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Is Parental Report of Use of Complementary Alternative Medicine (CAM) to Treat Children  
with Autism Associated with a Negative Parent-Pediatrician Relationship?

An Honors Thesis for the Department of Child Development

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## AUTISM AND COMPLEMENTARY ALTERNATIVE MEDICINE

### Abstract

This study examined whether parents' decision to use Complementary Alternative Medicine (CAM) to treat their children's autism was associated with a negative parent-pediatrician relationship. Participants were 53 parents of children with autism recruited through Facebook messages. Participants filled out an online survey that asked them to rate their satisfaction with their pediatrician on a number of measures, and to report whether or not they had tried a number of CAM and conventional treatments with their child. 30 parents reported using at least one CAM treatment, while 23 parents reported never using a CAM treatment. Analysis revealed a negative correlation ( $r = -0.352$ ,  $p = 0.01$ ) between Pediatrician Satisfaction Score (PSS) and number of CAM treatments used. In addition, parents who used CAM reported lower scores on all measures of pediatrician satisfaction than parents who did not, although this group difference was not statistically significant. One interpretation of these results suggests that parents' use of CAM negatively impacts their relationship with their pediatrician. Alternatively, these results could reflect that parents who are less satisfied with their pediatricians are more likely to try CAM. More research is needed to learn more about the population of parents of children with autism who choose CAM. In addition, more resources should be devoted to educating parents about safe, evidence-based treatments for autism, and preparing pediatricians to discuss CAM treatments with parents.

*Keywords:* Autism, Complementary Alternative Medicine (CAM), Pediatricians

### Is Parental Report of Use of Complementary Alternative Medicine (CAM) to Treat Children with Autism Associated with a Negative Parent-Pediatrician Relationship?

Refrigerator mothers. Until the 1970's, this was the term used to describe the cold, unfeeling mothers whose poor parenting caused their child to develop autism. Children of "refrigerator mothers" were simply untreatable: they would never be able to learn enough social skills to interact with others (Matson, J. L., Benavidez, D. A., Compton, L. S., Paclawskyj, T., Bagli, C., 1996). Although scientific advances have since disproved this hypothesis, the exact etiology of autism remains unclear. Researchers have identified a vast number of genetic and environmental risk factors that may contribute to the disorder, but parents who are searching for a clear-cut etiology of their child's autism are left disappointed (Levy & Hyman, 2008). This may explain why a variety of alternative theories about what causes autism have surfaced. Parents who advocate for these theories often believe that autism can be cured through a variety of Complementary Alternative Medical (CAM) treatments. The American Academy of Pediatrics defines CAM as "strategies that have not met the standards of clinical effectiveness, either through randomized controlled clinical trials or through the consensus of the biomedical community" (American Academy of Pediatrics, 2001). Common CAM treatments for autism include special diets, vitamin and mineral supplements, homeopathic medications, and a number of more controversial approaches such as hyperbaric oxygen therapy and chelation therapy (Smith, 2010).

Although CAM treatments for autism have yet to be supported by accepted empirical evidence, studies estimate that anywhere from 52-87% of parents choose to use such treatments for their child (O'Reilly, 2012). The use of CAM for autism has created a rift between those who claim they are unscientific or dangerous, and those who passionately believe that they have the

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power to cure autism. This creates a serious issue for pediatricians who must encourage parents to use safe, evidence-based treatments for their children with autism, while still maintaining an open and positive parent-pediatrician relationship (Gupta, 2010). One survey of 745 pediatricians found that 87% had been asked about a CAM treatment by a patient in the previous 3 months, yet fewer than 5% felt knowledgeable about CAM therapies (Kemper & O'Connor, 2004). Moreover, in a qualitative study of pediatrician's perspectives on autism, all pediatricians discussed a lack of formal training relating to autism (Finke, Drager & Ash, 2010). Thus, it follows that most pediatricians are not prepared to tackle the complex issue of CAM treatments for autism. This was made evident in a study of 121 families, in which parents rated physician's knowledge about CAM and their qualifications to manage developmental disabilities as "worse than neutral" (Liptak et al., 2006).

The present study examined the relationship between parental use of CAM treatments and their attitudes toward their pediatricians. It is possible that parents of children with autism turn to CAM treatments when they are unsatisfied with the care they are receiving from the pediatrician. Similarly, parents who choose CAM treatments may feel less satisfied with their pediatrician if they believe their pediatrician is dismissive of their treatments of choice. To shed light on these issues, the present study examined whether parents' use of Complementary Alternative Medicine for their child's autism predicted a negative parent-pediatrician relationship.

### **The Autism Diagnosis**

Autism is a developmental disorder, characterized by deficits in social interaction, communication, and restricted, repetitive, and stereotyped patterns of behavior (American Psychiatric Association, 2000). Children with autism have difficulty interpreting nonverbal cues

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and find it challenging to make friends or share enjoyment with others. Many display a delay in or lack of language development. Those who do develop language find it difficult to initiate or sustain a conversation, and use stereotyped language that may sound strange or “too formal” to others. In addition, children with autism often display narrow, restricted interests, adhere strictly to rituals or routines, and become distressed when change is introduced into their environment. These children may also display stereotyped movements, such as walking on their toes or flapping their arms. Finally, many children with autism become preoccupied with parts of objects, and may, for example, focus intently on spinning the wheels of a toy car, rather than pushing it along a track (American Psychiatric Association, 2000).

It is important to note that in the DSM-IV, the autism spectrum disorders are currently divided into five distinct diagnoses: Autistic Disorder; Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS); Asperger’s Disorder; Rett’s Disorder; and Childhood Disintegrative Disorder. In 2013, the DSM-V will incorporate each of these diagnoses into a single “Autism Spectrum Disorder” diagnosis (American Psychiatric Association, 2012). To reflect this change in diagnostic categories, this paper will refer to all autism spectrum disorders simply as “autism.”

