

Mothers' Challenges in Feeding their Children with Autism Spectrum Disorder—Managing More Than Just Picky Eating

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Abstract Mothers' perspectives of the processes involved in addressing the feeding challenges of children with autism spectrum disorder (ASD) were explored qualitatively. The research question was: What is the process of mothers' feeding their children with an ASD who have feeding challenges, and specifically what is the nature of these challenges? Data were from semi-structured interviews with 11 mothers of 12 children with ASD ranging from 4–11 years. This grounded theory study used constant comparative analysis in developing categories to define the processes mothers used in understanding and then meeting the feeding needs of their children with ASD. Four feeding processes emerged from the analysis. 1) recognizing the feeding challenges, 2) defining the underlying nature of the feeding challenges, 3) seeking support for and validation of the feeding challenges, and 4) staging their approach. The feeding challenges had three different patterns of onset and went beyond typical picky eating behaviors.

Keywords Autism · Picky eating · Feeding · Eating behavior · Grounded theory

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“I’m Worried About His Health. How Can He Stay Alive Eating Two Foods and Drinking Water?”

Many typically developing young children enter a stage of picky eating and fear of new foods as they gain independence from their mothers (Carruth et al. 1998). Feeding challenges are reported in 25–35% of typically developing young children (Lewinsohn et al. 2005; Linscheid 2006; Palmer and Ekvall 1978). This stage of picky eating can often include food refusal, difficulty accepting new foods, behavioral feeding problems, tantrums and slow eating. Determining if and when children’s feeding challenges are beyond the level of picky eating is difficult and even more so for children with autism.

Many children with developmental delays (33–80%) have feeding difficulties (Palmer and Ekvall 1978) including aversive feeding behaviors (Schwarz et al. 2001), and are rarely labelled as simply picky eaters. Aversive feeding behaviors include oral hypersensitivity, preferences for specific food textures, and food refusals (Schwarz et al. 2001). These children have diagnoses such as cerebral palsy or syndromes such as Down Syndrome. 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 (Field et al. 2003).

For children specifically diagnosed with an autism spectrum disorder (ASD), (Centers for Disease Control and Prevention 2010) 46–75% have feeding, eating and mealtime challenges (Ledford and Gast 2006). These children may inadvertently be classified as simply picky eaters. However, in a clinical study of 138 children with ASD aged 7 to 9 ½ years and a same aged control group ($n=298$), children with ASD had challenges that differed from those of their typically developing peers (Schreck et al. 2004). They were restricted by food category and texture and refused foods more. Parents reported more general feeding problems as their children with ASD had a narrow repertoire and required specific food presentations with specific utensils. The problems were not transient, requiring long-term follow-up and support for parents in dealing with significant mealtime challenges. Children with ASD also have more mealtime challenges than their typical siblings (Johnson et al. 2008; Nadon et al. 2011). These mealtime challenges included not staying seated at mealtimes, not eating with the family, eating less than 20 foods, and having phases of persistently wanting the same foods (Nadon et al. 2011). 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 is vision loss in a child with ASD due to a vitamin A deficiency (Uyanik et al. 2006).

Several studies have reported the range of feeding challenges experienced by those with autism (Ahearn et al. 2001; Kerwin et al. 2005; Kuschner et al. 2005; Lukens and Linscheid 2008; Matson and Fodstad 2009b; Schreck et al. 2004; Schreck and Williams 2006; Seiverling et al. 2010; Twachtman-Reilly et al. 2008). In a systematic review, Ledford and Gast (2006) identified seven descriptive studies with a total of 381 children with ASD that reported challenges including limited food repertoire often to the point of nutritional compromise; food refusal; food jags; inflexibility related to food presentation, utensils, dishes, brands and packaging; sensory issues (taste, texture, and smell sensitivities); mealtime behavior issues;

difficulty accepting new foods; and nutritional issues. Less common issues included oral motor problems, consumption of non-edibles, difficulties accepting medicine, and food retention in the mouth. In a later study, Johnson et al. (2008) reported idiosyncratic refusal of foods based on colour, texture and food type. In a study of parent feeding practices for children with feeding challenges, the children with ASD had food refusal, texture selectivity, a narrow range of foods, and oral motor delays (Williams et al. 2008). Adults with intellectual disabilities and autism had more severe feeding and mealtime challenges than those with intellectual disabilities without autism (Fodstad and Matson 2008).

