

Research Article

Autism Treatments used by Parents in Abu Dhabi, United Arab Emirates

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Abstract

Although autism is on the rise, there is a paucity in the literature examining the treatment of autism in the United Arab Emirates in the Middle East. This research analyzed treatment choices for children with autism by parents living in Abu Dhabi. Respondents (n=119) completed a bilingual survey listing 128 different autism treatments and indicated if they had never used, used in the past, or were currently using each treatment. The most commonly used treatment was speech and language therapy, followed by technology-based treatment and applied behavior analysis. On average, respondents were currently using 7.06 treatments, with one parent reporting the current use of 28. The implications of these findings for future research in the Middle East were discussed.

Keywords: Autism; Treatment; Evidence-based; Intervention; Parents; United Arab Emirates

Introduction

Autism is a developmental disability that is manifested during the first three years of a child's life and persists throughout the lifespan [1]. Autism is on the rise with an "incredible" increase in prevalence rate [2]. According to the Center for Disease Control and Prevention [3], approximately 1 in every 68 children (1 in 42 boys) has been diagnosed with autism. Hahler and Elsabbagh reported that globally, there are over 52 million individuals with autism, which indicates about 1-2% of children worldwide [4]. Unfortunately, there is limited research literature that targets the population of autism in Arab countries [5]. This is particularly the case with studies related to treatment outcomes and service delivery within the region [6]. Few researchers have explored the prevalence of autism in the Middle East and specifically in the United Arab Emirates [5,7,8]. The UAE is bordered by the Arabian Gulf and the Gulf of Oman, and is located between the Sultanate of Oman and the Kingdom of Saudi Arabia. The UAE is comprised of seven emirates: Abu Dhabi, Dubai, Sharjah, Ajman, Umm Al Quwain, Ras Al Khaimah and Fujairah and has a total population of about 8.19 million, of which 16.5 % are nationals [7].

Eapen, Mabrouk, Zoubeidi, and Yunis conducted a prevalence study with a representative random sample of 694 three-year-old children in the UAE [9]. In the first stage of the study, a questionnaire identified 58 per 10,000 children to have signs of autism. In the second stage, a clinical interview was used and the weighted prevalence was approximately 29 per 10,000 children with a diagnosis of pervasive developmental disorder. There are many centers for individuals with special needs in the UAE, including eleven that implement intervention based on the principles of Applied Behavior Analysis (ABA) [5].

Abu Dhabi is the federal capital of the UAE and is the largest of the seven emirates [10]. The population was estimated to be 2.45 million in 2013 (1.5 million in Abu Dhabi region, 0.65 million in Al

Ain region, and 0.3 million in the Western region). The UAE national population made up 20.19% of the total population. In 2012, the prevalence rate for autism was estimated to be 1 in 80 Emirati males and 1 in 240 Emirati females, in the Emirate of Abu Dhabi including the Al Ain region [11].

The increasing awareness of autism has led to parents seeking treatments, interventions, and therapies for their children with autism. However, as the number of children diagnosed with autism continues to rise steeply, so too does the number of treatment options, including culture-specific interventions such as Epsom salt baths and hijama [5]. According to the National Standards Report [12], families and professionals are often in a situation where they have to choose from a huge number of treatments. The information provided about these treatment options may be confusing and not fully supported by research, which makes the treatment selection a complicated process.

The National Autism Center [13] recently published a report that addresses the need for evidence-based practice guidelines for autism and reports the findings and conclusions from the National Standards Project. The primary goal of this NAC project was to provide critical information about which interventions have been shown to be effective for individuals with autism. A review of 389 studies published in peer-reviewed journals between 2007 and 2012 was conducted to evaluate educational and behavioral intervention literature for individuals with autism below and above the age of 22 years.

The autism interventions were classified as established, emerging, or unestablished [13]. It was revealed that for individuals under the age of 22 years there were: 14 established interventions (e.g., pivotal response training); 18 emerging interventions (e.g., music therapy); and 13 unestablished interventions (e.g., gluten-free, casein-free diet). Behavioral intervention was the largest category of established interventions in this group. For individuals aged 22 years and above, only one established intervention (behavioral intervention) and one

emerging intervention (vocational training package) were found with four unestablished interventions outlined (e.g., sensory integration package).

