers' predominant need during interactions with health care professionals was to experience "care". Dr. Frances Peabody, following personal experiences as a patient with an incurable illness, presented a series of lectures to medical students at Harvard Medical School exploring what it really means to be a physician. It was in one of these lectures that he made the now famous statement that "the secret of the care of the patient is in caring for the patient" (Peabody, 1926).

Dr Peabody's words are in line with the underlying premise of family-centred care, which highlights the importance of gaining an understanding of the needs of families and to provide more than health care but also emotional support (American Academy of Pediatrics Policy Statement, 2003). The success of the American Academy of Pediatrics model of health care provision is therefore largely dependent on the professional (Irlam & Bruce, 2002). Key characteristics of family-centred care as discussed in the literature review, include the provision of information and the sharing of power in such a manner that would empower families (Connell & Bradley, 2000). Empowerment within the health care context has been described as the human side of care which fosters mutual respect and trust between a health care professional and the patient (American Academy of Pediatrics Policy Statement, 2003). What emerged from the current study was that the mothers did not experience their interactions with health care professionals as empowering. These experiences were in line with findings that suggest that, despite policies such as the Patients' Rights Charter and conducting patient satisfaction surveys, there have been little improvement in health care professional interactions with patients in South Africa and that service delivery is not meeting the goals outlined in family-centred care (Schneider et al., 2007).

Two broad contexts emerged within which the mothers felt disempowered, namely in skill acquisition and in emotional capacity to meet the demands of providing home-based care. The mothers struggled to develop confidence in performing feeding related skills which they attributed to the limited time afforded to them by health care professionals during demonstration of these skills. The manner in which such skills were demonstrated was characterised as brusque and rushed thereby discouraging the mothers from raising questions or discussing their concerns and emotional reactions to the new skills to be performed. Modiba, Gilson and Schneider (2001) found that public sector health workers were frequently described as unsympathetic which was supported in this study. This sub-theme illuminated the absence of a parent-professional partnership and very little evidence that such a partnership was encouraged or enabled by the various health care professionals involved in the children's care. In this regard the study is in line with international and local research that claims, that the reality of public sector health care is that a partnership was seldom achieved despite the adoption of family-centred care principles (Judson, 2004).

Though it is not within the scope of the current study to explore reasons why an empowering relationship was not created with the mothers, a number of possible reasons for the difficulty in establishing a partnership emerged after analysing the mothers' stories. McIntosh and Runciman (2007) found that the creation of a parent-professional partnership is knowledge, skill and resource intensive on the part of the health care professional, as parents' trust has to be gained and information and skills tactfully imparted. One cannot ignore recent studies evaluating the South African public health care system. Exhaustion, stress and low morale due to the heavy workload experienced by nurses has been linked to difficulty in providing patient centred care in South Africa (Von Holdt & Murphy, 2007). A chief professional nurse working in a public hospital in South Africa stated that: "We always have to rush: we wash, we medicate, we move on. You miss some things. You cannot listen to the patient." (Von Hold & Murphy, 2007, p. 330). Staff shortages and low morale may therefore be one reason why interactions with health care providers were not empowering. What emerged in the current study was that the health care professionals appeared to face restrictions in the amount of time they had available, however they also appeared to lack the skills to engender trust. Another possible reason why a partnership was difficult to establish might have been because of incongruence between perceptions of needs. As the mothers often adopted an outward appearance of strength and seldom requested further information and support, it could have been possible that health care professionals were not aware of the extent to which they required emotional support. This finding would be in line with Scott's (1998) study of paediatric nurses and the parents of hospitalised children in which it was found that a mismatch between perceived needs occurred. In his study parents listed the need to see that health care professionals cared about their child as their primary need whereas nurses held the perception that a parent's primary need would be to receive information about the child's medical treatment.

Contrary to the establishment of an empowering relationship, the mothers experienced many negative interactions with health care professionals which resulted in feelings of distrust. For one mother disempowering interactions resulted in her choosing to avoid further interactions with health care professionals. The development of parental trust has been found to be positively related to the quality of care provided, honest and anticipatory information provision (Heuer, 1993), displaying dignity in treatment of a child (Meyer et al., 1998), importance of the parental role in the child's care being recognised (Leahey & Harper-Jaques, 1996), and participation in caregiving tasks such as feeding and bathing being encouraged (Thompson et al., 2003). When evaluating the current study's findings in light of the above mentioned requirements for the establishment of parent-professional trust, it is not surprising that the mothers felt disempowered by and distrustful of the health care professionals involved in their respective children's care. The quality of care provided within the public health care sector was questioned by the mothers in the current study; information provision was not empowering as the mothers acknowledged a lack of sufficient information about medical conditions and caregiving tasks; the mothers could furthermore not identify occasions during which health care professionals valued their caregiving expertise nor when they actively empowered them to participate in caregiving tasks and decision making.

Six of the seven mothers in this study never progressed to the desired stage of decision making that is characterised by collaboration, as described by Dixon (1996). Decision making about their child's care was perceived to be dominated by the professional. As Rita and Sumaya had only been caring for a child requiring adapted feeding strategies for six months at the time of the interviews it is possible that the non-participatory nature of their role in decision making was related to their lack of knowledge about care options and medical conditions. Mothers such as Margaret, Agnes and Kathy who had been providing home-based care for their children for a longer period of time demonstrated a much more challenging approach in relation to decision making through questioning and at times refusal to accept decisions made by medical professionals. Tanya was the only mother who perceived her interactions with her son's health care provider as collaborative in nature in that information was openly shared and her choices valued and supported. In her interview, she acknowledged awareness of difficulties experienced by other mothers that she knew, and attributed the collaborative nature of her relationship with a doctor to the fact that she had been able to see the same doctor when visiting the hospital and to personality characteristics of the doctor. Decision making between parents and professionals has been found to develop over time (Dixon, 1996) and follow a progression of stages. Initially decision making is dominated by the professional largely due to a lack of knowledge and expertise on the part of the parent. With time decision making takes on a challenging nature as parents question decisions make by the professional. The final stage of decision making is defined as collaboration in which the parent and health care professional make decisions together with mutual trust.

Disempowering public health care system

All of the children presented with complicated medical and feeding needs with the reasons for hospitalisation varying from seizures, placement or reinsertion of a gastrostomy tube and aspiration pneumonia. The length of hospitalisation ranged from a couple of days to six months. Frequent trips to hospitals were a reality for the mothers who took part in this study after their respective children was diagnosed with a chronic feeding difficulty.

> "He has been in and out of hospital, I would say 21 times since he was born and he is 3 years old." (Tanya, pg. 4, L 75).

This section will describe what it meant for the mothers to access public health care services and how certain systemic barriers resulted in disempowering experiences.

Recollections of negative experiences during a child's hospitalisation and when accessing out-patient public health care services, featured prominently in the mothers' stories. There were a number of accounts of witnessing distressing events such as a child passing away or a nurse struggling to insert a nasogastric tube. The wards did not allow for privacy due to an open-plan layout and the curtains were not always drawn. Margaret's words below indicate how she experienced the public health care system as uncaring and how a child is vulnerable in such a system due to a lack of compassion by health care professionals.

> "I got so heart sore about a girlie there. Her mother wasn't there at the time when she died. Not even a nurse went there to hold her hand, you know just leave her so, as if she is nothing in this world. It is sad, very sad." (Margaret, pg. 10, L 283).

> [57]"Daar was een tyd wat 'n nurse die pypie in die neus probeer insit het maar toe kan sy nie. Toe begin hy [her son] blooi. Ek gaan praat toe met die sister en sê hoe kan sy daai nurse wat nog in training is dit laat doen? Ek sê toe ek gaan vir die dokter vra wat gaan aan, toe sê sy vir my nee, dis oraait ek hoef nie vir die dokter te sê nie." (Sumaya, pg. 8, L 221)

The above quotation from Sumaya's story also addresses issues around the quality of care provided and ethical issues related to training nurses practicing on patients without supervision. The mothers in the current study accessed health care that was provided at a number of different hospitals, two of these hospitals are classified as training hospitals where medical and allied health care students, such as Physiotherapy and Speech-Language Pathology students obtain clinical experience.

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[57] There was a time when a nurse tried to insert an nasogastric tube but she couldn't get it in. He [her son] started bleeding. I went to speak to the sister and asked her how she can let a nurse who is still training insert the tube. I told her that I was going to ask the doctor what is going on but she said no it is okay I don't have to tell the doctor.

> [58]"Ek was baie ontsteld toe ek Zane [haar seun] na die hospitaal moes vat. Ek dog hy gaan vir 'n check-up met die dokter, maar toe was daar 'n student daar gewees. Ek was daar by die dokter, maar die dokter vra meestal vir die student goed. Hy het nie vir Zane ondersoek nie, hy het net in die pram gelê, en ek dink maar die dokter maak dan nou niks nie hy praat net met die student. Alles wat ek vir hom vra dan vra hy vir die student. Toe stuur hulle my stoma clinic toe en ek dink maar die stoma clinic is vir die PEG en ek kom dan nou vir dokter sien. Ek wou gehuil het want ek het 'n lift gesoek soontoe en dit het vir my R40 gekos. Toe vra ek die sister of ek weer terug na die dokter se kamer toe moet gaan, maar toe vra hulle: Hoekom, jy kom dan nou van die dokter af? Ek sê toe: Maar die dokter het nie eers my kind ondersoek nie, hy het nie eers gevra wat is nuut met die kind nie. Want ek vra toe vir die dokter wat beteken dit of dat en toe kyk hy my net so aan en vra toe vrae vir die student." (Sumaya, pg. 5, L 130)

Sumaya was the only mother who recounted an instance in which a medical student was present during a consultation. Her words show that the she was excluded from the discussion and her child not examined as the doctor focused on training the student.

The mothers also expressed frustration at the [59]public health care policy that different services are offered at different places and that they have to access many different hospitals to meet the care requirements of their children.

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[58] I was very upset when I took my son to the hospital. I thought he was going for a check-up with the doctor but when I got there there was a student with him. I was there with the doctor but he mostly asked the student questions. The doctor did not even examine Zane, he was just lying in his pram, and I thought but is the doctor not going to do anything he is just talking with the student. Everything I asked him he would then ask the student. Then they sent me to the stoma clinic and I thought but the stoma clinic is for the PEG and I came to see the doctor. I wanted to cry because I had to find a lift and it cost me R40. So I asked the sister if I should go back to the doctor's room but she asked me: Why? You just came from there. But I told her that the doctor did not even examine my child or ask what was new with him. When I asked the doctor what something meant he just looked at me and then asked the student questions.

[59] Policy content for decentralisation is informed by a number of documents including The White Paper on Transformation of Health (1997) and the National Health Act (2003).

> [60]“Ek verstaan nie hoekom ons nie alles op een plek kan doen nie. Eers was hy by [hospitaal se naam] toe na [hospitaal se naam]. Maar nou moet ons [hospitaal se naam] vir Physio en na die dag hospitaal vir Ensure (Kathy, pg. 3, L 75)

When a medical emergency arose the mothers also felt frustrated at the [61]policy which required from them to first go to their nearest primary level day hospital that would then in turn refer them to the tertiary level hospital. For the mothers who relied on public transportation, accessing the different services that they needed to therefore became unaffordable.

> “You must take him to the day hospital first. They check the child out and give you a letter and then they send you to [name of hospital]. But children like this, why must you first take him to the day hospital?” (Margaret, pg. 9, L 256)

> [62]“Dingetjies het partykeer so gegaan dan het ek nie taxi fare nie, dan wil ons altwee [mother and grandmother] by die hospitaal wees. Dan maak ons dit so, ek gaan vandag, môre gaan jy. Ek het net gewerk vir taxi.” (Rita, pg. 5, L 119)

What emerged from the mothers’ stories was that they experienced frustration when accessing both primary and tertiary level hospitals. Sumaya recalled an incident where her nearest day hospital did not have the anti-seizure medication that her son needed to take on a daily basis. She had to return to the hospital three times that week before they were able to fill the prescription.

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[60] I don’t understand why we cannot do everything at one place. First he was at [name of paediatric tertiary level hospital] then he went to [name of tertiary level hospital] now we have to go to [name of secondary level hospital] for physiotherapy and to [name of primary level hospital] for his Ensure.

[61] Health Sector Strategic Plan 1999 – 2004

[62] Things worked out sometimes that I had no money for taxi fare when we both [mother and grandmother] wanted to go to the hospital. So we worked it out that I would go the one day and my mother the next. I only worked for taxi fare.

> [63]"Daar is tye wat hulle [dag hospitaal] nie die pille het nie. My nerves was klaar en toe voel ek vir my ek kan mense doodmaak. En toe sê ek vir hulle: Maar julle weet dan hy is so 'n kind en makeer die pille. Toe bel ek [hospitaal se naam], maar hulle sê vir my ek moet dit by die dag hospitaal kry. Toe is dit 'n hele week wat hy sonder daai pille moes gaan." (Sumaya, pg. 9, L 255).

The ineffective management of the day hospital in respect of supply renewal as well as the rigidity in the health care system that did not make provision for emergencies or the realities of medicine shortages, generated anxiety in Sumaya. Her story showed that the public health care system disempowered her by making it impossible for her to meet her child's care needs which in turn reduced her emotional capacity to cope. Kathy also spoke about a lack of resources available at a primary level hospital. In her case the hospital did not have Ensure, which forced her to attempt to feed her son orally.

> [64]"...en hulle [hospitaal se naam] het nie altyd melk [Ensure] nie, dit is dalk ook hoekom ons maar aanhou probeer met die voer." (Kathy, pg. 3, L 78)

Margaret recounted frustrations in accessing public health care services at a tertiary level hospital. Her words indicate that tertiary level hospitals also faced limitations on availability of resources. In this particular case the hospital instituted a policy that determined who should be granted access to limited resources.

> "[Shows me a letter she wrote to a local newspaper about a paediatric hospital that refused to admit her son to the intensive care unit apparently because he presented with severe cerebral palsy]. But they didn't publish it. In 2002 I had the same problem with a doctor telling me my son would not be admitted. But I told him that it is not for him to say no, that if I must I'll push this child in there. But they

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[63] There are times that the day hospital does not have the tablets. My nerves were finished and I felt as if I could kill someone. I said to them: But you know he is this type of child who needs these tablets. I then phoned the tertiary hospital but they said that I have to get the tablets at the day hospital. So he was without those tablets for a whole week.

[64] And the primary level hospital do not always have Ensure which is possibly why we kept on trying to feed him orally.

> talk of staff shortages and beds; there is not enough beds and all that. So I said: Why don't you see to ICU first because that and theatre is the most important place. It is like they don't....They had a child there before, like Shane, on life support and it was like they are wasting oxygen on him. The hospital is not the same anymore, not the same." (Margaret, pg. 13, L 368)

What emerged from the mothers' stories was that they felt disempowered when accessing public health care services. It was challenging for the mothers to move from being a mother to simply watching others care for their child. They spoke of feeling powerless as few or no opportunities were provided through which they could become empowered. The mothers could not recall any opportunities created within the various hospitals that would have increased their information and skill acquisition, such as what might have been afforded through workshops, information posters or even the creation of a space within which mothers could share experiences and information.

> [65]"Die tyd wat ek daar was [naam van die hospitaal] was 'n lang tyd en dan sit die ma's maar net so en kyk vir mekaar en almal doen hulle eie ding met hul kind." (Sumaya, pg. 15, L 435)

> [66]"Ons het maar net gaan sit want ons kon mos maar eintlik niks doen nie. Ons het maar net gesit en bid. Hulle [verpleegsters] het maar die werkies gedoen." (Rita, pg. 4, L 104)

Providing information about available services at the different levels of care and how these might benefit a child, was not used as a tool to empower the mothers. For example it emerged that most of the mothers were not aware that Speech-Language Pathologists could be consulted at various hospitals, nor did they understand the type of services offered by a Speech-Language Pathologist.

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[65] I was at the hospital for a long time and then the mothers would just sit, watching each other, everybody doing their own thing with their child.

[66] We just went and sat because there was not really anything that we could do. We just sat and prayed while they [nurses] did all the little tasks.

> "I thought maybe they [Speech-Language Pathologists] are going to maybe help him to talk, make sounds or something like that. But then afterwards I saw it was just about feeding." (Margaret, pg. 11, L 312)

Few referrals were made, and the mothers often did not know how to go about to request a referral even when they thought it would be of value to see a Speech-Language Pathologist.

> "And then once, it was maybe two years ago the dietician said no she is going to make an appointment with the Speech Therapist. Because I said: Can I give him some yoghurt because somebody said I can give him some yoghurt? So she said: No you can't give him yoghurt and water. But she didn't make the appointment with the Speech Therapist, she left it just there." (Margaret, pg. 11, L 314)

> [67]"Ek het eintlik uitgesien om die Speech Therapist te sien. Hy begin so sounds to maak, so vir my lyk dit hy verstaan want iets wat ek praat met hom of doen met hom dan is daar 'n teken hy hoor vir my. Hy respond op sekere dinge. Maar daar was nie 'n Speech Therapist nie." (Sumaya, pg. 9, L 266)

The mothers' stories highlighted that they felt unsupported by the hospital and that there was a lack of continuation of care or follow up after discharge.

> [68]"Sien kom klaar. Ons voel dat ons is alleen gelaat met die hele situasie. Dan lyk dit ons is maar self die dokter en die nurse. Jy voel jy is alleen gelaat. Die moment Ben uitkom by daai hospitaal dan gee niemand meer om nie." (Rita, pg. 8, L 200)

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[67] I was looking forward to seeing a Speech Therapist. He is starting to make sounds so it looks as if he understands because he shows signs while I am talking to him or doing something with him. He responds to certain things. But there was not a Speech Therapist.