### **Conventional Treatments for Autism**

Autism is currently estimated to affect one out of every fifty children, or 2% of children ages 6-17 (Blumberg et al., 2013). Considering this high prevalence, a vast number of studies have focused on identifying the most effective ways to treat children with autism. However, just as there is no single, specific cause of autism, there is also no cure. Instead, autism interventions aim to improve children’s social and communication skills, help them function more successfully in society, and treat comorbidities such as anxiety and depression (NINDS, 2013). The following

section will provide an overview of some of the most common conventional treatments recommended for children with autism.

### ***Early Intensive Behavioral Intervention***

One intervention that is widely accepted as an evidence-based treatment for autism is Applied Behavioral Analysis (ABA) (Green, 2007). This group of techniques, based on the principles of Behaviorism, is often provided to children as young as two for up to 40 hours each week. This form of ABA is also known as Early Intensive Behavioral Intervention (EIBI). Dr. O. Ivar Lovaas spearheaded the use of EIBI for children with autism in the 1960's as a way to decrease challenging behaviors and improve communication abilities (Smith & Eikeseth, 2010). EIBI involves Discrete Trial Training (DTT), or breaking down skills into manageable components and teaching them in a highly structured way. By utilizing facets of operant conditioning such as positive and negative reinforcement, EIBI is designed to discourage negative behaviors and encourage positive ones. (CDC, 2012). In this way, EIBI helps to improve the social skills and overall functioning of children with autism. Numerous studies have supported the efficacy of EIBI for young children with autism. For example, a 2011 meta-analysis of 11 studies found strong empirical support for the effectiveness of EIBI (Peters-Scheffer et al., 2011).

### ***Other Behavioral Interventions***

In addition to EIBI, there are a variety of other behavioral interventions that have been empirically supported for children with autism, such as the TEACHH method (Treatment and Education of Autistic and related Communication-handicapped Children), Pivotal Response Treatment, the Early Start Denver Model, and many others (National Autism Center, 2011, Dawson, 2010). These interventions were not specifically included in the present study, but are

important to note as they have made significant contributions to the field of behavioral interventions for children with autism.

### ***DIR Model***

In addition to EIBI, there are a variety of other treatments that are frequently recommended for children with autism. For example, another popular intervention for autism is the Developmental, Individualized, and Relationship-oriented (DIR) model or Floortime Method developed by Dr. Stanley Greenspan. This approach aims to increase socialization, improve language, and decrease repetitive behaviors by “supporting parents as their child’s primary play partners and encouraging naturalistic play-based interactions,” (Solomon et al., 2007, p. 221). DIR has been supported by some research, however more well-designed studies are needed to determine its efficacy (Solomon et al., 2007).

### ***Picture Exchange Communication System***

Another common intervention for children with autism is the use of Augmentative and Alternative Communication (AAC), such as the Picture Exchange Communication System. PECS involves teaching a student to use a series of pictures to make requests and communicate with others (Lerna et al., 2012). A meta-analysis of 23 studies of AAC for children with developmental disabilities found that 89% of children demonstrated gains in speech (Millar, Light & Schlosser, 2006). It is important to differentiate PECS from “facilitated communication,” a controversial alternative therapy in which a therapist physically moves the child’s hand so that they may communicate through a computer or other device. Facilitated communication lacks empirical support and poses ethical issues, as the resulting “communication” is often that of the therapist, not the children themselves (Dayan & Minnes, 1995).

### ***Other Conventional Treatments***

Children with autism often receive other therapies that target specific symptoms that may not be unique to autism. For example, children with autism often receive Speech and Language Therapy, Occupational Therapy, and Physical Therapy. These therapies have not been extensively researched specifically with regard to autism, but are commonly included as part of the child's complete treatment package (CDC, 2012). Children with autism may also receive Cognitive Behavioral Therapy (CBT) to address negative thought patterns that might impact their emotional functioning. Although CBT has been empirically supported for children with depression and anxiety, it is a newly emerging treatment for autism and more research is needed to determine its effectiveness (National Autism Center, 2011). In addition, many children with autism are prescribed medication meant to treat comorbidities, such as anxiety, depression, or attention problems. The US. Food and Drug Administration has also approved the use of antipsychotic drugs to treat children with autism who experience severe behavior problems, such as tantrums or aggression that may cause self-injury (CDC. 2012). Many studies are currently underway to assess the effectiveness of a variety of medications to improve the behavior of children with autism.

### **Complementary Alternative Medicine (CAM) for Autism**

All of the treatments previously described share one thing in common: they are based on the premise that autism itself cannot be cured, and that interventions should aim to shape the behavior of children with autism, rather than "cure" the underlying cause of the disorder. Not all treatments for autism share this quality, however. Many interventions, specifically those deemed Complementary Alternative Medicines (CAM), aim to cure the symptoms of autism through biomedical treatments. Unfortunately, many of these treatments are based on flawed theories of



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what causes autism, and have been supported by little to no empirical evidence (Smith, 2010). Despite the lack of evidence, these treatments are growing increasingly popular among families. One study reported that CAM treatments are provided to about 1/3 of newly diagnosed children with ASD (Smith, 2010). Another study compared the patterns of CAM therapy use in children with and without autism, and found that over half of the parents in the autism group reported using at least one CAM therapy for their child (Wong & Smith, 2006). Individuals with autism may continue to receive these treatments, often multiple simultaneously, throughout adolescence and into adulthood. CAM treatments for autism not only place undue strain on a parent's time and financial resources, but many actually pose a risk to a child's physical health (Smith, 2010).

