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Alaoufi, Shatha H. *Investigation of Gluten-Free and Casein-Free Diets Among Autistic Children in the Kingdom of Saudi Arabia and the United States of America*

Abstract

Autism spectrum disorder (ASD) is a developmental disorder, which causes difficulties with communication, social skills, and a presence of stereotypic behavior. Gluten-free and casein-free (GFCF) diets received attention in the media and among parents. The purpose of this study was to obtain knowledge on the GFCF diet as it relates to ASD in a cultural comparison between the Kingdom of Saudi Arabia (KSA) and the United States of America (USA). Surveys and the Autism Treatment Evaluation Checklist (ATEC) were distributed to parents in organizations and centers for autism. In the KSA, 63% of the parents would like to learn more about the GFCF diet versus 30% in USA (Chi-square, $p = 0.000$). More parents in the KSA want to enhance their ability in label reading. Availability of GFCF products was a significant barrier in the KSA ($p = .014$). The ATEC mean scores indicated no significant differences between children in GFCF and non-GFCF groups in both countries. Further analysis revealed a difference in Speech/Language/Communication scores, indicating that children in the non-GFCF group performed better than the children on the GFCF diets. Parents of children with ASD should consider educational resources and consulting with registered dietitians.

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Chapter I: Introduction

Autism Spectrum Disorder (ASD) is a developmental disorder affecting many children around the world. This disorder causes difficulties with communication and social skills as well as a presence of stereotypic behavior and interest (American Psychiatric Association [APA], 2000). In the Kingdom of Saudi Arabia (KSA), although no formal statistics exist, ASD is a growing concern due to the increasing number of children diagnosed with the disorder (Alqahtani, 2012). In 2002, it was estimated that the number of children with ASD in the KSA reached 45,000 with many cases still undiagnosed (Yazbak, 2004). The number of children with ASD also has increased dramatically in other countries. According to Maston and Kozlowski (2011), between 1997 and 2010, Britain, Canada, France, Germany, Iceland, Iran, Israel, Norway, United Arab Emirates, and the United States of America (USA), all reported an increased number of children with ASD and related disorders.

Alqahtani (2012) explained that parents see their autistic children as physically normal when compared with other children. When their children are diagnosed with ASD, parents start to question themselves about the causes and treatments. Parents' beliefs toward ASD may affect their decision to choose a variety of interventions. In some cases, parents with autistic children may fail to provide proper treatments for their children due to a lack of knowledge or failure to seek professional help.

There is no particular treatment for ASD, but the use of complementary and alternative treatments such as dietary interventions are popular despite little evidence supporting that they work. Parents should seek professional assistance regarding diet as a treatment (Benson, 2016). Nonetheless, a treatment that has received recent attention in the media and among parents with autistic children is a gluten-free and casein-free (GFCF) diet (Le Couteur, Charlton, & Winburn,

2009). In a nonscientific design, The Interactive Autism Network (IAN) collected information from families about special diets. They proposed that 27% of parents with autistic children learn about and are encouraged to start the GFCF diet from doctors, 33% from the Internet, and 22% from friends (IAN, 2008).

Gluten, a nitrogenous substance, is present in wheat, rye, and barley. Casein is a protein present in dairy products such as milk, yogurt, and butter. The idea behind the GFCF diet was explained by Dohan (1966), who asserted that there is a connection between schizophrenia and celiac disease due to a genetic defect and noted that consuming specific food such as wheat, barely, and cereals are found to increase the prevalence of schizophrenia in several countries when compared to other countries who consumed less gluten-based food (Dohan, 1966).

Dohan's hypothesis was tested by Cade et al. (2000), who found that patients with schizophrenia and children with autism were sensitive to gluten and casein, and when they were placed on the GFCF diet for three months, they improved in social interaction, learning skills, hyperactivity, and repetitive behaviors.

Results of studies on ASD have been inconsistent regarding the efficacy of utilizing a GFCF diet. Johnson, Handen, Zimmer, Sacco, and Tuner (2011) discovered that after implementing GFCF diet for three months on 10 Norwegian autistic children, there were no significant differences on behavior, communication, and other variables compared to the control group. Seung, Rogalski, Shankar, and Elder (2007) concluded there is no statically significant difference on verbal and non-verbal communication after they implemented the GFCF diet on 13 children with ASD for six weeks compared to the control group. Yet, Knivsberg, Reichelt, Høien, and Nødland (2002) evaluated the use of GFCF diet on 10 autistic children for one year and asserted that children on the GFCF diet performed better than those on the non-diet group in

communication, cognitive, and motor skills. Additionally, Pennesi and Klein (2012) surveyed 387 parents with autistic children to test the effectiveness of GFCF diet. The online questionnaire included 90 items regarding food allergies, gastrointestinal (GI) symptoms, any food sensitivities, and the length of time using GFCF diet as well as the level of adherence during the implementation. The study posited that according to the parents' reports of their autistic children who have had one or more of these problems, improvements are present after the implementation of the diet compared to autistic children without these issues. However, according to Whiteley et al. (2012), there is "no universal theory that can explain the efficacy of utilizing GFCF diet on the behavior or the development of autistic children" (p. 5).

There is limited research about the GFCF diet in the KSA; however, the Alqahtani (2012) study about ASD in the KSA reported that when parents are asked about any use of alternative medical treatments, hyperbaric oxygen and dietary interventions are reported. The author noted that parents are afraid of the results of using GFCF diet and most discontinue the diet because it is either expensive or it is not beneficial.

Statement of the Problem

GFCF diets are considered one of the most common dietary interventions used among families with autistic children. Although the results of previous studies have been inconsistent regarding the efficacy of using this diet, some parents may chose it in conjunction with other treatments. Additionally, there also are some variables that have not been considered, thus the results of this study may give professionals in the KSA and the USA an overview of what should be taken into consideration when assessing parents who are trying to implement a GFCF diet for their autistic child. This study intended to discover the following:

1. To determine parents' awareness of the GFCF diet and willingness to learn more about it.
2. To determine how parents learned about the GFCF diet.
3. Investigate parents' reasons for starting the GFCF diet.
4. To determine parents' ability to follow the GFCF diet.
5. To determine challenges parents face during implementation of the GFCF diet.
6. To compare the effectiveness of the GFCF diet between children who implemented the diet and those who did not.

Purpose of the Study

The purpose of this study was to obtain knowledge about the GFCF diet as it relates to ASD in a cultural comparison between the KSA and the USA. The results provide professionals in the field an overview on some variables of the GFCF diet that need to be assessed before parents consider using it.

Assumptions

The sample population represented parents of ASD children from organizations of autistic children in the Western KSA and the Midwest section of the USA. It was assumed that the parents honestly answered the survey questions.

Definition of Terms

Terms might not be known to the readers are here with their abbreviation and definition.

Autism spectrum disorder (ASD). ASD is a developmental disorder, which causes impairments in social interaction and develops repetitive of certain behavior or activities. The condition might be different from one child to another based on the severity level (APA, 2013)

Autism treatments evaluation checklist (ATEC). The ATEC is not diagnostic, but it observes how well a child performs over time. Developed by Rimland and Edelson (1999), it is

one page containing four subsets: I Speech/Language Communication (14 items), II Sociability (20 items), III Sensory/Cognitive awareness (18 items), and IV Health/Physical/Behavior (25 items) (Autism Research Institute, 2016).

Casein-free diet (CFD). This diet involves the avoidance of consumption of products that contain casein such as milk, yogurt, and cheese (Hurwitz, 2013).

Celiac disease. Celiac disease causes damage in the intestinal wall. When celiac patients consume gluten, their bodies' immune system attacks the small intestine causing damage to the villi that impairs the absorption of important nutrients. Damaged villi cause malnutrition regardless of the amount and the quality of the food (National Digestive Diseases Information Clearinghouse, 2008).

Childhood autism rating scale (CARS). Developed by Schopler, Reichler, DeVellis, and Daly (1980), CARS is a scale of 15 items that can be used to identify the severity of ASD.

Complementary and alternative medicine (CAM). CAM is treatment that does not include pharmaceuticals (Hopf, Madren, & Santianni, 2016).

Gluten-free casein-free diet (GFCCF) group. The GFCCF group was a population within this study who adhered to either a gluten-free and/or casein-free diet.

Gluten-free casein-free diet (GFCCF) diet. The GFCCF diet is a diet free of gluten and casein food or beverages.

Gluten-free diet (GFD). The GFD diet involves avoiding all foods that contain gluten, which is a protein found in rye, wheat, and barley (Hurwitz, 2013).

Non- Gluten-free casein-free diet (non-GFCCF) group. The non-GFCCF group was a population within this study that was not on the gluten-free or/and casein-free diet.

Opioid-excess theory. The opioid-excess theory assumes that excessive opioid peptide is associated with autism symptoms and suggests that reducing the amount of opioid from reaching the brain can improve the symptoms (Panksepp, 1979).

Ritvo-Freeman real life rating scale (RLRS). RLRS is a scale used to measure 47 items of behaviors issues (Freeman, Ritvo, Yokora, & Ritvo, 1986).

Limitations

The sample survey for this study was smaller than anticipated. The sample size did not represent the entire population of parents with autistic children in the KSA and the USA. In addition, the heterogeneity of the children diagnosed with ASD in both countries did not allow an in-depth statistical analysis. For some analysis, the data from both countries were pooled together. Since this was a self-report study, there may have been an overestimate or underestimate for some answers by the participants.

The survey design took 15-20 minutes to complete, which was dependent on whether or not the parent participants were implementing a GFCF diet. Some parents did not respond to some questions in the survey or the items in the Autism Treatment Evaluation Checklist (ATEC). This may have been due to the time needed to finish the survey.

Methodology

This study was reviewed and approved by the Institutional Review Board (IRB) at the University of Wisconsin-Stout (see Appendix A). A survey questionnaire (see Appendix C) was developed and distributed to parents of autistic children via Qualtrics or hard copies in some ASD centers and organizations for ASD in the Western region of the KSA and in the Midwest section of the USA. Before beginning the survey, parents were given a consent form (see Appendix B), which addressed the provision that the participant gave their consent for providing

input on the survey. The survey collected information about two groups of parents within each country: the GFCF group, and the non-GFCF group. After completing the survey, parents were asked to fill out the ATEC (see Appendix D).

Chapter II: Literature Review

This chapter outlines a basic history of professional medical awareness and diagnosis of ASD as well as possible causes. Signs of ASD and possible treatments for it that are available to parents of autistic children are discussed. Common food selectivity issues among autistic children, recent studies related to the effects of the GFCF diet on autistic children, celiac disease, and specific diet studies related to ASD in the KSA are also explored.

History of ASD

Hewitt (2005) reported in her book that in 1943, Leo Kanner conducted a study on the behavior of a group of 11 unique children. Those 11 children appeared to be physically normal, but behaviorally, they demonstrated loneliness and withdrawal from society when compared with other children. Kanner found that these children exhibited several distinctive features, including difficulties developing relationships with parents or friends, poor eye contact, repetitive behavior and routines, language impairment and acquisition, and unusual interests.

Silverman and Weinfeld (2007) reported that almost concurrently with the Kanner study, the research of Hans Asperger in 1944 was conducted in Vienna, Austria with four children, boys ages 6-11, who manifested ASD-like characteristics. The Asperger study concluded that these boys, each of whom had come from families with one parent, the father, had the common characteristics of uncoordinated movement, engagement in special subjects, and an inability to form friendships. Asperger noted that a child named "Fritz" was able to overcome his symptoms. When he matured, he became a professor of astronomy and was able to solve some errors in the work of the British physicist Sir Isaac Newton. Asperger was so interested in these children, he opened a school for them near the end of World War II, but it was bombed and destroyed.

Unfortunately, the loss of the school delayed the transfer of his knowledge and research findings to the West. His work was translated into English 47 years later.

