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Mothers Feeding their Children with Autism Spectrum Disorder: Achieving a Tenuous Balance

by

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Dedication

This thesis is dedicated to my husband and best friend
Neil Mitchell Rogers
who has walked every step of the way with me and
supported me in this incredible journey.

Abstract

Children with autism can have a variety of feeding challenges and there is a paucity of research on the strategies that are effective in addressing these challenges**.** This study used constructivist grounded theory methodology to determine the process used by mothers to feed their children with autism spectrum disorder. It included 11 mothers of 12 children between the ages of four and eleven years old who had feeding challenges. The feeding challenges went beyond picky eating and mothers used unique strategies and approaches in addressing these feeding challenges based on their beliefs. The data indicated that there is a need to use a deliberate, individualized approach when feeding children with ASD, based on the individual child's needs and the family beliefs. "Achieving a Tenuous Balance" emerged as the core process, as mothers attempted to maintain or improve their child's feeding amidst changing expectations, environments, and life events.

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CHAPTER ONE

INTRODUCTION and RESEARCH PROBLEM

Background to the Problem

From the moment of their child's birth, mothers commence the intricate dance of responding to their children in order to meet their feeding needs. Mothers need to learn to read their children's cues and provide food in a manner that meets their children's nutritional needs and developmental level. As infants and children grow and develop, this mother-child interaction changes, with both parties adjusting to each others' cues and responses (Sumner & Spietz, 1994). Feeding is one of the most important responsibilities for parents (Schreck, Williams, & Smith, 2004). It involves a complex interaction of child, parent and environmental factors (Sumner & Spietz). While the responsibilities for feeding and nurturing a child within a family belong to mothers, fathers, and other caregivers, the focus of this study is on mothers as they often have the primary responsibilities for determining strategies that support successful feeding with their children (Carruth & Skinner, 2001).

The evolution of independence in feeding is a process starting initially with total dependence on the mother and growing towards independence through toddlerhood to school age. The feeding needs in typically developing children change over time as they integrate sucking reflexes, develop oral motor skills, become more aware of food properties, develop preferences, and grow in independent self feeding abilities. Typical stages in a child's feeding development include initial breast or bottle feeding; transition to purees; transition to solids and finger foods; gradual increase of repertoire of tastes and textures; and progression to self feeding and utensil use (Evans Morris & Dunn Klein, 2000). In addition, children learn expectations within different environments from home to preschool, with friends, at school, in restaurants and during special occasion meals. Typical children even enter a stage of picky eating and food neophobia (fear of new foods) as they gain independence from their mothers (Carruth et al., 1998).

But what happens when a child does not follow the typical feeding progression, or starts feeding in a typical manner and then develops feeding challenges? For children with Autism Spectrum Disorder (ASD), feeding challenges can occur in both of these ways. Some children with ASD have early feeding problems which continue to be problematic (Williams, 2000). Other children with ASD have no significant feeding challenges until 18 months to 2 years of age (Cornish, 1998; Williams). In my clinical practice, many children with ASD have progressed well through transitions of breast/bottle to purees and semi-solids to solids. Parents describe their children as eating well and then stopping their progress and starting to lose foods in their repertoire. Children with ASD are a heterogeneous group and the nature of their feeding disorders is multifaceted, as discussed in Chapter Two. The nature of the feeding disorders and appropriate strategies to deal with these feeding issues has not been well researched.

Children with ASD are diagnosed on the basis of having abnormal or impaired social interaction and communication, and a restricted symbolic or functional play repertoire (World Health Organization Collaborating Centre for Research and Training for Mental Health, 2004). These child factors are associated with feeding challenges. Atypical eating behaviours are so prevalent that they were initially included in the diagnostic criteria for autism (Ritvo & Freeman, 1978). Schopler (1995) indicated the feeding problems in ASD were related to underlying deficits such as tactile oversensitivity, fear of new foods, limited pleasure from food, need for sensory stimulation, a strong dislike of change, and communication difficulties.

ASD is a relatively high prevalence disorder with one in 150 children receiving the diagnosis (Centers for Disease Control and Prevention, 2007) and 46-89% of children with ASD having feeding, eating and mealtime challenges (Ledford & Gast, 2006). Children with autism have more feeding problems than their typically developing peers (Schreck et al., 2004). Many caregivers describe idiosyncrasies in eating behaviours. However, little is understood about the exact nature of the difficulties and the factors contributing to eating and mealtime challenges as perceived by mothers (Cornish, 1998). Given the high prevalence of challenges, it is important to understand the nature of the challenges in order to support children and their mothers in this essential life task. Developing a theory as to how challenges arise and are dealt with by the mother helps guide intervention efforts.

Purpose of the Study

This study explored qualitatively the processes and strategies involved in addressing the feeding challenges of young children with ASD from the mother's perspective. Although ASD has been the focus of much research, there are few studies specifically investigating ASD and feeding challenges, and further research is required. While the descriptive studies have provided information on the types of feeding challenges for these children, there have been no studies investigating how the feeding challenges develop, change over time, and what mothers do to ensure that their children with ASD are fed adequately. There are also no empirical studies investigating the impact of these significant challenges in terms of family life, parental stress, family eating patterns, extended family relationships, and other related processes. Answers to this type of inquiry help to determine appropriate areas for foci in assessment and appropriate treatment interventions. There is support from the literature recommending more investigation of clinical approaches (Ledford & Gast, 2006) and use of qualitative methodologies when defining evidence based practice (Strong, 2003).

CHAPTER TWO

LITERATURE REVIEW

In this literature review I begin by defining terms. I then examine factors associated with feeding for young children in general, address feeding problems in children with developmental disabilities, and examine more specifically the literature pertaining to children with ASD including treatment approaches. As feeding involves an interaction of child, parent and environmental factors (Sumner & Spietz, 1994), each section also reviews literature related to parent and environmental factors.

Definition of Terms

The Diagnostic and Statistical Manual of Mental Disorders – Text Revised (American Psychiatric Association, 2000) includes *Pervasive Developmental Disorders* as a broad category under which the diagnoses of *Autistic Disorder, Rett's Syndrome, Childhood Integrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified* fall. The term *Autism Spectrum Disorder (ASD*) is an umbrella term, described as the "most popular term for Pervasive Developmental Disorders" (World Health Organization Collaborating Centre for Research and Training for Mental Health, 2004, p.158). ASD is used in this study as an umbrella term to include children with a diagnosis of *Autistic Disorder/Autism, Pervasive Developmental Disorder-Not Otherwise Specified,* and *Asperger's Syndrome*, but excluding *Rett's Syndrome* and *Childhood Disintegrative Disorder.*

Feeding, eating and mealtime behaviours are used interchangeably in the literature. For the purposes of this thesis the term *feeding* is used to refer to all factors relating to the presentation and consumption of food and mealtime behaviours. This definition is broader than the bringing of food to the mouth and the ability to manipulate the food in the mouth, as feeding and eating are typically defined (American Occupational Therapy Association, 2003).

Feeding challenges as used in this thesis includes picky eaters but does not include children typically classified as having *eating disorders* such as anorexia or obesity. *Picky eaters* include those who reject both familiar and unfamiliar foods. Children with *food neophobia* are a subgroup of picky eaters as they reject new foods (Dovey, Staples, Gibson & Halford, 2007).

Feeding Development in Typical Children

Infancy and early childhood are critical times where difficulties with feeding and eating can have profound effects on growth and development (Woolston, 1983). Feeding challenges occur in 25-35% of typically developing young children (Lewinsohn et al., 2005; Linscheid, 1992). Feeding problems in childhood can include food refusal, picky eating, difficulty with acceptance of new foods, behavioural feeding problems, tantrums and slow eating (Dovey et al. 2007; Lewinsohn et al.).

There are several factors that affect the acceptance of new foods (Dovey et al., 2007). Parental factors include preferences for foods, pressure and approach used when introducing foods, and family culture. Child factors include age, cognition, attention, taste preferences, and the presence of food neophobia, and picky eating.

Environmental factors include the physical environment and mealtime routines. With typically developing children, foods with lumps need to be introduced by ten months to minimize difficulties handling food textures later (Northstone, Emmett, Nethersole & Avon Longitudinal Study of Pregnancy and Childhood Study Team, 2001). Smith, Roux, Naidoo and Venter (2005) suggested a relationship between tactile defensiveness in children and picky eating. Dovey et al. state that it is important to understand factors contributing to fussy eating through the different stages of childhood.

Multiple exposures to new foods are necessary to gain food acceptance (Carruth et al., 1998; Moore, Tapper & Murphy, 2007; Stang, 2006; Sullivan & Birch, 1994). The number of food exposures for food acceptance by typical children ranges from 10 (Carruth et al.; Sullivan & Birch) to 30 (Skinner et al., 1999). However, Carruth et al. report that mothers typically expose their children to new foods only up to three times before deciding that the child will not eat the food. Dovey et al. (2007) suggest that fussy eaters require many more food exposures for food acceptance than typical children.

In a qualitative study of 12 mothers of 3 to 5 year old children, Moore and colleagues (2007) found that children’s eating behaviours can be influenced by parents’ feeding strategies. These strategies can have positive or negative outcomes in typical children. Strategies used by mothers in this study included modeling by peers, adults and siblings; restricting access to foods; requirements to finish food; pressure; eating with the child; repeated exposure to a novel food; commenting on the food; removal of rewards; reserving some foods for special occasions; rewards for finishing a meal; not accepting a child's initial refusal of a new food; use of distraction; and specific food presentation (Moore et al.). In their analysis of questionnaires completed by 74 mothers of children aged 2 to 3 years, Carruth et al. (1998) proposed that picky eating with toddlers can become worse with use of some strategies including punishment and rewards. In typical toddlers who are picky eaters, food habits develop through consistent food avoidance and limited variety. Birch (1999) found that rewarding eating of a food resulted in reduced preference of that food. Further, Jansen, Mulkins, and Jansen (2007) found that forbidden foods became more attractive and desirable.

While the literature does not specifically discuss the role of the mother, it does provide insight as to the importance of the parental relationship regarding feeding. A positive atmosphere between parent and child is needed for acceptance of new foods (Dovey et al., 2007). Birch (1999) indicated that the environment is a critical factor in determining food selections and amounts. While children may be genetically predisposed to reject new foods and have preferences for salty and sweet foods, food preferences are also learned. In an observation study of the mealtimes of typical children and their parents, researchers found that children are capable of determining the amount they should eat and parent cues can be detrimental to a child being able to recognize when they are full (Orrell-Valente et al., 2007). These findings reinforce that parents need to provide nutritious foods and the children should determine which foods to eat and how much to consume. This approach is also advocated by Satter (1987) who added that the parent must also decide when food is presented and to present nutritious foods in a form the child can handle and the child is responsible for whether he/she chooses to eat the food.

The feeding process involves an interaction of child, caregiver and environmental characteristics (Sumner & Spietz, 1994). This includes caregiver/ child interaction; child characteristics of temperament and skills; caregiver skills and personality, adaptation and the social learning; and physical environments. Sumner and Spietz further indicate that there is mutual adaptation, regulation and modification of the child and caregiver in response to each other. These concepts are further expanded by Evans Morris and Dunn Klein (2000). They describe the child’s skills as including several inter-related factors in the feeding process such as sensory processing, motor coordination, physical comfort and child preferences. Other factors in the feeding process include parental culture, beliefs, values and experiences; beliefs about food and nutrition; socioeconomic factors; time available; parent and child emotional states; and family dynamics. Evans Morris and Dunn Klein also highlight the need to examine underlying factors in the child and family and identification of child and family strengths and needs.

The clinical feeding texts and research literature on feeding typical children provides information on developmental stages, factors influencing food acceptance, the importance of interaction of the child with caregiver and environment, and sources and types of strategies used to feed typical children. It also indicates ages and stages when feeding may be challenging and the prevalence of feeding challenges in children as they develop. The literature on typical children provides a rich source of information that can then be applied and used for comparison with information about children with developmental disabilities.

Feeding Challenges in Children with Developmental Disabilities

Palmer and Horn (1978) report that 33-80% of children with developmental delays have feeding challenges. They are at a greater risk than typically developing children for development of difficulties including aversive feeding behaviours (Schwarz, Correndor, Fisher-Medina, Cohen, & Rabinowitz, 2001). Field, Garland and Williams (2003) hypothesize that many feeding problems result from the interaction of medical, congenital, and developmental issues which affect child and caregiver behaviour. They found that early feeding difficulties can cause learned feeding aversions; for example, if children have gastroesophageal reflux, they can continue to refuse foods even after the reflux has resolved. Lewinsohn et al. (2005) advocate investigation of childhood feeding difficulties to see if there is a medical component.

The importance of social learning processes and eating has also been emphasized (Sanders, Patel, Le Grice, & Shepherd, 1993). Sanders and colleagues view feeding difficulties as a result of parenting behaviours. In contrast, Toomey (2006) estimates that in her practice for well over 90% of cases, the child’s eating challenges drive the parent behaviours as a response to the child’s dysfunction. There are no empirical studies to support Toomey’s position, but there is research concerning the types of eating challenges experienced by children with ASD.

Feeding Challenges in Children with ASD

In a clinical trial of children with ASD aged 7 to 9 ½ years (n = 138) and a same aged control group (n = 298), Schreck et al. (2004) found that children with autism have eating challenges to a greater extent than their typical peers. They are restricted by food category and texture and refuse foods more than typically developing children. In addition, parents reported more general feeding problems as their children with autism had a narrow repertoire and required specific food presentations and specific utensils. The problems were not transient in nature, required long-term follow-up and parents required support in dealing with significant mealtime challenges. Cornish (1998) indicated that children with ASD who have a repertoire of under 20 foods and are under 5 years of age are at particular risk for nutritional difficulties and require monitoring. A dramatic example of this involves a reported case of vision loss in a child with ASD due to a vitamin A deficiency (Uyanick, Dogangun, Kayaalp, Korkmaz & Dervent, 2006). Matson, Fodstad and Dempsey (2009) reported that even when children with ASD have adequate nutrition, feeding challenges can arise when there is limited access to preferred foods when children attend special occasion meals or restaurants.

Legge (2002) surveyed parents of children with ASD and found that the feeding challenges started at different times. In her sample of 89 children with ASD, “37% had demonstrated feeding problems by age one, 34.8% at age 1-2, 17.4% at age 2-3, 6.9% at age 3-4, and 2-3% at age 4-6” (Legge, p. 67). Further she reported that in 47% of the sample the feeding problems worsened over time.

This suggests that it is likely that feeding problems in children with ASD will be manifested by age six, and there is a need to examine feeding challenges over time.

In a systematic review, Ledford and Gast (2006) identified seven descriptive studies representing a total of 381 children with ASD and providing some preliminary information about the nature of feeding challenges in ASD. Based on these studies they reported that 46%-89% of children with ASD had feeding challenges. Challenges included limited food repertoire often to the point of nutritional compromise; food refusal; food jags; inflexibility related to varying food presentation, utensils and dishes, brands and packaging; sensory issues (taste, texture, and smell sensitivities); mealtime behaviour issues; difficulty accepting new foods; and nutritional issues (Cornish, 1998; Kuschner, Bennetto, & Silverman, 2005; Mayes & Calhoun, 1999; Schreck et al., 2004; Schreck & Williams, 2006; Williams, 2000). Other less common issues cited by these researchers included oral motor problems, pica (the consumption of non-edibles), difficulties accepting medicine, food retention in the mouth, and taking food from others' plates. In a later study, Johnson, Handen, Mayer-Costa and Sacco (2008) reported idiosyncratic refusal of foods based on colour, texture and type of food.

The World Health Organization (WHO) management recommendations for children with ASD include the need to manage feeding difficulties as children with ASD can be rigid in the types of foods they consume (WHO Collaborating Centre for Research and Training for Mental Health, 2004). A study of taste processing and eating reported that children with ASD had less accuracy in identifying tastes and there was a positive relationship between taste accuracy and food acceptance (Kuschner et al., 2005). Another study indicated that 30% of children with Pervasive Developmental Disorder cycled between times of good to poor eating (Kerwin, Eicher & Gelsinger, 2005). In the same study pica was reported in 29% of the children. The feeding problems in ASD are complex and varied and require in-depth investigation.

In these descriptive studies, methodological limitations included comparing children with ASD to other diagnostic groups, which identified feeding challenges relative to other diagnoses but did not provide an in-depth understanding of the feeding issues in ASD. One study compared the feeding challenges of the children with ASD to children with feeding challenges and Down Syndrome or Cri du Chat (Collins, Kyle, Smith, Laverty, & Eaton-Evans, 2003). Another compared the group of children with ASD to children with Cerebral Palsy or Down Syndrome (Field et al., 2003). The age ranges in the studies included children from 22 months to 18 years, and the children's level of functioning was not always stated. There was no indication in the studies as to when the feeding challenges peaked, or if they changed at different ages.

Ahearn (2001) emphasized the importance of including environmental factors in investigating mealtime behaviours for children with ASD. Schreck and Williams (2006) found that food selectivity in children with ASD was positively related to food selectivity of the family, therefore family eating patterns need to be considered in evaluation of feeding challenges.

Twachtman-Reilly, Amaral and Zebrowski (2009) advocated a detailed assessment of the many factors that could affect feeding in ASD. These include sensory processing issues, gastrointestinal problems, ritualistic behaviours, planning and sequencing behaviours needed to follow mealtime routines, anxieties, cognitive inflexibility, social and language skills, assessment of food selectivity and determining patterns of consistency and inconsistency in feeding in different environments. Matson and Fodstad (2009) expressed surprise that there had been so little emphasis on feeding difficulties in ASD given the potentially serious consequences of the problem. They summarized a number of the behaviourally-based feeding interventions for ASD. They advocated for more investigation in the areas of assessment and intervention, as well as research into environmental and biological factors which could potentially contribute to causing the feeding challenges in ASD.

There are few measurement instruments to comprehensively assess the components of feeding challenges in persons with ASD, including children, and without a standardized measure, there is no way of determining severity of the disorders and appropriate treatment interventions. Researchers in many of the descriptive studies employed checklists designed by their facilities without reported reliability and validity (Collins et al., 2003; Cornish, 1998; Kuschner et al., 2005; Mayes & Calhoun, 1999; Schreck & Williams, 2006; Williams, 2000). Three studies (Archer & Szatmari, 1990; Schreck et al., 2004; Schreck & Williams, 2006) used the same instrument, the Children’s Eating Behaviour Inventory (Archer & Szatmari), which has established reliability and validity for children with ASD (Archer, Rosenbaum, & Streiner, 1991). This measure however, does not investigate all areas of feeding challenge noted in the descriptive studies. Only three studies included child observation (Ahearn, Castine, Nault & Green, 2001; Field et al., 2003; Kuschner et al. 2005). One specific measure of feeding in ASD was developed, the Brief Autism Mealtime Behavior Inventory (Lukens & Linscheid, 2008), which the authors report to have good validity and reliability. Matson and Fodstad (2009) recommended further focus on the assessment of feeding problems using this or other measures specific for the ASD population. They also recommended further study of the severity levels and various symptom patterns for feeding challenges and further study of co-morbid factors that could affect feeding in these children.

When Ledford and Gast (2006) completed their systematic review of treatment studies of feeding children with ASD, they identified that the strategies reported in the treatment studies were different from those employed by parents and clinicians as described in three self-help books. Although not part of their systematic review, in their discussion Ledford and Gast noted that these three parent self-help books had information on feeding and ASD; one specifically looked at feeding and autism (Legge, 2002) and the other two were general books on managing autism written for parents (Ives & Munroe, 2002; Koegel & LaZebnik, 2004). These books described approaches to feeding that some parents had found helpful; however none of these approaches had been researched.

Ledford and Gast (2006) evaluated nine treatment intervention studies in their systematic review and described the treatments used in studies as “invasive procedures" (p. 163) that all focused only on food refusal. The studies were based on a behaviourist model, with intervention provided typically either by psychologists or educational psychologists. All were directive in telling the child to eat (Ahearn, 2002; Ahearn, 2003; Ahearn, Kerwin, Eicher & Lukens, 2001; Anderson & McMillan, 2001; Freeman & Piazza, 1998; Kern & Marder, 1996; Levin & Carr, 2001; Piazza et al., 2002; Nadjowski, Wallace, Doney & Ghezzi, 2003). Five involved keeping the spoon in the child's mouth (Ahearn, 2002; Ahearn et al. 2001; Anderson & McMillan; Kern & Marder; Nadjowski et al.). Two involved physically prompting the child by holding the jaw (Ahearn, 2002; Piazza et al.). In three studies, if food was accepted and then expelled, the expelled food was re-presented (Ahearn, 2002; Ahearn et al., 2001; Kern & Marder). In one study (Nadjowski et al.), if a food was expelled or vomited, a new bite of the expelled food was given. All except two studies (Anderson & McMillan; Nadjowski et al.) were done in controlled inpatient or school settings by trained staff. In the other two studies, the parent was trained to do the treatment.