Considering the potential serious consequences of feeding and mealtime difficulties in ASD, it is alarming that there is not more emphasis on their feeding difficulties (Matson and Fodstad 2009a). Matson and Fodstad reported that even when children with ASD have adequate nutrition, feeding challenges can arise when there is limited access to preferred foods at special occasion meals or restaurants. The World Health Organization (WHO) management recommendations for children with ASD include the need to address feeding difficulties (World Health Organization 2004). The nature of the feeding disorders over time and appropriate management strategies for the range of feeding difficulties in ASD have not been well researched.

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. Children with ASD are a heterogeneous group and the nature of their feeding disorders is multifaceted. While responsibility for feeding and nurturing a child within a family belong to mothers, fathers, and other caregivers, this study focuses on mothers as they often have the primary responsibility for determining strategies to support successful feeding (Carruth and Skinner 2001). Given the high prevalence and severity of challenges, it is important to understand how mothers manage this essential life task.

Purpose of the Study

This study explored qualitatively the processes involved in addressing the feeding challenges of young children with ASD from the mother's perspective. While descriptive studies have provided information on the types of feeding challenges, no studies have investigated how the feeding challenges develop and change, and what mothers do to ensure that their children with ASD are fed adequately over time. There is support from the literature recommending more investigation of clinical approaches (Ledford and Gast 2006) and use of qualitative methodologies when defining evidence based practice (Strong 2003). In this paper, feeding challenges do not include anorexia or obesity.

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, and specifically what is the nature of these challenges?

Methods

Recruitment

Data were obtained from 11 mothers of children with ASD who had feeding challenges. At the outset of the study, inclusion criteria specified biological mothers of six and seven year old children with a confirmed diagnosis of ASD. Children this age have transitioned to different stages of food textures and types as this typically occurs by age three (Evans-Morris and Dunn-Klein 2000) and they have typically been exposed to eating in different environments (e.g. school). As the study progressed mothers of younger and older children were recruited in order to expand emerging code categories. Mothers who did not speak English and/or whose child had a co-morbid physical condition known to independently affect feeding were excluded. Recruitment occurred via an Autism Clinic database; the ASD diagnosis having been made by an interdisciplinary team. There were 17 responses to 174 recruitment flyers. The first author conducted a phone screening of respondents. Five did not meet the study criteria (2 were fathers, 1 was a foster mother, and 2 children had co-morbid medical conditions), and 3 did not follow-up after the initial phone contact. This resulted in 9 participants. Two other mothers, who met inclusion criteria, heard about the study and were included. Ethics approval was obtained from the Health Research Ethics Board.

Participants

The participants were 11 mothers of 12 children with ASD. Two mothers parented one child, six parented two children, two parented three children and one had four children. Six mothers had intensive parenting roles as 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. While data were not collected on family income, three mothers indicated that there were financial challenges related to providing food for their child with ASD due to the need for expensive packaged food, reliance on “fast food” or because of the amount of food provided and not consumed. One family received government financial support for special formula (Table 1).

The children with ASD ranged in age from four to ten years. There were 11 boys and one girl, including two brothers. To preserve anonymity of the one girl, all quotations refer to the male gender. The children spanned the autism spectrum with approximately half classified at time of diagnosis as having higher functioning autism and one with Asperger’s Syndrome. The other children were either severely

Table 1 Demographics of the 11 mothers

Ages	28 to 47 years
Education	Grade 7 to University; 6 had University degrees
Marital Status	9 married; 1 single mother divorced; one blended family
Work	7 homemakers; 2 worked full time; 2 worked part time
Ethnicity	10 Caucasian Canadian; 1 African Canadian

or moderately-to-severely affected in the areas of language, cognition and/or behavior. The feeding difficulties did not appear to be directly related to the severity of ASD symptoms, as one child with severe symptoms had the least feeding problems while the highest functioning child had the most feeding challenges.

