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ORIGINAL ARTICLE

Parental Experience with Treatments for Autism

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Abstract Nineteen parents of children with autism were interviewed about their experiences with autism treatments. These parents had originally participated in an Internet survey of treatments for autism and were randomly selected to participate in the follow-up telephone interview. The questions focused on three current treatments that have varying empirical support in the research literature, namely Applied Behavior Analysis, Sensory Integration therapy, and a combination of Vitamin B6 and Magnesium. Most parents received information about these treatments from the Internet, other parents, and occupational therapists. In addition to recommendations from professionals and other parents to use a particular treatment, the study showed that ease of implementation, time commitment, and perceived effectiveness may also contribute to the continued use of treatments that lack empirical support. The findings highlight the need for parents to have access to unbiased, scientifically validated information about treatments for autism.

Keywords Autism · Treatment · Parents · Interview · Evidence-base

Over the past few decades a large number of treatments for autism have been proposed to ameliorate neurological, behavioral, and developmental problems associated with it and related disorders (Matson, 1994). Through the course of scientific validation some of these treatments have proven to be ineffective and are no longer used (e.g., fenfluramine) (Kerbeshian, Burd, & Avery, 2001). While other treatments, particularly those based on principles of applied behavior analysis (ABA) have considerable empirical support (Heflin & Simpson, 1998; Lovaas & Smith, 2003). However, there are a number of treatments, including facilitated communication and auditory integration training, that continue to be prescribed by clinicians and advertised on the Internet by institutes, despite having little or no scientific validation (Gillberg, Johansson, Steffenburg, & Berlin, 1997; Heflin & Simpson, 1998; Mostert, 2001).

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Of particular concern is that some of the proposed treatments are not only time consuming and expensive, but they may also be intrusive and potentially harmful. In addition, the psychological cost in terms of the false hope of a miracle cure is difficult to gauge (Goldstein, 2003; Heflin & Simpson, 1998; Shaw, 2002; Webster, Webster, & Feiler, 2002). Despite numerous research reports showing validation or lack thereof for many treatments, it is unclear to what extent the evidence base influences a parent's decision to use a particular treatment. Two recent Internet surveys that asked parents about their use of autism treatments found that the most frequently used strategies included a mix of both scientifically validated and non-validated treatments (Green et al., 2006; Myers, Goin-Kochel, & Mackintosh, 2005). In particular, in Green et al. (2006) three of the most frequently used specific treatments were Applied Behavior Analysis (ABA), Sensory Integration (SI) and a combination of Vitamin B6 and Magnesium (B6-Mg).

These three treatments have varying levels of empirical support. Treatments for autism based on principles of ABA focus on teaching functional skills across a range of domains. The programs that use ABA vary in intensity and the degree to which they rely on the use of discrete trial training or more naturalistic training paradigms (e.g., Lovaas, 1987; McEachin, Smith, & Lovaas, 1993). At its most intense, the treatment is implemented for 40 hrs per week for up to two years (Gresham, Beebe-Frankenberger, & MacMillan, 1999). However, other ABA-based programs are less intensive and implement treatment for approximately 27 hrs per week for 11 months (e.g., Harris, Handleman, Gordon, Kristoff, & Fuentes, 1991). There is a considerable amount of scientific evidence supporting the effectiveness of a wide range of interventions based on the principles of ABA. For example, McEachin et al. (1993) reported substantial gains in IQ for almost 90% of the children who had participated in the UCLA Young Autism Project. In addition, Harris et al. (1991) have also reported gains in intellectual functioning from their program, which is based on the principles of ABA and located at the Douglas Developmental Center at Rutgers University (Gresham et al., 1999). However, criticisms have been raised about the experimental methodology used in these studies (see Gresham et al., 1999; Webster et al., 2002) and most proponents of this treatment note that ABA is not a cure for autism and may not be effective in reducing problem behaviors for all children (Heflin & Simpson, 1998). Still, a large literature spanning over 40 years shows that ABA is the most consistently effective approach to the treatment of children with autism (Lord & McGee, 2001).