[68] Left to your own devices. We feel that we were abandoned with the whole situation. Then it seems as if we have to be the doctor and the nurse. You feel abandoned. The moment Ben left the hospital nobody cared anymore.

> "You just go for a check-up and that's it, you get no support from the hospital. Like a group you know, mothers come in and you can have a discussion, you know nothing like that. Just to talk about, maybe I got the same experience as you like looking after the child or family responsibility or whatever. But there is nothing like that." (Margaret, pg. 1, L 26)

Again the need for the provision of services that would address the emotional needs of mothers who are expected to provide long term home-based care emerged in Margaret's mention that no support is offered by the hospital.

Discussion of sub-theme: Disempowering public health care system

What emerged from the stories was that there were systemic barriers present in the public health care system. When reviewing the situations in which the mothers felt disempowered in their ability to meet their child's needs it emerged that the barriers were primarily related to access and resources. This finding is in line with the recent evaluation conducted by Schneider et al. (2007) who found that there are many problems present in the South African public health care system related to access and resources.

Fragmentation of services between different levels of care forced the mothers to spend considerable amounts of time and financial resources to meet their respective children's care needs. The public health care system was perceived as rigid and policies as insensitive to the needs of parents who have children with chronic medical needs requiring frequent access to health care. The mothers questioned policies that prevented them from accessing services at one central location, as many relied on public transportation, which was costly and often uncomfortable for the children. Philpott (2006) also identified a lack of adequate transportation as a barrier to service delivery in South Africa. A further barrier identified by the mothers in this study related to lack of resources, for example, a shortage of chronic medication, enteral feeds and specialised care services.

Parental concerns identified by Balling and McCubbin (2001) that were shared by the mothers in the current study was a concern over the quality of care received in the hospital. Similar to Balling and McCubbin (2001), the mothers were concerned about the lack of competency demonstrated by nurses "in-training", who were entrusted with performing tasks independently. Systemic barriers within the hospitals accessed by the mothers resulted in anxiety and frustration. Margaret's powerful recollection of witnessing a little girl passing away without any demonstration of compassion on the part of health care professionals might have created a perception that children are vulnerable within a cold and uncaring system which in turn may have contributed to her need to be present and vigilant during her son's hospitalisation.

The mothers' experiences within this study of paediatric hospital wards were different from what was found in a study by Garro, Thurman, Kerwin and Ducette (2005). They concluded that hospital-based intervention services can reduce stress levels in parents which they attributed to factors such as parental participation in caregiving tasks and the provision of information. The mothers in the current study experienced a sense of disempowerment with relation to the health care system in which they became passive observers in the care of their children since they were not afforded opportunities to participate in care-giving activities. Few or no opportunities to gain information or skills were created at the hospitals which may account for the experiences that they had during their respective children's hospitalisation. The mothers were generally left with unanswered questions regarding their child's feeding difficulty and health care needs.

Unanswered questions and unmet needs

> [69]"Vir my is daar klomp vrae. Ek het nog nie al my vrae beantwoord, hulle was nooit beantwoord nie. Soos daai PEG, sal ek hom eendag kan voer?" (Sumaya, pg. 12, L 343)

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[69] For me there are many questions that have not been answered. Like the PEG, wil I ever be able to feed him?

> [70]"Jy voel frustrated, jy weet nie wat om te doen nie want hulle is die mense met die antwoorde." (Sumaya, pg. 17, L 500)

Dysphagia was a concept that the mothers were unfamiliar with prior to a diagnosis of a chronic feeding difficulty being made. The stories show that some mothers never understood what was meant by dysphagia nor did they understand methods used to evaluate if oral intake was safe.

> [71]"Hulle het gesê daar is iets verkeerd hier binne in. Hy kry seer as hy sluk is wat hulle vir my gesê het. Dit is rou binne in [wys na haar keel]. Toe het ek nou afgelei dis rou want hy het hier gelê [wys na die deur] die dag met die skietery het hy hier kom val, en hy het aanhoudend mamma mamma gesê en ek het gedink dis seker maar omdat hy aanhoudend mamma gesê het dat sy keel seer was. Maar hulle het nie eintlik vir ons explain hoekom hy nie kan eet nie." (Rita, pg. 2, L 34)

> [72]"Hulle het vir my gesê dat dis nou 'n experiment. En toe doen hulle 'n toets met die water om in te spuit in sy mond maar toe verstaan ek nogsteeds nie." (Sumaya, pg. 2, L 60)

Even when a gastrostomy tube was placed, months after the diagnosis of dysphagia, Sumaya still lacked the information to understand the rationale for enteral feeding.

> [73]"Wat is die rede die PEG daar moet wees? Hulle het nog nie vir my verduidelik nie. Vir my was gesê die PEG gaan ingesit word." (Sumaya, pg. 11, L 314)

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[70] You feel frustrated; you don't know what to do because they are the people with the answers.

[71] They said there is something wrong inside. They said it is sore when he swallows because it is raw inside [points to throat]. So I deduced that it is raw because he was lying here [points to doorway] on the day of the shooting calling out mother over and over. So I thought it is because he said mommy repeatedly that his throat got sore. But they never really explained why he is unable to eat.

[72] They told me it is an experiment. Then they did a test with some water that they squirted into his mouth but I still did not understand.

[73] What is the reason for the PEG. They have not explained it to me yet. They only told me that a PEG was going to be inserted.

Sumaya, Rita and Margaret were left with unmet needs relating to the care of gastrostomy tubes. Even though they were shown how to replace the tube in the hospital little opportunity was given to practice doing it other than on a doll resulting in anxiety and a questioning of competence to be able to provide the care needed at home.

> [74]"Kyk soos toe die ding gister uitval toe panic ons almal in die huis in. Toe weet ons nou nie. Gister was ons heel confused. Want toe moet ek die gat toe druk en Rita moet weer op 'n pop kyk. Ons was heel hysterical gister in die huis." (Rita's mother, pg. 9, L 63)

At the time of her interview, Margaret had been giving exclusive enteral nutrition for many years, but even after years of handling nasogastric tubes initially, and then gastrostomy tubes there was still a lack of confidence and even fear surrounding the care of the tube, which was echoed by other mothers.

> "They showed me how to take it out and clean it. But I'm scared of this one, I don't know." (Margaret, pg. 6, L 159)

Discussion of sub-theme: Unanswered questions and unmet needs

Mothers in the current study felt they lacked adequate knowledge and reported that their information needs are often not met. The need for information about a child's condition and treatment options was identified as a universal theme in studies aiming to explore the needs of parents caring for a child with a chronic medical condition (Butler Simon & Smith, 1992; Cohen, 1993; Jerrett & Costello, 1996; Scharer & Dixon, 1989).

Unanswered questions and unmet needs could often be linked to disempowerment as the mothers initially seldom asked for clarification of medical management and conditions.

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[74] When that thing [PEG] fell out yesterday we all panicked in this house. We didn't know what to do. We were completely confused yesterday. Because I had to keep the hole closed and Rita had to look on a doll again. We were completely hysterical in this house.

Dysphagia was one diagnosis which was difficult for the mothers to make sense of as they reported lacking a true understanding of the swallowing mechanism, of their children's swallowing difficulty, and of the measures used to evaluate swallowing. Though I cannot make assumptions about whether health care professionals did or did not explain why dysphagia was present or what the implications of it would be, the stories reveal that health care professionals did not verify that the mothers understood and in this regard failed in their information provision. When probed during the interviews about their understanding of swallowing difficulties it emerged that the mothers made assumptions about the nature of swallowing that were not correct. Erroneous assumptions were reflected in Rita's quotation in which she linked dysphagia to her son hurting his throat when calling out for her. Rita's recollection of a health care professional telling her that "something was wrong inside his throat and that it hurts him to swallow", indicated that this concept was not sufficiently explained, or if it was, that no time was taken to verify her understanding of it. A similar finding emerged in Sumaya's words when she recalled that after evaluation of her son's swallowing ability she still did not understand, an understanding which was once again not verified by a health care professional. Neither Rita nor Sumaya reported that they requested further information at that time.

Even when a gastrostomy tube was placed some mothers lacked the information to understand the rationale for enteral feeding or the mechanics of gastrostomy tubes. Sumaya attributed her lack of understanding to health care professionals that did not explain the reasons for the placement of the PEG and her choice of words ([75]"vir my was net gesê die PEG gaan ingesit word") showed that a discussion did not take place.

Spalding and McKeever (1998) reported that all twelve of the mothers who took part in their study quickly mastered the skills required and that they felt confident in their ability to manage enteral feeding. A possible factor which might account for this difference between the mothers in the current study and those who participated in Spalding and McKeever's study was that at the time of the interviews children had been fed enterally

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[75] I was just told that a PEG would be placed.

between 1 ½ and 8 ½ years in the Spalding and McKeever study as opposed to three mothers in the current study giving nutrition enterally for less than one year. A difference in the length of time that a mother was providing enteral nutrition might therefore have played a role, however another possible factor emerged when considering that one mother in the current study quickly mastered competence. Tanya was the only mother out of the five mothers who was giving nutrition exclusively through a gastrostomy tube who reported feeling perfectly at ease and competent in the management of enteral feeding. Tanya attributed her competence in handling the gastrostomy tube to the time that her doctor spent in explaining it to her as well as to the availability of ongoing support should it be needed. It would therefore appear that Tanya was empowered in relation to information provision but also in terms of emotional capacity, which was not reflected in Sumaya, Rita and Margaret's recollections about gastrostomy care.

Summary of Essence 3: Disempowered: from mother to onlooker

Four sub-themes that addressed the concept of feeling disempowered as a mother emerged, namely "expected versus enabled to cope", "disempowering professional interactions", "disempowering public health care services" and "unanswered questions and unmet needs regarding feeding".

Expected versus enabled to cope was a reality as the mothers experienced pressure from family members and health care professionals to cope emotionally with the diagnosis of a feeding difficulty, together with the implications that it had for them in providing ongoing home-based caregiving without being given sufficient support. *Disempowering professional interactions* occurred which reduced the mothers' feelings of competence and created a barrier to the establishment of an empowering doctor-patient relationship. Aspects of professional interactions that reduced the mothers' capacity to cope included professional insensitivity in the manner and place in which information was provided, where no hope of improvement was provided, when inaccurate assumptions about the mothers' needs were made and when mothers were excluded from decision making and discussions. Recollections of *disempowering public health system* experiences featured prominently in the mothers' stories. The mothers experienced a sense of disempowerment with relation to the health care system in which they became passive observers in the care of their respective children, again highlighting a shift away from being a mother to merely being an onlooker. Few or no opportunities to gain information or skills were created at the hospitals. Frustrations were related to decentralisation of services, poorly equipped hospitals, lack of information on available services and limited interactions with allied health professionals. Poorly planned discharge processes and difficulty in obtaining resources and accessing services aimed at supporting home based care of children was also described.

The mothers in this study identified practical and personal needs for which insufficient support was available. From their stories it emerged that family, friends, health care professionals and the public health care system could enable their capacity to cope by offering respite, providing information and training opportunities, creating more opportunities to practice newly acquired skills, offering emotional support through support groups, making rehabilitation services more easily accessible as well as reducing the need to travel between different hospitals as happens with decentralised services. Follow up assistance, particularly home visits by Speech-Language Pathologists and nurses, were identified as a possible means to afford them greater access to services. Where home based assistance was offered (by government employed home-based caregivers) the mothers identified the need for training such caregivers in gastrostomy care and adapted feeding strategies. The unmet needs identified by the mothers will be discussed in greater depth under the theme of "Facilitating the journey" where the mothers provided potential solutions to many of these unmet needs.

Implications

A number of implications to be considered in relation to service provision emerged in this essence. The implications address needs identified by the mothers in relation to emotional support, information regarding diagnoses and feeding options, and access to limited resources.

a. Implications for mothers and family members

   i. An awareness of the prevalence of feelings of disempowerment and expectations to cope with feeding demands would assist mothers to prepare themselves emotionally for the role of home-based caregiver.
   ii. Mothers could be counselled on the need for them to adopt a more pro-active approach in requesting information and emotional support as these do not appear to be easily accessed in a health care system constrained by staff shortages.
   iii. Family members and friends may play an important role in assisting with specialised care needs and health care professionals should ideally explore the possibility of including them during skill demonstration.

b. Implications for health care professionals

   i. Health care professionals need to be aware that empowerment of mothers will require a combination of interventions to meet both practical and emotional needs. Practical needs in relation to adapted feeding strategies should be met by ensuring that sufficient time is spent in skill demonstration, verification of understanding is crucial and follow-up assistance must be provided.
   ii. The extent to which the mothers identified the manner in which a health care professional interacted with them as disempowering has implications for both practicing health care professionals as well as for institutions involved in training health care professionals. The development of an empowering parent-professional relationship will require insight into a mother's experiences thus necessitating the creation of an environment in which mothers are afforded the opportunity to discuss their needs. Health care professionals should guard against assumptions of parental needs. The restriction in resources created by staff shortages may not easily allow health care professionals to meet a mother's emotional needs. However they could play an important role in empowering the mother to access parent-to-parent support groups, to facilitate contact with other mothers possibly through creation of an information base of parents who are willing to be contacted or who would like to become involved in support groups within different areas. Furthermore they could provide them with literature on

the experiences of being a mother of a child with a chronic feeding difficulty in order to increase emotional capacity.

iii. In an attempt to reduce frustration with respect to fragmentation of services and limited referrals between health care professionals it would be beneficial to establish a team of professionals who work closely together during a child's hospitalisation and who would be able to meet the diversity of needs that are often present in children with chronic medical conditions. To aid the process, a meeting should be held during which these professionals are introduced to a mother, their individual roles explained, a case manager indentified whom the mother would be able to contact if need be, and the mothers desired degree of participation in caregiving tasks during the child's hospitalisation explored. As the mothers are required to access services at different hospitals a framework for managing chronic feeding difficulties and additional training where needed would be valuable to ensure uniformity of information provision and skill demonstration between different hospitals. An understanding of how mothers measure quality of care in paediatric hospitals should aid hospital administrators in their approaches to quality improvement.

iv. The strong need identified by the mothers to be afforded hope for a child's future development has implications for health care professionals in that careful consideration of the need to create a balance between providing hope while simultaneously creating an awareness of the reality of a child's medical prognosis is crucial. Communication should be honest and should allow for the expression of hope which should not be interpreted as a denial of reality or inability to accept the child's medical prognosis.

v. The presence of unanswered questions in relation to dysphagia has serious implications as it reduced the mothers' ability to accept the need for enteral nutrition. More time should be spent in describing the nature of swallowing difficulties which should ideally be accompanied by written information, encouragement of questions together with verification of what was understood. Mothers should furthermore be present, where possible, during Speech-Language Pathologists' evaluation of swallow safety which may increase a mother's ability to accept adapted feeding recommendations. Speech-Language Pathologists need to understand that mothers may have had no previous exposure to children with swallowing difficulties, nor to children who are receiving nutrition enterally. Mothers should ideally be allowed an opportunity to practice the newly demonstrated skills before a child is discharged.

vi. An awareness of the emotional reaction to seeing a child with a PEG tube in situ and then having to work on a child following placement of a PEG is crucial in order for Speech-Language Pathologists to prepare mothers emotionally and then to equip them to provide long-term enteral feeding upon discharge from the hospital.

vii. The mothers' difficulty in adapting to the demands of providing home-based care and in finding respite care has implications. Discharge planning after hospitalisation should involve the mother, to enable her to make practical arrangements relating to adapting the home environment and daily schedules to accommodate home-based caregiving. A home visit by a health care professional may assist mothers in identifying equipment needed, home alterations that may have to be made as well as developing schedules for administration of enteral feeds and medication. Health care professionals should ideally become aware of and liaise with support organisations that would be in a position to provide home based care support as well as ongoing emotional support. Information on area specific support groups and respite services would be valuable and reduce the experience of isolation and perceived expectations to cope alone.

viii. Speech-Language Pathologists should be aware of the potential limited assistance provided by respite organisations in relation to adapted feeding needs and may play a crucial role in training informal caregivers in this regard.

c. Future research

i. No information could be found on informal caregiving offered in South African in respect to the number of children with chronic feeding difficulties who are accessing such services, nor on the informal caregivers' training needs and perceptions about adapted feeding strategies, which should be explored in future research.

ii. During the interview with Agnes, Stephanie spoke about a perception she held that the black community may have a greater capacity to meet home-based care needs required by children who have a disability. Potential racial variations may be present and Stephanie's observation served as a reminder for the need to consider how mothers from different racial and cultural backgrounds experience the role of being a mother providing home-based care. The need to gain an understanding of variations between groups in relation to the meaning attached to disability and caregiving was also emphasised by Collins (1994). The bulk of available research that was reviewed in the current study appeared to report on the experiences of white mothers (Jackson & Mannix, 2004; Ranson, 2004; Seagram & Duniluk, 2002; Simon, 1995). The absence of racial variation within available research implies that mothers are universal in their experiences and constructions of the mother identity. Collins (1994) state that the experiences of white mothers have become the basis on which we gauge mothering because of a lack of research of how other groups in society may experience mothering practices and role formation. Future research could broaden understanding of variations found among different groups within South Africa.

CHAPTER SIX

6.1. RESULTS AND DISCUSSION: CATEGORY TWO

This chapter describes and discusses the second of the two categories, namely Reconstruction: "Getting through the brokenness". Four essences that address the concept of reconstruction were identified: 4) Letting go of the dream and valuing the real; 5) Self-empowered: becoming the enabler; 6) Facilitating the journey; and 7) The continuing journey: living in balance. As all seven of the identified essences should be considered in totality the numbering of this chapter follows a continuation of representation of the phenomenon and therefore starts with Essence 4.

