FACTORS AFFECTING PARENTS' DECISIONS TO TREAT THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER WITH COMPLEMENTARY AND ALTERNATIVE TREATMENTS

A Dissertation

by

SARAH ELIZABETH HALL

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

August 2011

Major Subject: School Psychology

Factors Affecting Parents' Decisions to Treat Their Children with Autism Spectrum Disorder with Complementary and Alternative Treatments

FACTORS AFFECTING PARENTS' DECISIONS TO TREAT THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER WITH COMPLEMENTARY AND ALTERNATIVE TREATMENTS

A Dissertation

by

SARAH ELIZABETH HALL

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Approved by:

Chair of Committee,	Cynthia Riccio
Committee Members,	Michael Ash
	Laura Stough
	Rob Heffer
Head of Department,	Victor Willson

August 2011

Major Subject: School Psychology

ABSTRACT

Factors Affecting Parents' Decisions to Treat Their Children with Autism Spectrum Disorder with Complementary and Alternative Treatments. (August 2011)

Sarah Elizabeth Hall, B.A., Texas A&M University

Chair of Advisory Committee: Dr. Cynthia Riccio

Autism affects approximately one in 110 children in the United States. Many parents choose to treat their children with autism spectrum disorder (ASD) with complementary and alternative (CAM) treatments. In this study, factors that contribute to parents' decisions to treat their child with ASD with a complementary or alternative (CAM) treatment were examined through the use of an online survey. Invitations to participate in the study were sent to approximately 800 support groups for parents of children with autism and information from 452 respondents was used in data analysis. Information regarding the impact of parental characteristics, children's behavioral symptoms, characteristics of specific CAM treatments, and possible barriers to treatment were obtained and analyzed.

Overall, the responding parents/guardians were mothers, fathers, and grandmothers with a mean age of 41.58. The majority self-identified as White (86.7%), with 41.8% having attained a college education. The average income of respondents was $89,106.66. 100% of the participants in the study indicated they had tried a CAM in the past, or were currently using one.

Results indicated a statistically significant relationship between severity of symptoms with having tried treatments in the past, and with currently using treatments. In addition, several specific treatments that were tried in the past and were currently being used were correlated with greater severity of symptoms. Severity of symptoms was not predictive of the total number of CAMs used. Educational level and marital status of parents were predictive of CAM use. In addition, individuals with a graduate level degree were more likely to use CAM than those with technical school/some college. Respondents who were married were significantly more likely to use CAMs than those who were divorced. Results indicated that accessibility and acceptance of treatments were predictive of CAM use. Possible barriers to treatment, as well as study limitations and implications, are also discussed. The findings of this study are important, as while the use of CAM treatments is growing among the population of children with autism, information regarding the reasons parents decide to use CAM treatments with their children with autism is relatively sparse.

DEDICATION

This dissertation is dedicated in memory of my grandmothers, Marie Boudreaux Chapman and Katherine Bevil Hall. Throughout my life, the love, support, and prayers of these strong women gave me the confidence to pursue my dreams, and I will be forever thankful.

ACKNOWLEDGEMENTS

Thank you to my committee chair, Dr. Cyndi Riccio, for her support and mentorship throughout graduate school, and for her ability gently to encourage me as I completed each step along the way. Thanks to my committee members, Dr. Mike Ash, Dr. Rob Heffer, and Dr. Laura Stough, for their guidance throughout the course of this research. Thanks to my Texas A&M cohort: Becki, Courtney, Emilie, Kelly, Leonor, Lisa, Nicole, Sophia, Casey, and Brittany. My time in graduate school was enriched by your support and friendship.

I learned a great deal while on internship at Lewisville ISD through the leadership of my supervisors, Dr. Jennifer Key and Dr. Linda Pedersen. Their knowledge and wisdom truly helped me grow as a clinician. I was also fortunate to form long-lasting friendships with my fellow interns: Kelly, Adrienne, Sally, Ashley, and Lisa.

Thank you to my parents, Mack and Beverly Hall, for all their love and support throughout my long academic journey. I am also grateful for the support and encouragement I received from my aunts, uncles, and cousins. To my great friends Sarah and Jan: your presence in my life has been a welcome relief from all things "grad school."

Thanks to the parents of children with an autism spectrum disorder who chose to complete this survey. Without your participation, the completion of this dissertation would not have been possible.

TABLE OF CONTENTS

Page

LIST OF TABLES

CHAPTER I

INTRODUCTION

Autism affects approximately one in 110 children in the United States (Centers for Disease Control and Prevention [CDC], 2009). Autism is a disorder in which the classic features are abnormal or impaired development in social interaction and communication, in combination with a severely restricted repertoire of activity and interests (American Psychiatric Association [APA], 2000). Children with autism also may display degrees of repetitive and stereotyped behaviors (APA, 2000) that are manifested in various ways, depending on the child and the level of impairment.

Goin-Kochel, Myers, and Mackintosh (2007) quoted Donald Cohen, "When there is no cure, there are 1000 treatments" (p. 195); this is particularly true for autism. In fact, there is no controversy regarding treatment in the area of developmental pediatrics more controversial than treatments for children with autism spectrum disorders (ASD; Levy & Hyman, 2005). Due to its chronic nature and lack of a cure, ASD have become the focus of several unconventional treatments (American Academy of Pediatrics, 2001). While there are many case studies and anecdotal evidence about the benefits of different treatments, many of these treatments have not been examined experimentally (Campbell, Schopler, Cueva, & Hallin, 1996), and there is little information about the frequency of use of these strategies and the characteristics associated with their use (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003). Since autism was first described in the 1940s, there have been numerous theories about

---

This dissertation follows the style of *Journal of Autism and Developmental Disorders*.

the etiology of autism and treatments to go with them (Fombonne, 2008). Parents face many difficulties in finding an appropriate treatment for their child with ASD. For example, when conducting a Google® search with the terms "autism" and "alternative medicine," Zimmer and Molloy (2007) found more than 600,000 sites. It is no wonder then that parents have difficulty sorting out legitimate medical information from pseudoscience in the mainstream media.

Of the numerous types of treatments available for children with autism, many are classified as complementary and alternative treatments. Complementary and alternative (CAM) treatments can be used alongside (complementary) and as a substitute (alternative) for conventional treatments (Hyman & Levy, 2005). The website of the National Center for Complementary and Alternative Medicine (http://nccam.nih.gov/health/whatiscam/) gives the following definition of complementary and alternative medicine: "CAM is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine". According to NCCAM, conventional medicine is medicine practiced by medical doctors and doctors of osteopathy, as well as other related health professionals (e.g., psychologists and physical therapists). Many complementary and alternative treatments have not been tested through scientific methods, but many families still use them (Levy et al., 2003).

CAM use is common among children with autism spectrum disorders, and caregivers of children with ASDs must sort through a wide variety of treatments promoted by various individuals and groups (Challman, 2008; Zimmer, 2011). Gupta

(2010) said that the lack of evidence regarding the biological causes of autism have led to greater exploration of complementary and alternative treatments for children with ASDs. A number of studies have explored the prevalence of children with ASD using complementary and alternative treatments. In a study examining the prevalence of the use of different types of treatments with 112 families, 74% were using complementary and alternative medicine for their child with ASD (Hanson et al., 2007). Levy et al. (2003) found that 31.7 % of the children with autism in their study were currently using one or more CAM therapies. Wong and Smith (2006) compared patterns of CAM therapy use in children with ASD to children with no ASD. Results indicated that 52% of parents of children with an ASD reported using at least one CAM therapy for their child, compared to 28% of parents in the control group. Of the therapies used in the ASD group, 70% were biologically based (e.g., vitamins, modified diets, etc.) Overall, 75% of the parents felt that the CAM therapies were beneficial. Senel (2009) surveyed 38 Turkish parents of children with ASD regarding their use of CAM treatments. Through an internet questionnaire, "vitamins and minerals," "special diet," "sensory integration," other dietary supplements," and "chelation" were five treatments that were frequently endorsed. Goin-Kochel et al. (2007) examined the types of therapies parents had tried or were currently using with their children with an ASD. While many endorsed conventional therapies (such as Applied Behavior Analysis), some alternative treatments were endorsed, including auditory integration therapy, chelation therapy, and music therapy. Of interest is that 60% of children younger than 5.9 years had tried a gluten-free or casein-free diet, as had 56% of children six to 11.9 years. On average, children in the

study had tried between seven and nine therapies and were currently using between four and six. The authors emphasized that families are using many treatments simultaneously for their children with ASD, and some of these treatments are not supported by scientific evidence.

Despite the high prevalence of CAM therapies used, there is little information available about how and why parents make these treatment decisions for their children with an ASD (Mandell & Novak, 2005). Levy et al. (2003) examined factors that correlated with the use of different types of complementary and alternative medicine in children with autism. Data were collected at an autism center that is part of a children's hospital in a large city in the United States. By reviewing 284 charts of children suspected of having autism or recently diagnosed with autism, they found that more than 30% of these children were using some type of CAM, and 9% of the children were using a potentially harmful CAM (e.g., cod liver oil, antibiotics, antifungals, chelation treatment, withholding immunization). It was found that having another diagnosis in addition to autism was a protective factor against CAM use. Children who had previously seen health care providers were more likely to engage in potentially harmful CAM use. Levy et al. (2003) suggested that this may be due to several factors. Families who have had time to see numerous providers might have been aware of their child's autism for a longer amount of time, and had more time to identify and use CAM treatments. The longer families were on a wait list for an appointment, their frustration may have increased, leading them to seek out riskier treatments. Longer wait time also allows parents more time to seek out information on the internet and connect with other

families using CAM. The authors did not examine whether behaviors of the child had an impact on CAM use.

Nickel (1996) stated, "The search for a magical cure may be one stage in a parent's adjustment to the diagnosis of a developmental disability in his or her child. The parent may try controversial treatments as a part of this search" (p. 29). Parents can be enticed by promises of a cure, and popular media (e.g., television programs, commercials) can be encouraging of untested therapies (Nickel, 1996; Christon, Mackintosh, and Myers, 2010). Child characteristics (the severity of the disability, the degree of behavior problems) can affect parents' decisions to try controversial treatments. The author also suggests that the growing focus of Americans on personal fitness and preventive health care has contributed to the increase in use of certain alternative treatments, such as megavitamins and diets. In an unpublished 1995 survey of parents of children receiving services from a local autism program, 50% of the children were using a nonstandard therapy, and 32% or more had tried two or more nonstandard therapies (Nickel, 1996).

There also appears to be a possible cultural component to treatment decisions in autism. A review of the literature on the cultural factors involved when families make treatment decisions for their child with ASD, Mandell and Novak (2005) concluded that parents' beliefs about child development, their personal interpretation of symptoms of ASD, its etiology and course, and their experiences with the health system all influence treatment decisions. They proposed that symptoms of autism may present differently in different cultures, due to genetic or environmental factors; however, evidence for this

has been mixed, and there are no studies that look at ethnic differences in the presentation of different symptoms of ASD (Mandell & Novak).

Norms about child development are shaped by culture, and symptoms that are seen as problematic in one culture may not be seen as problematic in another (Daley, 2004). Therefore, parents from different cultures may interpret the same symptoms differently. For example, Asian/Pacific Islander and African-American parents were less likely than white parents to agree with their adolescent children's teachers that the adolescent's behavior could be due to an underlying disorder (Lau et al., 2004). Persons from different cultures also may be more likely to notice certain behaviors early on. Daley (2004) found that Indian parents were more likely to notice social skills weaknesses, while American families are more likely to notice general developmental difficulties or regression in language abilities (Coonrod & Stone, 2004). Parents from different cultures may value certain abilities more than others (language, social skills), and may be more attuned to the skills they favor. In addition, culture is often associated with socioeconomic and geographical limitations that can lead to difficulties with accessing healthcare (Daley, 2004).

Families' beliefs about the cause of autism also may affect treatment decisions (Mandell & Novak, 2005). For example, if parents believe that their child's autism is caused by exposure to heavy metals, they may choose one of the controversial treatments aimed at heavy metal detoxification. Also, parents' understanding of their child's prognosis may affect treatment decisions. If they believe that autism can be cured, parents may seek out a treatment that claims the ability to cure autism. If parents

believe that autism is chronic, parents may seek out treatments to alleviate symptoms of the disorder. Mandell and Novak suggested that these parents may make the most stable treatment decisions. Alternatively, parents who believe autism is chronic and incurable may also decide not to try any treatment, and do little or nothing.

The interaction between healthcare systems and families also has an effect on treatment decisions. There has been some research showing that ethnic minorities have different experiences with the healthcare system, especially in obtaining accurate diagnoses (Mandell & Novak). In a study examining racial differences at first age of diagnosis, on average, African-American children were diagnosed with autism 18 months later than white children, and required three times the number of visits than white children to receive a diagnosis of autism (Mandell, Listerud, Levy, & Pinto-Martin, 2002).

Levy and Hyman (2003) found that Latino children with autism were six times more likely than children of other ethnicities to use complementary and alternative treatments. Their sample of Latino children was small, but results suggested the need for further research in this area; this is the only study specifically looking at the role of culture in treatment decisions for ASD (Mandell & Novak). Pachter and Weller (1993) examined level of acculturation and compliance with medical therapy in a sample of Puerto Rican families with a child with asthma. They found that families who were less acculturated tended not to adhere as strictly to conventional treatments prescribed by their physicians, suggesting that culture plays an important role in treatment decisions.

While more research is needed, it appears that cultural factors may play a role in parents' treatment decisions for their children with autism.

