#### **ORIGINAL PAPER**



# Autism Spectrum Disorder: When There is no Cure, There are Countless of Treatments

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Accepted: 4 September 2022 / Published online: 12 October 2022 © The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022

#### **Abstract**

We investigated parent reports of use of special education and support services, use of evidence-based practices (EBPs), use of past and current complementary and alternative medicine (CAM) treatments, non-use of CAM treatments, willingness, and unwillingness to use CAM treatments, reasons for use and non-use of CAM treatments, and perceptions of EBPs and CAM treatments in their children's functioning. We collected data from a total of 166 parents of children with autism spectrum disorder (ASD) through a web-based survey. 94% of the parents reported lifetime use of at least one CAM treatment. Parents weighed on a wide variety of factors in decision-making. CAM treatments use was positively associated with parental educational level, length of time since ASD diagnosis, and child's ASD severity.

**Keywords** Autism spectrum disorder · complementary and alternative medicine · treatment · parent perception · intervention choice · decision making

The prevalence of autism spectrum disorder (ASD) increased by 104% in the last decade to one in 44 children based on data according to the Centers for Disease Control and Prevention (2020). With this increase has come an increased demand for medical, behavioral, and educational interventions to relieve, treat, or eliminate core symptoms of ASD among families and professionals (Höfer et al., 2019). Thus, practices in educational and treatment process of the individuals with ASD have risen (National Autism Center [NAC], 2009) ranging from evidence-based practices (EBPs) including behavioral and educational interventions to complementary and alternative medicine (CAM) treatments (Hyman & Levy, 2011).

EBPs are defined as practices with proven effectiveness through rigorous empirical studies (Horner et al., 2005). Experts have published literature analyses or technical reports that focus on EBPs for individuals with ASD between different age groups (e.g., NAC, 2009; Simpson,

2005; Steinbrenner et al., 2020). These advances in intervention research provide guidelines and suggestions regarding effective practices for families and professionals working with individuals with ASD. In Turkey, however, it is hard to say EBPs are consistently used and implemented in educational settings. Furthermore, no studies have investigated the use of EBPs for students with ASD in Turkey. Therefore, the current study may contribute to understanding which EBPs are used for individuals with ASD in which settings by parent perceptions. On the other hand, one common and popular method widely used for individuals with ASD is CAM treatments (Lindly et al., 2018).

CAM refers to an umbrella term based on many different conventional and unconventional medical and philosophical systems (Hanson et al., 2007). CAM treatments include a heterogeneous array of health care practices that are not a part of health care system (World Health Organization [WHO], 2019). Despite different categorizations and definitions for CAM by researchers and organizations, the treatments used with conventional medicine are defined as *complementary treatments* while *alternative treatments* are used as a substitute for conventional medicine or treatments such as applied behavior analytic practices. Unlike conventional treatments, CAM treatments are not always used by health professionals in that they are promoted by various individuals or groups (Hall & Riccio, 2012). With



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the prevalence of between 10% and 76% in general public, CAM treatments are used by individuals with serious illnesses such as cancer, with a developmental disability such as ASD, or with no health problems (Harris et al., 2012). The use of CAM treatments in individuals diagnosed with a disability, ASD in particular, has been estimated to be higher than the general population (Wong & Smith, 2006). Their use in population with ASD has been estimated to be as high as 31.7% (Levy et al., 2003) and 74% (Hanson et al., 2007). Cultural, economic, social, and geographical factors influence the uptake of CAM treatments (Höfer et al., 2019), which makes it necessary that the reasons for using CAM treatments be investigated considering these factors. Due to its geographical location between Anatolia, the Aegean, Eastern Mediterranean, and the Balkans and interaction with Asian and Islamic cultures, Turkey is a developing country of an eclectic culture. This intersection point between Europe and Asia may increase and widen the reasons for using CAM treatments in Turkey. Therefore, findings from Turkish population-based samples may advance the literature.

Parents are often faced with the task of choosing from a confusing and wide array of intervention options that vary considerably in effectiveness for their children with ASD. There is diverse number of factors affecting parental decision-making regarding starting, continuing, rejecting, and discontinuing particular treatments for their children with ASD. Carlon et al., (2015) found that parents place greater weight on staff attributes and intuition/gut feelings than research evidence when making their decisions in treatment use. As to discontinuation of treatments, parents' belief that the child is not benefiting enough, regional proximity, and access to services affect their parental decisions (Bowker et al., 2011; Shepherd et al., 2018). Furthermore, research results indicate that many factors influence parents' choices of treatment use, including: Severity of ASD (e.g., Green et al., 2006; Hall & Riccio, 2012), individual needs of the child (e.g., Carlon et al., 2015; Hebert, 2014), parental educational level (e.g., Hall & Riccio 2012; Salomone et al., 2015). Carlon et al., (2013) reviewed studies exploring the parent-declared factors influencing their decision-making and concluded that frequently declared factors were recommendations from others, availability, regional proximity, and cost of the services. Other reasons included seeing the treatments as a cure for ASD (e.g., Carlon et al., 2015; Konuk-Sener & Karaca, 2020), recommendations from other families (e.g., Carlon et al., 2015; Finke et al., 2015), and the impact of media (e.g., Bilgic et al., 2013; Miller et al., 2012; Senel, 2010). Also, parents reported they were using CAM treatments because they felt educational and behavioral treatments were ineffective (Bilgic et al., 2013). However, there is limited research investigating the factors that parents have considered in decision-making to discontinue a treatment (Bowker et al., 2011; Christon et al., 2010), parents' perceived effectiveness of CAM treatments (Call et al., 2015; Konuk-Sener & Karaca, 2020), and the association between CAM treatments use and such variables as child's ASD severity, the length of time since the ASD diagnosis, family income level, and parental educational level (Miller et al., 2012). No studies investigated parental reasons for willingness and unwillingness to start a CAM treatment. Also, only Bowker et al., (2011) examined parents' perceived effectiveness of EBPs used in their child's special education. This information is significant because researchers and professionals gain a better understanding of the level of different factors influencing parental decision-making. Furthermore, most studies focused on parents' current and past, or lifetime use of CAM treatments, which limits inference of changes in current use of these treatments over time (Bilgic et al., 2013; Christon et al., 2010; Senel, 2010). In fact, Carlon et al., (2014) recommend collecting data about current and past use rather than lifetime use, which would allow researchers to track the changes over time. Clearly, there is a need for additional research to build on past research further exploring and identifying variables that influence parents' decision-making process to inform future efforts focused on promoting EBPs.

