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ABSTRACT OF THESIS

PARENTAL PERCEPTIONS OF NUTRITIONAL STATUS OF CHILDREN WITH AUTISM

Literature shows that nutritional deficiency and feeding behaviors in neuro-developmentally disabled children is secondary to an underdeveloped gastrointestinal tract. Fifty (50) parents with children with autism responded to a Nutritional Perception Assessment that they believe their children are at adequate nutritional status. They reported confidence in their nutritional knowledge, yet admitted to concern about the nutritional status of their children. The survey revealed that parents are not seeing a registered dietitian for their nutritional advice, leading to the question of soundness in nutritional information received. A marginal correlation was found between belief in adequate nutritional status of children and the use of credible sources for nutritional information, $p=0.0429$. Data from twenty-five 24-hour recalls was entered into the MyPyramid Food Tracker to determine nutritional status, which was compared to Daily Recommended Intakes (DRIs), showing adequate nutrient consumption.

KEY WORDS: Autism, parental perceptions, nutritional status, neuro-developmental disorder, feeding behavior

Rachel Corliss Holt, RD

July 28, 2008

PARENTAL PERCEPTIONS OF NUTRITIONAL STATUS OF
CHILDREN WITH AUTISM

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THESIS

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PARENTAL PERCEPTIONS OF NUTRITIONAL STATUS OF
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THESIS

A thesis submitted in partial fulfillment of the
requirements for the degree of Master of Science in the
College of Agriculture
at the University of Kentucky

By

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Lexington, Kentucky

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2008

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TABLE OF CONTENTS

Table of Contents	iii
List of Tables	v
List of Figures	vi
List of Files	vii
Section 1: Introduction.....	1
Section 2: Background Literature Review.....	4
Feeding Behaviors	4
Parent Perceptions	5
Measuring Behavior	6
Measuring Nutritional Status.....	7
Nutritional Information Sources.....	8
Role of the Dietitian	9
Section 3: Purpose.....	10
Section 4: Research Questions.....	10
Section 5: Methodology.....	10
Setting.....	10
Design.....	11
Survey Tool	15
Analysis	16
Section 6: Results.....	18
Statistical Analysis.....	23
Children’s Nutritional Status Determined by the 24-Hour Recall.....	25
Section 7: Discussion.....	28
Nutritional Perception Assessment	28
24-Hour Recall and Nutritional Status	30
Limitations.....	31
Conclusions and Recommendations.....	32
Appendices.....	33

References.....	34
Vita.....	37

LIST OF TABLES

Table 1: Responses to Nutritional Knowledge Construct.....	18
Table 2: Responses to Nutritional Status of Child Construct	19
Table 3: Responses to Nutritional Knowledge Sources Construct	20
Table 4: Responses to Child Feeding Behaviors Construct.....	22
Table 5: Distributions of Constructs	24
Table 6: Parameter Estimates of Relationship between Nutrition Status and Sources...	25
Table 7: Macro Nutrients Mean Amounts in 24 Hours	26
Table 8: Micro Nutrients Mean Amounts in 24 Hours	27

LIST OF FIGURES

Figure 1: Reported Parental Sources of Nutritional Information from Survey, Answer: “Agree and Strongly Agree”	21
Figure 2: Frequency of Nutritional Perception Survey: Nutritional Knowledge and Status	23

LIST OF FILES

1. RHoltThesis.pdf 723K

Section 1: Introduction

According to the Centers for Disease Control and Prevention (CDC), 1 in 150 children in the United States have been diagnosed with autism or a closely related Autism Spectrum Disorder (ASD) (1). The disorder recently has come into the spotlight though it has been researched since the 1970s. Autism was first believed to be a result of parental neglect. It is now characterized as a neuro-developmental and developmental disorder.

Proposed causes include genetics and environmental factors. Genetics of autism have been shown to be complex and it is unclear whether the disease is due to gene mutation or multi-gene interactions; nor has autism been traced to a single gene mutation or interaction (2).

Environmental factors include infectious disease, heavy metals, alcohol, smoking, illicit drugs and vaccinations. The theory on vaccines is directed toward the Measles, Mumps and Rubella (MMR) vaccine. Autism has been a suspected result of the once-used mercury-containing preservative thimerosal, though there has not been significant scientific evidence. A recent study released from the Journal of Neurological Science has revealed years of efforts and testing of the CDC's Vaccine Safety Datalink Database information. The study showed a significantly increased risk of Autism and other neuro-developmental disorders with increased mercury exposures (3).

A child with Autism displays characteristics before they are three years old. Ritualistic behavior, difficulty making friends, lack of eye contact, lack of ability to express needs, unusual gestures and lack of responsiveness have all been indicators of Autism or an Autism Spectrum Disorder (ASD) (4). The CDC defines ASDs as a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests while the thinking

and learning abilities of people with ASDs can vary from gifted to severely challenged (1).

Autism involves behavioral, medical and psychological effects which have been found to be connected to nutrition. Many children with autism have an underdeveloped gastrointestinal tract leading to feeding behaviors such as constipation, regurgitation, rumination and selective eating. The underdeveloped gastrointestinal tract has thin mucosa lining, allowing food molecules to be absorbed in the blood stream prematurely; it also causes inflammation and irritation. Behaviors may be a result of irritability due to inflammation and difficulty digesting food. In addition, the underdeveloped gastrointestinal tract is responsible for the deficiency of several essential nutrients, of which symptoms may mimic neuro-developmental disorders. The most common deficiencies found in children with Autism include vitamin A, vitamin C, thiamin, riboflavin, niacin, folic acid, vitamin B₆, vitamin B₁₂, calcium and iron. These missing vitamins and minerals exacerbate feeding behaviors as well as cause a decline in overall health (1). Chewing problems and behavioral problems have been identified as common in children with autism and have been identified as particularly prevalent in children with disabilities in early childhood (5). This is also due to the increased risk of developmental and motor skills delays as also found in the study by Collins in Northern Ireland, 2003.

One of the indicators of emotional responses linked to nutrition is a lack of the chemical, serotonin. Eighty percent of serotonin, which is essential for brain function, is synthesized in the gut. Production struggles to occur in an underdeveloped gastrointestinal tract of a child with autism. Signs of low serotonin levels include

carbohydrate cravings, migraines, PMS, depression, insomnia or problems falling asleep, obsessive-compulsive behavior and panic attacks (6).