Silverman and Weinfeld (2007) categorized Asperger as a pioneer in his field, and reported that when Asperger and Kanner met, the two researchers found that their discoveries revealed different types of unusual characteristics between the groups of children they had studied. They discovered that they were dealing with children who had different sets of disabilities. Asperger's subjects exhibited more intelligence and had disabilities that were less severe than those of Kanner's subjects. Kanner described ASD as a type of schizophrenia and related the causes to a lack of affection between mothers and children and rejection—intentional or unintentional—of the children by their mothers. According to Silverman and Weinfeld, at that time, it was common for parents to feel guilty because they thought they were the reason for their child's disability.

In 1966, a study by Lotter in the United Kingdom's (UK) Middlesex County was aimed to detect children with ASD by sending surveys to teachers and other professionals who worked with children aged 8 through 10 years old. In the beginning, the author found 54 children who seemed to experience ASD disorder; however, within that group of children, he actually concluded that only 35 met the criteria for having ASD, which was based on ratings of 24 behavioral criteria. Lotter estimated the number of children with ASD was 4.5/10,000 cases in 1966 in the UK, and the prevalence of ASD was higher in boys over girls with a ratio of 2.6 to 1 (Lotter, 1966).

Prevalence of ASD

Fombonne (2009) examined 43 published studies since the year 2000, examining the pervasive development disorder (PDD-NOS), autistic disorder, and Asperger disorder in 17

countries. The estimated average number of children with PDD-NOS was 30/10,000, autistic disorder was 20.6/10,000, and Asperger disorder a rare 6/10,000. The disorder continues to be more prevalent among males than females. Also, according to the Diagnostic and Statistical Manual of Mental Disorders, “ASD occurs four times more frequently in boys than in girls” (APA, 2013, p.57).

In 2010, the estimated number of ASD, according to the Autism and Developmental Disabilities Monitoring (ADDM), in some areas involving 11 sites in the USA including: Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Utah, and Wisconsin in 2010, was 1 in 68 children (147 out of 10,000) (as cited in Baio, 2014).

In the KSA, the prevalence of ASD in 2002 was 42,500 children (Yazbak, 2004). According to Zeina, Al-Ayadhi, and Bashir (2014), no recent studies on the prevalence of ASD in the KSA have been done. Mostafa (2011) explained that the reason for the low prevalence of ASD cases in the Middle East is due to several reasons, which includes that some parents might fail to report their child’s symptoms because they are not aware about ASD. Also, it might be that eating habits of the Arab countries may play a protective role in the low prevalence of ASD. Moreover, the low numbers of psychiatrists who are specialists and experienced in childhood development is still a problem in the Arab countries compared to the Western countries.

Causes of ASD

The causes of ASD currently remain unknown, although the condition may be associated with environmental facts such as older parental age and genetic factors such as genetic heredity (APA, 2013, p.57). Folstein and Rutter (1977) were the first to suggest a genetic heredity of ASD. They conducted a study on 21 twins: 11 monozygotic (identical) and 10 dizygotic (not

identical) twins. The concordance rate for ASD in the monozygotic twins was 36%, while it was 0% in the dizygotic twins.

Some researchers have linked ASD to parents with notable technical aptitude or ability. Baron-Cohen (2012) postulated that such genes pass to a child, and especially so when both parents have a propensity toward scientific pursuits. He added an explanation for this association might be something called “like pairs with like,” which means in this case, when two individuals with similarly high technical ability marry, the possibility of them having a child with ASD increases due to genetics.

Marrow et al. (2008) recruited 104 families from the Middle East, Pakistan, and Turkey to investigate the cause of ASD. Among those families, 88 had cousin-marriages, leading to the conclusion that some patients are more likely to inherit a recessive allele from related parents, which leads to ASD in the child.

Parental age can be considered as a risk factor for ASD in children. A study conducted in Egypt by El-Baz, Ismael, and Nour Eldin (2011) investigated possible factors that caused ASD in 100 children with confirmed ASD diagnosis. The study indicated that 55% of children had moderate to severe retardation. Advanced mother’s age at birth (≥ 35 years) was present in 23% of ADS subjects, and advanced fathers’ age (≥ 35 year) was present in 91% of subjects.

Low income may result in receiving less medical treatment affecting the development of an ASD child compared with other children in higher income families that have access to more medical resources. This is according to a study by Athari, Ghaedi, and Mohd Kosnin (2013), mothers with low incomes are significantly correlated with depression and their children’s severity of ASD due to a limited ability to provide proper therapy and treatment for their child.

Thus, a child exposed to a mother in a low-income setting who experiences stress and depression maybe negatively affected regarding social and behavioral development.

Other studies have examined possible causation of the pathology of ASD symptoms. For example, in a study conducted by El-Ansary, Ben Bacha, and Al-Ayahdi (2011) on 26 ASD children and 26 normal children in the KSA, data indicated that saturated fatty acid was elevated with a reduction in the polyunsaturated fatty acids in the ASD children compared to the normal children. Also, the plasma fatty acids profiles of the ASD children were different than the normal children due to oxidative stress and defect in the mitochondrial function.

In another study, heavy metals and trace elements were found to play an important role in ASD. Al-Ayahdi (2005) conducted a study on 77 ASD children in the KSA. Nine heavy metals as well as 11 trace elements were measured by examining hair samples. Data indicated a significant elevation in toxic heavy metals with a concentration especially in lead, mercury, arsenic, antimony, and cadmium in the ASD children group compared to the normal children. Also, the hair sample examination indicated a significant decrease in the level of calcium, chromium, copper, iron, manganese, and cobalt compared to normal children.

Mostafa and Al-Ayahdi (2012) asserted that a deficiency in Vitamin D is associated with an autoimmune disorder in ASD children. The authors examined the association of the concentration of serum 25-hydroxy Vitamin D and anti-myelin associated glycoprotein (anti-MAG) autoantibodies on 50 ASD children, and 30 matched normal children. The results showed a significant decrease in the concentration of the serum 25-hydroxy Vitamin D in the ASD children group and significant elevation in the concentration of the serum anti-MAG autoantibodies in 70% of the ASD children associated with this deficiency. There was also a

significant positive correlation between anti-MAG autoantibodies and the child's severity of ASD using the Childhood Autism Rating Scale (CARS).

Signs of ASD

There are some signs of ASD that can be identified by parents, but parents alone cannot diagnose ASD in their child without the help of professionals (Silverman & Weinfeld, 2007). Some common behaviors that can be seen among ASD children depending on the severity of ASD are the lack of social communication and relationships. In such cases, children usually exhibit resistance to holding, like to play alone, make no eye contact, lack facial expressions, have difficulty speaking or speech regression, may repeat words, and do not respond to their names. In the behavioral patterns, some children may exhibit repetitive behavior or do some activities that may cause self-injury. Also, they tend to be more resistant to change, can be sensitive to light, and prefer food with specific texture (Mayo Clinic, 2016). Children with ASD often overreact to some noises, especially sudden noises like those of thunderstorms. They may have muscle weakness that can affect their motor development, which may contribute to difficulties in some activities that require balance and coordination (Silverman & Weinfeld, 2007).

Diagnosis of ASD

The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders-Text Revision (DSM-IV-TR) contained five pervasive development disorders (PDDs): autistic disorder, Asperger disorder, Rett's disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and childhood disintegrative disorder. PDD-NOS can be identified by impairment in the social and communication (verbal and non-verbal) skills. Also, children may repeat certain behaviors or activities. Children with PDD-NOS may have ASD symptoms in one

criterion and have moderate or no symptoms in different criteria, but the criteria are not met for a particular pervasive developmental disorder or schizophrenia because of the age of onset (APA, 2000).

Autistic disorder can be identified by a lack of verbal and non-verbal communication as well as restricted behaviors in activities. This disorder can vary from one child to another depending on age (APA, 2000).

Asperger syndrome can be recognized by a severe defect in social interaction and restricted repetitive behaviors. Unlike autism, children with Asperger syndrome do not demonstrate language impairment and cognitive delay in the first three years of age. They may exhibit a lack of eye contact, facial expression, or developing friendships (APA, 2000).

Rett's disorder manifests in girls only and is associated with mental retardation. This is recognized by decreased head circumference, impaired hand manipulation skills, and social interaction (APA, 2000).

Childhood disintegrative disorder is usually combined with mental retardation in which the child loses multiple skills such as motor skills, play, and bowel control before the age of 10 (APA, 2000).

In 2013, the APA published the DSM-5 to diagnose mental health disorders including ASD. In the new edition, autism, Asperger disorder, and PDD-NOS are all under the term ASD. The criteria of ASD involve impairment in a) social communication and interaction, and b) restricted, repetitive behavior. Each of these contains three severity levels (APA, 2013).

Culture and socioeconomic are factors that influence early diagnosis of ASD. For example, in the USA, African-Americans may be diagnosed at a later age than others (APA,

2013). Any postponement of the child's diagnosis can be harmful because they will not receive the proper help. Also, ASD can range from light, to moderate, to severe (Shore & Rastelli, 2006).

There are two stages to diagnose children with ASD: developmental screening and comprehensive diagnostic evaluation. Nonetheless, it is difficult to diagnose ASD because there is no medical test available such as blood samples (CDC, 2015). However, professionals can diagnose children by observing their behavior and development by the age of 18 months or less, but the final diagnosis for many children cannot be determined until the age of two (Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006). ASD symptoms are most noticeable in a child's first or second year in life (APA, 2000).

Treatment for ASD

Many types of treatments are available for children with ASD, and the earlier the intervention treatment the greater the chance a child will improve. According to the U.S. Center for Disease Control and Prevention (CDC) (2015), there are four categories for the treatment of ASD: behavioral and communication therapy, dietary therapy, medication, and complementary and alternative medicine. Complementary and alternative medicine (CAM) is considered to be one of the alternative treatments used among parents of autistic children (Hopf et al., 2016).

Shore and Rastelli (2006) asserted that ASD is a biomedical disorder that can be treated by modifying the diet or eliminating the body from environmental toxins. These authors recommended a special diet for children with ASD such as a GFCF diet with the help of a physician. Also, vitamin therapy such as B₁₂, Omega-3 supplementation, and chelation therapy that eliminate the body of metals are examples for biomedical treatment for ASD. Medication can be used to treat some symptoms associated with ASD such as depression, anger, obsessive-compulsive disorder (OCD), self-injury, and anxiety. The use of these medications can be

discontinued once the symptoms are relieved. The most common medications are Risperdal for psychosis, Ritalin for hyperactivity, Prozac and Zoloft for depression, and Xanax for anxiety.

Fatimah and Alharbi (2016) reported that many studies have been done to test the efficacy of the GFCF on children with ASD, but some results indicated there is no harm or benefits of using this diet and considered the GFCF diet as having poor outcomes. The use of vitamins and minerals such as Vitamin B₆, Vitamin B₁₂, Vitamin C, and Vitamin D, Zinc, and Omega-3 are common among autistic children, and it is suggested that these supplements are well tolerated with the diet. According to Mohiuddin and Ghaziuddin (2013), the most common medications used in several randomized control trails to treat common symptoms for autism are “antipsychotic, antidepressants, anticonvulsants, and central nerves system stimulant medications” (p.646).

Hopf et al. (2016) examined the frequency of using CAM treatments by surveying 194 parents of ASD children about their perception of the efficacy of CAM on ASD symptoms. The study indicated that 80% of parents use CAM for their ASD children. The percentage of each treatment is multivitamins (58.6%), GFCF diet (54.8%), and methyl B-12 injections (54.1%). The study concluded that CAM treatments seem to be effective in helping autistic children, but future controlled studies are needed to determine the efficacy and safety of these treatments. Also, Reissmann, Hauser, Makulska-Gertruda, Tomsa, and Lange (2014) reviewed 29 published studies until 2013 and found that GFCF diet is considered a CAM treatment of choice for families, and it is used by 25% of children with ASD.

