

## **The Nature of Family Meals: A New Vision of Families of Children with Autism**

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**Abstract**

Families with children on the autism spectrum are often viewed in terms of their deficits rather than their strengths. Family meals are portrayed as sources of stress and struggle for parents and children. In this study, we take a resilience perspective to challenge underlying assumptions and get a more accurate picture of the nature of shared family meals. In-depth interviews were conducted and mealtimes were video recorded with 16 families for this thematic analysis. We identified four themes as being particularly salient to the mealtime experience: (1) schools and homework, (2) managing eating, (3) chores, and (4) intimate conversations. Our results elucidate the context of mealtimes as a site where parents struggle, yet negotiate, the challenges of everyday family life.

Key words: Autism Spectrum Disorders, Mealtimes, Family Processes, Picky Eating, Resilience

### **The Nature of Family Meals: A New Vision of Families of Children with Autism**

Mealtimes are an important context for understanding family processes: they provide a window to patterns of social interaction that are related to child well-being; they illustrate how a family negotiates and organizes feeding; and they elucidate processes of family identity creation and cohesion (Fiese, Foley, & Spagnola, 2006). Thus, family meals both reflect and create family functioning (Curtiss, in press). For families of children with typical development, mealtimes have been found to cause conflict as well as provide opportunities for togetherness and conversation (Fulkerson, Story, Neumark-Szainer, and Rydell, 2008). There is a small but growing body of research on mealtimes of families with children on the autism spectrum. Mealtimes have been found to be one of the most stressful caregiving activities for mothers and fathers of children with autism (Plant & Sanders, 2007); however, there are reasons to believe that mealtimes are beneficial for these families as well. Evidence suggests there is no difference in the frequency of shared family meals among families with children with autism compared to families of children with typical development (Lee, Harrington, Louie, & Newschaffer, 2008). Furthermore, although it was less than families of children with typical development, a study of problematic mealtime behavior found 72% of families of children with autism reported mealtimes do not cause a problem (Curtin et al., 2015). The nature of mealtimes for families of children with autism remains unclear as there has yet to be in-depth analysis of how mealtimes are experienced by families who have a child on the autism spectrum.

The literature on autism and mealtimes primarily focuses on food selectivity and problematic mealtime behavior. It is easy to find research suggesting picky eating is a common problem for children with ASD; however, there is controversy as to whether the presence of eating difficulties is significantly higher in children with autism compared to children with typical development. Some studies have reported no, or small differences between children with autism and children with typical development (e.g., Martins, Young, & Robson, 2008) and other studies have reported large differences between these groups (e.g., Sharp et al., 2010). Cermack and colleagues (2010) have pointed out inconsistencies when defining food selectivity such as treating picky eating, food refusals, limited food repertoires, excessive intake of foods, and food category selectivity as interchangeable phenomenon. Others challenge the methodological validity of studies that find large differences in food selectivity of children on the spectrum compared to other children (e.g., not matching for functional ability). The effect sizes have also been challenged, specifically, that only small differences in means may be statistically significant but not practically significant (Martins, Young, & Robson, 2008).

To address these concerns, Sharp and colleagues (2013) conducted a meta-analysis of 17 studies focused on feeding problems (most which focused on food selectivity) which found that children with ASD are five times more likely to have a feeding problem than children without ASD. Unfortunately, only three of the studies considered the child's medication which is important because many of the medications that children with autism are prescribed such as methylphenidate (e.d. Ritalin) and dextroamphetamine (e.g., Adderall) can cause decreases in appetite (Baptista et al., 2004). Other medications such as risperidone (e.g., Risperdal) and

aripiprazole (e.g., Abilify) can cause increased in appetite (Cortese et al., 2103) and prevent micronutrient absorption (Basu & Donaldson, 2003). Of the three that did consider medication, Nadon and colleagues (2011) found differences in rates of taking medications but could not control for the variation in their sample. On the other hand, both Schmitt and colleagues (2008) and Bandini and colleagues (2010) reported precluding participants who were on psychotropic medication. Schmitt and colleagues (2008) studied 20 children with autism including matched controls and found that both children with and without autism ate similar amounts, but that children with typical development had a broader food repertoire ( $22 \pm 6$  different foods compared to  $17 \pm 6$ ). Bandini and colleagues (2010) studied 53 children with autism paired with matched controls and found a difference in rates of food refusals (41.7% compared to 18.9% respectively). They also found that children with ASD had a more limited food repertoire (19.0 compared to 22.5), but also that parents of children with autism offered their children fewer foods. These findings suggest that when controlling for medication, differences in eating behavior may exist between children with autism and children with typical development, but at a smaller magnitude than previously estimated.

