Research in Autism Spectrum Disorders 6 (2012) 87–95

Contents lists available at ScienceDirect

Research in Autism Spectrum Disorders

Journal homepage: http://ees.elsevier.com/RASD/default.asp

Factors related to parents' choices of treatments for their children with autism spectrum disorders

Victoria A. Miller [a], Kimberly A. Schreck [a,*], James A. Mulick [b], Eric Butter [b]

[a] Penn State University – Harrisburg, W311 Olmsted Building, 777 W. Harrisburg Pike, Middletown, PA 17057-4898, USA
[b] The Ohio State University & Nationwide Children's Hospital, 187 West Schrock Road, Westerville, OH 43081, USA

ARTICLE INFO

Article history:
Received 14 March 2011
Received in revised form 17 March 2011
Accepted 17 March 2011
Available online 30 April 2011

Keywords:
Treatment choice
Autism
Treatment referrals
Autism treatment
Parent treatment choice
Treatment dissemination

ABSTRACT

The history of autism treatment has been plagued with fad therapies which waste parents' and children's time, energy, and money. To determine if referral sources, such as professionals' recommendations, media, or scholarly sources, have influenced parents' treatment decisions, parents of at least one child with an autism spectrum disorder ($N = 400$) were surveyed to determine the sources they used to obtain treatment. Recommendations from professionals in non-medical fields and autism books were the most popular sources of information. Due to the diverse range of influences on parents' treatment decisions, a multifaceted dissemination strategy for the most effective therapies is warranted.

1. Introduction

With the latest estimate of the childhood prevalence of autism spectrum disorders (ASDs) now surpassing that of Down Syndrome, diabetes, and cancer (Harrington, Patrick, Edwards, & Brand, 2006; Kogan et al., 2009), many more parents have faced the daunting tasks of contending with this diagnosis, and most importantly, selecting a treatment for their child in the face of numerous contradictory professional and non-professional recommendations about treatment (Maurice, Mannion, Letso, & Perry, 2001; National Autism Center, 2009). Not only may parents have experienced the shock of an official diagnosis of ASD, they also have been bombarded relentlessly with information from a wide range of sources (Green, 2007). Faced with this abundance of ideas, both good and bad, concerning "appropriate" treatments for ASDs, parents must decide what to do.

Further complicating parents' treatment decisions, the variety of professionally recommended treatments have included those that are frankly ineffective as well as those strongly supported by empirical evidence (Green et al., 2006; Heflin & Simpson, 1998; Mandell & Novak, 2005; Metz, Mulick, & Butter, 2005; National Autism Center, 2009). Unfortunately, the research on treatment choice has indicated that many parents may have elected to use ineffective therapies lacking empirical support (Smith, 2005). More research is needed to determine which of these ineffective treatments parents have been using. In addition, knowledge of possible determinants of parents' unfortunate choices might allow professionals to better advise parents against the use of potentially harmful treatments (e.g., chelation, facilitated communication) and treatment combinations (e.g., the eclectic "autism buffet") (Cohen, Amerine-Dickens, & Smith, 2006; Eikeseth, Smith, Jahr, & Eldevik, 2007; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Richdale & Schreck, 2008).

---

* Corresponding author. Tel.: +1 717 948 6048; fax: +1 717 948 6519.
E-mail addresses: vmiller@pacounseling.com (V.A. Miller), Kas24@psu.edu (K.A. Schreck), Mulick.1@osu.edu (J.A. Mulick), Eric.butter@nationwidechildrens.org (E. Butter).

1750-9467/$ – see front matter © 2011 Elsevier Ltd. All rights reserved.
doi:10.1016/j.rasd.2011.03.008

Factors contributing to parental decisions, such as autism-related media, Internet websites, and professional recommendations have provided parents with easily accessible information from diverse sources. For example, the Internet contains an expansive variety of websites devoted to autism awareness and treatment. Many of these sources have originated from trusted authority figures (e.g., medical doctors, behavior analysts, dieticians) or celebrities (Green, 2007; Smith & Antolovich, 2000). This variety of resources and information has contributed to confusion about autism treatment and the credibility of various sources.

Very little research exists regarding parents' reliance on professional recommendations to select treatments. Many parents of children with ASDs have sought the opinions of numerous professionals during the course of treatment decision-making and implementation (Mandell & Novak, 2005). These professionals can include psychologists, behavior analysts, medical doctors, occupational therapists, speech therapists, physical therapists, educators, audiologists, dieticians, etc. Research has suggested that some of these professionals recommend treatments based on their personal belief(s) about the etiology of ASDs rather than the demonstrated effectiveness of the treatments (Elder, 1994). Additionally, even professionals supposedly knowledgeable about scientifically supported effective treatments have sometimes recommended unsupported treatments for people with ASDs (Schreck & Mazur, 2008). However, although professionals may have been recommending unsupported and possibly ineffective treatments, it remains unclear which professionals tend to recommend particular treatments.