Some researchers discourage the use of the GFCF diet as a treatment for ASD and argue that the diet has limited outcomes compared with other interventions. According to Hurwitz (2013), there is limited evidence to support the benefits of the GFCF diet for ASD children and

their families. The author stated that between 1999 and 2012, there were only five studies that met inclusion criteria. Three of these studies found no positive effects of GFCF diet and the other two studies found a positive effect after one year of using GFCF diet. In essence, Hurwitz's suggestion was to confine the GFCF diet to children with celiac disease or food allergy and encourage families to save their time and money (Hurwitz, 2013).

Selective Eating Problems and ASD

Several studies have examined the relation of selective eating to ASD. Postorino et al. (2015) conducted a study to examine the clinical and behavioral issues related to ASD children with selective eating. The study was done on 158 children with ASD. They were divided into two groups: one with food selectivity, and one without food selectivity. Data indicated that the food selectivity group showed significantly more ASD symptoms, behavioral issues, and parental tension compared with the other group. The study concluded that autistic children with selective eating could be problematic for parents and therapists.

Cermak, Curtin, and Bandini (2010) posited that it is important to understand the eating behavior of children with ASD because they might be sensitive to some foods: they tend to be picky eaters. As a result, some parents are concerned about the amount and variation of food that is eaten by their ASD children. According to the authors, the term *picky eater* refers to any person who refuses to try new foods. ASD children have a limited intake of food. Sensory factors in autistic children such as smell, color, texture, and temperature result in their selectivity toward food. Therefore, children with ASD and food selectivity may need to be referred to a dietitian to ensure nutritional requirements are being met.

Williams, Dalrymple, and Neal (2000) conducted a study on factors that influence selectivity of food in ASD children. It involved more than 100 parents. They learned that 67% of

parents reported their child to be a picky eater, and 73% reported their child has a good appetite for the food they selected. The study also found that the factors affecting food selectivity were texture (69%), appearance (58%), taste (45%), smell (36%), and temperature (22%). In addition, 69% of the children refused to try new foods. Although the ASD children in the study were found to be selective eaters, data did not necessarily indicate that they have a low appetite.

Raiten and Massaro (1986) conducted a study on 40 ASD children and 34 non-ASD children. Parents recorded a 7-day food record and completed a survey regarding nutrition and health status. The authors noted no significant differences between the groups in the food intake adequacy. However, autistic children crave specific food and have eating disorders more than non-ASD children.

Effectiveness of the GFCF Diet and Related Studies

As mentioned earlier, Panksepp (1979) proposed that there is a connection between ASD symptoms and excessive opiates. In a review by Reissmann et al. (2014), previous studies indicated possible connections between specific foods containing gluten or casein and autism. They asserted that during digestion, opioid peptides build up, and they pass from the intestinal wall to the bloodstream. The literature for supporting an “excessive opioid theory” came out around the year 2000; however, recent studies do not support the opioid theory, and have not been found to have an effect after using GFCF diet among autistic children. In another review by Mari-Bauset et al. (2014), other studies did not find an increase level of opioid peptides in the plasma or the urine of children with ASD.

Children with ASD will respond to the diet differently due to the heterogeneity within the spectrum. The type of effects of the GFCF diet that were observed in some recent studies included communication and language, attention, social interaction, self-injuries, repetitive

behaviors, and motor skills (Whiteley et al., 2012). It is impotent to note that children with ASD might present some gastrointestinal problems with the most common symptoms being constipation, diarrhea, abdominal pain, and inflammation of the GI tract. The prevalence of GI symptoms among those children ranged from 9% to 70%, and the use of GFCF diet is not supported by some literature as a main treatment for ASD (Buie et al., 2010).

In a review by Zhang, Mayton, and Wheeler (2013) reported that some studies from 1977 until 2010 regarding GFCF diet and ASD were lacking more details making this an obstacle for other researchers who want to repeat these studies. Also, half of the studies reported in this review regarding GFCF diet implementation have been in conjunction with other interventions, thus making the decision about the efficacy of the GFCF diet difficult. Therefore, future studies are needed to implement the GFCF diet without other intervention. The authors added that utilizing the GFCF diet might affect families in different areas such as time in preparing or purchasing, finding substitute foods, cost, nutritional deficiencies, and probably needing for extra supplements. Also, according to Zhang et al., the majority of the parents learn about the GFCF diet from the media, and this source is lacking details about the effectiveness of the diet, scientific evidence, and positive or negative outcomes.

Studies have been inconsistent about the effectiveness of utilizing GFCF diet among autistic children for the reasons previously explained, and there is a lack of evidence to verify that GFCF diet is effective in improving the symptoms of ASD. The following are studies that have indicated different improvement in some ASD symptoms and some of which were not statistically significant, and a few which were based on parental report.

Winburn et al. (2014) investigated parents and professional's attitudes regarding the GFCF diet for children with ASD. The study indicated that 83% of parents use dietary

interventions as a treatment for ASD, and 29% are currently implementing the GFCF diet. Parents reported an improvement after implementing the GFCF diet with a decrease in GI symptoms in 54% of children, increased attention in 42%, increased communication in 29%, increased-social interaction in 20%, and decreased repetitive behavior in 25%. The study concluded that further studies are needed to evaluate GFCF as a dietary treatment for ASD.

Elder et al. (2006) examined the efficacy of utilizing the GFCF diet on 15 ASD children. These children were placed on the GFCF diet for 12 weeks. The childhood autism rating scale (CARS) was used to provide information about the children's symptoms before and after the treatment, and urinary peptides levels were used to measure gluten and casein concentration. Although the results indicated no statistical significance was present, seven parents reported improvement in their child's language and a reduction in their hyperactivity and tantrum behaviors, thus they decided to continue their child on the GFCF diet. The authors also suggested further studies on GFCF diet.

Harris and Card (2012) in a pilot study examined the influence of the GFCF diet on autistic children and suggested an existing relationship between gastrointestinal symptoms and behavioral problems. The study found that 7 out of 13 children were on a GFCF diet. Parents reported their child's GI symptoms and behavior issues were improved after the implementation when compared to children who were not on the GFCF diet. Although parents reported improvements in the GI symptoms, the result was not statistically significant based on the gastrointestinal symptoms rating scale (GSRS) and the CARS score. The study used the adapted food frequency questionnaire (FFQ) to examine parent's compliance with the diet.

Hyman et al. (2016) conducted a study on 14 autistic children who implemented GFCF diet for six weeks. After that time period, the researchers examined a double blind, placebo-

controlled challenge study while the children were still on the diet for 12 weeks. Snacks were given that included gluten and casein, or a placebo. Data indicated that there was no significant impact of the GFCF diet behaviorally or physiologically on symptoms related to ASD.

According to the authors, the diet was safe with less serious and infrequent side effects (i.e., abdominal pain, diarrhea, and constipation), but children should be checked for nutritional deficiencies. The authors could not recommend the diet due to the small sample size of the study.

Celiac Disease

Celiac disease is a digestive problem in the small intestine (National Digestive Diseases Information Clearinghouse, 2008). Asperger was the first who found a connection between celiac disease and behavioral disorders (Asperger, 1961). However, there have been inconsistent studies about the connection between ASD and celiac disease.

According to Converse (2009), celiac disease is usually caused by sensitivity to gluten, and there is substantial disagreement on whether celiac disease is prevalent among children with ASD. Most children with ASD do not have celiac disease, but some are positive to anti-gliadin antibodies when compared with non-ASD children. In other words, ASD children are often sensitive to gluten and may have intestinal inflammation after eating food-containing gluten. Therefore, the damage in their intestinal tract may be relieved once they eliminate gluten from their diet, even if they do not have celiac disease. The meaning of this is “autistic children need a test for gluten sensitivity, not a test for celiac disease” (p.107).

Celiac disease occurs in normal children and adults as well as in ASD children. According to Saadah (2011), celiac disease is pervasive in developing countries and among some Arab populations whose primary source of food is wheat. The author conducted a study among children and adults in the Western region of the KSA to examine whether they had symptoms of

celiac disease. Those patients who were diagnosed with celiac disease were placed on strict gluten-free diets. One of the obstacles in this study was the virtual absence of gluten-free products in the KSA, a situation that had affected many children and adults.. In brief, Saadah concluded that compliance with a gluten-free diet is significantly important for children and adults with celiac disease, but the lack of gluten-free products remains problematic in the KSA.

Specific Diet Studies Related to ASD in the KSA

There is a lack of scientific research about the effects of specific diets on ASD children, especially the GFCF diet in the KSA. Two types of dietary intervention have been reported in the scientific literature for the KSA (Al-Ayadhi, 2006, and Al-Ayadhi & Elamin, 2013). They include camel milk and the GFCF diet. The study reported in this thesis adds to the literature base of the GFCF diet studies in the KSA.

Al-Ayadhi (2006) investigated gluten sensitivity in relation to GI symptoms in approximately 30 ASD children compared to a healthy control group. Both groups were negative to antibodies tests including anti-transglutamase antibody, anti-reticulin antibody, anti-endomysial antibody, and anti-gliadin antibody. No relation was determined to exist between gluten sensitivity as a cause of ASD or GI symptoms.

Al-Ayadhi and Elamin (2013) examined the effect of camel's milk on symptoms of ASD. In the KSA, camel milk is believed to alleviate some diseases such as food allergies, diabetes mellitus, ASD, and Hepatitis B because it is high in minerals and vitamins compared to cow's milk. The study was conducted on 60 ASD children by obtaining blood samples and measuring ASD severity by CARS. The study concluded that after two weeks on camel milk, there is a significant decrease in oxidative stress and an improvement in the ASD child's behavior compared to the control group.

Chapter III: Methodology

This study was reviewed and approved by University of Wisconsin-Stout's Institutional Review Board (IRB). It examined the effectiveness of the GFCF diet among ASD children in the KSA and the USA. The research design was an observational study that used survey questions specifically for parents of ASD children who implemented the GFCF diet and parents who did not. Parents' awareness and willingness to learn more about the diet, reasons for starting the diet, and possible factors during the implantation were examined in both countries. Children performance was measured using ATEC. This chapter describes the subject selections and description, instrumentation, and data analyses for this study, and limitations.

Subject Selections and Description

The population of this study consisted of parents with ASD children in the KSA and the USA. The sample consisted of 201 parents representing 201 ASD children in both countries.

KSA subjects. Before beginning the survey (see Appendix C), a consent form (see Appendix B) addressed the details of the project and explained the volunteer nature of participation. This researcher translated the consent form, survey questions, and the ATEC from English to Arabic for the parents in the KSA. Hard copies and online version of these materials were distributed to the parents of ASD children in the KSA.

Parents of ASD children in the KSA who participated in this study are associated with organizations for ASD children. They included Leading the Academy for Autism, Little Genius Club, Dohat Altefl, Jeddah Autism Center, Zat Center For Special Care, Ethar for Rehabilitation, Little Hands for Special Needs Care, and Batterjee Medical College (a center for autism research and treatment). Some organizations like Dohat Altefl requested to receive hard copies of the materials as well as online versions. The other organizations received an online consent form

(see Appendix B) and the URL to access the Qualtrics survey. Parents read the consent form and completed the survey at their home, not in a group. According to Qualtrics statistics, 146 parents (including 26 survey hard copies) participated in the survey. The exact number of participants from each organization was unknown. The 26 hard copy surveys were collected and sealed in an envelope.

USA subjects. Parents of ASD children in the USA were selected from organizations that support parents with autistic children. Friends of Autism, Asperger's Network Support, and Autism Society of Minnesota each gave this researcher permission to attend meetings and recruit parents. The number of participants from the American organizations was 55. The Autism Society of Minnesota and MRCI (formerly known as Mankato Rehabilitation Center Incorporate) requested an on-line consent form as well as access to the URL to distribute the survey. According to Qualtrics, there were no online participants from these organizations. This researcher entered the information provided by the parents from the hard copy surveys into Qualtrics (see Appendix C).

