Selective Eating in Autism Spectrum Disorder: Child and Parent Factors

DISSERTATION

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Abstract

Selective eating is a significant problem for many children with ASD and their families. An estimated 46-89% of children with ASD have feeding problems (Ledford & Gast, 2006); food refusal and limited acceptance are the most commonly reported as the most common (Schreck & Williams, 2006). Although there is currently no standard definition, selective eating has been described as a combination of limited food variety and a high rate of food refusal (Bandini et al., 2010). Children with selective eating may have nutritional deficiencies due to their limited dietary variety (Zimmer et al., 2012). Selective eating has been primarily referred to as a discreet challenging or repetitive behavior in the intervention literature (Sharp et al., 2010); however, children with selective eating can have additional challenging behaviors which may complicate their clinical picture (Johnson et al., 2014). In addition, parents of children with ASD may be at risk for increased parenting stress, depression symptoms, and mental health problems due to their child’s feeding problems (Davis & Carter, 2008; Estes et al., 2009). The discovery of factors associated with selective eating can help determine appropriate treatment targets. The objective of this dissertation is to determine child and parent factors associated with selective eating, both through a scoping review of the literature and through a cohort study of a sample of children with ASD ages 4-10 and their parents. Results of the scoping review and the cohort study indicate that selective eating is a
multifaceted problem that warrants comprehensive, interdisciplinary assessment and intervention that takes the family context into account. Each child’s health status, sensory reactivity, psychosocial well-being, and physiological features should be considered along with selective eating and related challenging behaviors. Future research is needed to explore factors intrinsic to the child that are associated with selective eating, such as oral motor difficulties and stress responses during the presentation of new foods. In addition, the long-term impacts of selective eating on health and participation should be studied. Additional studies are also needed to understand attitudes of parents toward their child’s selective eating, the development of coping styles, and physiological correlates of stress during mealt ime.
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Chapter 1: General Introduction

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a neurodevelopmental disability characterized by qualitative impairments in social communication skills as well as the presence of restricted and repetitive behaviors and interests (American Psychiatric Association, 2013). Prevalence for ASD was estimated at 1 in 68 children in the United States for the year 2010 (Centers for Disease Control, 2014). The etiology of the disorder is unclear at this time, but it is likely to be the result of a complex interaction between genes and the environment. ASD is a disorder that requires intervention throughout the lifespan. Children with ASD access the healthcare system more frequently than typical children, resulting in a significantly higher cost of care (Liptak et al., 2006). The majority of children with ASD also receive special education services, which they may continue to receive until age 21. Overall, the estimated per capita lifetime expenses for ASD are estimated to be $3.6 million, with the most significant contributions arising from loss of productivity and adult care (Ganz, 2007). ASD thus presents a significant challenge not only for those who are affected by it, but also for society as a whole. It is important to develop interventions that are effective at a young age because they may result in decreased cost to society and better outcomes for youth and adults with ASD.
Impact of Selective Eating in ASD

Selective eating, which has been conceptualized as a combination of food refusal and limited acceptance (Bandini et al., 2010), is one problem that many children with ASD and their families encounter. Feeding problems are estimated to occur in 46-89% of children with ASD (Ledford & Gast, 2006), with food refusal and limited acceptance reported as the most common (Schreck & Williams, 2006). Although selective eating is common in typically developing toddlers (Carruth et al., 2004), the odds that a child with ASD will have selective eating are increased fivefold in comparison to other populations of children (Sharp et al., 2013). Selective eating decreases with age for both typically developing children and those with ASD (Bandini et al., 2010). However, children with ASD continue to eat fewer foods than typically developing children even beyond toddler age (Williams et al., 2008; Zimmer et al., 2012). Thus, selective eating is more than a developmental phase for most children with ASD.

Selective eating can result in negative effects on children’s health. Although these effects are not yet fully understood, the health and wellness for children with selective eating are at risk with potentially lifelong consequences. Although the current literature is inconclusive (Kral et al., 2013), children with ASD may have decreased nutrient intake due to limited food acceptance (Zimmer et al., 2012). Persons with ASD, particularly those with co-occurring intellectual disability, are at increased risk for being overweight in adolescence and adulthood (Eaves & Ho, 2008; Yamaki, 2005). Eating habits which may be formed early in life are one of the factors that contribute to this risk
Mitigating the effects of inadequate nutrition can decrease the likelihood of long-term health problems.

Selective eating may also contribute to mental health issues in parents of children with ASD. Parenting stress, depression symptoms, and the risk for other mental health problems are elevated in parents of children with ASD (Bromley et al., 2004; Dumas et al., 1991). Problems with regulation, which include eating difficulties, are especially stressful for mothers of children with ASD (Davis & Carter, 2008). Challenging behaviors that accompany selective eating, such as aggression and food refusal (Matson & Fodstad, 2009; Provost et al., 2010) may interfere with the family meal time and cause additional stress for parents. Parents of children with ASD and selective eating may have stress beyond the already elevated levels expected for parents of children with ASD.

Despite potential ill effects on both the child and parents, interventions for selective eating have not been studied extensively. Current evidence-based treatments for selective eating primarily use behavioral approaches or techniques (Sharp et al., 2010; Williams & Seiverling, 2013). Interdisciplinary programs have also shown promise (Laud et al., 2009), but there is less evidence to support their effectiveness. Other interventions are used in practice but have not yet been researched. A greater understanding of the factors that influence selective eating is needed. This understanding can lead to a conceptual framework for modifying key child, parent, or contextual variables to promote food acceptance and healthy eating behaviors. Learning what factors influence selective eating may also help us identify which children are likely to benefit from certain interventions. In addition, models that identify factors common in
selective eaters may lead to the development of new treatments. Factors intrinsic to the child that may be associated with selective eating include restricted and repetitive behaviors, sensory features, anxiety, and challenging mealtime behaviors. Contextual factors include parenting stress or anxiety, parent mealtime actions, and food insecurity.

Child-Specific Factors

*Restricted and repetitive behaviors*

Restricted, repetitive, and stereotyped patterns of behaviors and interests are included in the diagnostic criteria for ASD. They include stereotyped motor movements, insistence on sameness or adherence to nonfunctional routines, highly restricted interests that are abnormal in intensity, and hyper- or hyporeactivity to sensory experiences of unusual interest in sensory aspects of the environment (American Psychiatric Association, 2013). These behaviors can interfere with an individual’s ability to engage in meaningful daily activities. In addition, there is a high correlation between the presence of restricted and repetitive behaviors and parental stress (Gabriels et al., 2005), which makes them especially important to target for intervention. Restricted and repetitive behaviors can be very diverse in their presentation (Leekam et al., 2011; DiGennaro et al., 2012). Because of the heterogeneity of the category, efforts have been made to further describe subsets of restricted and repetitive behaviors. Most generally, restricted and repetitive behaviors included in the Autism Diagnostic Interview-Revised have been conceptualized as falling into two different categories: repetitive sensorimotor behaviors and insistence on sameness (Cuccaro et al., 2003; Szatmari et al., 2006). These two types of behaviors have also been referred to as “high order” (insistence on...
sameness) and “low order” (repetitive sensorimotor behaviors) in the literature (Boyd et al., 2012). Repetitive sensorimotor behaviors include complex hand movements, rocking, and repetitive use of objects. In contrast, insistence on sameness behaviors include compulsions, rituals, and difficulty with change. The prevalence of restricted and repetitive behaviors is negatively associated with non-verbal IQ (Bishop et al., 2006). Research suggests that these two types of behavior follow different developmental trajectories, with repetitive sensorimotor behaviors remaining stable over time and insistence on sameness behaviors increasing as children get older (Richler et al., 2010).

Restricted and repetitive behaviors vary widely in presentation, and selective eating may be considered one possible manifestation. Some researchers consider selective eating to be one type of higher order restricted and repetitive behavior, while other differentiate it as a separate phenomenon due to its complexity. Repetitive behaviors are significantly correlated with challenging mealtime behaviors (Johnson et al., 2014). In addition, children with ASD and selective eating are more likely to insist on sameness in their mealtime routine (e.g. using the same dishes for every meal or having food prepared the same way) (Williams et al., 2005). Because selective eating is multifaceted, however, it is currently not known whether it can be considered to be in the same category as stereotypic or ritualistic behavior (Volkert & Vaz, 2010). It is likely that selective eating shares features of other repetitive behaviors, but additional physiological and behavioral factors add to its complexity.
Sensory reactivity

As described above, hyper- or hyporeactivity to sensory experiences and unusual interests in sensory aspects of the environment are included as one manifestation of restricted and repetitive behaviors in the diagnostic criteria for ASD. Problems with determining, processing, and responding appropriately to sensory stimuli occur in up to 95% of children with ASD (Tomchek & Dunn, 2007), and they have been implicated specifically in children selective eating. Studies have found significant relationships between scores on the Short Sensory Profile (Dunn, 1999) and measures of eating problems (Johnson et al., 2014; Lane et al., 2014; Nadon et al., 2011b). Sensory hyperreactivity (referred to in the remainder of this document as “reactivity”) may also manifest itself as problems with or preferences for certain textures, which are common in children with ASD and selective eating (Ahearn et al., 2001; Kerwin et al., 2005; Matson et al., 2009; Schmitt et al., 2008). Sensory reactivity appears to play a role in the development and maintenance of selective eating, although it has not been explored extensively in the literature.

Anxiety links repetitive behaviors and sensory reactivity

Restricted and repetitive behaviors have been linked to sensory reactivity in the literature. Scores on the Short Sensory Profile are moderately and positively correlated with the scores on several different measures of repetitive behavior, including the ADOS repetitive/restricted behavior algorithm score (Rogers et al., 2003), the Childhood Routines Inventory (Chen et al., 2009), and the Repetitive Behavior Scales-Revised (Boyd et al., 2010). It has been suggested that there may be a subgroup of individuals
with ASD who have a high incidence of repetitive behaviors as well as highly atypical sensory processing abilities (Gabriels et al., 2008). Those individuals with both autism and sensory reactivity problems may engage in repetitive behaviors as an adaptive way of dealing with the anxiety brought on by sensory challenges (Gal et al., 2010). Boyd et al. (2010) propose that restricted and repetitive behaviors are observable manifestations of anxiety or stress caused by the presence of certain sensory stimuli or experiences. The authors draw a comparison to obsessive compulsive disorder in order to illustrate this concept: in the same way that compulsions are a means of relieving anxiety caused by obsessive thoughts in individuals with OCD, restricted and repetitive behaviors may be a coping mechanism for anxiety caused sensory disturbances in individuals with autism. Anxiety may be an underlying biological link between sensory reactivity and restricted and repetitive behaviors.

The nature of the relationship between sensory reactivity and anxiety is not yet clear. Green and Ben-Sasson (2010) offer three different possible models: 1) sensory hyperresponsivity causes anxiety (primary SOR), 2) anxiety causes sensory hyperresponsivity (primary anxiety), and 3) sensory hyperresponsivity and anxiety are not causally related but are associated through diagnostic overlap or a shared risk factor (Green & Ben-Sasson, 2010). One study by Lane et al. (2012) used the primary SOR model as a foundation for analysis. The results indicated that the magnitude of physiological response to a sensory stimulus, as measured by electrodermal reactivity and salivary cortisol levels, mediates the relationship between sensory hyperresponsivity and...
anxiety in children with autism and ADHD (Lane et al., 2012). This study offers preliminary evidence that the primary SOR model may be the most accurate of the three.

Additional literature also supports the use of the primary SOR model. Anxiety causes a physiological stress response that is marked by increase sympathetic nervous system activation, or the “flight or fight” reaction. The resulting increase in sweat on the skin can be measured using skin conductance, also known as electrodermal reactivity, while an increase in heart rate can be measured using a simple heart monitor. Studies have shown that there are differential patterns of sympathetic nervous system activation in response to sensory stimuli within ASD, with some children showing a higher propensity towards stress reactivity (Schoen et al., 2008). When compared to typically developing children, children with ASD have a higher skin conductance response after an auditory tone and even at rest (Chang et al., 2012). This stress response does not only occur in the presence of sensory stimuli; heart rate studies have shown that children with ASD experience an increased stress response in response to both environmental stimuli (Kootz et al., 1982) and social interaction (Corona et al., 1998). These studies represent a small sample of the evidence pointing to the fact that at least some children with ASD have increased arousal when exposed to sensory stimuli.

Addressing anxiety surrounding the mealtime experience may be a key component of effective, comprehensive interventions for selective eating. Eating is an intense sensory experience that may be anxiety-producing for many children with ASD (Twachtman-Reilly et al., 2008). One study found that sensory sensitivity in children with ASD was a mediator for the relationship between selective eating and anxiety.
(Farrow & Coulthard, 2012). Continued research along these lines will help to determine which model of the relationships among sensory reactivity, restricted and repetitive behaviors, and anxiety is most accurate and how they affect eating habits in children with ASD. Physiological arousal may be heightened for children with ASD when they are exposed to a new or non-preferred food. Future studies should explore changes in physiological markers of stress, such as electrodermal reactivity, during mealtime.

Contextual Factors Associated with Selective Eating

*Parent mealtime actions*

Parent mealtime actions include all of the behaviors that parents use around food and mealtime that may influence how their child eats. For example, parents can model fruit and vegetable intake, set limits on snacks, allow a wide variety of foods, or prepare special meals that are different from the family meal (Hendy et al., 2009). The preparation of special meals seems to be especially indicative of feeding problems in children with and without ASD (Seiverling et al., 2011); it has been found to mediate the relationship between fussy eating and limited diet variety in children with ASD (Hendy et al., 2010). Weight status has also been explored in relation to parent mealtime actions because it is an important indicator of health. In a sample of children referred to a hospital-based feeding clinic, parents of children with ASD were more likely to use fat reduction strategies than those with other special needs or typical development (Williams et al., 2011). Parents’ actions around food and mealtime are instrumental in shaping children’s eating habits.
Parent stress and mental health

Parents of children with ASD have higher parenting stress than those with typically developing children (Darling et al., 2012; Dumas et al., 1991; Estes et al., 2009). Problems with eating and other basic “regulation” issues seem to be particularly distressing (Davis & Carter, 2008), and increased stress can contribute to mental health problems. In fact, mothers and fathers of children with ASD are at increased risk of mental health issues and may have decreased satisfaction with life (Bromley et al., 2004; Darling et al., 2012). Parent stress levels are negatively correlated with treatment outcomes in young children with ASD (Osborne et al., 2008), suggesting that reducing parent stress may improve child outcomes. However, the direction of this relationship is unclear; interventions themselves may have a positive or negative effect on parent stress levels depending on how they are implemented. Some behavioral strategies, such as physical guidance and extinction with non-removal of the spoon, are potentially harmful and therefore may be unacceptable to parents (Gentry & Luiselli, 2008; Kadey et al., 2013). Behavioral approaches that align with positive behavior supports or use “positives only” are also effective and may be less stressful for parents to implement (Binnendyky & Lucyshyn, 2009; Gentry & Luiselli, 2008). Interdisciplinary interventions for feeding also may reduce parent stress (Greer et al., 2008). Selective eating can be a source of anxiety for parents who may already have increased stress levels.
Food security status

Another additional external stressor that must be considered is food security, or a family’s ability to obtain enough food to maintain healthy lives for all members of the household throughout the year (Nord et al., 2009). Food insecurity has been defined as a state in which the ability to access nutritionally adequate and safe foods in socially acceptable ways is limited or uncertain (Anderson, 1990). It was estimated that 14.6% of households in the U.S. experienced food insecurity at some point during 2008 (Nord et al., 2009). In addition to accessing federal assistance and other emergency food supplies at an increased rate, families with food insecurity often restrict the variety of foods they consume (Nord et al., 2009). As a result, children raised in households experiencing food insecurity may be exposed to a smaller variety of foods than those raised in food secure households. In addition to affecting access to different types of foods, food insecurity leads to increased stress and may disrupt relationships between family members (Hamelin et al., 1999). Food insecurity is also related to behavior problems in children (Huang et al., 2010) and mental health problems in parents of young children (Bronte-Tinkew et al., 2007; Whitaker et al., 2006). The negative effects of food insecurity have not been explored in relation to selective eating in children with ASD, but its potential role must be considered.

Proposed model of selective eating in ASD

Researchers have attempted to identify factors that children with selective eating have in common in order to determine which may be targets for intervention. Patterns of restricted and repetitive behavior, sensory reactivity, and anxiety (as well as the
relationships among them) have been explored in children with ASD. Studies indicate that they may be key factors in the development and treatment of selective eating. In addition, contextual factors related to parent characteristics may also be associated with selective eating. Salient factors may include parent mealtime actions, stress, and mental health. Food security status is also an important consideration because it has implications on the types and amount of foods available to families.