Although media and professional recommendations may influence parental treatment decisions, parents' understanding of treatments and their subsequent treatment choices also may be influenced by a variety of demographic variables (Smith & Antolovich, 2000; Williams, Oliver, Allard, & Sears, 2003). A parent's ability to conduct a sound appraisal of an ASD treatment may be influenced by their level of education. Similarly, parents may judge treatments differently based on their child's age (e.g., being opposed to psychotropic drugs for a toddler with an ASD but finding their administration to a school-age child with an ASD acceptable). Despite the potential for numerous demographic factors to strongly influence parents' treatment decisions, relevant research in this area has been lacking.

In an effort to address these gaps regarding parental choice of ASD treatments, the purposes of this study are to determine: (a) what treatments do parents report they are currently using for their child with an ASD, (b) if demographic factors are related to parents' choices of treatments, (c) what other sources of information influence parents' choices of ASD treatment (e.g., media, other parents, scholarly sources), and (d) where parents are obtaining professional recommendations regarding ASD treatment.

2. Materials and method

2.1. Participants

Before beginning the research, approval was obtained from the relevant office for research protections. After approval, a sample of parents of children with an ASD was compiled by contacting a wide range of organizations (e.g., national autism societies, Pennsylvania and Ohio autism societies, specialized autism schools, doctor's offices, parent support groups, and behavioral health services). To ensure confidentiality, participants were not asked for any personally identifying information. Since agencies contacted possible participants or advertised the study on list serves or newsletters, we were not able to determine the number of participants who passed up the opportunity to complete the questionnaire.

Participants were asked to complete items related to (a) demographics related to the child with an ASD, parents, and family; (b) treatments recommended by professionals regarding autism treatment; and (c) sources of information related to ASD treatment. Parents provided information about themselves, including: (a) relationship to the child with an ASD; (b) age; (c) highest level of education; (d) college major concentrations, and (e) annual income range. Family composition variables consisted of how many children were in the family. Variables related to the child with an ASD included: (a) age; (b) sex; (c) diagnosis; (d) time since diagnosis was made; and (e) professional who made the diagnosis.

2.1.1. Measurement of parent information

All respondents ($N = 400$) reported to be a parent or guardian of a person with an ASD (i.e., autism, pervasive developmental disorder not otherwise specified, and Asperger disorder). A large majority (88.8%; $n = 355$) of respondents reported to be the mother of a child with an ASD. The parents in the sample were mainly young to middle age (36.1% were between 30 and 40 years; 39.4% were between 40 and 50 years). More than half of the sample (59.7%; $n = 241$) reported to have a bachelor's level college degree or higher, and therefore, income ranges were relatively high (34.2% of the sample made yearly incomes greater than $70,000, 60% exceeded $50,000, and less than 10% made $30,000 or less). For those respondents with a college degree or post-secondary education, a wide variety of college major concentrations were reported. The most frequently reported college major concentrations included education (12.9%; $n = 52$), business (12.4%; $n = 50$), psychology (10.9%; $n = 44$), and medicine (8.9%; $n = 36$).

2.1.2. Measurement of family composition and child information

Analysis of family composition variables showed that over two-thirds (67.3%) of the participating families contained two or fewer children. Parents reported that 80.9% of their children with ASD were male and under 18 years old (94%), with the mean age being 9 (SD = 6 years; range = 2–43 years). Children were most often diagnosed with an ASD by a medical doctor

(56.7%) or a psychologist (33.9%) within the last 10 years (84.5%; mean number of years since diagnosis = 4; SD = 1 year). Many parents in this sample reported consulting a variety of professionals (mean number of professionals seen = 2.8) for information about diagnosis and treatment recommendations. Most parents reported they had taken their children to 10 or fewer professionals related to ASD treatment (84.6%). Among the most commonly seen professionals were occupational therapists (83.2%), psychologists (79.2%), dieticians (74.3%), and Board Certified Behavior Analysts (74%).

2.2. Materials

We used a revised version of the on-line autism treatment questionnaire used in Schreck and Mazur (2008) to obtain demographic information related to children with an ASD (age of child, sex of child, time since ASD diagnosis), their parents or guardians (age of parent, parent education level, parent income level), and family composition variables (number of children in family). Several items were developed to assess variables related to treatment selection, including (a) autism treatments that parents currently use (see Table 1 for a description of treatments included in the study); (b) professionals who recommended these treatments, and (c) parental sources of treatment decision influence.