Another frequently used treatment is Sensory Integration (SI) therapy. SI is based on the premise that many young children with autism have sensory and motor difficulties (Adrien, Ornitz, Barthelemy, Sauvage, & Lelord, 1987; Baranek, 2002; Hoshina et al., 1982). In particular, some children with autism are said to have unusual responses to their environment or are preoccupied with sensory information. Ayers (1972) developed SI therapy in order to provide controlled sensory experiences for the child. According to principles of SI therapy, it is through such experiences that "the nervous system is thought to be able to better modulate, organize, and integrate information from the environment, which in turn provides a foundation for further adaptive responses and higher order learning" (Baranek, 2002, p. 406). SI therapy is typically conducted in a one-to-one context, with an occupational therapist. SI sessions might be implemented one to three times per week with each session perhaps lasting 1 hour. There have been numerous studies conducted to ascertain the effectiveness of this treatment (e.g., Carte, Morrison, Sublett, Uemura, & Setrakian, 1984). However, the research base supporting SI is not conclusive (Baranek, 2002; Dawson & Watling, 2000; Gresham et al., 1999; Shaw, 2002).

Mega-vitamin therapy as a treatment for autism was originally based on a theory developed by Pauling (1968). It has been suggested that "each individual has his or her own genetically governed need for various concentrations of vitamins and minerals" (Pfeiffer, Norton, Nelson, & Shott, 1995, p. 482). One assumption is that children with autism have inadequate amounts of specific vitamins and minerals.

Particular attention has been paid to Vitamin B6, which – when coupled with Magnesium – is considered to be safe even in large doses. In a review of 12 studies on the use of Vitamin B6, plus Magnesium for treating individuals with autism, Pfeiffer et al. (1995) concluded that despite some serious methodological flaws in many of the studies, this therapy may hold some promise as a treatment for some individuals with autism. Currently, however, the effectiveness of this treatment remains unclear.

Existence of conflicting evidence concerning the scientific validation of these treatments suggests that the scientific community cannot assume that parents will have access to valid information about treatments. Parents are often faced with the overwhelming task of trying to sort through the proliferation of information about autism available through the Internet (Lynch, 2004). In addition, considering the continued use of both scientifically validated and non-validated treatments by parents, scientific evidence alone may not be the only factor in the decision making process for parents. For example, little is known about the process that parents go through when they seek out and adopt one particular treatment over another. In order to help parents make informed decisions, it is important to know more about where they are getting their information, their expectations with respect to various treatments, and their experiences in using various treatments. Along these lines Lynch (2004) interviewed 16 parents of children with autism about their use of dietary and nutritional supplements. She found that most parents obtained information about these supplements through literature, the Internet, and other parents. She also reported that most parents indicated marked improvement in their child across several developmental domains that they attributed to the use of these dietary interventions and nutritional supplements.

The aim of the present study was to extend the work of Lynch (2004) by focusing on three treatments that have varying levels of scientific validation and which were among the most frequently used by parents in the Green et al. (2006) survey. Information of this type may not only provide corroboration of the findings reported by Lynch (2004), but may also help inform the decision making processes that parents follow in selecting treatments for children with autism.

Method

Participants

The 19 parents in the present study (2 fathers and 17 mothers) had already been participants in an initial Internet survey (see Green et al., 2006 for details). In the initial survey, parents were asked to indicate which of 111 treatments they had used or were currently using with their child. Upon the completion of this survey parents were asked to indicate whether or not they would like to be contacted about a possible follow-up interview and if so they were asked to include their contact details. From the 552 usable submissions in the original survey, 300 parents indicated that they were willing to be contacted. Due to financial considerations of conducting lengthy international telephone interviews, only those parents who were residents within the United States were selected as possible interviewees.

In order to improve the chances of obtaining a more representative sample, the US sample was further divided into three categories according to the severity of the child's autism. We then randomly selected potential interviewees within each category. Therefore 10% of the selected parents had a child with Asperger's syndrome, 60% had a child with mild/high functioning autism, and the remaining 30% had a child with severe autism. The parents were located in the following 10 states; Alabama, California, Florida, Louisiana, North Carolina, Texas, Tennessee, New Jersey, New Mexico, and Vermont.