Other less invasive techniques have been described in the literature. In their study of three children, Piazza et al. (2002) found that simultaneous presentation of preferred and non-preferred foods resulted in better acceptance of non-preferred foods than sequentially giving a preferred food after a non-preferred food was consumed. A "social story" intervention was successfully used by Bledsoe, Smith-Myles and Simpson (2003) to improve mealtime behaviours such as reducing food and drink spillage and increasing face wiping in an adolescent with Asperger's Syndrome.

The parent self-help books and feeding clinicians used procedures including, for example "multiple presentations of non-preferred foods and social modeling" (Koegel & LeZebnik, 2004, p. 163). In clinical interventions used by feeding therapists but not studied empirically, the emphasis is on challenges broader than food refusal. Toomey (2006) in her "Sequential Oral Sensory" approach addresses repertoire issues within the context of sensory challenges, cognitive and developmental level, and social/relationship issues at mealtime. Nutritional assessment is integral to many approaches (Ernsperger & Stegen-Hanson, 2004; Evans Morris & Dunn Klein, 2000; Pasadena Child Development Associates, 2007; Toomey). Differentiation of parent and child roles is a key contribution by Satter (1987). Sensory issues and environmental considerations are key areas of intervention for several feeding teams (Ernsperger & Stegen-Hanson; Evans Morris & Dunn Klein; Pasadena Child Development Associates; Toomey). Practical issues such as timing and scheduling of meals, development of hunger and fullness cycles and introduction of changes gradually are key concepts in all of the clinical approaches (Ernsperger & Stegen-Hanson; Evans Morris & Dunn Klein; Ives & Munro, 2002; Legge, 2002; Koegel & LaZebnik, 2004; Pasadena Child Development Associates; Satter; Toomey). The social aspects of the meal and social environment are also emphasized in clinical interventions (Evans Morris & Dunn Klein; Pasadena Child Development Associates; Satter; Toomey). Another critical component of all clinical interventions is a gradual approach, within a comfortable and often playful environment, with the child guiding what foods he/she will accept (Ernsperger & Stegen-Hanson; Evans Morris & Dunn Klein; Pasadena Child Development Associates; Toomey).

While the clinical approaches are based on sound theories, none of the specific feeding protocols have been tested empirically. Ledford and Gast (2006) strongly recommended empirical study of these clinical approaches which parents are finding to be effective and which they describe as less invasive than procedures employed by the empirical study group. All of the descriptive studies describe feeding challenges at one point in time but do not address change in feeding status over time. Ledford and Gast also suggested that more research be done to investigate the strategies used by parents of children with ASD as to their effectiveness. DeGrace (2004) encouraged clinicians to support the efforts of families of children with ASD in enhancing positive daily life activities.

In summary, while feeding challenges are common in typically developing young children, the proportion and severity of feeding challenges are greater in children with developmental delays and particularly high in children with ASD. The empirical literature has not captured the breadth of the feeding challenges. There is a need to investigate the types of strategies that are effective in treating the multifaceted feeding difficulties that children with ASD face. Intervention studies have focused on relatively invasive approaches such as escape extinction (Ledford & Gast, 2006), and have not determined what strategies parents, and mothers in particular, actually use when feeding their children with ASD. A starting point for future intervention studies is to determine how mothers, the most frequently involved caregiver, develop strategies that address specific feeding challenges.

Research Question

The research question guiding this qualitative study was: What is the process of mothers' feeding their children with ASD who have feeding challenges? The study explicitly addressed the following questions: 1) What feeding challenges do the mothers face with their child? 2) What strategies have the mothers used? and, 3) What drives the strategies chosen?

CHAPTER THREE

RESEARCH METHODOLOGY AND METHOD

Methodology and Method

Qualitative research methods are being used within rehabilitation science to address the gap between theory and practice that stems partially from a reliance on purely quantitative methods and to address complex issues in service delivery and clinical practice (Hammell & Carpenter, 2004). Autism is a complex, heterogeneous disorder, and the complexity of the feeding issues within this diagnostic group warrants a rigorous methodology to address the research questions pertinent to clinical practice and service delivery. In grounded theory, the researcher seeks to understand a situation or a process by learning from the participants in order to develop theory that is grounded in the data. This methodology is often used in health care research where understanding of process and change are key (Richards & Morse, 2007). Different types of grounded theory have evolved over time and the choice of which type to use should fit the research question and purpose of the study (Richards and Morse).

Given that the research questions that arise from the literature review address issues of process, and given my clinical experience in the field, constructivist grounded theory was the research methodology of choice. This study investigated the processes involved as parents, and more specifically mothers, endeavored to meet their child’s feeding needs. In constructivist grounded theory, the role of the researcher in co-constructing the findings with the participants is acknowledged. The goal of the inquiry was to develop a relevant theory for clinical practice through the analysis of the data. In this chapter I further expand on the choice of constructivist grounded theory and its appropriateness in answering the research questions.

Constructivist Grounded Theory

Grounded theory research methods have evolved and developed since the original work of sociologists Glaser and Strauss in 1967 (Bryant & Charmaz, 2007). Richards and Morse (2007) state that grounded theory is the method of choice when dealing with a question that is process oriented, where there is change over time, and the research purpose is to identify social processes. A constructivist approach to grounded theory involves interpretation of the data derived from shared experiences of participants and the researcher (Charmaz, 2006), in contrast with Glaserian or objectivist grounded theory which sees data as standing separate from the participants and the analysis (Richards & Morse). In constructivist grounded theory the researcher is encouraged to “take a reflexive stance towards the research process and products and consider how their themes evolve” (Charmaz, p. 131). Constructivist grounded theory addresses the critique of Glaserian grounded theory that contends that this traditional qualitative methodology does not attend to the social context of the data, the researcher-participant relationship, or the influence of the researcher on the interpretation of the data due to the objectivist view that the data itself represents truth and reality (Charmaz; Glaser, 2002).

Corbin, who worked extensively with Strauss, one of the original developers of grounded theory, refers to methodology as a living concept, which changes over time. She discusses her own acceptance of the constructivist viewpoint and that each person gives meaning to experiences based on their own reality (Morse et al., 2009). Charmaz views constructivist grounded theory as a “contemporary version” of the original grounded theory of Glaser and Strauss (Morse et al., p. 129). She emphasizes the constructivist ontological view of multiple standpoints of the researcher and the participants, the need for reflectivity, and the social construction of reality by each person. As such the analytic process is interpretive, not purely objective.

The Researcher as Instrument

Within the constructivist paradigm, the researcher situates herself in relation to the participants and data. Constructivist grounded theory is particularly well suited to this study as the questions are designed by an experienced clinician and the findings were jointly constructed by the parent participants and the clinician researcher (Charmaz, 2006). I am an occupational therapist who specializes in the assessment and treatment of children with ASD who have feeding challenges. I also mentor parents and other caregivers of children with ASD and professionals who work with parents and children with ASD to assist them with feeding and other life skill challenges. My experiences with over 200 children with ASD and several hundred children with feeding challenges without ASD enabled me to identify the shared and unique feeding problems and strategies described by the mothers in this study.

Another key aspect of “researcher as instrument” is the relationship between the researcher and participant. A trusting relationship in which both parties can freely share their perspectives contributes to the generation of rich data for analysis (Rubin & Rubin, 2005). I had a prior clinical relationship with six of the mothers in this study, having provided four feeding consultations for one family and single feeding consultations for five families. However, I did not develop extensive feeding interventions for any of them, and had not played a significant role in the feeding interventions that they used. Therefore I am confident that my findings did not reflect my own views of feeding back to me through the participants. Rather, my prior relationship with some of the mothers facilitated rapport in the interview which may have contributed to the breadth within the interview data (Rubin & Rubin).

The combination of my clinical knowledge and skill with the specific experiences of each study participant has resulted in a rich form of data generation and analysis. As the instrument through which the data was generated and analyzed, the findings presented are my interpretation. However the data and my interpretations of the data were also examined by my co-supervisors, who ensured that I stayed close to the data in my interpretation. I viewed the data from an occupational therapy clinical feeding perspective, a perspective shared by many of my occupational therapy and speech/language pathology colleagues and other feeding specialists, especially in relation to concepts such as following the child’s lead and not forcing (Evans Morris & Dunn Klein, 2000). Charmaz (2006) states, “What you see in your data relies in part upon your prior perspectives” and advises researchers to see their perspective as “one view among many” (p. 54) rather than seeing their perspectives as truth. My role, as described by Charmaz

(2004), was to enter the experience of the participants, and learn the logic of their experience as expressed through their actions, rather than imposing my logic on it. It was from this open-minded clinically-based stance that I conducted this research.

Data Collection

Sample and Sampling

To obtain a rich description of feeding children with ASD I sought participants who were knowledgeable about the subject matter so as to provide the in-depth data required to understand the phenomena being studied (Field & Morse, 1985). Therefore the population from which I drew my sample was mothers of children with ASD who had feeding problems. I initially used purposeful sampling to maximize access to the phenomenon by selecting cases where the phenomenon of feeding challenges was most evident, namely in children with ASD whom the mothers self-identified as having feeding challenges (Richards & Morse, 2007).

The sample consisted of mothers of children with ASD. Mothers were chosen for two reasons. Mothers are intimately involved in determining strategies for feeding their children (Carrruth & Skinner, 2001). Homogeneity of the sample by sampling only mothers helped to provide a clear focus for the study ensuring its feasibility within the time frame available for a master’s thesis. This is not to say that the viewpoints of fathers are not important. In fact, theoretical sampling of fathers to compare the responses of mothers and fathers would be an excellent step for the next stage of research after this study.

Sample size.

The number of participants required is dependent on the study design, ease of obtaining data, data quality, study scope, number of interviews per participant and reporting of shadowed data, which is discussion of the experiences of others, thus broadening the scope of the data generated (Morse, 2000). In a review of grounded theory studies, Guest, Bunce and Johnson (2006) determined that the smallest sample size for a grounded theory study is six participants. In a grounded theory study, they analyzed data from 60 interviews with 60 participants and determined that major themes evolved after six interviews and that after 12 interviews they had developed 88% of the codes obtained from all 60 interviews. Given the above considerations and the fact that I was familiar with the topic area and anticipated early generation of rich data, I estimated a sample size of six to 12 participants. To the degree to which one can make claims about data saturation, I determined that I had achieved saturation with 11 participants, as I was obtaining no new information under the core categories identified by that point.

Inclusion and exclusion criteria.

At the outset of the study inclusion criteria specified a sample of biological mothers of six and seven-year-old children who had a confirmed diagnosis of ASD and had feeding challenges as identified by the mothers. The age group of six and seven year olds was chosen as these children have been exposed to most of the feeding stages from transitioning to different stages of foods to eating in different environments. Mothers of younger children were added as the study progressed as well as one mother of an older child.

To meet the vital inclusion criterion for this study of a confirmed diagnosis of ASD, recruitment occurred through the Glenrose Rehabilitation Hospital Autism Follow-up Clinic database. The children in this database had a diagnosis of ASD established by an interdisciplinary team assessment using DSM IV criteria and other supporting assessments such as the Autism Diagnostic Observation Schedule (Lord et al., 2000). One child, who was recruited from another region of the province, had a diagnosis of ASD established by an equivalent interdisciplinary team assessment with the above criteria. This child was added through theoretical sampling, as discussed under recruitment. The validity of a diagnosis of ASD was verified on screening when I asked the participants to tell me the wording of their child's actual diagnosis. I further validated the diagnosis during the interview through the mothers' description of their children that were consistent with the diagnosis. These three measures ensured that all of the participants met this inclusion criterion.

A maximally diverse sample was sought with only two exclusion criteria. Mothers were excluded if their child had a co-morbid physical condition that was known to independently affect feeding such as cerebral palsy, vision impairment, or Down syndrome or if they did not speak English. The sample recruited was diverse as it included married and single mothers of different socio-economic status, children of different cognitive levels and different levels of feeding difficulty, and both genders.

Recruitment.

Although recruitment could have been done by contacting autism service providers to distribute a flyer regarding the study to clients, it was important to ensure a valid diagnosis of ASD. Therefore the Autism Follow-up clinic was used to recruit a convenience sample that could then be screened to ensure maximal variation. The Autism Follow-up Clinic database team leader identified potential study participants who were mothers of children with ASD, aged six or seven years. An introductory flyer was mailed by the clinic clerk (see Appendix A) randomly in two separate mail-outs. This was done both to minimize mailing costs and to avoid contacting too many families if sufficient participants responded in the first mail-out. A third mail out was used to expand the age grouping. A total of 174 flyers were sent. Sixty were sent in August 2008, to mothers of six and seven year olds, resulting in eight responses. Forty-two flyers were sent on September 23, 2008 to another group of mothers of six and seven year olds, resulting in no responses. Seventy flyers were sent on October 28, 2008 to mothers of five and six year olds, resulting in nine responses. There were therefore seventeen responses from 174 flyers, representing a return rate of 9.8%.

In the flyer, mothers were invited to contact me by phone or email to obtain further information about the study. There was no way within the database used for recruitment to identify children with feeding issues; therefore the recruitment letter (see Appendix A) specified that the mothers have children with feeding challenges. When mothers contacted me I screened them to ensure they met the inclusion criteria (see Appendix B) to ensure that their children had feeding challenges, and to ensure variation in family structure and level of ASD. All participants who met the inclusion criteria initially were entered into the study as they each contributed to the variation in the sample. As the study progressed through simultaneous data generation and analysis, theoretical sampling was employed and mothers of younger children were recruited.

Of the 17 responses, nine mothers became participants. Eight were not able to participate as two were fathers, one was a foster mother, two had children with exclusionary medical conditions, and three did not follow-up after the initial contact. One participant did not initially meet the criteria for the study as her seven year child, although registered with the Autism Follow-up Clinic, had received a change in diagnosis and did not meet the criteria for ASD. There was however an older sibling in the family who did meet the study criteria, so the mother became a participant. The two other participants were recruited through theoretical sampling. As the analysis progressed, after the first six interviews I included participants who had found out about the study and volunteered to participate. They added diversity to the sample in gender (only girl) and by expanding the age range. This purposeful sampling was used to gain maximal diversity within the sample, thus the later participants were included as they expanded the age and gender distribution. Theoretical sampling was used in recruiting the last participant to expand an emerging category of “typical feeding strategies do not work.” As the analysis progressed and codes and categories emerged, based on information volunteered at the time of screening, the purposeful and theoretical sampling also added richness to underdeveloped categories.

While service providers and families expressed considerable interest in the study, interested participants were not easily reached through the mail-out recruitment process which was used to ensure an appropriate diagnosis. The clinic secretary had indicated that several other investigators were recruiting at the same time from the same database, so parents received the letters for this study shortly after receiving letters requesting their participation in other studies. Nevertheless, the 11 participants not only provided a diverse sample, the mothers were enthusiastic about the study and provided rich and meaningful data.

Ethical considerations.

Ethics approval was obtained from Health Research Ethics Board, Panel B, and administrative approval was obtained from the health region. Participants provided written consent (see Appendices C and D) and gave permission to record the interview and to use quotes verbatim with identifying information removed. I ensured anonymity of the participants through removal of any personal identifiers from transcriptions, presenting data collectively, and identifying the setting as two large urban settings in Western Canada, Edmonton and Calgary. Long-term confidentiality includes storage of the transcript CDs and password protected computer files in a locked storage area in the Faculty of Rehabilitation Medicine for the required seven years. Demographics have only been shared as group information. These measures to protect anonymity were discussed during the process of informed consent.

Data Collection Procedures

There were three forms of data generation. These included semi-structured interviews with participants, researcher field notes, and a researcher reflective journal.

Semi-structured interviews.

The primary form of data collection was through 1½ to 2½ hour semi-structured interviews with participants that were recorded and transcribed verbatim. I conducted interviews with the first 10 participants between September 14, 2008 and January 28, 2009. I completed interview 11 on June 5th, 2009. A series of guiding questions provided direction for the interview process. I started the interviews with general questions about the child and family. The first feeding question set the context for the interview by inviting the mother to “Tell me about your child’s feeding challenges.” Further questions guided the interview and I used probes to further explore topics (See Interview Guide in Appendix E). I clarified and amplified information from the participant during the interview by using a probe such as “can you tell me more about that?”

A pilot interview was conducted to refine the interview process and to ensure I was prepared with appropriate probes. Based on reflections on the first interview, the original questions were retained but re-ordered for a more logical flow. This format, in Appendix F, worked well for the remaining interviews. I also added questions to the guide (as indicated by * in Appendix F) as a result of simultaneous analysis of the data, in order to further explore developing themes and categories. In many interviews, I was able to gather the required data by posing some targeted questions and then followed the flow of the mothers' conversation, clarifying or adding questions only as needed.

I obtained demographic data at the end of the interview in order to provide a rich description of the study participants. This included information about the parents, the child with ASD, and siblings.

The participants chose a location where they would feel most comfortable for the interview. Nine were done in the family home, one at the University, and one, at the mother's request, at a quiet bistro. In one case the child was home during the supper-time interview, allowing the opportunity to observe and record in field notes the mother using the very strategies that she had described in the interview.

Digitally recorded interviews were transcribed verbatim by a transcriptionist and any identifying information removed at this time. The interviews were all transcribed by the same transcriptionist and received within a few days of the interviews. I listened to the first four interviews while reading the transcript line by line to ensure accuracy of the content of the transcriptions. My co-supervisors also listened to the first few interviews and provided feedback regarding my interview techniques and practical suggestions such as how to remove identifying information without losing meaning and assigning alphabetical pseudonyms to each family (e.g. Anna and Andrew, Bethany and Bobby). I gave the transcriptionist feedback on my requirements based on my in-depth review of the first four transcriptions and therefore procedures were in place after interview four, necessitating only minor edits to the last seven interviews. I reviewed these seven transcripts immediately upon receiving them but in less detail.

Field notes.

I recorded field notes at the end of each interview to document relevant information such as the emotional tone of the interview, non verbal communication including body language and expressions of emotion, and other information that may not have been reflected in the transcribed interview data. Field notes were also used to clarify content and in one interview observation of the child eating formed part of the field note for that interview. As the interviews progressed my field notes recorded emerging themes, concepts and insights.

Reflective journal.

I kept a reflective journal of impressions, thoughts and perceptions relating to the study, which was included as data for analysis. Hall and Callory (2001) propose that when using constructivist grounded theory there is a need to attend to reflexivity and the way data are socially constructed. They further propose that combining reflexivity and relationality of researcher and participant with theoretical sensitivity contributes to more rigor. Charmaz (2006) agrees as she states “Constructivists attempt to become aware of their presuppositions and to grapple with how they affect the research. They realize that grounded theorists can ironically import preconceived ideas into their work and starting assumptions. Thus constructivism fosters researchers’ reflexivity about their own interpretations as well as those of their research participants” (p. 131).

Rubin and Rubin (2005) discuss the role of personal bias affecting how the researcher conducts an interview and follows up on a lead. They counsel researchers to examine their preconceptions, rather than assuming they do not have biases. Bias is not a term used typically in constructivist grounded theory; however preconceived ideas are explored through documentation of *sensitizing concepts*. The researcher needs to guard against imposing beliefs and theories on the data, but rather uses these sensitizing concepts as starting points for analysis and theory development. Sensitizing concepts refer to the researcher's disciplinary and experiential perspectives which form the basic starting points for data analysis (Charmaz, 2003). My thesis research started with a conscious application of this concept of reflexivity as I documented my preconceived ideas and sensitizing concepts in the reflective journal prior to the study commencing, to account for my role in data generation and analysis. In this initial entry, I documented my personal beliefs about my approach to feeding children in autism, specifically my aversion to any kind of force feeding approach. By documenting these beliefs I then paid particular attention to these preconceptions when I did reflective notes at the end of each interview.

Early in my study, my reflective notes focused on my interviewing skills, including what was working and not working in the interview guide. I also reflected on my attitudes towards information that the mothers provided, particularly relating to my clinical experiences, preconceived ideas, and documented beliefs. I encountered several different viewpoints among the participants, some of which were contrary to my beliefs, and through this continuous reflection, ensured that the mothers' views were fully and fairly represented in my interpretations.