Treatment acceptability may also affect parents' decisions to treat their child with an alternative or complementary treatment. Kazdin (1980) conceptualized treatment acceptability as judgments of treatments by consumers or potential consumers. In her study of treatment acceptability, Carter (2008) examined treatment acceptability through the conceptualization of Lennox and Miltenberger (1990), who grouped important factors into four categories: efficacy considerations, secondary effects, social/legal implications, and practical considerations. Efficacy considerations include motivational variables, (which have the potential to increase treatment effectiveness), and treatment effectiveness, which is the demonstration of clinically significant change.

Secondary effects include side effects, which can be beneficial or detrimental, as well as the potential for abuse by those implementing the treatment. Social and legal implications include the restrictiveness or intrusiveness of the treatment (i.e., the amount of stress placed upon the patient), treatment precedence (the previous known effectiveness of a treatment), the social acceptability of the treatment, and the understanding of regulatory factors regarding the treatment (e.g., legislation, agency regulations, guidelines, etc.). Practical considerations include the competence of staff implementing treatments and the cost-effectiveness of the treatment. Carter (2008) suggested additional factors to be considered when examining treatment acceptability, including that treatment acceptability is not stagnant and can change over time, the immediacy of treatment effects, and the influence of the treatment provider on the

consumer. Also, Carter suggested that difficulties getting feedback from individuals with severe developmental disabilities regarding their acceptance of more restrictive treatments can pose a problem in understanding their preferences.

Purpose of the Study

Many factors potentially affect parent decisions for treatment for their child with an ASD (see Figure 1). Many of these factors, including the impact of child factors (e.g., behavioral severity) on their parents' decision to treat them with a CAM have not been examined. The purpose of this study was to examine factors that contribute to parents' decisions to treat their child with ASD using a complementary or alternative treatment. Specifically, the research questions are:

1. Do parents of children with an ASD who exhibit more severe behavioral symptoms gravitate toward complementary and alternative (CAM) treatments and therapies? It is hypothesized that parents of children with more severe behavioral symptoms will seek out more CAM treatments and therapies.
2. To what extent does demographic information of the parents affect their treatment decision for their child with an ASD? It is hypothesized that parent characteristics (e.g., marital status, country of origin, length of time in the United States, educational level, and employment status) will have an impact on their use of CAM.

3. Are there specific characteristics of the CAM treatments that impact decision-making (e.g., cost, accessibility, the child's living situation, the number of available treatments, treatment acceptability)?
4. What are some of the barriers to treatment (belief that Autism is/is not curable, ease of obtaining information, number of medical professionals consulted, and experience with health care system)?

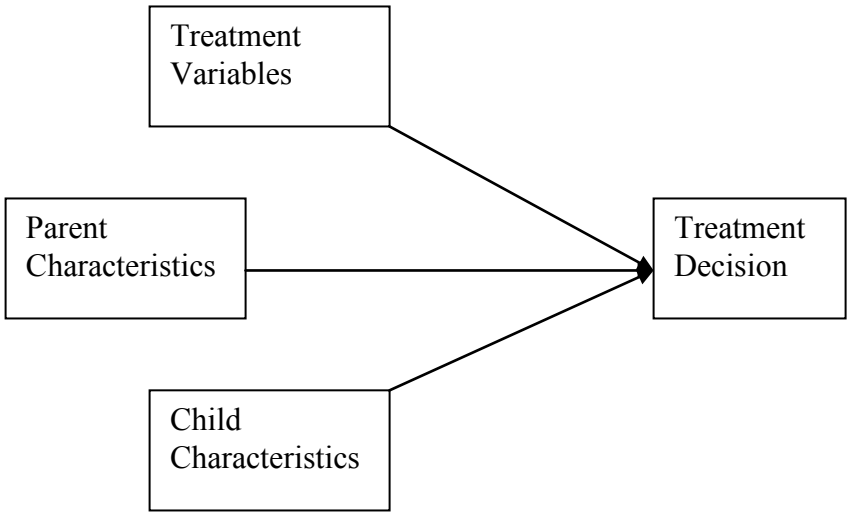

Figure 1 Factors Affecting Treatment Decisions

Implications for Practice

There are several reasons why it is important to understand the underlying factors that affect why parents of children with autism gravitate toward different types of treatments and therapies. Health care providers are increasingly being asked for advice and information about CAM treatments (Zimmer & Molloy, 2007). In a sample of 539 physicians, Golnik and Ireland (2009) found that 58.9% endorsed encouraging at least

one form of CAM treatment for a child with autism. In general, all types of health care providers who might possibly treat a child with autism (e.g., medical doctors, mental health professionals, etc.) should be aware of the high prevalence of use of CAM treatments among this population, and be prepared to discuss their use with families (Hanson et al., 2007). Levy et al. (2003) suggested that doctors be prepared to discuss potentially harmful treatments with parents, and even be prepared to negotiate with them. For example, if a family wants to treat the child's autism with vitamins that are toxic in high doses, the physician can negotiate with them to lower the dosage. Parents who are interested in CAM therapies will often be well-versed in the treatments in which they are interested, and doctors should be ready to help them understand the possible dangers involved with the treatment, as well as give them a realistic picture of the child's prognosis.

Definitions

1. Autism Spectrum Disorders (ASD), also known as Pervasive Developmental Disorders, "are characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities." ASD include Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Rett's Disorder, and Childhood Disintegrative Disorder (American Psychiatric Association [APA], 2000).

2. Conventional Treatment: medicine practiced by medical doctors and doctors of osteopathy, as well as other related health professionals http://nccam.nih.gov/health/whatiscam/).

3. Complementary and Alternative (CAM) Treatment: a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine (http://nccam.nih.gov/health/whatiscam/).

4. Treatment Acceptability: judgments of treatments by consumers or potential consumers.

CHAPTER II

LITERATURE REVIEW

As stated previously, autism affects approximately one in 150 children in the United States [Centers for Disease Control and Prevention (CDC), 2007]. The classic features are abnormal or impaired development in social interaction and communication, in combination with a severely restricted repertoire of activity and interests (American Psychiatric Association [APA], 2000). Children with autism also may display degrees of repetitive and stereotyped behaviors (APA, 2000) that are manifested in various ways, depending on the child and the level of impairment. The term autism spectrum disorder (ASD), also known as pervasive developmental disorder, encompasses five different disorders: Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Rett's Disorder, and Childhood Disintegrative Disorder (American Psychiatric Association [APA], 2000). It seems that many parents turn to complementary and alternative treatments for their children with autism. In one study, 74% were using complementary and alternative medicine for their child with ASD (Hanson et al., 2007). While there are many case studies and anecdotal evidence about the benefits of different treatments, most of them have not been tested experimentally, and many families still use them (Campbell et al., 1996; Levy et al., 2003). There is also little information about the frequency of use of these strategies and the characteristics associated with their use (Levy et al., 2003). Complementary and alternative (CAM) treatments can be used alongside (complementary) and as a substitute (alternative) for conventional treatments (Hyman &Levy, 2005). The website of the National Center for

Complementary and Alternative Medicine (NCCAM) gives the following definition of complementary and alternative medicine: “CAM is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine” (http://nccam.nih.gov/health/whatiscam/). According to NCCAM, conventional medicine is medicine practiced by medical doctors and doctors of osteopathy, as well as other related health professionals (e.g., psychologists and physical therapists).

Complementary and Alternative Treatments (CAM)

CAM treatments are either biologic or nonbiologic (Levy & Hyman, 2002). Based on the organization of Levy and Hyman (2005) and Zimmer and Molloy (2007), CAM treatments can be divided into five general categories, with some treatments overlapping: gastrointestinal and immune treatments, treatments aimed at modulating neurotransmitters and neuropeptides, treatments that target impaired methylation capacity, heavy metal treatments, and nonbiological interventions.

Gastrointestinal and Immune Therapies

There are several CAM therapies for children with ASD that target the gastrointestinal system, for different reasons. While some studies have shown increased prevalence of gastrointestinal (GI) symptoms in children with ASD (Molloy & Manning-Courtney, 2003), others have shown that GI issues occur no more in the population of children with ASD than in other populations (Black, Kaye, & Jick, 2002). It has also been suggested that the onset of GI difficulties coincided with onset of autistic symptoms at the time of the administration of the measles, mumps, and rubella vaccine

(Wakefield et al., 1998). In Wakefield's (1998) theory about onset coinciding with measles mumps rubella vaccine, the authors concluded after comparing results of endoscopies from children with ASDs and typically developing children that GI inflammation resulting from viral disease from the vaccine was an etiological factor in some cases of autism. This connection with the vaccine was later called into question and generally disproven, after the validity of the data supporting this was called into question (Zimmer & Molloy, 2007). There have also been several causes posited about the relationship between GI symptoms and symptoms of ASD. A higher number of persons with autism have increased intestinal permeability, which is called the "leaky gut" hypothesis (Levy & Hyman, 2005). This hypothesis is the underlying basis for several CAM therapies, including secretin and the gluten-free/casein-free diet. In addition to the theory that the vaccine caused the GI difficulty, others have hypothesized the GI tract contribution to symptoms of ASD to overgrowth of neurotoxin-producing bacteria (Sandler et al., 2000), dysfunction of secretin or secretin receptors (Horvath & Perman, 2002; Horvath, Papadimitriou, Rabsztyn, Drachenberg, & Tildon, 1999), or dysfunction of serotonin or serotonin receptors (Fiorica-Howells, Maroteaux, & Gershon, 2000).

Secretin

As a result of the belief that secretin is involved with GI difficulties, use of intravenous secretin is one of the most well-studied CAM for ASD, with at least fourteen randomized, placebo-controlled trials conducted (Zimmer & Molloy, 2007). Secretin is a 27 amino-acid polypeptide produced in the intestine that is involved in gastrointestinal

function (Williams et al., 2005). Until 1998, it was mainly used diagnostically by gastroenterologists during endoscopies to examine pancreatic secretion (Levy & Hyman, 2005). A case report by Horvath et al. (1998) reported changes in developmental and behavioral symptoms in children with ASD after secretin administration, leading to a number of studies searching for possible mechanisms of effect.

Numerous theories have been put forward to explain the possible connection between secretin and autistic symptoms. A meta-analysis conducted on trials of secretin use in children with autism indicated that no difference existed between the placebo and intervention groups (Williams, Wray, & Wheeler, 2005). Sandler (2005) suggested that there is a strong placebo effect for receiving intravenous injections of secretin, because in many studies improvements in symptoms of ASD were reported in both the treatment and control groups. Secretin treatments are very expensive, and also have many possible negative side effects, including abdominal cramps, abdominal discomfort, bradycardia, diaphoresis, diarrhea, nausea, vomiting, headache, lightheadedness, and hypotension (Zimmer & Molloy, 2007). Due to these risk factors and because of the lack of demonstrated efficacy in well-designed treatment studies, secretin is not recommended as a treatment for autism (Williams et al.; Zimmer & Molloy).

Gluten-free/Casein-free Diet

Levy and Hyman (2003) found that approximately 15% of children with an ASD follow a gluten-free/casein-free (GFCF) diet. The popularity of this diet may be due to a number of factors: it is presumed to be healthy, it is typically presented in a way that suggests a rapid response, and it is noninvasive (Levy & Hyman, 2005). This therapy is

also based on the "leaky gut" hypothesis, suggesting that children with autism cannot completely break down certain proteins (in this case, gluten and casein), and therefore absorb peptide fragments (Levy & Hyman, 2005). Peptides formed from the breakdown of milk and wheat products can be absorbed across the more permeable GI tract, having and opioid effect on the brain and leading to symptoms of ASD (Reichelt, Knivsberg, Lind, & Nodland, 1991; Shattock, Kennedy, Rowell, & Berney, 1990). Some studies have shown that eliminating gluten and casein from the diet may improve behavioral symptoms in children with autism. A randomized, single-blind trial of gluten and casein elimination demonstrated improvements in an overall score that encompassed nonverbal and verbal communication, behavior in learning situations, sharing of emotions, anxiety, rigidity, and peculiarity; no improvements in linguistic, cognitive, or motor abilities were evident (Knivsberg, Reichelt, Hoien, & Nodland, 2002). Limitations of the study included its relatively small sample size. Further, it did not control for other behavioral interventions or medications that may have contributed to the positive effects observed. It was suggested that the structure imposed on the household by following the diet, as well as behavioral therapies not accounted for, could be responsible for the promising results. Another trial of the GFCF diet failed to demonstrate differences in both language and behavior as a result of the intervention (Elder et al., 2006). No studies assessing the safety of GFCF diets have been completed (Zimmer & Molloy); however, there are several studies ongoing in the U. S. that will add to the research base with regard to whether this diet has therapeutic value for children with ASD. At the same time, it is worthy of note that many children with ASD have limited diets based on their sensory

aversions to different foods; further restricting their diet by eliminating milk products could be detrimental to their overall health (Levy & Hyman, 2005). In fact, one study has suggested that the GFCF diet can lead to loss of bone density (Hediger et al., 2008). Arnold, Hyman, Mooney, and Kirby (2003) found that children with autism on restricted diets had an increased prevalence of amino acid deficiencies and lower levels of essential acids than children with autism who were not on restricted diets. They suggested that more research be conducted to investigate the extent to which special diets possibly harm developing brains through protein malnutrition. Overall, while the GFCF diet may in the future be proven to have benefits for certain populations of children with ASD with some specific certain set of symptoms, current literature does not support or refute claims of its success in the general press (Levy & Hyman, 2005).

Specific Carbohydrate Diet (SCD)

The Specific Carbohydrate Diet (SCD) is also based on the assumption that children with ASD experience some type of GI dysfunction, usually associated with increased permeability of the intestines and microbial imbalances. The SCD aims to give children carbohydrates of smaller molecular size so that they do not have to be broken down in the body (Gottschall, 2004, as cited in Levy & Hyman, 2005). The SCD was initially developed for people with celiac disease (Levy & Hyman, 2005). There are no research studies of the efficacy of this diet in the treatment of ASD (Levy & Hyman, 2005); as with the GFCF diet, there is concern that the SCD might lead to nutritional deficiency.