RECONSTRUCTION: "GETTING THROUGH THE BROKENNESS"

In analyzing the mothers' stories it became apparent that there was more to their experiences of being the mother of a child with a chronic feeding difficulty than the deconstructive processes outlined in Chapter five. As the mothers shared their stories they spoke of more than sadness and struggle but also of triumph, joys and opportunities for growth which formed part of the essence of their experience. For the mothers who took part in this study, positive change occurred in the presence of a situation which they described as "traumatic", "harsh" and "overwhelmingly sad". "Getting through the brokenness" was a term used by one mother to describe the process of piecing together her life and identity, a process which was ongoing.

ESSENCE 4: LETTING GO OF THE DREAM AND VALUING THE REAL

Traumatic events have the capacity to threaten an individual's view of the self and of the world. A reconstruction of meaning is often needed to enable capacity to cope (Epstein, 1991). Meaning-making was a powerful theme that emerged as the mothers spoke of how they incorporated new and unexpected roles into their identity as mother.

Redefining 'mother'

The specialised care needs of the children required that the mothers perform tasks associated with roles performed by medical professionals, such as working with feeding tubes and suctioning. The mothers also had to perform tasks associated with those of allied health professionals such as Speech-Language Pathologists and Physiotherapists. A theme that emerged was that the mothers had to reconstruct the traditional definition of "mother" as they incorporated new caregiving tasks into their role identity.

> "So yes, you stop being a mother and you stop mothering in the traditional sense, you become a caregiver. You become a nurse." (Tanya, pg. 9, L 185)

The transition towards becoming a caregiver, not starting off as one, motivated a change in the title of this study. The initial inclusion criterion for this study was to recruit caregivers whether they were mothers, fathers, grandparents or non-related carers. Following analysis of the first two interviews a theme emerged that highlighted the presence of a transition towards becoming a caregiver. At that stage it was decided that only mothers would be recruited to enable the researcher to determine if such a transition forms an essence of the experience.

When Tanya first spoke of the transition from defining herself as a mother towards becoming a caregiver, it was portrayed as something less intimate and less nurturing than being a mother. There was initially a reluctance to take up the caregiving role. This was echoed in Sumaya's words, who experienced the new role and the tasks associated with fulfilling the role as a punishment.

> [76]"Ek is soos 'n nurse, vir my het dit gevoel daai is my daaglikse werk wat ek nou doen, nursing. En ek wou eintlik 'n nurse gewees het maar vir my lyk dit dat dit my straf is, hier is jou job nou." (Sumaya, pg. 4, L 93)

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[76] I am like a nurse. It felt as if nursing was my daily job. And I actually wanted to be a nurse but now it feels like I am being punished, here is your job now.

In contrast to Tanya and Sumaya's initial struggle to incorporate new tasks into their daily lives and identity as mothers, Kathy recounted an ease with which this process occurred for her. Kathy and her husband shared daily caregiving tasks. They appeared to take on these new roles with ease, an ease which was unique to them as all the other mothers experienced an initial period of reluctance to assume new roles. During the interview the couple spoke openly of how proud they were of each other in terms of their respective caregiving roles. The integration of new tasks into their lives may have been easier because of the way in which caregiving tasks were shared or possibly because of the manner in which they acknowledged each other's efforts. The following quotation showed how the roles of Physiotherapist and Speech-Language Pathologist were incorporated into their identities as mother and father.

> [77]"My vrou werk elke liewe dag met Johan dan doen hulle sy oefeninge en party aande dan sal ek sit en sy lees oefen." (Kathy's husband, pg. 3, L 55) "Ja ons vat so beurte en help mekaar met alles wat gedoen moet word, maar dis nie so 'n groote aanpassing as wat ons gedink het nie." (Kathy, pg. 3, L 57)

Spousal acknowledgement and sharing of caregiving tasks set Kathy apart from the other mothers. Another difference between the mothers, that emerged in relation to redefining their role identity, was the length of time that they had been providing home-based care. At the time of their interviews, Sumaya and Rita had only been performing the diverse tasks associated with feeding and caring for a child with multiple disabilities for a couple of months.

> [78]"Ek is nie meer dieselfde nie, in 'n split sekonde het ek soos 'n nurse geword. Die lewe het heeltemal gechange. Dit is 'n voltydse werk vir my. In die nag is ek nurse: Haal hy asem, gaan daar niks in sy mond in nie?" (Rita, pg 8, 205)

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[77] [husband] My wife works with Johan every day. She does his exercises and some evenings I will sit and practice reading with him. [wife] Yes, we take turns and help each other with everything that needs to be done, but it wasn't such a big adjustment as what we expected.

[78] I am no longer the same, I became a nurse in a split second. Life changed completely. It is a full time job for me. In the night I am like a nurse: is he breathing, is nothing going into his mouth?

While their stories highlighted a struggle to find role clarity, other mothers who had been performing the various tasks for a longer period of time, spoke of an increased ability to incorporate the new roles. For Margaret the incorporation of the role of nurse was empowering and her words showed a feeling of accomplishment.

> "I became everything. At work they [co-workers] joke and call me a doctor [mom laughs]. I learnt quite a lot. I suction him I put the nebulizer on. I mean there is a lot of things that I learnt. What nurses do I can do." (Margaret, pg. 12, L 332)

> "The Occupational Therapist is telling you what to do there [pointing to her daughter's arms] and the Speech Therapist is telling you what to do there [places hands on her daughter's cheeks] and the Physiotherapist is telling you what to do there [pointing to daughter's legs]. And then you need to eat, and sleep and you need to bath and work and you think, great where are all the hours? But eventually it just becomes the whole." (Rehana, pg. 16, L 471)

Rehana's words illustrate the transition that was seen in most of the mothers with time. The mothers went through initial feelings of struggle to find time for all the new tasks but they spoke of how all these separate tasks and roles were eventually incorporated into who they were as mothers. The process of incorporating the caregiver identity into their identity as mother, illustrated one aspect of positive personal growth that happened for the mothers. The initial struggle to find role clarity was gradually replaced as the mothers reconstructed a new identity based on the reality of their situations. Apart from having to redefine their role, reference was also made to a redefining of ideals held in terms of what a child should be like.

> "I think there are more moments now for me that I see her as the most incredible gift, um and I think the important thing is let the gift be who, what it is instead of what you want it to be." (Stephanie, from Agnes's story, pg. 2, L 36)

Discussion of sub-theme: Redefining 'mother'

A *redefining of 'mother'* occurred as the mothers reconstructed their identity by integrating roles associated with being a mother with the specialised care needs associated with caregivers. The initial reluctance to take up the caregiving role together with a struggle to gain competence in new skills was gradually replaced as the mothers reconstructed a new identity. The ability to incorporate the caregiver identity into their identity as mothers, as well as redefining their beliefs about what a child should be like, illustrated one aspect of positive personal growth that happened for the mothers.

The role conflict that emerged from the stories of mothers who took part in this study was mirrored in Judson's (2004) findings. She too found that a conflict between mothering versus nursing roles emerged for mothers who were providing home-based care. Judson found that two approaches to this conflict could be identified in mothers. Some mothers responded to the conflict by separating the role of mother from that of nurse/caregiver, while other mothers integrated the roles. Mothers who felt the need to disengage from one role in order to perform the other role effectively adopted the approach of separation of roles. The mothers in the current study also demonstrated this approach where they made references to "switching off" or "hardening themselves" during the times when caregiving tasks had to be performed. What emerged from the current study was that the mothers appeared to progress to a stage where the roles of nurturing mother and resolute caregiver became integrated, thereby enabling them to perform the diverse roles. Rehana's words serve as an example of this transition when she made reference to how all of the diverse roles "just becomes part of the whole".

Celebrating the positives

> "She is who she is, this is how we got her. There is nothing to be, ja nothing lost. Everything we get every day is a gain, it is something extra. And she can cough, and she can laugh and she can smile." (Rehana, pg. 16, L 461)

The ability to see positive outcomes following the loss of an ideal child emerged in the current study and formed the next sub-theme in this essence. Though the mothers' stories spoke about a chronic sadness about what was lost, they all recalled times when they celebrated little victories. They were all able to look past 'the brokenness' of the situation and find encouragement in change that happened in their children.

> "I think that is to me is often what one loses, is the magic in the situation because of the tragedy and the hardness and the harshness, and I think that is what I am trying to see again." (Stephanie from Agnes's story, pg. 4, L 84)

Rehana spoke of how the natural progression of developmental milestones is taken for granted by other mothers. She reached a point where she shifted her focus from these expected milestones, to appreciating small changes in her daughter. Her words show how she was able to appreciate changes in her daughter that signified progress or change even though such change may not be considered remarkable by others.

> "...so when I say now that she coughs so nicely and it is so well done that she coughs so nicely, people look at me and ask: She coughs well? But for me it is such a big thing." (Rehana, pg. 7, L 203)

Some positive moments celebrated by the mothers included signs of improvement in oral motor skills ("hy speel so met sy tong" – he plays with his tongue), sound production ("hy begin sounds te maak" – he is starting to make sounds), in the ability to understand ("so vir my lyk dit hy begin verstaan, hy hoor vir my" – it looks as if he is starting to understand me, he hears me), oral feeding ability ("now she is eating her vegetables nicely"), physical improvement ("hy lig sy bene op, hy lig sy hande op" – he lifts his legs and his hands) and in the ability to communicate and interact ("as hy honger is dan sal hy sy hand na sy mond sit" – if he is hungry he will move his hand towards his mouth).

As Rehana managed to shift her focus away from expected developmental milestones other mothers were able to shift away from the initial overwhelming emotional reaction following the loss of oral feeding. The term shift in focus was chosen deliberately because the mothers never reached a point where there was no more sadness left at not being able to feed their children orally. Rather, an intellectual shift towards understanding the benefits of enteral nutrition occurred, which in turn appeared to reduce their experience of loss. Margaret and Tanya, despite initially rejecting enteral feeding, reached a point where they were able to view enteral feeding as positive. They spoke of the benefits of enteral feeding in ensuring weight gain, reducing chest infections and in enabling them to administer medication to their children.

> "He was very thin. The food went into his lungs but since he got this PEG in he is picking up weight." (Margaret, pg. 4, L 99)

> "But for me the big thing why I probably wouldn't have the PEG removed if his swallowing ever improved is the sheer amount of medication that he has to take every day. Initially that was a real battle trying to get it in orally, I mean at the moment he is taking 14 different types of medicine. So the PEG is an absolute blessing in the sense that I can be sure he gets his medicine." (Tanya, pg. 9, L 192)

Discussion of sub-theme: Celebrating the positives

Identifying change was very important for the mothers in the current study and they became very good at identifying small improvements in a variety of areas. In line with the findings of the current study, Guerriere and McKeever (1997) also documented a reconstructive process through which mothers re-defined themselves and their children. One method described in their study that was used by the participants to come to terms with a "different child" was to regard the child as exceptional, based on what the mothers termed remarkable progress in their recoveries. The mothers in the current study also made reference to remarkable progress made by their respective children, which enabled them to shift their focus away from previously held notions of developmental expectations to identifying and celebrating positive changes.

For the mothers in this study it appeared that they were able to identify and celebrate positive changes in their children once they modified their ideals of a child and expectations of childhood development. The ability to celebrate positive changes was a universal theme that emerged from all the interviews irrespective of the length of time that the child had been living with disability. Sumaya and Rita, who had only been dealing with the challenges of caring for a child with multiple disabilities for six months, were also able to speak of small changes that they had observed in their children and of their excitement at seeing progress albeit slow. Two of the mothers were able to identify benefits of enteral feeding in terms of improved weight gain, ability to administer large amounts of unpalatable medication as well as in ending the battle of oral feeding which is similar to the findings of Thorne et al. (1997). In an evaluation of Canadian parents' experiences of caring for a child with a disability at home, it was found that parents also identified positive gains of caring and described their experiences as rewarding and satisfying (Roeher Institute, 1999). Judson (2004) found a similar ability to identify positive aspects of caring for a child with a chronic medical condition at home.

A recurring theme in the literature on home-based care provided to children with disabilities and chronic medical needs, was the presence of caregiver feelings of being over burdened by the demands of providing home-based care (Cuskelly et al., 1998; Fuller & Rankin, 1994). A study by Quint, Chesterman, Crain, Winkleby and Boyce (1990) found that parents who had been caring for their technology-dependent children for more than two years were more likely to experience burn out as they were emotionally and physically exhausted. Contrary to such findings, the mothers who took part in this study demonstrated an ability to balance feelings of overwhelming burden and an ability to cope as positive personal growth occurred over time. Both negative and positive outcomes associated with caring for a child with special needs were reported and the ability to cope with these outcomes appeared to increase over time. The ability to redefine themselves and to focus on positive changes was the first essence identified in a process of reconstruction.

Summary of Essence 4: Letting go of the dream and valuing the real

The ability to *redefine their beliefs about being a mother* and to *celebrate the positives*, in the presence of ongoing feelings of loss and sadness, was a universal theme that emerged from all the interviews. The mothers were all able to survive "the brokenness" of their situation, which was their reality, and find encouragement in change and progress. Two of the five mothers who were giving nutrition enterally spoke about the benefits of enteral feeding despite initially rejecting the notion of giving up on oral feeding. The mothers spoke of an increase in their capacity to meet caregiving demands by integrating the roles associated with being a mother with those of being a caregiver. They also demonstrated a growth in their ability to construct new meanings and beliefs about their respective children by focusing on the significance of positive changes. Personal growth in times of stress and trauma (or post-traumatic growth), has been documented in research (Cadell et al., 2003; Calhoun & Tedeschi, 1998); as has the possibility of achieving a level of greater competence than what was present during the pre-trauma state (Ickovics & Park, 1998). The mothers in the current study demonstrated growth arising out of a situation that they experienced as stressful and traumatic. Their ability to increase their competence and capacity to cope may have been influenced by a change that they adopted in perspective both of themselves as mothers as well as of their children and the traditionally celebrated developmental progression. Essence 5 will outline further examples of positive personal growth that emerged from the mothers' stories.

Implications

a. Implications for mothers and family members
   i. Mothers may be assisted in their capacity to integrate the roles of mother and caregiver if the initial difficulty to do so is acknowledged and support provided to be able to reach an intellectual acceptance of the need to perform potentially painful tasks on a child.

b. Implications for health care professionals

   i. A clinical implication that emerged from this essence is that those involved in the care of children with chronic feeding difficulties can potentially facilitate the process through which a mother redefines herself and how she constructs meaning regarding her child. It may be beneficial to the process if greater interest was shown, by health care professionals, in positive changes occurring in a child and to draw a mother's attention to such changes. A shift in focus from the disability and medical complications towards identifying abilities in the child could be fostered.

ESSENCE 5: SELF-EMPOWERED: BECOMING THE ENABLER

> "I must admit, I think I sort of feel like I'm starting to open up a bit more again. One needs to be able to say: No, I don't agree with it. But often one is so in awe, and especially in these situations, because you are so crushed by the whole thing." (Stephanie from Agnes's story, pg. 8, L 193)

In the essence "Everything changes: living life on the margins" the mothers' experiences of the extent to which a feeding difficulty had changed them, their lives and their future plans was described. They spoke of feeling isolated and that they and their children are almost invisible to the world. When recalling disempowering interactions with health care professionals it emerged that the mothers did not feel that they could request assistance or confront professionals. In direct contrast to such feelings of isolation and powerlessness was a change that occurred in the mothers towards demanding to be seen and becoming empowered. Baksi and Cradock (1998) define empowerment as a process whereby knowledge, skills, attitudes and self-awareness are gained which are deemed necessary to improve one's quality of live. The term self-empowered was chosen to define this essence, because for most mothers the enabler, or the agent that endowed them with power, was themselves. Their stories reflect the words of Victor Frankl (1963, p. 112): "When we are no longer able to change a situation - we are challenged to change ourselves."

The initial diagnosis of a feeding difficulty and the first couple of months of dealing with the demands of adapted feeding strategies was seen as a time of chaos ("It was mayhem"; "It was a struggle in the beginning"; "There was so much anxiety for me").

The chaos was replaced as the mothers took control of the situation. Examples of taking control can be seen in the constant vigilance of watching over their child while in hospital, in setting up daily schedules, becoming knowledgeable about medical and feeding issues and in their proficiency in care.

A particularly powerful theme that emerged, especially for the mothers who had been dealing with the demands of their children's disability for a longer period of time, was a growth in personal strength and resilience. Tanya recalled a time when she was asked to help another mother to replace her son's gastrostomy tube. She spoke of having to "harden" herself in order to cope with what had to be done. Though this notion of hardening directly contrasts the traditionally held view of the nurturing mother, Tanya reached a point where she identified this coping mechanism as an acquisition of strength rather than denial of the reality of the situation.

> "I suppose you have to make yourself a bit hard in a sense, mmm but actually you know initially I thought that I was making myself hard but I now realize that it was actually strength." (Tanya, pg. 8, L 162)

Finding information and support

All of the mothers described their early experiences following the diagnosis of a feeding difficulty as a time in which they were mostly passive observers. As they told their stories it became apparent that they changed in their ability to actively seek, and demand information. Tanya, Margaret, Rita, Rehana, Kathy and Sumaya expressed frustration that they as mothers had to ask for information, which they felt health care professionals should have been sharing with them.

> "It makes me frustrated but in the end I want to know as a parent. So tell me what I want to know." (Margaret, pg. 10, L 294)

> "The kind of information you need has to come from people, people who have worked with these type of kids. You have to ask and people have to tell you." (Rehana, pg. 14, L 428)

Having to ask for information and having to find services was a reality for the mothers. Rehana recalled trying to find services and feeling frustrated that hospitals did not provide parents with a resource list for children with disabilities. Through active searching she eventually found a great deal of assistance but much of it was through word of mouth referrals.