Morse (2007) emphasized the importance of the researcher doing a self-critique following the interview to ensure quality of the research data. She emphasized the need of the researcher during the interview to probe appropriately, not to cut off the participant’s stream of response and to reflect on each interview to make sure one was attending to these interview techniques as well as adhering to the questions of the study.

After the second interview I received detailed feedback from my co-supervisors on my interviewing skills and suggestions for improving them. By reflecting on my interviews through my journal entries, I discovered I needed a different skill set as a researcher than was needed for doing clinical interviews. Statements that are appropriate in a clinical interview to acknowledge a mother’s comment with an empathetic response needed to be worded differently in a research interview. For example, when a mother described her efforts at obtaining a calm mealtime I offered to her that she “needed to keep the peace at mealtime” rather than encouraging her to further describe her intentions and needs through a more open-ended inquiry. At times this felt awkward, such as when asking the mother how something made her feel when it seemed the answer was obvious. I continued to ask the more inviting questions and realized I was making the shift from clinician to researcher in my interviews when I noted that participants gave different answers to those I had assumed they would give. After the fourth interview I became increasingly comfortable with the interviewing and again received detailed mentor feedback after interview four confirming my progress and continued to record my insights in my reflective journal.

Data Analysis

Within the grounded theory process, data collection and analysis occur simultaneously, with the data analysis commencing after the first interview and as each subsequent interview is completed. In addition, an apriori theoretical framework was not used to analyze the data. Data analysis included different levels of coding and I recorded memos as the interviews progressed to record my thoughts as the analysis developed. Memo writing assists the researcher to start data analysis and reflection early in the research process (Charmaz, 2006). I used the terminology described by Morse (2008) to describe initial coding as codes, subsequent groups of codes as categories and the overall threads going through the data as themes.

Initial Coding

My initial coding involved line-by-line coding of the first two interviews followed by the same detailed coding of interviews three and four. Line-by-line coding provides provisional codes as action verbs tied closely with the data to see nuances and to determine how to proceed with subsequent interviews (Bowen, 2008; Charmaz, 2006). Actual participant quotations were used to illustrate the description of the specific phenomenon and to keep the analysis ‘alive’ (Richards & Morse, 2007). These *in vivo* quotes, which use particular language of the participants, were included as long as they fit with the development of the theory and fit with the comparison process (Charmaz), and did not identify participants. After interview four, I prepared a summary chart of each interview that included parent and child factors, codes regarding feeding challenges and one code labeled "strategies." Together with my thesis co-supervisors, I used a constant comparative process to identify emerging ideas and categories of coded data which resulted in a list of 22 categories. I returned to line-by-line coding of the rest of the interviews to provide further detail for the identified categories to further evolve a core category that had the potential to explain the key processes involved in feeding a child with ASD. This resulted in early emergence of a core theme initially labeled "beliefs and values."

Glaserian grounded theory emphasizes that the theory *emerges from the data*, rather than the researcher starting with preconceived ideas and forcing them on the data (Glaser, 1992). Charmaz (2006) claims that even the process of coding is an interactive process between the researcher and the data, as the researcher is the one determining what is significant while continuing to be open to having the themes emerge from the data. The researcher is charged with interpreting the data into emerging codes rather than fitting the data into predetermined categories as in quantitative research (Charmaz, 2003). I retained the 22 categories without forcing them into any preconceived structure and then moved systematically into the process of focused and theoretical coding.

Focused Coding and Theoretical Coding

Focused coding was the next phase of analysis and was used to further refine the categories (Charmaz, 2006). For example I analyzed all of the data that had been coded as "Strategies" in more detail. This coding resulted in 34 codes under the category of strategies, which were then collapsed to be 10 sub-categories under this category. These sub-categories included labels such as “visual strategies” and “verbal support.”

During focused coding I also analyzed for categories and themes that held particularly strong theoretical or explanatory value in my emerging theory of feeding children with ASD. As Stern (2007) stated “I never do line by line analysis because there is too much filler to skip over. Rather I do a search and seizure operation looking for cream in the data” (p.118). As a novice researcher, I did perform detailed line-by-line coding and this analysis activity revealed early underlying themes such as “valuing family mealtimes’ or “believing in healthy nutrition.” I compared these with related themes as the interviews progressed and a main theme of “beliefs and values” emerged. This major theme served to guide my line of questioning in the next three interviews in order to expand on the theoretically rich theme. I then returned to all of the interviews and through Stern’s “search and seizure operation”, I coded all related instances as “beliefs and values.”

Theoretical coding followed and was used to describe relationships among the codes and categories. Integral to this process of theoretical coding is *constant comparative analysis.* Constant comparative analysis is central to grounded theory research and consists of comparison of incident to incident and incident to concept in order to find patterns as concepts emerge (Glaser, 1992). In constant comparison, new data are compared with previous codes, theoretical concepts are developed and refined, and relationships and patterns are formed (Bowen, 2008). By interview eight through this constant comparative process the major categories of challenges, approaches and strategies emerged, some of which required further expansion. Most of these categories were saturated by interview eight, meaning that no new data pertaining to that category was appearing in subsequent interview data. The last category did not achieve saturation until interview 11, as this interview provided further confirmation of a question posed in a memo regarding use of typical feeding strategies for children with ASD.

Saturation is a concept described by Charmaz (2006) in defining the properties of an emerging category until there are no new characteristics emerging. I did not achieve saturation on every category that I initially discovered, but I did decide that I had reached saturation on all of the categories described in this thesis. For example, to saturate one particular category I would have had to sample fathers, which was beyond the scope of this study.

In April 2009 we had a group analysis meeting including my mentors and another graduate student to explore the major categories and themes in greater detail. I audio taped this meeting and used the information in writing the findings. One of the main insights that emerged at this juncture was how the choices of strategies used by mothers were based on their belief and value systems. This formed the basis for the answer to the third research question which was: What drives the strategies that the mothers used? With further analysis, when the core categories of “Challenges” “Approaches” and “Strategies” were considered in light of the core theme of “Beliefs and values,” a core process “Achieving a Tenuous Balance” emerged.

Memoing

Memo writing was an integral component of data generation and analysis. Memos were used to keep track of ideas, relationships, questions, and hunches while comparing pieces of data (Bowen, 2008). Memos were written to explore ideas about codes and categories, reflect on the data, create concepts, initiate new ideas, make comparisons among concepts and link the data and the analysis (Charmaz, 2006; Liamputtong & Ezzy, 2006; Stern, 2007). They were an essential component of the audit trail to track decisions as they were made. Stern states “if data are the building blocks of the developing theory, memos are the mortar” (p.119).

Following interview four and a team meeting on data analysis I documented the following memo:

> I’m only finished interview four and I already want to hear more than just strategies. Strategies on their own don’t help our understanding as much as knowing reasons for the strategy and how and why the mothers decided to use them. Listing of strategies may help in a survey in the future perhaps to see who benefits from what approach but right now we need more of the how and why. I want to know what led them to that strategy. How do they decide what strategy to use? What underlies the choices and decisions made? What makes them successful? Define success? When do they go on to another strategy?

Two things resulted from this memo and the team analysis meeting. I added questions to the interview guide to specifically ask mothers what drove their decisions about the strategies. Also the data analysis and constant comparison started focusing on the underlying reasons and meaning behind the use of the strategies. What emerged was the main category we named “beliefs and values.” My early thinking on this is reflected in a memo after interview ten:

> Mothers are very analytical and tend to put themselves in the child’s place to try to figure out what will work for them. But decisions on strategies to use are also based on the mother’s beliefs and values whether it is decisions about follow through of therapy recommendations, following the child’s lead or use of external reinforcers.

During the analysis I initially struggled with articulating the differences between approaches and strategies as these categories emerged. Initially I thought of the approaches as general strategies and the strategies as more specific. As I analyzed this further I determined that approaches reflected a more global way that mothers dealt overall with feeding issues and were largely determined by and linked with mothers’ beliefs. Strategies were very specific and often incident-by-incident ways of addressing a feeding concern. Strategies were often used in response to a specific child need and were addressed usually using the child’s strengths.

Data Management

I used QSR International’s NVivo 8 software system (NVivo) for data management to assist with data sorting and retrieval (Bazeley, 2007; Richards, 1999). I used NVivo both as an organizational tool and a word search tool to assist with the data analysis and generation of codes. After all major categories were identified through the initial and focused coding of all 11 interviews, I downloaded all interviews and coding into NVivo. I then used NVivo to manage the data arising from the major category of “beliefs and values.” While NVivo could have assisted in organizing the data on the different strategies, I did that coding and grouping manually as it was an effective method of staying close and analyzing the data that fit my personal style.

When I defined a higher level concept I used NVivo as a word search tool, to see if the mothers used the specific words or other words to define the concept. I was then able to define the terms correctly using the language of the mothers. When describing jargon words, such as *food jags*, I also used NVivo word search to find who used the terminology first in the interview, and therefore only used the jargon words if the mothers introduced them.

Theory Generation

The final step is the generation of theory which is the outcome of the data generation, theoretical sampling and data analysis. The theory that is developed must be integrated as new information adding to the current body of literature relating to the subject (Glaser, 1992; Stern, 2007). After the main categories emerged, I did a literature review in order to situate the core categories within the context of current child and family theories. The core process "Achieving a Tenuous Balance" is the beginning of the theory of strategies that mothers use to feed their children with ASD and reasons why they used those strategies.

Considering the Quality of this Research

Rigor

Several different approaches to ensure rigor have been suggested. Examples include the need for congruence throughout the study (Richards & Morse, 2007); credibility, transferability, dependability and confirmability (Guba & Lincoln, 1989); goodness and trustworthiness (Bowen, 2008; Tobin & Begley, 2004); reflexivity (Charmaz, 2006; Hall & Callery, 2001); credibility, auditability and fittingness (Beck, 1993); and fit, work, relevance and modifiability (Glaser, 1992). Watson and Girard (2004) state that the quantitative language of rigor should not be applied to qualitative methods and that rigor refers to the “methodological soundness of the research” (p. 876). However, Richards and Morse argue that it is necessary to continue to use the terms reliability and validity to describe rigor even within qualitative inquiry. They state that the qualitative researcher, to ensure rigor, is to use an inductive process and is to seek representation of the phenomena being studied by using different sampling techniques. Within this study the inductive process was used in data analysis and through simultaneous data collection and analysis. A sample representative of phenomena of feeding difficulty was obtained through purposeful sampling initially and theoretical sampling later in the process. Richards and Morse further state that in all qualitative inquiry, validity is obtained though the fit of or congruence between a question, method and data. They also claim that validity is obtained though the accounting of all steps in the analysis, also identified as auditability. The qualities of rigor that appear to be most relevant to constructivist grounded theory have been chosen for this study from all of the above concepts. These included congruence, credibility, grab, fit, relevance and auditability.

Congruence.

Rigor in grounded theory is enhanced when there is congruence among the different components of the research design including the research question, the methods selected, the data collected, data analysis, and the subsequent development of theory (Richards & Morse, 2007; Stern, 2007). This is echoed by Watson and Girard (2004), who further elaborate the need for congruence between the philosophy of the chosen paradigm and the research method chosen. In this study, there is congruence between the process-oriented research question and grounded theory methodology. All of the necessary components of a grounded theory study have been incorporated in this study from the sampling procedure to use of constant comparative analysis, and grounding the theory in the data. Rigor in sampling requires use of the appropriate sampling techniques for the study. Purposeful sampling requires the researcher to select participants who are familiar with the required information, have time to participate and are willing to reflect on the information asked (Richards and Morse, 2007). The data gathered including fields notes and interview data were appropriate for grounded theory, and use of simultaneous data collection and analysis and use of constant comparative methods are all key to grounded theory (Richards and Morse).

Credibility.

Credible research presents findings that are the best available approximation of the truth, the truth being participant-related. Participants were chosen through purposeful sampling in order to describe the feeding processes for children with ASD from the mothers' perspective. One way of ensuring credibility is through member checks. Limb (2004) advocates the use of member checking for credibility as the "participant has to be the greatest assessor of credibility" (p. 87). Member checking was done throughout the interview by asking "Are you saying?", "Do you mean?", and "Give me an example." These *clarification probes* ensured that I understood the information provided by the participant as being what they intended to report (Rubin & Rubin, 2005). Morse (2007) cautions against member checking by returning thematic codes and emerging theory back to the participants. This level of abstraction is not productive as the participants like to see themselves in the data, and the collective information may not have meaning for individual participants. Therefore this method of member checking was not employed.

Grab, fit and relevance.

Fit ensures threats to external validity have been controlled. These include a tendency to try to fit the data into a preconceived idea (Fielding & Fielding, 1986). Charmaz (2006) indicates that the process of coding from the data leads to "fit and relevance" which are needed for study rigor (Charmaz, p. 54). She describes *fit* as coming from constructing codes based on participant experiences, and *relevance* as occurring with creation of an analytic framework that links relationships among the data (Charmaz). Grab and fit occur when the researcher is able to balance the need to ground the theory in the data yet be distanced enough from it in order to have quality conceptualization (Bryant & Charmaz, 2007). Richards and Morse (2007) also contend that the findings must fit with the existing literature in the area to ensure fit with previous concepts and ideas.

The rigor of my research was supported when I received feedback from parents and clinicians that fit the findings of this study. As part of my clinical work, I consult with parents and professionals regarding feeding challenges in ASD. I conducted a province-wide feeding workshop on feeding in ASD with clinicians and parents in May 2009. Workshop participants included parents of children with ASD, occupational therapists, speech language pathologists, psychologists, dietitians, teachers, aides, service providers, administrators and physicians. They documented and submitted their questions and concerns in addressing the feeding needs and challenges of children with ASD. Questions frequently asked involved increasing food repertoire, addressing sensory issues, distinguishing sensory from other feeding behaviours, addressing anxiety around food, dealing with nutritional challenges and special diets, determining when picky eating is a problem, increasing texture progression and chewing, helping the child to eat outside the home environment, addressing the child losing foods and starving themselves if they do not get preferred foods, transitioning off the bottle, supporting parents with these feeding challenges, and addressing cultural diversity and the challenges it brings. There was a fit between these issues, the literature and the challenges represented in this study, although one area, that of cultural influences, was not a key finding in this study except within the context of specific extended family traditions.

Auditability.

Auditability refers to the ability of another researcher to follow the thinking and methods of the researcher (Beck, 1993). Throughout the research process, I recorded the dates of all important events including, for example, mail-out of recruitment letters, interview dates, analysis meetings and decisions made. This proved invaluable in tracking the process and decision-making needed for rigorous research. Decisions regarding coding were recorded (Richards & Morse, 2007). Analytical documentation was recorded in my reflective journal and memoing and provided an audit trail of my thought processes and methodological decisions. My conscientious recording of field notes and minutes of meetings with my mentors (Yonge & Stewin, 1988) also contributed to a rigorous audit trail. Using a mentor (research supervisor) to review the process and critique the analysis helped to ensure auditability. The mentors helped to monitor the process by guiding the development of coding, documentation, memoing and thematic analysis (Rothe, 2000).

To summarize, in this chapter on research methodology and method, I have included a description of the constructivist grounded theory methodology. I have also described in detail the grounded theory methods of sampling, recruitment, data generation and analysis, and integrated this with a discussion on the rigor of the study.

CHAPTER FOUR

DESCRIPTION OF PARTICIPANTS AND FEEDING CHALLENGES

"It's not just picky eating"

In this chapter I describe the participant sample and the challenges that the mothers faced when feeding their children with ASD. The challenges include a description of the children's feeding challenges as well as challenges mothers faced in having the feeding concerns recognized.

Participants

The participants represented a diversity of ages, education level, employment status, marital status, and family structures. The 11 mothers of 12 children with ASD ranged in age from 28 to 47 years with two mothers in their 20s, five in their 30s and three in their 40s. The age of one mother was unknown. The mothers' education ranged from grade seven to grade 11, to college or university degrees. Six mothers had university degrees. There was less diversity in cultural background as ten of the mothers were Caucasian and one was African-Canadian. Seven mothers were currently homemakers and four mothers worked outside the home; two of these mothers worked part time, one worked full time, and one mother worked an average of 62 hours per week. Nine mothers were married, two were divorced and one of these was currently in a common-law relationship with a blended family. Two mothers had one child, six had two children, and two had three children. One had a blended family of four children who also had visits from her partner's two additional children. One mother had two children with ASD, three mothers had another child with a disability and two were caring for infants.

Three mothers had another child in the family who was a “picky” eater, one had a husband who had many specific food preferences, and one mother herself had some food sensitivities.

While specific data were not collected on family income, three mothers indicated that there were financial challenges in the family related to providing food for their child with ASD due to the need for expensive packaged food, the reliance on “fast food” or because of the amount of food provided and not consumed. Two other mothers indicated that they had considered putting their child on a special diet but it was prohibitive from a financial viewpoint. One family was receiving financial support from Family Supports for Children with Disabilities for special formula. Most of the mothers’ partners worked full time including one husband who was a full time post-doctoral student, one who worked full time at home, one who worked out of town on rotation and one who was home on injury compensation.

There was diversity among the children with ASD as well. They ranged in age from four years ten months to eleven years six months. There were 11 boys and one girl, including two brothers. There was one 4-year-old, three 5-year-olds, four 6-year-olds, two 7-year-olds, one 10-year-old and one 11-year-old. Since there was only one girl represented, all quotations will refer to the male gender in order to retain anonymity of the participants and their children.

The children spanned the autism spectrum with approximately half classified at time of diagnosis as having higher functioning autism and one with Asperger’s Disorder. The other children were either severely or moderately-to-severely affected in the areas of language, cognition and/or behaviour. The children had diverse feeding challenges. All of them were missing or had a reduced repertoire of foods in at least one food group, with many of them having a very restricted repertoire in two and even three food groups including proteins, fruits/vegetables and/or dairy products. One child was at risk for needing a feeding tube if he stopped eating his main preferred food.

One child with severe ASD symptoms had the least feeding problems within the group while another child with severe ASD symptoms had the most feeding challenges in the group. Two of the most highly functioning children were also severely anxious and both had significant feeding challenges.

Some of the mothers had considered or placed their children on special diets. Three children in the study were on a gluten-free, casein-free diet (GFCF). Two children had previously been on the GFCF diet. Two mothers had considered the diet but did not put their child on it for financial reasons. One mother specifically said she had considered the GFCF diet for her son but had decided she had to trust that the foods he was getting were healthy. Since special diets were not the focus of this study, I did not seek out mothers with children on special diets and this topic, although relevant in the ASD community, is not specifically addressed in this study.

Feeding Challenges

Onset of feeding challenges.

Three patterns of onset of the feeding problems emerged. The first pattern was children who had typical feeding during infancy and then developed feeding problems. The second pattern were children who had feeding problems starting from birth and the third pattern were children with some feeding challenges during infancy which were resolved early and then other feeding problems subsequently occurred.

Four children represented the first pattern of later onset of feeding concerns. They had typical feeding skills for some time and then developed feeding challenges. Anna's son displayed typical feeding progression from breast to cup and from purees to textures and solids. At 18 months to two years however he began refusing foods and his repertoire diminished significantly. Anna described this sequence. She indicated that the change in food repertoire occurred at the same time the autism symptoms started appearing. She described the regression in her son's eating:

> He's a dream baby. He's eating everything. …Then, … I can remember the day – it's imprinted, tattooed on my mind and he hadn't eaten his lasagna. He's always enjoyed it. … For some reason that day – I can even picture it – it's imprinted in my mind … when things started changing with his eating. He was a kid who ate everything. ... Then more food started dropping off his list.

Three other children within this pattern progressed well to the point of purees and pablums and then became selective as to the type of purees accepted and all refused lumpy textures like junior baby foods. This occurred for these three at around one year of age, followed again by a significantly reduced repertoire. For most of the four children the feeding challenges coincided with the first recognition of the ASD symptoms.

The second pattern was demonstrated by six children who had early and persistent feeding challenges from birth. They either had difficulty taking the breast or were continually demanding the breast. They were extremely selective in their feeding repertoire from early on and some had difficulty accepting different formulas. Some had poor sucking on the breast or bottle, or had low muscle tone, or were selective in acceptance of purees or had extreme reflux and/or gastrointestinal issues. They had difficulty transitioning to textured foods in particular. Most were then diagnosed with ASD at age two to three years. One had a query diagnosis of autism at age five and was later diagnosed with Asperger's at age eight.