Digestive Enzymes and Probiotics

The use of digestive enzymes and probiotics in children with ASD is also related to the "leaky gut" hypothesis (Levy & Hyman, 2005). Digestive enzymes are hypothesized to break down food products into small, nontoxic particles (Zimmer & Molloy) and remove the toxic particles from the gastrointestinal tract (Levy & Hyman, 2005). According to Zimmer and Molloy, probiotics "are products containing microflora in amounts sufficient to alter intestinal flora with the purpose of sustained health benefits" (p. 270). In an open-label trial of digestive enzymes combined with probiotics, a few children with an ASD were reported to show some behavior improvements (Brudnak et al. 2002). In this trial, 40% of the subjects were already on a GFCF diet, and raters of outcome measures were not blinded to the treatment condition. Despite the lack of evidence for their use, digestive enzymes are frequently used (Levy & Hyman, 2005).

Immune Therapies

Antifungals and a yeast-free diet have been suggested as a treatment for colonic yeast overgrowth in individuals with ASD (Levy & Hyman, 2005). Colonic yeast overgrowth has been suggested as a possible contributor to symptoms of ASD through its affect on immune system function; however, colonic yeast overgrowth in individuals with ASD has not been substantiated in a peer-reviewed medical journal, and there are no published therapeutic trials of the use of oral antifungal agents in this population (Levy & Hyman, 2008; Zimmer & Molloy). Still, use of medication to treat yeast overgrowth in children with autism remains popular (Levy & Hyman, 2008). It is thought that yeast overgrowth is due to intestinal dysbiosis or immune factors unique to

autism (Levy & Hyman, 2008). It should be remembered that the chronic use of oral antifungal agents can cause hepatoxicity and requires close monitoring (Levy & Hyman, 2005; Zimmer & Molloy).

Antibiotics

There is growing evidence that there is some type of association between the immune system and ASDs, although no specific pattern of dysfunction has been identified (Zimmer & Molloy). Sweeten et al. (2003) found that children with an ASD were more likely to have a family history positive for autoimmune disease. Identified possibilities included abnormalities in cytokines (Croonenberghs, Bosmans, Deboutte, Kenis, & Maes, 2002; Gupta, Aggarwal, Rashanravan, & Lee, 1998; Jyonouchi, Sun, & Le, 2001), autoantibodies to neuronal elements (Connolly et al., 1999), and cell-mediated response and allergic immune response (Gupta, Aggarwal, & Heads, 1996). Related to this, Sandler et al. (2000) proposed that autistic symptoms are exacerbated by the increased use of antibiotics. The hypothesis was that repeated use of antiobiotics leads to gut bacterial overgrowth and colonization by "neurotoxic" bacteria, which cause an autistic regression. To test this hypothesis, Sandler et al. (2000) gave oral vancomycin (an antibiotic) to 11 children with a recent diagnosis of autism who had used antibiotics within two months of symptoms appearing and also had diarrhea. Improvement in symptoms of autism was noted and waned after treatment was withdrawn. While they did not say that this was a useful treatment for ASD, the authors presented this as evidence of the interaction of antibiotics and the brain in some children with ASD. D-Cycloserine is an antiobiotic that has been proposed as a treatment for

autism. It has shown to reduce disruptive symptoms in adults with schizophrenia when administered in conjunction with a neuroleptic medication (Goff et al., 1999), and a small uncontrolled study showed some reduced social withdrawal and increased social responsiveness as measured by the Aberrant Behavior Checklist (Posey et al., 2004). More research is needed to determine its usefulness in children with autism.

Intravenous Immunoglobulin (IVIG)

Intravenous Immunoglobulin (IVIG) is an expensive therapy that involves intravenous infusion and has many possible adverse side effects (Zimmer & Molloy, 2007). It has been used as a therapy for several immune disorders (Gupta et al., 1996), and it has been given to children with autism to treat various immune system deficits (Levy & Hyman, 2005). Some success was shown in a study by Gupta et al. (1996), where ten children with autism showed improvements after six months of treatment. Possible side effects include renal tubular acidosis, thromboembolic events, aseptic meningitis, rash, and blood-borne infection (Levy & Hyman 2005).

Therapies Targeting Neurotransmitters and Neuropeptides

It has also been suggested that multiple neurotransmitter systems are dysfunctional in individuals with ASD, due to observed clinical features of many individuals with autism (i.e., larger head circumference, larger brain volume, seizures, irregular sleep patterns, and mental retardation (Polleux & Lauder, 2004). Specific systems with the most evidence for abnormalities are the y-aminobutyric acid (GABA)-ergic system, glutaminergic system, and serotonergic system (Mulder et al., 2004; Polleux & Lauder, 2004; Spivak et al., 2004). The nature of these abnormalities is

generally unclear and undergoing continued study. For example, in the serotonergic system, some studies have suggested that autism is associated with hyperserotonemia (Anderson, Horne, Chatterjee, & Cohen, 1990; Mulder et al., 2004), while Spivak et al. (2004) suggested that autism is associated with hyposerotonemia. Medications that act on these transmitters (e.g., resperidone, fluoxetine, and fluvoxamine) have shown some benefits in some individuals with ASD; this has given further reason to examine the possible role of neurotransmitter systems in autism (Zimmer & Molloy).

*Neuromodulator*s

Dimethylglycine (DMG) is a commonly used dietary supplement that has been reported to benefit children with autism (Kern et al., 2001; Bolman & Richmond, 1999; Levy & Hyman, 2008). It is sold in health food stores as a supplement for athletes as well as individuals with ASD (Kern et al., 2001). Bolman and Richmond hypothesized that DMG might exert influence on the balance of inhibitory versus excitatory neurotransmission, because of its potential ability to cross the blood-brain barrier. Many parents of children with autism believe that supplementing their child's diet with DMG improves their child's symptoms (Kern et al., 2001). It is also believed by some that DMG is a cure for many illnesses (including cancer and hepatitis), but there is little scientific evidence to support these claims. Two double-blind, placebo-controlled trials in children with autism produced negative results (Bolman & Richmond, 1999; Kern et al. 2001). Even in light of these results, DMG is promoted as a therapy for autism by many alternative medical practitioners (Zimmer & Molloy). A possible negative side effect of fatty infiltration of the liver has been shown in long-term use of pangamic acid,

which is a closely-related compound to DMG (Ziemlanski, Wielgus-Serafinska, Panczenko-Kresowska, & Zelakiewicz, 1984).

Polyunsaturated Omega-3 Fatty Acids

Problems with the metabolism of fatty acids may have important biological and etiological significance in autism (Bu et al., 2006). Polyunsaturated fatty acids must be taken in through the diet and are essential for normal brain development and functioning (Amminger et al., 2007; Horrobin, Glen, & Vaddadi, 1994; Levy & Hyman, 2008). They are naturally occurring lipids that become part of phospholipids and have many neural functions as parts of neuronal cell membranes, such as cell signaling, neurotransmission, and second-messaging (Bennett & Horrobin, 2000; Horrobin & Bennett, 1999; Horrobin et al., 1994). Some studies have shown that individuals with ASD have less polyunsaturated omega-3 fatty acids in their red blood cell membranes and plasma (Bell et al., 2004; Vancassel et al., 2001), and one study has shown a slight increase in some minor fatty acids of children with autism (Bu et al., 2006). Abnormalities in the fatty acid design of phospholipids, which are the main elements of cell membranes, have been discovered in individuals with neurodevelopmental disorders (Bu et al., 2006). For this reason, Omega-3 fatty acid supplements (also known as fish oil, cod liver oil, evening primrose oil, and flax oil) are a type of nutritional supplement sometimes used in treatment of ASD. Clinical trials of use in treating other disorders have shown promise (Zimmer & Molloy, 2007), and a randomized double-blind, placebo-controlled trial using a similar supplement produced improvements in hyperactivity and stereotypy (Amminger et al., 2007). Despite these positive effects, this study should be replicated

with a larger sample size and stronger statistical analysis (Zimmer & Molloy). Common side effects of Omega-3 supplements include increased belching, fishy odor, skin rash, abdominal distention, diarrhea, increased risk of nosebleed, and easy bruising (Amminger et al.; Zimmer & Molloy). Overall, there are few research studies that support the practice (Levy & Hyman, 2005).

L-Carnosine

L-Carnosine is a dipeptide hypothesized to act as a general neuroprotective agent or modulator of GABA activity in the brain (Zimmer & Molloy, 2007; Chez et al., 2002; Zimmer & Molloy). GABA is an inhibitory neurotransmitter located in the cerebral cortex (Levy & Hyman, 2005), In a randomized, placebo-controlled trial, children treated with an oral supplement of L-Carnosine showed improvement on the Gilliam Autism Rating Scale and the Receptive One-Word Picture Vocabulary test, as compared with control subjects (Chez et al., 2002). While these results appear promising, Levy and Hyman (2005) pointed out that receptive language improvements could be due to maturation, educational interventions, placebo effect, and other possible confounds that were not addressed in the research design. Chez et al. (2002) acknowledged that while the mechanism of action is not well understood, L-Carnosine may work by enhancing neurologic functioning. No side effects except for occasional hyperactivity were reported by parents of children in Chez' study.

Tryptophan and Tyrosine

As mentioned previously, there have been a number of studies documenting abnormalities in the serotonergic system in individuals with ASD. Tryptophan is an

essential amino acid precursor to serotonin (Levy & Hyman, 2005; Zimmer & Molloy) that is sometimes used as a treatment for children with ASD. Some believe that supplementing tryptophan in children with ASD is a safer option than giving them a drug that would affect serotonin release or reuptake inhibition (Levy & Hyman, 2005). In their case study of an adult woman with autism, McDougle et al. (1993) suggested that dietary tryptophan depletion increased symptoms of ASD, and posited that this is due to reducing the supply of serotonin in the brain. Hanley, Stahl, and Freedman (1977) demonstrated that an oral dose of tryptophan increased excretion of urinary metabolites of serotonin production, but found no correlation to change in symptoms of ASD. In their examination of the plasma amino acid profiles of children with ASD, Arnold et al. (2003) found that children with autism on restricted diets had lower plasma amino acid levels of tryptophan and tyrosine, which is a dietary precursor to dopamine, norepinephrine, and epinephrine. Because of this, some argue for tyrosine supplementation in children with autism; however, no studies have evaluated its safety or effectiveness (Zimmer & Molloy).

Naltrexone

Naltrexone is an opioid agonist that is hypothesized to work by lowering high β-endorphin levels (Bouvard et al., 1995; Cazzullo et al., 1999; Gillberg, 1995; Willemsen-Swinkels, Buitelaar, Weijnen, Thijssen, & Van Engeland, 1996). It is theorized by some that autism is associated with hypersecretion of brain opioids, including β-endorphins (Feldman, Kolmen, and Gonzaga, 1999; Panksepp & Lensing, 1991). It is also suggested that highly elevated levels of brain opioids are responsible for self-injurious behavior in

autism (Willemsen-Swinkels et al., 1996). Naltrexone was used in a number of studies of individuals with autism to reduce hyperactivity, self-injurious behavior, and stereotypical and impulsive behavior (Campbell et al., 1993; Herman, Hammock, Arthur-Smith, Kuehl, & Appelgate 1989; Kolmen, Feldman, Handen, & Janosky, 1997; Panksepp & Lensing, 1991; Willemsen-Swinkels et al., 1996). In a randomized, double-blind, placebo controlled study by Feldman et al. (1999), naltrexone was not found to improve communication skills in children with autism. Bouvard et al. (1995) suggested that naltrexone only has therapeutic effects for a subgroup of children with autism who have certain plasma abnormalities. Possible side effects of naltrexone include excessive sedation, decreased appetite, and vomiting (Campbell et al., 1993). More research is necessary to establish naltrexone as a positive treatment for symptoms of autism (Gillberg, 1995; Campbell et al., 1993).

S-adenosylmethionine

S-adenosylmethionine (SAM-e) is involved in many biological reactions, including the methylation of DNA, phospholipids, and synthesis of several neurotransmitters (Zimmer & Molloy). It has been shown in some studies to be as effective as tricyclic antidepressants in clinical trials of depression, and in other studies has shown results equal to placebo (Zimmer & Molloy). There are no published studies of SAM-e in treatment of autism.

Hyperbaric Oxygen Therapy (HBOT)

Hyperbaric Oxygen Therapy (HBOT) is another alternative treatment that is being explored in children with autism (Levy & Hyman, 2008; Rossignol, Rossignol,

James, Melnyk, & Mumper, 2007). It provides pressurized oxygen at high pressures; possible side effects include ear pain and seizures. It is thought to increase blood flow and oxygen to the brain and decrease inflammation, and is currently being investigated in treating disorders of the central nervous system (Levy & Hyman, 2008). Because of its ability to reduce oxidative stress and inflammation, it is being explored as a treatment for autism (Rossignol et al., 2007). In an open clinical trial by Rossignol et al. (2007), parents of 18 children with autism treated with HBOT reported improvements in symptoms of autism, but subjective data and potential confounds affect the interpretability of these results (Levy & Hyman, 2008). There are currently no randomized controlled trials of HBOT in the treatment of symptoms of ASD available (Levy & Hyman, 2008).

Other Natural Supplements

Vitamin C is involved in the conversion of tryptophan to serotonin and tyrosine to dopamine; it also is a regulator of cellular immune function, and therefore might be useful in the treatment of ASD (Levy & Hyman, 2005). It is usually not used in an isolated fashion; rather, it is added to vitamin mixtures taken by children with ASD (Levy & Hyman, 2008). In a double-blind, placebo-controlled trial of children and adolescents with autism (Dolske, Spollen, McKay, Lancashire, & Tolbert, 1993), reduction of symptoms was noted in the treatment group, but the mechanism through which this worked was not clear. The study has not been replicated and Vitamin C has not gained popularity as a treatment for children with ASD (Levy & Hyman, 2008).