Over half of the responding parents in a survey study rated the CAM treatments they have used as effective for their children with ASD (Christon et al., 2010). On the other hand, empirical study findings suggest that many CAM treatments have little or no evidence for treating ASD symptoms, incur costs in terms of time and out-of-pocket expense, and take time to show positive outcomes for children with ASD (Lindly et al., 2018). Furthermore, the waste of time, energy, and money may prevent children with ASD from access to intensive and behavioral practices referred to as a cornerstone of treatment for core impairments of ASD (Howard et al., 2005). Despite the lack of scientific evidence on CAM treatments for ASD, there have been a wide array of CAM treatments offering the promise of a cure for ASD (Hanson et al., 2007; Nickel, 1996). Currently, however, no treatment has been shown to cure ASD, but the majority of effective practices for supporting children with ASD in acquiring skills are evidence-based, behavioral and, educational (Eldevik et al., 2009). Thus, it is significant to base the selection of interventions on scientific evidence (Kurt & Subasi-Yurtçu, 2017) as teaching children with ASD can be successful only when EBPs are employed (Cook & Odom, 2013).

There are several studies investigating the types of CAM treatments and reasons for using CAM treatments by parents of individuals with ASD in Turkey. For example, Guner et al., (2021) reported the most frequently used CAM



treatments were prayers, probiotics, and vitamins. Also, they found that the use of CAM treatments is affected by beliefs, health, and cost of the treatments. In another study, Konuk-Sener & Karaca (2020) found that wearing amulets, protein-weighted diet, nonvaccination, and prayers were the most used CAM treatments in children with ASD. The researchers indicated employing spiritual approaches, marketing strategies, and lack of knowledge contributed to high rates of using CAM treatments among mothers of individuals with ASD. Similarly, Bilgic et al. (2011) found that the CAM treatments that were commonly used in individuals with ASD were prayers, nutritional supplements, and diets. Furthermore, among the most reported reasons for using CAM treatments were dissatisfaction with conventional practices, socioeconomic and cultural factors. Finally, Senel (2010) reported vitamins, minerals, and special diets were the most commonly used CAM treatments in children with ASD in Turkey. They also reported that recommendations from other families were the main reason for using CAM treatments. One weakness of these studies is that they included small number of CAM treatments. Furthermore, the researchers focused on discussing the use of CAM treatments with child's health care. Therefore, there is a need for research assessing, and discussing its effects on education of individuals with ASD.

After educational evaluation and diagnosis, Turkish children with a disability can be provided 4-8h of free special education support service in special education and rehabilitation centers in addition to formal education in institutions. However, in Turkey, children with ASD are mostly in low socio-economic families and many of them cannot attend schools (Karadag & Bilsin, 2016; Meral & Cavkaytar, 2015). Families of children with ASD have a finite amount of money and time despite many numbers of educational needs to meet. Thus, adherence to EBPs is much about maximizing the possibility of conferring educational benefits as it is about minimizing or preventing harms related to ineffective practices, CAM treatments. Exploring the CAM treatments that the parents choose for their children with ASD and the nominated factors (e.g., educational level, family income, severity of ASD) that may be associated with decisionmaking regarding those treatments is significant because disseminating this information may allow professionals or organizations to direct parents of children with ASD to effective interventions (i.e., EBPs). Also, this information may guide parents to be able to make true and educated judgments in deciding what treatments they choose for their child with ASD. Given the strong emphasis on early intensive intervention with the use of EBPs for achieving major principles of special education (e.g., independent living), we think it is important to explore the reasons and factors influencing parental decisions regarding pseudoscientific treatments (Tekin-İftar, 2018). Moreover, data such as that collected in the current study can help professionals understand parents' treatment selection process and direct their time, effort, and money to treatments that are effective for their children with ASD, which in turn may positively affect parents' psychological well-being. Thus, the purpose of the current study was to investigate parent reports of: (a) Special education support services, (b) use of EBPs, (c) use of past and current CAM treatments, (d) non-use of CAM treatments, (e) willingness and unwillingness to use CAM treatments in future, (f) reasons for use and non-use of CAM treatments, and (g) perceptions of effectiveness regarding the treatments. Therefore, the following research questions guided the study:

- 1. According to parental reports, which EBPs are used in educational settings for their children with ASD?
- 1.1. How do parents rate the effectiveness of EBPs in improving their child's overall functioning?
- 1.2. According to parental reports, what types of treatments are used within the different types of educational settings?
- 2. What are the CAM treatments that the parents used and currently use?
- 2.1. How do parents rate the effectiveness of CAM treatments in improving their child's overall functioning?
- 3. What are the CAM treatments that the parents have never used, willing to use, and unwilling to use in future?
- 4. What reasons accompany parents' decisions regarding why they started and discontinued CAM treatments, and why they are willing and unwilling to use untried CAM treatments?
- 5. Is there an association between CAM treatments use and parents' educational level, family income, child's severity of ASD, and length of time since their child's ASD diagnosis?