The third pattern of onset of feeding challenges was evident for two children who started out with challenges similar to group two but the early feeding issues resolved until 18 months to two years when they then started refusing previously accepted foods, resulting in a significantly reduced repertoire similar to group one. Hannah described her experience with her son:

> Breastfeeding was horrible, wouldn't work. He didn't suck very well. … So we put him on formula. … We went around the block on the formulas. His first five months of life were pretty stressful with gas, with rashes. … At five months, he started eating rice cereal, and he never looked back … and he was that kind of eater until he was two years old. … He'd eat avocados, tofu, all kinds of vegetables, grapefruit, sausage, chicken, and turkey, all of it. Then he started to really narrow down the choices … and between two and three he really narrowed and slowed down the eating to where, one day, you wake up, he's three years old, and you realize he's only eating five different kinds of food.

All children from all three patterns of onset therefore had a very significantly reduced repertoire of foods (many less than six foods) by the ages of two to three years. The feeding issues did not lead the parents to investigate for ASD, but one mother reflected that when she looked back challenges with feeding was the only developmental issue that was present many months before he "lost all his verbal skills" (the mother's words) resulting in the communication impairments associated with a diagnosis of ASD. The following section outlines the types of feeding challenges experienced by the children.

Sensory challenges.

Many of the mothers described what they referred to as sensory challenges for the child which directly affected their child's ability to tolerate food. Many of the children gagged at the sight of another person eating or at being presented with a certain food. Bethany explained:

> He doesn't want to see those [mushy] foods. What he sees in his eyes in those foods I just don't understand. He feels like throwing up; like he finds [the foods] yucky. I don't know what does his vision show him, what he really see in this [food], which I don't really understand, and I wish I knew more in his mind what he sees in there. But you can see he wants it, but there's something that's not letting him have it.

Kim also described her puzzlement in attempting to understand her son's eating behaviour. She stated "I honestly don't know what it is that helps him determine what is edible and what isn't. He gives things a good second look … and then decides what goes in and what doesn't go in."

Mothers also described situations where there was a clear sensory aversion to the foods. "He'll gag and almost get physically sick just watching us eat something like spaghetti and meat sauce" (Kim). Ivy said her son "dry heaves when he looks at pasta." Gail said her son "vomits at the sight of his sibling's oatmeal." Cathy described her son's extreme sensitivity to smell and taste. She indicated she was not able to cook meat when Curtis was at home, so she needed to cook her meals and put them in the freezer to re-heat at mealtime. Mothers also gave examples of aversion to certain textures of foods. Mothers described sensory challenges particularly relating to the sight, smell and texture of foods, and sensitivities to changes in taste.

Rigidities, rituals, and need for sameness.

Some children's feeding challenges were more affected by the ASD characteristics of need for sameness and lack of flexibility. Some children required certain brands of foods and could tell if a company changed the recipe. Others decided that certain foods belonged in certain environments. Not only did the children only accept certain foods, the mothers said from experience that there was a risk of losing foods if the preferred foods were altered in some way. For example, Bethany risked losing Pediasure if it was presented in a sippy cup rather than the preferred bottle. Bobby would take water and juice from a sports water bottle but not the Pediasure. Cathy described her son as accepting macaroni and cheese and eating wieners, however if the two were mixed he would not eat them. Hannah described her son as accepting fresh mango until he ate dried mango. Then he would only eat the dried mango but rejected the fresh mango.

There were many examples of the child refusing non-preferred foods or food with a different presentation. Jessica's son stopped accepting Pediasure when he no longer had the bottle, even though she said she had "bought every different kind of cup from Wal-Mart." As an infant, Fiona's son stopped eating for a day and a half when presented with new pureed meats and it was difficult to get him back to his preferred purees. Cathy's son went on a two-day "hunger strike" when the bottle was taken away at age twelve months. Kim's son never returned to drinking milk after he had a period of not receiving milk when on a GFCF diet.

Bethany’s son lost weight when he stopped eating at daycare at the age of 18 months, when he was expected to follow the daycare routine and his cues for eating were not followed. He was also hospitalized at age two with what the doctors termed a “hunger strike.” Anna had a period of time that her son’s tantrums were so severe that she could not put a non-preferred food anywhere near his plate. Kim’s son refused to eat grilled cheese sandwiches after she hid egg or ham in his sandwiches.

Some children made strong associations with different foods which were difficult to change. Curtis happened to eat carrots for the first time the day he had the stomach flu. He did not eat carrots again as his mother said he associated carrots with being physically sick.

Children would sometimes eat in other environments and not at home, or would only eat certain foods in certain environments, and have certain rituals around eating. Bobby would often eat in a clinic setting but not at home. Henry would eat to please others yet not generalize this eating to his home environment. Jessica’s son ate his toast in a certain way and then ritualistically lined the crusts up around his plate in a specific pattern.

Feeding-related behaviours.

Some children had feeding challenges that would typically be classified as problem behaviours. These included having difficulty sitting at the table to eat, throwing food, grazing and not having a feeding routine, and taking food from others’ plates. Further analysis of these behaviours revealed some of the reasons behind the behaviours. The children who threw foods were often those with severe food aversions and even if they were verbal were not able to express their need to avoid the food especially in their overwhelmed state. Some children were quite active and this affected their ability to sit at the table for any activity, including eating at mealtime. Others, according to their mothers, were not supported enough physically at the table so did not sit to eat until they received more supportive seating. For both children who were not on a feeding routine, the mothers were working with them using language to request food, thus the goal of language superseded the goal of having a mealtime routine. These explanations for the behaviours suggested that it was important to look beyond a specific behaviour to see what was leading to it as the strategies for addressing the behaviours would change depending on the cause.

Impact of feeding in different environments.

The feeding challenges significantly affected home life and family mealtimes. Ivy described every mealtime as a battle, and Daphne emphasized the stressfulness of mealtime. Family mealtimes were further complicated when more than one child in the family had some degree of picky eating. Gail explained the impact of this on her:

> It would be nice to be able to make one supper, put it on the table and there you'll go. But [my younger son] won't eat if it's something that he doesn't like. [My younger daughter] won't eat if it's something she doesn't like and if it's something [Graham] doesn't like, he won't even come to the table.

Feeding challenges had an impact beyond the home environment. The children had different degrees of difficulty eating at school. All had preferred foods sent from home. Gail sometimes had to pack up her children at 7:00 am to take them to the store as her son had eaten all of his preferred foods in the night and she needed something for his lunch before the school bus came to ensure he would eat something that day at school. It was not unusual for the children to have only one to three foods that they would consistently eat at school. Sometimes the eating environment had to be changed as the child could not tolerate sitting beside another child who was eating a certain food. Children were also challenged at school when the food was not prepared the same way as at home and they were unable to explain the problem. At preschool the snack was often provided by the school and typically the child did not eat it. In the school situation mothers were often at a loss as to what to send to school for lunches. Some highly preferred foods such as peanut butter were not allowed in the school environment. Often there was no access to a microwave to heat a meal. Bethany summarized her anxiety of having her son eat at school and her relief when he did eat at school:

> At home … I take all my time – even I'll stop what I am doing – to make sure he eats something. … But in school they won't have the time I have for him. … So whenever he comes home I always open that [lunch] bag and see what he ate and what he did not eat, and now I'm so happy, when I open that bag most of the [foods] are gone.

Eating at extended family gatherings presented a whole other set of challenges for the mothers of these children. Not only were the children with ASD often overwhelmed by the number of people at family gatherings, the noise level, changes from the home environment, and array of foods and smells, but there were also extended family expectations. Mothers described the dilemmas of having to make the choice of meeting their children's needs or meeting the expectations of the relatives. Some chose not to go to family gatherings; others were able to make the experience easier by feeding the child before or after the gathering and others devised creative solutions such as arranging brunch with the relatives as their child loved “breakfast foods.” Mothers also described not attending social events and family gatherings with colleagues due to food and other ASD related issues.

Food jags.

The feeding challenges the mothers in this study experienced relating to their children were further complicated by inconsistencies and food jags. A food jag is when a food is accepted well for a time, sometimes to the exclusion of other foods, and then suddenly the child will no longer accept the food. Kim described food jags with her son where he happily ate yogurt and then suddenly, with no plausible explanation, stopped eating it. Gail remarked that she “doesn’t know how he can live on so little food. There’s jags where he doesn’t want anything but jam sandwiches, that’s it.” Gail also described the inconsistencies since “just because he ate it Tuesday doesn’t mean he’ll eat it Wednesday or Thursday.” Part of the challenge for mothers was to sort out what was a typical picky behaviour of a two year old, for example, and what was atypical and something to address.

Co-morbidities and feeding challenges.

Several children had co-morbidities that did not exclude them from the study, but further complicated the feeding challenges associated with ASD. Four children had early and significant reflux and for one of these the reflux persisted beyond infancy. Bethany’s son had undiagnosed reflux for at least three years, which accounted for some of his feeding challenges. From my clinical experience

I also judged that many of his feeding challenges were not only related to his reflux. Other co-morbidities affecting eating included generalized anxieties, food sensitivities, lactose intolerance, and gut issues such as pain, diarrhea, and constipation. Some children also had oral motor problems, chewing difficulties, hoarding of food and mouth-stuffing. Others appeared to have significant challenges with appetite and actually feeling and responding to hunger cues. All of these represented issues that needed to be considered for further investigation for these children with ASD who presented with feeding challenges, but were often not addressed in a timely manner.

Challenges beyond picky eating.

The most significant challenge faced by mothers of all the children was their significantly reduced repertoire of food and their difficulty in accepting new foods. They all had specific preferred foods and would refuse non-preferred foods. These restrictions had potential for causing nutritional challenges as the children could have low iron, or low calcium intake or deficiencies in vitamins or minerals, or insufficient calories or various other nutritionally related difficulties. Four of the mothers described significant weight challenges in their children. All four were underweight at certain times according to their mothers' viewpoint.

Whether the child started refusing foods or had feeding problems from the beginning the mothers described a tumultuous and confusing process of trying to feed their children who were displaying severe reactions to foods. Mothers described a very difficult phase around the age of two to three years where they were trying to get nutrition into their child and sort out what was a developmentally typical picky eating behaviour and what was a more significant feeding issue. Fiona said “I just wanted to be able to buy [baby food] and feed it to him and that didn’t work.” During this phase mothers described trying to get food into their child in some way, often catering to the child’s preferences. When her son was two to three years old, Anna was unable to even present non-preferred foods to her son.

> If you ever saw those meltdowns you wouldn’t want to offer [non-preferred] food either. … It’s not worth it to make mealtime like that. … It was just a flat line for a while there, where he just ate preferred food; it was just the same thing every day; we went about what worked for mealtimes.

Many of the children were down to three, four or five foods that they would accept at age three to four years.

Three mothers had other children without ASD who were also picky eaters which gave an interesting insight into what they perceived as a difference between a typical picky eater and a child with ASD. “This isn’t terrible twos being picky ‘I’m not going to eat my macaroni and cheese today’. This is like ‘I’m never going to eat this again because it’s hurting me in some way’” (Anna). Kim further explained the concept of picky eating in relation to ASD.

> Just remember that it’s not a picky eating thing; it’s not even a really picky eating thing, it’s a different thing; it’s a whole different thing and you have to wrap your head around that. … Kenny is not just a picky eater. It’s not the same as our daughter, it’s a different situation. … You can tell on that day, at that time, eating that [food] is not possible – it’s not physically possible for him. It’s like he would rather go hungry, he would rather be miserably hungry than eat that. [Picky eating for Kenny] is not a choice, it’s ‘I cannot eat that right now’. So to me that’s the difference. She can eat it, but she chooses not to, … but for Kenny … he physically is unable to eat something and mentally he can’t. … To him eating that [food]…is like the most revolting thing being offered to you or I where we simply can’t let our mind or our body accept it. … What if it’s just mentally,

> emotionally, sensory-wise just impossible for him to cross that threshold today? So I think you have to remember it's not a choice they're making.

Mothers formulated different explanations and analogies to explain their children's extreme reactions to food. A common way of explaining the issues was for the mothers to make an analogy to eating something revolting. Kim said that when she asked her son to eat something "what if it's like saying 'Drink this cow's blood'." Gail said that saying that children with ASD will eat when they are hungry is like "handing somebody a bowl of dandelions and saying, 'well if you're hungry you'll eat that'. … Oatmeal is his dandelions, Hamburger Helper is his ants. It's disgusting to him. That's not his fault." Cathy described that "as far as he is concerned at that moment [food] is a rotten rat. His perspective is his reality." Anna said it must be a sensory issue since "the food was not eels, it just was spaghetti and sauce." All of the mothers had an ability to see beyond the specific feeding behaviours to try to figure out what was going on for their child with ASD. They were convinced that their children were not to blame for their feeding challenges, that it was not "just a behavioural issue."

The Challenge of Getting Feeding Concerns Recognized

Some mothers sought support but had difficulty getting their child's related medical problems addressed because the child had a diagnosis of ASD. Bethany reported that even though she believed there was something wrong with her son's throat, and had sought help to resolve his pain for three years, his symptoms were viewed and perhaps even dismissed by medical professionals as behaviour problems due to autism. Bethany wept as she described their ordeal in finally getting the diagnosis of gastro esophageal reflux:

> Bobby would cry night and day, and he would not talk to me, so I would not know what's the problem. I know he has pain, but when the doctors tell you there's nothing wrong with him, what do you think, you're wondering what's happening. … He used to cry a lot, and nobody knew what was the problem. Finally when we came here I really put my foot down and told the doctor to see Bobby as Bobby, not as autism. … I told the doctor "Don't look at his autism; look at him as not autistic and then look at what's the problem … it is a throat problem … and they gave him the scope and then they found the reflux on his throat. It was just like it burned him really bad. It took three years to be diagnosed. … And he really really suffered a lot. He really really suffered. … And then when they found out that Bobby's throat was so bad I really cried that day, because I thought it was not fair for Bobby to go through that.

In a similar scenario, Daphne sought medical help for her son's "gut" issues and felt dismissed. She perceived that the autism diagnosis resulted in her son not being treated as a child with a physical illness. Leah reported having to deal with her son's severe constipation on her own. Jessica and her husband suspected that Jamie had autism and had him on a GFCF diet at around age two, just before his diagnosis. At that time they had considerable difficulty getting their concerns acknowledged. Jessica reported her anxiety and distress at this episode:

> I had taken him to doctors and I'd been, like, "Look at him. He looks terrible." He was losing weight, and [their response was] "Oh, no." I was, "He doesn't eat"; same thing: "Oh, well, my kids didn't eat, either." "No, no, no. When I say he doesn't eat, I mean he drinks milk out of his bottle all day; that's it. He doesn't eat." "Oh, they'll eat when they're hungry"—you know, all those things that you hear. And I was just sick, because I was, "*Look* at my child. He is basically dying in front of my eyes."

When a doctor at the Children's Hospital finally responded to her concerns, it became an urgent matter:

> [He saw] a doctor … [and he] put him on Pediasure. They said, "You have 2 weeks. Be back here in 2 weeks. If he has not gained weight, we will admit him. They will put a tube in," and they were really worried for him. … 'cause his hair was brittle; he was malnourished, completely. They classified him as "failure to thrive." … It was very scary. (Jessica)

When Gail sought support to address her son’s feeding issues, professionals told her that her son, who had already been diagnosed with ASD, would eat when he was hungry. Based on knowledge of her son, she believed that this was not the case.

Often when mothers sought support from health care professionals, their concerns were ignored and they were left on their own to figure out their children’s feeding. Cathy described what this was like for her.

> I was basically told to deal with it. And then told his nutrition will be, like, crap, and this and that and the next thing. Thanks for giving me the doom and the gloom of it. I had to finally tell the doctor to be quiet.

While some families were supported through specialized feeding clinics, others indicated that their child did not qualify for clinic support. This reflected some regional disparity. Table 1 summarizes the feeding challenges discussed in this chapter.

Table 1*: Feeding Challenges*

Onset of feeding challenges
Sensory challenges
Rigidities, rituals and need for sameness
Feeding related behaviours
Impact of feeding in different environments
Food jags
Co-morbidity and feeding challenges
Challenges beyond picky eating
The challenge of getting feeding concerns recognized

In summary, in this chapter I have described the sample of mothers who participated in this study and have presented not only the challenges faced by the mothers in striving to feed their children with ASD, but also the extraordinary challenge of being believed about the feeding challenges their children were facing. In the next chapter I describe the feeding approaches and strategies used by the mothers and the beliefs that guided these choices, in relation to a core process of “Achieving a Tenuous Balance.”

CHAPTER FIVE

ACHIEVING A TENUOUS BALANCE

“I was so proud of myself because I had done it. And then he stopped drinking”

Given the feeding challenges presented by their children with ASD mothers developed various feeding approaches and strategies over time. Decisions to use these different approaches and strategies were guided by and integrated within the mothers’ beliefs. In addressing their children’s feeding needs, mothers used these approaches and strategies as they continually strove to achieve change in their children’s feeding. A process emerged whereby they achieved a state of “tenuous balance” as circumstances changed in their child's and family’s lives. This process is cyclical as there was continuous change over time in terms of feeding challenges being resolved only to have new feeding challenges arise such as needing to eat in different settings or the child refusing a previously accepted food. This chapter addresses the approaches and strategies that the mothers used and the beliefs that drove their actions in meeting the persistent feeding needs of their children with ASD. Table 2 and Table 3 provide a list of the approaches and strategies used by the mothers, which I discuss in further detail.

Table 2: *Approaches used by Mothers*

Using a deliberate feeding approach
Initially ensuring adequate intake
Moving beyond intake
Proceeding gradually
Selecting the amount of structure to use
Negotiating co-parenting approaches

Table 3: *Strategies used by Mothers*

Tailoring the feeding strategies
Using visual supports
Modeling appropriate feeding behaviours
Managing sensory experiences
Implementing “social stories”
Using verbal strategies
Integrating choice-making strategies
Considering oral motor challenges
Determining typical ‘picky eating’ strategies do not work

Approaches Used by Mothers

Using a Deliberate Feeding Approach

All of the mothers described a deliberate process of working towards feeding approaches that would meet the feeding needs of their children. Approaches, in contrast to strategies, refer to an overall way of addressing the feeding challenges. Mothers initial feeding efforts when their children were under three years of age focused on finding ways of providing adequate food intake. They then strove to improve nutrition through an overall gradual step-by-step approach, as they had learned that abrupt changes and/or pushing their child did not work. While all approached change in feeding gradually, there was variation in the approaches related to the amount of structure they used. Some mothers adopted a systematic structured approach to feeding while others opted to provide more general feeding experiences and less structure. All mothers negotiated co-parenting approaches with their partners.

All of the mothers, whether they stated it or not, were intentional and purposeful in attempting to change their child’s feeding habits, repertoire and abilities over time. They made statements such as “don’t give up” (Anna), or “never stop trying to introduce new foods” (Gail), or “to get variety you have to offer variety” (Cathy). Daphne and her husband were determined to take control of feeding because it was something in their family’s life with ASD they felt they had the ability to control.

Initially Ensuring Adequate Intake

When feeding their infants and toddlers mothers were faced with significant feeding challenges. Depending on whether the child had feeding problems from birth or gradually reduced their food repertoire between 12 and 24 months, the initial months and first two or three years were typically devoted to figuring out their child’s issues and finding things that would work for feeding to ensure adequate intake. Anna described her son as having such severe tantrums when he was between two and three years old that she could only give highly preferred foods even though his repertoire continued to diminish. Fiona also described a phase of needing to totally avoid non-preferred foods of purees and textures and moving directly to finger foods and preferred textures. Ivy indicated that in the early toddler and early preschool years she did a lot of “short-order cooking” for her son, which she was able to move away from as he got older. Kim reported many unsuccessful approaches that included force-feeding, gimmicks, power struggles (with no winner), letting her son go hungry and waiting out her son.

This early stage was characterized by significant stress for both parties and the emphasis was on finding a way to feed the child without causing further distress. This was not a time for increasing repertoire or worrying about a balanced diet but instead was focused on finding and keeping foods the child would eat. The length of this phase varied from child to child and typically lasted until the child was at least three years old. By that time mothers usually had a good sense of what might or might not work as they proceeded to address their child’s ongoing feeding challenges.

Moving Beyond Intake

Following the initial phase, when most of the children were at least age three, all mothers moved into the phase of finding ways to expand the children’s food repertoires to increase the child’s nutrition. In contrast to the initial strategies related to intake, mothers placed an emphasis on working towards adequate nutrition for their children with ASD. Some families specifically followed recommendations from a dietitian while others educated themselves as to the importance of a nutritional diet in ASD. One mother who was a dietitian educated herself beyond what she had learned through formal education and what was needed for her professional practice. Another mother, Daphne, articulated her belief in the need for good nutrition for her son:

> We’re insanely healthy around our place; there are no cookies and cakes; it’s fruit. All the dietary stuff we’ve implemented has made huge changes [in our son].