Melatonin is a hormone derived from serotonin that is stimulated by darkness and is involved in the regulation of the circadian rhythm (Brzezinski, 1997; Melke et al., 2008). It is available over the counter, and is popular among parents of children with ASD for regulating their children's sleep problems (Zimmer & Molloy). Children with ASD have been shown to have low levels of melatonin, the reason for which is unknown (Melke et al.). From their study, Melke et al. concluded that low melatonin level is a risk factor for ASD. In a small, randomized, placebo-controlled double-blind crossover trial of melatonin, the authors found significantly reduced sleep latency, a reduced number of night wakings, and an increased overall sleep time in children with ASD (Garstang & Wallis, 2006). In their review of melatonin treatment of children with neurodevelopmental disabilities and sleep difficulties, Phillips and Appleton (2004) concluded that melatonin improves sleep latency in this population. The studies included in the review were all randomized, double-blind, placebo controlled, crossover trials with a small sample size. Using parental report as an indicator of children's response to treatment, Andersen et al. (2008) concluded that melatonin was a safe and well-tolerated treatment of sleep-onset insomnia and sleep-maintenance insomnia in a sample of 107 children. Although there are few randomized clinical trials of melatonin for disturbed sleep in children with neurodevelopmental disabilities, it is still commonly prescribed (Phillips & Appleton).

St. John's wort is a plant extract often used for depression because it is thought to contain substances that inhibit the reuptake of dopamine, serotonin, and norepinephrine

(Charrois, Sadler, & Vohra, 2007; Zimmer & Molly). There are no published clinical trials regarding use of St. John's wort in the treatment of autism (Zimmer & Molloy).

Nutritional Supplements Targeting Impaired Methylation Capacity

Vitamin B12

James et al. (2004) noted in their study that abnormalities exist in the methionine cycle in autistic individuals. Methionine is an amino acid important in many cellular processes, and it is hypothesized that abnormalities in its vitamin B12 – dependent cycle could lead to altered neurotransmission and cell signaling and maladaptive immune responses (James et al., 2004; Zimmer & Molloy). Because of this, vitamin B12 is also currently being explored as a possible treatment for ASD (Zimmer & Molloy).

Glutathione

Another alternative treatment for autism is glutathione, an antioxidant produced as a result of abnormalities in the methionine cycle that was demonstrated to be reduced in levels in the serum of persons with autism (James et al., 2004). This has lead to increased use of glutathione supplement as a treatment for autism, where it is administered intravenously or through a patch. According to Zimmer and Molloy, there is no information available regarding the safety or efficacy of this treatment, and there is not enough information about this treatment and its side effects in the treatment of children with autism.

Vitamin B6 (pyridoxine) and Magnesium

The combination of vitamin B6 (pyridoxine) and magnesium has also used as alternative treatment for symptoms of autism for more than twenty years (Levy &

Hyman, 2008). This became popular in the 1960s after speech and language improvements were reported (Nye & Brice, 2005). Side effects from large doses of vitamin B6 (irritability, hypersensitivity to sound, enuresis) are countered with doses of magnesium (Mg; Rimland, Callaway, & Dreyfus, 1978). Overall, results have been mixed as to the benefit of megadoses of vitamin B6 and magnesium in children with autism, with some studies showing promising results (Martineau, Barthelemy, Garreau, & Lelord, 1985; Rimland et al. 1978) and others showing no improvement in ASD symptoms (Findling et al. 1997). Findling et al. suggested that placebo effects may play a role in results of studies of high doses of B6 and magnesium in children with autism. Negative side effects include peripheral neuropathy, photosensitivity, nausea, vomiting, abdominal pain, cardiovascular effects, sweating, flushing, and central nervous system effects (Zimmer & Molloy, 2007). In their review of studies examining the effects of vitamin B6-magnesium treatments in autism, Nye and Brice (2005) concluded that there is currently not enough evidence to recommend the use of this treatment in autism.

Folic Acid

Folic acid is also given as a multivitamin to address symptoms of ASD (Levy & Hyman, 2005). Like vitamin B12, glutathione, B6 and magnesium, folic acid is thought to play a role in methylation reactions (James et al., 2006). It has also been hypothesized that exposure to toxic agents that lead to oxidative stress can cause neuron damage and lead to regression seen in some children with autism (Kern & Jones, 2006). A trial of folinic acid and other supplements was thought to play a role in normalizing metabolic imbalance in children with autism, but clinical outcome data were not reported (James et

al., 2004). Also, folate abnormalities were found in a small group of children diagnosed with an ASD, and the authors suggested that children with autism and other developmental difficulties may have central nervous system folate abnormalities (Moretti et al., 2008). There are currently no randomized controlled treatment trials in the literature, and further study is needed (Levy & Hyman, 2008).

Heavy Metal Treatments

Some individuals believe that children with autism have a weakened ability to detoxify their bodies of heavy metals, and that they require metabolic therapies (Zimmer & Molloy, 2007). These individuals base their beliefs on an article by Hornig, Chian, and Lipkin (2004), that showed that mice with a genetic predisposition to be particularly sensitive to the effects of mercury demonstrated developmental delays and decreased socialization after being exposed to mercury. Although there are few peer-reviewed studies of the metabolism of heavy metals in children with ASD, much debate has been stimulated in academic circles as well as the general population about the safety of mercury/thimerosal in vaccines (Zimmer & Molloy). Thimerosal is a mercury-containing preservative that has been used in vaccines since the 1930s (Hviid, Stellfeld, Wohlfahrt, & Melbye, 2003; Madsen et al., 2003). It was discontinued from use in vaccines in the United States in 2001, but autism rates have continued to rise steadily (Fombonne, 2008). Contrary to popular belief, there is strong evidence suggesting that mercury or thimerosal in vaccines does not cause autism (Andrews et al., 2004; Hviid et al., 2003; Madsen et al., 2003; Fombonne, 2008).

Metallothionein

Metallothionein dysfunction is one theory of difficulty with heavy metal detoxification in children with autism. Metallothioneins are cellular proteins that neutralize harmful influences of exposure to toxic metals like mercury, zinc, and copper (Zimmer & Molloy, 2007; Russo, 2008). One study has shown high levels of anti-metallothionein antibodies in families of children with autism, but concluded that the presence of the antibodies was not a cause of autism, and might result from immune systems difficulties seen in other children with autism (Russo, 2008). Treatment involves giving the patient a cocktail containing the amino acid precursors to metallothionein, as well as selenium and glutathione, which are believed to be diminished when the body deals with a higher heavy-metal burden. Trials examining the benefits and risks of this treatment have not been published. (Zimmer and Molloy, 2007).

Chelation

Another therapy intended to remove heavy-metals from the body is chelation therapy. Designed to be used after acute exposure to a heavy metal, chelation agents [dimercaptosuccinic acid (DMSA) and edentate calcium disodium (CaEDTA)] pull heavy metals from body tissues that are excreted through urine (Zimmer & Molloy). Chelation therapy is untested in children with autism (Sinha et al.[a], 2006; Zimmer & Molloy) and has many common adverse side effects, including rash, diarrhea, nausea, vomiting, and increased liver function tests (Zimmer & Molloy). Chemicals used for chelation have not been approved by the Food and Drug Administration for treatment of autism (Levy & Hyman, 2005). Other dangerous effects that have been reported include

hematological, renal, and liver toxicity (Levy & Hyman, 2005). Deaths of children have been reported during treatment, making this a dangerous treatment with little evidence of benefits (Centers for Disease Control and Prevention, 2006).

Nonbiological Treatments

Auditory Integration Training

Behaviors and responses can be altered through nonbiological interventions, because experiences early in life can alter the neural composition of the brain (Levy & Hyman, 2005). Currently, most nonbiological CAM therapies cannot be explained by present understanding of the functioning of the brain (Levy & Hyman, 2005). For example, heightened sensitivities to sounds and difficulties with auditory perceptions are common symptoms in children with autism (Levy & Hyman, 2005). Zimmer and Molloy (p. 278) defined Auditory Integration Training (AIT) as "…a therapy in which children are screened for sound sensitivities and then delivered a tailored program of auditory input that filters out the sound frequencies to which they are sensitive." It is intended to "retrain" the ear through repeat exposure to altered sounds (Levy & Hyman, 2002; Levy & Hyman, 2005). Therapy sessions take place over a number of months and can be expensive (Zimmer and Molloy). Supporters claim that benefits of AIT include improved attention, improved auditory processing, decreased irritability, reduced lethargy, improved expressive language, and improved auditory comprehension (American Academy of Pediatrics, 1998). Reviews of the literature on auditory integration training revealed studies that did not follow strict experimental guidelines and had varied results (American Academy of Pediatrics, 1998; Sinha, Silove, Wheeler,

& Williams, 2004). Overall, the reviewers concluded that not enough evidence exists to recommend this as a therapy for children with autism (American Academy of Pediatrics, 1998; Sinha et al., 2004).

Sensory Integration Therapy

Sensory integration therapy is intended to address the abnormal responses to typical stimuli displayed by some children with ASDs. It involves exposing the child to different sensory-based experiences, such as swinging, joint compressions, holding, brushing, and squeezing (Zimmer & Molloy). There are few well-designed clinical trials examining sensory integration therapy (Zimmer & Molloy).

Massage Therapy

Field et al. (1997) suggested that massage therapy may improve the attention of children with autism. In their study, children with autism showed less stereotypical behaviors (as measured by the Autism Behavior Checklist) and showed improved social relating (as measured by the Early Social Communicating Scales) after a month of twice weekly 20-minute massages conducted by massage therapists. Massage therapy has also been examined through a clinical trial involving 3- to 6- year olds with an ASD. Parents were trained by a massage therapist and delivered a massage 15 minutes prior to bedtime (Escalona, Field, Singer-Strunck, Cullen, & Hartshorn, 2001). The intervention group displayed fewer stereotypic behaviors, improvement in on-task behaviors, fewer sleep problems, and improved social abilities. Massage therapy in children with autism is an area in need of further study (Zimmer & Molloy, 2007). Hartshorn et al. suggested that a similar treatment, called creative movement therapy, that is also touted to improve the

attention and behavior of children with autism. In this study, children with autism aged 3 to 7 years were led through different movements by a therapist. Movements included jumping in and out of hoops and moving through an obstacle course of different gym mats. After two months of twice-weekly movement therapy sessions, the children showed improvement in response to touch, more on-task behavior, less time wandering, and improved compliance with the teacher (Hartshorn et al., 2001).

Craniosacral Manipulation

Craniosacral manipulation is a form of therapeutic touch performed by chiropractors, physical therapists, and occupational therapists who are trained in its use (Levy & Hyman, 2002). The therapist is believed to be able to sense the fluid waves of spinal fluid, and applies touch to manipulate these waves (Levy & Hyman, 2005; Zimmer & Molloy). There is no evidence that humans can detect through touch changes in spinal fluid pressure at the skin surface (Moran & Gibbons, 2001). While there are no controlled studies evaluating this therapy (Levy & Hyman, 2008; Zimmer & Molloy), therapeutic touch is often used as part of the overall sensory program in academic settings and it is possible that therapeutic touch as well as circumstances surrounding the therapy (e.g., a relaxing atmosphere) might produce changes in behavior (Levy & Hyman, 2005).

Facilitated Communication

Facilitated communication was designed to allow individuals with severe disabilities in motor skills to communicate with a typewriter or other communication device (Zimmer & Molloy). Because motor skills deficits have been observed in some

children with autism, this method was put forward to assist these children in communicating. The method involves another person (the facilitator) who supports the child's hand to allow him or her more ease in choosing letters on the communication device. Several studies examining the influence of the facilitator on the child's communication (i.e., Eberlin, McConnachie, Ibel, & Volpe, 1993; Regal, Rooney, & Wandas, 1994) found that children with autism and other developmentally disabled individuals were unable to answer questions unless the facilitator knew the answer (Zimmer & Molloy). In his review of studies on facilitated communication, Mostert (2001) concluded that this therapy is most likely to be confounded by the subconscious direction of the facilitator, and does not show true communication on the part of the individual. The American Academy of Pediatrics (1998) stated that current research does not support claims that facilitated communication works, and should not be used except in research.

Music Therapy

Music therapy involves using music to encourage the participant to take part in a relationship-focused exchange (Wigram & Gold, 2006). Initiating and sustaining joint attention and reciprocity are clear deficits in children with autism (Maestro et al., 2002), and initiating and sustaining joint attention is a primary therapeutic goal in music therapy (Wigram & Gold, 2005). A few non-experimental studies have examined music therapy with children with ASDs (i.e., Edgerton, 1994) and have reported an increase in communication and affecting relationship patterns. A review of studies of music therapy (Whipple, 2004) showed mixed results, and questionable designs (Wigram & Gold,

2005). No studies with control groups or experimental designs have been conducted (Zimmer & Molloy). While not directly a form of music therapy, interactive metronome is a theoretical treatment where a musical metronome is used to alter the timing of information presented to children to enhance their concentration. No studies have been published examining this treatment (Levy & Hyman, 2002).

Behavioral Optometry

Because many children with autism display stereotyped behaviors involving vision (close visual inspection of items, examining through peripheral field of vision) the use of prism lenses has been reported to improve behavior symptoms in children with autism (Kaplan, Edelson, & Seip, 1998). In their study, 18 children with autism showed a decrease in behavior problems after wearing ambient prism lenses for two months. Levy and Hyman (2005) classified this as a type of "behavioral optometry." Due to the lack of peer-reviewed literature on this topic (Levy & Hyman, 2005), the American Academy of Pediatrics (1998) does not recommend any type of optometric therapy for children with disabilities.