#### Methods

# **Research Design**

The research was designed as a descriptive study. A descriptive study is a type of research that involves describing and examining a real-life phenomenon to obtain information regarding the current status of it (Hocaoğlu & Akkaş-Baysal, 2019). In this type of research, the data can be collected using surveys, observations, or interviews (Büyüköztürk et al., 2019). In the current study, we collected the data via an internet survey that included both open- and close-ended questions.



## **Participants**

This study was carried out with the participants distributed over all seven regions of Turkey. The nuclear family is the modal family pattern in Turkey. The total population of Turkey is around 84million; of them, over 90% live in urban areas. The country has received too many immigrants from neighboring countries. When the study was undertaken, the current minimum wage was about 2825 ½ (364 \$) and the average household income in the country was 5779 ½ (744 \$). Per capita income was around 5044 ½ per month that was around 716 dollars in 2020. Compulsory education starts from the year in which children turn 6 until they reach the age of 18. Most children with disabilities attend schools with children without disabilities or attend special education schools (Turkish Statistical Institute, 2020).

Ethical approval for this study was gained from Hacettepe University Ethics Review Committee. Criterion sampling, a form of purposive sampling, was adopted to choose the potential participants since we aimed at gaining an in-depth understanding of a specific group of individuals eligible for the study (Johnson & Christensen, 2019). The eligibility criteria for the study included parents who had a child diagnosed with ASD and volunteered to complete the survey. A total of 175 parents initially completed the survey. However, nine respondents were screened out from the analyses for the following reasons: One was a teacher of a child with typical development and eight completed the survey partially. Thus, the surveys of the remaining 166 respondents were kept for analyses. The majority of the participants were mothers of children with ASD (n = 126, 75.91%), 37 (22.29%) were fathers, two (1.20%) were siblings, and one (0.60%) was an aunt. Mean participant age was 39.77 years (range = 22–64 years). Table 1 depicts the sociodemographic characteristics of the participants.

The majority of parents completed an undergraduate degree and had a monthly family income level between 5000 and 7400 ₺ (\$644 - \$965). The mean age of children with ASD was 9.33 (range = 2-33 years). According to parent report, 49 (29.52%) of the children with ASD were between 1 and 5 years of age, 75 (45.19%) between 6 and 10, 23 (13.86%) between 11 and 15, 11 (6.63%) between 16 and 20, and seven (4.22%) over 20. One parent provided no information about child's age. Of the children, 77 (46.39%) had a diagnosis of atypical autism, 52 (31.33%) ASD. Also, 10 (6.01%) of the children were reported a presence of comorbid conditions in addition to ASD. Furthermore, the mean child's age at diagnosis was 2.9 (range = 1-13), and mean length of time since ASD diagnosis was six years (range = 0–28). According to parents' perceptions of severity of their child's ASD, 80 (48.19%) children had an ASD diagnosis with severity level 1.

#### Instrument

The survey presented parents with a comprehensive list of treatment options including open-ended questions. In generating the list, we reviewed lists of CAM treatments used in existing studies (Christon et al., 2010; Gibbard, 2005; Goin-Kochel et al., 2007; Green et al., 2006; Konuk-Sener & Karaca, 2020; Levy & Hyman, 2002; Lindly et al., 2018; Salomone et al., 2015). Next, we identified additional treatments through databases search (Google Scholar and Web of Science) using a combination of autis\*, treatment, intervention, parent, and famil\*. From this pool of CAM treatments, each of the authors independently reviewed every single CAM treatment regarding whether it is used in Turkey. Thus, each author searched Google and Google Scholar web search engines using a diagnostic descriptor (autism OR autistic), AND the name of CAM treatment (e.g., autism AND biofeedback). Having generated the list of CAM treatments confirmed to be used in Turkey, the first and second authors independently classified them into categories based on the research on parents' CAM treatments use and the lists of various organizations (i.e., Association for Science in Autism Treatment and National Center for Complementary and Integrative Health). Disagreements were resolved by consensus after reviewing the literature and agreement of 100% was reached on categorization of CAM treatments. Similarly, we replicated the same methodology for the items regarding parents' CAM treatments use.

We used Google Forms to create an online parent survey. The first part of the survey included the purpose of the study, voluntary participation, contact information, procedures, and ethical issues. The second part of the survey included questions about demographic information regarding the child's diagnosis, child's diagnosis time, the parent's perception of the child's ASD severity level, parent's educational level, parent's job, monthly family income level, and city of residence. In the third part, the parents were provided with options about special education support services and 13 overlapping EBPs in NAC (2015) and NCAEP (2020) reports. Thus, the first and second authors searched Google web search engine using each overlapping EBP in these reports. Then, the authors narrowed the search by Turkish language. If the EBP was said to be applied by at least one Turkish institution, the authors determined that the EBP was used in Turkey. They also searched additional EBPs in curricula for individuals with ASD developed by Ministry of National Education (Turkey). The EBP categories included in the survey were naturalistic interventions, cognitive behavioral/instructional strategies, social narratives, behavioral interventions, visual supports, social skills training, modeling, technology-aided instruction and intervention, exercise and movement, augmentative and alternative