We propose a model of selective eating that takes into account both child-specific and contextual factors (see Figure 1). Some characteristics of selective eating are readily observed; for example food preferences may result in limited diet variety as well as food refusal and other mealtime behaviors. Although there is not yet a standard definition for selective eating, we propose that measures of eating habits be used to determine one. A child’s health status may be obviously compromised due to selective eating, as in a case of vitamin deficiency, or there may be more subtle problems such as gastrointestinal distress. The child may also have increased sensory reactivity, repetitive behaviors, challenging behaviors, or anxiety that contribute to their selective eating. The context plays an important role in this model; parenting stress, parent anxiety, and household food security status form the background for the child’s mealtimes. We propose that selective eating is a complex phenomenon that is influenced by both child-specific and contextual factors. Using a comprehensive model to understand selective eating can help to describe the phenomenon more fully, refine interventions, and identify possible barriers to effective treatment.
Conclusion

Selective eating is a multifaceted problem that affects many children with ASD and their families. Current research on selective eating indicates that there may be long-term effects on health and wellness for both the child and his or her parents. Comprehensive, interdisciplinary interventions have been recommended (Johnson et al., 2014; Kral et al., 2013; Sharp et al., 2013). However, most intervention studies reported in the literature have used single-discipline behavioral interventions and have failed to measure long-term effects, generalization, and health outcomes (Sharp et al., 2010). One barrier to the development and testing of treatments for selective eating has been the complexity of the presentation. Further exploration of factors associated with selective eating is needed in order to select effective intervention components. The objective of this dissertation is to investigate and identify behavioral, social-emotional, and sensory characteristics of children with autism and their parents that are associated with selective eating. By understanding the interaction among these variables and the mediating factors that influence selecting eating, we can inform future interventions for selective eating in autism.
Figure 1. Proposed model of selective eating in ASD
Chapter 2: Factors Associated with Selective Eating in ASD: A Scoping Review

Abstract

Selective eating is a significant problem for many children with autism spectrum disorder (ASD) and their families. The purpose of this scoping review was to determine factors associated with selective eating in ASD. Our literature search and review of potential studies identified 77 studies. The following themes emerged from our analysis: the link between selective eating and ASD, relationship to child’s nutrition, weight and health, influence of sensory reactivity, behaviors associated with selective eating, behavioral interventions for selective eating, parent participation in behavioral interventions, and contextual influence of family mealtime. A comprehensive model of care for selective eating includes evaluations and interventions that change and support behavior, consider psychosocial factors, optimize health, consider sensory reactivity, and support family participation.
Background

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by qualitative impairments in social interaction and communication skills as well as the presence of restricted and repetitive behaviors and interests (American Psychiatric Association, 2013). Selective eating, which has been defined as a combination of high food refusal and limited acceptance of a variety of foods (Bandini et al., 2010), is a significant problem for many children with ASD and their families (Ledford & Gast, 2006; Schreck & Williams, 2006). Children with ASD and selective eating often have a complicated clinical presentation. Social-emotional problems, sensory reactivity, and challenging behaviors are associated with selective eating. Children with selective eating show signs of anxiety and obsessive compulsive disorder (Timimi et al., 1997). Sensory sensitivity has also been linked to both anxiety and selective eating (Farrow & Coulthard, 2012). Understanding the interaction of these various child-specific factors can lead to the development of targeted interventions aimed at addressing selective eating in children with ASD.

Contextual factors can also impact eating patterns. Mealtime is often a family event, in which family members’ behaviors and interactions influence eating and meal participation. Selective eating presents a potential strain on the family meal, particularly when a child’s behaviors are disruptive, interactions are negative, or individual special meals are prepared (Hendy et al., 2010; Williams et al., 2008). Parents of children with ASD are at risk for emotional stress and mental health problems (Bromley et al., 2004), and the child’s problems with self-regulation, such as eating difficulties, may be
particularly stressful for mothers of children with ASD (Davis & Carter, 2008).
Understanding how mealttime social interactions among family members can mediate or exacerbate selective eating patterns among children with ASD may lead to the development of strategies to remediate the effects of selective eating on family mealtine and reduce parents’ stress.

Research on selective eating in ASD has been conducted across many different professional fields, resulting in a diffuse literature without consistent definitions or standard procedures and suggesting the need for a broad research review to understand this phenomenon in ASD. Scoping reviews (Arksey & O’Malley, 2005) are a technique used to identify and map the current literature in a field, to determine the gaps in the field, and propose a conceptual map for future research efforts (Levac et al., 2010). The purpose of our scoping review is to determine factors associated with selective eating in children with ASD.

Methods

To complete our scoping review of selective eating in ASD, we used the five steps outlined by Arksey and O’Malley (2005) that were further specified by Levac et al. (2010). The 5 steps were: 1) identifying the research question, 2) identifying the relevant studies, 3) study selection, 4) charting the data, and 5) collating, summarizing, and reporting the results. Consultation is an optional final step that can be used to inform the interpretation of results.

The research question that guided our search of the literature was: Which factors have been identified in the literature as being associated with selective eating in children
with ASD? We searched PubMed, CINAHL, ERIC, and PsychInfo to identify relevant studies. The following search terms were used in various combinations: *Autism Spectrum Disorder, ASD, Autism, Autistic Disorder, pervasive developmental disorder, Asperger’s Disorder, selective eating, picky eating, feeding, and eating*. The following MeSH terms were also used: *child nutrition physiology, nutrition therapy, child nutrition disorders, child nutrition science, nutrition assessment, eating, nutritional status, and food habits*. We consulted with a medical librarian to ensure that our search strategy was thorough and precise. Our initial search yielded 1688 abstracts, which KT reviewed for broad relevance. Of those 1688 abstracts, 133 were deemed to be potentially relevant to the research question. Inclusion and exclusion criteria for the studies were developed a priori and agreed upon by both KT and JCS. Inclusion criteria were that articles pertain to selective eating in children with ASD and be published in English in peer-reviewed journals or in the grey literature from 1990-2014. Articles that addressed nutrition as a potential cause of or treatment for ASD were excluded. Each of those 133 abstracts was independently reviewed by both KT and JCS and initial agreement for inclusion and full review was 70%. After meeting twice and clarifying inclusion and exclusion criteria, 100% agreement for study selection was achieved.

After agreeing upon the final set of articles, we completed a detailed table listing study design, participants, purpose, and results. We then extracted factors identified in the studies and combined them into wider themes. We used an iterative process to determine which factors were salient for summarization and reporting.
Results

A total of 77 articles were selected for inclusion in the review. Although appraisal of articles for experimental rigor is not typically included, we noted the type of design used for each study in order to capture the nature of the current evidence. Of the 77 articles, 5 were systematic reviews or meta-analyses, 7 were non-systematic reviews of the literature, 17 were single subject designs, 10 were case studies or expert opinion, 37 were non-experimental (i.e. descriptive, associational, or comparative), and 1 was qualitative. From the factors included in each study, the following themes were identified: the link between selective eating and ASD, relationship to child’s nutrition, weight and health, influence of sensory reactivity, behaviors associated with selective eating, behavioral interventions for selective eating, parent participation in behavioral interventions, and contextual influence of family mealtime. We briefly describe the research findings for each theme.

The Link between Selective Eating and ASD

Descriptive research and systematic reviews of the literature identify an association between ASD and selective eating (Ledford & Gast, 2006; Marshall et al., 2013; Mari-Bauset et al., 2013; Sharp, Berry, et al., 2013). A meta-analysis of the literature found that the odds of selective eating increased fivefold in the population of individuals with ASD when compared to those without ASD (Sharp et al., 2013). Children with ASD are more likely to show signs of selective eating than children without disability (Bandini et al., 2010; Martins et al., 2008; Provost et al., 2010; Schmitt, et al., 2008; Schreck et al., 2004), with developmental delay, and with clinically
significant psychopathology (Beighley et al., 2013; Matson et al., 2009). In comparison to their typically developing siblings, children with ASD have been reported as either slightly more likely to be selective (Martins et al., 2008) or significantly more selective (Nadon, et al., 2011b; Schreck & Williams, 2006). In summary, children with ASD are more likely than typically developing children or those with developmental delay to have selective eating.

Parents of children with ASD report that they are selective eaters. One study of 115 children ages 4-18 with ASD found that the feeding problem reported most often by parents (58% of the time) was selective eating (Bicer & Alsaffar, 2013). Williams et al (2000) reported that 67 out of 100 parents of children with ASD surveyed reported that their child was a “picky eater.” In another survey of parents of children with pervasive developmental disorder (PDD) ages 3-17, 60% of the 89 surveyed reported that their child had “strong food preferences,” although only 6.7% endorsed that their child had a “feeding problem” (Kerwin et al., 2005).

Several studies explored whether factors such as age, cognitive level, and symptom severity relate to selective eating. Children with ASD are more likely to have selective eating when they are younger (Beighley et al., 2013; Nadon et al., 2011b) and have a history of early feeding problems (Emond et al., 2010; Provost et al., 2010; Williams et al., 2000). One study of children ages 3-11 found that the relationship between age and selective eating did not depend on ASD diagnostic status (Bandini et al., 2010). This link between age and selective eating indicates a potential developmental course for selective eating regardless of whether or not a child has ASD; i.e., selective
eating observed in early childhood becomes less of a problem in late childhood and adolescence. Interestingly, cognitive level and autism severity are not significantly related to food selectivity status (Johnson et al., 2014; Matson et al., 2009; Sharp et al., 2013).

Relationship of Selective Eating to Nutrition, Weight, and Health

Associations between selective eating and nutritional status, weight status, and health (e.g., GI problems) have been explored in the literature. Restriction of dietary intake can lead to a lack of nutrients. Case reports found in the literature highlight some of the extreme consequences of selective eating in ASD, including malnutrition (Keown et al., 2014; Tang et al., 2011), an exclusively liquid diet (Chater et al., 2012), and vitamin deficiencies including scurvy (Clark et al., 1993; Duvall et al., 2013; Monks et al., 2002; Tanoue et al., 2012). Although the effects of selective eating may not be this extreme for most children with ASD, these case studies highlight the grave nature of health concerns that may arise.

Children with ASD may also fail to maintain adequate nutrition, either in relation to a comparison group or national dietary standards. In general, as a group, children with ASD have less variety in their diet than typically developing children (Marshall et al., 2013; Williams et al., 2008; Zimmer et al., 2012). Specifically, they are less likely to eat dairy (Graf-Myles et al., 2013; Herndon et al., 2009), vegetables, salad, fresh fruit, sweets, and fizzy drinks (Emond et al., 2010; Evans et al., 2012) and more likely to consume sweetened beverages and snack foods (Evans et al., 2012). The lack of variety in foods consumed may or may not be linked to nutritional intake or to selective eating.
Both Schmitt et al. (2008) and Hyman et al. (2012) found that children with ASD had no differences in nutrient intake when compared to typically developing children. Differences between children with ASD and those with typical development may accounted for by intentional restrictions of diet (e.g. gluten-free diet) by parents (Graf-Myles et al., 2013), while differences in nutritional adequacy within groups of children with ASD are influenced by child behaviors such as limited food repertoire and challenging behaviors (Bandini et al., 2010; Johnson et al., 2014).

Findings were variable for intake of macronutrients and energy in children with ASD. Two studies found that children with ASD consumed less protein than those who were typically developing (Sharp et al., 2013; Zimmer et al., 2012), while two others found that they consumed more (Herndon et al., 2009; Levy et al., 2007). Hyman et al. (2012) found that children with ASD ate fewer calories overall than typically developing children. In contrast, Levy et al. (2007) found that children with ASD consumed average amounts of calories, carbohydrates, and fat.

Findings on micronutrient intake for children with ASD are inconsistent. Compared to typically developing children, those with ASD have been reported to consume less vitamin B12 (Zimmer et al., 2012), vitamin D (Emond et al., 2010; (Zimmer et al., 2012), vitamin A (Hyman et al., 2012), vitamin C (Emond et al., 2010; Hyman et al., 2012), and calcium (Graf-Myles et al., 2013; Herndon et al., 2009; Sharp, Berry, et al., 2013; Zimmer et al., 2012). Compared to standard recommendations, children with ASD have been reported to consume less than the recommended amounts of vitamin A (Xia et al., 2010), vitamin C (Xia et al., 2010), vitamin B6 (Bicer &
Alsaffar, 2013; Xia et al., 2010), folic acid (Xia et al., 2010), folate (Bicer & Alsaffar, 2013), zinc (Bicer & Alsaffar, 2013; Xia et al., 2010), and calcium (Bicer & Alsaffar, 2013; Xia et al., 2010). Hyman et al. (2012) reported that children with ASD met recommended levels for vitamins K and E. Comparison to dietary guidelines can be problematic, however, because many children, regardless of diagnostic status, fail to meet recommendations for fiber, choline, calcium, vitamin D, vitamin K, vitamin E, iron, or potassium (Herndon et al., 2009; Hyman et al., 2012). Children with ASD have been reported to consume more magnesium (Zimmer et al., 2012), vitamin B6, and vitamin E (Herndon et al., 2009) than typically developing peers. Iron status was of particular concern for two studies; Sidrak et al. (2014) found that children with ASD were at greater risk than typically developing children for iron deficiency and iron deficiency anemia; however, Reynolds et al. (2012) reported that only 2% of their sample with ASD consumed less than the estimated average intake. Taken together, the current literature on nutrient intake in children with ASD is mixed and is not conclusive about the nutritional status of selective eaters (Kral et al., 2013).

Weight status is another important indicator of health; among individuals ages 6-19 in the U.S., 30% are either overweight or obese (Ogden et al., 2008). Because intake of fruits and vegetables is inversely related to childhood overweight (Academy of Nutrition and Dietetics, 2014) and children with ASD are less likely to consume fruits and vegetables (Emond et al., 2010; Evans et al., 2012), one may reasonably posit a link between ASD and overweight. In support of this hypothesis, one systematic review of 44 studies noted a tendency for individuals with ASD to be overweight (Marshall et al.,
In addition, among children with feeding problems, those with high zBMI scores were more likely to have ASD and be older (Williams et al., 2008). Specifically, children with ASD were more likely to be overweight when they were between the ages of 2-5, and underweight when ages 5-11 (Hyman et al., 2012). Complicating the picture further, a study found that German males, ages 7-18 with high-functioning ASD, had significantly lower BMI percentile scores than a matched psychiatric control group (Sobanski et al., 1999).

Several studies have found a lack of difference in BMI between children with ASD and typical controls (Emond et al., 2010; Evans et al., 2012). In relation to selective eating, Hendy et al. (2010) found that the relationship between body mass index (BMI) percentile and diet variety only held for typically developing children and not for those with ASD. Researchers in China and Turkey have also explored the link between weight status and ASD. In a cohort of 111 Chinese children with ASD ages 2-9, 35 were overweight or obese (Xia et al., 2010). In a group of 115 Turkish children ages 4-18, 58% were overweight or obese, and 11% were underweight (Bicer & Alsaffar, 2013). Based on current research, children with ASD, including those with or without selective eating, do not appear to differ in weight status from typically developing children.

Researchers have also explored gastrointestinal (GI) health as it relates to selective eating. One extreme case reported in the literature revealed eosinophilic esophagitis, a chronic inflammation of the esophagus, as the cause for food refusal and other feeding problems in a 17 year old boy with ASD (Jarocka-Cyrta et al., 2011). A systematic review of the literature found that the prevalence of GI problems in children
with ASD ranges from 9 to 70%, with the most common being abdominal pain, constipation, diarrhea, and reflux (Kral et al., 2013). In Levy et al. (2007), 54% of parents reported that they observed GI problems children with ASD ages 3-8. Many GI problems are not observable, however, and assessment can be challenging when relying on report by children with low verbal skills (Kerwin et al., 2005). It seems that GI problems may play a role in food selectivity but are difficult to study in children and adolescents with low verbal skills or severe ASD. In summary, although selective eating can influence nutritional intake and may be associated with being under- or overweight, findings about these relationships are inconsistent in the research literature, limiting understanding of the influence of selective eating on health.

Influence of Sensory Reactivity

Sensory processing refers to an individual’s interpretation of and response to stimuli. Sensory hyper- or hyporeactivity is included in the DSM-V diagnostic criteria for Autism Spectrum Disorder as one type of restricted and repetitive behavior (American Psychiatric Association, 2013) and sensory processing difficulties have been estimated to occur in up to 90% of children with ASD (Tomchek & Dunn, 2007). Related to selective eating in children with ASD, Johnson et al. (2014) in a descriptive study of 256 children with ASD ages 2-11 found a strong association between sensory reactivity as measured by total score on the Short Sensory Profile (Dunn, 1999) and feeding problems as measured by the Brief Autism Mealtime Behavior Inventory (BAMBI) (Lukens & Linscheid, 2008). Two studies with smaller sample sizes also reported similar findings.
of the Eating Behaviors Questionnaire: Vision and Taste (Paterson & Peck, 2011) in a sample of 20 children with ASD. Scores on the Short Sensory Profile correlated with eating problems on the Eating Profile in a sample of 95 Canadian children with ASD (Nadon et al., 2011b). However, another study found that scores on the SSP were not associated with healthy eating for a sample that included children with ASD, other developmental disabilities, and typical development (Graf-Myles et al., 2013).