> "And also I never knew there were so many places in Cape Town, so much assistance until I needed them, until I started looking. Fortunately the circle of people I met could tell me about other things." (Rehana, pg. 13, L 390)

Information and support was found through formal and informal means, including health care professionals, support groups and the internet. Rehana and Tanya actively sought professionals who could help them with different aspects of their children's care. Both mothers sought Speech-Language Pathologists and Paediatricians who they felt were knowledgeable about children with special needs. When asked what her greatest sources of support were, Tanya listed her Paediatrician and her support group. Faced with no appropriate services in her area, Tanya decided to start a support group for mothers and in so doing enabled both herself as well as the other mothers who joined her support group, to cope with the demands of home-based caregiving.

> "The nice thing about my support group is that at difficult times we phone each other, we sms each other, we give each other support. So it has been very very important for me." (Tanya, pg. 11, L 228)

Discussion of sub-theme: Finding information and support

The experience of being the mother of a child with a chronic feeding difficulty encompassed the need to *find information and support*. It has been found that caregivers experience less stress during a child's hospitalisation when coping strategies that involve understanding the child's medical situation is adopted. In this regard parents who were more active in learning about their child's medical problems showed lower parenting stress (Garro et al., 2005). One method used by parents to gain control over a situation is through the gathering of information (Cohen, 1993; Thornes, 1993). These findings are relevant to the current study as the mothers also demonstrated an increased perception of control of their situation through the gathering of information. Information was sought from health care professionals but when parents were not able to obtain the information they needed from professionals they also consulted other parents, support groups and the internet, similar to the findings of Cohen (1993) and Diehl et al. (1991).

In the sub-themes of "Disempowering professional interactions" and "Unanswered questions and unmet needs" the same mothers spoke of times when their information needs were not met. They made reference to an initial inclination not to confront health care professionals to request explanations. A change occurred in them with time as they enabled themselves through seeking and requesting information. The ability to actively seek information and to create sources of support was therefore another example of positive personal growth that occurred in the mothers who took part in this study.

Acquiring skills and confidence

> "I just said I need to learn. I gained a lot because if I didn't suction him or put a nebulizer on then I have to go back to the hospital." (Margaret, pg. 12, L 339)

Adapted oral feeding strategies, suctioning, care of gastrostomy tubes and planning of schedules for administration of medication and giving of feeds were some of the feeding-related skills the mothers acquired.

The three mothers who were feeding their children only orally or in combination with enteral feeds made many references to adapting feeding strategies. Two of the three mothers acquired these skills on their own through trial and error by trying different methods of feeding and different food consistencies.

> [79]"Ons [man en vrou] het baie getry [met voeding per mond]. Ons gee vir hom dan kyk ons hoe werk dit. En hy eet, hy eet alles, hy drink alles. Nou laaste het hulle [mediese personeel] gesê ek moenie rys gee nie, ek moenie dit doen nie ek moenie dat doen nie. Ek gee dit. Ek gee Basmati rys, dis mos 'n sagte rys, dan meng ek dit saam met sagte aartappel en gee dit vir hom. Dan eet hy dit. Daar is nie 'n probleem nie." (Kathy, pg. 1, L 6)

Rehana was the only mother who was assisted in adapting feeding strategies by a Speech-Language Pathologist; however the first two years of her daughter's life was also a time of acquiring the needed skills and confidence on her own.

> "[in response to how she found out that her daughter had a feeding difficulty] Just in me trying to get her to breast feed and in the difficulty to instigate that sucking motion. There was not anybody specifically guiding you as to what the process should be [in the neonatal intensive care ward]. And we [wife and husband] tried all sorts of different dummies and kind of the cheapest dummy was the one she took. Yes, and that sort of got the sucking motion going." (Rehana, pg. 3, L 69)

The need for feeding related adaptations through trial and error attempts appear to be ongoing in Rehana's story.

> "You have to find out what works. The cup feeding is not working, or rather not going well. It is taking too long still. But you just have to be so patient. And then you sort of have this 20, 30 minutes thing, and I'm watching the clock. Do I give up now or carry on trying? That's what I did in the beginning I would sit for a whole hour and the child had not eaten half the lunch yet. The child is not doing whatever they are doing on purpose you cannot get angry, you sometimes want to get upset, you know: Why aren't you eating, why are you spitting it out? They

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[79] We [wife and husband] tried with oral feeding a lot. We give him something and then see how it works. And he eats, he eats everything, he drinks everything. The last time they [health care professional] told me I should not give him rice, I should not do this, I should not do that. I give it. I give him Basmati rice, which is a soft rice. I mix it with a soft potato and give it to him. Then he eats it. There is no problem.

> don't understand. So it is just patience, understanding, trying different things. You have to find what works and don't give up." (Rehana, pg. 13 L 379)

Rehana's words show how she had gained insight into factors that would aid oral intake or that would make it hard for her daughter to eat a particular type of food. Feeding-related skills that she spoke about during her interview were related to making changes to the temperature of food; to progressing slowly from easy to more challenging consistencies; and in choosing feeding utensils.

> "She will eat things but it has to be warm, not room temperature or cold. Nothing cold, her reaction is obviously shock. You still can't put ice cream in her mouth but she can take cold things now. Now if this tea [points to bottle] gets to room temperate she will still take it, but not initially. (Rehana, pg. 6, L 167)

> "Yes, um then with the porridge first, the rice porridge um then moving on to some of the other things, you know the butternut and potato. Now she is eating her vegetables nicely. But of course not whole pieces it is still sort of roughly mashed. From very finely mashed to roughly mashed." (Rehana, pg. 7, L 199)

> "She has one bowl for porridge, one for lunch and they are all the same colour, the spoons match. So that she will associate the feeding time with those colours, those things and make the whole thing more pleasant." (Rehana, pg. 12, L 359)

Yet another example of how the mothers empowered themselves was in the creation of daily schedules. Feeding schedules and schedules for the administration of medication were devised, which both met the children's' needs but also made the task more manageable as it became a part of daily family life.

> "There is a diary every morning on the kitchen table, even though most days are exactly the same I write it in there every day. So I will write down: bottle, porridge, vitamins, chocolate, tea, lunch, whatever. At night I put her porridge in

> a bowl, I put the yoghurt and fruit in separate bowls in the fridge, little chocolates, everything is ready for the day. (Rehana, pg. 12, L 346)

Many references were made by the mothers of how they initially questioned their ability to perform certain tasks, which they were able to do at the time of the interview. The stories showed that there were differences among the mothers in terms of the amount of time they needed to feel competent with feeding related skills. Only one mother, Tanya, felt that she quickly mastered the skills required for managing a gastrostomy tube. Tanya attributed her ability to feel confident in managing a gastrostomy tube to a health care professional who took the time to demonstrate skills and who provided follow up assistance in the form of availability to answer questions.

> “But the taking out and cleaning [PEG] was never something that I could see myself doing. But then I was very fortunate that my doctor spent a lot of time explaining things to me and also there is ongoing support so I could literally just phone her and ask a question. So, I learnt. And I actually leant to take care of the PEG quite quickly.” (Tanya, pg. 6, L 130)

However, the other four mothers whose children were fed through a gastrostomy tube reported that it was not easy to acquire the needed skills. Though these mothers were shown how to perform certain tasks by health care professionals, it was mostly out of their own continued attempts at home that they became competent. The need to be persistent in their self-empowerment emerged because of the limited period of time and practice opportunity afforded to them by health care professionals.

> [80]“Ek het nog nie begin brand [cauterize] nie toe leer hulle vir my hoe daai dag. Nie eers geleer in ‘n uur of ‘n half uur nie, sommer net vinnig. Toe kos dit vir myself om my hier by die huis te leer en om my plak vas te maak om dit te doen.” (Sumaya, pg. 14, L 399)

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[80] At that stage I was not burning [cauterizing] yet. They showed me how, not in an hour or half an hour just quickly. So it meant that I had to teach myself at home and to build up the resolve to do it.

The mothers recounted specific situations during which they were challenged in their capacity to cope. It was often out of these moments that a new ability emerged in terms of mastering situations and tasks that seemed impossible initially.

> [81]"Gister het ek self een ingesit [PEG]. Ek het gemaak soos hulle [mediese personeel] vir my verduidelik het. Dit was baie moeilik, ek het baie gestress, maar dis [PEG] in." (Rita, pg. 3, L 56)

> "But I have also become able to deal with all of the responsibilities, because it is massive, the responsibility." (Tanya, pg. 13, L 289)

Discussion of sub-theme: Acquiring skills and confidence

Acquiring skills and confidence illustrates positive personal growth that occurred as the mothers took control of their situations and became their own sources of strength and empowerment. The mothers spoke of growth that occurred over time in terms of their ability to perform various care tasks associated with adapted feeding strategies. One mother was greatly assisted by a health care professional who took the time to ensure that skills were mastered, however, the reality for the remaining mothers was that competence was gained through their own trial and error attempts. Chaos was replaced by order as daily schedules were put in place and as competence with adapted feeding strategies was developed. As was found in a study aimed at examining the process of mothering a child who is reliant on parenteral nutrition (Judson, 2004) the mothers in this study also experienced a powerful need to find structure and routine in the chaos of new tasks to be performed. The establishment of routines and schedules assisted them in gaining control of the challenges of caring for their respective children.

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[81] Yesterday I re-inserted a PEG myself. I did as they told me. It was very difficult, I stressed a lot but the PEG is in.

Empowering others

The ability to not only grow in their own ability to meet the care needs of their children, but furthermore to become enablers of family members and even strangers' ability to understand and engage in adapted feeding strategies, illustrated another aspect of positive personal growth.

> "I downloaded information from the internet. We printed everybody a booklet about cerebral palsy, worse case scenarios with diagrams how their bodies can go out of line, feeding issues. We bound a copy for each auntie, grannie, grandfathers." (Rehana, pg. 6, L 155)

Rehana and her husband were very pro-active in empowering their families by providing them with detailed information about cerebral palsy and about the special care that their daughter required. Personal growth was evident in the ability to share newfound skills and information.

> "Finger-feeding, she would bite the hardest bite. I trained Betty [part-time caregiver] to finger-feed her. We had little finger protector things so that Betty could feed her because she was not comfortable sticking her fingers in my daughter's mouth. Working with a speech therapist we all became a bit more comfortable with putting our fingers in her mouth." (Rehana, pg. 5, L 129)

> "And we [wife and husband] also taught everybody how to bottle feed her, her aunties and grandmothers." (Rehana, pg. 5, L 138)

Margaret recalled how a couple of years after her son's diagnosis she was able to share information and skills with another mother in a hospital setting who had just received the diagnosis that her daughter would be severely disabled.

> "And then the mother will come later and say: Hi and ask how are you, what is wrong with him? And then I tell them what happened and all that. I take whatever cream and powder and stuff and massage him there in the hospital and I give him physio. So the mother said: You know I must learn all these things." (Margaret, pg. 8, L 230)

A feeling of pride in their ability to share information and skills with other mothers was reflected in both Margaret and Tanya's words. From their stories it was evident that the women experienced personal growth as a result of helping other mothers in similar situations.

> "It has also been wonderful to be able to give other mothers support because that is actually what I would like to do." (Tanya, pg. 11, L 229)

> "I would love to be there in the doctors' rooms when an initial diagnosis is made to say to that mother that she is not alone and that there are other mothers who can walk the road with her, and who understands." (Tanya, pg. 11, L 231)

Discussion of sub-theme: Empowering others

The ability to not only grow in their own skill and acquire information, but also to *empower others* or to become enablers of capacity for family members and even strangers, illustrated another aspect of positive personal growth that happened for the mothers. The mothers recalled times when they shared their newly acquired skills with family members and with mothers who were in similar situations to them. This sharing of skills and information happened within the context of a support group as well as during a child's hospitalisation. The need to fulfil the role of empowering others in similar situations by providing information, practical skill demonstration and emotional support was not identified in other studies looking at the experiences of caring for a child with a chronic feeding difficulty (Adams et al., 1999; Craig & Scambler, 2006; Raina et al., 2005).

Challenging and advocating

Strong feelings of being invisible to society, professionals and even to their families who were perceived as not really understanding their needs, was discussed in Chapter six ("Living on the margins"). Initially, even though the mothers questioned some advice given by health care professionals and felt that their needs were not met; they did not confront health care professionals, as illustrated in the following quotations.

> "I actually should have stood up and told them: You know you are a bunch of, I don't know what. I wish I had, but you are intimidated". (Agnes, pg. 6, L 153)

> "I am alone with this doctor, why don't I say something! But I didn't." (Margaret, pg. 1, L 14)

> "Then your fear says: Well actually I don't really know, because I am not really trained." (Agnes, pg. 9, L 226)

Personal growth occurred in the mothers with time, as they spoke of an increased ability to challenge health care professions and to be acknowledged by others. Margaret recalled a few occasions in which she had wanted to act and speak her mind but had not. Her story revealed how she had grown in her ability to confront professionals and insist on information. Her words illustrated how acquiring information helped her to feel confident in questioning a health care professional.

> "I gave him [doctor] a mouthful. I told him: You don't say! When I say I don't want my child on morphine, then I don't want him on there. Because I found out a lot about morphine, it has a lot of side effects. That morphine closes up their breathing, but they don't tell the parents that. And I found out because I spoke to the pharmacist and they explained it to me." (Margaret, pg. 10, L 275)

With time, and as the mothers felt more competent in their caregiving role they challenged professionals and even refused to follow some of their advice and recommendations.

> "One needs to be able to say: No I don't agree with it." (Agnes, pg. 8, L 196)

> [82]"Maar ek het nie hulle dinges gedoen nie, ek het net self probeer." (Kathy, pg. 1, L 5)

A theme that emerged from the stories was a need to advocate for the rights of children with disabilities. Margaret spoke of her frustration with public health care policy and how she questioned existing policy by confronting health care professionals about it. She recounted a time when her son was refused admittance to the intensive care ward based on hospital policy which limited the extent of care that was to be provided to children with severe disabilities.

> "I told them [doctors] if you did try something and it didn't help, then I'll accept it. But don't tell me before the time what you won't do. Don't just leave him. No he is not walking, he is not talking so leave him like that. Let him ma go. They mustn't have that attitude, they must fight for him and whatever handicapped child till the end." (Margaret, pg 14, L 414)

The above incident led Margaret to actively lobby for the rights of children with disabilities by writing letters to the hospital's superintendent as well as to local newspapers. She allowed me to read a letter that she had written in which she questioned hospital policy and highlighted the need to provide equal services to all children irrespective of ability. What also emerged was her perception that there was reluctance among health care professionals to provide interventions beyond what they consider to be a child's limitations. Margaret questioned this attitude.

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[82] But I didn't do what they told me to, I just tried things on my own.

Rehana also expressed frustration with how children with disabilities were not represented in popular media and how retailers seemed unaware of their presence and needs. She recalled a number of items that she needed for her daughter, which were not available at regular "baby and children's stores" such as diapers for children over the age of three and books that focus on caring for children with special needs. In her interview Rehana expressed a commitment to contact a local television station and chain of bookstores to request representation.

> "There is a TV program all about feeding, you know that program on TV? So they go through talking to all kinds of specialists, all sorts of moms, all ages but there is not a single thing on feeding a special needs child. And every time I think about it I think that I should write to them, because they do nothing for special needs kids. They do not automatically eat a porridge at that stage. And the other program and there is nothing on special needs kids either. Talking about all the different stages of development, the pregnancy, everything but nothing nothing and there are so many kids in South Africa that need further assistance." (Rehana, pg. 14, L 394)

Discussion of sub-theme: Challenging and advocating

Acquired information was identified as one reason why parents felt empowered to be able to demand a partnership with health care professionals (Butler Simon & Smith, 1992; Cohen, 1993; Jerrett & Costello, 1996). A similar personal growth occurred for the mothers in this study, as they spoke of an increased ability to *challenge* health care professionals and as they started to question public health care policies with time. The parents in Balling and McCubbin's (2001) study whose children were hospitalized, expressed a desire for collaboration while simultaneously challenging the health care professionals' decisions, similar to the mothers in the current study.

Assertiveness when dealing with health care professions was similarly documented in a study looking at mothers engaged in complex preservative work during home-based care (McKeever, 1991). The current study therefore supports findings that mothers may initially adopt a passive role in relation to being acknowledged as a caregiver and in relation to medical management of their respective children, but that this is replaced by an assertive attitude in which they demand to be acknowledged and for medical management to be in line with their wishes.

An additional role identity emerged in most of the mothers, as they felt a need to *advocate* for the rights of children with disabilities. Advocating for the rights of children with special needs and challenging health care services and policies were also found in McKeever's study (1991) as the mothers moved from a compliant to an assertive role through knowledge and skill acquisition. Similar to the finding of Douglas and Michaels (2004) some of the mothers in this study were also very aware of the images portrayed in popular media of motherhood and how they were not able to relate to such images of a mother caring for a child who does not present with specialised care needs. They identified the need to promote equal treatment options for children with disabilities in the public health care system, representation of children with feeding challenges in popular media as well as to informally educate others when confronted with ignorance about feeding difficulties.

> "We even take him out with us to restaurants and sometimes people stare and sometimes they don't and sometimes it will bother me and sometimes it won't. But if people ask I explain to them about the PEG and why he needs it." (Tanya, pg. 13, L 375)

> "I'm very open, everybody knows about Kevin. As far as I'm concerned the more people who are aware, even if your name features somewhere and they can phone you or contact you that's great." (Tanya, pg. 1, L 6)

Summary of Essence 5: Self-empowered becoming the enabler.

