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AN ANALYSIS OF VARIABLES INFLUENCING PARENTAL CHOICES OF
TREATMENTS FOR THEIR CHILD WITH AUTISM SPECTRUM DISORDER

by

Kimberly Noel Frame

A Dissertation

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Education

Major: Instruction and Curriculum Leadership

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Dedication

This dissertation is dedicated to my husband. You have helped me through two graduate degrees, through the long hours and tears. Without you none of this would have been possible. You have been my shoulder to lean on and inspiration. I love you very much.

I would also like to dedicate this dissertation to my daughter, you came to us half way through this degree, and have had to live with long hours and sometimes frustration. I hope this inspires you to go as far as you want to in life. Anything is possible with hard work. I also love you very much.

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Abstract

Frame, Kimberly Noel. Ed. D. The University of Memphis. December 2014 degree to be conferred. An analysis of variables influencing parental choices of treatments for their child with autism spectrum disorder. Major Professor: Laura Baylot-Casey, Ph. D.

Autism is a diagnosis that often leaves families faced with more questions than answers. With a multitude of choices for possible treatments for a child with autism spectrum disorder (ASD), it is important to understand parental perceptions of what they report as reasons for choosing ASD treatments for their child. The following research used a mixed methods approach in an effort to identify these reasons. This study used a survey that was available online through autism related communities. The quantitative analysis consisted of a Fischer's Exact test. The results for these tests indicated that there were no correlations between the ASD diagnoses or length of time the child had an ASD diagnosis and the treatments the parents reported selecting. In addition, there was no correlations between the parent's education and the ASD treatments parents reported selecting. From a qualitative perspective, five themes emerged. The themes were as follows: 1) Parents were overwhelmed with the enormous amount of information about ASD treatments; 2) Information about ASD treatments was confusing and conflicting; 3) Parental input and desired outcomes were significant factors when determining the types of goals selected for ASD treatment(s); 4) Concerns about safety, ability to use a treatment, or the necessity of a treatment largely contributed to the treatments parents reported they did not select; and 5) Encountering problems when selecting or implementing an ASD treatment affected the selection of or continued use of a treatment. This mixed methods approach was an initial step toward future research that may delve into a more scientific causal analysis of parental treatment choices for ASD.

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Chapter 1

Introduction

According to the Centers for Disease Control and Prevention, autism spectrum disorder (ASD) affects 1 in 68 children in the United States (Centers for Disease Control and Prevention, 2014), and prevalence has increased by 23% since 2006 (Baio, 2014). With the increase in diagnoses there has also been an increase in awareness across the nation from published research to mainstream media (Mackintosh, Myers, & Goin-Kochel, 2005). With the wealth of information and misinformation surrounding this diagnosis coupled with the anomalous characteristics exhibited by the children affected, families often experience heightened levels of stress (Mancil, Boyd, & Bedesem, 2009) and may be faced with more questions than answers related to how to help their child. Many parents know their child will require therapy, but they may not know where to locate information about the many therapies available to treat ASD or how to decide which ones to use. This leads researchers and those in helping professions to ask the questions: What and/or who guides parents to choose treatments for their child with ASD? Once parents are introduced to possible treatments, what are their reasons for choosing ASD treatments for their child? This question guided the current study, which investigated parental perceptions of the process that ultimately resulted in selecting a treatment or multiple treatments to aid their child.

To date, there have been multiple studies on the types of treatments selected by parents to assist their child. Green et al. (2006) identified 108 different treatments being used by parents to treat ASD. Many of these studies identified the types of treatments in use, how many treatments were used at one time, and how many treatments were used

across a child's lifetime (Bowker, D'Angelo, Hicks, & Wells, 2011; Goin-Kochel, Mackintosh, & Myers, 2009; Green et al., 2006; Mackintosh et al., 2005). However, more research is needed to better understand the perceptions and thoughts of parents as they choose treatments. Knowing the variables that parents identify as influencing their choice(s) can help identify ways to better present or articulate empirically tested treatments so they may be more likely to be chosen over treatments with little or no evidence base for the treatment of ASD. This study attempted to build on the extant research that identified an array of potential influences on a parent's decision-making process. A survey was utilized that asked questions specifically relating to a parent's unique journey from their child receiving an ASD diagnosis, how they found and sorted through information about possible treatments, to the selection of treatments for their child with ASD. The format of the current study lends itself to uncovering the parents' voices as they navigated their individual path down the road to a lifetime of helping their child with ASD.

A mixed methods research approach was used to design the study and analyze the data. In mixed methods research, the data is analyzed both quantitatively and qualitatively. Quantitative data analysis typically measures the extent and pervasiveness of an issue but does not provide an account of the how individuals may live with the problem being researched. The data are typically analyzed graphically or statistically but this does not capture the "perceptions, feelings, and views" (Petros, 2012, p. 278) of the families participating in the research. Qualitative data analysis provides a context for the data, the story behind the numbers, but cannot be generalized to the general population and does not identify the scope of the issue under study.

Qualitative data may be viewed as unsystematic by researchers more comfortable with quantitative analyses because the data cannot be graphed or tested statistically, however, qualitative research can “provide insight into complex issues and are more useful in studying new topics or exploring topics on which little is known” (Petros, 2012, p. 278). Qualitative research provides participants with a platform in which they are able to express in their own words their daily experiences. Mixed methods research provides an opportunity to gain a more inclusive approach to understanding the problem and can provide results that are enhanced in a way that a single research method would not offer. “Moreover, it may be argued that no method on its own can provide for the gathering of comprehensive data on a full range of the human experience and behavior” (Petros, 2012, p. 278).

The parent’s responses to the open-ended questions of the survey were used to inform the qualitative data analysis. With a qualitative analysis the parent’s responses guided the researcher so their story could be told. Parent’s responses to demographic information about themselves and their family as well as questions about treatments they reported using were used to inform the quantitative data analysis. These data were used to identify if there were any correlations between parent and/or their child’s demographics and the types of choices parents made when selecting treatments for ASD. The following study attempted to elucidate the reasons parents reported for choosing treatment(s) for their child with ASD.

Rationale For Study

Current research for ASD treatments shows that there is no known cure for ASD; however, there are numerous treatments touted to significantly improve or even cure the

disorder (Bowker et al., 2011; Green et al., 2006; Matson, Adams, Williams, & Rieske, 2013). There are studies available, which research and/or identify ASD treatments and report the efficacy of these treatments; however, the existing research studies evaluating ASD treatments are not all easily accessible or easy to understand to the layperson (Davis, 2010; Mackintosh et al., 2005; Zane, Davis, & Rosswurm, 2009). According to Davis (2010), “some practitioners and parents of children with autism may knowingly or unknowingly accept treatments with proof of evidence consisting of one poorly-designed, non-scientific study; personal testimonials; or commercial advertisement[s]” (p. 231). In addition, parents may turn to sources that have dubious credibility such as books/magazines, newspaper articles and the television. The internet has also become a wealth of information with hundreds of thousands of websites promoting various ASD treatments. Some of these sources may have excellent information on ASD treatments while others may have information that is counterproductive or even harmful (Mackintosh et al., 2005). Zane et al. (2009) labeled the treatments that are not helpful, a waste of time, or possibly dangerous as fad treatments. They defined these treatments as:

... interventions that use scientific jargon, sound logical, are supported by celebrities, and are discussed in the media and on the Internet, where many parents can be exposed to them. Fad treatments, by definition, have no substantial body of research showing that they are effective in treating any aspect of autism (p. 45).

Zane et al. (2009) also detailed the various costs of fad treatments including extensive monetary costs (some over \$16,000 a year), physical costs for the child, and the emotional costs on the parents and the child (including stress and the cost of false hope).

The research to date has identified some variables that may be involved in parental decision making for ASD treatments including demographic variables such as family makeup and socioeconomic status of the parents. In addition the parent's belief of the causal agent for their child's diagnosis of ASD, the therapy itself, as well as the severity of the child's behavioral issues have also been identified as variables that may influence parental decision making (Hall & Riccio, 2012; Mackintosh et al., 2005; Shyu, Tsai, & Tsai, 2010). However, it is unclear why these variables would affect a parent's treatment choice and why parents would choose or avoid a treatment course for ASD.

There are many variables reported in the literature that potentially may influence a parent's treatment choice. The following research will attempt to clarify the variables parents report influencing their decision making when choosing ASD treatments. In addition, this research will attempt to identify if there are variables, which influence whether a parent will choose evidence based treatments over treatments with little to no evidence for the treatment of ASD.

Literature Review

The research on parental decision making has identified multiple variables that may be involved in a parent's selection of treatment(s) for ASD such as family makeup, socioeconomic status, the parent's belief of the causal agent for of the ASD diagnosis, the therapy itself, as well as the severity of the child's behavioral issues (Hall & Riccio, 2012; Mackintosh et al., 2005; Shyu et al., 2010). Most of the existing research has been conducted using online surveys posted on autism related websites, distribution lists, autism support groups, autism listservs and newsletters from autism agencies/societies (Bowker et al., 2011; Green et al., 2006; Hall & Riccio, 2012; Mackintosh et al., 2005;

Miller, Schreck, Mulick, & Butter, 2012). Only two studies talked to parents directly through either a telephone survey (Green, 2007) or an in person survey (Shyu et al., 2010).

Parents face a multitude of choices when searching for therapies they could use to treat ASD. Green et al. (2006) conducted a study to find out how many different treatments were reportedly used by parents. An internet survey was posted on several autism websites, which were available to anyone who had a child diagnosed with ASD. Five hundred and fifty-two individuals across the nation responded to this online survey. The goal of the study was to identify which treatments and how many treatments were being used with children with ASD. The findings were divided into two categories cumulative treatments used across the child's lifetime and total number of treatments used at any one time. Participants identified 108 different treatments being used currently or previously to treat autism. The top five most used treatments were speech therapy, visual schedules, sensory integration, and applied behavior analysis (ABA). Only one of these treatments (ABA) has been identified as an efficacious treatment for ASD according to the literature (Rogers & Vismara, 2008). The mean number of treatments used were seven at one time; "the highest number of different treatments used by any 1 parent was 47 (currently) and 39 (in the past)" (p. 78). While it is difficult to know if parents were using too many, too few, or the correct amount of treatments at one time, using multiple treatments can make it difficult to identify which treatment or combination of treatments could be responsible for any changes observed in the child.

Variables for selecting treatments. The research indicated that parents reported using multiple sources of information when they were attempting to make decisions about the treatments they would use with their child. The sources of information parents report using included other people (parents, professionals, doctors), scholarly journals, books/magazines, autism communities (conferences, autism groups), and the internet. Demographic information about a parent or child were also identified by the researchers as variables influencing treatment choice. Parental demographics included level of education and marital status while child demographics include the ASD diagnosis of the child and the severity of the child's behavioral issues. While the research identified possible variables affecting treatment choices it remains unclear why parents used multiple sources when identifying treatment information and what types of treatments these sources recommended (i.e., treatments with an evidence base for treating ASD or treatments without an evidence base for treating ASD). It is also unclear why the demographic variables reported in these studies affected a parent's treatment choices. The sections below will describe the possible variables influencing parental choices within the existing research.

Some researchers did not differentiate between research-based and non-research-based treatments for parental choices when reporting their research. The following is a description of studies that did not differentiate between these types of treatment choices. The sources of information used to identify ASD treatments may vary according to the autism diagnosis (Asperger's vs. Pervasive Developmental Disorder, not otherwise specified (PPD-NOS)) (American Psychiatric Association, 2000) of the child as well as the parent's income. Information sources included written sources (books, scientific

journals, the internet, and autism newsletters), group gatherings (conferences, workshops, and autism group meetings), personal relationships (other parents of children with ASD, family members, friends, neighbors), and professional relationships (physicians, educators, other professionals). Mackintosh et al. (2005) conducted a study using an internet survey posted on autism related websites; there were 498 respondents to the survey. The researchers were attempting to determine what sources of information parents used when learning about ASD and where they found social support to help handle the stress associated with having a child with a disability. Their results indicated that parents used approximately seven different sources of information to identify treatments to use with their children. Mackintosh et al. found correlations between parent demographic variables and the sources of information used to inform treatments. Parents of children with autism were more likely to use family members and spouses as sources of information than parents of children with Asperger's and PDD-NOS (Mackintosh et al., 2005). Higher and middle-income parents were more likely to use other parents, conferences/workshops, scientific journals, and autism group meetings than lower income parents were. According to Mackintosh et al. lower-income parents did not have access to the variety of sources of information to which higher and middle-income parents had access.