Medications are prescribed to help combat the impulsivity, hyperactivity and short attention span observed in children with autism. Antidepressants, anti-anxiety and mood stabilizing drugs prescribed have a nutritional effect on the child. Neuro-leptics, or anti-psychotics, such as Risperidol and Geodon, are responsible for excessive weight gain by increasing appetite, altered metabolism of nutrients as well as overall nutritional status and developing risks for cardiac and glucose dysfunction (7). Studies of food intake, feeding behaviors and nutrient-drug interactions will increase the understanding of the needs of this population.

Parents of children with autism are faced with their child's limited food preferences and eating behaviors. Some parents feel that changes in their child's diet may make a difference in how the child feels or acts (1). With so much information circulating, particularly on the internet, it is difficult to discern parents' nutritional knowledge. Parents may feel anxious or stressed, as they wish to provide the best nutrition for their child. It may be difficult for them to apply their knowledge, especially if they do not feel confident. Therefore, parental perceptions of their own nutritional knowledge and their perception of the nutritional status of their child may provide insight for the dietitian on how to treat children with Autism and provide nutritional education. .

Research will ultimately allow parents to help children healthy eating patterns and ways to overcome eating behaviors. It will allow health care professionals to better serve their patients and families.

Section 2: Background Literature Review

Feeding Behaviors

Children with autism exhibit feeding behaviors and emotional responses as a result of their underdeveloped gastrointestinal tract and difficulties with digestion. Feeding behaviors may be defined as any conduct or actions during mealtime the child exhibits toward food or being fed. The literature on typical children and feeding behaviors provides a starting point to address feeding behaviors in children with autism. Addressing the feeding behavior problem may make a difference in intervention for children with disabilities (5).

Limited food preferences are often an issue in feeding behaviors in children with autism (5). This may be mild to severe, where the child may prefer only one or two foods, or only one type of texture. This restriction becomes a threat to nutritional status as it limits a necessary variety of nutrients consumed. Regurgitation, rumination and pica are also common in children with autism. The child may expel food back from the stomach and esophagus (regurgitation) or continually chew the food (rumination). Some children have also been known to ingest non-food items such as dirt, paper or plastic (pica) (8).

In addition to limited preferences, regurgitation and rumination, emotional behaviors complicate feeding. As the child feels uncomfortable or threatened or over stimulated due to anxiety, she or he may often act out, throwing food, crying, spitting biting or fussing in general. A study by Williams et al reported significance between mealtime dispositions, or temperament, and nutrition. 'Easy-going' children were

described as having adequate nutrition versus those children who were fussy or upset during mealtime (8).

The literature suggests that typical children are also ‘fussy eaters.’ Children ages 3, 5 and 7-11 years in Wales showed more unhealthy preferences in food choices despite the variety offered and known health consequences (9). Ritualistic behavior is a common observation in children with autism, especially at mealtime. However, typical young children have also shown some ritualistic behavior regarding food choices. Children with autism have been shown to marginally exhibit more limited food choices and more difficult feeding behaviors than their siblings or matched typically developing children (10).

Environment has been identified as a major factor in mealtime behavior. Typical children have been shown to exhibit different food preferences as well. Time of day has determined food acceptability in children ages 3-5 years in terms of food preferences and types of foods consumed (11). Similarly in children with autism, the environment and time of day affects mealtime choices. Although preference of breakfast or lunch foods and time of day has not been studied in children with autism, this study shows that typical children are also psychologically motivated in their food preferences.

Parent Perceptions

Little literature exists on the perceptions or feelings of the parents of children with autism, especially regarding how they view the nutritional status of their child. This may be due to the newness of the research on autism.

Feeding a child can be difficult responsibility for parents of both children with autism and typical children. An Australian study concluded that almost half of children

ages 3-9 are ‘fussy eaters’ and that over 70% of parents of children ages 1-12 felt irritated, frustrated, guilty or concerned if their children did not eat a balanced meal (12). As it stands, typical children and children with autism are still children; they may not always agree with their parents or understand why they should eat a balanced diet. Family meal environments are associated with adult eating patterns as well. In a study conducted in Minnesota, television during meal time led to less consumption of fruits and vegetables, as well as more arguments regarding eating behaviors (13).

Similarly to typical children, children with disabilities have been found to be ‘fussy eaters’ and parents are frustrated. Their perception of their child’s nutrition may be helpful in allowing dietitians and healthcare professionals to provide care. In a study in Pennsylvania, parents of children with autism were asked to complete a seven day diet record and answer a questionnaire on their attitudes and beliefs about nutrition. Parents reported a positive belief in the relationship between diet and behavior, as well as a positive attitude about the importance of nutrition (14). Parents of children with autism have also perceived their children to be under-nourished. These parents were significantly more likely to admit frustration and/or anxiety when feeding their child with autism (15).

Measuring Behavior

Despite research observing child behavior, no standardized measures to evaluate mealtime behaviors and feelings of parents of children with autism exist. The Brief Autism Mealtime Behavior Inventory (BAMBI) has been used in research along with the Behavioral Pediatric Feeding Assessment Scale (BPFAS) and the Gilliam Autism Rating Scale (GARS) (16). These tools have measured behaviors and emotional responses at

meal time including how often a child engages in a particular behavior. This may be throwing food, spitting, refusing foods, not sitting at the table or screaming and aggressiveness. Each of the tools have been compared to one another and it was concluded that after examining the psychometric properties of the BAMBI, clinical cutoff scores could be determined, therefore determining it to be more functional in a clinical setting (16). From these tools, researchers and health care professionals are able to gain insight into feeding behavior frequency.

A tool used in measuring eating behavior in typical children, or children without autism, is the About Your Child's Eating (AYCE) inventory. This inventory has measured families with physically healthy as well as chronically ill children with a life-threatening condition, between 8 and 16 years old. In particular, three areas were studied including Child Resistance to Eating, Positive Mealtime Environment and Parent Aversion to Mealtime. Results of the study conducted in Milwaukee, Wisconsin determined the AYCE to be a psychometrically sound measure of the parent-child feeding relationship for this age group (17). These mealtime behaviors compare with those identified in the Brief Autism Mealtime Behavior Inventory (BAMBI), Behavioral Pediatric Feeding Assessment Scale (BPFAS) and the Gilliam Autism Rating Scale (GARS). The literature may therefore suggest that children with autism and children without autism exhibit some of the same feeding behaviors.