"Self-empowered: becoming the enabler" illustrated positive personal growth that occurred in the mothers in areas such as acquiring information, support, skills and confidence. A couple of factors appeared to contribute to the mother's ability to reach a position of empowerment. The mothers empowered themselves out of necessity as they were required to perform specialised care tasks as the primary caregivers often without support from others, through trial and error attempts. This was achieved by taking control of the situation demonstrated in the establishment of daily schedules, by finding and/or creating sources of support, and through a discovery of their own inner strength and reserves.

Their stories illustrate a growth that occurred from initially being passive observers in their respective children's care to becoming empowered women as they took control of their lives. The growth that occurred in the mothers did not however completely replace feelings of loss and a reduced capacity to cope. What emerged was that growth and loss co-occurred. Even though the mothers moved towards a position of strength with time they also recounted instances where they returned to feelings of disempowerment and sorrow which will be discussed further in Essence 7.

Implications

a. Implications for mothers and family members
  i. Mothers appear to have the capacity and desire to play a role in educating and supporting other mothers who are providing home-based care for children with chronic feeding difficulties. An awareness of the role that they could potentially play in this regard may act as a catalyst for the establishment of parent-to parent-support groups.
  ii. Another implication of these findings was that mothers might have to become more pro-active in lobbying for support as it may not be provided in a public health care context that faces resource constraints.

b. Implications for health care professionals

   i. The educational and support role that mothers may be able to fulfil has important implications in a country such as South Africa where the public health care service offers limited support services for parents. Health care professionals should recognise and draw on the expertise of mothers who have been providing home-based care as a potential cost-effective means of enabling other parents to meet the demands of providing care for a child at home.

   ii. Health care professionals should acknowledge the presence of the negative sequelae of traumatic situations as well as the potential for positive outcomes or post-traumatic growth. It is important for health care professionals to understand posttraumatic growth in order to help facilitate it.

c. Future research

   i. Further research into variables that are associated with growth following trauma in mothers who are providing long-term home-based care would assist health care professionals to facilitate such a process. A longitudinal study may also provide insight of how mothers respond to ongoing challenges faced by a child who has chronic feeding and medical difficulties and if post-traumatic growth is positively related to a recurrence of experiences of loss.

   ii. The mothers in the current study empowered themselves out of necessity as limited support was offered in the public health care setting. Self-empowerment occurred despite of a lack of support, however, one is left wondering whether this did not occur because of a lack of support. Future research is required to evaluate potential differences in parents' ability to feel competent in caregiving tasks in relation to the amount of support that they receive from health care providers.

ESSENCE 6: FACILITATING THE JOURNEY

The phenomenon of being the mother of a child with chronic feeding difficulties needs to be understood within the life contexts of the women who took part in this study. The experiences of the mothers and how they made sense of these experiences occurred within specific contexts, namely the home where they provided care and the public health care settings within which they interacted with various individuals. The stories were filled with information about things that shaped their experiences within these two contexts.

The mothers spoke about factors that enabled their capacity to cope or helped them through their journey of providing care for their respective children. Thus the essence, "Facilitating the journey emerged". Sources of support identified ranged from spouses, extended family members, co-workers, support groups, spirituality and health care professionals. What also emerged from the interviews was a desire for more and very specific support to meet both practical and emotional needs. In addition to identifying current sources of support the mothers showed insight into solutions to unmet needs by identifying factors that would help them to continue their journey.

Current and desired sources of support for both practical and emotional needs are described in this essence. The mothers described various people and organisations who provide support within the two contexts of home-based caregiving and the public health care setting. The first two sub-themes in this essence that describe context specific sources of support are thus "Facilitating home-based caregiving" and "Facilitating capacity to cope within the public health care setting". Finally a third sub-theme, which focuses on the emotional needs of "being heard and given hope" is discussed.

Facilitating home-based caregiving

As the primary home-based caregivers, the mothers who took part in this study were responsible for most of the tasks involved in caring for their child's special needs. Spouses, extended family members, co-workers and home-based caregiving providers were all identified as additional sources of practical and emotional support, and facilitated the mothers' ability to provide care within their homes.

Three of the five married mothers named their *spouses* as an important source of support.

> "**[Your greatest source of support?]** Would be him [husband]. I think we are the only two who actually understand because for everybody else it is momentary. Their concern is not tomorrow; their concern is the moment they have with her. Our concern is the future." (Rehana, pg. 10, L 297)

Rehana expressed a belief that her husband was the only person who shared an understanding of the long-term commitment to their child. Sumaya also made reference to emotional support provided by her husband in that he enabled her to talk about her challenges; however he could not provide support with caregiving tasks at the time of the interview.

> [83]"Net ene wat ek trust [verwys na man]. Ek sien so uit om daar [tronk] te kom, dan praat ek dit alles uit dat ek so lekker voel as ek daar weggaan, lig." (Sumaya, pg. 16, L 470)

In addition to emotional support spouses also played an important role in providing practical support with caregiving tasks.

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[83] My huband is the only one I trust. I really look forward to visiting him [in prison] then I can talk about everything which makes me feel so good by the time that I leave there, light (relieved).

> [84]"Ja, ons vat so beurte en help mekaar met alles wat gedoen moet word." (Kathy, pg 3, L 58)
>
> "Her dad gives her her last bottle and then puts her down to sleep." (Rehana, pg. 12, L 340)

In contrast to Kathy and Rehana, who spoke about their spouses as active partners in caring for their children, Tanya and Margaret did not identify their spouses as a source of either practical or emotional support. The degree of paternal participation in caregiving tasks appeared to be important in determining the perception of support gained from a spouse.

Grandmothers also played an important role in providing support by assisting with caregiving tasks. Rita and her mother were living together at the time of the interview and shared responsibility for the tasks related to feeding and managing the care of the gastrostomy tube.

> [85]"Somtyds raak ek baie moeg, maar ek kan net vir die Here dankie sê dat my ma my so help met hom [haar seun]." (Rita, pg. 7, L 169)

The mothers were well supported by others who helped with the daily care needs of their children. Taking turns in providing care offered some of the mothers respite which enabled their capacity to cope. There was a time when Stephanie (grandmother) lived with Agnes and Rose. As Rose's biological grandmother, Stephanie recalled how she valued the time when she could remove herself from the demands of caring for her granddaughter and how the sharing of caregiving responsibilities enabled her capacity to cope.

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[84] Yes, we take turns and help each other with everything that needs to be done.

[85] Sometimes I get very tired but I can only thank the Lord that my mother helps me so much with my son.

> "If I had been with her all day, every day, in that sorrow, I don't think that I would have actually been able to, no well I won't say that but it has been easier for me to grow the hope because I haven't had to be in that situation all the time. And Agnes has got a greater capacity to carry it than me, it's fascinating that." (Stephanie, from Agnes's interview, pg. 4, L 89)

Of note during analysis of the interviews was the absence of reference made to support offered by friends or by family members other than spouses and grandmothers.

The ability to take time away from providing home-based caregiving was also highly valued by Margaret. She worked part-time and described how this time away from her child and the company of understanding co-workers who acknowledged her efforts in light of her trials assisted her in coping emotionally. Margaret identified her *co-workers* as a source of support as she was able to talk and share her feelings with them.

> "You know I talk a lot at work. I do general work at a clinic. There are a lot of sisters (nurses) and we have psychologists there. I go and talk to them, that is the way I feel better. I don't keep it back I tell them how I feel and you know about my family and whatever. I just talk about it. And they say: No Margaret, you won't say it because you just smile, you never look down. And I say: No, why must I be like that? I just take every day as it comes." (Margaret, pg. 7, L201)

Sumaya was the only mother in this study who had access to *Home Based Carers*. This is a South African non-profit organisation that provide respite by assisting with the provision of basic care needs to people in their own homes (www.capegateway.gov.za).

> [86]"Maar my ma en my pa werk so ek is in die dag alleen, maar die Home Based mense kom help my uit vier keer 'n week. Daar is tye wat ek moeg is en so, dan is hulle daar om in te val. Dit het nogal gehelp vir my. (Sumaya, pg. 1, L 5)

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[86] My mother and father work so I am alone all day but the Home Based Carers come to help me four times a week. There are times that I am tired then they are there to assist, it helped me a lot.

Though they assisted her with certain aspects of her son's care, the *Home Based Carers* were not trained in enteral feeding, nor in looking after gastrostomy tubes. Since these were the areas in which Sumaya required the greatest amount of assistance, she identified the need for caregivers to be trained in adapted feeding strategies.

> [87]" Ek het die Home Based Carers gevra is daar nie iemand wat my kan uithelp nie. Ek het vir een gevra en vir haar gesê dat ek haar sal leer om dit te doen. Maar toe kom sy nooit weer terug nie. Sy sê: Sy is jammer sy sal dit nie kan doen nie, sy kan nie op 'n kind werk wat 'n PEG het nie. Baie is bang daarvoor [PEG], elkeen wat kom wil nie werk daarmee nie." (Sumaya, pg. 7, L 188)

At the time of the interviews Tanya was the only mother who was part of a *support group*. When asked what helped her the most she identified her support group as offering her the most support. Her story showed that emotional support was provided by mothers who shared an understanding of providing home-based care for a child with special health care needs.

> "The nice thing about my support group is that at difficult times we phone each other, we sms each other, we give each other support. So it has been very very important for me." (Tanya, pg. 11, L 228)

The ability to attend a support group meeting or to have contact with other mothers in similar circumstances was identified as something that the mothers would find helpful. When I asked what would aid their capacity to cope, five of the mothers firstly identified access to a support group.

Some mothers felt that follow up home visits by health care professionals may assist in meeting their needs. This was most strongly expressed by mothers who had been

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[87] I asked the home based carers if there is not somebody who could help me. I asked one of them and told her that I would teach her how to do it. But then she never came back. She said that she is sorry but she would not be able to do it, she can't work on a child with a PEG. A lot of them are scared. None of the carers want to work with it.

providing home-based care for their children for a short period of time. Rita and her mother felt that a home visit from health care professionals would have assisted them in terms of reviewing and further practicing the care of a gastrostomy tube which they both felt ill-prepared to do by the time the child was discharged from the hospital.

> [88]"Ek dink sou iemand laas week kom check het. Dan sou ons darem gevoel het daar is mense wat omgee. Die moment Ben uitkom by daai hospitaal dan gee niemand meer om nie. Hier is niemand wat help nie. Maar as iemand kom check, alles is oraait dan voel ons gerus. Net een dag." (Rita, pg. 8, L 202)

Kathy, on the other hand felt that a home visit by a Speech-Language Pathologist would be valuable as she felt strongly that her son was better able to manage oral intake in the familiar environment of her home. Her need for a home visit appeared to be motivated by a wish to demonstrate her son's ability in relation to oral feeding through which she could potentially change the Speech-Language Pathologist's management strategies.

> [89]"Ek wil graag hê dat 'n Spraak Terapeut moet kom kuier by die huis en sien hoe lekker eet Ronald hier in sy eie omgewing wannneer sy ma hom voer. Want daar by die hospitaal wou hy nie eet nie. Self nou as ons hom vat vir sy medisyne dan is hy 'n ander kind. Ek dink hy is bang ons gaan hom daar los, dan will hy net niks doen nie." (Kathy, pg. 4, L 82)

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[88] I think if someone came to check last week then we would have felt that people care. The moment that Ben left the hospital it felt as if no-one cares anymore. There is no-one to help, but if somebody came to check if everything is okay then we would have felt at ease. Even if it is just once.

[89] I would like for a Speech Therapist to visit us at home and see how well Ronald eats in his own environment when his mom is feeding him. Because at the hospital he never wanted to eat. Even now, when we take him for his medicine he is a different child. I think he is scared that we are going to leave him there, then he does not want to do anything.

Discussion of sub-theme: Facilitating home-based caregiving

The experience of being the mother of a child with chronic feeding difficulties encompassed the presence of factors that facilitated the mothers' ability to meet a child's caregiving needs within a home-based care context. Their experiences also highlighted an awareness of factors that would facilitate their journey and an ability to provide solutions to practical difficulties faced by them and their families. Spouses, grandmothers, co-workers, informal home-based caregivers and support groups emerged as valued sources of support. Emotional support was gained when the mothers felt that others understood their respective children's caregiving needs, the concerns they had for the child's future, and the emotional impact of having to fulfil the role of primary home-based caregiver.

The availability of respite care or the sharing of daily caregiving tasks with a family member was highly valued by the mothers. As noted earlier, only spouses and grandmothers were identified as supportive family members. Judson (2004) documented how the mothers in her study also found that extended family members were not perceived as being very supportive. A reason for this was provided in that it was felt that extended family lived with a great degree of fear regarding the child's fragility and possible demise while in their care. The current study did not explore possible reasons why family members were perceived as providing limited support, however, what emerged from analysis of the interviews was that extended family members lacked familiarity with the child in terms of the child's needs and physical constraints and that the mothers experienced additional stress when their feeding and handling suggestions were not followed.

The mothers in this study demonstrated a number of coping behaviours which can be categorised as action-oriented (seeking information and acquiring new skills), cognitive (appraisal and redefining of meaning which will be discussed in Essence 7) as well as interpersonal (finding support). McCubbin, Thompson and McCubbin (1996) define coping behaviours as actions taken in an attempt to manage or balance tensions and reduce stress. This sub-theme highlighted interpersonal coping behaviours as the mothers accepted support offered by spouses, extended family members, co-workers and support groups. Where such support was not present one mother (Tanya) was proactive in creating a support group that could meet her practical and emotional needs. Sharing caregiving tasks and seeking out others in similar circumstances through which opportunities to talk about challenges are created, were similarly identified in other studies looking at families providing home-based caregiving for chronically ill children as stress management strategies (Ireys et al., 2001; Sterling, 1990).

What emerged in this study was that the mothers were very aware of enabling factors in their lives and the value that it had in increasing their ability to provide home-based care. They were able to identify and accept support offered by a number of people including family members, co-workers, other mothers and informal home-based caregivers. Despite the presence of available support most of the mothers felt that they still had unmet practical and emotional needs. Informal caregivers trained in adapted feeding strategies and home visits by health care professionals were identified as possible solutions to unmet home-based caregiving needs.

Facilitating capacity to cope within the public health care setting

The second context that emerged as pivotal in understanding what it means to be a mother of a child with a chronic feeding difficulty was that of public health care settings. During a child's hospitalisation the mothers' capacity to cope was facilitated by health care professionals and other mothers. The mothers recalled instances when health care professionals played a role in helping them by affirming their role, showing kindness to the child, providing them with options and demonstrating respect.

> "And the nurses are very caring there, they will talk to him. And when I talk to them they say: You know Margaret you are really a fighter." (Margaret, pg. 15, L 431)

The above quotation illustrated how Margaret valued the caring interactions that she observed between the nurses and her child. Acknowledgement and validation of the role that she played was important for her. The manner in which health care professionals interacted with families and in particular the ability to demonstrate a caring attitude was also valued by Stephanie. She recalled an interaction with a Speech-Language Pathologist that she found to be enabling. When asked what she found enabling about the interaction she identified the caring manner demonstrated rather than the individual's knowledge or skills.

> "I think she [Speech-Language Pathologist] was actually a special lady, I liked her. Hey, Agnes? I think she was older, and she was very caring. She was caring, otherwise I would have just gone away because I am inclined to pick up Rose and just say goodbye we are out of here." (Stephanie, from Agnes's story, 7, L 174)

Positive professional interactions were also related to creating a personal relationship with a mother, as was seen in Kathy's story where she knew the health care professionals involved in her son's rehabilitation during in-patient care by their first names. What emerged from the quotation was that she also valued the manner in which the Physiotherapists showed her how to do physical exercises with her son.

> [90]"Daar was allerhande therapists wat elke dag met hom gewerk het. Die Physios het vir ons lekker gewys watter oefeninge om te doen en ons het almal mekaar op die eerste naam geken." (Kathy, pg. 3, L 62)

Health care professionals appeared to play a crucial role in the mothers' ability to cope with the challenges of a feeding difficulty. Tanya spoke about how fortunate she felt in having found a doctor who provided her with information on feeding options. What she valued was the doctor's willingness to support her decision not to have a PEG placed initially, even though this was recommended as the most appropriate intervention at that

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[90] There were all sorts of therapists working with him daily. The Physiotherapist showed us which exercises to do and we all knew each other by the first name.

time. Her doctor allowed her to make the decision and gave her sufficient time to eventually accept the need for the removal of the nasogastric tube and placement of a PEG.

> "You know I am very fortunate with my paediatrician. She recommended that we go onto PEG feeding. Initially I was resistant to the idea because it sort of felt like that was the end, you know only very sick people or people close to death goes onto tube feeding. So I was resistant to the idea, but agreed to nasogastric feeding to get his weight up. So initially we started off with NG feeding and he was on that for about a month and then it just became too much, because his nose got sore and the stress of having to test constantly that it is in his stomach and not in his lungs, it was just too much for us. So I went back to my doctor and I said that I would consider PEG placement and at that stage she arranged that I could see a little baby who had a PEG in place…." (Tanya, pg. 6, L 113)

Interacting with other mothers during a child's hospitalisation was seen as valuable as it offered the mothers the opportunity to share information about a child's care as well as offering emotional support.

> [91]"Sy ['n ander moeder] was soos die social worker. Ons het beste vriende geraak. Ons het alles gedeel. Die eerste week by die huis toe was dit swaar want toe mis ek vir haar en met wie gaan ek nou praat, en te vra hoe doen sy, slaap sy ooit, want ek kan nie slaap nie." (Sumaya, pg. 15, L 439)

Even though Sumaya recalled times when she interacted with other mothers there were also times in the hospital that she struggled to initiate a conversation with other mothers in spite of having a sense that they too must have shared common concerns and needs.

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[91] She [another mother] was like the social worker. We became best friends. We shared everything. The first week at home was difficult because I missed her and wondered who am I going to talk to now, and to ask her how she is doing and if she is sleeping because I can't sleep.