According to Tristram Smith, Ph.D., an Associate Professor within the Department of Pediatrics at University of Rochester Medical Center, CAM treatments commonly used to treat autism can be divided into: special diets, nutritional supplements, herbs, naturopathic and homeopathic medication, hyperbaric oxygen therapy, chelation therapy, and non-vaccination or change in vaccination schedule (Smith, 2010). The following section will explain what each of these treatments consists of, as well as the theory behind them.

### ***Special Diets***

One popular, yet unproven, theory of what causes autism is the Opioid-Excess Theory (Mulloy et al., 2010). Proponents of this theory believe that children with autism do not adequately produce the enzymes needed to digest casein (a protein in dairy products) or gluten (a protein in wheat products.) In addition, this theory posits that children with autism have increased gut permeability that allows toxins to leak into the brain and cause behavioral symptoms. This is the rationale for the increasingly popular Gluten-Free Casein-Free (GFCF) diet that many children with autism follow (Mulloy et al., 2010). A survey by Green et al. of 552

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parents of children with autism found that 27% implemented special diets with their children (Green et al., 2004). Mulloy et al. conducted a systematic review of research surrounding the GFCF diet, and concluded that despite the large number of children with autism who currently adhere to this diet, a number of small studies of its efficacy have found negative results, and do not support its use (Mulloy, 2010). The GFCF diet can be costly, as children often require special foods that are not readily available. In addition, if the diet is not followed properly, children could be at risk for nutritional deficiencies, or hindered bone development (Mulloy et al., 2010). More research is needed to determine with certainty whether diet may influence autism symptoms.

### ***Nutritional Supplements***

Another alternative theory of autism is that children with autism lack certain nutrients that are naturally present in typically developing children. Interventions based on this theory require that children with autism receive high doses of certain vitamins or minerals (Smith, 2010). Supplements that have been proposed as autism interventions include B6 and Magnesium, Dimethylglycine (DMG), Vitamin C, Amino Acids, and Omega 3 Fatty Acids (Levy & Hyman, 2008). Very few studies have been published that examine the efficacy of vitamin and mineral supplements for treating autism. Among those that have been published, small sample sizes and poor study design pose significant challenges (Levy & Hyman, 2008).

### ***Herbs, Naturopathic and Homeopathic Medication***

In addition to vitamin and mineral supplements, many children with autism are given homeopathic medication as a way to bolster their immune systems, increase brain activity, and reduce toxins in the body (Smith, 2010). These interventions usually consist of oral doses of herbs or substances that are naturally produced in the body. One homeopathic medication that

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has been extensively researched is Secretin- a hormone that aids in digestion. At least 15 randomized, controlled studies have reported no positive effects of Secretin on autism symptoms (Levy & Hyman, 2008). Other homeopathic medications proposed to treat autism, such as melatonin, have yet to be studied extensively, and it is unclear whether they are associated with any benefits for children with autism (Levy & Hyman, 2008).

### ***Hyperbaric Oxygen Therapy***

This intervention, based on the theory that autism is associated with oxidative stress, requires exposing a child to pure oxygen at high atmospheric pressure (Smith, 2010). Traditionally, this treatment is used for patients suffering from carbon monoxide poisoning, to accelerate the healing of wounds, or as a pressure equalizer for divers. However, because the treatment helps increase blood flow to the brain it has been proposed to treat a variety of conditions of the central nervous system, including cerebral palsy and traumatic brain injury (Levy & Hyman, 2008). A meta-analysis of 18 studies of hyperbaric oxygen therapy for autism reported that although some studies support the use of this therapy for autism, most did not use a randomized controlled trial design. Potential beneficial effects of the treatment have yet to be replicated in a well-designed study (Ghanizadeh, 2012). This therapy is especially controversial, as it poses a risk of ear damage to the child. In addition, the high presence of oxygen increases the risk of a fire (Leach, Rees, & Wilmhurst, 1998).

### ***Chelation***

Another theory of autism proposes that symptoms are due to heavy metal toxins in the body- this theory is closely linked with the notion, discussed in the next section, that mercury in vaccines causes autism. Chelation is a medication that is used to strip the body of the heavy metals that are believed to be responsible for the child's autism (Davis et al., 2013). The

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treatment involves administering either DMPS (2,3-dimercaptopropane-1-sulfonate) or DMSA (2,3-dimercaptosuccinic acid) to bind to heavy metals and cause them to leave the body (Levy & Hyman, 2008). There is little evidence that children with autism have higher exposure to heavy metals than other children. In addition, a review of five studies of chelation treatment for autism reported that four studies found mixed results, with only one study finding a positive result. The authors concluded that given the severe methodological limitations of the studies, current research does not support the use of chelation therapy for autism (Davis et al., 2013). Moreover, chelation can have significant side effect on a child's health, and in some cases can even lead to death (Davis et al., 2013).

### ***Immunizations and Nonvaccination***

As mentioned previously, a pervasive myth in the autism community is that mercury in vaccines, specifically an ingredient known as thimerosal, is responsible for causing autism (Levy & Hyman, 2008). Parents who believe this to be true often choose not to vaccinate their children, or to do so on a reduced or altered schedule. This myth can be traced back to a study published in the *Lancet* in 1998 by Andrew Wakefield, which reported a link between vaccines and autism. In addition, autism often becomes evident around the same time that children receive the Measles Mumps Rubella (MMR) vaccine, leading parents to assume a causal link between them (Levy & Hyman, 2008). However, Wakefield's study has since been discredited and disavowed by its co-authors, and numerous, well-designed studies have rejected the possibility of an autism-vaccine link. This myth continues to be propagated in the popular media by anti-vaccine activists such as actress Jenny McCarthy, who strongly believes that vaccines were the cause of her child's autism (Offit, P., 2008). The decision not to vaccinate has led to the rise of many once-eradicated diseases. For example, in 2008, there were more reported cases of measles in the United States

than there were in 1996, mainly due parents' decision not to vaccinate their children (Ratzan, 2010).

