MOTHERS’ EXPERIENCES OF AN INTERDISCIPLINARY TEAM PROCESS FOR THEIR CHILD WITH A FEEDING DISORDER

by

ROCHELLE H. STOKES
B.Sc. (Occupational Therapy), University of British Columbia, 2004

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ABSTRACT

**Purpose:** (1) to describe mothers’ experiences of an interdisciplinary feeding team process for their child with a feeding disorder; (2) to explore the perspectives of mothers as they implement recommendations from the feeding team.

**Methods:** In this qualitative descriptive phenomenological study, nine mothers whose child had a complex feeding disorder and who recently went through an interdisciplinary feeding assessment participated in two semi-structured interviews. The first interview took place just after the feeding assessment, while the second was conducted a few months later. Colaizzi’s method of data analysis was used to analyze the data.

**Findings:** Five themes emerged from the analysis. *Taking Action* reflects the recognition and the action that was being taken by mothers to address their child’s feeding disorder. *The Balancing Act* describes the range of experiences that mothers identified during the interdisciplinary assessment process. *The Impact* reflects the mix of emotions that mothers experience at the conclusion of the feeding assessment, as well as the knowledge and insight gained regarding their child’s feeding. *We Are On Our Own* represents the process of positive change that mothers go through as they implement recommendations from the team; and finally, *We Can Now Move Forward* describes the restoration of balance in the lives of mothers as they adapt to the recommendations provided by the team. Knowledge gained from the feeding team facilitates mothers’ acceptance of their child’s feeding difficulties and helps them to look towards the future with renewed hope. The stressors that mothers’ experienced prior to the feeding assessment had an impact on their experience of the assessment. Mothers described uncertainties and anxieties prior to and during the feeding assessment. These stressors have the potential to be alleviated with increased communication with families.
**Implications:** This study has highlighted the importance of using an interdisciplinary team to address paediatric feeding difficulties. In addition, the findings suggest that receiving knowledge helps to facilitate problem-focused coping in mothers. Understanding the broader impact of an interdisciplinary feeding team on decreasing caregiver stress is critical for further legitimizing the service and ensuring funding when the healthcare system is already strained.
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LIST OF ABBREVIATIONS

BC..........................................................................................................................British Columbia
CPG........................................................................................................................Central Swallowing Pattern Generator
DVD..........................................................................................................................Digital Video Disc
FAAR......................................................................................................................Family Adjustment and Adaption Response Model
FM..........................................................................................................................Formulated Meanings
GER........................................................................................................................Gastroesophageal Reflux
GERD......................................................................................................................Gastroesophageal Reflex Disease
G-tube.....................................................................................................................Gastrostomy Tube
LSI-P.......................................................................................................................Life Satisfaction Index-Parents
NG-tube..................................................................................................................Nasogastric Tube
OPA.........................................................................................................................Oropharyngeal Aspiration
PSS.........................................................................................................................Parenting Stress Scale
SHFT.......................................................................................................................Sunny Hill Feeding Team
SHHC.....................................................................................................................Sunny Hill Health Centre for Children
SS.........................................................................................................................Significant Statements
UBC.......................................................................................................................University of British Columbia
VFSS......................................................................................................................Videofluoroscopic Swallow Study
GLOSSARY

**Aspiration**
Passage of any material (e.g. food, liquid, saliva) below the level of the true vocal folds into the trachea (Weir, McMahon, Barry, Ware, Masters & Chang, 2007). If there is no cough, choke or other signs of problems when food or liquid enters the trachea, it is considered ‘silent aspiration’ (Arvedson, 2008).

**Dietitian**
Dietitians plan, implement and manage nutrition and food service programs in a variety of settings. Programs are directed at encouraging healthy nutrition outcomes and the prevention of nutritional disorders; and providing treatment of nutrition-related diseases and conditions (CIHI, 2005).

**Feeding Disorders/Feeding Difficulties/Feeding Impairments**
Problems in a broad range of eating activities that may or may not be accompanied by a difficulty with swallowing food and liquid. Feeding disorders may be characterized by food refusal, disruptive mealtime behaviour, rigid food preferences, less than optimal growth and failure to master self-feeding skills expected for developmental levels (Arvedson, 2008).

**Gastrostomy Tube**
A gastrostomy tube is a surgically created fistula through the abdominal wall and into the stomach. A tube is placed through this fistula into the stomach, where it remains to be used for feeding. These tubes are open for bolus feedings, then sealed with a clamp and secured beneath a child’s clothing when the feeding is completed. Gastrostomy tubes can also be kept open and used for continuous drip pump feedings (Nelson & Hallgren, 1989).
Interdisciplinary Team

The interdisciplinary approach involves the interaction of a group of professionals, each of whom brings a specific area of expertise. A true interdisciplinary approach involves each member of the group sharing the philosophy for diagnosis and treatment and being willing and able to work with other team members within the group. Important members of an interdisciplinary feeding team include: an occupational therapist, a speech and language pathologist, a social worker, a dietitian, a nurse clinician and a paediatrician (Arvedson & Brodsky, 2002).

Nasogastric Tube

A slender, flexible gavage tube is passed through either the nose or mouth into the stomach. It can be removed and replaced for each feeding, or it can be taped in place and left “indwelling” for several days, weeks and sometimes months (Wolf & Glass, 1992).

Occupational Therapy

Occupational therapy is a health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists have a broad education that equips them with the skills and knowledge to work collaboratively with people of all ages and abilities that experience obstacles to participation. These obstacles may be caused from an impairment of body structure, a change in function or from barriers in the social and physical environment (adapted from the World Federation of Occupational Therapists, 2004) (CIHI, 2005).
**Paediatrician**

A paediatrician is a physician who specializes in paediatrics. Paediatrics is the branch of medicine dealing with the development, care, and diseases of children (http://www.merriam-webster.com/medical/pediatrics-fix).

**Pneumonia**

Pneumonia has been defined as pulmonary infiltrates on a chest radiograph or by clinical signs and symptoms (Wright, Pomerantz & Luria, 2002).

**Registered Nurse/Nurse Clinician**

Nurses’ duties include planning, implementing and evaluating care and programs on the basis of the nursing assessment. They play a key role in illness prevention and health promotion, as well as treating health conditions and assisting clients, families and communities throughout the life cycle. Within the collaborative health care team environment, registered nurses work autonomously. Some of the areas of responsibility include medicine, surgery, obstetrics care, psychiatric care, critical care, paediatrics, geriatrics, community health, occupational health, emergency care, health promotion, rehabilitation and oncology (CIHI, 2005).

**Social Worker**

Social workers promote social change aimed at improving conditions that affect the health and well-being of individuals, families, groups and communities; they provide counselling, therapy and problem-solving interventions to create a functional relationship between the system and those that interact with it (CIHI, 2005).

**Speech and Language Pathologist**

Speech-language pathologists are autonomous professionals who have acquired an expertise in the area of human communication and its disorders. They are engaged in the prevention,
identification, evaluation, assessment, treatment and management of and counselling, research and education about communication and swallowing disorders. Communication disorders include disorders of speech, language, voice and fluency in individuals from all age groups (CIHI, 2005).

**Sunny Hill Health Centre Feeding Team**

The Feeding Team serves children, birth to 19 years, and their families across British Columbia (BC). They provide services to meet the needs of children with significant feeding and swallowing difficulties. The team assists families and community professionals to ensure their child is meeting his or her nutritional requirements as safely as possible. This interdisciplinary team works together with the child, the family and the community to address the feeding concerns. The team acts as a resource to supplement, rather than duplicate, community services.

**Swallowing**

Swallowing is a complex motor sequence involving the coordination of a large number of muscles in the mouth, pharynx, larynx and the esophagus. Swallowing provides the mechanism by which food is transported from the environment to the alimentary tract for the survival of the child (Wolf & Glass, 2002). The normal swallowing process consists of three phases: oral, pharyngeal, and esophageal (Bass, 1997).

**Swallowing Disorders/Dysphagia**

Problems in one or more of the phases of the swallow, particularly in the timing and coordination of these phases (Arvedson, 2008).

**Videofluoroscopy Swallowing Study**

Videotaped x-rays that show how food passes from the mouth through the pharynx. This study is commonly recommended and accepted as the criterion standard for evaluating the unseen
pharyngeal and oesophageal stages of swallowing and the presence of aspiration or penetration (Lefton-Grief & Arvedson, 1997).
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CHAPTER ONE

1. INTRODUCTION

1.1 Background

Feeding and swallowing are vital bodily functions. Sucking and swallowing can be seen as early as 12-14 weeks gestation, and a swallowing reflex is present in a newborn. Even though feeding and swallowing may appear to be an automatic function, recent dramatic increases in feeding disorders have been reported and suggest that problems with and treatment of this vital activity of daily living are complex. Indeed, increasing numbers of children are surviving complex medical conditions and severe prematurity. Improved neonatal survival has resulted in a significant increase in feeding and swallowing deficits (Field, Garland & Williams, 2003; Rommel, De Meyer, Fennstra & Veereman-Wauters, 2003). In addition, the prevalence of feeding impairments includes 33-80% of children with neurological disabilities (Field et al., 2003), as well as 25-40% of normally developing infants and young children (Beautrais, Fergusson & Shannon, 1982; Forsyth, Leventhal & McCarthy, 1985).

Typical feeding impairments are complex, multi-causational in nature and often have a combination of organic and non-organic etiologies (Budd et al., 1992). Numerous causes of feeding disorders in children are described in the literature, including metabolic diseases, sensory defects, anatomic abnormalities, disorders affecting neuromuscular coordination of the swallow and esophageal peristalsis (Rudolph & Link, 2002). As a result, children may present with oral-motor delays, dysphagia, food refusal, and oral aversions (Fayed, Berall, Dix & Judd, 2007; Field et al., 2003).

Feeding impairments have serious implications for the health and well-being of children. Some children with feeding difficulties present with problems gaining weight, or are diagnosed
as ‘failure to thrive’ (Garg, 2003). For the purposes of this study, the term ‘feeding disorder’ includes a number of conditions that interfere or prevent children from obtaining adequate nutrition, for example: food refusal, food selectivity, oral-motor dysfunction, gastroesophageal reflux and dysphagia. Dysphagia, or swallowing disorder, is a term used for children who have alterations in the coordinated act of swallowing (Garg, 2003). Children with dysphagia will often present with feeding or respiratory difficulties. Additional consequences of swallowing disorders include the risk of acquiring pneumonia. Oropharyngeal aspiration (OPA) is defined as small volume aspiration of fluids, food particles and/or oral secretions below the level of the true vocal folds (Weir et al., 2007). OPA is particularly high in children with disabilities; a study by Mirrett, Riski, Glascott and Johnson (1994) found that in a sample of 22 children with cerebral palsy, 68.2% were found to have OPA on a videofluoroscopic swallowing study (VFSS). OPA is reportedly the most common cause of recurrent pneumonia and responsible for 8% of children hospitalized for pneumonia (Owayed, Campbell & Wang, 2000). Complex feeding disorders have serious implications for the health of children, but also for the costs incurred by our medical system due treatment and hospitalization required for these children (Carter & Jancar, 1983; Rempel, Colwell & Nelson, 1988).

Literature is growing on the multiple etiologies of paediatric feeding disorders. As a result of the multi-factorial nature of feeding disorders, an interdisciplinary team approach to assessment and treatment is critical. Research has been conducted on the use of interdisciplinary teams for assessing and managing feeding and swallowing disorders (Fayed et al., 2007; Geggie, Dressler-Mund, Creighton & Cromack-Wong, 1999; Miller, Burlow, Santoro, Mason & Rudolph, 2001; Puntis, 2008; Simonsmeier & Rodriguez, 2007). Professionals in an interdisciplinary team complete separate assessments and then combine the results of their
knowledge to prioritize and provide recommendations (Geggie et al., 1999). The use of an interdisciplinary team allows multiple disciplines to evaluate a child during only one or two visits, saving the family time and money (Miller, et al., 2001). Communication is also streamlined when professionals work together and discuss their findings, resulting in a reduction in miscommunications with families (Miller et al., 2001).

A comprehensive assessment for a child’s feeding disorder involves consideration of the broad environment, the health status of the child, the interactions between parents and their child and parental concerns (Arvedson, 2008). King, Cathers, King and Rosenbaum (2001) found that parents who were highly satisfied with service delivery reported the elements of respectful and supportive care (i.e. feeling listened to and having a sense of rapport with service delivery providers), as being the most important to them. The reality for many interdisciplinary feeding teams is that time is limited to build rapport with families and to understand fully the family’s broader environment. Interdisciplinary teams would benefit from having a prior understanding of parents’ experiences of an interdisciplinary team process. This knowledge would expand their understanding of the stresses that parents may be experiencing and in understanding what elements of a feeding assessment may be difficult for parents. Having knowledge regarding the experiences of parents going through an interdisciplinary assessment may help professionals to build faster relationships with families and assist professionals in making more concerted efforts to listen to families, thus providing more respectful and supportive care. While the literature suggests that an interdisciplinary team assessment is the most effective way to manage and provide service to families of children who have feeding and/or swallowing disorders, no formal studies examining parents’ experiences of this type of assessment have been reported.
1.2 Purpose and Objectives of Study

The purpose of this study was to understand mothers’ experiences of an interdisciplinary team assessment for their child with a complex feeding disorder. This study had the following objectives to: (1) describe the experiences of mothers of children with complex feeding difficulties who have gone through an interdisciplinary team process; (2) explore the perspectives of the mothers as they implement recommendations from the feeding team.

To date there have been no studies examining the experiences of mothers as they go through an interdisciplinary team process for their child with complex feeding difficulties. Qualitative research is often used when there is a need to understand a complex issue (Creswell, 2007). This type of research enables health science researchers to delve into questions of meaning, examine institutional and social practices and processes, identify barriers and facilitators to change, and discover the reasons for the success or failure of interventions (Starks & Trinidad, 2007). Specifically, phenomenology is one qualitative methodology which expresses the meaning for several individuals, or a group of individuals, the lived experience of a particular phenomenon (Creswell, 2007). When a phenomenon is not well understood, and is central to the lived experience of the human being, phenomenology is appropriate (Carpenter, 1995). The phenomenological method is grounded in the belief that truth can be found in lived experience (Spiegelberg, 1965).

In chapter two, literature will be presented to aid in the understanding of paediatric feeding disorders. Literature on interdisciplinary teams as a form of service delivery will also be highlighted. Background research will be presented to assist in the understanding of stresses experienced by parents of children with disabilities, as well the stresses experienced by parents of children with feeding disorders. Finally, there will be a focus on qualitative studies which
address parents’ experiences of having a child with feeding disorders. This will highlight the
gaps in current research and address the need for this study.

Chapter three will provide an introduction to the methodology and methods that were
chosen for this study, as well as discuss reflexivity and the personal reasons for embarking on
this project. Next, the rationale behind using descriptive phenomenology as the methodology will
be presented. Finally, an explanation behind the method of data analysis and the steps that were
taken to ensure rigour in this study will be outlined.

Chapter four will present the 12 theme clusters and five major themes that have emerged
from this study. Excerpts from interviews with participants will be used to describe the
experiences of mothers who have gone through an interdisciplinary team assessment process.
The chapter will conclude with a description of the fundamental structure of the experience of an
interdisciplinary team assessment process for mothers of children with complex feeding
disorders.

The fifth and final chapter will discuss the results of the study, implications in the context
of relevant literature, limitations of the study, and areas for future research.
CHAPTER TWO

This chapter will review the relevant background literature supporting this study. Paediatric feeding and the prevalence of feeding and swallowing disorders in the paediatric population will also be discussed. An introduction to the interdisciplinary team as a model of service delivery and a description of the feeding team at Sunny Hill Health Centre for Children (SHHC) will be described and the literature which pertains to parental stress and parental stress in relation to paediatric feeding disorders will be examined. Finally, in order to set the stage for the importance of this study, the most recent qualitative research examining parental experiences in relation to feeding disorders will be reviewed.

2.1 LITERATURE REVIEW

2.1.1 The Normal Swallow

Swallowing is a multifaceted process whose complexity is often taken for granted. Swallowing involves 26 muscles in the face and throat, along with six cranial nerves (Siktberg & Bantz, 1999). The full description of the anatomical and physiological nature of the swallowing process is beyond the scope of this project; however, a brief description of the process is important to provide as it is part of the context for the information provided to the participants and their children included in this study. A common framework divides the swallowing process into four phases: oral preparatory phase, oral phase, pharyngeal and esophageal. Although there are four distinct phases of swallowing, each component of the swallow is interdependent. The oral preparatory phase and oral phase are often described together. These two phases involve the processing of food so that a bolus is small enough to progress through the pharynx, esophagus and into the stomach. This phase also entails the transport of food or liquids into the pharynx (Garg, 2003; Wolf & Glass, 1992). In infants this process solely involves the transport of liquids
into the pharynx via the act of sucking. The oral phase is for setting the stage for proper timing and coordination of the swallow reflex. The oral phase is the primary phase under voluntary control; however, in young infants the act of sucking is guided by subcortical control (Wolf & Glass, 1992).

The third phase of the swallow begins when the food or liquid reaches the back of the oral cavity. The pharyngeal phase involves the rising of the soft palate, with the base of the tongue pushing food into the laryngopharynx while the superior esophageal sphincter relaxes. This process is highly coordinated as the airway must be closed off to prevent food from going into the lungs, preventing aspiration. To do so, the soft palate closes off the nasal cavity and the larynx moves up and forward to close the glottis (located over the airway) (Garg, 2003). Food is then pushed into the esophagus and eventually into the stomach (esophageal phase).

Each phase of the swallow involves both sensory and motor input from cranial nerves (V, VII, IX, X, XI, XII). These cranial nerves innervate muscles of the mouth, face and pharynx (Dusick, 2003). Sensory input from the oral and pharyngeal phases sends information to the ‘swallowing centre’, located in the brainstem (medulla oblongata). Swallowing is organized by a network of swallowing related neurons that form the central swallowing pattern generator (CPG). The CPG is thought to be responsible for the generation of the sequential swallowing response (pharyngeal swallow). The CPG processes the sensory information from the cranial nerves and sends the information back via efferent (motor) portion of the cranial nerves, initiating the swallow.

The complexity of the swallow mechanism is further highlighted by research which has demonstrated a definite route from the cortex to the CPG in the brainstem. The cerebral cortex has a modulation role in the control of the brainstem (Hamdy, 2006). Animal studies have
demonstrated that swallowing can be evoked by stimulation of both hemispheres, suggesting a bilateral and equi-hemispheric contribution to cortical swallowing control. During a volitional swallowing, there is activation of areas of the cortex involved not only in the organization of a swallow itself, but also in the pure recognition, response and planning of the event (Hughes, 2003). Using functional magnetic resonance imaging (fMRI), the regions of the cortex most consistently and prominently activated in both voluntary and reflexive swallowing are the lateral precentral gyri, postcentral gyri, supplementary motor area and insular cortex. Subcortical structures in the brain, particularly the cerebellum and basal ganglia, are also thought to play a role in swallowing, possibly in the coordination or modulation of the swallowing response (Gow, Rothwell, Hobson, Thompson & Hamdy, 2004).

2.1.2 Differences in Swallowing Between Adults and Infants/Children

For the most part, the mechanism of the swallow is the same in both adults and children; however, some important differences are evident. In children, evolving neuromotor development and physical growth dynamically affect swallowing behaviour (Kramer & Eicher, 1993). As previously mentioned, swallowing is present early in foetal life. The purpose of swallowing is to help maintain amniotic fluid balance (Ross & Nyland, 1998). Infant sucking is also fully developed in the newborn. To help accommodate for efficient sucking, the newborn’s anatomy is designed for nipple feeding; the tongue fills the oral cavity, the pharynx is small and the hyoid bone and larynx are more anteriorly and superiorly positioned than in adults (Kramer & Eicher, 1993; Wolf & Glass, 1992). In the pharyngeal phase, differences are seen between the pharyngeal stripping wave and the speed and frequency of the pharyngeal swallow (Kramer & Eicher, 1993). Significant changes are seen in infant feeding and swallowing between the ages of 6 months and 3 years, coinciding with the development of the central nervous system. As a child
gains the ability to control the position of the head and trunk and develops muscle tone, the child is better able to achieve a safe swallow (Jelm, 1994). This period of time is also when children struggle to achieve a sense of self. Parents begin to implement boundaries and structure and strive to create a balance between autonomy and dependency (Rogers & Arvedson, 2005). Between 3 and 6 years of age, children’s feeding closely resembles that of adults as the coordination of mastication is mastered (Jelm, 1994).

2.1.3 Classification of Feeding Disorders

Feeding is a highly integrated, multisystem skill, therefore, if there is dysfunction in one or more contributing systems, problems will arise. To date there are no universal classification systems for the causes of feeding disorders (Rommel et al., 2003). In the past, it was more common for feeding disorders to be classified into an organic (e.g., structural abnormalities, neuromuscular problems) and nonorganic (social and environmental causes) dichotomy (Wittenberg, 1990); however, this classification is no longer appropriate. Several researchers have attempted to account for the multiple factors that can contribute to a feeding problem (Burklow, Phelps, Schultz, McConnell & Rudolph, 1998; Field et al., 2003; Rommel et al., 2003). Burklow et al. (1998) identify five categories that reflect the nature of complex feeding and swallowing disorders: structural abnormalities, neurological conditions, behavioural issues, cardiorespiratory problems and metabolic dysfunctions. All five categories are typically not present in one child, even though there are multiple causes for a child’s feeding/swallowing difficulty. Burklow et al. applied this classification system to a population of 103 children who ranged in age from 4 months to 17 years who were referred to an interdisciplinary team with complex feeding disorders. They found that 85% of the population they examined met the
criteria for two to four categories, with 85% of children having a significant behavioural component to their feeding disorder.

Rommel et al. (2003) used a similar classification system with a sample of 700 children with feeding disorders and found that 86% of patients had a medical disorder (e.g. neurologic, genetic, cardiologic, metabolic, oncologic, gastrointestinal, etc.), 61% has oropharyngeal dysfunction (e.g. oral motor, sucking, pharyngeal dysphagia, etc.) and 18% had a behavioural problem. These authors suggested that a classification system should contain these three main categories. Interestingly, Rommel et al. found that the majority of conditions occurred in combination with each other. Finally, Field et al. (2003) used a different type of classification system, one based on feeding behaviours and their functions. Feeding disorders were classified as being either motivationally based (e.g., behavioural or environmental factors) or skill based (child does not have the necessary skills for eating). While these researchers have all used different classification systems, the consensus is that complex paediatric feeding problems are biobehavioural, with biological and behavioural aspects interacting mutually (Burklow et al., 1998; Field et al., 2003; Rommel et al., 2003).

As a result of a feeding disorder, some children may not be physically able or have a ‘safe’ enough swallow to obtain the nutrition they require to live through oral means. Typically, at the time of discharge from the hospital after birth or after a feeding and/swallowing assessment, a child might require an alternative means of feeding so that they can meet their caloric needs. Therefore, children with feeding disorders are also sometimes classified into one of three categories: tube dependent (require tube feedings for all or some of their daily caloric needs either via a nasogastric tube or via a gastrostomy tube), liquid dependent (consume primarily liquids orally), or food selective (consume all or some of their caloric needs orally, but are
selective about which solids and/or liquids they consume) (Greer, Gulotta, Masler & Laud, 2007).

For the purposes of this study, the term ‘feeding disorder’ will encompass difficulties feeding as a result of two broad categories: (1) skill deficits, including dysphagia and oral-motor delays and (2) behavioural feeding disorders, including food selectivity and food refusal.

**Skill Deficits**

*Dysphagia*

Dysphagia is any disturbance in the coordinated act of swallowing with either solids or liquids. This disturbance includes oral-motor disorders (e.g., abnormalities in sucking and chewing), swallowing discoordination (with or without laryngeal penetration leading to aspiration) and pharyngoesophageal dyskinesia (impaired movement of the bolus to the esophagus) (Schwarz, 2003). In children, dysphagia typically presents with feeding or respiratory difficulties and in infants difficulties with sucking is often observed (Garg, 2003). The common signs of dysphagia include: slow sucking, pooling of foods/liquids in the mouth, leakage of food/liquid from the mouth, nasal reflux, coughing during feeding, failure to gain weight, colour change while eating, history of pneumonia and noisy breathing (Garg, 2003).

*Oral-Motor Delays*

Oral-motor delays are defined as difficulties with motor movements of the oral structures, including: movements of the tongue, jaw and lips. Oral-motor delays and dysphagia are often associated with neurological deficits (Field et al., 2003).

**Behavioural Feeding Disorders**

The second diagnostic group of feeding problems is comprised of aversive feeding behaviours and sensory-based feeding disorders (Schwarz, 2003). Behavioural problems include
food refusal/selectivity, choking, gagging, as well as textural aversions (seen in sensory-based feeding problems). A study by Field et al. (2003) looked at the predisposing factors for five feeding problems typically seen in children with feeding disorders and the contributing etiologic factors. The sample of children analyzed had various developmental disabilities and included three major subgroups: autism, Down syndrome, and cerebral palsy. The results indicated that 62% of children with autism presented with food selectivity by type, 45% of children with Down syndrome presented with food selectivity by texture, and 30% of children with cerebral palsy presented with food refusal. The study concluded that many feeding problems were the result of learned aversions (due to gastroesophageal reflux, constipation, delayed oral skills, etc.) and the children with the most severe medical/developmental conditions produced the most feeding problems due to exposure to aversive feeding experiences.