Table 1 Characteristics of the participating parents and children with ASD

Parents		Children with ASD	
Category	n(%)	Category	n(%)
Gender		Years of Age	
Female	128 (77.12)	1–5	49 (29.52)
Male	38 (22.88)	6–10	75 (45.19)
<b>Educational level</b>		11–15	23 (13.86)
Primary school	14 (8.43)	16–20	11 (6.63)
Secondary school	10 (6.02)	Over 20	7 (4.22)
High school	40 (24.10)	No information	1 (0.58)
Associate degree	21 (12.65)	Diagnosis	
Undergraduate degree	63 (37.95)	Atypical autism	77 (46.39)
Postgraduate degree	18 (10.84)	ASD	52 (31.33)
Monthly family income		PDD-NOS	16 (9.649
<2500 ₺	22 (13.25)	Asperger syndrome	11 (6.63)
(< \$322)			
2501-4999 £ (\$322 - \$644)	41 (24.70)	A presence of comorbid conditions	10 (6.01)
5000-7499 £ (\$644 - \$965)	49 (29.52)	Parental Perception of Severity of ASD	
7500–9999	13 (7.83)	Level 1 (Mild impairments in social communication and interaction skills, unsuc- cessful attempts to make friends, and failure in maintaining a conversation despite speaking in full sentences)	80 (48.19)
> 10,000 £ (> \$1287)	41 (27.70)	Level 2 (Marked impairments in social communication and interaction skills, difficulty coping with changes, and frequent appearance of restricted/repetitive behaviors)	61 (36.75)
,		Level 3 (Severe impairments in social communication and interaction skills, lack of intelligible speech with a few words, and excessive use of restricted/repetitive behaviors)	15.06
		The Special Education and Support Services that Children with ASD Receive	
		Full-time mainstreaming in regular education classes	37 (22.29)
		Special education classes	34 (20.48)
		Special education schools	23 (13.86)
		A part-time basis	7 (4.22)
		Kindergartens	2 (1.20)
		Special education and rehabilitation centers	127
		•	(76.51)
		Private lessons	42 (25.30)
		Special education counseling	30
		Shadow aide	16 (9.64)

*Note*.  $\mathfrak{t} = \text{Turkish lira}, \$ = \text{United States dollar}.$ 

communication, parent training, peer-based instruction and intervention, and self-management. In this part of the survey, parents were asked to indicate special education support services and EBPs that were used in their child's education based on their observations and knowledge. At the end of this part, an open-ended question asked the respondents to indicate any other special education support services and EBPs not given in the list. Furthermore, this part contained 47 CAM treatments, which were grouped under four categories as biological treatments, energy therapies, mind-body therapies, animal therapies, and other therapies. Parents reported their use of CAM treatments for their child with ASD using 4-item Likert type scales ("Past use", "non-use and unwilling to use", "non-use and willing to use", "current use"). At the end of each category, open-ended questions regarding (a) additional CAM treatments and comments and (b) the factors that influenced decision-making to start these treatments were provided so that parents could make additional comments. Also, ratings for how effective parents believed each CAM treatment category to be consisted of (1) "Highly effective", (2) "somewhat effective", (3) "not sure", (4) "ineffective", and (5) "child got worse". The final part addressed factors that may have affected decision-making regarding their discontinuation, willingness, and unwillingness to use CAM treatments through check-all-that-apply question format. The decision factors (later in Table 6) were frequently declared factors by parents in the literature (Carlon et al., 2013) and by Turkish parents in a recent study (Konuk-Sener & Karaca, 2020). They were also asked to comment on why they do not want to use the CAM treatments that they were unwilling to use.

For validity purposes, three academic experts in the field of ASD reviewed the survey list to determine that treatments (EBPs and CAM treatments), categories, items, and



questions were appropriate and comprehensible. Based on their comments, we added a hyperlink at the beginning of the survey which redirected to a file that included brief explanations of each CAM treatment.

# **Survey Development and Administration**

The survey was piloted with two parents who had a child with ASD across different socioeconomic statuses and education levels. After they submitted the form, five to 10-min semi-structured interviews were conducted with each to gain feedback regarding whether the instructions were clear; the interface was easy to use; any questions were ambiguous; any treatments or questions should be added or omitted; how long it took them to complete. Both parents reported that they knew all treatments in the list; it took around five min to complete the survey; the layout was easy to complete; and the content was comprehensive. Based on their comments, we made a few minor additions: Including Sensory Activation Solutions (SAS) method in the list and a statement to let respondents be aware that the question was mandatory. We also tested the analysis procedures at this point to ensure the analysis of the results would address the objectives of the study.

After pilot testing, we distributed the internet survey to parents via colleagues and administrators in various autism organizations such as foundations, associations, schools, and private special education and rehabilitation centers across 81 cities in the country. Regarding the geographic locations of the 166 respondents, 54 lived in Central Anatolia Region (Ankara, Eskisehir, Konya, and Yozgat), 35 in Marmara Region (Istanbul, Canakkale, Tekirdag, and Bursa), 27 in Mediterranean Region (Adana, Hatay, Antalya, and Mersin), 14 in Aegean Region (Izmir, Mugla, Denizli, and Aydin), and 12 each in Black Sea Region (Samsun, Ordu, Bolu, and Trabzon), Eastern Anatolia Region (Kars, Erzurum, Hakkari, and Elazig), and Southeastern Anatolia Region (Sanliurfa, Gaziantep, and Adiyaman).

The standard analysis procedures of frequencies and percentages were used for quantitative data. These procedures were performed for parents' use of special education support services, EBPs, current and previous CAM treatments, their willingness and unwillingness to use untried CAM treatments, their reasons for starting CAM treatments, and their perceived effectiveness of each CAM treatment category. Furthermore, we analyzed the association between parental educational level, family income level, ASD severity, time length since child's ASD diagnosis and parents' CAM treatments use for their children with ASD using SPSS-22. We analyzed the data using Kruskal-Wallis test and Mann-Whitney U test. For qualitative data, we used descriptive analysis. We imported parent textual comments

into Microsoft Excel, which allows for summarization of data sets. We then coded textual comments and identified emerging themes (Yıldırım & Şimşek, 2016).

#### Results

# Use and Perceived Effectiveness of EBPs in Educational Settings

Parents were given the categories of 13 EBPs and 7 educational settings (e.g., special education class, private lesson) to indicate which EBPs they knew or observed to be used in their children's educational settings. Table 2 shows what types of EBPs were employed within educational settings of children with ASD based on their observation and knowledge. It is notable that parents generally knew what types of treatments were employed in given settings. It is also notable all EBPs were used in special education and rehabilitation centers most. This was followed by educational settings of either full-time mainstreaming or private lesson, except modeling in special education class.