> [92]"Die tyd wat ek daar was [by the hospitaal] was 'n lang tyd en dan sit die ma's maar net so en kyk vir mekaar en almal doen hulle eie ding met hul kind. Dan kry mens die tye wat die een nurse en 'n ma staan en stry. Ons [moeders] kan niks doen nie dan dink ek nogal as ons 'n groep was dan kon ons mos saamstaan. Daar sit baie mas, ons weet nie hoe voel daai persoon nie. Ek het dit gevoel so hoe voel hulle?" (Sumaya pg. 15, L 435)

The need for support services to address personal or emotional needs was a theme present in all the stories told by the mothers. Although none of the mothers initially spoke about such services being offered by the public health care system or non-governmental service providers, after some prompting, they all thought that public health care hospitals should provide support services. Their stories highlighted a perception that hospital based support would have assisted them in the provision of information, development of competence in caregiving skills and meeting their emotional needs.

> [93]"'n Talk miskien oor die ding en daai ding, miskien vir die ma's wat daar [hospitaal] slaap vir 'n lang tyd. Ek glo dit sal help, want jy kan nie oor jou situasie praat by die huis nie. Dan kan jy dit uitpraat by daai groep. Ons almal lyk happy by die hospitaal maar niemand weet wat by die huis aangaan nie." (Sumaya, pg. 14, L 454)

> "Like a group you know, mothers come in and you can have a discussion, you know nothing like that is available at the hospital. And they don't know how I feel so why don't they make like a support group and let mothers come in. Just to talk

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[92] I spent a long time at the hospital. The mothers would just sit around and look at each other and everybody was doing their own thing with their child. Then there were the times when a nurse would be arguing with a mother. We [the mothers] could not do anything and I use to think that if we were a group we could have stood together. There are many mothers sitting there and you don't know how they feel. I felt it so how do they feel?

[93] Maybe a talk about this or that, possibly for the moms who are sleeping at the hospital for a long time. I believe it will help because you can't always talk about your situation at home. Then you can talk it out at that group. We all look happy at the hospital but nobody knows what is happening at home.

> about, maybe I got the same experience as you like looking after the child or family responsibility or whatever. But there is nothing like that." (Margaret, pg. 1, L 28)

All of the mothers identified information and training needs that were unmet and they believed that information groups offered at the hospitals would have enabled them through skill development.

> [94]"Of miskien soos een keer, soos mommies wat sulke goed oorgekom het. Daar is 'n saaltjie by die hospitaal, wat jy kan sê: Hoe gaan jy of jy te werk met jou kind?" (Rita, pg. 9, L 222)

As discussed under the sub-theme of "Disabling public health care" the mothers felt that the division of services between different hospitals resulted in greater financial expenditure on travel. Assistance in the form of transportation to and from hospitals was identified as a possible solution to difficulties in accessing public health care services.

> [95]"Wat dit rerig eerlik moeilik maak is om elke maand daar te moet uitkom sonder eie transport. Die pram is te groot om in 'n taxi te kom so ek moet hom dra, maar mens kan nie vir Ben so ophou nie want dan gooi hy op, hy moet eintlik lê. As hulle miskien kan transport stuur wat ons elke maand op ons afspraak datums kan kom haal." (Rita, pg. 4, L 89)

The mothers also felt that limited support was offered by rehabilitation professionals in the public health care system. They thought that a better referral system would have afforded them greater access to the services offered by Speech-Language Pathologists, Physiotherapists, Dieticians and Occupational Therapists.

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[94] Or maybe once in a while for moms who are in the same situation. There is a room at the hospital where you can meet and ask: how do you do things, how do you work with your child?

[95] What makes it very difficult is getting to the hospital every month without my own transport. The pram is too big to fit into a taxi which means that I must carry Ben, but you can't hold him up because he vomits he should lie down. If they could maybe send transport to fetch us for our monthly appointments it would help.

> "And then once, it was maybe two years ago the Dietician said no she is going to make an appointment with the Speech Therapist. Because I said: Can I give him some yoghurt because somebody said I can give him some yoghurt. So she said: No you can't give him yoghurt and water. But she didn't make the appointment with the Speech Therapist, she left it just there." (Margaret, pg. 11, L 313)

> "I don't take him to [name of hospital] for physiotherapy either because I can cope. But I need sometimes, there is more basics that maybe they can show you." (Margaret, pg. 11, L 307)

Discussion of sub-theme: Facilitating capacity to cope within the public health care setting

The mothers in this study recalled many experiences related to accessing public health care services. Health care professionals and other mothers played an important role in how these experiences were perceived.

Supportive professional interactions appeared to play a role in facilitating the mothers' ability to cope with the challenges of a feeding difficulty as well as creating a positive perception of the public health care setting. The mothers valued interactions with professionals where they showed an interest in the child ("talked to him"), acknowledged the mother's efforts ("you are really a fighter"), displayed kindness ("she was caring"), developed a relationship with the mother ("op die eerste naam geken" – knew each other by the first name), imparted skills ("gewys watter oefening om te doen" – showed which exercises to do), when they provided them with options and allowed them to make decisions, as was shown in Tanya's story. It is noteworthy that professional knowledge and experience, in itself, was not mentioned as an enabler of capacity to cope. From the interviews it emerged that the mothers only valued professionally held knowledge and experience when the professional shared information and skills and empowered them to make decisions after which they supported them.

The key factor that emerged out of the current study was that professional interactions were valued and regarded to be enabling when a partnership rather than a paternalistic professional-patient relationship was established. Mothers valued professionally held knowledge and experience when the professional shared information and skills. These findings are in line with research that focused on parent-professional communication in paediatric health care settings. A review of thirty-one articles by Nobile and Drotar (2003) found that parental satisfaction with care was most frequently associated with effective parent-professional communication in which the professional showed a genuine interest in the family. Affirming the results of the current study, it was also found that during a child's hospitalisation a mother is greatly assisted when her needs related to confirmation of her efforts and participation, are met.

Tanya reported feeling very fortunate that she found a paediatrician who met her needs as a mother by "taking time to explain", "giving her options", "respecting her decision", "showing real interest", and "making herself available" as a source of information. What emerged from this study was that practical needs were best met when health care professionals adopted a partnership attitude during discussions of feeding management as well as during demonstration of adapted feeding strategies. Emotional support needs during a child's hospitalisation were met through empathic engagements during which health care professionals demonstrated respect, understanding and a caring attitude. The recognition that a health care professional's ability to meet both practical and emotional needs are of importance to mothers, is well summarized in the following quotation by Marks (1996):

"Patients know intuitively, their needs include both humanity and expertise; it requires little additional thought to realize that fragmentation of these qualities between different medical personnel, with the doctor providing only science and the nurse only sympathy, is neither humane nor scientific...we are all of us in need not of alternately science and tenderness but of a humane expertise from every sort of health care worker we encounter" (Marks, 1996, p. 213).

The potential role that allied health care professionals, and in particular Speech-Language Pathologists could play in enabling capacity to cope emerged as most of the mothers uncertainties about adapted feeding strategies were related to needing opportunities to practice during a child's hospitalisation and to acknowledgment that they were managing their child's care appropriately. An individual or department responsible for coordinating the diverse interventions and services that have to be provided by mothers to children requiring ongoing home based care and in particular ongoing adapted feeding strategies and who could furthermore ensure appropriate follow up services, may have served to address many of the mothers unmet needs.

Interacting with mothers in similar situations during a child's hospitalisation also emerged as an enabling factor when accessing public health care services. Parent-to-parent support has been shown to be a valuable tool in enabling capacity to cope (Singer, et al., 1999), which, in the current study, did not appear to be encouraged or facilitated in different hospitals accessed by the mothers. The value of such interactions may not be well known by health care professionals despite past research that clearly demonstrates the efficacy of parent-to-parent support for mothers of children with chronic illness. Such studies found that the personal nature of one-to-one support offered by parents in similar situations played an important role in increasing a parent's confidence which may possibly not be provided through any other means (Ainbinder et al., 1998).

The importance of being heard and offered hope

The previous two sub-themes summarised context specific support that was valued, and identified solutions to unmet needs within home-based caregiving and accessing public health care services. Apart from the agencies and individuals that were offering support, two attributes emerged from the stories that were highly valued by the mothers, namely "hearing" another person and "offering hope". "Hearing" is used in this context to signify a true understanding of the person rather than merely affording them time through listening. Experiencing a sense of being "heard" or understood has been identified as a powerful positive influence on a person's ability to make meaning of their lives (Rogers, 1980). Carl Rogers' person-centred approach to therapy is based on the premise that great therapeutic value is gained from the creation of an environment in which the person feels understood (Rogers, 1980). For the mothers who took part in this study, the perception of truly being heard was seen as an enabler of capacity to cope.

> "I go and talk to them [co-workers] that is the way I feel better. I don't keep it back I tell them how I feel and you know about my family and whatever. I just talk about it." (Margaret, pg. 7, L 203)

> [96]"Dan is dit nou my man is nie hier nie, en dan as ek daar [tronk] kom dan bars ek sommer uit met trane want ek kan dit nie meer vat nie. Dan vra hy: 'Wat is dit met jou nou?' Dan sê ek vir hom: 'Weet jy hoe hou ek dit heeltyd nou al in? Ek kan dit nie meer in hou nie.' Net ene wat ek trust, ek sien so uit om daar te kom, dan praat ek dit alles uit dat ek so lekker voel as ek daar weggaan, lig." (Sumaya, pg. 16, L 468)

> [97]"Ek het 'n vriendin ontmoet wat langsaan Ben gelê het. Ons het baie gepraat onder mekaar oor wat gebeur het. Dit het eintlik baie gehelp." (Rita, pg. 6, L 135)

> "You know, even as I'm talking to you [addressing me] now, I'm starting to see it [referring to her story and experiences] more clearly." (Agnes, pg. 4, L 99)

Tanya recalled a time when she employed a part time caregiver. She had forgotten how traumatic it was to care for her child in the beginning and experienced remorse at her expectation that another person should be able to deal with it without being given the time to adjust.

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[96] My husband is not here. When I get there [prison], I burst out in tears because I cannot take it anymore. Then he asks me: What is the matter with you? Then I tell him: Do you know how I keep it all inside, I can't keep it inside anymore. He is the only one I trust. I always look forward to visiting him then I let it all out, I talk about it which makes me feel so good, lighter [relieved].

[97] I met a friend who's son was lying next to Ben in the hospital. We spoke often about what had happened. It helped a lot.

> "But I think the thing is that doctors forget, you know even for myself. When I got my nanny you know initially when she said to me that she doesn't think that she would be able to work with the PEG. You know what I said? I turned around and said: Well then I'm not sure whether you are the right person for the job. I felt so bad afterwards because I had forgotten my initial reaction about having to deal with the PEG and here I was just expecting another person to walk in and do it. So I think certainly doctors forget about what it is like for parents, and you know every mom who they must give the diagnosis to or make the recommendation about a PEG they forget. And I think it would be amazing for them to come face to face with it to actually sit and read through what it is like and what the experiences are like and I think it will also help other mothers a great deal to show them that some of the feelings I have are normal and that it is going to be this journey which will be filled with positives and negatives." (Tanya, pg. 12, L 256)

Tanya thought health care professionals should listen to or read the stories of mothers caring for children with special needs, in order to better understand their experiences. Additionally, she felt that the mothers of children newly diagnosed with a feeding difficulty would also benefit from these shared experiences and be better prepared for the nature of the journey awaiting them. This suggestion may help enable caregivers to cope following a diagnosis of a chronic feeding difficulty.

The second attribute identified, which was highly valued by the mothers was that of giving hope. The concept of giving hope emerged when the mothers recounted interactions with health care professionals.

> "I think it is nice to give somebody a hope, not to say that no nothing is going to happen [referring to prognosis of future development]. Just give them that hope then they will push forward." (Agnes, pg 8, L 209)

> [98]"Luister na die ouers – moenie net vir ons sê nee nie. 'n Mens moet mos aanhou probeer." (Kathy, pg. 4, L 92)

The concept of hope was closely linked to a need to see a way forward, or a plan for the future. Stephanie and Agnes's words highlight their need to be part of an environment in which hope is fostered.

> "I just think, God you have to be in this thing! Where are we going from now? There has to be a way forward." (Stephanie, from Agnes's story, pg. 4, L105)

> "**[What would help?]** A caring environment of positive moving forward." (Agnes, pg. 7, L 186)

Two of the mothers (and Stephanie, a grandmother) spoke of the role that spirituality played in their ability to find meaning, or to make sense of their situations.

> "That we are walking this thing together, in a like mindedness of love for Rose, that we can pray together. It is actually, that is enormously comforting for me." (Agnes, pg. 3, L 80)

> [99]"Ons get geglo dat hy dit gaan maak, want ons het die drome gekry van die Here af. Ek het gedroom hoe hardloop Ben weer. Ons het geglo." (Rita, pg. 5, L 107)

> "I've always had this strong sense that, you know I believe God is the healer. I really do believe that actually there is healing for Rose. I really believe that. So that is for me a huge comfort." (Stephanie, from Agnes's story pg. 3, L 67)

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[98] Listen to the parents – don't just tell us no. A person has to continue trying.

[99] We believed that Ben would survive because we were getting dreams from the Lord. I dreamed how Ben was running again. We believed.

Spirituality is closely linked to the concept of hope and can be defined as a tendency to create meaning through finding relatedness in dimensions that transcend the individual (Reed, 1992) through a belief in something that is considered greater than the self (Haas, Britt, Coward, Leidy, & Penn, 1992). From the above quotations it emerged that spirituality had a positive influence on the mothers' ability to construct meaning and cope with their changed lives. Furthermore the mother's spirituality could be tested following the diagnosis of multiple disabilities.

> "I was a believer before and I can only say [laughs] it was tested in the fire, severely tested in the fire. Because it is very easy to believe and trust when everything is fine, but when it is not! But I just think that, yes that is how your character is built. I think even until even recently I believed that God would heal Rose and everything would be okay and we can go on with our lives. But definitely my faith is much stronger, or just my trust in God." (Stephanie from Agnes's story, pg. 1, L 11)

Discussion of sub-theme: The importance of being heard and offered hope

Two attributes were identified as being highly valued by the mothers, which was summarised as *the importance of being heard and offered hope.* Truly being heard and thereby understood was seen as enabling their capacity to cope. The mothers felt able to provide home-based caregiving and enabled during a child's hospitalisation when they felt understood by spouses, co-workers, health care professionals and other mothers in similar situations. The second attribute, being offered hope, was closely linked to a need to see a way forward, or a plan for the future. A discourse of hope also emerged from a study by Thorne et al. (1997) which they summarised as a theme of "Giving up hope". They found that health care professionals often failed to understand the significance of recommending gastrostomy placement to parents. The underlying meaning of gastrostomy placement for parents in their study was that it signified an end in the hope of recovery for a child, which often resulted in what the health care professionals' thought were irrational refusals of enteral feeding. Tanya's quotation about her initial reluctance to accept the placement of a PEG because she perceived it as signifying the end demonstrated a similar finding in the current study.

Spirituality can have a positive influence on an individual's ability to cope during an illness (Landis, 1996). What has also been documented is that the meaning system related to spirituality is often challenged at times of crisis which can either strengthen or weaken the person's spiritual beliefs (Dyson, Cobb & Forman, 1997). In a study conducted by Wilson and Miles (2001) of spirituality in mothers coping with a seriously ill infant, it was found that six of the fourteen mothers experienced both conflict and growth related to spirituality. This was similarly found in Stephanie and Agnes's story.

Summary of Essence 6: Facilitating the journey

Essence 6 highlighted various facilitators of the ongoing journey travelled by the mothers in this study. Their journey or experiences played out and must be understood within the contexts of providing home-based care and accessing public health care services. Various facilitators of their ability to continue this journey were identified. Factors that were already in place and that were meeting both practical and personal needs were discussed. The mothers identified existing *sources of support* that played a part in their journey towards reconstruction, which included family members, co-workers, support groups, other mothers and spirituality. The availability of respite care or sharing daily care tasks with a family member had immense value in meeting both personal and practical needs. When asked what would make their journey easier, in addition to access to a support group and respite care, they spoke of the need to be given hope, the need to see a way forward and to see change in their child. The mothers also felt that professionals who took an interest in and who spend time in understanding their needs and feelings would help. Two attributes were identified as highly valued by the mothers, namely empathic understanding and fostering hope.

What emerged in this study was that the mothers were very aware of enabling factors in their lives which increased their ability to provide home-based care, meet their emotional needs and during a child's hospitalisation. What also became apparent was that when these mothers were given the opportunity they could suggest solutions for how their unmet needs could be addressed. Many of their unmet needs were related to services that could potentially be offered within the public health care service or by independent agencies and health care professionals.