In addition to difficulties in determining the rates of problematic eating in the autism community, there is also uncertainty when considering if problematic eating causes poor health outcomes. For example, the results of the meta-analysis conducted by Sharp et al. (2013), indicated no evidence of compromised growth or *macronutrient* intake (e.g., carbohydrates, fats, and proteins), but did find differences in *micronutrient* intake (e.g., vitamins, minerals, trace elements, phytochemicals, and antioxidants). A recent study of micronutrient consumption among children diagnosed with autism ( $n = 368$ ) calls the findings from the meta-analysis into question (Stewart et al., 2015). Stewart and colleagues (2015), in the most large-scale study of its kind, found similar patterns of micronutrient consumption and deficiency among the children on the spectrum as is expected from children with typical development (Stewart et al., 2015). When looking at within-group differences, a comparison of children with ASD with and without food selectivity issues found no difference in gastrointestinal symptoms, growth adequacy, or adaptive skills (Postorino et al., 2015).

Food selectivity may lead to problematic mealtime behavior. For example, a study of children with autism found picky eating was associated with parental stress and parent reports of problem behaviors (Postorino et al., 2015). Conversely, a study of co-parent quality that used a different measure of eating behavior found that although picky eating was the most common challenging feeding behavior, it was not associated with parenting stress (Thullen & Bonsall, 2017). Thullen and Bonsall (2017) found problematic mealtime behavior and rigidity about mealtimes were related to stress. DeGrace (2004) reported that the primary objective in family life for families with children on the spectrum, including meal times, was to “occupy and pacify” their children leaving parents feeling “robbed” of the experience of family mealtimes. Similarly, Marquenie and colleagues (2011) described the mealtimes of the families of children with autism to be “bereft” of meaningful interactions and overwhelmed by chaos. There is research that draws into question the prevailing themes of desperation into question. For example, in a

qualitative comparison of families of children with autism and children with typical development, both groups felt that mealtimes were meaningful but had to make accommodations for sensory sensitivity, plan to carry out a routine, and avoid specific elements of a routine (Bagby, Dickie, & Baranek, 2012). However, families of children with autism had more intensity or frequency in their accommodations, plans, and avoidance (Bagby et al., 2012).

To date, there is little known about the mealtimes of families of children with autism beyond what is known about picky eating and problematic mealtime behavior. In this study, we ask “*What is the nature of family meals when a child is on the autism spectrum?*” to elucidate family processes.

### **Methods**

This research uses thematic analysis to provide a grounded understanding of the nature of family meals for families of children with autism through observing family meals and interviewing parents about their experiences.

#### ***Sampling and Participants***

We used opportunistic sampling (Miles & Huberman, 1994) which allowed us to follow leads and take advantage of opportunities to include participants as they were identified. The researchers made contacts with autism advocates and community leaders in Midwestern medium size communities who referred parents directly and disseminated information about the study. Partnership with autism advocates lent credibility to the research team and helped to establish trust with the parents. To be included in the study, a parent had to have a child who was elementary or middle school aged who they identified as having autism (or autistic), agree to have their family dinner video recorded, and agree to be interviewed.

The age range was selected for three reasons: (1) 80.7 % of families with children in this age range eat dinner together four or more times per week (The National Survey of Children’s Health; NSCH, 2012) suggesting it is an important time for family meals; (2) Most children with autism are not diagnosed until after age four (Baio, 2014) creating a practical barrier to reaching families of younger children; (3) In the life course of the family, as intense caregiving for young children diminishes the symbolic elements of family rituals increase (Fiese, Hooker, Kotary, & Schwagler, 1993). This makes middle childhood a more established phase in the family life course as well as a time where children are more active participants (Fiese, 2006). These features of family life may be different for families whose children have unique caregiving needs. Sixteen families agreed to participate (see Table 1 for participants’ demographic characteristics). Although the children varied regarding the intensity of their impairments, all the children had at least some reciprocal verbal communication skills (e.g., could answer simple questions, make spontaneous comments, and ask for desired items).

**Table 1***Participant Demographics*

Demographic Variable		N = 16
Number of Children in the home		1 to 3
Additional Immediate Family Member with ASD	None	10
	Parent	2
	Sibling	2
	Both Parent and Sibling	2
Home type	Apartment	6
	Single-Family Home	10
Community	Mid-sized City	11
	Small Town	5
Number of Different Communities		8
Race/Ethnicity of Target Child	White/European American	10
	Black/African American	1
	Latino/Latina	1
	Asian	1
	Multi-ethnic	3
Family Structure	Two-parent	6*
	Blended	6**
	Single-parent	4***
Mother's Highest Level of Education	High School	1
	Some College	5
	Bachelor's Degree	6
	Advanced Degree	4
TC's Age Range		5 to 14
Mother's Age Range		30 to 53

Note: \*All heterosexual couples. \*\*5 heterosexual and 1 lesbian blended couples, 3 of whom share custody with former spouses. \*\*\*All single mothers, 1 of whom shared custody with former spouse.