Mothers had many creative ways of adapting meals that their children would eat to both increase nutrition and increase palatability specific to the child’s needs. Leah had a “gluten free, casein free” (GFCF) recipe for pancakes, to which she added nutritious ingredients such as pea flour. Kim described her unique recipe for waffles:

> I make him waffles … full of stuff. ... I use pureed baby foods, so I always put a jar of meat, so either chicken or beef—usually beef—and then two jars, or the equivalent of two jars of vegetables in his waffle mix, and then, of course, they’re made with eggs, and then I usually put in some soy milk; so I put a whole bunch of stuff in his waffles. So almost every morning, he has a waffle or a pancake for breakfast, so in that way, I get some iron and some veggies into him.

Aided by resources such as Deceptively Delicious (Seinfeld) and The Sneaky Chef (Lapine), which are resources readily available to the general public, many of the mothers reported that they conscientiously loaded accepted foods with hidden nutrients. There were two important features of this approach: the mothers did not stop presenting foods in their pure form as they continued to attempt to increase their child’s food repertoire and they had to be inconspicuously deceptive to make this approach work. Any noticeable difference detected by the child resulted in non-acceptance of the modified previously accepted food. Kim reported that she had attempted to trick her son by adding egg to his grilled-cheese sandwiches, only to have him lose ground with his feeding because she lost his trust. Cathy explained what changing the food was like for her son:

> He won’t eat generic macaroni. I accidentally bought whole wheat mac and cheese; before it was even out of the pot, “That’s gross. I don’t want it.” “But you like mac and cheese.” “No, that’s gross. I don’t want it.”… He never saw the box, he never saw me make it, nothing. *I* knew it was different ‘cause I read and went, “Uh-oh, maybe,” and sure enough, yeah, before he even went anywhere near it, he knew the difference. … He hadn’t seen the mac and cheese in the pot, even. And it doesn’t look any different—the whole wheat stuff, it looks like normal mac and—once you put cheese on it, it all looks like mac and cheese.

Three children required supplementation through specific meal replacement formulas, but only two accepted them. One child relied on the formula for most of his nutrition, resulting in less urgency for his mother to try to increase his food repertoire. For the child who required the supplementation but would not accept it, there was increased worry if he should reduce his repertoire of his limited accepted foods as he was at risk for needing a feeding tube. The decision to put the children on the GFCF diet in many ways made increasing food repertoire more difficult, as all three children who were on the GFCF diet at the time of the study liked foods that were not permitted on the special diet.

Even though many of the mothers were able to ensure adequate nutrition through much hard work, most of them actively engaged in changing and working on other aspects of the feeding process such as sitting at the table to eat. Many stated that they were guided by their desire to follow their child's lead and they all used a gradual approach to implement individualized feeding strategies. My memo after interview ten reflected my thinking about mothers' following their child's lead:

> Following the child's lead is not the same as letting them run the show. If the mothers let them only and always eat the same food, change does not happen. If they force them, no progress is made and feeding can get worse. If left on their own the children seem to stay rigid and even lose foods. So although the approach is to follow the child's lead there is still a deliberate attempt on the mother's part to increase repertoire. This is indeed a dance. The dance seems to be dependent on reading the child's cues. These mothers know when they can push their child and when to back off. They know a good day from a bad day. They can't leave them to improve on their own. Is this contrary to the Satter approach used for typical children who are picky eaters?

Proceeding Gradually

The mothers illustrated in many ways the challenges of increasing their child’s feeding repertoire and the need to do this gradually. They typically described the process as a “marathon and not a sprint” (Ivy). This gradual approach was characterized by initially meeting their child at his level and then gradually increasing the exposure to types and amounts of new foods or the expectations around feeding behaviours. Anna would give Andrew a small amount of a new food, and then more as he tolerated it. This gradual process often involved carefully analyzing the food for its properties and then building from there. Anna chose foods similar in taste and texture to accepted foods. This approach was similar to one used by Cathy who indicated that sometimes it worked and sometimes it didn’t:

> My kid eats pepperoni on pizza. My kid eats cheese buns. I found a little pastry thing with a piece of pepperoni in the middle at Save-On Foods; I put it down, he went *[imitates gagging]* and pushed it away. That theoretically had all the qualities; realistically, no. Okay, there goes a buck 29 out the door; bye! But it theoretically should have worked.

At other times she was successful, for example in generalizing a food from one environment to another:

> [In the restaurant] I said, “Oh, that’s cantaloupe you’re eating. Is that good cantaloupe?” “Mm, cantaloupe.” So I went shopping, I got a cantaloupe. I didn’t hand it to him in any other format other than in the little shape that it was at the restaurant. I made sure that it looked exactly the same. Now that he’s had it a few times, I bought a melon baller and I bought a honeydew, and now I can ball it and put it on a kabob and hand it to him. But it had to be brought in the same way it was at the restaurant, and then it was fine. (Cathy)

Out of necessity, many of the mothers used a detailed, systematic, step-by-step approach to food exposure to gain acceptance of the food. Leah described having to go through a process of putting a picture of a food at the table, then passing the food in a bowl, then accepting it on the plate, then gradually working up to touch, smell, and taste. In order to reduce anxiety, Daphne achieved success by using a fun approach to food exposure through having her son play with food. Hannah involved her son in making food crafts with his home aide outside of the typical eating environment in another part of the house.

Even in describing their children's progress, the mothers repeatedly emphasized the necessity of using a gradual process. Hannah stated that she needed to use distraction of the computer and later the TV to be able to feed her son when he was younger. She was then gradually able to move him to the table to eat. Cathy talked about gently nudging and moving Curtis forward in a non-forceful way. Jessica specifically said that she gauged the progress not necessarily by the change in repertoire but in the volume of food and knowledge that Jamie was not hungry anymore. In addition to logging progress with food repertoire, Daphne also recorded behavioural and educational changes that came with the changes in dietary repertoire.

Selecting the Amount of Structure to Use

Some of the parents had a defined structure for their feeding and mealtime routines and clearly outlined goals and expectations. These included expectations around mealtime behaviours, sequence of foods eaten, and/or number of mouthfuls to be taken. The approach still considered where the child was at in terms of skills and proceeded in a gradual fashion. Several mothers used a strategy of increasing the number of bites of a non-preferred food. In Leah's family both children were required to have at least one bite of a new food. Daphne’s children were required to eat the main meal, then the vegetable before the preferred fruit. Leah had the expectation of tasting new foods:

> It would be “Here’s what we’re having for supper, and you need to taste some things. Spit it out if you like, but you need to at least put it in your mouth.”

Ivy had even more structure to her requirements:

> Our family rule is they at least have to try everything. And for most things, they eat their age, so [younger female sibling] is 4, so she has to have four bites; Ivan’s 10, so he has to at least try ten bites.

From the descriptions the mothers gave of their children’s eating, it was apparent that strategies that were successful for one child would not necessarily work for another. This was the case even with siblings, both of whom had ASD but each requiring an individualized approach.

Some of the mothers said that their children did not like structure. Therefore they employed an approach that, although still deliberate, involved provision of more opportunities for food exploration and exposure, but not structured expectations around, for example, the number of bites required. Strategies included exposing their children to new foods, following their lead with requesting food, and taking advantage of opportunities to present new foods as they came along. Hannah gave an example of this approach:

> He hasn’t spent a lot of time in a grocery store. Yesterday, I had to go and get four things. … I was by myself [with him and his brother], and I thought, “Well, we’ll just go get these four things and get out.” Well, it turned into this wonderful shopping experience that you wouldn’t believe. It was really *[laughs]* fantastic! ... He was really interested in the food on the shelves. ... Then I just kind of threw it out—I said, “While we’re here, why don’t you look and see if there’s some things you’d like to try? Maybe there’s some things—you’re kind of getting tired of some of the

> same old things; why don’t we see if there’s something”—. Well, we ended up doing this aisle by aisle at Superstore, which I can’t even believe I’m saying this; like, it’s shocking. Aisle by aisle, and he was *amazing*! … He’s picking things out. And almost everything he said, “Can we try this?” and I said, “Yes, sure.” It ended up with $200 later.

The mother who was a dietitian stated that early on she had purposefully used a pure non-directive approach following her understanding of the Satter (1987) approach to feeding to address her son’s feeding challenges, believing that this was the best approach to address her son’s picky eating. She described the Satter approach as the “gold standard” used by dietitians for picky eaters. For 18 months, from the ages of three to five she did not direct or even encourage her child to try new foods, but let him eat whatever he chose. Following this approach meant that bread and milk were always on the table and available, in addition to the family meal. For 18 months her son only ate bread, milk and dessert. As a dietitian she had had success with this approach in her clinical practice with picky eaters, in that children with other diagnoses gradually increased their repertoire on their own. For her son with ASD, this approach resulted in a significantly reduced food repertoire and poor nutrition. She and her husband thereafter changed their approach and obtained increased success through adding structure and expectations to try new foods. She and her husband had a collaborative approach to addressing their child’s feeding challenges as did a number of mothers in the study.

Negotiating Co-parenting Approaches

Three distinct co-parenting approaches emerged from the data analysis. The first approach was described by mothers who defined themselves as the one most involved in all aspects of the feeding process from deciding the approach to use, to determining the menu and presenting the food to the child. There were three mothers in this group, including the single mother whose ex-husband not only followed but relied on the mother’s feeding guidelines for their son. One of the reasons for this style of parenting seemed to be related to beliefs in more traditional parenting roles. In addition the fathers appeared to rely on the mothers to know what to do with the child. It could have also related to practical reasons, as the mothers were more available or had more time with the child to carry out these tasks.

The second approach involved parents sharing the responsibilities in food preparation and in presenting the food. In this co-parenting approach both followed through on the mutually agreed-upon feeding approach. Most of the time the mother was still the one who planned the menus, but their partners assisted in all other aspects of feeding including food preparation. They described mutual problem-solving and used similar approaches to dealing with the children’s needs. Five families fell into this group. One of these mothers, who had a blended family, disclosed that although she and her partner routinely shared most aspects of feeding, they had agreed that the biological parent would be responsible for specific decisions concerning their biological children where needed. This mother described that this was in part due to her having a better knowledge of her son with special needs than did her fiancée, and in part due to the newness of the relationship.

The third approach involved the parents having different, almost opposite, styles in dealing with the child's feeding issues. Two families clearly fell into this group. After much discussion and debate, these parents recognized the value of their disparate approaches, as they each had success with their own methods. Sometimes, as with Ivy, this took the form of a tag-team approach.

> So my husband just sat with him, and I'm … contradicting him, saying, "He can't do, he can't do"—he said, "He *can* do it. You just need to leave the room." So I stepped back, because I knew—and he said, "I respect you when you use all your strategies. I use them at breakfast, but this time," he's, like, "you need to let me—you need to respect and let me try mine as well." So I had to step back. ... He's appreciated and respected my approach, I've learned to appreciate and respect his, and somehow *[laughs]* call it good cop, bad cop if you will *[laughs]*, but somehow, the approach has worked for our kids. So the balance of those two things has enabled us both to accomplish things that maybe neither of us thought possible with our kids.

This approach appeared to be based on a value of mutual respect, and essentially agreeing to disagree.

This leaves one set of parents, who actually had a blend of all three co-parenting approaches, likely because the father worked shifts out of town. While the mother was largely responsible for the child's diet, they co-parented mostly using the same approach when the father was home. The father was also able to present food in a different way than his wife did at times, similar to the fathers in group three. Deciding on the co-parenting approach to use was only one of the many approaches and strategies that were used and tailored to the child's needs.

Strategies Mothers Used

As all children did not have all of the feeding challenges, not all of the strategies were needed for each child. Strategies refer to the specific interventions used at a particular time, usually based on the child’s needs. The strategies needed to be tailored to each child’s individual challenges. Also none of the strategies or approaches were used in isolation. Combined strategies were all geared specifically to the child’s needs and challenges and often targeted what was happening on a particular day.

Tailoring the Feeding Strategies

For mothers of children with ASD there was a continuous period of learning and adjusting to their child’s ever-changing feeding capabilities and needs. Mothers of typically developing children are involved in a dance with their children, where each reads the other’s cues and they arrive at a place of balance as the mother and child get to know each other around the feeding process. For mothers of children with ASD this problem-solving stage lasted longer, and the mothers needed to continually work hard to seek to understand their children to make the feeding process work. These mothers knew their children’s needs precisely and in-depth. They felt, as the mothers, that they were the ones who understood their child best, more so than the fathers and other members of the family. This involved continuous problem-solving and detective work on the part of the mothers to try to make some sense of what would work for their child. These mothers needed to gain in-depth knowledge of their child’s likes and dislikes and responses/reactions to food to ensure the feeding strategies and approaches worked. Hannah figured out which days to try new foods:

> I also found he definitely has eating days and non-eating days, and you kind of have to be a little instinctive about that. And on a non-eating day, I wouldn’t push anything; I only give him what I know he liked. Because what I found was if I picked a non-eating day to try something new or to

> even try a newish food or anything different, there was a bigger reaction to it, and it became more ingrained in his head that he didn't like it. So it was more of a—I don't know how to explain it—there was just more reaction to it—"No, I don't want that!"—and then he *really* got stuck on the "No, I don't," even if he'd had it once before—and then he'd get stuck there. But if it was more of an eating day where he was hungry and eating, then if I tried a food he'd had once before, then there was less of a reaction; he maybe would try it or wouldn't try it, but there wouldn't be the big fanfare, so it wouldn't get as stuck—not so ingrained in his head.

Knowing her child well, Jessica could tell if her son showed an interest in a food. She would then make sure that she had the food available at the next meal and then consistently present the new food, knowing that if she did not take advantage of this hint of emerging interest with constant exposure she would need to start all over with that food.

The mothers realized that they would have the best chance of success if their children were hungry, so they learned to determine if their child was hungry based on his or her behaviour in order to orchestrate meal and snack times with the child's hunger. This strategy was individualized based on the mother's knowledge of their child. Cathy would offer food earlier in the hunger cycle knowing that negative behaviour could result if Curtis was over hungry. Jessica wanted to work on Jamie's language skills, so would wait for him to request food even when she knew he was hungry. He was able to tolerate this and therefore his mother could integrate his language goal of requesting food as part of the feeding process. Ivy knew that her son would not ask for food and therefore she needed to determine meal and snack times.

Foods were offered based on the mothers' knowledge of their child's preferences, tolerances, sensitivities and nutritional requirements. Daphne modified recipes based on how the food would look and taste as it needed to be the right color, temperature and flavour in order to be accepted. Mothers described that they chose their battles, with, for example, consumption of food being more important for Jessica than where it was consumed. Ivy would shred cheese since she knew her son would not eat the cheese if it was cubed. Timing of food presentation was based on consideration of other factors in the child's day. Based on the child's strengths, abilities and challenges, mothers used an array of specific strategies.

Using Visual Supports

Visual strategies were a strong adjunct to food presentation for many children and were very successful. These strategies ranged from having actual photographs to Boardmaker (Mayer-Johnson, 2000) program pictures, to visual schedules, puppets, poems with pictures and use of printed words. Visual schedules outlined the meal and snack routine for the day, the order of food presentation (first, next, last) and expectations for the child (touch, lick, bite). A schedule including content of meals and snacks was placed on the fridge by some mothers to add predictability. For the children who could read and who benefited from use of word cards, this added another way of directing the children and giving them more information. Printing on dry-erase boards at the table aided both in providing distraction and in clarifying expectations. Food play was used with the context of animal story books and puppets and other characters were helpful in demonstrating and adding fun to food presentation. Visual charts defined mealtime behaviour such as sitting on the chair and taking dishes to the sink.

Visuals were also used to define the number of bites needed and the food choices that were available that meal. Made-up poems and rhymes with pictures were a helpful adjunct to assist in defining expectations.

Modeling Appropriate Feeding Behaviours

Mothers used modeling as a successful strategy by demonstrating themselves the appropriate sitting at the table, enjoyment of food, and specific desired behaviours. Other models also helped. Bethany reported that Bobby was more likely to accept a food with a group of his peers who were enjoying a food. Bethany believed he would also have a better chance of trying a new food if another child encouraged him to try it. Fiona described her son requesting a food because his favorite friend ate it at school. The oldest child in the study was more likely to request foods that his peers were eating and his mother stated that this occurred more as the child got older.

Managing Sensory Experiences

Various sensory modifications to the food or the environment were naturally done by the mothers even before they recognized or labeled the problem as a sensory challenge. Cathy gave her son a fork to stab the food that he did not want to touch and Gail gave her son a toothpick for corn kernels. Gail also found that her son would eat better when she dimmed the lights and reduced the sounds at mealtimes. Kim did not require that her son sit at the table to watch his parents eat food that was not tolerable to him, but had him sit with his little sister while she had different foods on her plate than he had. Bethany recognized that Bobby could not handle the texture of cantaloupe but thought he would enjoy the taste so she pureed the cantaloupe and he enjoyed drinking it.

Anna achieved success if she could make a new food as similar in sensory properties to another food that Andrew already ate. She could use this strategy to a point:

> If I can find something that’s similar in looks and texture and consistency to something that he’s already eating, then it’s a lot easier. So like hot dogs, right, sausage is the next—he’ll eat sausage now because it looks similar. … And then try and get him to eat something that’s the same shape as a sausage. I did try that a couple of times, but then I thought, “No, I’m not going to overdo it.” *[chuckles]* … Like, spending that extra time to make something into a sausage shape, … and he just kind of picked at it, he didn’t actually eat it. I think maybe it would be more rewarding if he’d actually eaten it.

Quite often mothers used food preparation to expose their children to new foods. The children would often enjoy the experience of cooking or baking with their parents or aides and this became a non-pressured way of children getting different sensory experiences with food without the expectation to taste or eat. Hannah anticipated an interesting and sensory-stimulating food preparation time between her son and husband:

> Harrison asked, “What kinds of ways can you cook salmon?” So [husband responds], “Well, you can fry it, you can bake it, you can put it in a paper bag and cook it like that, you can poach it, you can barbecue it.” So they were going through all these different ways that you can cook salmon. They started talking about these peppers that they got, and [husband]’s, like, “That would give it a really nice flavour. We can cut the peppers really fine.” So they’ve got a whole project today where they’re going to cook salmon and cut peppers and do lemon and whatever else they’re going to do with it. … We think he’ll probably go for it. And he’s going to get really involved in it, so he has more invested in it.

Children also enjoyed experiencing food by planting and growing a garden. This strategy was helpful for Fiona, whose son wanted to try fresh peas because he planted them and Leah’s son who enjoyed eating freshly picked carrots.

Implementing “Social Stories”

Social stories are a particular strategy developed by Gray (2000) to assist children in understanding a concept, which often results in a change of behaviour. Some mothers learned how to use social stories through their home-based therapy team. Daphne used social stories to talk about healthy food choices. Hannah very successfully used social stories and visual charts to explain that the same food can be presented in different forms:

> So [the OT] drew up a social story, and it would be about how food comes in different forms. You’ve got potatoes; well, they can be made into all kinds of different forms. They can be French fries, they can be mashed potatoes, they can be boiled. … So we made up a whole little project. So there’d be a little social story about different shapes and sizes, how they feel. … Then we’d have him go to the computer—which was all part of this whole little exercise that he loved—and find pictures of those kinds of foods; so find a potato chip, find a hash brown, find a mashed potato, find different pictures of potatoes, print them off, then we had him … cut them out, glue them on. Then he’d come upstairs and—these things would be on the table for his snack, all the varieties.

Using Verbal Strategies

Anna felt she had more success with feeding her son when his receptive language improved. Once Andrew understood that he only had to lick, taste or touch a food rather than eat the whole piece, the meltdowns over food exposure decreased. Once Jessica knew that her son was able to feel hunger, she worked to give him the language related to hunger, resulting in him being able to use single words to request food in response to his hunger. Verbally expressed concepts such as “first this, then that” were successful within the context of food with Daphne’s son.

Verbal strategies were also often successful with the higher functioning children and were used even more by the mothers as the children got older. Leah used verbal reasoning to explain to her son the need to overcome his sensory aversions, to describe his over-responsiveness to scents, and to dispel his anxiety. She also explained to her son how taste buds mature with age, reassuring him that tolerating new foods would become easier through more tasting experiences. Verbal reasoning was also used to acknowledge the child’s emotion and response while still requiring a behaviour such as taking one bite.

