THE COMPARISON OF TWO PROTOCOLS EXAMINING FOOD VARIETY OF YOUNG CHILDREN (2-8 YEARS) WITH AUTISM SPECTRUM DISORDER

BY

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Abstract

Autism spectrum disorder, a neurodevelopmental disease that can cause social and behavioral difficulties, is commonly associated with repetitive behaviors. One such behavior is food selectivity. To assess food selectivity, the Bandini and Neūfood methods of determining food repertoire were compared. Data were analyzed for 74 subjects; average age was 5.28 ± 0.59 years, 57 were boys and 17 were girls. The sample was predominantly Caucasian (64.9%), and participants had an average BMI percentile of 65.04% ± 29.03%. Bandini's protocol had a mean score of 28.34 ± 8.34, while Neūfood had a mean score of 21.94 ± 6.97; the two methods' average scores were significantly different from one another [t(73) = 9.446, *p*=0.0001]. Both the Bandini and Neūfood methods were significantly correlated with Healthy Eating Index scores (r=0.466, *p*=0.0001 and r=0.339, *p*=0.004, respectively). Neither scoring method was associated with weight or BMI percentile. Higher Neūfood scores were significantly associated with a decrease in autism severity (r=-0.310, *p*=0.01), while Bandini's scores were not (r=-0.111, *p*=0.373). Neūfood scores were related to parents' perceptions of restrictiveness at a correlation that approached significance applying an adjusted p-value of 0.01 for multiple tests (r=-2.72, *p*=0.021). In contrast, Bandini's scores were not correlated with parents' perceptions of restrictiveness (r=-0.207, *p*=0.082). The data suggests the two food repertoire protocols are indicative of food- and health-related outcomes.

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Megan Murray

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Chapter 1: Introduction

Food selectivity, also known as selective eating, is commonly observed in children and adolescents and can be a source of concern for parents. It is particularly worrisome to families of children with autism spectrum disorder (ASD) because this population tends to have higher rates of food selectivity than typically developing (TD) children (1, 2). Nutrient deficiencies and unhealthy weight are immediate concerns for children who demonstrate selective eating (3, 4). Furthermore, long-term complications of childhood obesity include the development of diabetes, cardiovascular disease, hypertension, digestive diseases and joint disorders (5). Thus, it is important to create healthy eating habits in children beginning at a young age.

The eating habits of children with autism have been the focus of an extensive amount of research. For example, researchers have examined the cause of selective eating, such as heightened sensory sensitivity, texture, taste, temperature, limited oro-motor skills, gastrointestinal distress or family preferences as possible causes (6-10). Researchers have also implemented interventions to determine if improvements in food repertoire occur (11-15). For instance, techniques such as repeated exposure or modeling have been studied to determine how a child with ASD might respond to newly presented foods (15). Due to the need for additional research and the inconsistency of results, the majority of research questions remain inconclusive.

The term "food selectivity" is widely used in autism research, but there is no agreed upon definition. In addition, there is no universal method or protocol for analyzing the data. Consequently, there are discrepancies among studies, which could be a reason why results vary. For example, some studies categorize foods into the main food items and add the total number of foods to achieve a food selectivity score (1, 16, 17). Suarez and colleagues evaluated food selectivity by using a simple questionnaire to ask parents how many foods the child consumes in his or her normal diet (18). Differences in scoring systems can result in significant outcome disparities, an area which has received limited attention. Therefore, the purpose of this project was to determine how two distinct protocols evaluate food repertoire and how the results of these evaluations relate to health indicators of children with ASD.

Research questions

Primary research question

1. How do two methods determining food variety in children with ASD (ages 2-8 years) compare to one another?

Secondary research questions

1. How do the two methods used to score food variety in children with ASD (ages 2-8) relate to dietary quality measured by the Healthy Eating Index-2010 based on total score and subcomponent scores?
2. What is the relationship of the two protocols detecting food repertoire in children with ASD (ages 2-8) to child weight and body mass index percentile?
3. What is the association between the two methods establishing food variety in children with ASD (ages 2-8) and the child's autism symptom severity?
4. How do parents' perceptions of restrictiveness correlate to the two methods when determining food repertoire in children with ASD (ages 2-8 years)?

Chapter 2: Review of Literature

Autism spectrum disorder and food selectivity

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by repetitive patterns of behavior and impairments of social interaction (19). The disorder was previously divided into four separate diagnoses: autistic disorder, Asperger's disorder, childhood disintegrative disorder and the broad category of pervasive developmental disorder not otherwise specified. However, these four autism categories were recently merged into one diagnosis of ASD (20). The disorders on the spectrum range from highly functioning to caretaker-dependent. As many as 1 in 68 children are diagnosed with ASD, and the number of children diagnosed each year continues to grow (21).

Challenging eating behaviors are common in children with ASD, though not considered a diagnostic criterion (6, 10). Food selectivity, also known as selective eating, is characterized by food refusal, a diet of limited variety and high-frequency single food intake (1). Food selectivity is more common in children with ASD than in typically developing (TD) children and is not related to a child's age or sex (1, 2, 22-24). Indeed, 90 percent of caregivers reported selective eating in their child with ASD (25).

Food selectivity is the most prevalent feeding problem among children with ASD, surpassing other feeding problems, such as oral motor delays (26). The diet of a selective eater is typically high in starches, snacks and processed foods and low in fruits, vegetables and proteins (25, 27). There is a variety of contributing factors to selective eating, including behavioral characteristics and environmental influences. The objective of this paper is to examine contributors and challenges related to selective eating and explore interventions and methods of measuring food variety.

Inherent contributors affecting food selectivity

There are a number of plausible intrinsic reasons selective eating is more prevalent in children with ASD than TD children. First, heightened sensory sensitivity of foods may generate bias against particular foods (6, 18). Examples include enhanced texture, taste, temperature and aroma, as well as packaging styles of specific brand names (7, 28). Additionally, unusual sensory processing or limited oro-motor skills, such as difficulty blowing bubbles on command, may inhibit intake (8). Another potential explanation is gastrointestinal (GI) problems. One study examined the GI symptoms of children with ASD and found that those with ASD experienced more GI symptoms than TD children (37.4% vs. 14.8%, respectively) (9). Moreover, symptoms, such as constipation, were more severe in children with ASD. Finally, behavioral inflexibility may be a leading contributor to the selective eating habits of children with ASD (29).

The large spectrum of ASD diagnoses encompasses many functional levels. Two hundred fifty-six children with ASD between the ages of 2 and 11 years were studied for feeding problems, behavioral characteristics and nutritional quality (30). Researchers used the Autism Diagnostic Observation Schedule (ADOS) to determine the severity of each child's autism and the Brief Autism Mealtime Behavior Inventory (BAMBI) to rate mealtime behaviors. Researchers did not find an association between the ADOS severity score and mealtime behaviors, suggesting the severity of deficits does not impact feeding and mealtime behaviors. Similar results have been found in other studies (16, 17). On the other hand, a study examining gastrointestinal symptoms (i.e. abdominal pain, constipation, diarrhea) found that children with more severe ASD had more symptoms compared to children with less severe ASD, suggesting there could be a relation between physical symptoms and ASD severity (31). Though gastrointestinal stress has been found to increase food selectivity, it was not examined in this study, so how ASD severity and gastrointestinal stress relate to food selectivity remains unknown.

Environmental contributors to food selectivity

In addition to the inherent qualities of the child, environmental factors may contribute to the presence of food selectivity. A number of studies suggest the family's food preferences may have the greatest impact on the food sensitivity of children with ASD rather than characteristics associated with the disorder, such as repetitive behaviors or sensory sensitivity (10). Schrek and colleagues utilized a survey completed by parents of children with ASD to examine the families' diet variety (10). The results showed the fewer items the families incorporated into their diets, the less variety of foods the children with ASD consumed. However, these results may be skewed due to subjectivity. Further research was conducted to determine if there might be an association between the eating habits of children with ASD and their siblings. One cross-sectional study found children with ASD had an average of 13.3 eating problems compared to their TD siblings' average score of 5.0 in the same social environment (32). Moreover, children with ASD were more likely to eat fewer than 20 different foods compared to their siblings, and children with ASD were more selective with respect to food texture, temperature and type of recipe, which suggests the family does not impact the child's food selection. Therefore, the influence of a family's habits on the food selectivity of a child with ASD is inconclusive.

It should be noted that the vast majority of studies measuring parents' perceptions of food selectivity are subjective studies, often presented in a survey format. One study examined parents' perceptions of mealtime behaviors of preschool-aged children with ASD compared to parents’ perceptions of TD children. Parents completed 3-day food records and a questionnaire about their child’s food behaviors (33). Researchers found parents of children with ASD were more likely to report their child as a selective eater and less likely to try new things, even though both groups had similar nutrient intakes. This suggests that parents' negative perceptions of their child's intake may be a contributing factor to food selectivity measurements when using a subjective method.