***Data Collection***

This study used both observational and interviewed data. Observations were used as they are an excellent tool when “the preconceived image we have of the settings and people we intend to study may be naïve, misleading, or downright false” (Taylor & Bogdan, 1998, p. 25) as is the case for families of a child with autism. Interviews were used for eliciting how people view events and the meanings that they attribute to them (Rubin & Rubin, 2012).

First, families participated in the mealtime observation conducted in their home. Consent was given by each adult in the family who was present during the observation and assent was

given by each child present during the observation. Video cameras were placed in the eating and food preparation areas as indicated by the parents. During the set-up period, the researchers were friendly and conversational with families to establish rapport and trust. The researchers left during the meal, and a parent called after the meal, at which point, a researcher returned to collect the cameras. Mealtime observations ranged from 37 to 152 minutes. They included meal preparation, eating, and after meal cleaning. Two families had food prepared when we arrived. One family was still planning on eating dessert after we had collected the cameras.

Interviews were conducted on a different day in a location of the parents choosing: their home, the public library, or an academic research facility. Although the study was not limited to mothers, only mothers elected to participate in the interviews. The interviews were audio recorded and conducted by three members of the research team with advanced training in qualitative interviewing. The interview used a combination of general interview guide approach and a standardized open-ended interview (Patton, 1990) to create a natural flow. This means that the order of the questions changed depending on the respondent and specific questions were expanded upon or minimized based on participant responses. The flexibility of the interview protocol as well as the experience of the interview team allowed the interviewer to establish trust with the parent. During the interview, we showed a brief clip from the family meal and asked the parent to discuss how they reacted to the clip. The general outline for the interview consisted of five parts: (1) family description, (2) the form of family meals, (3) the function of family meals, (4) reaction to observation, and (5) the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003). The interviews ranged from 0:52 hours to 3:00 hours, however, most of the interviews were between 1:05 and 1:30 hours.

### *Data Analysis*

Only pseudonyms were used in data analysis and presentation. The results of this study are a thematic analysis (Braun, Clarke, & Terry, 2014) done as part of a grounded theory study (Corbin & Strauss, 2008). A team of eight undergraduate students participated in coding under the close supervision of the primary author. Coding was conducted using a combination of episode profile analysis (Maietta, Petruzzelli, Hamilton, & Mihas, 2016) and constant comparative analysis (Glaser and Strauss, 1967). Both the interviews and the observations were analyzed holistically. In the first phase, we selected sections from the interviews and observations to examine and then write extensively about how that selection contributed to our understanding of family meals. From this initial phase, we identified broader themes to explore across families. We wrote analytic memos regarding how each family contributed to our understanding of that theme. The themes were then refined, expanded, developed and reworked – a process that Corbin and Strauss (2008) call “integration.”

To ensure rigor, we followed the strategies outlined by Morse (2015) which expand upon Guba and Lincoln’s (1985) criteria: prolonged engagement, persistent observation, rich description, negative case examples, clarifying researcher bias, and peer debriefing. Data were analyzed concurrently with collection; this allowed preliminary findings to be discussed with participants throughout the analysis process to refine and shape the results. All data were

examined and discussed by at least two members of the research team. Additionally, the lead researchers met each week to debrief the interviews and observations conducted that week and to discuss and refine themes. We ended recruitment when the lead researchers determined the data had reached saturation- when the themes had been fully developed in terms of their properties, dimensions, relationships, and variations (Corbin & Strauss, 2008).

### Results

*Hectic, stressful, calming, chaos, miscellaneous, togetherness, debriefing, conversation, bonding, perspective, instilling manners and values, warmth, home-cooked, laid-back, fun, and care-free* were some of the words mothers used to describe their family meals. These words provided a short answer to our research question, *what is the nature of shared family meals when a child has autism*. Both the joy and the stress of family life could be heard. Most mothers used a balance of positive and negative words to describe her family's mealtimes which highlighted both the struggle and the rewards. For these families, mealtimes were a place to come together, but they could also be chaotic or monotonous. The nature of family meals was hard to capture in a cohesive story as was often evident in the interviews. Having a meal took intentionality but also felt like something that just happens. To present the nuance and variation in the nature of family meals, we present the themes identified in our analysis as a series of snapshots that provide a picture of family life. This album in words captures the candid, unexpected, mundane, and episodic nature of family meals. Sometimes the snapshots take the form of vignettes featuring a family in the study. The vignettes are based on a specific family, but they have been written to reflect an important part of the nature and significance of mealtimes and may capture elements of other families' stories. Sometimes the snapshots take the form of a description of a theme which was a prominent feature of family meals. The four themes we identified were: (1) school and homework: intersecting contexts of school and family life, (2) managing eating: difficulties understanding the function of eating behavior (3) mealtime chores: Laura and Whitney's families, and (4) dinner as a time for intimate and meaningful conversations: Sylvia's family. Through these *snapshots*, it is possible to *see* the context in which the mealtime ritual is completed.