2.1.4 Incidence of Feeding Disorders in Children

The current epidemiologic data on the prevalence and incidence of paediatric feeding disorders are limited and confusing, primarily because of the complexity of feeding disorders and the differing terminology that has been used in coding feeding behaviours. Some have suggested that in the future, the International Classification of Functioning, Disability, and Health (ICF) may be used as a potential framework for establishing a common language to help define the prevalence and incidence of paediatric feeding disorders (Lefton-Greif & Arvedson, 2007). Until a universal language is implemented, the current research may not give a completely accurate account of the epidemiological trends that are being observed in paediatric feeding disorders. From what is known, the prevalence of paediatric feeding disorders ranges from 33 to 80% in children with disabilities, and from 25 to 40% in typically developing children (Linscheid, 2006; Manikam & Perman, 2000). As a separate category, the incidence of
swallowing disorders in children is unknown; however, the rates appear to be increasing. This increase in prevalence could be a result of the rise in neonatal survival as more and more children are surviving complex medical conditions, prematurity and low birth weights (Ramsay & Gisel, 1996; Rommel et al., 2003). For example, the percentage of infants delivered preterm has increased 20% since 1990 (Hamilton, Minimo, Kochanek, Strobino & Guyer, 2007). In conjunction with this increase, the proportion of infants born with low birth weight (LBW; <2500g) has increased more than 20% in the past 20 years (Hamilton et al., 2007). Other factors that may account for the increase in the prevalence of feeding disorders includes the increased life expectancy of children with disabilities and the increase in the numbers of children with developmental disorders (Hirtz et al., 2007; Strauss, Shavelle, Reynolds, Rosenbloom, & Day, 2007). In a study by Rommel et al. (2003), children born before 34 weeks were found to have more gastrointestinal and oral sensory problems. A high correlation was also found between oral feeding disorders and a history of ventilation, aspiration, and nasogastric tube feedings. These findings indicate the influence of medical interventions on feeding disorders.

2.1.5 Complications Arising from Lack of Feeding Treatment

feeding disorders are associated with adverse developmental outcomes and decreased growth (Motion, Northstone, Edmond, Stucke & Golding, 2002). Evidence supports that early intervention, diagnosis and nutritional intervention may avoid secondary feeding-associated complications (Schwarz, 2003). The lack of feeding intervention or inability to implement feeding recommendations may not only impact the progression of feeding and swallowing skills, but also may have serious health consequences for the child. For example, recommendations are often made to decrease a child’s risk of aspirating food and liquids into the airway; undiagnosed aspiration can lead to pneumonia. Few studies distinguish between bacterial/viral pneumonia and
aspiration pneumonia; however, according to the World Health Organization, in North America the annual incidence of pneumonia in children, 0-3 years is estimated to be as high as 74/1000, with 41-42% requiring hospitalization (Jokinen et al. 1993). The most common causes of community acquired pneumonias are bacterial and viral in origin; however, oropharyngeal aspiration (OPA) is the most common cause of recurrent pneumonia and responsible for 8% of children hospitalized for pneumonia (Murphy, Henderson, Clyde, Collier & Denny, 1981; Owayed, Campbell, & Wang, 2000).

In the study by Rommel et al. (2003) on the causes of feeding problems in the paediatric population, 33% of children in their sample (228 of 700) suffered from gastroesophageal reflux disease (GERD). GERD was associated with 47% of the patients with medical conditions. This finding is concerning as research has demonstrated that untreated GERD can result in recurrent aspiration pneumonia in children (Leape, Holder, Franklin, Amoury & Ashcraft, 1977). Weir et al. (2007) supported this finding in a retrospective study of 150 children who were recruited from those attending a videofluoroscopic swallow study (VFSS) for feeding and swallowing evaluation. Using multivariate analysis, they found that the factors which were significantly associated with OPA included gastroesophageal reflux (GER). Other factors included a diagnosis of Down syndrome or asthma, moist coughs, oxygen supplementation and a history of lower respiratory tract infections (Weir et al., 2007). Another study examining children with severe neurological disabilities supports the association between lower respiratory tract infections and aspiration either from GER or direct aspiration. Morton, Wheatley and Minford (1999) found that, in one group of children with severe neurological disabilities (n=16) who had recurrent respiratory tract infections, 94% had aspiration on a VFSS. Seven of these children had direct aspiration (or OPA), eight had both aspiration due to GER and direct aspiration (or OPA), and
only one had only aspiration due to GER. In the group of children who did not present with chest
infections, none demonstrated aspiration during eating or drinking. Thus, health care costs due to
unidentified or untreated feeding and swallowing issues that may result in aspiration are high.
Some suggest that for many children with feeding and/or swallowing issues, minimal medical
intervention can help prevent health issues from becoming serious; however, in about 3% of
children, health issues can become life-threatening and require hospitalization (Garro, Thurman,
Kerwin & Ducette, 2005). The long-term effects of chronic aspiration has significant costs for
the health care system, and more importantly, can lead to serious and long-term lung damage
when the child enters adolescence and adulthood.

2.1.6 Service Delivery for Children with Feeding Difficulties

Interdisciplinary Feeding Clinics

Literature is growing on the multiple etiologies of paediatric feeding disorders. As a result
of the multi-factorial nature of feeding disorders, an interdisciplinary team approach to
assessment and treatment is critical. Research has been conducted on the use of interdisciplinary
teams for assessing and managing feeding disorders (Geggie, et al., 1999; Fayed, et al., 2007;
Miller et al., 2001; Puntis, 2008; Simonsmeier & Rodriguez, 2007). Members in an
interdisciplinary team share the responsibility for making the ultimate decision about a patient’s
care. An interdisciplinary team assessment uses a group process and is described as highly
interactive, with the assessment plan reflecting the integration of expertise from individual
disciplines. Once professionals on the team complete separate assessments, the results of their
knowledge are combined, and prioritized recommendations are provided to the family (Geggie et
al., 1999; Patel, Pratt & Patel, 2008). The use of an interdisciplinary team improves
communication between professionals and decreases the amount of time families need to spend making separate trips to see professionals (Miller et al., 2001).

Research has shown that the most effective means of conducting a proper assessment and evaluation of paediatric feeding and swallowing disorders is through an interdisciplinary team approach (Jones & Altschuler, 1987). Sunny Hill Health Centre (SHHC) is a tertiary care facility in BC that offers one such team. The Sunny Hill Feeding Team (SHFT) provides assessment and consultation to children with complex feeding difficulties; in the 12 months during 2007-2008 this team assessed over 140 children. Many of the children seen by the SHFT have swallowing safety and nutrition problems, though at least 25-30% of the referrals each year are for children with the potential to eat orally, but due to physical, developmental, social and behavioural factors, have insufficient intake. The SHFT is the largest specialized team of its kind in the province and the demand for the service is high. The waitlist fluctuates, but typically a high priority child will be seen in less than four weeks, while lower priority children wait four-six months for an assessment (Janice Duivestein, personal communication January, 2010). The team consists of an occupational therapist, a speech and language pathologist, a dietitian, a social worker, a clinical nurse, and a paediatrician.

A typical SHFT assessment takes two days. The first day is comprised of two assessments, the first assessment is with an occupational therapist, a speech and language pathologist and a dietitian for a combined feeding history interview, feeding observation, oral-motor exam and nutritional consultation. The afternoon may or may not consist of a session with the SHFT social worker, to discuss community resources and interpersonal issues.

The second day of the SHFT assessment begins at BC Children’s Hospital, where families are asked to sign into the radiology department at 7:45 am in preparation for the VFSS.
Thereafter, both the occupational therapist and speech-language pathologist meet with family and prepare the food items for the study. Therapists request that a variety of foods are trialled during the VFSS so as to cover a range of consistencies and textures; some that may challenge the child and others that are anticipated to be easier. The child’s parent/caregiver, who typically feeds the child, is able to stand in front of the child and feed him or her on the instruction of the radiologist.

The VFSS it often completed by 9:30 am, after which time, families return to SHHC. The final hour and a half assessment is conducted by a paediatrician and a nurse clinician. Families have a break after this assessment and meet again with the entire team at 1:30 pm for a family conference. Before the family conference, each discipline prepares their assessment results and determines what recommendations they would like to make. The team meets for half an hour before the family conference to discuss their findings and the recommendations for the family. It is during this time that the team discusses the overall assessment, brings assessment findings together and comes up with an overall plan for the recommendations. At the family conference, feeding specialists present their assessments results in turn, review a DVD with the child’s VFSS, and finish the meeting with recommendations. During this meeting, the team emphasizes that families can ask questions at any time. An important aspect of the family conference is the encouragement of participation from community therapists if they are available. It is not uncommon for feeding specialists to contact the community team shortly after the family conference to update them on assessment findings and recommendations if they were unable to attend the conference. Refer to Figure 2.1 for an outline the two-day, SHHC feeding assessment.
Figure 2.1-Sunny Hill Health Centre Interdisciplinary Feeding Team Assessment

**Sunny Hill Health Centre for Children**
**Interdisciplinary Feeding Assessment**

**DAY 1**
- Assessment with Occupational Therapist, Speech and Language Pathologist and Dietitian
  - 1.5 hrs
- Assessment with Social Worker
  - 1 hr

**DAY 2**
- Videofluoroscopy Swallow Study at Acute Care Hospital (off site)
  - 1.5 hrs
- Assessment with Paediatrician and Nurse Clinician
  - 1.5 hrs

- **Interdisciplinary Team Meeting (discussion of results from days 1 & 2)**
  - ¼ hr

- **Family Conference (may include all caregivers and members of the community team)**
  - 1.5 hrs
Some recommendations can be general and straightforward in nature, such as trying a particular nutritional supplement, or following up with a medical specialist regarding a particular aspect of the child’s health in relation to feeding. Other recommendations can be life-changing. Suggestions to initiate tube feeding or change the textures of foods or liquids require significant changes in the mealtime routines of families. The latter recommendations are made typically if a child’s nutritional intake is severely compromised or if a child has the high risk for choking or aspirating. Assessment details and recommendations are provided to families in a comprehensive interdisciplinary team report. This report contains sections from each feeding specialist, and will often take four to six weeks to be compiled and sent to families. Handouts may or may not be provided to families, and are often given at the time of the family conference or sent in the mail with the report. It is typical for reports to be sent to the child’s entire medical team, as well as their community therapists. While the cost of the full interdisciplinary team assessment unknown, it can be estimated to cost close to $3,000 per child (Janice Duivestein, personal communication November, 2009).

The SHFT is based on a model that integrates medical and rehabilitative perspectives through a variety of assessments conducted by each discipline. Compared with other feeding teams in the province, unique to the SHFT, is that at the time of the interdisciplinary assessment, a VFSS is also provided; the VFSS is considered the ‘gold standard’ in dysphagia assessment (Lefton-Greif & Arvedson, 1997). A VFSS involves dynamic visualization of the oral and pharyngeal phases of swallowing with particular attention to the assessment of airway protection and the occurrence of aspiration (O’Donoghue & Bagnall, 1999). The occupational therapist and speech and language pathologist examine a range of swallowing parameters; however, of
particular interest include delayed swallow reflex, pharyngeal residue, laryngeal penetration, and OPA.

Despite its thoroughness, this interdisciplinary model of service delivery has limitations. For the SHFT, typically, time available to build rapport with the family is limited, and it is often difficult for the team members to be aware of all the psychological stresses experienced by caregivers. The SHFT re-assesses approximately one quarter of all its referrals within a 2-year period, and approximately one third of all referrals over a 5-year period. Re-assessment may occur because of a change in a child’s health status which may be a positive or negative change. During a re-assessment, the team goes through the assessment process again and determines whether recommendations need to be modified or changed. However, there are occasions when the team sees families who have not been able to adequately follow recommendations from the initial assessment. As yet, the reasons for lack of adherence to suggestions are not clear.

2.1.7 Parental Stress

The children who visit the SHFT must have a diagnosis of a developmental disability. The SHFT assesses children who are diagnosed with cerebral palsy, Down syndrome, autism, developmental delay, and genetic disorders, to name a few. Children are diagnosed \textit{in utero}, at the time of birth, or for some, it may take years until a definitive diagnosis is given. For the purposes of this study, it is important to review the literature surrounding the stressors that parents who have children with disabilities are experiencing because it provides the context for the family experience before the feeding assessment.

Numerous studies have indicated that parents and other caregivers of children with disabilities experience considerable stress (Hoare, Harris, Jackson & Kerley, 1998; Sanders & Morgan, 1997). Stressors are the events which are perceived as having no readily available
adaptive responses. These perceptions induce personal tension and affect an individual’s well-being and adjustment (Antonovsky, 1987). The birth of a child with a disability has a significant impact on a family with ensuing demands on parents to advocate for their child, to manage medications and nutrition, and to manage repeated and multiple appointments with professionals. These families must also cope with various uncertainties about their child’s medical condition and their future. Anthony et al. (2005) defined parenting stress as the difficulty emerging from the demands of being a parent, which affects behaviour, well-being, and the child’s adjustment. This stress can be expressed in different ways including social isolation, emotional depression and relationship conflict (Keller & Honig, 2004; Margalit, Levser, Ankonina & Avraham, 1991).

All families and parents experience stress, whether they have a child with a disability or not. However, recent literature describes differences in the stress that is experienced by parents who have a child with a disability compared with parents who do not. Parents of children with disabilities have been shown to have higher rates of depression, physical health problems and a lower quality of life (Eker & Tuzun, 2004; Veisson, 1999).

One way of thinking about the potential stressors that are confronting families of children with a developmental disability has been suggested by Guralnick (2000). Here stressors can be classified into four categories, those related to: (1) the difficulties families have in seeking medical information, (2) the interpersonal and family distress experienced upon receiving a diagnosis, (3) the stress placed on family resources and (4) threats placed upon the ability to confidently parent. These four categories of stressors influence a child’s development adversely and can impact family interaction patterns in three ways: (1) the quality of parent-child interactions, (2) the child’s experiences that occur within the larger physical and social environment organized by his or her parents and (3) the health and safety provided by the family.
Stressors impact a child’s development when they perturb one or more of the three family patterns of interaction. When parents have difficulties coping adequately and adapting to stress there can be significant implications not only for their quality of life, but also for the development and well-being of their child.

Evidence on parental stresses associated with having a child with disabilities fits within Guralnick’s (2000) categories. Sloper and Turner (1992) highlight the first category of stressors, the difficulties families have in seeking medical information. In a sample of 107 families of young children with severe disabilities, despite their being in contact with numerous professionals and services, many of the families described their needs as being “unmet”. The greatest areas of unmet needs were related to provision of information; 59% of families felt that they lacked information about services, and 43% felt that they lacked information about their child’s condition. Furthermore, families’ unmet needs were associated with high levels of family strain. Hawley, Ward, Magnay and Long (2003) confirmed the association between parental stress and unmet information needs. Their study assessed parental stress of 97 parents following paediatric traumatic brain injury. Regardless of injury severity, one-third of families claimed no information was given to them at the hospital following the injury; 70% of families felt that their information needs were unmet. While the unmet information needs of parents were not directly correlated with parental stress, it was found that overall parents of children who suffered a traumatic brain injury experience significantly greater stress than parents of control children.

The second category of stressors suggested by Guralnick (2000) is that of the interpersonal and family distress experienced upon receiving a diagnosis. Lawson (2004) conducted a qualitative study which examined parents caring for their children with disabilities and their experiences of the disclosure of their child’s impairment. For the parents in this study, the
experience was negative and they felt that the services did not meet their needs. A study by Quine and Rutter (1994) also investigated parent satisfaction with medical communication at the time of diagnosis of a child’s severe disability. One hundred and sixty parents were involved in this study, with 58% stating dissatisfaction with the communication. While interpersonal and family distress can be experienced at the time of initial diagnosis, it can also have serious implications beyond this period. A study by Rone-Adams, Stern and Walker (2004) examined the relationship between caregiver stress and parent participation in home physical therapy programs for their child with a disability. While this study (n=80) was aimed at addressing parental involvement in their child’s therapy, the researchers found that there was a statistically significant relationship between interpersonal and family problems, parental stress and parental involvement in therapy programs. The results from this research demonstrated that a caregivers’ level of participation can be predicted by the levels of stress that they are experiencing. This study is critical as previous literature has shown that increased parental involvement improves a child’s outcomes (Kendal, Sloper, Lewin & Parson, 2003; Law & King, 1993; Piggot, Paterson & Hocking, 2002).

The third category of stressors is that of the stress placed on family resources. Warfield (2005) tested family resources, parenting challenges, work rewards and work demands as predictors of parenting stress among parents of 5 year-old children with disabilities. Warfield showed that the number of children in a family significantly correlated with less income and showed a trend toward greater difficulty finding child care. As a result, with fewer resources, greater demands are placed on parents leading to greater parental stress. Finally, addressing the fourth category of parental stressors, that of the threats placed upon the ability to parent confidently, is a study by Hassall, Rose and McDonald (2005). Researchers investigated the
relationship between parental cognitions (parenting self-esteem and parental locus of control), child characteristics, family support and parenting stress. They found a strong inverse relationship between the Parenting Stress Index and the Parenting Sense of Competence Scale. Parenting stress in mothers of children with a disability was associated with their locus of parenting control and their sense of satisfaction with parenting.

2.1.8 Impact of Feeding Difficulties on Caregiver Stress and Functioning

Severe feeding problems have serious implications for how a child develops physically, developmentally and socially (Budd et al., 1992; Garro et al., 2005; Samson-Fang et al., 2002), but also for how their family functions. A study by Pederson, Parsons and Dewey (2004) examined the stress levels of parents of children with chronic disabilities who were involved in an enteral (tube) feeding program, and compared them with stress levels of parents who had healthy children, and parents of children with other chronic illnesses. The researchers found that of the sample of parents with children in the feeding program (n=64), 42% of the parents scored above the 85th percentile on the Parenting Stress Index - these are stress levels that may adversely impact parenting. A study by Winston, Dunbar, Reed and Francis-Connolly (2010) used a mixed methods design to examine mothers’ perceptions of their occupations when mothering a child with a feeding disorder. Using phenomenological interviews, the Parental Stress Scale (PSS) and the Life Satisfaction Index-Parents (LSI-P), two groups of mothers were compared, those with typically developing children and those who had children with feeding difficulties. Quantitative analysis did not find statistically significant differences between the two groups on the PSS, but did find significant differences on the LSI-P in areas of recreation and leisure; mothers of children with feeding difficulties reporting less satisfaction. Qualitative data found issues related to stress and concerns related to anxiety and worry.
Garro et al. (2005) examined stress in 37 caregivers and found that stress was positively correlated with the presence of oral-motor dysfunction in a hospitalized child. This study has significance for health professionals who may be able to help identify stressors and develop coping strategies for parents. These strategies can help to avoid negative parent-child interactions, including feeding interactions that may form as a result of high stress. Another study by Garro (2004) used the Coping Health Inventory for Parents (CHIP) with 35 mothers of children with chronic feeding problems who were hospitalized for these issues. The CHIP is a questionnaire designed to assess the types of coping behaviours that parents use in everyday life when one of their children has a serious and/or chronic illness (McCubbin, McCubbin, Nevin & Cauble, 1981). This study demonstrated the different ways that mothers of children with feeding difficulties coped with their situation. For example, mothers were less likely to use coping behaviours related to maintaining social support and self-esteem, but did use the coping strategy of maintaining family integration through family activities. They were also more likely to use the coping pattern of understanding the medical condition through reading materials, asking questions or talking with other families. The author believes that the results of this study reflected the lack of time or opportunity mothers had to access social support and develop self-esteem coping mechanisms (Garro, 2004).

2.1.9 Qualitative Literature

To date, few qualitative studies have explored the perspectives and experiences of families with children who have feeding problems. Franklin and Rodger (2003) used a phenomenological approach to explore parents’ perceptions of the impact of feeding difficulties on family life, parenting and relationships. Four themes emerged from the study that drew together parent’s experiences of chronic stress and ‘survival’ and the impact on everyday life. The first theme,
‘fear for their child’s physical survival’, described the fears families endured when they were unsure whether their child was going to live or die as a result of their medical condition and inability to feed. The second theme, ‘the impact of stress on the parent-child relationship’, was further broken down into the ‘mother-child relationship’ and the ‘father-child relationship’. Mothers expressed a desire to be ‘good’ mothers, and regrets about their inability to ‘bond’ with their child. Unlike mothers, fathers did not expressed doubt about their role or about their ability to bond with their child. Father did express concerns related their child’s distress related to feeding, perhaps reflecting their own feelings towards the situation. The third theme, ‘increased parenting responsibility’, encompassed the sense that there were increased demands when parenting a child with a medical condition and feeding difficulties. Lastly, the fourth theme, ‘adjustment and coping with chronic stress’, referred to the combination of strategies parents used to help them cope with the stress in their lives. Overall, the researchers described the unifying theme that drew together parents’ perceptions of how they ‘survived’ and coped with chronic stress (Franklin & Rodger, 2003).

Sleigh (2005) examined the experiences of mothers feeding their children with cerebral palsy. Here, the themes that emerged resulted in two prose accounts that described the essence of the experience: (1) the experience of feeding children by mouth who have severe difficulty eating and (2) the experience of feeding children via a gastrostomy tube who have severe difficulty eating, both as a result of cerebral palsy. The first account describes mothers having to relinquish dreams of breastfeeding, but also feeling determined to continue to feed their child the ‘normal way’, by mouth. This account describes the participants’ vindication of their decision to not have a gastrostomy tube for their child. The second account, describing the experience of feeding a child with a gastrostomy tube, depicts the complex emotions of mothering and
nurturing. Participants differed in their experience if the gastrostomy tube was felt to be successful or not. The majority of participants were pleased with the gastrostomy tube, despite their ‘secret ambivalence that results from the loss of normality and intimacy that is associated with oral feeding’ (Sleigh, 2005, pp. 380).

Stoner, Bailey, Angell, Robbins and Polewski (2006) examined parents’ experiences related to their children’s feeding/swallowing problems. Four primary themes emerged from the data analysis: (a) negative experiences upon diagnosis of their child’s feeding problem; (b) positive experiences with professionals involved in early intervention; (c) difficulties with service delivery in early intervention and school-based intervention; and (d) the cumulative result of parents’ experiences leading to self-education concerning their children’s disabilities and strong parent advocacy for their children. This study showed that parents felt overwhelmed with their children’s feeding/swallowing problems and were given limited hope by professionals. Parents’ experiences were primarily positive when it came to the service delivery of early intervention, but these experiences became negative when their child entered the school system due to lack of training of the school staff.

Finally, a recent study by Hewetson and Singh (2009) used a phenomenological approach to examine the lived experience of mothers of children with chronic feeding and/or swallowing disorders. The results from semi-structured interviews with seven mothers found two theme clusters, (1) deconstruction: a journey of loss and disempowerment and (2) reconstruction: getting through the brokenness. The first theme cluster was comprised of three themes: ‘losing the mother dream’, ‘everything changes: living on the margins’ and ‘disempowered: from mother to onlooker’. The second theme cluster included four themes: ‘letting go of the dream and valuing the real’, ‘facilitating the journey’, ‘self-empowered: becoming the enabler’ and ‘the
continuing journey: negotiating balance’. This study found that mothers had both positive and negative experiences associated with having a child with a feeding and/or swallowing disorder, and that these experiences were often concurrent. The experience of having a child with a feeding and/or swallowing disorder was found to be a transformative experience involving personal growth, but also resurgences of struggles and losses. Researchers of this study identified that future research should focus on improving service delivery for these families.

While these studies begin to help us understand how parents experience having a child with feeding difficulties, no studies have evaluated caregivers’ experiences of the interdisciplinary feeding team assessment process. Moreover, the majority of qualitative articles that focus on children with feeding difficulties examine the experiences of families with children who have gastrostomy tubes. These articles explore the psychological implications of this operation for families as well how gastrostomy feeding affects the daily lives of children and their parents (Brotherton, Abbott & Aggett, 2007; Craig & Scambler, 2005; Craig, Scambler & Spitz, 2003; Rouse, Herrington, Assey, Baker & Golden, 2002; Spalding & McKeever, 1998). Understanding the perspectives of these families is critical for feeding teams across Canada; however, this is only one population that is seen by feeding teams. These studies did not address parents’ perspectives of going through an interdisciplinary feeding team assessment or examine the barriers that parents encounter in implementing recommendations from feeding specialists.

2.2 CONCLUSION

The aim of this chapter was to present literature to help with the understanding of paediatric feeding and swallowing disorders. By delving into the stressors parents of children with disabilities face, specifically those with children who have feeding and/or swallowing disorders, the hope is to highlight the need to further understand parents’ experiences in the
context of service delivery. In-depth feeding and swallowing assessments can save the health care system millions of dollars by preventing serious respiratory tract infections as well as other chronic lung diseases. However, increased research is needed to focus on the caregivers of children with feeding disorders so that we can understand more clearly what they may be experiencing. It is the parents who must implement feeding and swallowing recommendations, often with the support of a community team, but sometimes on their own. Knowledge regarding parents’ experiences of an interdisciplinary team assessment and their perceptions of implementing recommendations will give interdisciplinary teams critical information to know whether increased supports are needed to ensure treatment recommendations can be successfully implemented.
CHAPTER THREE

Chapter one introduced the subject matter for this thesis and the rationale behind embarking on this study. The gaps in the research and the importance of understanding caregivers’ experiences of an interdisciplinary team assessment process for their child with a feeding and/or swallowing disorder were highlighted briefly. Chapter two furthered the argument for the need to embark on this research, and drew attention to the studies pertaining to paediatric feeding and swallowing, service delivery and the complexities behind caring for a child with feeding and/or swallowing disorders. In this chapter, the topic of reflexivity will be discussed, as well as the assumptions and biases that may impact this project. A discussion on qualitative research and the choice of methodology will be presented. Finally, the methods used in this study will be described, including sampling methods, data collection and the process of data analysis.

3.1 QUALITATIVE RESEARCH

Qualitative research focuses on questions pertaining to human experience. It is a holistic approach which recognizes the complexity of humans. Researchers are interested in the subjective involvement in the objective world and the interplay between these two realities. The aim of qualitative research is to come to the understanding of how a particular situation impacts a person (Denzin & Lincoln, 1994). By doing so, one is able come closer to understanding that person’s reality and to see what is true from his or her point of view. Qualitative research can also be described as the discovery of the emic or insider’s point of view. Qualitative researchers seek to understand the perspective of the individual or group who has lived through and interpreted an experience (Carpenter & Suto, 2008). The research is often characterized by
inductive reasoning, subjectivity, discovery, description and a high level of researcher involvement with participants (Munhall, 2001).

My decision to do a qualitative study stemmed from my observations as an occupational therapist on the feeding team. I was interested in understanding the experiences of parents/caregivers when going through an interdisciplinary team assessment. I was curious about the events that brought them to the team, the feelings they had during and after the assessment, and if there were aspects of the assessment that could be changed to help make this experience better for them. I wondered about their perspectives of implementing recommendations and whether this was something that caused them stress, or whether it was a process that came naturally for them. I was interested in ‘experience’ and therefore this study lent itself to a qualitative approach. My decision to embark on this study was also influenced by my desire to understand whether our team was ‘missing something’.