Measuring Nutritional Status

Methods for measuring dietary intake and nutritional status have evolved over years of research. The 24-hour recall has been used frequently in the research in measuring dietary intake and determining nutritional status. However, the 24-hour recall

requires a trained individual to administer. Multiple pass 24-hour recalls used by the Minnesota Nutrient Data Bank Assessment and in the Bogalusa Heart Study were determined to increase the validity of this assessment measure (18). Researchers using the multiple pass method work backwards with the subject to recall the most recent meal. Once all items are consumed, the researcher reviews the diary with the subject several times for thoroughness. In 24-hour recalls, amounts of foods could be skewed or misreported. Subjects may easily forget all that has been consumed, thus skewing the data (19). It has also been reported that both men and women, who are the parents reporting about children with autism, tend to over-report and may underreport energy intake (20). Due to these human errors and possible unreliability, a food frequency questionnaire, which allows intake to be recorded as number of servings of any food item per day, week and month, may also be used to support data obtained from the 24-hour recall.

Nutritional Information Sources

An issue relating to the perceptions of parents feeding typical children and children with autism is where do parents obtain their nutritional information. Non-credible sources and new and scarcely researched information regarding supplementation may be interfering with children receiving proper nutrition. It may also contribute to a parent's anxiety, especially when using the internet which offers millions of pages of information. Women using the internet for information and discussion in general with other parents have indicated high perceived support (21). This support may be the only source of information on which they are relying and it is unknown whether parents discern credible from non-credible sources. Other sources of information for nutrition,

other than a registered dietitian, may include the physician, family, friends and books and journals in addition to the internet.

Role of the Dietitian

Due to their broad and in-depth education on nutrition, dietitians should play an important role in the care of children with autism, as well as the education of parents. Dietitians interviewed felt it necessary to educate the parents and encourage them to look at research regarding supplementation effects and costs, or other dietary practices (22). Dietitians also feel it is necessary to warn parents of undocumented claims regarding treatments for autism. The internet offers a wealth of information but it is not all credible as previously stated. The dietitian may therefore play a role by providing information to families via internet discussions and support groups. By understanding the knowledge level and information sources of parents of children with autism, the registered dietitian may be able to focus on specific areas of nutrition education with the family.

By reviewing the literature on parent perceptions and determining that children with autism need more nutritional attention, the research study evolved. The researcher aims to gain insight into the situation by examining parent perceptions and nutritional status of children with autism through the following methods. The information gathered and results collected will serve as a starting point to providing nutritional care to this population.

Section 3: Purpose

The purpose of this study is to examine the parental perceptions of the nutritional status of children with autism and to compare the perceptions with the actual nutritional status of the children observed in the study.

Section 4: Research Questions

#1: Are parents of children with autism confident about their nutritional knowledge?

#2: Do parents of children with autism perceive the nutritional status of their child to be poorer than actual?

#3: Do parents of children with autism who are confident about the nutritional status of their child get their information from credible sources?

Section 5: Methodology

Setting

Research was conducted at the University of Kentucky in the Department of Nutrition and Food Science (NFS). The NFS assessment lab in the Funkhouser building on campus was used for meetings with families. The lab contained a round table with several chairs. Toys such as magnets and small cars were provided for children while discussions were held with parents. The room was set up with a balance scale for height and weight. Other measurement materials, including calipers and a measuring tape for mid-arm circumference and head circumference, were available. Measuring cups and wooden representations of bottles, cups and food portions were located in the lab to

estimate serving sizes when the 24-hour recall was discussed. Researchers present at meetings included a dietitian, a graduate student in dietetics and the research advisor. One or both parents, grandparents or caregiver were present with the child.

Design

To explore parental perceptions and feelings about the nutritional status of their children, families were recruited to the study from autism support groups in Kentucky. An oral invitation was presented to several autism related service provider groups and contact information including phone number and email of the researcher was provided. The audience was encouraged to inform family members and clients about the study. An invitation email was also sent to support group members around the state. Following the invitations to participate in the study, phone calls and emails were received from interested families. Meeting times were then established and directions provided.

Of the 25 families assessed from the longitudinal study, this researcher assessed ten families and therefore ten children. The sample was comprised of males and females. Age ranged from 3-11 years old. Race included non-Hispanic white, African American and Asian backgrounds. Permission was previously obtained from the Institutional Review Board to work with human subjects; the researcher also passed the Institutional Review Board exam.

The initial meeting of the study lasted approximately one to one and one-half hours, depending on questions and availability of the families. During this time, several steps were taken to obtain information.

The first form and parameter addressed with parents was the informed consent form, which was previously approved by the Institutional Review Board. The title of the consent form was “Nutritional Intake of Children with Neurodevelopmental Disorders.”

The researcher explained each section with parents before signing two copies. The parent was given a copy to keep for their records while another copy was kept in the research file in a locked cabinet at the University of Kentucky.

The consent form included seventeen informational sections which provided participants of a detailed view of the entire study. They were informed that they were invited to participate because their child had been diagnosed with autism or an autism Spectrum Disorder including Retts Disorder, Pervasive Developmental Disorder-Not Otherwise Specified, Aspergers Disorder and Childhood Disintegrative Disorder, or as part of a control group if the child is a typically developing child or sibling of a child in the study. In its entirety, 75 families have been included since the beginning of the study. The participants were also informed about the purpose of the study, who was involved, what they would be asked to do, benefits and risks, timeframe, confidentiality and questions they may have.

The next step was for the families to complete a comprehensive health and nutritional history form. The health history form asked about the birth of the child and health of the mother, including any complications during pregnancy. A checklist of any previously existing conditions or diseases the child may have was completed. Injuries or previous surgeries and hospitalizations were also documented.

Nutritional history provided information as to the child's previous nutritional status and eating behaviors. A checklist including feeding skills, eating behaviors, rumination, throwing food, feeding environment, ingestion of non-food items and food preferences was completed. Additional information was requested from parents that did not appear on the checklist.