CHAPTER III

METHODS

The purpose of this study was to examine factors that contribute to parents' decisions to treat their child with ASD with a complementary or alternative (CAM) treatment. The study used an electronic survey approach to gain information from parents/guardians of individuals with ASD related to CAM.

Participants

Data for this study was collected from parents of children with an autism spectrum disorder. The survey was made available online via SurveyMonkey® (http://www.surveymonkey.com/) after obtaining approval by the Institutional Review Board. Email invitations to participate were then sent to approximately 800 support groups for parents of children with autism. Email addresses were obtained by searching for parent support groups on the websites autismspeaks.org and autism-society.org. Because only those parents/guardians who have access and use online resources could participate, there is selection bias in the sample and there is no means of determining response rate. In total, 453 responses were collected; one respondent indicated he/she was the child with an ASD and their data was excluded; this resulted in 452 usable surveys. Overall, the responding parents/guardians were mothers, fathers, and grandmothers. The majority self-identified as White (86.7%), with a majority having attained a college education (41.8%). The mean age of respondents was 41.58 (SD= 8.07), and the mean income was $89,106.66 (SD = $61601.88). Additional demographic information is provided in Table 1.

Table 1 Study Participants (N=452)

	Frequencies	*Percent*
Relationship to Child		
Mother	413	91.4
Father	33	7.3
Grandmother	5	1.1
Other	1	.2
No response	0	0
Marital Status		
Married	384	85
Single	16	3.5
Widowed	9	2
Divorced	40	8.8
No response	3	.7
Ethnicity		
White	392	86.7
Black or African American	20	4.4
American Indian/Alaskan Native	1	.2
Asian	8	1.8
Hispanic or Latino	16	3.5
Biracial	5	1.1
Other	6	1.3
No Response	4	.9
Number of children in family		
One	78	17.3
Two	226	50
Three	92	20.4
Four	33	7.3
Five	11	2.4
Six	7	.9
Eight	1	.2
Nine	1	.2
No Response	6	1.3
Country of Birth		
United States	416	92
Germany	5	1.1

Table 1, Continued

	Frequencies	*Percent*
Canada	4	.9
United Kingdom	5	1.1
Colombia	2	.4
Ethiopia	1	.2
Jamaica	1	.2
Cuba	1	.2
Argentina	2	.4
India	1	.2
Italy	1	.2
Mexico	1	.2
Venezuela	1	.2
Japan	1	.2
Indonesia	1	.2
Panama	1	.2
No Response	8	1.8
Country lived in majority of life		
United States	419	92.7
Canada	3	.7
Germany	2	.4
United Kingdom	2	.4
Argentina	2	.4
Italy	1	.2
Mexico	1	.2
South Africa	1	.2
Venezuela	1	.2
Colombia	1	.2
Indonesia	1	.2
No Response	18	4
Level of education		
Less than high school	1	.2
High school diploma	32	7.1
Technical School/Some college	104	23
College graduate	189	41.8
Master's degree	103	22.8
Specialist or Ed.S. Degree	2	.4
Doctorate	17	3.8
No response	4	.9

Table 1, Continued

	Mean	*SD*
Mean Age	41.58	8.07
Combined Family Income	89106.66	61601.88

Procedures

Prior to conducting this study, the researcher obtained permission to work with human participants from the Texas A&M Institutional Review Board (IRB). The questionnaire was entered into SurveyMonkey® and assigned a URL for access. Invitations to participate were then sent to approximately 800 support groups for parents of children with autism. Email addresses were obtained by searching for parent support groups on the websites autismspeaks.org and autism-society.org. All data was recorded anonymously by SurveyMonkey®, with a respondent number attached to the data, and the data then extracted into SPSS from SurveyMonkey®.

Measures

A questionnaire was developed by the researcher and reviewed by members of the dissertation committee. On the questionnaire, participants were asked to complete questions regarding their use of and feelings toward different types of treatments, their perception of their child's behavior, and demographic information. The parent was also asked to indicate the severity of their child's autistic behaviors on a line with end points of Mild to Severe. This was intended to provide an indication of the parent's perceptions of the severity of their child's problems. Codes were attached to the data as it was entered into Survey Monkey ™, so that it was not be identifiable in the data base. A copy of the questionnaire is provided in Appendix A.

Data Analyses

All data were checked prior to beginning the analyses. In some instances, the data as provided by SurveyMonkey® needed to be aggregated to create variables for analysis. As will be seen in Chapter IV, the analyses included frequency counts, descriptive information (means and standard deviations), correlations, and regression. The data are sufficient to address the questions with the sample size obtained.

CHAPTER IV

RESULTS

This chapter provides the results of the analyses. Data from the survey were transformed into SPSS and any aggregate variables needed were created. The results are presented by research question as follows:

1. Do parents of children with an ASD who exhibit more severe behavioral symptoms gravitate toward complementary and alternative (CAM) treatments and therapies? To what extent does severity predict the number of CAMs ever used?

It is not known the extent to which severity is associated with individual CAM treatments. It was hypothesized that parents of children with more severe behavioral symptoms would seek out more complementary and alternative treatments and therapies. To address this question, the frequencies for individual CAMs, as well as total CAMs used or currently using were determined. Two-way correlational analysis was then conducted to determine the level of relationship between the use of specific CAMs with severity as indicated by distance on the severity line on the questionnaire. Results are presented in Table 2. In addition, regression was used to test the hypothesis that severity would predict the total number of CAMs used (see Table 3).

Table 2 Treatment by Severity Correlations

	Severity	
Treatment	*Tried in the Past*	*Currently Using*
Gluten-Free/Casein-Free (GFCF) Diet	.16***	-.03
Specific Carbohydrate diet	.09*	.06
Digestive enzymes	.06	-.02
Probiotics	.13**	-.06
Antifungals	.08	.07
Antibiotics	-.01	.07
D-Cycloserine	---	---
Intravenous Immunoglobulin	.09	.05
Secretin	.21***	.02
Dimethylglycine	.08	.01
Omega-3 Fatty acid supplements	.16***	-.10*
Tryptophan	.06	-.02
Tyrosine	-.001	.02
Cyproheptadine	-.08	.08
Naltrexone	-.02	.01
SAM-E (S-adenosylmethionine)	.12*	.05
Oxytocin infusion	-.02	-.07
Hyperbaric oxygen therapy	.06	-.002
Vitamin C	.03	-.01
Melatonin	.10*	.11*
St. John's wort	.04	.05
Vitamin B12	.06	-.01
Glutathione	.12**	-.05
Vitamin B6 and magnesium	.09	.01
Folic acid	.09	.02
Metallothionein	.07	-.04
Chelation	.07	-.04
Auditory integration training	.04	-.04
Sensory integration therapy	.001	.10*
Massage therapy	.04	.01
Craniosacral manipulation	.07	-.003
Facilitated communication	.08	.13**
Music therapy	.09	.03
Behavioral optometry	.03	.01

Results indicated a statistically significant relationship between severity of symptoms with having tried treatments in the past, and with currently using treatments. Treatments tried in the past that were correlated with greater severity of symptoms included: Gluten-Free/Casein-Free diet (.16, $p \leq .001$), Secretin (.21, $p \leq .001$), Omega-3 Fatty acid supplements (.16, $p \leq .001$), Probiotics (.13, $p \leq .01$), Glutathione (.12, $p \leq .01$), Specific Carbohydrate diet (.09, $p \leq .05$), SAM-E (S-adenosylmethionine) (.12, $p \leq .05$), and Melatonin (.10, $p \leq .05$). Treatments that were currently being used that were correlated with greater severity of symptoms included: Facilitated Communication (.13, $p \leq .01$), Melatonin, (.11, $p \leq .05$), and Sensory integration therapy (.10, $p \leq .05$). Interestingly, current use of Omega-3 Fatty Acid supplements (-.10 , $p \leq .05$) had a negative relationship with severity of symptoms, while previous use of Omega-3 was positively correlated with greater severity of symptoms. In addition, it was noted that no one endorsed ever having used D-Cycloserine. Severity of symptoms was not predictive of the total number of CAMs used.

Table 3 Regression for Severity and CAM Use

Variable	*B*	*SE B*	*β*	*t*	*Sig.*
Total Number of CAMs Ever Used	.313	.113	.131	2.779	.006

Note. $R^2 = .017$; Adjusted $R^2 = .015$; CI for $\beta = .092$ to .535

2. To what extent does demographic information of the parents affect their treatment decision for their child with an ASD?

It was hypothesized that parent characteristics (e.g., marital status, country of origin, length of time in the United States, educational level, and employment status) will have an impact on their use of CAM. To address this question, regression was used. Variables of marital status, country of origin, educational level, and employment status were coded and used as independent variables. Country of origin was collapsed to two groups – born in the U.S. or not born in the U.S., due to the number of differing countries of origin. Educational level was also collapsed into 5 groups: less than high school, high school diploma, technical school/some college, college graduate, and graduate level degree. The total number of CAMs used was entered as the dependent variable. Results are presented in Table 4.

Table 4 Demographic Variables as Predictors of CAM Use

Variable	*B*	*SE*	*B*	*t*	*Sig.*
Marital Status	-1.24	.61	-.1	-2.02	.04
Country of Origin	-.83	1.11	-.04	-.75	.45
Educational Level	1	.3	.16	3.39	.001
Ethnicity	-.1	.1	-.05	-.93	.35

Note. F (4, 435) = 3.98, $p = .003$

Based on the multivariate regression, educational level ($p \leq .001$) and marital status ($p \leq .05$) were predictive of CAM use. In order to better understand the ways in which marital status and educational level were predictive CAM use, Analysis of Variance was used. Results are presented in Table 5 and Table 6.

Table 5 Analysis of Variance – Marital Status

Variable	*N*	*Mean*	*Standard Deviation*	*F*	*p*
Single	16	4.5	4.13		
Married	384	6.4	5.8		
Divorced	40	3.8	3.35		
Widowed	9	3.89	2.42		
Total	449	6.06	5.59	3.62	.01

Table 6 Analysis of Variance – Educational Level

Variable	*N*	*Mean*	*Standard Deviation*	*F*	*p*
High School Diploma	32	4.47	5.38		
Technical School/Some College	104	4.85	4.58		
College Graduate	189	6.45	5.47		
Graduate level degree	122	6.96	6.3		
Total	447	6.07	5.57	3.95	.008

No interaction effect was found (p=.76). Results of a Tukey analysis indicated that individuals with a graduate level degree were much more likely (p=.002) to use CAM than those with technical school/some college. In addition, respondents who were married were significantly more likely to use CAMs than those who were divorced (p=.05).

3. Are there specific characteristics of the CAM treatments that impact decision-making (e.g., cost, accessibility, the number of available treatments, research base, treatment acceptability)?

It was hypothesized that specific characteristics of CAM treatments would impact decision-making. As with Question 2, regression was used to determine the extent to which these factors impact on the use of CAM treatments. Cost, accessibility,

availability, research base, and acceptability were all coded and entered as independent variables. Total number of CAM treatments was the independent variable. Results are provided in Table 7. These results indicate that accessibility ($p \leq .05$) and acceptance ($p \leq .05$) were predictive of CAM use.

Table 7 CAM Characteristics as Predictors of CAM Use

Variable	*B*	*SE*	*β*	*t*	*Sig.*
Cost	-.31	.26	-.06	-1.20	.23
Accessibility	.64	.31	.12	2.06	.04
Research	.48	.32	.09	1.51	.13
Side effects	-.47	.33	-.86	-1.44	.15
Difficulty	.40	.33	.07	1.22	.22
Acceptance	.77	.32	.14	2.41	.02

Note. F (6, 429) = 5.54, $p < .001$

4. What are some of the barriers to treatment (belief that Autism is/is not curable, ease of obtaining information, number of medical professionals consulted, and experience with health care system)?

It was hypothesized that there would be multiple barriers to treatment. Results for each of these potential barriers were calculated and are presented in Table 8. Based on responses, 78.1% of respondents indicated a belief that autism was not curable, while 20.1% indicated a belief that autism is curable. When asked to rate the level of difficulty to obtain information about treatments, a majority of respondents (42.5%) indicated that it is "somewhat hard" to obtain information, while 25.9% indicated that it is "not hard" to obtain information, 17.9% indicated that it is "hard" to obtain information, 8% indicated that it is "very hard" to obtain information, and 5.1% indicated that it is "extremely hard" to obtain information.

Regarding overall experience with the healthcare system, a majority (39.8%) indicated having had a "good" overall experience. 29% of respondents indicated a "bad" overall experience, and 13.1% indicated a "very bad" experience. 15% indicated a "very good" experience, and 1.8% indicated an "extremely good" experience. In addition, the respondents indicated consulting with an average number of 4.1 medical professionals (SD = 5.89) when seeking a diagnosis for their child.

Table 8 Barriers to Treatment

	Frequencies	*Percent*
Belief that autism is not curable	353	78.1
Belief that autism is curable	91	20.1
No response	8	1.8
Obtaining information about treatments is:		
Not hard	117	25.9
Somewhat hard	192	42.5
Hard	81	17.9
Very hard	36	8
Extremely hard	23	5.1
No response	3	.7
Overall Experience with healthcare system:		
Extremely good	8	1.8
Very good	68	15
Good	180	39.8
Bad	131	29
Very bad	59	13.1
No response	6	1.3
	Mean	*SD*
Number of Professionals Consulted	4.1	5.89

Supplemental Information

Two questions on the survey were open-ended. There were 258 responses to the question, "Have you tried any treatments that are not listed above?" Parents endorsed several treatments that were not listed in the survey, and they also included treatments that are not considered CAMs. Several medications were endorsed, including: Abilify, Prozac, Ritalin, Vyvanse, Risperidone, Risperidol, Lexapro, Zoloft, Stratterea, Adderall, Celexa, Concerta, Intuniv, Clonidine, Aricept, Metroprolol, and Focalin. Medical marijuana and Respen-A were also endorsed as a treatments. In addition, supplements and vitamins such as Vitamins C, D, and E, Iron, Zinc, Enhansa (curcumin supplement), Ecchinacea, Inositol, Syndion, rhodiola, Agrisept-L (citrus seed extract) and olive leaf extract were endorsed.