### ***Why Parents Choose CAM Treatments***

Considering the lack of evidence supporting the effectiveness of CAM treatments, why do so many parents continue to seek them out for their children? One answer is the multitude of misinformation available on the Internet and throughout the media. A simple Internet search for "autism treatments" will lead to a world of mixed information about the best autism interventions (Coates, 2009). Considering there is no known cure for autism, therapies that claim to "cure" children are especially appealing to parents. A 2011 survey reported that certain factors make a parent more likely to choose CAM treatments. For example, parents with a graduate degree were more likely to use CAM than those with a technical school/some college, and parents who were married more were more likely to use CAM than those who were divorced (Hall, 2011). Even when parents understand that a treatment is not evidence-based, many report that they would prefer to leave "no stone unturned" rather than risk missing out on a treatment that could possibly work (Gupta, 2010). Finally, the presence of celebrity advocates for CAM treatments promote the idea that autism can be cured, and provide hope to parents who have previously been told that their child's diagnosis is permanent (Smith, 2010).

## **Method**

### **Participants**

Participants in this study were 53 parents of children with autism, 49 female and 4 male. Age of parents involved in the study ranged from 18 to 65+ with the majority of parents falling into either the 31-40 year age range (49.1%) or the 41-50 year age range (26.4%). Participants had an average of 2.53 children, with a mean of 1.17 children diagnosed with an ASD. Age of

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children with an autism diagnoses ranged from 0-18+, with the highest percentages of children in the 3-5 year age range (28.3%) and 6-8 year age range (26.4%). The participants were predominately Caucasian (81.1%). Figures 1 and 2 highlight parental education level and relationship status. Participants were recruited through private messages on Facebook. The investigator contacted parents who posted publicly about their child’s autism on “Fan Pages” that were relevant to autism.

		Parent Relationship Status			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Married	33	62.3	63.5	63.5
	Single, Never Married	8	15.1	15.4	78.8
	Separated	2	3.8	3.8	82.7
	Divorced	9	17.0	17.3	100.0
	Total	52	98.1	100.0	
Missing	System	1	1.9		
Total		53	100.0		

Figure 1. Summary of parent relationship status.



		Parent Education Level			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less Than High School	1	1.9	1.9	1.9
	High School/GED	12	22.6	22.6	24.5
	Some College	10	18.9	18.9	43.4
	2-4 Year College	13	24.5	24.5	67.9
	4-Year College	10	18.9	18.9	86.8
	Professional Degree	1	1.9	1.9	88.7
	Master's Degree	4	7.5	7.5	96.2
	Doctoral Degree	2	3.8	3.8	100.0
	Total	53	100.0	100.0	

Figure 2. Summary of parent education level.

### Measures

Subjects filled out a 22-item questionnaire that was designed to require approximately five minutes to complete. First, parents reported whether or not they had utilized a number of

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conventional and CAM interventions for their child with autism. The following conventional treatments were included in the survey: Applied Behavioral Analysis, Cognitive Behavioral Therapy (CBT), Picture Exchange Communication System (PECS), Anti-Depressants, Play Therapy, Occupational Therapy (OT), Speech and Language Therapy, Anti-Psychotics, Physical Therapy (PT), DIR Method (Floortime Therapy), and Anti-Convulsants/Mood Stabilizers. In addition, the following CAM treatments were included in the study: Vitamin/Mineral Supplements, Chelation, Amino Acid Supplements, Omega 3 Fatty Acid Supplements, Melatonin, Special Diet (Gluten Free/Casein Free, Feingold Diet, Specific Carbohydrate Diet, etc.), Hyperbaric Oxygen Therapy, Gastrointestinal Medicines, Electroconvulsive Therapy, Acupuncture, Lightwave Stimulation, Not Vaccinating Their Child, Delay or Change in Vaccination Schedule, and Sulphation. CAM and conventional treatments were distributed randomly throughout the survey, so as not to highlight the distinction between them.

Participants then rated various aspects of their relationship with their child's pediatrician on a scale of 1 (strongly disagree)-7 (strongly agree). Parents reported how satisfied they were with their child's pediatrician, whether they felt they could express their opinions to their pediatrician without feeling judged, how satisfied they were with their pediatricians' recommendations, whether their pediatrician knows about all treatments they have used, how comfortable they feel consulting their pediatrician before trying a new treatment, how qualified their pediatrician is to answer questions about autism, and whether their pediatrician is dismissive of their opinions. These ratings were averaged to calculate an overall Pediatrician Satisfaction Score (PSS). Parents were also asked if they were considering changing pediatricians, and if so, for what reason. Finally, parents were asked about their pediatrician's stance on alternative treatments. A copy of the full questionnaire can be found in Appendix A.

### **Procedure**

The experimenter contacted parents who posted publicly about their child's autism on the following Facebook pages within the previous year: *Autism Awareness*, *Autism Speaks*, *World Autism Awareness Day*, *The Autism Society of America*, *Autism Support Network*, *Autism Research Institute*, *Center for Autism Research (CAR) at The Children's Hospital of Philadelphia*, *Southwest Autism Research & Resource Center (SARRC)*, *Autism Treatment Center of America*, and *The Autism Site*. Parents received a message in their Facebook inbox asking if they would like to participate in the study. They were informed that by clicking "submit" on the survey, they were providing consent to participate. A copy of the Facebook message that participants received can be found in Appendix B. The Tufts University Institutional Review Board (Medford Campus) reviewed all the procedures and approved them on 10/17/2012. The approval form can be found in Appendix C.

