Gluten-free and casein-free diets as a form of alternative treatment

for autism spectrum disorders

by

Gwenda Washnieski

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Committee Chair

Carol Seaborn

Carol Seaborn, Ph.D., R.D., C.D., C.F.C.S.

Committee Members

Charlene Schmidt

Charlene Schmidt, Ph.D., R.D., C.D.

Ruth Nyland

Ruth Nyland, Ph.D.

The Graduate School
University of Wisconsin-Stout
August, 2009

The Graduate School
University of Wisconsin-Stout
Menomonie, WI

Author: **Washnieski, Gwenda L.**

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ABSTRACT

The diagnosis for autism spectrum disorders (ASD) is not based on a clear cut test or examination, and there is currently no cure. The gluten-free/casein-free (GFCF) diet is a common alternative intervention used for ASD management. The purpose of this study was to determine the knowledge and perceptions of parents of children with ASD regarding the GFCF diet when used as a form of alternative treatment. Through the use of surveys, food records, and behavioral evaluations, the barriers to initiating and maintaining the diet, accuracy of implementation, perceived behavioral benefits, and parent preferences for receiving reliable information were evaluated.

Participants who have used the diets were placed in the diet group (n= 11), and those who have not were in the nondiet group (n=17). Significant differences were found in behavior evaluations between the diet and nondiet groups in the speech, social, sensory, and health

behavior changes (Chi Square $p \leq 0.001$). Participants in the nondiet group reported using drug treatment significantly more than the diet group ($p<0.05$). This study suggests that GFCF diets can impact the behavior of children with ASD positively, and highlights the importance of including a nutritional professional on the child's health care team.

The Graduate School

University of Wisconsin-Stout

Menomonie, WI

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Chapter I: Introduction

Autism has recently received a great deal of attention in the media. Bowers (2002, p. 141) states that autism "is often described as a 'triad of impairments' affecting a person's social communication, social interaction, and imaginative understanding." Autism is one of today's most puzzling disorders. The cause of autism is unknown, the diagnosis is not based on a clear-cut test or examination, and there is currently no cure. Many studies have been conducted, and more are in progress to help understand this very complex disorder.

Children with an Autism Spectrum Disorder (ASD) elicit many different characteristics. Among the most common are problems relating to communication, social interactions, routines, or repetitive behaviors. Problems with communication encompass both verbal and non-verbal aspects. Patients with ASD may have problems with social interactions, such as expressing empathy, carrying on a conversation, and the ability to spend time with others. The routines and repetitive behaviors specific to children on the autism spectrum may include: repeating words or actions, obsessively following routines or schedules, eating the same foods every day, and playing with toys in a repetitive manner (National Institutes of Health, 2005).

According to Hollenbeck from the organization Fighting Autism (2004b), there has been an increase in prevalence of autism across the United States. In 2003, 163,773 children had autism, or 1 in 264 children. This is an 805% cumulative growth rate from 1992 in the United States. Minnesota alone reported 5,838 children with autism in 2003, or 1 in 113 children (Hollenbeck, 2004a). This is a 1,609% cumulative rate of growth from 1992 in Minnesota. According to the Center for Disease Control and Prevention's (CDC) Autism Developmental Disabilities Monitoring Network (ADDM) (2007), the prevalence of autism in 8-year old children at ADDM sites is now about 1 in 150 children.

This number seems to have risen from previous years, but because the ASD classification was just added as a reporting requirement in 1991 (Hollenbeck, 2004b), it cannot be assumed that the prevalence has risen. Before the ASD category was included as a separate classification, parents identified their child with the umbrella category of developmental disabilities. Therefore, it is not known if the recent increase in reported cases is due to an increase in children having the disorder, or if it is simply the response to the new category of people who have always had the disorder (CDC, 2008). Regardless, Hollenbeck (2004b, p.1) states that "the increase in autism prevalence is systemic across the entire United States and should be an urgent public health concern."

The disorder is prevalent and has recently caught the attention of the general public like never before. However, awareness does not equate to acceptance of the disorder. Often, families with a member who has ASD face public discrimination, because people still do not understand ASD. Lack of knowledge in situations which include children with ASD can lead to very undesirable results.

A story reported by Ed Crump (2008) told of a mother and her son, Jarrett, who has ASD. The mother and son were about to depart on a flight from the Raleigh-Durham International Airport when the two-year old started having a tantrum. The mother, Janice Farrell, told Crump that the flight attendant had made matters worse. The flight attendant kept tugging on her son's seatbelt to make it tighter while he wiggled to try to get out of it. The attendant reprimanded Jarrett for not keeping it tight. Then, one of the pilots came to the cabin to sternly address the situation, which elevated the level of frustration for Janice, and in turn, Jarrett. Janice said, "He just melted down. He saw me getting upset. He was upset. He was on the floor rolling around" (Crump, 2008, p. 1). The pilot returned to the cockpit and taxied the plane back to the terminal.

The pilot then announced that there was a woman on the plane with an uncontrollable child. Janice and Jarrett were kicked off the plane.

Though the situation was most likely uncomfortable for all involved, the attendant and pilot handled the situation poorly, making the outcome worse. The prevalence of ASD is on the rise, and society must learn how to accept and tolerate it - no matter how distant or close the situation.

This increase in awareness reaches further than just the general public. People in the scientific community also need to recognize the scope of this problem, and must unify to help find a solution. More studies need to be done to identify and eliminate the causes of autism. The scientific community must also unify to find a range of services that best help manage the disorder.

Current intervention services range from speech therapy, occupational therapy, physical therapy, to pharmacological therapy. Alternative therapies include various types of massage, nutritional interventions, auditory integration therapy, and more. Some parents whose children have had positive experiences with the interventions have gone so far as to say that the children are no longer afflicted with ASD, rather they are cured.

Unfortunately, some practitioners are not willing to support some of the alternative therapies, and may shun the idea of trying them. The Committee on Children with Disabilities (2001) from the American Academy of Pediatrics published a technical report to discuss the pediatrician's role in the diagnosis and management of autism. Though many personal stories have suggested positive results from alternative treatments, the report regards them as easy, unconventional, and temporary solutions.

From parent testimonials, it has become quite evident that alternative therapies are effective for some children, and in many cases even more effective than conventional therapies. The Autism Research Institute (2008b) has been collecting information on various treatments used on children with autism since 1967, and has received responses from over 23,700 parents. The parents rated various treatments within the categories of Drugs, Biomedical/Non-Drug/Supplements, and Special Diets on a six point scale. The results show much more positive results for alternative therapies than for drug therapies. The results of this survey are discussed in more detail in Table 1 in Chapter II.

The parent testimonial survey (Autism Research Institute, 2008b) also reported that some of the most beneficial alternative therapies have been special diet interventions and biomedical/non-drug/supplements. Some of the most popular diets today are the gluten-free and casein-free diets, and supplementation with zinc, vitamin B_6, omega-3, and melatonin. Each macronutrient and micronutrient has a specific role within the body, and depletions or excesses of any can impact biochemical reactions in the body. This can result in various changes in the body's functioning, with behavior being one possible clinical sign that an excess or deficiency exists. Eliminating or supplementing with certain nutrients may alter behavior according to that specific nutrient's role in the body.

According to Dr. John Green (2006), a Defeat Autism Now! (DAN!) practitioner and a specialist in clinical ecology and nutritional medicine, there are 4 specific reasons why challenges arise when treating a child with ASD. The first is that autism is a multifactor illness and current medical training teaches medical professionals to group patients by diseases, thus losing the holistic approach to curing a disease. Green said that currently practicing medical doctors have a "western materialistic (Newtonian) view of reality and illness" (Green, 2006, p.

2), leading them to focus not on restoring the balance and harmony within the child, rather just on treating the condition.

Other challenges Green (2006) mentioned are time and money. In order for families to go to doctor appointments, parents have to take time off of work and the children may miss important intervention appointments. Also, many treatments for these children are not covered by insurance. The cost of managing ASD alone can range well beyond the parent's financial abilities.

Lastly, Green (2006) discussed the problem of the risk and uncertainty of advising patients to begin alternative treatments. An organization of medical providers called DAN! offers alternative advice without the endorsement of the medical community. Green (2006) reports that doctors found to be advising against the medical board can be subject to investigation, and parents have been reported to child protection agencies for letting their child receive therapies that are not approved by the medical establishment. Parents are then forced to use treatments provided by conventional doctors, which often include expensive, sometimes ineffective pharmaceuticals.

When parents are willing to use nutritional interventions as a form of management, there are a few options for them to try. Elimination diets, specifically gluten-free and casein-free diets, have been found to be very effective for some children when implemented properly. Once implemented and maintained, the biochemical influences are shown through the child's behavior. Many parents report that they are amazed that a change in diet can make such a difference in the child's behavior.

Regardless of their effectiveness, elimination diets can be very difficult to implement. Gluten and casein are present in many foods, and their elimination significantly restricts what the

child can eat. Children with ASD like to adhere to strict patterns and rules. They often have set dietary patterns that they rely on, and changing those patterns can be an insurmountable challenge. Helping parents understand the physiological mechanism behind the diets may help them feel more comfortable implementing the diets. Accessibility to accurate information and knowing the scientific basis behind the diets may help them understand the process better.

Statement of the Problem

Though there have been significant discoveries about the effectiveness of nutrition intervention on behavior in children with ASD, many barriers exist, preventing parents from considering and attempting the diets. Those who do implement the diets might not have reliable resources guiding them on the accuracy of implementation of the diets, because they do not know where to find reliable information. This could leave them without worthwhile results, and could possibly put the child at risk for malnourishment.

Purpose of the Study

The purpose of this investigation was to determine the knowledge and perceptions of parents of children with ASD regarding the use of gluten-free and casein-free (GFCF) diets when used as a form of alternative treatment for ASD. Information was gathered through the use of a survey, food record, and behavior evaluation tool. Data was collected in February and March 2009 from intervention agencies throughout the Twin Cities Metro area.

Several objectives were identified for meeting the purpose of this study. They are as follows:

Objective 1: Identify sources where parents find reliable information about the GFCF diet.

Objective 2: Identify concerns parents in both groups have about using the GFCF diet.

Objective 3: Determine barriers to initiating the GFCF diet.

Objective 4: Find the best ways to meet with and educate parents to discuss the GFCF diet.

Objective 5: Identify most common treatments used by both groups.

Objective 6: Determine accuracy of implementation of the GFCF diet for those who are currently using the diet.

Objective 7: Determine the percentage of gluten and casein foods eaten by all children in both groups.

Objective 8: Compare behavior changes when looking at percentage of gluten and casein foods eaten by children in the diet and non-diet groups.

Objective 9: Compare behavior changes over a specified amount of time between the diet and non-diet groups.

Assumptions of the Study

The assumptions of this study were that people would be willing to participate, parents would answer all the questions on the survey accurately, and there would not be a significant scientific breakthrough in autism research while the study was being conducted.

Limitations of the Study

The limitations were that the sample was not representative of the entire population of parents of children with ASD. The parents participating in this study were more likely to know about the intervention, because the sample was selected from treatment agencies that support the intervention. The survey was long and in-depth, which could have lead to a smaller number of participants who completed and returned the survey. Both the food record and the behavior checklist relied on self-reporting by parents, which could have decreased the accuracy of the results.

Definition of Terms

The following are definitions for terms that will be used throughout the rest of the study.

American Dietetic Association (ADA). The largest organization of food and nutrition professionals in the world. The organization helps to advance the dietetic profession through research, education, and advocacy in order to improve the nation's health (ADA, 2008).

Auditory integration therapy. A therapy used to help normalize hearing and the way that the brain processes auditory information.

A*utism and Developmental Disabilities Monitoring Network (ADDM).* A group of programs funded by the CDC to determine the prevalence of ASD in the United States. Its goals are to provide baseline data about ASD prevalence, to describe the population of children with ASD, to compare ASD prevalence in different groups of children and different areas of the country, to identify changes in ASD prevalence over time, and to understand the impact of autism and related conditions in U.S. communities (CDC, 2007).

Autism Research Institute (ARI). A network of parents and doctors concerned with autism. The institute focuses on conducting and fostering scientific research to help prevent, diagnose, and treat autism (ARI, 2008a).

Autism Spectrum Disorders (ASD). Disorders that present in children with poor verbal and nonverbal communication, poor social interaction, and repetitive behaviors or interests. ASD is an umbrella term for autism disorder (AD), pervasive developmental disorder - not otherwise specified (PDD-NOS), and Asperger's Syndrome.

Autism Treatment Evaluation Checklist (ATEC). A tool intended to measure the effects of various interventions in children with autism. This evaluation tool examines the parent's perceptions of the child's behavior in the following areas: Sensory/Cognitive Awareness,

Speech/Language/Communication, Sociability, and Health/Physical/Behavior (Autism Research Institute, 2008a).

Blood-brain barrier. A highly selective barrier that separates brain tissue from the blood supply. It limits passage of blood-borne materials, such as most ions and large molecular weight compounds, into the vulnerable brain tissue (Lukens et al., 2005).

Casein-free (CF). Casein is a protein found in dairy products. A casein-free diet eliminates all sources of casein.

Chelation therapy. A method used to remove heavy metals from the body.

Committee on Children with Disabilities. A group within the American Academy of Pediatrics who publishes reports for pediatricians regarding treatment protocol for children with disabilities (Committee on Children with Disabilities, 2001).

Defeat Autism Now! (DAN!). A project of the Autism Research Institute founded by Dr. Bernard Rimland in the 1960's. DAN! trains doctors to approach ASD as a biomedical disorder and to provide treatment on that basis. The DAN! doctors believe that autism is caused by a lowered immune response, external toxins from vaccines and other sources, and other problems caused by certain foods (Autism Research Institute, 2008a).

Diagnostic and Statistical Manual of Mental Disorders (DSM). A tool published by the American Psychiatric Association to diagnose mental health disorders (Lukens et al., 2005). Currently edition 4 is used, indicated by a roman numeral 4, DSM-IV.

Elimination diet. An approach to therapy which focuses on methodically removing a food source thought to be causing problems within the body.

Gluten-free (GF). Gluten is found in wheat, barley, oats, and rye. A gluten-free diet eliminates all possible sources of gluten.

Joint attention. The ability to share an experience with others socially by using eye contact and pointing (Committee on Children with Disabilities, 2001).

Macronutrients. Nutrients required in the greatest amount; e.g., carbohydrates, protein, fats (Lukens et al., 2005).

Micronutrients. Essential food factors required in only small quantities by the body; e.g., vitamins, trace minerals (Lukens et al., 2005).

National Institutes of Health (NIH). "The nation's medical research agency" (NIH, 2005, n.p.). NIH focuses on finding important medical discoveries to improve people's lives. NIH funds and conducts scientific research to help find causes, treatments, and cures of disease (NIH, 2005).

Nutritional intervention. Any therapy utilizing nutrition as a form of treatment or management.

Pica. An appetite for substances not fit as food or of no nutritional value; e.g., clay, paint chips, laundry detergent (Lukens et al., 2005).

Protodeclarative pointing. The child will point to an object, verbalize, and look alternatively between the object and the caregiver. The child does not do this to obtain the object, rather to direct the adult's attention to the object of interest (Committee on Children with Disabilities, 2001).

Protoimperative pointing. In an effort to communicate to the caregiver the child's desire for an object, the child will look alternatively at the object and the caregiver (Committee on Children with Disabilities, 2001).

Secretin. A peptide secreted by cells in the douodenum in response to falling pH as the stomach contents enter the small intestine. This stimulates the secretion of water and bicarbonate

from the pancreas and supports cholecystokinin action. This further stimulates the secretions from the pancreas (Erickson et al., 2005).

Stimming. Stimming is short for "self-stimulation." It refers to a repetitive body movement that stimulates one or more senses.

Methodology

The rest of this paper is divided into the following sections: literature review, methodology, results, and discussion. The literature review examines various facts about ASD and treatment options. The methodology section discusses the protocol for the actual research project. Then, the results section reports the information obtained from the participants. And finally, the discussion section reflects on the findings from this research project, as related to the study objectives.

Chapter II: Literature Review

This chapter defines Autism Spectrum Disorders, discusses how these disorders are diagnosed, and describes typical autistic behaviors. Current medical recommendations and various alternative therapies available for the management of the disorder are discussed. The theory behind gluten and casein elimination diets is reviewed. Lastly, nutritional issues in autism and the importance of access to reliable information while implementing special diets are discussed.

Autism Spectrum Disorders

Although the recent media attention to autism makes the disorder appear new, it has been around since at least the 18th century. The Centers for Disease Control and Prevention (2008) state that Dr. Leo Kanner published the first description of autism in 1943 when he observed a small group of children who demonstrated extreme aloofness and indifference to other people. The children had severe language deficits and made very little eye contact with others. Around the same time, another form of autism was described by Dr. Hans Asperger. He studied 400 children who elicited behavior of a different severity of autism, which came to be called Asperger's Syndrome.