Interview protocol

The interview protocol included eight questions that focused on how parents came to learn about the various treatments, their expectations and experiences with implementation, as well as their perceptions about the outcomes of the treatment.

1. How did you find out about this treatment?
2. Who provided the treatment?
3. Was the treatment easy or difficult to administer?
4. How long did you use the treatment?
5. How many hours per week (if applicable) did you use the treatment?
6. What kind of expectations did you have about this treatment?
7. What has been your experience with this treatment?
8. What changes (if any) did you notice with your child?

Procedure

Of the 30 parents who were contacted, 19 were willing and able to complete a telephone interview. Graduate students conducted the interviews, which lasted 1 hr on average. Each interviewee had a list of all the treatments the parents had indicted using in their initial survey response. The interviewees asked the same 8 questions about each of the treatments the parents had used or were currently using. The responses were typed by the interviewer into Excel spreadsheets during the interview for later coding and analysis.

Results

Child characteristics

All 19 children of the parents interviewed in the present study were male. Considering the population from which they were drawn was 84% male, this is perhaps not surprising. Table 1 presents the age by type/severity of disability breakdown for the 19 children. The majority of children in the present study were under 15 years of age.

Specific treatments

The following three treatments were used by at least 60% of the sample. Applied Behavior Analysis (ABA) was used by 13 parents. Sensory Integration (SI) therapy, was used by 15 of the parents and a combination of Vitamin B6 and Magnesium (B6-Mg) was used by 14 parents. One parent did not use any of the three treatments and therefore all the subsequent analyses were based on information from 18 parents. Seven of the 18 parents had used all three treatments (39%). A further four (22%) had used both SI and a combination of B6-Mg,

Table 1 Demographic characteristics of the 19 children with autism

	Type of disability		
	Asperger syndrome	Mild/High functioning autism	Severe autism
<5 Years	–	3	1
6–10 Years	2	3	–
11–15 Years	1	3	2
16–20 Years	–	2	–
>21 Years	–	2	–

while three (17%) had used both SI and ABA. Two parents indicated that they had used both ABA and a combination of B6-Mg. The remaining 2 parents had used only SI or ABA respectively.

Parental responses to the 8 interview questions

Responses to question 1: How did you find out about this treatment?

Parental responses to this question covered a wide range of sources. From the responses, 11 different categories were formulated. As Table 2 shows, other parents and the Internet were two of the most frequently used sources of information. Almost half of the parents who used SI found out about this treatment from an occupational therapist, whereas fewer parents gained information from conferences, research journals, teachers, or medical practitioners. For ABA, a third of the parents gained information about this treatment from other parents, who had presumably used the treatment themselves, whereas most of the others read a book about it. For the B6-Mg treatment, parents obtained their information from a wide range of sources: A clinic or institute was the most frequent source of information followed by the Internet, newsletters and other parents.

Table 2 Number (and percentage) of parents indicating each source of information across the three treatments

	ABA ($n = 13$)		Sensory Integration ($n = 15$)		VB6 & Magnesium ($n = 14$)	
Source of Information	*n*	%	*n*	%	*n*	%
Research/journal article	2	15.4	0	–	1	7.1
Book	4	30.8	1	6.7	1	7.1
Newsletter	0	–	1	6.7	3	21.4
Internet	4	30.8	1	6.7	3	21.4
Conference	1	7.7	0	–	0	–
Clinic/Institute	1	7.7	1	6.7	4	28.6
Early Intervention Service	2	15.4	2	13.3	0	–
School/teacher	1	7.7	2	13.3	0	–
Occupational Therapist	0	–	7	46.7	0	–
Medical doctor, neurologist	0	–	2	13.3	2	14.3
Other parents	5	38.5	1	6.7	3	21.4

Note. Percentages exceed 100% because some parents reported multiple sources of information.