### **Results**

The most common conventional treatments parents reported using included Speech and Language Therapy (86.8%), Occupational Therapy (83%), and Applied Behavioral Analysis (62.3%). See Figure 3 for a complete description of the frequencies of conventional treatments among respondents. The most common CAM treatments parents reported using included Vitamin and Mineral Supplements (37.7%), Special Diets (37.7%), and Melatonin (28.3%). See Figure 4 for a complete description of the frequencies of CAM treatments among respondents. 30 parents (56.6%) reported using at least one CAM treatment, while 23 parents (43.4%) reportedly did not use any CAM treatments. Among parents who used CAM treatments, the mean number of treatments used was 3.2, with parents reportedly having tried as many as 9 CAM treatments.



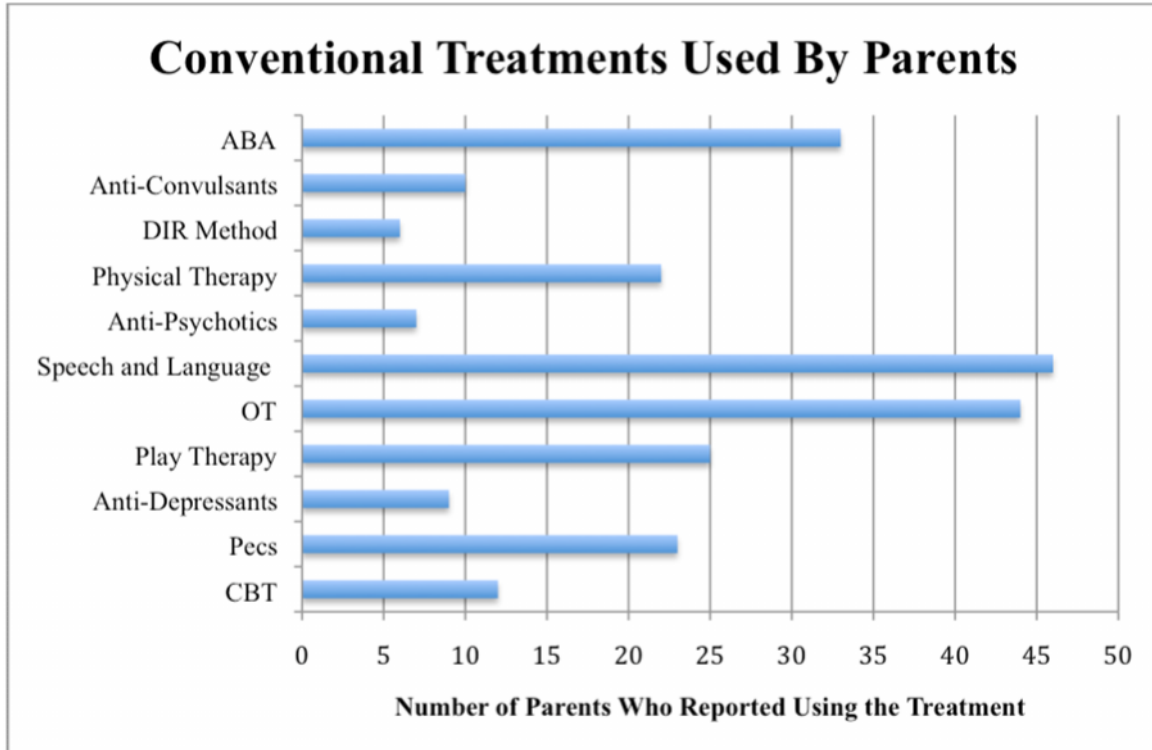


Figure 3. Frequencies Among Parents for Each Conventional Treatment.