Instrumentation

Participants filled out a self-reported survey (see Appendix C), which was designed for parents who did or did not implement GFCE, CF, or GF diets. Parental information such as age, gender, level of education, and working status was obtained. If the parents were utilizing the GFCE, CF, or GF diet for their child, they were asked to continue answering additional questions. Also, information about the child such as age, gender, diagnosis, current treatment, and current diet was obtained.

The effectiveness of GFCE diet was measured by the ATEC, which contains 77 items regarding speech/ language/communication, sociability, sensory/ cognitive awareness, and

health/physical/ behavior of children with ASD (see Appendix D). All participants were asked to complete the ATEC. For each subset, the distribution of the scores is as follows:

- Speech/Language/Communication (14 items with 1 = not true, 2 = somewhat true, and 3 = very true). The higher the score, the better the child's performance.
- Sociability (20 items with 1= not descriptive, 2 = somewhat descriptive, and 3 = very descriptive). The lower the score, the better the child's performance.
- Sensory/Cognitive Awareness (18 subscales with 1 = not descriptive, 2 = somewhat descriptive, and 3 = very descriptive). The higher the score, the better the child's performance.
- Health/Physical/Behavior (25 items with 1= not a problem, 2 = minor problem, 3 = moderate problem, and 4 = serious problem) The lower the score, the better the child's performance.

Data Analysis

The Statistical Package for the Social Science (SPSS, Version 21, IBM) and Excel (Version 14.5.9, Microsoft 2011) were used for data analyses. Personnel in the Applied Research Center at UW-Stout provided assistance. Chi-square, *t*-test, and Spearman's correlation were specified in the results where used. For the ATEC scores, values are expressed as Mean \pm SD.

Limitations

The small sample size affected the interpretation of the data. The validity of translating the ATEC from English to Arabic had not been tested. The diagnosis of ASD was different between the groups in both countries. The time for completing the survey estimated as 15-20 minutes might have contributed to a large, drop out of some parents from taking the survey.

Also, the study population was from people who are members of organizations; therefore, they might have been exposed to specific literature and biases that might skew the data.

Chapter IV: Results

The purpose of this study was to gain knowledge on the GFCF diet as it relates to ASD in a cultural comparison between Saudi Arabia and the United States. Parents of ASD children were divided into two groups in each country based on whether or not they are implementing GFCF diets. The objectives of the study were:

1. To determine parent's awareness of the GFCF diet and willingness to learn more about it.
2. To determine how parents learned about the GFCF diet.
3. Investigate parent's reasons for starting the GFCF diet.
4. To determine parent's ability to follow the GFCF diet.
5. To determine challenges parents faced during implementation of the GFCF diet.
6. To compare the effectiveness of the GFCF diet between children who implemented the diet and those who did not.

Demographics

One hundred forty six parents from the KSA responded to the survey. Six surveys were excluded because the parents answered that they did not have a child with ASD, and 61 parents did not sufficiently complete enough of the survey to be included in the analysis. Thus, there were 79 surveys included for the KSA. In the USA, 55 parent's responded; however, five surveys were excluded because the child's age was older than the inclusion criteria (2-17 years), which left 50 surveys for analysis. The demographics of all participants and how they were grouped for analysis is summarized in Table 1.

Table 1

Characteristics of Participants in the USA and the KSA

Participants in both countries (parents and children)	United States <i>N</i> = 50			Saudi Arabia <i>N</i> = 79		
	GFCF group <i>N</i> = 11	Non-GFCF group <i>N</i> = 39	Total 50	GFCF group <i>N</i> = 27	Non-GFCF group <i>N</i> = 52	Total 79
Parents' age	46.6 ± 9.2	40.7 ± 7.8	41.9 ± 8.3	34.1 ± 3.3*	38.5 ± 6.6	36.6 ± 6.5*
Parents' gender	8 females 3 males	33 females 6 males	41 9	25 females 2 males	44 females 8 males	69 10
Parents' education						
Some, or graduated high school	0	7	7	2	14	16
A technical college degree or some college	5	11	16	0	3	3
Bachelor's, Master's, or PHD degree	6	21	27	24	35	59
Working status						
Not working	2	10	12	10	31	41*
Part time	1	9	10	7	8	15
Full time	8	10	18	10	15	25
Children's age	14.0 ± 2.9	10.56 ± 4.1	11.34 ± 4.1	6.5 ± 2.4*	7.4 ± 3.6*	7.6 ± 3.5*
Children's gender	9 boys 2 girls	34 boys 5 girls	43 7	19 boys 8 girls	45 boys 7 girls	64 15
Frequency of celiac disease	1	-		5	-	

Note. * $p \leq 0.05$ as compared to the USA, *t*-test, and Chi-square analyses

In the USA, 22% of parents with ASD children reported they are utilizing the GFCF diet. In the KSA, 34% parents are utilizing the GFCF diet (Chi-square, $p = .168$). The average age of

American parents completing the survey was higher than Saudi Arabian parents (t -test, $p = .000$). Most of the respondents were females (85.2%). No significant difference in education level was observed between the two countries (Chi square, $p > 0.05$), but there was significant difference in the working status. The majority of parents in the KSA are not employed compared to parents in USA (Chi-square, $p = 0.05$).

The mean age of children with ASD was statistically different between the KSA and USA (t -test, $p = 0.000$). In both countries, there were more boys (82.9%) with ASD than girls; however, in the USA, the ratio of boys to girls was approximately six, whereas in the KSA, it was approximately four. Two percent of the ASD children in the USA have celiac disease, whereas 6% of the ASD children in the KSA have been diagnosed with celiac disease. All children with celiac, regardless of country, are utilizing the GFCF diet. Levels of ASD diagnosis are provided in Tables 2 and 3 for each country. Medical practice in the two countries used different scales to indicate the type and severity of ASD.

Table 2

Child Diagnosis of ASD in the USA

					Moderate	High	Not
	PDD-NOS	Asperger	Autism	ASD	autism	functioning	answered
GFCF group	1	3	4	2	1	0	0
Non-GFCF group	7	6	14	5	4	1	2

Table 3

Child Diagnosis of ASD in the KSA

	Light autism	Moderate autism	Severe autism	Autism	Asperger	Not answered
GFCF group	8	6	3	5	0	5
Non-GFCF group	21	9	1	16	1	4

As shown in Figure 1, parents in the USA are utilizing medication significantly more in the non-GFCF diet group compared to the non-GFCF diet group in the KSA (Chi-square, $p = 0.048$). Parents in the KSA in the GFCF group are utilizing more supplements compared to the non-GFCF group (Chi-square, $p = 0.007$).

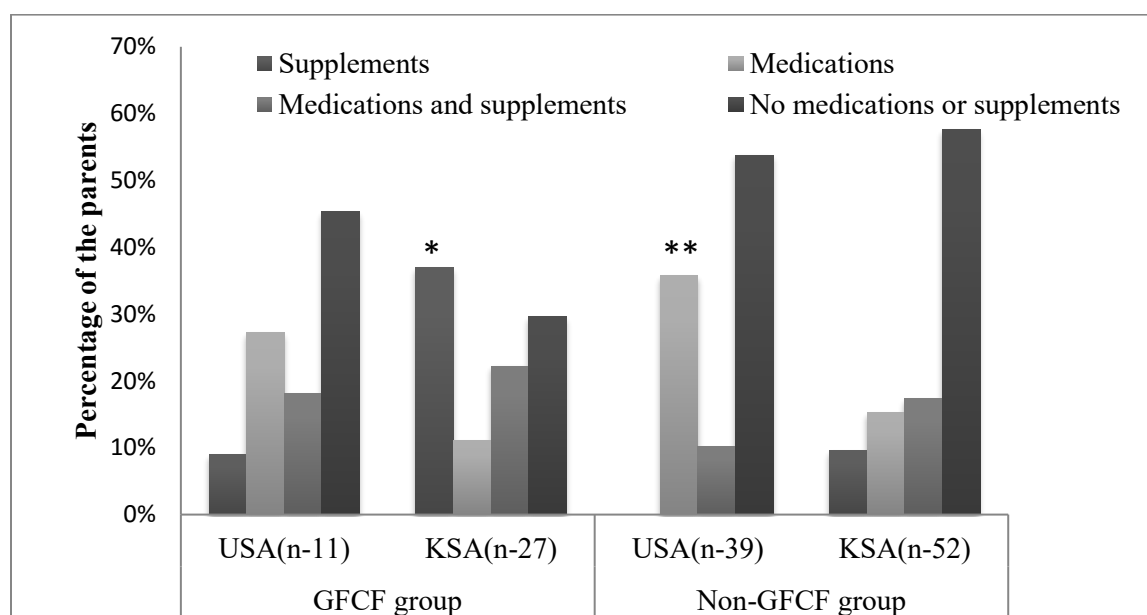


Figure 1. Reported use of supplements and medications.

Note. * $P \leq 0.05$ compared to KSA non-GFCF group, Chi-square analyses. ** $P \leq 0.05$ compared to KSA non-GFCF group, Chi-square analyses

The average duration on the diet in USA was 3.0 ± 2.3 years compared to 1.6 ± 1.5 years in the KSA (t -test, $p = 0.055$). Most ASD children in the both countries were on the diet for more than six months (see Figure 2).

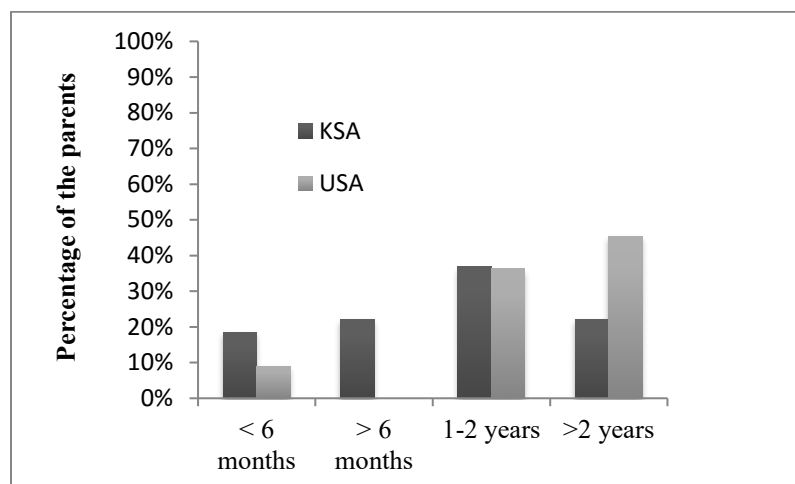


Figure 2. Duration of the diet for the ASD children in the GFCF group.

Parents' Awareness of the GFCF Diet and Their Willingness to Learn More About It

When asked if they had ever heard about the GFCF diet, 89% of the parents in the KSA answered “yes” versus 86% of the parents in the USA (Chi-square, $p = .884$). Although there was no difference between awareness of the diet in both countries, parents in the KSA more frequently expressed their willingness to learn more about the GFCF diet. In the KSA, 63% of the parents answered “yes” they would like to learn more information about GFCF diet compared to only 30% of the parents in the USA (Chi-square, $p = 0.000$). Table 4 summarizes the questions that were asked in relationship to this objective. For parents of children in the GFCF group in the KSA ($n = 27$, see Table 1). Of this group, twenty (74%) wanted to learn more about the diet compared to in the USA. This value is only 33% (5 out of 11) (data not shown).