In recent years the term ‘evidence based practice’, defined as the integration of best research evidence with clinical expertise and patient values, has become part of the culture in the clinical setting (Sackett, Straus, Richardson, Rosenberg & Haynes, 2000). Therapists are constantly reminded to incorporate evidence into their practice decisions. Knowledge brokers are becoming more common in hospitals and rehabilitation centres as the link between research and practice, disseminating the most current and relevant literature in the field. To my knowledge, no research evaluates the efficacy or the effectiveness of an interdisciplinary assessment process for children with feeding and/or swallowing disorders in an outpatient setting; therefore, it seemed pertinent to conduct a study evaluating the delivery of this service and contribute evidence to guide future practice. A starting point is to better understand caregivers’ experiences of this form of service delivery. Due to the inductive nature of qualitative research, knowledge can be
generated. This knowledge can create a foundation from which future research can be produced that may address specific aspects of an interdisciplinary team assessment to treat children with feeding and/or swallowing disorders.

When embarking on a qualitative study, the researcher must frame the study within the assumptions and characteristics of the qualitative approach to research (Creswell, 2007). Understanding ones’ beliefs and assumptions about reality helps to give researchers stability and direction in the research process. The beliefs that guide our action are known as personal paradigms or worldviews (Guba & Lincoln, 2005). Until beginning this research process, I had not considered my stance and view on the creation of knowledge. I became even more bewildered as I began to read qualitative texts that discussed the many theoretical perspectives and philosophical underpinnings behind various methodologies. Many of the research articles I read during my education in the biological sciences and later in the field of occupational therapy primarily exposed me to a scientific or ‘objective’ lens. The epistemological view that I was exposed to held the belief that things exist as meaningful entities independent of consciousness, with truth and meaning residing in them as objects. It is careful scientific research that can attain that objective truth and meaning within (Crotty, 2003). Experimental and survey research was what I was most familiar and comfortable with, as I had not considered other perspectives on the acquisition of knowledge. In order to make my assumptions, paradigms and frameworks explicit in the study, I will begin by briefly describing four elements in my research process that inform one another; epistemology, theoretical perspective, methodology and methods (refer to Figure 3.1 & 3.2).
3.1.1 Epistemology

Epistemology is the theory of knowledge embedded in the theoretical perspective and thereby in the methodology; it is a way of understanding and explaining how we know what we know (Crotty, 2003). The majority of qualitative researchers tend to align themselves with the epistemology of constructionism. Constructionism holds the view that there is no objective truth waiting for us to discover it. Instead, meaning (truth) comes into existence in and out of one’s engagement with the realities in one’s world (Crotty, 2003). Meaning does not exist without a mind, and therefore, is not discovered but constructed. With this view of knowledge, people construct meanings in different ways, even in relation to the same phenomenon. The notion of multiple realities and the different, yet legitimate views people hold about their lives is one of the key characteristics of qualitative research (Carpenter & Suto, 2008).

3.1.2 Theoretical Perspective

A theoretical perspective is the philosophical stance informing the methodology, and thus provides a context for the process and grounds its logic and criteria (Crotty, 2003). Interpretivism, a paradigm that is often combined with constructivism, holds the worldview that people seek to understand the world in which they live. Individuals create subjective meanings of their experiences which are complex, varied and multiple (Creswell, 2007). The interpretivist
approach looks for culturally derived and historically situated interpretations of the social life-world (Crotty, 2003). If one aligns oneself with the interpretivist paradigm, one holds the assumption that human action is meaningful and the goal of research is to understand how people interpret and make meanings of social phenomena (Carpenter & Suto, 2008). Falling under the interpretivist approach are three historical streams: phenomenology, hermeneutics and social interactionism (Crotty, 2003).

Interpretivism forms the philosophical underpinnings of phenomenology (Carpenter & Suto, 2008). Phenomenology is a theoretical perspective under the umbrella of interpretivism, which suggests that researchers must lay aside the understanding of those phenomena of interest and revisit our immediate experience of them, so that possibilities for new meaning can emerge for us, or so that we can observe an enhancement of some former meaning (Crotty, 1996). Phenomenology seeks to draw meaning from complex realities through careful analysis of narrative subjective materials (Beck, 1994; Jasper, 1994). Its major assumptions are that “perceptions present us with evidence of the world-not as it is thought to be, but as it is lived... [and] human existence is meaningful and of interest in the sense that we are always conscious of something” (Morse & Richards, 2007, p. 45). Phenomenology’s focus is on describing what all participants have in common as they experience a particular phenomenon. The purpose of phenomenology is to reduce these experiences to a description of the universal essence of that phenomenon (Dahlberg, 2006).

Phenomenology draws heavily on the beliefs of Edmund Husserl (1859-1938), a German mathematician and philosopher. Husserl’s transcendental phenomenology holds the assumption that phenomenology is the study of lived experiences of persons and the development of descriptions of the essences of these experiences, not explanations or analyses. Three important
concepts of Husserl’s phenomenology are intentionality, essences and phenomenological reduction. Intentionality is the idea that the mind can be directed towards objects, which may be physical objects, thoughts, concepts or feelings. Within our environment, we have precognitive perceptions about the meanings we hold for phenomena. By intentionality we bring these precognitive perceptions into consciousness and discover meaning. Phenomenological reduction, or *epoche*, is the setting aside of preconceived beliefs about phenomenon and our assumptions (Fochtman, 2008). This strategy is also commonly referred to as bracketing (Dowling, 2007).

### 3.1.3 Methodology

A methodology is the strategy, plan of action, process, or design lying behind the choice and use of particular methods (Denzin & Lincoln, 2000). The methodology links the choice and use of method to the desired outcomes (Crotty, 2003). Phenomenology is both a philosophy and a research methodology (Crotty, 2003; Fochtman, 2008). Within phenomenology there are two separate, but overlapping philosophies: descriptive phenomenology and interpretive or hermeneutic phenomenology. The latter philosophy was developed by Heidegger, an assistant of Husserl, and focuses on using hermeneutics as a process and a method for bringing out the meanings embedded in daily life. Heidegger’s focus is ontological (the study of being), believing that the primary phenomenon that concerns phenomenology is that of the meaning of ‘Being’ or presence in the world (Cohen & Omery, 1994). He advocated for the utilization of hermeneutics as a research methodology founded on the ontological view that lived experience is an interpretive process (Racher & Robinson, 2003). Research is orientated to lived experience and interpreting the ‘texts’ of life (van Manen, 1990).

For the purposes of this research study, I chose to use descriptive phenomenology as my theoretical perspective/methodology. Figure 3.2 outlines the research process I chose to use for
this study. My research questions were directly linked to the experiences that caregivers have as they go through the process of an interdisciplinary team assessment (the phenomena).

**Figure 3.2-Four Elements of Rochelle’s Research Process**

![Diagram showing the four elements of Rochelle's research process: Constructionism, Interpretivism/Constructivism, Phenomenology, In-Depth Interviews.]

I was interested in describing these experiences, as accurately as I can, to illuminate what these experiences may be like. As Kvale (1996) writes:

Phenomenology is interested in elucidating both that which appears and the manner in which it appears. It studies the subjects’ perspectives of their world; attempts to describe in detail the content and structure of the subjects’ consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings. (p. 53).

Giorgi, A.P. (1985), a descriptive phenomenologist, states that the task of the researcher is to describe the self-interpretations or any other interpretations regardless of their complexity. The participant’s interpretation does not have to be interpreted by the researcher; it can be described. Given that this study is my first attempt at conducting phenomenological research, I needed a structured framework to assist with the complex analysis of phenomenological data.
Several psychological researchers offer such frameworks for data analysis, including Giorgi, Moustakas and Colaizzi, all of whom ascribe to the methodology of descriptive phenomenology. I chose to use the latter framework introduced by Colaizzi (1978), who outlines a series of seven steps for data analysis (refer to Table 3.2).

3.2 BRACKETING

As mentioned previously, phenomenological reduction is a key epistemological strategy of Husserl’s descriptive phenomenology. Individuals naturally hold knowledge judgementally, but phenomenological reduction requires a fresh way of looking at things. To be able to do this, one must try to bracket his or her preconceptions and presuppositions, by doing so making them overt and as clear as possible. Researchers using phenomenology must try to meet the phenomena described by participants as non-judgementally as possible so that the phenomena can present itself as precisely as described (Parse, 2001). Bracketing can also be viewed as a reflective process by which researchers’ opinions and prejudices are suspended to focus attention on the phenomena (Le Vasseur, 2003). There are numerous critics of Husserl’s phenomenological reduction (Crotty, 1996; Salsberry, 1989), who hold the belief that it is impossible to be removed from individual conceptual understandings and historical points of view. While it may not be possible to bracket all of my preconceived notions, I agree with Le Vasseur (2003) when she writes that we naturally bracket prior understanding of a phenomenon when we become curious. Le Vasseur (2003) believes that researchers have to assume that they do not know or understand something so that the effect is a questioning of our prior knowledge. My role as a therapist on an interdisciplinary feeding team has had an influence on my decision to embark on this study. I will discuss the strategies I have taken to bracket my preconceptions later in this chapter.
3.3 RESEARCH QUESTION

The goal of this study was to understand caregivers’ experiences of an interdisciplinary team assessment for their child with a complex feeding and/or swallowing disorder. The objectives of this study were to: (1) describe the experiences mothers’ of a child with feeding and/or swallowing problems who goes through an interdisciplinary team process; (2) explore the perspectives mothers as they implement recommendations from the feeding team.

3.4 RESEARCH DESIGN

3.4.1 Sampling

In qualitative research, the aim is to understand complex issues related to human behaviour. Qualitative researchers recognize that some participants are ‘richer’ than others, and therefore, are more likely to be able to provide understanding and insight for the researcher (Marshall, 1996). Given this point, a purposive sampling method was used to obtain information-rich informants who were expected to have varied experiences. This sampling method involved selecting certain units of cases “based on certain purposes rather than randomly” (Tashakkori & Teddlie, 2003, p. 713). Purposive sampling, also synonymous with purposeful sampling, involves the researcher actively selecting participants who have had diverse experiences, so as to distill the essence of the phenomenon, in this case, the close examination of caregivers of children requiring a detailed feeding assessment. Teddlie and Yu (2007) outline three broad categories of purposive sampling techniques: sampling to achieve representativeness or comparability, sampling special or unique cases and sequential sampling. This study used a combination of purposive techniques, which is common practice in many qualitative research studies due to the complexities of the issues being examined (Teddle & Yu, 2007). In conjunction with purposive sampling, this study utilized criterion sampling. This form of
sampling stipulates that all cases meet some criterion (Creswell, 2007). In this study all participants had to be primary caregivers of children who had recently gone through an interdisciplinary feeding assessment, the phenomenon of study.

Morse (2000) states that multiple factors should be considered when determining sample size, including quality of the data, the scope of the study, the nature of the topic, the amount of useful information obtained from each participant, the number of interviews per participants, the use of shadowed data and the qualitative method and study design used. The study design that was employed, phenomenology, aims to obtain descriptions in great depth and uses primarily in-depth interviews to collect data. As a result, phenomenology requires only a small number of participants; often between 1-10 participants (Creswell, 2007; McCracken, 1998; Starks & Trinidad, 2007). In this study, the sample size was nine participants. This number was determined by the variety of participants who each had the commonality of the experience of an interdisciplinary assessment. The ethnic backgrounds, children’s ages and family size varied among participants. Upon data analysis, similar experiences were emerging to help indicate that the study was reaching saturation (Rubin & Rubin, 2005). In addition, each participant had two lengthy interviews. Due to the scope of the project and limited resources, a sample size of nine was appropriate.

3.4.2 Inclusion Criteria

Primary caregivers were recruited from families who had an interdisciplinary Sunny Hill Health Centre (SHHC) feeding team (SHFT) assessment, in Vancouver, BC. To be seen by the feeding team, children must present with complex developmental needs and/or have a condition that primarily affects their physical or motor development, be between birth and 19 and have a complex feeding disorder.
3.4.3 Exclusion Criteria

Participants were excluded if the commute to their area of residency was over four hours from the Greater Vancouver area, or if they are not able to speak or understand English. Translating non-English interviews was beyond the scope of this graduate project. Participants were not excluded on the basis that they may have received services from the primary investigator.

3.4.4 Contacting the Participants

All families who met the inclusion and exclusion criteria for this study were sent an information package regarding the study. The package included the Letter of Initial Contact and the Study Consent Form (refer to Appendix A & B). In the Letter of Initial Contact, families were provided with a number to call at SHHC if they did not want to be contacted at all regarding this study. The Letter of Initial Contact made it explicit that not all families who agreed to participate in the study would be accepted into the study. The letter stated that if consent was given for them to be contacted, I would be asking them several demographic questions to ensure that a wide range of perspectives were gathered. When contacting each participant, I asked them specifically about their location of residence, the age of their child involved with the feeding team and their cultural background. These three demographic questions were noted in the Letter of Initial Contact.

Two weeks after sending the study information package, a booking clerk, using a telephone protocol contacted each primary caregiver to ensure they had received the information package. This booking clerk was familiar to the families, as she had previously contacted families for their initial feeding assessment. If families had not received the information, another study package was sent to the primary caregiver. If they had received the information package,
the booking clerk inquired whether the primary caregiver was interested in participating in the study or in obtaining more information. If the answer was yes, the booking clerk then asked their permission to release their telephone number to myself. Participants were notified prior to giving consent to participate in the study that I would be the researcher interviewing the family. To attempt to avoid bias when conducting interviews with families I had had previous contact, before starting the interview, participants were reassured that their descriptions of their experiences would have no bearing on their future involvement SHHC.

I contacted each participant after permission was given. During this initial telephone call, I was able to respond to any questions or concerns regarding the study and to determine whether the participant would add to the diverse sample the study was seeking. As my role in this study was the primary investigator, as well as an occupational therapist on the interdisciplinary feeding team, it was also important to recruit an equal number of participants with whom I had previous contact and participants who had other therapists on the feeding team. During this telephone call, the participants were able to choose a location to be interviewed, as well as a time and a date. Participants were also informed that consent forms would be collected before the start of the initial interview.

3.4.5 Data Collection: Interviews

The primary method of data collection in this study employed in-depth interviews. The goal of an in-depth interview is to obtain depth, detail and richness, or thick description (Creswell, 2007). I chose to follow Rubin and Rubin’s (2005) responsive interviewing model. This approach relies heavily on the interpretive constructionist philosophy and is shaped by the practical needs of doing interviews (Rubin & Rubin, 2005). The goal in this approach to interviewing is depth of understanding rather than breadth. This model emphasizes that the
interviewer and interviewee are human beings who form a relationship during the interview. There is also the recognition that each conversational partner has a unique set of experiences, and therefore, a different construction of meanings. As a result, different questions are asked at times with different participants, or questions are worded slightly differently. Thus, I created an interview guide with main questions, probes and follow-up questions. I wanted to ensure that I covered similar questions with each participant, although they were not necessarily worded the same, or asked in the same order. This was an appropriate format with which to address my research question, as semi-structured interviews can serve as a guide to facilitate a more focused exploration of a specific topic (Fossey, Harvey, McDermott & Davidson, 2002). My questions were informed by my observations as an occupational therapist on the SHHC interdisciplinary feeding team, as well as my past observations as a community therapist. Participants were encouraged to describe their experiences of a team assessment for their child with a complex feeding/swallowing disorder as well as their experiences implementing recommendations in narrative form (refer to Appendix C for a summary of the interview guide).

In this study, it was very important that descriptions of participants’ experiences were not influenced by my role as a feeding specialist at SHHC. In order for participants to freely describe their experiences, the goals of the study were reiterated with participants before starting the interview. I reminded participants that their answers would in no way have any influence on their involvement with SHHC, but instead would add to the knowledge of caregivers’ experiences. The responsive interviewing approach recognizes that the interviewer and interviewee interact and influence each other (Rubin & Rubin, 2005). It was very important that as an interviewer I was aware of how my own biases or expectations may have influenced the interviewee. This self-awareness can help to improve the quality of interview. As a way to help
me become more aware of my feelings and thoughts about the interview process, I used the
recording of field notes directly after the interview.

This study was dependent on understanding caregivers’ experiences of an interdisciplinary
team assessment, but also on understanding their perspectives of implementing recommendations
from the feeding team. In order to capture the experiences of caregivers, it was thought that the
initial interview should take place as closely as possible to the completion of the interdisciplinary
team feeding assessment (within 3-4 weeks). In order to obtain an understanding of caregivers’
perspectives of implementing recommendations from the team, caregivers needed a period of
time after the assessment to begin implementing recommendations. As a result, the second
interview was conducted at least three months after the interdisciplinary assessment. Nine
primary caregivers participated in the study over a period of eight months. All primary
caregivers who participated in this study were the biological mothers of children who went
through the interdisciplinary feeding team assessment, therefore, the term “mother”, will be used
throughout this study to describe the participants. The research process trajectory is outlined in
Table 3.1.
Table 3.1 The Research Process Trajectory

<table>
<thead>
<tr>
<th>Participant</th>
<th>Date of Feeding Assessment</th>
<th>Date of Contact by a Third Party</th>
<th>Interview 1</th>
<th>Interview 2</th>
<th>Further Involvement-Participant Feedback</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susan Participant #3</td>
<td>January, 2009</td>
<td>February 13, 2009</td>
<td>March 6, 2009</td>
<td>July 7, 2009</td>
<td>October 5, 2009</td>
</tr>
<tr>
<td>Ester Participant #6</td>
<td>February, 2009</td>
<td>April 1, 2009</td>
<td>April 17, 2009</td>
<td>July 3, 2009</td>
<td>October 5, 2009</td>
</tr>
<tr>
<td>Kuldeep Participant #7</td>
<td>March, 2009</td>
<td>April 1, 2009</td>
<td>April 23, 2009</td>
<td>July 7, 2009</td>
<td>October 5, 2009</td>
</tr>
</tbody>
</table>

**Pseudonyms have been used for all participants. The exact date of feeding assessment has not been provided to further enhance anonymity.**

The interviews began with a brief explanation of the study, and the signing of the consent form. Participants were informed that the interview was to be audio-taped, but the machine could be turned off at any point during the interview. The interviews took between 45-90 minutes, with the second interview being slightly shorter on average than the first. Prior to commencing interviews with study participants, a pilot interview was conducted. A pilot interview gives the researcher important information about whether the questions are appropriate, the relevance of the research question, and the time allotted for interviews (Carpenter & Suto, 2008). I interviewed each participant in a location chosen by the participant. Seventeen out of 18 interviews were conducted in the participants’ home. One interview was conducted in a quiet, isolated room at SHHC. At the end of each interview, a 20 dollar honorarium was provided to participants.
3.4.6 Personal Use of Bracketing

Gearing (2004) has suggested several elements for the process of bracketing. The initial elements of bracketing recommend that the researcher should state his or her epistemological position and theoretical framework. Both of these elements were made clear earlier in this chapter. The next set of elements involves bracketing out internal (researcher) suppositions (Gearing, 2004). When starting this study, I was aware of how my personal knowledge, history, culture, experiences and values might influence my research. My history in coming to be interested in the topic of paediatric feeding and swallowing has influenced my assumptions of the complex bodily function of feeding and swallowing and the experiences that are associated with it. My interest in feeding and swallowing disorders in children began when I took my first paediatric position as an occupational therapist in a community outside the greater Vancouver area. Paediatric feeding and swallowing was an area that was extremely intimidating for me at the time. Feeding and swallow is a complex issue that requires additional training and knowledge. It is also an area that has serious health implications for the child if not adequately assessed and treated. Over the next year, I made an effort to become knowledgeable in the area of feeding and swallowing, taking courses and liaising with therapists at larger centres.

During my time as a community therapist, I met several families with children who had complex feeding and swallowing disorders. A couple of these children went through in-depth, interdisciplinary feeding and swallowing assessments at SHHC in Vancouver. As the community therapist, my role was to assist families in the implementation of recommendations from the feeding team. In this role, I had the unique opportunity to see what this experience was like for families in their home environment, and had the responsibility to assist parents with recommendation implementation.
After several years working in the community, an opportunity arose to take a position as a member of an interdisciplinary feeding team at SHHC. After working for several months on this team, I began to wonder what the experience of this interdisciplinary assessment was like for families. I was unsure about whether families understood all elements of the assessment. I also wondered about their experiences of implementing recommendations from the team. My own experience working in the community led me to believe that some families had a hard time with implementing recommendations. In examining my professional background and my experiences as an occupational therapist, I am able to identify several assumptions I hold regarding the experiences of caregivers going through an interdisciplinary team process for their child with a feeding disorder:

- Feeding a child with a feeding disorder is a stressful experience for parents/caregivers.

- Caregivers’ regard feeding with high importance.

- The experience of an interdisciplinary team assessment is stressful for families.

- Families have a difficult and overwhelming time implementing recommendations.

- The realities of life can sometimes get in the way of being able to properly implement recommendations.

- Recommendations can be too much work for families and they get discouraged. Sometimes it is easier to not push oral feeding with their child to avoid conflict and struggle.
Another technique I used to bracket my internal suppositions included the use of a bracketing interview. Bracketing interviews are also used to enrich the reflexive process (Dowling, 2007). Reflexivity refers to the engagement by the qualitative researcher in continuous self-critique and self-appraisal, as well as the provision of an explanation of how his or her own experiences did or did not influence the state of the research process (Koch & Harrington, 1998). Bracketing and reflexivity are not synonymous terms; however, as Paterson and Groening (1996) propose, bracketing and reflexivity are similar, as one must be reflexive in order to bracket. At the time of initiating this study a doctoral student in Rehabilitation Sciences conducted a ‘bracketing interview’ with me. Refer to Appendix D for a portion of the bracketing interview transcript. This interview allowed me the opportunity to reveal my thoughts about the topic of study and discuss my personal perceptions and biases. The role of this activity is to make the researcher more aware of potential judgements that may occur during the data collection and analysis process based on the researcher’s beliefs instead of the participants’ experiences (Streubert & Carpenter 1999).

3.4.7 Transcription of Interviews

A professional transcriptionist who was familiar with qualitative research transcribed each interview. Prior to transcribing the first interview, the transcriptionist signed an agreement to keep confidential all of the research data entrusted to her. After each interview was conducted, a copy of the interview was burned onto a digital video disc (DVD). Within the week that the interview was conducted, I would meet with the transcriptionist to give her the DVD. Once each interview was transcribed the transcriptionist would return the DVD to me. Once I received each transcribed interview, I would listen to the recording of the interview with the transcript in hand. I did this to ensure the quality of the transcribed interview and to obtain an overall sense of the
interview. This is the first step in Colaizzi’s phenomenological method of data analysis (Colaizzi, 1978). During many of the interviews, the participants’ child was present because the families lacked child care and because of the nature of the child’s often complex disability. During several of the interviews, sections of recording were compromised for several moments due to vocalizations or disruptions from the child. If the transcriptionist had any doubt over the words that were said during this time, she would indicate this with a question mark. I diligently reviewed and clarified all question marks. I often deciphered the words because of my familiarity with the context of the conversation with the participant. The majority of interviews were transcribed within several weeks of the interview.

3.4.8 Field Notes and Audit Trails

During the interview process, field notes were an integral part of data collection. Immediately following each interview, often in the car, once I had returned from a participant’s home where the interview was conducted, I recorded a field note. I decided to use an audio recorder to dictate my field notes, as it was faster for me to talk about my feelings and experiences during the interview rather than to write or type them. I also wanted to capture my initial reaction to the interview as there was often a lengthy car ride to get to participants’ homes. I started each field note with describing, in detail, the setting in which each interview took place. I would describe the participants’ neighbourhood, their home, and the individuals present during the interview. I would talk about the interview process and my thoughts and feelings during the interview. In the field note, I would note any questions that came up during the interview and describe any thoughts that came to mind. For example, if I felt uncomfortable at anytime during the interview, I would make note of this feeling and try to analyze the reasons for why I may have felt this way. There were also times when I was interviewing participants where I had been
the occupational therapist involved in their interdisciplinary team assessment. While I felt that the participants during these interviews were open and candid with me, I was very aware of any potential influence my role in their child’s care may have had on the interview. I was diligent about not discussing clinical questions with participants. However, my role as an occupational therapist working in the area of feeding did make it easier for participants, regardless of my previous contact with them, to ask questions related to their child’s feeding. I was also careful to identify in my field note if there was any time where I felt my role as the therapist on their child’s feeding team may have influenced their response to one of my questions. In reflection, I do not think this to be the case. I did notice that my previous involvement with some of the participants made it easier to build a rapport with the caregiver and helped us both to feel more at ease. I did wonder whether these families were able to open up to me about their experiences faster than the families where I did not have previous contact. Recording of field notes was an exercise in reflexivity. During this process I was thoughtful about my interactions with participants and was self-aware of my feelings during the interview process.

Throughout the research process I kept a research log/journal. This journal served several purposes in my research process. I thought it important to clearly record everything that I had done during the study over the past year. I noted all activities including phone calls I made with participants and interactions I had with my research committee regarding my data analysis. This strategy helped me to not only see the progress I made with the project, but also helped me to identify where critical decisions were made in my research process. Use of an audit trail is one technique that can be used to enhance the rigour of a qualitative study. The audit trail ensures that the reader has sufficient information to be able to audit the events, influence and actions of the researcher, through careful record keeping of decisions and thought processes that occur.
during the study (Koch, 1994). Finally, to help me organize and keep track of my interviews, the last activity that I engaged in was to create a summary of the contents of the interview. Usually, I created this summary after I reviewed the transcript and listened to the interview following transcription. This summary contained information about the length of the interview, the name of the interview, the location of the interview and a brief summary of the contents of the interview (Miles & Huberman, 1994).

3.4.9 Confidentiality

Confidentiality has been maintained by ensuring all data obtained from this study, including all transcripts, written field notes, reflexive journals, and audiotapes, have been stored securely in a locked cabinet in a UBC facility. The following steps were also taken to further ensure confidentiality: all computer files were password protected, laptops and confidential materials were never left unattended in a vehicle and no confidential information was collected or exchanged via e-mail. The interviews did at times include names and/or other identifiers, such as area of residency, the name of their child’s school, which can be used to link the data to the participant’s name. This information was kept confidential from members of my research committee. No one other than those specified in the consent form that was given to participants had access to the data. Although the participants were not anonymous to the research team, as face to face interviews were conducted, to ensure confidentiality, all identifiers were removed from the data.