The word "autism" is often used interchangeably with Autism Spectrum Disorder (ASD); however, there are differences between the two. Autism disorder is one classification within ASD, and is often referred to as "classic autism." Children with ASD are also interchangeably referred to as being "on the spectrum." Both references are used in this paper. Children on the spectrum typically have the same types of problems, but in varying degrees. There are five disorders within the spectrum: autistic disorder (AD), pervasive developmental disorder-not otherwise specified (PDD-NOS), Asperger's Syndrome, Rett syndrome, and childhood

disintegrative disorder (National Institutes of Health, 2009). Because of the rarity of Rett syndrome and childhood disintegrative disorder, they will not be discussed in detail in this paper.

ASD Diagnosis

There are 12 DSM-IV criteria that currently characterize AD. A diagnosis is confirmed when 6 or more criteria are present, with at least two or more relating to social development disorders, and one relating to communication and stereotypic behavior pattern disorders (American Psychiatric Association, 2000). See the American Psychiatric Association DSM-IV Diagnostic Criteria for AD in Appendix A.

The Committee on Children with Disabilities (2001) reported the following guidelines used to diagnose an individual with AD. Signs of AD are usually seen before the child is three years old, but can be seen as early as 18 months old. At least one of the delays in the groupings must onset before three years of age to diagnose AD. However, the DSM criteria were developed for children three years or older, so it may not take into account the many developmental stages specific to children younger than three.

Pervasive developmental disorder-not otherwise specified (PDD-NOS), or "atypical autism," is diagnosed when a child meets some, but not all, of the criteria for autism (Committee on Children with Disabilities, 2001). This can commonly happen if the child is being assessed before the age of three, and this diagnosis may be upgraded to AD if the child develops additional symptoms to fit the required criteria to diagnose autism at a later time (National Institutes of Health, 2005).

Asperger's Syndrome is a higher functioning or less severe form of autism. It is characterized by poor peer relationships, lack of empathy, and a tendency to obsess on certain

topics. Patients with this syndrome commonly have a typical or high IQ and typical language skills (National Institutes of Health, 2005).

The Committee on Children with Disabilities (2001) states that there are many different symptoms for ASD, and not all children will show the same behaviors. It is important for a practitioner to observe the child and listen to the parents in order to diagnose a child with ASD. If practitioners feel incapable of treating the child, they are advised to refer the child to a specialist.

Typical Autistic Behaviors

Children on the autism spectrum elicit a wide range of behaviors. The Committee on Children with Disabilities (2001) lists the following as some common developmental delays seen in children with ASD: impairment in joint attention and pretend play, impaired protoimperative pointing, impaired protodeclarative pointing, lack of eye contact and aloofness, and nonverbal or extremely advanced repetitive speech. The children also elicit a need for extremely rigid schedules, and may have sleep problems, including frequent night terrors. Intellectual functioning may range from severe mental retardation to superior mental functioning, and many may be particularly talented in specific areas. Some may illicit visible behaviors, such as hand-flapping, finger-flicking, and tip-toeing.

The American Dietetic Association (ADA) (2004) states that frequently reported nutrition problems in children with autism are limited food selections, strong food dislikes, pica, and medication/nutrient interactions. Children with autism may also have severe sensory issues, which can prevent them from trying foods with different textures. This, in combination with the need for rigid schedules, can limit the variety of foods the children consume. These strict dietary patterns can leave the child at risk for deficiencies in essential nutrients.

Page (2000) reported that approximately 40-60% of individuals with autism have chronic diarrhea or constipation, and gastrointestinal dysfunction may be so severe that potty training is almost impossible. Horvath, Medeiros, and Ravszlyn (2000) found that 85% of children with ASD suffered at least one gastrointestinal problem, such as diarrhea or constipation, while only 28% of typically developing children did. It is important to note that the definition of diarrhea is three or more loose stools a day for two weeks, and constipation is less than two hard bowel movements a week. Liu, Li, and Nue (2005) comment that several studies suggest that children with ASD have a widespread gastrointestinal pathology which is exhibited through ASD behavior and symptoms.

Management

Because there is no proven medical cure for ASD, the treatment interventions can only concentrate on the management of autism. The most common interventions currently aim to focus on "promoting the development of communication, social, adaptive, behavioral, and academic skills, and lessening the maladaptive and repetitive behaviors" (Committee on Children with Disabilities, 2001, p. 9).

The most common medical interventions recommended are behavioral therapies, parent training, habilitative therapies, medical management, community support, and alternative therapies. Some of the most common alternative therapies include: nutritional supplements, elimination diets (e.g., gluten-free and casein-free diets), secretin, chelation therapy, auditory integration training, and facilitated communication.

A controlled study of early intervention services in young children with ASD conducted by Ivar Lovaas (1987) found that almost 50% of children were functioning at a typical intelligence and academic level after one-on-one behavior training, 40 hours a week for 2 years.

At a 5 year follow-up, most maintained the positive gains (McEachin, Smith, & Lovaas, 1993). The Committee on Children with Disabilities (2001) reports that two other studies found similar results. These studies support the implementation of interventions as early as possible, to assure the greatest positive impact on the child.

Parent Ratings of Treatments

An ongoing study conducted by the Autism Research Institute (2008b) asks parents to self-report the efficacy of certain treatments their children with autism are using. The treatments are broken into three categories: drugs, biomedical/non-drug/supplements, and special diets. There are more negative reports regarding drug treatments, and more positive reports regarding the biomedical/non-drug/supplements and special diet categories. The results are shown in Table 1 (Autism Research Institute, 2008b). Permission to use this table was received from S.M. Edelson and B. Rimland on June 22, 2009.

When rating the special diets, all, except for removing eggs, showed at least 50% of the parents reporting a positive effect. The participants answered got worse, no effect, or got better for each question. The highest percentage of parental reporting of "got better" was 76% for chelation therapy and 65% for gluten-free/casein-free diet use. Of all the medications given, 45% or more of parents reported their children "got better" when drugs were given for specific problems, such as anti-fungal and anti-seizure medications and enzyme replacement therapy. There were only two drugs given specifically to manage behavior that resulted in 45% or more of a "got better" response. Only 10 of the 46 (22%) listed medications resulted in 40% or more "got better" response, while 25 of the 39 (64%) listed biomedical/non-drug/supplements and special diet categories resulted in 40% or more "got better" response.

Table 1

Parental Ratings of Efficacy of Certain Treatments Utilized by their Children with ASD

(Autism Research Institute, 2008)

DRUGS	Parent Ratings: Got Worse[A]	No Effect	Got Better	Better: Worse	No. of Cases[B]
Aderall	43%	25%	32%	0.8:1	775
Amphetamine	47%	28%	25%	0.5:1	1312
Anafranil	32%	38%	30%	0.9:1	422
Antibiotics	33%	53%	15%	0.5:1	2163
Antifungals[C]					
Diflucan	5%	38%	57%	11:1	653
Nystatin	5%	44%	50%	9.7:1	1388
Atarax	26%	53%	22%	0.9:1	517
Benadryl	24%	50%	26%	1.1:1	3032
Beta Blocker	17%	51%	31%	1.8:1	286
Buspar	27%	45%	28%	1.0:1	400
Chloral Hydrate	41%	39%	20%	0.5:1	459
Clonidine	22%	31%	47%	2.1:1	1525
Clozapine	37%	44%	19%	0.5:1	155
Cogentin	19%	54%	27%	1.4:1	186
Cylert	45%	36%	20%	0.4:1	623
Deanol	15%	57%	28%	1.9:1	210
Depakene[D]					
Behavior	25%	43%	32%	1.3:1	1071
Seizures	11%	33%	56%	4.8:1	705
Desipramine	34%	35%	31%	0.9:1	86
Dilantin[D]					
Behavior	28%	49%	23%	0.8:1	1110
Seizures	15%	37%	48%	3.3:1	433
Felbatol	20%	55%	25%	1.3:1	56
Fenfluramine	21%	52%	27%	1.3:1	477
Haldol	38%	28%	34%	0.9:1	1199
IVIG	10%	44%	46%	4.5:1	79
Klonopin[D]					
Behavior	28%	42%	30%	1.0:1	246
Seizures	25%	60%	15%	0.6:1	67
Lithium	24%	45%	31%	1.3:1	463
Luvox	30%	37%	34%	1.1:1	220
Mellaril	29%	38%	33%	1.2:1	2097
Mysoline[D]					
Behavior	41%	46%	13%	0.3:1	149
Seizures	19%	56%	25%	1.3:1	78
Naltrexone	20%	46%	34%	1.8:1	302
Paxil	33%	31%	36%	1.1:1	416
Phenergan	29%	46%	25%	0.9:1	301
Phenobarb.[D]					
Behavior	47%	37%	16%	0.3:1	1109
Seizures	18%	43%	39%	2.2:1	520
Prolixin	30%	41%	29%	1.1:1	105
Prozac	32%	32%	36%	1.1:1	1312
Risperidal	20%	26%	54%	2.8:1	1038
Ritalin	45%	26%	29%	0.7:1	4127
Secretin					
Intravenous	7%	49%	44%	6.3:1	468
Transderm.	10%	53%	37%	3.6:1	196
Stelazine	28%	45%	26%	0.9:1	434
Steroids	35%	33%	32%	0.9:1	132
Tegretol[D]					
Behavior	25%	45%	30%	1.2:1	1520
Seizures	13%	33%	54%	4.0:1	842
Thorazine	36%	40%	24%	0.7:1	940
Tofranil	30%	38%	32%	1.1:1	776
Valium	35%	41%	24%	0.7:1	865
Valtrex	6%	42%	52%	8.5:1	65
Zarontin[D]					
Behavior	35%	46%	19%	0.6:1	153
Seizures	19%	55%	25%	1.3:1	110
Zoloft	35%	33%	32%	0.9:1	500

BIOMEDICAL/ NON-DRUG/ SUPPLEMENTS	Parent Ratings: Got Worse[A]	No Effect	Got Better	Better: Worse	No. of Cases[B]
Calcium[E]	3%	62%	35%	14:1	2097
Cod Liver Oil	4%	45%	51%	13:1	1681
Cod Liver Oil with Bethanecol	10%	54%	37%	3.8:1	126
Colostrum	6%	56%	38%	6.1:1	597
Detox. (Chelation)[C]	3%	23%	74%	24:1	803
Digestive Enzymes	3%	39%	58%	17:1	1502
DMG	8%	51%	42%	5.4:1	5807
Fatty Acids	2%	41%	56%	24:1	1169
5 HTP	13%	47%	40%	3.1:1	343
Folic Acid	4%	53%	43%	11:1	1955
Food Allergy Trtmnt	3%	33%	64%	24:1	952
Hyperbaric Oxygen Therapy	5%	34%	60%	12:1	134
Magnesium	6%	65%	29%	4.6:1	301
Melatonin	8%	27%	65%	7.8:1	1105
Methyl B12 (nasal)	15%	29%	56%	3.9:1	48
Methyl B12 (subcut.)	7%	26%	67%	9.5:1	170
MT Promoter	13%	49%	38%	2.9:1	61
P5P (Vit. B6)	12%	37%	51%	4.2:1	529
Pepcid	12%	59%	30%	2.6:1	164
SAMe	16%	63%	21%	1.3:1	142
St. Johns Wort	18%	66%	16%	0.9:1	150
TMG	15%	43%	42%	2.8:1	803
Transfer Factor	10%	48%	42%	4.3:1	174
Vitamin A	2%	57%	41%	18:1	1127
Vitamin B3	4%	52%	43%	10:1	927
Vit. B6/Mag.	4%	48%	48%	11:1	6634
Vitamin B12 (oral)	7%	32%	61%	8.6:1	98
Vitamin C	2%	55%	43%	19:1	2397
Zinc	2%	47%	51%	22:1	1989
SPECIAL DIETS					
Candida Diet	3%	41%	56%	19:1	941
Feingold Diet	2%	42%	56%	25:1	899
Gluten- /Casein-Free Diet	3%	31%	66%	19:1	2561
Removed Chocolate	2%	47%	51%	28:1	2021
Removed Eggs	2%	56%	41%	17:1	1386
Removed Milk Products/Dairy	2%	46%	52%	32:1	6360
Removed Sugar	2%	48%	50%	25:1	4187
Removed Wheat	2%	47%	51%	28:1	3774
Rotation Diet	2%	46%	51%	21:1	938
Specific Carbo-hydrate Diet	7%	24%	69%	10:1	278

A. "Worse" refers only to worse behavior. Drugs, but not nutrients, typically also cause physical problems if used long-term.
B. No. of cases is cumulative over several decades, so does not reflect current usage levels (e.g., Haldol is now seldom used).
C. Antifungal drugs and chelation are used selectively, where evidence indicates they are needed.
D. Seizure drugs: top line behavior effects, bottom line effects on seizures
E. Calcium effects are not due to dairy-free diet; statistics are similar for milk drinkers and non-milk drinkers.

According to the Technical Report released by the Committee on Children with Disabilities (2001), alternative therapies are not highly regarded by the medical community despite overwhelming self-reported success. One reason is the lack of double-blind randomized controlled trials in this area. However, the individual results of self-reported success and the results in Table 1 provide evidence that alternative therapies can be effective. As practitioners still recommend alternative therapies to parents, it appears that they take self-reports into account at least occasionally.

Elimination Diets

Elimination diets are some of the most common alternative therapies utilized. One of the most frequently used in autism eliminates gluten and casein proteins. Gluten is a protein found in foods containing wheat, barley, rye and gluten-contaminated oats. It is commonly used as an additive in processed foods and day-to-day items, such as envelop glue and play dough. Casein is a protein found in milk products. The elimination diets remove all of those sources from the child's daily intake. The following section discusses the scientific reasoning behind the gluten-free and casein-free (GFCF) diets.

In normal gastrointestinal physiology, enzymes, such as pepsin and gastrin are needed to break protein down into amino acids (Sherwood, 2001). When insufficient enzymes are unable to break the protein down completely, the amino acids are bound as a short chain, called a peptide. Normally, the epithelial and mucosal lining of the digestive tract prevents these peptides from squeezing between the cells and into the blood-stream. If the peptide is able to escape into the blood-stream, certain peptides can cross the heavily regulated blood-brain barrier, causing severe neurological problems (Lewis, 1998). The peptides can also induce antigenic responses (Liu, Li, and Nue, 2005).

Children with ASD may be unable to breakdown some proteins completely, so they may have higher levels of circulating peptides. Though there are some theories, it is not clear why they cannot break the proteins down completely (Lewis, 1998). Page (2000) suggests that the partially digested peptides may be a result of abnormal activity of proteolytic enzymes. Liu, Li, and Nue (2005) link the incomplete digestion to peptidases.

Liu, Li, and Nue (2005) also discuss the importance of the structural integrity of the gastric and intestinal lining in preventing and treating various pediatric diseases. The cells that make up these linings are bound together by tight junctions, which limit the passage of the digestive contents between the cells preventing transport into the blood-stream (Sherwood, 2001). Liu, Li, and Nue (2005) suggest that the tight junctions may not function normally in children with ASD leading to increased gut permeability. This allows large molecular weight structures, such as peptides, to pass out of the digestive tract to the blood-stream and is commonly called "leaky gut." The etiology behind "leaky gut" in ASD has not yet been determined. D'Efemia et al. (1996) provided evidence that nine out of 21 (43%) of children with ASD had altered gastrointestinal functions as compared to none of the 40 controls, indicating that there was damage to the tight junctions. This finding was also supported by Horvath, Medeiros, and Rabszlyn (2000).

Some children with ASD also elicit an immune response to gluten and casein proteins. Vojdani et al. (2004) measured the immune response to gliadin and cerebellar peptides in children with autism. They reported that dietary peptides, such as gliadin and casein, result in autoimmune reactions in autism. In an MRI of children with these antibodies, the cerebellum is seen in atrophy, while the brainstem and cerebrum are normal. Lucarelli et al. (1995) showed that children with autism had at least one positive pin prick reaction to a panel that tests for

reactions to casein, lactolbumin, beta-lactoglobulin, egg white, rice, and soy. The total immune response was elevated in the children with ASD, but it was not statistically significant. These results support GFCF dietary interventions.

Opiate Theory

As Converse (2008) explains, the gluten and casein elimination diets are based on the opiate theory. The common casein and gluten proteins result in the peptides casomorphin and gliadinomorphin (respectively). These peptides can bind with opiate receptors in the central nervous system (CNS) and illicit an opiate-like effect if they are not digested properly.

The CNS is responsible for perceiving and suppressing pain. The entire physiology of this pain regulating system is not fully understood, but it is known that the system is dependent on the presence of opiate receptors. The receptors are there to bind with endogenous opiates (endorphins, enkephalins, and dynorphin), but also allow exogenous sources to bind with them (morphine, casomorphin, and gliadinomorphin). Binding with the opiate receptor suppresses release of the pain signal. This is the reason that morphine is such a useful pain-reducing drug. The endogenous opiate system is usually inactive, and it is not clear how the mechanism is activated. An exogenous source (morphine, casomorphin, and gliadinomorphin) can activate this system when it is present (Sherwood, 2001).