Implications

The following summary of recommendations stems directly from the solutions provided by the mothers in the current study. It should be acknowledged that some of these recommendations may not be feasible, especially in relation to services offered in the public health care context, due to resource constraints.

a. Implications for mothers and family members
   i. Spouses, family members and friends could help mothers by providing support. Examples of support that would assist mothers include assistance with general caregiving tasks, feeding related tasks, and respecting and following instructions made by the mothers related to adapted feeding and handling of the child.
   ii. Emotional support could be provided by allowing the mothers to talk about challenges and through showing true understanding of the implications of providing ongoing home-based care.
   iii. Employers could facilitate the journey by negotiating flexible working schedules which would enable the mothers to provide care when unexpected medical complications arose or when a child has to be seen for follow up medical consultations. Part-time employment would allow the mothers to continue working, providing respite, while at the same time enabling them to spend time caring for their respective children.

b. Implications for health care professionals
   i. Much of the uncertainty and possible fear of handling gastrostomy tubes and suctioning could potentially be reduced by inviting family members to participate during training sessions at the hospital.

ii. Health care professionals can facilitate the journey by taking cognizance of the valuable influence that interactions with other parents in similar situations could have for mothers. In this regard small group sessions facilitated by allied health care professionals, rather than providing exclusive individual sessions, could be a viable means of enabling mothers to establish links with other parents.

iii. Paediatric hospital wards could be structured in a manner where children with similar healthcare needs are placed in a specific area which would also enable mothers to establish contact with other parents.

iv. Improved systems of referral would have assisted the mothers in the current study, as would closer collaboration between the health care professionals involved in the respective children's' care.

v. A realisation that mothers require both humanity and expertise (Marks, 1996) from health care professionals should result in an increased focus on the nature of parent-professional interactions which should ideally encompass the dimensions of truly "hearing" and, despite having to offer truthful information about a child's prognosis, not discouraging the hope that a mother has for a child.

vi. The South African public health care system can facilitate the ability to cope by creating support services. Where resource constraints make this impossible the public health care system can play a role by providing the opportunity and physical space where support groups could meet.

vii. Information needs could be met by creating opportunities for parents to attend information sessions related to providing care in a diverse range of areas. In this regard health care professionals such as Speech-Language Pathologists, and Occupational Therapist could play an important part by presenting workshops which should be encouraged by the hospitals in which they are employed.

viii. Unmet needs related to providing home-based care and in particular to providing enteral nutrition could be met by offering more opportunities to practice newly acquired skills during a child's hospitalisation. Follow up support, and most notably home visits, would also ensure that mothers feel confident in providing newly acquired skills after a child's discharge.

ix. The possibility of providing assistance with transportation to hospitals for children requiring specialized medical care should be explored. Dial-a-ride is a governmental agency that is currently operating in South Africa with the intention of assisting individuals with disabilities who have financial constraints to access services. The mothers in the current study were not aware of this service which highlighted the need for improved information provision upon discharge.

x. Non-governmental agencies can help mothers by closer collaboration with health care professionals. The fact that only one of the mothers in the current study was accessing services offered by Home Based caregivers might be related to a lack of information about home-based care services available in South Africa. Non-governmental agencies should ideally form part of the management team when a child has been identified as requiring home-based care. Discharge plans that include ongoing support offered by such agencies would facilitate the mother's ability to provide caregiving at home. Where children require specialised care, as would be needed by a child who is receiving nutrition enterally or through adapted oral feeding strategies, caregivers trained in management of these would be required. Training of Home Based caregivers in assisting parents with feeding related tasks should be considered. Speech-Language Pathologists could potentially play an important part in such training programs.

c. Future research

i. Many of the above suggestions that emerged from the wishes expressed by the mothers are resource intensive. Future research that evaluates the management protocols that are currently in place in paediatric hospitals would be valuable to ascertain the financial and human resource expenditure that is required to assist parents in becoming home-based caregivers. Valuable information may also be gained by conducting a comparative study of financial expenditure incurred by the South African government in either providing placement options for children with disabilities or home-based caregiving. Information gained from such studies would potentially demonstrate that additional expenditure in equipping parents for the demands of caring for a child at home is justified.

ESSENCE 7: THE CONTINUING JOURNEY: NEGOTIATING BALANCE

The mothers in this study all spoke about the future, which for them held both certainties as well as uncertain paths for which they felt they could not prepare. An essence that emerged is that they experienced the phenomenon of being the mother of a child with a chronic feeding difficulty as travelling along a path without end. This "absence of an ending" or of a "temporal horizon" was identified by Hyden (1997) as the reason why there is a continued search for meaning in those living with chronic illness.

Sumaya used the words "gewoond te raak" (get use to), and "aan te pas" (adapt to) as opposed to "aanvaar" (accept) which illustrated a universal theme that emerged from the mothers' stories. The stories showed that the mothers were able to adapt to their changed lives but not necessarily accept the changes. At the time of Sumaya's interview she was still not able to dispose of the clothes worn by her son on the day that he sustained traumatic brain injuries six months prior. This powerful statement captured the difficulty that the mothers had in letting go of memories, the dream of their child and accepting their current situation.

> [100]"Dit was moelik toe ek eers terug huis toe kom. Ek wou alles wegpak, ek wou nie meer die fotos sien nie [haar seun voor die ongeluk]. Ek kon nog nie eers ontslae geraak het van sy ongeluk klere nie. Ek wil dit net nie weggee nie, uit my gesig nie, daar is nog iets wat my vashou. Daar is klomp dinge. Dit is swaar om aan te pas. Dit gaan my nog tien jaar vat om gewoond te raak aan wat gebeur het met hom." (Sumaya, pg. 13, L 388)

The other mothers also made reference to the fact that adaptation would take many years; that it is ongoing and may in fact never be completed. In contract to an expected negative impact, the continual redefining and search for meaning in the face of

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[100] It was difficult when I first got home after the accident. I just wanted to pack all the photos away [of her son before the accident]. I have not even been able to get rid of the clothes he wore on the day of the accident. I don't want to give it away. There is something that keeps me in that moment. There are a lot of things that make it difficult to adjust. It is going to take me another ten years to get use to what happened to him.

challenges resulted in personal growth for the mothers who took part in this study. It would however be an oversimplification to ignore the complexity of the cyclical nature of deconstruction and reconstruction which formed part of the mothers' stories. The journey continues as the mothers move between contradictory feelings of acceptance and denial. Rehana's difficulty in either putting away or continuing writing in a diary she started while she was pregnant illustrates this oscillation between acceptance and non-acceptance.

> "I started writing a book [diary] before she was born, while I was pregnant and then I started writing again a couple of months after she was born and then I just left it there. It is still next to my bed [starts to cry], just there, ja maybe I will pick it up again." (Rehana, pg. 16, L 483)

A philosophical, spiritual and emotional journey

Ongoing re-definition of meaning was evident in a changed world view expressed by some of the mothers. Rehana, Tanya, Rita, Sumaya and Agnes spoke of a change in the way they made sense of the world and in particular in what they considered to be important in their lives. For Sumaya and Rita there was a move towards growing hope, an emotional reaction to traumatic events which they were both surprised that they possessed.

> [101]"Ek het nooit geweet van hope hê nie. Ag as 'n ding gebeur dan gebeur dit so was dit met my. Maar nou lately het ek net hope. Want kyk hy is hier dit is a miracle. Ek kan dit nie explain nie maar moet nie hope opgee nie, waar daar nie hope is nie is daar nie lewe nie." (Sumaya, pg. 11, L 335)

What emerged from the interviews was an increased degree of introspection or ability to examine and question one's own thoughts, beliefs or emotional state resulting in changes

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[101] I never knew about hope. If something happened then it happened but lately I have hope because look at my child, it is a miracle. I can't explain it but don't give up hope because where there is no hope there is no life.

in philosophical and spiritual beliefs. A questioning of materialism as a means to define happiness rather than appreciation of a healthy child emerged.

> "I have changed as a person. Good and bad. I do become irritable more often and quicker. But for me the main thing is I use to be a very easy go lucky type of person. Now I have acceptance of the way things are but I've also got a change in outlook at how I look at the world where materialism becomes so apparent for me." (Tanya, pg 12, L 269)

> "That is sometimes I look at other people who have everything, and everything is going really well and I think why do they not appreciate it, why do they want it to be about worldly things, or material things when they should appreciate what they have?" (Rehana, pg. 15, 455)

Agnes spoke often of her journey in which she had to focus on living life in the present moment instead of focusing on a distant goal. Her words highlight a change in philosophical orientation where uncertainty and change was embraced and where growth was valued.

> "If we embrace the changes I think we grow otherwise we do get stuck. I've been very stuck… something came into my heart and I realized you cannot run if you are to go forward, you must walk. I was looking there [points far away]. Learn and grow." (Agnes, pg. 2, L 27)

Discussion of sub-theme: A philosophical, emotional and spiritual journey

Due to possible previous exposure to literature in the field of grief I initially started identifying reactions to loss which appeared to correspond to a stage theory of grief. However after a preliminary analysis of the interviews a pervasive, persistent sorrow emerged similar to that described in chronic sorrow theories. Further evaluation of the interviews revealed however that immense personal growth was occurring at the same time that chronic sorrow was experienced. Personal growth occurred despite or possibly because of obstacles and challenges that the mothers identified and met. The presence of both strength and perceptions of "brokenness" and how the mothers managed to balance these contradictory feelings is encapsulated within a metaphor of an ongoing journey in which balance is constantly negotiated.

This sub-theme highlights the cognitive coping behaviours used by the mothers in this study as they appraised and redefined meanings related to their beliefs about their children, approaches to living life and value systems. An ability to identify positive aspects of caring for a child with specialised care needs, a focus on the present moment rather than distant goals and re-evaluation of what is valuable in life, emerged as the mothers became introspective. The changed perception about what is important in life together with a questioning of the value of materialism as predicting personal happiness was also reported in a study of Asian parents' attitudes about parenting children with disabilities (Li-Tsang, Yau & Yuen, 2001).

Professional journals and popular media are filled with apparently contradictory statements focusing on either the positive (Hastings & Taunt, 2002; Scorgie & Sobsey, 2000) or negative (Cusckelly et al., 1998; Fuller & Rankin, 1994) implications of parenting a child with special needs. What emerged from the stories of the mothers who took part in this study, was that these are not mutually exclusive experiences. The mothers who took part in this study spoke of increased demands and stress associated with caring for a child with a chronic feeding difficulty while at the same time speaking about their increased personal resilience and ability to cope. It appeared that adjustment was ongoing and that they were in an ever continuing process of re-negotiating the meaning of their lives. This ongoing process or journey stands in contrast to theories emphasising the need to reach a point of stability or balance as is described in stage theories of grief (Silverman, 2001). What emerged in the current study is a continual balancing between opposing emotions (strength and insecurity) and tasks (caregiving and mothering). Though a perfect balance may seem to be the ideal that the mothers should strive towards in order to reach acceptance, what in fact emerged was that their experience and adjustments to a state of unbalance was the driving force that often resulted in positive personal growth. Their "brokenness" in fact led to openness to change.

Their journey became a *philosophical, spiritual and emotional journey* as they developed an increased degree of introspection, or ability to examine and question their own thoughts, beliefs and emotions, resulting in changes in philosophical and spiritual beliefs. This re-definition of meaning was evident in a changed world view, particularly in terms of what the mothers considered to be important in their lives since the diagnosis of a feeding difficulty was made. Focusing on the present and accepting uncertainty and change, as means to reach personal growth, emerged from the stories. While Judson (2004) found that the mothers who took part in her study refused to dwell on the past, in the current study the mothers reached a point where they could balance acknowledged losses with a future focused outlook.

Summary of Essence 7: The continuing journey: negotiating balance

The continuing journey: negotiating balance, emerged as an essential part of the mothers' experiences. Without acknowledging this aspect of their experience, the phenomenon of being a mother who is providing home-based care and accessing public health care services for a child with a chronic feeding difficulty cannot be fully understood. The mothers were engaged in an ongoing process of re-negotiating personal meanings as they "got use to" and "adapted to" their changed lives but not necessarily reaching a state of complete acceptance.

Post-traumatic growth (PTG) was discussed as a potential theory to understand how individuals respond to grief and loss. The current study supports the premises of PTG theories, that experiences of loss can act as a catalyst through which a person is changed by the experience and that a person may thrive under such conditions (Cadell et al., 2003). The current study also supports findings that growth occurs within three domains. The three domains in which growth occurred in this study, also identified by Tedeschi et al. (1998), were seen in changes in perceptions of self, changed relationships with others and a changed outlook on life that often includes a deeper appreciation for life and setting of new priorities.

The journey continues as the mothers move between contradictory feelings of acceptance and denial in an ongoing negotiation of balance-seeking both in terms of emotions (strength and insecurity) as well as in opposing tasks (mothering and caregiving). This continual meaning making in the face of challenges resulted in personal growth for the mothers. The process appeared to be cyclical in the sense that it was never a straight path towards reconstruction without at times returning to feelings associated with deconstructive processes. Positive or negative implications of parenting a child with special needs were not mutually exclusive experiences for the mothers but often co-occurred. Being a mother of a child with chronic feeding difficulties therefore afforded opportunities to find sources of support, to take control by becoming empowered, and resulted in an increased introspection which for the mothers in this study resulted in practical, emotional, spiritual and philosophical growth.

CHAPTER EIGHT

8.1. SUMMARY OF THE ESSENCES

This chapter provides an integrated description of the lived experience of being the mother of a child with chronic feeding difficulties, who is accessing public health services in Cape Town. This descriptive summary is intended to provide a more holistic view of the data. Some unique experiences emerged during the analysis of the interviews, however a number of core or fundamental aspects emerged that were universally experienced by the mothers. The seven essences that were identified formed the fundamental meaning of the phenomenon. I contend that should any one of these essences be removed, only a partial understanding of what it means for the participants in this study to be a mother of a child with a chronic feeding difficulty would be gained. The essences were shaped by factors operating in two contexts that dominated the mothers' stories; that of the home where the mothers were providing home-based care and public health care services. The analysis furthermore revealed that a mere description of the seven essences in relation to the two contexts could not provide insight into the dichotomy of positive and negative experiences that were present nor of the process or continuing journey within which the experiences were framed. The need for two categories or journeys that represented the seemingly contradictory experiences of deconstruction and reconstruction was required, in order to gain insight into how such processes are experienced and shaped within different contexts as well as to provide insight into their continuing and frequently overlapping nature.

8.1.1. Deconstruction: a journey of loss and disempowerment

Deconstruction was a universal process characteristic of the phenomenon that brings together experiences of loss and disempowerment. Deconstruction was strongly experienced and revealed in a loss of role clarity, questioning of competence and a loss of social connectedness.

For the women who participated in this study, being the mother of a child with a chronic feeding difficulty meant starting a journey filled with many emotional and practical challenges. They described initial feelings of loss in relation to the incongruence of expectation versus the reality after their child was diagnosed with a feeding difficulty. The incongruence between expectation and reality was most strikingly experienced in the inability to feed a child, as well as having to perform tasks that elicit discomfort or pain. The mothers experienced an intense emotional crisis in relation to the loss of oral feeding and to the need for enteral feeding. "Losing the mother dream" was the first experience in a journey which challenged personal capacity to cope. Losing the mother dream continues to be an ongoing experience as the mothers struggle to let go of ideals and dreams, both of motherhood as well as of the "ideal child". One part of being the mother of a child with a chronic feeding difficulty meant that these mothers had to make sense of societal, professional, and even personally held perceptions and beliefs about the link between the mothering role and the ability to feed a child. These mothers, through necessity, tried to feed their children on their own and engaged in a process of seeing what worked as there was not always sufficient support or guidance about adapted feeding strategies. For most of the mothers feeding became a tiring and overwhelming task, which challenged their emotional capacity to accept the loss of what they expected to be bonding opportunities.

The experience of loss described in "Losing the mother dream" continues as a thread throughout "Everything changes: living on the margins". Being the mother of a child with a chronic feeding difficulty resulted in changes within a broad range of contexts and has implications for social participation, employment status and future plans for these mothers. Feelings of isolation from the family and broader community resulted in the mothers describing themselves as "living life on the margins". Activities engaged in with ease prior to the diagnosis of a chronic feeding difficulty became difficult due to the time consuming nature of caregiving tasks. These mothers also experienced isolation from others who were perceived as lacking an understanding of the complexity and implications of integrating the roles of mother with caregiver. A dimension of the mother's lived worlds that is greatly affected is therefore relatedness to others. In

From their stories it was evident that these mothers experience sorrow recurrently, sometimes triggered by everyday losses. Chronic sorrow is thus experienced as these mothers adapt to their new lives but never completely accept the losses which it brings. The mothers' stories did not reveal an orderly progression through stages of bereavement and irresolvable grief continues to be an ongoing dimension of the phenomenon of being the mother of a child with a chronic feeding difficulty.

8.1.2. Reconstruction: "Getting through the brokenness"

The deconstructive processes that emerged in response to the question: "What does it mean to be the mother of a child with a chronic feeding difficulty?" only encapsulates one part of the core meaning of the phenomenon. In addition to experiences of loss and disempowerment the mothers in this study also experienced reconstructive processes as a direct result of being the mother of a child with a chronic feeding difficulty who is providing home-based care and accessing public health care services.

Being the mother of a child with chronic feeding difficulties encompassed a process of "getting through the brokenness" for the mothers in this study. The brokenness is an emotional captivity as they struggled to see past the "tragedy and harshness" of the situation. Reconstruction is part of the phenomenon as these mothers made positive personal adaptations through a process of "redefining the mother identity", "celebrating the positives", "becoming the enabler" and engaging in an "ongoing journey of philosophical, emotional and spiritual change".

For the mothers in this study the experience of ongoing loss resulted in opportunities for introspection which enabled self-knowledge and an increase in action-oriented (seeking information and acquiring skills), cognitive (redefining of meaning) and interpersonal (finding and accepting support) coping strategies. From their stories it was evident that these mothers experienced more than sadness and struggle as a consequence of becoming the primary caregiver of a child with a chronic feeding difficulty, but also experienced joy, triumph and opportunities for personal growth. As the roles of mother and caregiver becoming transformed as caregivers, these mother's relationships with spouses, extended family members and friends were altered and took on new meanings. Feelings of isolation also emerged because the mothers perceived themselves and their children to be invisible, as children requiring adapted feeding strategies are not reflected in popular media. Restrictions in participation occurred because of the demanding nature of the child's caregiving needs; because of a lack of support in providing the care; and because of family members, friends and health care professionals who may not have an understanding of the needs of mothers who are providing home-based care.