Table 3 provides a rank ordering for each EBP according to the number of parents who have observed or known that EBP has been used in their children's education. 95 (57.23%) parents reported social skills training was used in their children's education. This was closely followed by cognitive behavioral/instructional strategies (92, 55.42%) and behavioral interventions (90, 54.22%). Six (3.61%) parents commented they had no information regarding the practices used.

Table 3 also shows the parental perceived effectiveness of the EBPs used in education of participating parents' children. Responding parents rated EBPs used in their children's education as effective. Parents rated social skills training, behavioral interventions, and cognitive behavioral/instructional strategies as the three most effective EBPs. It is also notable that there were ratings of child got worse for these three EBPs each, in addition to exercise and movement. Also, social skills training, behavioral interventions, and cognitive behavioral/instructional strategies were the top three EBPS that were rated as highly effective, somewhat effective, and child got worse. The only EBP that parents were sure of its effectiveness was social narratives in that responding parents rated them as highly effective or somewhat effective.

# **Use and Perceived Effectiveness of CAM Treatments**

Regarding lifetime use of CAM treatments that was defined as use at any point during the individual's lifespan (either in the past or currently), the treatments with by far the



**Table 2** EBPs used in educational settings based on parental knowledge by n (%)

	Supportive education class	Full-time mains.	Part-time mains.	SPED school	SPED class	SPED and rehabilitation centers	Private lesson	Total
Soc. Sk. Tr.	4 (2.42)	28 (16.97)	5 (3.03)	19 (11.52)	15 (9.09)	69 (41.82)	25 (15.15)	165 (100)
Cog. Beh./Ins. Str.	3 (1.96)	24 (15.69)	3 (1.96)	13 (8.50)	20 (13.07)	69 (45.10)	21 (13.72)	153 (100)
Beh. Int.	3 (2.1)	22 (15.38)	4 (2.8)	11 (7.69)	18 (12.59)	64 (44.76)	21 (14.68)	143 (100)
Nat. Int.	3 (2.33)	22 (17.05)	2 (1.56)	8 (6.2)	14 (10.85)	56 (43.41)	24 (18.6)	129 (100)
Ex. & Mo.	3 (2.64)	13 (11.40)	2 (1.75)	13 (11.40)	16 (14.04)	45 (39.47)	22 (19.30)	114 (100)
Vis. Sup.	1 (1.04)	13 (13.54)	3 (3.13)	7 (7.29)	14 (14.58)	42 (43.75)	16 (16.67)	96 (100)
Soc. Nar.	2 (3.77)	15 (28.3)	1 (1.89)	2 (3.77)	4 (7.55)	17 (32.08)	12 (22.64)	53 (100)
Tech. Ins. & Int.	-	8 (15.38)	-	3 (5.77)	10 (19.23)	18 (34.62)	13 (25)	52 (100)
Aug. & Alt. Com.	1 (2.95)	6 (17.65)	1 (2.94)	3 (8.82)	3 (8.82)	17 (50)	3 (8.82)	34 (100)
Modeling	-	4 (11.76)	-	1 (2.94)	7 (20.59)	18 (52.94)	4 (11.77)	34 (100)
Parent training	-	6 (37.50)	1 (6.25)	-	-	9 (56.25)	_	16 (100)
Peer-based Ins. & Int.	-	2 (20)	2 (20)	-	-	4 (40)	2 (20)	10 (100)
Self-man.	-	1 (14.29)	-	-	-	4 (57.14)	2 (28.57)	7 (100)

Note. Aug. & Alt. Com. = Augmentative and Alternative Communication, Beh. Int. = Behavioral Interventions, Cog. Beh./Ins. Str. = Cognitive Behavioral/Instructional Strategies, Ex. & Mov. = Exercise and Movement, mains. = mainstreaming, Nat. Ins. = Naturalistic Interventions, Peer-based Ins. & Int. = Peer-based Instruction and Intervention, Self-man. = Self-management, Soc. Nar. = Social Narratives, Soc. Sk. Tr. = Social Skills Training, SPED = Special education, Tech. Ins. & Int. = Technology-aided Instruction and Intervention, Vis. Sup. = Visual Supports.

Table 3 Lifetime (Past or Current) Use and Perceived Effectiveness of EBPs by n (%)

EBP	Lifetime Use	Highly Effective	Somewhat Effective	Not Sure	No Effect	Child Got Worse
Soc. Sk. Tr.	95 (57.23)	50 (30.12)	37 (22.29)	6 (3.61)	1 (0.60)	1
						(0.60)
Cog. Beh./Ins. Str.	92 (55.42)	46 (27.71)	29 (17.47)	6 (3.61)	-	1
						(0.60)
Beh. Int.	90 (54.22)	49 (29.52)	28 (16.87)	6 (3.61)	-	1
						(0.60)
Nat. Int.	70 (42.17)	43 (25.90)	21 (12.65)	5 (3.01)	1 (0.60)	-
Ex. & Mo.	68 (40.96)	32 (19.28)	27 (16.26)	5 (3.01)	1 (0.60)	1
						(0.60)
Vis. Sup.	53 (31.93)	30 (18.07)	16 (9.64)	4 (2.41)	-	
Tech. Ins. & Int.	50 (30.12)	16 (9.64)	7 (4.22)	1 (0.60)	1 (0.60)	-
Soc. Nar.	30 (18.07)	24 (14.46)	4 (2.41)	-	-	-
Aug. & Alt. Com.	25 (15.06)	16 (9.64)	4 (2.41)	1 (0.60)	1 (0.60)	-
Modeling	22 (13.25)	10 (15.15)	6 (3.61)	1 (0.60)	1 (0.60)	-
Parent training	16 (9.64)	10 (6.02)	4 (2.41)	1 (0.60)	1 (0.60)	-
Peer-based Ins. & Int.	10 (6.02)	6 (3.61)	2 (1.20)	1 (0.60)	-	-
Self-man.	7 (4.22)	3 (1.80)	2 (1.20)	1 (0.60)	1 (0.60)	-
Do not know	6 (3.61)					
Mean %		25.77 (16.19)	14.38 (8.66)	2.92 (1.76)	0.62 (0.37)	0.31 (0.18)