3.4.10 Ethics

Ethical approval was obtained from the Behavioural Research Ethic Board of the University of British Columbia, and the Children’s and Women’s Hospital Research Review
Committee (refer to Appendix E). Written informed consent was obtained from each participant before the participant was interviewed.

### 3.4.11 Data Analysis Process

I chose to use Colaizzi’s method of data analysis because it is a framework based on descriptive phenomenology. For novice researchers it has been said that a structured framework can assist with the complex analysis of phenomenological data, which can often be overwhelming (Creswell, 2007; Sanders, 2003). Table 3.2 outlines Colaizzi’s seven stages for data analysis.

#### Table 3.2—Colaizzi’s Seven Stages of Data Analysis

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>Acquiring a sense of each transcript</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Extracting significant statements</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Formulation of meanings</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Organizing formulated meanings into clusters of themes</td>
</tr>
<tr>
<td>Stage 5</td>
<td>Exhaustively describing the investigated phenomenon</td>
</tr>
<tr>
<td>Stage 6</td>
<td>Describing the fundamental structure of the phenomenon</td>
</tr>
<tr>
<td>Stage 7</td>
<td>Returning to the participants</td>
</tr>
</tbody>
</table>

The first stage of Colaizzi’s (1978) method advocates reading participants’ narratives to acquire a feeling for their ideas in order to understand them. After each interview, I listened to the audio-taped interview in order to get a sense of the overall experience of the participant. I did this once again after I received the transcribed interview, to ensure that the interview was transcribed as accurately as possible. Parts of the transcripts were read and re-read numerous times over the research process. The second stage is the extracting of significant statements (SS) (Colaizzi, 1978). This involved reading through the transcript carefully and using the ‘highlight’ feature on my computer’s Word program to extract phrases or sentences that directly pertained to the phenomenon of interest. When I first initiated this stage, I was careful to not ‘under
highlight’ as I was not sure whether or not certain sections of the transcript would be significant. For example, some participants would begin their interview by telling me about their child’s disability and by providing information about their child’s personality. While some of this information is not directly related to the phenomenon of ‘the experience of an interdisciplinary assessment’ I did not want to eliminate potentially significant data too early in the data analysis process.

Stage three of Colaizzi’s method involves the formulation of more general restatements (termed formulated meanings) or meanings for each significant statement. Colaizzi (1978) cautions that the researcher must not sever the connection between the original transcript, rather the formulations should “discover and illuminate the meanings hidden in the various contexts and horizons of the investigated phenomenon” (p. 59). The researcher must go beyond what is given in the original data, but at the same time stay with it. In other words, formulated meanings (FM) must have a connection with the data. Several times throughout this stage of the data analysis I consulted with my research committee to obtain clarification regarding my FM. Initially, I received feedback from my committee that my FM needed to be brought to another level of abstraction, with more interpretation. Therefore, I went through my initial formulated meanings to reflect this feedback.

During the third stage of Colaizzi’s method, I found it helpful to reflect on Giorgi and Giorgi’s method of data analysis, particularly the third stage of “transformation of meaning units into psychologically sensitive expressions” (p. 252) (Giorgi & Giorgi, 2003). Giorgi and Giorgi’s method of data analysis is similar to Colaizzi’s, both being descriptive, psychological, phenomenological methods of data analysis (Dowling, 2007). However, as Giorgi and Giorgi provide more detail regarding their stages of data analysis, I incorporated their process of data
analysis at this stage into my study. Giorgi and Giorgi describe the transformation of ‘meaning units’ (similar to term ‘significant statements’) into ‘psychologically sensitive expressions’ (similar to formulated meanings’) (Giorgi & Giorgi, 2003). Giorgi and Giorgi describe that the purpose of this stage is to discover and articulate the psychological meanings being lived by the participant that reveal the nature of the phenomenon being researched. The meanings expressed by the participants have to be made explicit. To do so, the researcher must find the essential structure of the experience within the participants’ language (Giorgi & Giorgi, 2003). My interpretation of this idea was that I needed to find the key constituents of the experience that participants were describing and identify these from within their language. I did this analysis by copying and pasting each significant statement (SS) from the original transcript and putting them into a new document. I was careful to record the line number from which the SS was removed, so it could be traced if required. In the new document, under the SS, I wrote the FM using the guidance from Giorgi and Giorgi (2003). The SS and FM were kept together throughout the data analysis process so that I stayed close to the participants’ own words.

The fourth stage of Colaizzi’s (1978) method of data analysis involves organizing the formulated meanings into clusters of themes. Colaizzi stresses that it is important in this stage to refer the clusters of themes back to the original transcript in order to validate them. To do so, one has to ask if there is anything that is contained in the original transcript that is not accounted for in the clusters and vice versa (Colaizzi, 1978). During this stage I decided to physically cut and move the SS and FM pairs into folders to represent a theme. Throughout the research process I had become familiar with using the qualitative research software program NVivo. As I learned more about this program I did not feel that it ‘fit’ with the method of data analysis I chose to use or with descriptive phenomenology. As a result of having a small sample size and not needing to
‘code’ my transcripts, I felt that it was faster and more transparent for me to physically handle my data. Throughout this stage I moved 486 SS/FM pairs into 12 theme clusters and five major themes. Appendix F provides a sample of the data analysis process used in the study for stages two to four of Colaizzi’s data analysis method.

Colaizzi’s (1978) fifth stage of data analysis involves exhaustively describing the investigated phenomenon. In this stage the researcher integrates all the resulting ideas into a comprehensive description (Sanders, 2003). From the exhaustive description, stage six of Colaizzi’s method advocates reducing this description into an essential structure. Finally, the seventh stage of Colaizzi’s method is the returning the findings of the analysis to the participants for validation. While it would have been possible for me to arrange another interview with participants to discuss my findings, I was conscious of families’ time commitments and busy schedules. As a result, I decided to mail each participant the exhaustive description of the themes, rather than the essential structure of the phenomenon of study. I thought that this alternative would be more recognizable to participants, which was supported by Holloway and Wheeler (1996), who suggested that this strategy would help to enhance the rigour of the study. I asked each participant to verify that the themes that were identified represented their experiences of the feeding team and the implementation of recommendations. If participants felt that the themes were not representative, they were given the opportunity to contact me, or write their suggestions or comments in the space provided in the letter and return it to me in the pre-addressed, stamped envelope provided. Seven of the nine participants responded, each indicating that the themes were representative of their experiences.
3.4.12 Strategies Used to Enhance the Rigour of the Research

In qualitative research, there are specific ways in which to establish the rigour of findings to ensure that results depict the meanings that individuals hold for a particular phenomenon. Establishing rigour in qualitative research helps to minimize bias and legitimize findings (Padgett, 2004). Lincoln and Guba (1985) have proposed four criteria for evaluating the quality of qualitative research: credibility, transferability, dependability and confirmability. These criteria are parallel to the four criteria used to evaluate quantitative research: internal validity, external validity, reliability and objectivity (Carpenter & Suto, 2008). Another term for confirmability is ‘trustworthiness’. Here the data are checked to ensure that the data reflect the meanings described by participants as closely as possible (Lincoln & Guba, 1985). This concept is one way to conceptualize rigour, as it does not occur naturally and can only be established through defined procedures (Padgett, 2004). One of the primary threats to trustworthiness is bias on the part of the researcher. In order to ensure that the findings of a qualitative research study represent the meanings of participants, researchers can engage in several strategies: an initial bracketing interview, an audit trail, reflexivity, peer debriefing, triangulation and respondent validation (Lietz, Langer & Furman, 2006; Lincoln & Guba, 1985; Sandelowski, 1993).

Several techniques to enhance rigour have been mentioned previously in this chapter, including the use of a bracketing interview, use of an audit trail and the use of reflexivity. The strategy of peer debriefing involves the frequent discussions between the members of the research team regarding the analysis of the data and the logistics of the categories and themes that are uncovered (Creswell, 2007). The individuals who reviewed my data analysis were members of my research committee, all of whom had extensive research experience. This process was very important for me as a novice researcher. Peer debriefing helped me to minimize
bias in the findings, but also helped to ensure that I was on the right track with my data analysis, a process that was very new to me.

Source or data triangulation is another strategy used to enhance the rigour of a qualitative study. This approach refers to the use of multiple data quotes from participants in the study, or the involvement of multiple participants as a way to illuminate emerging themes or the phenomenon (Flick, 2007; Carpenter & Suto, 2008). This study involved nine participants, all with varied backgrounds and experiences. In order to elaborate on each caregiver’s experience, I have included quotes throughout this manuscript. Finally, respondent validation is a process in which researchers ask participants to check the accuracy of the findings in the areas of descriptions, themes, and interpretations (Creswell, 2007). This step is also the final stage in Colaizzi’s method of data analysis. The process for respondent validation was previously described as the technique to ensure the accuracy of my findings.

3.5 CONCLUSION

In this chapter, the aim was to introduce the study and understand the position of the researcher. The epistemological assumptions of the study, as well as the theoretical perspective and methodology were made explicit. In addition this chapter covered the methods of recruitment that were used, the methods of data collection, the strategy for data analysis and the techniques that were used to ensure the rigour of the study. In the next chapter the study findings will be discussed. Each theme that has emerged from mothers’ experiences of an interdisciplinary feeding team will be presented with quotes that reflect their perceptions of their world.
CHAPTER FOUR

This chapter will describe the results of the present study, which examined the experiences of nine mothers who went through an interdisciplinary feeding team assessment for their child with a feeding disorder. Colaizzi’s (1978) seven-step process for data analysis was applied to the descriptive data collected for this study. Analysis revealed 12 theme clusters and five themes. This chapter represents Step Five in Colaizzi’s process, the integration of the results into an exhaustive description of the investigated topic. Chapter four will conclude with a description of the fundamental structure of mothers’ experiences, the sixth step in Colaizzi’s analysis process.

4.1 RESULTS

4.1.1 Description of Participants

In total, nine primary caregivers consented and participated in two separate interviews. All but one of the participants had both interviews conducted in their own homes; the remaining participant requested that the second interview take place at the SHHC. The mothers were between the ages of 27 and 45 years and identified themselves as Canadian citizens. Two participants identified themselves as being from distinct ethnic backgrounds (refer to Appendix G for a summary of participant information.) All mothers were married and stated that their husbands were employed outside of the home. Each of the mothers identified themselves as being the primary caregiver for their child/children, and stated that they were also the primary parent to address their child’s feeding issues. All the families resided in the Lower Mainland of BC.

At the time of the initial interview, five children were being fed orally by their mothers, three children had gastrostomy tubes and one child had a nasogastric tube. Of the nine
participants, the primary researcher had previous contact with five of them, having acted as one of the therapists on their child’s interdisciplinary feeding team. To ensure confidentiality, pseudonyms were used for the names of participants and their family members. In addition, details of each child’s diagnosis were not included in this study, to further ensure confidentiality. The following paragraphs briefly describe each of the nine participants and their children, as well as the reasons the children were referred for an interdisciplinary feeding team assessment.

Participant 1, Kim, has a daughter who was five years of age at the time of the initial interview. Kim’s daughter, Megan, was diagnosed prenatally with Down syndrome. Megan was referred to the SHHC feeding team to assess the safety of her swallow. Her mother also had concerns that Megan was not chewing while eating solids. Prior to the feeding assessment, Megan had two episodes of pneumonia in 2007, one of which required hospitalization.

Participant 2, Amber, has a daughter (Becky) who was 14 months of age at the time of the interview. Amber reported that both she and her husband were unaware that their daughter would be born with a rare chromosomal disorder which affects Becky’s ability to feed orally. When Amber was born, she did not open her eyes and was unable to manage feeding during her first few weeks of life. She was provided with nutrition via a nasogastric feeding tube. Soon after birth, Amber and her husband, upon recommendation from their physician, elected to have a gastrostomy tube placed surgically for their daughter. Although Becky was gaining all necessary nutrition from her gastrostomy tube, she was referred to the SHHC to assess whether her swallow was safe enough to take liquids and/or solids orally.

Participant 3, Susan, has a son named Thomas, who was five years of age at the time of the interview. Thomas has been diagnosed with spastic quadriplegia and Autistic Spectrum Disorder. At the time of the interview, Thomas had been using a nasogastric tube for three
months due to his limited oral nutritional intake. Thomas had already completed his second
feeding assessment at SHHC at the time of the initial interview, although his first assessment did
not involve a VFSS. Thomas was referred to the SHHC feeding team to determine the cause of
his regressing oral motor skills and to assess his nutritional intake and growth.

Participant 4, Crystal, has a daughter who was born with a very rare genetic disorder that
has affected her growth. When Jessica was born she was intubated and put on a ventilator for
several days, and had a nasogastric tube (ng-tube) placed at that time. Jessica was fed using an
ng-tube for a year before her parents elected to have surgery for gastrostomy tube (g-tube)
placement. Two and a half year old Jessica was referred to the SHHC feeding team to rule out
structural abnormalities that may be causing her discomfort while swallowing. Although Jessica
had been resistant to swallowing foods, she was very interested in licking and tasting foods. The
goal of the feeding assessment was to determine whether Jessica was safe to swallow so that her
parents could feel confident in encouraging her to begin oral feeding.

Participant 5, Carol, has a 15 ½ year old daughter named Abigail with a diagnosis of Down
syndrome. At the time of Carol’s interview, Abigail previously had three feeding assessments at
SHHC. During Abigail’s second feeding assessment, some abnormal tissue was identified at the
base of her tongue. Medications were prescribed at the time to decrease the size of the abnormal
tissue. Her most recent assessment was to determine whether the medications were successful in
not only minimizing the size of the tissue, but also in diminishing Abigail’s signs of dysphagia.
Carol’s hope was that her daughter would be found safe to drink thin liquids, instead of having to
continue to offer the recommended thickened liquids.

Participant 6, Ester, immigrated from Eastern Europe several years ago. Ester’s only son,
Dennis, experiences infantile spasms and hypothyroidism. Dennis was two and a half when he
was referred to the SHHC feeding team to assess the safety of his swallow. Ester was concerned with how to progress Dennis’ oral skills so that he could begin eating more solids and textures.

Participant 7, Kuldeep, is mother to four and a half year old Mandeep. Mandeep was born with a cephalic disorder, which has resulted in developmental delays, diabetes and epilepsy. For the first year and a half of her daughter’s life, Kuldeep had a very hard time feeding her daughter. Consequently, at approximately 21 months of age, Mandeep had surgery for g-tube placement. As Kuldeep had slowly been providing Mandeep with oral tastes, their family physician as well as their community child development team referred Mandeep to the SHHC feeding team to confirm the safety of Mandeep’s swallow.

Participant 8, Erin, has a four year old daughter named Nicole, who was diagnosed with global developmental delay. After a previous feeding assessment, Nicole was referred to the SHHC feeding team to follow up with her nutritional intake. Erin also wanted suggestions on how to progress Nicole’s oral motor skills.

Participant 9, Jennifer, has a son named Matthew. At the time of Matthew’s birth, he was diagnosed with an extremely rare genetic disorder affecting his skeletal development. At eight months of age, Matthew was referred to the SHHC feeding team to assess whether he was at risk for aspiration. Matthew was displaying signs while drinking that he might have impairments with the safety of his swallow.

4.1.2 Themes

The analysis in the present study involved transcribing and analyzing 18 interviews from nine participants. Using Colaizzi’s method, 12 theme clusters and five major themes were identified (refer to Table 4.1 for a summary of the data analysis). The five themes include: (1) “Taking Action”, (2) “The Balancing Act”, (3) “The Impact”, (4) “We Are On Our Own”, and
(5) “We Can Now Move Forward”. The experiences captured by these themes were common to all or the majority of the mothers in this study, and are presented in the timeline described by all mothers when they talked about the process of the interdisciplinary feeding team assessment.

Table 4.1: Summary of Analysis

<table>
<thead>
<tr>
<th>Topic I</th>
<th>Theme Cluster</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-Feeding assessment</td>
<td>1. When Is The Right Time?</td>
<td>Taking Action</td>
</tr>
<tr>
<td></td>
<td>2. Uncertainty and Anxiety About What to Expect</td>
<td></td>
</tr>
<tr>
<td>Topic II</td>
<td>Theme Cluster</td>
<td>Theme</td>
</tr>
<tr>
<td>During the feeding assessment</td>
<td>1. Assessment Stressors</td>
<td>The Balancing Act</td>
</tr>
<tr>
<td></td>
<td>2. Positive Team Interactions And Support</td>
<td></td>
</tr>
<tr>
<td>Topic III</td>
<td>Theme Cluster</td>
<td>Theme</td>
</tr>
<tr>
<td>Post feeding assessment &lt; 1 month</td>
<td>1. The Emotional Rollercoaster</td>
<td>The Impact</td>
</tr>
<tr>
<td></td>
<td>2. “Now I Understand”</td>
<td></td>
</tr>
<tr>
<td>Topic IV</td>
<td>Theme Cluster</td>
<td>Theme</td>
</tr>
<tr>
<td>Perceptions of Implementing Recommendations</td>
<td>1. It Is Hard Work Before It Gets Better</td>
<td>We Are On Our Own</td>
</tr>
<tr>
<td></td>
<td>2. Integrating Recommendations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Positive change</td>
<td></td>
</tr>
<tr>
<td>Topic V</td>
<td>Theme Cluster</td>
<td>Theme</td>
</tr>
<tr>
<td>Post Feeding Assessment &gt; 3 months</td>
<td>1. Adaptation and Gaining Acceptance</td>
<td>We Can Now Move Forward</td>
</tr>
<tr>
<td></td>
<td>2. Learning From Their Child</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Hopes For The Future</td>
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</tbody>
</table>

Prior to their child’s referral for an interdisciplinary feeding assessment, mothers reflected upon their lack of knowledge regarding their child’s feeding difficulties and the constant concern that they had in their everyday life caring for a child with a feeding disorder. These experiences were not the focus of this study; however, they are important for therapists
and practitioners to understand as they give some context to parents’ home environments and insight into the emotions primary caregivers may be experiencing. In addition, mothers’ experiences prior to the interdisciplinary feeding team assessment appear to influence their experiences of the assessment and their approach to the implementation of recommendations. A brief discussion of mothers’ experiences of having a child with a feeding disorder will be presented in terms of four primary areas: “Mothers’ Instinct”, “Missed Experience”, “The Stressors” and “Lacking Knowledge”.

A Mothers’ Instinct

Mothers sensed that their child had feeding difficulties early on but there was little or no support until acknowledgement by professionals that their child had a feeding disorder. Though many mothers already knew that their child had a disability, they did not know that their child’s disability would also entail feeding difficulties. Mothers had an instinctual sense that something was “not right” when their child would feed. Jennifer described this feeling as her “maternal instinct”:

... it was at that point that they (professionals) thought he was doing fine, but I didn’t think he was...I said to them, “Well, you know, he still vomits like his food. You know, he still chokes on thin fluids.” So it wasn’t until we went to Sunny Hill and he had the videofluoroscopy study done that everything came to light and we knew exactly what was wrong and why.

Carol did not formally learn that her daughter (Abigail) had feeding difficulties until Abigail was several years old, yet she could sense that her daughter could not handle certain consistencies of foods. Carol’s instinct guided her to adapt meals in order to minimize her daughter’s feeding difficulties:

I think she’s always had trouble feeding. In fact even with her milk, now looking back, she used to have – it was odd but it was like a projectile vomiting, so she never fed well, and I couldn’t nurse because she didn’t have the strength. I tried the toddler foods, and the toddler food has solid pieces and liquid...she couldn’t do that...We noticed all the foods she
had trouble with. We just knew. I know other kids with Down’s syndrome were eating normally, like they’d eat sandwiches and that. But we just knew she couldn’t do it. I kept telling the paediatrician when she was five; I would say she had trouble. But I guess when she was really little it wasn’t as noticeable to him.

Mothers felt that at times they were “unheard” by professionals. They knew their child could not feed adequately but were unsure what was “normal”. This uncertainty made it difficult for mothers to describe their concerns to health professionals. A quote from Ester depicts her experience:

I always said to everybody, everybody, including family doctors, he has problems with swallowing but nobody paid attention to this. So, I thought maybe it’s okay, it’s common...the assessment helped me realize it’s a safety concern.

Many of the mothers, including Ester, now look back at the period of time before the feeding assessment with a different perspective. These mothers now feel validated that their concerns and feelings of unease while feeding their child were indeed warranted.

**Missed Experience**

When a child has a feeding disorder, it becomes difficult to feed him or her outside of the home environment, as feeding often requires specialized equipment or supportive seating. In addition, having a child with a feeding disorder often requires specialized diets and planning ahead. This makes it difficult for mothers to participate in some of the experiences that are typical for many families, such as going to restaurants, other homes and travelling. It is difficult for mothers to leave their child in the care of others due to the added challenges and responsibilities related to feeding. Having independence from their child is often impossible for mothers to obtain. Susan described how maintaining her son’s caloric intake is an all-consuming task:

Three meals a day with a child that’s not eating, it feels like a 12-hour day just focusing on what are they going to eat or how are they feeling or how much did they drink? You’re always measuring or counting in your mind sort of where they are in the day...It’s just
always thinking and thinking and thinking...You know, you wish for more independence for both you and him, but it’s just not something at this point that we’re able to do.

In addition to these missed experiences, many participants described not having the experience of breastfeeding their child. The inability to breastfeed may be secondary to a child’s physical abnormalities, a child’s lack of oral strength, or related to a child’s level of alertness. When mothers lose the ability to breastfeed their child, they experience frustration and sadness at the loss of this bonding activity.

**The Stressors**

Mothers experience significant stress when their child’s health is compromised due to feeding difficulties. They recognize how their child’s ability to feed is dependent on the health of their child and vice versa. If a child has difficulties feeding, giving medications becomes very stressful. Proper nutrition is also essential in maintaining good health, and feeding disorders can compromise a child’s ability to gain adequate nutrition. Kuldeep described her experiences trying to maintain her daughter Mandeep’s caloric intake in order to prevent Mandeep’s medical condition from worsening:

> It was very stressful for us to get enough nutrition into her. We were using syringes to feed her and everything. It was very hard. We were always in the hospital...when we were trying to feed her solids, it would take an hour and a half sometimes to feed her...that took a LOT of time. I think the whole day we were just trying to feed her. The first three years I think was the most stressful in my life.

A common stressor for mothers and their child was the child’s interaction with food. Many children with feeding difficulties do not demonstrate that they sense the feelings of hunger, or find enjoyment and pleasure from eating. This behaviour could be secondary to the discomfort feeding may cause, or because of negative experiences with food. The resistance to eating is a source of stress for mothers, as mothers are often concerned with the amount of nutrition their child is consuming. A quote from Susan describes her experience:
So many times we’d be eating and he would get turned off by OUR meals, even though they’re very typical meals, just by us eating them. He would not be able to cope. He would be almost like his stomach would be turned upside down, in a sense of feeling sick. He’d gag a lot and so we’d end up feeding him here so it’s away from the family.

A significant source of stress arose from trying to avoid the need for a gastrostomy tube (g-tube) surgery for their child. These mothers viewed a g-tube as a last resort, to be used only if their child was unable to gain enough nutrition orally. As Carol described, “I think the worst case scenario we’ve said is if she has to get a feeding tube, like if she keeps aspirating more. So I always look at it as I think it could be worse”. For participants whose children were fed orally, the g-tube represented a “step backwards” on the road to creating normality in their family life.

Erin described the pressure she put upon herself to avoid a g-tube for her daughter and the associated stress:

...there was that one time, one period, where she gained a pound in a year so I think they were kind of concerned about that. So I probably felt a bit more pressure and there was also the threat of a feeding tube, which, you know, that was a whole other thing to take on and I wanted to try and avoid that. I was trying to pressure myself to get her nourished properly so that I didn’t have to go that route. I know I probably put a lot of pressure on myself. That was going to be our last resort because I didn’t want to do it at all.

Instances of conflicts with participants’ partners and other family members, over decisions about feeding, constituted additional stressors. The participants in this study were often the caregivers who met with community therapists and attended medical appointments, and as a result, their knowledge regarding their child’s health and feeding often differed from their husbands’ understanding of the issues involved. This discrepancy in knowledge increased the difficulty of joint decision-making with partners and family members with respect to health decisions and approaches to feeding.
Lacking Knowledge

Mothers recognized that prior to the feeding assessment they had suffered a lack of knowledge regarding their child’s feeding difficulties. Their lack of knowledge made it difficult for them to recognize signs of feeding difficulty or to understand what those signs meant. The implications of lacking knowledge not only perpetuated the mothers’ reliance on medical professionals for information, but added to the stressors they faced due to their fears associated with the health complications linked with feeding difficulties. Several mothers described feeling “in the dark” during times when their child’s health was compromised. Kim described her experience when her daughter became very ill with pneumonia as a result of her feeding difficulties:

When you don’t know what’s happening it’s just all over petrifying. It just makes you immobile because there could be so many things and you could be doing the wrong thing. And you’re sitting there and you get yourself to the point where you’re paralyzed because you don’t know whether putting the steamer in the room is a good thing or a bad thing. Well, should you put vapour rub in? Should you...you know, what do you do?

Mothers spoke about feeling as if they were in “limbo”, waiting to be told what they should do next. When a child has feeding difficulties, the situation is complicated by the serious health consequences that can ensue. Mothers feel the need to provide nutrition so that their child will live and thrive, while on the other hand, they realize that the very food they are providing could potentially make their child ill. Lacking knowledge surrounding feeding difficulties can be a scary experience for mothers, as Carol describes, “I think you just-sometimes the fear of the unknown is worse than when you’re actually going through anything.”

4.2.1 Theme One: Taking Action

Understanding mothers’ experiences of having a child with a feeding disorder has created a foundation from which to examine the two objectives of this study. The first theme, “Taking
Action”, represents the beginning of mothers’ experiences of an interdisciplinary team process; the period of time prior to commencing the interdisciplinary feeding assessment. At this point in time, participants had been alerted to the idea of having an in-depth assessment by either their community therapy team or their child’s physician. Once mothers have made the decision to have an interdisciplinary feeding assessment for their child, they wait for the assessment with feelings of anxiety and uncertainty.

4.2.1.1 “When Is the Right Time?”