Different types of diets were also endorsed. These included: the Feingold diet, the "rotation" diet, the "Body Ecology" diet, diets free of artificial preservatives, soy, lactose, corn products, MSG, yeast, and organic diets. Taking baths with Epsom salts was also endorsed as a treatment. Several parents endorsed using behavior modification techniques and programs, such as Applied Behavior Analysis, the Lovaas method, TEACCH, and Floortime. Speech therapy, occupational therapy, and physical therapy were endorsed as treatments.

Parents also indicated that their children participated in different types of counseling (e.g., cognitive-behavioral therapy, "talk therapy," "therapeutic listening," "hypno-therapy" "emotional development therapy") and social skills groups. Some other treatments endorsed were "joint compressions," reflexology, acupuncture,

aromatherapy, yoga, "brushing," hippotherapy, equine therapy, dolphin therapy, and "foot zoning." Reiki, which according to Hyman and Levy (2010) is "…a form of spiritual healing in which the practitioner channels "universal life energy" to the recipient through light touch," (p. 287) was also endorsed. Several parents indicated that they considered using "toxin-free" products in the home (e.g., shampoo, laundry detergent) as a type of treatment. Finally, Heilkunst, Nambudripad's Allergy Elimination Techniques (NAET), Sound and Light Therapy, Neurofeedback, Oxidative stress relief were indicated.

A total of 426 people responded to the question, "What behaviors most concern you about your child?" Several respondents described maladaptive behaviors as most concerning. These were described as temper tantrums, meltdowns, outbursts, fits, and rages; behaviors that involved screaming; behaviors that were aggressive or violent. Physical aggression (e.g., hitting, biting, and clawing) and self-injurious behaviors (e.g., head-banging, biting oneself) were also endorsed as main areas of concern. Several parents indicated concerns that their children lack "common sense" or do not have a sense of "personal safety," which often causes them to be in dangerous situations (e.g., running into the street). Oppositional Defiant Disorder (ODD) was specifically mentioned, as well as Obsessive-Compulsive Disorder (OCD). Sexually inappropriate behaviors (e.g., making inappropriate comments, touching other people, masturbating in public) were listed as a main area of concern as well.

Not surprisingly, several respondents indicated several areas of communication as most concerning. Difficulties with speech (including being non-verbal), speech

development delays, echolalia, functional communication, and understanding pragmatics (casual conversation) were listed as main areas of concern. Their child's difficulties with nonverbal communication were also endorsed as a main area of concern. Also related to behaviors in the diagnostic criteria, repetitive, ritualistic, and stereotypical behaviors (e.g., arm flapping) were endorsed. In the academic domain, parents endorsed difficulties with learning, including reading and writing disabilities, as main areas of concern. Fine and gross motor skills were also a major area of concern. Social skills were also endorsed as a main area of concern. Parents indicated that their children have a lack of awareness of others, difficulty with empathy, and difficulty understanding others' points of view. The ability to make friends, relate to peers, and a lack of desire to make friends or interact with other children were also areas that were endorsed as areas of concern. Parents of older children on the spectrum also had some specific concerns. One parent of a college student with an ASD mentioned that difficulties understanding subtleties of social interactions with fellow students and professors was her biggest concern. In addition, other parents of older children endorsed "lack of a social life" as their biggest concern. Navigating the social demands of holding a regular job after high school, the ability to be self-sufficient and manage one's own finances, were also endorsed as areas of concern. One parent expressed concern that their child is "easily taken advantage of," due to difficulty understanding social norms. Difficulties with transitions or changes in routine, rigidity, and "black and white" thinking were endorsed as areas of concern. In addition, having a limited range of interests, or perseverating on "strange topics or ideas" was listed as a main area of concern.

Potentially related to the choices for CAM treatments, sensory behaviors, such as "stimming," biting and mouthing objects, and hypersensitivity to sounds were frequent. Concerns about stimming behaviors were often related to issues of safety. For example, one parent said that their child enjoyed staring into bright light (including the sun). Feeding disorders (e.g., Pica), as well as their children having a limited diet due to being aversive to sensory aspects of some foods (e.g., texture) were concern for some parents. Heightened sensitivity to sensory input was also listed as a concern.

Emotional concerns, such as depression, anxiety, and self-esteem, were endorsed by some parents. Attention-Deficit Hyperactivity Disorder (ADHD) was specifically endorsed as a concern by several parents. In addition, symptoms related to ADHD (e.g., inattention, hyperactivity, impulsivity) were often mentioned. Difficulties with sleep (e.g., abnormal sleep patterns) were endorsed by some parents as were gastrointestinal difficulties (e.g., bowel discomfort) and toilet training. Notably, one parent endorsed having a child who was "recovered," saying that the child had "lost his diagnosis and shows no signs of autism."

CHAPTER V

CONCLUSIONS

The purpose of this study was to examine factors that contribute to parents' decisions to treat their child with ASD using a complementary or alternative treatment. In order to determine this, an online survey was developed, and invitations to participate were sent to approximately 800 support groups for parents of children with autism. Results from 452 respondents indicated that a statistically significant relationship existed between severity of symptoms with having tried treatments in the past, as well as with currently using treatments.

Overall, the responding parents/guardians were mothers, fathers, and grandmothers with a mean age of 41.58. The majority self-identified as White (86.7%), with a majority having attained a college education (41.8%) and of moderate income ($89,106.66). 100% of the participants in the study indicated they had tried a CAM in the past, or were currently using one.

Severity and CAM Treatment

Treatments tried in the past that were correlated with greater severity of symptoms included: Gluten-Free/Casein-Free diet, Secretin, Omega-3 Fatty acid supplements, Probiotics, Glutathione, Specific Carbohydrate diet, SAM-E (S-adenosylmethionine), and Melatonin. Treatments that were currently being used that were correlated with greater severity of symptoms included: Facilitated Communication, Melatonin, and Sensory integration therapy.

Socioeconomic and Educational Level

Educational level and marital status were found to be predictive of CAM use. Specifically, individuals who were married were more likely to use CAMs than those who were divorced. In addition, individuals who endorsed having attained a graduate level degree were more likely to report use of CAMs with their children than those having attained an educational level of technical school/some college.

CAM Characteristics

Although when taken together characteristics of treatments themselves are not predictive of CAM use, results indicate that accessibility of treatments and the child's acceptance of the treatments were predictive of CAM use.

Barriers to Treatment

As an initial barrier, 78.1% of respondents indicated a belief that autism is not curable. When asked to rate the level of difficulty to obtain information about treatments, a majority of respondents (42.5%) indicated that it is "somewhat hard" to obtain information. Regarding overall experience with the healthcare system, a majority (39.8%) indicated having had a "good" overall experience. At the same time, however, the respondents indicated consulting with an average number of 4.1 medical professionals when seeking a diagnosis for their child.

Other Treatment Approaches

When asked about other treatment approaches that were not listed on the survey, parents endorsed several treatments that would also be considered CAM treatments (e.g., dolphin therapy, Reiki), as well as treatments that are considered conventional (e.g.,

medications, Applied Behavior Analysis). Several medications, supplements, and vitamins were endorsed. Different types of diets, counseling, and therapies based on behavior modification techniques were also endorsed. Some parents also endorsed the use of "toxin-free" products in the home as a type of treatment.

Limitations

There are several limitations to this study. The survey was only available online, so individuals without access to a computer were unable to complete the study. Recruitment was extensive, but it is not possible to determine a return rate, furthering the possibility of selection bias. No control for severity or recency of diagnosis was included.

Conclusions and Future Directions for Research

Every parent who participated in this study indicated that they had either tried a CAM treatment in the past, or were currently using a CAM treatment with their child with ASD. Married parents endorsed more use of CAM treatments than divorced parents. In addition, individuals with graduate level degrees endorsed more use of CAM treatments than those with technical school/some college. Several reasons for these findings can be hypothesized. Individuals who are married possibly benefit from mutual support from one another when seeking out treatments that are considered alternative. It may be informative for future researchers to seek more detailed information regarding marital status (e.g., whether an individual who endorses himself or herself as currently "married" is with the child's other biological parent). Regarding educational level, individuals with higher levels of education are possibly more comfortable seeking out

alternative sources of information, and are more comfortable seeking out multiple professional opinions.

When asked to give information regarding other treatment approaches that were being used that were not listed on the survey, parents endorsed some different treatments that would be considered complementary and alternative (e.g., dolphin therapy), and also listed treatments that are considered to be conventional (e.g., medications, therapies based on behavioral principles). Regarding behaviors considered most concerning, parents described physically aggressive behaviors and self-injurious behaviors as main areas of concern. Concerns about personal safety, sexually inappropriate behaviors, communication, academics, social skills, and emotionality (e.g., anxiety and depression) were also endorsed. Overall, it appears that a combination of individual characteristics of parents, as well as characteristics of the treatments, influence treatment decisions.

The findings of this study are important for a number of reasons. As has been shown, use of CAM treatments is growing among the population of children with autism. However, information regarding the reasons parents decide to use these treatments with their children is relatively sparse. In addition, while research has shown some promising results regarding use of some treatments, further information regarding their usefulness is needed before they are recommended (Zimmer & Molloy, 2007; Zimmer, 2011). In addition, while many parents endorsed using different types of animal therapies (e.g., dolphin therapy, equine therapy) with their children, these methods are generally not included in literature regarding CAM treatments with children with autism. Further investigation into these therapies is warranted, as many families

appear to seek out these therapies and regard them as treatments. As many CAM treatments are being used, methodologically sound research regarding efficacy and safety of these treatments is needed. The same type of random clinical trials for medications and evidence based practices should be in place for CAM treatments. This would include (but is not limited to) taking into consideration the use of clear diagnostic criteria, sample size, control groups, and subject treatment status (Zimmer and Molloy, 2007).

In addition, ways to educate and disseminate information to families making treatment decisions is needed. It will be important that medical professionals working with these families become well-versed in the different types of CAM treatments available, and are able to sensitively and clearly communicate information regarding these treatments. Parents should be made aware of the extent and quality of research conducted on potential treatments, including possible side effects and safety concerns associated with the use of some treatments. Professionals working with parents should also be able to use their knowledge of scientifically-based treatments when consulting with parents, and be able to recommend empirically-supported treatments.

REFERENCES

American Academy of Pediatrics. Committee on Children with Disabilities. (1998). Auditory integration training and facilitated communication for autism. *Pediatrics, 102*(2), 431-433.

American Academy of Pediatrics (2001). The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics, 107*(5), 1221-1226.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

Amminger, G.P., Berger, G.E., Schafer, M.R., Klier, C., Friedrich, M.H., & Feucht, M. (2007). Omega-3 fatty acids supplementation in children with autism: A double-blind randomized, placebo-controlled pilot study. *Biological Psychiatry, 61*(4), 551-553.

Anderson, G.M., Horne, W.C., Chatterjee, D., & Cohen, D.J. (1990). The hyperserotonemia of autism. *Annals of the New York Academy of Sciences, 600,* 331-342.

Andrews, N., Miller, E., Grant, A., Stowe, J., Osborne, V., & Taylor, B. (2004). Thimerosal exposure in infants and developmental disorders: A retrospective cohort study in the United Kingdom does not support a causal association. *Pediatrics, 114*(3), 584-591.

Arnold, G.L., Hyman, S.L., Mooney, R.A., & Kirby, R.S. (2003). Plasma amino acids profiles in children with autism: Potential risk of nutritional deficiencies. *Journal of Autism and Developmental Disorders, 33*(4), 449-454.

Bell, J.G., MacKinlay, E.E., Dick, J.R., MacDonald, D.J., Boyle, R.M., & Glen, A.C.A. (2004). Essential fatty acids and phospholipase A_2 in autistic spectrum disorders. *Prostaglandins, Leukotrienes and Essential Fatty Acids, 71*(4), 201-204.

Bennett, C.N., & Horrobin, D.F. (2000). Gene targets related to phospholipid and fatty acid metabolism in schizophrenia and other psychiatric disorders: An update. *Prostaglandins, Leukotrienes and Essential Fatty Acids, 63*(1-2), 47-59.

Black, C., Kaye, J.A., & Jick, H. (2002). Relation of childhood gastrointestinal disorders to autism: nested case-control study using data from the UK General Practice Research Database. *British Medical Journal, 325*(7361), 419-421.

Bolman, W.M., & Richmond, J.A. (1999). A double-blind, placebo-controlled, crossover pilot trial of low dose dimethylglycine in patients with autistic disorder. *Journal of Autism and Developmental Disorders, 29*(3), 191-194.

Bouvard, M.P., Leboyer, M., Launay, J.M., Recasens, C., Plumet, M., Waller-Perotte, D., et al. (1995). Low-dose naltrexone effects on plasma chemistries and clinical symptoms in autism: A double-blind, placebo-controlled study. *Psychiatry Research, 58*(3), 191-201.

Brudnak, M.A., Rimland, B., Kerry, R.E., Dailey, M., Taylor, R., Stayton, B., Waickman, F., Waickman, M., Pangborn, J., & Buchholz, I. (2002). Enzyme-based therapy for autism spectrum disorders: Is it worth another look? *Medical Hypotheses, 58*(5), 422-428.