Sensory features of selective eating in children with ASD are primarily described as sensitivity to food texture (Ahearn et al., 2001; Kerwin et al., 2005; Matson et al., 2009; Schmitt et al., 2008). In addition, many children with ASD have difficulty accepting foods with developmentally appropriate textures, especially those who are younger, male, and born prematurely (Seiverling et al., 2011). Although researchers and practitioners have developed and applied interventions to help children accommodate to the sensory features of a variety of foods (e.g., Twachtman-Reilly et al., 2008), studies of these interventions have not been reported. Two narrative reviews of the literature recommend assessment of sensory processing and accommodations for sensory processing differences in interventions for selective eating in ASD (Cermak et al., 2010; Twachtman-Reilly et al., 2008).

**Behaviors Associated with Selective Eating**

Selective eating itself is often considered a challenging behavior that can appear concurrently with related challenging behaviors. For example, mouthing non-food items, resisting new foods, limiting foods based on textures, and “picky eating” behaviors were more common in children with ASD than those with typical development (Provost et al.,
2010). More severe challenging behaviors, such as aggression and choking, have also been associated with selective eating (Matson & Fodstad, 2009). Both internalizing and externalizing problems, e.g. anxiety and aggression, correlate with problem mealtime behaviors (Johnson et al., 2014). Food refusal behaviors relate to selective eating (Williams et al., 2008) or are one aspect of selective eating (Bandini et al., 2010). Restricted and repetitive behaviors also are more prevalent among children with ASD who have selective eating. A study of 256 children with ASD found a moderate significant correlation between the Repetitive Behavior Scales-Revised (Bodfish et al., 1999; Bodfish et al., 2000) and the BAMBI, indicating that children with more repetitive behaviors may have more challenging mealtime behaviors (Johnson et al., 2014). Selective eaters with ASD insist more often than selective eaters with typical development on using the same dishes or having food prepared the same way for every meal (Williams et al., 2005).

**Behavioral Interventions for Selected Eating**

Consistent with the widely held conceptualization of selective eating as a challenging behavior, the majority of interventions reported in the literature use a behavioral approach. Reinforcement is a major component of many successful interventions, whether it is positive (Freeman & Piazza, 1998; Koegel et al., 2012; Kozlowski et al., 2011), non-contingent (Allison et al., 2012), or differential (Allison et al., 2012; Valdimarsdóttir et al., 2010). Other elements of behavioral interventions include a combination of fading, prompting, and reinforcement (Freeman & Piazza, 1998; Valdimarsdóttir et al., 2010), repeated taste exposure (Paul et al., 2007), and hierarchical
exposure (Koegel et al., 2012). The combination of a high-probability request sequence combined with low-probability demand fading has also resulted in positive effects (Penrod et al., 2012). Simultaneous v. sequential presentation of foods has been investigated with positive effects noted for both methods (Ahearn, 2003; Kozlowski et al., 2011; Piazza et al., 2002). Researchers report that escape extinction with or without non-removal of the utensil has resulted in increased intake of novel foods (Allison et al., 2012; Freeman & Piazza, 1998; Kozlowski et al., 2011; Paul et al., 2007; Valdimarsdóttir et al., 2010). Alternatives to non-removal of the utensil include the use of a Nuk brush instead of a physical prompt (Kadey et al., 2013) and the use of music as reinforcement (Dellatan, 2003). Several studies looked specifically at liquid refusal problems and reported positive effects with backward chaining and fading (Hagopian et al., 1996; Luiselli et al., 2005).

Behavioral interventions successfully increase intake of a variety of foods across several different settings, including hospital-based (Seiverling et al., 2011), intensive day programs (Laud et al., 2009; Sharp et al., 2011), and inpatient units (Laud et al., 2009). Comprehensive interventions to improve feeding and eating of children with ASD in the schools are also important, although those reported in the research literature are not necessarily behavioral in nature and may include an interdisciplinary team (Twachtman-Reilly et al., 2008). Despite the effectiveness of interventions that are solely behavioral in nature, several studies have commented on the need for multidisciplinary input to address selective eating because of the complexity of associated factors (Johnson et al., 2014; Kral et al., 2013; Sharp et al., 2013).
Behavioral treatments for selective eating in children with ASD use a range of assessment methods to determine the nature of the behavior and to identify target behaviors or foods for intervention. These include parent report questionnaires, e.g. the BAMBI or the Brief Assessment of Mealtime Behavior in Children (BAMBIC) (Hendy et al., 2013), direct observation, e.g. the food preference protocol outlined by Ahearn et al. (2001), functional assessment, and functional analysis (Kodak & Piazza, 2008; Seiverling et al., 2010). A multi-method assessment that uses both information from questionnaires and observation provides a comprehensive picture of the child’s eating behaviors both at home and in the clinic (Sharp et al., 2013).

*Parent Participation in Behavioral Interventions*

Parents must be involved in eating interventions for their children, and have participated in behavioral interventions for feeding difficulties in children with ASD (Gale et al., 2011; Gentry & Luiselli, 2008; Milnes, 2012; Najdowski et al., 2010; Seiverling, 2011). The Autism MEAL Plan is a curriculum-based parent training group program with high social validity that resulted in decreased caregiver stress (Sharp et al., 2013). Other interventions have been successful when conducted in the home. A parent and ABA tutor mediated intervention in the home resulted in increased acceptance of a variety of foods and decreased disruptive behavior, with gains maintained at follow-up (Gale et al., 2011). Parents have been trained to implement behavioral interventions in the home that include differential reinforcement of alternative behavior, non-removal of the spoon, and demand fading with resulting increased acceptance of non-preferred foods and decreased problem mealtime behaviors (Najdowski et al., 2003; Najdowski et al.,
Parents have also been taught to conduct repeated taste exposure, fading, and escape extinction in the home, resulting in fewer disruptive behaviors and less time from presentation of the bite to acceptance (Seiverling, 2011). Gentry and Luiselli (2008) found that a child’s consumption of previously rejected foods increased when antecedent and positive reinforcement procedures were implemented by a parent in the home. In a 2012 study, Milnes extended the work of Gentry and Luiselli and found similarly positive results in 2 out of 3 participants (Milnes, 2012). Following training, parents can implement behavioral interventions with positive effects on their children’s selective eating. However, randomized trials and long term results of these interventions have not been reported. In addition, the effects of many of these interventions on parent stress and family interactions have not been reported.

**Contextual Influence of Family Mealtime**

The family context can have an impact on selective eating in children with ASD. Parents of children with ASD report more concerns about their children’s diet than those with typically developing children (Anderson et al., 2012), even when nutritional intake may be similar between groups (Lockner et al., 2008). These concerns begin early in life, tend to increase around the child’s first birthday (Provost et al., 2010) and may be accompanied by parental stress (Anderson et al., 2012). In a qualitative study of mothers’ experiences of mealtime, participants described “coming to terms” with their child’s feeding challenges and learning to cope over time (Rogers et al., 2012). Parent concerns about selective eating can be highly stressful but may become less salient as the child grows and parents learn strategies to manage nutrition and food selectivity.
Interactions between parent mealtime actions and child eating patterns have also been explored in the literature. Feeding problems in children are associated with “overly permissive” actions such as inconsistent expectations of eating during mealtimes and the preparation of special meals (Seiverling et al., 2011). Special meal preparation is also associated with diet variety and fussy eating (Hendy et al., 2010), while lower variety in children’s diets is associated with parents using food as a reward for eating (Williams et al., 2008). Because these studies are descriptive in nature, it is not known whether child behavior influences parent behavior or vice versa; however, it is likely the influence is bidirectional. Family preferences may influence the food a child selects more than diagnostic characteristics (Schreck & Williams, 2006), although children with ASD have more mealt ime problems than their typically developing siblings (Nadon et al., 2011a). The family context plays an important role in shaping a child’s eating behavior; however, the research literature has not fully elucidated how family mealtime context influences individual child behaviors.

Discussion

The results of our scoping study suggest that selective eating in children with ASD is a multifactorial phenomenon that extends beyond the bounds of challenging behavior to relate to health, participation in mealt ime, and family dynamics. Selective eating is not an isolated challenging behavior; rather, it is associated with other behavioral difficulties (both internalizing and externalizing), sensory reactivity, and risk for diet-related health conditions, GI problems, and family stress. Given the complexity of the problems, interdisciplinary approaches are needed to assess for and intervene to
improve selective eating in children with ASD. A comprehensive model of care
considers the physiology, behavior, health, nutrition, and psychosocial context as factors
associated with selective eating and essential outcomes of an intervention program.

Current evidence-based practices for selective eating in ASD are primarily
behavioral techniques. Behavioral interventions have been examined using single-subject
research designs with limited rigor and limited generalizability. These small sample
studies have investigated individualized protocols that use specific behavioral techniques
(Sharp et al., 2013). In addition, most studies did not include measurement of food
variety, weight status, oral motor skills, generalization of treatment effects and long-term
follow up (Sharp et al., 2010). Many interventions took place in the home and therefore
had high social validity. However, generalization of the findings to other settings or
beyond the intervention period requires additional study. In addition, some behavioral
techniques, such as escape extinction, non-removal of the spoon, and physical guidance,
have been characterized as ineffective at best and potentially harmful at worst (Gentry &
Luiselli, 2008; Kadey et al., 2013). Behavioral interventions may work in isolation for
specific target behaviors, but further work is needed to incorporate known information
about the many factors associated with selective eating into a comprehensive model of
care. Other interventions are used in practice, but they have not been studied. Studies
that examine the effects of these holistic interventions that include elements that consider
sensory, motor, and health-related factors are needed. Results from the present study
may lead to a better understanding of the types of interventions that should be developed
or further investigated.
Children with ASD seem to be at a greater risk for selective eating patterns that are linked to sensory reactivity and restricted and repetitive behaviors (Boyd et al., 2010; Rodgers et al., 2012). In addition, sensory hyper-reactivity also can relate to increased anxiety (Lane et al., 2012). Although the nature of these relationships are unclear at this time, these studies indicate that anxiety, sensory reactivity, and repetitive behaviors, which are all associated with selective eating, may be interrelated. Johnson et al. (2014) recommend that multidisciplinary teams assess and consider the child’s sensory reactivity, anxiety, and repetitive behaviors when planning an intervention program for selective eating. For example, the authors suggest that the team may decide to “honor” the child’s mealtime rituals to prevent increasing the child’s anxiety.

Specific health outcomes, particularly long-term outcomes, have not been identified in the research literature despite the potential effect of selective eating on nutrition and health in children with ASD. Our review included 1 longitudinal study (Emond et al., 2010) and 5 included adolescents (Bicer & Alsaffar, 2013; Beighley et al., 2013; Kerwin et al., 2005; Matson et al., 2009; Sobanski et al., 1999). Although parents express concerns, measures of nutritional intake in children with ASD when compared to children without ASD have been inconsistently applied with mixed interpretation of nutritional deficits, making it difficult to interpret the nutritional outcomes for children with ASD and more specifically those with selective eating. Gastrointestinal (GI) problems, primarily reported by caregivers, may influence or result from selective eating. These problems are difficult to detect in children with significant communication challenges (i.e., those with low verbal or cognitive skills); therefore, conclusions about
the influence of GI problems remains elusive. Obesity is common in young adults with ASD (Eaves & Ho, 2008) and those with intellectual disability are at greater risk for obesity in adulthood (Yamaki, 2005). Eating habits are one of the factors that contribute to the disproportionate representation of overweight and obesity in individuals with developmental disabilities (Grondhuis & Aman, 2013). Weight status does not appear to differ in children with ASD as compared to typically developing children; long term studies that use consistent standards for measurement, comparison, and definition of selective eating are needed to fully understand the health outcomes of individuals with ASD and selective eating. Few researchers have clearly defined their criteria for selective eating, limiting comparisons between children with ASD who have and do not have selective eating. A gold standard definition of selective eating is needed in order to truly understand the impact of limited dietary variety on nutrition and health. Because of the health risk that selective eating may carry, it is important that nutrition be monitored in children with selective eating. Assessments and interventions for children with ASD and selective eating should include a nutritional component, with a registered dietitian as part of the interdisciplinary team to ensure adequate nutrition. A pediatric gastroenterologist can offer valuable insight on how GI issues may play a role in the diagnosis and treatment of selective eating. Primary care physicians can also play an important role in monitoring progress and health over time.

Parents and other family members play a major role in understanding, assessing, and developing an effective intervention plan for selective eating in a child with ASD. Family routines and habits influence the eating behaviors of children and positive
interactions among family members may result in increased participation in mealtime, including appropriate social behaviors and eating a variety of foods. The relationships between selective eating and parent actions or parent stress have not been well defined in the research literature. For example, it is not currently known how offering new foods at mealtime influence the child’s consumption of a variety of foods or how parent behaviors influence the child’s eating. Although a number of studies suggest that selective eating is not related to parental stress, qualitative studies (Rogers et al., 2012) suggest that the child’s high selectivity is stressful at times and that some parents are more concerned about their child’s eating habits than others. Some parents appear to learn how to cope with their child’s selective eating (Rogers et al., 2012) while others continue to struggle as their child ages. The process of intervening itself may be stressful for many parents, and those that are parent-implemented might be especially stressful depending on the methods used. Interventions that use positive behavioral supports (Binnendyk & Lucyshyn, 2009) or a “positives only” approach (Gentry & Luiselli, 2008) may promote positive interactions between parents and children.

Further research needs to be conducted to elucidate how parent attitudes toward food can transfer into actions that may affect child eating habits. In addition, more research is needed on parent stress and parent satisfaction, especially related to the intervention process for selective eating. Understanding patterns of coping and adaptation may lead to interventions that are family-centered and provide supports for parents to manage behaviors. Interventions that consider the participation of all family members in mealtime can promote social interaction during and optimize this family
routine. The evaluation process for selective eating in ASD should include a discussion of mealtime structure and expectations for the family as well as screening for parent stress. If interventions are conducted outside the home, factors that may support or challenge the successful transfer of skills from the intervention setting to the home and other settings should be considered.

While evidence-based behavioral techniques should be included in a comprehensive treatment plan as appropriate, other intervention strategies may be included as well. For most children, multiple strategies are needed for optimal results. Evidence-based behavioral strategies, such as positive reinforcement, chaining, and demand fading, may be paired with positive behavior supports, such as visual supports and “mystery motivators” (Binnendyk & Lucyshyn, 2009). Nutrition must be assessed and supplements considered (Geraghty et al., 2010). An intervention plan needs to include strategies to reduce sensory reactivity and improve related behaviors as these affect eating. Interventions should take place in the natural setting or home and involve parents whenever possible to promote transfer and generalization of skills. Additional and more rigorous research is needed to determine the effectiveness of comprehensive interventions to improve selective eating in children with ASD (Johnson et al., 2014; Mari-Bauset et al., 2013; Sharp, Berry, et al., 2013).

Limitations

We limited our search to articles published in English in peer-reviewed journals or the grey literature from 1990-2014. We did not include articles on adolescents or
adults, although they were included if there were children in the sample as well. Due to the nature of the scoping review, we did not exclude articles based on study design or rigor. The wide range of types of articles included contributed to difficulties with collating results. Although we did broadly report the types of studies included, we did not appraise each article’s scientific rigor, which is typical for a scoping review. Because of this, it may be difficult to draw conclusions about the strength of evidence for particular interventions.

Conclusions

In conclusion, selective eating is a significant issue for many children with ASD and their families. Although behavioral, sensory, and health risks are associated with reduced dietary variety, studies report inconsistent findings for how these factors are associated with selective eating. Parents of children with ASD are concerned about their children’s eating habits, and can play an integral role in intervention programs for selective eating. Current evidence-based practices for selective eating are primarily behavioral in nature and may fail to take into account many of the underlying factors identified in the literature. Because selective eating in ASD is a complex, multifaceted behavior, an interdisciplinary and comprehensive model of care is needed. Future research should focus on defining selective eating, understanding parent factors and the family context, and evaluating the effectiveness of holistic methods of assessment and intervention.
Chapter 3: Child Factors Associated with Selective Eating in ASD

Abstract

Many children with autism spectrum disorder (ASD) have selective eating, which may put them at risk for health problems such as malnutrition or gastrointestinal complications. In order to provide effective treatments, we must have a clear understanding of the factors associated with selective eating. However, the lack of a standard definition for selective eating in the literature has made it difficult to compare reports across researchers and professional fields. The objectives of this study were to examine a new definition of selective eating, to compare behavioral measures between children with ASD and selective eating and those without selective eating, and to determine relationships among behavioral measures and measures of selective eating. We hypothesized that grouping participants using a standard definition would result in significant differences between groups on measures of food acceptance and refusal as well as in challenging behaviors, anxiety, repetitive behaviors, and sensory reactivity, and that behavioral variables would be highly correlated with measures of food variety and refusal.