A 24-hour recall was used to obtain information about the child's diet. The process used the multiple pass method to ensure accuracy in the reporting. The dietitian discussed each meal and snack the child consumed the previous day. When discussing the 24-hour recall, the researcher started with the most recent meal or snack eaten. The reasoning behind this is that it is most easily recalled. The dietitian then worked backwards to the first consumption of the day with many prompts to help with recall. An important part of the 24-hour recall is serving size and being as detailed about the food as possible so that the information can be accurate in representing the child's diet. The dietitian asked what type of food was consumed, how it was prepared and approximate serving size. Measuring cups and shaped representations of portions were shown to the participant so that they could accurately describe the amount consumed. For example, the dietitian would ask about any beverages consumed. If the child had milk with dinner, the dietitian asked what kind of milk, chocolate or plain, and what percent fat the milk contained, 1, 2 or fat free. If the amount was described as 'one glass,' the dietitian determined the size of the glass. Various representations of a 'glass' of milk were shown for the participant to choose. This allowed the dietitian to determine approximately how many ounces were consumed. The dietitian then would ask how much of the 'glass' was ingested. This could be a full glass, half glass or another fraction. All food items were recorded, including sips and bites. This allowed the researcher to closely determine calories and nutrient amounts.

The next step in the meeting with the family was presenting and explaining the food frequency list to be used in combination with the 24-hour recalls. Participants were provided an extensive list of food items based on a Block food frequency questionnaire

(FFQ) and standard serving sizes to take home. The family was instructed to keep the form on their refrigerator or in a convenient place at home where they would be able to check off items. Participants were asked to observe their child's diet closely for about three months. The dietitian would call at intervals to ask and answer questions about the progress. The food frequency questionnaire asked how often per day, week and month the child consumed one serving, which was listed, of a particular food item. Families were asked to circle what they observed over this time. For example, one serving size of mashed potatoes is listed as one half cup. If the child is consuming one cup in one day, the parent would circle '2' servings of mashed potatoes. If a food item was not listed on the form, the parents were asked to write in the item and serving size. Participants were contacted after three to six months and asked to return their completed food frequency to the Department of Nutrition and Food Science via fax, email or US mail.

A benefit of the study for the parents included a free counseling session from a registered dietitian. This allowed parents to ask questions regarding their child's nutritional status and feeding behaviors and receive nutritional advice. For example, if the child had limited food preferences and only preferred one to two types of foods, ideas for introducing new foods were provided. Clinical information regarding diarrhea and gastrointestinal problems were also discussed; suggestions were offered how to relieve symptoms and explain their occurrence. If time did not permit a nutrition counseling session, a follow-up session was completed by telephone with the registered dietitian and family member.

Survey Tool

A final evaluation completed by parents in the study as well as other parents around the state of Kentucky was a Nutritional Perception Assessment. The purpose of the tool was to evaluate the feelings of parents regarding feeding their child and their nutritional knowledge and confidence.

The instrument was developed based on the Behavioral Pediatric Feeding Assessment Scale (BPFAS), which has been previously tested for validity (16). Questions on the BPFAS included descriptions of feeding behaviors of children during mealtime and the feelings of parents while mealtime occurred. Thirty questions were developed by the researcher and separated into four constructs. Nutritional Knowledge was the first addressed. Six questions asked parents about their own personal nutritional knowledge and whether they felt confident about it, needed or desired more information, or had seen a registered dietitian. The Nutritional Status of the Child construct addressed how parents felt about their child's nourishment and weight. The Nutritional Knowledge Sources section aimed to identify where participants were obtaining their nutritional knowledge. Credible and non-credible sources were listed as choices, including physicians, dietitians, friends and the internet. The final eight questions addressed Child Feeding Behaviors. This construct asked about feeding behaviors, feelings of parents during feeding times and influence of behaviors on nutritional status.

Questions were entered into the online survey program, Survey Monkey at www.surveymonkey.com. A 5-point Likert-type scale was used for question responses. An abridged version of ten of the thirty questions was created and pilot tested. The shortened version of the survey contained questions from each of the four sections to

represent the entire questionnaire. A Survey Monkey link was sent to a group of eleven graduate students for testing of questions and survey vehicle. The students were instructed to respond to the questions as though they themselves were parents of children with autism. Eleven fully completed surveys were evaluated to determine usability of the questions and electronic survey method.

A hyperlink to the full thirty question Nutritional Perception Assessment survey was sent to several autism support groups via an invitation email, providers of autism services such as physical therapy and occupational therapy. Participants were asked to share and forward the survey to other parents of children with Autism Spectrum Disorders. They were also asked to send the link over any list serves or post on websites for others to participate. Parents answered questions on a Likert scale using strongly disagree, disagree, neutral, agree and strongly agree. Only one answer was allowed to each question. Fifty surveys were attempted, though not all completed. All responses to each question in the survey were used for analyses. A copy of the Nutritional Perception Assessment questions may be seen in Appendix A.

Analysis

Responses to each of the survey questions were entered into the statistical software program, JMP 7. Frequencies and descriptive statistics were calculated by the number of parents responding to each question. Though fifty parents responded to the survey, not all fifty answered each question. The questions in each of the four constructs of the survey were recoded if negatively worded to obtain an accurate mean. Questions were collapsed and responses averaged to represent each of the four constructs. Questions were removed that did not represent the goal of the construct. For example, the Child

Feeding Behavior construct aimed to determine parental feelings during mealtime.

Questions such as ‘My child refuses to try new foods’ and ‘My child frequently throws food at meal time’ were removed to allow the construct to represent one single idea to be used in analysis. Mean responses to individual constructs were compared and correlations were determined using the Spearman Correlation. Parental confidence in nutritional knowledge and nutritional sources used were compared to how parents perceived their child’s nutritional status and feelings of parents during mealtime.

Information from the 24-hour recalls was entered into the MyPyramid Food Tracker for nutrient analysis. Eight of the ten 24-hour recalls performed by this researcher were used and added to seventeen 24-hour recalls collected by this researcher’s advisor. A total of twenty five families $n=25$ were used in the current study.

Mean amounts of macronutrients, including energy, protein, carbohydrate, fat and saturated fat, were calculated. Micronutrients calculated and reviewed for this study due to common deficiencies reported from research sources including the on-going study in NFS on children with autism were vitamin A, vitamin C, thiamin, riboflavin, niacin, folate, vitamin B₆, vitamin B₁₂, calcium and iron. Mean amounts consumed were compared to the Daily Recommended Intake (DRI) amounts for children ages 1-3, 4-8 and 9-13 to determine nutritional status.

Section 6: Results

Parent responses to the Nutritional Perception Assessment are separated by category in the tables below. Each table shows individual questions and frequency of responses. Not all questions on the survey were answered by all 50 participants; frequency of responses was recorded from participants' responses.