Treatment descriptions included in the survey (i.e., Applied Behavior Analysis, Auditory Integration, Competent Learner Model, Chelation therapy, Chiropractic therapy, Craniosacral therapy, Discrete Trial Instruction, Facilitated Communication, Faith-based therapy, Floortime, Gentle Teaching, Gluten-free Casein-free Diet, Holding therapy, Hyperbaric Oxygen therapy, Music therapy, Occupational therapy, Picture Exchange Communication System, Positive Behavior Support, Physical therapy, Person Centered Planning, Sensory Integration, Sonrise, Speech therapy, TEACCH, Verbal Behavior, and Vitamin therapy) were selected from the treatments included in *Controversial Therapies for Developmental Disabilities: Fad, Fashion, and Science in Professional Practice* (Jacobson, Foxx, & Mulick, 2005) and treatments listed on websites such as the Autism Society of America webpage. Each of the treatments was classified as having the following research support: (a) supported by research, (b) limited support, (c) mixed support, (d) unavailable support, or (e) no support. Decisions for available research support were determined from Jacobson et al. (2005), Richdale and Schreck (2008), or Romanczyk, Gillis, White, and Digennaro (2008).

Treatment descriptions were developed, with special care to avoid jargon, primarily from Romanczyk et al. (2008). Each individual treatment was specifically defined in the questionnaire as it appears in Table 1. Parents reported whether they used specific treatments for their child with an ASD currently or had used them in the past. Participants were asked to indicate who had recommended these treatments (i.e., psychologist, behavior analyst, medical doctor, occupational

Table 1
Interventions and descriptions.

Treatments	Description
Applied Behavior Analysis	A science based on behavioral principles that are used to systematically change behavior
Auditory Integration	Individuals listen to music for a pre-specified amount of time to help retrain the auditory system
Chelation therapy	Treatment involves injection of medication to bind to metals and assist the body with purging the metals (e.g., mercury)
Chiropractic therapy	Adjustments of the spine and joints are used to realign the body; thus, relieving autism symptoms
Competent Learner Model	A newly developed curriculum for assessing and educating children with autism
Craniosacral therapy	Physical manipulation to alter the body's bio-electric field
Discrete Trial Instruction	Skills are broken down into discrete parts with each part being taught individually
Gluten-free Casein-free Diet	Gluten-free diets exclude proteins found in wheat; casein-free diets exclude milk products
Holding therapy	Assumes a lack of mother/child bond; treatment involves comforting children, physically restraining a resistant child, or "rebirthing"
Hyperbaric Oxygen therapy	Treatment involves spending time in a pressurized chamber while breathing pure oxygen
Facilitated Communication	An individual assists another in pointing to or typing letters as a means of communication
Faith-based therapy	Systematic use of prayer or other religious practices
Floortime	A method of teaching play skills that involves following the child's initiations and teaching skills based on those initiations
Gentle Teaching	A specific methodology for helping individuals using love and understanding as the basis for positive interactions
Music therapy	Using music to develop and maintain pro-social behaviors in individuals
Occupational therapy	A therapy that focuses on teaching fine and gross motor skills
Picture Exchange Communication System	The use of pictures as a means of communication
Person Centered Planning	A specific methodology based on values and ideas that focuses on improving the lives of individuals
Physical therapy	A therapy that focuses on building strength in all of the muscles of the body
Positive Behavior Support	The use of positive approaches to changing behavior in school settings
Sensory Integration	A means of stimulating the sensory system to improve an individual's level of functioning
Sonrise	Parents teach their child by imitating their child's stereotypic behavior to build a "non-judgmental" relationship that assists with learning
Speech therapy	A therapy designed to teach individuals how to speak and use language
TEACCH	A specific intervention focused on arranging the environment to facilitate the learning process
Verbal Behavior	A focus on teaching language based on the Assessment of Basic Language and Learning Skills (ABLLS)
Vitamin therapy	Deficiencies in vitamins (typically B_6 and magnesium) alleviated by providing high doses of vitamins

therapist, speech therapist, physical therapist, educator, audiologist, or dietician). If someone who was not one of the professionals listed had recommended a treatment, space was provided for parents to enter the professional title of the person who recommended the treatment.

Sources of influence for treatment decisions were also examined by having parents specify which of the following played a role in choosing treatment(s) for their child with an ASD: (a) workshop or training at an agency; (b) workshop or training at a conference; (c) hands-on training by an agency; (d) continuing education coursework; (e) autism-related books; (f) autism movies or television shows; (g) college coursework; (h) recommendations from non-medical professionals; (i) recommendations from medical doctors; (j) school or IEP; or (k) other parents. Space was also provided in the event that parents' treatment decisions were influenced by sources not listed on the questionnaire.