Participants were 35 children with ASD ages 4-10 who were assigned to selective and non-selective groups based on the number of foods a parent indicated that they ate over the past year in comparison to a population-based sample. Challenging behaviors,
anxiety, repetitive behaviors, and sensory reactivity were compared between groups using one-way multivariate analysis of variance. Associations between key variables were analyzed using Pearson’s correlation coefficient.

Results indicated that members of the selective eating group ate significantly fewer foods and had significantly higher Limited Variety and food refusal rates, supporting the definition of selective eating that we used. There was no overall effect of group for behavioral differences, although between-subjects tests indicated that scores for Compulsive Behaviors were significantly lower for the selective eating group. Correlations were moderately strong among variables relating to food intake and behavioral variables, respectively, but there were no significant correlations between selective eating variables and behavioral variables. Further research is needed to validate the definition of selective eating and to identify salient factors that can be targeted in intervention.
Background

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication and the presence of restricted and repetitive patterns of behavior and interests (American Psychiatric Association, 2013). Current estimates indicate that 1 in 68 children in the U.S. have ASD (Centers for Disease Control, 2014). Selective eating, which has been defined as accepting a limited variety of foods and refusing many foods (Bandini et al., 2010) is a common problem for children with ASD (Ledford & Gast, 2006; Schreck et al., 2004). Compared to other populations, the odds that a child with ASD will have selective eating are increased fivefold (Sharp et al., 2013). Selective eating can have a negative impact on both the child with ASD and his or her family. Although the research is not conclusive, several studies have found that children with ASD may be at risk of nutritional deficits due to limited dietary variety (Emond et al., 2010; Hyman et al., 2012; Zimmer et al., 2012). Parents of children with ASD consistently report concern about their child’s eating habits (Bicer & Alsaffar, 2013; Williams et al., 2000), which may be accompanied by stress (Anderson et al., 2012; Rogers et al., 2012). Despite these potential negative impacts, long-term effects of selective eating have not yet been explored in the literature.

One reason for this paucity of studies on the effects of selective eating is the lack of an objectively measured definition that is consistently applied. Several studies have compared the dietary variety of children with ASD to those with typical development or developmental disability and concluded that those with ASD have less dietary variety and more food refusal (Bandini et al., 2010; Marshall et al., 2013; Williams et al., 2008;
Zimmer et al., 2012). Others have found that children with ASD do not meet standard recommendations for nutrient intake and dietary variety (Bicer & Alsaffar, 2013; Hyman et al., 2012; Xia et al., 2010). However, these studies have failed to separate children with ASD into those with selective eating and those without. An estimated 58-67% of parents of children with ASD report selective or picky eating in their child (Bicer & Alsaffar, 2013; Kerwin et al., 2005; Williams et al., 2000). Thus, although selective eating is a problem for many children with ASD, there are many for which it is not. A standard definition of selective eating would be helpful for further study of the phenomenon.

The clinic presentation of children with ASD and selective eating is often complex. Feeding problems have been associated in the literature with aggression, internalizing behaviors, externalizing behaviors, repetitive behaviors, anxiety, and sensory reactivity (Johnson et al., 2014; Matson et al., 2009; Nadon et al., 2011b; Paterson & Peck, 2011). This complicated presentation can lead to difficulty with identifying and applying effective interventions for selective eating. Recognizing this problem, researchers have recommended the need for multidisciplinary assessment and treatment (Johnson et al., 2014; Kral et al., 2013; Sharp et al., 2013). However, most interventions that are reported in the literature are behavioral in nature and may not take into account potential underlying causes (Kodak & Piazza, 2008; Sharp et al., 2010). A deeper understanding of the factors associated with selective eating is needed in order to develop and test holistic interventions for selective eating in ASD.
The objectives of this study were to examine a new definition of selective eating, to compare behavioral measures between children with ASD and selective eating and those without selective eating, and to determine associations between behavioral measures and measures of selective eating. We hypothesized that grouping participants using a standard definition would result in significant differences in measures of food acceptance and refusal between groups as well as in challenging behaviors, anxiety, repetitive behaviors, and sensory reactivity, and that behavioral variables would be highly correlated with measures of food variety and refusal.

Methods

Participants

This study was approved by the Institutional Review Board prior to recruitment. Study flyers were distributed to outpatient clinics and schools for children with ASD. Inclusion criteria for this study were that children be between the ages of 4 and 10 and have English speaking parents. Children who were currently in a non-oral feeding phase (e.g. using a gastrostomy tube) were excluded from the study. All participants were also screened for inclusion using the Social Communication Questionnaire (SCQ) (Rutter, Bailey, & Lord, 2003). The SCQ is a 40-item parent report screening tool for autism spectrum disorders. Cutoff scores that allow for maximum sensitivity in younger age groups were used in this study, as suggested by Corsello et al. (2007). Participants were offered a gift card for participation in the study.
**Instruments**

*Demographic information*

A demographic questionnaire captured general participant information.

*Body mass index percentile*

A portable stadiometer and electronic scale were used to measure each child’s height and weight. Children were weighed and measured three times each in light clothing (except for one child who was only able to be weighed twice), and the average of each was used to calculate z-scores for body mass index (zBMI) using the Centers for Disease Control BMI Percentile Calculator for Child and Teen (http://apps.nccd.cdc.gov/dnpabmi/).

*Food intake*

Food intake was measured using a Food Frequency Questionnaire (FFQ), which was a modified version of the Youth and Adolescent Food Questionnaire (YAQ) (Rockett et al., 1995). The FFQ contained 126 food items (with spaces to write in any other foods that the parent wished to include) and was developed based on the original Harvard Food Frequency Questionnaire (Willet, 1998). It was modified by changing questions from self-report to parent-report, adding a “NA/ don’t offer” category for all items, and splitting the category “never/less than once a month” into two categories (“never-will not eat” and “less than one time per month) (Bandini et al., 2010).

*Sensory reactivity*

Sensory reactivity was measured using the Short Sensory Profile (SSP), which is derived from the Sensory Profile (Dunn, 1999). The SSP is a 38-item parent
questionnaire designed to measure behaviors associated with abnormal sensory processing in children aged 3-10 years (McIntosh et al, 1999). A total score is given for overall sensory processing ability, as well as domain scores for the following areas: Tactile Sensitivity, Taste/Smell Sensitivity, Movement Sensitivity, Underresponsive/Seeks Sensation, Auditory Filtering, Low Energy/Weak, and Visual/Auditory Sensitivity.

Challenging behaviors

Anxiety and challenging behaviors were measured using the Child Behavior Checklist (CBCL) (Achenbach & Rescorla, 2001). The CBCL is a 118-item caregiver report measure that evaluates the frequency of a variety of behaviors. Empirically based syndrome scales, DSM-oriented scales, and broad band behavior scales are derived from parents’ responses. The appropriate form (ages 1 ½-5 or ages 6-18) was used depending on each participant’s age. Only variables that are included on both the versions were included in analysis.

Mealtime behaviors

Mealtime behaviors were measured using the Brief Assessment of Mealtime Behavior in Children (BAMBIC) (Hendy et al., 2013). The BAMBIC is a 10-item parent report questionnaire on mealtime behavior. It was derived from the 18-item Brief Autism Mealtime Behaviors Inventory (BAMBI) (Lukens & Linscheid, 2008) in order to improve psychometric properties and reflect its applicability to other populations. Subscales of the BAMBIC are Limited Variety, Food Refusal, and Disruptive Behavior.
Restricted and repetitive behavior

Restricted and repetitive behaviors were measured using the Repetitive Behavior Scales, Revised (RBS-R) which is a 43 item caregiver report measure (Bodfish et al., 1999; Bodfish et al., 2000). Scoring for the RBS-R was performed using the algorithm developed by Lam & Aman (2007) as part of an independent validation in a sample of individuals with ASD. The scoring algorithm yields a Total Score as well as scores for the following five domains: Ritualistic/Sameness Behavior, Stereotypic Behavior, Self-injurious Behavior, Compulsive Behavior, and Restricted Interests.

Procedures

Participants were screened for inclusion either on the phone or in person using the SCQ. Data collection took place over one or two sessions, either in the family’s home or at an outpatient visit depending on parent preference and availability. All measures were administered using standard instructions in a setting with as little distraction as possible.

Analysis

Data were analyzed using SPSS V. 21. Key variables were selected based on our hypotheses and previous literature. Total food intake was calculated by counting the total number of foods that a parent endorsed the child having eaten over the past year on the FFQ and subtracting the number of beverages that they endorsed. Refusal rate was calculated by dividing the total number of foods and beverages by the number of foods offered to the child (total number of foods on FFQ subtracted by number of foods not offered). For the SSP, raw Total Score and Taste/Smell Sensitivity were analyzed. For the CBCL, T-scores were analyzed for the syndrome scales Anxiety/Depression and...
Somatic Complaints and the broad-band behavior scales Internalizing Behaviors and Externalizing Behaviors. Raw subscale scores for Limited Variety and Food Refusal were analyzed from the BAMBIC. On the RBS-R, raw total scores were analyzed for the Compulsive Behavior and Ritualistic/Sameness Behavior subscales and the Total Score. Demographic characteristics were compared between groups using paired t-tests for continuous variables (SCQ score, age in months, zBMI) and chi-squared for dichotomous variables (sex, race/ethnicity, respondent, food security status). Differences between groups were analyzed using one-way multivariate analysis of variance (MANOVA). Correlations between variables were analyzed using Pearson’s correlation coefficient. Statistical significance was assessed at an alpha level of .05.

Results

Parents of 45 total children responded to the flyer and were screened for inclusion. Of those who were screened, 39 qualified for the study based on inclusion and exclusion criteria. Thirty-five participants completed data collection; 4 were not able to complete due to scheduling difficulties. Parents of all but one participant reported the source of their child’s ASD diagnosis; 31 were diagnosed by an interdisciplinary team and 3 by a licensed clinician. The mean SCQ score for the sample was 19.9 (SD=4.97, range 12-32). Children ages 4-10 were eligible for inclusion in the study; the average age of participants was 81.34 months (range 49-131, SD=22.73). In the sample there were 32 males and 3 females, with 28 mothers as informants and 7 fathers. Caucasian children made up 62.9% (n=22) of the sample, 2.9% (n=1) were Asian American, 20% (n=7) were African American, and 14.3% (n=5) indicated multi-ethnicity. Ten parents (28.6% of the
sample) identified the presence of household food insecurity using a validated screening tool (Hager et al., 2010). Nineteen children in the sample were reported to have one or more comorbid conditions (see Table 1). Vitamins, minerals, herbals, or other dietary supplements were reported to be given to 19 of the children (see Table 2). Five children were on special diets at the time of the study; one was on a gluten-free diet due to Celiac Disease, one was on a dairy-free diet due to lactose intolerance, and one was on a chocolate-free diet due to gastric reflux. Two parents indicated that they did not offer their child pork products, one for health reasons and the other for religious reasons.

Assignment to Groups

Participants were assigned to the “selective” and “non-selective” groups based on the number of foods eaten yearly in comparison to a population-based sample of 872 children ages 4-11 included as part of the National Health and Nutrition Examination Survey (NHANES) 2005-2006 (Watowicz & Tanner, 2014). First, items included on the FFQ used for the present study were matched to the items included on the NHANES FFQ, which was developed based on the National Cancer Institute’s Diet History Questionnaire. We removed all beverages and any food items that were not included on the study FFQ. Next, we computed the total number of foods consumed (>0 times in the past year) by each participant in the NHANES sample. The mean number of foods eaten by children in the NHANES sample was 83.09 (SD=17.59, range 21-116). Participants in the “selective” group consumed 50 (5th %ile of foods eaten in NHANES) total foods or fewer in the past year (see Figure 2).
There were no statistically significant differences between the selective and non-selective eaters for SCQ scores, age, zBMI scores, sex, respondent, race/ethnicity, or food security status (see Table 3). We used one-way multivariate analysis of variance (MANOVA) to determine whether there were differences between groups on measures of food intake (FFQ parameters and BAMBIC scores). Results indicated a main effect of group ($F[1, 34]=14.31$, $p<.001$, Observed Power=1.00; see Table 4). Between-subjects analyses revealed that the selective eating group ate fewer total foods ($p<.001$) and had a higher rate of food refusal ($p<.001$) on average than the non-selective eating group (see Table 4). The selective eating group also had significantly higher scores on the Limited Variety subscale of the BAMBIC ($p<.001$); the difference in scores on the Food Refusal domain of the BAMBIC approached significance ($p<.082$) (see Table 4).
Table 1

*Parent-reported comorbid diagnoses*

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>No additional diagnoses</td>
<td>15</td>
</tr>
<tr>
<td>Speech and/or language delay/disorder</td>
<td>8</td>
</tr>
<tr>
<td>Attention Deficit Hyperactivity Disorder</td>
<td>3</td>
</tr>
<tr>
<td>Global Developmental Delay</td>
<td>3</td>
</tr>
<tr>
<td>Fine motor delay</td>
<td>3</td>
</tr>
<tr>
<td>Gross motor delay</td>
<td>2</td>
</tr>
<tr>
<td>Hearing loss (one participant had hearing loss in one ear, one had mild hearing loss)</td>
<td>2</td>
</tr>
<tr>
<td>Hypotonia</td>
<td>2</td>
</tr>
<tr>
<td>Learning problems</td>
<td>2</td>
</tr>
<tr>
<td>Lower extremity problems (“feet deformities,” “wears braces”)</td>
<td>2</td>
</tr>
<tr>
<td>Celiac Disease</td>
<td>1</td>
</tr>
<tr>
<td>Childhood Apraxia of Speech</td>
<td>1</td>
</tr>
<tr>
<td>Chromosome 15q11.2-13.1 Duplication Sy ndrome</td>
<td>1</td>
</tr>
<tr>
<td>Disruptive Behavior Disorder</td>
<td>1</td>
</tr>
<tr>
<td>Dyspraxia</td>
<td>1</td>
</tr>
<tr>
<td>Landau-Kleffner Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Oppositional Defiant Disorder</td>
<td>1</td>
</tr>
<tr>
<td>Sensory dysfunction</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note.* Some parents reported more than one diagnosis in addition to ASD.
Table 2

*Parent-reported use of dietary supplements*

<table>
<thead>
<tr>
<th>Vitamins, minerals, herbals, or other dietary supplements</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>No dietary supplements</td>
<td>13</td>
</tr>
<tr>
<td>Multivitamin (“gummy vitamin,” “Children’s vitamin,” “vitamins,” etc.)</td>
<td>13</td>
</tr>
<tr>
<td>Melatonin</td>
<td>5</td>
</tr>
<tr>
<td>Gummy fiber</td>
<td>3</td>
</tr>
<tr>
<td>Iron</td>
<td>2</td>
</tr>
<tr>
<td>Omega-3</td>
<td>2</td>
</tr>
<tr>
<td>Probiotic</td>
<td>2</td>
</tr>
<tr>
<td>Vit. D</td>
<td>2</td>
</tr>
<tr>
<td>Vit. B12</td>
<td>1</td>
</tr>
<tr>
<td>Ca+D3</td>
<td>1</td>
</tr>
<tr>
<td>“immune support”</td>
<td>1</td>
</tr>
<tr>
<td>“Juice Plus”</td>
<td>1</td>
</tr>
<tr>
<td>“Enhansa (curcumin)”</td>
<td>1</td>
</tr>
<tr>
<td>“Ther-Biotic Complete”</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note.* Some parents reported giving their child more than one dietary supplement.
Figure 2. Division of sample into groups
### Table 3