Parents answered questions on a Likert-type scale with choices numbered 1-5. The numbers correspond to Strongly Disagree (1), Disagree (2), Neutral (3), Agree (4) and Strongly Agree (5). The choices of Disagree and Strongly Disagree, and Agree and Strongly Agree have been combined as frequencies for a clearer representation.

Table 1: Responses to Nutritional Knowledge Construct

Nutritional Knowledge	Disagree	Neutral	Agree	n=
1. I am confident about my nutritional knowledge.	12.2%	16.3%	71.5%	49
2. I am confident about where I obtain my nutritional knowledge.	10.4%	14.6%	75.1%	48
3. I do not feel I have basic nutritional knowledge.	75.5%	10.2%	14.2%	49
4. I feel I have the nutritional knowledge I need to care for my child.	14.3%	14.3%	71.4%	49
5. I would like to obtain more nutritional information.	8.4%	18.8%	72.9%	48
6. I have seen a Registered Dietitian for my child.	73.5%	4.1%	22.4%	49

Table 1 shows parental perceptions of their nutritional knowledge. When asked if they felt confident in their nutritional knowledge, 71.5% of 49 parents who responded agreed or strongly agreed. The other questions in this category reflected similar responses where 75.1% of parents, n=48, agreed that they were confident about where they obtain their nutritional knowledge. Seventy five and one-half percent (75.5%) of parents, n=49, disagreed with not having basic nutritional knowledge, indicating confidence, while 71.4%, n=49, felt they had the nutritional knowledge they needed to care for their child. Concerning nutritional knowledge, 72.9% of parents, n=48, reported

wanting to obtain more nutritional knowledge while 73.5% of parents, n=49, had not seen a registered dietitian for their child.

Table 2: Responses to Nutritional Status of Child Construct

Nutritional Status of Child	Disagree	Neutral	Agree	n=
7. I believe my child is well-nourished.	25.5%	10.6%	63.9%	47
8. I do not believe my child is getting adequate amounts of vitamins/minerals.	36.2%	19.1%	44.7%	47
9. I am concerned about the nutritional status of my child.	23.9%	8.7%	67.4%	46
10. I do not feel my child is overweight.	23.4%	6.4%	70.2%	47
11. I believe my child is getting enough to eat.	13.1%	13.0%	74.0%	46
12. I do not believe my child is at a healthy weight.	68.1%	6.4%	25.6%	47
13. I believe my child is underweight.	87.3%	8.5%	4.2%	47
14. I feel the medication(s) my child is taking influences his/her nutritional status.	36.2%	38.3%	25.6%	47

Table 2 examines parent perceptions of the nutritional status of their child. Out of 47 parents who responded, 63.9% believed that their child was well-nourished. When asked if they did not think their child was getting adequate amounts of vitamins and minerals, 36.2%, n=47, disagreed, indicating that they felt their child was indeed getting adequate vitamins and minerals. A neutral response was reported from 19.1% of parents who responded to this question, while 44.7% agreed to not believing that their child was getting adequate vitamins and minerals.

Of 46 parents who responded to feeling concerned about the nutritional status of their child, 67.4% agreed. In contrast, of 47 parents reporting, 70.2% did not feel that their child was overweight. Seventy four percent (74.0%) of parents who responded, n=46, agreed that their child was getting enough to eat and 68.1% of parents, n=47, disagreed when asked if they did not believe their child was at a healthy weight. Similarly, 87.3% of parents, n=47, disagreed that their child was underweight. Parents

reported feeling that medications influenced their children’s nutritional status where 36.2%, n=47, disagreed, 38.3% answered neutral and 25.6% of parents agreed.

Table 3: Responses to Nutritional Knowledge Sources Construct

Nutritional Knowledge Sources	Disagree	Neutral	Agree	n=
15. I obtain my nutritional information from family and friends.	63.6%	22.7%	13.6%	44
16. I obtain my nutritional information from a physician.	31.8%	15.9%	52.3%	44
17. I use the internet for nutritional information.	15.9%	11.4%	72.8%	44
18. I get my information from credible sources such as medical journals and books.	7.0%	16.3%	76.7%	43
19. I see a Registered Dietitian for nutritional information for my child.	74.4%	11.6%	13.9%	43
20. I do not seek additional nutritional information.	73.8%	14.3%	11.9%	42
21. I trust the nutritional information I receive.	2.3%	30.2%	67.5%	43
22. I do not feel I am well-informed about nutrition for my child.	63.6%	15.9%	20.4%	44

Parents then answered questions about the source of their nutritional information.

These results are also displayed in Figure 1. The highest frequency of sources of information were the internet, where 72.8% of parents, n=44, agreed. Another majority, 76.7% of parents, n=43, agreed to obtaining their nutritional information from credible sources such as books and journals. Of 44 parents who responded, 52.3%, agreed to obtaining information from a physician while 13.6%, n=44, agreed to obtaining information from family and friends. Finally, 13.9%, n=43, agreed to seeing a registered dietitian for their child.

When asked if additional information was sought, 73.8% of parents, n=42, disagreed to not seeking additional information, meaning they would like additional nutritional information. Of 43 parents who responded, 67.5% agreed to trusting the

nutritional information they receive and 63.6%, n=44, disagreed to not feeling well-informed about nutrition for their child, indicating confidence in nutritional knowledge.

Figure 1: Reported Parental Sources of Nutritional Information from Survey, Answer: “Agree and Strongly Agree”