#### ***School and Homework: Intersecting Contexts of School and Family Life***

For several families, the theme that predominated the meal was something that is not typically associated with mealtimes: school and homework. Behaviorally, children sat and completed homework at the kitchen table while a parent (or parents) prepared the meal or cleaned up after dinner. Regarding conversations, during the meals parents often talked about homework assignments and quizzes. In fact, most of the conversations at mealtimes were about school. In short, school and homework played a significant role in the course of the evening. Like the meal itself, homework was an activity that established roles, shaped relationships, and caused conflict. There were three main threads to the theme school and homework: reinforcing parents teaching role, using school as a method for connection at home, and causing conflict.

#### ***Reinforcing Parents Teaching Role: Samantha's Family***



Parents provided direct support for school work before and after the meal which reinforced an instructional component of their parenting role. For example, 38-year-old Samantha helped her nine-year-old son, Lionel, with his homework as she was cooking. When he had a question about what a word meant and how to look something up she gave him the answer or showed him how to do it. She was acting in a role of a teacher: a person who can help, explain, and strategize. Samantha excelled in this role. Samantha went to workshops and networked with other parents to enhance her abilities to provide instruction. Homework and mealtimes were enmeshed activities for this family and were both tasks that reinforced Samantha's role as an instructor. Samantha used the same strategies for helping Lionel figure out what to do with the brat he was having for dinner that was too hot that she used to help him figure out a word he did not understand. Her patience and ability to break down problems so that he could manage them created and maintained a special relationship.

***Using School as a Method for Connection at Home: Heather's Family***

Like Samantha, 40-year-old Heather's used school during mealtimes to reinforce connections, but in a way that was not as instructionally focused. For her son, seven-year-old Camden, discussing school work at home established Heather's role as the person who holds him accountable, supports him with success, and can see him for who he really is. Camden struggled to express himself with words, but Heather found several strategies to help him communicate. For example, like many parents, Heather supported Camden with confirming or elaborating on written correspondence from teachers. Unfortunately, communication from Camden's school was usually negative, but on the day of our observation, it was positive.

At the end of dinner, before he was allowed to leave the table, Heather held Camden in a tight embrace and whispered audibly in his ear, "I'm so proud of how hard you worked at school" seizing on the opportunity to praise him. Camden pulled away, but Heather pulled him back, "Listen to me. I'm so proud of how hard you worked at school. I want to know your secret recipe right now. How do you do so good in school?" After teasing his mom that he would not tell her and making Heather beg to hear it, Camden replied "I AM really good." Heather asked, "Your recipe is really good?" Camden said, "No – my recipe is that I am good. That's my secret recipe."

The communication supported their relationship and built their ability to share, and problem solve. This is another example of the intersecting contexts of school and family life.

***Causing Conflict: Sally's Family***

For some families, discussions about school and support with homework were much more conflict-laden; however, they still shaped relationships and established roles. For example, many families spent hours doing homework. The work assigned rarely was expected to take hours, but some children needed intensive. For some children, struggling to do homework was about perfectionism, but for others, like eight-year-old Margaret, it was a lack of desire to participate. Margaret's 42-year-old mother Sally describes her husband Jim helping Margaret with her homework:

He has to sit next to her for two hours, and she'll say, 'I don't want to' or 'I've done it' [briefly her voice gets angry and unintelligible as she imitates Margaret]. She's ripped her homework up; she's done all that stuff. I mean you have to do two hours of being patient - of sitting next to her and being like I'll wait for you, and that's a lot.

Although it is fraught with tension, homework shapes the relationship between Margaret and her parents. Margaret gets to spend prolonged time with her father's attention focused on her while they are working together to achieve a task, but the exchange is characterized by conflict. It creates tension for Sally as well as she struggles to understand if that is a reasonable amount of support to provide. Another example from Margaret's family illustrates the difficulty that families have to understand the boundaries between typical childhood struggles, impairments associated with autism, and conflicting agendas. This intersects with another piece of the picture critical for understanding family meals: managing eating.

### ***Managing Eating: Difficulties Understanding the Function of Eating Behavior***

Many families struggled with issues related to their child's eating mostly related to issues of under consumption. They were worried that their children did not eat enough, did not eat a varied enough diet, and did not want to eat at the times the parent thought they should eat. Parents varied considerably in terms of the intensity of their concern and their strategies for addressing concerns related to eating. Underlying each of their eating apprehensions was difficulty understanding the function of the behavior. There were two main challenges: (1) the difference between normative and nonnormative picky eating and (2) the role of medication.

### ***The Difference Between Normative and Nonnormative Picky Eating: Heather and Francine's Families***

To understand this sub-theme, we will describe the eating behavior of two nonnormative picky eaters and compare the strategies parents utilized to address their eating. We will then contrast the eating patterns of the extremely picky eaters with those of more normative picky eaters.