**Characteristics of participants by group**

<table>
<thead>
<tr>
<th></th>
<th>Selective (n=17)</th>
<th>Non-selective (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>% (n)</td>
</tr>
<tr>
<td>SCQ Score</td>
<td>19.8 (5.1)</td>
<td>20.1 (5.0)</td>
</tr>
<tr>
<td>Age in months</td>
<td>79 (22.5)</td>
<td>83.6 (23.4)</td>
</tr>
<tr>
<td>zBMI</td>
<td>59.8 (32.6)</td>
<td>72.2 (28.8)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>88.2 (15)</td>
<td>94.4 (17)</td>
</tr>
<tr>
<td>Female</td>
<td>11.8 (2)</td>
<td>5.6 (1)</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>76.5 (13)</td>
<td>50 (9)</td>
</tr>
<tr>
<td>Non-Caucasian</td>
<td>23.5 (4)</td>
<td>50 (9)</td>
</tr>
<tr>
<td>Respondent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>88.2 (15)</td>
<td>72.2 (13)</td>
</tr>
<tr>
<td>Father</td>
<td>11.8 (2)</td>
<td>28.7 (5)</td>
</tr>
<tr>
<td>Food security status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secure</td>
<td>76.5 (13)</td>
<td>66.7 (12)</td>
</tr>
<tr>
<td>Insecure</td>
<td>11.8 (4)</td>
<td>33.3 (6)</td>
</tr>
</tbody>
</table>

*Note.* No statistically significant differences between groups were observed.
Table 4

Comparison of eating parameters between groups

<table>
<thead>
<tr>
<th></th>
<th>Selective (n=17)</th>
<th>Non-Selective (n=18)</th>
<th>F(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
</tr>
<tr>
<td>Total Foods</td>
<td>36.75 (9.56)</td>
<td>73.06 (14.5)</td>
<td>75.303</td>
</tr>
<tr>
<td>Refusal Rate</td>
<td>.588 (.172)</td>
<td>.236 (.179)</td>
<td>35.471 (&lt;.001)**</td>
</tr>
<tr>
<td>BAMBIC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited Variety</td>
<td>18.41 (1.77)</td>
<td>13.56 (3.58)</td>
<td>25.335 (&lt;.001)**</td>
</tr>
<tr>
<td>Food Refusal</td>
<td>7.82 (3.81)</td>
<td>5.89 (2.47)</td>
<td>3.211 (.082)</td>
</tr>
<tr>
<td>Disruptive Behaviors</td>
<td>4.65 (2.32)</td>
<td>3.72 (1.13)</td>
<td>2.296 (.139)</td>
</tr>
</tbody>
</table>

**p<.01.
Behavioral Differences between Groups

There was no significant main effect of group for behavioral variables (F [1, 34]= 1.348, p= .263, Observed Power=0.445; see Table 5). The selective eating group had marginally higher scores on the Taste/Smell Domain of the SSP (p=.051), but not on Total Score (p=.946) (see Table 5). The non-selective group had significantly higher scores on the Compulsive Behaviors subscale of the RBS-R (p=.036), but there were no differences for Ritualistic/Sameness Behaviors (p=.387) or Total Score (.370) (see Table 5). One item on the RBS-R addresses repetitive behaviors during mealtime; there was a significant difference between groups for this item (t=7.046, p=.012). The mean score for participants in the selective group on this item was 2.235 (SD=.2191) while the mean score for participants in the non-selective group was 1.389 (SD=.2306). There were no significant differences for CBCL variables included in the analysis (Anxious/Depressed p=.608, Somatic Complaints p=.861, Internalizing Behaviors p=.684, and Externalizing Behaviors p=.273; see Table 5).
Table 5

Comparison of behavioral variables by group

<table>
<thead>
<tr>
<th></th>
<th>Selective (n=17)</th>
<th>Non-Selective (n=18)</th>
<th>F(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SSP</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Score</td>
<td>9.17 (4.6)</td>
<td>12.28 (4.38)</td>
<td>.005</td>
</tr>
<tr>
<td>Taste/Smell Sensitivity</td>
<td>120.12 (17.8)</td>
<td>120.50 (15.4)</td>
<td>4.092</td>
</tr>
<tr>
<td>RBS-R</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compulsive Behavior</td>
<td>2.52 (1.84)</td>
<td>4.5 (3.2)</td>
<td>4.773</td>
</tr>
<tr>
<td>Ritualistic/Sameness Behavior</td>
<td>8.47 (6.44)</td>
<td>10.67 (8.22)</td>
<td>.768</td>
</tr>
<tr>
<td>Total Score</td>
<td>27.12 (14.35)</td>
<td>32.44 (19.75)</td>
<td>.825</td>
</tr>
<tr>
<td>CBCL</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxious/Depressed</td>
<td>56.65 (6.16)</td>
<td>57.8 (6.73)</td>
<td>.267</td>
</tr>
<tr>
<td>Somatic Complaints</td>
<td>58.59 (8.64)</td>
<td>59.11 (8.91)</td>
<td>.031</td>
</tr>
<tr>
<td>Internalizing Behaviors</td>
<td>61.35 (9.87)</td>
<td>62.72 (9.81)</td>
<td>.169</td>
</tr>
<tr>
<td>Externalizing Behaviors</td>
<td>59.71 (7.83)</td>
<td>63.06 (9.76)</td>
<td>1.244</td>
</tr>
</tbody>
</table>

*p<.05.
Correlations among Food-Related and Behavioral Variables

Correlations among variables measuring aspects of food intake were moderate to strong overall. There were statistically significant strong relationships among measures of total foods, refusal rate, and the Limited Variety subscale of the BAMBIC ($r=\pm.642-.790$, $p<.01$; see Table 6). There were statistically significant moderate positive relationships between the Food Refusal subscale of the BAMBIC and the Limited Variety ($r=.486$, $p<.01$, see Table 6) and Disruptive Behavior ($r=.588$, $p<.01$, see Table 6) subscales of the BAMBIC. There was a statistically significant moderate positive relationship between Taste/Smell Sensitivity scores on the SSP and total foods eaten ($r=.363$, $p<.05$; see Table 6). In addition, there were statistically significant strong negative relationships between Taste/Smell Sensitivity scores and Limited Variety ($r=-.528$, $p<.01$; see Table 6) as well as Food Refusal ($r=-.419$, $p<.01$; see Table 6) scores on the BAMBIC.

Correlations among behavioral variables were also moderate to strong. There were statistically significant moderate to strong positive relationships between RBS-R Total Score and scores on subscales of the CBCL ($r=.343-.566$, $p<.01$; see Table 7). Subscales of the CBCL were strongly positively correlated with each other ($r=.547-.744$, $p<.01$; see Table 7). There were no statistically significant relationships between scores on the RBS-R or CBCL and the number of total foods eaten or refusal rate (see Table 7).
Table 6

*Relationships among food-related variables*

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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</thead>
<tbody>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Total Foods</td>
<td>–</td>
<td>-.790**</td>
<td>-.733**</td>
<td>-.284</td>
<td>-.224</td>
<td>.363*</td>
</tr>
<tr>
<td>2. Refusal Rate</td>
<td>-.790**</td>
<td>–</td>
<td>.642**</td>
<td>.324</td>
<td>.201</td>
<td>-.199</td>
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<tr>
<td><strong>BAMBiC</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Limited Variety</td>
<td>.733**</td>
<td>.642**</td>
<td>–</td>
<td>.486**</td>
<td>.298</td>
<td>-.528**</td>
</tr>
<tr>
<td>4. Food Refusal</td>
<td>-.284</td>
<td>.324</td>
<td>.486**</td>
<td>–</td>
<td>.588**</td>
<td>-.419*</td>
</tr>
<tr>
<td>5. Disruptive Behavior</td>
<td>-.224</td>
<td>.201</td>
<td>.298</td>
<td>.588**</td>
<td>–</td>
<td>-.262</td>
</tr>
<tr>
<td><strong>SSP</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Taste/Smell Sensitivity</td>
<td>.363*</td>
<td>-.199</td>
<td>-.528**</td>
<td>-.419*</td>
<td>-.262</td>
<td>–</td>
</tr>
</tbody>
</table>

*p < .05; ** p < .01.
Table 7

*Relationships among food-related and behavioral variables*

<table>
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<tr>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Total Foods</td>
<td>–</td>
<td>-0.790**</td>
<td>0.145</td>
<td>0.236</td>
<td>0.010</td>
<td>0.185</td>
<td>0.202</td>
</tr>
<tr>
<td>2. Refusal Rate</td>
<td>-0.790**</td>
<td>–</td>
<td>-0.039</td>
<td>0.012</td>
<td>-0.111</td>
<td>-0.090</td>
<td>-0.113</td>
</tr>
<tr>
<td><strong>RBS-R</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Total Score</td>
<td>0.145</td>
<td>-0.039</td>
<td>–</td>
<td>0.343*</td>
<td>0.471**</td>
<td>0.566**</td>
<td>0.460**</td>
</tr>
<tr>
<td><strong>CBCL</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Anx/Dep</td>
<td>0.236</td>
<td>0.012</td>
<td>0.343*</td>
<td>–</td>
<td>0.255</td>
<td>0.676**</td>
<td>0.475**</td>
</tr>
<tr>
<td>5. Somatic Comp.</td>
<td>0.010</td>
<td>-0.111</td>
<td>0.471**</td>
<td>0.255</td>
<td>–</td>
<td>0.744**</td>
<td>0.564**</td>
</tr>
<tr>
<td>6. Internalizing</td>
<td>0.185</td>
<td>-0.090</td>
<td>0.566**</td>
<td>0.676**</td>
<td>0.744**</td>
<td>–</td>
<td>0.642**</td>
</tr>
<tr>
<td>7. Externalizing</td>
<td>0.202</td>
<td>-0.113</td>
<td>0.460**</td>
<td>0.475**</td>
<td>0.564**</td>
<td>0.642**</td>
<td>–</td>
</tr>
</tbody>
</table>

*p<.05; **p<.01.*
Discussion

The objectives of this study were to examine a new definition of selective eating, to compare children with ASD and selective eating to those without selective eating on food-related and behavioral variables, and to examine associations between measures of food intake and behavioral variables. Our hypotheses were that there would be significant differences in measures of food refusal and acceptance as well as in challenging behaviors, anxiety, repetitive behaviors, and sensory reactivity. In addition, we hypothesized that behavioral variables would be highly correlated with food-related variables. We found evidence to support our hypothesis that there would be a significant difference between groups for variables relayed to food intake, but we did not find evidence to support our other hypotheses. Below, we discuss why this might have been the case.

The differences observed between the selective and non-selective groups lend additional support to the definition of selective eating used in the study. A gold standard definition for selective eating does not exist in the current literature (Tanner & Case-Smith, submitted) and other researchers have proposed different definitions (Bandini et al., 2010). The selective eating group had significantly lower intake of foods, higher food refusal rates, and higher Limited Variety scores on the BAMBIC. They did not have increased scores on the remaining sections of the BAMBIC. This may be due to the fact that the items included on the BAMBIC for Food Refusal and Disruptive Behavior depict actions (e.g. refusing to open one’s mouth, pushing food away) rather than simple refusal. Although refusal rates were significantly different between groups, we did not include it
in our definition of selective eating. This is primarily because of the contextual influence that repeated refusal may have over time. Parents of typically developing infants and toddlers only offer a food 3-5 times before concluding that the child does not like it (Carruth et al., 2004). Thus, although food refusal may be a feature of selective eating, it may represent parent persistence in continuing to offer new foods more than the child’s preferences.

Selective eaters in this study had significantly lower scores on the Compulsive Behaviors subscale of the RBS-R; however demonstrated no difference between groups on Total Score or Ritualistic/Sameness Behaviors. There were also no significant correlations between RBS-R scores and the total number of foods eaten or refusal rate. This is not consistent with the findings of Johnson et al. (2014), who found a significant correlation between RBS-R Total Score and Healthy Eating Index scores. However, results from several studies, including the same study mentioned previously, found that cognitive level and autism severity are not significantly related to food selectivity status (Johnson et al., 2014; Matson et al., 2009; Sharp et al., 2013). Since restricted and repetitive behaviors are negatively correlated with cognitive level (Bishop et al., 2006), the link between restricted and repetitive behaviors and selective eating is still unclear. The RBS-R has one item on repetitive behaviors during mealtime, and it is not included in Lam & Aman’s (2007) scoring algorithm. The selective group scored significantly higher on this item in comparison to the non-selective group, indicating more repetitive behaviors in this area. The repetitive behaviors of children with selective eating may
manifest in mealtime routines, eating rituals, or food selection that are not fully captured in the RBS-R.

Participants in the selective eating group had marginally lower (worse) scores in the Taste/Smell Sensitivity domain of the SSP, and no difference in SSP Total Score. This suggests that sensory reactivity for selective eaters may be limited to the gustatory and olfactory systems and is not generalized to others such as the auditory, visual, or tactile. Significant differences were not observed between groups for Anxiety or Somatic Complaints as measured by the CBCL. This may indicate that selective eating is not associated with social-emotional problems as we hypothesized. However, Johnson et al. (2014) found significant correlations between each of these measures and scores on the BAMBI. Scores on 2 out of 3 subscales of the BAMBIC, which is derived from the BAMBI, were not significantly different between groups. It may be that parent-report measures that ask about child behavior are more likely to result in the false identification of eating problems in a child than measures derived from FFQ data. In addition, the BAMBI includes a wide variety of feeding problems in addition to selective eating, so total score on the BAMBI may not be representative of selective eating status.

Variables that measured food intake were highly correlated with each other, as were those that measured sensory reactivity, repetitive behaviors, and challenging behaviors. Bandini et al., 2010, also found strong correlations between food refusal and number of foods eaten. Similarly, Johnson et al. (2014) found strong correlations between CBCL, RBS-R, and SSP scores. These results, along with those of the present study, indicate that difficulties with sensory reactivity, repetitive behaviors, and
challenging behaviors may make up a cluster of symptoms that are often seen together. This is supported by the suggestion of Gabriels et al. (2008) that there may be some individuals with ASD who have both increased repetitive behaviors and atypical sensory reactivity. It is unclear at this time whether these individuals might also have a tendency toward selective eating.

Our results indicate that it may not be possible to identify a “typical profile” of children with ASD and selective eating at this time. We cannot make generalizations about anxiety, sensory reactivity, and non-food-related challenging and repetitive behaviors in children with selective eating and ASD. That is, if a child walks into clinic and we are able to determine that he is a selective eater, we cannot say for sure whether he will also have increased anxiety or generalized sensory reactivity. Therefore, clinicians must conduct a thorough interdisciplinary evaluation of each child to assess each of these factors. In addition, potential physiological causes must also be examined. The wide range of factors that may be at play for any individual child highlights the need for a comprehensive, interdisciplinary approach to evaluation and treatment for selective eating. Several authors have highlighted the need for this type of holistic treatment (Johnson et al., 2014; Kral et al., 2013; Sharp et al., 2013). However, most of the treatments currently reported in the literature are conducted by a single discipline and primarily use behavioral principles (Sharp et al., 2010). Models for assessment and intervention that take into account sensory reactivity and psychosocial problems in addition to patterns of behavior should be developed and tested.
This study had several limitations. First, diagnosis of ASD was based on parent-report and scores on the SCQ rather than being independently validated though administration of the ADOS. Second, the small sample size resulted in decreased power for analyzing differences between groups on behavioral variables. It may also limit our ability to generalize results. Third, we used parent-report tools for all measurements. However, this is true of many similar studies due to the current lack of objective measures. Observation-based tools of food intake and related behaviors should be further developed and tested.

Future work should validate the definition of selective eating used in this study in a larger sample of children with ASD and in other populations, such as children with typical development. Further research is also needed to determine behavioral, social-emotional, and physiological factors associated with selective eating in ASD. One factor that should be explored in future studies is the role of oral motor skills in selective eating. Oral motor skills are often assessed as part of a comprehensive evaluation for children with feeding problems because it is thought that the child’s ability to chew and swallow food effectively may influence food selection. Although there is little research on the oral motor skills of children with ASD, there are motor coordination deficits in children with ASD that may be apparent even from an early age (Dziuk et al., 2007; Fournier et al., 2010; Lane et al., 2012). In addition, oral motor skills have been associated with feeding problems in children with anatomical and neurological anomalies (Field et al., 2003). Future research should explore the association between oral motor delays and selective eating in children with ASD.
In conclusion, we recommend that selective eating may be defined accurately using our cutoff of 50 foods or less consumed in the past year; however, further research is needed to validate this definition in a larger population of children with ASD and across other populations of children. Children with ASD and selective eating do not have higher rates of repetitive behavior, and may in fact have fewer compulsive behaviors than those without selective eating. They do not appear to have more anxiety or challenging behaviors, but may have more sensory reactivity to taste and smell. Interventions for selective eating in children with ASD should follow a comprehensive approach that addresses each of these factors due to the individualized, complex presentation.
Chapter 4: Parent Factors and Selective Eating

Abstract

Selective eating is a problem for many children with autism spectrum disorder (ASD) and their families. Parents of children with selective eating may be at risk for increased parenting stress and anxiety due to their child’s eating habits. Child behaviors may in turn be influenced by parent actions during mealtime and the types and amounts of food available in the home. The objectives of this study were to determine: 1) whether parenting stress and anxiety differ in parents of children with ASD and selective eating as compared to those without selective eating, 2) whether parents of children with and without selective eating and ASD differ in the frequency with which they engage in mealtime actions to encourage food intake, and 3) to determine the relationships among key variables relating to parent stress and child characteristics.