In another study, the source of information was found to vary depending on the treatment(s) selected. Respondents from the Green (2006) study which, described how many treatments parents reported using at one time, were contacted about participating in a telephone survey. Nineteen participants were recruited for the Green (2007) study, and were interviewed about specific treatments they had used with their children. An open-

ended interview was used in which the authors attempted to identify the source of information parents reported using to identify the treatments they selected, as well as particular information about each treatment used (who provided the treatment, administration difficulty, length of time in treatment, etc.). Some treatments were recommended by specific sources. For example, sensory integration was typically recommended by occupational therapists (OT) and applied behavior analysis (ABA) was typically recommended by other parents or through a book about ABA. The internet and other parents were identified as the most popular sources for information about ASD treatments.

In a qualitative study completed by Mackintosh, Goin-Kochel, and Myers (2012) researchers attempted to identify how parents communicated with other parents about treatments for ASD. They identified that how a parent reported they felt about a particular treatment appeared to affect treatment use, duration, and compliance with the treatment. How a parent reported feeling about a treatment may also affect whether a parent will recommend the treatment to another parent. A survey was posted online and participants were recruited through online autism organizations. Parents were asked to list the treatments they had used with their children and evaluate those treatments. The researchers reported that 70.6% of respondents had at least one negative comment about the treatment their child was using, however, no single treatment was uniformly liked or disliked by all or most of the parents.

Several themes which were identified by these researchers, which appeared to affect a parent's treatment choice including "relationships with professionals, access to desired treatments, costs (including money, effort, and time), concerns about using

medications, and stress” (Mackintosh et al., 2012, p. 58). Parents identified some supportive relationships and some adversarial relationships with professionals. These relationships reportedly affected treatment selection, with parents identifying that some professionals prevented the parents from obtaining the treatments they wished to use. Parents identified access to treatments as a problem. They described being placed on waiting lists (which delayed treatments) they also reported a lack of specialists in their area (preventing a child from receiving a treatment) and limited access to treatments (not receiving the treatment for the desired length of time or at the desired intensity) as problems. Many parents expressed concerns about using medication with their children, regardless of the effectiveness of the medication regimen. Parents also reported concern about using drugs in general with their children or about the possible short term and/or long-term side effects of using medication. The researchers reported that all of the variables mentioned previously could create family stress and parental stress, which could affect the choices that were made by parents. For example, some parents may have been so overwhelmed by the stress of obtaining a desired treatment that they were not able to fight the insurance companies, school, doctor/therapist or figure out complicated state systems in order to obtain the treatments they believed their child needed.

Some studies have shown that parents may use multiple treatments at one time when treating ASD. Bowker et al. (2011) reported that parents will also discontinue a treatment for a variety of reasons including a belief about the effectiveness of the treatment, termination of access to the treatment, the treatment was no longer necessary, or the treatment was of limited duration. Bowker et al. (2011) used an online survey, which was accessible through several autism websites and distribution lists. The survey

was made available for three months, and many of the questions on the survey were open-ended. The goal of the research was to identify the number and types of treatments being used to treat autism, how the treatments chosen affected the child's functioning (improvements in areas of functioning such as cognitive, behavioral, attention, linguistic, physical, and social) as well as why past treatments were discontinued. Results indicated that treatment selection varied according to the child's diagnosis. Children with Asperger's were less likely to receive some form of treatment, compared to children with autism and PDD-NOS. Parents were less likely to select ABA treatments for children with diagnoses of Asperger's and reported less improvement overall than children with either autism or PDD-NOS diagnoses. The majority (72%) of respondents in the sample reported using some type of treatment for their child and 12% were using five or more treatments at the same time. The results of the Bowker et al. (2011) study indicated that a parent's choice of treatments may be influenced by what ASD diagnosis the child may have. The researchers hypothesized that the treatment choices parents made may be related to specific goals for their children. The authors suggested that children with diagnoses of Asperger's typically have skill deficits related to social skills and treatment choices may be made to address these skill deficits. For example, children with Asperger's were more likely to use relationship-based treatments than ABA treatments. Children with diagnoses of PDD-NOS and Autism, however, were more likely to use ABA treatments than relationship-based treatments.

Only one group of researchers attempted to identify if there were any differences in the variables that affected a parent's treatment choices when selecting treatments, which had a research-base for treating ASD, and treatments, which did not have a

research-base for treating ASD. Miller et al. (2012) attempted to identify what variables may affect treatment choice when parents chose research-based treatments over non-research based treatments. Miller et al. (2012) conducted a study using an online questionnaire. Four hundred participants were recruited from autism listservs and newsletters from autism agencies/societies. The purpose of the study was to identify the treatments parents were currently using with their children to treat ASD, if demographic variables were associated with treatment selection, how sources of information guided treatment choices, and “where parents [were] obtaining professional recommendations regarding ASD treatment” (p. 88). On the survey, participants were asked to identify demographic information about themselves and their child, treatment recommendations from professionals, as well as other sources of information used for autism treatments. The results indicated that there was no statistical relationships between demographic variables (the parent’s education level, major in college, income, age range, time because child’s diagnosis, and child’s age) and treatment choices regardless of the scientific support for the treatment. According to the authors, the results of the survey indicated that parent’s treatment choices were more heavily influenced by “word of mouth” (p. 94) than by treatments supported by research. “Word of mouth” included information sources such as “print media, professional recommendations, and other parents’ recommendations” (p. 94). The recommendations made by professionals for research-based treatments varied by professional. Psychologists and behavior analysts were the most likely to make research-based treatment recommendations and “medical and allied medical professionals” (p. 94) were most likely to make recommendations with mixed or no research base for the treatment of ASD. The authors indicated that psychologists and

behavior analysts were more likely to recommend therapies within their field which were research based, and while they did make recommendations that were not research based they did so infrequently. An analysis of recommendations made by educators, speech therapists, occupational therapists, and physical therapists were also completed. Many of these therapists recommended therapies in their field for the treatment of ASD, which were not research based (less than 15%). Examples of non-evidence based recommendations included OT's recommending sensory integration and speech therapists recommending auditory integration. Because parents may view "professionals" as a source of information that can be relied upon, it is important that the recommendations from these professionals be grounded in the research, so that children with ASD are receiving the best treatment available to them and parents and children are not wasting their time and money on unproven treatments.

Some researchers specifically looked at parental treatment choices for non-research-based treatments when conducting their research. Many parents reported using complementary and alternative medicine (CAM) treatments for their child with ASD. CAM treatments are typically treatments that are used in addition to or as a substitute for traditional treatments. "CAM approaches are not routinely used by medical or related health professionals" (Hall & Riccio, 2012, p. 159). These types of treatments typically have a lot of anecdotal support but many "have not been examined empirically or have yielded equivocal results" (Hall & Riccio, 2012, p. 159). Examples of CAM treatments include craniosacral therapy, chelation, weighted vests, and facilitated communication (Baxter & Krenzelok, 2008; Hodgetts, Magill-Evans, & Misiaszek, 2011; Montee et al., 1995; Zane, 2011). A couple of research studies including, Hall and Riccio (2012) and

Shyu et al. (2010) attempted to identify variables that may influence a parent to choose CAM treatments over treatments with an evidence base for treating ASD. The following is a description of studies, looking specifically at parental choices for non-research-based treatments.

Hall and Riccio (2012) used an online survey sent to autism support groups to identify how many parents were using CAM treatments and what factors may have contributed to their choice to do so; 450 respondents filled out the survey. The survey asked demographic information, what types of CAM treatments had been used, as well as the severity of their child's behavioral issues. The researchers reported that parents were more likely to use CAM treatments if their children had been treated by multiple physicians or therapists, if parents had more time to research potential treatments for autism, if parents were looking for a cure (which is promised by many CAM treatments), and if their child's behavioral issues were severe. The child's acceptance of the treatment was also reported as a variable affecting the continued use of a CAM treatment once it had been started. Demographic information that was correlated with an increase in CAM usage was the parent's marital status and level of education. Parents who were married and parents who had a higher level of education were more likely to use CAM treatments.

Shyu et al. (2010) reported that what parents think caused the ASD diagnosis, "effect of the selected treatment strategy, the child's preference/resistance to treatment strategy, and the fit of the child/parents with the therapist" appeared to play a role in treatment selection (p. 1328). Shyu et al. (2010) attempted to identify the relationship between how Chinese parents understand and explain their child's autism (the believed cause of the autism) and how they found treatments for their children, which they termed

the parental explanatory model. Thirteen parents of children with autism were interviewed in person using a semi-structured interview; a qualitative analysis was used to analyze the data. Shyu et al. (2010) divided the attribution causes reported by parents into two groups, biomedical (such as a food allergy) and supernatural causes (such as a soul following the child). Treatment selections categorized in this study for ASD included a combination of both “orthodox treatments” (p. 1330) (such as occupational therapy and speech) and CAM treatments. Chinese parents referred to treatments available from their healthcare system as orthodox. Some of the CAM treatments identified in the research were acupuncture, vitamins, and sensory integration. While this research may be an accurate representation of decision making for Chinese parents, there were cultural and/or religious differences that may not translate to American parents. One example of these differences is supernatural causes as a causal agent for autism. Treatment choices Chinese parents selected for supernatural causes were reading the Buddhist bible or seeing a fortuneteller, treatments American parents may not be likely to select for their children (p. 1328).

According to the preceding qualitative and mixed methods research studies, there were many variables that may influence a parent’s treatment choice for their child. Multiple demographic variables of both the parents and children were correlated with research-based and CAM treatment choices for most of the studies. In the surveys and interviews, parents reported source of information as a variable in treatment selection. With multiple treatment choices available parents were most likely to turn to other parents, print and visual media (books, journal articles, celebrities, and the internet), and

professional associations (Green, 2007; Mackintosh et al., 2005; Miller et al., 2012) to learn about ASD treatments.

While there are multiple variables reported in the previous research that may influence how a parent makes treatment choices for their child with ASD, the literature is fragmented and does not appear to have a clear direction. The researchers do not appear to be building upon previous research results and do not attempt to clarify why their results may be similar or dissimilar to the current body of research. There are also problems associated with the variables some researchers report affecting a parent's decision-making. Multiple researchers attached belief statements to parental responses or reported the belief statements of parents (Bowker et al., 2011; Mackintosh et al., 2012; Shyu et al., 2010). Beliefs are private events and as such are difficult to observe or measure. Reporting choices based on a parent's report of a belief statement or attaching a belief statement to the data can be problematic since there is no way to identify the veracity of these reports. Replicating the research also becomes more difficult; two people may not label the same event/feeling in the same way. Correlational data is also reported throughout the research, but again the research is fragmented with different researchers reporting different variables so there is no consistency across the body of research. In order to draw preliminary conclusions which can inform a more scientific causal analysis of parental treatment choices the research should build on previous research so that possible variables can be included or excluded based on the data available.

There is a lot of speculation in the available research about what variables are involved in parental decision making, however, only one study Miller et al. (2012)

attempted to identify if the variables affecting choice differ if the treatment choice a parent makes has an evidence base for treating ASD. Knowing what variables may influence parental treatment choices may help researchers and practitioners identify ways to increase evidence-based treatment choices and decrease choices that do not have an evidence-base for the treatment of ASD. The intent of this research project is to obtain findings that may shed light on the reasons parents reported choosing ASD treatment(s) for their children using a mixed methods research approach.

Chapter 2

Methodology

Instrument

Appropriate approvals were obtained by the University of Memphis before conducting this study. A survey was created using Qualtrics software, Version 2013 of the Qualtrics Research Suite. Copyright 2013 by Qualtrics. A link to the survey was provided to prospective participants via Facebook, LinkedIn, Twitter, email, a monthly electronic newsletter from a regional autism group, and a link posted on an autism website. From a regional autism group affiliated with a reputable national organization. The survey was available for three months. Participants consented to the study in order to access the survey. In order for a survey to be included in the study the participant had to report having at least one child diagnosed with ASD and they had to complete the entire survey. Of the 15 surveys begun only 11 met the inclusion criteria, 4 were not included due to participants not finishing the surveys.