The opiate theory states that the improperly digested protein peptides are able to escape the "leaky gut" and enter into the blood-stream. Casomorphin and gliadinomorphin are structurally similar to endorphins which allow them to cross the blood-brain barrier and enter the CNS. They are called exorphins, because of the structural similarity to endorphins and they originate from an exogenous source (Liu, Li, and Nue, 2005).

result in withdrawal-like symptoms. The withdrawal process can be compared to removing morphine from an addict's body, which binds to the same exorphin receptor. Assuming the intervention works for the child, the withdrawal symptoms will subside, and the child will begin to progress in development again while on the diet. Some progressions that parents have reported are that their children show less resistance to trying new foods, various gastrointestinal problems are alleviated, and certain behaviors, such as acting aloof or spacey, improve.

Gluten-free and Casein-free Diet Research Studies

Though there is much comment on the lack of scientific studies looking at the effects of GFCF diets in autism, a few studies have been conducted. Harrison-Elder et al. (2006) conducted a pilot double-blind clinical trial looking at the use of GFCF diets in autism management. The researchers evaluated the effects of a GFCF diet on the severity of autistic symptoms using the Childhood Autism Rating Scale (CARS), Ecological Communication Orientation Scale (ECOS), and direct behavioral observation frequencies. They also evaluated the effects of a GFCF diet on urinary peptide levels and the role of parent behavior in therapeutic and placebo effects of a GFCF diet. They had a small sample size of 13, and had insignificant findings. However, they illustrated a type of study design that is essential to this type of research. This would be a very informational study if it were replicated with larger numbers.

Knivsberg, Reichelt, Hoien, and Nodland (2003) stated that they have published the first controlled, randomized study with an intervention period of 1 year looking at the effect of GFCF diets on autistic behavior and urinary peptide levels. Twenty children were matched pair-wise according to age, cognitive level, and severity of behavior. The researchers used a single-blind controlled design to prevent assigning GFCF children to the non-diet group. This alleviated the

risk of possible regression associated with the reintroduction of gluten- and casein-containing foods.

The child's behavior in the Knivsberg et al. (2003) study was assessed with Diagnose of Psykotisk Adfard hos Born (DIPAB) and parent reports. DIPAB gives information about social isolation and strange or bizarre behavior. Cognitive tests, linguistic tests, and motor assessment tests were collected through structured interviews and tests. Urine samples were not analyzed because they did not receive enough urine samples to compare.

In the Knivsberg et al. (2003) study, all children were diagnosed with autism by a professional, and had urinary peptide abnormalities. Professionals placed the matched pair-wise children in either the diet or non-diet group. The project leader was unaware of the assignment of the children, and had no contact with the families during the year long experimental period. A registered dietitian (RD) visited the parents of children in the diet group, and gave them oral and written information about the GFCF diets. The parents were able to contact the RD, but there was no other formal monitoring of dietary compliance.

After the one year intervention (Knivsberg et al., 2003), significant positive changes were seen in the diet group, while insignificant changes were seen in the non-diet group in each of the following categories: social isolation, ability to communicate, resistance to communication and interaction, reduction of strange behavior, and decrease in autistic behavior. The non-diet and diet groups both increased in linguistic age, 9 months and 12 months (respectively). There were significant differences in cognitive abilities and motor skills between the groups, with the diet group having more positive results.

It is challenging to provide specific double-blind scientific evidence for the elimination diets, because the design requires experts from all areas of intervention to objectively monitor

the child's response to the diet, and the diet needs to be strictly controlled. Designing a study of that scale takes tremendous resources and support from various groups. It is imperative that larger organizations with the resources to complete such a study realize the importance of this topic, and take it upon themselves to implement such a project. Harrison-Elder et al. (2006) and Knivsberg et al. (2003) provide study designs that would offer valuable information to benefit this population if conducted with larger groups.

Another challenge to implementing a controlled study is recruiting participants. If the child is already on the GFCF diet, and positive results have been seen, parents will probably not want to risk the possibility of having their child be in the experimental group. Knivsberg et al. (2003) addressed this problem with a single-blind controlled study design.

Following Elimination Diets

Patients who have celiac disease also use a gluten-free diet. Celiac disease is an autoimmune disorder that leads to intestinal mucosal damage in the presence of gluten. The only treatment for this disease is the use of a gluten-free diet to eliminate the response. Treatment of this disease consists of nutritional counseling by an experienced RD, lifelong elimination of gluten and other food intolerances, and replacement of micronutrients needed (Lysen, 2006). In patients with celiac disease, it is very important that all sources of gluten are removed, including hidden sources, such as processed foods and play dough. The hidden gluten may stay on the child's hands after playing with play dough, and then it may be transferred into the child's mouth by touching the hands to the mouth allowing it to enter the digestive system. Eliminating all sources of gluten can help to prevent a flare up of the disease.

Following elimination diets closely when used as a treatment for autism is just as important as when it is used as a treatment for celiac disease. The elimination diets focus on

eliminating foods that are found in abundance in the American diet. Often the proteins that need to be excluded are hidden in other, less obvious foods (e.g., sauces). The diets are very strict and complex, which can leave the possibility for inaccurate implementation and deficiencies of important nutrients.

The following example was observed by the author while shadowing an autism intake appointment at a medical facility. One set of parents had described the benefits of the GFCF diet that they implemented. However, these parents reported that they still offered yogurt, as they were not aware that yogurt contains casein. As a result of lack of knowledge about food ingredients or composition, the parents were still offering the protein, casein, that they were trying to eliminate.

Without 100% compliance to the diet, the full potential of the diet will not be seen. Reliable, accurate, accessible information is greatly needed for parents who wish to pursue this course of treatment, because of the limiting nature of the diet and the importance of the strict adherence to the diet.

Nutrition in Developmental Disabilities

The position of the ADA is that "nutrition services are essential components of comprehensive care for infants, children, and adults with developmental disabilities and special health care needs" (ADA, 2004, p. 97). The ADA (2004) also reports that a survey of children from birth to age three years with developmental delays in early intervention programs found that 79-90% had one or more nutrition risk indicators. The use of elimination diets can increase those risk indicators. Although elimination diets can be effective, it is important that the diet is monitored to ensure that the child is meeting the daily requirements for all macronutrients, micronutrients, and energy needs (Peregrin, 2007).

Lockner, Crowe, and Skipper (2008) compared nutritional intakes of 20 children with ASD to 20 normally developing children and examined parents' perceptions of their child's diet. Both groups of children had similar nutritional intakes, and met most all of their daily needs. The study found that parents of typically developing children have a more positive opinion of their child's diet and food behaviors than do parents of children with ASD. Lockner, Crowe, and Skipper (2008) also found that more parents of children with ASD reported that their children have favorite textures, resist trying new foods, are picky eaters, and eat less variety than the controls.

Cornish (2002) conducted a study with 37 ASD participants: 8 were using the GFCF diet, 4 previously used the GFCF diet, and 25 had never used the diet. The researcher examined if the GFCF diets placed the children at risk of nutrient deficiencies and also examines if there were differences in food choices between those who used the GFCF diet and those who did not. All children were at risk for inadequate intakes of minerals, calcium, zinc, iron, riboflavin, and fat-soluble vitamins. There was no significant difference in the median daily energy, carbohydrate, and protein intakes between the two groups. This supports the notion that simply using the GFCF diet does not imply that the child will be deprived of adequate macronutrients.

The study also found that the children who had been following the GFCF diet for greater than six months were less likely to follow repetitive and selective food patterns than those who used it for less than six months or had never used it. Cornish (2002) stated that the children in the diet group had a lower median intake of cereal, bread, and potato products and higher fruit and vegetable intakes than those not following the GFCF diet. There was no difference in the median intake of dairy between the two groups (Cornish, 2002).

Cornish (2002) also found that the majority (59%) of participants first heard about the GFCF diet through media sources rather than from a health care professional, and they were more likely to seek help from voluntary support groups than their health care provider.

Bowers (2002) conducted a study to audit the referrals made to the dietetic service over a three month period, identify key dietetic issues, and assess other factors affecting outcome in children with ASD. In this study, records from three past months showed that 26 children were referred to a dietitian, and of the 26 diet records examined, 14 cases (54.1%) were referred by medical practitioners for GFCF diets. The remaining 12 cases (46%) were referred for nutritional assessment due to risk of diet inadequacy due to food selectivity and dysfunctional feeding behaviors. All, except two children who had severe food selectivity, met their protein and energy needs, but none met all of the needs for other nutrients (Bowers, 2002).

Of the 14 referred for the GFCF diet in the Bowers (2002) study, there were many differences in the effects the diet had on the behaviors, with a general positive effect. The researchers (Bowers, 2002) reported improvements were successful in day-to-day management of the child, but not for the core problem of the disorder. The researchers (Bowers, 2002) concluded that this study suggests the need of a dietitian in the multi-disciplinary, inter-agency team of the child to assure adequate intakes of all nutrients necessary for all children with ASD.

There is a great need for double-blind randomized controlled studies to support the use of GFCF diets when used as an alternative treatment for autism. Until such studies are conducted, those who wish to support the treatment must rely on self-reported successes from parents. The present study attempted to discover barriers to initiation of the diet, identify the sources parents use for reliable information about the diets, the accuracy in which they implement the diet, and parental perceptions of how the diets have affected their child's behavior.

Chapter III: Methodology

This section discusses how the hypotheses were tested. The subject selection and subject description will be explained first. Then the instrumentation will be explained and the data collection and data analysis procedures will be discussed. Lastly, the limitations of the method, sample, and procedure will be detailed.

Subject Selection and Description

This research study was approved by the University of Wisconsin-Stout's Institutional Review Board of Human Subjects (Appendix B). Parents of children with Autism Spectrum Disorder (ASD) from the Twin Cities metro area were included in this study. Participants were recruited from an Autism Workshop, the Steps of Hope Autism Walk, and three intervention agencies: FRASER, St. David's Child Development & Family Services, and Therapy for Me! with the help of therapists at each of the agencies. All interested parents were included in the study, regardless of their use of the diet therapies.

Instrumentation

Three methods were used to collect data: a survey, a common foods list, and a behavioral evaluation tool modified from the Autism Treatment Evaluation Checklist (ATEC) obtained from the Autism Research Institute (ARI) (Rimland and Eldelson, 2008). There were two different surveys used for the groups examined. The first was for the group that had never used diet as a form of alternative treatment (non-diet group) (Appendix C). The second was for the group that had used gluten-free and/or casein-free diets as a form of alternative treatment (diet group) (Appendix D). Both surveys evaluated the parent's perceptions of the diets, barriers to initiation, and accessibility to resources. Information was collected to identify ways to make resources about the diets more accessible. The survey for the diet group also collected

information about how the parents implemented the diets and other important details about successful compliance to the diets. No measures of validity or reliability have been documented for these surveys, because they were designed specifically for this study.

In addition to the surveys, both groups completed a common foods worksheet (Appendix E). The list helped determine if certain foods could be related to certain behaviors in both groups. The list completed by the diet group also helped examine the accuracy of implementation of the diets. A common foods list is often used by nutrition professionals to assess dietary intake.

The ATEC (Appendix F) is a tool intended to measure the effects of various interventions in children with autism. To best fit the objectives of this study, the ATEC questions were presented in a revised format. Each group was given the modified version of the ATEC (Appendix G) to help evaluate changes in key behaviors that are prevalent in children with autism. This evaluation tool examined the parent's perceptions of changes in the child's behavior over a specified period of time based on the following areas: Sensory/Cognitive Awareness, Speech/Language/Communication, Sociability, and Health/Physical/Behavior. The ATEC given with the non-diet survey used a reference time of three months to monitor behavior changes, while the ATEC given with the diet survey used a reference time that began when the child started to follow the diet.

Data Collection Procedures

While recruiting participants, individuals were informed of the voluntary nature of the study in the University of Wisconsin-Stout approved informed consent form (Appendix H). The parents were informed of their right to withdraw at any time during the study.

When the parents filled out the informed consent, they selected which study group they would be placed in by answering the question, "Have you ever used the gluten-free diet OR the

casein-free diet as a form of alternative treatment to help manage your child's Autism Spectrum Disorder?" If they answered no they were placed in the "non-diet" group, and if they answered yes they were placed in the "diet" group. The informed consent was collected with the survey.

Most parents who agreed to participate in this study received sample size packets of Ian's wheat-free/gluten-free chocolate chip or crunchy cinnamon cookie buttons and Bob's Red Mill gluten-free/casein-free products. Both companies donated the products to be used as incentives for the participants.

Parents of both groups completed a survey, a common foods list, and a behavior evaluation. The researcher's contact information was given on the consent to participate. If the participants had any questions, they were encouraged to contact the researcher for clarification. Two health practitioners at the treatment centers were trained by the researcher to hand out and collect the surveys to increase the access to the study. Both the practitioners and researcher handed out and answered questions about the survey.

Upon completing the three documents, the parents placed all information into a pre-stamped, pre-addressed envelope that was mailed to the researcher or was given to the trained practitioners. The completed surveys were kept in a monitored location until they were collected, and all parties involved maintained the confidentiality that was needed for this project. The final results were provided to the treatment centers, so that any interested parties could examine them.

Data Analysis

Frequencies were run on all data by the statistician, Susan Greene from UW-Stout. Chi-square was run on the behaviors when comparing the diet group to the non-diet group.

Limitations

The limitations were that the sample was not representative of the entire population of parents of children with autism, as they came from locations where most parents are actively involved in some form of treatment, and thus may be more likely to try various interventions. The survey was long and in-depth, which could have led to a low response rate. Both the food record and the behavior checklist relied on self-reporting by parents, which could decrease the accuracy of the results.

Another limitation is that the non-diet group used a time reference point of three months to measure behavior changes, while the diet group used a time reference point of "since beginning the diet." Those in the diet group have been on the diet for an average of 13 months. The comparison of three months to 13 months when examining behavior modification in children is a maturation threat that challenges the internal validity of the study. The three month time point was initially chosen based on the Cade et al. (2000) findings that showed that 81% of children saw improvements in behavior within three months of treatment with a GFCF diet.

Chapter IV: Results

The purpose of this study was to examine parents' perceptions and knowledge about gluten-free (GF) and casein-free (CF) diets when used as a form of alternative treatment for Autism Spectrum Disorder (ASD). A survey was given to any interested parents of children with ASD, and they were grouped according to GFCF diet use. Those who had used either the GF or CF diet or both were placed into the diet group and those who had not used either the GF or CF diet were placed into the non-diet group.

Participant Information and Diet Information

Of the 28 returned surveys, 11 parents of children with ASD (10 boys, 1 girl) were in the diet group and 17 parents of children with ASD (all boys) were in the non-diet group. The median age was 4 years 9 months old in the diet goup, and 7 years 4 months in the non-diet group. In the diet group, seven children were diagnosed with autism and four were diagnosed with pervasive developmental disorder-not otherwise specified (PDD-NOS). In the non-diet group, six children were diagnosed with autism, six with Asperger's Disorder, and five with PDD-NOS. The median age of diagnosis in the diet group was 2 years 5 months, and in the non-diet group the median age was 4 years 5 months. Participant information is listed in Table 2.

Table 2

Participant Information and Treatment Groups

Characteristic	Diet Group	Non-diet Group
Total Participants (Male:Female)	11 (10:1)	17 (17:0)
Median Age of Children	4 years 7 months	7 years 11 months
Median Age at Diagnosis	2 years 4 months	5 years 2 months
ASD Diagnosis		
Autism	7	6
Asperger's Syndrome	0	6
PDD-NOS	4	5

Of the 17 participants that returned the non-diet survey, 15 participants were aware that some caregivers use a GFCF diet as a form of alternative treatment for ASD and two were not aware. In the non-diet group, the most common way the information was obtained about the GFCF diet was from a friend or family member, online, or books. Only one non-diet group participant listed that they had heard of the CF diet from a dietitian/nutritionist. The most common way the participants in the diet group reported hearing about the GFCF diets the first time was online, books, or doctors. None in the diet group reported hearing about the diets from a dietitian/nutritionist or nurse. The results are shown in Figure 1.

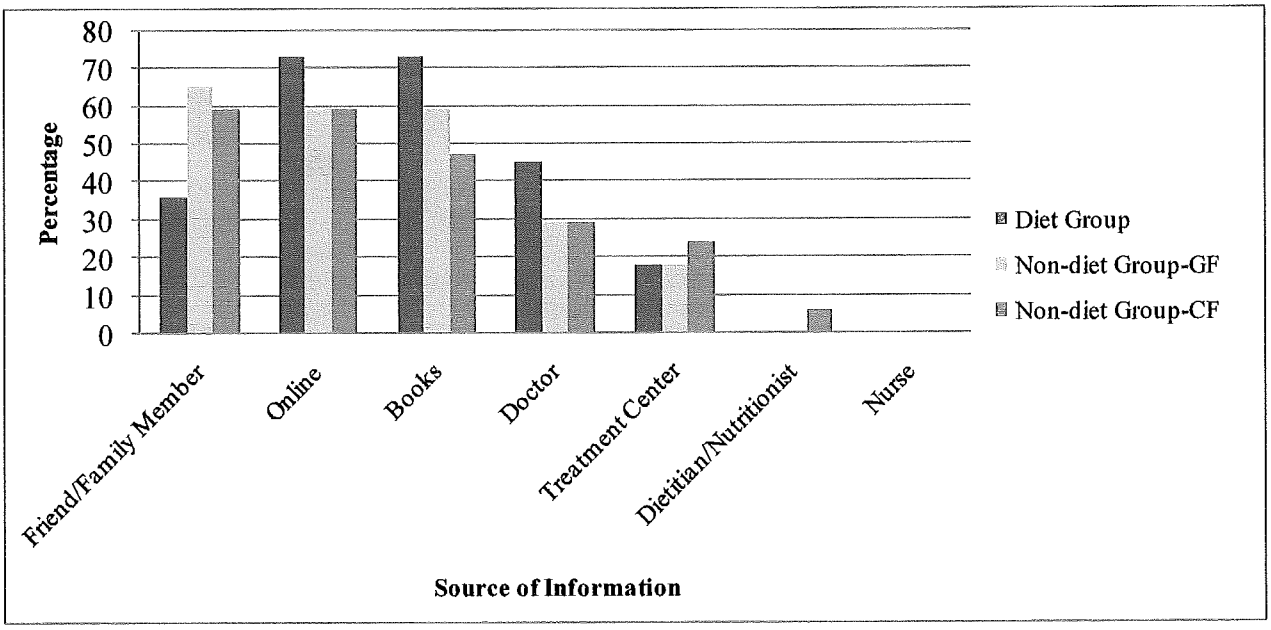


Figure 1. Sources of information where parents first heard about the GF/CF diets.