Seven-year-old Camden was a very picky eater and his mother, Heather, had to negotiate for every bite that Camden ate. Camden preferred very salty and sweet foods and had sensory sensitivity to smell. Heather worked on food expansion regularly with Camden despite never having gotten any formal support from diet therapy or a nutritionist. She described it as them being on the same team and needing to take turns picking out what to eat. She and Camden planned their meals together, and she checked back in with Camden to make sure he still wanted to eat what he said in advance. That did not mean he ate what they planned, but she was trying. Heather used intentional strategies to reach Camden, but they did not come from getting training in a therapy method; Heather lived in a rural area with very limited services so relied on her informal networks for ideas. She did not use the name, but what Heather did at home most closely resembled positive behavior support (PBS). Although PBS as a package of strategies has a different history and emphasis compared with ABA, they are consistent philosophically (e.g., behaviorally based, seek to identify the function of the behavior, and use reinforcement to change behavior; Johnston, Foxx, Kevinson, Green, & Mulick, 2006). Heather used a lot of

praise throughout the meal and during setup and cleanup. Camden was engaged in all these tasks – he had cooking, social, eating, and cleaning responsibilities. Heather gave him direction, praise, and rewards when he completed tasks. What he ate was just one part of many skills that Heather addressed with Camden. Heather was focused on setting Camden up to, one day, be as independent as he was capable of.

Nine-year-old Tristan ate very few foods and was brand specific even after several months of feeding therapy. Tristan seemed to be disgusted by many foods and showed signs of sensory sensitivity, especially to smell. The foods they were willingly eat were calorie dense, high-fat, high-salt foods such as pizza and chicken nuggets. Tristan’s mom, 50-year-old Francine full-heartedly believed in applied behavioral analysis (ABA) not just as an instructional strategy, but as a mindset for being able to understand and reach her son. Tristan had a system of rewards throughout his day. Francine used ABA throughout the meal but did not use it to address his eating behavior as it was one area she felt ABA was unsuccessful: she accepted his restricted diet and made him a special meal. Francine did practice extinction during dinner to address communication. Extinction is an ABA technique in which reinforcement is withheld to eliminate occurrences of behavior. In the case of dinner, the behavior that she was trying to eliminate was non-standard forms of communication. The reinforcement that she is withholding was her attention and conversation. This meant that if Tristan said something unexpected or in a non-standard way, it was completely ignored by his mother, but Tristan had very few phrases that he could say in a standard way. She went out of her way to set him up to be able to use them, but Tristan got ignored a lot at dinner. The only area where Tristan was in complete control of his behavior was what he ate. Francine had tried many reinforcements to get him to eat, but nothing worked although he would spontaneously add a new item to his repertoire. She would have loved for Tristen to eat the same thing as the rest of the family, but for now she was settling with him turning and facing forward at the table – something she felt was possible to change. Francine’s main goal for the meal was on Tristen having a normative mealtime experience.

For Heather and Francine, the strategies they used were based on their access to information: Heather relying on informal support and Francine relying on formal parent training. Also, their own goals for the meal played a significant role in how they interacted with their children: Heather’s goal of independence and Francine’s goal of normativism. This idea of normativism played out with families who had picky eaters in two different ways. Besides Tristen and Camden, all the other picky eaters looked like picky eaters who were typically developing. Children with typical development sometimes interrogate their parents about what is being prepared, get sad when food is not cooked just right, refuse to try new foods, hate it when their foods touch, avoids specific textures of foods, have difficulty with foods with mixed ingredients, or like to eat the same foods all the time (Boquin, Moskowitz, Donovan, & Lee, 2014). These are the same types of behavior we found in our observations and parent descriptions of picky eating. In this way, children were participating in a highly normative aspect of childhood, but parents did not view it this way. Parents conceived of a “normal”

food-based interaction much more akin to what would be considered to be an “ideal” food-based interaction. Essentially, parents wanted children to accept what was offered without complaining.

Parents struggled to understand if their child’s reaction to food was related to their autism. Samantha had two sons on the spectrum who both had picky eating that was similar to picky eating in children with typical development. Both boys had negative reactions to unfamiliar foods and difficulty with complex foods like lasagna (layers of different ingredients, different textures, and elements that cannot be seen). Samantha had different appraisals for each of her son’s reactions. Eddy, who was the youngest, simply did not like specific foods; however, Lionel reacted to something in the food, “something offensive in the smell or how it looks.” With Eddy, his issue was his preferences, but with Lionel, his issue was the food. To complicate this picture further, although the boys picky eating may have been within the normative range, their reactions to food may not have been. Eddy would run out of the room screaming. In the past, he had run out of the house when presented with food he did not like. Lionel got anxious about food and would sit in a different room by himself. In this example, it was clear to see how the behavioral reaction to non-preferred food affected the mom’s appraisal of picky eating. Furthermore, in this family, and others for whom the children had extreme reactions to non-preferred food, it seemed as if exposure to undesired food was perceived as a threat: that the presence of the food represented a threat to their very safety. Eddy and Lionel were dependent on Samantha to be able to anticipate their needs and help them to navigate the world. In general, she was good at it, but in this case, she did not realize that she was testing them.