Challenges associated with food selectivity

Increased food selectivity results in additional complications for children with ASD and their families (34, 35). For example, some parents of children with ASD observed their children eating foods of one color or with a specific packaging type (25). These eating habits were shown to start at a young age, as early as six months (3). Their children continued to demonstrate these "picky" patterns through the age of five; however, energy intake and growth were not adversely affected in this study (3). The dietary issues, which start at a young age in children with ASD, increase stress levels among family members and may impact the child's weight and nutrient adequacy (35).

Behavioral problems

Parents of children with ASD reported specific concerns about their child's eating habits, including food refusal, a need for consistency and problem behaviors while eating (3, 10, 36). Parents' concerns for their child's eating behavior also included pica disorder, resisting sitting at a table, throwing food, mouthing nonfood items, refusing to eat at a restaurant or school and rejecting food due to texture or temperature (3, 25, 37).

The role of the family and food selectivity in children with ASD

Parents of children with ASD experience atypical family dynamics. DeGrace examined the influence a child with ASD has on the family, irrespective of food selectivity (38). The results showed four common themes: the family revolves around the child with autism, it is difficult to experience satisfaction, the family is constantly trying to pacify the child and parents struggle to feel like a family. Moreover, when the child has difficulty consuming a balanced meal without becoming irritated, the family experiences further distress, and many parents become submissive to the desires of their child with ASD. A study revealed that parents of children with ASD and food selectivity had greater stress than parents of children with ASD without food selectivity (35). In contrast, efforts to overly control a child's intake to correct a suboptimal eating cycle may be counterproductive for the child. Multiple studies discovered parents who restricted their TD children from eating particular foods led their child to overconsume these food, resulting in weight gain (39, 40).

Body mass index in children with ASD

An additional consequence of poor food variety is suboptimal body mass index (BMI) (41). Preferential intake of foods high in energy and low in fruits, vegetables and fiber puts children at risk for excess weight gain and ultimately becoming overweight or obese (6). A survey of 42,747 adolescents, including those with ASD and TD adolescents, revealed those with a higher autism severity were more likely to be in the category of overweight or obese (4). Furthermore, these individuals were also less likely to participate in physical activity, sports or a club team. These findings are similar to results reported in other parts of the world. For example, the majority of children with ASD in Turkey are categorized as overweight or obese (23). In another study by Shmaya et al., BMI and nutrient deficiencies were collected from children with ASD and TD children (42). The researchers found children with ASD were more likely to have a higher BMI compared to TD children, despite their increased risk of nutritional deficiencies. This is particularly problematic because adolescents who have both a developmental disability and obesity are at a higher risk of respiratory, GI, dermatological and neurological conditions compared to those who have a developmental disability or are obese (43).

In addition to high BMI scores, children with ASD were shown to have greater abdominal waist circumferences and waist-to-height ratios compared to TD children (44). The waist-to-height ratio is significant because of its correlation to increased risk of cardiovascular disease (45). Decreasing excess weight among children with autism is critically important to prevent additional health problems.

Nutrient adequacy and food selectivity

Selective eating raises another area of concern: dietary adequacy. Since a child with food selectivity consumes a limited variety of foods, the nutrient sufficiency must be carefully examined. Evans and colleagues found children with ASD between the ages of 3-11 years were more likely to consume sugar-sweetened beverages and snack foods and less likely to consume fruit and vegetable servings compared to TD children (46).

` As a result of excessive consumption of unhealthy foods and limited consumption of many healthy foods, vitamin and mineral deficiencies should be closely monitored (3). In a case control study, researchers examined the nutritional deficiencies of 22 children with autism, using age-matched TD children as a control group (47). The results showed children with autism had a higher intake of magnesium but a lower intake of protein, calcium, vitamin B12, vitamin C and vitamin D compared to the control group. Bicer and Alsaffar collected and analyzed a 3-day record and found children with ASD were frequently deficient in calcium, zinc, vitamin B6 and folate (23). Another study found a limited selection of foods was associated with increased nutrient inadequacies (1).

A study of 75 boys aged 4-8 years with ASD found the subjects were more likely to have poor bone growth, especially when on a casein-free diet, compared to the Centers for Disease Control and Prevention (CDC) reference (48). Subsequently, children consuming a diet low in nutrient-dense foods can have significant health and physical implications. For example, in the past five years, seven cases of scurvy were diagnosed at Boston Children's Hospital (11). All seven children had a developmental disorder, and four of the seven were children with autism. The lack of ascorbic acid intake, found most abundantly in fruits and vegetables, resulted in symptoms such as gingival swelling, knee pain, weight loss and a limp. These symptoms are observed in only severe vitamin C deficiencies. The diagnosed scurvy cases at Boston Children's Hospital suggest the need to focus on nutrient deficiencies to avoid serious adverse health effects.

In contrast, there are several studies that do not find discrepancies between nutrient intake of children with ASD and TD children. Lockner, Crowe and Skipper utilized 3-day food records to determine nutrient intake of children with and without autism and found it was similar between the two groups, often exceeding the recommended intake (33). Additionally, children with ASD were more likely to consume a vitamin and mineral supplement than TD children, though supplement data were not included in the nutrient analysis. Parents of children with autism were more likely to describe their child as a "picky" eater, which could be the reason for the supplement usage. It is important to evaluate each child's individual diet to best understand what vitamins, minerals or macronutrients he or she may require.

Interventions to improve food selectivity

Food selectivity can negatively influence the child's health and disrupt the family equilibrium, causing stress and frustration at mealtimes (35). Many well-constructed, large sample studies have examined the cause of food selectivity, but interventions to improve or resolve this problem have received less attention (3, 9, 22, 35, 44). Furthermore, studies utilizing an experimental design often enroll only one child in the study, not accounting for a comparison. Studies investigating how interventions impact the food repertoire of children with ASD can be divided into two broad categories: interventions targeting the child with ASD and those targeting the family of the child with ASD.

Interventions to the child to improve food selectivity

Studies examining the effects of behavioral and sensory behaviors on food selectivity of children with ASD in a large group are limited. One study found that a child was more likely to accept a new food on a spoon if an empty spoon was first presented (12). In another study, two children with ASD with severe food selectivity were given new foods with the techniques of repeated exposure and escape prevention. At the beginning of the treatment, Child 1 ate two foods, and Child 2 relied on gastrostomy tube feedings for nutrition. After the 13-15 day intensive treatment, Child 1 met the criteria for eating 65 foods, and Child 2 met the criteria for 49 foods and no longer relied on a feeding tube (12).

The amount and texture of food presented can dictate if the food is consumed. Sharp and Jaquess found increased bite size resulted in an increase of disruptive behavior and decreased swallowing (13). Moreover, higher textures resulted in increased gagging. Texture fading can aid in increasing solid food consumption by starting with a pureed texture. This gradual change of food texture has been shown to increase overall consumption in a clinical setting (14). The studies described reveal the impact the presentation method, texture and size of bites can have on a child's consumption, though more research is warranted.

Interventions to the family to improve food selectivity

The influence a family has on the eating behaviors and lifestyle of a child with ASD is considerable. A parent-centered, home-based intervention was conducted to determine the most effective manner of increasing vegetable intake in 115 children between the ages of 2 and 4 years (15). Parents gave their children a non-preferred vegetable for 14 days to examine which method of food introduction was most effective in increasing vegetable consumption: method 1: repeated exposure, method 2: modeling and repeated exposure, method 3: rewards and repeated exposure or method 4: modeling, rewards and repeated exposure. Method 4 yielded the best results for increased non-preferred vegetable intake, followed by method 3, rewards and repeated exposure. The control group exhibited the least amount of change. This study indicated home-based interventions can positively affect children's consumption and increase intake of non-preferred vegetables (15).

Odar Stough and colleagues examined parents' behaviors and interactions with children during mealtime in a study called Mealtimes in ASD. Families of children with ASD between the ages of 2 and 8 were studied to determine the relationship of parent and child behaviors and food intake (49). Parents provided the child with an unfamiliar food (such as pears or broccoli) during a videotaped meal. Researchers measured mealtime behaviors of parents and children, parents' opinion about typicality of the mealtimes and a 3-day food record. Fifty-eight percent of children took a bite of the unfamiliar food and consumed an average of three bites of the unfamiliar food. The only behavior found to reduce intake of an unfamiliar food was child sips, that is, the child was less likely to take a bite of the unfamiliar food if he or she took more drink sips during the meal. Parental prompts and direct feeds increased the number of bites of the unfamiliar food. These results indicate that characteristics related to ASD, such as sensory sensitivity or motor deficits, may influence food selectivity more than the parent and child behaviors measured in this study. However, to better understand the characteristics of ASD that influence food selectivity, examination of additional behaviors and their effects would be pertinent. Of note, one important finding from this study was that parent-reported behaviors and direct observation behaviors did not correlate. One example of this discrepancy is the child remains seated at the table until the meal is finished. Researchers concluded that parent education and training is critical in optimizing diet variety in children with ASD (49).