The non-diet group participants were asked in an open-ended question where they would look to find reliable information about the GF and CF diets. Most non-diet participants reported that they would find reliable information about the GFCF diet online, in books, or from a doctor. The diet group was also asked where they find reliable information about the GFCF diet. They reported online, books, and support groups as the top three sources. All responses from both groups are shown in Table 3.

Table 3

Sources Identified to Find Reliable Information about the GF and CF Diets

Information Source	Non-diet Group-GF # (%)	Non-diet Group-CF # (%)	Diet Group # (%)
Online	13 (76)	14 (82)	9 (82)
Books	7 (41)	7 (41)	5 (46)
Doctor	6 (35)	7 (41)	2 (18)
Dietitian/Nutritionist	4 (24)	2 (12)	1 (9)
Nurse	1 (6)	1 (6)	-
Expert	1 (6)	1 (6)	1 (9)
Friends	-	2 (12)	1 (9)
Support Group	1 (6)	-	3 (27)
Food Allergy Organization	1 (6)	-	-
Unsure	-	1 (6)	-

The non-diet group participants were asked in an open-ended question what concerns they would have if their child were to be put on a GF or CF diet. All responses are listed in Table 4. The most common concern about the GF diet in the non-diet group was that the child would not like it. The two most common concerns in the non-diet group about the CF diet were that the child might miss out on adequate nutrition due to the dietary restrictions and that the child would not like it.

The diet group was also asked in an open-ended question what concerns they have about the diet(s). Their responses are also found in Table 4. The most common concern about the GF diet was that the child may be missing out on adequate nutrition due to the dietary restrictions.

The most common concern of the diet group about the CF diet is that the child may not be getting adequate intakes of Vitamin D and calcium.

Table 4

Concerns about Using the GF and CF Diets

Concerns	Non-diet-GF # (%)	Diet-GF # (%)	Non-diet-CF # (%)	Diet-CF # (%)
Nutrition	2 (12)	4 (36)	8 (47)	6 (55)
Child will not like it	4 (24)	-	4 (24)	-
Taste/texture	3 (18)	-	2 (12)	-
Cost	3 (18)	-	2 (12)	-
Don't know/none	3 (18)	1 (9)	1 (6)	-
Lack of variety	2 (12)	-	2 (12)	-
Compliance	2 (12)	-	1 (6)	-
No proof it works	1 (6)	-	1 (6)	-
Time	1 (6)	-	1 (6)	-
Eating out	1 (6)	-	1 (6)	-
Extra effort needed	1 (6)	-	1 (6)	-
Family cooking	1 (6)	-	1 (6)	-
Child will feel left out	1 (6)	1 (9)	1 (6)	-

Questions 8 and 12 on the non-diet survey asked the parents to rank the three biggest barriers that might prevent them from initiating the GF or CF diets (respectively). They were asked to rank the top three barriers with one being the biggest barrier. Table 5 lists the barriers identified in questions 8 and 12 reported by the non-diet group and shows the number of

responses for first, second, and third choice. The total, which is in bold in Table 5, represents the number of times the barrier was reported as being anywhere in the top three. Of the total, the most commonly reported barriers when initiating the GF diet in the non-diet group were: resistance from child, cost, and time issues. The most commonly reported barriers to initiating the CF diet in the non-diet group were: resistance from child, time issues and cost.

In the non-diet group, eight listed the following "other" responses for the GF diet: tastes bad, don't know enough about it, skeptical that behaviors are related to the diet, difficult to measure effectiveness, child already has limited preferences, and it takes time and sacrifice to change the family's diet. One of the eight participants said, "It is hard to invest time into the diet when there is no proof it works," and another listed "difference of opinion with spouse." Six of the non-diet group participants listed the following "other" responses for the CF diet: don't know enough about it, skeptical the behaviors are diet related, difficult to measure effectiveness, child already refuses it, and the taste or texture will be bad.

Table 5

Ranking of the Three Biggest Barriers That Might or Have Already Prevented the Initiation of the GF or CF Diets in the Non-diet Group

Barrier	1st Choice # (%)	2nd Choice # (%)	3rd Choice # (%)	**Total** # (%)
Resistance from my child	G 5 (30) C 5 (30)	G 3 (18) C 2 (12)	G – (0) C 1 (6)	**G 8 (47)** **C 8 (47)**
Cost	G 4 (24) C 2 (12)	G 3 (18) C 2 (12)	G 1 (6) C 1 (6)	**G 8 (47)** **C 5 (30)**
Time Issues	G 2 (12) C 1 (6)	G – (0) C 2 (12)	G 4 (23) C 3 (18)	**G 6 (35)** **C 6 (35)**
My child only seems to want to eat foods that contain gluten or casein	G – (0) C 1 (6)	G 2 (12) C 1 (6)	G 4 (24) C 2 (12)	**G 6 (35)** **C 4 (24)**
I didn't know how to prepare gluten-free or casein-free meals	G 1 (6) C 1 (6)	G 1 (6) C 1 (6)	G – (0) C – (0)	**G 2 (12)** **C 2 (12)**
The diet restrictions made it difficult to eat out	G – (0) C – (0)	G 2 (12) C – (0)	G 1 (6) C – (0)	**G 3 (18)** **C – (0)**
Trouble with compliance from the school	G – (0) C – (0)	G 1 (6) C 1 (6)	G – (0) C 1 (6)	**G 1 (6)** **C 2 (12)**
I don't know where to find appropriate foods	G – (0) C – (0)	G 1 (6) C – (0)	G – (0) C 1 (6)	**G 1 (6)** **C 1 (6)**
I have never heard of it	G - (0) C 1 (6)	G – (0) C – (0)	G – (0) C – (0)	**G – (0)** **C 1 (6)**
I don't believe it works	G – (0) C – (0)	G – (0) C 1 (6)	G – (0) C – (0)	**G – (0)** **C 1 (6)**
Resistance from my child's healthcare provider	G – (0) C – (0)	G – (0) C – (0)	G – (0) C – (0)	**G – (0)** **C – (0)**
I don't know where to find resources to help me start implementing the diets	G – (0) C – (0)	G – (0) C – (0)	G – (0) C – (0)	**G – (0)** **C – (0)**
Other	G 3 (18) C 2 (12)	G 3 (18) C 2 (12)	G 2 (12) C 2 (12)	**G 8 (47)** **C 6 (35)**

Note: G= initiating gluten-free diet, C= initiating casein-free diet

Question 8 on the survey for the diet group asked the parents to rank the three biggest barriers that were the hardest to overcome when initiating the GFCF diet. Table 6 lists the results for the first, second, and third biggest barriers, and the total, listed in bold, represents the barriers found anywhere among the top three. The most commonly reported barriers to initiating the GFCF diet were: resistance from child, cost, and not knowing how to prepare the GF and/or CF foods. Three people wrote in barriers for the "other" category, which included: It was hard to... "let him be a kid," "find GFCF foods that taste good," and "find foods that he would eat."

Table 6

Ranking of the Three Biggest Barriers that were Hardest to Overcome When Initiating the GF/CF Diet in the Diet Group

Barrier	1st Choice # (%)	2nd Choice # (%)	3rd Choice # (%)	**Total** # (%)
Resistance from my child	5 (46)	1 (9)	- (0)	**6 (55)**
I didn't know how to prepare gluten-free or casein-free meals	1 (9)	1 (9)	3 (27)	**5 (46)**
Cost	3 (27)	2 (18)	- (0)	**5 (46)**
Time Issues	- (0)	2 (18)	2 (18)	**4 (36)**
The diet restrictions made it difficult to eat out	- (0)	1 (9)	1 (9)	**2 (18)**
I didn't know where to find resources to help me start implementing the diets	- (0)	2 (18)	- (0)	**2 (18)**
I didn't know where to find appropriate foods	1 (9)	- (0)	1 (9)	**2 (18)**
Resistance from my child's healthcare provider	- (0)	- (0)	- (0)	**- (0)**
Trouble with compliance from the school	- (0)	- (0)	- (0)	**- (0)**
Other	1 (9)	- (0)	2 (18)	**3 (27)**

Non-diet Survey

Non-diet survey participants were asked if they were interested in meeting with a specialist to discuss the use of the GFCF diet as a form of alternative treatment. Nine replied yes while eight replied no. The two best ways for the non-diet group participants to be in contact with a specialist for diet implementation were individual sessions and online, while group classes and phone sessions ranked third and fourth. Results are shown in Figure 2.

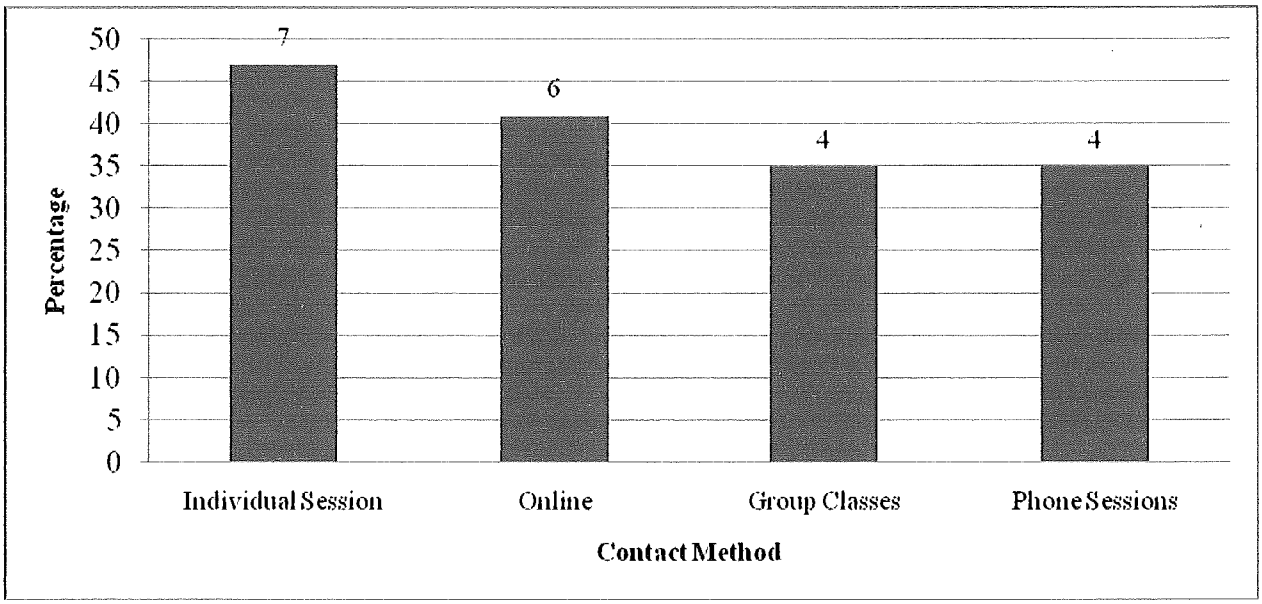


Figure 2. Best ways to be in contact with a specialist for diet implementation in the non-diet group.

Diet Survey

Of the 11 participants who returned the diet survey, three (27%) were no longer following either of the diets. One participant (9%) was following the GF diet only, and one (9%) was following the CF diet only. Six of 11 (55%) were following the GFCF diet. The participants who were using the diet at the time of the study had been on it for an average of 13 months. Those who ended one or both of the GF/CF diets followed the diet for a minimum of 6 months

and a maximum of 22 months with an average amount of time following the GF/CF diets of 14 months.

The 11 participants in the diet group were asked how they implemented the GFCF diets. Five (45%) implemented both at the same time, four (36%) implemented CF and then GF, and two (18%) implemented GF and then CF.

When asked if the child showed resistance to trying new foods prior to implementation of the diet(s), eight (73%) of the diet group participants reported that prior to implementing the diets their child showed resistance to trying new foods. Five (45%) said that the resistance did not change to trying new foods and four (36%) reported less resistance to trying new foods. One participant reported that the child had some resistance to dairy-free milk, but it was better after 3 months. Another participant reported that she needed to provide foods that looked similar to gluten-containing foods liked by the child, and that after also taking away rice and corn, he showed much less resistance to trying new foods. Another participant stated that her two year old child has a severe oral aversion which requires the use of Neocate formula and pureed foods.

The diet group participants were asked if the child appeared to slow or regress in development upon implementation of the diet(s). Only one person out of 11 reported a slowing or regression in development upon implementation of the diets. That person stated that her son went through "major detox - tantrums - head banging - he was a nightmare for about one week," and after that week development began to advance again.

The diet group participants were asked if anyone in the family followed the diet with the child. Four (36%) reported that only the child followed the diet, four (36%) reported that the whole family usually followed the diet, and three (27%) stated that only sometimes the whole family followed the diet.

When the eight who were still on one or both diets were asked how many times a day the child was offered the foods that contain the gluten and casein, seven (88%) responded never and one (12%) responded a couple of days in a week. Four wrote that the child was only given the eliminated food if given by someone else accidentally.

The diet group was asked if they have ever given the child breaks from the eliminated foods. Five (45%) participants reported that they have given the child breaks from the diet. Three of those five (60%) reported that there were changes in the child's behavior when the break occurred. The participants reported the following behavior changes seen after a break from the diet: 36 hours pain/screaming/crying, more agitated and restless, cried out in sleep, bowel habits were worse, attention was worse, and more intense stimming.

The diet group participants were asked about the type of processed foods the child consumed. Four (36%) participants reported that they only use GF/CF processed foods, and one (9%) reported only using processed food in an emergency. Other processed foods reported were canned vegetables, organic jarred baby food and rice cereal, fruit leathers, and deli-mex chicken taquitos.

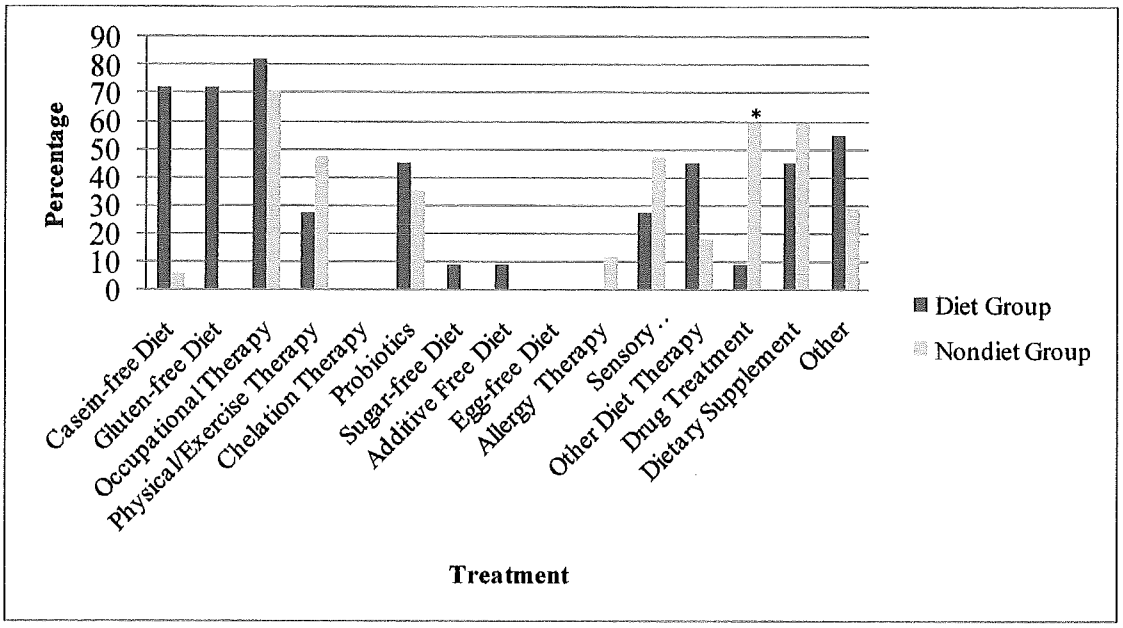
When asked if they read the food ingredient list on food packages to check for hidden gluten and/or casein products, 10 of the 11 (91%) diet group participants reported that they read the food labels. One participant reported, "It is tough, but I do my best."