Data Collection and Analysis

The primary form of data collection was through single 1 ½ to 2 ½ h semi-structured interviews conducted by the first author between September 2008 and June 2009. Interviews were recorded and transcribed verbatim, and field notes were documented after each interview. In keeping with the grounded theory process, data collection and analysis occurred simultaneously, with the data analysis commencing after the first interview and as each subsequent interview was completed (Charmaz 2006). Data analysis included initial line by line coding and then progressed to focused coding (Bowen 2008; Charmaz 2006). Through a constant comparative analysis process new data were compared with previous codes, theoretical concepts were developed and relationships were formed (Bowen 2008; Glaser 1992). Memos were written to explore ideas about codes and categories, and reflect on the data, create concepts, and conceptualize the emerging processes (Charmaz 2006; Liamputtong and Ezzy 2006; Schreiber and Stern 2001). Nvivo 8 qualitative software was used for data management, data sorting and retrieval (QSR International Pty Ltd. 2008).

Rigor

Rigor was enhanced through congruence among research question, methods, data collection, data analysis, and the subsequent development of social processes (Richards and Morse 2007). Fit was ensured through allowing the concepts to emerge from the participants' experiences rather than forcing data into preconceived categories, and through situating the findings within the literature. Relevance was attained through the linking of the relationships among the data and within the existing evidence base (Charmaz 2006).

Results

Four core processes emerged from the data: 1) recognizing the feeding challenges, 2) defining the nature of the feeding challenges, 3) seeking support for and validation of the feeding challenges and 4) staging their approach.

Recognizing the Feeding Challenges: “You Wake Up and Realize He’s Only Eating Five Different Foods”

Mothers described a process of attempting to feed their children and encountering difficulties. There were three patterns of onset. As the children got older, their children became more limited in repertoire, and the mothers tried to sort out what was typical and what was cause for concern.

Patterns of Onset Some of the mothers recognized their child's feeding challenges from birth including difficulty with breast feeding or acceptance of different formulas. As one mother reported, "breastfeeding was horrible, wouldn't work. He didn't suck very well. We went around the block on the formulas." Feeding problems persisted as the child got older and had difficulty with progression to different food textures and acceptance of new foods.

Another reported pattern of onset was that the child's feeding progressed typically until 12–24 months, when the number of foods gradually diminished to a limited repertoire of foods. This often coincided with the first onset of symptoms of ASD. A mother described this process:

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 lasagne. He's always enjoyed it. For some reason that day ... things started changing with his eating. He was a kid who ate everything. ... Then more food started dropping off his list.

A third pattern of onset was a combination of the other two patterns. These children had feeding problems from birth which resolved. They then started losing foods at 12–24 months. All children therefore had a significantly reduced repertoire of foods by ages two to three years.

Beyond Picky Eating Irrespective of the onset pattern, the mothers described a tumultuous and confusing process of trying to feed children with severe reactions to foods. In this difficult phase when the child was two to three years old, they were trying to get nutrition into their child and sort out what was typical picky eating behavior and what was a more significant feeding issue. During this phase mothers tried to get food into their child in any way possible, often having to cater to the child's preferences, since "if you ever saw those meltdowns you wouldn't want to offer [non-preferred] food either." Many children were down to three to five foods at age three to four years.

Three mothers had other children without ASD who were also picky eaters. This gave insight into their perceived difference between a typical picky eater and a child with ASD.

Just remember that it's not a picky eating thing; it's not even a really picky eating thing. It's a whole different thing and you have to wrap your head around that. ... It's not the same as our daughter [without ASD], it's a different situation. ... You can tell on that day, at that time, eating that [food] is not physically possible for [son with ASD]. It's like he would rather be miserably hungry than eat that. ... So to me that's the difference. She can eat it, but she chooses not to, but for him 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 me. 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.