Brzezinski, A. (1997). Melatonin in humans. *New England Journal of Medicine, 336*(3), 186-195.

Bu, B., Ashwood, P., Harvey, D., King, I.B., Van de Water, J., & Jin, L.-W. (2006). Fatty acid composition of red blood cell phospholipids in children with autism. *Prostaglandins, Leukotrienes and Essential Fatty Acids, 74*(4), 215-221.

Campbell, M., Anderson, L.T., Small, A.M., Adams, P., Gonzalez, N.M., & Ernst, M. (1993). Naltrexone in autistic children: Behavioral symptoms and attentional learning. *Journal of the American Academy of Child and Adolescent Psychiatry, 32*(6), 1283-1291.

Campbell, M., Schopler, E., Cueva, J.E., & Hallin, A. (1996). Treatment of autistic disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*(2), 134-143.

Carter, S.L. (2008). Further conceptualization of treatment acceptability. *Education and Training in Developmental Disabilities, 43*(2), 135-143.

Cazzullo, A.G., Musetti, M.C., Musetti, L., Bajo, S., Sacerdote, P., & Panerai, A. (1999). β-Endorphin levels in peripheral blood mononuclear cells and long-term naltrexone treatment in autistic children. *European Neuropsychopharmacology, 9*(4), 361-366.

Centers for Disease Control and Prevention (2009). Prevalence of Autism Spectrum Disorders: Autism and Developmental Disabilities Monitoring Network, United States, 2006. Retrieved April 25, 2011 from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm

Centers for Disease Control and Prevention (2006, March). Deaths associated with hypocalcemia from chelation therapy: Texas, Pennsylvania, and Oregon, 2003-2005. *Morbidity and Mortality Weekly Report, 55*(8), 204-207.

Challman, T.D. (2008). Complementary and alternative medicine in autism: Promises kept? In B.K. Shapiro & P.J. Accardo (Eds.), *Autism frontiers: Clinical issues and innovations* (pp. 177-190). Baltimore, MD: Paul H Brookes Publishing.

Charrois, T.L., Sadler, C., & Vohra, S. (2007). Complementary, holistic, and integrative medicine: St. John's wort. *Pediatrics in Review, 28*(2), 69-72.

Chez, M.G., Buchanan, C.P., Aimonovitch, M.C., Becker, M., Schaefer, K., Black, C., et al. (2002). Double-blind, placebo-controlled study of L-Carnosine supplementation in children with autistic spectrum disorders. *Journal of Child Neurology, 17*(11), 833-837.

Christon, L.M., Mackintosh, V.H., & Myers, B.J. (2010). Use of complementary and alternative medicine (CAM) treatments by parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 4* (2), 249-259.

Connolly, A.M., Chez, M.G., Pestronk, A., Arnold, S.T., Mehta, S., & Deuel, R.K. (1999). Serum autoantibodies to brain in Landau-Kleffner variant, autism, and other neurologic disorders. *The Journal of Pediatrics, 134*(5), 607-613.

Coonrod, E.E., & Stone, W.L. (2004). Early concerns of parents with autistic and nonautistic disorders. *Infants and Young Children, 17*(3), 258-269.

Croonenberghs, J., Bosmans, E., Deboutte, D., Kenis, G., & Maes, M. (2002). Activation of the inflammatory response system in autism. *Neuropsychobiology, 45*(1), 1-6.

Daley, T.C. (2004). From symptom recognition to diagnosis: Children with autism in urban India. *Social Science & Medicine, 58*(7), 1323-1335.

Dolske, M.C., Spollen, J., McKay, S., Lancashire, E., & Tolbert, L. (1993). A preliminary trial of ascorbic acid as supplemental therapy for autism. *Progress in Neuro-Psychopharmacology & Biological Psychiatry, 17*(5), 765-774.

Eberlin, M., McConnachie, G., Ibel, S., & Volpe, L. (1993). Facilitated communication: A failure to replicate the phenomenon. *Journal of Autism and Developmental Disorders, 23*(3), 507-530.

Elder, J.H., 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 and Developmental Disorders, 36*(3), 413-420.

Escalona, A., Field, T., Singer-Strunck, R., Cullen, C., & Hartshorn, K. (2001). Brief Report: Improvements in the behavior of children with autism following massage therapy. *Journal of Autism and Developmental Disorders, 31*(5), 513-516.

Feldman, H.M., Kolmen, B.K., & Gonzaga, A.M. (1999). Naltrexone and communication skills in young children with autism. *Journal of the Academy of Child and Adolescent Psychiatry, 38*(5), 587-593.

Field, T., Lasko, D., Mundy, P., Henteleff, T., Kabot, S., Talpins, S., et al. (1997). Autistic children's attentiveness and responsitivity improve after touch therapy. *Journal of Autism and Developmental Disorders, 27*(3), 333-338.

Findling, R.L., Maxwell, K., Scotese-Wojtila, L., Huang, J., Yamashita, T., & Wiznitzer, M. (1997). High-dose pyridoxine and magnesium administration in children with autistic disorder: An absence of salutary effects in a double-blind, placebo-controlled study. *Journal of Autism and Developmental Disorders, 27*(4), 467-478.

Fiorica-Howells, E., Maroteaux, L., & Gershon, M.D. (2000). Serotonin and the 5-HT (2B) receptor in the development of enteric neurons. *The Journal of Neuroscience, 20*(1), 294-305.

Fombonne, E. (2008). Thimerosal disappears but autism remains. *Archives of General Psychiatry, 65*(1), 19-24.

Garstang, J., & Wallis, M. (2006). Randomized controlled trial of melatonin for children with autistic spectrum disorders and sleep problems. *Child: Care, Health and Development, 32*(5), 585-589.

Gillberg, C. (1995). Endogenous opioids and opiate antagonists in autism: Brief review of empirical findings and implications for clinicians. *Developmental Medicine and Child Neurology, 37*(5), 239-245.

Goff, D.C., Guochuan, T., Levitt, J., Amico, E., Manoach, D., Schoenfeld, D.A., Hayden, D.L., McCarley, R., & Coyle, J.T. (1999). A placebo-controlled trial of D-Cycloserine added to conventional neuroleptics in patients with schizophrenia. *Archives of General Psychiatry, 56*, 21-27.

Goin-Kochel, R.P., Myers, B.J., & Mackintosh, V.H. (2007). Parental reports on the use of treatments and therapies for children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 1*(3), 195-209.

Golnik, A.E., & Ireland, M. (2009). Complementary alternative medicine for children with autism: A physician survey. *Journal of Autism and Developmental Disorders, 39* (7), 996-1005.

Gupta, S., Aggarwal, S., & Heads, C. (1996). Brief report: Dysregulated immune system in children with autism: Beneficial effects of intravenous immune globulin on autistic characteristics. *Journal of Autism and Developmental Disorders, 26*(4), 439-452.

Gupta, S., Aggarwal, S., Rashanravan, B., & Lee, T. (1998). Th1- and Th2- like cytokines in CD4+ and CD8+ T cells in autism. *Journal of Neuroimmunology, 85*(1), 106-109.

Gupta, V.B. (2010). Communicating with parents of children with autism about vaccines and complementary and alternative approaches. *Journal of Developmental and Behavioral Pediatrics, 31* (4), 343-345.

Hanley, H.G., Stahl, S.M., & Freedman, D.X. (1977). Hyperserotonemia and amine metabolites in autistic and retarded children. *Archives of General Psychiatry, 34*(5), 521-531.

Hanson, E., Kalish, L.A., Bunce, E., Curtis, C., McDaniel, S., Ware, J., et al. (2007). Use of complementary and alternative medicine among children diagnosed with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 37*(4), 628-636.

Hartshorn, K., Olds, L., Field, T, Delage, J., Cullen, C., & Escalona, A. (2001). Creative movement therapy benefits children with autism. *Early Child Development and Care, 166*, 1-5.

Hediger, M.L., England, L.J., Molloy, C.A., Yu, K.F., Manning-Courtney, P., & Mills, J.L. (2008). Reduced bone cortical thickness in boys with autism or autism spectrum disorder. *Journal of Autism and Developmental Disorders, 38*(5), 848-856.

Herman, B.H., Hammock, M.K., Arthur-Smith, A., Kuehl, K., & Appelgate, K. (1989). Effects of acute administration of naltrexone on cardiovascular function, body temperature, body weight and serum concentrations of liver enzymes in autistic children. *Developmental Pharmacology and Therapeutics, 12*(3), 118-127.

Hornig, M., Chian, D., & Lipkin, W.I. (2004). Neurotoxic effects of postnatal thimerosal are mouse strain dependent. *Molecular Psychiatry, 9*(9), 833-845.

Horrobin, D.F., & Bennett, C.N. (1999). Depression and bipolar disorder: Relationships to impaired fatty acid and phospholipids metabolism and to diabetes, cardiovascular disease, immunological abnormalities, cancer, ageint and osteoporosis. Possible candidate genes. *Prostaglandins, Leukotrienes and Essential Fatty Acids, 60*(4), 217-234.

Horrobin, D.F., Glen, A.I.M., & Vaddadi, K. (1994). The membrane hypothesis of schizophrenia. *Schizophrenia Research, 13*(3), 195-207.

Horvath, K., Papadimitriou, J.C., Rabsztyn, A., Drachenberg, C., & Tildon, J.T. (1999). Gastrointestinal abnormalities in children with autistic disorder. *The Journal of Pediatrics, 135*(5), 559-563.

Horvath, K., & Perman, J.A. (2002). Autism and gastrointestinal symptoms. *Current Gastroenterology Reports, 4*(3), 251-258.

Horvath, K., Stefanatos, G., Sokolski, K.N., Wachtel, R., Nabors, L., & Tildon, J.T. (1998). Improved social and language skills after secretin administration in patients with autistic spectrum disorders. *Journal of the Association for Academic Minority Physicians, 9*(1), 9-15.

Hviid, A., Stellfeld, M., Wohlfahrt, J., & Melbye, M. (2003). Association between thimerosal-containing vaccine and autism. *Journal of the American Medical Association, 290*(13), 1763-1766.

Hyman, S.L., & Levy, S.E. (2005). Introduction: Novel therapies in developmental disabilities – hope, reason, and evidence. *Mental Retardation and Developmental Disabilities Research Reviews, 11*(2), 107-109.

Hyman, S.L.,, and Levy, S.E. (2011). Dietary, Complementary, and Alternative Therapies. In B. Reichow, P. Doehring, D.V. Cicchetti, & F.R. Volkmar (Eds.), *Evidence-based practices and treatments for children with autism* (pp. 275-293). New York: Springer Science + Business Media.

James, S.J., Cutler, P., Melnyk, S., Jernigan, S., Janak, L., Gaylor, D.W., et al. (2004). Metabolic biomarkers of increased oxidative stress and impaired methylation capacity in children with autism. *American Journal of Clinical Nutrition, 80*(6), 1611-1617.

James, S.J., Melnyk, S., Jernigan, S., Cleves, M.A., Halsted, C.H., Wong, D.H., et al. (2006). Metabolic endophenotype and related genotypes are associated with oxidative stress in children with autism. *American Journal of Medical Genetics Part B (Neuropsychiatric Genetics), 141*(8), 947-956.

Jyonouchi, H., Sun, S., & Le, H. (2001). Proinflammatory and regulatory cytokine production associated with innate and adaptive immune responses in children with autism spectrum disorders and developmental regression. *Journal of Neuroimmunology, 120*(1-2), 170-179.

Kaplan, M., Edelson, S.M., & Seip, J.A. (1998). Behavioral changes in autistic individuals as a result of wearing ambient transitional prism lenses. *Child Psychiatry and Human Development, 29*(1), 65-76.

Kazdin, A.E. (1980). Acceptability of alternative treatments for deviant child behavior. *Journal of Applied Behavior Analysis, 13*(2), 259-273.

Kern, J.K., & Jones, A.M. (2006). Evidence of toxicity, oxidative stress, and neuronal insult in autism. *Journal of Toxicology and Environmental Health, Part B, 9*(6), 485-499.

Kern, J.K., Miller, V.S., Cauller, L., Kendall, R., Mehta, J., & Dodd, M. (2001). Effectiveness of N,N-Dimethylglycine in autism and pervasive developmental disorder. *Journal of Child Neurology, 16*(3), 169-173.

Knivsberg, A.M., Reichelt, K.L., Hoien, T., & Nodland, M. (2002). A randomized, controlled study of dietary intervention in autistic syndromes. *Nutritional Neuroscience, 5*(4), 251-261.

Kolmen, B.K., Feldman, H.M., Handen, B.J., & Janosky, J.E. (1997). Naltrexone in young autistic children: Replication study and learning measures. *Journal of the American Academy of Child & Adolescent Psychiatry, 36*(11), 1570-1578.

Lau, A.S., Garland, A.F., Yeh, M., McCabe, K.M., Wood, P.A., & Hough, R.L. (2004). Race/ethnicity and inter-informant agreement in assessing adolescent psychopathology. *Journal of Emotional and Behavioral Disorders, 12*(3), 145-156.

Lennox, D.B., & Miltenberger, R.G. (1990). On the conceptualization of treatment acceptability. *Education and Training in Mental Retardation, 25*(3), 211-224.

Levy, S.E., & Hyman, S.L. (2002). Alternative/Complementary approaches to treatment of children with autism spectrum disorders. *Infants and Young Children, 14*(3), 33-42.

Levy, S.E., & Hyman, S.L. (2003). Use of complementary and alternative treatments for children with autistic spectrum disorders is increasing. *Pediatric Annals, 32*(10), 685-691.