Table 3 Number (and percentage) of parents indicating who implemented the treatments

	ABA ($n = 13$)		Sensory Integration ($n = 15$)	
	n	%	*n*	%
Therapist	7	53.8	7	46.7
Therapist in training	1	7.7	1	6.7
Parent	3	23.1	3	20.0
Parent & therapist or parent & teacher	2	15.4	3	20.0
Teacher or early intervention specialist	0	–	1	6.7

Responses to question 2: Who provided the treatment?

Parents were asked who provided each of the specific treatments. As vitamin supplements are usually given in the home, we only focused on Sensory Integration and ABA for this question. As shown in Table 3, a similar pattern of results was found for both SI and ABA. In particular, at least half of the parents indicated that a therapist was responsible for implementing the treatment. However, parental involvement was high with just over a third to a half of parents either implementing the treatment alone or in combination with a therapist or teacher.

Responses to question 3: How long did you use the treatment?

For all three treatments, there was a considerable range in the number of years/months parents had committed to using them. The least amount of time that parents had used these treatments before stopping was 2 weeks for the B6-Mg combination and 2 months for ABA and SI. The longest commitment was 12 years for B6-Mg and 8 Years for ABA and SI. Three parents who had indicated using ABA were still using this treatment while another four parents were still using SI. Nine parents were currently using the B6-Mg.

In Table 4, it is evident that for the ABA treatment, the majority of parents had used the treatment for less than 2 years (one parent was still using it), whereas for SI the majority of parents indicated that they had been involved in this treatment for over 2 years (three of these parents were still using this treatment). Just over half of those who indicated using B6-Mg had used this treatment for less than 2 years (five of these parents were still using the treatment).

Table 4 Number (and percentage) of parents indicating the length of time they had used specific treatments

	ABA ($n = 13$)		Sensory Integration ($n = 15$)		VB6 & Magnesium ($n = 14$)	
	n	%	*n*	%	*n*	%
<Than a year	4	30.8	2	13.3	5	35.7
Between 1–2 years	5	38.5	3	20.0	3	21.4
Between 2–5 years	2	15.4	7	46.7	4	28.6
>Than 5 years	2	15.4	3	20.0	2	14.3

Table 5 Number (and percentage) of parents indicating the weekly time commitment for each treatment

	ABA (*n* = 13)		Sensory Integration (*n* = 15)	
	n	%	*n*	%
>5 hrs	3	23.1	10	66.7
Between 5–10 hrs	1	7.7	3	20.0
Between 10–20 hrs	2	15.4	2	13.3
>20 hrs	7	53.8	0	–

Responses to question 4: How many hours per week?

In addition to asking how long parents had been using or had used a particular treatment, I was also interested in finding out about their weekly time commitment for both ABA and SI. For both treatments, the least amount of time for any one parent was 4 hrs per week. However for ABA, the upper limit was 40 hrs week and for SI therapy it was 15 hrs per week. Table 5 shows that over half of those parents who had used or were still using ABA indicated that their child was receiving treatment for over 20 hrs per week. Almost 2/3rds of the parents who were using SI indicated that they were using this treatment for less than 5 hrs a week.

Responses to question 5: Was the treatment easy or difficult to administer?

In light of the time and energy that can be required to implement treatments, I was interested in gaining information about parents' perceptions of the treatment. In particular, parents were asked if they considered each treatment to be difficult or easy to administer. Of the 13 who had used or were currently using ABA, 9 said that the treatment implementation was difficult or difficult at first. The remaining four indicated that it was easy or fairly easy. Seven of the parents who had used SI or were currently using it said it was easy to administer, whereas three said it was difficult or at least difficult at the beginning. One parent said that some aspects were easy while others were difficult and no responses were given by the remaining two parents on this question.

Responses to question 6: What kind of expectations did you have about this treatment?