Mothers’ experience stress related to the decision of whether or not their child should have a feeding assessment, and when the optimal time should be for the assessment to occur. For participants whose children receive their nutrition orally, the decision to have a feeding assessment is made quickly – often based on signs and symptoms that the child may be suffering from dysphagia and the realization that delaying a feeding assessment could potentially pose a health risk for the child. Kim described her experience of determining when to have a feeding assessment for her daughter:

I thought it was awful because they told me it (her feeding difficulties) would get better as she got older, and I found last year was the sickest she’d ever been. And I thought well, the only thing I can think of is she’s eating and trying more different foods and, you know, some of the situations are changing for her so there’s things going on that, you know, I’ve got to start having a plan for. I’ve got to have people aware of her difficulties. I’ve got to have it followed because this is, you know, not okay for Megan to be like this.

For Amber, the decision regarding timing of assessment was based upon her need to get answers about how safe her daughter was to feed:

We went ahead with the one (feeding assessment) in December even though we thought that she might not do the best at it, but we just needed to know whether – I wanted to know whether we, you know, what we were doing was safe or not.

For children who do not receive their nutrition orally and have a g-tube already in place, there are no risks for respiratory illnesses as a result of aspiration. This situation allows for more
flexibility in the timing of an assessment. Mothers recognize the importance of needing to feel that they have given their child adequate time to be able to do “their best” on the assessment. When the timing is not ideal, this can lead to regret that perhaps the feeding assessment was rushed. For mothers of children with g-tubes, the decision on when to “take action” and have a feeding assessment was, in part, based up how well they thought their child would perform.

Additional uncertainties mothers experience regarding the timing of the feeding assessment stem from mothers’ awareness of the number of tests and procedures their child has had to endure in the past. Going through a VFSS involves bringing their child to a hospital setting that their child may have visited on multiple prior occasions for x-rays and other diagnostic tests. Mothers are conscious of the negative associations their child may have with the hospital and various medical procedures. For Crystal, her decision to have a feeding assessment for her daughter who had a g-tube was based upon her child’s physical and emotional readiness:

We just thought that at this stage she would probably be fine to do it and, you know, my biggest thing was that it wasn’t so much that she could swallow enough to do the test, it was more being in the hospital environment, because she has had so many experiences at the hospital that I didn’t know if she would cooperate, so that was the only thing I thought...I didn’t know how she’d react to it, you know it is hard...you don’t ever want to put them into a situation where they are upset... I think actually the delay [in having the assessment] worked in our favour because she’s now at a point where she can handle hospital visits a lot better and has more confidence in those experiences.

Mothers’ confidence that their child is functioning at their optimal level at the time of the feeding assessment has an impact on how mothers view the recommendations that they receive. Mothers may be more inclined to feel that the assessment is not representative of their child’s true abilities if the timing of the assessment is judged by the mother to be poor. Unfortunately, the reality of feeding teams is that there are often lengthy waitlists, which do not allow mothers flexibility in determining when their child’s feeding assessment takes place.
4.2.1.2 Uncertainty and Anxiety about What to Expect

The interdisciplinary team assessment creates an atmosphere of uncertainty in which mothers are unsure about what to expect. The detailed orientation package that the SHHC team sent to prepare mothers for the assessment did not effectively communicate the scope of the assessment. As Susan states, “I think it was verbalized but, you know, you kind of show up just kind of not sure of what will happen.” Other mothers were given additional information from their community therapists regarding the assessment, yet they did not feel adequately prepared for the assessment. A quote from Jennifer illustrates this concern:

When I got the package mailed out to me, where I had to send back the permission forms that kind of gave me an idea of what was going to go on. This is who you’re going to see, this is what’s going to happen and this, you know, for these two days and then it kind of gave me an overview of what was going to happen. But then when we got into the details – I just didn’t expect it.

Generally mothers come to the interdisciplinary team feeding assessment with at least some knowledge of what will take place, however, this information is often not enough to minimize their reservations about the experience. Susan related her experience prior to the feeding assessment:

You know, I think it’s a long haul doing like two days like that, that was physically leading up that was really stressful because we didn’t really know how it was going to go, what exactly the videofluoroscopy was. It sounded really scary. They tried to, you know, help me feel better about it and they did in a sense, but, you know, just all that unknown stuff. And then you’re always as a mom trying to make sure your child’s well rested, well fed, well happy and everything, you know. But it was, you know, as the time passed everything went very well. Again, it was very, you know, you felt very scared. You felt very nervous.

In addition to feelings of uncertainty regarding the assessment, participants felt anxious at the anticipation of the VFSS portion of the assessment, particularly with respect to their child’s exposure to radiation. Information regarding this portion of the assessment would have helped to diminish mothers’ fears. One participant, Kuldeep, described her experience prior to the feeding
assessment. While she herself felt comfortable with what would take place, her husband and family were very concerned, believing that the feeding assessment might be invasive. Kuldeep had to console her family and explain to them that her daughter would not experience pain during any portion of the assessment. Kuldeep admitted that the task of having to alleviate her family’s concerns created additional pressure for her.

The period of time prior to the feeding assessment is often filled with anxiety and fear. Mothers communicated anxiety regarding the repercussions of negative assessment results on their child and family. For example, many participants expressed fears that their child may need to be fed by gastrostomy tube. Prior to the assessment, participants wondered whether it would be determined after the assessment that their child was no longer safe to eat orally, or was not gaining adequate nutrition by mouth. While mothers understand the importance of a feeding assessment, they worry about putting their child through another set of tests and procedures, and worry about receiving negative assessment findings.

4.2.2 Theme Two: The Balancing Act

When participants were asked to describe their experiences during the multi-day feeding assessment, the majority of mothers did not focus on describing the details of the assessment itself. Mothers recalled their experiences surrounding interactions with team members and the stressors they experienced during the assessment. Participants’ most recent experiences with the interdisciplinary team assessment were generally positive, despite the fact that not all mothers received the results they were expecting or hoping for. The experience of going through an interdisciplinary feeding team process involves a paradox of positive interactions and extreme stressors. Mothers’ perceptions of the balance between these two groups of events have an influence on their overall experience of the assessment.
One of the participants, Erin, reported two very different experiences with the feeding team, which occurred approximately two years apart. Erin described her first experience with the feeding team as negative. One of the greatest differences she identified between the two assessments was that during the second assessment, she had the sense that team members were finally “listening” to her. As Erin expressed:

The second time, I got to talk to – I can’t remember her name now, but we sat and chatted for a while about just everything, you know, how things were happening in my life and, you know, we talked about my other son...I felt that they kind of understood where I was at, which I think helped in some of the recommendations that they had for me too.

At Erin’s first assessment, approximately two years ago, she did not experience a balance between the support she felt she received from the team and the stressors she experienced during the assessment. Erin explained that because no time was taken by team members to understand the stressors she was experiencing in her home life, the recommendations she received were unrealistic for her to implement. Erin’s experiences changed during her daughter’s most recent assessment, in part due to her sense of “being heard”, which helped to balance the stressors that the assessment entails.

### 4.2.2.1 Assessment Stressors

Mothers experienced stressors during the interdisciplinary team assessment, whether it was their first assessment or their second. Mothers were aware of the importance of the feeding assessment, and as a result, worried about whether their child would be compliant during the assessment. Kuldeep stated, “I was stressed to see if she would eat or not. Because she is a picky eater and she only likes to eat when she feels like eating.” Ester also described her heightened anxiety at witnessing her son’s reaction to the VFSS, “Dennis was very stressed. He just didn’t want it. He was so upset in his little chair.” Mothers were so keenly aware of the difficulties their children have with feeding and the struggles they experience around mealtimes that the
anticipation of their child eating in a strange environment led them to fear the worst case scenario: that their child would not eat for the assessment. Susan described her experience during the VFSS portion of the study:

So when we did the study, I felt again fairly stressed out because I knew he had to eat for the videofluoroscopy, but then I felt justified at the same time...he was having all the foods that he would technically never get to usually have or that’s a really big treat for him, and he still wouldn’t eat it. And so I thought, ‘okay, it’s not just me.’ He’s very much affected by stress or environment or whatever. He was just very – absolutely his mind was made up. He wasn’t participating, and so I think that was his maybe coping mechanism, like he just absolutely refused to be – he’s very bright and he just wasn’t going to be put in a position where he was eating something he doesn’t trust, and, you know, it is coated with something white.

Mothers’ fears about their child’s performance were not isolated to the VFSS. Ester’s experience meeting the paediatrician caused her anxiety. She longed for her son to perform at his best, “I was stressed. I always want Dennis to show his best and he was not at his best that time, because he was tired and stressed after his videofluoroscopy. He wasn’t performing well.”

Mothers felt fear that their feeding practices would be judged negatively and by implication, their mothering abilities would be questioned. As Kim stated, “...she was kind of like the nutritionist and I’m, I was like, ‘oh my God, they’re probably going to think I’m not feeding her well.’”

The experience of the interdisciplinary assessment is an overwhelming experience for mothers. While mothers experienced support from the team, at times they felt in the dark regarding the initial impressions of the therapists. Several mothers felt that what was being said and done around them during the assessment was not always well explained by the therapists, which created the feeling that they were simply passive observers. Crystal described how she was unaware of what was going on around her during the VFSS:

I think I was kind of stressing because I didn’t – obviously my back was to the screen so I didn’t know that the therapists were actually getting anything, so I was kind of feeling like,
“Come on, let’s swallow.” So I think even just if I would have been more aware that okay, that we’re seeing some things now that might have been helpful.

The feeding assessment takes place in an environment that is very different from home. Throughout the interviews several mothers commented on how they would have liked the feeding assessment to take place in their home environment. Mothers expressed that if the feeding assessment occurred at home, then the results would be more representative of their child’s day-to-day life.

4.2.2.2 Positive Team Interactions and Support

Throughout the interdisciplinary feeding team assessment, mothers experienced positive interactions with the team members. For many participants it was the first assessment they experienced that involved a team approach. Susan commented that she felt everyone on the feeding team was very honest and truthful with her. For this mother, her hope was that information was being shared equally between the team members and the family because of the seriousness of the information that was being discussed. The openness she felt from the team helped to alleviate her fears. For other mothers it was the first time they were able to receive emotional support, as well as connections to the community resources available to them -- a link provided by the team’s social worker. Jennifer depicts this realization:

You know, every time we go into Children’s we educate every specialist we see except for genetics, and even genetics hasn’t seen anyone with (name of genetic syndrome) and she’s been there for like 35 years. So in that sense, yeah, it’s very hard. Do I know what kind of supports are out there? I have no idea. I don’t have the time. Up until his surgery in January he was very needy. He was in pain ALL the time, so I didn’t have a chance until I went - until Judy, we saw Judy the social worker, and she just kind of went, “Okay, well what are your needs and what can I help you with? And well, there’s this, this, this, this,” and I couldn’t believe all the things that you could possibly utilize.

Mothers felt that an interdisciplinary team approach gave them confidence in the recommendations they received regarding their child’s feeding difficulties. Mothers appreciated
the opportunity to review assessment results with the entire team, including the detailed discussion of the VFSS. By meeting with all professionals in one setting, the participants felt that they were saving time, as they did not have to meet individually with each professional. One mother commented that she felt more convinced of the results because of this act. In a team meeting, mothers could see what each team member’s role was in addressing their child’s feeding difficulties and be confident that everyone was in agreement with the recommendations. One of the participants, Ester, had reservations about the feeding assessment. The assessment had been recommended by the community occupational therapist working with Ester’s son Dennis. Prior to coming for a feeding assessment, Ester did not believe her son had serious feeding risks. As Ester recalls:

…maybe it’s a good thing that it’s such a big group (of people). It’s more – like, you know, when one person says something to you, you could not pay so much attention, but then when a group of people say the same thing to you -you understand how important it is.

A sense of caring was experienced by mothers, who appreciated the flexibility the team employed to make their experience of the feeding assessment positive. Positive interactions with team members not only helped to build connections between mother and professional, but also helped them to endure the more stressful portions of the assessment.

4.2.3. Theme Three: The Impact

At the end of the two day assessment, mothers met with the entire interdisciplinary team to hear the findings of the individual or joint assessments and the team recommendations. The impact of this complex assessment affected mothers’ lives in a variety of ways, especially if the assessment results were unanticipated. The ensuing moments and days following the assessment were filled with many emotions: shock, relief, guilt, validation, disappointment, reassurance, and fear. Despite the flood of positive and negative emotions mothers felt following the assessment,
mothers acknowledged that they had a new understanding and awareness of what their child is going through when they swallow. The knowledge gained from the feeding assessment provided mothers with confidence to manage their child’s feeding difficulties.

4.2.3.1. The Emotional Rollercoaster

Specific recommendations were provided to each mother at the family conference. Some mothers received recommendations that required major changes in their family routine. However, despite the complexity of some of the recommendations, each mother had different reactions to receiving the recommendations. As Erin relates, her reaction to the recommendations the first time she went through a feeding assessment for her daughter was very different from her second experience. Upon reflecting on the two experiences, Erin recognized that during the first assessment she was grieving her daughter’s disability and the circumstances of her life. She acknowledges that this grief may have impacted her reactions to the recommendations. This finding highlights the potential impact of the timing of a feeding assessment. Erin described her experience as follows:

Well, I think the first time everything was so new and we were just learning about her disability and it was a very stressful time for everybody. There were endless doctors’ appointments...I don’t think mentally I was in the right place either. I was getting bombarded with SO much information that I didn’t have a chance to digest everything properly. And with the second assessment I was probably more mentally in a better place where, I had become more accepting of what’s going on with her. The first assessment I was still in shock. At the first assessment, I was going through so many tests with her, like I spent over I think it was 120 hours away from work in that one period just going to doctors’ appointments, so that was probably weighing on me too, right? The first assessment, I felt that, you know, I was starving my child, that’s how I came out of it...“well, you know, if you just feed her little bits at a time.” I mean the advice I got I think was not practical for a regular family. If I had nothing else to do other than sit there and spoon feed her all day long that could be done.

During Erin’s first feeding assessment with her daughter, she described feeling very overwhelmed with the recommendations she received and the way in which they were presented
to her. Erin’s experience when receiving recommendations at her daughter’s first feeding assessment caused her to question her ability to be an adequate parent.

Initial reactions to receiving the results from the interdisciplinary team were unique for each participant. Ester had no previous understanding of the significance or magnitude of her son’s feeding difficulties. Her son’s feeding difficulties were so severe that a g-tube was recommended at the assessment. As Ester described:

It was stressful. Stressful because it was a big surprise for me that he has big issues and that it could be so dangerous...Yes, it was a big shock for me. And it was the first I heard that it could be dangerous to choke. I never thought about it....Actually it was a big shock because it was the first time we talked about a gastrostomy tube too, was at the assessment. I was surprised. I was so surprised...Every new assessment that indicates he has some problem is stress for me.

Receiving the recommendation that your child may require an alternate means of receiving nutrition can be very shocking. For many mothers the concept of receiving nutrition from somewhere other than the mouth is a very foreign concept. Oral feeding is associated with mothering tasks, and when a mother’s ability to feed her child is comprised, feelings of failure and guilt can arise. Susan commented how overwhelming it was for her to process the recommendation for a g-tube surgery for her son despite anticipating the news:

Like I did find the one thing that was overwhelming was they did have the nurse come in and quickly show us how that – what it actually was and how it works and what it looks like. It was a bit too much information, in that aspect. Like maybe just seeing it was okay but we went through the whole, like what do you do...you fill it with water- it was like information overload.

Kuldeep also experienced shock at receiving the recommendations. Kuldeep came to the interdisciplinary team because she felt her daughter has significantly improved with her oral feeding; her hope was to be able to wean her daughter off of her g-tube. However, Kuldeep did not know that the difficulties her daughter was experiencing were “silent”, so there were no outward signs that she could have identified to know her daughter was aspirating.
Mothers experienced feelings of relief and reassurance upon the completion of the feeding assessment, despite receiving results which may have been perceived as disappointing. Jennifer described her feelings at the family meeting, “It was more of a relief because something was finally being done. That is what it really came down to, it’s like, and ‘I’m finally going to get an answer today’. So yeah, it was more of a relief than anything.” As Crystal describes, the assessment reassured her that she was appropriately supporting her daughter’s oral feeding:

...we started to feel like oh, my God, what if we’re like pressuring her to eat and it’s actually, you know, doing her more harm than good. So, that pressure was taken off and now we definitely feel more confident, putting a little bit more emphasis on the oral feeding...it reaffirmed for us that we’re doing, you know, the best we can do with what she’s capable of doing at this stage. So it’s helped us to sort of stay focused on what we’re doing and not kind of waver and feel like uh-oh, you know.

Amber also experienced a sense of relief at finally having some answers for her daughter’s difficulties. For Amber, trying to feed her daughter had been at the forefront of her life for the previous year. Receiving recommendations from the feeding team allowed Amber to put oral feeding aside for the time being and turn to other goals. Participants described the feeding assessment as legitimizing their concerns regarding their child’s feeding. As Carol described:

I actually look forward to the assessments. I think in some ways it makes you feel like yeah, there is something. Because sometimes you just think it’s yourself, is it in my mind or maybe she’s fine...it’s just the way she eats. If you know there’s a reason, it’s easier to say to people, “Okay, she has this. This is the way.”

The completion of the interdisciplinary feeding team assessment is very emotional for mothers. Participants had varying experiences at the family conference; however, each participant described a range of emotions, from relief to disappointment. The conclusion of the interdisciplinary team assessment involves the compilation of observations and recommendations from a variety of team members. Not only do mothers experience varying emotional reactions to the recommendations, but they have to process a vast amount of
information. Having awareness of the emotions that mothers experience at the conclusion of the assessment is important for team members to understand so they can spend some time validating the feelings mothers may be experiencing.

4.2.3.2. “Now I Understand!”

Each child who goes through an interdisciplinary feeding assessment has unique feeding difficulties. During the family conference, each feeding team member explains their assessment findings. Time is taken to review the VFSS with the family and explain the observations that have been made. Following the discussion of the assessment findings, feeding team members provide recommendations to the family and the rationale behind these recommendations. Regardless of the complexity of the recommendations, mothers felt that their understanding of their child’s feeding difficulties improved. Other mothers experienced a deeper understanding of their child’s difficulties, resulting in a renewed appreciation for the discomfort that feeding may be causing their child. This in-depth understanding aided participants’ abilities to make informed decisions regarding their child’s feeding, thus fostering a sense of empowerment. Jennifer described her experience following the feeding assessment:

Because before we had no idea what was happening. Now we know what’s happening now I know what I need to watch for and what I should and shouldn’t be feeding him, right? So that makes sense now...before there was increased stress for sure because we weren’t sure what was happening. Like we knew he was aspirating, but to what degree and why and how, right? Yeah. And now I know - like I knew kind of what to watch for before, but now I know what I should and shouldn’t be giving him.

Amber described how the interdisciplinary feeding assessment increased her understanding of her daughter’s ability to swallow. Prior to the feeding assessment, Amber felt guilt that she had not given her daughter (Becky) adequate time to learn to swallow when Becky had her initial assessment, at a few months of age. Amber left the most recent feeding assessment with the understanding that although Becky had had an opportunity to swallow, Becky’s feeding
difficulties are indeed significant and that time had not changed her ability to feed. As Amber stated:

We just, you know, rather than spoonfuls of stuff now we just do like a little taste of it on her tongue, what we’re having for dinner or something, and she still really likes it. We don’t give her enough to swallow anymore because we know what’s happening back there…. I kind of thought until I realized she was still aspirating from the last feeding study that maybe if she were given a bit more of a chance to bottle feed longer then she might have gotten it, so now I realize.

The knowledge from the interdisciplinary team helped mothers to accept their child’s feeding difficulties. Mothers understand that there are challenges that lie ahead; however, they feel empowered to manage these difficulties. Kim describes how she is now able to move ahead since receiving new knowledge about her daughter’s feeding:

I mean there’s nothing worse than knowing things aren’t going right and you don’t exactly know why. You need to know why. And while I’m not fully like waving the flag of joy here, I’m quite happy that I have a really much clearer picture on it and I know how to deal with it better. You face it and you go okay, well that’s what we’ve got and then you live with it and you work around it.

The ability to observe a moving image on a VFSS of their child swallowing helped mothers to appreciate the difficulties their child experiences during mealtimes. Particularly for mothers whose children were identified to be aspirating during the VFSS, witnessing food and/or liquid go into their child’s lungs was shocking. Kuldeep commented that had she not observed the VFSS at the family conference she would have argued the results; “I do think the recommendations were good, especially the video really pointed everything out. If it wasn’t there I would have argued...But I knew it because of the video, okay it’s not safe.” Jennifer described that since the feeding assessment, she now imagines what is happening to the foods and liquids her son swallows as she has a clear mental image of what is taking place:

…there was a lot of other stuff too that we saw with the videofluoroscopy, that it was kind of narrowing just in behind and so that’s why thickened fluids kind of - it doesn’t necessarily get stuck but it takes him a while to kind of get it down. And so when he takes
the second and third bite when he’s hungry, that’s why he ends up vomiting it up because he can’t get it down all the way.

For mothers whose husbands had limited understanding of their child’s feeding difficulties, observing the VFSS was an “Ah Ha!” moment. Carol described her experience of having her husband see the images of their daughter swallowing, “I think even my husband, it was almost as if a light bulb went on. He was like, ‘NOW I understand’.”

The VFSS is key component of the feeding assessment that helps to identify feeding difficulties, but it is also a knowledge translation tool that adds to the impact of the interdisciplinary assessment. Mothers were able to view the VFSS and visually understand exactly what was taking place as their child swallowed different consistencies of food and liquid. As a result, the VFSS helped mothers to recognize the rationale behind the recommendations that were provided by the interdisciplinary team. In addition, the VFSS allowed mothers to understand the discomfort their child may be experiencing when food and liquid residue is left in the pharynx after the swallow, or when he or she aspirates food or liquid into the lungs. Because of this, mothers gain an appreciation of their child’s feeding difficulties and insight into why their child may not want to eat. As Susan states:

...so he was drinking not too bad but then I said, “Well, let’s change the straw and then let’s take away the straw,” because those were all scenarios that we’ve been put in, and that’s definitely where he aspirated, just the beginning a little bit. So I felt it was good for me to see, just to understand, like this is uncomfortable. What does that feel like, I can only imagine. It’s just not something that yeah, he could maybe trust, and maybe he just learned that the less he ate the better he felt in some strange way. I don’t know.

For mothers, the VFSS had the largest impact on their understanding of their child’s swallowing difficulties. With increased knowledge regarding their child’s feeding difficulties, mothers also described feeling increased guilt over the tendency to at times blame their child for difficulties at mealtimes. Prior to the feeding assessment, some mothers assumed that their child
had control over their feeding difficulties and behaviours. With the VFSS, mothers understood that their child’s feeding difficulties were “out of their control”. Ester describes her reaction to the results of the assessment:

The main concern for him, I think it’s swallowing because he’s afraid of swallowing because it doesn’t feel good. I think that this assessment was good because I never thought that he had problems with swallowing, like physical problems. I thought he’s lazy. I need to push him more. And I sometimes tried to push him to eat when it was a big mouthful of food. “You should eat, you should eat.”

As a result of the interdisciplinary feeding team assessment, the increased knowledge provided mothers with the tools necessary to look towards the future with added confidence and a sense of empowerment. Not all mothers received positive news from the assessment, yet each mother left the assessment more confident in her ability to make decisions surrounding her child’s feeding.

4.2.4. Theme Four: We Are On Our Own

The days and months following an interdisciplinary feeding team assessment is a period of time during which adaptation occurs and struggles arise. Mothers slowly learn how to integrate feeding recommendations into their daily lives, which may require changing family routines. Despite the struggles, mothers report observing positive changes in their child’s health, nutritional intake, or interaction with food; these changes motivated mothers to persevere with the modifications of their routines. The theme “We Are on Our Own” represents the period of time following the interdisciplinary team assessment, when mothers are left with the task of implementing the recommendations.

4.2.4.1 It is Hard Work Before It Gets Better

Initial challenges are experienced by mothers when first attempting to implement recommendations. Not only did mothers identify struggles within themselves as they tried to
interpret the recommendations, but struggles also arose between mothers and their husbands due to their differing views on their child’s feeding. Other mothers experienced struggles between family members, as well as struggles with their children as mothers attempted to alter their child’s routines. As a result of these conflicts, mothers experienced periods of significant stress as they made sense of the recommendations and tested how they could be incorporated into their lives. For some children who went through the feeding team, the recommendations provided were limited. There are several reasons why this may have been the case; for example, children with very significant feeding difficulties may have received the recommendation to continue with g-tube feeding. In this case, mothers were not able to progress oral feeding, and instead were limited to oral stimulation techniques. Several mothers described the internal struggles they faced in coming to terms with the realization that there was nothing more they could do to help their child with their feeding difficulties at that time.

At Kuldeep’s second interview, she described the struggles she was experiencing with her daughter. Kuldeep observed that as she exposed her daughter Mandeep to more tastes of food, her daughter’s desire to eat orally was heightened. Following the feeding assessment, Kuldeep was made aware of her daughter’s swallowing risk factors, which were previously unknown to her. Kuldeep described her dilemma of trying to juggle Mandeep’s desire and demands to eat orally with her new understanding that her daughter is at risk for aspiration. Kuldeep’s need to ensure her daughter is safe when swallowing prevented her from offering foods that Mandeep was used to previously. Kuldeep described how the recommendations caused her to feel guilt when eating in front of her daughter. As Kuldeep explains:

It is emotionally very stressful. I think everything, if you have a special needs child it becomes emotionally very stressful. I mean it’s even more stressful when you see other kids; they’re normal and they’re fine, they’re eating perfectly, they’re healthy and you’re trying to struggle just to, you know, maintain. I think just comparing. I mean when she
wants to eat something, I can’t give it. I mean now I sometimes I don’t eat in front of her. She knows I’m eating so she’ll cry. It IS hard. So now we try not to eat in front of her so much.

Kim described the tensions and struggles she experienced between her and her husband following the interdisciplinary feeding assessment. She described feeling overwhelmed by the recommendations when her husband was out of town, but on the other hand, also feeling relieved because she knew she would not have to worry about whether her husband was properly implementing the recommendations.

Participants experienced struggles as they began to incorporate recommendations into their daily lives. The process of incorporating a recommendation first involves interpreting the recommendation, and then transforming it from its written form to an alteration in a mealtime routine. Mothers experienced struggles as they attempted to interpret the recommendations from the team. Jennifer described her struggles adapting the recommendations made by the team in order to fit with her son’s dairy allergies:

We’ve just been thickening with the rice cereal but it takes a lot of rice cereal to thicken. And the problem is the recommendations that they gave me, the foods have a lot of dairy in it, such as milkshakes and yogurts. And he has a dairy and soy allergy. So with the allergy, I’m kind of stuck.