Survey questions were a combination of multiple choice, rank order, and open-ended questions. Skip logic was used when developing the questions, meaning, if the participant answered “no” to a question they were not shown any follow-up questions to the original question. The 74-question survey (see Appendix) provided data to analyze quantitatively and qualitatively. Quantitative data came from fixed response and rank order questions. These questions included demographic information about the parents including location, marital status, ethnicity, education completed, number of children, and relationship to the child with ASD. Participants were also asked demographic information about the child they chose to talk about including the child’s gender, age

(current and at diagnosis), diagnoses, behavioral issues, and sleep issues. Participants were asked to identify if there was a family history of ASD and the relationship of those family members to the child. Participants were also asked what they thought caused ASD and if they thought there was a cure.

In order to identify if there were treatment specific decisions, treatment categories were created. The literature did not have well defined categories for the numerous treatments available for ASD (Green et al., 2006; Hall & Riccio, 2012), so treatments were broken up into four general categories similar to those used by the Center for Disease Control and Prevention. The four categories for treatments used on the survey were 1) Diet Treatments, 2) Medication Treatments, 3) Behavioral and Educational Treatments, and 4) Other Treatments (which was comprised of CAM treatments). Each treatment category was labeled in the survey and the participants were asked to identify which treatment(s) they chose for their child within the treatment category. Participants were also asked to rank order their preferences for the source of information used to identify ASD treatments as well as the source of information they used for the actual treatments they selected for their children. These questions were similar to those asked by Bowker et al. (2011) and Hall and Riccio (2012).

To obtain a better perspective on the reasons parents reported making treatment choices for their children the parents were asked a series of questions pertaining to treatment selection. Similar to Bowker et al. (2011) many of the questions on the survey were open-ended so parents were able to provide answers without guidance from the author. These open-ended questions were interspersed throughout the survey and included questions about how they felt searching for treatments, if they found any

conflicting information, what the doctor who diagnosed their child with ASD identified as treatment(s) to use or avoid and what other people they spoke to identified as treatment(s) to use or avoid. Parents were also asked treatment specific questions including: how the parent found out about the treatment(s) they selected, why they selected the treatment(s), what they expected from the treatment(s), and if they planned on using or avoiding any treatment(s) in the future and why.

Participants

All participants identified themselves as parents, 10 were mothers and 1 was a father. Parents from six different states within the United States filled out the survey; the states were located in the mid-west, south, east coast, and northeast. Ten of the parents were white and 1 was African American; all of the parents were married at the time of survey. Six of the parents finished technical school and some college, 4 of the parents were college graduates, and 1 parent had a master's degree. The parents had 2-5 total children and at least one child was diagnosed with ASD. Only two of the parents identified a family history of ASD (second cousin); however, Sue, a mother of two with one daughter with PDD-NOS did state that she suspected "we have cousins who are undiagnosed" (see Table 1 for individual parent demographics; pseudonyms are used in place of the parent's real names).

Table 1

Parent Demographic Information

	Parental Status	Marital Status	Ethnicity	Education	Number of Children	Family History of ASD
Sue	Mother	Married	White	Master's Degree	2	No
Violet	Mother	Married	White	Technical School/ Some College	3	No
Simon	Father	Married	White	College Graduate	2	No
Diana	Mother	Married	White	Technical School/ Some College	2	Yes
Rhonda	Mother	Married	White	College Graduate	3	No
Lola	Mother	Married	African American	Technical School/ Some College	4	Yes
Nadine	Mother	Married	White	Technical School/ Some College	5	No
Gloria	Mother	Married	White	College Graduate	2	No
Melissa	Mother	Married	White	Technical School/ Some College	3	No
Barbara	Mother	Married	White	College Graduate	4	No
Ann	Mother	Married	White	Technical School/ Some College	2	No

Parents reported having female (n = 4) and male (n = 7) children, with ASD diagnoses including Asperger's, PDD-NOS, and Autism (American Psychiatric Association, 2000). Six parents also reported their children having diagnoses in addition

to ASD including, OCD (Obsessive Compulsive Disorder), SPD (Sensory Processing Disorder), seizure disorder, ADHD (Attention Deficit Hyperactivity Disorder), and Mental Retardation. Ten of the 11 parents reported that their children had behavioral issues. The behaviors reported as a problem ranged from inappropriate social interactions and stereotypy to self-injury (SIB) and physical aggression (see Table 2 for individual child demographics including specific diagnoses and comorbidity).

Table 2

Child Demographic Information

Parent	Child's Gender	Age at Diagnosis	Current Age	ASD Diagnosis	Other Diagnoses	Reported Behavioral Issues
Sue	Female	7	8	PDD-NOS	None	Rude behavior, ignoring people when they speak to her, rude tone of voice.
Violet	Male	3	7	Autism	ADHD, SPD	Self-Stimulatory Behaviors
Simon	Male	6	7	PDD-NOS	ADHD	None
Diana	Female	6	7	PDD-NOS	SPD	SIB, Inappropriate Toileting, Self-Stimulatory Behaviors
Rhonda	Male	3	7	Autism	Mental Retardation	Property Destruction, Self-Stimulatory Behaviors
Lola	Female	2	3	Autism	SPD	SIB, Property Destruction
Nadine	Male	2	7	Autism	Seizures, OCD	Physical Aggression, Self-Stimulatory Behaviors
Gloria	Male	2	9	Autism	None	SIB, Elopement, Self-Stimulatory Behaviors, Echolalia
Melissa	Male	5	7	Asperger	None	Elopement
Barbara	Female	4	7	Autism	None	Self-Stimulatory Behaviors, Echolalia
Ann	Male	4	8	PDD-NOS	ADHD	Elopement, Echolalia, Fixations

Methodological Approaches

Quantitative Methods. A Fisher's Exact test was used to analyze any correlations between the demographic characteristics of the parents and children and the treatment choices parents made. A Fisher's Exact test was used due to the small sample size. Treatment choices were divided into two categories: Evidence-Based treatments and Non-Evidence-Based treatments. To identify if a treatment was Evidence-Based or not the researcher consulted the Association for Science in Autism Treatment's (ASAT) website (www.asatonline.org) which lists most ASD treatments and whether there is a research base supporting the efficacy of the treatment for ASD. Only the treatments parents reported using were included in this analysis (see Table 3 for list of Evidence-Based treatments and Non-Evidence-Based treatments). For treatments not listed on the ASAT website (such as occupational and speech therapy) the diagnostic criteria for ASD according to the DSM IV-TR were compared to the skills each therapy proposed to treat. If the therapy treated behaviors identified by the diagnostic criteria, a search was completed using Google Scholar (scholar.google.com) to identify if there was any research supporting the treatment for ASD.

Table 3

List of Evidence-Based Treatments and Non-Evidence-Based Treatments

Treatment Category	Evidence-Based Treatments	Non-Evidence-Based Treatments
Diet treatments		Gluten Free Casein Free Gluten-Free Casein-Free Diet removal of food dyes Omega 3 Fatty Acids Magnesium Other (please describe): "Limit processes food, purchase mostly preservative & nitrate free. Also added in Bach's Rescue Remedy"
Medication Treatments	Antipsychotics	Anticonvulsant Psychostimulant Antidepressants
Behavioral/Education Treatments	Augmentative and Alternative Communication Applied Behavior Analysis Early Intensive Behavioral Intervention/Treatment Lovaas Therapy/Discrete-Trial Training Picture Exchange Communication System Social Skills Groups Social Stories Special Education Speech Therapy	Cognitive/Behavior Therapy Occupational Therapy

Table 3 (continued)

Treatment Category	Evidence-Based Treatments	Non-Evidence-Based Treatments
Other Treatments		Animal Therapy Art Therapy Craniosacral Manipulation Developmentally-based Individual-difference, Relationship-based Intervention, Floor Time, Greenspan Method Socialization related classes Vision Therapy Weighted vests/blankets

Descriptive statistics were completed for treatment choices, the ranked preference of the sources of information, and recommendations parents reported receiving. The descriptive statistics for treatment choices included comparing the demographic variables of the parent and child to the evidence base of the treatment choices parents reported making. Reported preferences for sources of information were ranked across parents. Descriptive statistics were completed comparing the rank of the source of information to the actual sources of information parents reported using. The sources of information parents reported using were grouped by treatment (Diet, Medication, Behavioral/Education, Other) to identify if 1) different sources were used for different types of treatments and 2) to identify if the sources actually used matched the sources parents reported a preference for using. For example did parents report using their most preferred sources of information when selecting Diet Treatments. Descriptive statistics were also completed for the treatments parents reported the diagnosing doctor and other informants recommended using and avoiding to treat ASD. Specifically, the

recommendations were analyzed to identify if there was a research base supporting the efficacy of the treatments for ASD.

Qualitative Methods. An interpretative phenomenological analysis (IPA) was used to analyze the data, that were collected from the survey (refer to Appendix A for survey), and to answer what reasons parents reported for making treatment choices for their children with ASD. In IPA the participants are considered experts of their own experiences. IPA “attempts to explore personal experience and is concerned with an individual’s personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself” (Smith, 2007, p. 53). The goal of the research is to make evident the participants perspectives.

Purposive sampling was used to recruit participants for this study. In purposive sampling participants with experiences specific to the phenomenon being studied were selected for the experiment. “Data from only a few individuals who have experienced the phenomenon—and who can provide a detailed account of their experience—might suffice to uncover its core elements” (Starks & Trinidad, 2007, p. 1375). In IPA research small samples are typical, ranging from 1-15 (Smith, 2007).

Acknowledgement of Researcher Bias. The researcher has over 10 years’ experience working with adults and children with developmental and neurological disabilities. The researcher has a master’s degree in applied behavior analysis and is currently completing a doctorate in special education. As a board certified behavior analyst, the researcher has worked with many families with children with ASD and has seen them struggle to implement various treatments for their children. Some of those treatments have been highly successful and some have been ineffective.

Data Analysis. Data were gathered from the open-ended questions in the survey, the data were analyzed using an “iterative, inductive process of decontextualization and recontextualization.” (Starks & Trinidad, 2007, p. 1375). During decontextualization, the raw data were separated from each question and the data were coded based on individual phrases or words within the raw data. A code can be any part of the data collected including a word or phrase the participant gave (Saldana, 2009). In qualitative research, refinements to codes are often necessary such as increasing or decreasing breadth of the code, adding new codes, etc.

In this research, the author first looked at each individual participant’s responses and attempted to identify common words, phrases, or ideas (see Figure 1 for a flow chart of the data analysis process). Once the researcher was familiar with each individual’s responses, the researcher looked at the responses across participants and coded the data using the coding process described above. Verification of the original codes was achieved by randomizing all the open-ended responses across participants so the responses could not be identified by participant. The participant’s own language, obtained from the open-ended responses on the survey, were used to create codes in this research. An example of coding, with this research, was assigning the code, Monetary, to the participant’s phrase “It’s expensive!!!” In qualitative research codes sometimes overlap (Thomas, 2006). An example is one participant’s response “... he won't eat when he is completely gluten free”. This was coded as a problem with therapies and an undesirable treatment. The data that were coded Goals, offer an example of how the data were refined. As the data were analyzed two categories of Goals became evident and the

code of Goals was further refined to Child Specific Goals and Therapy Specific Goals for treatments.

In recontextualization the data were reanalyzed in the context of the questions that were asked. In this research, once the data were matched to the original questions the data were then recoded a second time to ensure none of the participant's responses were taken out of context. Any discrepancies between the two coding sessions were addressed. Following the second analysis, the researcher looked for common themes that described the coded data. "A theme is an *outcome* of coding, categorization, and analytic reflection, not something that is, in itself, coded" (Saldana, 2009, p. 13). Coded data came from multiple questions within the survey, i.e., there was no one question which produced all of the coded data for a theme. The following is an example of how codes became themes. Parents reported problems in selecting and implementing treatments throughout the survey. The researcher identified four codes that appeared to be related to one another: Monetary, Amount of Information, Therapies/Therapists, and School/School system. From these four codes a theme was created to describe these codes: "Parental reports of encountering problems when selecting or implementing an ASD treatment, which affected the selection of or continued use of a treatment". Table 4 shows an example of some of the coded data (Amount of Information and Therapies/Therapists) and the matching theme (Parental reports of encountering problems when selecting or implementing an ASD treatment, which affected the selection of or continued use of a treatment).