Table 4

Awareness and Willingness to Use the GFCF Diet

	KSA		USA	
	Yes	No	Yes	No
Have you heard about the GFCF diet?	70	9	43	6
Would you like to learn more about the GFCF diet?	50	27	15	34

Sources for Learning About the GFCF Diet

In a multiple selection question, parents were asked how they learned about the GFCF diet. Nine choices were given: Internet, doctor, dietitian, friend, book, magazines, family, TV, and nurses. Chi-square analysis was used to compare the most significant. In both countries, the frequency of the parents who chose the Internet as a source was (70.3%) in the KSA compared to (54.5%) in the USA (Chi-square, $p = .351$). In the KSA, parents (62%) were significantly more likely to learn about GFCF diet from doctors compared to 18% of parents in the USA ($p = .012$). Also, parents (63.6%) in the USA were significantly more likely to learn about the diet from books compared to parents (22.2%) in the KSA ($p = .015$). The third primary source was magazines. In the USA, parents (27.7%) learned about the GFCF diet from magazine compared to no parents in the KSA ($p = .005$) as shown in Figure 3.

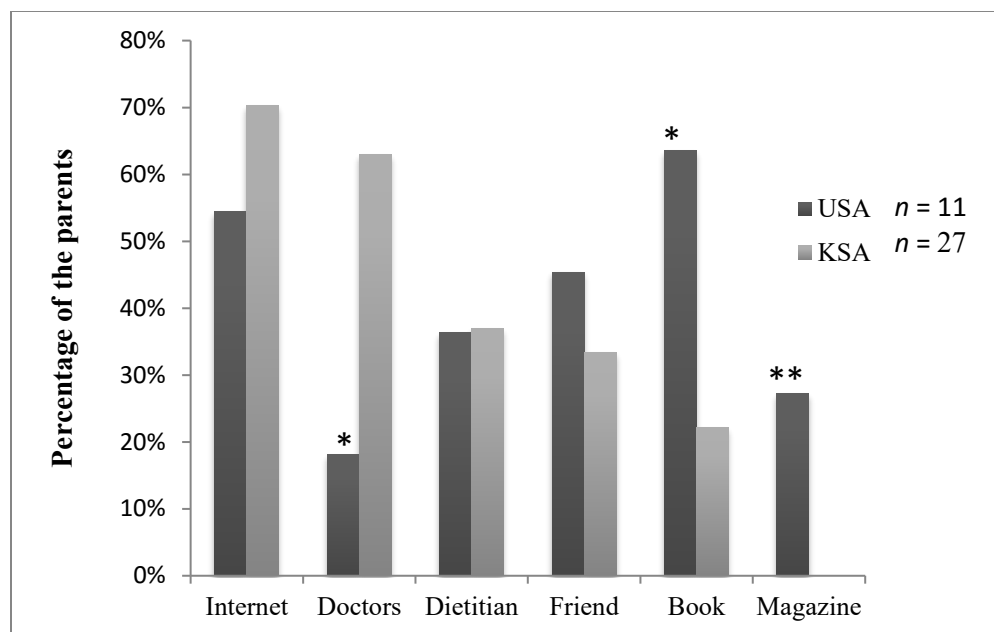


Figure 3. How parents learned about the GFCF diet.

Note. * $P \leq 0.05$ as compared to the KSA, Chi-square analyses. ** $P \leq 0.01$ as compared to the KSA, Chi-square analyses.

Parents' Reasons for Starting the GFCF Diet in the USA and KSA

There were different reasons why parents started the GFCF diet. Table 5 provides a sampling of some answers to this question.

Table 5

Quotes of Some Parents' Responses about Reasons for Starting the GFCF Diet

USA	KSA
“Yeast build-up in system, constipation and stomach aches, and experiment to see if sleep and behavior would improve.”	“Severe diarrhea after eating or drinking yogurt or dairy products.”
“She had mild stomach ache frequently, and night episode of vomiting and shaking.”	“Constipations and digestion problems.”
“For health issues (lactose intolerant and has a sensitive stomach.”	“I heard that the diet is beneficial.”
“For severe, explosive, and loose stools.”	“Doctor’s advice.”
“Once weaned to whole milk, began having intestinal discomfort then was diagnosed with autism.”	“For hyperactivity.”
“Brother had had success with the diet.”	“For experiment.”
	“Fingerprint test indicated that he is sensitive to gluten and casein.”
	“ Severe diarrhea.”
	“ Severe constipation.”
	“Sever constipation, stomach ache, smelly gas.”
	“Because I read that some children improved after implementing the diet.”

The most common theme for starting the diet was for gastrointestinal (GI) reasons. Eighty-one percent (9 of 11) of parents in the USA and 56% (15 of 27) of parents in the KSA reported that their children have GI symptoms.

Parents' Ability to Follow the GFCF Diet

Parents were asked if they have enough information about how to implement the diet (Table 6). The majority of parents in both countries answered “yes.” Also, parents were asked to check the options they thought were needed for more information to enhance their ability to follow the diet. More parents in the KSA want to enhance their ability in label reading compared to parents in the USA. No significant differences were found in the other variables. The majority of parents in the USA do not seek professional help. Only one out of every five parents in either country sought the advice of a dietitian. In the KSA, 30% of the parents saw a doctor regarding their diet (see Table 6).

Table 6

Factors That Impact Ability to Follow the GFCF Diet

	USA	KSA	Chi-square (p-value)
Having enough information	8 (73%)	18 (67%)	0.832
Information desired by the parents			
Label reading	5 (46%)	21 (78%)	.022*
How to prevent cross-contamination	3 (27%)	6 (22%)	.715
Hidden gluten ingredients in glue and play dough	2 (7%)	7 (26%)	.291
Professionals sought			
Dietitian	2 (18%)	6 (22%)	.805
Doctor	1 (9%)	8 (30%)	.238
Other	1 (9%)	2 (7%)	.866
None	7 (64%)	11 (41%)	.352

Note. Data is frequency (% of total).

Challenges Parents Faced During Implementation of the GFCF Diet

In the USA, cost and taste were the primary challenges. In KSA, the major challenges in order of importance were availability, cost, and taste. Since availability did not pose a top challenge in the USA, but it did in KSA, it was not surprising that the frequency for selecting this variable was significantly greater in the KSA. No other differences existed between the two countries as is shown in Table 7.

Table 7

Major Obstacles Parents Faced in Implementing the GFCF Diet

	USA	KSA	Chi-square (<i>p</i> -value)
Cost	8 (72%)	14 (52%)	.800
Availability of products in the market place	4 (36%)	20 (74%)	.014*
Difficulties at school	5 (45%)	8 (30%)	.981
Unsatisfactory taste	7 (64%)	11 (41%)	.990
Time	5 (45%)	3 (11%)	.155
Child had an increase in negative behaviors	0	1 (4%)	.424
Child's resistance	2 (18%)	5 (19%)	.569

Note. Data is frequency (% of total).

Additionally, obstacles may cause parents to discontinue the GFCF diet from time to time. In both countries, parents sometimes discontinue the diet (64% in the USA, 50% for KSA, chi-square, $p = .447$). In the USA, nearly half of the parents discontinued the diet once a week (3 of 7, 43%) with four parents providing alternative descriptions regarding the discontinuation: “Rare occasions, when GF is not available at restaurant,” “small cheat on major holidays,” “only

buy it on sale,” and “we have discontinued casein free diet for one year, but we have reintroduced this diet.” In the KSA, some parents discontinue the diet once a week (7 out of 13, or 54%), once a month (4 out of 13, or 31%), and one month out of the year (1 out of 13, or 8%).

In both countries, most parents did not notice side effects when there was a break in the diet, (64% for the USA, 63% for the KSA, Chi-square, $p = 0.919$). However, for parents in the USA who did notice side effects, the comments demonstrated the magnitude of the effects of going off the diet: “bad behaviors return almost immediately,” “... started throwing up, less ability to focus and concentrate,” “became moody,” and “child bloated when off the diet.” Similarly, for parents in the KSA who noticed side effects, the following information was provided: hyperactivity, less concentration, laughing without a reason, problems with eye movements, and becoming angry as well as sleeplessness.

Comparing the Effectiveness of the GFCE Diet

The effect of the diet was measured using the ATEC instrument, which categorized a child’s performance in Speech/Language/Communication, Sociability, Sensory/Cognitive Awareness, and Health/Physical/Behavior as indicated in Table 8. In a comparison between the countries only Speech/Language /Communication was different with the USA children performing better than the KSA children. In each of the two countries, there were no differences between children who implemented the diet and those who did not in any of the subscales. Further analyses combined the data from both countries to reveal a difference in Speech/Language/Communication scores, indicating that children in the non-GFCE group performed better than the children on the GFCE diet (see Table 8).

Table 8

ATEC Scores Between the GFCF Group and Non-GFCF Group in Both Countries

Category	KSA		USA		Combined	
	<i>N</i>	ATEC Scores Mean \pm <i>SD</i>	<i>N</i>	ATEC Scores Mean \pm <i>SD</i>	<i>N</i>	ATEC Scores Mean \pm <i>SD</i>
Speech/Language/Communication						
GFCF	21	23.95 \pm 8.00	11	36.09 \pm 8.75*	32	28.12 \pm 10.02**
Non-GFCF	28	26.78 \pm 7.59	39	36.43 \pm 5.98	67	32.40 \pm 8.1
Sociability						
GFCF	22	32.71 \pm 6.97	11	35.72 \pm 6.88	33	34.54 \pm 8.25
Non-GFCF	51	33.54 \pm 8.30	39	33.51 \pm 7.50	90	33.52 \pm 7.90
Sensory/Cognitive Awareness						
GFCF	22	34.04 \pm 9.16	11	39.09 \pm 9.76	33	40 \pm 8.3
Non-GFCF	47	36.87 \pm 8.81	39	43.33 \pm 6.04	86	47 \pm 12
Health/physical Behavior						
GFCF	21	44.80 \pm 11.73	11	50.36 \pm 12.83	32	47 \pm 12
Non-GFCF	47	42.08 \pm 10.37	39	43.92 \pm 11.22	86	43 \pm 11

Notes. * $p \leq 0.05$ as compared GFCF group in KSA, t-test analyses.

** $p \leq 0.05$ as compared to non-GFCF group, t-test analyses.

The primary reason parents started the GFCF diet in either country was for various issues related to the digestive tract. Because of this factor, the population of all subjects in the GFCF group was further divided into those with and without GI symptoms. Two measures from the ATEC scale were analyzed to determine if the children with GI symptoms at the start of the diet had improved outcomes when on the diet as compared to children who started the diet but did not have any reported GI symptoms. A frequency distribution is shown in Table 9. Chi square analysis indicated no significant differences.

Table 9

ATEC Rating of Diarrhea and Constipation for Children with Gastrointestinal Symptoms

ATEC Response	<i>N</i>	<i>MI</i>	<i>MO</i>	<i>S</i>
Diarrhea				
GI (<i>n</i> = 23)	(13) 56%	(3) 13%	(5) 21%	(2) 8%
Non-GI (<i>n</i> = 9)	(7) 77%	(1) 11%	(1) 11%	0
<i>p</i> -value	0.494	0.889	1.708	0.376
Constipation				
GI (<i>n</i> = 23)	(13) 56%	(1) 4%	(7) 30%	(2) 8%
Non-GI (<i>n</i> = 9)	(6) 66%	(2) 22%	(1) 11%	0
<i>p</i> -value	0.737	0.137	0.325	0.376

Notes. (N) Not a problem, (MI) Minor problem, (MO) Moderate problem, (S) Serious problem. Data is (frequency) % of total. Chi-square analyses.

Table 10 shows further analysis to investigate if the duration of being on the diet affected the data, and if the age of the child made a difference. Spearman's correlations were conducted between these variables in relation to the ATEC scores for diarrhea, constipation, or both. There were very "weak" correlations with both groups (GI and no GI symptoms) between the duration of GFCF diet for any of the ATEC scores. In addition, there were weak correlations in the children without GI symptoms with age and any of the ATEC scores.