The diet group participants were asked if they do anything special to make sure that gluten-containing foods do not come in contact with GF foods. Six of the 11 (55%) said that they take special care to make sure that gluten-containing and GF foods do not come into contact with one another. Four (36%) reported that they have a separate toaster/bread and muffin pan/shelf/bowls/utensils for GF foods. One participant reported they wash the dishes often.

The diet group was asked if they were aware that some products may have hidden sources of gluten. Only one of the 11 was not aware of hidden sources of gluten. Seven of the 11 (64%) have eliminated hidden sources of gluten from the child's life, with play dough being the most frequently eliminated product. Most reported that they made play dough at home or requested hand washing immediately after playing with it. Participants also responded that they eliminate as many hidden gluten sources as possible, such as sunscreens, lotions, shaving cream, diaper creams, shampoo and conditioner, and toothpaste. One participant said she was aware of hidden gluten sources, but when asked if she eliminated them, she wrote, "I didn't go that far."

Treatments

Both the diet group and the non-diet group were asked to list all of the treatments that were used with the child at the time of the study. The results are shown in Figure 3. The most common treatment used in the non-diet group was occupational therapy, followed by drug treatments and dietary supplements. The most common treatments used in the diet group were occupational therapy and the GF/CF diets. There was a statistically significant difference between the number of participants who used drug therapy between the two groups (Fisher's Exact Test, $p = 0.016$). In the non-diet group, 59% of the participants reported using drug therapy, while only 9% of the participants in the diet group reported using drug therapy.



*Statistically significant (Fisher's Exact Test, p = .016)

Figure 3. Treatments currently used by the participants.

Common Foods Worksheet

All participants in the diet and non-diet groups were asked to fill out a common foods worksheet. They were asked to list everything that the child eats and drinks in a typical day. The author determined the percentage of gluten- and casein-containing foods offered to the child as reported in the common foods worksheet. The percentages of gluten- and casein-containing foods were determined as follows: The researcher counted up the total number of foods listed on the common foods worksheet. Then the researcher determined which foods contained gluten and casein. Each total number of gluten or casein containing foods was divided by the total number of foods to get the percent of the gluten and casein content of the diet.

In the non-diet group, 15 participants filled out the common foods worksheet. Twelve of the 15 (80%) participants were found to have more than 30% of their intake as having gluten. Three of the 15 were found to have an intake of 50% or more from gluten-containing foods. See Table 7. Eight of the 15 (53%) were found to have more than 20% of their intake from casein-

containing foods. See Table 8. When combined, 11 of the 15 (73%) reported offering more than 50% of gluten- and casein-containing foods in a typical day. See Table 9.

In the diet group, ten participants filled out the common foods worksheet. Of the seven participants who were still following the GF diet, all reported having 0% of their intake from gluten-containing foods. See Table 7. All seven participants who were still following the CF diet reported having 0% of their intake from casein-containing foods. See Table 8. When combined, the six (75%) who were following the GFCF diet were found to offer 0% of gluten- or casein-containing foods. The one participant who was following only the GF diet was found to have 13% of foods containing casein in a typical day. The one participant who is following only the CF diet was found to have 20% of foods containing gluten in a typical day. See Table 9.

Table 7

Percent of Foods Listed on the Common Foods Worksheet that Contain Gluten

Percent	Non-diet # (%)	Diet # (%)
0-9%	1 (6)	7 (100)
10-19%	- (0)	- (0)
20-29%	2 (12)	- (0)
30-39%	5 (29)*	- (0)
40-49%	4 (24)*	- (0)
50+%	3 (18)*	- (0)

*Identifies percentages that exceed those of a "typical" American child's diet. See Chapter V for more detail.

Table 8

Percent of Foods Listed on the Common Foods Worksheet that Contain Casein

Percent	Non-diet # (%)	Diet # (%)
0-9%	2 (12)	7 (100)
10-19%	5 (29)	- (0)
20-29%	1 (6)*	- (0)
30-39%	4 (24)*	- (0)
40-49%	2 (12)*	- (0)
50+%	1 (6)*	- (0)

*Identifies percentages that exceed those of a "typical" American child's diet. See Chapter V for more detail.

Table 9

Percent of Foods Listed on the Common Foods Worksheet that Contain Gluten and Casein

Percent	Non-diet # (%)	Diet # (%)
0-9%	- (0)	6 (60)
10-19%	1 (6)	1 (10)
20-29%	- (0)	1 (10)
30-39%	2 (12)	- (0)
40-49%	2 (12)	- (0)
50-59%	4 (24)*	- (0)
60-69%	2 (12)*	- (0)
70-79%	2 (12)*	- (0)
80-89%	1 (6)*	- (0)
90-99%	2 (12)*	- (0)

*Identifies percentages that exceed those of a "typical" American child's diet. See Chapter V for more detail.

Behavior Evaluation Checklist

The diet group participants were asked in an open-ended question what changes they had seen in the child's behavior since beginning the diet. The most common changes seen were: improvements with GI problems, calmer, more aware of surroundings, and potty training success. All responses are listed in Table 10. One parent reported there was a "huge change in gut/bowel movements - before GF he had 4 loose diapers a day, and I had no hope of potty training (him). That changed in 24-hours."

Table 10

Changes that Parents Reported Seeing in the Child's Behavior since the Implementation of the GFCF Diet

Behavior Change	# (%)
Decrease in gastrointestinal problems (firmer stools, fewer stomach aches, etc.)	7 (64)
Calmer (less aggressive, fewer tantrums, decreased self-injurious behaviors, less stimming, more organized)	7 (64)
More present (less zoning-out, attending/referencing improved, more interactive/communicative	4 (36)
Able to potty train	3 (27)
Fewer sleep problems (night terrors, sleeping through the night)	2 (18)
Nothing significant	1 (9)

All participants in the diet and non-diet groups were asked to fill out a behavioral evaluation for their child. The evaluation listed 67 behaviors which belonged to one of the four following categories: speech/language/communication, sociability, sensory/cognitive awareness, and health/physical/behavior. For each behavior listed, the parents were asked to choose the best response that corresponded to the changes they had seen in their child over a given period of

time as improved (I), not changed (NC), worsened (W), or not applicable (NA). The diet group was asked to report the changes they had seen since beginning the diet, while the non-diet group was asked to report the changes they had seen in the past 3 months. The results from the behavior evaluation are reported in Appendix I.

Though there were no individual statistically significant differences in behavior change for single behaviors within categories between the diet and non-diet groups, there is a trend for more "improved" reports in the diet group than the non-diet group. There were 25 behaviors that received at least 50% of the scores as "improved" in the diet group, while none of the behaviors in the non-diet group had a reporting of greater than 41% for the "improved" score. Of the 25 behaviors that 50% or more of the diet participants reported "improve," five behaviors were from the speech category and eight behaviors were from the sociability category (see Table 11). The nine behaviors from the sensory category and three behaviors from the health category that at least 50% of the scores were improved are listed in Table 12.

Table 11

Speech and Social Behaviors where 50% of the Responses were "Improved" Over Time

Behavior	Diet	Non-diet
Does not respond to 'No' or 'Stop'	73%	6%
Does not follow commands	55%	6%
Cannot use sentences with 4 or more words	55%	12%
Is not able to explain what he/she wants	55%	12%
Speech is not meaningful and relevant	64%	18%
Seems to be in a shell	73%	12%
Pays little or no attention when addressed	82%	12%
Shows no affection	55%	24%
Fails to greet parents	64%	18%
Avoids contact with others	73%	18%
Does not imitate	64%	12%
Temper tantrums	55%	6%
Rarely smiles	55%	6%

Table 12

Sensory and Health Behaviors where 50% of the Responses were "Improved" Over Time

Behavior	Diet	Non-diet
Does not respond to own name	73%	6%
Does not respond to praise	55%	12%
Does not draw, color, or create art	55%	6%
Does not play with toys appropriately	82%	12%
Does not understand stories or explanations	55%	6%
Unable to initiate activities	64%	24%
Is not curious/interested in general	73%	18%
Is not venturesome	55%	18%
Is not tuned in/is spacey	64%	18%
Diarrhea/constipation/vomiting	64%	6%
Eating patterns are irregular	55%	0%
Does repetitive movements (stimms, etc.)	55%	18%

Accuracy of Diet and Behavior Evaluations

The behaviors that had 50% or more of the diet group participants chose as "improved" were analyzed against the amount of gluten and casein foods the child was allowed to eat in a day. Figure 4 shows behaviors that showed improvement when 0% of the respected foods were allowed in the child's diet. Behaviors found in the sensory category, such as "speech is not meaningful or relevant," "is not curious/interested in general," and "is not tuned in/is spacey" improved more often when following the GF diet. Behaviors found in the social category, such

as "does not respond to no or stop," "seems to be in a shell," "fails to greet parents," "does not imitate," and "eating patterns are irregular" improved more often when following the CF diet.

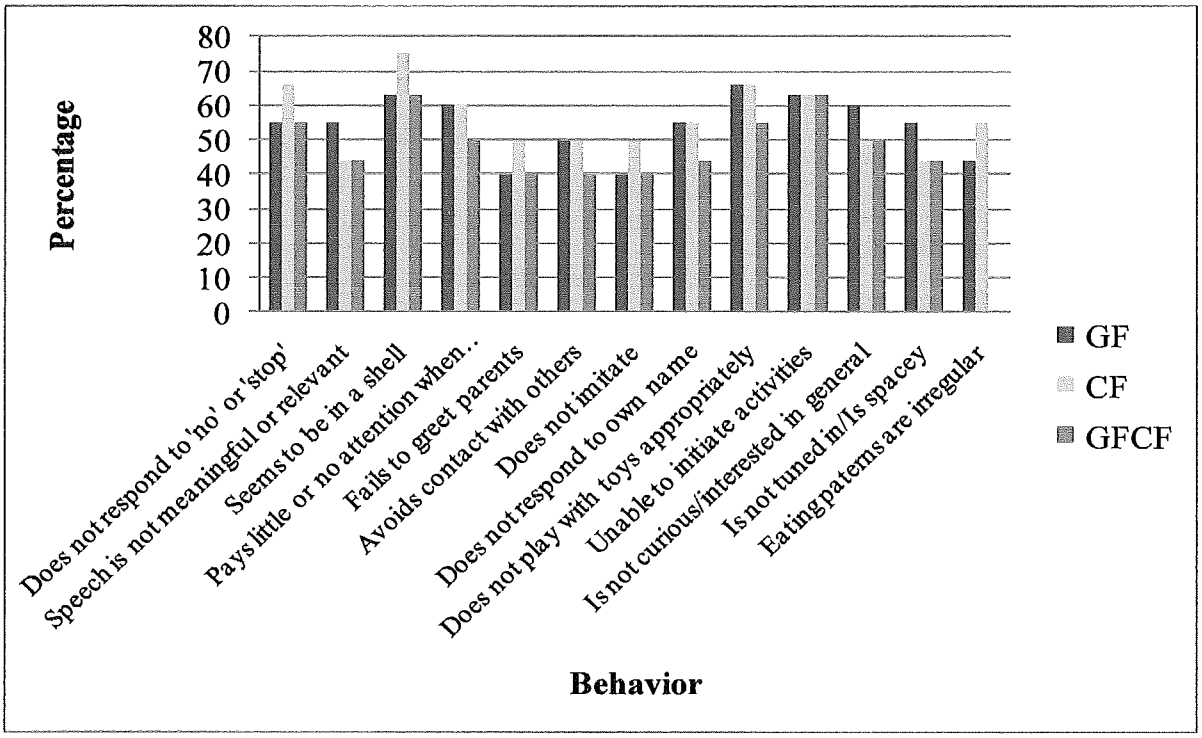


Figure 4. Behaviors that at least 50% of participants who allow 0% of the eliminated foods for the respected diet chose "improved" since beginning the diet.

Behavior Results

After analyzing each behavior individually, all the behavior responses were grouped into one of the four categories to which they belonged. The four categories were speech, social, sensory, and health. The diet group and the non-diet group responses (improved, no change, worsened, not applicable) were compared to each other in each of the four behavior categories. The differences between the "not applicable" and the other responses were statistically significant ($p < 0.001$) in the speech, social, and sensory categories. Table 13 shows the differences in those who responded "not applicable" to any of the "improved," "no change," or

"worsened" choices. Because of the significant difference found here, the "not applicable" responses were removed from both of the groups, and further analysis was done.

Table 13

Differences between Improved/No Change/Worsened (I/NC/W) and Not Applicable (NA) Behavior Ratings in each Behavior Category (Speech, Social, Sensory, and Health) in the Diet and Non-diet Groups

Behavior Category	Diet I/NC/W # (%)	Non-diet I/NC/W # (%)	Diet NA # (%)	Non-diet NA # (%)	Chi Square statistic	df
Speech*	90 (82)	61 (36)	20 (18)	108 (64)	56.10	1
Social*	153 (85)	139 (48)	28 (16)	149 (52)	62.22	1
Sensory*	156 (83)	112 (39)	31 (17)	176 (61)	91.45	1
Health	159 (63)	229 (59)	94 (37)	160 (41)	1.01	1

*Indicates a statistically significant difference ($p = 0.001$) between the diet and non-diet groups.

The behaviors were then analyzed once more after the "not applicable" answers withdrawn. This allowed the responses of "improved" and "no change/worsened" to be compared to each other. Table 14 shows the differences in responses between the diet group and non-diet group according to the behavior rating of "improved" and "no change/worsened." All four behavior categories have a statistically significant difference from one another.

Of the diet group participants who responded "improved," "no change," or "worsened," 60% reported an overall improvement in the speech category, while only 28% of the non-diet group did. For the social category, 61% of this subset from the diet group reported improvements, while only 32% of this subset from the non-diet group reported improvements. For the sensory category, 63% of this subset from the diet group reported improvements, while only 30% of this subset from the non-diet group reported improvements. And, for the health

category, 65% of this subset from the diet group reported improvements, while only 16% of this subset from the non-diet group reported improvements. The significance of these findings is discussed in Chapter V.

Table 14

Differences between Improved (I) and No Change/Worsened (NC/W) Behavior Ratings in each Behavior Category (Speech, Social, Sensory, and Health) in the Diet and Non-diet Groups

Behavior Category	Diet I # (%)	Non-diet I # (%)	Diet NC/W # (%)	Non-diet NC/W # (%)	Chi Square statistic	df
Speech*	54 (60)	17 (28)	36 (40)	44 (72)	15.07	1
Social*	94 (61)	44 (32)	59 (39)	95 (68)	25.92	1
Sensory*	98 (63)	33 (30)	58 (37)	79 (71)	29.03	1
Health*	79 (50)	36 (16)	80 (50)	193 (84)	51.91	1

*Indicates a statistically significant difference ($p = 0.001$) between the diet and non-diet groups.

Chapter V: Discussion

This chapter discusses the findings reported in the results section and compares the results to research previously done. The limitations of this research study are discussed, and general conclusions are summarized. Lastly, recommendations are given to offer ways to improve the study and to use the findings.

Discussion

The children in the diet group were younger than the non-diet group at the time of the study and at the age of diagnosis. Six children in the non-diet group and no children in the diet group had the less severe Autism Spectrum Disorder (ASD), Asperger's Syndrome, which may have resulted in diagnosis at a later age in the non-diet group. Lovaas (1987) and Myers (2007) offer support for beginning intervention for ASD management as early as possible. It may be possible that because changes are thought to be seen more prominently in early intervention, doctors are more likely to suggest the gluten-free casein-free (GFCF) diet use for younger children. Doctors might also be more willing to suggest the GFCF diet to more severe ASD cases, which were found in the diet group in this study.

The majority of children with ASD in this study were boys. Boys are ten times more likely to have ASD than girls. Autism Disorder (AD) specifically is found in boys four times more than in girls. As reported by Schmidt (2009), Dr. Nelson of the David Geffen School of Medicine at UCLA has identified a variant of a gene that may increase the risk for developing ASD. This gene variant has been found in families with two or more sons diagnosed with ASD, suggesting a genetic and sex link.

Objective 1 and 2: Identify sources where parents find reliable information about the GFCF diet, and identify concerns that parents in both groups have about using the GFCF diet.

To examine objective one, all participants were asked to circle from a list of eight options

to identify the source where they first heard about the GFCF diet. Online and books were among the top three sources listed in both groups. The International Food Information Council (2007) found that 71% of respondents (n=1000) of the "Consumer Attitudes toward Functional Foods/Foods for Health" survey chose media as the top source for finding information about health and nutrition. Cornish (2002) found more specifically that the most common way parents of children with ASD heard about the GFCF diet was from the media.

The non-diet group also listed friends and family members, and the diet group listed doctors as the third most common source where they first heard about the diets. Forty-five percent of the diet group participants reported first hearing about the diet from a doctor, while only 29% of the non-diet group participants reported first hearing about the diet from a doctor. This suggests that those who hear about the diet from a doctor may be more willing to try it.