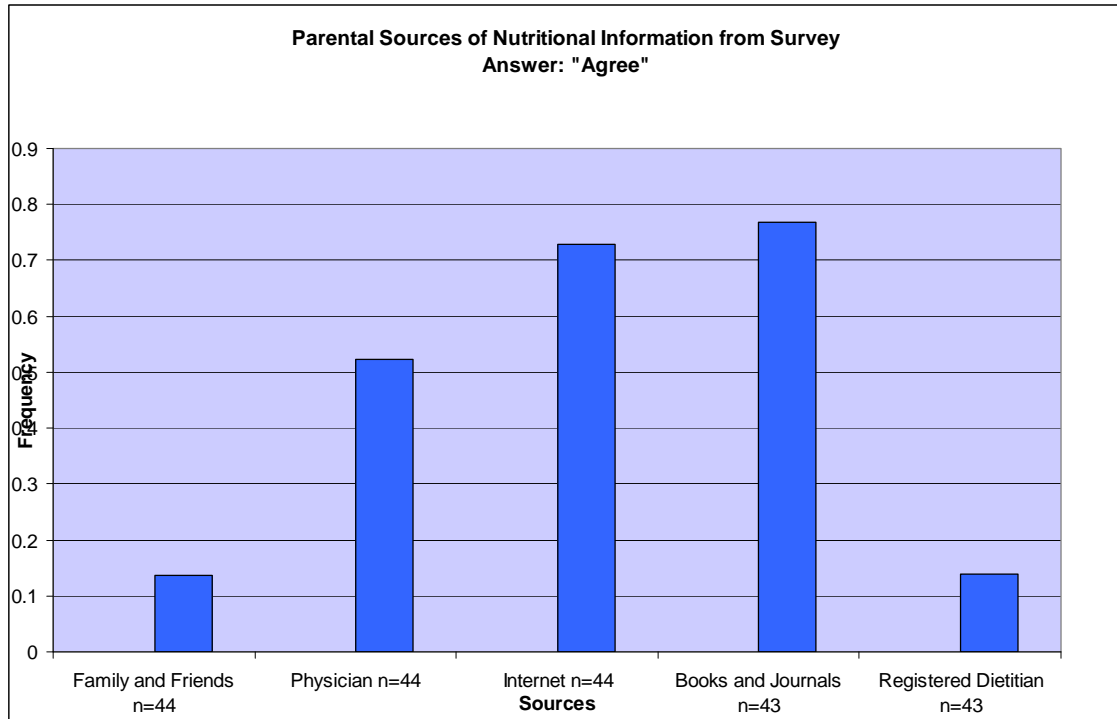


Table 4: Responses to Child Feeding Behaviors Construct

Child Feeding Behaviors	Disagree	Neutral	Agree	n=
23. I believe my child's feeding behaviors influence his/her nutritional status.	2.3%	7.0%	90.7%	43
24. I do not feel it is inappropriate for my child to eat alone and not join others at the table.	50.0%	14.3%	35.7%	42
25. I do not get frustrated when trying to feed my child.	58.1%	16.3%	25.6%	43
26. My child frequently throws food at meal time.	97.7%	2.3%	0.0%	43
27. I am not worried that my child is not eating at school.	41.8%	30.2%	27.9%	43
28. My child refuses to try new foods.	27.9%	4.7%	67.4%	43
29. I feel anxious/stressed when I have to feed my child.	58.2%	16.3%	25.6%	43
30. I feel my child misbehaves because he/she does not like the food presented.	46.6%	25.6%	27.9%	43

Parental perceptions of child feeding behaviors are shown in Table 4. A high frequency of 90.7% of parents who responded, n=43, agreed to believing that their child's feeding behaviors influence nutritional status. Varied responses were collected regarding feeling that it is inappropriate for their child to eat alone and not join others at the table. Fifty percent (50.0%) of parents, n=42, disagreed to this question. In addition, 58.1%, n=43, disagreed to not getting frustrated when feeding their child, indicating frustration at meal time, while 58.2% of parents, n=43, disagreed to feeling anxious/stressed when feeding their child.

A high frequency of 97.7% of parents, n=43, disagreed that their child throws food at meal time and 41.8% of parents, n=43, disagreed to not being worried that their child is not eating at school. Of 43 parents who responded, 67.4% agreed that their child refuses to try new foods and 46.6%, n=43, disagreed that their child misbehaves because he/she does not like food presented.

**Figure 2: Frequency of Nutritional Perception Survey:
Nutritional Knowledge and Status**

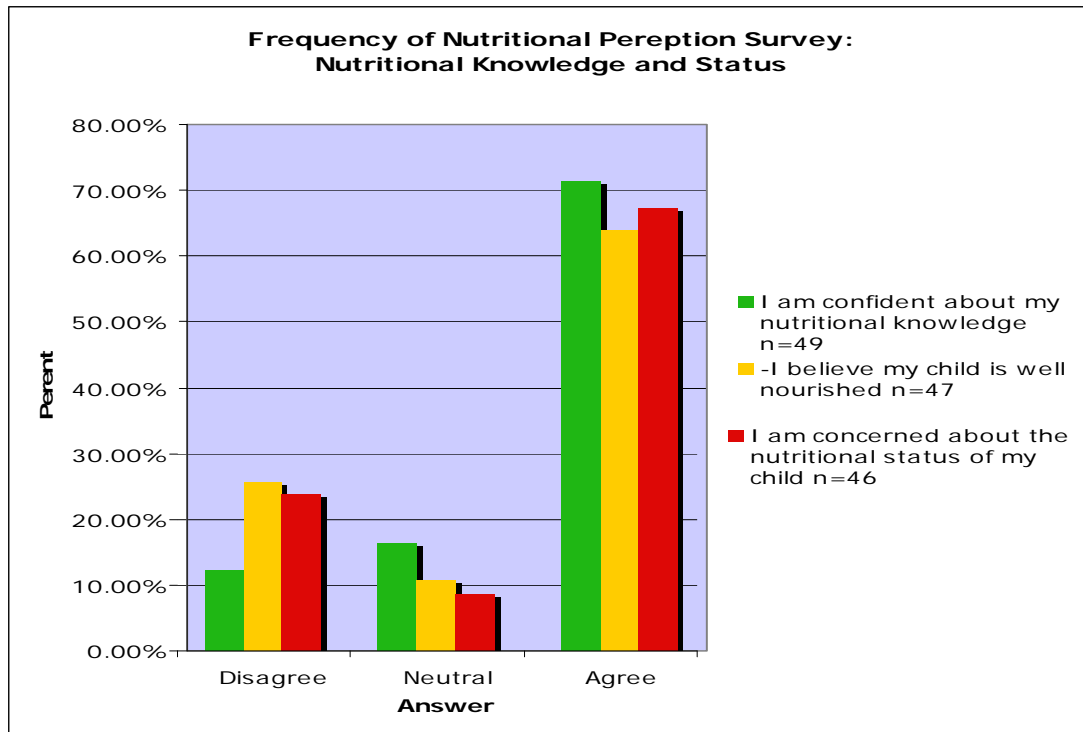


Figure 2 shows frequencies of parental perceptions of their own nutritional knowledge and their feelings about the nutritional status of their child. The graph shows that 71.5%, n=49, agreed to feeling confident about their nutritional knowledge. Sixty three percent (63.0%), n=47, also agreed that they believe their child is well-nourished. However, 67.4% of parents, n=46, agreed to being concerned about the nutritional status of their child.