Being the mother of a child with a chronic feeding difficulty encompassed a number of disempowering experiences. "Expected versus enabled to cope" is a reality as these mothers experienced pressure from family members and health care professionals to deal with the diagnosis of a feeding difficulty, together with the practical and emotional implications of such a diagnosis without being given sufficient support. Disempowering interactions with health care professionals are a reality for the mothers, who frequently had to access health care services because of the chronic nature of their children's difficulties. Being the mother meant that frequent interactions with health care professionals were needed who may appear brusque, uninterested and not skilled in creating a trusting partnership through which skills and information could be shared in an empowering manner. Interactions with health care professionals and experiences within the public health care system resulted in feelings of disempowerment, distrust and anger. Such feelings may, with time, alter the manner in which these mothers interact within this context in order to build their own capacity to cope and have their needs met. Capacity to cope and role confidence was further deconstructed when accessing public health care services that are fragmented and focused on medical management without considering the mother's needs. A sense of disempowerment occurred in relation to a health care system in which the mothers became passive observers in the care of their children.

Emotions of isolation, sorrow, fear, helplessness and frustration are experienced both within the home context as well as during interactions with the public health care system.

became integrated they experienced an increase in their capacity to meet home-based caregiving needs. A growth occured in the ability to construct new meanings and beliefs about "the good mother" as well as of the "ideal child" by focusing on the significance of positive changes observed in a child with time. The experience of being a mother within a perceived traumatic context therefore resulted in personal growth that corresponds to an increased capacity to cope that has been documented in post-traumatic growth research. "Self-empowered: becoming the enabler" is a process that formed a core principle of these mothers' experiences. Self-empowerment was gained through necessity, trial and error attempts, by taking control of the situation, by finding and accepting support and through a discovery of inner strength and reserves. Being the mother of a child with a chronic feeding difficulty meant that information, skills and confidence can be acquired however that this process might have to be embraced by a mother as these may not readily be offered or enabled by others.

For the mothers in this study practical and emotional support needs, in relation to providing home-based care and when accessing public health care services, were present and at times remained unmet. The mothers were aware of the support that they need, could identify supportive people and organisations, and were prepared to accept such support where available. An increased capacity to seek out and potentially create sources of support may emerge with time. Through redefining role identities, celebrating the positives, becoming enablers and finding sources of support the mothers appeared to progress from initially being passive observers in their children's care to becoming empowered woman as they took control of their lives. Personal growth occurred despite or possibly because of obstacles and challenges that they faced.

8.1.3. The ebb and flow of deconstruction and reconstruction

Even though these mothers transcended the emotional captivity and became empowered there are still times when they feel beaten down, mostly when reminded of what was lost. What emerged from this study was that growth and loss co-occur. Even though they move towards a position of strength with time, they also re-experience feelings of disempowerment and sorrow. Post-traumatic growth therefore co-occurs with chronic sorrow. The presence of both strength and perceptions of "brokenness" and how these mothers managed to deal with such opposing experiences can be understood in relation to a continual balancing of loss with a focus on positive outcomes. The phenomenon of being the mother of a child with a chronic feeding difficulty continues to be a transformative experience for these mothers, in which personal growth emerges in the face of struggle and loss. The journey continues as the mothers move between contradictory feelings of acceptance and denial in an ongoing negotiation of balance-seeking both in terms of emotions (strength and insecurity) as well as in opposing tasks (mothering and caregiving). The process appears to be cyclical in the sense that it is not a straight path towards reconstruction without at times returning to feelings associated with deconstructive processes. Positive or negative implications of parenting a child with special needs are not mutually exclusive experiences for them but often co-occur.

"What man actually needs is not a tensionless state but rather the striving and struggling for some goal worthy of him. What he needs is not the discharge of tension at any cost, but the call of a potential meaning waiting to be fulfilled by him" (Frankl, 1963, p.166).

8.2. LIMITATIONS OF THIS STUDY

The goal of this study was to obtain a full and true representation of the mothers' experiences. It is possible that this study failed to fully or accurately describe the observations and therefore possible sources of error should be considered. Researcher held beliefs about a phenomenon may become a source of bias and error. Filtering occurs when the researcher selects some data that is considered to be valued while rejecting other data. Valued data may be identified based on what a researcher hopes to find but may also occur as participants influence the data by withholding or focusing on certain aspects of their experience. When I embarked on this study I held no preconceptions of what might emerge only that a truthful understanding of these mothers has not been documented.

A small number of participants is often identified as a limitation to research. I contend that the small sample used in this study was in line with the aims of phenomenological research that focus on depth of meaning rather than the need to make statistical projections. Though some might consider 7 participants to be a small sample set, I rather found that an immense wealth of information emerged from these interviews which often left me feeling that the time consuming nature of identifying essences was challenging. A larger sample would have resulted in a superficial exploration which in turn would have revealed less about the essence of the experience. It is my contention that a balance between the number of participants and the depth of analysis was maintained.

At times I shared Edmund Husserl's thoughts regarding Transcendental Phenomenology, "It is all of it hard." (Husserl, 1932, p. 164). As a novice to qualitative research I struggled at times to analyse the immensely rich data and was concerned that some of the depth was lost as I attempted to provide a full description of the essence of the phenomenon. A potential limitation of this study was that a wealth of information emerged from the interviews and that it might therefore be argued that a narrower delineation of the study, possibly only focusing on what it means to provide home-based care or what it means to access public health care services, would have resulted in greater depth of insight. I attempted to provide sufficient information, on these two contexts, by incorporating thick descriptions and many direct quotations which should aid the reader in gaining insight into the meaning of being a mother within both contexts, namely home-based caregiving and accessing public health care services. In this regard it is felt that the rigor of the study was increased as transferability, or gaining an insight of other mothers within the same contexts, should be possible.

Potential differences might also emerge in the interpretation of sections of text. As Ricoeur (1998) stated, "it is true that there is always more than one way of construing a text." In order to limit error and researcher bias in interpretation of the text, validation strategies were used. The mothers were asked to review a preliminary summary of their stories to verify my interpretation thereof, and a multiple coding strategy during which ten independent coders provided insight into their interpretations of segments of text was also used.

8.3. CONCLUSION

The objective of this study was to identify issues through the lens of mothers of children with chronic feeding difficulties. It is hoped that this study will stimulate thought and guide interventions for mothers who are providing home-based care and accessing public health care services in Cape Town, South Africa. Little is known about the impact that providing such care may have on factors such as the mother-child relationship, restrictions on social and economic participation, and the mother's construction of meaning for her changed role and life. No studies have been conducted in South Africa that would create an understanding of how mothers experience the role of providing home-based care for a child with chronic feeding difficulties, nor of their experiences during times when they access public health care services for their children. These two contexts, which may be fundamentally different in other countries, emerged as significant in shaping the mothers experiences.

A number of implications of the current study were identified as they relate to an understanding of who these mothers are and how they define themselves; how their experiences are influenced by others particularly, health care professionals; and the role played by the public health care system in how they create meaning in their lives. These implications were provided following the summary of each essence. It is hoped that the analysis of the structure and processes of the mothers' experiences will add towards the development of theory concerning this experience, as well as identifying theoretically and clinically important outcomes, and defining effective practice. The intention of this study was not to provide the final word on the phenomenon, but hopefully to increase awareness of the need for further research aimed at improving service delivery in South Africa. Though the study was delineated within the context of the public health care service it is believed that the findings will add value to all health care professionals and organisations involved in the care of children with chronic feeding difficulties.

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Research Ethics Committee
E53 Room 44.1. Old Main Building
Groote Schuur Hospital
Observatory
Tel: (021) 406 6592

Appendix A

Research information sheet

Research title:
"The lived experience of being the mother of a child with chronic feeding difficulties."

The researcher: Ronelle Hewetson

Dear caregiver,

I am a Speech-Language Pathologist who is a Masters' student at the University of Cape Town. I would like to invite you to take part in my study which looks at the experience of caring for a child with a long-term feeding difficulty. This study has been approved by the University of Cape Town Research Ethics Committee (RECREF 373/2006).

Aim of the research:
I would like to describe the experiences of mothers, caring for the daily feeding needs of a child with a long-term feeding difficulty. To be able to do this I am interested in your experiences, how you see yourself as a caregiver and what things have played a role in shaping your experiences of caregiving.

For this study, I will ask you:
- about your experiences of caring for a child with a long-term feeding difficulty,
- to describe things that help you to cope,
- to describe things that make it difficult to cope with caring,
- about your support needs, and
- about your experience of available services.

Benefits:
The information gathered will assist Speech-Language Pathologists to develop better services for caregivers of children with chronic feeding difficulties.

Time and venue:

I will need about one and a half hours of your time to do the interview. You will be asked to fill out a short questionnaire and to read a short summary of your interview to make sure that I understood your experience correctly. You can choose a place that will be most convenient for us to meet.

Costs:

There will be no costs involved.

Confidentiality:

I will be audio taping the interview and then transcribing it verbatim. All the information I collect will be handled as confidential and under no circumstances will your or your child's name be made known. Some quotations of your interview may be included in the final report. The quotations chosen will not in any way make known your or your child's name. If during the interview or when reading the summary you decide that something should not be included in the final report you may indicate so.

Your participation in my study will be greatly appreciated and is completely voluntary. If at any time you wish to withdraw I would like to assure you that there will be no negative consequences. Please ask questions if further information is needed.

If you are willing to take part in this study please e-mail or phone me at the contact details below. If you are willing to take part I will contact you to arrange a convenient time and place for the interview. I will then also ask you to sign a consent form in which you show that the aims and nature of this study has been explained to you.

Kind Regards
Ronelle Hewetson

E-mail: rhewetson@gmail.com
Telephone: (021) 782 0107 – work
(021) 785 4038 – home
082 6290873 – cellphone

Navorsing Etiese Komitee **Appendix B**
E53 Kamer 44.1. Old Main Building
Groote Schuur Hospitaal
Observatory
Tel: (021) 406 6592

Navorsing informasie blad

Navorsing titel:
"Die ondervinding van ma's van kinders met kroniese voeding probleme."

Die navorser: Ronelle Hewetson

Geagte versorger,

Ek is 'n Spraak Terapeut wie 'n Meesters by die Universiteit van Kaapstad doen. Ek will u graag uitnooi om deel te neem aan my studie waarin ek kyk na die ondervindings van moeders wie sorg vir die langstaande voedings behoeftes van kinders. Hierdie studie was goedgekeur deur die Universiteit van Kaapstad se Navorsing Etiese Komitee (RECREF 373/2006).

Die aard en doel van die navorsing:
Die doel van hierdie studie is om die persepsies van versorgers te beskryf, veral met betrekking tot voedings probleme. Om dit te kan doen wil ek graag meer leer oor hoe u die rol as versorger ondervind en watter faktore 'n rol gespeel het in u ondervindings.

Prosedure van die navorsing
Vir hierdie studie het ek nodig om u te vra oor:

- u ondervindings van die daaglikse voedings behoeftes van u kind,
- dinge wat u help,
- dinge wat dit vir u moeilik maak,
- hulp wat u van andere ontvang, en
- u ondervindings met betrekking tot beskikbare dienste.

Voordele:
Die inligting sal vir Spraak Terapeute help om beter dienste te ontwikkel vir beide versorgers en kinders met kroniese voedings probleme.

Tyd benodig:

Ek gaan omtrent 'n uur van u tyd benodig om die onderhoud te doen. U sal ook gevra word om 'n kort opsomming van die onderhoud te lees, of ek kan u bel na die onderhoud om seker te maak dat ek u ondervindings korrek beskryf het. U kan 'n plek kies wat vir u pas waar ons die onderhoud kan hou.

Kostes:

Daar is geen kostes betrokke nie.

Vertroulikheid:

'n Bandopnemer sal gebruik word om the onderhoud op te neem. Daarna word die onderhoud verbatim getranskribeer. Al die inligting wat ek insamel sal vertroulik gehanteer word en beide u en u kind sal anoniem bly, u name sal nie gemeld word nie. Van die transkripsies mag dalk gebruik word in die finale verslag. Die dele wat gebruik gaan word sal nie op enige manier u of u kind identifiseer nie. As u voel dat u eerder iets persoonlik wil hou mag u vir my dit so noem en dan sal ek nie die inligting in my studie gebruik nie.

U deelname in die studie sal waardeer word en is heeltemal vrywillig. U kan ook op enige stadium van die studie onttrek, sonder om enige nadeel te ervaar. Vra my gerus indien u vrae het of meer inligting benodig.

As u bereid is om deel te neem stuur vir my asseblief 'n e-pos of kontak my by die telefoon nommers wat volg. As u belangstel sal ek u kontak om 'n tyd en plek te reël wat vir u pas om die onderhoud te voer. Ek sal op daardie stadium vir u vra om 'n toestemming form te teken waarin u meld dat die doel en prosedure van hierdie studie aan u verduidelik was.

Vriendelike Groete

Ronelle Hewetson

E-pos: rhewetson@gmail.com
Telefoon: 082 6290873 – selfoon
(021) 785 4038 – huis
(021) 782 0107 – kantoor

Research Ethics Committee
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Appendix C

Date: ……………………...

Research Consent Form

Research title:

"The lived experience of being the mother of a child with chronic feeding difficulties."

Researcher: Ronelle Hewetson

I …………………………………………… hereby consent to participate in this research study. The aim and nature of the study has been explained to me. I understand that participation will entail an interview which will be audiotaped and transcribed as well as reading a short prelimary analysis of the information at which stage I will be asked to indicate if my experience has been understood accurately or to make amendments if need be. My right to voluntary participation and withdrawal from the study, at any time without any penalty or without having to make my reason known, has been explained to me.

Name of participant:	Signature
Ronelle Hewetson Name of researcher:	Signature

E-mail: rhewetson@gmail.com

Telephone: (021) 782 0107 – work
(021) 785 4038 – home
082 6290873 – cellphone

Name of supervisor: Prof. Shajila Singh

E-mail: sasingh@uctgsh1.uct.ac.za

Telephone: (021) 406 6317

Appendix D

Throughout the study I made entries into a research journal which reflected my observations, thinking, my decisions about how to proceed, what to change, thoughts about possible themes and even my feelings at the different stages of the process. I also made entries as to the feelings that were evoked in me which served an important part in that they were often reflections of what the mothers themselves were experiencing.

Extracts from reflective journal

Interview: Sumaya

"I left the interview feeling absolutely drained, finished. I feel a great sadness, lonely really. Her story was similar to Rita's and yet I did not feel this heaviness afterwards. What is different between the moms – they are both in their 20's, both have another child, both are financially constrained with no personal transport, two months difference in terms of the length of time that caregiving has been provided, both children experienced a sudden loss of feeding following a period as independent eaters, both are receiving exclusive enteral nutrition. The only notable difference is that Rita is helped by her mother whereas Sumaya is solely responsible for all caregiving needs....evaluate the perception of coping in terms of practical caregiving support received."

Interview: Tanya

"Today I was asked "How do you cope with hearing our stories?" Tanya was recalling personal emotions, other mothers' stories that she had heard and while speaking about this she turned to me and posed the question. I have been thinking about this, because yes, there is an emotional investment, a very powerful need to fully understand, to try to feel the emotions of the mothers and I have been feeling their sadness, strength, sorrow, frustration, anger, loneliness so powerfully. I wasn't prepared for their emotions, their honesty, the way they laid open their hearts for me to see and entrusted me with their stories of shattered dreams and changed lives. It has been a long journey for me too. I am concerned about my ability to capture the intensity of the stories– it seems so detached and cold to select pieces of text that address an arbitrary theme when it is in fact a piece of a mother, a piece of another human's life and heart."

Appendix E

Biographical Questionnaire

Please complete the following questionnaire. Neither your, nor your child's name will be reported in the research.

Caregiver and family information:

1. What is your age? ______________________
2. Are you married/living with somebody? ______________________
3. What is your relationship to the child? ______________________
4. Are you employed? ______________________
5. How many people make up your household? ______________________

Child information:

1. What is your child's age? ______________________
2. What type of physical or other difficulties ______________________
   does your child have? ______________________
3. How long has your child had feeding difficulties? ______________________
4. How is your child fed? ______________________
   (Orally, enteral, combination of oral and enteral)

Support received:

1. Does anybody help you to feed your child? ______________________
   (Who? How often?) ______________________
2. Do you receive help from anybody else? ______________________
   (In the family/community? From professionals?) ______________________

Thank you for completing the questionnaire.

Appendix F

Interview Guide

Main question:

"Please tell me as fully as you can about your experiences of being the mother of a child with chronic feeding difficulties. In answering this question think about the things that have played a role in how you experience your role as the child's mother."

Probes, relating to:

1. Mother's experience of caring for a child with a chronic feeding difficulty

a) How do you feel about caring for your child? (Feeling question).
  - initial feelings when you realized that the child had a feeding difficulty
  - has your feelings changed since then?

b) How does your experiences differ from others? (Opinion question)
  - Spouse, other family members, mothers of children without feeding difficulties

b) Tell me about mealtimes. (Experience and behaviour question).

2. External and intrinsic factors that enhances a mother's ability to cope

a) Tell me about the things that help you? (Opinion question)

b) Who has been the most supportive? (Opinion question)

3. Challenges and barriers

a) What has been difficult for you? (Feeling and Opinion question)

b) Describe whether caring for your child has influenced your relationship with others? (Opinion question)

4. Support needs

a) Thinking of the things that have helped you, what information and advice would you give to other mothers? (Opinion question)
  - by whom should information be given, when should it be given

5. Mothers' perceptions of available services

a) Tell me about your experiences with health care providers and other professionals who have been involved with your child. (Experience and behaviour question)

b) How do you feel about the services that are available to you? (Feeling question)

Flowchart of Data Analysis Procedure

Appendix G