Interestingly, mothers all used an analogy to explain their child's feeding issues, such as "what if it's like saying 'drink this cow's blood'?" 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 ... It’s disgusting to him. That’s not his fault.” “As far as he is concerned at that moment [food] is a rotten rat. His perspective is his reality.”

Restricted and Narrowing Repertoire Food refusals resulted in difficulties achieving a food repertoire to achieve adequate intake and nutrition. All the children had specific preferred foods and refused non-preferred foods to the point of not eating and even hospitalization for two children when presented with only non-preferred foods. Four mothers described times when their child was underweight and did not follow their growth curve. All 12 children were missing or had a reduced repertoire in at least one food group. Many of them had a restricted repertoire in two and even three food groups.

Defining the Nature of the Feeding Challenges: “He Gags at the Smell of Food Cooking”

All of the mothers went beyond the specific feeding behaviors to figure out what was going on for their children. They were convinced that their children were not to blame, that it was not “just a behavioral issue.” The children had a variety of feeding challenges and the mothers tried to determine the source of the problems.

Sensory Differences Mothers described sensory aversions relating to the sight, smell and texture of foods, and sensitivities to seemingly small alterations to taste. “He’ll gag and almost get physically sick just watching us eat something like spaghetti and meat sauce. He “dry heaves when he looks at pasta.” One child had such an extreme reaction to smell that she was unable to cook meat when he was at home. She had to return home from a family Christmas gathering as he was vomiting in the backyard when the turkey was cooking.

Need for Sameness Some feeding challenges were related to characteristics of ASD such as “need for sameness” and lack of flexibility. Children required certain brands of foods and were particularly sensitive to changes in food taste and presentation. Mothers reported that there was a risk of losing foods if preferred foods were altered in some way. There were instances of children no longer accepting preferred foods if attempts were made to, for example, hide ham in their grilled cheese sandwich. The child would not just refuse that grilled sandwich, but refused to eat grilled cheese sandwiches again. In an extreme example, a five year old child who relied on Pediasure for his nutrition refused to accept the formula again when the bottle was removed over a weaning week. He never returned to drinking Pediasure, even two years later, as he refused to accept it in any other vessel.

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 it. A mother 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.” Further, he was inconsistent 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 behavior of a two year old, for example, and what was atypical and requiring further attention.

Behavioral Challenges Some children displayed problem behaviors. 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. "My younger children won't eat the food they don't like, but [my son with autism] won't even come to the table." Mothers explained some of the reasons behind the behaviors. The children who threw foods often had severe aversions. Even verbal children were unable to express their need to avoid the food in their overwhelmed state. Some children were unable to sit at the table for any activity, including eating, or until they received more supportive seating. For the children without a feeding routine, the mothers were working on their use of language to request food. The goal of language superseded the goal of a mealtime routine.

Co-morbidities Co-morbidities affecting feeding 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 had significant challenges with appetite and feeling and responding to hunger cues.

These feeding challenges significantly affected home life, family mealtimes and eating in other environments where, for example, it was not unusual for the children to have only one to three foods they would eat at school. Mothers described the dilemma of meeting their child's needs or the expectations of relatives at family gatherings. Trying to feed the child while on family vacation affected the whole family.

Seeking Support for and Validation of the Feeding Challenges: "When I Say He Doesn't Eat, He Doesn't Eat"

This study took place in a city where there was access to specialized feeding consultation. Unfortunately mothers who sought support from health care professionals perceived that their feeding concerns were often dismissed and they were left on their own to manage. In particular the mothers were frequently advised to present the family meal and that their children would eat when they were hungry. Mothers reported that if their child was not given preferred foods, they would not eat. Some mothers had difficulty getting medical problems addressed because the child had a diagnosis of ASD. One mother felt that symptoms were viewed and perhaps even dismissed by medical professionals as behavior problems due to autism. She wept as she described finally getting the diagnosis of gastro-esophageal reflux:

[My son] would cry night and day, and he could not talk to me. I know he has pain, but when the doctors tell you there's nothing wrong with him, what do you think? ... Finally I really put my foot down and told the doctor "Don't look at his autism; look at him as not autistic and then look at the problem, it is a throat problem", and they gave him a scope and then they found the reflux, it burned him really bad. It took three years to be diagnosed.