Levy, S.E., & Hyman, S.L. (2005). Novel treatments for autistic spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11*(2), 131-142.

Levy, S.E., & Hyman, S.L. (2008). Complementary and alternative medicine treatments for children with autism spectrum disorders. *Child and Adolescent Psychiatric Clinics of North America, 17*(4), 803-820.

Levy, S.E., Mandell, D.S., Merhar, S., Ittenbach, R.F., & Pinto-Martin, J.A. (2003). Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *Developmental and Behavioral Pediatrics, 24*(6), 418-423.

Madsen, K.M., Lauritsen, M.B., Pedersen, C.B., Thorsen, P., Plesner, A., Andersen, P.H., et al. (2003). Thimerosal and the occurrence of autism: Negative ecological evidence from Danish population-based data. *Pediatrics, 112*(3) Part 1, 604-606.

Maestro, S., Muratori, F., Cavallaro, M.C., Pei, F., Stern, D., Golse, B., et al. (2002). Attentional skills during the first 6 months of age in autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*(10), 1239-1245.

Mandell, D.S., Listerud, J., Levy, S.E., & Pinto-Martin, J.A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry, 41*(12), 1447-1453.

Mandell, D.S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11*(2), 110-15.

Martineau, J., Barthelemy, C., Garreau, B., & Lelord, G. (1985). Vitamin B6, magnesium, and combined B6-Mg: Therapeutic effects in childhood autism. *Biological Psychiatry, 20*(5), 467-478.

McDougle, C.J., Naylor, S.T., Goodman, W.K., Volkmar, F.R., Cohen, D.J., & Price, L.H. (1993). Acute tryptophan depletion in autistic disorder: A controlled case study. *Biological Psychiatry, 33*(7), 547-550.

Melke, J., Goubran Botros, H., Chaste, P., Betancur, C., Nygren, G, Anckarsater, H., et al. (2008). Abnormal melatonin synthesis in autism spectrum disorders. *Molecular Psychiatry, 13*(1), 90-98.

Molloy, C.A., & Manning-Courtney, P. (2003). Prevalence of chronic gastrointestinal symptoms in children with autism and autism spectrum disorders. *Autism, 7*(2), 165-171.

Moran, R.W., & Gibbons, P. (2001). Intraexaminer and interexaminer reliability for palpitation of the cranial rhythmic pulse at the head and sacrum. *Journal of Manipulative and Physiological Therapeutics, 24*(3), 183-190.

Moretti, P., Peters, S.U., del Gaudio, D., Sahoo, T., Hyland, K., Bottiglieri, T., et al. (2008). Brief report: Autistic symptoms, developmental regression, mental retardation, epilepsy, and dyskinesias in CNS folate deficiency. *Journal of Autism and Developmental Disorders, 38*(6), 1170-1177.

Mostert, M.P. (2001). Facilitated communication since 1995: A review of published studies. *Journal of Autism and Developmental Disorders, 31*(3), 287-313.

Mulder, E.J., Anderson, G.J., Kema, I.P., DeBildt, A., VanLang, N.D.J., DenBoer, J.A., et al. (2004). Platelet serotonin levels in pervasive developmental disorders and mental retardation: Diagnostic group differences, within-group distribution, and behavioral correlates. *Journal of the American Academy of Child and Adolescent Psychiatry, 43*(4), 491-499.

Nickel, R. (1996). Controversial therapies for young children with developmental disabilities. *Infants and Young Children, 8*(4), 29-40.

Nye, C., & Brice, A. (2005). Combined vitamin B6-magnesium treatment in autism spectrum disorder. *Cochrane Database of Systematic Reviews, 4.* Retrieved from Cochrane Library database at: http://www.thecochranelibrary.com/view/0/index.html

Pachter, L.M., & Weller, S.C. (1993). Acculturation and compliance with medical therapy. *Developmental and Behavioral Pediatrics, 14*(3), 163-168.

Panksepp, J., & Lensing, P. (1991). Brief report: A synopsis of an open-trial of naltrexone treatment of autism with four children. *Journal of Autism and Developmental Disorders, 21*(2), 243-249.

Phillips, L., & Appleton, R.E. (2004). Systematic review of melatonin treatment in children with neurodevelopmental disabilities and sleep impairment. *Developmental Medicine and Child Neurology, 46*(11), 771-775.

Polleux, F., & Lauder, J.M (2004). Toward a developmental neurobiology of autism. *Mental Retardation and Developmental Disabilities Research Reviews, 10*(4), 303-317.

Posey, D.J., Kern, D.L., Swiezy, N.B., Sweeten, T.L., Wiegand, R.E., & McDougle, C.J. (2004). A pilot study of D-cycloserine in subjects with autistic disorder. *American Journal of Psychiatry, 161*(11), 2115-2117.

Regal, R.A., Rooney, J.R., & Wandas, T. (1994). Facilitated communication: An experimental evaluation. *Journal of Autism and Developmental Disorders, 24*(3), 345-355.

Reichelt, K.L., Knivsberg, A., Lind, G., & Nodland, M. (1991). Probable etiology and possible treatment of childhood autism. *Brain Dysfunction, 4*(6), 308-319.

Rimland, B., Callaway, E., & Dreyfus, P. (1978). The effect of high doses of Vitamin B6 on autistic children: A double-blind crossover study. *The American Journal of Psychiatry, 135*(4), 472-475.

Rossignol, D.A., Rossignol, L.W., James, S.J., Melnyk, S., & Mumper, E. (2007). The effects of hyperbaric oxygen therapy on oxidative stress, inflammation, and symptoms in children with autism: an open-label pilot study. *BMC Pediatrics,* **7**:36.

Russo, A.J. (2008). Anti-metallothionein IgG and levels of metallothionein in autistic families. *Swiss Medical Weekly, 138*(5-6), 70-77.

Sandler, A. (2005). Placebo effects in developmental disabilities: Implications for research and practice. *Mental Retardation and Developmental Disabilities Research Reviews, 11*(2), 164-170.

Sandler, R.H., Finegold, S.M., Bolte, E.R., Buchanan, C.P., Maxwell, A.P., Vaisanen, M., et al. (2000). Short-term benefit from oral vancomycin treatment of regressive-onset autism. *Journal of Child Neurology, 15*(7), 429-435.

Senel, H.G. (2010). Parents' views and experiences about complementary and alternative medicine treatments for their children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*(4), 494-503.

Shattock, P., Kennedy, A., Rowell, F., & Berney, T. (1990). Roles of neuropeptides in autism and their relationships with classical neurotransmitters. *Brain Dysfunction, 3*(5-6), 328-345.

Sinha, Y, Silove, N., & Williams, K.. (2006). Chelation therapy and autism. *British Medical Journal, 333*(7571), 756.

Sinha, Y., Silove, N., Wheeler, D., & Williams, K. (2004). Auditory integration training and other sound therapies for autism spectrum disorders. *Cochrane Database of Systematic Reviews,1*. Retrieved from Cochrane Library database at: http://www.thecochranelibrary.com/view/0/index.html

Spivak, B., Golubchik, P., Mozes, T., Vered, Y., Nechmad, A.,& Weizman, A., et al. (2004). Low platelet-poor plasma levels of serotonin in adult autistic patients. *Neuropsychobiology, 50*(2), 157-160.

Sweeten, T.L., Bowyer, S.L., Posey, D.J., Halberstadt, G.M., & McDougle, C.J. (2003). Increased prevalence of familial autoimmunity in probands with pervasive developmental disorders. *Pediatrics, 112*(5), e420-e424.

Vancassel, S., Durand, G., Barthelemy, C., Lejeune, B., Martineau, J., Guilloteau, D., et al. (2001). Plasma fatty acid levels in autistic children. *Prostaglandins, Leukotrienes and Essential Fatty Acids, 65*(1), 1-7.

Wakefield, A.J., Murch, S.H., Anthony, A., Linnell, J., Casson, D.M., Malik, M., et al. (1998). Ileal-lymphoi-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *The Lancet, 351*(9103), 637-641.

Whipple, J. (2004). Music in intervention for children and adolescents with autism: A meta-analysis. *Journal of Music Therapy, 41*(2), 90-106.

Wigram, T., & Gold, C. (2006). Music therapy in the assessment and treatment of autistic spectrum disorder: Clinical application and research evidence. *Child: Care, Health and Development, 32*(5), 535-542.

Willemsen-Swinkels, S.H.N, Buitelaar, J.K., Weijnen, F.G., Thijssen, J.H.H., & Van Engeland, H. (1996). Plasma beta-endorphin concentrations in people with learning disability and self-injurious and/or autistic behavior. *British Journal of Psychiatry, 168*(1), 105-109.

Williams, K.W., Wray, J.J., & Wheeler, D.M. (2005). Intravenous secretin for autism spectrum disorder. *Cochrane Database of Systematic Reviews*, *3.* Retrieved from Cochrane Library database at: http://www.thecochranelibrary.com/view/0/index.html

Wong, H.H.L., & Smith, R.G. (2006). Patterns of complementary and alternative medical therapy use in children diagnosed with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 36*(7), 901-909.

Ziemlanski, S., Wielgus-Serafinska, E., Panczenko-Kresowska, B., & Zelakiewicz, K. (1984). Effect of long-term diet enrichment with selenium, vitamin E and Bitamin B15 on the degree of fatty infiltration of the liver. *Acta Physiologica Polonica, 35*(4), 382-397.

Zimmer, M.H. (2011). Complementary and alternative therapies for autism. In E. Hollander, A. Kolevzon, & J. Coyle (Eds.), *Textbook of autism spectrum disorders* (pp. 493-512). Arlington, VA: American Psychiatric Publishing, Inc.

Zimmer, M., & Molloy, C.A. (2007). Complementary and alternative therapies for autism. In E. Hollander & E. Anagnostou (Eds.), *Clinical manual for the treatment of autism* (pp. 259-288). Arlington, VA: American Psychiatric Publishing, Inc.

APPENDIX A

QUESTIONNAIRE

Demographic information:

Are you the child's
___Mother
___Father

Your Age: _____

Marriage status:
___Single
___Married
___Divorced
___Widowed

Ethnicity:
___White
___Black or African American
___American Indian and Alaska Native
___Asian
___Native Hawaiian or other Pacific Islander
___Hispanic or Latino
___Biracial
___Other

Level of Education:
___Less than High School
___High School Diploma
___Technical School/Some College
___College Graduate
___Master's Degree
___Specialist or Ed.S. Degree
___Doctorate

How many children are in your family?

_____

What country were you born in?

_____

If you were not born in the United States, how long have you lived here?

_____

In what country have you lived most of your life?

_____

Combined family income (approximate):

_____

Treatment characteristics:

Please mark on the line (/) how severe you consider your child's behavioral symptoms to be.

Mild Severe
_____

Do you believe that autism is currently curable?

___Yes
___No

When choosing a treatment, where do you get most of your information about the treatment? (Please indicate all sources you consider)

_____
_

_____
_

_____
_

When choosing a treatment, do you seek treatments that will:
___Cure autism
___Reduce symptoms of autism

How hard is it to obtain information about possible treatments for you child?

___Not hard
___Somewhat hard
___Hard
___Very hard
___Extremely hard

When considering a treatment for your child, which of the following are important to you? Please indicate importance by circling the following:

1 – most important
2 – very important
3 – important
4 – not very important
5 – not at all important

Cost of the treatment	1	2	3	4	5
How easy it is to get access to the treatment	1	2	3	4	5
Amount of research about the treatment	1	2	3	4	5
Possible side effects of the treatment	1	2	3	4	5
Difficulty of giving the treatment	1	2	3	4	5
Child's acceptance of the treatment	1	2	3	4	5

Have you ever tried any of the following treatments for your child:

Treatment	*Tried in the past*	*Currently using*
Secretin……	__	__
Gluten-free/Casein-free diet (GFCF diet)…….	__	__
Specific Carbohydrate diet……..	__	__
Digestive enzymes……...	__	__
Probiotics……..	__	__
Antifungals……...	__	__
Antibiotics…….	__	__
D-Cycloserine……...	__	__
Intravenous Immunoglobulin……...	__	__
Dimethylglycine……..	__	__
Omega-3 Fatty acid supplements……	__	__
Tryptophan……	__	__

Tyrosine……	__	__
Cyproheptadine……..	__	__
Naltrexone……..	__	__
SAM-E (S-adenosylmethionine)……	__	__
Oxytocin Infusion……...	__	__
Hyperbaric oxygen therapy……..	__	__
Vitamin C……...	__	__
Melatonin……	__	__
St. John's wort……	__	__
Vitamin B12……..	__	__
Glutathione……	__	__
Vitamin B6 and magnesium……	__	__
Folic acid……	__	__
Metallothionein……..	__	__
Chelation……	__	__
Auditory integration training……..	__	__
Sensory integration therapy……	__	__
Massage therapy……	__	__
Craniosacral manipulation……	__	__
Facilitated communication……	__	__
Music therapy……	__	__
Behavioral optometry……	__	__

Have you tried any treatments that are not listed above? Please list:

Treatment	Tried in the past	Currently using
_____	___	___
_____	___	___
_____	___	___
_____	___	___
_____	___	___

How many medical professionals (doctors, psychologists, etc.) have you visited in order to obtain a diagnosis for you child?

____

Overall, how do you rank the quality of your experiences with the health care system when seeking treatment for you child?

___Extremely good
___Very good
___Good

___Bad
___Very Bad

What behaviors most concern you about your child?

Thank you for completing this questionnaire.

VITA

Name:	Sarah Elizabeth Hall
Address:	Department of Educational Psychology 4225 Texas A&M University College Station, TX 77843-4225
Email Address:	hallse22@gmail.com
Education:	B.A., Psychology, Texas A&M University, 2005 Ph.D., School Psychology, Texas A&M University, 2011