Table 4

Example of Coded Raw Data and Matching Themes

Parental reports of encountering problems when selecting or implementing an ASD treatment, which affected the selection of or continued use of a treatment	
Monetary	Therapies/Therapists
It would have been helpful to know of a way to pay for all of the therapies she needed. A way to provide the many hours of treatment.	Where to find these therapists. We have done ABA in home because the diagnosis but it is difficult to replace workers when they leave.
It's expensive!!!	... he won't eat when he is completely gluten free
oxygen treatments expensive...	...the regular pediatrician overmediated [sic] her.

Credibility Check. A credibility check was obtained by giving independent observer, who was a Masters level clinician working with families of children with Autism, a list of all open-ended interview questions and corresponding participant responses. The independent observer was asked to read all the responses and familiarize himself with the data (see Figure 1 for a flow chart of the credibility check process). Once this was completed, the independent observer was given the coded data that were categorized by the corresponding themes. The independent observer was then asked to identify if all the coded data corresponded to the theme it was matched to and that no data were left out. Original agreement was 95.96%, the researcher and independent observer discussed any discrepancies until an agreement was made about how the data were coded and categorized. Final agreement was 100%.

Data Analysis Procedure

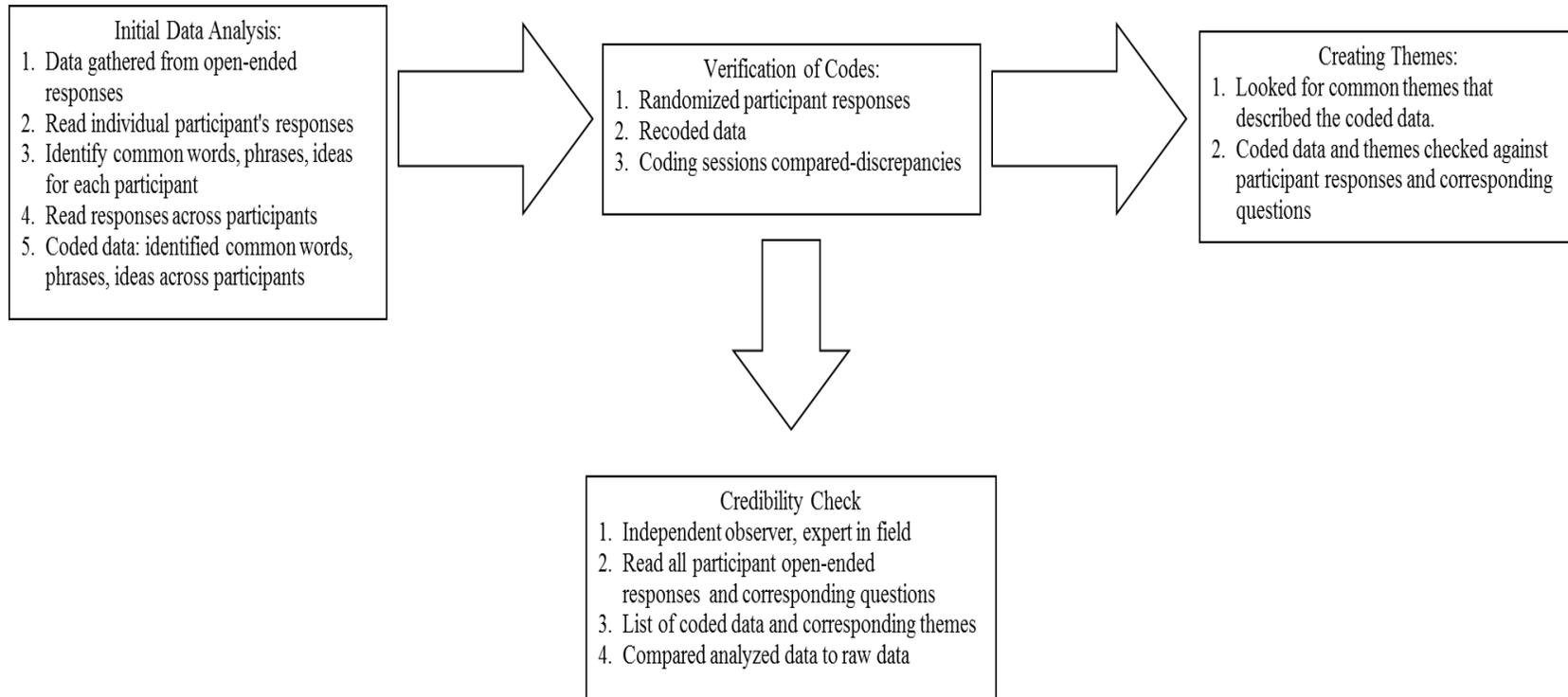


Figure 1. Flow chart of data analysis and credibility check process

Chapter 3

Results

A mixed methods approach was used to analyze the self-reported data collected from the online survey. A mixed methods approach combines both quantitative and qualitative data analyses for a more comprehensive understanding of the research questions under study. Both types of analyses are described below followed by the findings.

Quantitative Analysis

Analysis of Demographic Variables. A Fisher's exact test was used to examine if there was a correlation between the types of treatments a parent chose, such as evidence-based or CAM treatments, and the demographic variables of interest including the specific ASD diagnosis of the child (according to the DSMR IV-TR), length of time the child had an ASD diagnosis, and the parent's education. A Fisher's exact test was used due to the small sample size of the categorical data. The Fisher's exact test analyzes the statistical significance of contingency tables. The test analyzes categorical data, which are characterized in two different ways, and tests the significance of the relationship of the classification. A chi-squared test, the usual test for statistical significance with this type of data, could not be used since the sample size for all of the data sets fell below 10 and there was only one degree of freedom. The Fisher's exact test, however, can be used regardless of the sample size of the data set. All tests were calculated at .05 significance level (see Table 5 for the results of the Fisher's Exact test).

Table 5

Results of Fisher's Exact Test Comparing Demographic Variables to Treatment Choice

Comparisons	n	d.f.	Significance
Master's Degree/College Degree	5	1	p=.162
Some College/Technical School	6		
Length of time with ASD diagnosis is less than 3 years	5	1	p=.056
Length of time with ASD diagnosis is more than 3 years	6		
Diagnosis of PDD-NOS	4	1	p=.162
Diagnosis of Autism	6		

Note. Significance calculated at .05 level.

The first analysis was to statistically determine if there was a correlation between the parents' level of education and the treatments reportedly selected. In an effort to determine if the level of education reported by the parent affected their treatment choices, two categories were formed based on their responses. The two categories included parents who completed a college degree, including baccalaureate and masters, (n = 5) and those who completed some college or technical school (n = 6). Based on the analysis, no correlation was found between the parent's level of education and their treatment choices (p>.05).

Descriptive statistics were completed (see Table 6) comparing the sum, average, and SD of the treatments parents reported using. Treatments used were divided into three groups: total treatments, evidence-based treatments, and non-evidence-based treatments (see Table 3 for the list of treatments parents reported using and how they were categorized) and compared to the two education groups for parents (master's/college

degree and some college/technical school). Total number of treatments used by parents were very similar across parent group with n = 41 for parents with master's/college degree and n = 42 for parents with some college/technical school. There was a difference found the types of treatments parents reported choosing. Parents with a master's/college degree reported choosing less Evidence-Based treatments (n = 12) compared to parents with some college/technical school (n = 20). A much smaller difference was found in treatment choices for Non-Evidence-Based treatments. Parents with master's/college degree chose more Non-Evidence-Based treatments (n = 29) compared to parents with some college/technical school (n = 21).

Table 6

Descriptive Statistics for Parental Choices Across Parent Groups

Parent Group		Total Treatments Used	Evidence- Based Treatments	Non-Evidence- Based Treatments
Master's/College Degree				
	Sum	41	12	29
	Average	8.2	2.4	5.8
	SD	7.46	2.51	5.31
Some College/ Technical School				
	Sum	42	20	21
	Average	7	3.33	3.5
	SD	3.79	2.87	2.74

The second analysis was conducted to determine if the length of time the child had an ASD diagnosis was correlated with specific treatment choices or an increase in

CAM treatment use. To identify if there were any correlations between the length of time with an ASD diagnosis and treatment choice of the parents the children were divided into two groups, children who had an ASD diagnosis for three years or less ($n = 5$) and children who had an ASD diagnosis for more than three years ($n = 6$). No correlation was found between the length of time with an ASD diagnosis and the parent's treatment choices ($p > .05$) (see Table 4 for results).

Descriptive statistics were completed comparing the sum, average, and SD of the treatments parents reported using. Treatments were divided into three groups: total treatments, evidence-based treatments, and non-evidence-based treatments and compared to the length of time the children had an ASD diagnosis (see Table 7). The two groups used in the Fisher's Exact test (children who had an ASD diagnosis for three years or less and children who had an ASD diagnosis for more than three years) were used to complete the descriptive statistics. A difference was found in total treatment parents reported using across the two child groups with $n = 35$ for children who had an ASD diagnosis for three years or less and $n = 48$ for children who had an ASD diagnosis for more than three years. A difference was also found in treatment choices that were Evidence-Based. Parents who had a child with an ASD diagnosis for three years or less chose less Evidence-Based treatments ($n = 11$) compared to parents with a child who had an ASD diagnosis for more than three years ($n = 21$). A negligible difference was found in treatment choices for Non-Evidence-Based treatments with $n = 24$ for parents who had a child with an ASD diagnosis for three years or less chose and $n = 26$ for parents with a child who had an ASD diagnosis for more than three years.

Table 7

Descriptive Statistics for Parental Choices Across Child Groups: Length of Time Child Had an ASD Diagnosis

Child Group		Total Treatments Used	Evidence-Based Treatments	Non-Evidence-Based Treatments
Length of time with ASD diagnosis is less than 3 years	Sum	35	11	24
	Average	5.83	1.83	4
	SD	4.96	1.94	3.52
Length of time with ASD diagnosis is more than 3 years	Sum	48	21	26
	Average	9.6	4.2	5.2
	SD	5.86	2.95	4.97

Lastly, in order to identify if there was a correlation between the specific ASD diagnosis and a parent's treatment choice the children were divided into two groups, children with a diagnosis of PDD-NOS ($n = 4$) and children with a diagnosis of Autism ($n = 6$). Children with Asperger's were not included in the analysis because there was only one child who had this diagnosis and it was unknown if this child was a random sample of the population of children with Asperger's. No correlation was found between the specific ASD diagnosis of the child and the parent's treatment choices ($p > .05$) (see Table 4 for results).

Descriptive statistics were completed comparing the sum, average, and SD of the treatments parents reported using. The same treatment division described above was used again and was compared to the diagnoses of the children: children who had an ASD

diagnosis of PDD-NOS and children who had an ASD diagnosis of Autism (see Table 8). There was a large difference in total treatment choices parents reported using across the two child group with $n = 22$ for children with an ASD diagnosis of PDD-NOS and $n = 53$ for children with an ASD diagnosis of Autism. A difference was also found in treatment choices that were Evidence-Based. Parents who had a child with an ASD diagnosis of PDD-NOS chose less Evidence-Based treatments ($n = 8$) compared to parents with a child who had an ASD diagnosis of Autism ($n = 21$). A large difference was also found in treatment choices that were Non-Evidence-Based. Parents who had a child with an ASD diagnosis of PDD-NOS chose less Non-Evidence-Based treatments ($n = 14$) compared to parents with a child who had an ASD diagnosis of Autism ($n = 31$).

Table 8

Descriptive Statistics for Parental Choices Across Child Groups: ASD Diagnosis

Child Group		Total Treatments Used	Evidence- Based Treatments	Non-Evidence- Based Treatments
Diagnosis of PDD-NOS	Sum	22	8	14
	Average	5.5	2	3.5
	SD	3.51	2.16	3.11
Diagnosis of Autism	Sum	53	21	31
	Average	8.83	3.5	5.17
	SD	6.85	3.15	5.08

Sources of Information. On the survey, parents were asked to rank order their preferred source of information as well as identify what sources of information they used

to make treatment choices. Parents were given a list of potential sources of information and then asked to rank order their most preferred sources of information when researching treatments. Table 9 shows the range of the rankings parents gave each source. Some sources, such as “Professionals in Autism” had a very tight range, with all eleven parents ranking this source in their top five most preferred sources. “Celebrities” also had a very tight range, with all 11 parents ranking the source between 12-15. Other sources, such as “Teachers” had a range that varied considerably (2-14) on the rankings. It is interesting that there was such diversity with the ranks for teachers because all but one parent had a child that was school age and seven of the eleven parents reported using teachers as a source of information for ASD treatments. Table 9 also identifies the summative rank for the sources of information. The lower the rank, the higher the preference for the source of information. Parents reported “Professionals in Autism” (rank = 23) as their most preferred source of information and “Celebrities” (rank = 150) as their least preferred source of information. Parents reported “Teachers” (rank = 80) as a moderately preferred source of information, they were in the middle of the rankings. Parents ranked scientific/scholarly journals (rank = 73) as moderately preferred source, but none of the parents reported this as a source of information for treatment choices on the survey. Three parents did refer to “research” as informing their treatment choices on the survey, but did not elaborate where they found/heard about this research.