In short, there was a subclass of children with autism who had extremely picky eating that seems related to heightened sensory sensitivity. This caused food to be revolting and could be difficult to manage. There was another group of children, who were also picky eaters, but their picky eating fell into the “normal” range of picky eating although their behavioral reactions may be extreme. In both cases, parents struggled with understanding the function of the behavior which could lead to less effective strategies to address the behavior. In the case of normative picky eaters, parents could pathologize typical childhood behavior. The difficulty in understanding the boundaries of impairment made it difficult for parents to provide appropriate support. There was a similar mechanism interfering with parents understanding the role of medication in eating behavior.

### ***The Role of Medication: Sally and Vanessa’s Families***

Children were prescribed medicine that could affect both appetite and metabolism, but parents rarely identified this a component of challenging eating behavior. For example, Sally talked about struggling to get Margaret to eat, switching medication, and then shortly after that, Margaret having a healthy appetite. Sally described how Margaret’s eating changed:

Margaret when she was on a medication, it was an appetite suppressant. She was not hungry. And so there was a lot of, ‘you need to eat four more bites.’ So it was a lot more controlling cause you know she really wasn’t hungry. Now she eats like a champ. And

so I don't know if she's on something that stimulates her appetite or not but you know she's really changed. I'd say in the last four months.

Even if Sally understood beforehand that medication was an appetite suppressant, when they were at the table trying to get Margaret to eat, it felt like Margaret was defiant.

Medication could also cause increased appetite and weight gain. Thirty-year-old Vanessa's six-year-old son, Lincoln struggled with weight gain: "the medicine he was on is a huge one for weight gain. Lincoln gained like 80 pounds, and they finally had to- even though the medicine was working- they had to take him off and put him on something else." She was trying to get the whole family to eat healthier, but it was a struggle to make so many changes at once- no more fries at McDonald's, no more soda, pre-bagging snack-size portions, and only allowing healthy snacks between meals. At the same time that she must limit consumption, she wanted Lincoln to learn to have a diverse diet, so she was also pushing him to try at least a few bites of what was served at meals. To Lincoln, it must seem very confusing that in some cases he was supposed to limit his intake, and in others, he was supposed to eat more than he would choose for himself. Throughout the theme, managing eating, parents employed a wide variety of strategies. They also had difficulty understanding how to set appropriate expectations. These elements continue to the next theme: mealtime chores.

#### *Mealtime Chores: Laura and Whitney's Families*

Most of the children in the study had chores related to the mealtime routine including cooking, setting the table, washing dishes, sweeping the floor, loading the dishwasher, and taking out the trash. Chores could be a struggle for parents but also presented an opportunity to teach independent living skills. Mealtime chores were a task in which parents had to negotiate the tension between what their children could do and what their children would do. Eleven-year-old Kevin needed step-by-step support to set the table. Thirty-seven-year-old Laura believed she has to increase control over Kevin to make him comply with an undesired task:

I'm reminding the boys to get the placemat, put the placemats out, put the silverware out, Kevin you do this, Hayden you do that, so that way there's shared responsibility and contribution to what's going on in the household. Kevin just- even though we've been doing this for years, it's still step-by-step for him because he doesn't like to do it. Now if it's something that he did enjoy or that he was even kind of okay with, he would be able to do it on his own with his eyes closed but because there's that resistance there it's me having to step-by-step with him.

Laura did not recognize that some of Kevin's "resistance" could be due to physiological difficulties that impair the executive functioning abilities needed to perform that kind of task. Executive functioning is even more critical for non-preferred tasks because of having to internally navigate an alternative motivation for completing something without intrinsic value. To Laura, it just felt as if Kevin was defiant, so she did not use a visual tool, like a checklist, to help him remember all of the steps or adjust his responsibilities based on his abilities. In contrast, 39-year-old Whitney spent a lot of time thinking about what her 10-year-old son was capable of and what expectations were reasonable:

He only helps me until his patience runs out and then he's gone. So he's, he's never actually helped me cook start to finish, but I take whatever help I can get. Just because the more I can expose him, the more comfortable he'll be. I try to make it as positive an experience as possible so that he wants to come back and help... I get it; I get you don't wanna stick your hands in the dirty water. I get you don't wanna touch a greasy plate. That makes him crazy. To do a dirty dish makes him insane. It is not worth the fight. But once the dishes are done, once they're clean, it's his responsibility to put them away mostly because (A) you eat off of them and (B) it's a chore that teaches you responsibility, and it teaches you that you are part of this unit. You live here as part of this family... Having expectations that you can do this but also accommodating for the things that you actually can't do. That's the - I mean that's, it's a really fine to balance. For Whitney, doing chores was more than just a task. It was a strategy for creating that *family feeling*. Another strategy families used for creating a sense of cohesion and togetherness was conversation.