Statistical Analysis

To further examine the Nutritional Perception Assessment responses, distributions of constructs and correlations among constructs were determined. Data were entered into the statistical software program, JMP 7. Names of the constructs were modified to reflect the idea examined. Nutritional Knowledge is noted as ‘Confidence’; Nutritional Status of

Child is ‘Nutrition Status’; Nutritional Knowledge Sources is noted as ‘Sources’ and Child Feeding Behaviors is ‘Feeding Feelings.’

Distributions of the four constructs were examined by constructing histograms. Shapiro-Wilkes tests of normality were used to determine each distribution. The null hypothesis was that $\mu=3$, where the parents felt neutral in response to each construct. Significance level was set at $\alpha=0.05$. The null hypothesis is rejected where the variable is non-normal in the constructs of Confidence and Nutrition Status. There is failure to reject the null hypothesis in the constructs of Sources and Feeding Feelings. Mean responses of the constructs (variables) were tested equal to 3 (neutral) and all were rejected. The Confidence construct, Nutrition Status construct and Sources construct means were greater than 3, toward ‘agree’ and ‘strongly agree’ while Feeding Feelings was less than 3, toward ‘disagree’ and ‘strongly disagree.’

Table 5: Distributions of Constructs

Construct	Mean	SD	n	Shapiro Wilkes p<W
Confidence	3.8520408	0.7771448	n=49	0.0207*
Nutrition Status	3.46875	0.7131223	n=48	0.0489*
Sources	3.1507576	0.4042084	n=44	0.2207
Feeding Feelings	2.25	0.5695654	n=43	0.2931

* Small p-values reject Ho

The Spearman Correlation was used to compare the constructs of Nutrition Status and Source. Research Question #3 asks: Do parents of children with autism who are confident about the nutritional status of their child get their information from credible sources? Regression using ANOVA in this correlation gave marginal significance about how parents responded to these constructs ($p=0.0429$).

A full linear model was created comparing Confidence, Nutrition Status and Sources with Feeding Feelings. None of the interactions among the constructs were significant, with p values >0.05. A main effects model for comparing Feeding Feelings to the other three constructs was created. Confidence was not significant at p=0.9546 and eliminated from the model. A final model compared Feeding Feelings with Nutrition Status and Sources. Results are listed in Table 6. Nutrition Status has a positive effect at high confidence, p=0.0040, and Sources has a negative effect at marginal confidence, p=0.0382.

Table 6: Parameter Estimates of Relationship between Nutrition Status and Sources

Term	Estimate	Std Error	t Ratio	Prob> t
Intercept	2.3642017	0.67709	3.49	0.0012*
Nutrition Status	0.3506593	0.114787	3.05	0.0040*
Sources	-0.422275	0.197037	-2.14	0.0382*

Children’s Nutritional Status Determined by the 24-Hour Recall

Mean daily intakes of macro and micro nutrients are represented in tables 6 and 7. The tables reflect mean values from a sample of 25. Daily Recommended Intakes (DRIs) are listed for children, both male and female, in the age categories of 1-3 years, 4-8 years and 9-13 years, which are the designated categories according to the Institute of Medicine (23).

Table 7: Macro Nutrients Mean Amounts in 24 Hours

Nutrient	Mean Amount in 24 Hrs. n=25	Range	DRI Ages 1-3	DRI Ages 4-8	DRI Ages 9-13
Food Energy/Total Calories (kcal)	1643.64	835-2507	1046	1742	2279
Protein (gm)	60.2	18-124	13	19	34
Carbohydrate (gm)	226.16	96-330	130	130	130
Total Fiber (gm)	13.24	3-39	19	25	31
Total Fat (gm)	58.632	13.9-119	30-40	25-35	25-35
Saturated Fat (gm)	20.024	4.1-36.3	Less than 10% total fat	Less than 10% total fat	Less than 10% total fat

Mean amounts of total energy intake met the DRIs for children ages 1-3 and 4-8. The mean amount of protein, carbohydrate and fat consumed exceeded DRIs for all three age categories. The mean amount 20.024 was 34% of mean total fat consumed, and therefore exceeded the recommended daily amount. The only macronutrient where none of the three categories met the DRI was fiber, where 70%, 53% and 43% were met, respectively.

Table 8: Micro Nutrients Mean Amounts in 24 Hours

Nutrient	Mean Amount in 24 Hrs. n=25	Range	DRI Ages 1-3	DRI Ages 4-8	DRI Ages 9- 13
Vitamin A (mcg RAE)	718.748	109.7-2208	300	400	600
Vitamin C (mg)	81.456	20.1-226.7	15	25	45
Thiamin (mg)	1.388	0.4-2.7	0.5	0.6	0.9
Riboflavin (mg)	1.992	0.5-4.3	0.5	0.6	0.9
Niacin (mg)	17.488	5.8-41.7	6	8	12
Folate (mcg, DFE)	315.704	62.2-621.7	150	200	300
Vitamin B6 (mg)	1.64	0.6-2.8	0.5	0.6	1.0
Vitamin B12 (mcg)	4.568	0.7-12.6	0.9	1.2	1.8
Calcium (mg)	978.88	219.4-2100.7	500	800	1300
Iron (mg)	11.708	2.0-20.2	7	10	8

Micronutrients that are of concern in children with autism are listed in Table 7. The mean amounts were also compared to the DRIs for children ages 1-3, 4-8 and 9-13 years. Results show that the sample of children studied exceeded the DRIs for all three age groups in their consumption of Vitamin A, Vitamin C, Thiamin, Riboflavin, Niacin, Folate, Vitamin B6, Vitamin B12 and Iron. The mean amount of calcium met and exceeded the DRI for children ages 1-3 and 4-8. It fell short of meeting the DRI for children ages 9-13, having only met the recommended amount by 75%.

Section 7: Discussion

Nutritional Perception Assessment

Results show that a majority of parents are confident about their nutritional knowledge, where 71.5% of 49 parents who responded agreed to this question. The mean of the Confidence construct was 3.8520408, indicating the parents responded higher than neutral and agreed to the questions. This response frequency answers Research Question #1: Are parents of children with autism confident about their nutritional knowledge? However, parents also reported feeling concerned regarding the nutritional status of their child. In addition, a majority of the parents reported getting frustrated but not feeling anxious or stressed when having to feed their child. These responses may be explained by actual parental perceptions or by misreading or misunderstanding the question asked. The wording of the questions may have contributed to the contradictions found in the survey responses and may have influenced the accuracy of the results. Literature shows that questionnaire design affects problematic deviations of the respondent in addition to mismatch answers. However, changing the answers from negative to positive responses in a Likert scale ensure that participants read the questions carefully before making a response (24). Some questions were worded in the negative to ensure thorough reading of the question and therefore an accurate answer.