Table 9

Rank of Preferred Sources of Information Across Parents

Preferred Source of Information	Sum Rank ^a	Range of Rankings ^b	Average Ranking ^c	SD of Rankings ^d
Professionals in Autism	23	1-5	2	1.22
Doctors/Physicians	43	1-13	4	3.96
Other parents	58	2-10	5	2.53
Autism Websites	62	1-12	6	3.8
Autism Communities	71	3-9	6	2.29
Books/Magazines	73	4-9	7	1.69
Scientific/scholarly journals	73	1-13	7	3.59
Teachers	80	2-14	7	3.98
Other Individuals with Autism	84	5-12	8	2.42
Blogs	99	1-12	9	3.1
Social Media (Facebook, Twitter, etc.)	104	2-14	9	3.7
Media Outlets	118	4-12	11	2.28
Email	140	7-15	13	2.24
Other	142	3-15	13	4.04
Celebrities	150	12-15	14	1.12

Smallest rank=most preferred source of information

^a Sum Rank= summative rank by parents for each source of information

^b Range of Rankings= The range (1-15) that participants ranked the source of information

^c Average Ranking= The average ranking for each source of information

^d SD of Rankings= The standard deviation of the rankings

After parents ranked their preferred sources of information for learning about treatments, they were asked to identify the sources of information they actually used for treatments within each treatment category (Diet Treatments, Behavioral/Educational Treatments, Medication Treatments, and Other Treatments). Table 10 shows the actual sources of information parents reported using to learn about treatments. Parents identified some sources, which were not included in the rank order list such as

online/internet. The source of information used by parents varied by treatment category. The treatment category in which parents reported using the most sources was the Behavioral/Educational Treatment category.

There were discrepancies between parents' reported preferences for sources of information and the actual sources parents reported using to identify treatments. Only two parents (Simon and Gloria) used sources of information to identify treatments that they had ranked as highly preferred on the rank order list. Gloria also identified the "internet" as a source of information, which was not on the rank order list, so it is unclear where this source ranks among her preferences. Four parents (Violet, Rhonda, Melissa, and Ann) used a combination of highly preferred and moderately preferred sources (according to the parent's rankings of sources) of information to identify treatments. Rhonda and Melissa also identified the "internet" as a source of information, which was not on the rank order list, so it is unclear where this source ranks among their preferences. Nadine was the only parent who reported using moderately preferred sources of information exclusively to identify treatments. Three parents (Sue, Barbara, and Diana) were the only parents to use a combination of highly preferred and least preferred sources of information (according to the parent's rankings of sources) to identify treatments. Only two of the parents that reported using teachers as a source of information for Behavioral/Educational Treatments identified them as a highly preferred source of information.

Table 10

Actual Source of Information Used by Treatment Category

Source of Information Used	Diets Treatments	Behavioral/Educational Treatments	Medication Treatments	Other Treatments
Professionals in Autism	3	1	1	1
Doctors/Physicians	1	3	5	0
Other Parents	1	1	1	0
Books/Magazines	1	1	0	0
Internet	1	3	0	1
Teachers/School	0	8	0	2
Blogs	0	0	0	1
Autism Conferences	0	0	0	1

Note: Diet Treatments n = 3; Behavioral/Education Treatments n = 9; Medication Treatments n = 6; Other Treatments n = 5

Recommendations from the Diagnosing Doctor. Parents on the survey were asked to identify any recommendations they received of treatments to use or avoid from the doctor who diagnosed their child with ASD. These treatments were analyzed to identify if the recommendations were evidence-based or non-evidence-based using the procedures identified in the methods section (see Table 11 for results). According to parental reports, half of the diagnosing doctors' recommendations for treatments to use were non-evidence-based treatments. These treatments included specific medications that have not been tested for efficacy in treating ASD, the book 1-2-3-Magic, occupational therapy (OT), cognitive behavior therapy (CBT), starting school at age three, physical therapy, and hippotherapy. Evidence-based treatments doctors recommended parents use to treat ASD included social skills training, ABA and a speech language pathologist (SLP). Three recommendations were categorized as "unknown" because the parents were not clear with their answers; these included

“medications”, “teacher”, and “early intervention”. Early intervention was included in the unknown list because it was unclear what Nadine meant by this term. She identified the following recommendations from her doctor “ABA therapy, speech therapy, [and] early intervention”.

The diagnosing doctors did not give as many recommendations about treatments to avoid when treating ASD. Treatments that the doctors recommended a parent avoid that did not have a research base indicating they were efficacious in the treatment of ASD were categorized as evidence-based recommendations. Treatments that did have a research base indicating their efficacy in treating ASD, which the doctor recommended the parent, avoid were categorized as non-evidence-based recommendations. Seven of the eleven parents (64%) reported that the diagnosing doctor did not give recommendations of treatments to avoid. For the four parents who did report recommendations, 60% (3/5) of the recommendations were evidence-based and included diet changes, supplements, and invasive medical treatments like chelation. One of the recommendations was not evidence-based. An example comes from Gloria who reported that her doctor warned her to be “weary [*sic*] of ABA”. One of the recommendations was categorized as unknown; Ann reported that her doctor recommended against “medications”. One recommendation was not included in the analysis because a specific treatment to use or avoid was not recommended. Rhonda reported that her doctor recommended against “magic bullet treatments”.

Table 11

Recommendations from the Diagnosing Doctor of Treatments to Use or Avoid

	Recommendations from Diagnosing Doctor						
	To Use			To Avoid			
	Total	Average	SD	Total	Average	SD	
Evidence-Based	11	1.00	0.77	Evidence-Based	3	0.27	0.47
Non-Evidence-Based	12	1.09	0.83	Non-Evidence-Based	1	0.09	0.30
Unknown	4	0.36	0.50	Unknown	1	0.09	0.30

Recommendations From Other Informants. Parents were asked to identify if they spoke to other individuals about treatments to use or avoid when treating ASD. “Other” was not defined so it was not clear, to whom parents spoke to for these recommendations (see Table 12 for results). Simon reported not asking any other informants about treatments to use or avoid. Of the remaining 10 parents, 67% reported recommendations by other informants, which were not evidence-based. Examples of these recommendations include OT, CBT, diet changes, music therapy, hippotherapy, child directed therapy, vitamins, biomedical treatments, craniosacral therapy, nutritional therapy, DAN! Doctor (Defeat Autism Now! Doctor), and probiotics. Twenty-five percent of the recommendations by other informants were evidence-based. Examples of these include social skills training, ABA, SLP, and Lovaas. Recommendations categorized as unknown included “medications” and “therapy”. Nadine reported that she “...involved special education staff to support our child in an inclusion general education classroom.” This was not included in the analysis because a specific treatment to use or avoid was not identified.

Only four parents reported asking other informants about treatments to avoid. From these recommendations none were evidence-based, one was not evidence-based (ABA), and one was unknown (medications).

Table 12

Recommendations from Other Informants of Treatments to Use or Avoid

	Recommendations from Other Informants						
	To Use			To Avoid			
	Total	Average	SD		Total	Average	SD
Evidence-Based	6	0.55	0.69	Evidence-Based	0	0.00	0.00
Non-Evidence-Based	16	1.45	1.69	Non-Evidence-Based	1	0.20	0.30
Unknown	2	0.18	0.40	Unknown	1	0.20	0.30

There were some similarities in recommendations of evidence-based treatments to use across the diagnosing doctors and other informants including, ABA, SLP, and social skills training. There were also similarities in recommendations for non-evidence-based treatments to use, including OT, CBT, and hippotherapy. Overall, however, other informants gave more of a variety of non-evidence-based recommendations of treatments to use than doctors did. Only one parent (Gloria) reported similar recommendations between her doctor and other informants of an ASD treatment to avoid, which was ABA therapy.

Qualitative Analysis

A qualitative analysis was used to analyze the open-ended responses from the survey. Five themes emerged from the data, which are reported below. Tables 13-16 identify the themes, number of parents that contributed to the themes and the questions parents responded to for each theme. The majority of parents (64%-100%) contributed to each theme. Each theme was derived from parent responses to multiple questions from within the survey.

Theme 1: Parents reported being overwhelmed with the enormous amount of information about ASD treatments. Theme 1 presents the perspective of the parents as they searched for ASD treatments for their child. It also helps explain how parents reported they felt searching for treatments and sorting through the vast amount of information available for treatments for ASD. While reading parent's responses to questions on the survey (see Table 13 for specific questions) it was remarkable how much information about treatments for ASD parents reported having to sort through. Some parents reported actual numbers for ASD treatment choices they were given, while others used phrases like "huge", "too many", and "a lot".

Rhonda, a mother of three with a son with autism supported this theme with her statement "...at first there was a flood of information and no one to really help us sift through. I would leave a dr office with 20 papers on options."

Many parents described being inundated with information. They reported struggling to determine which treatments would actually work, and which treatments were just a waste of time.

Barbara a mother of four with a daughter with autism reported “there is a lot of it out there. At first it was hard to determine what was fact from what was garbage.”

Violet a mother of three with a son with autism supported this theme with her statement “Overwhelmed...There are a lot of therapies, remedies, devices being sold as cures...”

Parent responses were differentiated between attempting to find information about possible ASD treatments and sorting through the information that they found. Many described the sorting experience as overwhelming (Simon, Diana, Rhonda, Lola, Nadine, Gloria, Melissa, and Barbara), confusing (Ann), and frustrating (Sue). Ann, a mother of two with a son with PDD-NOS, described her experience attempting to find treatments for her child.

“Confused. No real authority on treatments other than ABA but I believed there was more help, just did not know which one to spend all time and money on.”

Melissa a mother of three with a son with Asperger’s described the frustrating experience of not knowing whether a treatment would work for her child.

“It is a huge maze of information, resources and trial and error with each child.”

The amount of information parents were flooded with helps explain why a parent would use a variety of sources of information (other people, books/magazines, the internet, etc.) when attempting to find ASD treatments and sort through the information they found. The sheer amount of information that needs to be condensed into a useable format could be a contributor to parents feeling overwhelmed and frustrated.

Table 13

Questions Parents Responded for Theme 1 and Theme 2

Theme	Parent's contributing	Questions from which data was coded
Theme 1: Parents reported being overwhelmed with the enormous amount of information about ASD treatments	11	Q28: Did you find any conflicting information when looking up treatments for Autism Spectrum Disorder? Q29: If so, how did the information about treatments for Autism Spectrum Disorder conflict? Q 36: When you found out your child was diagnosed with Autism Spectrum Disorder what would have been helpful to know about selecting treatments for this disorder? Q 38: How did you feel searching for through all the information about Autism Spectrum Disorder treatments? Q 74: What would have been helpful for you to know once you found out about your child's Autism Spectrum Disorder?
Theme 2: Information about ASD treatments was reportedly confusing and conflicting	7	

Theme 2: Information about ASD treatments was reportedly confusing and conflicting. Many parents described the information they found or were given about treatments for ASD as confusing and conflicting. Parents reported that this confusing and conflicting information came from a variety of sources including doctors, personal testimonies, and “research”. For parents who may have depended upon personal testimonies as a source of information it is not surprising that the information they found might conflict because the personal experiences of one family with a treatment may not represent the majority of experiences. Personal testimonies may also leave out critical information about a therapy experience, which can changes the impact of a story, i.e., a family may have great success with a gluten-free diet but leave out the part about their son having celiac disease. Many of the parents reported confusing and conflicting

information when searching for ASD treatments throughout the survey (see Table 13 for questions relating to theme).