***Dinner as a Time for Intimate and Meaningful Conversations: Sylvia's Family***

In contrast to popular conceptualizations, for almost all families in the study, mealtimes were an important space for conversation. Sylvia and Freddy's shared meal illustrated how this important function of mealtimes looked, felt, and sounded like for families on the spectrum.

It had always been just Sylvia and Freddy and as such Freddy has had to be more flexible than other children with autism. When it was time to go to the grocery store or laundromat, Freddy had to go too. Over the years, Sylvia had also learned to make things more predictable. When we came to observe, they were having a very calm, routine night. Sylvia helped Freddy with his homework as she cooked. They talked while they ate and then Sylvia cleaned up while Freddy played in his room. Sometimes they had crazy weeks. For the past couple, they had hardly been at home between Tae Kwon Do, visiting Sylvia's mom, and other things that just came up. When things get like that, they ate out or relaxed in front of the television while they ate.

Our observation was not one of those hectic days, and they both seemed focused on one another. After Freddy led the family prayer, he explained to his mom that he liked it when she asked him to pray with her pouty face. Freddy explained to his mom about "the other woman" which was when his mother asked him to do things sternly. If "the other woman" [stern mom] asked him to pray, he would not do it, but if she asked him just right, with her pouty face, he would say yes. Freddy loved his mother. He asked her for a hug and told her, "your mom is everything ... if anyone takes me away than everyone is nothing ... I will never leave you." They talked about this idea, the idea that someone might take Freddy away for a long time. Sylvia was worried about how difficult it was for Freddy to read the intentions of others. A man gave him money for a video game at the store, and he accepted it, which made Sylvia uncomfortable. You could understand why during their conversation. She tried to explain the dangers of strangers in a story. In the story, an old man tricks Freddy with skittles. As mom

narrated the story and the old man says, “would you like skittles?” As if on cue, the real-life Freddy’s eyes lit up, and he said “YES!”

Sylvia’s fear that Freddy had a vulnerable combination of naiveté, social desirability, and difficulty communicating was well founded even if the specific situation she was trying to prepare him for was unlikely. She used dinner time as an opportunity to talk about her fears and try to explain them to Freddy. Freddy was trying to discuss his fears, but Freddy was not worried about strangers. He was worried about his mom dating for the first time and that someone might come between them and their special bond. Freddy could have difficulty with pronouns, and even though Sylvia was usually good at understanding him; however, when Freddy said, “if anyone takes me away” he really meant you – “if anyone takes you away than everyone is nothing.” In the end he entered her world and talked about stranger danger. He even told his version of the story to show that he understood.

All the children in the study could use short phrases and sentences; however, they varied in their ability to engage in independent verbal conversation. Despite impairments to reciprocal communication skills, families used mealtimes as a time to connect and share. With few exceptions, the function of mealtimes as a time for engaging and connection was critical for the families in the study. For those families who did not use mealtime as a site for conversations, other contexts such as car rides and impromptu chats took their place; however, mealtime conversations were the only routine included the entire family.

### **Discussion**

The objective of this study was to explore the nature of family meals for families of children with autism. Our results identified four themes that were salient features of family meals: (1) school and homework, (2) managing eating, (3) chores, and (4) conversations. By using in-depth interviews and mealtime observations from a qualitative paradigm, it was possible to understand both the stress that families experience during mealtimes and the strength that mealtimes bring to the family. Three aspects of this analysis seem especially important: how normal in many ways family meals are; the difficulty that parents have in understanding child development in the context of autism; and the role of medication in eating behavior.

Despite the nuance in each family’s story, the overwhelming image that is left behind is how *normal*, in many ways, the family meals were despite having a child with unique sets of support needs. Each family mealtime had characteristics that made it idiosyncratic to that particular group of people; however, what was most striking was how recognizable mealtimes were to what you would expect in any household regardless of a child’s disability status. The overall arc of the meal was essentially the same. The family comes together and eats. There was laughter, singing, and joking. People shared about their day, their feelings, and frustrations. Sometimes there were bursts of conflict or passive-aggressive jabs. There was a universality to the nature of family meals, despite the struggles and challenges families face and despite their children’s impairments. This is indirect contrast to most of the existing qualitative research of family meals and autism (e.g., Bagby, et al., 2012; DeGrace, 2004; Gray, 1997; Marquenie et al., 2011). The reason for this discrepancy is likely that we did not exclusively recruit families under

intense distress. Additionally, our rigorous methodological approach allowed us to challenge a deficit-oriented mindset.