Both the diet group and non-diet group were also asked in an open-ended question where they would find reliable information about the diets. Both groups listed online, books, doctor, and dietitian/nutritionist as the top four choices (in that order). Cornish (2002) also found that the study participants would seek help from a support group over a health care provider. Online and books can be resourceful places to find information, but only if the seeker knows how to use the resources in the most effective way. As anyone is able to post information on the internet, there is a good chance that some parents will end up with false information, and may possibly put their child in harm's way. Doctors can offer general nutrition information, but in depth nutrition education should be led by a dietetic professional, such as a registered dietitian (RD).

One of the main concerns that both the diet and non-diet groups had about the GFCF diet was that the child may not be getting adequate nutrition. Cornish (2002) and Bowers (2002) showed that though children with ASD met the protein, fat, carbohydrate, and kilocalorie needs

through their current diets, they were at risk for nutritional deficiencies. These nutrients are very important and intakes need to be examined by a healthcare provider.

In the position paper on nutritional services for children with developmental disabilities, the American Dietetic Association (ADA) (2004) states that there is a high percentage of children with developmental disabilities who have nutritional risk factors. Parents are concerned about adequate nutrition in children with ASD, and there are various research reports, such as Cornish (2002) and Bowers (2002), that support the need for nutritional counseling. It is imperative parents have access to a nutritional professional in order to implement the GFCF diet properly.

Though nutrition was the most common concern for both groups, parents reported going to an RD as the fourth choice to get information about the diets. Parents should consider talking about nutritional concerns that arise when using the diet with an expert.

Objective 3: Determine barriers to initiating the GFCF diet.

Participants of both groups were asked to rank the top three barriers to initiating the diet. Both groups listed "resistance from my child" as being the biggest barrier. However, when the diet group was asked about the change in resistance that the child exhibited to trying new foods after implementation of the diet, the majority said that the resistance either did not change or it decreased. Although this was a major concern for both groups, reports from the diet group suggest that its implementation at best decreases resistance to new foods, while at the very worst has little or no effect on resistance to trying new foods.

The non-diet group also listed "my child only seems to want to eat foods that contain gluten or casein" as a top barrier. The opiate theory assumes that if exorphins are in the body, they will bind with the opiate receptors and initiate an addiction-like response. This theory

implies that the children who are experiencing this addiction-like response are going to be the most affected by the elimination of the exorphins as a form of management. These children are most likely already craving and demanding foods that contain gluten or casein. Children who experience this reaction may demand these foods, and these parents may be less likely to try the diet because they may not understand the biochemical reasoning behind elimination diets. Or, if they decide to try the diet, they may not understand the importance of following it closely and may cave in when the child starts demanding the banned foods. The theory suggests that when the diet is used as a treatment for these children, the body will eliminate these exorphins and the addiction-like behaviors will subside.

The parents of children with ASD must manage various responsibilities at once and be adaptive to any situation, good or bad, that may arise. A form of management that predicts that behaviors will get worse in a 'withdrawal phase' before they get better is a decision many parents might not make lightly. However, of all 11 participants in the diet group, only one reported a withdrawal period with regression in development for one week.

Both groups listed cost as one of the top three barriers. GFCF diets result in the use of more natural ingredients, which can be more expensive. One participant said, "The diet can be expensive, but we are finally eating the foods we are supposed to be eating (referring to fruits and vegetables)." Allergen-free prepackaged products can be more expensive than the more conventional type prepackaged foods, but there are many products available. Bob's Red Mill and Ian's are two examples of companies who offer palatable gluten-free products that children can enjoy. Both companies donated some of their products to this study to be given to participants as incentive gifts.

The diet group listed that not knowing how to prepare GFCF foods was the second

biggest barrier to implementing the GFCF diet. This information is something that they would be able to find via their preferred sources of information, online, and books. Reliable information about diet changes can also be found from an RD. Both groups listed time issues of one as the top four choices for barriers.

One barrier that a participant wrote in was "difference of opinion with spouse." Though it was expected to be found that cost and time issues were significant barriers, disagreements between caregivers about trying the GFCF diet was not considered. This is important to remember when in a counseling session with more than one caregiver. Though one member might be 100% ready to try the diet, the other member might have no desire to try it, leaving the counselor to provide information to help the two caregivers make an informed choice together.

Objective 4: Find the best ways to meet with and educate parents to discuss the GFCF diet.

About half of the parents who completed the non-diet survey responded that they would be interested in meeting with a specialist to discuss the diet, suggesting that the need for educators who are knowledgeable about the GFCF diet is growing. Whether the healthcare professional providing the main source of care for the child believes that the GFCF diet is effective or not, it is important that caregivers are allowed access to a nutritional professional to discuss concerns. Then, if the diet is initiated, the child has a greater chance of being monitored by a professional to make sure that he/she is receiving adequate nutrition.

Most parents in the non-diet group who were interested in meeting with a professional reported that they would like to learn more about the GFCF diet through individual counseling sessions. However, online, group classes, and phone sessions were also reliable options for most.

Objective 5: Identify the most common treatments used by both groups.

The most common treatment for ASD management used by participants of both groups

was occupational therapy. This may be an inaccurate representation, because most of the participants were recruited from treatment agencies who offer occupational therapy as a form of management.

The second and third most common treatments for the diet group were the GF and CF diets (respectively). On the other hand, the second most common treatment for the non-diet group was drug treatment and the third was dietary supplements. The non-diet group's drug treatment use was significantly greater than the diet group's drug treatment use (Fisher's Exact Test $p < 0.001$). These findings coincide with the parental ratings of success for certain treatments found in Chapter II, Table 1. The significance of this is discussed in Objective 9.

Objective 6: Determine accuracy of implementation of the GFCF diet for those who are currently using the diet

Those who were using the GFCF diet had been on the diet for an average of 13 months. There was not one common way the diets were implemented (e.g., gluten-free first and then casein-free or vice versa).

Prior to beginning the diet, 73% of the diet group participants reported that the children showed resistance to trying new foods. One reason for the resistance may be sensory issues, which are common in children with ASD, preventing the allowance of new foods. Bowers (2002) reported that 46% of referrals of children with ASD to an RD were because of food selectivity and dysfunctional feeding behaviors. Lockner, Crowe, and Skipper (2008) found that most participants reported that their children had favorite textures and were more resistant to trying new foods than the controls.

Another reason for the resistance to trying new foods may be that the opiate theory is true and the child is addicted to these foods. If the theory is true, the child may not want to try new

foods that might not contain the exogenous opiate source.

As stated earlier, most of the diet group participants reported either the resistance did not change or the resistance decreased after trying the diets. This finding suggests that if a parent is interested in the diet, the negative effects on food acceptance are minimal. It may be worthwhile to try the diet to see if the child will accept a greater variety of foods, and consequently consume a wider variety of nutrients.

Out of all of the participants who tried the diet, only one reported a regression in development upon implementation of the diets. The regression lasted for a week, and then development progressed again. It was expected that more participants would report a regression in development, as the opiate theory implies that every participant should have a withdrawal period.

Four participants reported that only the child with ASD was on the diet. The rest of the participants said that the entire family followed the diet at least occasionally. Most in the diet group reported that they do not offer banned foods, which shows that they are implementing the diet correctly.

Only a few participants gave the child breaks from the diet. Periodic allowance of the banned foods will not promote improvement according to the opiate theory or evidence gained from celiac disease treatment. All participants admitted that the banned foods were sometimes given to the children accidently, and some of the children completely regress in behavior when the food was inadvertently given. Most reported that the accident occured when other caregivers (day care, school, etc.) were overseeing meals. Thompson (2006, p. 33) states that when a person is following an elimination diet, they should follow it very strictly to maximize outcomes.

Most of the participants are conscious of the types of processed foods they use and read the food labels to prevent using foods that contain a hidden gluten or casein source. Only 55% say that they take special care to prevent gluten-free and gluten-containing foods from contacting one another. Cross contamination of gluten could allow the child an exorphin they are trying to avoid. Thompson (2006, p. 18) states that when following an elimination diet, "it is important to minimize contact between gluten-free and gluten-containing food."

Only one of the participants in the diet group did not know that there were hidden sources of gluten in objects, such as play dough and envelop glue. Of those that did know, most tried to limit the contact the kids had with those sources. However, one woman stated that she "didn't go that far" when asked if she eliminated those things. Unfortunately, she may not know the theory behind this diet and may not understand the importance of close compliance in order to see significant results.

Objective 7: Determine the percentage of gluten and casein foods eaten by all children in both groups.

A child who eats a "typical" American diet with the recommended amounts from each food group based on the Food Guide Pyramid consumes about 30% of foods that contain gluten and 15% of foods that contain casein, with a total of about 45% of gluten- and casein-containing foods based on the author's protocol used in this study. An example of this "typical" American child's diet is shown in Table 15.

To find the total percent, all of the foods listed on the common foods list were counted to get a total number of foods eaten by the child during a typical day. Then the foods that contain gluten were counted and the foods that contain casein were counted. In the example shown in Table 15, there are 14 foods listed. Cereal, bread, noodles, and cookies all commonly contain

gluten, totaling four gluten-containing foods. When these foods were listed on the common foods worksheet, they were counted as gluten-containing if the participant did not indicate that the food was GF. Milk, yogurt, and cheese contain casein, totaling three casein-containing foods. The number of gluten-containing and casein-containing foods were combined. All three totals were divided by the total number of foods to get the percentage that each makes up of the total daily intake. The example in Table 15 equals 30% of the intake from gluten and 15% from casein, representing the "typical" child's daily intake.

Table 15

"Typical" American Child's Diet

Breakfast	Lunch	Dinner	Snacks
Cereal*	Peanut Butter/Jelly	Meatballs	Cookie *
Milk+	Whole Wheat Bread*	Noodles*	Yogurt+
Fruit	Vegetable	Tomato Sauce	Fruit
		Vegetable	
		Milk+	

*Gluten-containing foods

+Casein-containing foods

Those who were following the GFCF diet in this study were complying with the dietary recommendations fully by not offering any of the banned foods. One person in the diet group contradicted her response by saying that she offered the banned foods 2-3 times a week in the questionnaire, but did not include any banned foods on the common foods worksheet. It may be possible that the common foods worksheet was a listing of all the foods that those on the diet know the child should be eating in the day, but might not be the foods the child actually eats

during the day. That could have caused inconsistency in answers in the example listed above, and for other of the participants. This inconsistency is discussed later in the limitations.

Those participants who consume over the amount of gluten (30%) and casein (15%) that a typically developing child would consume may be a sign that that child is acting as the opiate theory would suggest. The combination of both gluten and casein containing foods in the non-diet group made up more than 50% of intake in 11 of 15 participants (73%). This may be able to support the opiate theory, or at least suggest a way of monitoring and evaluating the addictive response to the opiates, along with urinary protein analysis and behavioral evaluation.

Objective 8: Compare behavior changes when looking at percentage of gluten and casein foods eaten by children in the diet and non-diet groups.

The influence of each individual elimination diet by itself is not statistically significant in this study. No statistically significant findings were found when looking at differences in scores (I, NC, W, NA) based on percentage of gluten- and casein-containing foods when behaviors were analyzed individually. Thirteen behaviors that received at least 50% of an "improved" score in the diet group allowed 0% of the banned foods. These are listed in Figure 4. These findings suggest that some behaviors may be influenced more by one diet or the other.

Interestingly, the two behavior categories that seem to be most influenced by the diet each showed a different diet as bringing on the effect. The social behavior category responded more positively with either the CF diet or the GFCF diet, where as the sensory category responded more positively with the GF or GFCF diet. This suggests that each protein may influence a different category of behaviors.

Interestingly, the non-diet group chose "not applicable" more often than the diet group with statistical significance in the speech, social, and sensory groups. The description for not

applicable was listed as, "this behavior is not applicable to my child." It is uncertain why a statistically significant amount of participants chose this option in the non-diet group. Possibly, the time period was not adequate enough to measure the specific change, or the negative behaviors were not as severe as the diet group, or the child never exhibited the specific behavior.

Objective 9: Compare behavior changes over a specified amount of time between the diet and non-diet groups.

When the GF, CF, and GFCF diets were all combined, the four categories of behaviors were significantly improved in the diet group over the non-diet group. These findings are similar to Knivsberg et al. (2003) findings of improvement in certain behavioral categories. Analyzing the broad categories of speech, social, sensory and health instead of just each individual behavior showed that the diet may impact the various types of behavior positively rather that just one specific behavior.

For those participants who chose the "improved," "no change," or "worsened" behavior responses, all of the behavior categories had a statistically significant response for more "improved" responses than "no change" and "worsened." If there had been more participants, significant differences may have been found between the groups for some of the individual behavior changes.

Some behaviors were reported as "improved" by the parents when asked in both the open-ended question and in the modified ATEC form. The behaviors that received high scores from both methods were decreased gastrointestinal problems, calmer, and more attentive. All three of these behaviors are common concerns for children with ASD. No standard treatments have been found to alleviate any of these symptoms, while the elimination diet appears to positively affect all of them.

It is interesting that the non-diet group reported drug treatment use more often than the diet group, yet the non-diet group had significantly more "no change" or "worsened" responses than the diet group. The findings from this study suggest that it is more beneficial to use a GFCF diet than to use pharmaceuticals. These findings are similar to the findings from the parental ratings of treatments provided by the Autism Research Institute (2008), which reported greater improvement with biomedical/non-drug/supplements and special diets than with drugs.

This study, along with the others discussed in this paper, suggest that it is possible to help alleviate some of the autistic behaviors the children exhibit by using the GFCF diet. Using a natural form of treatment, such as diet therapy, minimizes the amount of foreign substance introduced into the child's body. The benefits of this natural approach to ASD management may make the GFCF diet a viable option for parents of children with ASD.

Limitations

The sample size was small and almost all of the participants were seeking treatment of some kind at an intervention agency. The results may have been different if the sample were bigger or if they were recruited from a larger variety of locations.

The major limitation in this study is the time reference used in the behavioral evaluation. The non-diet group used a 3 month time period, while the diet group evaluated changes since beginning the diet, which was an average of a 13 month time period. This may have been an unfair comparison and may have skewed the responses. As discussed in Chapter III, the three month time point used to determine change in the non-diet group was initially chosen based on the Cade et al. (2000) findings, which showed that 81% of children saw improvements in behavior within three months of treatment with a GFCF diet.

All responses were self reported. It is well known that it is better to have an outside

objective observer who uses a standardized method to report qualitative data. This would help insure that the validity of the all aspects of the study is maintained. The participant may have written foods on the common foods worksheet that were not actually consumed by the child, just to make it look like they were implementing the diet correctly. Or, all details about the foods may not have been listed on the worksheet, leading them to be classified as GF or CF falsely. Also, the behavior changes are based purely on parental reporting, which could be influenced by the placebo effect, resulting in more "improved" scores.

Study Recommendations

If this study were to be replicated, some things should be reconsidered. In order to monitor the progression on the diet, the same time point and duration must be in place for each group. Also, to make sure that each answer is standardized, it would be best if the behavioral evaluation was conducted in an interview rather than a survey. That might eliminate the overwhelming difference in 'not applicable' answers between the two groups. Or, if resources allow, having a therapist evaluate behaviors would provide more objective responses.

The ATEC is designed to monitor changes over time. The original ATEC is found online and anybody is allowed to use it. It is designed so that the user can rate all behaviors online at the beginning of a treatment and again at another time point. Using the original ATEC tool the way that it was designed to be used would provide a more accurate reporting of behavior changes.

The common foods worksheet would have provided more accurate responses if the information was obtained from an interview. That way, the researcher would have been able to report the findings of gluten-containing and casein-containing foods with more confidence. Also, including a nutritional analysis of all the foods would provide important information about the nutritional status of the children.

Professional Recommendations

Adequate nutrition is a very important part of a child's development. To maximize the outcome of the child's development, nutrition counseling should be offered regardless of desire to use the GFCF diet. If all concerned parents were referred to an RD, not only would they know if their child is getting adequate nutrition, but they would also have the opportunity to ask questions about the highly specialized GFCF diets.

University nutrition programs should consider focusing some time on teaching the students about this diet, if it is not already covered in the curriculum. Those who are knowledgeable about the GFCF diet should advocate the need to be involved in the child's care team. These nutritional professionals should also consider outreach projects in their community to offer nutrition education to this population, as many people are currently implementing the diet without any formal nutritional guidance.

The limitations of this study may cause the reader to interpret the findings with caution. However, the findings of this study which demonstrate that GFCF diet use in children with ASD may help improve behavior in the categories of speech, social, sensory, and health coincide with findings from other studies mentioned throughout this paper. The findings also demonstrate that there is a growing need for nutritional education for all involved in this population, including caregivers, therapists, and other health care professionals. Larger, randomized, objective studies need to be conducted to help make the GFCF diet use a respected form of alternative management for children with ASD.