Gloria a mother of two, with a son with autism supported this theme with her statement “There are a lot of conflicting opinons [*sic*] about treatments. There is also tons of options, with little proof of what actually works. “

Further, Rhonda a mother of three, with a son with autism reported “Personal testimonies on how some treatment "cured" their child or radically changed behavior. Can't be duplicated in a medical research trial. For example: going gluten free”.

In addition, Lola a mother of four, with a daughter with autism supported this theme with the statement “some research says ABA and some says don't do [*sic*].”

Several parents (Gloria, Ann, Sue, Violet) reported wanting to know which treatments actually worked before trying them with their children. While there are websites, which report the efficacy of ASD treatments, such as www.asatonline.org, this was not a tool reported by parents in this survey to help them identify potential treatments that could work for their child. In fact, none of the parents in the survey reported using specific websites that have attempted to condense the research on ASD treatments into an easily accessible format for parents. Instead, when reporting online experiences, most parents used vague terms such as “internet”, “online”, and “blogs” to refer to research they completed on the internet. If a parent is not using or does not have access to information about the efficacy of treatments, this can create an unnecessary burden for them when they are attempting to decipher information about treatments for ASD.

Theme 3: Parental input and desired outcomes were significant factors when determining the types of goals selected for ASD treatment(s). Parents reported two types of goals they had for treatments for their children. These goals were either specific to the child or to the therapy itself. In their responses (see Table 14 for questions), parents did not differentiate between goals for their child or the therapy before a treatment had been tried or after the treatment had been tried and was unsuccessful. Because experience with how a child reacts to a treatment may affect a parent's decision to continue that treatment or try a similar treatment, in the future their responses will not be differentiated in this report. This is similar to how parent's responses were reported in the literature (see Hall & Riccio, 2012; Mackintosh et al., 2012; Shyu et al., 2010).

The majority of parents reported Child Specific Goals when identifying treatments to use with their child. Child Specific Goals typically included addressing medical problems such as allergies or the child's response to certain foods, behavioral problems, or remediating educational/life skill deficits. Parent's responses about the goals for their child varied; some had very specific goals for their child that would make it easy to identify improvement. Other parents had goals that were more nebulous which could make it difficult to tell if the child was making any progress. Parental goals appeared to be tailored to the needs of each individual child.

Rhonda supported this theme when she identified goals for her son when selecting treatments "...we work on anything that helps communication using a combination of "talkers" PECS, gestures, signs, increasing receptive language...we also have some goals that don't [neatly fit] in either category but may be described as self help [*sic*] or basic preschool skills."

Further, Sue a mother of two with a daughter with PDD-NOS, stated her goal for her daughter was “better social skills so she can live a productive life.”

Melissa supported this theme with the following goals for her son “his safety, wellbeing and happiness along with gaining independence.

Most parents reported both Child Specific Goals and Therapy Specific Goals for choosing treatments for their children. Therapy specific goals parents identified included the level of difficulty in implementing a therapy and the perceived safety of the treatment.

Ann supported this theme when she stated “convenience” as a reason for using Medication Treatments.

Further, Diana a mother of two with a girl diagnosed with PDD-NOS, said she chose Diet Treatments for her daughter because “It was an easy treatment alternative vs heavy drugs...”

Barbara supported this theme with the comment “if the therapy is something offered in our area and there are no perceived side effects I will try them.”

According to parent responses on the survey, their goals for selecting treatments appeared to relate to what parents reported their child needed. However, if a parent had specific goals for their child or the type of therapy they may have been looking for; these goals may have unnecessarily restricted their treatment search. In addition, descriptions of therapies often do not list all of the skills the therapy may help remediate or identify how safe and/or easy to implement the therapy may be. This may contribute to parental responses found in Theme 1 and Theme 2 where parents reported being overwhelmed and confused searching for ASD treatments for their children.

Table 14

Questions Parents Responded for Theme 3

Theme	Parent's contributing	Questions from which data was coded
Theme 3: Parental input and desired outcomes were significant factors when determining the types of goals selected for ASD treatment(s).	11	<p>Q 26: Do you think there is currently a cure for Autism Spectrum Disorder?</p> <p>When you found out your child was diagnosed Q 36: with Autism Spectrum Disorder what would have been helpful to know about selecting treatments for this disorder?</p> <p>Q 37: What is your goal when you are selecting treatments for your child's Autism Spectrum Disorder? In other words, what do you expect to see from these treatments?</p> <p>Q45: Why did you choose to change your child's diet to treat their Autism Spectrum Disorder?</p> <p>Q50: Why did you choose medication to treat your child's Autism Spectrum Disorder?</p> <p>Q56: Why did you choose to use behavioral educational treatments to treat their Autism Spectrum Disorder?</p> <p>Q62: Why did you choose to use other treatments to treat their Autism Spectrum Disorder?</p> <p>Q70: What do you expect from the treatment(s) you hope to use in the future?</p> <p>Q75: What would you tell a parent who just found out their child has Autism Spectrum Disorder?</p>

Theme 4: Concerns about safety, ability to use a treatment, or the necessity of a treatment largely contributed to the treatments parents reported they did not select. On the survey, parents were asked to identify what treatments they were avoiding and why they were avoiding them. However, parents described some of the treatments they were avoiding throughout the survey (see Table 15 for questions) with similar language across respondents. The undesirable treatments described by parents were treatments that their child was unable to use or treatments that were bizarre and/or

intrusive in some way. Some parents also reported specific beliefs about a treatment course, which reportedly affected their choice(s). Parents were typically specific about why they would consider a treatment undesirable and avoid using that treatment with their child.

Treatments parents were unable to use included treatments that a parent did not see a need to use with their child (child tested for allergies but none were found) or treatments the parent thought the child may not be able to handle. The following parents supported this finding with their statements about treatment use with their children.

Barbara supported this theme when she reported avoiding a special diet for her daughter because “...the diet didn't seem to pertain to her we had her tested for allergies and nothing showed up”

Further, Melissa said she was not using the suggested gluten-casein free diet because her son “has so many sensory/texture issues that diet at this time would be a battle.”

Bizarre and/or intrusive treatments parents found undesirable included any treatment that was invasive, had side effects, or was harmful or perceived to be harmful to the child. Parental reports of treatments labeled as undesirable fell in line with the reported recommendations of treatments to avoid from the diagnosing doctor and other informants.

Rhonda supported this theme with her comment that she would avoid “anything invasive or causes great distress to child. Can't give a specific name or type. More of a I know it when I see it.”

Further, Diana said she was avoiding medications to treat her daughter’s autism because of “side effects”.

Beliefs about ASD treatments were specific and appeared to affect the parent’s treatment choices.

Nadine, a mother of five, with a son with autism supported this theme with her statement that she would not use certain treatments for her son because she did “... not believe that diet or medications can treat autism”.

Table 15

Questions Parents Responded for Theme 4

Theme	Parent’s contributing	Questions from which data was coded
Theme 4: Concerns about safety, ability to use a treatment, or the necessity of a treatment largely contributed to the treatments parents reported they did not select.	9	Q26: Do you think there is currently a cure for Autism Spectrum Disorder? Q28: Did you find any conflicting information when looking up treatments for Autism Spectrum Disorder? Q29: If so, how did the information about treatments for Autism Spectrum Disorder conflict? Q 34: Did you talk to anyone else (besides the doctor that diagnosed the Autism Spectrum / Disorder) about treatments to <u>avoid</u> ? Q35: If so, what treatments did they tell you to <u>avoid</u> when treating your child’s Autism Spectrum Disorder? Q62: Why did you choose to use other treatments to treat their Autism Spectrum Disorder? Q72: If so what were the treatment(s) you decided to avoid when treating your child’s Autism Spectrum Disorder? Q73: Why did you decide to avoid these treatments to treat your child’s Autism Spectrum Disorder?

The first four themes described how parents reportedly found and selected treatments for their children to treat ASD. While parents cannot control the amount of information available on ASD treatments, they can control how they conduct their research and what sources they use to help make their treatment choices. Parents also determine what goals they have for their children and appeared to choose treatments that would help their child meet these goals. While researching treatments parents may also develop concerns about the necessity or safety of certain treatments and choose to avoid these types of treatments.

Once parents found and selected the treatments they thought their children needed their journey was not complete. While some parents may have been able to use the treatments they selected for their children with no problems. Other parents reported encountering unforeseen problems, which affected their treatment selection. These problems are described in Theme 5.

Theme 5: Parental reports of encountering problems when selecting or implementing an ASD treatment, which affected the selection of or continued use of a treatment. Parents reported encountering multiple problems when implementing or attempting to implement a chosen treatment throughout the survey (see Table 16 for questions). Some parents reported encountering problems before they began the therapy and some once the therapy was in place. The problems parents reported encountering when selecting and implementing treatments fell into two sub-categories: problems with the therapy or therapist implementing the therapy and monetary problems.

Problems with the therapy itself included lack of access to the desired therapy, the therapy differing according to where it was implemented, and the child's response to the therapy.

Barbara supported this theme with her statement that she was not able to use some therapies because "we are not in an area that has a lot of qualified/specialist treating autism as far as therapies ie music dance swim...."

Further, Diana stated she is "... still struggling to get [the] school to provide anything and also didn't know some schools have sensory rooms. These schools vary widely for sped services..."

Gloria identified the following problem with Diet Treatments with her son. "...I have struggled with this issue for years about the diet, and have tried to get my son gluten free, but it never works, that is he wont eat when he is completely gluten free"

Problems with therapists included the therapist implementing the therapy in an undesirable way or being able to keep therapists so that a therapy can be implemented consistently.

Sue supported this theme with her report of changing doctors for Medication Treatments for her daughter because "... the regular pediatrician over medicated her."

Further, Rhonda described problems she has encountered with therapists include "where to find these therapists. We have done ABA in home because diagnosis but it is difficult to replace workers when they leave..."

Many parents also identified monetary problems as a barrier to treatment implementation. Parents reported being unable to implement therapies due to financial concerns. Other parents reported that the financial burden made it difficult to give their child all of the treatments they thought their child needed.

Barbara supported this theme when she reported, “it would have been helpful to know of a way to pay for all of the therapies she needed. A way to provide the many hours of treatment.”

Further, Diana stated “... we've gone years unable to pay for ANY therapy. ...”

Lola said she hasn't been able to use ABA therapy with her daughter because “it's expensive!!!”

The problems parents reported encountering when selecting treatments for their children appeared to affect their treatment choice(s). Unlike the previously mentioned variables, these variables were not controlled by the parents and may have forced the parent to make choices they had not originally intended to make (i.e. they may have wanted to use a therapy but were not able to do so because of availability or financial barriers). While some of these variables may not be specific to the selection of treatments for ASD it is important to recognize that a parent's treatment choice can be affected by variables which have nothing to do with the child or their diagnosis.

Table 16

Questions Parents Responded for Theme 5

Theme	Parent's contributing to theme	Questions from which data was coded
<p>Theme 5: Parental reports of encountering problems when selecting or implementing an ASD treatment, which affected the selection of or continued use of a treatment.</p>	<p>10/11</p>	<p>Q26: Do you think there is currently a cure for Autism Spectrum Disorder?</p> <p>Q36: When you found out your child was diagnosed with Autism Spectrum Disorder what would have been helpful to know about selecting treatments for this disorder?</p> <p>Q37: What is your goal when you are selecting treatments for your child's Autism Spectrum Disorder? In other words what do you expect to see from these treatments?</p> <p>Q45: Why did you choose to change your child's diet to treat their Autism Spectrum Disorder?</p> <p>Q50: Why did you choose medication to treat your child's Autism Spectrum Disorder?</p> <p>Q56: Why did you choose to use behavioral educational treatments to treat their Autism Spectrum Disorder?</p> <p>Q62: Why did you choose to use other treatments to treat their Autism Spectrum Disorder?</p> <p>Q70: What do you expect from the treatment(s) you hope to use in the future?</p> <p>Q75: What would you tell a parent who just found out their child has Autism Spectrum Disorder?</p>

Chapter 4

Discussion

The reasons parents reported for choosing treatment(s) for their child with ASD is a complicated issue not easily explained by one particular variable or set of circumstances. Previous research in this area has identified correlations between demographic variables of the parents and/or child and treatment choices; however, the findings have been mixed. Bowker et al. (2011) found a correlation between treatment choices and ASD diagnosis. Hall and Riccio (2012) found a correlation between variables such as parental education and length of time with and ASD diagnosis and an increase in CAM treatment use. However, Miller et al. (2012), found no correlation between demographic variables and parental choices of evidence-based treatments or CAM treatments. The findings in this study match those of Miller et al. (2012), in that no correlations were found between the demographic variables of the parent or child and parental treatment choices. The lack of correlations found may be due to the small sample size or the homogeneous nature of the parents who participated in the study. In addition, only one parent reported having a child diagnosed with Asperger's so differences of parental choices by ASD diagnoses were calculated between Autism and PDD-NOS and a comparison to Asperger's was not completed (the comparison in the Bowker et al. (2011) study was between children with Asperger's diagnosis and children with Autism or PDD-NOS).