Participants included 35 parents (28 mothers and 7 fathers) of children with ASD ages 4-10. Children were assigned to selective and non-selective eating groups based on data from a food frequency questionnaire. Food security status was compared between the groups using a chi-squared test. Parenting stress, parent anxiety, and parent mealtime actions were compared between groups using a one-way multivariate analysis of variance. Associations among key variables were also explored using Pearson’s correlation coefficient.
Results indicated that parents of children with selective eating did not have increased parenting stress, anxiety, or food insecurity. They were more likely to prepare special meals for their children. Parenting stress was positively correlated with child aggression, but not with other variables. Parenting stress and general symptoms of anxiety do not appear to differ among parents of children with ASD between those with and without selective eating. Mental health needs of parents and food security status should be considered when making treatment recommendations for selective eating.
Background

Selective eating has been defined as the presence of food refusal and limited acceptance of foods (Bandini et al., 2010). Estimates indicate that 46-89% of children with autism spectrum disorder (ASD) have feeding difficulties (Ledford & Gast, 2006), with the most commonly reported being food refusal and limited acceptance (Schreck & Williams, 2006). The family context is vital to understanding selective eating in children with ASD. Family members interact during mealtime, shaping each other’s behavior. Within families, children with ASD tend to have more problems with feeding than their typically developing siblings (Nadon et al., 2011a; Schreck & Williams, 2006), although the difference may only be slight (Martins et al., 2008). In fact, although children with ASD are more likely to be selective eaters, family preferences are more influential than diagnostic status on the food that a child selects (Schreck & Williams, 2006). Parent actions surrounding food can also influence child eating behavior. Actions such as preparing special meals, using food as a reward, and not setting consistent mealtime expectations have been associated with reduced dietary variety and other feeding problems (Hendy et al., 2010; Seiverling et al., 2011; Williams et al., 2008). Parent mental health, family dynamics, and parent actions around mealtime must be taken into account in order to understand selective eating in children with ASD.

Parents of children with ASD are at risk for elevated stress and depression symptoms (Dumas et al., 1991) as well as anxiety disorders (Piven et al., 1991). Mothers in particular are at increased risk of mental health problems and parenting stress in comparison to parents of children with other developmental disabilities or typical
development (Bromley et al., 2004; Estes et al., 2009). Problems with regulation (including feeding and eating) have been reported to be particularly stressful for mothers of children with ASD (Davis & Carter, 2008). However, fathers of children with disabilities have also been reported to have more stress and less life satisfaction than those with typically developing children (Darling et al., 2012). Increased parenting stress has been associated with poorer treatment outcomes for children with ASD (Osborne et al., 2008), making it an important consideration in treatment. However, research has not yet elucidated whether there is a relationship between selective eating and parenting stress or mental health problems. Anxiety, in particular, has not been explored in parents with selective eating despite parents of children with ASD consistently reporting significant concerns about their children’s eating habits (Bicer & Alsaffar, 2013; Williams et al., 2000). One reason for this is the current lack of a standard definition for selective eating. While children with ASD are at increased risk for selective eating (Sharp et al., 2013), a significant proportion of children with ASD do not have selective eating. Most studies on selective eating, however, have compared children with ASD as a group to those with typical development or developmental disabilities (Bandini et al., 2010; Martins et al., 2008; Provost et al., 2010; Schmitt et al., 2008; Schreck et al., 2004). In order to study factors associated with selective eating, there must be clearly defined groups of children based on eating habits.

Selective eating can be understood as a type of restricted and repetitive behavior that has many other contributing factors. Restricted and repetitive behaviors are one of the core diagnostic criteria for ASD, and their presence is positively correlated with
parenting stress (Gabriels et al., 2005). Similarly, parents of children with selective eating report high anxiety during mealtime (Timimi et al., 1997). One reason that this may be is the high burden of care associated with selective eating. For example, selective eaters with ASD insist more often than selective eaters with typical development on using the same dishes or having food prepared the same way for every meal (Williams et al., 2005). They may also require a special meal that is different from the rest of the family’s meal, and may engage in challenging mealtime behaviors such as aggression and food refusal (Matson & Fodstad, 2009; Provost et al., 2010). In addition, children with selective eating are more likely to have other types of challenging behaviors (Johnson et al., 2014). Selective eating may be one contributor to increased parenting stress and anxiety in parents of children with ASD.

Family systems theory can illuminate the ways in which parents adapt to and cope with selective eating and other behaviors related to their child’s diagnosis of ASD. According to family systems theory, families must adapt when homeostasis is disrupted by a major event such as the presence of a child with a disability (Dore, 2008). Family members use coping strategies to adapt to the change in order to restore homeostasis to the system. Parents of children with ASD use different styles of coping strategies to deal with their stress (Hastings et al., 2005). There is no one coping style that is more effective than another; the style of coping that a parent adopts is not related to the amount of marital happiness, family cohesion, or family adaptability that they experience (Altiere & Kluge, 2009; Higgins et al., 2005). Selective eating is one aspect of parenting a child with ASD to which parents must adapt. It is likely that parents are able to apply coping
strategies to their child’s selective eating; in fact mealtime actions such as the preparation of special meals or encouraging a child to finish their meal may serve as coping strategies for many families.

Food security status is another factor that may affect parent mental health and mealtime dynamics. Household food security is defined as having enough food for the entire year to maintain active, healthy lives for all members (Nord et al., 2009). In contrast, food insecurity is the lack of access to nutritionally adequate and safe foods or the ability to acquire acceptable foods in socially acceptable ways (Anderson, 1990). In 2008, an estimated 14.6% of U.S. families experienced food insecurity at some point during the year (Nord et al., 2009). Food insecurity disrupts household dynamics, leading to increased stress, both overall and during mealtimes, and strained parent-child relationships (Hamelin et al., 1999). It has been shown to be associated with depression in parents of toddlers (Bronte-Tinkew et al., 2007), as well as anxiety and depression in mothers of preschoolers and behavior problems in preschool-aged children (Whitaker et al., 2006). The relationship between child behavior problems and food insecurity is mediated by parent stress (Huang et al., 2010). Thus, food insecurity is an important factor to consider when evaluating parenting stress in relation to child behavior.

In addition to the affecting the mental health of household members, food security status may also influence the types and variety of foods that are available to children. Families with food insecurity use coping strategies to deal with their lack of available food. In addition to using federal assistance programs and accessing other sources such as pantries and emergency shelters, one of the most common strategies used is restricting
the variety of foods consumed in the household (Nord et al., 2009). Thus, children who live in households experiencing food insecurity may have access and exposure to a smaller variety of foods. Because of the effects on food availability in the household, it is important to consider the potential role of food insecurity when assessing food intake.

The objectives of this study were to determine whether: 1) parenting stress and anxiety levels differ in parents of children with ASD and selective eating as compared to those without selective eating, 2) there are differences in mealtime behaviors between parents of children with ASD with or without selective eating, and 3) there are significant associations among child behavioral food intake variables and contextual variables. We hypothesized that there would be differences between groups on parenting stress and anxiety as well as the types of mealtime behaviors parents engage in. In addition, we hypothesized that there would be significant associations among variables relating to child food intake and measures of parenting stress, anxiety, and mealtime behaviors.

Methods

Participants

Institutional Review Board approval was obtained for this study prior to initiation of recruitment and data collection. Participants were recruited from outpatient clinics and schools for children with ASD via study flyers. Children who were currently in a non-oral feeding phase (e.g. using a gastrostomy tube) were excluded from the study. In addition, all children were screened for inclusion in the study using the Social Communication Questionnaire (SCQ) (Rutter et al., 2003) using cutoff scores for
younger children to allow for maximum sensitivity (Corsello et al., 2007). Participants were offered a gift card for participation in the study.

*Instruments*

*Demographic information*

A demographic questionnaire captured general participant information. A two-item screening for food insecurity (Hager et al., 2010) was also included.

*Food intake*

Food intake was measured using a modified version of the Youth and Adolescent Food Questionnaire (Rockett et al., 1995), which contains 126 food items and was developed based on the original Harvard Food Frequency Questionnaire (Willet, 1998). The food frequency questionnaire (FFQ) was modified in the following ways: questions were changed from self-report to parent-report, a “NA/ don’t offer” category was added for all items, and the category “never/less than once a month” was split into two categories (“never-will not eat” and “less than one time per month), and extra spaced were added for parents to write in additional foods as needed (Bandini et al., 2010).

*Parenting stress*

The Parenting Stress Index, Fourth Edition Short Form (PSI-4-SF) (Abidin, 2012) was used to measure parent stress. The PSI-4-SF is a 36-item parent report questionnaire. Scoring yields a Total Stress Scale as well as three domain scores: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child.
Parent anxiety

Parent anxiety was measured using the Beck Anxiety Inventory (BAI) (Beck, 1993). The BAI is a commonly used 21-question self-report screening measure for anxiety symptoms.

Parent mealtime actions

The Parent Mealtime Action Scale (PMAS) (Hendy et al., 2009) was used to measure parent actions during mealtime. The PMAS is a 31-item parent report measure that aims to identify target behaviors for parent-mediated interventions. Domains of particular interest for the population of this study include positive persuasion, use of rewards, insistence on eating, and special meals.

Child sensory reactivity

Sensory reactivity was measured using the Short Sensory Profile (SSP), which is derived from the Sensory Profile (Dunn, 1999). The SSP is a 38-item parent questionnaire designed to measure behaviors associated with abnormal sensory processing in children aged 3-10 years (McIntosh et al, 1999). A total score is given for overall sensory processing ability.

Child repetitive behaviors

Restricted and repetitive behaviors were measured using the Repetitive Behavior Scales, Revised (RBS-R) which is a 43 item caregiver report measure (Bodfish et al., 1999; Bodfish et al., 2000). A total score was obtained using the algorithm developed by Lam & Aman (2007).
**Child challenging behaviors**

Anxiety and challenging behaviors were measured using the Child Behavior Checklist (CBCL) (Achenbach & Rescorla, 2001). The CBCL is a 118-item caregiver report measure that evaluates the frequency of a variety of challenging behaviors. Domains include: Emotional Reactivity, Somatic Complaints, Withdrawn, Attention, Aggression, Sleep Problems, and Anxiety/Depression. Two separate versions of this assessment exist; one is for children ages 1 ½-5 years old and the other for ages 6-18. The appropriate form was used depending on each participant’s age. Only variables that are included on both of the versions were included in analysis.

**Procedures**

Participants were screened for inclusion either on the phone or in person using the SCQ. Data collection took place either in the family’s home or at an outpatient visit over one or two sessions, depending on parent preference and availability. All measures were administered in a standardized manner with as little distraction as possible.

**Analysis**

Data were analyzed using SPSS V. 21. Total number of foods was calculated from the FFQ by adding all foods that the parent indicated that the child ate and subtracting the number of beverages. Food insecurity was entered as a dichotomous variables; an affirmative answer (i.e. “often true” or “sometimes true”) to at least one of the two screening questions was defined as a positive screen. For the PSI-4SF, subscale T-scores were analyzed as well as a Total Score T-score. Raw total scores were entered
for the BAI, SSP, and RBS-R. For the CBCL, subscale and index T-scores were entered. Demographic characteristics were compared between groups using paired t-tests for continuous variables (child’s SCQ score, age in months, zBMI) and chi-squared for dichotomous variables (child’s sex and race/ethnicity, respondent’s sex, household food security status). Differences between groups on demographic variables was analyzed using independent samples t-tests and chi-squared. One-way analyses of variance (MANOVAs) were performed to analyze differences between groups. Relationships between variables were explored using Pearson’s correlation coefficient.

Results

Parents of 45 total children responded to the flyer and were screened for inclusion. Of those who were screened, 39 qualified for the study based on inclusion and exclusion criteria. Thirty-five participants completed data collection; 4 were not able to complete due to scheduling difficulties. All diagnoses of ASD were reported by parents to be made by licensed professionals (except one, who did not indicate where the diagnosis was made). The mean score on the SCQ for participants was 9.9 (SD=4.97, range 12-32). There were 32 boys and 3 girls in the sample, with a mean age of 81.34 months (SD=22.73 range 49-131). The sample included 22 Caucasian children (62.9%), one Asian American child (2.9%), 7 African American children (20%), and 5 children indicating multi-ethnicity (14.3%). Parents who participated in the study included 28 mothers and 7 fathers. Food insecurity was measured using a validated two question screen (Hager et al., 2010); 10 parents (28.6%) indicated the presence food insecurity. Among the sample, 19 children had one or more comorbid conditions. The majority
reported language or motor delays; however, one child had Chromosome 15q11.2-13.1 Duplication Syndrome and another had Landau- Kleffner Syndrome. Vitamins, minerals, herbals, or other dietary supplements, the majority of which were a daily children’s multivitamin, were reported to be given to 19 (54.3%) of the participants. Five parents reported that their children were on special diets at the time of the study; one was on a gluten-free diet due to Celiac Disease, one was on a dairy-free diet due to lactose intolerance, and one was on a chocolate-free diet due to gastric reflux. Two parents indicated that they did not offer their child pork products, one for health reasons and the other for religious reasons.

Children were assigned to “selective” and “non-selective” groups based on the total number of foods that parents indicated they ate on a FFQ. Those who ate 50 foods or less were categorized as “selective” relative to a population-based sample in which this number corresponded to the 5th percentile of total foods eaten (Watowicz & Tanner, 2014). There were no significant differences between groups on any demographic variables, including food security status (see Table 8).

Parent anxiety, stress, and mealtime actions by selective eating status

Differences between the selective and non-selective groups in parent anxiety and parenting stress were analyzed using MANOVA. There was no significant main effect of group (F [1, 34]= 1.503, p=.220, Observed Power=0.45; see Table 9). In addition, the scores for each group were within one standard deviation of the mean indicating sub-clinical levels of stress. Differences in parent mealtime actions between groups were also analyzed using MANOVA. Results indicated a significant main effect of group (F [1,
Tests of between-subjects effects revealed a statistically significant difference between groups for Special Meals (p<.001, see Table 10).