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Appendix A

DSM-IV Diagnostic Criteria for Autistic Disorder

Diagnostic Criteria for Autistic Disorder (American Psychiatric Association, 2000)

A. A total of six or more items from (1), (2), and (3), with at least two from (1) and one from each (2) and (3):

1. Qualitative impairment in social interaction, as manifested by at least two of the following:

    a. Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.

    b. Failure to develop peer relationships appropriate to developmental level

    c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

    d. Lack of social or emotional reciprocity

2. Qualitative impairments in communication as manifested by at least one of the following:

    a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime)

    b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

    c. Stereotyped and repetitive use of language or idiosyncratic language

d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

b. Apparently inflexible adherence to specific, nonfunctional routines or rituals

c. Stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)

d. Persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Appendix B

Institutional Review Board for Protection of Human Subjects Approval

STOUT
UNIVERSITY OF WISCONSIN

Research Services
152 Voc Rehab Building

University of Wisconsin-Stout
P.O. Box 790
Menomonie, WI 54751-0790

715/232-1126
715/232-1749 (fax)
http://www.uwstout.edu/rs/

Date: July 23, 2009

To: Gwenda Washnieski

Cc: Dr. Carol Seaborn

From: Sue Foxwell, Research Administrator and Human Protections Administrator, UW-Stout Institutional Review Board for the Protection of Human Subjects in Research (IRB) Susan Foxwell

Subject: **Protection of Human Subjects in Research**

Your project, "*Knowledge and Perceptions of Parents of Children with an Autism Spectrum Disorder Regarding the Use of Gluten-Free and Casein-Free Diets as a Form of Alternative Treatment*" is **Exempt** from review by the Institutional Review Board for the Protection of Human Subjects. The project is exempt under **Category 2** of the Federal Exempt Guidelines and holds for 5 years. Your project is approved from **November 18, 2008**, through **November 17, 2013**.

The reviewer also provided the following comment: "It is not necessary to have a 'signed' consent form since forms are not identifiable. We would recommend taking out address in form. In signed consent form, there does not seem to be a need for the address."

Please copy and paste the following message to the top of your survey form before dissemination:

> This project has been reviewed by the UW-Stout IRB as required by the Code of Federal Regulations Title 45 Part 46

Please contact the IRB if the plan of your research changes. Thank you for your cooperation with the IRB and best wishes with your project.

***NOTE: This is the only notice you will receive – no paper copy will be sent.**

Appendix C

Non-diet Group Survey

About Your Child and Diagnosis

1. How old is your child? _____years _____months

2. What is the gender of your child? _____boy _____girl

3. Please select your child's diagnosis below.
_____Autism _____Asperger's Disorder _____ PDD-NOS _____ Other (please list):

4. How old was your child when diagnosed with an Autism Spectrum Disorder?
_____years _____months

Gluten-free Diet

Gluten is a type of protein found in foods that contain wheat, rye, and barley. Gluten can also be found in sauces and several processed foods. A **gluten-free diet** aims to eliminate all foods that contain the gluten protein.

5. Are you aware that some caregivers use a **gluten-free** diet as an alternative form of treatment for ASD?
_____Yes _____No (If no, please proceed to question 6).

a. If yes, how did you hear about the gluten-free diet? Please check all that apply.

_____Treatment Center	_____Online	_____Dietitian/Nutritionist
_____Nurse	_____Doctor	_____Friend/Family Member
_____Books	_____Other (please list):	

6. Where would you look to find reliable information about the **gluten-free** diet?

7. What concerns, if any, would you have about your child if he/she was on the **gluten-free** diet?

8. What barriers might prevent you or have prevented you from initiating the **gluten-free** diet? Please rank the 3 biggest barriers to initiating the diet with 1 being the biggest barrier. If you have never heard of it please just check "I have never heard of it."

_____I have never heard of it
_____I don't believe it works
_____My child only seems to want to eat foods that contain gluten
_____Resistance from my child's healthcare provider
_____Cost
_____Resistance from my child
_____I don't know where to find appropriate foods
_____Time issues
_____The diet restrictions make it difficult to eat out
_____Trouble with compliance from the school
_____I don't know where to find resources to help me start implementing the diet.
_____I don't know how to prepare gluten-free meals
_____Other (please list):

Casein-free Diet

Casein is a protein found in milk. A **casein-free diet** aims to eliminate all foods that contain the casein protein.

9. Are you aware that some caregivers use a **casein-free** diet as an alternative form of treatment for ASD?
_____Yes _____No (If no, please proceed to question 10).

a. If you have heard of the **casein-free** diet, how did you hear about it? Please check all that apply.

_____Treatment Center _____Online _____Dietitian/Nutritionist
_____Nurse _____Doctor _____Friend/Family Member
_____Books _____Other (please list):

10. Where would you look to find reliable information about the **casein-free** diet?

11. What concerns, if any, would you have about your child if he/she was on the **casein-free** diet?

12. What barriers might prevent you or have prevented you from initiating the **casein-free** diet? Please rank the 3 biggest barriers to initiating the diet with 1 being the biggest barrier. If you have never heard of it please just check "I have never heard of it."

_____I have never heard of it
_____I don't believe it works
_____My child seems to only eat/drink food/beverages that contain casein
_____Resistance from my child's healthcare provider
_____Cost
_____Resistance from my child
_____I don't know where to find appropriate foods
_____Time issues
_____The diet restrictions make it difficult to eat out
_____Trouble with compliance from the school
_____I don't know where to find resources to help me start implementing the diet.
_____I don't know how to prepare casein-free meals
_____Other (please list):

Meeting with a Specialist and Other Concerns

13. Would you be interested in meeting with a specialist to discuss the use of either of the diets as a form of alternative treatment? ____Yes ____ No

a. If yes, what would be the best way to be in contact with a specialist for diet implementation? Check any that apply.

_____Online _____Group Classes _____Phone _____Individual Sessions
_____Other (please list):

Treatments

Please check all treatments utilized with your child currently.

_____Casein-free Diet _____Gluten-free Diet _____Occupational Therapy
_____Physical/Exercise Therapy
_____Chelation Therapy _____Sensory Training/Desensitization _____Probiotics
_____Sugar-free Diet _____Additive-free Diet _____ Egg-free Diet _____Allergy Therapy

_____Other diet therapy (please list):

_____Drug treatment (please list):

_____Dietary Supplements (please list):

_____Other (please describe):

Appendix D

Diet Group Survey

About Your Child and Diagnosis

1. How old is your child? _____years _____months

2. What is the gender of your child? _____boy _____girl

3. Please select your child's diagnosis below.
_____Autism _____Asperger's Disorder _____ PDD-NOS _____ Other (please list):

4. How old was your child when diagnosed with an Autism Spectrum Disorder?
_____years _____months

Information About the Diets

5. How did you hear about the gluten-free (GF) and casein-free (CF) diets? Please circle GF and/or CF for all that apply.

GF / CF	Friend/Family Member	GF / CF	Treatment Center	GF / CF	Online
GF / CF	Books	GF / CF	Doctor	GF / CF	Nurse
GF / CF	Dietitian/Nutritionist	GF / CF	Other (please list):		

6. Please document your usage of gluten-free and/or casein-free diets below. Please list when you started the diet(s), how old the child was, AND if applicable, when you ended the diet(s) and the age of the child when the diet ended.

Diet	Date Started	Age of child when the diet was started	Date Ended	Age of child when the diet ended
Gluten-free				
Casein-free				

a. If you have ended any of the diet treatments, please describe the specific reasons why you decided to end the diet therapy, and then continue filling out the remainder of the survey.

7. When using the diet(s), please describe how they were implemented by checking one of the answers below.
_____I have only implemented casein-free
_____I have only implemented gluten-free
_____I implemented casein- free, and then gluten-free
_____I implemented gluten-free, and then casein-free
_____I implemented both at the same time
_____Other (please list):

8. What barriers were the hardest to overcome when initiating the diet(s)? Please rank the top 3 barriers with 1 being the biggest barrier.

_____Resistance from my child's healthcare provider
_____Cost
_____Resistance from my child
_____I didn't know where to find appropriate foods
_____Time issues
_____The diet restrictions made it difficult to eat out
_____Trouble with compliance from the school
_____I didn't know where to find resources to help me start implementing the diet.
_____I didn't know how to prepare gluten-free or casein-free meals
_____Other (please list):

9. Did your child show resistance to trying new foods before the implementation of the diet(s)?
_____Yes _____No

10. After the diet(s) was/were initiated, did your child show:
_____less resistance to trying new foods
_____more resistance to trying new foods
_____resistance did not change to trying new foods
_____Other (please list):

11. Did your child appear to slow or regress in development (i.e. potty training, acceptance of new foods) upon implementation of the diet(s)? _____Yes _____No

a. If your child did appear to regress, in what specific ways did he/she regress?

b. If your child did appear to regress, how long did it take for your child to move forward in development again?

12. What changes, if any, have you seen in your child's behavior since implementing the diet(s)?

Food Preparation and Diet Compliance

13. When using the diet(s), is your child the only family member who follows the diet guidelines, or do others in the family follow the diet guidelines too? Please explain.

14. How often does your child eat the foods that are eliminated in the diet(s)? Please check the best answer.
_____Never
_____A couple of days in a year
_____A couple of days in a month
_____A couple of days in a week
_____A couple of times during the day
_____Other (please list):

15. Have you ever given your child breaks from the diet(s), when he/she is allowed to eat the eliminated foods?

_____Yes _____No

a. If yes, did there appear to be a change in your child's behavior when the break occurred?

_____Yes _____No

a. If yes, please list the behavior changes that occurred.

16. What types of processed foods (e.g., hamburger helper, canned vegetables), if any, does your child consume?

17. Do you read the food ingredient list of foods to check for hidden gluten and/or casein products?

_____Yes _____No

18. Do you do anything special (e.g., use special bake ware for gluten-free foods or have a special cabinet for gluten-free foods) to make sure that the gluten-containing and gluten-free foods don't come into contact with one another?

_____Yes _____No

a. If yes, what do you do?

19. Are you aware that things, such as play dough and envelope glue, can have hidden sources of gluten?

_____Yes _____No

a. If yes, have you eliminated hidden sources of gluten from your child's life?

_____Yes _____No

a. If yes, what have you eliminated?

Concerns and Information

20. What concerns, if any, do you have about your child when using either the gluten-free diet or the casein-free diet?

Gluten-free Diet Concerns:

Casein-free Diet Concerns:

21. Where do you find reliable information about the specialized diets?

Treatments

Please check all treatments utilized with your child currently.

_____Casein-free Diet	_____Gluten-free Diet	_____Occupational Therapy
_____Physical/Exercise Therapy	_____Chelation Therapy	_____Probiotics
_____Sugar-free Diet	_____Additive-free Diet	_____ Egg-free Diet
_____Allergy Therapy	_____Sensory Training/Desensitization	

_____Other diet therapy (please list):

_____Drug treatment (please list):

_____Dietary Supplements (please list):

_____Other (please describe):

Appendix E

Common Foods List Worksheet

Common Foods Your Child Eats in a Typical Day

Please list everything that your child eats/drinks in a typical day from the time he/she gets up in the morning until he/she goes to sleep. List the foods eaten and the approximate serving sizes of the foods. Please include all foods, condiments, beverages, and anything else consumed by the child.

Time Eaten	Serving Size	Food Eaten

Appendix F

Original Autism Treatment Evaluation Checklist (ATEC)

Unlike most of the scales used, the ATEC is not copyrighted.

It is available for use by any researcher free of charge at www.autism.com/ari.

ARI/Form
ATEC-1/11-99

Autism Treatment Evaluation Checklist (ATEC)

Bernard Rimland, Ph.D. and Stephen M. Edelson, Ph.D.
Autism Research Institute
4182 Adams Avenue, San Diego, CA 92116
fax: (619) 563-6840; www.autism.com/ari

Project/Purpose:				
Scores: I	II	III	IV	Total

This form is intended to measure the effects of treatment. Free scoring of this form is available on the Internet at: www.autism.com/atec

Name of Child _____ _____ ☐ Male Age _____
Last First ☐ Female Date of Birth _____
Form completed by: _____ Relationship: _____ Today's Date _____

Please circle the letters to indicate how true each phrase is:

I. Speech/Language/Communication: *[N] Not true [S] Somewhat true [V] Very true*

N S V 1. Knows own name
N S V 2. Responds to 'No' or 'Stop'
N S V 3. Can follow some commands
N S V 4. Can use one word at a time (No!, Eat, Water, etc.)
N S V 5. Can use 2 words at a time (Don't want, Go home)
N S V 6. Can use 3 words at a time (Want more milk)
N S V 7. Knows 10 or more words
N S V 8. Can use sentences with 4 or more words
N S V 9. Explains what he/she wants
N S V 10. Asks meaningful questions
N S V 11. Speech tends to be meaningful/ relevant
N S V 12. Often uses several successive sentences
N S V 13. Carries on fairly good conversation
N S V 14. Has normal ability to communicate for his/her age

II. Sociability: *[N] Not descriptive [S] Somewhat descriptive [V] Very descriptive*

N S V 1. Seems to be in a shell – you cannot reach him/her
N S V 2. Ignores other people
N S V 3. Pays little or no attention when addressed
N S V 4. Uncooperative and resistant
N S V 5. No eye contact
N S V 6. Prefers to be left alone
N S V 7. Shows no affection
N S V 8. Fails to greet parents
N S V 9. Avoids contact with others
N S V 10. Does not imitate
N S V 11. Dislikes being held/cuddled
N S V 12. Does not share or show
N S V 13. Does not wave 'bye bye'
N S V 14. Disagreeable/not compliant
N S V 15. Temper tantrums
N S V 16. Lacks friends/companions
N S V 17. Rarely smiles
N S V 18. Insensitive to other's feelings
N S V 19. Indifferent to being liked
N S V 20. Indifferent if parent(s) leave

III. Sensory/Cognitive Awareness: *[N] Not descriptive [S] Somewhat descriptive [V] Very descriptive*

N S V, 1. Responds to own name
N S V 2. Responds to praise
N S V 3. Looks at people and animals
N S V 4. Looks at pictures (and T.V.)
N S V 5. Does drawing, coloring, art
N S V 6. Plays with toys appropriately
N S V 7. Appropriate facial expression
N S V 8. Understands stories on T.V.
N S V 9. Understands explanations
N S V 10. Aware of environment
N S V 11. Aware of danger
N S V 12. Shows imagination
N S V 13. Initiates activities
N S V 14. Dresses self
N S V 15. Curious, interested
N S V 16. Venturesome - explores
N S V 17. "Tuned in" — Not spacey
N S V 18. Looks where others are looking

IV. Health/Physical/Behavior:

Use this code: [N] Not a Problem [MI] Minor Problem [MO] Moderate Problem [S] Serious Problem

N MI MO S 1. Bed-wetting
N MI MO S 2. Wets pants/diapers
N MI MO S 3. Soils pants/diapers
N MI MO S 4. Diarrhea
N MI MO S 5. Constipation
N MI MO S 6. Sleep problems
N MI MO S 7. Eats too much/too little
N MI MO S 8. Extremely limited diet
N MI MO S 9. Hyperactive
N MI MO S 10. Lethargic
N MI MO S 11. Hits or injures self
N MI MO S 12. Hits or injures others
N MI MO S 13. Destructive
N MI MO S 14. Sound-sensitive
N MI MO S 15. Anxious/fearful
N MI MO S 16. Unhappy/crying
N MI MO S 17. Seizures
N MI MO S 18. Obsessive speech
N MI MO S 19. Rigid routines
N MI MO S 20. Shouts or screams
N MI MO S 21. Demands sameness
N MI MO S 22. Often agitated
N MI MO S 23. Not sensitive to pain
N MI MO S 24. "Hooked" or fixated on certain objects/topics
N MI MO S 25. Repetitive movements (stimming, rocking, etc.)

Appendix G

Modified Autism Treatment Evaluation Checklist

For each of the statements below, please report the changes that you have seen in your child's behavior **in the past three months (non-diet group) or since beginning the diet (diet group).** Please circle the best response (I/NC/W/NA) for each of the behaviors listed below.

I The behavior has improved
NC The behavior has not changed
W The behavior has worsened
NA The behavior is not applicable to my child.

I NC W NA Does not know own name
I NC W NA Does not respond to 'No' or 'Stop'
I NC W NA Does not follow commands
I NC W NA Cannot use more than one word at a time
I NC W NA Does not know 10 or more words
I NC W NA Cannot use sentences with 4 or more words
I NC W NA Is not able to explain what he/she wants
I NC W NA Does not ask meaningful or relevant questions
I NC W NA Speech is not meaningful and relevant
I NC W NA Does not carry on fairly good conversation
I NC W NA Seems to be in a shell
I NC W NA Pays little or no attention when addressed
I NC W NA Uncooperative and resistant
I NC W NA No eye contact
I NC W NA Shows no affection
I NC W NA Fails to greet parents
I NC W NA Avoids contact with others
I NC W NA Does not imitate
I NC W NA Dislikes being held/cuddled
I NC W NA Does not share or show
I NC W NA Does not wave bye-bye
I NC W NA Disagreeable/not compliant
I NC W NA Temper tantrums
I NC W NA Rarely smiles
I NC W NA Lacks friends/companions
I NC W NA Insensitive to other's feelings
I NC W NA Indifferent if parents leave
I NC W NA Does not respond to own name
I NC W NA Does not respond to praise
I NC W NA Does not look at people or animals
I NC W NA Does not look at pictures or TV
I NC W NA Does not draw, color, or create art
I NC W NA Does not play with toys appropriately
I NC W NA Does not use appropriate facial expressions
I NC W NA Does not understand stories or explanations
I NC W NA Is not aware of the environment
I NC W NA Is not aware of danger
I NC W NA Does not show imagination
I NC W NA Unable to initiate activities
I NC W NA Unable to dress him/her self
I NC W NA Is not curious/interested in general
I NC W NA Is not venturesome
I NC W NA Is not tuned in/Is spacey
I NC W NA Does not look where others are looking
I NC W NA Wets/soils pants/diapers
I NC W NA Is unhappy/cries often
I NC W NA Has diarrhea/constipation/vomiting
I NC W NA Has sleep problems
I NC W NA Eating patterns are irregular
I NC W NA Diet does not include a variety of foods
I NC W NA Is hyperactive
I NC W NA Is lethargic
I NC W NA Hits/injures self
I NC W NA Hits/injures others
I NC W NA Is destructive
I NC W NA Is sound and/or light sensitive
I NC W NA Is anxious/fearful
I NC W NA Is unhappy/cries often
I NC W NA Has seizures
I NC W NA Has obsessive speech
I NC W NA Has rigid routines
I NC W NA Shouts/screams
I NC W NA Demands sameness
I NC W NA Is often agitated
I NC W NA Is not sensitive to pain
I NC W NA Is fixated on certain objects
I NC W NA Does repetitive movements (stimms, etc.)