Another variable affecting treatment choices, which was repeated throughout the literature, was where parents found out about treatments for ASD, the source of information. Similar to Green et al. (2006); Mackintosh et al. (2005), and Bowker et al.

(2011) parents in this survey reported using multiple sources of information to inform treatment choices. In addition, the sources of information used were differentiated according to the treatment category, a finding similar to Green et al. (2006). For example, the sources used to identify Diet Treatments differed from the sources used to identify Behavior/Educational Treatments.

Throughout the survey parents were asked to report the sources they used to inform their treatment choices. These sources were compared to the rank order list of preferred sources parents identified at the beginning of the survey. Most parents used a mixture of highly preferred, moderately preferred, and least preferred sources to inform their choices. It is interesting that parents did not report all the sources they actually used to inform their treatment choices as highly preferred. This could be due to several factors, while parents reported having specific preferences for sources of information about treatment choices they may have been willing to use any source available to gain information about ASD treatments. Parents may also have been using sources that were not highly preferred because some treatment choices may necessitate the use of specific sources (as with medication) or they may have had a negative experience, which colored their perception for that source of information. For example, Sue ranked doctors/physicians as a least preferred source of information (rank =10) and reported a negative experience with her child's pediatrician: "... The regular pediatrician over medicated her." This corresponds to a finding of Mackintosh et al. (2012) where parents reported relationships with professionals affecting treatment selection.

On the surface, it may appear unreasonable to ask parents to learn how to read and comprehend the research literature on ASD treatments, because they have professionals

they can turn to for information. However, the data in this study indicated otherwise. According to parents, at least half of the recommendations for ASD treatments made by the diagnosing doctor were not evidence-based. In addition, the other informants parents turned to for information gave mostly non-evidence-based recommendations for the treatment of ASD. Interestingly there were not many recommendations for treatments to avoid by either the diagnosing doctor or other informants. This is particularly troubling considering the plethora of treatments available, which have no evidence base for the treatment of ASD (Matson et al., 2013).

Five themes emerged during the qualitative data analysis, which may have affected parental treatment choices for ASD treatments. Theme 3: Parental input and desired outcomes were significant factors when determining the types of goals selected for ASD treatment(s) and Theme 5: Parental reports of encountering problems when selecting or implementing an ASD treatment, which affected the selection of or continued use of a treatment corresponded to similar themes found in the literature (Bowker et al., 2011; Hall & Riccio, 2012; Mackintosh et al., 2012; Shyu et al., 2010).

Bowker et al. (2011) reported in their paper that treatment selection may be affected by a child's diagnosis of ASD. Parents in the current study reported that they had goals for their child or treatment when selecting ASD treatments (Theme 3). While some parents reported goals relating to skill deficits, which are commonly associated with specific ASD diagnoses, they also reported other goals which were not associated with a specific diagnosis (such as behavioral and medical issues). Hall and Riccio (2012) reported that treatment selection may be affected by a child's behavioral issues which is consistent with reports by some of the parents in this study. Parents also reported having

goals for the therapy in addition to goals for their child, a result not previously mentioned in the literature. These results indicate that the specific needs of the child as well as the perceived safety of the treatment and/or difficulty of implementation of the treatment are variables, which may affect why parents would choose an ASD treatment.

Parental reports of encountering problems when selecting or implementing an ASD treatment, which affected the selection of or continued use of a treatment (Theme 5) also corresponded to themes reported by Mackintosh et al. (2012) and Shyu et al. (2010). In their paper, Mackintosh et al. (2012) reported that relationships with professionals, access to desired treatments, and costs (including money, effort, and time) affected parental treatment choices. Shyu et al. (2010) reported in their study that the effects of a treatment strategy affected treatment selection. Parents in the current study reported similar variables affecting their treatment choices. Parents reported changing doctors due to how a treatment was implemented, struggling to get providers to deliver the services their child needed, and being unable to access treatments because therapists were unavailable in their location. Several parents also reported that they were unable to use or continue a treatment due to how their child reacted or could potentially react to the treatment. Multiple parents also reported financial obligations, which affected their treatment choices. Some were completely unable to use treatments because of the expense while others reported being unable to use the treatment at the desired dose or frequency. The results indicated that it is not enough to guide a parent to select research-based treatments for their child; other variables can influence their decision, which have nothing to do with the child or the therapy. Lola is an example of this scenario. She

reported wanting to use a treatment that is considered efficacious for the treatment of ASD (ABA therapy), but was not able to do so for financial reasons.

Several researchers in the literature reported how parents used multiple sources to inform treatment choices (Green et al., 2006; Mackintosh et al., 2005; Miller et al., 2012). Theme 1 (Parents reported being overwhelmed with the enormous amount of information for ASD) and Theme 2 (Information about ASD treatments was reportedly confusing and conflicting) may help explain why parents use multiple sources of information. Most parents reported discussing treatment options with the diagnosing doctor and other informants and reported using multiple sources to inform treatment choices. According to parents in this study, there was an overwhelming amount of information about possible ASD treatments and the treatment information was confusing and conflicting. Parents may need to consult with multiple sources in order to help them condense the incredible amount of information available into a easily accessible format.

Theme 4 (Concerns about safety, ability to use a treatment, or the necessity of a treatment largely contributed to the treatments parents reported they did not select) was not reported in the literature as a possible variable affecting treatment choice, but may be an important factor for parents when selecting a treatment for their child. While there have been parents who reported using invasive procedures such as chelation (Baxter & Krenzelok, 2008) in the literature, parents in this study reported that they would not use treatments they considered bizarre and/or intrusive in some way. The results indicated that how a parent perceived a treatment could affect their choices.

Parents throughout the literature, and in this study, reported using treatments with little to no evidence base for the treatment of ASD. The research to date has identified

many variables which may contribute to treatment choice but the literature is fragmented. In addition, none of the research to date has directly asked parents to report what their reasons may have been for choosing or avoiding a particular treatment. This study sought to clarify what variables may affect parental treatment choices as well as identify if specific variables may be associated with specific treatment choices (Evidence-Based and Non-Evidence-Based). So how can researchers help make the task of choosing a treatment less overwhelming and less confusing and how can we help parents make Evidence-Based choices when selecting ASD treatments. While this is an empirical question that can only be resolved with more research, this study indicates that giving parents more information may not be the best approach. In addition, there are variables that may affect treatment choices, which the researcher and the parent may not be able to control, such as cost of and access to treatments. More research, going beyond a survey, is needed to identify how the variables identified in this research can help make the task of choosing or avoiding treatments less overwhelming for parents.

Limitations

Some limitations of the current research involve the sample of respondents. This research did not reach any parents that did not have internet access. In addition, all parents were reached through an autism related community, so parents that were not involved in this type of activity did not have access to the survey. All of the respondents had similar demographics, so the responses of these parents may not generalize to the larger population of parents with children with autism. In addition, the survey itself had very personal questions, which may have been the reason some respondents did not complete the entire survey. There was also a limitation with the data, in that it was all

verbal self-reports from the parents. While filling out the survey, parents may not have accurately represented what they remember thinking while searching for treatments or with whom they spoke to about ASD treatments. Another limitation included the way the research was conducted. While an attempt was made to uncover what reasons parent's gave for specific treatment choices there was no manipulation of an independent variable to determine a functional relation between what parents reported as variables affecting their choices and the choices they reported making. There is also a limitation of generalizability to the larger population due to the sample size and nature of inquiry; this research was a snapshot of each parent's experiences with identifying treatments for their child with ASD, and the results are not generalizable to the larger population and are exclusive to the sample used in the study. This research was mostly a qualitative approach to the issue under study. With the small population studied (n=11) there were limited quantitative findings, but these findings help give context to the qualitative findings provided. In addition, the author brings in personal biases when analyzing and interpreting the qualitative data. Although a credibility check was completed with the coded data, the other observer could have had similar biases to the lead investigator.

Recommendations for Future Research

Selecting and finding ways to implement treatments for a child with ASD is a complicated decision for parents with multiple variables affecting treatment choice. Future areas of research could involve identifying ways to influence treatment choices so parents are choosing treatments that are evidence-based. This could include how information about treatments is delivered to parents with ASD, how treatments are advertised to parents, and how to educate parents about researching ASD treatments.

Another area of research could include how parents search for ASD treatments (a systematic analysis). Future research could also include identifying if educating the sources parents typically use to inform treatment choices, such as doctors, therapists, and teachers could influence a parent's treatment selection. Future research should systematically investigate why choices are made. One way to evaluate how choices are made could be to look at how ASD treatments are advertised to the public to see if this could affect treatment choice. Variables parents in this research reported as relevant in choice making, such as, perceived safety of the treatment, what goals the treatment purportedly addresses, and treatment access could be systematically manipulated to identify which variables actually affect a parent's choice when choosing ASD treatments. By doing this, it may help researchers understand the causal relationship between treatment selection and the myriad of choices. Once studies have been completed that answer the question "why parents select what they select" and go beyond perceptions, therapist can increase the likelihood of parents choosing treatments that have been found to be effective in treating ASD and avoid those that have not been shown to be effective at all.

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Appendix

Survey Questions

- I consent to participate
- I DO NOT consent to participate
- If I DO NOT consent Is Selected, Then Skip To End of Survey

Q1 What are your initials?

Q2 What is your marital status?

- Married
- Divorced
- Other (please describe)

Q3 What is your ethnicity?

- White
- Black or African American
- American Indian and Alaska Native
- Asian
- Native Hawaiian or other Pacific Islander
- Hispanic or Latino
- Biracial
- Other (please describe)

Q4 What formal education have you completed?

- Less than High School
- High School Diploma
- Technical School/Some College
- College Graduate
- Master's Degree
- Specialist or Ed.S. Degree
- Doctorate
- Other (please describe):

Q5 How many children do you have?

- 1
- 2
- 3
- 4
- 5
- 6 or more

For the following questions please select one child (if you have more than one) for which you will answer the remaining questions. Please make sure that the child you choose to report on has a diagnosis on the Autism Spectrum.

Q6 What is your relationship to the child you will be reporting about?

- Mother
- Father
- Sibling
- Grandmother
- Grandfather
- First cousin
- Second cousin
- Aunt
- Uncle
- Other (please describe)

Q7 What is your child's gender?

- Male
- Female

Q8 How old is your child?

- Less than 1
- 1
- 2
- 3
- 4
- 5
- 6-10
- 11-14
- 15-20
- 21 or older

Q9 Does your child have an Autism Spectrum Disorder diagnosis?

- Yes
- No
- If No Is Selected, Then Skip To End of Survey

Q10 If your child has an Autism Spectrum Disorder diagnosis what is the specific diagnosis?*

- Autism
- Asperger
- PDD-NOS
- Other (please describe)

Q11 Does your child have any other diagnoses?

- Yes
- No
- If No Is Selected, Then Skip To Q13

Q12 If so what other diagnoses does your child have? (check all that apply)

- Seizure Disorder
- Intellectual Disability
- Attention Deficit Disorder (ADD)
- Attention Deficit Hyperactivity Disorder (ADHD)
- Obsessive Compulsive Disorder (OCD)
- Bi-Polar Disorder
- Other (please describe)

Q13 Does anyone else in your family have an Autism Spectrum Disorder diagnosis?

- Yes
- No
- If No Is Selected, Then Skip To Q15

Q14 If there is a relative with an Autism Spectrum Disorder diagnosis please name the relationship of the relative to your child (check all that apply).

- Mother
- Father
- Sibling
- Grandmother
- Grandfather
- First cousin
- Second cousin
- Aunt
- Uncle
- Other (please describe)

Q15 How old was your child when (s)he was diagnosed with Autism Spectrum Disorder?