**Correlations among parent stress and child variables**

Associations among child behavioral variables were moderate to strong. There was a moderate negative relationship between score on the SCQ and Total Score on the SSP (r=-.398, p<.05; see Table 11) and a strong positive relationship between score on the SCQ and Total Score on the RBS-R (r=.549, p<.01; see Table 11). Total Score on the SSP was also strongly negatively related to RBS-R Total Score (r=-.425, p<.05; see Table 11) and Aggression on the CBCL (r=-.402, p<.05; see Table 11). Scores on the RBS-R and CBCL were strongly correlated with each other (r=.465-.941, p<.05; see Table 11). There were no statistically significant relationships between the total number of foods eaten and any other variable (see Table 11). Parenting stress Total Score was strongly positively correlated with Aggression (r=-.561, p<.01; see Table 11) and Externalizing (r=-.505, p<.01; see Table 11) scores on the CBCL, but not with any other child-related variables.
Table 8

*Characteristics of participating families*

<table>
<thead>
<tr>
<th></th>
<th>Selective (n=17)</th>
<th></th>
<th>Non-selective (n=18)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>% (n)</td>
<td>M (SD)</td>
<td>% (n)</td>
</tr>
<tr>
<td>Child’s SCQ score</td>
<td>19.8 (5.1)</td>
<td>88.2 (15)</td>
<td>20.1 (5.0)</td>
<td>94.4 (17)</td>
</tr>
<tr>
<td>Child’s age in months</td>
<td>79 (22.5)</td>
<td>94.4 (17)</td>
<td>83.6 (23.4)</td>
<td>94.4 (17)</td>
</tr>
<tr>
<td>Child’s Sex</td>
<td>11.8 (2)</td>
<td>5.6 (1)</td>
<td>11.8 (2)</td>
<td>33.3 (6)</td>
</tr>
<tr>
<td>Male</td>
<td>88.2 (15)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>11.8 (2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child’s race/ethnicity</td>
<td>76.5 (13)</td>
<td>72.2 (13)</td>
<td>50 (9)</td>
<td>72.2 (13)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>23.5 (4)</td>
<td>50 (9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Caucasian</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respondent</td>
<td>88.2 (15)</td>
<td>72.2 (13)</td>
<td>28.7 (5)</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>11.8 (2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>11.8 (2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food security status</td>
<td>76.5 (13)</td>
<td>66.7 (12)</td>
<td>33.3 (6)</td>
<td></td>
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<tr>
<td>Secure</td>
<td>11.8 (2)</td>
<td></td>
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</table>

*Note.* No statistically significant differences between groups were observed.
Table 9

*Comparison of parent anxiety and parenting stress by group*

<table>
<thead>
<tr>
<th></th>
<th>Selective (n=17)</th>
<th>Non-Selective (n=18)</th>
<th>F(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BAI Total Score</td>
<td>14.18 (12.46)</td>
<td>9.78 (7.82)</td>
<td>1.585</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(.217)</td>
</tr>
<tr>
<td>PSI-4SF</td>
<td></td>
<td></td>
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<tr>
<td>Parent Distress</td>
<td>53.47 (10.7)</td>
<td>48.89 (9.52)</td>
<td>1.791</td>
</tr>
<tr>
<td></td>
<td>(10.7)</td>
<td>(9.52)</td>
<td>(.190)</td>
</tr>
<tr>
<td>Parent-Child Difficult Interaction</td>
<td>55.88 (7.82)</td>
<td>56.50 (9.95)</td>
<td>.041</td>
</tr>
<tr>
<td></td>
<td>(7.82)</td>
<td>(9.95)</td>
<td>(.840)</td>
</tr>
<tr>
<td>Difficult Child</td>
<td>59.47 (8.85)</td>
<td>56.33 (10.04)</td>
<td>.957</td>
</tr>
<tr>
<td></td>
<td>(8.85)</td>
<td>(10.04)</td>
<td>(.335)</td>
</tr>
<tr>
<td>Parenting Stress Total</td>
<td>56.58 (8.31)</td>
<td>54.22 (9.54)</td>
<td>.609</td>
</tr>
<tr>
<td></td>
<td>(8.31)</td>
<td>(9.54)</td>
<td>(.441)</td>
</tr>
</tbody>
</table>

*Note.* No statistically significant differences between groups were observed.
### Table 10

*Comparison of PMAS scores by group*

<table>
<thead>
<tr>
<th></th>
<th>Selective (n=17)</th>
<th>Non-selective (n=18)</th>
<th>F(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Special Meals</strong></td>
<td>2.04 (.43)</td>
<td>1.47 (.34)</td>
<td>19.295 (&lt;.001)*</td>
</tr>
<tr>
<td><strong>Insistence on Eating</strong></td>
<td>1.43 (.70)</td>
<td>1.48 (.47)</td>
<td>.059 (.810)</td>
</tr>
<tr>
<td><strong>Positive Persuasion</strong></td>
<td>2.40 (.63)</td>
<td>2.19 (.50)</td>
<td>1.133 (.295)</td>
</tr>
<tr>
<td><strong>Use of Rewards</strong></td>
<td>1.91 (.45)</td>
<td>1.81 (.43)</td>
<td>.506 (.482)</td>
</tr>
</tbody>
</table>

*p<.05.*
Table 11

*Relationships among child and parent variables*

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Total Foods</td>
<td>–</td>
<td>.078</td>
<td>-.259</td>
<td>.125</td>
<td>.208</td>
<td>.202</td>
<td>-.083</td>
<td>-.029</td>
</tr>
<tr>
<td>2. SCQ Score</td>
<td>.078</td>
<td>–</td>
<td>-.398*</td>
<td>.549**</td>
<td>.135</td>
<td>.080</td>
<td>.020</td>
<td>.217</td>
</tr>
<tr>
<td>3. SSP Total</td>
<td>-.259</td>
<td>-.398*</td>
<td>–</td>
<td>-.425*</td>
<td>-.402*</td>
<td>-.363</td>
<td>.016</td>
<td>-.102</td>
</tr>
<tr>
<td>4. RBS-R Total CBCL</td>
<td>.125</td>
<td>.549**</td>
<td>-.425*</td>
<td>–</td>
<td>.534**</td>
<td>.465**</td>
<td>.015</td>
<td>.284</td>
</tr>
<tr>
<td>5. Aggression</td>
<td>.208</td>
<td>.135</td>
<td>-.402*</td>
<td>.534**</td>
<td>–</td>
<td>.941**</td>
<td>.312</td>
<td>.561**</td>
</tr>
<tr>
<td>7. Parent</td>
<td>-.083</td>
<td>.020</td>
<td>.016</td>
<td>.015</td>
<td>.312</td>
<td>.273</td>
<td>–</td>
<td>.844**</td>
</tr>
<tr>
<td>8. Total Score</td>
<td>-.029</td>
<td>.217</td>
<td>-.102</td>
<td>.284</td>
<td>.561**</td>
<td>.505**</td>
<td>.844**</td>
<td>–</td>
</tr>
</tbody>
</table>

*p<.05; **p<.01.
Discussion

Our findings suggest that parents of children with ASD and selective eating likely do not experience more parenting stress or anxiety in comparison to parents of children with ASD who are not selective eaters. They are more likely to prepare special meals for their children, but they are not likely to use other strategies to encourage eating such as insisting on eating, positive persuasion, or rewards. These results are contrary to our hypotheses, and may have occurred for a variety of reasons that we will discuss.

We hypothesized that parents of children with ASD and selective eating would have increased parenting stress in comparison to those without selective eating; our results indicated no differences between groups and scores within the clinically insignificant range for both groups. A recent meta-analysis of the literature found large effect sizes for the differences in stress between parents of children with ASD and both those with typical development and those with other disabilities (Hayes & Watson, 2013). However, 5 of the 15 studies included in the meta-analysis found no difference between groups (Hayes & Watson, 2013). It is not clear why there is a discrepancy between the results of studies; however, it is likely that differences in methodology, percentage of fathers included in the samples, and use of different comparison groups may play a role. The lack of elevated stress in the participants in this study may be due to the sampling method. Participants were recruited through flyers distributed through specialized schools for children with ASD and outpatient clinics, which indicates that they were likely receiving services. Parents of children who are receiving effective services for ASD may be less likely to be stressed. In addition, parents who are concerned about their
child’s eating habits may have been more likely to volunteer for the study. Concerns about selective eating, despite being often reported by parents of children with ASD (Bicer & Alsaffar, 2013; Williams et al., 2000), may be minor in relationship to concerns about other behaviors. Externalizing behaviors, especially aggression, may be more difficult to control and potentially dangerous to others, therefore making them more stressful for parents. In a study of mothers of preschool-aged children with ASD, psychological distress and parenting stress were positively correlated with the presence of problem behaviors (Estes et al., 2009). In our sample, Aggression scores were significantly positively correlated with scores on the PSI-4-SF. Repetitive behaviors in children with ASD are also associated with increased parent stress (Gabriels et al., 2005). Thus, selective eating may not result in increased parenting stress.

We also hypothesized that parents of children with ASD and selective eating would have increased anxiety in comparison to those without selective eating; again, results did not indicate a difference between groups and scores in the sub-clinical range. This lack of difference between groups may be due to several factors. First, the BAI is a general screening for anxiety symptoms and does not capture anxiety due to selective eating or other aspects of parenting. It may be that a more sensitive tool could distinguish whether aspects of selective eating cause anxiety for parents. Second, parents may not have been experiencing anxiety symptoms at that time due to being in treatment for an anxiety disorder, which are relatively common in U.S. adults (Kessler et al., 2012). Although we did not collect this information, it is likely that several of the participants have an anxiety disorder that is well-controlled with medication, psychotherapy, or a
combination of the two. Finally, we only had one parent of each child fill out the battery of assessments used in this study. It could have been that another parent or caregiver has higher stress than the one who filled out the survey; selection of which parent participated in the study may have been influenced by selection bias.

The lack of difference in parenting stress and anxiety scores between parents of selective and non-selective children may be a result of several different factors. First, children with selective eating appear to be growing and gaining weight. There was no difference between groups on zBMI, and only 1 child in the sample had a zBMI in the underweight range. Second, parents may believe that selective eating can be “treated” using supplements. Parents of children with ASD are more likely to give their child vitamin supplements (Lockner et al., 2008). Vitamins, minerals, herbals, or other dietary supplements were reported to be given to 54.3% of the participants in this study, which is consistent with the results of a survey that found 43% of parents gave vitamin supplements to their children with ASD (Green et al., 2006). Parents may use supplements to successfully assuage their concerns about their child’s limited diet variety, or they may not be concerned at all. In typically developing children, a lack of correlation has been found between parent concerns about their child’s nutrition and the presence of nutritional deficits (Koski, 2014). Finally, our sample may have been affected by selection bias. Parents with less stress or anxiety overall might have been more likely to volunteer for a study, whereas those with high stress and anxiety levels may have felt overwhelmed by the prospect.
Another interpretation of our results may be that parents are adapting well and coping with their child’s selective eating better than we expected. Just as parents cope with their child’s diagnosis, they may discover how to adapt to their child’s eating style early on. Selective eating is common in typically developing infants and toddlers (Carruth et al., 2004) and some aspects of it may persist into childhood (Carruth & Skinner, 2000). Mothers of typically developing children with selective eating cope with their child’s eating behaviors by using strategies such as continuing to offer new foods in social situations (Carruth & Skinner, 2000). Likewise, parents of children with ASD and selective eating likely develop strategies to either change or adapt to their child’s eating habits. They may discover coping skills early in life that serve them well into late childhood, since there is no effect of child age on the type of coping style that parents use (Hastings et al., 2005). Additional research is needed to understand how parents adapt to and cope with selective eating in their child with ASD.

The percentage of food insecure families in this sample (28.6%) was roughly twice the national 2008 estimate (14.7%) (Nord et al., 2009). This increased rate of food insecurity may have been due the expenses associated with having a child with ASD. Families with children with ASD ages 3-7 encounter over $45,000 per year in direct medical and non-medical costs; most of these costs are due to behavioral therapies (Ganz et al., 2007). In comparison to children without ASD, children with ASD have a threefold higher cost for medical expenses ($2757 vs $892) (Croen et al., 2006) It is difficult to assess actual out of pocket expenses for parents of children with ASD because reimbursement varies highly. However, a survey of 423 parents found that many
respondents reported financial strain as a result of providing therapy for their child with ASD; this included a decreased sense of future financial security in some parents and even bankruptcy in others (Sharpe & Baker, 2007). Thus, families of children with ASD may be at risk of food insecurity due to the high costs associated with treatment.

Household food insecurity may have also played a role in the lack of difference observed between groups. This is because families experiencing food security commonly reduce their dietary variety as a coping strategy (Nord et al., 2009). For parents in this study, selective eating may be less of a concern due to the presence of food insecurity. Food preferences are somewhat heritable, although they are also influenced by environmental factors such as parent modelling (Cullen et al., 2001; Wardle & Cooke, 2008). Foods naturally preferred by children tend to be calorically dense, such as desserts and snack foods (Skinner et al., 2002). This preference for foods dense in calories is especially pronounced in children with food neophobia (Wardle & Cooke, 2008). Households experiencing food insecurity are more likely to consume calorically dense foods because they are less expensive than lower-calorie foods (Drewnowski & Specter, 2004). Thus, the eating habits of a child with selective eating may not be concerning in a household experiencing food insecurity.

Limitations of this study included the small sample size that may not have allowed us to analyze differences between groups on parenting stress and anxiety. In addition, all measures were parent report and ASD diagnosis was not independently confirmed except by a screening tool. It should also be noted that generalization of findings to fathers may be limited since they were underrepresented in the sample.
Differences between mothers and fathers were not explored in this study, although they have been shown to have differing mealtime actions and levels of stress (Darling et al., 2012; Hendy, 2009). Another limitation of our sample is that it included only children with ASD ages 4-10. There may be unique concerns of parents with younger children or adolescents that we were unable to capture. Parent-reported selective eating appears to follow a developmental trend that may be due to either changes in dietary intake or changes in parent perspective. Selective eating is reported to be more common in young children with ASD (Beighley et al., 2013; Nadon et al., 2011a). However, eating habits may persist into adulthood and contribute to the tendency towards overweight in adults with ASD and IDD (Grondhuis & Aman, 2013). Concerns about selective eating may decrease as children become older because parents may develop coping skills to deal with their child’s eating habits over time (Rogers et al., 2012). This may be a difficult process for some, as fathers of children with ASD have less coping ability than those with typically developing children (Darling et al., 2012). As children age into adolescence, new concerns may come to the forefront. Our results may not generalize to those under 4 or over 10 years of age.

Further research is needed to determine whether there is a relationship between parent anxiety or stress and selective eating. Longitudinal studies can help to determine whether there is a change in stress over time and when parents begin to develop coping strategies. Qualitative studies of parent attitudes may help us to understand which aspects of mealtime are most stressful and how coping strategies are developed to adapt to challenging mealtime behaviors. Physiological measures (e.g. heart rate variability or
electrodermal reactivity) taken during mealtime may also help to elucidate whether there are conditions which make mealtime particularly stressful for parents.

In conclusion, parents of children with ASD and selective eating are more likely to prepare special meals for their children but they may not experience heightened parenting stress or anxiety as we hypothesized. Parents of children with ASD must be involved in interventions for selective eating, but their mental health should be monitored since they are at risk for increased stress and psychological difficulties. Household food security should be taken into account when making recommendations for treatment.
Chapter 5: Conclusion

Summary of Findings

We proposed a model of selective eating in ASD that combines child factors and contextual factors. We suggested that measures of food intake be used to develop a standard definition of selective eating to guide future research. We identified anxiety, sensory reactivity, and restricted and repetitive behaviors as important factors that are intrinsic to the child. Contextual factors included parent mealtime actions, parenting stress and anxiety, and food security status. The objective of this dissertation was to determine which behavioral, social-emotional, and sensory characteristics of children with ASD and their parents are associated with ASD. In order to reach this objective, we completed a scoping review of the literature and two cohort studies.

The results of our scoping review revealed that selective eating is common in children with ASD and it has been associated with many factors in the literature. Selective eating is common in children with ASD (Sharp et al., 2013). Parents of children with ASD consistently report concerns with their child’s eating habits (Bicer & Alsaffar, 2013; Williams et al., 2000). However, these concerns may not correlate with actual nutritional deficits (Lockner et al., 2008). Feeding problems have been associated with repetitive behaviors, challenging behaviors and sensory reactivity (Johnson et al., 2014; Provost et al., 2010). In addition, health outcomes of children with ASD have been
explored. Children with ASD are at risk for decreased intake of a variety of foods and other feeding problems, although the effect on their intake of nutrients is unclear at this time (Kral et al., 2013). GI problems appear to be common as well, although they are difficult to identify in children with low verbal skills (Kral et al., 2013). Weight status does not appear to differ between children with ASD and typically developing children, but the long-term effects of a restricted diet have not yet been studied.

The results of our cohort studies on child and parent factors associated with selective eating indicate that children with ASD and selective eating do not appear to have increased repetitive behaviors, sensory reactivity, or challenging behaviors in comparison to those without selective eating. Parents did not appear to have more parenting stress or anxiety when their child with ASD was a selective eater; however, externalizing behaviors such as aggression appear to be significantly correlated with parenting stress. The definition of selective eating used in the study was supported by significant differences in food refusal and the variety of foods eaten by children in each group.

In conclusion, our model for selective eating was supported by the results of the scoping review and partially supported by the results of the cohort studies. Further research is needed to understand the long-term impact of selective eating on individuals with ASD. Interdisciplinary evaluation and treatment necessary to identify problems at the individual level because generalizations are not fruitful for this population. Parent involvement in the treatment process is also key; special attention should be paid to the
stress and anxiety level of families, as well as food security status. Our definition of selective eating may be helpful for future studies exploring selective eating in ASD.

Limitations

Limitations of the scoping review included the fact that several of the studies used single-subject research designs or were expert opinion. Intervention studies were limited, and the majority that were reported had very small sample sizes and did not include measures of generalization or maintenance. The scoping review methodology intentionally includes a wide variety of research designs from many different fields; however, this makes it difficult to draw conclusions between studies due to different definitions and measurement.

Limitations of the cohort studies of child and parent factors associated with selective eating include the small sample size, use of parent report measures, and the fact that the ADOS was not performed on child participants. The lack of a standard definition of selective eating also may limit generalization of results.

Future Research

Future research for this project includes extension of the work and application to new population. First, the definition of selective eating used in Chapters 3 and 4 should be validated in a larger sample and in other populations of children (e.g. typically developing, feeding clinic population). Second, future studies need to explore eating habits in adolescents and adults with ASD.

With regard to parent stress and anxiety, future research should explore the roles that different types of stress play. Qualitative research on parent perceptions and
experiences may help to elucidate which aspects of their child’s eating are most stressful for parents and what role environmental stressors (e.g. food insecurity) play. Physiological measures, such as heart rate variability or electrodermal reactivity, may also help to establish whether long-term stress or child behaviors during mealtime are more troublesome for parents.