2.3. Procedure

Organizations likely to come into contact with parents of children with ASDs ($n = 256$) were contacted via e-mail, mail, telephone, and facsimile and asked to provide parents with a website where the online questionnaire was available. Organizations were asked to advertise the study by distributing or posting a prepared flyer or directly contacting their members who were eligible to complete the online survey. Paper questionnaires were also made available at several community education workshops designed for parents of children with autism conducted by the 3rd and 4th authors in Ohio. All paper questionnaires were returned anonymously. Personal identifying information of the respondents was not requested at any point in the questionnaire.

3. Data analysis and results

Parent responses were initially transferred from Microsoft Excel into an SPSS database and checked for accuracy by the first author. The database was then evaluated and analyses were conducted. In accordance with our purpose we (a) calculated which treatments were being used by parents for their children with an ASD; (b) analyzed parent demographics related to treatment use; (c) identified parents' reports of sources that reportedly influenced their choices of ASD treatments; and (d) determined those professionals who reportedly recommended specific ASD treatments.

3.1. Parent reports of current treatment use

The percentage of parents who reported current use of various ASD treatments was calculated by dividing the number of parents indicating they currently used the treatment by the total number of survey participants and multiplying by 100. All of the treatments included in the online questionnaire were reported to be used by at least one parent. Of the treatments categorized as having scientific support, mixed scientific support, or limited scientific support (see Table 2 for treatments by level of research support), parents reported using ABA ($n = 179$; 44.8%) the most. Although parents reported using ABA treatments, they also were likely to report using treatments that had limited scientific support, such as Speech therapy ($n = 275$; 68.8%); Sensory Integration ($n = 142$; 35.4%), Floortime ($n = 54$; 13.4%), TEACCH ($n = 35$; 8.7%), and Hyperbaric Oxygen therapy ($n = 13$; 3.2%).

Many of the treatments included in the survey have not yet undergone sufficient scientific evaluation to draw conclusions about their efficacy. Since research remains unavailable regarding these interventions, these treatments have not been labeled as supported or unsupported. The most-utilized treatment with unavailable research support reported by parents was Positive Behavior Support ($n = 142$; 35.6%), followed by Physical therapy ($n = 112$; 28%). A number of other treatments with unavailable research were reported to be used by less than 25% of parents, including Faith-based therapy ($n = 81$; 20.3%), Verbal Behavior ($n = 71$; 17.8%), Picture Exchange Communication System ($n = 66$; 16.6%), Gentle Teaching ($n = 42$; 10.6%), Person-Centered Planning ($n = 40$; 10.1%), Competent Learner Model ($n = 27$; 6.7%), Chiropractic therapy ($n = 25$; 6.2%), Craniosacral therapy ($n = 11$; 2.7%), and Sonrise ($n = 8$; 2%).

Also included in the survey were treatments not supported by research had the potential to cause harm. Among these unsupported treatments, parents reported using Vitamin therapy ($n = 124$; 30.9%) the most. Treatments such as Auditory Integration ($n = 35$; 8.7%), Facilitated Communication ($n = 31$; 7.7%), Chelation therapy ($n = 20$; 5%), and Holding therapy ($n = 6$; 1.5%) were reported to be used less frequently but still at high rates considering their unsupported research status and potential consequences.

Since parents reported using listed treatments within every category despite the status of research support, we explored possible influences to parents' treatment choices. The first analysis was conducted on familial demographic variables.

3.2. Demographic variables

Several demographic variables were analyzed to determine their relation to the use of empirically supported treatments for ASDs. We conducted Chi square analyses for each of these demographic variables by parent-reported current treatment use: (a) *parent education level* (i.e., high school graduate, some college, bachelor's degree, master's degree, and doctoral degree); (b) *parent college major concentration* (i.e., education, business, medicine, psychology, mathematics, arts, and sciences); (c) *parent income level* (i.e., less than \$30,000, \$31,000–\$40,000, \$41,000–\$50,000, \$51,000–\$60,000, \$61,000–

Table 2
Interventions by their level of research support.