Due to an oversight by one of the interviewers not all parents were asked about their expectations for the various treatments. Of the 13 parents who used ABA, only nine were specifically asked about their expectations for the treatment. Four of the parents mentioned specific skills that they would like their child to acquire. For example, the following comment was from the mother of a 4-year-old child, "*I hoped my child would become more reciprocal and would be able to hold conversations.*" The remaining five parents either had high expectations or no real expectations. Some hoped that the treatment would cure their child as exemplified by the following comment from the mother of a 7-year-old child, "*I hoped for a miracle and that my child would be normal.*" While others indicated that they were willing to "*take what they could get as far as improvement went*" (mother of a 16-year-old).

For those parents who had used or were using SI, only eight were specifically asked about their expectations. Although all the expectations were related to improving the child's sensory experiences, some parents were more specific than others with regard to their expectations.

Table 6 Number (and percentage) of parents reporting positive, neutral and negative outcomes for each treatment

	ABA ($n = 13$)		SI ($n = 15$)		VB6 & Mag. ($n = 14$)	
	n	%	*n*	%	*n*	%
Positive – parents saw improvements	9	69.2	12	80.0	6	42.9
Neutral – parents did not see any effects	2	15.4	2	13.3	8	57.1
Negative – parent saw no effects and had a negative experience with the treatment	2	15.4	1	6.7	0	–

For example the parent of a 4-year-old child indicated that she wanted her child to be able to "*eat course food*" whereas the parent of a 12-year-old child said she wanted the treatment to "*calm his system down so that he could tolerate the outside world*."

Only eight of the 15 parents that used B6-Mg were asked about their expectations for the treatment. Three indicated that they had no expectations or few expectations – they were just hoping to see some improvement. Another four individuals indicated that they hoped that the treatment would be calming and specified that they were expecting to see improvements in cognitive functioning including language. Another parent indicated that she hoped that the treatment would help her child with social functioning.

Responses to questions 7 and 8 – What has been your experience with this treatment? For example, what changes if any did you notice in your child?

The responses to these questions ranged from very positive to very negative for both ABA and SI, however most parents were positive about the treatment outcomes. In particular, as can be seen from Table 6, the majority of parents using ABA and SI indicated that they saw improvements in their child and were positive about the experience. For example one parent who had used ABA for 5 years with her 9-year-old child said:

> "He is indistinguishable from his peers now. The treatment far surpassed our expectations. The changes seemed miraculous, He is like a different child. We are glad we did not choose any other behavioral treatment."

Another parent who had used SI for 2 years with her 16-year-old child said:

> "It had improved his learning, he was more communicative, more social, his balance is better and he can ride a bike. If I saw improvement in one sense I saw improvement in others. Of all the different things we tried, this would be the most important for children with sensory issues."

A small number of parents indicated that they had negative experiences with ABA and SI. For example, one parent who had used ABA for 2 months and had a 4-year-old child said: "*The treatment was too rigid, too much like training a dog and the child rebelled. It caused temper tantrums*." One parent of a 9-year-old child who had used SI for 1.5 years said "*Overall, it was negative, self-stimulatory behaviors increased.*"

Four parents were neutral about the experience. In particular one parent who had used SI with her child for 2 years said that it didn't meet her expectations. Whereas a parent who had used ABA with her 14yr old child for a short time (3 months) said:

> “The therapist cut it short because she was busy, but I think it definitely has merit. It’s just that we didn’t stick with it long enough here to get benefit from it, but I know other parents have been very positive about it working with their children.”

Just under half of the parents using B6-Mg were positive about the treatment outcomes. For example, one parent who was currently using this treatment and had been using it for one year with her 8yr old child, said that it “*calmed him, and helped with her son’s sensitivity*.” However, most parents were neutral. For example one parent who had used the treatment for just 2 weeks with her 7-year- old child said: “*I didn’t use it long enough to notice any changes, but wouldn’t hurt others to try*.” It must be noted however, four parents indicated that they were mainly using this treatment for health reasons and not necessarily for the treatment of autism.