Feeding recommendations often provide general examples of foods to provide the child. In the family conference appropriate food textures and liquid consistencies are discussed; however, there are no visual examples of what this may look like. Mothers need to be able to adapt and alter the recommendations so that they are specific to their child. The team often assumes that adapting the food recommendations to fit their situation is intuitive for mothers; however, several of the participants described not feeling comfortable with altering the recommendations.
Modifying and adapting recommendations may be a task that is less familiar to mothers, and this may cause them stress and uncertainty.

Prior to the interdisciplinary feeding assessment mothers had already experienced challenges with feeding their child outside of the home environment because their child’s feeding difficulties. However, implementing recommendations from the feeding team involves further challenges when feeding their child in a new environment. Recommendations which involve texture modification or alterations to liquid consistencies may require a blender or thickening agents. The hardest transition for mothers appeared to be the need to be diligent about planning ahead for any environment in which their child may need to be fed. Carol described her experience:

...now we have to remember now when we go anywhere to bring something. Like we were at a soccer tournament for her, well, I made sure I had enough snacks and everything for Abigail, because I know these concession stands, there’s nothing that she could have....It is overwhelming at first because you think oh God, I’ve got to mix each meal...I have to find a place to plug in my blender. It’s extra work.

While further understanding of their child’s feeding difficulties provided mothers with confidence, struggles surrounding meal times were not completely eliminated after the assessment. For several mothers, new stressors emerged. For Susan’s son, a g-tube was recommended. Susan discovered after the surgery that the g-tube was more work than initially anticipated. Susan described feelings of further isolation as she was not able to leave him in the care of family members who are not familiar with how to use the g-tube. Susan described her experience:

Like it is a lot of work for sure, and I think having an understanding of how much work is involved prior to is helpful. That’s one thing that I didn’t any have comprehension of. But again, that’s what he needs... It does narrow down who cares for Thomas. That’s the one drawback to having that kind of an intervention. Sometimes families may not be able to consider or think about that ahead of time. That’s something as a family though that you
should consider, is who can actually care for your son if you’re not there. I think that’s a big consideration and change that has happened.

 Mothers whose children had g-tubes prior to their feeding assessment expressed frustrations with the recommendations they received from the feeding team, in part due to the lack of resources in Canada. As Amber states:

 ...the only thing I wish is that there was more we could do to help her at this point. Basically we can’t feed her anything. Just keep her mouth clean and let her chew on this. You know, and then what’s the next step?

 With access to information on-line, mothers are knowledgeable about potential treatments offered elsewhere in the world, outside of Canada. In the United States, private insurance will often cover very costly feeding treatment programs for families. These treatments are intensive and boast high success rates. Unfortunately, in Canada no such programs are available. Mothers described frustrations at not being able to access treatments and resources which could possibly benefit their child.

 4.2.4.2. Integrating Recommendations

 As mothers became comfortable with the recommendations provided by the interdisciplinary team, integrating recommendations into their daily lives became easier. As stated in chapter three, mothers were interviewed for the second time approximately five months after their interdisciplinary feeding team assessment. After the initial interview, one month post assessment, mothers described the struggles of implementing recommendations. At the second interview, it was evident that mothers’ perceptions of implementing recommendations had begun to change. The participants described their confidence in working towards optimizing their child’s safety while feeding or improving their child’s oral skills. Kuldeep states, “It forces you to think a lot. And you have to be really active to try to find the answers. It’s like, for example,
when she really wants to eat something, okay, I have to think what can we do?” A quote from
Amber also indicates her proactive approach to her child’s feeding:

You know, it’s difficult, but you know, advocate for your child and use all the resources
that you can, and when they say, you know, the different little therapies you can do and
things to help them with their oral stimulation, you know, it’s easy NOT to do it, but do it.
So far she’s not orally aversive and I have to be very careful to keep that going. And I
think it’s helped. Especially with someone as easygoing as her, you know, like you can just
put her in a high chair and leave her there for three hours if you wanted to. You know,
because she doesn’t call out to you and she doesn’t, you know, she’s happy there. But you
need to be, you know, doing things that will help her develop and stuff.

Only one of the participants, Carol, had a child who was a teenager (Abigail). Carol’s
experience integrating recommendations from the feeding team into her family’s daily life was
unique from the other participants. Carol had to teach her daughter Abigail the necessary skills
so that Abigail could be independent in managing her own feeding difficulties. Carol was able to
observe her daughter incorporating the recommendations, for example independently drinking
thickened liquids from the fridge and asking before trying a new food to see whether it was safe
for her.

Mothers were also able to articulate how and why they changed the way they feed their
child. Ester described how she has changed her mealtime behaviours with her son:

All our feedings have been changed. I always now hold him upright on my chest, like his
head supported, at bedtime especially. Not a lying down position. And I don’t let him to
hold bottle anymore, because when he holds bottle he could choke easily and he will eat it
but not take it out in time, so I hold bottle and I give him little sips from bottle and then I
take it out and wait until he swallows.

Similarly, Kuldeep described how the recommendations provided by the interdisciplinary team,
helped to give her guidelines on when to feed her daughter. Kuldeep expressed that she still
needed to use her own judgement to know when her daughter was safe to feed, but she did not
feel alone in making those decisions.
Mothers integrated the team recommendations and felt motivated by having a plan of action for their child’s feeding difficulties. Instead of being passive observers of their child’s feeding difficulties, they were able to take steps to make mealtimes more enjoyable and safe.

4.2.4.3. Positive Change

Mothers observed encouraging changes in their child following the implementation of feeding recommendations. These changes were related to their child’s general health, gains in their child’s interest in eating, as well as in decreased feelings of stress and anxiety surrounding mealtimes for both mother and child. Other mothers described how the report from the interdisciplinary feeding team had an influence on the school system. Mothers felt more confident that there would be increased diligence by school staff to ensure their child was safe during school mealtimes.

Despite the struggles in implementing recommendations, mothers were able to observe why they were working hard to implement them. Kim described how she can rationalize the struggles involved in implementing recommendations with the improvements she had observed in her daughter:

A couple of them were a little harder but, you know, when you see why you’re doing them and you understand why, it’s like oh, okay. And for me, like I don’t like the coughing episodes. I’m motivated to have them stop and yeah, so for me it wasn’t hard because just the whole idea of getting rid of some of these issues around, you know, just even in the mornings, to have her wake up and not crying every morning because she was so sore all the time. Yeah, that really makes a big difference.

Susan received the recommendation that her son should have surgery for a gastrostomy tube. When Susan was interviewed for the second time, her son had recently had the surgery. Susan’s experience with this recommendation was very positive, as she described:

...as far as his health, he’s better. He feels good, and if he doesn’t feel great, then we still know he’s getting nutrition and he’s putting on weight at a fair, like at nice steady rate, along with really big growth spurts. So he just overall, it seems like it’s the perfect time for
him...think in a way it’s probably - it’s easier on Thomas having a g-tube, and, you know, looking back at pictures of him when he did wear it, it’s a lot more obvious when you see that than when we lived with him. It just became normal for us.

The recommendation for a g-tube has allowed Susan and her family more flexibility in their lives, and peace of mind knowing their son is getting adequate nutrition. The g-tube has brought them hope for obtaining some normality in their lives.

The interdisciplinary feeding team assessment is a process that has legitimized mothers’ concerns regarding their child’s feeding difficulties. Having a formal course of action, such as a feeding assessment, which documents a child’s feeding difficulties, makes it hard for staff in the school system or in childcare settings to ignore recommendations. The increased diligence by the staff when working with children with feeding difficulties helps to ease the stress that mothers experience when worrying about the care of their child outside of the home.

4.2.5 Theme Five: We Can Now Move Forward

4.2.5.1. Adaptation and Gaining Acceptance

For families to be able to cope with their child’s feeding difficulties, adaptation has to occur. Adaptation is a process by which an individual or family feels competent and confident in using their resources and know-how in managing their daily life, determining their own future and realizing their new life goals (Pelchat & Lefebvre, 2004a). The participants in this study had to change their behaviour in response to the recommendations that were provided by the team. The process of adaptation appears to have helped mothers gain some acceptance of the circumstances that life has put forth and aided them in being able to move forward. For mothers of a child with a feeding disorder, adaptation may signify compromising with their child to make mealtimes more enjoyable. Adaptation may also represent changing the typical mealtime routines, for example, following their child’s pace and listening to their cues surrounding food.
Not only does the process of adaption lead to acceptance, but it also helps to minimize the stressors mothers encounter when feeding their child.

The process of adaptation can help mothers to accept their child’s feeding difficulties. “Acceptance” may have different definitions for different participants, for Susan, “acceptance” meant coming to terms with the reality of her situation. As Susan describes, “…as a parent you still want them to eat, so I think that has taken some time for me to resolve in myself that he’s doing all that he can do.” By accepting their situation, mothers can move forward with new insight. Erin found that after she came to terms with her daughter’s disability and accepted her daughter’s feeding difficulties, she then made the decision to create boundaries for herself and for her family. Erin chose to not direct all of her energy towards worrying about her daughter’s ability to feed. As a result, Erin made conscious decisions about which battles were worth fighting over with her child:

The second assessment was like more of a follow up and I guess just going through the whole process, starting to realize that, you know, if she doesn’t want to eat she doesn’t want to eat. You know, I’m not going to get all uptight about it. Because I mean she was gaining weight and I mean she’s very rarely sick. I mean she gets the odd colds here and there but she’s not sickly...So I’m at the point where okay, if she doesn’t want to eat today, she doesn’t want to eat today, you know, I’ve come to accept this.

Mothers’ ability to gain acceptance of their child’s difficulties may also be influenced by how mothers deal with the stressors they are experiencing in their lives and where they are in coming to terms with their child’s disability, in other words, their grieving process. For example, after Erin’s first assessment, she found the recommendations were not realistic as she felt that she was still coming to terms with her daughter’s disability and the associated guilt that she felt. It was not until after the second feeding assessment when Erin was able to come to terms with her daughter’s feeding difficulties. Each participant has a unique experience in coming to accept their child’s feeding difficulties. While the feeding assessment may not directly result in mothers...
accepting their child’s feeding difficulties, it may assist in providing mothers with knowledge
that has an impact on their ability to gain acceptance.

4.2.5.2. Learning from Their Child

The experience of having a child with feeding difficulties has taught mothers about life and
its fragility. Mothers describe that through observing the difficulties their child is experiencing
with a simple activity such as eating, the other challenges that mothers face are put into
perspective. Susan has come to the understanding that feeding is just one more difficult task her
son has to deal with. “I think you just get to the point where you just feel like it’s just one more
really hard aspect of his...I don’t know, time, and you just wish he had one less fight or one less
struggle.” Mothers recognize the strength and the resilience their child exudes in circumstances
that are not typical for other children their age. Kim described the impact her daughter’s strength
has on her:

She’s a good girl. She actually, it makes me feel upset and sad because she puts up with it
all and you KNOW she’s terrified and she tries to be so nice. Even when she was in the
hospital and she had the pneumonia and she’s just crying because they got her head
strapped down, her arms strapped down, and she’s in that funny little chair way up in the
air and she’s getting x-rayed, and they need her to hold still...and she’s trying so hard not to
cry....I don’t love her any less. In fact I sometimes think you love them more because when
they have trouble feeding, you realize a little bit more how life is a bit tenuous and you
have to take care of and treasure that and make the extra effort to make it good for them.
So to me it just is a case of appreciating her more, you know?

Having a child with a disability brings unique stressors. Ester describes the impact her son
has had on her life and how his positive aspects help her to move forward.

My life has changed and now and I’m a different person, you know. Before Dennis was
born I couldn’t say that I was happier because I was stressed out on such, you know, minor
things, because I didn’t know what really matters, what problems people could have. Of
course I will be happier if Dennis was healthy. But, you know, life is life. I have a different
life and I should be happy in this life. And Dennis, you know, he has been a good boy and I
have lots of positive emotions with him.
Despite the numerous stressors mothers experience surrounding their child’s feeding difficulties, mothers are able to look past the stressors and recognize what they have learned from their child. The knowledge gained about their child’s feeding difficulties appears to help mothers understand what their child is enduring while feeding, thus putting their stressors into perspective. As the stressors experienced by mothers are diminished, as a result of the feeding team recommendations, mothers may be better able to look past the difficulties and further focus on the positive aspects that their child brings to their lives.

4.2.5.3. Hopes for the Future

Mothers continue to have some concerns for the future of their child’s feeding, despite their increased knowledge and the observation of positive improvements in their child’s health and ability to feed. While mothers have gained some acceptance of their child’s feeding difficulties, they continue to have hopes for observing further improvements in their child’s ability to feed. Other mothers recognized that the future will bring new challenges with their child’s transition to school, and worry whether there will be experienced others available to support their child along the way.

While mothers described their hopes for the future, they were realistic in their expectations. For mothers, the interdisciplinary feeding assessment made them aware of the significant challenges their child faces with feeding. Their new knowledge gained from the assessment made it even more apparent to mothers that the difficulties their child faces with feeding will not be resolved in the near future; the process may take many years. Other mothers recognized that, regardless of the difficulties their child faces, they have to take cues from their child and give their child time to indicate when they are ready to progress with feeding. A quote from Crystal described her hopes for the future:
I would like to see that by the time she’s, you know, five or six that we can even just get her down to the night time feeds so that she’s getting enough nutrients through the day to sustain her and to be able to like, you know, go out and play and do whatever and not have to rely on tube feeds during the day; just get enough during the night to make up calories if she needs it. So that’s my goal. That’s what I would hope to see happen. Whether that’s, you know, five or six or six or seven, whatever, like I think that we’ve come to the realization that it just has to be when she’s ready and it’s not our decision to make. And so I just hope that we’re aware enough to see, you know, when it’s going to be a good time and when it’s appropriate...I don’t want to set unrealistic expectations and say, “By next year . . .” We want eating to be a really positive experience for her too. We don’t want it to be something that’s going to be, “Oh, I’ve tried it again and I can’t do it and I don’t like it.” You know, it’s like I love food. I like to eat and I like to cook and I don’t want it to be something that’s not going to be enjoyable for her as well.

Participants described goals that their child may one day be able to participate in the social aspect of mealtimes. Amber described her hopes for her daughter’s future with feeding:

Well, it would just mean that she can, you know, once she goes to school and stuff, you know. I mean, she’ll always have special needs, we know, but be more part of the social aspect and be able to have like a snack at school so she wouldn’t have to be excluded.

With mothers’ acceptance and hope comes the wish to move forward and create some normality in their lives. Mothers experienced significant challenges prior to the feeding assessment, because of the lack of knowledge surrounding their child’s feeding difficulties. Unfortunately, none of the participants left the assessment with the magic answer or solution to their child’s feeding difficulties; however, mothers were empowered to work towards their future goals. Susan described her hopes for the future:

Not to be overly stressed and not to limit his activities in things just because he has that. Like really feeling comfortable with myself and him and just really trying to get him back into having more of a normal kind of play parts of his day and outings as part of his day, and that would be really important as a family, so it’s not always focused on the negative.

The completion of the interdisciplinary feeding team assessment is comparable to filling in a missing piece to the puzzle of understanding why their child has a feeding disorder. While the puzzle still may be missing several pieces, mothers have gained further confidence in managing their child’s feeding difficulties on their own. Mothers can now focus their energy on the positive
aspects of their child, which in turn helps to create normality in the lives of families. When there is constant fear that a child may become sick as a result of feeding, or not be able to meet their caloric intake, the functioning of the family is far from normal.

4.3 SUMMARY

4.3.1 Exhaustive Description

The fifth step in Colaizzi’s (1978) method of data analysis involves integrating the results of the study into an exhaustive description which provides the overall structures and all elements of the experience. Chapter four has presented this exhaustive description, including 12 theme clusters and five major themes, which illustrate the experiences of mothers who have gone through an interdisciplinary feeding team assessment for their child with feeding difficulties.

4.3.2 Fundamental Structure

The sixth step in Colaizzi’s (1978) method of data analysis involves reducing the exhaustive description into a statement of the phenomenon’s fundamental structure. Colaizzi advocates that the fundamental structure should represent a clear, unambiguous statement of the phenomenon under investigation.

The experience of an interdisciplinary feeding team assessment is a process. This process is influenced by mothers’ experiences prior to the assessment and how they are coping during this time. Mothers who are grieving their child’s disability and having difficulties coping with their situation may have more difficulties in implementing the recommendations provided by the interdisciplinary team. The process of the interdisciplinary feeding assessment begins with mothers feeling disconnected, not only from understanding what is happening when their child feeds, but also from society. This disconnect creates stress for mothers and feelings of fear and anxiety. While elements of the feeding assessment are stressful, mothers leave the assessment
with acquired knowledge and understanding that helps them to gain acceptance of their child’s feeding difficulties. In the months following the feeding assessment, mothers experience new stressors and struggles as they implement recommendations. The process of adapting and integrating recommendations takes time. As mothers slowly observe positive changes in their child’s feeding and health, they are able to feel renewed confidence in their future and are empowered to make decisions regarding how to manage their child’s feeding. Increased knowledge from the team helps mothers to focus on the positive aspects of their child and approach normality in their lives.

Each participants’ experience is unique, as each child’s feeding difficulties are a result of numerous factors. However, the essences of mothers experiences have commonalities which are critical for interdisciplinary team members to know.

4.4 CONCLUSION

Chapter four concluded with a statement of the fundamental structure of the phenomenon under investigation, which is the sixth step in Colaizzi’s method of data analysis. Chapter five discusses the study’s results and implications of the findings, along with study limitations and suggestions for future research.
CHAPTER FIVE

Using descriptive phenomenology, this study sought to describe the experiences of mothers who have gone through an interdisciplinary team assessment process for their child with a feeding disorder and their perceptions implementing recommendations from the team. As described earlier, the data were collected through two semi-structured interviews with mothers of children, ages 0-16 years, residing in the Lower Mainland of BC. The data collected from these interviews were analyzed using Colaizzi’s method of data analysis, from which five themes emerged.

This chapter will use the Family Adjustment and Adaptation Response model (Patterson, 1988) as a framework from which to examine mothers’ experiences of an interdisciplinary feeding assessment. Findings will be compared with previous qualitative studies that have examined mothers’ experiences of having a child with a feeding disorder. Implications for health care services will be presented within the discussion for each theme, with the conclusion of the chapter addressing the study’s limitations and areas for future research.

5.1 DISCUSSION

As demonstrated by the data collected for this study, the experience of going through an interdisciplinary feeding team assessment is in part shaped by events that take place before the child’s assessment. From the time a child is born to when contact is made with the feeding team, mothers have had various experiences which ultimately shape their experience with the team. Despite the uniqueness of each participant and their child, the essence of the experience of going through an interdisciplinary feeding team was common to all participants. Mothers experience numerous stressors in their lives--prior to the feeding assessment, during the assessment, and after the assessment--as they attempt to implement recommendations. Stress is ubiquitous, and
can be seen as an undercurrent to all of the themes identified. Numerous models of stress and coping have been presented in the literature, including (but not limited to) the Stress, Appraisal and Coping Model (Lazarus & Folkman, 1984), the Sense of Coherence Model (Antonovsky, 1987), and the ABCX Model (Hill, 1949). One model, the Family Adjustment and Adaption Response (FAAR) Model (Patterson, 1988), is the most appropriate when examining family adjustment and adaptation in the context of stress. This model is used as a framework to discuss the themes from mothers’ experiences of an interdisciplinary assessment process for their child with feeding difficulties.

5.1.1 The Family Adjustment and Adaptation Response Model (FAAR)

The FAAR model initially took its origins from the model of family stress, the ABCX model, developed by Hill in 1949. The ABCX model details how three factors (the ABC components) of a stressful event, the family’s perception of that stressor, and the family’s existing resources all interact to predict the likelihood of a crisis (X) occurring. Revisiting Hill’s model, McCubbin and Patterson (1983a, 1983b) created the Double ABCX model, which added post-crisis variables (e.g. coping mechanisms) to explain how families recover from crisis and adapt over time. The Double ABCX model was later revised into a process model, the FAAR model, to describe the process that families use to adjust and adapt after a crisis (Patterson, 1988).

The process orientation of the FAAR model resulted from the recognition that changes in family patterns of interaction, as well as recovery from crisis, involve complex family interactions (McCubbin, Dahl & Hunter, 1976). The FAAR model recognizes that the family attempts to maintain balanced functioning by using their “capabilities” (resources and coping behaviours) to meet the “demands” (stressors and strains) they encounter in their lives (Patterson,
The “meanings” that families attribute to what is happening to them and the resources they have for dealing with the demands are critical factors in achieving balanced functioning. The FAAR model describes two phases, the “adjustment phase” and the “adaptation phase”, separated by personal or family “crises”. The adjustment phase represents a relatively stable period, during which time the family makes only minor changes and uses their already existing “resistance capabilities”. However, a state of disequilibrium or imbalance emerges when the demands exceed the capabilities of the family. During the adaptation phase, the family attempts to recreate balance by (1) acquiring new adaptive resources, (2) reducing demands they must deal with, or (3), changing the way they view their situation (Patterson, 1988).

While the current study was specific to the experiences of mothers, mothers are part of the larger system level--the family. The FAAR model focuses on three levels of systems: the individual, the family, and the community. When an individual experiences stress there is an impact on the family. Similarly, stress on the family impacts the individual. Communities are impacted when families have difficulties coping, impacting their ability to contribute to society. Each system is characterized by both demands and capabilities, which may differ between the system levels (individual, family and community). Families may attempt to arrive at a balance by using capabilities from one level of the system to meet the demands at another level. Another theory, the Family Systems Theory, highlights the link between the individual and the family (Bowen, 1978). From a family systems perspective, the experience of one family member has an impact on the experiences of other family members (Patterson, Holm & Gurney, 2004). Mothers’ experiences of going through an interdisciplinary team feeding assessment and implementing recommendations may have direct and indirect effects on other family members, just as other family members may have influenced the experiences of the mothers in this study. Similarly, the
family’s ability to cope with multiple sources of stress and uncertainty associated with a child’s
disability is also likely to impact their child’s quality of life (Patterson & Garwick, 1994). The
FAAR model uses principles of the Family Systems Theory to explain how individuals and families adapt to a child’s disability, growing either stronger or weaker over time in response to stressors associated with their child’s health. Individual or family perceptions of the stressors they encounter, combined with the resources available to them, result in their potential vulnerability to the stressor. When individuals or families have the appropriate resources to manage a stressor, they are more likely to become confident and adaptive (Murray, Kelley-Soderholm & Murray, 2007). The FAAR model can be used to examine an individual’s processes of adjustment and adaptation, as well as the processes experienced by the larger family system (see Figure 5.1).

5.1.2 Stressors, Strains and Capabilities

The months or years prior to the feeding assessment can be regarded as the “Adjustment Phase” in relation to the FAAR model. Mothers describe both stressors and strains during this period of time. Stressors and strains create demands on the mother, which challenge the mothers homeostatic functioning. A mother may work towards meeting these demands using her available capabilities; however, if there are no appropriate capabilities, a state of stress can arise. This state of stress is perceived as a demand-capability imbalance (Patterson, 1988). The FAAR model defines stressors as life events that occur at discrete points in time, which have the potential to produce change in the individual or family. For the mothers in this study, the birth of a child with a disability can be described a stressor, due to the discrete onset of the event.
A strain is defined as a condition of felt tension associated with the need or desire to change something (Patterson, 1988). Strains do not have discrete onsets and arise more gradually in the family. Strains can emerge when an individual or family is unable to resolve a stressor. In
this study, the birth of a child with a disability who also has feeding difficulties created strains in
the lives of the participants. In fact, many of the stressors that mothers initially experienced in
association with their child’s feeding difficulties would be considered strains, according to the
FAAR model. The FAAR model recognizes that often individuals or families are dealing with
multiple demands at any one point in time, seldom focusing on a single demand. While the birth
of a child with a disability may begin as a stressor for the mother, if the mother is unable to
resolve this stressor, the stressor turns into a strain. As the mother discovers that her child has
difficulties feeding, this additional stressor may interact with the strains she is already
experiencing, contributing to an accumulation of demands in her life.

An individual’s or family’s “capability” is defined as the potentiality available to meet the
demands that are being experienced. Capabilities consist of resources and coping behaviours. A
resource is a competency, trait, or a characteristic, which can be either tangible (e.g. money) or
intangible (e.g. self-esteem, knowledge.). A coping behaviour is defined as a specific effort by
which an individual or a family attempts to reduce or manage a demand (Patterson, 1988).
Coping behaviours can help to maintain or restore the balance between demands and resources.
For example, coping can involve taking action to acquire additional resources not already
available to the individual, or coping can involve cognitive appraisal to change the meaning of a
situation to make it more manageable. The FAAR model differentiates between “resistance
capabilities” in the adjustment phase and “adaptive capabilities” in the adaption phase, to
highlight the dynamic process of change over time in the individual or family as new resources
and coping behaviours are acquired (Patterson, 1988).

The FAAR model can be applied to mothers’ experiences of having a child with a feeding
disorder. Mothers described their initial experiences of lacking knowledge surrounding their
child’s feeding difficulties and the experiences of missed social opportunities. Mothers lacked the personal resources necessary to meet the demands they were experiencing. The lack of these resources may have also impacted mothers’ self-esteem and their sense of mastery – the sense that they had some control over the circumstances of their lives. The mothers in this study described their lives prior to the interdisciplinary feeding team assessment as consisting of multiple demands. Mothers used their existing resources and coping behaviours to meet these demands, however, the demands exceeded their capabilities and a state of disequilibrium ensued in their lives and in the lives of their families.

Similarities were found between the experiences of this study’s participants and the experiences described in other qualitative articles. A study by Stoner et al. (2006) found that parents/guardians experienced challenges in managing their child’s feeding and swallowing problems at the time of their child’s initial diagnoses. Many of these challenges stemmed from receiving little or no information on how to manage feeding problems. A recent study by Hewetson and Singh (2009) supports the description by mothers in the current study of experiencing “loss”. These authors identified losses that mothers’ experienced, related to the ‘Mother Dream’ and the inability to feed their child orally. Other losses included missed opportunities for social participation, a finding also identified in the current study. Finally, Hewetson and Singh identified that mothers felt disempowered, due to a lack of skills and knowledge surrounding their child’s feeding difficulties. This theme is also applicable to mothers in the current study, who described feelings of inadequacy and helplessness due to their lack of knowledge surrounding feeding.