Most parents agreed that they received most of their nutritional knowledge from the internet and physicians. This is a concern, as parents are not visiting dietitians for nutritional help. The internet is of particular concern because it offers copious amounts of information but not all credible and sound. Another study on parents' knowledge of credible sources may yield insight as to which information they are applying to their

children's lives. Physicians are a credible and professional source; however, they do not share the credentials and nutritional education of registered dietitians. This indicates a need for nutritional education from dietitians and medical nutrition therapy counseling for the autism community. A possible explanation of why parents are not seeing a registered dietitian may be the type of schedule a parent of a child with autism keeps. It is common to have frequent appointments with physicians, therapists and other healthcare professionals for the health of their child, that sometimes nutritional information is obtained and discussed there. It should be an important goal for dietitians to become a major part of the healthcare team and communicate to parents their knowledge and availability to guide the nutritional well-being of children with disorders that can affect nutritional status.

Research Question #3 asked: Do parents of children with autism who are confident about the nutritional status of their child get their information from credible sources? Parents who felt confident about the nutritional status of their child also reported obtaining information from credible sources such as medical journals and books. The correlation was marginally significant at $p=0.0429$. This may be correct; however, it is unknown whether parents have a true understanding of what is 'credible.' Belief passed on by family members and friends in nutritional treatments or advice may lead parents to make nutritional judgments, no matter the source.

Feelings about the nutritional status of children and nutritional sources had the highest, most significant effect on the way parents responded about their feelings when feeding their children.

24-Hour Recall and Nutritional Status

Research Question #2 asked: Do parents of children with autism perceive the nutritional status of their child to be poorer than actual? Parents averaged 3.46875 as a score in the Nutrition Status construct, meaning that they responded higher than feeling neutral and overall slightly agreed to the questions asking if they felt their child's nutritional status was good. Results show that the 24-hour recalls completed indicate that the children studied are meeting daily recommendation of macro and micronutrients. The exception is fiber for all three age groups and calcium in the age group of 9-13 years, which only met the DRI by 75%. The gluten-free, casein-free diet that is commonly used among children with autism may provide an answer. The children would not be consuming dairy products, which are major sources of dietary calcium. It may also be explained by food aversions in the child. Results show, however, that most daily recommended amounts of nutrients studied were exceeded by the mean amount reported. It may be said that these 25 children have good nutritional status.

A majority of parents are confident about their nutritional knowledge as well as the nutritional status of their child. Though parents also reported being concerned, the results of the 24-hour recall study may provide some relief as the 25 children studied met the Daily Recommended Intakes for all nutrients except calcium in comparison to the older age group. These contradictions, confidence and concern, may be explained by the reliability of parental perceptions of their child's health and well-being. Literature shows that parents have reported a significantly higher perception of health related quality of life than did their children (25).

Limitations

Limitations of this study include sample sizes, question wording and accuracy of the nutritional measurement method. Although the sample size was appropriate for providing credible statistical information only 50 parents in Kentucky answered the questionnaire. Thus the results cannot be extrapolated to the entire autism community. Statistically, a larger sample of the population of parents of children with autism may have yielded a more significant insight into parental feelings. Responses to the questions may have been clearer and more correlations drawn if the questions had been worded differently. Finally, as discussed in the literature review, the 24-hour recall is not the most accurate method of measuring dietary intake. The food diary reflects only one day, which may not always be typical of a child's diet. Food frequency questionnaires have been shown to be the most practical and economical method for collection of comprehensive dietary data in large epidemiologic studies (19). Though food frequency questionnaires were obtained from parents in the study, there were not enough returned with time permitting to compile an adequate sample size for analysis. However, the 24-hour recall multiple pass method was used, where prompting parents and thoroughly discussing meals and snacks allowed for a more accurate recall. Therefore, the information gathered in this study by the researcher was still useful to determine nutritional status.

Section 8: Conclusions and Recommendations

The literature on parental perceptions of nutritional status of children with autism is limited. Feeding behaviors are common in both typical children as well as children with autism. Parents of children with autism have reported feeling confident about their child's nutritional status, while also admitting to feeling frustrated and anxious at the same time. There is a significant correlation between confident parents and the reported use of credible references used as nutritional sources. Mean amounts determined by multiple pass 24-hour recalls met and exceeded DRIs for children ages 1-3, 4-8 and 9-13 years. It is recommended that more research be conducted to determine a standard tool for measuring behavior and nutritional status for children with autism. Dietitians should use parental perceptions and understand parental insights when treating children with autism for the best nutritional results.

Appendix A: Nutritional Perception Assessment

1. I am confident about my nutritional knowledge.
2. I am confident about where I obtain my nutritional knowledge.
3. I do not feel I have basic nutritional knowledge.
4. I feel I have the nutritional knowledge I need to care for my child.
5. I would like to obtain more nutritional information.
6. I have seen a Registered Dietitian for my child.
7. I believe my child is well-nourished.
8. I do not believe my child is getting adequate amounts of vitamins/minerals.
9. I am concerned about the nutritional status of my child.
10. I do not feel my child is overweight.
11. I believe my child is getting enough to eat.
12. I do not believe my child is at a healthy weight.
13. I believe my child is underweight.
14. I feel the medication(s) my child is taking influences his/her nutritional status.
15. I obtain my nutritional information from family and friends.
16. I obtain my nutritional information from a physician.
17. I use the internet for nutritional information.
18. I get my information from credible sources such as medical journals and books.
19. I see a Registered Dietitian for nutritional information for my child.
20. I do not seek additional nutritional information.
21. I trust the nutritional information I receive.
22. I do not feel I am well-informed about nutrition for my child.
23. I believe my child's feeding behaviors influence his/her nutritional status.
24. I do not feel it is inappropriate for my child to eat alone and not join others at the table.
25. I do not get frustrated when trying to feed my child.
26. My child frequently throws food at meal time.
27. I am not worried that my child is not eating at school.
28. My child refuses to try new foods.
29. I feel anxious/stressed when I have to feed my child.
30. I feel my child misbehaves because he/she does not like the food presented.

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