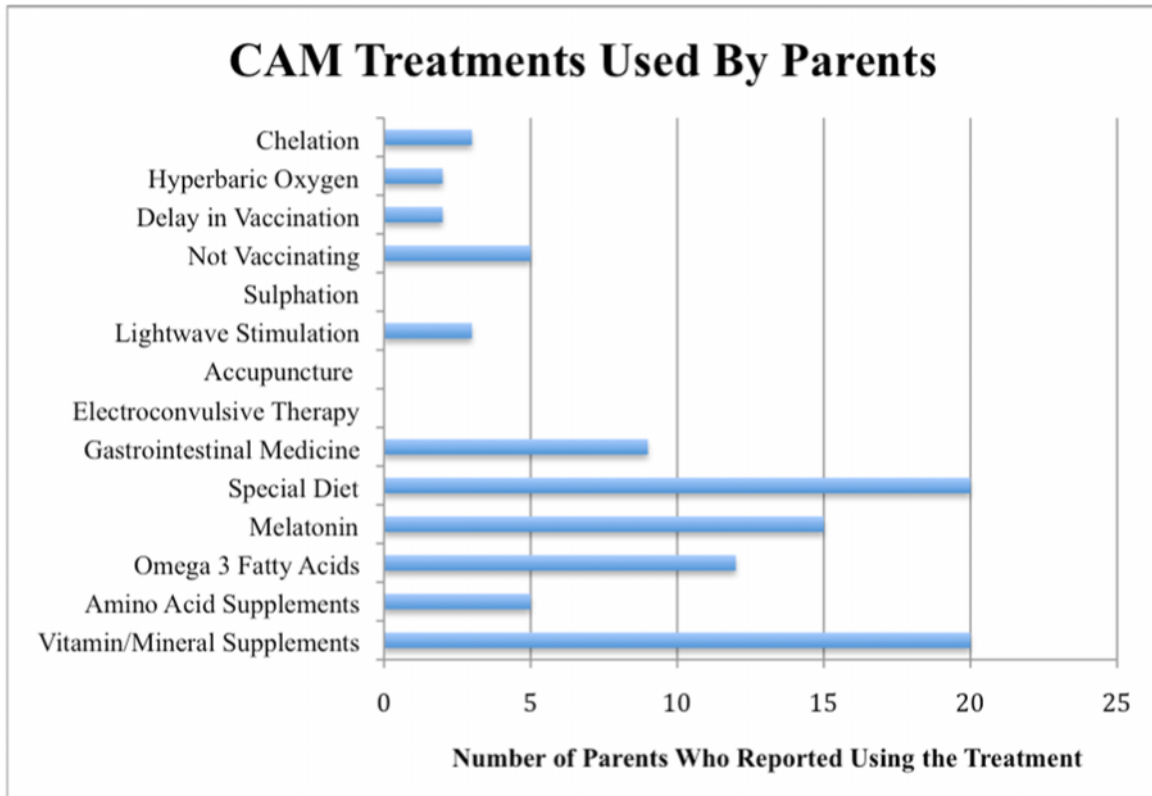


Figure 4. Frequencies Among Parents for Each CAM Treatment.

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Parent’s ratings of their pediatricians for each variable were averaged to calculate an overall Pediatrician Satisfaction Score (PSS). The mean PSS for all participants was 4.8 out of a maximum possible rating of 7. Analysis revealed a negative correlation ( $r = -0.352, p = 0.01$ ) between PSS and number of CAM treatments used (See Figure 5). Thus, as parents used more CAM treatments, their satisfaction with their pediatrician decreased. In addition, parents who used CAM reported lower scores on all measures of pediatrician satisfaction than parents who did not, although this group difference was not statistically significant (See Figure 6). When PSS of parents who used 3 or more CAM treatments were compared to those who used fewer than 3 CAM treatments using an Independent Samples T-Test, parents who used 3 or more CAM treatments had a significantly lower PSS ( $M = 4.03$ ) than those who used fewer than 3 CAM treatments ( $M = 5.20$ ), ( $t(51) = -2.20, p = 0.03$ ) (See Figure 7). Number of CAM treatments used was not correlated with parent race, age, or level of education.

Correlations			
		PSS	Number of CAM Treatments Used
PSS	Pearson Correlation	1	-.352**
	Sig. (2-tailed)		.010
	N	53	53
Number of Alternative Treatments	Pearson Correlation	-.352**	1
	Sig. (2-tailed)	.010	
	N	53	53

\*\* . Correlation is significant at the 0.01 level (2-tailed).

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Figure 5. Significant negative correlation between Pediatrician Satisfaction Score (PSS) and number of CAM treatments used.

Group Statistics- CAM Treatments Used (Y/N)					
	CAM Treatment Used?	N	Mean	Std. Deviation	Std. Error Mean
PSS	Yes	30	4.5633	2.02050	.36889
	no	23	5.2116	1.57402	.32821
Satisfied with Ped.	Yes	30	4.8667	2.22421	.40608
	no	23	5.6087	1.58800	.33112
No Fear of Judgement From Ped.	Yes	30	4.8667	2.47377	.45165
	no	23	5.7391	1.57299	.32799
Satisfied with Ped. Recommendations	Yes	30	4.5667	2.16051	.39445
	no	23	5.2609	1.91210	.39870
Ped. Knows About Treatments	Yes	30	5.0000	2.36352	.43152
	no	23	5.2174	2.29538	.47862
Comfortable Telling Ped. About Treatments	Yes	30	4.6000	2.48582	.45385
	no	23	5.1739	2.03720	.42479
Always Follows Ped. Advice	Yes	30	4.1667	2.13482	.38976
	no	23	4.6957	1.94082	.40469
Feels Ped. is Qualified	Yes	30	3.6000	2.32824	.42508
	no	23	4.2609	2.07183	.43201
Feels Ped. Is Accepting	Yes	30	4.4333	2.32947	.42530
	no	23	5.0870	1.92857	.40213

Figure 6. Overview of pediatrician ratings among parents who reported using at least one CAM treatment, and those who reported using no CAM treatments.

Group Statistics- More Than 2 CAM Treatments					
	More Than Two Cam Treatments	N	Mean	Std. Deviation	Std. Error Mean
PSS	Yes	16	4.0250	2.13897	.53474
	No	37	5.1991	1.61882	.26613

Independent Samples Test- More Than 2 CAM Treatments										
		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
								Lower		Upper
PSS	Equal variances assumed	5.015	.030	-2.195	51	.033	-1.17410	.53487	-2.24789	-.10031
	Equal variances not assumed			-1.966	22.769	.062	-1.17410	.59731	-2.41042	.06222

Figure 7. Independent Samples T-Test revealing a significant difference between PSS of parents who reported using more than 2 CAM treatments, and those who reported using 2 or fewer CAM treatments.

### Discussion

The results of the present study are consistent with those of previous studies with regard to patterns of treatment use. For example, the present study found that over half of parents (56.6%) reported using at least one Complementary Alternative Medical (CAM) treatment for their child with autism. This is consistent with the findings of Wong & Smith’s 2006 survey, which reported that over 50% of parents of children with autism had used at least one CAM treatment (Wong & Smith, 2006). In addition, the most frequently used CAM treatments in the present study (vitamin and mineral supplements and special diets) were also the most popular CAM treatments according to a survey by Green et al. in 2004. Green et al. found that 27% of parents had tried implementing special diets, while 43% were using vitamin supplements (Green et al., 2004). These results are similar to the present study, which found that 37.7% of parents had tried special diets and 37.7% had tried vitamin and mineral supplements. Moreover,

consistent with Green et al., the most frequently used conventional treatment in the present study was speech and language therapy (Green et al., 2004).

In contrast to some previous studies, however, the present study found no relationship between parental marital status or level of education and the number of CAM treatments used. This is inconsistent with a 2011 survey, which reported that individuals with a graduate degree were more likely to use CAM than those with technical school/some college, and that parents who were married were more likely to use CAM than those who were divorced (Hall, 2011). One possible reason for this discrepancy is that the 2011 study had a much larger sample size (452 respondents), which may have enabled a more accurate comparison between subgroups of respondents.