Studies that provide interventions to parents and include a control group and specific outcome measures are limited. The first randomized-control study to incorporate a feeding intervention to address selective eating concerns of children with ASD was published in 2014. Sharp et al. conducted a pilot study of a behaviorally based parent-training program of children with ASD between the ages of 3 and 8 years (34). Ten families who received the intervention were compared to a control group of nine families. The measures included a general questionnaire, an ASD severity rating scale, a checklist to measure mealtime behavior problems, a dietary diversity questionnaire, Parenting Stress Index and a posttreatment questionnaire. The intervention group participated in eight group sessions, each comprised of 1-hour group training. A new topic was introduced each week. Examples of topics included structuring meals, monitoring behaviors and teaching self-feeding skills. Though not the primary target of the study, the intervention group had less parental stress. Despite positive parent responses, there was no improvement in mealtime behaviors or food intake of children with ASD (34). The evidence of long-term change was possibly hindered by the limited 8-week timeline.

A review of the inconsistent findings between family behaviors and the child's intake suggests that more research is warranted. First, additional behaviors should be examined in children and adults to determine the influences that reveal causes of selective eating. Second, revisions should be made to current parent-based interventions for more effective results regarding feeding concerns. Additionally, larger sample sizes with maximum retention should be researched to ensure conclusions are reflective of the ASD population. Finally, detailed diagnostic testing on children with ASD would measure the child's individualized abilities and may help to determine effective interventions.

The Healthy Eating Index

There are multiple techniques to evaluate nutrient adequacy and diet quality. One commonly used method is the Healthy Eating Index (HEI). The HEI is a quantitative score based on adherence to the Dietary Guidelines for Americans (DGAs) (50). The U.S. Department of Agriculture (USDA) publishes the DGAs every five years to reflect the most up-to-date nutrition research. The most recent update was HEI 2010, and there are plans to update it again to align with 2015-2020 DGAs.

There are several notable features of the HEI: it is comprised of twelve components, uses density (per 1,000 calories) to determine its value and utilizes least-restrictive standards of dietary recommendations (50). The HEI is based on a maximum score of 100 points and consists of nine adequacy components and three moderation components. The adequacy components include total fruit, whole fruit, total vegetables, greens and beans, whole grain, dairy, total protein foods, seafood and plant protein and fatty acids; the moderation components are refined grains, sodium and empty calories. Increased consumption of foods in the adequacy components increases the total HEI score; conversely, increased consumption of foods in the moderation components decreases total HEI score. The HEI's ability to deduce the diet quality of a myriad of circumstances makes it ideal for evaluating changes in diet quality over time, diets of subpopulations and the foods provided through USDA nutrition assistance programs (50).

Methods for evaluating food selectivity

There is no standardized method or criteria for measuring food selectivity. There is significant variation of protocols within studies. For example, some studies classify a raw carrot and a cooked carrot as two foods items due to different preparation methods, while others count these items as one food due to similar nutritional value. Tanoue et. al. investigated food repertoire history in children with ASD using a detailed method (17). First, all food items eaten by each child over a three day period were listed, and researchers grouped similar foods (e.g. French fries and fried potatoes) together to avoid redundancies (17). This information was then recorded in a computer software system to determine the number of unique foods (including beverages) a child consumed. A cross-sectional study conducted in 2010 divided the term "food selectivity" into three subcategories: food refusal, limited food repertoire and high-frequency single food intake (1). A modified food frequency questionnaire was then used to assess food refusal and high-frequency single food intake by evaluating the number of foods a child would not eat and single food items eaten 4-5 times daily, respectively. A 3-day food diary evaluated the number of unique foods consumed over the timeframe to calculate the limited food repertoire. The scores of these three categories determined overall food selectivity. Curtin et al. also utilized a modified food frequency questionnaire to depict food refusal, a component of food selectivity (51). Schrek and Williams used a food preference inventory (FPI) to evaluate food selectivity in a study of 138 children with ASD (16). The FPI is a checklist of the five food groups; a final score is obtained by summing the scores from each food group. Another study used an even more basic method to evaluate food selectivity: researchers asked parents to choose the best category to describe how many foods their child with ASD ate on a regular basis (i.e. less than 5, 6-10, 11-20, 21-30, and 30+) (18). This reliance on a subjective method may allow bias to skew results, and the inconsistency between methods can lead to incompatible results surrounding selective eating. Furthermore, no studies have been published evaluating and comparing the effectiveness and accuracy of different techniques.

Conclusion

The purpose of this paper was to examine challenges and contributors related to selective eating and explore interventions and measurements of food selectivity among children with ASD. There are numerous contributors that correlate with food selectivity in children with ASD: heightened sensory sensitivity, unusual sensory processing, behavioral flexibility and family food preferences. Children with food selectivity can suffer from nutrient inadequacy and increased BMI and waist-to-height ratio, which can result in various health-related issues. Selective eating patterns and behavioral problems can be influenced by the manner and presentation of new foods. Further studies are needed to understand the influences of various behaviors and interventions. Additionally, the discrepancies of food selectivity measurements could have an effect on the outcomes of the studies and require further evaluation. Discovering methods to promote optimal intake is essential to provide a healthy future for children with ASD.

Chapter 3: Methods

Overview

Selective eating is a prevalent problem in children with ASD and can cause undesired health outcomes and a burden on the family. There are a number of methods that have been utilized to evaluate food selectivity in this population, though no technique has been tested for accuracy of determining subjective or objective outcomes (1, 16-18, 27, 49). This study aimed to compare two distinct protocols to assess selective eating in children with ASD.

Sample

Data were taken from the study Mealtimes in ASD, which comprised of 74 participants at baseline. Participants in this home-based study were young children with autism recruited through Children's Mercy Hospital (CMH) and from outpatient clinics at The University of Kansas Medical Center (KUMC). There were multiple recruitment techniques employed. First, families received a packet upon their child's ASD diagnosis at the Developmental and Behavioral Sciences Clinic. Second, research assistants provided clinical staff with flyers detailing the study; the flyer was inserted into the packet and included contact information for those interested in participating. Third, a research assistant reviewed medical records and past billing codes of families scheduled for appointments in the Developmental and Behavioral Sciences Clinic, Special Needs Weight Management Clinic or Occupational Therapy Clinic at CMH and sent letters to these families. Fourth, a flyer detailing the study was given to patients at their appointment visits or posted in clinic waiting rooms and office areas. Fifth, a flyer was sent in an email "blast" to eligible families and providers at CMH and KUMC. Sixth, families receiving an ASD assessment at CMH received a letter in the mail informing them of their eligibility for the study. Finally, a research registry was obtained from KUMC to locate families who met eligibility requirements for the study and had previously indicated interest in research. A research assistant contacted interested families who met inclusion criteria to schedule their first home visit.

The primary objectives of the Mealtimes in ASD study were as follows: identify child and parent mealtime behaviors associated with weight problems in young children with ASD and identify whether these associations vary across age, evaluate whether consumption of unhealthy and healthy foods by children with ASD is associated with weight and identify how parents' mealtime behaviors influence the acceptance of new foods among children with autism. To be eligible for the study, the child had to have an ASD diagnosis, fall between the ages of 2 and 8 years and be a member of an English speaking family. Food selectivity was not a requirement to be eligible. Subjects were excluded if the child lived in foster care or the child had a chronic illness that directly impacted their diet, such as an illness that required tube feeding.

Setting

For this home-based study, participants were generally located within the Kansas City metropolitan area and received care at Children's Mercy Hospital or The University of Kansas Medical Center. The recruitment started in February 2013, and six-month follow-ups were conducted through March 2016.

Ethics

For the Mealtimes in ASD study, the child's parent or a legally authorized guardian gave informed consent according to the guidelines of the Institutional Review Boards (Appendix E). The Pediatric IRB at The Children's Mercy Hospital and Clinics reviewed and approved the protocol and any modifications (IRB #12020105).

Procedures

Anthropometrics

A research assistant measured height and weight at baseline using a portable stadiometer (Holtain, Crymych, United Kingdom) and a portable SECA digital scale (SECA, Hamburg Germany) (Appendix D). Participants were dressed in regular clothing and removed their shoes and any heavy jackets or coats. Each measurement was taken three times, and the median measurement was accepted. Weight was measured to the nearest tenth of a kilogram, and height was measured to the nearest tenth of a centimeter. BMI was calculated using the program UpToDate from Children Mercy's system.