Level of research support	Treatments
Supported	Applied Behavior Analysis Discrete Trial Instruction
Limited Support	Floortime TEACCH Hyperbaric Oxygen therapy (single-subject only)
Mixed Support	Sensory Integration Gluten-free Casein-free Diet Speech therapy
Research Unavailable	Chiropractic therapy Craniosacral therapy Sonrise therapy Faith-based therapy Gentle Teaching Picture Exchange Communication System Positive Behavior Support Verbal Behavior Competent Learner Model Person-Centered-Planning Physical therapy
Not Supported	Holding therapy Auditory Integration Music therapy Facilitated Communication Chelation therapy Vitamin therapy

$70,000, and $70,000+); (d) *parent age range* (i.e., 20-30 years, 30-40 years, 40-50 years, 50-60 years, or 60+ years); (e) *time since ASD diagnosis* (i.e., less than 3 months, 3 months to 1 year, 1–2 years, 3–5 years, 5–10 years, or greater than 10 years); and (f) *child age* (i.e., age in months).

3.3. Analysis of demographic variables and treatments' levels of research support

A number of hypotheses were generated concerning numerous parent, child, and family variables' relationships to parent treatment choice. We hypothesized that parents with higher levels of education, and therefore higher income levels, would be more likely to use treatments with empirical support. We also proposed that parents with science-based education major concentrations (medicine, sciences, mathematics) would be more likely to use empirically supported treatments. We also posited that the length of time since the child's ASD diagnosis would affect the likelihood of using supported treatments; more specifically, the longer past the diagnosis was made, the less likely parents were to use treatments with empirical support. To evaluate the relationships of demographic variables to parents' report of current ASD treatment use, each demographic variable was compared to parents' reported current use of the treatment for their child with autism. Chi square analyses comparing these demographic domains by parental reports of current treatment use were conducted for each variable. However, no statistically significant relationships existed for any of the demographic variables and current treatment use regardless of the scientific support for the treatments.

3.4. Parent sources of treatment decision influence

In addition to demographic variables, other sources may potentially exert an influence on parents' treatment decisions. Parents' responses to sources of information, such as media, education, anecdotal reports, and professional recommendations were evaluated. The percentage of parents who reported different sources of treatment decision influence was calculated by dividing the number of parents who indicated that a particular source influenced their treatment decision by the total number of survey participants and multiplying by 100.

Parents reported that their treatment decisions were influenced by a wide variety of sources listed on the questionnaire, with many parents indicating multiple sources of influence. The three most-often cited sources were recommendations found in autism books ($n = 342$; 85.6%), from professionals other than medical doctors ($n = 341$; 85.4%), and recommendations made by other parents ($n = 301$; 75.2%). Workshops or trainings at a conference ($n = 288$; 72%), workshops or trainings at an agency ($n = 266$; 66.6%), their child's school ($n = 271$; 67.8%), other autism media (e.g., television shows, movies; $n = 212$; 53%), and hands-on trainings by an agency ($n = 211$; 52.7%) were additional sources reported to be influential in parents' ASD treatment decisions. Sources that influenced treatment decisions that were cited by fewer than half of parents included continuing education courses ($n = 133$; 33.2%), and college coursework ($n = 64$; 16.1%).

Table 3
Most and least common professional recommenders of treatments by level of research support.

Level of research support	Most common recommenders (>10%)	Least common recommenders (<5%)
Supported	Psychologist (38.8%) Behavior analyst (30%) Medical Doctor (16.5%) Educator (14%)	Physical therapist (2.1%) Audiologist (0%) Dietician (0%)
Limited	Educator (11.4%) Medical Doctor (9.2%)	Psychologist (4.5%) Occupational therapist (3.1%) Speech therapist (3%) Physical therapist (0%) Audiologist (0%) Dietician (0%)
Mixed	Medical Doctor (34.9%) Occupational therapist (21.2%) Speech therapist (19.7%) Educator (14.1%) Behavior analyst (13%)	Physical therapist (2.5%) Dietician (2.4%) Audiologist (1.8%)
Unavailable		Psychologist (3.9%) Speech therapist (2.8%) Occupational therapist (2.4%) Physical therapist (1.7%) Audiologist (0.2%) Dietician (0.2%)
Unsupported	Medical Doctor (10.9%) Speech therapist (10.8%)	Educator (4.9%) Behavior Analyst (4.6%) Occupational therapist (4.2%) Psychologist (1.6%) Audiologist (1.3%) Dietician (0.5%) Physical therapist (0%)

3.5. Parent sources of professional recommendations by support level

As we expected, a large number of parents (85.4%) reported that the recommendations of professionals influenced their choices of treatment decisions. To further evaluate what type of recommendations parents perceive these professionals to be making regarding ASD treatment, we evaluated parent report of professional recommendations for treatment. Instead of evaluating each profession's recommendations, we ranked the top recommenders and non-recommenders for treatments based upon research support (see Table 3). However, since parents reported that schools significantly influenced their decisions ($n = 271$; 67.8%), we separately analyzed the types of treatments that educators reportedly recommended.