Health presentations at school presented a further opportunity for the mothers to verbally explain the value of nutrition. Ivy’s son enjoyed the science behind the food and took the food guide to school with him each day. This health focus was used with children of varying ages and functioning levels when presented at a level that they could comprehend. Ivy made up lots of rhymes similar to Dr. Seuss to help her child understand the feeding expectations appropriate to his developmental level.

Mothers were able to capitalize on their children’s interests in computers and media to assist in the feeding process. Cathy’s son liked to memorize TV scripts especially commercials and then used these to request foods that he attributed positive properties to because of the advertising. He started eating a certain brand of bread because of the advertized promise of making him smarter and requested his mother’s yogurt because of the advertized promise of health. Hannah’s son thoroughly enjoyed a particular TV show which used food play in a creative and fun way, and he started using some aspects of the show for his own food exploration.

Integrating Choice-Making Strategies

Giving the children choices helped them have some control over the feeding process. Typically mothers gave their children a choice of two foods, both of which were acceptable to the mother. Another example was choosing to take five or seven bites of a food. Provision of choices also helped the mothers promote their children's independence. Mothers addressed the need to empower their children to give them control over their own ability to explore and progress with expanding their food repertoire. Ivy described her joy at her son applying the strategies he had learned and therefore having the confidence to choose to try a piece of a new food on his own one night.

Cathy had a unique but effective strategy of introducing new foods through choice-making as part of a restaurant experience:

> Food courts are a no-go, but a buffet, on the other hand, which is the way that I got him to eat a lot of the stuff that he eats now—I would take him to the all-you-can-eat buffet … and I'd load his plate up with stuff I knew he wouldn't eat. I would put zero comfort food on the plate, bring the plate back to the table—'cause I wouldn't take him up to the buffet. … I'd go back, load up the plate with stuff that I know is something that he *may* eat, but if given comfort food, he's definitely not going to bother trying; like, it's hard to rock his norm. And I'd hand him a plate: those are your options, and lo and behold, he would eat stuff.

Again, the use of a strategy such as this emphasized the importance of individualizing the feeding experience for each child, as the all-you-can-eat buffet strategy would not work for all children with ASD.

Considering Oral Motor Challenges

Some children had difficulties with oral motor control and overall low muscle tone, which affected their ability to eat safely and handle the progression of textures to solid foods. Mothers needed to directly work on these skills through specific strategies. Some mothers had to pay attention to the food presentation from an oral motor perspective beyond what would be needed for children at the same age level. Oral motor strategies included teaching children how to chew or addressing the problem of the child stuffing too much food in his mouth. Daphne needed to completely change her dining room furniture and adapted the chair to properly support her son's position for eating, as total body positioning has a direct effect on oral motor control.

Determining Typical 'Picky Eating' Strategies Do not Work

Some of the mothers also had children who did not have ASD who had different levels of picky eating and others were familiar with picky eaters either through their professional work or through the children of their friends. Their reflections about the differences between typical picky eaters and their children with ASD were insightful. They described that 'gimmicks' such as making a smiley-face pancake or an octopus wiener worked with their picky eaters but not with their children with ASD. While some of the children were interested in these gimmicks, mothers explained that this interest was not enough to overcome the negativity of the food. Moreover if the mothers changed a preferred food they would run the risk of losing a preferred food. Kim provided an example of this and compared it with her daughter, who was a picky eater:

> I had someone tell me once, “Try to make meatloaf into—if he likes muffins, make meatloaf in a muffin tin and make it look like a muffin, and you can use mashed potatoes to spread on as icing.” That would work awesome on our daughter; she would love that. Well, first of all, she likes meat, but you could do that with zucchini loaf or anything, and she would fall for that. *[chuckles]*. But Kenny,[son with autism] you’d run the risk of him never eating a muffin again.

Working from Their Beliefs

As the themes emerged from the data, I not only obtained detailed information on the specific feeding approaches and strategies, I also delineated some of the reasons the mothers selected the strategies. While use of the strategies was guided in part by the child’s challenges, the selection of approaches and strategies was strongly guided by the mother’s beliefs. I have used the term “beliefs” in a broad sense to include beliefs, values, world views, attitudes, and spiritual and cultural beliefs.

Acting on their Beliefs

The mothers acted on their beliefs when they used descriptive terms such as “parenting philosophy”, “family rules”, “goals and jobs”, “instincts”, “parenting styles”, “attitudes”, “opinions”, and “family expectations.” Family values and beliefs were clearly stated by some mothers and were a conscious guiding force in helping to determine the strategies they would use. Daphne’s values were clear relating to healthy eating:

> It’s just part of our family values that they need to eat their healthy foods before they get their treat foods, is what we call them.

In a similar way, Ivy articulated that her family had clear family rules, expectations and guidelines around all aspects of mealtime behaviour. For other mothers, their beliefs were evident in their accounts of feeding their child with

ASD even though not articulated as a guiding or motivating force. Bethany's values did not come as much from what she said but from the actions she described. It was evident in the interview data that she valued family, friendships and hospitality. Food was highly valued in her culture and was not to be wasted. She spoon-fed her seven year old son his meal at her friend's home and would not let him eat independently as she did not want him to be messy because she valued the hospitality aspect of eating.

The mothers represented an array of family and cultural beliefs that influenced the feeding process within their individual and extended family contexts. Some mothers described tensions and choices that they had to make when the convictions they held to be true for their children's needs were in conflict with extended family expectations. With her family, Hannah was able to adjust to meet the expectations of both groups:

> We've now realized that our best meal as a family—extended family—is a brunch, because both my kids love breakfast foods, so *[laughs]* I mean, we *all* love breakfast foods, so if we have bacon and sausage and French toast and whatever, whatever, everybody eats, and it's a great time, right?

Believing and Persevering

The mothers displayed a determination beyond just persistence in addressing the feeding challenges they encountered when parenting their child with ASD. This perseverance was clearly expressed in beliefs statements such as "don't give up", "face it head on", "never stop trying" and "do what you have to do." They enacted these strongly held beliefs through their perseverance. This perseverance included a persistent attitude of "doing [feeding work] regularly", "keep offering [food]", "do it slowly", and "have [food] around and available." It was apparent that this persistence involved a considerable amount of hard work for the mothers and they valued being able to work hard for their children.

Enacting Family Beliefs about Mealtime

Having a family mealtime was associated with a range of opinions as to its value. Family mealtime was linked to a sense of balance and give and take. Fiona highly valued, even cherished family mealtime but it seemed to be an unattainable goal most of the time, resulting in a sense of loss.

> I want to have the whole family sitting at the kitchen table—or at the table, eating together, because that is a great social and family kind of glue together; that's a great time to be together. Like, there's so many good, positive things about just being here together, eating over a meal that we all enjoy. From my stance, that's a privilege that other people have; it's not something I have here on a consistent basis.

For Cathy family mealtime was clearly not a priority. She commented:

> We don't eat at the table; we eat in the living room, and if he doesn't like what I'm eating, he'll go upstairs or he'll go downstairs.

Anna had expectations for mealtimes as pleasant times and did not view them as times to work on increasing her son's food repertoire.

> We've always just wanted to keep mealtime pretty low-key and a nice time, so it was never high up on our goals list to push a whole bunch of different foods. It was always on our goals list that Andrew will sit with us at the dinner table for the whole meal, and he will tolerate the food that we're having on his plate if appropriate, and he'll use a spoon when appropriate, use a fork when appropriate, but the specific food, we never stressed out about it.

Daphne used family mealtimes as a vehicle to increase food repertoire resulting in challenging mealtimes. Gail had specific reasons for including her son at the table at mealtimes and expressed strong beliefs about her son feeling included:

> He shouldn't feel excluded. He shouldn't feel different. It's nice to have my family together and sharing a meal. And on the other side, it's also a

> skill that he needs to learn. He needs to be able to sit with other people, eating. If he ever wants to go to a restaurant or have dinner with other people, it’s also a skill he needs to learn. But mainly, I want him to feel included.

Ivy viewed family meals within a broader framework:

> We were just struggling with just basic manners, and understanding that mealtime isn’t just about the food and eating the food, but it’s about the experience and the family experience, and learning the routine.

Applying Beliefs about Using Reinforcement and Rewards

The mothers’ beliefs pertaining to the use of reinforcements and rewards resulted in a range of behaviours that demonstrated polarized viewpoints. Several mothers described in detail their reinforcement schemes. Ivy had charts for her children and they received stickers for displaying appropriate mealtime behaviour. When the chart was full they all went to a children-friendly restaurant. Daphne had rewards of “high-fives”, praise, and dollar-store trips in place. These mothers used the reinforcers as their children showed a change in their feeding behaviours, such as sitting at the table to eat, if there was an extra incentive provided. These reinforcers were applied to each small step of the feeding process such as touching a new food. These incremental steps were necessary and for these children each tiny attempt towards eventually eating the food had to be rewarded.

The mothers who did not reward particular feeding behaviour had an explicit rationale for not doing this. Cathy held the belief that feeding was one of Curtis’ jobs and had this response when he ate a cheeseburger for the first time:

> I don’t want to draw attention to him having normal behaviour. Like, I just asked him, “Is that good?” and he’s, “Yeah.” Okay, cool. But I would have asked him if his nuggets were good, too. But I don’t want to overhype him doing something that a typical kid would do just because he finally figured out he was ready.

In a similar way, Jessica and her husband did not want to draw attention to a spontaneous new feeding skill:

> We're all sitting down having pizza, and he had asked for toast, and I made him toast, but I had set my plate down, and he climbed right up to my chair. So I just stayed back, and he sat down here at the chair and he picked up my piece of pizza and he licked it and put it down. My husband and I both just kind of stood back and just let him explore. He never did take a bite, but he certainly was interested in the pizza. … We just kind of looked at each other, and we were, like, "Oh, my goodness, he's actually going to try something." So I just kind of stayed back in the kitchen, because I didn't want him to see me and suddenly be, like, "Oh, this is Mom's plate, not mine." … [My husband] just kind of looked at me out of the corner of his eye, and he didn't even touch his food, he just kind of sat there, and he slowly picked up his food. We didn't really say anything, because we were, like, we don't want to push anything or make a big deal out of it, because I didn't want it to become an issue. And he was probably there for a minute, and he explored it a little and licked it, and then he put it down and went to his chair. But it was pretty exciting; we were, like, "Oh, wouldn't that be crazy if he just suddenly decided to eat it!"

Hannah and her husband in a similar way did not want to draw attention to their son eating a new food, and Hannah related it to her son's sense of control:

> I think part of it is control—6 months ago, he asked to go to Pizza Hut. He wanted to go to Pizza Hut; we'd never been there before. So we all went as a family to Pizza Hut. He ordered a little cheese pizza, and he ate it. [Husband] and I were trying not to be dancing on the ceiling, right; we're, like, "Is it good? Oh, good. Mine's really good, too." … I'm just afraid that if I make too big a deal of it, it's going to backfire, good or bad. … we'll say, "I'm glad you like it; that's great," but it won't be, like, "*Excellent job!*" because then, it's, like, "Why are you making such a big deal of this?"

Believing in Their Role as a Mother

Mothers came to the belief that they could trust in their own instincts as a mother in guiding the feeding process and valued this intuitive process. Hannah noted that this is something that her husband did not have:

> I think all mothers know their kids, but I could tell right in the morning if this is going to be an eating day or not. … I just say instinctively because … my husband wouldn't notice if he's eating more or less on any given day, but I, as the mom, would. … Why is that? *[laughs]* Why do women know anything that we know?

Ivy counseled other mothers of children with autism to believe in their instincts and act on them:

> Trust your instincts and trust in your abilities. I think sometimes this process can be very discouraging, and it's easy for us—I think as women, as mothers, we naturally feel an extraordinary amount of guilt even for the most ridiculous things, and I think particularly when you have a child with autism and with certain weaknesses and challenges, we tend to project them onto ourselves and think, "It's because of something I've done," and "Could I do something better?"

Mothers also had strong beliefs about what it meant to be a good mother and placed certain expectations on themselves. For Fiona these expectations of herself in meeting the challenges of her family members all of whom had some degree of feeding challenges were difficult:

> It's hard. It's *[pause]* it can reinforce all the other negative stuff that I talked about before, the self esteem, but then even not just as a cook—as a mother: you know, I need to get nutrition into my kids and I need to get that social value at the dinner table as a family. Like, it creeps into other aspects of me being a parent and a homemaker.

Many of the mothers also reflected on a shift in belief as they adapted to being a mother for a child with special needs. Daphne said she achieved a "new normal." Anna also spoke about the need to have normalcy:

> …because I can't get out of it; this is my life, so you just do it, and it becomes normal and doesn't occur to you that it's over and above what average families are doing. You're just, like, "This is what my life looks like." And being organized like this helps me feel more, you know, average.

The high value that mothers placed on their mothering role was reflected in Ivy's description of this role:

> I've never looked at being a stay-at-home mom as something I do until I go back to work; for me, I've always looked at it "This is my career, this is my job." As a result, I try to put all the energy and resources that I would put outside the home within this, and so for me, it's actually been extremely rewarding for me to be able to do this and to come up with these strategies. … When I go shopping and still look for books and toys, I look for things that are going to enable me to do this, and this will teach this, and yeah, I still bring my teacher approach to my children, and it's been very—it's been as rewarding for me as, I think, hopefully, it's been benefitting to my family.

Deeply held beliefs about what mothers did for their children, especially related to feeding, resulted in a sense of loss when these mothering actions did not work with their child with ASD. Anna reflected that she was not able to act on the advice given to parents of typical children:

> With all the stuff that you get coming back from school about offering all sorts of different things for lunch for kids, and there's always ideas from nutritionists and dietitians. And it's great, 'cause they've got some good ideas, some great ideas. But it's, like, "Yeah, but that works for normal kids." *You know*, I'd love to do those kind of funky things for lunches and stuff, but I can't really, 'cause then he wouldn't eat. (*spoken very quietly*). I'd love to make fancy little sandwiches with the faces on them. No, no.

Mothers described their beliefs that extended beyond feeding. Bethany believed that she had been given a special responsibility to mother a son with ASD:

> I believe that every person in this world has been born for a purpose. Our test in this world, we were given an autistic son, so God is seeing how we are going to cope with him. Sometimes it is very, very difficult, *really* difficult, but I try my best to cope. … So I really do a lot of things, too, for Bobby's sake. I try my best. Sometimes I think I feel that I've not done enough for him; then I wish I would do more. And sometimes some things, they are just beyond my control; I just have to pray to God to help me through that.

Acting on Beliefs about Support

Mothers had beliefs that influenced how and when they sought support, understanding and validation from others including their friends and other parents. While only a few of the mothers indicated they received ideas from other parents, they described the value they placed on parent-to-parent support in contrast to the support they received from professionals.

> I honestly think it's because in the course of a 24-hour day, there is so many feedings, whether it's snack, lunch, dinner, supper, that a parent intrinsically knows that "This therapist isn't in my house all day long and doesn't see this day after day and have the power struggles," where talking to a parent [of a child with autism], they both know that they *live* with a child with autism. (Daphne)

The mother who was a dietitian believed she could not seek support from her colleagues as she was using strategies that were different than those typically accepted and valued within her professional field and her use might create a clash of values.

Mothers typically sought support from their husbands/partners, including trouble-shooting regarding their child's feeding challenges. While fathers shared in many aspects of the feeding process including food preparation and feeding the child, mothers believed that they were the ones ultimately responsible for determining what foods the child would be offered.

Mothers sought and valued support from professionals and while some mothers felt they had been on their own, others described positive relationships with professionals who supported them. Mothers valued collaboration among the team and believed she was integral to the team decision-making process. Sources of support for these mothers included: specialized feeding clinics with interdisciplinary teams; occupational therapists from home-based programs, school programs and private practitioners; dietitians; public health nurses; and feeding courses given by occupational therapists. Mothers accessed dietitian support for specific nutritional questions, but most mothers read and researched nutrition on their own.

Mothers valued support from professionals and wanted validation from them, which Daphne did not receive:

> I started explaining [to the doctor], “We really reduced the sugar, we’ve really reduced the carbs, and we’re trying to work on lots of healthy vegetables.” “Oh, isn’t that hard?” he says, trying to make me feel—like, talk me out of it, and I was mad. I was, like, “You’re not doing this! I’ve come so far.” I thought to myself, “Shouldn’t he be saying ‘Good job, you did it’?” He was just, like, “Oh, that must be so hard to change all that.” I was just, like *[laughs]*—at that point, I was over the point where he could have talked me out of it, but I thought to myself, “Gee, how many parents are coming to this doctor, and he’s talking them out of it because of his own personal beliefs about how hard it is to change your diet.”

Believing in and Promoting Positive Attitudes

Mothers, regardless of the individualized approaches used, were universal in their belief that their children should not have negative associations around food. Daphne, who described using a structured approach to increasing food repertoire, nevertheless did so in a playful, positive, and fun way. Cathy reinforced that “you can’t make him want [food] in a battle of wills.” Bethany was cautious in how she presented food so it did not become an issue for debate with her son. None of the mothers believed in a force-feeding approach. One had tried force-feeding and reported its failure as an approach.

This positive attitude around food presentation was a belief that extended beyond food. Mothers chose to have a positive approach to their child’s progress.

Many expressed their positive attitude in dealing with the diagnosis of ASD and its impact on their lives:

> I think being positive is huge. It’s easy to feel sorry for yourself but I don’t think that gets anyone anywhere. And I think that’s the biggest thing for me, is I don’t feel sorry for myself. I mean, this is what we were dealt, and either you can face it head-on and do a good job with it, or you can sit there and feel bad and feel sorry for yourself, and that’s not helping anyone. (Jessica)

All of the mothers sought out and celebrated their child’s strengths, validating them for who they were as people, but also for how they positively influenced the world around them.

Striving to Achieve a Tenuous Balance

When mothers balanced their children’s feeding needs with their personal beliefs about feeding, they seemed to be able to optimize their children’s chances of eating and being adequately nourished. When the balance was upset and their child did not eat, the child’s nutrition was jeopardized as well as the mother’s beliefs in herself being a good mother. This was an ongoing cycle. Feeding successes reinforced their beliefs positively and fueled their ongoing feeding efforts which potentially resulted in further feeding successes. In meeting their children’s feeding challenges, mothers balanced their children’s needs at home and in different environments against their deeply held beliefs regarding mealtimes, mothering, hard work, and nutrition.

Mothers balanced the child’s feeding needs against family beliefs, expectations of extended family and expectations of consulting professionals. Sometimes the mother’s beliefs were in conflict with the child’s demands, and the mothers changed their expectations accordingly. Mothers also balanced their in-depth knowledge of their child against the well-meaning recommendations of professionals. Mothers defended their beliefs about their child's needs from opinions of others by, for example, ignoring well meaning advice of friends that would not fit with their child's needs.

Mothers even balanced expectations of fathers against what they believed would work for their child that day. Mothers were so "in tune" with their child's needs that any threat to the hard-fought success they had achieved caused anxiety. Hannah expressed this anxiety when her husband tried to offer her son a new food on a day she had determined was a "non-eating" day for her son:

> I'd be, like, "Don't give him that today." *[laughs]* Where [husband]'s more inclined to just give whatever he has, I'd be, like, "I don't want him to react." … And I can tell easier when he's going to lose it; like, when he's too anxious or too stressed or too high or too whatever, I get that first, before [husband]. I also think I'm more cautious about it, too. Like, I would want to stop Harrison—like, Harrison gets pretty hyper and high. When he gets too high, he can really go over the edge and lose it, so I want to stop it here, where [husband] might stop it quite a bit closer to the top. I'm a little bit more protective; protective of all of us, I think that's what it is.

Mothers made decisions on how to deal with feeding issues by balancing their expectations with possible consequences. Attempts to increase food repertoire at mealtimes were balanced against the belief, for instance, in having a calm family mealtime. Decisions to work on feeding goals were balanced against priorities to develop other skill areas such as language for requesting food. Mothers' beliefs about nutrition could be challenged by professionals. By acting on what they believed to be best for their child they felt judged by others.

Mothers attempted to keep feeding stable, their child healthy and well nourished amidst the many constantly changing life events, opinions of others and changing environments. Each new environment and any change in the child's world could potentially result in an upset to this tenuous balance. It is as if the mothers continually strove to achieve a balance, while the fulcrum was continually changing.

This cycle of continually trying to keep this tenuous balance repeated itself with new experiences and environments, and the balance was critical at many levels. Balance was necessary for the child's nutrition and successful feeding behaviours, but imbalance impacted much more than the child. Success in feeding their child was inextricably linked with the mother's feelings of worth as a mother, how well she was doing as a mother of a child with challenges, and reinforcement of all of her hard work.