Studies have investigated the types and number of treatments including medications, therapies, and other holistic approaches used by parents [14]. Parents priorities are to seek for possible treatments rather than look for scientific studies or treatment efficacy. Meeting the needs of children with autism imposes a huge emotional and financial burden on families [13]. Mackintosh, Goin-Kochel & Meyers [15] found that parents experienced stress and frustration in accessing services, and working with professionals. It becomes even more demanding for parents, especially in contexts where access to services and support are inadequate. Therefore, it becomes imperative to survey the kinds of treatments that parents have used for children with autism.

Green, Pituch, Itchon, Choi, O'Reilly and Sigafoos [16] developed an internet survey to identify which of the 111 listed treatments was used by parents of children with autism with the majority of the respondents (80%) living in the United States of America (USA). The treatments were grouped under several categories including: (a) medications (e.g., antidepressants), (b) vitamin supplements, (c) special diets, (d) medical procedures, (e) educational/therapy approaches (e.g., applied behavior analysis; ABA), (f) alternative therapy/medicine (e.g., acupuncture), and (g) combined programs (e.g., Eden program). Specifically, parents were asked to indicate whether they were: currently using the treatment with their child; had used the treatment in the past, but were not currently using it; or had never used the treatment. Of the 552 respondents, on average the parents reported using seven different treatments with one parent reporting the current use of 47 treatments. The most frequently reported treatment was speech therapy (70% currently using this treatment) followed by visual schedules (43.2%), sensory integration (38.2%), and ABA (36.4%).

The aim of the current research was to replicate the Green et al. survey in both English and standard Arabic to assess the number and types of procedures, programs, or approaches used by parents in the treatment of their children with autism in Abu Dhabi in the UAE [16]. Furthermore, the aim was to identify and be informed of the most and least commonly used treatments by parents in the local region. The results of the current study will demonstrate if these findings can be generalized to a new sample in Abu Dhabi.

Method

Participants

The 119 participants of the study were parents (76.47% were mothers and 21.85% were fathers) or guardians (1.68%) of individuals with autism residing in the Abu Dhabi Emirate (excluding the Al Ain region). Since hard copies of the survey were used in this study, respondents could skip questions if they wished. Sixty-six (55.46%) of the respondents were Emirati and 53 (44.54%) were not Emirati. The majority of the respondents (74.79%) were educated beyond high school. The percentages presented were calculated from the total 119 respondents.

Materials

The original survey developed by Green et al. was obtained directly

from the corresponding author of the original study [16]. Permission was granted from this author to employ their survey for the current replication. Two versions of the survey were created with the same content in each. The hard copy of the survey was 13 pages long. It was printed in color, and used both sides of each page. The online version was created using eSurveysPro [17] online survey software.

Survey development and editing

The original survey was translated by the third author into standard Arabic. Many of the terms could not be translated into Arabic and were provided in English only. The majority of these terms were in the section listing biological treatments. Once the original survey was translated into a bilingual document (with the English and Arabic beside each other), it was distributed to five autism specialists from around the Cooperation Council for the Arab States of the Gulf (two of the specialists resided in the Kingdom of Saudi Arabia and three of the specialists resided in the UAE). One of the specialists was bilingual and also checked the Arabic translations. The suggestions and feedback from the specialists were incorporated into the survey. The current survey contained an extra section on assistive technology and additional options (e.g., occupational therapy, hijama), which were absent from the original survey.

Survey content

The survey contained questions in four main sections related to the respondent's child, the respondents themselves, non-biological treatments and biological treatments. A total of 128 treatments were listed. The 67 non-biological treatments were divided into the following categories: (i) educational/therapy approaches (e.g., applied behavior analysis); alternative therapy/medicine (e.g., Epsom salt baths); combined programs (e.g., Son-Rise program); and assistive technology (e.g., Proloquo2Go). The 61 biological treatments were grouped according to the following categories: (i) medications (e.g., antidepressants); (ii) vitamin supplements (e.g., vitamin B6); special diets (e.g., gluten-free diet); and medical procedures (e.g., chelation).

As in the Green et al. study, parents were asked to indicate if: (i) they were currently using the treatment with their child; (ii) they had used the treatment in the past, but were not currently using it with their child; or (iii) they had never used the treatment with their child [16]. Spaces were provided after each group of treatments to allow parents to add in any treatments that they had used that was not listed in the current survey. A copy of the current survey is available from the corresponding author.