3.5.1. Professional recommendation of supported treatments

The percentage of parents who reported that a particular professional recommended an autism treatment was calculated by dividing the number of parents reporting that they received a treatment recommendation from a particular professional by the number of parents who indicated that they had seen the particular professional regarding ASD treatment and multiplying by 100.

The professions most likely to recommend supported treatments (Applied Behavior Analysis, Discrete Trial Instruction) were psychologists (38.8%) and behavior analysts (30%). Dieticians (0%), audiologists (0%), physical therapists (2.1%), occupational therapists (6.1%), and speech therapists (6.4%) infrequently or never recommended supported treatments.

3.5.2. Professional recommendation of treatments with limited support

Treatments with limited research support (Floortime, TEACCH, Hyperbaric Oxygen Treatment) reportedly were not recommended by more than 15% of any of the listed professions. Educators (11.4%) were the professionals most likely to recommend treatments with limited research support, followed by medical doctors (9.2%) and behavior analysts (6.3%). Dieticians (0%) and audiologists (0%) were the professionals least likely to recommend treatments with limited research support.

3.5.3. Professional recommendation of treatments with mixed research support

The interventions for ASDs with mixed research support included Sensory Integration, Gluten-Free Casein-Free Diet, and Speech therapy. These treatments were recommended at fairly high levels by a variety of professionals. Medical doctors (34.9%) were most likely to recommend treatments within this category, followed by occupational therapists (21.2%). Over 10% of speech therapists (19.7%), educators (14.1%), behavior analysts (13%), and psychologists (11.4%) recommended treatments with mixed research support.

Table 4
Treatments most recommended by professionals working within school systems.

Treatment	Level of research support	Most common recommenders
Sensory Integration	Mixed	Occupational therapist (53.2%) Educator (12.2%) Speech therapist (8.2%) Physical therapist (5.4%)
Speech therapy	Mixed	Speech therapist (49.1%) Educator (29.1%) Occupational therapist (8.6%) Physical therapist (2.2%)
PECS	Unavailable	Educator (39.5%) Speech therapist (26.3%) Occupational therapist (8%)
Positive Behavior Support	Unavailable	Educator (36%) Occupational therapist (3.5%) Speech therapist (2.7%) Physical therapist (1.5%)
Auditory Integration	Unsupported	Speech therapist (34.5%) Occupational therapist (15.5%) Educator (5.2%)

3.5.4. *Professional recommendation of treatments with unavailable research support*

Numerous treatments in the questionnaire were categorized as having no research support available on which to base determination of treatment efficacy for ASDs. These treatments included Chiropractic therapy, Craniosacral therapy, Sonrise, Faith-based therapy, Gentle Teaching, PECS, Positive Behavior Support, Verbal Behavior, Vitamin therapy, Competent Learner Model, Person-Centered Planning, and Physical therapy. Like the treatments in the limited research support group, treatments with unavailable research support are being recommended by a relatively low percentage of professionals. Medical doctors (8.6%) and educators (8.4%) were almost equally likely to be recommending these treatments, followed by behavior analysts (7.7%). Dieticians (0.2%) and audiologists (0.2%) were the professionals least likely to recommend treatments within the unavailable category.

3.5.5. *Professional recommendation of unsupported treatments*

Treatments for ASDs that remain unsupported were recommended at some level by all professions included in the survey with the exception of physical therapists. Medical doctors (10.9%) and speech therapists (10.8%) recommended unsupported treatments the most. In addition to physical therapists (0%), dieticians (0.5%), audiologists (1.3%), and psychologists (1.6%) were least likely to recommend unsupported ASD treatments.

3.6. *Parent-reported recommendations of ASD treatments by educators*

Parents reported schools or IEP teams as a significant influence on their ASD treatment decisions. Since various school staff in addition to classroom teachers may be involved in delivering services to children with ASDs, such as speech therapists, occupational therapists, and physical therapists, we evaluated the types of treatments parents reported that "education-based" professionals reported to recommend. Educators were reported to be recommending PECS (39.5%), Positive Behavior Support (36%), and speech therapy (29.1%) for ASD treatment the most among all interventions listed in the questionnaire (see Table 4). Speech therapists also recommended speech therapy (49.1%) and PECS (26.3%) at fairly high levels. However, parents also reported receiving a significant number of recommendations for Auditory Integration (34.5%) from speech therapists, a potentially dangerous and unsupported treatment. Sensory Integration (53.2%) was the treatment that occupational therapists recommended the most. The next most-often recommended intervention by occupational therapists was Auditory Integration (15.5%). Physical therapy (18.3%) was the treatment that physical therapists recommended most frequently. They did not recommend any other treatment listed in the questionnaire more than 6% of the time.