Questionnaires

Demographics

Each family completed a demographic form to obtain baseline information that included the child's health-related information and education and parents' employment and income level (Appendix A).

Diet Record form

A 3-day detailed record of their child's diet was recorded and consisted of two weekdays and one weekend day (Appendix B). Parents were given a scale to measure the amounts of food consumed and instructed to provide as much detail as possible about the foods including the brand, how it was prepared and the amount served, left and consumed. Each day was divided into six segments: breakfast, morning snack, lunch, afternoon snack, dinner and evening snack. Vitamins and nutritional supplements and physical activity were also recorded. In addition, researchers gave families a recipe "cheat sheet" form to list out the ingredients, brands and amounts used to make homemade foods. Once researchers received the diet records, families were called to clarify any uncertainties and obtain additional details needed.

Brief Autism Mealtime Behavior Inventory

Parents completed the Brief Autism Mealtime Behavior Inventory (BAMBI), which identifies aspects of children's behaviors at mealtime (52) (Appendix C). The questionnaire lists a range of mealtime behaviors and asks parents to rate their child as to if he or she never/rarely (1), seldom (2), occasionally (3), often (4) or at almost every meal (5) exhibits a particular behavior.

Child Autism Rating Scale, Second Edition

Research assistants completed the Childhood Autism Rating Scale, Second Edition (CARS^{TM}-2), which is a quantifiable rating to classify the severity of a child's autism: minimal-to-no symptoms of ASD, mild-to-moderate symptoms of ASD or severe symptoms of ASD (53). There are 15 category ratings ranging from 1 to 4 for a maximum score of 60. The researcher interacted with the child and made notes for each category based on the child's behavior or response to a stimulus.

Questionnaire for Parents or Caregivers

In conjunction with CARS-2, parents completed the Questionnaire for Parents or Caregivers (CARS2-QPC) (53). This questionnaire examines areas where a child may display difficulty, such as communication, emotions, movement and play. Parents categorize difficulty as one of the following: not a problem, mild-to-moderate problem, severe problem, not a problem now but was in the past or don't know. Parents were also able to write examples to expand upon their selection and provide comments. The researcher's interactions with the child and CARS2-QPC scores were used to evaluate the autism severity of the child.

Six-month follow-up

Although only baseline data were used for this project, it should be noted that families were also recruited to complete a 6-month follow-up. During the follow-up, a research assistant collected the child's height and weight and parents completed another 3-day detailed diet record and BAMBI questionnaire. Of the 74 children that completed all measurements at baseline, 57 completed 6-month follow-up questionnaires. Due to the 21.9% attrition rate and partial follow-up data collection compared to baseline collection, this information was not analyzed in this project.

Nutrition Data System for Research

The Nutrition Data System for Research (NDSR) is maintained by the Nutrition Coordinating Center at the University of Minnesota and is used to assemble and analyze dietary intake information (54). Food is identified based on the type and brand of food, and the system produces outputs estimating 165 nutrients, nutrient ratios and other food components.

To determine the nutritional composition of the children's diets, all 3-day food records were inputted and analyzed using NDSR software version 2014. NDSR training was required for data entry, which included completing NDSR tutorials and reliability based on the completion of 10 test records. Quality assurance was performed on all records to check for data entry errors.

Healthy Eating Index

As discussed previously, the Healthy Eating Index (HEI) can be used to measure the diet quality of a population based on the adherence to the Dietary Guidelines for Americans (DGAs) (50). The United States Department of Agriculture (USDA) developed the index, and it is a universally accepted method for assessing dietary quality. An individual's diet can be scored once their 3-day diet records are inputted into NDSR and analyzed (55). Subcomponent scores were calculated based on the HEI-2010 calculation instructions from three output files of NDSR: component ingredient (file 1), intake property (file 4) and serving count (file 9). The subcomponent scores were then added to obtain the overall HEI score. The closer the score was to the maximal HEI score of 100, the more the participant complied with the DGAs.

Research assistants at the Center for Children's Healthy Lifestyles and Nutrition analyzed the NDSR data to calculate the children's HEI score. All research assistants were trained how to calculate the scores then tested against a standard. Any discrepancies were noted and corrected until the standard was reached.

Food selectivity protocols

Dr. Linda Bandini was responsible for developing one of the protocols used for analysis, referred to as the Bandini protocol, and Drs. Susana Patton and Meredith Dreyer Gillette were responsible for developing the second protocol, known as Neūfood. One similarity is both methods recommend two different individuals code each participant's diet and reach a consensus. However, Dr. Bandini's protocol, which has been published (1), differs in several distinct ways. First, the protocol references only the NDSR Food Report form and not the food record because she and her team believed it resulted in fewer mistakes due to unclear writing and misinterpretation. Second, the foods are divided into 10 categories: beverages, protein-rich foods, dairy, breads/cereals/grains, snacks, vegetables, fruits, desserts and nuts. Food items in each category are then checked once if they were consumed during the day. For example, only beef would be checked if an individual ate steak, pot roast and meatloaf in the same day and would therefore only score as one food consumed. Another example is the consumption of milk; chocolate milk, skim milk, whole milk, milk in a cup and milk on cereal would receive a score of one if all were consumed on the same day. Mixed dishes are divided into their main ingredients, defined as those that can be checked off on the food list. For example, homemade chili would be divided into beef, onion, tomatoes and beans. Finally, the food count is calculated daily, so there is not a running total over the three days.

The Neūfood protocol to determine food variety focuses more on the presentation and texture of food rather than the category of food. Each food item is scored separately if it is prepared, displayed or cooked differently. For example, milk in a bowl of cereal is counted as a separate item from milk in a glass, an uncooked ham and cheese sandwich is different than a grilled ham and cheese sandwich and Great Value wheat bread is different than Sara Lee® wheat bread. The food record is referenced to determine the presentation of the food. Mixed dishes, such as chili and lasagna, are counted as one food each, irrespective of the ingredients. Additionally, the total number of food items is calculated over the three days on the diet record.

To code the protocols, researchers became well acquainted with the methodologies. To score Dr. Bandini's protocol, a Registered Dietitian Nutritionist scored each child's diet record using NDSR's Food Report. A second Registered Dietitian Nutritionist scored 25% of the participants, chosen randomly, to provide reliability. Any scores that were not the same were discussed until a consensus was reached. For the Neūfood method, a primary coder and a secondary coder scored the 74 children's diet records. Interrater reliability was assessed using Pearson correlations. Since a consensus was reached between the two scorers in Bandini's method, interrater reliablity was perfect (r=1.000, *p*=0.0001). For the Neūfood method, interrater reliability was also high (r=0.955, *p*=0.001).

Finally, to maintain uniformity between the two protocols, each food record was scored daily for each of the three days. For example, a gala apple eaten on day one and day two was scored as one item according to the Neūfood protocol but was rescored as two foods to simulate Dr. Bandini's procedure. The results of the daily scores were added to obtain a 3-day total score. It should be noted since the methodology of Bandini's scores remained consistent, Bandini's food repertoire scores did not change when the three daily totals were added compared to its original food variety scores.

Analysis of data

All values were inputted into IBM SPSS Statistics (version 22, Aramonk, NY) for statistical analysis. Any participant that did not have complete 3-day record information was excluded from analysis. Descriptive statistics were used for the protocols as well as to analyze baseline characteristics of the sample. Pearson correlations measured the linear relationship between the protocols and dependent variables, and paired sample t-tests compared Bandini and Neūfood mean scores. The significance level was set at p=0.01 to control familywise error due to multiple tests.

Chapter 4: Results

The primary purpose was to determine how two methods of scoring food variety in children with ASD (ages 2-8) compare to one another. The secondary objectives were to examine how the two protocols related to a) the Healthy Eating Index-2010 and its subcomponents, b) weight and body mass index, c) the child's autism symptom severity and d) the parents' perceptions of restrictiveness.

Subject characteristics

Seventy-four participants returned 3-day diet records with complete information usable for analysis. The sample consisted of 57 boys and 17 girls with a mean age of 5.28 ± 0.59 years. Of the 74 children, the majority (64.9%) were Caucasian. The mean CARS-2 score was 34.4 ± 6.23; according to the cutoff score of 30, 22.4% were not considered autistic by the CARS-2 rating scale but had a physician-applied diagnosis. The sample's demographic characteristics are found in **Table 1**.