Another mother sought medical help for her son's "gut" issues and felt dismissed. She perceived that the autism diagnosis prevented her son from being treated as a child with a physical illness. Another mother had to deal with her son's severe constipation on her own. Many mothers felt that their feeding issues were not treated as important and being typical of toddlers, even though they recognized their seriousness.

I had taken him to doctors and I'd been, like, "Look at him. He looks terrible." He was losing weight, "He doesn't eat"; [and the doctor] said "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"—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 she sought help at the hospital,

[The doctor] 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 ... 'cause his hair was brittle; he was malnourished, completely. They classified him as "failure to thrive." ... It was very scary.

While some families were eventually supported through specialized feeding clinics, getting a referral to the clinic was often challenging or discouraging. One mother described being told nothing could be done to improve her son's feeding. "I was basically told to deal with it. And then told his nutrition will be, like crap." Like many of the other mothers, she then proceeded to figure out on her own how to approach the feeding challenges.

Staging Their Approach: "I Basically Try to Follow My Own Instincts"

Mothers 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 approaches and strategies.

Initially Ensuring Adequate Intake The initial months and first two or three years were devoted to figuring out their child's issues and finding ways to ensure adequate intake. Mothers reported doing "short order cooking" which they were able to move away from as the children got older. Often between the ages of two and three years they could only give highly preferred foods even though the feeding repertoire continued to diminish. This early stage was characterized by significant stress for both mother and child. The emphasis was on finding a way to feed the child without causing distress. This was not a time for increasing repertoire or having a balanced diet. Instead the focus was on finding and keeping foods the child would eat. The length of this phase varied and typically lasted until the child was at least three years old. By then mothers usually sensed what might or might not work as they addressed the ongoing feeding challenges.

Moving Beyond Intake All mothers moved into the phase of finding ways to increase the child's nutrition. They had creative ways of adapting meals that their children would eat to both increase nutrition and palatability specific to the child's needs.

Many mothers loaded accepted foods with hidden nutrients. “I put a whole bunch of stuff in his waffles.” They continued presenting foods in their pure form and they used inconspicuous deception. Any noticeable difference detected by the child resulted in non-acceptance of the modified previously accepted food.

Increasing Repertoire Once the mothers ensured adequate nutrition through diligent effort, they actively engaged in increasing the child’s repertoire and variety of foods changing and continuing their work on other aspects of the feeding process such as sitting at the table to eat.

Discussion

Mothers have valid concerns when their children with ASD have feeding challenges that do not respond to typical feeding approaches. These feeding challenges affect the child, parents, and family mealtime and to date have only been described in terms of one point in time (Ledford and Gast 2006). This study specifically asked mothers to describe challenges over time, resulting in a better understanding of the processes involved. The findings from this study also add to the existing literature in several ways: 1) many children with ASD have feeding behaviors that go beyond picky eating, suggesting clinicians need to consider interventions that are beyond those used with typical picky eaters, 2) the need for more individualized interventions based on types of challenges is clearer, 3) an additional pattern of onset not currently described in the literature and requiring further investigation was identified, 4) processes that mothers engage in when trying to determine the nature and extent of their child’s feeding problems were described, and 5) mothers encountered system-wide access difficulties in getting their feeding concerns recognized.