Maintaining the Balance in New Environments

The mothers clearly stated that whatever their children's feeding habits, repertoire or behaviours were at home, eating away from home presented a whole new challenge and threat to the balance. Mothers described having to consciously consider how their children would eat at school, at friends' and relatives' homes, at special events, and while on vacation.

Lunch at school was often the most difficult meal for the mothers to provide, as they were not there to specially prepare the food and encourage their children to eat. All mothers consciously sent preferred foods to school to ensure that their child was eating during the day. Fiona expressed the differences in her perspective and the teacher's perspective, and her problem-solving attempt in trying to figure out why her son was bringing his lunch home. The teacher praised her son for having a nutritious lunch but did not seem to understand that if he did not eat his lunch, the nutritional value was a non-issue:

> Seeing what was coming home, I was trying to figure out why, why is that food coming home? Was he just not eating it because he didn't want to? And asking him that can be a bit of a challenge because it's hard to ask a question like "Why? Don't you like it? Did somebody make fun of you and you don't want to take it to school anymore?"—I can't ask that level of question to him. Or was it not having enough time? So then, *why* does he not have enough time? Is it because he's distracted by all the other kids around him? Because that could be something that could happen with him. Or is it because the food is too much or too hard for him to get into? Like, we made sure that he could open his own lunch kit. … So we made sure he could get into everything. … That's what I was trying to work through: why is this food coming home and how can it be addressed. Where she [the teacher] was, when I was wanting to talk about him and lunchtime, she was saying, "He's our best student. We praise him up all the time for the foods he has." Well, does it help if he's not eating them?

Leah gave another example of how precarious the balance was in ensuring her child had something to eat for lunch at school. Her son would accept very few lunch items and was on a GFCF diet, so his lunch options were limited. Leah prepared a specially-designed nutritious pancake with three kinds of protein flour and lots of fibre. The influence of one seemingly innocent comment from a lunchtime supervisor who seemed to be questioning the nutritional value of what appeared to her to be leftover breakfast pancakes was striking. Leah explained her frustration at how little it took to upset the balance:

> And I'm thinking "Lady you have no idea of the lengths I go to to make that pancake nutritious". … I was ticked. He doesn't want to take those pancakes anymore. … She just doesn't know what we're up against to get that protein in. … Maybe people who aren't fully informed need to not voice their opinions.

Cathy explained the misunderstanding that occurred at school when her son's lunch was not prepared the way he needed it prepared:

> He wigged out at school over his noodle bowl. When I make a noodle bowl, I just put in the broth, fill it with water, let it sit, drain out all the water, and I give it to him. The woman didn't drain out the water. He went to go walk it to the sink to drain out the water; she grabbed it away from him and told him he couldn't put it in the garbage. He wasn't putting it in the garbage, he was going for the sink. Put it back down. He got up again, and finally, he just threw the noodle bowl at her, broth and all *[pause]* 'cause he needed the water out; like, that was very important to Curtis: there is no water in a noodle bowl.

All mothers expressed the importance of exposing their children to different environments but expectations for eating away from home varied. Many of the children would not (or could not) eat at special family celebrations or at the homes of friends. Often mothers would feed their children ahead of time at home or do what Anna did:

> We don't use [family celebrations] as learning opportunities at all. It's just, like, we're here to just celebrate the time being together with other friends and family. So "If you want to have a bun, have two; it's up to you."

These mothers had to continually balance the pros and cons of going out to a restaurant to eat or being able to take a family vacation. Trips to restaurants involved preplanning, packing extra toys and different foods and knowing that the excursion might have to be abandoned at any time. Restaurant excursions were sometimes used to help prepare the child for foods that would be served at birthday parties to assist the child with socialization. However this socialization goal had to be balanced against the child's ability to handle the challenges to feeding within a new feeding environment. Considerable advance planning was required for vacations and even for part-day excursions to ensure success. Leah had to prepare her son for the upcoming trip out of town and told her son:

> "I can't just pack all your food with you, so you're going to have to be able to manage getting foods that we can get in [vacation place]." And he really wanted to go [on vacation], so he agreed, yeah, he would be trying things. We went to an Indian restaurant, so we ordered stuff, and we also asked if they could cook—like, just grill some chicken, so he actually ate … grilled chicken.

Working Through Value Conflicts

For some mothers, choices had to be made to meet their child's needs or their relatives' expectations. Daphne expressed this frustration in having to accommodate her child's needs within the extended family values about family celebrations:

> We just started giving up on going to [family gatherings] because—well, it's a typical thing that every parent with autism deals with: you know…everybody has to sit around the big table and be all social. … So there's always these dynamics happening where everybody's got these different values and whatever. At first, we just avoided them because it was impossible to get [our son] to sit there, and it was like we were disrupting this perfect little family social gathering.

Many of the mothers felt judged by others who held different values even as they worked so hard to provide nourishment for their children. Cathy described what this was like:

> I've gotten judgments from everybody and their dog. That I should apply more pressure, that I should try harder, that I should do more, that I should, I should, I should, I should, I should. Okay. Because society looks at you, if you feed your kid nothing but pizza and McDonald's, as a lazy parent, as a deadbeat, as someone who's taking the easy way out. Like every other parent, and parents before them, you should make your kid sit at the table till it is dark and eat their frickin' roast beef, because that's the way you parent. Okay, my philosophy is if it's not illegal, immoral, or life threatening, go ahead and do it.

Daphne also expressed that she did not appreciate a professional imposing their beliefs on the behaviours that she chose to do. Jessica expressed regret that one of her reasons for discontinuing the use of the bottle for Jamie was because of the judgment of others.

> Then at 4, I thought it was time to get rid of his bottle, because the bottle was hanging out of his mouth all day long. And he would drink … only two things, and only out of a bottle; he didn't drink out of anything else. When I look back now, I kind of wish I hadn't done that, because again, I think it was a big thing of what other people are thinking instead of what's really best for him sometimes, because I could feel the judgment. I heard people, "Look at that kid. Look how big he is, and he's still got a bottle." Those things were hard, so I think that was—I also thought he was getting too old for a bottle and he didn't need it hanging out of his mouth all the time. So it was kind of a combination of those two things, I think, the reason why I—and it was a week of pure hell to get rid of the bottle, but I did it, and I was so proud of myself because I had done it. And then he stopped drinking Pediasure, and I was, like, "Oh, no."

Mothers had examples of conflicting beliefs and articulated the importance of parents and clinicians working out their differences of opinion. Daphne described an example with one of the child's therapists:

> I needed to communicate to her the way we were approaching it, because he is an anxiety kid, and I think she was actually trying to express her professional opinion that if we all of a sudden dropped the hammer and expect him to—it's going to increase anxiety, it's not going to help at all. So I really respected that. So we sat down one day, and now we're totally on the same page. I think she needed to see mealtimes a bit to realize, "Okay, this is for real; like, they'll just run around and jump on the couch"; it's, like, chaos. So now we're on the same page, and she's been very supportive about trying to give us some ideas about how to maybe work on the next few things we want to tackle.

Other mothers described positive interactions with medical professionals and other clinicians where they felt that they were working collaboratively with shared values regarding goals and approaches. Ivy noted her satisfaction with this collaboration:

> The service provider … [was] a phenomenal support to us, and the aides that we've had over the course of the years, we're still in touch with; I mean, they've been like family to us, and it's been great. I've been lucky,

> because I am a stay-at-home parent, so I was able to really participate and collaborate a lot with the aides.

Mothers learned to always balance advice and recommendations against their perceptions of their child’s needs, their family beliefs and their belief in what was right for their child at that moment. This was best expressed by Jessica:

> I basically try to follow my own instincts a lot. I think we know what works best for him, so I feel like I’ve become an expert in the field myself now, so I kind of go with my own instincts. My husband and I talk a lot about things. I am certainly up for any suggestion from people; I’m willing to listen. … But other people and whoever’s willing to tell me, I’m willing to listen, but I have to take it with a grain of salt, sit back, and then do my own—have my own thinking on it and be, like, “I don’t think this is going to work for us right now,” or “It’s a great idea, but maybe he’s not ready for that.”

In summary, for the mothers of children with ASD in this study, addressing their child’s persistent and varied feeding challenges was characterized by a process of striving to achieve a tenuous balance. Table 4 illustrates some examples of threats to the tenuous balance that the mothers described, and the results.

Table 4: *Threats to a Tenuous Balance*

Scenario	**Threat to the balance**	**Result**
Mother decided child needed to stop using the bottle.	Mother removed the bottle	Child stopped drinking formula.
Mother strove to achieve nutrition through a nutritionally loaded pancake.	“Innocent” negative comment made to the child by a stranger at school.	Child refused to take pancakes to school.
Mother believed her child should be offered new textured foods a certain way based on experiences from child’s older sibling	Child with ASD refused textured foods and screamed uncontrollably when these foods were presented.	Mother had to go against her initial beliefs to meet the child’s nutritional needs.
Child required more meat in repertoire	Friend recommended making meatloaf cupcakes to look like child’s preferred cupcakes.	Mother weighed this recommendation based on her knowledge of her child and kept the balance by not following the recommendation.
Mother believed her child should be exposed to new foods using a structured, systematic approach using small reinforcers.	Clinician recommended a less structured, less directive approach to food exposure.	Family followed their own beliefs and appeared non-compliant to therapy recommendations.
Child required more protein in diet	Mother hid ham in the grilled cheese sandwich	Child lost trust in the mother and refused grilled cheese sandwiches.

The process of feeding the child with ASD involved the mother using a deliberate approach to improve feeding and choice of approaches and strategies based on the child’s individual needs. Central to the mother’s decisions were her beliefs which guided her actions. The tenuous balance reflected that success with feeding could change at any time based on changes in the child’s life and environments. Threats to the tenuous balance could come from many sources, resulting in the mother having to strive again to gain success with feeding guided by her beliefs in what would work for her child and her family.

CHAPTER SIX

DISCUSSION OF FINDINGS AND IMPLICATIONS

Mothers were faced with their child’s numerous feeding challenges, strove to meet their child’s feeding needs through an individualized feeding approach and, choosing strategies that worked within their family beliefs, achieved a tenuous balance in feeding their child with ASD. In this chapter I discuss this core process of achieving a tenuous balance, and situate the findings of this study within the literature on ASD, feeding in ASD and literature on parental beliefs. I also address the strengths and limitations of the study and define future directions.

Co-Constructing “Achieving a Tenuous Balance”

The process that was co-constructed between the participants’ experiences and my perspective as a feeding clinician was “Achieving a Tenuous Balance.” This core process contains several key components including facing the feeding challenge, using an individualized feeding approach, acting on the family beliefs, and facing the many challenges to the tenuous balance. The mothers initially determined whether a feeding challenge required intervention at a given point in time. They made these decisions based on what the current goals were for their child and rated the importance of working on a feeding intervention against all of the other priorities in the child’s and family’s lives. The second component was implementing an individualized, tailored approach to feeding. This involved knowing the child well, reading his cues, following his lead and persisting using a deliberately chosen approach.

Third, all decisions about feeding approaches to use, implementing specific strategies were based on the mothers' beliefs. While the mothers did not necessarily state their beliefs, they made decisions based on them. These beliefs guided each decision such as the treatment models to follow, use of reinforcement/rewards, use of structured or more play-based approaches, and setting priorities for goal setting. Mothers held certain beliefs around feeding, however, the behaviours exhibited by their children with ASD often necessitated going against their own original long-standing beliefs or priorities. Mothers who valued healthy nutrition emphasized increasing food repertoire and worked hard to achieve positive results. Mothers who valued extended family time were more relaxed and accommodated to their children's feeding challenges to accomplish their goal of positive family time.

The last component is balancing feeding needs through times of transition, with other priorities within the child's life and the family circumstances and fitting the feeding routine within the complex mosaic of the family's life. Mothers knew and hypothesized what was going on with their child's feeding and walked a fine line in the balance of keeping them nourished and expanding their repertoire while dealing with threats to the balance. Mothers have shown us that the feeding process is not just about the child and meeting their needs. It is also about balancing their beliefs and the child's needs. Wright and Leahey (2009) agree with this perspective as they advocate a "systems theory" approach to helping address children's specific behaviours which includes not just a child assessment, but investigation of the child’s behaviour within the family context, including investigation of the family’s beliefs.

Clinicians can help the feeding process by applying knowledge of family beliefs and being aware of the strong influences that beliefs bring. They can support mothers’ efforts in finding a tenuous balance and making it less tenuous. Clinicians can help by collaborating with families and discussing family priorities for their child. They can be aware that seemingly benign recommendations can result in tipping the tenuous balance if the recommendations are not well thought through with the family before implementation.

When documenting the challenges and strategies used by the mothers I wrote a memo, asking the question “so what makes feeding these children so different than other children with special needs or typical children who are picky eaters?” The answer came with looking at all of the factors within the process of a tenuous balance. These families are already in some of the most stressful situations related to raising a child with autism. The mothers found that typical strategies for feeding did not work for their children. They sought help and were not believed, and sought support and validation with varying degrees of success. To add further complication they found that if they inadvertently made mistakes by trying a certain approach, their child may stop eating or refuse a food, further decreasing his already diminished repertoire of foods. ASD in itself is a disability in which the children have difficulty at times of transition. Further, the mothers were looking to meet a basic human need for nutrition and the mothers’ perceived role is to fill that need. All of this adds up to be a tenuous balance. These children and the difficulties these parents face in feeding them are different and unique from other diagnostic groups I have treated. A similar population in terms of challenges to expanding feeding repertoire is the children who are fed by g-tube (Evans Morris & Dunn Klein, 2000). However with the g-tube group, the children have a means of adequate nutrition and can work on expanding their repertoire from this base of nutritional needs being met.

Wright and Leahey (2009) stated that there is a constant shift between change and stability within the family system today and this is especially true for families dealing with illness and forced to adjust in order to find a new balance. This concept is readily apparent in this study of ASD. By the very nature of having a child with ASD within the family there is constant balancing as the child is constantly exposed to change and a common feature of ASD is difficulty with change and transitions.

Application Beyond Feeding in ASD

The concept of “Achieving a Tenuous Balance” also has potential for utility beyond just feeding for the family living with ASD. Families of special needs children face numerous challenges to the balance in their family as they adapt to the different changes in their children’s lives. If families are making decisions to feed their children in certain ways driven by their beliefs, it stands to reason that they will make other treatment decisions in a similar fashion. If so, this has implications for success of different treatment approaches used within ASD. I pose the question: Should families consider their own and service providers’ beliefs when selecting service providers and service provision models for their family? Different service provision models for ASD have different core tenets which could be made clear to families who are selecting a service delivery model that should be a match for the family as well as the child.

Situating This Study within the Literature

Literature on Beliefs and Values

Having a child with a disability can lead parents to look at and evaluate their own belief systems, values and priorities (King et al., 2006; Myers, Mackintosh, & Goin-Kochel, 2009). “Belief systems broadly encompass values, convictions, attitudes, biases, and assumptions, which coalesce to form a set of basic premises that trigger emotional responses, inform decisions, and guide actions” (Walsh, 2006, p. 50). King et al. emphasized the importance of families being aware of their values as it is the values that drive their decision-making and setting of goals and priorities. Conversely, service providers can engage parents in the process of intervention by understanding the family’s beliefs (King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009). When service providers acknowledge parents’ beliefs there is improvement in the therapeutic relationship and a better fit of recommendations within the family’s life and priorities. This study had similar results to the King et al. (2009) study of beliefs of families with ASD and Down syndrome. These authors reported similar results as the parents reported having a positive outlook, accepted their children for who they were and celebrated the child’s small accomplishments.

We know from the current literature that parents of children with ASD determined the treatment approaches that they would use based on the belief of causes of autism and what they think will address that cause. Mandell and Novak (2005) proposed that cultural context be used to assess the parental beliefs as to the causes of autism, prognosis and types of treatments the parents view as effective. They proposed that parent's beliefs about causes would affect the choice of treatment approaches. Families who believe that autism is curable may choose a different treatment regimen or multiple treatments than parents who view the condition as chronic. This study expands on that concept as it includes the role that beliefs play in affecting the feeding process. Harrington, Patrick, Edwards, and Brand (2006) also called for the physician to find out parental beliefs about autism in order to develop a collaborative approach to care with the family. Mandell and Novak cautioned that strategies parents use may become alternative rather than complimentary if professionals do not respect parent choices or are unwilling to negotiate around treatment strategies used. Solish and Perry (2008) found that parents who believed in the "Intensive Behavioural Intervention" program for their child were more likely to be involved in their child's programming. Other researchers cautioned that if treatments do not mesh with family's priorities, daily routines and beliefs, they will likely not be attempted and thus may not be viewed as efficacious (Goin-Kochel, Mackintosh & Myers, 2009). All of these authors found similar results to the current study that it is important to find out about the parents' beliefs and values in order to have collaborative plans that mesh with the family system.

Wright and Leahey (2009) stated that change occurs within a family when there is a fit between a nursing intervention and the family's "biopsychosocialspiritual structures” (p. 43). They further stated that when this concept of fit is overlooked or not appreciated nurses tend to label family members as non-compliant. Wright and Leahey emphasize the need for a fit between the “cognitive, affective and behavioural domains of family functioning” (p. 303) and the interventions offered by the nurse. Interventions need to match the family’s strengths. These included consideration of areas such as ethnicity and culture. The results of this study fit well with the model created by Wright and Leahey. Feeding clinicians need to individualize the feeding programs (and other interventions) to fit with the family beliefs. “Non-compliance” with therapy recommendations should be viewed within the context of the whole family context and the family beliefs. Clinicians need to be aware that they also bring their own beliefs into the feeding process. Often these may be in conflict with the family’s beliefs. Bringing in a systematic reinforcement protocol for targeting feeding behaviours will likely not work well with a mother who believes it is her child’s job to eat and do not believe in drawing attention, positive or negative, to feeding behaviours. Equally, assigning a treatment protocol that requires a neutral non-reward system will likely not be accepted by a mother who knows her child will have a better chance of changing specific behaviours if there are rewards in place.

Literature on Feeding in Autism

This study contributed to the literature on feeding in ASD by focusing on the challenges and strategies that mothers used to feed their children with ASD, and the reasons behind their choice of strategies, an area that has not been previously addressed. This study advanced the literature beyond describing strategies the mothers used. It provided rich description in the areas of onset of feeding challenges, types of feeding challenges and reasons for use of chosen approaches and strategies. Ledford and Gast in their 2006 systematic review on feeding children with autism called for further research addressing strategies that parents have found to be effective that were not necessarily as invasive as the treatment studies reported in their review. Specifically they cited strategies such as “the premack principle”, shaping, simultaneous presentation of non-preferred foods and social modeling for further study (p. 163). The “premack principle”, also know as “grandma’s rule,” refers to the requirement to first do a task which is then followed by doing a preferred task. Shaping refers to the gradual presentation of food by touching, licking and gradually working towards consuming the foods. Depending on the child’s responses, some mothers were able to simultaneously present new foods with preferred foods; however the mothers cautioned against changing the preferred foods for fear of losing the preferred food. Many mothers described the necessity of providing multiple presentations of non-preferred foods. The above strategies were all described by the mothers in this study adding preliminary evidence that some mothers view these as effective. It is also clear that mothers used more than one strategy which will make research more challenging in determining the most effective strategies.

Literature regarding onset of feeding challenges.

The quantitative descriptive literature outlined two patterns of onset of the feeding problems in the children with ASD. The first pattern included children whose feeding challenges did not commence until 18 months to two years of age (Cornish, 1998; Williams, 2000). The second pattern, reported by Williams, included children who had early feeding problems which continued to be problematic. These two patterns were both represented in my sample and in addition a third pattern emerged in this study which was not described in the literature. In this third pattern, children started out with feeding challenges, and then the feeding issues resolved only to come back again at 18 to 24 months of age when they started refusing foods. Further research is required to determine the incidence of each of these three patterns and possible links to outcomes.

Two mothers interpreted the feeding challenges as the first signs of ASD that they perceived in their children and linked the feeding challenges directly with an early sign of ASD in their minds. This perception requires further research within the ASD early diagnosis literature to determine if such a correlation exists. Keen (2008) reported that children with early feeding problems and atypical failure to thrive should be investigated for ASD. Further research could also address if any children have feeding problems starting after 24 months. This study did not address children who have early feeding problems which then resolve by school age. Correlational studies linking age of onset with feeding outcomes would be beneficial.

Literature regarding feeding challenges.

Mothers described the significant challenges they faced in striving to feed their children with ASD. They described numerous considerations that seem unique to ASD. For instance, when they used inappropriate strategies their children refused to eat. Strategies that work for typically developing children could result in their children stopping eating. Their children did not behave like typical children and may not eat when they are hungry or would go hungry if not given preferred foods. Other people did not understand the challenges these mothers faced and they are often given platitudes.