Survey distribution

The survey was distributed via hard copies and an online link. The first author contacted several autism schools and centers in Abu Dhabi and delivered 386 hard copies of the survey to seven of these organizations. Each of the centers/schools then sent a copy of the survey home with each student with autism. Each hard copy was placed in an A 4-size resealable envelope and a label was placed on the front of the envelope. The label was marked with the word "confidential" and instructed parents to place the survey into the envelope when complete and to seal it and return it to the autism center or school. The results from the hard copy version were entered manually into the eSurveysPro online survey software for data analysis [17]. The link to the online version of the survey was posted on three different social

Table 1: Most commonly used treatments for children with autism in Abu Dhabi.

	Treatment name	Respondents currently using		Respondents used in past	
		n	%	n	%
1	Speech and Language Therapy	63	52.94	21	17.65
2	iPhone/iPad applications	61	51.26	8	6.72
3	Applied Behavior Analysis (ABA)	59	49.58	16	13.46
4	Picture Exchange Communication System (PECS)	44	36.97	27	22.69
5	Cognitive Behavior Therapy (CBT)	42	35.29	14	11.76
6	Occupational Therapy	33	27.73	20	16.81
7	Holding Therapy	26	21.85	8	6.72
8	Social Stories	20	16.81	12	10.08
9	Equine therapy / Therapeutic Horseback Riding	20	16.81	6	5.04
10	Essential Fatty Acids	19	15.97	30	25.21

Table 2: Present and past use of vitamin supplements and alternative diets for the treatment of children with autism.

	Treatment name	Respondents currently using		Respondents used in past	
		n	%	n	%
Vitamin Supplements	Essential Fatty Acids	19	15.97	30	25.21
	Vitamin B6	18	15.13	24	20.17
	Vitamin C	15	12.61	23	19.32
	Vitamin A	11	9.24	20	16.81
	Magnesium	5	4.20	20	16.81
	L-Glutamine	3	2.52	12	10.08
	Dimethylglycine (DMG)	3	2.52	8	6.72
	Megavitamin therapy	1	0.84	7	5.88
	Pyridoxine	1	0.84	3	2.52
Alternative Diets	Casein-free	11	9.24	26	21.85
	Gluten-free	9	7.56	27	22.69
	Gluten-free Casein-free diet (GfCf)	8	6.72	22	18.49
	Sugar-free	7	5.88	16	13.45
	Yeast-free	4	3.36	10	8.40
	Feingold	1	0.84	5	4.20

networking sites related to autism in the UAE. The online surveys and hard copy surveys were completed by the respondents in a location of their own choosing.

Results

Survey return rate

Of the 386 hard copies that were provided to the seven autism centers and schools in Abu Dhabi, 106 (27.46%) were returned. Since hard copies of the survey were used in this study, respondents could skip questions if they wished. The completed data from the hard copies was analyzed. Thirteen participants completed the survey online using the eSurveysPro software [17]. Nine online surveys were incomplete and the data from these surveys were not analyzed. The findings of the survey were automatically generated in a summary report by the eSurveyPro software package [17]. The percentages presented are calculated from the total 119 respondents.

Characteristics of the participant's children with autism

The majority of the respondent's children with autism were

male (64.71%). In terms of autism severity, 42.64% were categorized as having mild to moderate functioning autism, 35.29% with high-functioning autism and 10.08% with severe autism. Almost half (46.22%) of the 119 respondents indicated that their child was aged 6 to 10 years, and only 25 (21.01%) were aged 11 years or older. Ninety-one (76.47%) of the respondent's children were being educated in an autism center in Abu Dhabi.

Most frequently used treatments

Of the 128 listed treatments, 100 were currently being used or had been used in the past. The following 28 treatments (3 non-biological and 25 biological) were not being used or had ever been used by the participants: rolifing, watsu, BIGmack, clozapine, dilantin, clonopin, paxil, tofranil, ativan, buspar, valium, xanax, adderall, cylert, dexedrine, pentoxifylline, transfer factor, naltrexone, bethanechol, pepcid, secretin, electroconvulsive shock, psychosurgery, vagal nerve stimulation, fenfluramine, inderal, lithium, and tenex.

The 100 treatments were ranked from highest to lowest according to the number of respondents who indicated that they are currently

Table 3: Percentage of respondents indicating current use for each treatment category.