Table 1. Subject characteristics of the sample (n=74)

Characteristic	n (%)
Age (y)[1]	5.28 ± 0.59
Gender	
Male	57 (77.0%)
Female	17 (23.0%)
Race	
Caucasian	48 (64.9%)
African American	13 (17.6%)
Latino	1 (1.4%)
Other	10 (13.5%)
Missing	2 (2.7%)
CARS-2 Score	34.4 ± 6.23

[1] mean ± SD

Bandini and Neūfood scores

The average scores of Bandini's protocol and Neūfood's protocol were 28.34 ± 8.34 and 21.94 ± 6.97, respectively. Even though the scores were correlated (r=0.725 *p*=0.0001), the average scores were significantly different [t(73) = 9.446, *p*=0.0001]. The range of scores was

14 to 53 for Bandini and 11 to 41 for Neūfood, and both appeared fairly equally distributed. The data for the Bandini and Neūfood methods are found in **Table 2**.

Table 2. The Bandini and Neūfood scores (n=74)

	Bandini	Neūfood
Average[1]	28.34 ± 8.34	21.94 ± 6.97
Range	14-53	11-41

[1] mean ± SD

To account for methodology discrepancies between the protocols, Neūfood was rescored to calculate unique foods daily, which is consistent with Bandini's method. This new scoring enabled researchers to analyze the unique food items rather than discrepancies within methodologies. A daily total for day 1, day 2 and day 3 was calculated, and the daily scores were added to achieve the 3-day total. The total scores for Bandini's protocol for day 1, day 2 and day 3 were 9.73 ± 3.19, 9.16 ± 3.15, and 9.30 ± 3.46, respectively, for a total of 28.19 ± 8.39. The total scores for Neūfood's protocol for day 1, day 2 and day 3 were 9.61 ± 3.30, 9.21 ± 2.77, and 9.13 ± 3.3.5, respectively, for a total of 27.95 ± 8.01. The daily scores and total scores are found in **Table 3**. Here a paired t-test comparison of the 3-day total for Bandini and the modified 3-day total for the Neufood protocols was not different [t(73)=2.80, *p*=0.780].

Table 3. The Bandini and Neūfood daily scores and total scores (n=74)

	Bandini	Neūfood
Days[1]		
Day 1	9.73 ± 3.19	9.61 ± 3.30
Day 2	9.16 ± 3.15	9.21 ± 2.77
Day 3	9.30 ± 3.46	9.13 ± 3.3.5
Daily Total[1]	28.19 ± 8.39	27.95 ± 8.01

[1] mean ± SD

Healthy Eating Index-2010

Healthy Eating Index-2010 scores were available for 68 children. The average score was 57.21 ± 11.44, and each of the subcomponents was also scored (see Table 4). Bandini and Neūfood's methods were both significantly correlated with the HEI total score (r=0.466, *p*=0.0001 and r=0.339, *p*=0.004, respectively). Bandini's method was significantly associated with the following subcomponents: total fruit (r=0.470, *p*=0.0001), whole fruit (r=0.477, *p*=0.0001), greens and beans (r=0.449, *p*=0.0001) and dairy (r=0.330, *p*=0.006). Neūfood's method was significantly associated with total vegetables (r=0.326, *p*=0.006) and greens and beans (r=0.387, *p*=0.001). All data are shown in **Table 4**.

Table 4. Healthy Eating Index-2010 total and subcomponent scores (n=68)

Dietary Component (Maximum Score)	Average Score	Bandini Correlation	*p*-value	Neūfood Correlation	*p*-value
Total HEI[1] (100)	57.21 ± 11.44	0.466	0.0001	0.339	0.004
Subcomponents[1]					
Total Fruit (5)	2.60 ± 1.76	0.470	0.0001	0.295	0.013
Whole Fruit (5)	2.74 ± 2.02	0.477	0.0001	0.286	0.16
Total Vegetables (5)	1.79 ± 1.11	0.241	0.048	0.326	0.006
Greens and Beans (5)	0.56 ± 1.12	0.449	0.0001	0.387	0.001
Dairy (10)	6.48 ± 3.09	0.330	0.006	0.214	0.075
Total Protein (5)	4.33 ± 2.40	0.130	0.291	0.225	0.061
Seafood and Plant Protein (5)	2.34 ± 1.99	0.158	0.199	0.252	0.035
Fatty Acids (10)	6.07 ± 2.72	-0.125	0.311	-0.113	0.353
Whole Grains (10)	4.15 ± 3.10	0.087	0.479	-0.031	0.800
Refined Grains (10)	6.06 ± 3.28	0.179	0.144	0.095	0.433
Sodium (10)	5.12 ± 2.85	0.292	0.016	0.117	0.334
Empty Kcal (20)	14.79 ± 4.41	-0.052	0.675	0.022	0.857

[1]mean ± SD

Body mass index and weight

The average BMI percentage for the sample was 65.04 ± 29.03. Contrary to expectations, there was no relation between children's BMI percentile and the Bandini scores (r=-0.032, *p*=0.784) and no relation between children's BMI percentile and the Neūfood scores (r=-0.130, *p*=0.270). Furthermore, weight at baseline was not significantly associated with the Bandini method (r=0.093, *p*=0.429) or the Neūfood method (r=0.061, *p*=0.604). The data are shown in **Table 5**.

Table 5. Body mass index and weight (n=74)

	Bandini Correlation	*p*-value	Neūfood Correlation	*p*-value
BMI Percentile	-0.032	0.784	-0.130	0.270
Weight	0.093	0.429	0.061	0.604

Autism symptom severity

The CARS^{TM}-2 determined autism symptom severity: the higher the score, the more severe the autism symptoms. The questionnaire was completed on 66 of the 74 children. Higher Neūfood scores were significantly associated with a decrease in autism symptom severity (r=-0.310, *p*=0.01), while Bandini's scores were not significant (r=-0.111, *p*=0.373), suggesting the Neūfood method may be more sensitive to ASD symptoms than the Bandini method. Data are displayed in **Table 6**.

Table 6. Autism symptom severity (n=66)

	Bandini Correlation	*p*-value	Neūfood Correlation	*p*-value
Autism Symptom Severity	-0.111	0.373	-0.310	0.01

Parents' perceptions of restrictiveness

The BAMBI questionnaire calculated the parents' perceptions of restrictiveness. Seventy-two of the 74 children's parents returned a completed questionnaire. Though neither method was significant based on the adjusted p-value, Neūfood approached significance, suggesting it may be a better indicator of parents' perceptions of restrictiveness (r=-0.272, *p*=0.021) compared to Bandini's method (r=-0.207, *p*=0.082), as shown in **Table 7**.

Table 7. Parents' perceptions of restrictiveness (n=72)

	Bandini Correlation	*p*-value	Neūfood Correlation	*p*-value
Parents' Perceptions of Restrictiveness	-0.207	0.082	-0.272	0.021

Chapter 5: Discussion

Bandini and Neūfood scores

Based on the differing methodologies of the two protocols, it was expected that Bandini's scores would be higher than Neūfood's cumulative scores. Due to Bandini's procedure, it is not uncommon for food variety scores to be deceivingly high. According to the protocol, the main ingredients of a food, defined as those that could be checked off on the food variety checklist, are recorded for each mixed dish. One example, found in a diet recall, is a child who ate Amy's garden vegetable lasagna. The lasagna contained foods from the following categories: pasta and noodles, tomatoes, cheese, broccoli, onion, zucchini, spinach, peas and carrots for a total of nine foods. Furthermore, this food was eaten on days 1 and 3, so if each of the main ingredients were calculated separately, the child would receive a score of 18 different foods for eating two pieces of lasagna. In contrast, the Neūfood procedure would evaluate the lasagna in its entirety, leading to counting this as only one unique food on day 1 but not on day 3. Another potentially misleading item is baby food. If a child consumes baby food containing strawberry, banana, peaches and rice, the child would receive a score of four foods according to Bandini's method but only one food according to the Neūfood method. Therefore, the Neūfood method allows researchers to examine true unique food variety of youth because it looks at mixed food as a single food and calculates a cumulative score over several days.

Though the initial research question examined the methods as a comparison, this study also analyzed both protocols based on a daily count of new foods. This modification yielded no changes in the Bandini scores because per the Bandini protocol, new foods are calculated daily. However, the modification led to a remarkable change in children’s Neūfood scores. Interestingly, when the Neūfood was rescored to reflect Bandini's protocol of scoring each food daily instead of as a cumulative total over the three days, the actual mean scores for the two protocols were quite similar (28.01 versus 28.19, Neūfood and Bandini, respectively). Essentially these modified analyses reveal a mean of 6.39 foods separating Bandini and Neūfood's original scores, which may be explained by using a daily versus cumulative score.