Note. Aug. & Alt. Com. = Augmentative and Alternative Communication, Beh. Int. = Behavioral Interventions, Cog. Beh./Ins. Str. = Cognitive Behavioral/Instructional Strategies, Ex. & Mov. = Exercise and Movement, Nat. Ins. = Naturalistic Interventions, Peer-based Ins. & Int. = Peer-based Instruction and Intervention, Self-man. = Self-management, Soc. Nar. = Social Narratives, Soc. Sk. Tr. = Social Skills Training, Tech. Ins. & Int. = Technology-aided Instruction and Intervention, Vis. Sup. = Visual Supports.

highest lifetime use for biological treatments were vitaminmineral supplements (n = 140, 84.30%), followed by special

diets (n=62, 37.34%) and medications (n=50, 30.12%).



Regarding other treatments, lifetime CAM use was 56.62% (n=94). Slightly less than half of parents (n=69, 41.56%) reported using energy therapies, 57 (34.33%) animal therapies, and 42 (25.30%) mind-body therapies. Additionally, six (3.61%) responding parents used at least one CAM treatment across all categories, whereas 10 (6.02%) did not use any at all.

Table 4 provides a rank ordering for each of the treatments according to the number of parents indicating that they were currently using, had used, unwilling to use, and willing to use that treatment. Past use column in Table 5 also indicates the CAM treatments that were discontinued. In general, parents indicated non-use and unwillingness to use CAM treatments. As shown in Table 4, fish oil (n=50,31.12%) Vitamin D (n=42, 25.30%), and Omega 3 (n=42, 25.30%)25.30%) in biological treatments category were ranked significantly higher than the other treatments in current use. It is notable that the only treatment that parents never used currently, antifungal drugs, was in the same category. Similarly, regarding past use, fish oil (n=70, 42.17%) Vitamin D (n=57, 34.33%), and Omega 3 (n=52, 31.33%) were the highest in prevalence of use in addition to play therapy (n=58, 34.94%) in other therapies. On the other hand, dolphin therapy had the lowest mean ranking, of 0.60% (n=1) in both current use and past use but was rated significantly higher than all other CAM treatments in non-use and willingness to use (n=89, 52.62%). The first four treatments that were checked as "non-use and unwilling to use" by the parents were, again, in biological treatments category. These treatments were secretin (n = 137, 82.53%), Feingold diet (n = 134, 80.72%), ketogenic diet, and specific carbohydrate diet 130 (n = 78.31%, each). Regarding non-use and willingness to use, three highest ranked treatments were in animal therapies category which were dolphin therapy (n=89, 52.62%), pet therapy (n=82, 49.40%), and horse therapy (n = 80, 48.20%).

In general, parents were not sure of the effectiveness of the CAM treatments they had used or were currently using (see Table 5). However, the parents who were sure that CAM treatments were effective rated other therapies as effective. The majority of the 113 responding parents rated the effectiveness of other therapies (e.g., play therapy, hyperbaric oxygen therapy) as highly effective (n=39, 34.51%) and somewhat effective (n=32, 28.32%). However, there were one (0.88%) with child got worse in this category, and 3 (3.37%) in animal therapy category.

## **Reasons for Parental Decisions**

Table 6 shows that common reasons endorsed by parents for using CAM treatments were recommendations (n=69, 40.12%). When considering scores of reasons within

recommendations, only recommendation from other families was relatively highly ranked (n = 30, 17.44%). Regarding stopping using CAM treatments, the most common reasons were that the parents found CAM treatments unaffordable (n=59, 20.21%) and that they felt the treatments did not work (n=56, 19.18%). Recommendations (n=55, 18.84%) were also linked to the parental decisions of discontinuing CAM treatments. Regarding the reasons of unwillingness to use untried CAM treatments, the most frequently reported reason was recommendations (n=104, 23.07%) in which medical doctors (n=35, 7.77%) were reported as a frequent source of recommendations not to use CAM treatments. On the other hand, parents were willing to use untried treatments mostly because they believed that these treatments would enhance child's development (n=186, 37.80%).

#### **Variables Associated with CAM Treatments Use**

Because the data did not normally distribute, we conducted Kruskal-Wallis test to analyze the association between CAM treatments use and parental educational level, family income level, length of time since child's ASD diagnosis, and child's ASD severity. The results suggested statistically significant differences across parental educational level categories (primary school, secondary school, high school, associate degree, undergraduate degree, and postgraduate degree; H=16.846, SD=5, p=.005). Due to the presence of a significant Kruskal-Wallis test, we conducted followup Mann-Whitney U test to determine where the differences occurred between categories. A Bonferroni correction was performed to control for Type 1 errors (Field, 2009). That yielded in a significance level of 0.003. Results indicated a significant difference only between primary school and associate degree categories (U=50.500, p=.001, z = -3.263), with the effect size of 0.55 (r=.55). Results of Kruskal-Wallis test indicated no association between CAM treatments use and family income level (H=8593, SD=4, p = .072). Moreover, the results indicated there was a statistically significant difference between CAM treatments use and time length since child's ASD diagnosis (0-1 years, 2-5 years, 6-9 years, 10-13 years, and above 13 years; H=12,868, SD=4, p=.012). Therefore, we conducted follow-up Mann-Whitney U test with Bonferroni correction to determine where the differences occurred. That yielded in a significance level of 0.005. Results indicated significant differences between CAM treatments use and the group of 2–5 years; CAM treatments use and the group of 10-13 years (U=286.000, p=.001, z=-3.262), with the effect size of  $0.36 \ (r=.36)$ . Lastly, the results suggested statistically significant differences between CAM treatments use and child's ASD severity (Level 1, level 2, and level 3; H=14.448, SD=2, p=.001). Thus, we conducted Mann-Whitney U