The present study represents the first attempt to examine the relationship between parents' satisfaction with their pediatrician and the number of CAM treatments they use to treat their child's autism. The negative correlation between Pediatrician Satisfaction Score (PSS) and number of CAM treatments used can be interpreted multiple ways. This result may reflect that a parent's decision to use CAM treatments causes them to feel uncomfortable discussing their child's care with their pediatrician, or to feel that their pediatrician is dismissive of their opinions regarding their child's care. According to this interpretation, the parent's decision to use CAM treatments resulted in a poorer parent-pediatrician relationship. On the other hand, it may be the case that parents who are dissatisfied with their pediatrician and the care their child has received are more likely to turn to CAM treatments. Thus, it may be the case that a negative parent-pediatrician relationship prompts parents to use CAM treatments. In reality, it is likely that both of these interpretations are accurate. Because pediatricians reportedly know very little about CAM treatments (Kemper & O'Connor, 2004), it is likely that they do not know how to advise

parents who inquire about them. Similarly, because there is no cure for autism, it is likely that parents will feel unsatisfied with conventional care and thus turn to CAM treatments.

An alternate interpretation of these results stems from the proposition that the number of CAM treatments a parent uses is correlated with the severity of the child's autism. This has been supported by some research (Hall, 2004). A parent of a child with more severe autism may be more likely to be dissatisfied with their child's care, regardless of whether they use CAM treatments. Thus, the correlation between higher rates of CAM use and a more negative parent-pediatrician relationship may actually be the result of increasing rates of autism severity. Unfortunately, one limitation of the present study was the absence of a measure of autism severity. Because parents did not report the severity of their child's autism symptoms, it is unclear how this may have impacted the results. Future researchers should consider this variable when designing their studies.

### **Limitations**

In addition to the absence of a measure of autism symptom severity, another potential limitation of this study resulted from its method of distribution. Because the survey was distributed through Facebook, the respondents represent a subsample of parents of children with autism who are active Facebook users and who subscribe to "Fan Pages" related to autism. Because many parents learn about CAM treatments through the Internet, it is possible that parents who are active on the Internet use higher frequencies of CAM treatments than those who do not. Thus, the frequency of CAM treatments reported in the present study could represent higher rates than the general population. However, because rates of CAM use were similar to those found in other surveys not distributed through the Internet, this limitation seems unlikely.

Another limitation of this study is that it focused solely on Complementary Alternative Medical (CAM) treatments for autism, and not alternative treatments as a whole. There are many other controversial treatments for autism that lack an evidence base, such as facilitated communication, patterning therapies, and holding therapies. Although a few of these treatments were included in the survey, they were not included in analysis because they only represented a small subset of non-CAM alternative treatments. Future studies should incorporate a wider range of treatments, as it is possible that the use of other controversial interventions for autism may also be associated with a negative parent-pediatrician relationship.

A final limitation of this study was that it did not take into account the perspective of pediatricians. Although it is important to understand parent's attitudes toward their pediatricians, it is equally important to learn more about how pediatricians approach CAM treatments and autism. Because studies have reported that pediatricians feel they know very little about CAM treatments in general, it is likely that the same is true for CAM treatments for autism. However, more research needs to be done in order to understand pediatricians' approach to discussing CAM treatments with parents of children with autism.

### **Future Directions and Conclusions**

Despite the lack of empirical evidence supporting Complementary Alternative Medical treatments for autism, as many as 52-87% of parents report using them with their children (O'Reilly, 2012). Parents prefer to leave "no stone unturned" with regard to treatment options for their children, as conventional treatments are unable to cure autism (Gupta, 2010). CAM treatments offer parents a hope for a cure that conventional medicine is unable to provide. Pediatricians are then charged with the complex task of serving as a primary resource for parents looking for answers about CAM treatments. Considering the diverse mental and physical needs

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facing children today, it is not surprising that pediatricians are less knowledgeable about CAM treatments, which are largely neglected in their medical school training (Kemper & O'Connor, 2004). Pediatricians must find ways to encourage parents to use treatments that are safe and effective, and discourage those that may be risky or unproven, while still maintaining a positive and open relationship with parents. This extremely challenging process may account for the negative correlation between parental CAM use and parents' satisfaction with their pediatricians.

This study has critical implications for the pediatric health community. Parents' high rates of CAM use reflect a greater need for educational resources that highlight safe, effective treatments for autism. Because there is an abundance of false information available on the Internet and through the media, more resources should be devoted to helping parents navigate through misinformation and distinguish between effective treatments and those that are ineffective and possibly risky. In addition, this study highlights pediatricians' need for increased support in caring for children whose parents choose CAM treatments. Because so many parents choose these treatments, simply pretending they do not exist is not an effective approach. Pediatricians need to be educated about the types of CAM treatments as well as their potential risks and side effects, in order to be prepared to advise parents successfully and promote a positive parent-pediatrician relationship.