Table 10

Correlations Between the Duration of the GFCF Diet or Age and Children's Scores for Diarrhea and Constipation

Correlations	GI symptoms	No GI symptoms
Duration of the GFCF diet and diarrhea scores	$r_s = .19$	$r_s = .07$
Duration of the GFCF diet and constipation scores	$r_s = .07$	$r_s = -0.1$
Duration of the GFCF diet and total scores for diarrhea and constipation	$r_s = .01$	$r_s = -0.16$
Age and diarrhea scores	$r_s = .08$	$r_s = .33$
Age and constipation scores	$r_s = .18$	$r_s = .33$
Age and total scores for diarrhea and constipation	$r_s = .15$	$r_s = .39$

Note. Spearman's correlation .00 - .19 "very weak" and .20 - .39 "weak."

Chapter V: Discussion

The purpose of this study was to gain knowledge of the GFCF diet as it relates to ASD in a cultural comparison between the KSA and the USA. Variables that might affect the implementation of the GFCF diet to help professionals in the field are discussed in this chapter.

This study discovered that most parents are aware of the GFCF diet in both countries, with few parents reporting that they do not know about the diet. However, many parents who are aware of the diet do not implement it. This might be because those children might not present GI problems or may exhibit selective eating problems that prevent the parents from trying or starting a new diet. According to Cermak et al. (2010), some ASD children tend to be picky eaters. Williams et al. (2000) reported that texture, appearance, taste, and smell are factors affecting food selectivity, and 69% of ASD children refuse to try new foods. The results of the current study also support this concept in that taste was a major obstacle in both countries. Other reasons for why ASD families do not implement the diet include some parents being aware of the reports in the literature that do not support the diet, or they distrust resources on the Internet.

When the parents were asked if they would like to learn more about the GFCF diet, some answered no. This was possibly because they tried the GFCF diet before and it did not work. This was one reason reported by some parents on the survey; however, there may be other reasons. According to Johnson et al. (2011), compliance with the GFCF diet is difficult, and some families may lose their interest over time, especially if they do not observe a change in their child's behavior. Parents in the KSA are significantly more willing to learn additional information about the GFCF diet compared to the parents in USA, with the majority of the parents (74%) being from the GFCF diet group. Therefore, nutritional education about the GFCF diet is needed in the KSA.

Parents' Source of Learning About the GFCF Diet

When parents were asked how they learned about the GFCF diet, the majority in both countries learned about the diet from the Internet. Green (2007) reported that parents receive their information about particular treatment from the Internet; however, it is unclear whether or not the parents have the ability to judge the validity of the information based on scientific evidence. Additionally, parents might depend on the testimony of others, which has been posted to websites.

The primary source for parent information about the GFCF diet in the USA comes from books. This is not surprising, as there has been an increase in the number of self-help books on this topic according to Green (2007). Some information in these books may not be valid since most books are not peer-reviewed. However, it is encouraging that parents are seeking information that is available.

Parents in the KSA significantly learn about the diet more from doctors compared to parents in the USA, thus it is important to know if doctors have enough information to provide the parents with facts about the GFCF diet, or if they do referrals of parents to see a registered dietitian. For example, in the KSA, there is a deficiency in nutritional knowledge among physicians. A study conducted by Al-Numair (2004) on 105 physicians in the KSA discovered that 75% describe their nutritional knowledge as poor in several topics. Also, a study conducted by Vetter, Herring, Sood, Shah, and Kalet (2008) on 114 physicians found that 86% agree that they do not have enough nutritional information to provide their patients. Other thing to note, according to Green (2007), is that some parents think that professionals only recommend the approved treatment; therefore, they think this particular treatment is effective for their autistic

child. This study noted that the majority of parents in the KSA learn about the diet from doctors, and they may think that doctors recommend this diet because it is proven to help.

Parents' Ability to Follow the GFCF Diet

The majority of the parents in this study answered that they have enough information about how to implement the GFCF diet; however, it is unclear how parents are actually implementing the diet. This study design did not utilize a food frequency questionnaire (FFQ) to measure the food consumption of the child. Harris and Card (2012), who adapted their own FFQ, asserted that children on the diet significantly consume less food containing gluten and casein compared to the non-GFCF diet group.

Parents in both the KSA and the USA indicated that label-reading skills would enhance their ability to recognize all forms of gluten and casein in products. Nonetheless, it is important to note that food labeling might still pose a problem in the KSA. According to Washi (2001), some food labeling does not meet the international standard due to missing nutritional information, health claims, and warnings. The author also stressed the importance of nutrition education among people and encourages manufacturers to improve food labels in the KSA. This suggests that receiving help and education from a registered dietitian would help overcome the paucity of information on food labels in the KSA.

According to Niewinski (2008), patients who are on the gluten free diet will benefit from meeting with a registered dietitian to be educated about label reading and how to shop for food. The role of the registered dietitian is important: they can make a difference when advising patients. In the current study, less than one fourth of the parents using the GFCF diet consulted with a dietitian, and most parents did not seek professional help.

Ireton-Jones, Garritson, and Kitchens (1995) conducted a study on two groups of patients with cancer. The first group received help from a registered dietitian, which included assessment and counseling. The second group had no intervention. The parameters in the first group improved by 53%, and the study emphasized the importance of a registered dietitian in helping patients with nutritional issues.

This study found that one fourth of all parents in both countries would like more information about cross-contamination. Education about this topic is essential for parents who are implementing GFCF diet for their children to ensure better adherence to the diet. Cross-contamination education includes how to store, cook, and prepare food (Niewinski, 2008).

Challenges

The majority of the parents in the KSA (74%) agreed that the availability of GFCF products in the market place was an obstacle, which was statistically significant compared to parents in the USA, which was consistent with the conclusion in the study by Saadah (2011). The author reported that one obstacle in his study on adults and children with celiac disease in the KSA were the absence of the gluten-free products. He concluded that this could affect the compliance of the gluten-free diet.

In this study, half of the ASD children in the KSA discontinued the diet, or most of them interrupted their use of it on a weekly basis. This might be explained by the lack of the availability of gluten free products in the market place. Parents in both countries indicated cost as an issue with no significant difference between the countries. This may reflect the difficulty of the parents in the USA (73%) who chose cost as an obstacle. One American parent reported only buying GF products if they are on sale, which is a factor in adhering to the diet. Stevens and Rashid (2008) reported in their study that gluten free products are 242% more expensive than

regular products on average. Cost can be a burden for a family over time and may limit adherence to the diet. The results of this study concurred with the conclusion by Villafuerte-Galvez et al. (2015), which found that patients with celiac disease report that cost is an issue for compliance with gluten-free diet.

The majority of parents noticed no side effects after breaks in the diet in both the KSA and the USA. This finding was consistent with the study of Johnson et al. (2011), which found decreased adherence of the GFCF diet, but no serious side effects (diarrhea, constipation, vomiting, and appetite loss) after implementing the GFCF diet for three months on 22 children. There was no direct comparison with the Hyman et al. (2016) study, which concluded there are no significant differences on autism symptoms after reintroducing gluten or casein during snack after 12 weeks of implementation, and no serious side effects were reported.

Effectiveness of the Diet

To test the effectiveness of the GFCF diet, the ATEC was used. It is a valid method that is free of charge to be used by parents or professionals (Geier, Kern, & Geier 2013). The ATEC scores indicated no significant differences between the GFCF diet group and non-diet group in each of the subscales in the KSA and the USA. This was consistent with the study of Hyman et al. (2016), which found no statistical differences after implementing the GFCF diet on ASD children behaviorally, physiologically, or autism related symptoms using the Ritvo-Freeman Real Life Rating Scale (RLRS).

Elder et al. (2006) found no statistical differences after implementing the diet for 12 weeks using the CARS to rate the scores of the child's behavior before and after GFCF diet compared to the control group. Seung et al. (2007) also concluded there is no statically

significant difference on verbal communication after that study involved implementing the GFCF diet on 13 children with ASD for six weeks compared to the control group. However, Elder et al. (2006) indicated that the small sample size might affect the result of the study, which led to non-significant results although some parents reported some improvements. In addition, the heterogeneity of the children's age, severity of autism, and cognitive ability may have confounded the analysis.

Although this study did not involve implementing the diet, this researcher did face similar issues with the small sample size that prevented the ability to run statistical tests based on the severity of autism, age, or the duration of the diet. Also, in the Elder study, seven parents wanted to continue on GFCF diet because they noticed improvement in language, reduction in hyperactivity, and reduction in tantrum. In this study, some parents in the KSA and the USA reported keeping their children on the diet for a long time. This fact cannot be ignored because the parents might see improvements and know their child's symptoms better, and once they break the diet, they might see side effects immediately as reported by some parents.

Previous studies have reported that children with ASD are at a higher rate of having GI symptoms compared to normal children (Buie et al., 2010). This study attempted to narrow down the questions listed in the ATEC to investigate the severity of GI symptoms after implementing the diet, especially constipation and diarrhea. Some parents reported that they started the diet for their children due to GI problems and some for other reasons as mentioned in chapter 4. Thus, a comparison was made between the children with GI and no GI symptoms regardless of the small sample size. Although nearly half of the ASD children on the GFCF diet group have problems with diarrhea and constipation, no correlations were found between the duration of the diet and the total scores of diarrhea and constipation in the GFCF diet group. Klaveness, Bigam, and

Reichelt (2013) conducted a study to test how fast gluten and casein can make a change in the children with ASD after implementing the diet for two weeks. The results indicated no significant difference in the child's ATEC scores before and after implementing the GFCF diet. They determined that using the diet for a short time is a waste of time: it should be used for at least three to six months.

On the other hand, Johnson et al. (2011) found no significant differences on behavior, communication, and other variables in their study on 10 Norwegian autistic children after implementing GFCF diet for three month compared to the control group. The authors concluded that although no clinical improvements were observed, there also were not any significant side effects related to diarrhea and constipation and other GI symptoms. The current study did not investigate why some children in the GFCF diet group have problems with diarrhea and constipation and others do not, regardless of the time they have been on the diet or their age.

The mean age of the children on the GFCF diet in this study was 6.5 years in the KSA compared to the mean age in the USA, which was 14 years old. The study by Pedersen, Parlar, Kvist, Whiteley, and Shattock (2014) found that children at a younger age, 7-9 years, do better on the diet than children who are at an older age. However, in this study, the older children from the USA performed better in Speech/language/ Communication than the younger children in the KSA. This might be explained due to speech developing later than other characteristics in ASD.

When the ATEC scores of both countries were pooled together, data revealed a difference in Speech/Language/Communication. This indicated that children in the non-GFCF group performed better than the children in the GFCF diet, which was inconsistent from the study of Winburn et al. (2014), who found "significant improvement" in communication in 29% of those utilizing the GFCF diet. The result in this study might be skewed because the sample size of the

non-GFCF diet group was much larger than the GFCF diet group. It is possible that GFCF diet can be an effective treatment in conjunction with supplements according to Fatimah and Alharbi (2016). Supplements are beneficial and can be recommended as adjunctive treatment for children with ASD, but each parent in this study reported different supplements, medications, and special diets beside the GFCF diet and behavioral treatments with their child, which may have been factors affecting the GFCF diet either positively or negatively.

Conclusion

There were factors discovered during this study that may have affected the results. Parents are aware about the GFCF diet, but some are significantly more willing to learn about it in the KSA, especially among GFCF diet group, than in the USA. The majority of parents in both countries learn about the diet from the Internet. Some parents in the KSA receive their information about GFCF diet predominantly from doctors compared to parents in the USA, who learn about the diet from books and magazines. Moreover, parents in both countries desire more information about the GFCF diet in label reading, but substantially more in the KSA. This is followed by information pertaining to cross-contamination in both countries. Additionally, the majority of parents in both countries do not see registered dietitians to assist them with the diet.