Discussion

Results of this study provide some preliminary information on the experiences of parents in using three specific types of treatments for autism. Most of the respondents had used all three of the treatments (i.e., ABA, SI, B6/Mg) at some point in time. Parents generally learned about these treatments from one of three sources: (a) other parents, (b) the Internet, or (c) from professionals (e.g., occupational therapists).

In considering why parents might choose to use a particular treatment, there are at least two points to consider. First, it appears from these data that parents may often rely on testimonials from other parents and the Internet for their information. It is unclear whether the information so obtained is based on empirical evidence. It is also unclear whether parents evaluate the scientific validity of information obtained from other parents or the Internet. Secondly, when parents rely on professional recommendations, it is unclear if they assume that this information is any more valid than that obtained from other sources. One might speculate that parents would assume professionals will be more likely to recommend and use only proven procedures. For example, when occupational therapists recommend SI, parents may assume that SI must therefore have proven effectiveness, otherwise why would this professional be recommending it.

With respect to SI, however, there appears to be little evidence to support its use in the treatment of autism. In two recent reviews, for example, the general conclusions have been that evidence for use of SI is far from conclusive (Shaw, 2002; Vargas & Camilli, 1999). Indeed, SI often has no overall positive effect and is often no more effective than alternative treatments (Vargas & Camilli, 1999).

Rather than its strong empirical support, the fact that information of this procedure is often obtained from professionals and the finding that many parents reported that SI was easy to implement may be two reasons why many parents choose to use this procedure. SI would seem much easier to implement than ABA, which often involves a weekly commitment of 20 or more hours per week for several years. In contrast to SI, these parents reported that ABA was more difficult to implement. Therefore, popularity of (SI) therapy among these parents of children with autism could be partly explained by the difference in the perceived ease of implementation, as well as the fact that most received their information about the procedure from an occupational therapist.

Given the time commitment that many parents devote to use of ABA and SI, it is perhaps not surprising that many not only had high expectations, but also tended to report positive outcomes as a result of using these treatments. With B6-Mg, in contrast, the reported outcomes were less positive, perhaps because with less commitment there might also be lower expectations. However, it is unclear to what extent the commitment parents made to implement a treatment and the parents' expectations for a treatment, influenced their perceptions of that treatment's effectiveness.

When we consider where many parents obtained their information, it is perhaps not surprising that treatments that lack evidence continue to be used. A positive parental report may have a ripple effect as it is passed onto parents of children who have been recently diagnosed. Some evidence for this comes from a previous study conducted Green et al. (2006), whereby parents were asked to indicate their current/or past use for various treatments. For each of the treatments discussed in this paper, there was an increase from past to present use indicating that the popularity of these treatments is increasing.

Taken together findings from the present study suggest that regardless of the evidence base for a particular treatment, there are other factors that may influence a parent's decision to choose and continue to implement a particular treatment. The source of information may have a significant impact on both the duration of the treatment and the perceived outcomes. For parents who receive their information from other parents, there may be a hope that 'if it worked for their child then it must work for mine.' When parents receive information from a professional there may be an implicit assumption that the treatment must be efficacious. Once a commitment has been made, it is perhaps not surprising that the longer parents use a treatment and invest both time and money there is an increased likelihood that they will report positive outcomes regardless of whether this is in fact true or not. It may be that in some cases parents are experiencing the placebo effect, which is a common phenomenon in any treatment process (Shaw, 2002).

One limitation of this study is that the sample may not have been representative due to the fact that parents were randomly selected from a highly educated sample who participated in the Green et al. (2006) study. In addition, sample size was relatively small and probably included parents who were motivated and committed to participating in the phone interview. Therefore, their experiences with various treatments may not be representative of all parents who have used these treatments. Considering the large number of treatments that many parents have used it was not possible in the present study due to time constraints to obtain detailed information about the specific decision making process parents undergo when choosing one treatment over another or choosing to stop one treatment and begin another.

Considering lack of regulation concerning validity of information provided on Internet sites and proliferation of self-help books (some of which may not scientifically valid), the findings from this study highlight the need for parents of children with autism to have access to valid non-commercial information about the efficacy of different treatments.

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