The feeding challenges represented in the feeding literature and the feeding challenges represented in this study were very similar despite use of different methodologies. This situates the study well within the body of literature on feeding in ASD. This study also expands the literature available in the field by adding strategies and approaches mothers used to address feeding challenges. Four of the mothers described significant weight challenges (underweight) in their children, which is not an area highlighted in the literature. This is an important consideration for clinicians who need to continue to screen for weight and growth challenges in this population. Clinically, older children with ASD can have difficulties with being overweight. This group was not represented in this study. This study did not find a direct relationship between the severity of the feeding challenge and the severity of the autism, which is an area for further study.

Literature on strategies.

Keen (2008) reported that “there is a notable discrepancy between the wealth of clinical experience of eating problems in autism and paucity of its systematic study” (p. 211). Keen recommended that in order to address the complex and unusual challenges involved in feeding with the ASD population it is necessary to integrate several management approaches. She recommended addressing attachment, cognitive flexibility issues, learned behaviours, sensory processing difficulties and associated phobias and anxieties within an integrated intervention approach. This was the same message given by the mothers in this study, however this study expanded on the types of approaches and the need to individualize the approach for the child. The mothers also added to this by reporting on their decision making process which was influenced by their beliefs. From my experience as a feeding clinician following the approaches of speech pathologists, occupational therapists, and interdisciplinary feeding teams, I note a difference in the empirical literature relating to treating feeding problems with ASD and clinician teams who have a long standing clinical history with a range of diagnoses. This poses some interesting questions as the clinical literature from feeding clinicians has not been forthcoming.

The empirical literature on feeding in autism parallels the literature on treatment approaches used for autism. The most documentation in autism treatment relates to the Applied Behaviour analysis approach, just as the empirical feeding literature in autism addressed intervention largely from a behaviourist perspective. Other multi-faceted treatment approaches for autism in general are emerging but are less well represented in the empirical literature. These include approaches such as Floortime (Greenspan & Weider, 2006), the Model of Social Communication, Emotional Regulation and Transactional Support (Prizant, Wetherby, Rubin, Laurent & Rydell, 2006), and Relationship Development Intervention (Gutstein & Sheely, 2002). The area of feeding in autism is complex and multifaceted and thus it is not surprising that empirical evidence for multifaceted interventions and approaches is lacking. This area of study poses significant challenges to researchers.

The strategies mothers described in this study were quite different than the strategies employed in the nine quantitative treatment intervention studies reported by Ledford and Gast (2006). One primary areas of difference was the limited use of “escape extinction” procedures which was common in the quantitative studies. Escape extinction refers to placing the food in the child’s mouth or holding the food in front of the child’s mouth until the food is accepted. Only one mother reported using this, which she referred to as “force feeding” and she abandoned this strategy after it did not work for her son. None of the other mothers used escape extinction. Mothers have described many different approaches and strategies as effective and none described escape extinction as effective. Use of this approach is present within the behavioural approaches to feeding; however it tends not to be found in the clinical feeding texts. Binnendyk and Lucyshyn (2009) used a family centred care approach and reported their single case study findings. The mother followed through on the program which follows that she accepted or believed in the therapy approach recommended. This study approach used escape extinction which may or may not be accepted by the mothers in this study, so may represent one approach rather than “the” approach to feed a child with ASD. Based on the child’s cues and the family beliefs clinicians need to be aware of when to use a behavioural approach and when to try other approaches depending on the presenting problems.

Past feeding literature has focused on the need for clinicians to help children with feeding challenges who have ASD due to inappropriate strategies used by the mothers. This study has given us an insight into the difficulties of feeding a child with ASD and the lengths the mothers go to to feed their children.

Researcher Reflection

In doing this study my views and awareness of successful feeding approaches has broadened. I see the role of reinforcement as beneficial for some children where this was not a technique I used within my practice two years ago. I have broadened my perspective to include the role of family beliefs in guiding the feeding approaches used by families. This is reflected in my journal entry of two months ago:

> I had an interesting revelation today in reviewing a case. I read a report by a feeding clinician with recommendations similar to what I would have given last year. I didn’t agree with what was written. It hit me the wrong way. I thought to myself that there were so many other factors of this child that the clinician did not attend to. What the clinician recommended would not have fit with what I knew about the parent’s beliefs as represented by the parent behaviours. The recommendations were too black and white and did not consider all the factors involved. Interesting how far I have come.

With one interview in this study I struggled with the approach the mother chose as I felt the child could have responded well to a structured approach with use of behavourist principles. As a clinician I would have needed to negotiate with the mother about her beliefs, use of structure and my beliefs about her child’s capacity for change given a different approach. Such is the reality of pediatric therapy. As clinicians we are constantly working through the challenges of integrating our knowledge, perceptions and beliefs about the child and balance this within the family context. Explicitly talking with the mothers about different beliefs of the family as part of development of family goals is critical to this process.

Strengths of this Study

This study has several strengths. The combination of the descriptions, enthusiasm and openness of the participants with an experienced feeding clinician with strong mentorship support from researchers in child and family care has led to rich data. The study participants were diverse in age, education, socio-economic status, marital status, and cultural background. The children of the participants were diverse in the severity of the autism, severity of feeding challenges, age, and represented both genders. Two different geographical regions within the province were represented. The study was rigorous with congruence among the research problem, research question, choice of method and data analysis.

Limitations of this Study

While this study had many strengths, there were some limitations. This study only represented the mother’s viewpoint on feeding and information regarding the fathers was only obtained through the mother’s perspective. The participants were motivated to participate and elected to respond to the general call for participants, however nothing is known about the mothers who did not choose to participate. Some of the participants knew the researcher and therefore may have participated in the study for this reason, or provided information that they perceived I wanted to hear. However since there had been limited clinical contact this was unlikely to have introduced sample bias. All of the mothers who participated were articulate and demonstrated an intuitive ability to understand and interpret nuances in their child’s behaviour. Challenges experienced by mothers who do not have this level of insight were not obtained through this study. Also the results represent one point in time and required the mothers to recollect information of past experiences and processes. This study did not determine if there were mothers whose children had early feeding challenges which they were able to resolve and the successful strategies used. It also only addressed a specific age group of children aged four to 11 years.

Future Directions

Clinical practice implications.

This study presents feeding clinicians an opportunity to understand the processes that mothers use when feeding their children with ASD. While the aim of the qualitative research is not generalization, the rich description allows the reader to apply relevant concepts to similar populations. Consciously incorporating a discussion of beliefs and values with families has implications for improving clinical relationships with families and subsequent fit of recommendations within the family priorities. Knowledge of this tenuous balance that mothers walk with their children will help clinicians to understand the mother’s viewpoint and the necessity of her evaluating each treatment recommendation for fit with her child and family.

Feeding clinicians from the rehabilitation disciplines often claim adherence to the “Family Centred Care” model. This study shows a way of consciously applying this model in clinical practice. Questions could be added to the feeding interview such as: What is the importance of family mealtime to you? How do you view your child’s [specific feeding behaviours]? What is most important to you for your child’s feeding?

I am often asked as a feeding clinician whether one should work on feeding if the child has adequate nutrition. The mothers in this study have shown us the lengths they have to go to in order to achieve basic adequate nutrition and often the child still has a restricted repertoire of foods. Feeding goes beyond nutrition. At various stages they have defined feeding behaviours that they wanted to change. They wanted to expand repertoires, knowing that their child may stop eating a food at any time. They wanted to work on sitting at the table. They wanted mealtime to be more than consuming adequate nutrition. They wanted to be able to take their children out to eat with friends. They wanted to expand their child’s nutrition to be healthier. In doing all of this they wanted feeding to be easier for their child or the family. The feeding goals change over time depending on the family situation, environmental factors and others stressors in the child and family’s life. Clinicians need to be aware of all of the factors that contribute to the challenges faced by the child and family at a given point in time.

Clinicians will also realize through this research the importance of individualizing the feeding approaches to the child and family and not come in with a “one size fits all” feeding approach. Clinicians must attend to the child’s individual needs. Are there sensory sensitivities, oral motor issues, or difficulties sitting at the table for a meal? Is the child inflexible, with a need for sameness? Clinicians must be sensitive to family beliefs and co-parenting approaches.

Attending to the families' beliefs requires a conscious effort for the clinician to the values being represented within the family context. Depending on the co-parenting approaches adopted within a family, the mother and father may come from different perspectives in addressing the feeding needs of the child, and each may be achieving success within their individual approach. Clinicians should be aware of the differing approaches within the family and be prepared to assist the parents in working out their roles around the feeding process. They should be cognizant of the implications of their attempts at supporting the child and family, and be aware of how their recommendations are received by the family. Clinicians should be in tune with the belief messages communicated through their behaviours yet not necessarily explicitly stated. It may be helpful for clinicians to bring to the forefront a discussion about belief systems with their peers, especially if intervention has been less successful, to see if disparate beliefs could account for the limited progress.

This means having a range of feeding strategies available, not a recipe with one approach. It involves attending to the hidden messages of families and bringing to the forefront if needed a discussion about beliefs that are driving the behaviours of the family. It especially means "doing no harm" by imposing clinician beliefs on a family or inadvertently upsetting the tenuous balance.

Research implications.

While this study has added to the body of literature on feeding in ASD, there are several directions for future research. Further studies are needed to determine what strategies may work with what kind of feeding problem; relationship of beliefs to choice of overall feeding approach including use of reinforcement and escape extinction; further investigation of structured and unstructured feeding approaches and whether this is a continuum; assessment of feeding challenges in ASD including assessment of beliefs and values, and further study on strategies and approaches that work and may be necessary to use with this population.

This study has described three groups of patterns of onset of the feeding challenges. We do not know if there are any differences in responses to treatment among the different groups.

We know that there are a myriad of feeding challenges faced by children with ASD and a variety of approaches and strategies used by mothers. We know that there are other approaches to feeding interventions in the literature that were not described by mothers. Further research is needed to determine what approach works with what types of challenges and how parental beliefs shape the success of the different feeding interventions.

This research may have implications beyond addressing just feeding issues of children and parents living with ASD. Treating the child with ASD involves treating the child within the context of family. Family beliefs drive behaviours. Just as children should be treated as individuals with strengths and needs, intervention for feeding involves attending to the whole family context.

Many of the interventions in the ASD treatment studies involved someone other than the parent doing the intervention. Further investigation is needed to see why this may be beneficial and for what kind of feeding challenges. Perhaps there is more than just a different co-parenting approach when fathers are able to gain success in having their children try different foods than the mothers. It may be specifically breaking the rigid pattern that accounts for the success. In the single case study by Binnendyk and Lucyshyn (2009) the clinician did the feeding program first with the child away from the regular feeding space. This involvement of another person who the child does not relate certain feeding behaviours to warrants further study. Studying fathers' approaches would be helpful to see what strategies and approaches they find successful, and to see how they achieve a balance when feeding their children with ASD.

Conclusion

There is no standardized intervention for feeding difficulties with children with ASD and an individualized approach needs to be based on the child's needs and the family's beliefs, offered within a trusting, mutually respectful parent-professional relationship. Mothers strive to achieve a tenuous balance when feeding their children with ASD and work hard to achieve a measure of success. It is no wonder they celebrate victories such as Ivy expressed after all of the efforts they have made in assuring their children are nurtured and fed:

> That moment was so magical for me last night when all he did was eat a cube of pineapple, but it was, like, "Da-ta-da! We've made the Olympic marathon."

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Appendix A Introductory Flyer

UNIVERSITY OF ALBERTA

Department of Occupational Therapy
Faculty of Rehabilitation Medicine

2-64 Corbett Hall
Edmonton, Alberta, Canada T6G 2G4
www.ot.ualberta.ca
Tel: 780.492.249
Fax: 780.492.462

Research Study

Are you a mother of a child with Autism who has feeding problems?

We are interested in finding out how you get your child with Autism to eat. We want to know about your child’s feeding problems and what strategies have or have not worked for feeding. We would like to meet with you for 1-2 hours.

If interested, in finding out more about this study, please contact

Laura Rogers

(780)- 732-0123

lgrogers@ualberta.ca

Appendix B: Screening Questions

☐ Child age 6 or 7

☐ Co-morbid diagnoses____

☐ Severity of feeding issues

☐ Location

☐ Child verbal/non-verbal

☐ Marital status

☐ Biological mother

☐ Conversant in English

Appendix C: Information for Participants

(Flesch-Kincaid Grade level 7.8)

UNIVERSITY OF ALBERTA
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Faculty of Rehabilitation Medicine

2-64 Corbett Hall
Edmonton, Alberta, Canada T6G 2G4
www.ot.ualberta.ca
Tel: 780.492.249
Fax: 780.492.462

Information Letter for Participants

Title of Research Study Feeding a Child with Autism Spectrum Disorder:
Mothers' Strategies at Different Stages

Investigator Laura G. Rogers, Masters Student,
Faculty of Rehabilitation Medicine, University of
Alberta
(780) 732-0123 lgrogers@ualberta.ca

Supervisors Joyce Magill-Evans, PhD, Professor, Occupational
Therapy
(780) 492-0402
Gwen Rempel, PhD, Assistant Professor, Nursing,
University of Alberta, (780) 492-8167

Background

Many children (46-89%) with Autism Spectrum Disorders have feeding problems. We do not know how these problems change over time or how best to address the problems.

Purpose

We are interested in finding out how you get your child with Autism Spectrum Disorder (ASD) to eat. We want to know about your child's feeding problems and what strategies have or have not worked for feeding.

Participation

If you take part in this study, Laura will meet you once at a time and place you choose. Laura is an occupational therapist focusing on feeding. The meeting will last between one and two hours. Laura will ask about your child, your experiences, and some background information. This interview will be taped and later sent to a typist. Your name will not be on the tape when it is sent for typing. Taking part in this study is your choice. There will be no problems if you decide not to take part, or do not want to answer any question

Benefits and Risks: The meeting will take you away from your family for 1 to 2 hours and may remind you of experiences that were hard. You may take a break or stop the interview at any time. There are no direct benefits to you. The information you provide will help therapists and researchers to better understand how to feed children with ASD and support parents.

Please note: This is not an assessment or treatment for your child's feeding needs. If you require information on how to get an assessment and treatment, it will be given to you.

Confidentiality and Security: Any information that identifies you will be removed and replaced with a code number. The results of the study will be written in a summary form so individual responses will not be identified. The study location will be described as a large urban setting in Western Canada. Original tapes will be kept locked in Faculty of Rehabilitation Medicine for seven years.

Contact Information

You can contact Laura at (780) 732-0123 or email lgrogers@ualberta.ca

If you have concerns about how this study has been conducted, please contact Dr. Joanne Volden, Faculty of Rehabilitation Medicine, (780) 492-9674.

Appendix D: Consent form for Participants in the Study

Flesch Kincaid Grade level 7.0

Consent Form

Title of Research Study Feeding a Child with Autism Spectrum Disorder: Mothers' Strategies at Different Stages

Investigator
Laura G. Rogers, Masters Student,
Faculty of Rehabilitation Medicine, University of Alberta
Phone: (780)732-0123

Supervisor
Joyce Magill Evans, PhD
Professor, Occupational Therapy
Phone: (780) 492-0402
Gwen Rempel, PhD,
Assistant Professor, Nursing,
University of Alberta, Phone: (780) 492-8167

Research participant to complete	Yes	No
I understand I have been asked to be part of a research study on feeding challenges in Autism Spectrum Disorder		
I have read the attached information letter and have been given a copy		
The study was explained to me by:		
I understand the benefits and risks of this study		
I have had my questions answered about this study		
I understand I may stop the interview at any time, or ask for a break.		
I understand who has access to the information I provide		
I understand this is not an assessment or treatment of my child's feeding problems		
Information about confidentiality has been explained to me		
I agree to let the researcher quote my words if I am not able to be identified by the quote.		

I agree to take part in this study Yes No (circle choice)

______________________________________ ________________________

Signed Date

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

______________________________________ ________________________

Researcher Date

Appendix E: Interview Guide

1. Tell me about your child
    - His/her age
    - The impact of ASD on his/her behaviour, communication, sensory system
2. Tell me a bit about your family
    - Siblings and ages
    - Who else lives in the home?
3. Does your child have any particular medical concerns that affect feeding (reflux, allergies/sensitivities)
4. Do you have any concerns about your child's weight (over or underweight)
5. Tell me about feeding your child right now
    - When did these challenges start? (Can use a photograph to cue memory).

Questions geared for different ages and stages

1. How did your child eat as an infant?
2. How did he/she transition from
    - Breast to bottle
    - Bottle to cup
    - To purees, such as applesauce
    - To lumpy solids, such as mashed pasta or junior baby foods
    - To finger foods
    - To using utensils
3. How does he/she manage in different environments?
    - Special occasions/ cultural celebrations
    - Friends and relatives homes
    - Preschool and daycare
    - School

As issues come up in the interview at different stages:

- ▪ What was the nature of the challenge?
- ▪ What did you do to try to make things easier?
- ▪ What did you try first?
- ▪ What strategies worked?
- ▪ Who suggested the strategies? How did you make your choices?
- ▪ Were the strategies offered by others helpful?
- ▪ Was there an age where things became resolved or easier?
- ▪ Was there an age when things got worse?
    - o What do you think contributed to this?
    - o What else was happening in your lives at the time?
- ▪ Is your child particular about
    - o Brands of foods?
    - o Specific food presentation?
    - o Eating in certain environments?
    - o Specific food groups
- ▪ How do you cope with these issues?
- ▪ Do you feel that through these strategies your child has adequate nutrition?
- ▪ Does your child have a particular meal and snack routine or does he/she graze throughout the day?
- ▪ Does your child take any supplements? (vitamins, supplements, Pediasure)
- ▪ Does meeting your child’s feeding needs and nutritional needs cause any significant financial challenges for your family?

Probes

- ▪ What happened when?
- ▪ What did you do next
- ▪ Tell me more
- ▪ Can you give me an example?

At the end of the interview:

I would like to find out some other non-identifying information in order to describe my study sample. Do you mind telling me your age (Mom and Dad); education level. Are either or both of you working outside of the home?

Appendix F Interview Guide Revised Sept 17, 2008

1. Tell me about your child
    - His/her age
    - The impact of ASD on his/her behaviour, communication, sensory system
2. Tell me a bit about your family
    - Siblings and ages
3. Who else lives in the home?
    - Does your child have any particular medical concerns that affect feeding (reflux, allergies/sensitivities)
4. Do you have any concerns about your child's weight (over or underweight)
5. Tell me about feeding your child right now.
    - What are your specific feeding challenges with your child?
    - Is your child particular about
        i. Specific food groups?
        ii. Brands of foods?
        iii. Specific food presentation?
    - Eating in certain environments?
        i. Friends and relatives homes
        ii. Preschool and daycare
        iii. School
    - Special occasions/ cultural celebrations
    - Does your child have a particular meal and snack routine or does he/she graze throughout the day?
    - Does your child take any supplements? (vitamins, supplements, Pediasure)
    - Does meeting your child's feeding needs and nutritional needs cause any significant financial challenges for your family?
6. What are the strategies you currently use to feed your child?
7. Do you feel that through these strategies your child has adequate nutrition?
8. When did these challenges start? (Can use a photograph to cue memory).
    - *Lead into ages and stages*

Go through ages and stages:	**At each age or stage:**	**Strategies**
1. How did your child eat as an infant? 2. How did he/she transition from ▪ Breast to bottle ▪ Bottle to cup ▪ To purees, such as applesauce ▪ To lumpy solids, such as mashed pasta or junior baby foods ▪ To finger foods ▪ To using utensils 3. Age two 4. Age three 5. Age four 6. Age five 7. Age 6 8. Age 7 As issues come up in the interview at different stages: ▪ How do you cope with the issues?	▪ What was the nature of the challenge? ▪ *If issues, move to strategies column* ▪ Was there an age when things got worse? o What do you think contributed to this? o What else was happening in your lives at the time? ▪ Was there an age where things became resolved or easier? **Probes** ▪ What happened when? ▪ What did you do next ▪ Tell me more ▪ Can you give me an example? **Roles around feeding***	▪ What did you do to try to make things easier? ▪ What did you try first? ▪ What strategies worked? ▪ Who suggested the strategies? ▪ Were the strategies offered by others helpful? ▪ How did you make your choices?* What guided the choices you made* **At the end of the interview:** Expand on coping issue – how deal with these challenges* Non identifying sample information Age – Mom and Dad Education level Work – full time/ part time