Healthy Eating Index-2010

Since the Healthy Eating Index-2010 is composed of 12 subcomponents, it is expected that children with a more varied diet would have a higher HEI score. For example, if a child consumed only processed foods, such as breads, pastas and granola bars, their fruit, vegetable, dairy, and seafood and plant protein scores would suffer. The majority of children had low fruit, vegetable, greens and beans, seafood and plant protein and whole grains scores. Moreover, many of the food choices were processed, convenience foods - foods that could be prepared with little or no effort. The majority of children ate fast food at least once during their 3-day record, and numerous children ate it several times. This intake resulted in lower subcomponent scores, thereby decreasing the overall HEI score.

Interestingly, the Bandini method had two more significant relations with subcomponent scores than the Neūfood method. It is possible this happened because of the training backgrounds of the two teams who invented these protocols. A team of Registered Dietitian Nutritionists developed the Bandini method, and it seems logical that their focus may be to assess children’s nutritional status. In contrast, the Neūfood protocol was developed by two pediatric psychologists who conceptualized food variety based on the type of treatment goals they might develop with families.

Body mass index and weight

Contrary to previous findings, there was not a significant relationship between either protocol and weight or BMI percentile (6). It is possible that those who had a more varied diet, higher in fruits and vegetables, were also consuming more overall calories than those with a lower food repertoire. However, more research is necessary to explain possible reasons weight and BMI are or are not associated with food variety.

Autism symptom severity

Based on the literature, it was expected that ASD severity would inversely associated with children's food variety, suggesting higher ASD severity is related to less food variety. Interestingly, when analyzed, only children's Neūfood's scores were significantly related to their ASD severity score. As stated above, it is possible this happened because of the backgrounds of the teams who created these protocols since this variable is more closely related to psychological outcomes as opposed to nutritional outcomes.

Parents' perceptions of restrictiveness

As expected, children's food repertoire scores were lower for children whose parents perceived a higher degree of child food restrictiveness, but again, only for the Neūfood method. Similar to the relations found with ASD severity, it is expected this outcome resulted because the Neūfood method may relate more to concepts and challenges treated primarily by psychology versus a child's nutritional status.

Limitations

Since the data were retrospective, it was not possible to expand or disclose any additional measurements or data. Though the majority of data were complete, there were some participants who had incomplete information. For example, NDSR data was not available for all participants, and several children did not have all questionnaires completed. However, there did not appear to be any systematic pattern to the missing data, which is why it is expected that the results are still informative of children’s food variety. Ideally there would have been two trained individuals calculating the number of new foods using Dr. Bandini's scale for each child. This, however, would have required a significant amount of time, so a secondary coder was requested to randomly analyze and discuss discrepancies of food records for a subset of the participants. While the interrater reliability for these participants was very good, there is still a chance for bias because the same individual calculated the majority of scores. The study results may also be limited by the use of parent-report questionnaires and food diaries, which could have been affected by a response bias. Therefore it is important not to over-interpret the results. The study sample lacked racial and ethnic diversity, which may also limit the generalizability of the study findings to families of children who are non-white and/or Hispanic.

Implications

No research has been conducted to evaluate food variety protocols for their prediction of health indicators. For validation purposes, the Neūfood protocol was compared to Dr. Bandini’s published protocol (1). Furthermore, by comparing the Bandini and Neūfood methodologies, a more predictive measure of specific outcomes can be determined. Increasing measurement accuracy may result in a better understanding and definition of selective eating and its impact on the child and family.

Conclusion

Both the Bandini and Neūfood protocols are associated with a variety of variables. Bandini's protocol has a better relationship with HEI scores and several of its subcomponents, and Neūfood's protocol is more closely associated with autism symptom severity and parents' perceptions of restrictiveness. But notably, the two measures were highly correlated, suggesting that there may be some commonality in the construct they seek to measure. Therefore, it may be that the best course is to determine the desired outcome variable before deciding which protocol should be used. Since this is the first evaluation examining the predictability of indicators based on methodology, more research is warranted. It is suggested that future research studies investigate additional dependent variables and food variety protocols as well as interventions to most effectively increase a child's food repertoire. Furthermore, it is recommended to investigate how the protocols compare among a population without ASD and evaluate their sensitivity to treatment. Continued research is recommended for discovering additional ways to enrich the lives and health of children with autism in the future.

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Appendix A: Demographic Form

Child Information

My child is a :

☐ Female ☐ Male

Child's Birthday (month/day/year) __________

Ethnicity

☐ Caucasian ☐ Black/African-American ☐ Asian
☐ Latino(a)/Hispanic ☐ American Indian ☐ Other ___________

What language does your family speak at home most of the time (check one)

☐ English ☐ Spanish ☐ Other ___________

Does your child experience another health concern?:

☐ Yes ☐ No

If Yes, what condition:

☐ Asthma ☐ Diabetes ☐ Arthritis
☐ Seizure Disorder ☐ Cancer ☐ Other ___________

Child Health-related Information

Date of child's diagnosis with an Autism Spectrum Disorder (month/day/year) ____________________

Child's Diagnosis (check-one)

☐ Autism ☐ Asperger's Disorder
☐ Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

Is your child currently taking medication for any reason?

☐ Yes ☐ No

If yes, list the medications and reasons for taking them.

Medication	Reason
________________________________	________________________________
________________________________	________________________________
________________________________	________________________________

Please list any types of clinical services, such as treatment, therapy, in-home ABA, that your child has received for their ASD.

____

____

____

Your gender

☐ Female ☐ Male

Your date of birth (month/day/year) ____________

Your Ethnicity:
☐ Caucasian ☐ African-American ☐ Asian
☐ Hispanic ☐ American Indian ☐ Other ________

Your relationship to the child:
☐ Biological Mother ☐ Biological Father ☐ Step-parent
☐ Grandparent ☐ Aunt/Uncle ☐ Other ________

Your Marital Status:
☐ Now Married ☐ Not Married, but living with partner ☐ Divorced
☐ Single, never married ☐ Separated ☐ Widowed

Who lives at home with the child? (PLEASE DO NOT INCLUDE NAMES)
Relationship Gender Age

____

____

____

____

____

____

____

____

What is the highest level of education YOU have completed?:
☐ Less than seventh grade ☐ 9th grade ☐ 10th or 11th grade
☐ High School Degree ☐ Partial College or Specialized Training
☐ College Degree ☐ Graduate Degree ☐ Other ________

What is YOUR employment status?:
☐ Employed Full-time ☐ Employed Part-time
☐ Not employed, not looking for work ☐ Not employed, looking for work
☐ Employed but on maternity or medical leave

What is YOUR current occupation?

____

What is the highest level of education YOUR SPOUSE has completed?: (if applicable)
☐ Less than seventh grade ☐ 9th grade ☐ 10th or 11th grade
☐ High School Degree ☐ Partial College or Specialized Training

☐ College Degree
☐ Graduate Degree
☐ Other ___________

What is YOUR SPOUSE'S employment status?: (if applicable)

☐ Employed Full-time
☐ Employed Part-time
☐ Not employed, not looking for work
☐ Not employed, looking for work
☐ Employed but on maternity or medical leave

What is YOUR SPOUSE's current occupation?: (if applicable)

____

What is your family's total yearly income (including all supports, such as government assistance, child-support, etc.)

☐ $0 - $19,999
☐ $20,000 - $39,999
☐ $40,000 - $59,999
☐ $60,000 - $79,999
☐ $80,000 - $99,999
☐ $100,000 +

Does anyone else contribute to your family income besides yourself and your spouse (e.g., child support payments, health insurance payments from deceased spouse, etc.)?

☐ Yes
☐ No

If yes, whom? __________________________________

What is THIS PERSON'S employment status?

☐ Employed Full-time
☐ Employed Part-time
☐ Not employed, not looking for work
☐ Not employed, looking for work
☐ Employed but on maternity or medical leave

What is THIS PERSON'S current occupation?

____

What is THIS PERSON'S highest level of education completed?:

☐ Less than seventh grade
☐ 9th grade
☐ 10th or 11th grade
☐ High School Degree
☐ Partial College or Specialized Training
☐ College Degree
☐ Graduate Degree
☐ Other ___________

Does your family receive any of the following (check all that apply)

☐ Food Stamps
☐ WIC
☐ SSI
☐ TANF
☐ Disability
☐ Food pantry Assistance
☐ Weekend Backpack Snack Program
☐ Free or Reduced Lunch Program
☐ None

Appendix B: Diet Record Form

Child's Initials: ________________ Subject #:_____________

Date: ___________________ Site: ________________

DIET DIARY- DAY 1

REMEMBER: Please measure liquids in fluid ounces (fl oz); use scale to weigh foods in grams (g); use spoons or cups for measuring foods: teaspoon (t), Tablespoon (Tbsp), & cups (C).