Feeding challenges in ASD extend far beyond what is seen with typical picky eaters. The children have more feeding challenges than their typically developing peers (Schreck et al. 2004) and more mealtime challenges than their siblings (Nadon et al. 2011). Further investigation is required to determine if mothers facing these challenges use strategies for typical picky eaters, (Satter 1987) and find the strategies ineffective. Such strategies include recommendations to wait children out as they will eat when they are hungry, and to present the family meal instead of including some of the child’s preferred foods. This study suggests that these strategies were not effective for these children with ASD. Additionally this study demonstrated that, if ignored, there can be significant nutritional issues and possible hospitalization. It was a balancing act for mothers to meet the nutritional needs of their children, knowing that they could risk losing the limited foods in the child’s diet if they altered them or made changes too quickly.

These issues point to the need for early and comprehensive medical investigation to determine if medical issues are contributing to the negative feeding behaviors for children with ASD. Researchers advocate investigation of childhood feeding difficulties for all children in general, even in absence of a diagnosis to see if there is a medical component (Field et al. 2003; Lewinsohn et al. 2005). Many feeding

problems result from the interaction of medical, congenital, and developmental issues which affect child and caregiver behavior (Field et al. 2003). Even parent magazines that purport to have all the answers for feeding picky eaters recommend that parents document concerns and seek further medical input if the child is missing a whole food group or has extreme physical or emotional reactions to foods (Reynolds 2011). In our study medical investigations were not provided for some children despite repeated requests from their mothers. Our study also indicated a need for assessment and intervention beyond a medical assessment, including a dietary assessment if there are growth and nutritional challenges. Only four children in this study had growth challenges while all had nutrition challenges. Adequate growth can be misleading as the mothers reported adequate growth was used to reassure them that there was no cause for concern. However failure to thrive in early infancy coupled with atypical feeding problems has also been identified as a red flag for underlying diagnoses, including autism (Keen 2008).

Mothers clearly articulated the multifaceted nature of the feeding challenges that their children faced. What makes things more difficult from an assessment and intervention perspective is that each child had a different combination of the challenges described by the mothers and in the literature to date (Ledford and Gast 2006). All had difficulties accepting new foods and had a limited food repertoire, some to the point of nutritional compromise. Some children had sensory issues with food, others were affected by rigid behaviors and a need for sameness. Some had oral motor difficulties and low muscle tone which influenced their ability to handle textures of foods, while others could not tolerate different food textures from a sensory perspective. Others displayed significant behavioral challenges often as a result of not being able to explain their aversions due to communication difficulties. Ahearn et al. 2001 emphasized the importance of including environmental factors in investigating mealtime behaviors 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. Family eating patterns need to be considered in evaluation of feeding challenges. Williams et al. (2008), in studying parent feeding practices of children with feeding problems including those with ASD, surmised that one interpretation of their correlational data could be that parent practices could be a consequence rather than a cause of children's mealtime challenges. Given all of these factors, it is important to determine the type of feeding challenge in order to target appropriate interventions, as there appears to be a complex set of dysfunctional areas impacting feeding, requiring a multifaceted and even novel treatment approach (Keen 2008).

Given the multifaceted and individualized nature of the feeding challenges, an interdisciplinary team assessment of the complex feeding issues can assist in addressing the specific nature of the challenges. Such an assessment is necessary when the feeding issues extend beyond medical and dietary concerns. An expanded team approach including occupational therapy, speech language pathology, psychology, and others is advocated for many other complex feeding issues, (Evans-Morris and Dunn-Klein 2000) yet for the children in this study, the ASD diagnosis seemed to preclude further evaluation. Researchers have specifically advocated for in-depth assessment of children with ASD who have complex feeding issues (Twachtman-Reilly et al. 2008). Areas to assess include sensory processing issues, gastrointestinal

problems, ritualistic behaviors, planning and sequencing behaviors, need to follow mealtime routines, anxieties, cognitive inflexibility, social and language skills, food selectivity, and patterns of consistency and inconsistency in feeding in different environments (Twachtman-Reilly et al.). The necessity of adequately assessing the nature of the feeding problems rather than just looking at the feeding behavior has been reported. In a study of six cases, all presenting with food refusal, the multidisciplinary team determined that there were six individual and different reasons for the food refusal (Dovey et al. 2010). However, to further complicate both assessment and intervention with these children and families, the children's feeding also changes over time.