The FAAR model states that as demands (stressors and strains) accumulate, further threats are placed on mothers’ personal resources. The literature provides substantial documentation for
the impact of the positive use of personal resources and coping behaviours on mitigating the negative impacts of stressful situations (Folkman & Moskowitz, 2000; Hastings & Brown, 2002; Trute, Benzies, Worthington, Reddon & Moore, 2010; Trute, Hiebert-Murphy & Levine, 2007). While mothers’ early feeding experiences with their child were not the focus of the current study, understanding the stressors and strains experienced by mothers is critical for appreciating what mothers have endured prior to the interdisciplinary feeding assessment and the potential state of the resources available to them.

5.2. THEMES

The themes that developed from this research describe the strains that participants experience prior and during the interdisciplinary feeding assessment, as well as the range of emotions that are felt at the assessments’ culmination. Mothers describe initial challenges in implementing recommendations from the team. As mothers integrate the recommendations into their lives, they begin to see positive changes in their child. The new resources acquired from the feeding team, help mothers cope and adapt to the stressors associated with mealtimes. Mothers describe positive outlooks for the future as new meaning is given to having a child with a feeding disorder. Refer to Figure 5.2 for a summary of the themes.
5.2.1 Theme One-Taking Action

The first theme signifies a shift towards the “adaptation phase” described in the FAAR model. All mothers in this study described disequilibrium in their lives prior to the
interdisciplinary feeding team assessment. Mothers believed that the resources and coping behaviours they had to manage their child’s feeding difficulties were inadequate relative to their perceived demands. The FAAR model regards this interpretation as the “meaning” individuals ascribe to their situation (Patterson, 1988). Many participants had been experiencing stress surrounding their child’s feeding for many years, however, were only now coming to a point where action was being taken to address their child’s feeding disorder. The process of being referred to the interdisciplinary feeding team was different for each participant. The majority of mothers recognized their need for assistance in the area of feeding. For example, Kim described “needing a plan” to understand her daughter’s feeding difficulties so that her daughter’s school would be able to ensure safety while feeding. For other mothers, the feeding team assessment was a suggestion made by a healthcare professional.

For several of the participants whose children had g-tubes, their motives for “taking action” and their decisions surrounding the timing of the feeding assessment were in part based upon their desire for creating some normalcy in their family’s life. Mothers hoped that the feeding assessment would indicate that their child could feed orally, allowing them to move towards a more typical form of feeding. While mothers recognized the extreme benefits of having a g-tube for their child, it was their hope that they would one day be able to transition their child off of the g-tube. These mothers needed to feel that they had given their child an adequate opportunity to demonstrate whether or not they could feed orally. The experiences of these mothers are similar to the experiences of mothers in Sleigh’s (2005) qualitative study of mothers of children with cerebral palsy, both with and without a g-tube. Regardless of whether their child already had a g-tube, participants held the belief that each child should be given the chance to demonstrate if they could feed orally (Sleigh, 2005). For many of the participants in
the current study, g-tubes were placed in their children at a very young age. Mothers were faced with guilt and uncertainty as to whether they gave their child an adequate chance to try to eat orally.

The uncertainties and anxieties mothers experienced prior to the interdisciplinary feeding assessment have implications for service delivery. Although all mothers should have received information regarding the interdisciplinary team assessment, both verbally over the phone and via an information package sent in the mail, mothers described contrary experiences. Mothers described having some sense of what was going to take place during the assessment, but this information was not adequate to meet their needs. Recognizing the demands that mothers are experiencing prior to the interdisciplinary team assessment may help to understand their information needs. Mothers who are experiencing extreme stress may require additional resources to help them prepare for an assessment. Interdisciplinary feeding teams should re-evaluate how information is given to parents and caregivers before the assessment. Providing an additional pamphlet in the information package that families already receive prior to their assessment may help diminish some of the uncertainties and anxieties that were described in this study. This pamphlet could outline the components of the assessment including, the roles of the health professionals that families will meet, and details about the VFSS, including the child’s exposure to radiation. To help families further prepare, a checklist of sample feeding assessment questions could be provided in the information package in order to get families to think about the types of questions they will be asked during the assessment. These questions can help trigger parents to watch for signs and symptoms of feeding difficulties during mealtimes at home, thus aiding in the information gathering during the assessment and helping to calm parents’ anxieties about what will be asked.
Consideration should also be given to the timing in which families are provided with information regarding the assessment. Currently, information is provided over the phone when a feeding team member obtains background information from the parent regarding their child’s feeding difficulties. Children who are not a high priority may wait months before they are seen by the feeding team, making it difficult for families to remember the information provided. In addition, the information package that families receive regarding the assessment is often sent to families long before they come to SHHC. Considering the stressors that families are experiencing, a phone call a week before the assessment might be more beneficial for preparing families effectively. This phone call would ensure that the information regarding the assessment is not only fresh in parents’ minds, but would also serve to remind them to locate and review the previously received information package.

5.2.2 Theme Two-The Balancing Act

The theme “The Balancing Act” describes the range of experiences that mothers identified during the interdisciplinary assessment process. Mothers described stressors during the assessment that were balanced by positive interactions with professionals on the team. Ultimately, the positive interactions and the provision of an interdisciplinary team to address their child’s feeding difficulties helped to make the experiences of participants in this study positive overall.

Many of the positive team interactions mothers described stemmed from the use of an interdisciplinary team approach. The literature extensively cites the need for an interdisciplinary approach when addressing paediatric feeding disorders (Couriel, Bisset, Miller, Thomas & Clarke, 1993; Geggie et al., 1999; Simonsmeier & Rodriguez, 2007). While many of these studies describe interdisciplinary feeding teams that are currently in place, very few studies
identified have examined parental satisfaction with this model of service delivery. Research examining parental satisfaction and the use of an interdisciplinary team for service delivery is also lacking in other areas of paediatric disability. Naar-King and Siegal (2002) examined consumer satisfaction with an interdisciplinary clinic for children with special needs, and found that parents appreciated the use of a collaborative and family-centered program involving an interdisciplinary team. Parents reported that this approach aided in their understanding of their child’s disability because of access to a greater variety of resources and support. The interdisciplinary team also gave parents increased confidence to manage their child’s condition at home (Naar-King & Siegal, 2002).

This research has provided insight into mothers’ perceptions on the use of an interdisciplinary team to assess children with feeding disorders. Mothers described how the use of the interdisciplinary team increased their confidence in the findings of the assessment and in the provision of recommendations. Mothers were able to sense that there was agreement among professionals regarding assessment findings, thus adding further weight to the importance of what was being said to them. This is particularly important in light of previous research suggesting that parents often lack confidence and trust in services providers’ competence. For example, Watson, Kieckhefer and Olshansky (2006) found that early parental experiences of delays in recognition of childhood disability by service providers impacted the feelings and expectations that parents brought to future treatment and assessment situations. Gaining parental trust in service providers is critical, especially when there is the need for parents to understand and implement recommendations based on assessment findings.

The experiences of stress that mothers described during the feeding assessment bear similarities to some of the experiences identified by mothers in a study by Hewetson and Singh
(2009). These authors found that mothers reported feelings of distress as they felt that professionals were judging of their feeding practices. Mothers also experienced a sense of disempowerment in the healthcare system. Similar findings were described by participants in the current study, however, this time within the context of the feeding assessment. In the current study mothers expressed sometimes feeling as if they were passive observers in the assessment, because they did not always understanding what was being said and done around them. This finding has implications for the service delivery of interdisciplinary feeding assessments. With the identification of the stressors mothers experience during the interdisciplinary assessment, steps can be taken to minimize the stressors, thus enhancing the positive experiences of the feeding assessment.

Open and honest communication was described by participants as impacting the positive interactions they experienced with interdisciplinary team members. While team members may be more focused on providing open communication during the family conference when describing assessment results and recommendations, team members need to be conscious of their communication during the entire assessment. A number of studies have supported the experiences of mothers in the current study, documenting that parents would like to receive disability-related information with respect, co-operation and open communication (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004; Goddard, Lehr & Lapadat, 2000; Konrad, 2005; Mitchell & Sloper, 2002; Prezant & Marshak, 2006). By understanding the anxieties mothers are experiencing, including possible fears of judgement and difficulties with feeding their child in the assessment setting, team members can provide more effective communication during their initial encounters with mothers to help alleviate some of these fears. The simple process of keeping families informed during the initial stages of the assessment can
help to involve mothers more quickly in the assessment process, thus creating an empowering process. Empowering families begins by creating opportunities for families to acquire the necessary knowledge and skills (Dunst, Trivette & Deal, 1988).

Additional concerns mothers expressed in the second theme surrounded the environment in which the assessment takes place. Mothers articulated that their home environment is very different from the hospital environment, therefore, potentially creating assessment data which is not truly representative of the typical feeding scenario. With advances in technology, families often have access to video cameras and can record their child during meals at home. At the time of intake, families coming for a feeding assessment could be informed that video/digital recordings of their child feeding are welcome, should there be concerns that the child may perform differently in an alternate environment. Being able to provide a home video of their child feeding may give mothers further confidence that the assessment is taking into account the environment in which the child usually feeds.

5.2.3 Theme Three-The Impact

The third theme, describes mothers’ experiences of receiving the results from the interdisciplinary feeding assessment. At this point, mothers are awaiting the assessment results and the information that will help them to understand their child’s feeding difficulties. This is a point of transition, during which time mothers must emotionally and cognitively process the information from the team, in preparation for implementing recommendation on their own.

Receiving results of the assessment from the feeding team is described as an extremely emotional experience. Mothers express feelings of shock and disappointment when learning about their child’s difficulties, yet they also express feelings of validation and relief. Insight into
the emotions that mothers are experiencing during this time has an impact for service delivery and the ways in which professionals interact with caregivers during this emotional time.

Each participant in this study had a unique reaction to receiving the results of the feeding assessment. Feeding teams need to acknowledge the differences in the emotional reactions that mothers may have in response to assessment results. Findings from this study also indicated that emotional responses to results from the assessment may not necessarily coincide with the severity of the child’s feeding difficulties. For example, at Susan’s family conference, she received the recommendation that her son should have a g-tube surgery. Upon receiving these results, Susan had feelings of relief and validation. In contrast, at the team conference for Kuldeep’s daughter, Kuldeep received the results that her daughter had aspirated on the VFSS and therefore was not safe to begin to take thin liquids. This information was a shock for Kuldeep, leading to feelings of disappointment and sadness. One may have assumed that it would have been more difficult for Susan to receive the recommendation that her son needed to be fed by a g-tube, given the life-changing implications of this surgery. Feeding teams should assume that every mother or caregiver will struggle with receiving the results, regardless of how minor the recommendations may appear. With this insight, teams may need to consider taking time to discuss caregivers’ feelings regarding the results. While some caregivers may need to have their feelings of disappointment and sadness validated, other families may need further time to process assessment information before going on to discuss topics such as gastrostomy tube placement surgery or how to alter food textures.

In this study, mothers often reported positive experiences going through the interdisciplinary team. One participant, Erin, reported that her first feeding assessment with her daughter, several years prior, was particularly negative for her. Erin was able to identify several
possible explanations for this negative experience, expressing that she felt “unheard” and had not
fully accepted daughter’s disability. Erin’s experience is important for interdisciplinary team
members to be aware of. While Erin described aspects of the interdisciplinary team assessment
that she felt could have been improved upon (e.g., increased open communication, active
listening) she also described her personal process of coming to terms with her daughter’s
disability. As previously described, how mothers come to be referred to the interdisciplinary
feeding team varies from family to family. While some mothers may be actively seeking help for
their child’s feeding disorder, other mothers may just be coming to terms with their child’s
disability. Mothers need time to grieve for the ‘expected child’, and to adapt to the child and the
health problem, in order to cope with the emotional and practical aspects of living with them and
providing proper care (Pelchat, Lefebvre & Perreault, 2003). The FAAR model can be used to
potentially understand Erin’s experience. Erin may have been in the “adjustment phase” with
regard to the diagnosis of her daughter’s disability. Due to the accumulation of demands, Erin
may have been struggling to maintain balance in her life. Erin may not have had the resources or
the coping strategies to deal with the stresses and strains associated with her daughter’s
disability. According to the FAAR model, families are continuously faced with multiple
demands. As a result, individuals or families have to give priorities to some demands over others
(Patterson, 1988). Erin’s initial feeding assessment with her daughter appeared to have come at a
time when she was attempting to deal with the foremost demand in her life, acceptance of her
daughter’s disability. The multiple stressors and strains in a mother’s life appear to not only
impact their experience of the assessment, but also their ability to adequately acquire resources
for dealing with their child’s feeding disorder. In order for the assessment process and provision
of recommendations to be effective, it is critical for interdisciplinary feeding teams to have an awareness of the multiple demands in a mother’s life.

The knowledge acquired throughout the process of the feeding assessment aided mothers in meeting the demands of having a child with a feeding disorder. Coping is defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). One type of coping strategy for dealing with disability-related problems is problem-focused coping (Frey, Greenberg & Fewell, 1989; Noojin & Wallander, 1997). This strategy involves efforts to alter the cause of the stress through increased knowledge, information-seeking and cognitive restructuring. The knowledge gained from the interdisciplinary feeding team assessment can be regarded as a form of problem-focused coping, one predictive of improving family confidence and strength (Judge, 1998).

Mothers described the interdisciplinary feeding assessment as providing them with knowledge and resources to understand their child’s feeding disorders. A unique finding from this study was the subjective impact of the VFSS as being the most effective component of the interdisciplinary assessment for transferring knowledge to mothers. The ability to see their child’s feeding difficulties on x-ray gave mothers awareness of the discomfort their child experiences during feeding. Mothers were also able to further understand the reasoning behind the recommendations that were provided by the team. Research has documented that mothers of children with feeding disorders often do not have their information needs met (Judson, 2004). Hewetson and Singh (2009) found that mothers reported a lack of understanding of the swallowing mechanism and their child’s feeding difficulties. As a result, mothers did not
understand the rationale behind adapted feeding, further impacting their feelings of incompetence and their experience of disempowerment.

5.2.4 Theme Four-We Are On Our Own

With the completion of the interdisciplinary feeding assessment, mothers experience a second process as they integrate recommendations into their lives and into their child’s routines. The initial days and months following the interdisciplinary feeding team assessment are described by mothers as being stressful. Findings from the assessment have created additional stressors and strains as mothers must alter their feeding routines in order to incorporate the recommendations from the team. This research highlights that the task of integrating recommendations into daily life is a process that takes place over weeks and months. Several months after the initial interview, notable differences were observed in mothers’ perceptions of implementing recommendations and in the intensity of the stresses they reported. Mothers appeared to experience a positive change over time as they discovered which recommendations worked for their child and their family.

Mothers’ experiences were facilitated by the encouraging changes they observed in their child as a result of the feeding team recommendations. The positive changes that mothers observed helped to increase their sense of mastery and their confidence in their abilities to help their child with their feeding difficulties. As mothers felt more confident in their abilities to positively impact their child’s feeding, the integration of recommendations into their daily life was described to become easier. Problem-solving confidence is the belief in one’s ability to solve new problems successfully (Heppner & Paterson, 1982). A study by Noojin and Wallander (1997), examined 160 mothers of children with disabilities to understand the impact of mothers’ perceived problem-solving ability or confidence on their adjustment. They found that perceptions
of competence in problem-solving were associated with better overall adjustment. Problem-solving is a component of problem-focused coping which was previously discussed as an additional adaptive capability mothers can use to help meet the stressors and strains they may be encountering. More recent literature also has found that mothers’ cognitive appraisal of disability and positive affect are associated with family adjustment (Trute et al., 2007, 2010). Further research is needed to examine whether feelings of competence in problem-solving can activate positive emotions, therefore leading to improved adjustment to disability.

The weeks and months following the interdisciplinary team assessment is a period in which balance is restored in the lives of mothers and their families. Mothers’ confidence and increased self-esteem related to their abilities to problem-solve further contributes to mothers’ positive adaptation to their circumstances. Figure 5.2 describes the link between the three theme clusters identified in theme four.
5.2.5 Theme Five-We Can Now Move Forward

The theme "We Can Now Move Forward" involves the restoration of balance in the lives of participants. As previously mentioned, the adaption phase of the FAAR model is characterized by the alteration and/or expansion of the meanings mothers attribute to the stressors and strains in their lives, a reduction in the accumulation of demands in their lives, and the development of new adaptive resources and methods of coping (Patterson, 1988). In the months following the feeding assessment, participants indicated that they had begun to restore balance in their lives.
through the utilization of their newly acquired knowledge and the resources gained to help them further understand and manage their child’s feeding difficulties.

Empowerment is the process whereby knowledge, skills, attitudes and self-awareness are gained (Baksi & Cradock, 1998). Empowerment can also be seen as a health promoting and curing social process by which individuals gain control over their lives (Dellve, Samuelsson, Tallborn, Fasth & Hallberg, 2006). The mothers in this study described the interdisciplinary team assessment as aiding in their understanding of their child’s swallowing mechanism and in their understanding of the rationale behind recommendations. In a sense, the interdisciplinary feeding team has aided to empower mothers by confirming their suspicions of their child’s difficulties. Mothers reported that seeing the difficulties their child was experiencing on the VFSS made them realize the difficulties were severe and would take many years to overcome, if ever. While mothers did not imply that they had reached full acceptance of their child’s feeding difficulties, mothers were able to move closer to accepting their child’s difficulties allowing them to move forward with their lives.

Following the feeding assessment mothers were offered new perspectives on their child’s feeding difficulties. With a new perspective on the complexity of feeding, mothers also gained further appreciation of the struggles their child had been enduring. A study by Judson (2004) on mothering children dependent on parenteral (intravenous) nutrition found that in order to maintain the intensity of care required for their child, mothers needed to continually put their lives in perspective and recognize what their child has taught them. While these mothers acknowledged the stressors in their lives, they needed to regard their world with a new perspective in order to “keep their balance” (Judson, 2004). One of the participants in the current study, Ester, was able to put her life into perspective and recognize that before her son was born,
she did not know what was important in life. In the current study, mothers did not appear to need to put their lives into perspective in order to maintain balance; rather, mothers appeared to look at their lives with new clarity and recognition of the strengths in their child.

In the current study, mothers described their hopes for their child’s future, which included improvements in their child’s feeding. Several qualitative studies on paediatric feeding discuss mothers’ contemplation of the future of their child with feeding difficulties as being integral to their experience of having a child with a feeding disorder (Hewtetson & Singh, 2009; Judson, 2004). The current study furthers the understanding of how mothers view the future involving a child with a feeding disorder. Knowledge gained from the interdisciplinary team assessment, helped mothers to be realistic about their expectations for change. As mothers gained confidence in the management of their child’s feeding difficulties, mothers were able to “let go” of feeding for the time being and focus on other areas of their child’s development and other members of their family.

Problem-focused coping involves doing something to help resolve the distress, emotion-focused coping helps to regulate overwhelming emotions and appraisal-focused coping refers to the way a person thinks about the stressors or circumstances they are experiencing (Lazarus & Folkman, 1983). The final theme in this study is comprised of three theme clusters which demonstrate mothers’ primary use of appraisal-focused coping. Through mothers’ processes of adapting and gaining increased acceptance of their situation, to recognizing the positive life lessons they have learned from their child and finally to looking towards the future with hope; mothers are demonstrating they have created new meanings or perceptions associated with having a child with a feeding disorder. The FAAR model recognizes that an important component of the adaptation phase is this shift in the meanings an individual or family attributes
to their demands and capabilities (Patterson, 1988). How mothers perceive their situation will affect their choice of strategies, enabling or impeding the accomplishment of adaptive tasks whether by mothers adjust to their situation (Pelchat et al., 2009).

5.3 LIMITATIONS OF THE STUDY

The findings of this study are specific to the experiences of the participants in this study, and may not reflect the experiences of all mothers who have gone through the feeding team at SHHC. Purposive sampling was used to obtain a diverse a sample as possible. As the recruitment process proceeded, difficulties were encountered in recruiting participants. Several factors may have contributed to this, including the limited number of feeding assessments that take place each month. Difficulties with recruitment made it harder to obtain the depth of diversity that was intended for the sample of participants. Further into the data collection process it was observed that many of the participants were describing positive experiences with the interdisciplinary team assessment. While it is encouraging that mothers had positive experiences with the assessment, one cannot assume that this is the case with all mothers who go through the interdisciplinary feeding assessment. Mothers who had negative experiences with the team may not want to have had further interactions with SHHC, or were experiencing a numbers of stressors that limited their time and desire to volunteer. The limited numbers of negative cases is a limitation of this study, as understanding these participants’ experiences may have provided further insight into the study’s objectives. Despite not being able to recruit participants with negative experiences, there was cultural diversity in the sample, as well as diversity in the ages, diagnoses and methods of feeding of the participants’ children.

Findings from qualitative research are not intended to be generalizable (or transferable), however, knowledge gained can be applicable beyond the immediate research group (Morse,
1999; Sandelowski, 2004). In this study, participants went through the feeding team at SHHC, and within each province in Canada several similar feeding teams exist. In addition to these feeding teams, analogies can be made between the findings from this study, and other paediatric teams, which potentially address other areas of child development. The responsibility lies with the reader of this study to decide whether analogies exist between the experiences of participants from the feeding team at SHHC and their paediatric settings.

My experience as a therapist working in the area of paediatric feeding has given me unique experiences and knowledge. In chapter three I made my assumptions known in order to be able to critically reflect upon my potential impact on the data collection and data analysis phases. To ensure that I allowed the perspectives of participants to emerge from the data, versus looking for evidence in the data to support my assumptions, I took several steps. At the initial stages of the data analysis process, samples of coded transcripts were given to the committee for review to ensure the appropriateness of the decisions regarding significant statements. During the construction of formulated meanings, I wanted the voices of participants to speak for themselves. I attempted to stay as closely as possible to the descriptions of participants, but brought the statements to a higher level of abstraction. Throughout the research process, I made a conscious effort to approach the data as a researcher and not as a therapist, putting aside, as best I could, my previous experiences with families. While efforts were made to minimize my impact on the research, it is not possible to completely eliminate the impact the researcher has on the research process. The impact of the researcher needs to be considered when using findings from the current study.
5.4 AREAS FOR FUTURE RESEARCH

This study has generated knowledge on mothers’ experiences of going through an interdisciplinary feeding team assessment, creating a foundation from which future research can be produced. Sandelowski (2004) points out that the utility of qualitative research can be in three forms: (1) instrumental utilization, the concrete application to practice of research findings that have been translated into material forms such as appraisal tools or intervention protocols, (2) symbolic utilization, the use of research findings as a persuasive or political tool to legitimize a position or practice, and (3) conceptual utilization, the alteration of the ways in which users think about problems, persons, or events (Sandelowski, 2004). This study has the potential to act as a foundation for research in each of these forms of research utilization.

In light of this study’s limitations, more research is needed to examine the experiences of mothers who have had difficulties implementing recommendations from the feeding team. Using a long-term study, children who are re-referred to the feeding team, due to illnesses associated with the lack of implementation of recommendations, could be identified. Using the FAAR model to organize the data, the strains and resources experienced by mothers could be identified and compared to the findings from this study. A comparison of the strains and resources experienced by mothers with positive experiences of the interdisciplinary feeding team process would potentially lead to an understanding of the factors that may be contributing to difficulties with implementation.

This study has identified critical areas for improvement of the interdisciplinary feeding team service. With knowledge from this study regarding areas for service improvement, including increased resources for assessment preparation and improved communication, interdisciplinary teams can assess whether they are addressing client needs. Measurement tools
can be created and implemented in order to examine parental satisfaction with the interdisciplinary feeding team.

Areas for future research could examine the impact of an interdisciplinary feeding team assessment, aimed at increasing caregiver knowledge on reducing caregiver stress. Several studies have been conducted on the outcomes of intensive inpatient interdisciplinary treatment programs for children with feeding disorders. Results have demonstrated that caregiver stress is diminished following the intervention; however, reductions in stress levels have been associated with decreases in problematic feeding behaviours surrounding mealtimes and not necessarily as a result of improved problem-focused coping by caregivers (Garro, et al., 2005; Greer et al., 2008). Several other studies aimed specifically at increasing the knowledge of caregivers of children with disabilities have indeed found significant correlations between decreased caregiver stress and increased knowledge and competence (Dellve et al., 2006; Pelchat, Bisson, Ricard, Perreault & Bouchard, 1999; Pisterman et al., 1992). Understanding the larger impacts of an interdisciplinary feeding team on decreasing caregiver stress is critical for further legitimizing the service and ensuring funding when the healthcare system is strained.
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APPENDICES

Appendix A: Letter of Initial Contact

LETTER OF INITIAL CONTACT

STUDY TITLE: CAREGIVERS’ EXPERIENCES OF AN INTERDISCIPLINARY TEAM PROCESS FOR THEIR CHILD WITH A FEEDING AND/OR SWALLOWING DISORDER

Principal Investigator: Dr. Liisa Holsti, Ph.D. (C), OTR
Assistant Professor, Department of Occupational Science and Occupational Therapy, The University of British Columbia.

Co-investigators:
- Rochelle Stokes, BSc. OT (C), OTR
  Occupational Therapist, Sunny Hill Health Centre for Children
  MSc. candidate (2009) in the Department Of Occupational Science and Occupational Therapy, UBC
- Dr. Melinda Suto, Ph.D., B. S. (OT), M.A.
  Assistant Professor, Department of Occupational Science and Occupational Therapy, The University of British Columbia
- Dr. Catherine Backman, Ph.D., B.S.R. (OT), M.S.
  Assistant Professor, Department of Occupational Science and Occupational Therapy, The University of British Columbia

Study Coordinator: Rochelle Stokes

Purpose:

You have been invited to participate in a study because you and your child have recently had a feeding team assessment at Sunny Hill Health Centre for Children. The purpose of this study is to examine the primary caregivers’ experiences of an interdisciplinary team assessment for their child with a complex feeding and swallowing disorder. The objectives of this study are:

1.) To describe the experiences of the primary caregiver of a child with feeding and/or swallowing problems who goes through an interdisciplinary team process.

2.) To explore the perspectives of caregivers as they implement recommendations from the feeding team.
In order to fulfill this study’s objectives we will be asking for the permission to conduct two separate interviews with you. The results from this study will potentially give interdisciplinary feeding teams’ important information on ways to improve service to children and their families.