Treatment Category	Number of treatments	Most Commonly Used Individual Treatment	Least Commonly Used Individual Treatment
Standard therapies	5	Speech and Language Therapy (52.94%)	Osteopathy (0%)
Assistive Technology	3	iPhone/iPad (52.94%)	GoTalk (2.52%)
Skills training based on principles of ABA	9	ABA (49.58%)	Electro-aversive therapy (1.68%)
Relationship-based treatments	5	Holding therapy (21.85%)	Extended breastfeeding (2.52%)
Vitamin supplements	9	Essential fatty acids (15.97%)	Pyridoxine (0.84%)
Alternative therapies/medicines	13	Art therapy (13.45%)	Cupping therapy (hijama), acupuncture (both 0%)
Skills based	8	Facilitated Communication (13.45%)	Van Dijk Approach (0%)
Physiological	14	Brush Therapy (12.61%)	Irlen lenses (0%)
Alternative diets	6	Casein-free (9.24%)	Feingold (0.84%)
Combined programs	8	TEACCH (8.4%)	Son-Rise program (0%)
Medication	17	Probiotics (6.72%)	Thorazine, Depakote, Prozac, Haldol, Intravenous Immunoglobulin, Vancomycin (all 0%)
Detoxification	3	Chelation (0.84%)	Clathration (0%)

using the treatment. Table 1 shows the ten most commonly used treatments for children with autism in Abu Dhabi, as indicated by the 119 respondents. The most frequently used treatment was speech and language therapy, which was currently being used by 52.94% of the respondents with a further 17.65% having used it in the past. The next most frequently used treatments included iPhone/iPad applications, Applied Behavior Analysis (ABA), Picture Exchange Communication System (PECS), and Cognitive Behavior Therapy (CBT) (Table 1).

For 49 of the treatments, there was an increase in the percentage of respondents indicating that they currently use the treatment, compared to the past. For example, Table 1 shows that 6.72% of parents indicated that they used iPhone/iPad applications in the past, whereas 51.26% of parents indicated their current use. There was a noted decrease in the percentage of parents using 51 of the treatments from the past to the present. For example, chelation was used by 8.40% of parents in the past and 0.84% of parents currently. For each of the vitamin supplements and alternative diets listed in the survey, there was a decrease from past to present use (see Table 2). The average percentage of respondents who used vitamin supplements as a treatment for autism in the past was 13.72% and 7.10% currently. An average of 14.85% of respondents used an alternative diet in the past, with 5.6% currently using a diet as a treatment for autism (Table 2).

Number of treatments being used by parents

The mean number of treatments being used by parents of children with autism in Abu Dhabi was 7.06 currently and 6.65 in the past. The highest total number of different treatments used by any one parent was 48 (35 in the past, 13 currently). The highest number of treatments being used by one parent currently was 28, and 35 in the past.

Types of treatments

As in Green et al., the 100 treatments were grouped across 12 categories [16]. Table 3 presented the most and least commonly used treatment in each category. Four of the ten most frequently used treatments (see Table 1) were in the category labeled skills training based on the principles of ABA. Categories of treatments that were not included in the ten most frequently used treatments

include: medications, physiological treatments, alternative diets, detoxification and combined programs (Table 3).

Discussion

The current study aimed to extend the investigation of the treatments used by parents of children with autism. Out of the 128 types of treatment surveyed, 100 were reported as being used in the past or present by parents or guardians of children with autism in Abu Dhabi in the UAE. This plethora of available treatments may explain why one respondent was currently using 28 different treatments at the time they completed the survey. Parents keep trying treatment after treatment attempting to find the intervention that will be of most benefit to their children with autism [18]. This would explain why 33 (27.73%) of the parents were currently using 10 or more treatments and similar to the findings of Green et al. [16], 14 respondents (11.76%) indicated that they were using 15 or more treatments at the time of completing the survey.

The mean number of treatments being used by parents of children with autism in Abu Dhabi was 7.06 currently and 6.65 in the past. These findings were similar to that found by Green et al. [16], where 20% of the respondents were living outside of the USA and were currently using seven treatments on average and had tried an average of eight treatments with their children with autism in the past. Goin-Kochel, Mackintosh, and Meyers also conducted an internet questionnaire and found that 479 parents (22.6% of respondents were from outside of the USA) had tried on average between seven and nine therapies in the past and between four and six therapies currently [19]. Collectively, these studies highlight that parents are using a wide variety of treatments simultaneously for their child with autism [18] regardless of the location of the participants.