BREAKFAST: Time at start of meal _____________ Time at end of meal ___________________
Location of Meal: ___________ Eaten With: ___________

Food eaten	Brand	How prepared	Amount served -	Amount left =	Amount consumed
			-	=	
			-	=	
			-	=	
			-	=	
			-	=	
			-	=	
			-	=	

SNACK: Time at start of meal _____________ Time at end of meal ___________________
Location of Meal: ____________ Eaten With: ___________

Food eaten	Brand	How prepared	Amount served -	Amount left =	Amount consumed
			-	=	
			-	=	
			-	=	
			-	=	
			-	=	

LUNCH: Time at start of meal _____________ Time at end of meal ___________________
Location of Meal: ____________ Eaten With: ___________

Food eaten	Brand	How prepared	Amount served -	Amount left =	Amount consumed
			-	=	
			-	=	
			-	=	
			-	=	
			-	=	
			-	=	
			-	=	

Date: ________________

SNACK: Time at start of meal ____________ Time at end of meal _________________
Location of Meal: ___________ Eaten With: ___________

Food eaten	Brand	How prepared	Amount served - Amount left = Amount consumed
			- =
			- =
			- =
			- =
			- =

DINNER: Time at start of meal ____________ Time at end of meal _________________
Location of Meal: ___________ Eaten With: ___________

Food eaten	Brand	How prepared	Amount served - Amount left = Amount consumed
			- =
			- =
			- =
			- =
			- =
			- =
			- =

SNACK: Time at start of meal ____________ Time at end of meal _________________
Location of Meal: ___________ Eaten With: ___________

Food eaten	Brand	How prepared	Amount served - Amount left = Amount consumed
			- =
			- =
			- =
			- =
			- =

VITAMINS OR NUTRITIONAL SUPPLEMENTS TAKEN (when?):
____

Type of vigorous exercise/activity	Time (afternoon/evening)	How long?

DAILY NOTES:

Appendix C: Brief Autism Mealtime Behavior Inventory

Subject # ______

Brief Autism Mealtime Behavior Inventory

Think about mealtimes with your child over the past 6 months. Rate the following items according to how often each occurs, using the following scale:

Never/Rarely	Seldom	Occasionally	Often	At Almost Every Meal
1	2	3	4	5

Circle YES if you think an item is a problem for you or NO if you think it is not a problem.

1. My child cries or screams during mealtimes.	1 2 3 4 5	Y N
2. My child turns his/her face or body away from food.	1 2 3 4 5	Y N
3. My child remains seated at the table until the meal is finished.	1 2 3 4 5	Y N
4. My child expels (spits out) food that he/she has eaten.	1 2 3 4 5	Y N
5. My child is aggressive during mealtimes (hitting, kicking, scratching others).	1 2 3 4 5	Y N
6. My child displays self-injurious behavior during mealtimes (hitting self, biting self).	1 2 3 4 5	Y N
7. My child is disruptive during mealtimes (pushing/throwing utensils, food).	1 2 3 4 5	Y N
8. My child closes his/her mouth tightly when food is presented.	1 2 3 4 5	Y N
9. My child is flexible about mealtime routines.	1 2 3 4 5	Y N
10. My child is willing to try new foods.	1 2 3 4 5	Y N
11. My child dislikes certain foods and won't eat them.	1 2 3 4 5	Y N
12. My child refuses to eat foods that require a lot of chewing (e.g., eats only soft or pureed foods).	1 2 3 4 5	Y N
13. My child prefers the same foods at each meal.	1 2 3 4 5	Y N
14. My child prefers "crunchy" foods (e.g., snacks, crackers).	1 2 3 4 5	Y N
15. My child accepts or prefers a variety of foods.	1 2 3 4 5	Y N
16. My child prefers to have food served in a particular way.	1 2 3 4 5	Y N
17. My child prefers only sweet foods (e.g, candy, sugary cereals).	1 2 3 4 5	Y N
18. My child prefers food prepared in a particular way (e.g., eats mostly fried foods, cold cereals, raw vegetables).	1 2 3 4 5	Y N

Appendix D: Height and Weight Form

Study ID ________________

1. Baseline

Person Collecting Information ___________________________

Date Information Collected ______________________

Weight (in kilograms) _________________

Height (in centimeters) __________________

BMI ________________

BMI-z ______________

BMI percentile _____________

2. Follow-up

Person Collecting Information ___________________________

Date Information Collected ______________________

Weight (in kilograms) _________________

Height (in centimeters) __________________

BMI ________________

BMI-z ______________

BMI percentile _____________

Appendix E: Consent Form

PARENTAL PERMISSION TO PARTICIPATE IN A RESEARCH STUDY AT THE CHILDREN'S MERCY HOSPITAL

FACTORS RELATED TO OVERWEIGHT AND CONSUMPTION OF NEW FOODS IN CHILDREN WITH AUTISM SPECTRUM DISORDERS

WHO IS DOING THIS STUDY?

A study team led by Meredith Dreyer Gillette PhD is doing this study. Susana Patton, PhD, at the University of Kansas Medical Center will be collaborating on this study. Other health care professionals may help them.

The National Institutes of Health has funded The Children's Mercy Hospital and the University of Kansas Medical Center to do this research study. The study team will not receive any personal payment because of your decision.

We are asking your child to be in this research study. Please read the information below and ask questions about anything that you do not understand before you make a decision.

WHY IS THIS STUDY BEING DONE?

Children with Autism Spectrum Disorders (ASD) and their families can do things at meals that are different from other families. These different behaviors may lead to changes in your child's health and weight.

The purpose of this research study is to learn about behaviors kids with ASD and their families do at meals. We will then see if these behaviors are connected to children's health and eating. We can use this information to make meals better for children and families to help children with ASD have better health.

WHO CAN BE IN THIS STUDY?

We are asking your child to be in this study because he or she is between 2 and 8 years old and has an ASD. Your family must also speak English during meals at home.

About 125 children will be asked to be in this study at Children's Mercy Hospital, and about 25 children will be asked to be in this study at the University of Kansas Medical Center, totaling 150 children.

WHAT WILL HAPPEN TO MY CHILD IN THIS STUDY?

Being in this study involves 3 home visits by someone from the study team, answering questions about how your child acts at meals and using a video camera to record 4 meals in your home over 10 days. During one of those 4 meals you will be asked to give your child a new food given to you by the researcher. A study team member will come to your home to lend you the study materials, including the video camera and tripod you need to videotape the meals. They will also show you how to do the things in this study. We will also give you some forms to fill out. The researcher will come back to your house to pick up the study materials, including the video camera, the tripod and the study forms, when you are done. We will also get information about your child, such as your child's birth date and ASD diagnosis from his/her medical record at the hospital. At the first visit and at the second visit six months later, the researcher will measure your child's weight and height. It will take you about 4 hours over 10 days to do the things for this study, plus about 15 minutes for the extra visit when we record weight. The time in the study will be different depending on how long meals are.

This study involves a research assistant coming to your home. All research assistants are considered mandated reporters, which means they are required by law to report any situations in which a child is in danger or potential abuse or neglect has occurred. If research assistants become aware of any abuse, neglect, or risk to your child's safety during this study, this information will be reported to you and to the appropriate organizations for the state you live in.
If you decide to let your child be in this study the following things will happen:

- We will come out to your home to do study activities.
- We will measure your child's height and weight when we first come to your house. We will measure it 6 months later too. You can do this second appointment at your house or you can come to the Children's Mercy Hospital or the University of Kansas Medical Center and we can measure your child there.
- We will observe and measure your child's behaviors during the first visit to your house.
- We will write down information about your child (e.g., gender, birth date) from his/her medical record.
- You will be asked to measure and write down what your child eats for 3 days. We will lend you a scale to record the weight of food and give you measuring cups to measure food. You will also be asked to record what your child eats during the video taped meals. You will do this during the next 10 days and 6 months later too.
- You will be asked to fill out 5 forms about 1) you and your child's behaviors at meals 2) child and family demographics 3) and 2 forms about your child's behaviors related to his/her ASD. You will be asked to do one of these 6 months later too.
- You will give your child a new food at one family meal and videotape this meal. We will give you this new food.
- You will videotape 4 of your child's meals at home during the next 10 days. We will lend you the video camera and tripod and tell you how to use it. You will also be asked to answer how much each meal was like your usual meals at home.
- You will be provided information sheets about how to videotape meals and measure the food eaten by your child.
- As part of this study, we will submit information about your child's height, weight, food choices, meals, and behaviors to the National Institute of Health (NIH) database. The data will have your child's name and date of birth removed, and will not be able to be linked back to you or your child. This secure database will include many other children's data, and will be available to the public to help improve understanding of children with autism spectrum disorders.

In this study you will not receive any specific feedback or information about your child or mealtimes in your home. No recommendations or assessment for individual children will be provided.

WHAT ARE THE RISKS OF THE STUDY?