Questions were derived from the Autism Treatment Evaluation Checklist. Authors: Bernard Rimland, Ph.D, and Stephen M. Edelson, Ph.D. from the Autism Research Institute. 4182 Adams Ave, San Diego, CA 92116.

Appendix H

Informed Consent Form

Consent to Participate in UW-Stout Approved Research

Title: Perceptions and knowledge of parents of children with autism regarding the use of gluten-free and casein-free diets as a form of alternative treatment.

Investigator:
Gwenda Washnieski
washnieskig@uwstout.edu
763-213-6027

Research Sponsor:
Carol Seaborn, Ph.D., R.D., C.D., C.F.C.S.
Home Economics Room 219
University of Wisconsin-Stout
Menomonie, WI 54751
715-232-2216
seabornc@uwstout.edu

Description:
This study aims to determine the knowledge and perceptions of parents of children with autism regarding the use of gluten-free and casein-free diet interventions as a form of alternative treatment. Through the use of a survey, a list of the common foods the child eats, and a behavior evaluation, the barriers that parents face when implementing the diets, the accuracy of implementation, and the knowledge and perceptions of the effect the diet has on the child's behavior will be addressed.

Risks and Benefits:
The risks associated with this study include loss of time for completion of the survey, common foods list, and evaluation. The survey and evaluation might cause minimal emotional distress due to focusing on problems your child may be experiencing. The benefit of participating in this study is that the information will help parents who want to use dietary interventions as an alternative form of treatment for children with autism in the future. The information collected will help practitioners provide adequate information and services to parents of children with autism.

Time Commitment:
The survey, common foods list, and behavior evaluation form will require no more than 30 minutes to complete.

Confidentiality:
Your name will not be included on any for the documents, and you cannot be identified by any of the information collected. This informed consent will not be kept with any of the other documents completed with this project. The researcher will be the only person with access to any identifying information. Once the study is complete, all forms will be shredded and disposed of properly.

Right to Withdraw:
Your participation in this study is entirely voluntary. You may choose not to participate without any adverse consequences to you. Should you choose to participate and later wish to withdraw

from the study, you may discontinue your participation at that time without incurring adverse consequences. However, we have no identifier or name to remove your data at a later date.

IRB Approval:

This study has been reviewed and approved by the University of Wisconsin-Stout's Institutional Review Board (IRB). The IRB has determined that this study meets the ethical obligations required by federal law and University policies. If you have questions or concerns regarding this study, please contact the Investigator or Advisor. If you have any questions, concerns, or reports regarding your rights as a research subject, please contact the IRB Administrator.

Investigator:
Gwenda Washnieski
763-213-6027
washnieskig@uwstout.edu

Advisor:
Carol Seaborn, Ph.D., R.D., C.D., C.F.C.S.
Home Economics Room 219
University of Wisconsin-Stout
Menomonie WI 54751
715-232-2216
seabornc@uwstout.edu

IRB Administrator:
Sue Foxwell, Director, Research Services
152 Vocational Rehabilitation Bldg.
UW-Stout
Menomonie, WI 54751
715-232-2477
foxwells@uwstout.edu

Statement of Consent:
By signing this consent form you agree to participate in the project entitled, perceptions and knowledge of parents of children with autism regarding the use of gluten-free and casein-free diets as a form of alternative treatment. Please choose the proper category in which you fit regarding this topic by answering the question below and filling in the proper box.

Question: Have you ever used the gluten-free diet OR the casein-free diet as a form of alternative treatment to help manage your child's Autism Spectrum Disorder?

Please fill in the appropriate box that corresponds to your answer to this question.

If your answer is NO please fill in the box below.

I **have never** used the gluten-free diet OR the casein-free diet as a form of alternative treatment to help manage my child's Autism Spectrum Disorder.
By providing your signature you are agreeing to participate in this study.

Name

Street Address

City State Zip Code

Signature Date

If your answer is YES, please fill in the box below.

I **have** used the gluten-free diet AND/OR the casein-free diet as a form of alternative treatment to help manage my child's Autism Spectrum Disorder.
By providing your signature you are agreeing to participate in this study.

Name

Street Address

City State Zip Code

Signature Date

Appendix I

Frequencies in Changes in Behavior of Children with ASD in the Past Three Months for the Non-diet Group and for the Duration for the Diet Treatment for the Diet Group

Frequencies in Changes in Behavior of Children with Autism in the Past Three Months for the Non-diet Group and for the Duration for the Diet Treatment for the Diet Group

[a]**Non-diet Group: N # of participants (% of non-diet group participants)**
Diet Group: D # of participants (% of diet group participants)

***Represent at least a 50% reported improvement in the specified behavior.**

Speech

Behavior	***Improved***	***No Change***	***Worsened***	***Not Applicable***
Does not know own name	N 1 (6)[a] D 4 (36)	N 2 (12) D 4 (36)	N - (0) D - (0)	N 14 (82) D 3 (27)
Does not respond to 'No' or 'Stop'*	N 1 (6) D 8 (73)	N 4(24) D 2 (18)	N 1 (6) D - (0)	N 11 (65) D 1 (9)
Does not follow commands*	N 1 (6) D 6 (55)	N 5 (29) D 3 (27)	N 3 (18) D - (0)	N 8 (47) D 2 (18)
Cannot use more than one word at a time	N 1 (6) D 5 (46)	N 2 (18) D 3 (27)	N - (0) D - (0)	N 14 (82) D 4 (36)
Does not know 10 or more words	N 2 (12) D 4 (36)	N 1 (6) D 3 (27)	N - (0) D - (0)	N 14 (82) D 4 (36)
Cannot use sentences with 4 or more words*	N 2 (12) D 6 (55)	N 2 (12) D 4 (36)	N - (0) D - (0)	N 13 (77) D 1 (9)
Is not able to explain what he/she wants*	N 2 (12) D 6 (55)	N 5 (29) D 4 (36)	N 1 (6) D - (0)	N 9 (53) D 1 (9)
Does not ask meaningful or relevant questions	N 1 (6) D 4 (36)	N 8 (47) D 5 (46)	N - (0) D - (0)	N 8 (47) D 2 (18)
Speech is not meaningful and relevant*	N 3 (18) D 7 (64)	N 5 (29) D 3 (27)	N - (0) D - (0)	N 9 (53) D 1 (9)
Does not carry on fairly good conversation	N 3 (18) D 4 (36)	N 5 (29) D 5 (46)	N - (0) D - (0)	N 8 (47) D 2 (18)

Sociability

Behavior	*Improved*	*No Change*	*Worsened*	*Not Applicable*
Seems to be in a shell*	N 2 (12) D 8 (73)	N 1 (6) D 1 (9)	N - (0) D - (0)	N 14 (82) D 2 (18)
Pays little or no attention when addressed*	N 2 (12) D 9 (82)	N 7 (41) D 2 (18)	N - (0) D - (0)	N 8 (47) D - (0)
Uncooperative and resistant	N 4 (24) D 5 (46)	N 8 (47) D 3 (27)	N 3 (18) D - (0)	N 2 (12) D 3 (27)
No Eye Contact	N 4 (24) D 5 (46)	N 5 (29) D 4 (36)	N - (0) D - (0)	N 8 (47) D 2 (18)
Shows no affection*	N 4 (24) D 6 (55)	N 2 (12) D 2 (18)	N - (0) D - (0)	N 11 (65) D 3 (27)
Fails to greet parents*	N 3 (18) D 7 (64)	N 3 (18) D 4 (36)	N - (0) D - (0)	N 11 (65) D - (0)
Avoids contact with others*	N 3 (18) D 8 (73)	N 4 (24) D 3 (27)	N - (0) D - (0)	N 10 (59) D - (0)
Does not imitate*	N 2 (12) D 7 (64)	N 3 (18) D 4 (36)	N - (0) D - (0)	N 12 (71) D - (0)
Dislikes being held/cuddled	N 3 (18) D 5 (46)	N 2 (12) D 3 (27)	N - (0) D - (0)	N 12 (71) D 3 (27)
Does not share or show	N 3 (18) D 3 (27)	N 3 (18) D 6 (55)	N - (0) D - (0)	N 11 (65) D 2 (18)
Does not wave bye-bye	N 1 (6) D 4 (36)	N 2 (12) D 7 (64)	N - (0) D - (0)	N 14 (82) D - (0)
Disagreeable/not compliant	N 3 (18) D 3 (27)	N 9 (53) D 3 (27)	N 3 (18) D 1 (9)	N 1 (6) D 3 (27)
Temper tantrums*	N 3 (18) D 6 (55)	N 7 (41) D 2 (18)	N 5 (29) D 1 (9)	N 2 (12) D 1 (9)
Rarely smiles*	N 1 (6) D 6 (55)	N 3 (18) D 2 (18)	N - (0) D - (0)	N 13 (77) D 2 (18)
Lacks friends/companions	N 2 (12) D 4 (36)	N 6 (35) D 5 (46)	N 2 (12) D - (0)	N 7 (41) D 1 (9)
Insensitive to other's feelings	N 3 (18) D 4 (36)	N 7 (41) D 3 (27)	N 2 (12) D - (0)	N 5 (29) D 3 (27)
Indifferent if parents leave	N 1 (6) D 4 (36)	N 7 (41) D 3 (27)	N 1 (6) D - (0)	N 8 (47) D 3 (27)

Sensory/Cognitive Awareness

Behavior	*Improved*	*No Change*	*Worsened*	*Not Applicable*
Does not respond to own name*	N 1 (6) D 8 (73)	N 3 (18) D 2 (18)	N - (0) D - (0)	N 13 (77) D 1 (9)
Does not respond to praise*	N 2 (12) D 6 (55)	N 4 (24) D 3 (27)	N - (0) D - (0)	N 11 (65) D 2 (18)
Does not look at people or animals	N 1 (6) D 5 (46)	N 2 (12) D 2 (18)	N - (0) D - (0)	N 14 (82) D 4 (36)
Does not look at pictures or TV	N 1 (6) D 4 (36)	N 1 (6) D 3 (27)	N - (0) D - (0)	N 15 (88) D 4 (36)
Does not draw, color, or create art*	N 1 (6) D 6 (55)	N 3 (18) D 3 (27)	N - (0) D - (0)	N 13 (77) D 2 (18)
Does not play with toys appropriately*	N 2 (12) D 9 (82)	N 4 (24) D 1 (9)	N - (0) D - (0)	N 11 (65) D 1 (9)
Does not use appropriate facial expressions	N 2 (12) D 5 (46)	N 6 (35) D 4 (36)	N - (0) D - (0)	N 9 (53) D 2 (18)
Does not understand stories or explanations*	N 1 (6) D 6 (55)	N 7 (41) D 4 (36)	N - (0) D - (0)	N 9 (53) D 1 (9)
Is not aware of the environment	N - (0) D 5 (46)	N 7 (41) D 4 (36)	N - (0) D - (0)	N 10 (59) D 2 (18)
Is not aware of danger	N 2 (12) D 4 (36)	N 7 (41) D 7 (64)	N - (0) D - (0)	N 8 (47) D - (0)
Does not show imagination	N 2 (12) D 3 (27)	N 4 (24) D 5 (46)	N - (0) D - (0)	N 11 (65) D 3 (27)
Unable to initiate activities*	N 4 (24) D 7 (64)	N 6 (35) D 2 (18)	N 1 (6) D - (0)	N 6 (35) D 2 (18)
Unable to dress him/her self	N 4 (24) D 4 (36)	N 4 (24) D 4 (36)	N 1 (6) D - (0)	N 8 (47) D 3 (27)
Is not curious/interested in general*	N 3 (18) D 8 (73)	N 4 (24) D 3 (27)	N - (0) D - (0)	N 10 (59) D - (0)
Is not venturesome*	N 3 (18) D 6 (55)	N 5 (29) D 4 (36)	N 1 (6) D - (0)	N 8 (47) D 1 (9)
Is not tuned in/is spacey*	N 3 (18) D 7 (64)	N 4 (24) D 3 (27)	N - (0) D - (0)	N 10 (59) D 1 (9)
Does not look where others are looking	N 1 (6) D 5 (46)	N 5 (29) D 4 (36)	N 1 (6) D - (0)	N 10 (29) D 2 (18)

Health/Physical/Behavior

Behavior	*Improved*	*No Change*	*Worsened*	*Not Applicable*
Wets/soils pants/diapers	N 2 (12) D 5 (46)	N 6 (35) D 5 (46)	N - (0) D - (0)	N 9 (53) D 1 (9)
Is unhappy/cries often	N 1 (6) D 5 (46)	N 2 (12) D 3 (27)	N 1 (6) D - (0)	N 13 (77) D 3 (27)
Has diarrhea/constipation/vomiting*	N 1 (6) D 7 (64)	N 4 (24) D 3 (27)	N 1 (6) D - (0)	N 11 (65) D 1 (9)
Has sleep problems	N 1 (6) D 5 (46)	N 9 (53) D 2 (18)	N 2 (12) D 1 (9)	N 5 (29) D 3 (27)
Eating patterns are irregular*	N - (0) D 6 (55)	N 5 (29) D 3 (27)	N 1 (6) D 1 (9)	N 11 (65) D 1 (9)
Diet does not include a variety of foods	N 3 (18) D 5 (46)	N 7 (41) D 4 (36)	N 2 (12) D - (0)	N 5 (29) D 2 (18)
Is hyperactive	N 1 (6) D 3 (27)	N 8 (47) D 3 (27)	N 3 (18) D - (0)	N 5 (29) D 5 (46)
Is lethargic	N 1 (6) D 2 (18)	N 4 (24) D 3 (27)	N - (0) D - (0)	N 12 (71) D 6 (55)
Hits/injures self	N 2 (12) D 2 (18)	N 6 (35) D 2 (18)	N 1 (6) D - (0)	N 8 (47) D 7 (64)
Hits/injures others	N 1 (6) D 2 (18)	N 6 (35) D 1 (9)	N 5 (29) D - (0)	N 4 (24) D 8 (73)
Is destructive	N 2 (12) D 2 (18)	N 5 (29) D 2 (18)	N 3 (18) D - (0)	N 7 (41) D 7 (64)
Is sound and/or light sensitive	N 1 (6) D 3 (27)	N 14 (82) D 5 (46)	N - (0) D - (0)	N 2 (12) D 3 (27)
Is anxious/fearful	N 7 (41) D 3 (27)	N 5 (29) D 5 (46)	N 2 (12) D - (0)	N 3 (18) D 3 (27)
Is unhappy/cries often	N 1 (6) D 4 (36)	N 4 (24) D 3 (27)	N - (0) D - (0)	N 12 (71) D 4 (36)
Has seizures	N - (0) D 1 (9)	N 1 (6) D 1 (9)	N - (0) D - (0)	N 16 (94) D 9 (82)
Has obsessive speech	N - (0) D 4 (36)	N 6 (35) D 3 (27)	N 2 (12) D - (0)	N 8 (47) D 4 (36)
Has rigid routines	N 2 (12) D 3 (27)	N 11 (65) D 4 (36)	N 1 (6) D - (0)	N 3 (18) D 4 (36)
Shouts/screams	N 1 (6) D 2 (18)	N 8 (47) D 3 (27)	N 5 (29) D - (0)	N 3 (18) D 6 (55)
Demands sameness	N 2 (12) D 1 (9)	N 14 (82) D 6 (55)	N 1 (6) D - (0)	N - (0) D 4 (36)
Is often agitated	N - (0) D 2 (18)	N 7 (41) D 4 (36)	N 3 (18) D - (0)	N 7 (41) D 5 (46)
Is not sensitive to pain	N 1 (6) D 3 (27)	N 7 (41) D 3 (27)	N - (0) D - (0)	N 9 (53) D 5 (46)
Is fixated on certain objects	N 3 (18) D 3 (27)	N 12 (71) D 7 (64)	N - (0) D - (0)	N 2 (12) D 1 (9)