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### *Appendix A.*

#### Survey Questions

1. How many children do you have?
2. How many of your children have been diagnosed with an Autism Spectrum Disorder?
3. What are the age(s) of your child(ren) who have received an ASD diagnosis? (0-2 → 18+)
4. Please check all treatments that you have used for your child(ren), past and present
  - a. Applied Behavioral Analysis
  - b. Vitamin/Mineral Supplements
  - c. Gastrointestinal Medicines
  - d. Play Therapy
  - e. Chelation
  - f. Hyperbaric Oxygen Therapy
  - g. Electroconvulsive Therapy
  - h. Patterning Therapies
  - i. Melatonin
  - j. Special Diet (Gluten Free/Casein Free, Feingold Diet, Specific Carbohydrate Diet, etc.)
5. Please check all treatments that you have used for your child(ren) past and present:
  - a. Acupuncture
  - b. Anti-Depressants
  - c. Lightwave Stimulation
  - d. Omega 3 Fatty Acid Supplements
  - e. Occupational Therapy (OT)
  - f. Speech and Language Therapy
  - g. Not Vaccinating my Child
  - h. Delay or Change in Vaccination Schedule
  - i. Picture Exchange Communication System (PECS)
  - j. Music Therapy
6. Please check all treatments that you have used for your child(ren) past and present:
  - a. Cognitive Behavioral Therapy (CBT)
  - b. Anti-Psychotics
  - c. Animal Therapy
  - d. Physical Therapy (PT)
  - e. Art Therapy
  - f. Facilitated Communication
  - g. Amino Acid Supplements
  - h. Sulphation
  - i. DIR Method (Floortime Therapy)
  - j. Gastrointestinal Medicines
  - k. Anti-Convulsants/Mood Stabilizers
  - l. Other

*For questions 7-14, rate answers on a scale of 1-7.  
1 = Strongly Disagree, 7 = Strongly Agree*

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7. I am satisfied with my child(ren)'s pediatrician.
8. I can express my opinions regarding my child(ren)'s health to my pediatrician without fear of being judged.
9. I am satisfied with the recommendations my pediatrician has made for my child(ren).
10. My pediatrician knows about all of the treatments I have used for my child(ren).
11. I feel comfortable consulting with my pediatrician before trying a new treatment for my child(ren).
12. I always follow my pediatrician's advice.
13. I believe that my pediatrician is qualified to answer my questions about autism.
14. I feel that my pediatrician is dismissive of my opinions regarding my child(ren)'s treatment.
15. Are you thinking of changing pediatricians?
16. If you are thinking of changing pediatricians, what is your reason for changing?
  - a. N/A (I am not thinking of changing pediatricians.)
  - b. The pediatrician's office is inconvenient to where I live.
  - c. I feel that my pediatrician is not qualified to treat children with autism.
  - d. I feel that my pediatrician does not respect the treatments I choose for my child.
  - e. I am not satisfied with the care my child has received.
  - f. Other
17. How does your pediatrician feel about the use of Complementary and Alternative Treatments (CAM) for autism?
  - a. My pediatrician encourages the use of alternative treatments.
  - b. My pediatrician is okay with alternative treatments, as long as they are not potentially harmful
  - c. My pediatrician discourages the use of alternative treatments.
  - d. I do not know how my pediatrician feels about alternative treatments or I do not know what alternative treatments are.
  - e. Other
18. Are you male or female?
19. What is your current marital status?
  - a. Single. Never Married
  - b. Married
  - c. Separated
  - d. Divorced
  - e. Widowed
20. What is the highest level of education you have completed?
  - a. Less than high school
  - b. High School/GED
  - c. Some College
  - d. 2-4 Year College Degree (Associates)
  - e. 4-Year College Degree (BA, BS)
  - f. Master's Degree
  - g. Doctoral Degree
  - h. Professional Degree (MD, JD)

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21. What is your age?
- a. 18-21
  - b. 22-25
  - c. 26-30
  - d. 31-40
  - e. 41-50
  - f. 51-60
  - g. 61 or Over
22. What is your race?
- a. White, non-Hispanic
  - b. African American
  - c. Hispanic
  - d. Asian-Pacific Islander
  - e. Native American
  - f. Other



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### *Appendix B.*

#### Facebook Message to Potential Participants

Dear \_\_\_\_\_,

My name is Elizabeth McGarry and I am a student at Tufts University working on my Senior Honors Thesis. I am conducting a survey about the way parents of children with autism view their relationship with their child's pediatrician. I am contacting you because you recently posted publicly about your child's autism on Facebook, and I would like to invite you to participate in my study. The link to the survey can be found here:

<https://docs.google.com/spreadsheets/viewform?fromEmail=true&formkey=dE5pRThWUnNIT2xzemIySEZiSjd3UHc6MQ>

Participation in the survey is completely voluntary and you may choose to discontinue the survey at any time. Completion of the survey will take approximately five minutes. All answers will remain anonymous. If you choose to complete the survey, you may contact me by email with any further questions. My email address is [Elizabeth.mcgarry@tufts.edu](mailto:Elizabeth.mcgarry@tufts.edu).

Thank you so much for your time.

Sincerely,

Elizabeth McGarry

*Appendix C.*

IRB Approval Form



OFFICE OF THE VICE PROVOST

Social, Behavioral, and Educational Research  
Institutional Review Board  
FWA00002063

Title: Perceptions of the parent-pediatrician relationship among parents who choose complementary and alternative (CAM) treatments for their children with autism

October 17, 2012 | Notice of Action

IRB Study # 1210017 | Status: EXEMPT

PI: Elizabeth McGarry  
Faculty Advisor: Martha Pott  
Review Date: 10/17/2012

The above referenced study has been granted the status of Exempt Category 2 as defined in 45 CFR 46.101 (b). For details please visit the Office for Human Research Protections (OHRP) website at: [http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html#46.101\(b\)](http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html#46.101(b))

- The Exempt Status does not relieve the investigator of any responsibilities relating to the research participants. Research should be conducted in accordance with the ethical principles, (i) Respect for Persons, (ii) Beneficence, and (iii) Justice, as outlined in the Belmont Report.
- Any changes to the protocol or study materials that might affect the Exempt Status must be referred to the Office of the IRB for guidance. Depending on the changes, you may be required to apply for either expedited or full review.

IRB Administrative Representative Initials:

Handwritten initials, possibly "JMS", written in black ink over a horizontal line.