The obstacles that the parents face are availability of GFCF products in the market place, especially in the KSA. This is followed by cost in both countries. Although some parents are utilizing the GFCF diet for their ASD children, this study did not find significant differences in each subscale of the ATEC scores among children with ASD in either country. Also, no correlations are found between the age of the children, duration of the diet, and the scores of diarrhea and constipation among the subgroup of children specifically with GI symptoms.

Based on the data in this study, there is a need for nutritional education for parents in the KSA and the USA before starting the GFCF diet. This will enable parents to become aware of possible issues and risks with the diet that may face them in the future. This study is consistent with other studies that reached the conclusion about the importance of dietitians in the education process. Stevens and Rashid (2008) suggested that parents may benefit from meeting with registered dietitians before starting GFCF diet to educate and provide them with guidance on how to read food labeling or prevent cross-contamination and to ensure that the ASD child is meeting all the nutritional requirement for growth. It also will help prepare parents about the financial burden and making recommendation for substitute foods that are either less expensive or do not contain gluten.

Recommendations

This study cannot be generalized to all ASD children in the KSA or the USA due to the small sample size. Future research is needed on a more homogenous group and larger sample size. This researcher translated the ATEC from English to Arabic. The Arabic version has not been tested for validity. Knowing the baseline of the children before and after implementing the diet would contribute to a better understanding on how well an individual child responds to the GFCF diet. In addition, this study may be strengthened by the use of a food frequency questionnaire (FFQ) or other methods to measure parents' compliance with the diet.

It is important to continue investigating parents who are utilizing a restricted diet because parents' preference to a treatment is based on their belief and priorities to help their children improve and integrate with other children (Bowker, D'Angelo, Hicks, & Wells, 2011). The results of this study indicated no significant differences in both countries between ASD children on the GFCF diet and those who did not participate in the diet. In a comparison between the

countries, only speech/language/communication was different, and that may be related to the subjects in the USA being older.

Thus, it is not possible to interpret any cultural differences between the KSA and the USA regarding the efficacy of implementing the GFCF diet with ASD children. Future studies are needed to determine if there are some cultural factors that may affect the diet.

References

- Al-Ayahdi, L. Y. (2005). Heavy metals and trace elements in hair of autistic children in central Saudi Arabia. *Neurosciences (Riyadh)*, 10(3).
- Al-Ayahdi, L. Y. (2006). Gluten sensitivity in autistic children in central Saudi Arabia. *Neurosciences (Riyadh)*, 11(1), 11-14.
- Al-Ayahdi, L. Y., & Elamin, N. (2013). Camel milk as a potential therapy as an antioxidant in autism spectrum disorder (ASD), *Evidence-Based Complementary and Alternative Medicine*, 2013 (602834). doi:10.1155/2013/602834
- Al-Numair, K. (2004). Nutrition knowledge of primary care physicians in Saudi Arabia. *Pakistan Journal of Nutrition*, 3(6), 344-347.
- Alqahtani, M. (2012). Understanding autism Saudi Arabia: A qualitative analysis of the community and cultural context. *Journal of Pediatric Neurology*, 10(1), 15-22. doi:10.3233/JPN-2012-0527
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Arlington, VA: Author.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Asperger, H. (1961). Psychopathology of children with coeliac disease. *Annales Paediatrici*, 197, 346-351.
- Athari, P., Ghaedi, L., & Mohd Kosnin, A. (2013). Mothers' depression and stress: Severity of autism among children and family income. *International Journal of Psychological Research*, 6(2), 98-106.

- Autism Research Institute. (2016). *Autism treatment evaluation checklist*. Retrieved from http://www.autism.com/ind_atec
- Baio, J. (2014). Prevalence of autism spectrum disorder among children aged 8 years- autism and developmental disabilities monitoring network, 11 sites, Unites States, 2010. *MMWR Surveillance Summaries*, 63(2), 1-22.
- Baron-Cohen, S. (2012). Autism and technical mind. *Scientific American*, 307(5), 72-76.
- Benson, S. (2016). What is autism spectrum disorder? *American Psychiatric Association*. Retrieved from <http://www.psychiatry.org/patients-families/autism/what-is-autism-spectrum-disorder>
- Bowker, A., D'Angelo, N., Hicks, R., & Wells, K. (2011). Treatments for autism: Parental choices and perceptions of change. *Journal of Autism & Developmental Disorders*, 41(10), 1373-1383.
- Buie, T., Campbell, D. B., Fuchs, G. J., Furuta, G. T., Levy, J., de Water, J. V., & ... Lewis, J. D. (2010). Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with AS's: A consensus report. *Pediatrics*, 125, S1-S18. doi:10.1542/peds.2009-1878C
- Cade, R., Privette, H., Fregly, M., Rowland, N., Sun, A., Zele, V. ... & Edelstein, C. (2000). Autism and schizophrenia: Intestinal disorders. *Nutritional Neuroscience*, 3, 57-72.
- Center for Disease Control. (2015). *Autism spectrum disorder (ASD)*. Retrieved from <http://www.cdc.gov/ncbddd/autism/treatment.html>
- Cermak, S. A. Curtin, C., & Bandini, L. G. (2010). Food selectivity and sensory sensitivity in children with autism spectrum disorders. *Journal of the American Dietetic Association*, 110(2), 238-284. doi:10.1016/j.jada.2009.10.032

- Converse, J. (2009). *Eating right: Special needs kids*. New York, NY: Perigee.
- Dohan, F. C. (1966). Cereals and schizophrenia data and hypothesis. *Acta Psychiatrica Scandinavica*, 42(2), 125-152.
- El-Ansary, A., Ben Bacha, A., & Al-Ayahdi, L. (2011). Plasma fatty acids as diagnostic markers in autistic patients from Saudi Arabia. *Lipids in Health and Disease*, 10(62).
doi:10.1186/1476-511X-10-62
- El-Baz, F., Ismael, N. A., & Nour Eldin S. (2011). Risk factor for autism: An Egyptian study. *Egyptian Journal of Medical Human Genetics*. doi:10.1016/j.ejmhg.2011.02.011
- Elder, J., Shankar, M., Shuster, J., Theriaque, D., Burns, S., & Sherrill, L. (2006). The gluten-free, casein-free diet in autism: Results of a preliminary double blind clinical trial. *Journal of Autism & Developmental Disorders*, 36(3), 413-420.
- Fatimah, S. B., & Alharbi, M. S. (2016). A review study on dietary implications in autism. *European Journal of Pharmaceutical and Medical Research*, 3(1), 353-359.
- Folstein, S., & Rutter, M. (1977). Infantile autism: A genetic study of 21 twin pairs. *Journal of Child Psychology and Psychiatry*, 36(4), 297-321.
- Fombonne, E. (2009). Epidemiology of pervasive development disorder. *Pediatric Research*, 65(6), 591-599. doi:10.1203/PDR.0b013e31819e7203
- Freeman, B. J., Ritvo, E. R., Yokora, A., & Ritvo, A. (1986). A scale for rating symptoms of patients with the syndrome of autism in real life settings. *Journal of the American Academy of Child Psychiatry*, 25(6), 130-136.

- Geier, D. A., Kern, J. K., & Geier, M. R. (2013). A comparison of the autism treatment evaluation checklist (ATEC) and the childhood autism rating scale (CARS) for the quantitative evaluation of autism. *Journal of Mental Health Research in Intellectual Disabilities*, 6(4), 255-267. Retrieved from <http://doi.org/10.1080/19315864.2012.681340>
- Green, V. A. (2007). Parental experience with treatments for autism. *Journal of Developmental & Physical Disabilities*, 19(2), 91-102.
- Harris, C., & Card, B. (2012). A pilot study to evaluate nutritional influences on gastrointestinal symptoms and behavior patterns in children with autism spectrum disorder. *Complementary Therapies in Medicine*, 20(6), 437-440.
- Hewitt, S. (2005). *Specialist support approaches to autism spectrum disorder students in mainstream settings*. Philadelphia, PA: Jessica Kingsley.
- Hopf, K. P., Modren, E., & Santianni, K. A. (2016). Use and perceived effectiveness of complementary and alternative medicine to treat and manage the symptoms of autism in children: A survey of parents in a community population. *Journal of Complementary Medicine*, 22(1), 25-33.
- Hurwitz, S. (2013). The gluten free, casein free diet and autism. Limited return on family investment. *Journal of Early Intervention*, 35(1), 4-17.
- Hyman, S., Stewart, P., Foley, J., Cain, U., Peck, R., Morris, D., & Smith, T. (2016). The gluten-free/casein-free diet: A double-blind challenge trial in children with autism. *Journal of Autism & Developmental Disorders*, 46(1), 205-220. doi:10.1007/s10803-015-2564-9
- Interactive Autism Network (IAN). (2008). *(IAN) Research findings: Special diets*. Retrieved from https://iancommunity.org/cs/ian_treatment_reports/special_diets

- Ireton-Jones, C., Garritson, B., & Kitchens, L. (1995). Nutrition intervention in cancer patients: Does the registered dietitian make a difference? *Topics in Clinical Nutrition, 10*(4), 42-48.
- Johnson, C., Handen, B., Zimmer, M., Sacco, K., & Tuner, K. (2011). Effects of gluten free/casein free diet in young children with autism: A pilot study. *Journal of Developmental & Physical Disabilities, 23*(3), 213-226.
- Klaveness, J., Bigam, J., & Reichelt, L. (2013). The varied rate of response to dietary intervention in autistic children. *Open Journal of Psychiatry, 3*, 56-60.
- Knivsberg, A., Reichelt, K., Høien, T., & Nødland, M. (2002). A randomized, controlled study of dietary intervention in autistic syndromes. *Nutritional Neuroscience, 5*(4), 251-261.
- Le Couteur, A., Charlton, J., & Winburn, E. (2009, October). PADIA: Parents' and professionals' attitudes to dietary interventions in autism. Can you help with their research in the efficacy of the gluten-free/casein-free (GFCF) diet? *Foods Matter (UK), 20*.
- Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of General Psychiatry, 63*(6), 694–701.
doi:10.1001/archpsyc.63.6.694
- Lotter, V. (1966). Epidemiology of autistic conditions in young children. *Social Psychiatry, 1*(3), 124-135. doi:10.1007/BF00584048
- Mari-Bauset, S., Zazpe, I., Mari-Sanchis, A., Llopis-González, A., & Morales-Suárez-Varela, M. (2014). Evidence of the gluten-free and casein-free diet in autism spectrum disorders: A systematic review. *Journal of Child Neurology, 29*(12), 1718-1727.

- Marrow, E., Yoo, S. Y., Flavell, S., Kim, T., Lin, Y., Hill, R., Mukaddes, N ... & Walsh, C. (2008). Identifying autism loci and genes by tracing recent shared ancestry. *Science*, *321*, 218-222.
- Maston J. L., & Kozlowski, A. M. (2011). The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorder*, *5*(1), 418–425. Retrieved from <http://www.sciencedirect.com/science/article/pii/S1750946710000917>
- Mayo Clinic. (2016). *Autism spectrum disorder: Symptoms*. Retrieved from <http://www.mayoclinic.org/diseasesconditions/autismspectrumdisorder/basics/symptoms/con-20021148>
- Mohiuddin, S., & Ghaziuddin, M. (2013). Psychopharmacology of autism spectrum disorders: A selected review. *Autism*, *17*(6), 645-654. Retrieved from <http://researchautism.net/publications/4605/psychopharmacology-of-autism-spectrum-disorders:-a-selective-review>
- Mostafa, A. (2011). Addressing autism in the Arab world. *Nature Middle East*. doi:10.1038/nmiddleeast .2011.147; Published online 2 November 2011.
- Mostafa, G., & Al-Ayadhi, L. (2012). Reduced serum concentration of 25-hydroxy vitamin D in children with autism. *Journal of Neuroinflammation*, *9*(102). doi:10.1186/1742-2094-9-201.
- National Digestive Diseases Information Clearinghouse. (2008). *Celiac disease*. (NIH publication; no. 08-4269).
- Niewinski, M. (2008). Advances in celiac disease and gluten-free diet. *Journal of the American Dietetic Association*, *108*(4), 661-672.
- Panksepp, J. (1979). A neurochemical theory of autism. *Trends in Neuroscience*, *2*, 174-177.