- Less than 1
- 1
- 2
- 3
- 4
- 5
- 6-10
- 11-14
- 15-20
- 21 or older

Q16 Does your child display any inappropriate behaviors?

- Yes
- No
- If No Is Selected, Then Skip To Q20

Q17 Which of the following inappropriate behaviors does your child display? Check all that apply.

- Injures self (Example: biting self, hitting self, etc.)
- Physically aggressive to others (Example: hitting, pushing others, etc.)
- Destroys property
- Runs away (elopes)
- Toileting in places other than the toilet (do not include using diapers or pull ups)
- Self-stimulatory behaviors (Example: rocking, hand flapping, spinning)
- Echolalia (Example: repeating words, phrases, or sounds the child has heard)
- Other (please describe)

Q18 How often do the inappropriate behaviors you identified occur?

Q19 How severe are the inappropriate behaviors you identified? Please state, for example, if the behaviors leave bruises or marks, require hospitalization, have caused permanent injury to others, damage to property, social isolation, etc.

Q20 How does your child communicate with you?

- Verbally
- With pictures
- With signs
- With an electronic communication device
- Nonverbal but can gesture/lead
- Nonverbal cannot indicate wants/needs
- Other (please describe)

Q21 Does your child have sleep issues?

- Yes
- No
- Other (please describe)

Q22 In your opinion what is the most noticeable feature of your child's Autism Spectrum Disorder? In other words, what is the single most "autistic" characteristic that describes your child's behaviors?

- Self-stimulatory behaviors (example: rocking, hand flapping, spinning)
- Injures self
- Echolalia (Example: repeating words, phrases, or sounds child has heard)
- Fixations (Example: getting stuck on ideas, activities, objects, etc.)
- Rigid/inflexible
- Lack of social connectedness
- Other (please describe)

Q23 What do you think causes Autism Spectrum Disorder?

Q24 Do you think there is currently a cure for Autism Spectrum Disorder?

Q25 What methods have you used to find out about treatments for your child's Autism Spectrum Disorder? Please rank the methods below from most preferred to least preferred .

- _____ Social Media (Facebook, Twitter, etc.)
- _____ Autism Websites
- _____ Autism Communities
- _____ Blogs
- _____ Media Outlets
- _____ Celebrities
- _____ Other Individuals with Autism
- _____ Books/Magazines
- _____ Other parents
- _____ Professionals in Autism
- _____ Doctors/Physicians
- _____ Scientific/scholarly journals
- _____ Email
- _____ Teachers
- _____ Other (please describe)

Q26 Did you find any conflicting information when looking up treatments for Autism Spectrum Disorder?

- Yes
- No
- Other (please describe)
- If No Is Selected, Then Skip To Q28

Q27 If so, how did the information about treatments for Autism Spectrum Disorder conflict?

Q28 When your child received an Autism Spectrum Disorder diagnosis what did the doctor identify as treatments to use when treating your child's Autism Spectrum Disorder?

Q29 When your child received an Autism Spectrum Disorder diagnosis what did the doctor identify as treatments to avoid when treating your child's Autism Spectrum Disorder?

Q30 Did you talk to anyone else (besides the doctor that diagnosed the Autism Spectrum Disorder) about treatments to use?

- Yes
- No
- If No Is Selected, Then Skip To Q32

Q31 If so, what treatments did they tell you to use when treating your child's Autism Spectrum Disorder?

Q32 Did you talk to anyone else (besides the doctor that diagnosed the Autism Spectrum Disorder) about treatments to avoid?

- Yes
- No
- If No Is Selected, Then Skip To Q36

Q33 If so, what treatments did they tell you to avoid when treating your child's Autism Spectrum Disorder?

Q34 When you found out your child was diagnosed with Autism Spectrum Disorder what would have been helpful to know about selecting treatments for this disorder?

Q35 What is your goal when you are selecting treatments for your child's Autism Spectrum Disorder? In other words, what do you expect to see from these treatments?

Q36 How did you feel searching for/through all the information about Autism Spectrum Disorder treatments?

Q37 Does your child have any food allergies/sensitivities?

- Yes
- No
- If No Is Selected, Then Skip To Q40

Q38 If so, what food allergies/sensitivities does your child have?

Q39 Who diagnosed/identified the food allergies/sensitivities your child has?

Q40 Have you made any dietary changes to treat your child's Autism Spectrum Disorder?

- Yes
- No
- If No Is Selected, Then Skip To Q45

Q41 If so, what dietary changes have you made to treat your child's Autism Spectrum Disorder? Check all that apply.

- Gluten-free (wheat)
- Casein-Free (dairy)
- Feingold
- Gluten-Free Casein-Free Diet (GfCf Diet)
- Specific Carbohydrate Diet
- Sugar free
- Removal of food dyes
- Yeast Free
- Vitamin A
- Vitamin B6
- Vitamin B12
- Vitamin C
- Vitamin D
- Calcium
- Dimethylglycerine (DMG)
- Omega 3 Fatty Acids
- L-Glutamine
- Magnesium
- Megavitamin therapy
- Pyridoxine
- St. John's Wort
- Other (please describe)

Q42 Where did you get information to try dietary changes to treat your child's Autism Spectrum Disorder?

Q43 Why did you choose to change your child's diet to treat their Autism Spectrum Disorder?

Q44 What area of improvements do you/did you expect to see by changing your child's diet? Check all that apply.

- Cognitive
- Behavioral
- Attention
- Speech
- Physical
- Other (please describe)

Q45 Have you made any medication changes to treat your child's Autism Spectrum Disorder?

- Yes
- No
- If No Is Selected, Then Skip To Q51

Q46 If so, what medication changes have you made to treat your child's Autism Spectrum Disorder. Check all that apply.

- Antipsychotics (Risperdal, Haldol, Thorazine, Seroquel, Clozapine, etc.)
- Anticonvulsant (Depakote, Dilantin, Klonopin, Tegretol, etc.)
- Psychostimulant (Ritalin, Dexedrine, Adderal, Cylert, etc.)
- Antidepressants (Prozac, Paxil, Tofranil, Zoloft, etc.)
- Antianxiety (Ativan, Buspar, Valium, Xanax, etc.)
- Anti-Fungal Medication (Diflucan, Nystatin, Sporanox, etc.)
- Anti-Yeast Medication
- Antiviral Medication (Intravenous Immunoglobulin, Pentoxifylline, Transfer Factor, etc.)
- Antibiotics (Vancomycin, etc.)
- Opiate Antagonists (Naltrexone, etc.)
- Digestive Aids (Bethanechol, Pepcid, Probiotics, Secretin, etc.)
- Sleep Aids (Antihistamine-Benedryl, Melatonin, etc.)
- Other (please describe)

Q47 Where did you get information to try medication to treat your child's Autism Spectrum Disorder?

Q48 Why did you choose medication to treat your child's Autism Spectrum Disorder?

Q49 What area of improvements do you/did you expect to see by using medication? Check all that apply.

- Cognitive
- Behavioral
- Attention
- Speech
- Physical
- Other (please describe)

Q50 Who prescribed medication to treat your child's Autism Spectrum Disorder? Check all that apply.

- Pediatrician
- Neurologist
- Psychologist
- Psychiatrist
- Other (please describe)

Q51 Have you used any behavioral/educational treatments to treat your child's Autism Spectrum Disorder?

- Yes
- No
- If No Is Selected, Then Skip To Q57

Q52 If so, what behavioral/educational treatments have you made to treat your child's Autism Spectrum Disorder (check all that apply)?

- Applied Behavior Analysis (ABA)
- Augmentative and Alternative Communication (AAC)
- Cognitive/Behavior Therapy
- Developmental Therapies (Denver Model, Social Communication, Emotional Regulation, and Transactional Support (SCERTS))
- Developmental Interventions-Other Research Models
- Early Intensive Behavioral Intervention/Treatment
- LEAP Model
- Lovaas Therapy/Discrete-Trial Training
- Occupational Therapy
- Picture Exchange Communication System (PECS)
- Social Skills Groups
- Social Stories
- Special Education
- Speech Therapy
- Video Modeling
- Other (please describe)

Q53 Where did you get information to try behavioral/educational treatments to treat your child's Autism Spectrum Disorder?

Q54 Why did you choose to use behavioral/educational treatments to treat their Autism Spectrum Disorder?

Q55 What area of improvements do you/did you expect to see by using behavioral/educational treatments? Check all that apply.

- Cognitive
- Behavioral
- Attention
- Speech
- Physical
- Other (please describe)

Q56 Who provided the behavioral treatment(s)? Check all that apply.

- Behavior Analyst (BA)
- Occupational Therapist (OT)
- Physical Therapist (PT)
- Speech Language Pathologist (SLP)
- Family Member
- Doctor
- Teacher
- Other (please describe)

Q57 Have you used any other treatments to treat your child's Autism Spectrum Disorder?

- Yes
- No
- If No Is Selected, Then Skip To Q65

Q58 If so, what other treatments have you made to treat your child's Autism Spectrum Disorder? Check all that apply.

- Acupuncture
- Animal Therapy (Therapeutic Horseback Riding, Dolphin Therapy, Pet Therapy)
- Aromatherapy
- Art Therapy
- Auditory Integration Therapy (AIT)
- Behavioral Optometry
- Bonding (Attachment) Therapies (Gentle Teaching)
- Chelation Therapy
- Craniosacral Manipulation
- Developmentally-based Individual-difference, Relationship-based Intervention (DIR), Floor Time, Greenspan Method
- Extended Breastfeeding
- Facilitated Communication
- Herbs and Homeopathic Treatments
- Holding Therapy
- Homeopathy
- Hyperbaric Oxygen Chamber
- Iridology
- Magnets
- Massage Therapy
- Music Therapy
- Oral-Motor Training/Therapy (Kaufman Method, Prompts for Restructuring Oral Muscular Targets (PROMPT), Rosenfeld-Johnson Method)
- Patterning
- Project TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children)
- Psychoanalytic and Humanistic Play Therapy
- Rapid Prompting Method (RPM)
- Recreational Sports/Exercise
- Relationship Development Intervention (RDI)
- Sensory Integrative Therapy (Sensory Integration, SI, or SIT)
- Sensory-motor Therapies
- Socialization related classes
- Son Rise (Options)
- Vision Therapy (Irlen lenses, Glasses, Eye exercises, Rapid Eye Therapy, Ambient lenses, Yoked prisms)
- Weighted vests/blankets
- Other (please describe)

Q59 Where did you get information to try other treatments to treat your child's Autism Spectrum Disorder?

Q60 Why did you choose to use other treatments to treat their Autism Spectrum Disorder?

Q61 What area of improvements do you/did you expect to see by using other treatments? Check all that apply.

- Cognitive
- Behavioral
- Attention
- Speech
- Physical
- Other (please describe)

Q62 Did anyone prescribe the other treatments you identified to treat your child's Autism Spectrum Disorder?

- Yes
- No
- If No Is Selected, Then Skip To Q64

Q63 Who prescribed these other treatment(s) to treat your child's Autism Spectrum Disorder? Check all that apply.

- Pediatrician
- Neurologist
- Psychologist
- Psychiatrist
- Other (please describe)

Q64 Who provided the other treatment(s)? Check all that apply.

- Behavior Analyst (BA)
- Occupational Therapist (OT)
- Physical Therapist (PT)
- Speech Language Pathologist (SLP)
- Family Member
- Doctor
- Teacher
- Other (please describe)

Q65 Are there any treatment(s) you have not used but plan on using in the future to treat your child's Autism Spectrum Disorder?

- Yes
- No
- If No Is Selected, Then Skip To Q69

Q66 If so what treatment(s) do you plan on using to treat your child's Autism Spectrum Disorder?

Q67 Why haven't you used these treatment(s) yet?

Q68 What do you expect from the treatment(s) you hope to use in the future?

Q69 Are there any treatment(s) you decided to avoid when treating your child's Autism Spectrum Disorder?

- Yes
- No
- If No Is Selected, Then Skip To Q73

Q70 If so what were the treatment(s) you decided to avoid when treating your child's A

Q71 Why did you decide to avoid these treatments to treat your child's Autism Spectrum Disorder?

Q72 What would have been helpful for you to know once you found out about your child's Autism Spectrum Disorder diagnosis?

Q73 What would you tell a parent who just found out their child has Autism Spectrum Disorder?

Q74 Do you have any other comments you would like to add?