4. Discussion

Parents of children with ASD reporting treatment choices for this study indicated choices of treatments within all areas of research support (i.e., supported, limited, mixed, unavailable, and unsupported). Slightly less than 1/2 of the parents reported choosing a research supported treatment for their child with an ASD. Parents also were likely to report choosing unsupported treatments or those with limited scientific support, such as sensory integration, positive behavior support, speech therapy, physical therapy, faith-based therapy, vitamin therapy, and music therapy.

Although we suspected that demographic variables (e.g., education levels, college majors, and time since their child's ASD diagnosis) might influence parental choices of ASD treatments, these factors did not significantly contribute to treatment choices. The analysis of demographic variables showed that parents from a variety of financial, educational, and familial backgrounds are susceptible to the allure of fad treatments for ASD. Parents' reports of sources leading to their exposure and reliance for treatment choices ranged from popular media (i.e., autism books, TV, and media) to professionals (e.g., educators, doctors, behavior analysts), to anecdotal reports (e.g., workshops and other parents). Unfortunately, according to these results, parents are more influenced by anecdotal reports and "word of mouth" referrals than from scientific sources of research support.

Since professionals' referrals were one form of powerful influence for parents' treatment choice, we examined the trends for professionals' reported ASD treatment recommendations. This examination indicated that psychologists and behavior analysts were the most likely professionals to recommend scientifically supported treatments to parents, which is consistent with the fact that supported treatments tended to be those with which their discipline would be most familiar. Whereas, the medical and allied medical professionals were least likely to recommend scientifically supported treatments and were most likely to recommend treatments with mixed to unavailable research support. Although psychologists and behavior analysts also recommended ASD treatments with mixed or unavailable research support, psychologists and behavior analysts were among the professionals least likely to do so.

Parental report of reliance upon educators' recommendations for treatment choices necessitated a separate analysis of the recommendations reportedly made by educators who may practice within educational environments (e.g., teachers, speech therapists, physical therapists, occupational therapists). Parents indicated that speech therapists and educators recommended treatments across many different categories of research support. Fewer than 15% of educators and professionals typically within educational environments reportedly recommend ASD treatments in the scientifically supported to mixed levels of research support categories. Additionally, physical therapists, speech therapists, and occupational therapists were ranked as the least likely to recommend treatments with any type of research support. As expected, these professionals recommended treatments within their own specialty areas (e.g., sensory integration/OT). Of the reportedly top five ASD treatments recommended by education teams (i.e., Sensory Integration, Speech Therapy, PECS, Positive Behavior Support, and Auditory Integration), none qualified with a level of research support higher than mixed support. However, Positive Behavior Support has a significant marketing advantage in education settings for general behavior management (Johnston, Foxx, Jacobson, Green, & Mulick, 2006). Most disturbingly, auditory integration was recommended by speech therapists, occupational therapists, and educators despite its ranking as unsupported by research and possibly unsafe for children (Romanczyk et al., 2008).

The combination of parental report of reliance upon professionals' reportedly invalid recommendations creates a precarious situation. Many children may be receiving ineffective and possibly unsafe treatments as a result of these recommendations. In fact, this paper's observation that allied medical and educational professionals reportedly are more likely to recommend an assortment of mixed to unsupported treatments and that parents rely upon these professional recommendations presents a detrimental combination of influence. Additionally, even when parents perceive that professionals recommend scientifically supported treatments, parents often report that the same professionals might recommend treatments with little to no scientific support. These inconsistencies can result in the "buffet treatment" for autism (Richdale & Schreck, 2008) and a tempering of the effectiveness of scientifically supported treatments by those treatments without research support.

Although these preliminary results of professionals' recommendations for ASD treatments and consequences remain disturbing, several limitations of the study necessitate replication and expansion. For example, the percentages of reported professional recommendations for treatments within each category remain relatively low, with many below fifty percent. This may be related to the types of questions asked in the survey. We asked parents what professionals they have worked with relating to their child's autism. However, we did not clarify the purpose of the visit. Thus, parents could see a variety of professionals for purposes other than treatment recommendations, resulting in low endorsement for recommendations. The methods for collecting parental data (i.e., subjective responses) also could have influenced results. Although we attempted to survey parents with no direct connection to specific treatment methodologies, parents associated with specific professionals and specific treatments may have completed the online questionnaire.