Through evaluating the process of feeding in ASD this study has demonstrated the need to look at time of onset of challenges and change over time. Our study delineated three patterns of onset of feeding challenges. Some children had feeding problems from birth; others started having feeding issues at 12–24 months while others had initial challenges that were resolved, only to have different problems surface at 12–24 months. Cornish (1998) described the first two types of onset in their research. Further research is required to determine the nature of these patterns of onset, their significance, and whether they differ in presentation. This information will further guide intervention approaches and strategies. As time progresses, the feeding challenges present insidiously, as mothers described the gradual loss but sudden awareness and alarm when they realized their child was now severely limited in repertoire. Mothers reported that their children continued to lose foods over time and this is a significant red flag requiring further investigation. Other warning signs included the reduction of food repertoire to exclude one or more food groups, strong behavioral reactions to introducing new foods, and significant mealtime challenges. Attention to such issues has the potential to not only direct intervention approaches, but also possibly prevent further feeding issues. Further research is required to investigate from a physiological perspective what is contributing to the severe reactions that these children have to different foods and to investigate behavioral feeding issues as a result, not as a cause of feeding challenges.

Limitations

While there was considerable interest in this study from service providers and parents, interested participants were not easily reached through the clinic mail-out process. Recruitment occurred during a heavy recruitment phase for other ASD studies through the same database. Nevertheless, the 11 participants provided a diverse sample and rich and meaningful data within the necessary six to twelve interviews minimally required for a grounded theory study (Guest et al. 2006). While the aim of the qualitative research is not generalization, the rich description provided in this study allows the reader to apply relevant concepts to similar populations. This study's strength of having a group of educated and perceptive women as participants has led to rich description and understanding of the issues, however this is also a limitation. Nothing is known about the mothers who did not choose to participate. All of the participant mothers articulated their intuitive ability to understand and interpret nuances in their child's behavior. Challenges experienced by mothers who do not have this level of insight were not obtained. This study only represented the

mother's viewpoint on feeding and information regarding the fathers was only obtained through the mother's perspective.

Summary

Feeding challenges are but one of the many issues that parents must face when parenting a child with ASD, and it is essential that their concerns be validated and not dismissed as simply part of the diagnosis. Parents need the support of professionals who validate their concerns and come alongside parents in their problem solving of feeding problems that can extend beyond typical picky eating. Such early validation and assessment of the feeding issues will direct the development of appropriate intervention approaches and strategies.

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Interview Guide

1. Tell me about your child (age, influence of ASD).
2. Tell me a bit about your family (siblings, who lives in home).
3. Does your child have any particular medical concerns that affect feeding?
4. Do you have any concerns about your child's weight?
5. Tell me about feeding your child right now.
Specific feeding challenges; particular about specific food groups, brands of foods, food presentation;
 - Eating in certain environments (friends/ relatives' homes, preschool/daycare, school)
 - Special occasions/ cultural celebrations
 - Meal and snack routine or graze throughout the day
 - Any supplements (vitamins, supplements, Pediasure)
 - Does meeting your child's feeding needs and nutritional needs cause any significant financial challenges for your family?
6. When did these challenges start?
7. Tell me about your child's feeding as an infant. Transitions from breast to bottle, bottle to cup, to purees, to lumpy solids, to finger foods, to utensils.
8. Tell me about your child at the following ages: 2, 3, 4, (and other ages if older).
As issues arose asked:
 - 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?

9. Was there an age when things got worse? What do you think contributed to this? What else was happening in your lives at the time?
10. Was there an age where things became easier?
11. What are the strategies you currently use to feed your child?
12. Do you feel that through these strategies your child has adequate nutrition?
13. Is there anything else that you would like to tell me about your child's feeding?

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