**Table 4** Rank order of each CAM treatment usage by n (%)

CAM	Category	Current	Past Use	Non-use and	Non-use
CAW	Category	Use	1 ast Osc	unwilling to	and will-
				use	ing to use
1.Fish oil	Biological Tr.	50 (30.12)	70 (42.17)	28 (16.87)	18 (10.84)
2.Vitamin D	Biological Tr.	42 (25.30)	57 (34.33)	41 (24.70)	26 (15.67)
3.Omega 3	Biological Tr.	42 (25.30)	52 (31.33)	41 (24.70)	31 (18.68)
4.Vitamin C	Biological Tr.	26 (15.67)	35 (21.08)	58 (34.94)	47 (28.31)
5.Play therapy	Other Th.	21 (12.65)	58 (34.94)	20 (12.05)	67 (40.36)
6.Vitamin B	Biological Tr.	20 (12.05)	36 (21.69)	68 (40.96)	42 (25.30)
7.Pet therapy	Animal Th.	19 (11.45)	21(12.65)	44 (26.50)	82 (49.40)
8.Massage	Energy Th.	18 (10.84)	40 (24.10)	75 (45.18)	33 (19.88)
9.Vitamin A	Biological Tr.	14 (8.43)	23 (13.86)	79 (47.59)	50 (30.12)
10.Psychotherapy	Mind-body Th.	14 (8.44)	9 (5.42)	87 (52.41)	56 (33.73)
11.Magnesium	Biological Tr.	13 (7.83)	31 (18.68)	74 (44.57)	48 (28.92)
12.Antivirals	Biological Tr.	12 (7.22)	11 (6.63)	123 (74.10)	20 (12.05)
13.Calcium	Biological Tr.	11 (6.63)	27 (16.27)	76 (45.77)	52 (31.33)
14.Hugging therapy	Mind-body Th.	11 (6.63)	7 (4.22)	102 (61.44)	46 (27.71)
15.Gluten-Casein diet	Biological Tr.	8 (4.82)	33 (19.88)	101 (60.84)	24 (14.46)
16.Reflexology	Energy Th.	8 (4.82)	14 (8.43)	105 (63.25)	39 (23.50)
17.Auditory integration	Energy Th.	7 (4.22)	29(17.47)	87 (52.41)	43 (25.90)
18.Art therapy	Mind-body Th.	7 (4.22)	5 (3.01)	86 (51.81)	68 (40.96)
19.Heavy metal chelation	Other Th.	5 (3.01)	24 (14.46)	82 (49.40)	55 (33.13)
20.Antibiotics	Biological Tr.	5 (3.01)	21 (12.65)	120 (72.29)	20 (12.05)
21.Aromatherapy massage	Energy Th.	5 (3.01)	10 (6.02)	109 (65.67)	42 (25.30)
22.Specific Carbohydrate diet	Biological Tr.	5 (3.01)	5 (3.01)	130 (78.31)	26 (15.67)
23.Craniosacral	Energy Th.	5 (3.01)	4 (2.41)	111 (66.87)	46 (27.71)
24.Meditation-Yoga	Energy Th.	5 (3.01)	3 (1.81)	118 (71.08)	40 (24.10)
25.Horse therapy	Animal Th.	4 (2.41)	35(21.08)	47 (28.31)	80 (48.20)
26.Oxytocin	Biological Tr.	4 (2.41)	8 (4.82)	127 (76.50)	27 (16.27)
27.Ketogenic diet	Biological Tr.	4 (2.41)	7 (4.22)	130 (78.31)	25 (15.06)
28.Candida body ecology	Biological Tr.	4 (2.41)	5 (3.01)	126 (75.90)	31 (18.68)
29.Magnetic therapies	Energy Th.	4 (2.41)	5 (3.01)	125 (75.30)	32 (19.28)
30.Elimination allergy	Biological Tr.	3 (1.81)	8 (4.82)	127 (76.50)	28 (16.87)
31.Hyperbaric oxygen therapy	Other Th.	3 (1.81)	6 (3.61)	110 (66.27)	47 (28.31)
32.Osteopathy-Manuel Therapy	Energy Th.	3 (1.81)	3 (1.81)	123 (74.10)	37 (22.28)
33.Chiropractic	Energy Th.	3 (1.81)	3 (1.81)	127 (76.50)	33 (19.88)
34.Acupressure	Energy Th.	3 (1.81)	3 (1.81)	127 (76.50)	33 (19.88)
35.Neurofeed- back	Mind-body Th.	3 (1.81)	2 (1.20)	113 (68.07)	48 (28.92)
36.Interactive metronome	Mind-body Th.	3 (1.81)	1 (0.60)	124 (74.70)	38 (22.89)
37.Acupuncture	Energy Th.	2 (1.20)	4 (2.41)	126 (75.90)	34 (20.49)
38.Feingold diet	Biological Tr.	2 (1.20)	3 (1.81)	134 (80.72)	27 (16.27)
39.Hypnosis	Mind-body Th.	2 (1.20)	3 (1.81)	130 (78.31)	31 (18.67)
40.Biofeedback	Mind-body Th.	2 (1.20)	1 (0.60)	120 (72.30)	43 (25.90)
41.Reiki	Energy Th.	2 (1.20)	6 (3.62)	129 (77.71)	29 (17.47)
42.GAPS diet	Biological Tr.	1 (0.60)	16 (9.64)	119 (71.69)	30 (18.07)
43.Homeopathy	Biological Tr.	1 (0.60)	8 (4.82)	129 (77.71)	28 (16.87)
44.SAS method	Mind-body Th.	1 (0.60)	6 (3.61)	125 (75.30)	34 (20.4)
45.Secretin	Biological Tr.	1 (0.60)	2 (1.20)	137 (82.53)	26 (15.67)
46.Dolphin therapy	Animal Th.	1 (0.60)	1 (0.60)	75 (45.18)	89 (53.62)
47.Antifungal drugs	Biological Tr.	0	10 (6.02)	129 (77.71)	27 (16.27)
Mean %		9.13 (5.44)	16.40 (9.88)	100.51 (47.25)	39.96 (24.07)