**Procedures:**

1. Within two weeks of receiving this information package, a booking clerk from Sunny Hill Health Centre will be contacting you to ensure that you have received this package. You will be asked whether or not you would be interested in participating in this study. If you are interested in participating in this study, the booking clerk will ask for your permission to release your telephone number to the researchers and whether the researchers may call you. If you do not want to be contacted regarding this study, please call 604-453-8319.

2. This study requires a limited number of participants. In order to obtain a breath of participant experiences, the researcher would like to ask you several questions. This means that there is a chance that you may not be chosen as a participant for this study. If you give consent to have the study coordinator contact you she will begin by asking you three questions:
   - Your location of residence (city/town)
   - Your cultural background
   - The age of your child involved with the feeding team

3. If you agree to participate in this study and the study coordinator indicates that she would like to interview you, the study coordinator will set up two separate interviews with you. The first interview will take place within two to four weeks of your feeding team assessment at Sunny Hill Health Centre. The second interview will take place approximately three to four months after the initial interview. Each interview will take between 60-90 minutes and will take place at a location and time of your choice. At any point before, during, or after the first or second interviews you may choose to withdraw from the study and any information given during the study will not be recorded.

**Contact for information about this study:**
If you have any questions or want more information about this study, please contact Rochelle Stokes at xxx-xxx-xxxx. **If you wish to not be contacted at all regarding this study please call xxx-xxx-xxxx.**

Thank you for your time,

Sincerely,

Dr. Liisa Holsti, PhD (C), OTR

Contact: Study Coordinator-Rochelle Stokes xxx-xxx-xxxx ext xxxx
Appendix B: Informed Consent

INFORMED CONSENT

STUDY TITLE: CAREGIVERS’ EXPERIENCES OF AN INTERDISCIPLINARY TEAM PROCESS FOR THEIR CHILD WITH A FEEDING AND/OR SWALLOWING DISORDER

Principal Investigator: Dr. Liisa Holsti, Ph.D. (C), OTR
Assistant Professor, Department of Occupational Science and Occupational Therapy, University of British Columbia.

Co-investigators: Rochelle Stokes, BSc. OT (C), OTR
Occupational Therapist, Sunny Hill Health Centre for Children
MSc. candidate (2009) in the Department Of Occupational Science and Occupational Therapy, UBC
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Assistant Professor, Department of Occupational Science and Occupational Therapy, University of British Columbia
Dr. Catherine Backman, Ph.D., B.S.R. (OT), M.S.
Assistant Professor, Department of Occupational Science and Occupational Therapy, University of British Columbia

Study Coordinator: Rochelle Stokes xxx-xxx-xxxx ext xxxx

The objectives of this study are: (1) to describe the experiences of the primary caregiver of a child with feeding and/or swallowing problems who goes through an interdisciplinary team process; (2) to explore the perspectives of caregivers as they implement recommendations from the feeding team.

You are being invited to participate in a study because you and your child have recently gone through an interdisciplinary, feeding team assessment at Sunny Hill Health Centre for Children. We are interested in the primary caregivers’ experiences of an interdisciplinary team assessment for their child with a complex feeding and swallowing disorder. Face-to-face interviews will be used to identify these participants’ experiences and perspectives as they relate to the feeding team as a form of service delivery and mode of knowledge transfer between health professional and family.
Your decision to participate in the study is voluntary. The care that you and your child receive at Sunny Hill Health Centre in the future will not be affected in any way by your decision to participate or not in this study.

If you agree to participate in this study, we will ask for you to participate in two separate interviews. The first interview will take place within two to four weeks of your feeding team assessment at Sunny Hill Health Centre. The second interview will take place within three to four months after the initial interview, to allow you to have a chance to implement recommendations made by the feeding team. Each interview will take place in a location of your choice, for example, in your home or in a quiet public area such as a library or coffee shop. Information given during the interview will be recorded by an audio tape recorder as well as by notes taken by the interviewer. Your name, and other personal details, will not be disclosed. You are free to not answer any questions that you do not wish to. Your name or any other personal details will not be identified. The total time required for participation in this study is estimated to take up to three hours. This time will be split between two separate interviews, each taking between 60-90 minutes in length.

Confidentiality:
Confidentiality will be respected. Although you, as a participant will not be anonymous to the research team, as face to face interviews will be conducted, to ensure confidentiality all identifiers will be removed from the data. In the final manuscripts quotes from the interview may be used. If you wish to have your comments attributed, you will have the opportunity to request that this is to be done. Any information, including the audiotapes, resulting from this research study will be kept confidential and will be retained in a secure information system and locked filing cabinet. No data records, which identify you or your child by name or initials, will be allowed to leave the Investigators' offices. After a 5-year period, any data related to the study will be destroyed. Only the Principle Investigator - Dr. Liisa Holsti, the Study Coordinator - Rochelle Stokes and study team members - Dr. Catherine Backman and Dr. Melinda Suto, will have access to the raw data obtained from the interviews. An independent transcriptionist will transcribe all audiotapes. To ensure confidentiality, the transcriber will be asked to also sign a confidentiality agreement.

There will be no direct benefits to your participation in this study. We hope that learning about the experiences of caregivers going through a feeding assessment will benefit future families visiting this feeding team, as well as benefit families visiting similar feeding teams across Canada. Information from this study may also give some insight into the experiences of caregivers, which may benefit various paediatric rehabilitation settings other than those related to feeding.

Remuneration/Compensation:
Your participation in this study is voluntary, however you will be offered a forty dollar honorarium to subsidize the cost of child care during the interviews if required, as well as the cost of transportation should you choose to meet the researcher at a location other than your home. Twenty dollars will be provided to you after the completion of each interview. Receipts will not be required for expense claims, as only the honorarium will be provided.
Contact for information about this study:
You are welcome to discuss this study further with the study coordinator, Rochelle Stokes or any of the other investigators who are available to answer any questions, which you may have about the study. A signed and dated copy of this consent form will be made available to you. If you have other concerns about your rights as a research participant, you may telephone the Research Subject Information Line in the UBC office of Research Services at 604-822-8598.

In signing this consent form, you are agreeing that you have had the opportunity to ask questions and to discuss this study with the research team, and that your questions have been answered to your satisfaction. You understand that your participation in the above study is entirely voluntary, and that you may refuse to participate, or may withdraw from the study at any time without any consequences to your involvement with B.C.’s Children's & Women’s Hospital or Sunny Hill Health Centre for Children. You acknowledge receipt of a signed and dated copy of this consent form for your own records. You give consent to participation in this study, and in signing this document you are in no way waiving you or your child’s legal rights against the sponsors, investigators, or anyone else.

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<td>Person Obtaining Consent</td>
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<td>Principal Investigator’s Signature</td>
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Appendix C: Interview Guide

1. Can you please describe your child for me and your relationship to him or her?
   (Probe: the child’s personality, the child’s diagnosis, the child’s interests and activities)

2. Can you describe the difficulties your child is having with feeding and/or swallowing?
   (Probe: the length of time the child has had feeding difficulties, the type of feeding and/or swallowing disorder)

3. Can you describe your family?
   (Probe: family life: a typical day or week, family routines, family interests, family interactions and functioning, family stress, the pace of family life, family roles and responsibilities)

4. Describe a typical mealtime with our child. Can you describe any unusual or out of the ordinary feeding experiences? What has been your experience of managing your child’s feeding and/or swallowing difficulties?

5. Can you describe the feeding clinic at Sunny Hill Health Centre that you were recently a part of? What was your understanding of the purpose of the SHFT assessment?
   (Probe: specific sessions with various professionals, length of time, outline of the assessment, components: videofluoroscopy, feeding observation, etc., information delivery from professionals)

6. At the end of the assessment, a team meeting was conducted with the entire team of professionals. What was this experience like for you?

7. At the end of the team meeting, you received recommendations on how to assist your child with their feeding and/or swallowing. Can you describe this experience?
In the second interview, the principal investigator will use previous information obtained from the primary caregiver in the initial interview and ask the following questions:

1. It has been approximately three to four months since our initial interview. Can you describe what your life has been like since then?

   (Probe: major events or disruptions, family functioning, stress)

2. Can you describe how your child has been doing in regards to their feeding and/or swallowing? How have they been managing since I saw you last?

3. What was your experience in following the recommendations from the feeding team?

   (Probe: Was there support from community therapists or other community resources? What did you feel worked or did not work? Fit of recommendations with home life.)

4. Have you observed changes in your child since the feeding assessment at Sunny Hill Health Centre in regards to their feeding and/or swallowing? What are mealtimes like Has your home life changed as a result? If so, how has it changed?

   (Probe: stress, meals interactions, changes in weight and health.

5. In looking back at the feeding assessment at Sunny Hill Health Centre, have your perceptions about this experience changed since our initial interview?

6. What are your hopes and dreams for the future, for your child and for your family? For parents with a child who has a feeding and/or swallowing difficulty, what advice would you give them, prior to a SHFT assessment?

   (Probe: in life, in terms of feeding and/or swallowing.)
Appendix D: Sample of Reflexive Interview

Interview with researcher and a UBC graduate student

1. Have you always worked in pediatrics as an occupational therapist or do you work in other areas?

RS: I started out in acute neurology at Vancouver General Hospital and worked there for about a year and a half. And then I’ve always wanted to go into pediatrics and I went into pediatrics as soon as the opportunity arose and I guess I’ve been there, been in paediatrics now for I guess three years or so.

2. And have you always worked on the feeding and swallowing team?

RS: No, I started my first job within the community at a child development centre and that was actually where I started to be kind of interested in feeding and swallowing because I was the only occupational therapist at the child development centre at the time and it was pretty intimidating for me to be on my own. And because of that I guess feeding was definitely the scariest area for me so I started taking lots of courses on the subject, and then an opportunity came up to work on the feeding team at Sunny Hill. So that was I guess a year and a half ago, so I guess I’ve been both in the community and now I’m at a tertiary care centre.

3. Alright. What impact do you think your gender will have on outcomes of the study?

RS: Good question. Gender. I think as maybe as a female, although I don’t have children, I don’t know if I will relate a little bit differently to participants in my study than if I were male. I’m not sure if that will probably have some kind of impact. I think that maybe for some cultures that I’m going to be interviewing, maybe they’re not as familiar with females in kind of a role of researcher or role of therapist. I’m not sure if some cultures identify more with males. I think some of my experiences on the feeding team is that certain cultures definitely listen more to male
doctors, and so I don’t know if that is going to have any kind of impact that I’m going to be interviewing either males or females and so there might be some differences in how responses I get from male participants versus female participants.

4. Are you interviewing parents together, or?
RS: Just the primary caregiver so I’m assuming that there’s sort of potential that a lot of the participants I’m going to be interviewing will be female, just because in our culture and that females are usually the ones to do a little bit more of the childcare and feeding and that sort of thing. But I guess there is the potential that there might be fathers who are the primary givers.

5. Right, okay. And do you think your age and the fact that you don’t have children will impact your study?
RS: Yeah, I think I do. I mean I think there’s some families that I’ve encountered, there’s the perception that I’m quite young and so maybe they might feel that I’m not - don’t have as much understanding as far as maybe what they’re going through because of my age. I think if I did have children I would have a different perspective on potentially what families may be going through, the stresses that may be involved in their lives. I think that participants would probably relate to me a bit differently if they knew that I had children. I might be able to be able to talk about my own experiences of being a mother and help build rapport with participants if I had some of those same experiences. Although I think I’d probably try to still basically build rapport with some of my clinical observations and just the observations that I have that families are going through a lot and are very stressed out. So I think from my clinical work have gained kind of empathy for what families are going through. But I think if I did have children I would probably - it might be easier to build rapport quicker. I’m not sure.
6. Okay. Do you think because you work on the feeding and swallowing team that although you’re not interviewing families that you have seen personally, do you think if they’re aware that you are a member of the team that they will be open and forthright with you? 

RS: I think that’s a definite possibility that because of my position on the team and because they know that I’m involved with Sunny Hill that they may feel that whatever they tell me may influence the care that their child might get in future or they might be a little bit more cautious to talk negatively about the feeding team. Because they know I’m a therapist they might be - they might not be as honest about how things really are for them at home if there were recommendations that are just not working for them at all, they might feel a bit hesitant about telling me that, knowing I am a therapist. I think that yeah, I think that will definitely have a large impact on maybe just their general comfort versus if I was someone who didn’t really have any kind of affiliation with, you know, having that position on the feeding team. Their responses may be a little bit different.

7. Right. Do you have a sense of how you can manage that in the interview? 

RS: I think what I can do is talk about the reasons for doing the study and that I’m really just trying to get parents’ perspectives and experiences of going through the feeding team assessment and their experiences with implementing recommendations so as to help other families down the road, and it’s really important that they try to be as honest and forthcoming as possible in how they truly feel because this might be a good opportunity where changes can be made. I guess I’ll try to make them feel comfortable in understanding my own position and that, you know, anything that they tell me is confidential as far as - well, I guess it might not be confidential necessarily if it’s going to be in my study, but that there’s not going to be any kind of impact on any care that their child is going to get down the road, whether it’s with the feeding team or with
Sunny Hill. But I’ll try to maybe emphasize my position during the interview as that of a researcher, not as a therapist, and hopefully some of those things might kind of help them in feeling a little bit more comfortable in talking about the good and I guess positive and negative experiences.

8. Okay. You had talked a little bit already about your motivation for doing the study. So can you just elaborate on that a little bit more? Is it primarily coming from your experience on the team or would this information be valuable to others?

RS: I think my motivation for doing the study and for deciding to go back to school was it started from personal reasons and just wanting to further my own knowledge, being able to potentially increase opportunities for myself professionally down the road if let’s say I don’t want to do clinical work, to have the options of doing some work as a researcher. So I think when I started thinking about whether I wanted to go back to school, it kind of started from just it was a good time for me to go back to school, which kind of coincided with also what I previously mentioned, starting to get interested in specifically feeding and swallowing and then kind of the timing of getting a position at Sunny Hill. Everything kind of happened around the same time and I made the decision to go back to school but also had this strong area of interest in feeding and swallowing and so it kind of seemed to fit that I would try to do a research project in that area. But then working on the feeding team and especially being a new therapist and just seeing how the team was running and meeting families who are obviously having a hard time with implementing recommendations or were visibly stressed, made me realize that this might be an area that should be explored a little bit more. Because I think like most probably teams and therapists might always talk and wonder about how parents are feeling about the service delivery but do not actually look into it further. So that’s I guess my motivation was initially
personal in wanting to increase my knowledge but then also coming from a therapist on the feeding team and seeing some of the gaps.

9. Are your bosses at Sunny Hill aware of your study?

RS: They are, yes.

10. And are you intending to share the results with them?

RS: Yes. Yeah, the team, Sunny Hill’s very supportive of the study because I’m going to be using some of their resources like their booking clerk, which will be using some of her time for the team at Sunny Hill. So they’re very supportive of the study and I think it will be important regardless of whether they were kind of supporting the study in a way I guess by offering resources, it would be important to share the results of the study with them because I think it will probably have a direct impact on maybe how our team, the feeding team, and potentially on the way other teams are run at Sunny Hill. So I do plan on sharing the information with them.

11. Okay. Do you see any potential conflict for you? Say for example if the findings are of a negative nature where families have not had a good experience, is that going to be awkward for you to share that information?

RS: I don’t think so because I think the team already recognizes that there’s things that we as a team can work on and that there’s probably things that aren’t - that we might not be as sensitive about I guess in relation to families just because of our own time constraints and our own funding constraints. And so I think our team is already aware that there probably are some things that we could change, and so I think they seem to welcome kind of the results of the study and I think that is whether it’s positive or negative. Because I mean it might be an assumption but I think there’s probably things that work well and things that don’t. It might be a bit awkward if
everything is very negative, but hopefully there’s - I mean we’ll see what happens but some positive and negative things.

12. So it sounds like you’re expecting some negative or constructive thing to come out of the study?

RS: Yeah. I mean I think - well, I kind of wonder a little bit as to whether there’ll be anything that’s earth shattering coming out of the study. I think as a therapist I feel like I see families who appear like they’ve had a really good experience by the feedback that they’ve given, and it definitely appears that there’s families who have had a really hard time with the study and with the process and implementing recommendations. So I do anticipate that there’ll be kind of negative and positive things coming out, or feedback from families about I guess their experiences. Yeah.

13. I’m wondering what would be the difference between you doing the interviews compared to somebody else who is not working on the feeding team? Would they get different results and if so how, how do you think that would happen?

RS: I think my experiences of just being a therapist and I guess working with families and even probably different from some families who work let’s say only at a feeding team at Sunny Hill, I think my experience of working in the community as well as in a tertiary care centre will give me different insights into families’ experiences than let’s say another therapist or even someone who’s not a therapist just because I can probably pull on some of my clinical observations and just interactions that I’ve had with them. It might affect like how I probe families maybe in my interviewing or even the questions that I’ve chosen to ask families. I’m sure my previous experiences have influenced just yeah, the questions I’m planning to ask. And probably my assumptions of what families are going through or my perspectives of what I think families
might be going through are probably different than for example just seeing when I was working in the community there was families that I had on my caseload where I was the community therapist going with them to the feeding team at Sunny Hill and then having to work with families on coming up with recommendations - or not coming up with recommendations, working on the recommendations that therapists had given at Sunny Hill and just seeing how difficult it was for families to do that and how it was really - I mean for example with one family it was just not the right timing for them to be able to work on the recommendations because they worked on a farm and summer was blueberry season and they weren’t - they didn’t have the time to work on the recommendations so they didn’t until almost wintertime. And as a community therapist it was frustrating. I was a little bit in the middle but I had a different - I was able to kind of see what the family was going through at home and the fact that they can’t just - for them they can’t stop their I guess their way of getting income, for mom to stay at home with the child during the day and do some of the feeding. The mom was leaving the child with the grandparents who weren’t able to follow through with recommendations. So just an example of that perspective, or that experience of being a community therapist I think is very different than some of the therapists on the feeding team who have not had some of the long term contact with families in the community. So yeah, so I think just my clinical experiences will have an impact on just how the study or some of the results of the study, because I’ll probably be looking for different things too in even my data analysis than other therapists who are were, someone who has had the same clinical experience.

14. And it sounds like you have experience in seeing the family from different perspectives and you also have different assumptions related to that?

RS: Yeah.
15. So, and if that’s guiding the questions that you’re asking, how can you account for that?
RS: I think I’m not sure how I would necessarily maybe account for it except for maybe being really explicit in stating my experiences and have my experiences be known, or some of my perspectives be known going into the study or, you know, putting that in my proposal or having it so anyone reading my study knows where I’m coming from so that they could maybe make that decision whether my perspectives have influenced the study, or I guess acknowledging that my perspectives are influencing the study and just letting that be known. I think what I need to probably do is really make sure my questions are like quite broad in that really making sure I’m not trying to steer any answers that I might get from participants in a particular way, so really trying to keep things as open as possible so that they can tell their own story without any influence from myself. I think the best thing I could do is probably make it known what my experiences have been.

16. Are you going to be keeping a journal?
RS: Yes, I plan to keep a journal, yeah.
### CERTIFICATE OF APPROVAL - FULL BOARD

<table>
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<th>PRINCIPAL INVESTIGATOR:</th>
<th>INSTITUTION / DEPARTMENT:</th>
<th>UBC BREB NUMBER:</th>
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<tr>
<td>Liisa Holsti</td>
<td>UBC/Medicine, Faculty of/Occupational Science and Occupational Therapy</td>
<td>H08-01068</td>
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**INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:**
- Children's and Women's Health Centre of BC (incl. Sunny Hill)
- Children's and Women's Health Centre of BC (incl. Sunny Hill)

Other locations where the research will be conducted:
The location where the interviews will be conducted will be determined by the individual participants. The participants may choose do have the interview completed in their home, or in a quiet environment near their home (e.g. coffee shop, library, interview room at a local hospital, etc.).

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<td>Rochelle Hilary Stokes</td>
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**SPONSORING AGENCIES:**
- Canadian Institutes of Health Research (CIHR)

**PROJECT TITLE:**
Caregivers' Experiences of an Interdisciplinary Team Process for their Child with Complex Feeding and/or Swallowing Disorders

**REB MEETING DATE:**
September 11, 2008

**CERTIFICATE EXPIRY DATE:**
September 11, 2009

**DATE APPROVED:**
October 14, 2008

**DOCUMENTS INCLUDED IN THIS APPROVAL:**

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The application for ethical review and the document(s) listed above have been reviewed and the procedures were
found to be acceptable on ethical grounds for research involving human subjects.

Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:

Dr. M. Judith Lynam, Chair  
Dr. Ken Craig, Chair  
Dr. Jim Rupert, Associate Chair  
Dr. Laurie Ford, Associate Chair  
Dr. Daniel Salhani, Associate Chair  
Dr. Anita Ho, Associate Chair
### Appendix F: Example of Colaizzi’s (1978) Method of Data Analysis

<table>
<thead>
<tr>
<th>Participant 4-1st Interview</th>
<th>Stage 2 Extracting Significant Statements</th>
<th>Stage 3 Formulation of Meanings</th>
<th>Stage 4 Organization of Formulated Meanings into Theme Clusters and Themes</th>
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</thead>
</table>
| **Lines 398-406**           | “...the OT had mentioned, “You know, are you sure she’s not aspirating and that’s developing into these infections and things?” Which we didn’t think, and we also talked to the different doctors who were looking at her x-rays, and that wasn’t their impression either, that it was necessarily aspiration. But at the same time we’re like well, it would be good just to know that her swallow IS safe and that we were confident that, you know, we can continue to orally feed her and not have to worry about that. Because she does choke and gag on stuff, and has a pretty strong gag reflex when she needs to.” | The decision to have a feeding study was a complicated one, based on ‘timing’. A feeding study would give parents the confidence to push forward with oral eating. | Theme: Taking Action  
Theme Cluster: When Is The Right Time? |

| Participant 2-1st Interview | **Lines 291-294** | “We just, you know, rather than spoonfuls of stuff now we just do like a little taste of it on her tongue, what we’re having for dinner or something, and she still really likes it. We don’t give her enough to swallow anymore because we know what’s happening back there.” | Mother had adjusted her expectations of her daughter’s feeding abilities because she now has an understanding of the reasons behind her daughter’s feeding disorder | Theme: The Impact  
Theme Cluster: Increased Knowledge |

| Participant 6-1st Interview | **Lines 158-169** | “...you know, before he was as I said, he was okay with a bottle, and if I left him with his bottle he was reclined and he ate and sometimes he’d choke. I didn’t pay attention to it. Now it’s different.” | After feeding assessment mother can now identify when her son is having difficulties feeding and is able to work to prevent those difficulties | Theme: We Are On Our Own  
Theme Cluster: Integrating Recommendations |

| Participant 3-2nd Interview | **Lines 44-47** | “...as far as his health, he’s better. He feels good, and if he doesn’t feel great, then we still know he’s getting nutrition and he’s putting on weight at a fair, like a nice steady rate, along with really big growth spurts. So he just overall, it seems like it’s the perfect time for him.” | Mother has observed that her son is healthier and happier with his g-tube. There is no longer the pressure to constantly ensure that he taking adequate nutrition orally. The timing was right for the family. | Theme: We Are On Our Own  
Theme Cluster: Positive Change |
Appendix G: Participant Information

<table>
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<tr>
<th>Name of Participant &amp; Child</th>
<th>Age &amp; Gender of Child</th>
<th>Diagnosis of Child</th>
<th>Child’s Birth Order</th>
<th>Cultural Background</th>
<th>Type of Feeding (Oral, NG Tube, G-tube)</th>
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<tr>
<td><strong>Participant #1</strong>&lt;br&gt;Mother: Kim&lt;br&gt;Child: Megan</td>
<td>F 5 yrs</td>
<td>Down Syndrome</td>
<td>2nd (1 sibling)</td>
<td>Caucasian</td>
<td>Oral</td>
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<tr>
<td><strong>Participant #2</strong>&lt;br&gt;Mother: Amber&lt;br&gt;Child: Becky</td>
<td>F 14 months</td>
<td>Genetic Disorder</td>
<td>2nd (1 sibling)</td>
<td>Caucasian</td>
<td>G-Tube</td>
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<tr>
<td><strong>Participant #3</strong>&lt;br&gt;Mother: Susan&lt;br&gt;Child: Thomas</td>
<td>M 5 yrs</td>
<td>Spastic Quadriparesis &amp; Autistic Spectrum Disorder</td>
<td>Only Child</td>
<td>Caucasian</td>
<td>NG Tube at Interview #1&lt;br&gt;G-tube at Interview #2</td>
</tr>
<tr>
<td><strong>Participant #4</strong>&lt;br&gt;Mother: Crystal&lt;br&gt;Child: Jessica</td>
<td>F 2 ¾ yrs</td>
<td>Genetic Disorder</td>
<td>Only Child</td>
<td>Caucasian</td>
<td>G-tube</td>
</tr>
<tr>
<td><strong>Participant #5</strong>&lt;br&gt;Mother: Carol&lt;br&gt;Child: Abigail</td>
<td>F 15 ½ yrs</td>
<td>Down Syndrome</td>
<td>3rd (3 siblings)</td>
<td>Caucasian</td>
<td>Oral</td>
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<td><strong>Participant #6</strong>&lt;br&gt;Mother: Ester&lt;br&gt;Child: Dennis</td>
<td>M 2 ½ yrs</td>
<td>Genetic Disorder</td>
<td>Only Child</td>
<td>Eastern European Immigrant</td>
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<td><strong>Participant #7</strong>&lt;br&gt;Mother: Kuldeep&lt;br&gt;Child: Mandeep</td>
<td>F 4 ½ yrs</td>
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<td><strong>Participant #8</strong>&lt;br&gt;Mother: Erin&lt;br&gt;Child: Nicole</td>
<td>F 4 yrs</td>
<td>Global Developmental Delay</td>
<td>2nd (1 sibling)</td>
<td>Caucasian</td>
<td>Oral</td>
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<td><strong>Participant #9</strong>&lt;br&gt;Mother: Jennifer&lt;br&gt;Child: Matthew</td>
<td>M 8 months</td>
<td>Genetic Disorder</td>
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<td>Caucasian</td>
<td>Oral</td>
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** For purposes of participant confidentiality, specific names of rare diagnoses are not stated.
* Pseudonyms are used for all participants to ensure participant confidentiality.