The ten most commonly used treatments for children with autism in Abu Dhabi (see Table 1) are similar to the lists produced by Peacock [20] and Green et al. [16]. Four of the treatments listed involved skills training based on the principles of ABA. According to the NAC [13], behavioral intervention is the most established treatment for individuals under the age of 22 years and it is the only treatment to be identified as established for adults aged 22 years and older. One restriction of this study was that parents were recruited

using convenience sampling via local autism centers and some of these centers use ABA with their students. The finding that ABA was the third most frequently used treatment (49.58% of parents reported its current use) may therefore be an overestimation of the general Abu Dhabi autism population.

The list in Table 1 included treatments that are categorised as established (e.g. ABA), emerging (e.g. PECS) and unestablished (e.g., equine therapy) by the NAC [13]. Likewise, treatments that were currently being used by less than 10% of parents also included the three categories: established treatments (e.g., pivotal response therapy), emerging (e.g., music therapy) and unestablished (e.g., GfCf diet). The same trends were found by Green et al. [16] in the most and least frequently used treatments suggesting that parents do not take the evidence-base of treatments into account when making choices about treatment regardless of where they live.

Sensory integration (used by 38.2% of parents) was ranked as the third most currently used treatment by Green et al. [16] but was ranked much lower at 26th in the current list (8.4% of respondents). Also, holding therapy was ranked seventh (21.85% of respondents) in the current list, but was only ranked 44th (4.3%) in Green et al. [16]. These disparities may indicate that choices made by parents may be determined by availability of therapists in the region under investigation. Further analysis is required to determine if this is the case.

The decrease in the past to current use for each of the listed vitamin supplements (mean decrease of 6.62%) was presented in Table 2. Even with the decrease in usage, essential fatty acids was ranked as the tenth most commonly used treatment in current use (15.97% of parents) with Vitamin B6 in 11th place with 15.13% of parents reporting its current use. In fact, there were three specific vitamin supplements listed in the top 15 most popular treatments.

The highest ranking alternative diet was casein-free, which was the 23rd most frequently used treatment (currently used by 9.24% of parents). There was a similar decreasing trend with each of the alternative diets. Table 2 showed a mean decrease of 9.25% in the past to current use of the diets. It would be interesting to follow-up with the respondents in the current study to find out why the decreasing trend seen in Table 2 occurred. Did the parents stop using special diets because they were made aware of the unestablished nature of the treatment? [12,13] Or perhaps it became too difficult to follow the diet? Suitable foods can be more expensive, harder to find and can take longer to prepare [18,21]. Another potential reason why the parents decided to stop using an alternative diet may be due to increased health risks such as essential amino acid deficiencies and bone loss [22]. Further research is required to determine the cause of this trend and to investigate parent perception of the efficacy of each treatment used for their children with autism.

There are a few limitations to the current study. The survey consisted of 128 types of treatments as well as several demographic questions. Thus the length of the survey could have impacted the accuracy of the survey responses of the participants as they may have skipped questions or perhaps skimmed through sections, missing relevant treatments. Missing data should have been addressed using the same method for both online and hard copy surveys. Furthermore,

although the survey was in Arabic and English, participants may not have understood the names of certain treatments, especially when Arabic translations were not possible.

Another limitation identified by two respondents by writing on their survey was that they were unaware of the specifics of the treatment(s) being used by their child's autism center. For example, one mother wrote in Arabic, "These questions should be asked to the center in which my son is studying. Maybe the center is using some of these treatments and we are not aware". This threatens the accuracy of the current findings as some treatments being frequently used on a daily basis may have been unidentified by the parents. This finding indicates that autism centers need to ensure that parent education and training is addressed as a higher priority.

Conclusion

Finally, Abu Dhabi is just one of seven emirates of the UAE. Future research requires a larger, random sample including individuals living in both the Al Ain and Western regions of the Emirate of Abu Dhabi, as well as an extension to the other six emirates of the UAE: Dubai, Sharjah, Ajman, Umm Al Quwain, Ras Al Khaimah and Fujairah. It is necessary to investigate the decision-making process that parents use when deciding upon which treatments to use using a qualitative analysis. This will enable autism professionals to improve parents' access to, and understanding of, the importance of using evidence-based treatments for autism.

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