Families with children on the autism spectrum are often viewed in terms of their deficits rather than their strengths (Bayat, 2007); however, this study is the first to use a resilience lens to understand family meals for families with children on the autism spectrum during mealtimes. The family resilience perspective emerged from theories of individual resilience in the 1980s about how and why some individuals thrive despite adverse life experiences (Walsh, 2003). Family resilience is “the positive behavioral patterns, and functional competence individuals and the family unit demonstrate under stressful or adverse circumstances” (McCubbin & McCubbin, 1996, p. 5). Family resilience theory suggests that families engage in active processes to balance demands with resources and this process determines family functioning (Patterson, 2002). A resilience perspective shifts the focus from deficit and pathology toward health, strength, and capacities (Antonovsky & Sourani, 1988). This is not to say that challenges are ignored, but rather that adversity is placed in the context of strengths. In this study we challenged the underlying assumption that mealtimes are necessarily sources of stress. In doing so, we paid special attention to family capacities that might mediate risks and vulnerabilities assumed to be inherent in families with children on the spectrum. Future research could benefit from taking a reliance approach when examining families with children on the autism spectrum.

Although the family meals were in many ways normative, that is not to say that autism was not in focus for each snapshot. One task that was very challenging for parents was understanding developmentally appropriate expectations given their child’s autism. Although setting developmentally appropriate expectations is important for all families, doing so for children on the autism spectrum is inherently more complex. This would be expressed *as is it the autism?* We believe *is it the autism* signified a question as to whether or not the challenge they are facing is related to a neurological impairment or limitation and as such, should be accommodated. The alternative, *not being the autism* had two paths. At times this seemed to mean, a limitation or characteristic that is typical of child development. *Do all kids do [fill in the blank]?* In this case, it would mean the behavior is something the parent should be patient with and the child may grow out of. *Not being the autism* could also refer to something the child refused. *It’s not that he can’t do it, it’s that he won’t do it.* In this case, the behavior would be something the parent felt they should directly address. The mothers were knowledgeable about autism but struggled to integrate that knowledge with specific mundane tasks for their individual children. Thus, they sometimes attributed behavior as being related to autism and provided accommodations when it was unnecessary, and conversely, did not provide support when needed.

Other studies have suggested parents struggle with understanding child development in the context of autism. For example, Schaaf and colleagues (2011) reported a parent’s concern that their child only sat down to dinner for ten minutes, but this is just outside the average range of family dinners which is fifteen to twenty minutes (Kiser et al., 2010). Other studies have shown a difference in parenting perceptions of eating. A study that compared parents of children



with autism with parents of children with typical development found that the parents of children with autism reported their children as being pickier even though the groups consumed the same amount of food (Lockner et al., 2008). This can be particularly difficult when considering eating behavior as some children with autism experience clinical levels of eating disorders which can be overly generalized to the entire autism community. Furthermore, as found in this study, for children who are within the normal range of picky eating, their behavioral reactions to food may be unexpected and this, in turn, may shape parent perceptions of eating.

The final conclusion focuses on the role of medication in mealtimes. Although it is a relatively minor finding in the thematic analysis, it has important implications for future research and patient education. Our results indicate medication should be considered in future mealtime and eating research especially since parents rarely attributed selective eating and loss of appetite to medication and instead attributed it to children's willingness to eat which caused conflict in the family. Future research should examine the role of medication in children with autism's eating behaviors and parent's abilities to manage eating as well as the quality of patient education parents receive when being prescribed medication.

### ***Limitations***

Although we used robust data collection procedures and a rigorous analytic strategy, several factors may limit the trustworthiness of our findings. This study did not use a true theoretical sample as is best practice in qualitative research. Although we were able to theoretically sample from within our data, participants were selected because they were willing to participate and met inclusion criteria. This led to all the children in the study having some spoken language. The results would likely be different for families whose children have greater impairments related to communication skills. Future research should examine mealtimes among families with children who have minimal spoken language. Additionally, none of the families in the study were currently struggling with issues related to food insecurity: a lack of reliable access or availability of nutritious food (United States Department of Agriculture [USDA]; 2006). Food insecurity represents a different context for mealtimes, and the themes we identified may or may not be present. Finally, we only had reports from one family member at one-time point. Although the mothers could report on change, future research should follow families to examine how mealtimes change throughout childhood. Future research can include interviews with multiple family members including fathers, siblings, and children with autism in order to have a comprehensive picture of the nature of family meals.

### ***Conclusion***

Our inquiry suggests mealtimes are a stressful task for families of children with autism, but they are also joyous, important, satisfying, and rich with potential for feeling connected and supported. Mealtimes were the activity around which parents enacted roles such as instructor, nurturer, and confidant. The results of our qualitative analysis highlight how normal family meals are, the difficulty that parents have in understanding child development, and the role of medication in eating behavior through the themes school and homework, managing eating,

chores, and conversations. Future research should explore the processes that promote resilience in families of children with autism.

### Compliance with Ethical Standards

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all adult individual participants included in the study. Assent was obtained from all individual participants included in the study who were under the age of 18.

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