Clinical Bottom Line

Children with ASD and selective eating should be evaluated by an interdisciplinary team to determine the role of behavior, sensory reactivity, anxiety, and health-related factors. Interventions should be individualized and design should include input from multiple professionals to address the unique needs of each child. Parents should be involved in their child’s care throughout the evaluation and treatment process, and their mental health and ability to access food should be taken into account.
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Appendix A: Recruitment Flyer
Request for Participants in a Research Study
Targeting Children with Autism Spectrum Disorder

We are looking for parents and children to be a part of a study about eating habits in children with Autism Spectrum Disorder (ASD). We are looking for children ages 4 to 10 years old who either have a diagnosis of ASD or who meet a minimum ASD cutoff score, or both.

What will happen?

You will be asked to sign a consent form. Your child’s height and weight will be measured. You will be asked to answer questions about both your child and yourself. The appointment will take about one hour.

Your child’s health information and identity will be protected. You will receive a gift card in appreciation of your time and effort.

If you are interested in being a part of the study, please email Kelly.Tanner@osumc.edu or call Kelly Tanner at (614) 688-2081.
Appendix B: Consent Form
CONSENT TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

STUDY TITLE: Selective eating in autism spectrum disorder: Child and parent factors

PRINCIPAL INVESTIGATOR: Kelly Tanner, MOT, OTR/L

CONTACT TELEPHONE NUMBER: (614) 688-2081

SUBJECT’S NAME: ____________________________ DATE OF BIRTH: __________________

NOTE: The words “you” and “your” are used in this consent form. These words refer to the study volunteer whether a child or an adult.

1) INTRODUCTION

We invite you to be in this research study because you have a child with autism.

Participation is voluntary. Using this form as a guide, we will explain the study to you. If you have any questions about the study, please ask. Once you understand this study, we will ask you to decide whether you would like to participate or not. By signing this form, you agree to be in this study. If you do not want to be involved with this study, all regular and standard medical care will still be available to you here or at another institution. You also have the right to leave this study at any time, even if you agree to join now.

If this study involves a child between 9 and 10 years of age, the child will receive an explanation of the study in a separate form, called an Assent form. If they agree to be in the study, they will be asked to sign this form.

You will be given a signed and dated copy of the consent and the assent form.

2) WHY ARE WE DOING THIS RESEARCH STUDY?

This is a study to find out more about selective eating in children with autism. “Selective eating,” also known as “picky eating,” is when someone eats only a few different foods or refuses a lot of foods that are offered to them. This can be very stressful for parents, and it may lead to future health problems for the child if they do not have a healthy diet. Children with autism may try many different treatments for eating before they find one that helps them. The purpose of this study is to explore which child and parent factors are associated with selective eating in children with autism. Some of the factors we will be exploring include child challenging behaviors, sensory features, and body mass index. We will also be measuring parent stress, anxiety, and mealtimes to help us understand how parents are affected by selective eating and what they do to help their children eat. This study is necessary because we might be able to help parents find better treatments the first time or develop new treatments that work even better than current treatments.
3) WHERE WILL THE STUDY BE DONE AND HOW MANY SUBJECTS WILL TAKE PART?
   This study will be done at Nationwide Children’s Hospital and we hope to enroll 42 participants.

4) WHAT WILL HAPPEN DURING THE STUDY AND HOW LONG WILL IT LAST?
   You and your child will attend one study visit, which will take about one hour. Your child does not need to be present for the whole study visit; measurement of your child’s height and weight can take place either at the beginning or end of the visit. You will also be asked to fill out several questionnaires about both you and your child.

5) WHAT ARE THE RISKS OF BEING IN THIS STUDY?
   We believe that there is very little chance that bad things will happen as a result of being in this study. It is possible that you could feel upset when answering questions about your diagnosis or medical treatment, but it may be more likely that you find the questions or feedback process a little boring. If you do find any of the questions upsetting or don’t want to answer a question, you don’t have to, and the study coordinator will be available to discuss this with you further.

6) ARE THERE BENEFITS TO TAKING PART IN THIS STUDY?
   Although there may be no benefit to you from being in this study, we hope to learn something that could help others.

7) WHAT ARE THE COSTS AND REIMBURSEMENTS?
   All costs related to the research parts of this study will be covered by the research team.
   For your time and inconvenience, you will receive $20 per study visit up to $20.

8) WHAT HAPPENS IF BEING IN THIS STUDY CAUSES INJURIES?
   We believe that there is very little chance that injuries will happen as a result of being in this study.

9) WHAT HAPPENS IF I DO NOT FINISH THIS STUDY?
   It is your choice to be in this study. You may decide to stop being in this study at any time. If you decide to stop being in this study you must tell the Principal Investigator. If you stop being in the study, there will not be a penalty or loss of benefits to which you are otherwise entitled. If the study instructions are not followed, participation in the study may be stopped.

10) OTHER IMPORTANT INFORMATION
    If you are an employee of Nationwide Children’s Hospital or the Research Institute at Nationwide Children’s Hospital, your job or performance appraisal will not be affected in any way if you decline to participate or withdraw your consent to participate in this study.
Nationwide Children’s Hospital is a teaching hospital and we are committed to doing research. Doing research will enable us to learn and provide the best care for our patients and families. You may be asked to participate in other research studies in the future. You have the right to decide to participate or decline to participate in any future studies. We will not share your contact information with researchers outside Nationwide Children’s Hospital.

11) HOW WILL MY STUDY INFORMATION BE KEPT PRIVATE?

Information collected for this study may include information that can identify you. This is called "protected health information" or PHI. By agreeing to be in this study, you are giving permission to Kelly Tanner and the study staff to collect, use, and disclose your PHI for this research study unless otherwise allowed by applicable laws. Information collected is the property of Kelly Tanner.

The reason why this PHI is collected, and what information will be used is listed below. The PHI will only be shared with the groups listed, but if you have a bad outcome or adverse event from being in this study, the Principal Investigator and staff or other health care providers may need to look at your entire medical records. In the event of any publication regarding this study, your identity will not be revealed.

The PHI collected or created under this research study will be used or disclosed as needed until the end of the study. The records of this study will be kept for an indefinite period of time and your authorization to use or disclose your PHI will not expire.

PHI that may be used or disclosed: Names (child and parents); Address (including city, state, zipcode and county); Telephone/Fax Numbers; Birth Date; E-mail Addresses/URLs; Medical Record Numbers.

People or Companies authorized to use, disclose, and receive PHI collected or created by this research study:

- PI and study staff
- The Nationwide Children’s Hospital Institutional Review Board (the committee that reviews all human subject research)
- Nationwide Children’s Hospital internal auditors
- The Office for Human Research Protections (OHRP) (the federal government office that oversees human subject research)

Because of the need to give information to these people, absolute confidentiality cannot be guaranteed. Information given to these people may no longer be protected by federal privacy rules.

Reason(s) why the use or disclosure is being made:
This information is needed to locate medical charts and contact you in the future if needed.

You may decide not to authorize the use and disclosure of your PHI. However, if it is needed for this study, you will not be able to be in this study. If you agree to be in this study and later decide to withdraw your participation, you may withdraw your authorization to use your PHI. This request must be made in writing to the Principal Investigator at: Kelly Tanner 406 Atwell Hall 453 W. 10th Ave. Columbus, OH 43210. If you withdraw your authorization, no new PHI may be collected and the PHI
already collected may not be used unless it has already been used or is needed to complete the study analysis and reports.

12) WHOM SHOULD I CALL IF I HAVE QUESTIONS OR PROBLEMS?

If you have questions about anything while on this study or you have been injured by the research, you may contact the Principal Investigator by calling (614) 888-2081 and asking for the selective eating study, Monday – Friday, between 9am-5pm.

If you have questions, concerns, or complaints about the research; if you have questions about your rights as a research volunteer; if you cannot reach the Principal Investigator; or if you want to call someone else - please call (614) 722-2708, Nationwide Children’s Hospital Institutional Review Board, (IRB, the committee that reviews all research involving human subjects at Nationwide Children’s Hospital).
SUBJECT or SUBJECT’S PARENT OR PERSON AUTHORIZED TO CONSENT ON BEHALF OF THE CHILD (SUBJECT TO THE SUBJECT’S GENERAL MEDICAL CARE)

I have read this consent form and I have had an opportunity to ask questions about this research study. These questions have been answered to my satisfaction. If I have more questions about participating in this study or a research-related injury, I may contact the Principal Investigator. By signing this consent form, I certify that all health information I have given is true and correct to the best of my knowledge.

I have been given a copy of the Nationwide Children’s Hospital Notice of Privacy Practices. If allowed by law, I understand that my right to any information that is created or collected by Nationwide Children’s Hospital for this study can be temporarily suspended if necessary for the purposes of this research project. I also understand that my right to access to this information from this study will be reinstated upon completion of this research unless I have been told by the Principal Investigator that I will not receive study results.

I agree to participate in this study or I give permission for my child to participate in this study. I will be given a copy of this consent form with all the signatures for my own records.

CONSENT SIGNATURES

SUBJECT or SUBJECT’S LEGAL REPRESENTATIVE

DATE & TIME AM/PM

SUBJECT or SUBJECT’S LEGAL REPRESENTATIVE

Permission of the second parent not obtained because (select all that apply):

___ Not required by the IRB (risk level 1 or 2).
___ Other parent is deceased.
___ Other parent is unknown.
___ Other parent is not reasonably available.
___ Only one parent has legal responsibility for the care and custody of subject.

PERSON OBTAINING CONSENT

I certify that I have explained the research, its purposes, and the procedures to the subject or the subject’s legal representatives before requesting their signatures.

IRB Rev. 3/1/12  Page 5 of 5  Initials ________
Appendix C: Assent Form
ASSENT TO PARTICIPATE IN RESEARCH
(For Subjects 9 Years Up to 18 Years of Age)

Study Title: Selective eating in autism spectrum disorder: Child and parent factors
Study Doctor: Kelly Tanner

Subject’s Name: ___________________________  Date of Birth: _____________

You are being asked to be in a research study. Studies are done to find better ways to treat
people or to understand things better.
• This form will tell you about the study to help you decide whether or not you want to
volunteer to participate.
• You should ask any questions you have before making up your mind. You can think about it
and discuss it with your family or friends before you decide.
• It is okay to say “No” if you don’t want to be in the study. If you say “Yes” you can change
your mind and stop being in the study at any time without getting in trouble.
• If you decide you want to be in the study, an adult (usually a parent) will also need to give
permission for you to be in the study.

1. What is this study about?
This study is about why some children with autism eat fewer different kinds of foods than others.
We want to understand more about what kinds of things about a child may make them less likely
to try new foods or to always eat the same foods. We also want to understand how parents feel
about this and what they do to help their children eat.

2. What will I need to do (what will be done to me) if I am in this study?
If you are in this study, we will have one of your parents answer a lot of questions. We will also
measure your height and weight.

3. How long will I be in the study?
You will be in the study for one visit. We will talk to your parents for about an hour, and will
need to see you for about 15 minutes.
4. Can I stop being in the study?
   
   You may stop being in the study at any time.

5. What bad things might happen to me if I am in the study?
   
   We do not think that any bad things will happen to you if you are in the study. The taste test might taste a little bit bad, or it may not taste like anything. We will give you a drink of water after you taste it.

6. What good things might happen to me if I am in the study?
   
   You will not benefit from being in this study but we might learn something that could help others.

7. Will I be given anything for being in this study?
   
   You will be paid for being in the study. You and your parent will be given one gift card to Target to share.

8. Who can I talk to about the study?
   
   For questions about the study you may contact Kelly Tanner by calling (614) 688-2081 and asking for the selective eating study or at 406 Arwell Hall 453 W. 10th Ave. Columbus, OH 43221.

   To discuss other study-related questions with someone who is not part of the research team, you may contact the Institutional Review Board Office (the group that reviews all human subject research) at 614-722-2708.
Signing the assent form

I have read (or someone has read to me) this form. I have had a chance to ask questions before making up my mind. I want to be in this research study.

Signature or printed name of subject ___________________________ Date and time ___________________________ AM/PM

Investigator/Research Staff

I have explained the research to the participant before requesting the signature above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining assent ___________________________ Signature of person obtaining assent ___________________________

Date and time ___________________________ AM/PM

This form must be accompanied by an IRB approved consent form signed by a parent/guardian.

5/19/09

Page 3 of 3

Initials _____
Demographic Questionnaire

Today’s Date: ____________________

Child’s Name: ____________________   ____________________   ____________________
   First   Middle   Last

Date of Birth: ____________________   ____________________   ____________________
   Month   Day   Year

Parent’s Name: ____________________   ____________________
   First   Last

Address: ___________________________________________________________________
   Street
   ____________________   ____________________   ____________________
   City   State   ZIP

Preferred phone number: ____________________
   Which number is this?   __Home   __Work   __Cell

Child’s gender:   __Female   __Male

Child’s ethnicity:
   __Caucasian
   __Hispanic
   __Asian
   __African American
   __Native American
   __Other: ____________________

Please indicate whether the following two statements are often, sometimes, or never true:
1. Within the past 12 months we worried whether our food would run out before we got money to buy more.
   __Often true
   __Sometimes true
   __Never true
2. Within the past 12 months the food we bought just didn’t last and we didn’t have money to get more.
   ___Often true
   ___Sometimes true
   ___Never true

Please answer the following questions to the best of your knowledge.
1. Has your child been diagnosed with any of the following?
   ___Autism Spectrum Disorder
   ___Autism
   ___Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)
   ___Asperger’s Disorder

   a. At what age was your child diagnosed?

   ____________________________________________

   b. Where/by whom was your child diagnosed?

   ____________________________________________

2. Has your child been diagnosed with any other neurological, orthopedic, or psychological diagnoses?
   ___No
   ___Yes
   (specify): ________________________________________________________________

3. Has your child been diagnosed with any other developmental, behavioral, or learning disabilities?
   ___No
   ___Yes
   (specify): ________________________________________________________________

4. Does your child have any known food allergies?
   ___No
   ___Yes
   (specify): ________________________________________________________________

5. Does your child now have or have they had in the past any known food intolerances such as lactose or gluten?
6. Does your child have now have or have they had in the past any chronic gastrointestinal issues such as diarrhea, constipation, nausea or vomiting?
   __No  
   __Yes  
   (specify):________________________________________________________

7. Is your child currently or have they ever been on any special diet?
   __No  
   __Yes  
   (specify):________________________________________________________

8. Are there any foods that are not offered to your child due to religious, cultural or vegetarian reasons?
   __No  
   __Yes  
   (specify):________________________________________________________

Please list any supplements (including formulas, vitamins, etc.) or medications that your child consumes, along with the dosage:

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<th>Medication/Supplement</th>
<th>Dosage</th>
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Appendix E: Glossary
Glossary

**Antecedent:** Conditions or events occurring immediately before a target behavior.

**Backward chaining:** A procedure in which the instructor begins with the final step in a behavior chain, then teaches each previous step in sequence.

**Escape extinction:** A procedure for extinguishing a target behavior in which the learner is not permitted to escape from a situation.

**Fading:** Gradually removing a stimulus.

**Hierarchical exposure:** Gradually introducing new elements or larger amounts of a stimulus.

**High-probability request sequence:** A request sequence that contains behaviors the learner is very likely to engage in.

**Low-probability demand fading:** The gradual removal of stimuli that precede a behavior the learner is not likely to engage in.

**Mystery motivator:** A positive behavior support strategy in which the learner engages in a brief game of chance (e.g. spinning a wheel, reaching into a bag) in order to determine the type of positive reinforcement that he will receive.

**Physical prompt:** The application of a physical touch by the instructor to the learner in order to increase the probability that the learner will engage in the target behavior.

**Positive behavior supports:** A type of applied behavior analysis that focuses on the application of positive reinforcement and antecedent changes in order to promote behavior change.

**Prompting:** The application of a secondary stimulus after the presentation of a primary stimulus that increases the probability that a learner will engage in the target behavior.

**Reinforcement:** A consequence that follows a behavior and increases the probability that the learner will emit that behavior in the future.

  - **Positive reinforcement:** A stimulus which is added to increase the target behavior.
  - **Non-contingent reinforcement:** Reinforcement that occurs regardless of whether the learner engages in the target behavior.
**Differential reinforcement**: Reinforcement that is applied only when the learner engages in the target behavior.

**Differential reinforcement of alternative behavior**: Reinforcement that is only applied when the learner engages in a desired behavior that is different from the target behavior.

**Repeated taste exposure**: Repeated application of a taste stimulus to the learner.

**Sequential presentation of foods**: Presenting foods one at a time; often a novel food is presented before or after a familiar or preferred food.

**Simultaneous presentation of foods**: Presenting novel foods at the same time as familiar or preferred foods.