There are certain risks in this study. These risks may include feeling uncomfortable about being videotaped or answering questions about what you and your child do at meals. Children may also be sensitive about having their weight or height recorded.

If your child has any of these problems or changes in the way he or she feels, you should tell the investigator or other study personnel as soon as possible.

There may be risks we don't know about right now. We will tell you about any new information that might change your decision to keep your child in the study.

WHAT ARE THE BENEFITS OF BEING IN THIS STUDY?

There is no direct benefit to your child from being in this study. Being in the study may help children with ASD in the future by telling us about how to keep children healthy and make better programs about health for children with ASD.

WHAT ABOUT EXTRA COSTS?

You will not have to pay anything extra if your child is in this study. There are no extra costs to you or your child's insurance company from being in this study.

You or your child's insurance company will still have to pay for all of your child's routine care.

WHAT ABOUT CONFIDENTIALITY?

Your child has rights regarding the privacy and confidentiality of his or her health information. When health information includes identifiers (like names, addresses, phone numbers and social security or individual taxpayer identification (ITIN) numbers) that link it directly to an individual, it is called protected health information (PHI). Federal laws require that PHI be kept secure and private. In certain situations, federal law also requires that you approve of how your child's PHI is used or disclosed. A research study is one of those situations.

By signing this permission form, you are permitting the following people to have access to your child's **medical record** and use your child's PHI for the research purposes described in this form:

- The research team, which includes the study personnel listed on this form and other persons involved in this study at The Children's Mercy Hospital and the University of Kansas Medical Center;
- The Institutional Review Board at The Children's Mercy Hospital;
- Other researchers, hospitals, and institutions that are part of this study and their Institutional Review Boards;
- A group that oversees the data (study information) and safety of this research;
- The sponsor for this research study;
- People from organizations that provide independent accreditation and oversight of hospitals and research;
- Federal agencies such as the Office for Human Research Protections.

The research record is separate from your child's medical record. Information about your child that is obtained during this study will be recorded in a research record. A research record will be created and kept in the Center for Children's Healthy Lifestyles & Nutrition research office. That file may include documents that have your child's name, study ID number, date of birth, medical record number, address, telephone number, and full face and voice video recordings from home mealtimes.

The videotaped meals will be stored on DVDs, which will be dubbed and your child's name will not be listed on the DVD. The coded DVDs will have your child's study ID number and full face and voice. The DVDs will be stored in a secure location and will be destroyed upon completion of all data collection and analyses.

There will be a separate database, in which all study information is collected. This database will be used to analyze the study information and find out the study results. Information in this database will include your child's study ID number, date of birth and dates of service. The database will be shared with Dr. Susana Patton at the University of Kansas Medical Center.

By signing this permission form, you are allowing your child's information to be recorded in the research record. You are also permitting your child's research record to be shared with everyone listed above.

We may collect you or your child's social security number so that we may process your payment for participation in the study. Your social security number will be kept confidential and will be destroyed when the study is complete.

The persons and groups listed above are required by federal law or by contract to keep any PHI in your child's research record secure and private. While confidentiality cannot be guaranteed, it will be protected to the greatest extent possible. There also may be some situations where laws require the release of your child's PHI. If your child's PHI is shared with an organization that is not required to comply with federal privacy laws, your child's health information is no longer considered protected and may be used and shared freely by that organization.

You may choose not to sign this permission form and not have your child be in the study. You may cancel your permission to use and share your child's PHI at any time by contacting the study personnel listed on this form. You may also contact The Children's Mercy Hospital Medical Records Correspondence Department in writing. If you cancel your permission, your child may no longer be in this study. Your child's PHI that has already been collected for the study may still be used; however, no new information will be collected except information related to adverse events or other safety issues.

If you do not cancel your permission, your child's PHI may continue to be recorded until the entire study is finished. This may take years. Some information about the study may be included in your child's medical record. Any study information recorded in your child's medical record will be kept there indefinitely. Unless stated elsewhere in this form, you may not have access to your child's research record or research test results.

Results of this study may be made public. Your child will not be identified in any publications or presentations.

WHAT ARE THE ALTERNATIVES TO BEING IN THIS STUDY?

Instead of being in this study, your child does not have to participate. The decision to be in the study or not will not impact your child's clinical care.

WHAT WILL MY CHILD RECEIVE FOR BEING IN THIS STUDY?

You will receive a $10 gift card to Wal-Mart (funded by the National Institute of Health) and a measuring cup set at the time of the first visit. You will also receive a $20 gift card to Wal-Mart upon completion of the second visit. Your child will also receive a small toy (valued at less than $2.00) and you will receive a $10 Wal-Mart gift card after you complete the 6 month follow-up visit. Maximum compensation for participating in the study is $40, a small toy, and a measuring cup set (valued at less than $2.00).

If your child does not complete the study, your child will be compensated for the visits that were completed. Your child will not be compensated for any unscheduled visits.

If the total value of payments/property provided to you and your child from The Children's Mercy Hospitals totals more than $600 in any calendar year, the hospital must report this to the IRS on a Form 1099 with the recipient's social security number (SSN) or individual tax identification number (ITIN). You will receive a copy of this tax form. Accepting payment/property for taking part in the study may affect eligibility for Medicaid or other programs.

The Children's Mercy Hospitals can only make payments/provide property if we have your/your child's SSN or ITIN Number. If you do not provide this number, your child can still participate in the research study; however, you/your child will not receive payment/property. Your/Your child's SSN or ITIN Number will be maintained in a secure manner.

WHAT ARE MY CHILD'S RIGHTS AS A STUDY PARTICIPANT?

Being in a research study is voluntary. Your child does not have to be in a study to receive care for her/his ASD. If you choose not to have your child participate, there will be no penalty or loss of benefits to which your child is otherwise entitled.

You may withdraw your child from the study at any time without penalty or loss of benefits to which your child is otherwise entitled. We will inform you of any new information that develops during this study. This information may affect your decision to keep your child in the study. If you choose to withdraw your child from the study or if you are asked by your child's personal doctor to withdraw your child from the study, you must tell the research doctor as soon as possible.

The investigator(s) may stop the study at any time. The investigator(s) or your child's doctor may remove your child from the study at any time without your permission. This might happen if it is not in your child's best interest to continue in the study.

WHO SHOULD I CALL IF I HAVE QUESTIONS OR PROBLEMS?

Meredith Dreyer Gillette PhD is in charge of this study. You may call her at (816) 234-9233 with questions at any time during the study. You can also call Susana Patton, PhD at the University of Kansas Medical Center at (913) 588-6323. You may also call Teresa Pan MA or Lauren Pollack, the study coordinators, at (816) 234- 9217 with any questions you may have. You should call Dr. Dreyer Gillette or Dr. Susana Patton if you believe that your child has suffered injury of any kind or is sicker as a result of being in this research study.

You may also call the Chair of the Pediatric Institutional Review Board (IRB) at (816) 701-4358 with questions or complaints about this study. The IRB is a committee of physicians, statisticians, researchers, community advocates, and others that ensures that a research study is ethical and that the rights of study participants are protected.

SPONSOR AND INSTITUTIONAL RESPONSIBILITIES

This study involves data collection only. As detailed in the “What About Confidentiality?” section, your child’s PHI will be kept safe to the greatest extent possible. Possible risks may be the unintentional use of your child’s PHI. This could be by any of the parties listed in the “What About Confidentiality?” section. If an unintentional use of PHI occurs by The Children’s Mercy Hospital, there are not funds set aside to pay you. By signing this form, you, or your child, are not giving up any legal rights to seek damages for harm.

PERMISSION OF PARENT OR LEGALLY AUTHORIZED REPRESENTATIVE

The purposes, procedures, and risks of this research study have been explained to me. I have had a chance to read this form and ask questions about the study. Any questions I had have been answered to my satisfaction. I give permission for _______________________________ to participate in this research study. A copy of this signed form will be given to me.

____ _________ ________ ______________________

Signature of Parent/Legally Authorized Representative Date Time Relationship to Participant

---

CONSENT TO VIDEOTAPING

By signing in this box, I agree to have my family videotaped for this research study. I have had this aspect of the study explained to me and my questions so far have been answered.

____ _________ ________ _____________________

Signature of Parent/Legally Authorized Representative Date Time Relationship to Participant

____ _________ ________ _____________________

(For second Parent, if Present) Date Time Relationship to Participant
Signature of Parent/Legally Authorized Representative

STUDY PERSONNEL

I have explained the purposes, procedures, and risks involved in this study in detail to:

____

Print name(s) of Parents/ Legally Authorized Representative

____ _________________ ___________________

Signature of Person Obtaining Permission Date Time

Print Name of Person Obtaining Permission _____________________________________
(8-12-2015)