5. Conclusion

While participants' responses in this study may only approximate the actual behavior of all parents of children with ASDs, we revealed trends in parental treatment decision making that indicated that parents rely upon "word of mouth" (i.e., possibly unsubstantiated print media, professional recommendations, and other parents' recommendations) that must be further examined. From these referral sources, parents receive a variety of recommendations resulting in the "buffet approach" to autism treatment (Richdale & Schreck, 2008). Further clarification of the types of sources most likely to influence parents' treatment choices (e.g., specific professions, print media, TV, and movies) must be conducted to influence regional, national, and international dissemination of information about scientifically supported treatments for children with ASD. Without appropriate advertisement and education geared toward parents, educators, and allied medical professionals, misconceptions about empirically based treatments and inappropriate treatment choices will continue to proliferate.

Acknowledgements

We would like to thank Ilhan Kucukaydin for his assistance with the online questionnaire and the many parents who provided us with information regarding their experiences with autism treatments.

References

Cohen, H., Amerine-Dickens, M., & Smith, T. (2006). Early intensive behavioral treatment: Replication of the UCLA model in a community setting. *Journal of Developmental and Behavioral Pediatrics, 27*(2), 145–155.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7: A comparison controlled study. *Behavior Modification, 31*(3), 264–278.

Elder, J. H. (1994). Beliefs held by parents of autistic children. *Journal of Child and Adolescent Psychiatric Nursing, 7*(1), 9–16.

Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafoos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities, 27*, 70–84.

Green, V. A. (2007). Parental experience with treatments for autism. *Journal of Developmental and Physical Disabilities, 19*(2), 91–101.

Harrington, J. W., Patrick, P. A., Edwards, K. S., & Brand, D. A. (2006). Parental beliefs about autism: Implications for the treating physician. *Autism, 10*(5), 452–462.

Heflin, L. J., & Simpson, R. L. (1998). Interventions for children and youth with autism: Prudent choices in a world of exaggerated claims and empty promises. Part 1. Intervention and treatment option review. *Focus on Autism and Other Developmental Disabilities, 13*(4), 194–211.

Howard, J. S., Sparkman, C. R., Cohen, H. G., Green, G., & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities, 26*(4), 359–383.

Jacobson, J. W., Foxx, R. M., & Mulick, J. A. (2005). *Controversial therapies for developmental disabilities: Fad, fashion, and science in professional practice*. Mahwah, NJ: Lawrence Erlbaum Associates.

Johnston, J. M., Foxx, R. M., Jacobson, J. W., Green, G., & Mulick, J. A. (2006). Positive behavior support and applied behavior analysis. *The Behavior Analyst, 29*, 51–74.

Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., et al. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US. *Pediatrics, 124*(5), 1395–1403.

Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities, 11*, 110–115.

Maurice, C., Mannion, K., Letso, S., & Perry, L. (2001). Parent voices: Difficulty in accessing behavioral intervention for autism; working towards solutions. *Behavioral Interventions, 16*, 147–165.

Metz, B., Mulick, J. A., & Butter, E. M. (2005). Autism: A late-20th-century fad magnet. In J. W. Jacobson, R. M. Foxx, & J. A. Mulick (Eds.), *Controversial therapies for developmental disabilities: Fad, fashion, and science in professional practice* (pp. 237–263). Mahwah, NJ: Lawrence Erlbaum Associates.

National Autism Center. (2009). *National standards report: National Standards Project – Addressing the need for evidence-based practice guidelines for autism spectrum disorders*. Randolph, MA: National Autism Center.

Richdale, A., & Schreck, K. A. (2008). A history of assessment and intervention in autism. In J. Matson (Ed.), *Clinical assessment and intervention for autism* (pp. 3–32). New York: Elsevier.

Romanczyk, R. G., Gillis, J. M., White, S., & Digennaro, F. (2008). In J. Matson (Ed.), *Clinical assessment and intervention for autism spectrum disorders* (pp. 351–381). Boston, MA, USA: Elsevier.

Schreck, K. A., & Mazur, A. (2008). Behavior analyst use of and beliefs in treatments for people with autism. *Behavioral Interventions, 23*, 201–212.

Smith, T. (2005). The appeal of unvalidated treatments. In J. W. Jacobson, R. M. Foxx, & J. A. Mulick (Eds.), *Controversial therapies for developmental disabilities: Fad, fashion and science in professional practice* (pp. 45–57). Mahwah, NJ, USA: Lawrence Erlbaum Associates Publishers.

Smith, T., & Antolovich, M. (2000). Parental perceptions of supplemental interventions received by young children with autism in intensive behavior analytic treatment. *Behavioral Interventions, 15*, 83–97.

Williams, G., Oliver, J. M., Allard, A. M., & Sears, L. (2003). Autism and associated medical and familial factors: A case control study. *Journal of Developmental and Physical Disabilities, 15*(4), 335–349.