- Pedersen, L. Parlar, S., Kvist, K., Whiteley, P., & Shattock, P. (2014). Data mining the ScanBrit study of a gluten- and casein-free dietary intervention for children with autism spectrum disorders: Behavioural and psychometric measures of dietary response. *Nutritional Neuroscience, 17*(5), 207-213.
- Pennesi, C., & Klein, L. (2012). Effectiveness of gluten and casein free diet for children diagnosed with autism spectrum disorder. Based on parental report. *Nutritional Neuroscience, 15*(2), 85-91.
- Postorino, V.1., Sanges, V., Giovagnoli, G., Fatta L. M., De Peppo, L., & Armando, M. (2015). Clinical differences in children with autism spectrum disorder with and without food selectivity. *Appetite, 92*, 126-158. doi:10.1016/j.appet.2015.05.016
- Raiten, D. J., & Massaro, T. (1986). Perspectives on the nutritional ecology of autistic children. *Journal of Autism Development Disorder, 16*(2), 133-176.
- Reissmann, A., Hauser, J., Makulska-Gertruda, E., Tomsa, L., & Lange, K. W. (2014). Gluten-free and casein-free diets in the treatment of autism. *Functional Foods in Health & Disease, 4*(8), 349-361.
- Rimland, B., & Edelson, M. (1999). *Autism Treatment Evaluation Checklist*. Autism Research Institute, 4812 Adams Avenue, San Diego, CA 92116. Retrieved from <https://www.autismeval.com/ari-atec/report1.html>
- Saadah, O. (2011). Celiac disease in children and adolescents at a single center in Saudi Arabia. *Annals of Saudi Medicine, 31*(1), 51-57.

- Schopler, E., Reichler, R., DeVellis, R. F., & Daly, K. (1980). Toward objective classification of childhood autism: Childhood autism rating scale (CARS). *Journal of Autism and Development Disorders, 10*(1), 91-103.
- Seung, H., Rogalski, Y., Shankar, M., & Elder, J. (2007). The gluten- and casein-free diet and autism: Communication outcomes from a preliminary double blind clinical trial. *Journal of Medical Speech-Language Pathology, 15*(4), 337-346.
- Shore, S., & Rastelli L. G. (2006). *Understanding autism for dummies*. Hoboken, NJ: Wiley.
- Silverman, S. M., & Weinfeld, R. (2007). *School success for kids with Asperger's syndrome*. Waco, TX: Prufrock Press Inc.
- Stevens, L., & Rashid, M. (2008). Gluten-free and regular foods: a cost comparison. *Canadian Journal of Dietetic Practice & Research, 69*(3), 147-150.
- Vetter, M. L., Herring, S. J., Sood, M., Shah, N. R., & Kalet, A. L. (2008). What do resident physicians know about nutrition? An evaluation of attitudes, self-perceived proficiency and knowledge. *Journal of the American College of Nutrition, 27*(2), 287–298.
- Villafuerte- Galvez, J., Vanga, R. R., Dennis, M., Hansen, J., Leffler, D. A., Kelly, C. B., & Mukherjee, R. (2015). Factors governing long-term adherence to a gluten- free diet in adult patients with coeliac disease. *Alimentary Pharmacology & Therapeutics, 42*(6), 753-760.
- Washi, S. (2001). Nutritional aspects of food labeling in Saudi Arabia. *Ahfad Journal, 18*(2), 17-29.
- Whiteley, P., Shattock, A., Knivsberg, A., Seim, K., Reichelt, L., Todd, K., ... & Hooper, P. (2012). Gluten- and casein-free dietary intervention for autism spectrum conditions. *Frontiers In Human Neuroscience, 6*, 344. doi:10.3389/fnhum.2012.00344

- Williams, P. G., Dalrymple N., & Neal, J. (2000). Eating habits of children with autism. *Pediatric Nursing, 26*(3), 259-267.
- Winburn, E., Charlton, J., McConachie, H., McColl, E., Parr, J. O'Hare, A., Baird, G., & Couteur, A. (2014). Parents' and child health professionals' attitudes towards dietary interventions for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(4) 747-757.
- Yazbak, F. (2004). Autism seems to be increasing worldwide, if not in London. *British Medical Journal, 328*(7433), 226-230.
- Zeina R., Al-Ayadhi, L., & Bashir, S. (2014). Autism spectrum disorder: Main problem waiting for solution in Kingdom of Saudi Arabia. *International Scholarly and Scientific Research & Innovation, 8*(8).
- Zhang, J., Mayton, R., & Wheeler, J. (2013). Effectiveness of gluten-free and casein-free diets for individuals with autism spectrum disorders: An evidence-based research synthesis. *Education and Training in Autism and Developmental Disabilities, 48*(2), 276-287.

Appendix A: IRB Approval



April 1, 2015

Shatha Alaoufi
 Food and Nutritional Sciences
 University of Wisconsin-Stout

RE: The Perception of Gluten-free and Casein-free Diets among Parents of Autistic Children

Dear Shatha:

The IRB has determined your project, "*The Perception of Gluten-free and Casein-free Diets among Parents of Autistic Children*", 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 **March 31, 2015** through **March 30, 2020**. If a renewal is needed, it is to be submitted at least 10 working days prior to the approvals end date. Should you need to make modifications to your protocol or informed consent forms that do not fall within the exemption categories, you will need to reapply to the IRB for review of your modified study.

Informed Consent: All UW-Stout faculty, staff, and students conducting human subjects' research under an approved "exempt" category are still ethically bound to follow the basic ethical principles of the Belmont Report: 1) respect for persons; 2) beneficence; and 3) justice. These three principles are best reflected in the practice of obtaining informed consent from participants.

If you are doing any research in which you are paying human subjects to participate, a specific payment procedure must be followed. Instructions and form for the payment procedure can be found at <http://www.uwstout.edu/rs/paymenttohumanresearchsubjects.cfm>

If you have questions, please contact Research Services at 715-232-1126, or foxwells@uwstout.edu, and your question will be directed to the appropriate person. I wish you well in completing your study.

Sincerely,

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

CC: Dr. Carol Seaborn

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

Appendix B: Parents' Consent Form

Consent to Participate In UW-Stout Approved Research

Title: The Perception of Gluten-free and Casein-free Diets among Parents of Autistic Children

Description:

The purpose of this study is to investigate the perceptions of gluten-free and casein-free diets among parents of autistic children in the Kingdom of Saudi Arabia (KSA) and the United States. The survey is designed to examine the awareness of gluten-free and casein-free diets, willingness to offer the diets, and evaluate the behavior changes after following implementation of the diets.

Risks and Benefits:

There is a minimal risk associated with emotional discomfort that may arise after answering questions that deal with problems your child may be experiencing. However, support group leaders or therapists that have sent the survey are available to provide assistance. A benefit to parents is the introduction of a diet as a treatment that may accompany and assist current treatment for their autistic child. The research will provide information of parental knowledge regarding gluten-free and casein-free diets specifically parents of autistic children in the US and KSA. In addition, this research may validate current research that supports gluten-free, casein-free diets to improve autistic children's behavior.

Time Commitment:

The survey and the autism treatment evaluation checklist will take about 15-20 minutes.

Confidentiality:

Your name will not be included on any documents. You cannot be identified from any of this information. The data will be stored on Qualtrics and can only be accessed by the researcher. The hard copies of the survey will be stored in a secure place and destroyed after completing the study.

Right to Withdraw:

Your participation in this study is entirely voluntary. You may choose not to participate without any adverse consequences to you. You have the right to stop the survey at any time. However, should you choose to participate and later wish to withdraw from the study, there is no way to identify your anonymous document after it has been submitted to the investigator. If you are participating in an anonymous online survey, once you submit your response, the data cannot be linked to you and cannot be withdrawn.

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. The IRB has determined your project, *"The Perception of Gluten-free and Casein-free Diets among Parents of Autistic Children"*, is **Exempt** from review by the Institutional Review Board for the Protection of Human Subjects.

Investigator:

Shatha Alaoufi ,
715-440-4872
alaoufis0389@my.uwstout.edu

IRB Administrator

Sue Foxwell, Research Services
152 Vocational Rehabilitation Bldg.
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715.232.2477
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Advisor:

Carol Seaborn, Ph.D., R.D., C.D., Food and Nutrition
Department
University of Wisconsin-Stout, Menomonie WI 54751
715-232-2216, seabornc@uwstout.edu

Statement of Consent:

By completing the following survey you agree to participate in the project entitled "The Perception of Gluten-free and Casein-free Diets among Parents of Autistic Children"

Appendix C: Survey Questionnaire

Statement of Consent:

By completing the following survey you agree to participate in the project entitled, *The Perception of Gluten-free and Casein-free diets Among Parents of Autistic Children.*

Parental information:

1. Please provide your age in years: _____
2. Check your gender:
 Male
 Female
3. Please check your level of education:
 Some, or graduated high school
 A technical college degree or some college
 A Bachelor's, Master's, or PHD degree
4. Please check if you work outside the home.
 No
 Part-time
 Full-time

Information about your child:

5. Please provide your child's age in years _____
6. Please check your child's gender:
 Male
 Female
7. Has your child been diagnosed with autism or related disorder?
 Yes, please specify _____
 No

8. Please describe the current treatment for your child, including all medications.

"Celiac disease can develop when a person eats gluten (a protein found in wheat, rye, and barley) which increases the immune response leading to an attack on the small intestine."

9. Has your child been diagnosed with celiac disease?
 Yes
 No

10. Please check if you feel that your child needs to change the kinds of food he or she is eating and why?
 ___ Yes, why _____
 ___ No, why _____
11. Is your child consistently consuming any special diet?
 ___ Yes, please specify what kind of diet _____
 ___ No
12. Have you heard about the gluten-free, casein-free (GF/CF) diet?
 ___ Yes
 ___ No
13. Would you like to learn more about a gluten-free, casein-free, or gluten-free and casein-free diet?
 ___ Yes
 ___ No
14. Are you currently giving your child a gluten-free, casein-free, or gluten-free and casein-free diet?
 ___ No, **please stop and continue the autism treatment evaluation survey**
 ___ Yes, please indicate which diet below and continue this survey
 ___ Gluten-free (GF) diet
 ___ Casein-free (CF) diet
 ___ Gluten-free and casein-free (GF/CF) diet
15. Why did you start your child on the diet you selected above?

16. How long you have been using the diet (months, years)? _____
17. Please check the options that describes how you learned about this diet (choose all that apply)
 ___ Book
 ___ Internet
 ___ TV
 ___ Magazine
 ___ Doctors
 ___ Nurses
 ___ Dietitian
 ___ Friend
 ___ Family

18. **Do you feel that you have enough information about how to implement the diet?**
 Yes
 No
19. **Do you see a registered dietitian to assist you with the diet?**
 Yes
 No
 Someone else, please describe who _____
20. **Please check the options below that you would like more information to enhance your ability to follow the diet:**
 Label reading to recognize all forms of gluten/casein in processed products and beverages
 How to prevent cross-contamination
 Hidden gluten ingredients in glue and play dough
21. **Please check the major obstacles that you faced with this diet:**
 Cost
 Availability of products in the market place
 Child's resistance
 Difficulties at school
 Unsatisfactory taste
 Time
 Child had an increase in negative behaviors
22. **Do you discontinue the diet from time to time?**
 No
 Yes, please specify
 Once a week
 Once a month
23. **Did you notice any side effects with your child's behavior after the breaks?**
 No
 Yes, please specify _____
24. **Please complete the checklist attached to describe your child's behavior after they consumed the diet.**