*Note.* Th. = Therapy, Tr. = Treatment

test with Bonferroni correction, yielding in a significance level of 0.017. The results suggested that there were significant differences between CAM treatments use and level 1;

CAM treatments use and level 3 (U=459.500, p=.000, z = -3.824), with the effect size of 0.38 (r=.38).



Table 5 Parental perceived effectiveness of CAM treatments by categories

	Highly Effective	Somewhat Effective	Unsure of Their Effectiveness	Have No Effect	Child Got Worse	Total
Biological Tr.	6 (8.82%)	13 (19.12%)	40 (58.82%)	9 (13.24%)	-	68 (100%)
Energy Th.	12 (16.67%)	19 (26.39%)	31 (43.05%)	10 (13.89%)	-	72 (100%)
Mind-body Th.	15 (20%)	19 (25.33%)	37 (49.34%)	4 (5.33%)	-	75 (100%)
Animal Th.	20 (22.47%)	25 (28.09%)	31 (34.83%)	10 (11.24%)	3 (3.37%)	89 (100%)
Other Th.	39 (34.51%)	32 (28.32%)	35 (30.97%)	6 (5.32%)	1 (0.88%)	113 (100%)
Mean (%)	18.4 (20.5)	21.6 (25.45)	34.8 (43.40)	7.8 (9.8)	0.8 (0.9)	

Note. Th. = Therapy, Tr. = Treatment

**Table 6** Reasons for starting, discontinuation, willingness, and unwillingness to use CAM treatments by n (%)

Reasons	Start	Discontinue	Unwilling	Willing
Recommendations	69 (40.12)	55 (18.84)	104 (23.07)	89 (18.10)
Other families who used these treatments	30 (17.44)	5 (1.71)	30 (6.66)	18 (3.66)
Doctors (e.g., psychiatrist)	15 (8.72)	17 (5.82)	35 (7.77)	17 (3.45)
Regular and special education teachers	11 (6.40)	21 (7.19)	28 (6.22)	42 (8.54)
Therapist (e.g., physical, occupational)	6 (3.49)	-	-	-
Psychologist	1 (0.58)	12 (4.10)	11 (2.45)	12 (2.45)
Scientific records, books, and internet	19 (11.05)	-	-	-
Effectiveness	-	56 (19.18)	-	-
Price	-	59 (20.21)	69 (15.32)	2 (0.40)
Intuition/gut feelings	16 (9.30)	23 (7.88)	-	50(10.16)
Evidence base	-	-	67 (14.88)	14 (2.84)
Local government services	5 (2.90)	-	-	-
Accessibility	-	44 (15.07)	30 (6.66)	6 (1.22)
Consequences on child's development	-	-	37 (8.22)	186(37.80)
Never heard	_	-	40 (8.75)	-
Ineffectiveness of medical and edu- cational practices	-	-	-	30 (6.10)
Endorsing an eclec- tic approach		-	-	26 (5.28)

# Discussion

The qualitative and quantitative results of this study enable us to provide several comments on parents' use of CAM treatments. This study describes the parents' knowledge and perceptions of effectiveness of EBPs used in their child's education. Overall, parents reported that they knew these practices, and generally rated them as *highly effective* and

somewhat effective, and more effective than CAM treatments on their child's functioning. A possible explanation for this might be that CAM treatments do not focus on individual behavioral and educational needs of those with ASD as much as EBPs do. On the other hand, lost or inadequate access to effective instruction may serve as adequate justification to choose CAM treatments for the few parents who rated EBPs as ineffective. Perceptions of the parents who rated EBPs as ineffective can be influenced by decreased improved outcomes in their children resulting from lower level of EBP intensity and duration with poor fidelity in educational settings. Thus, future studies may investigate the factors that influence parents' negative perceptions of EBPs. Also, future researchers may examine whether professional stakeholders (i.e., special education teachers) rely on EBPs in their classroom and implement them with high fidelity.

Notably, all the 47 CAM treatments were used by at least one parent, and 94% (n = 156) of the parents reported a lifetime use (currently or in the past) of at least one CAM treatment. Also, the average number of CAM treatments in lifetime use was seven (range = 0-47), and one third of the parents were willing to use the CAM treatments that they had never tried. Our study also showed that the most commonly used CAM treatment category was other therapies previously, and biological treatments (vitamins and minerals in particular) currently. Also, there was a decrease in the mean percentage of parents currently using all CAM treatment categories except mind-body therapies compared to the past. Regarding the decrease in other therapies, pandemic might account for why parents prefer them less than before, considering these therapies require highly specialized equipment, locations, and specialists. The frequent biological treatments use may also be associated with the pandemic in that parents may have wanted to improve or maintain their child's general health.

The biological treatments with the highest lifetime usage included fish oil, Vitamin D, and Omega 3. These results match those found in previous studies conducted in Turkey as well as in other countries (An et al., 2020; Bilgic et al., 2013; Lindly et al., 2018; Lucas et al., 2020; Masri et al., 2020; Senel, 2010; Smith et al., 2020). One reason that the use of CAM treatments is common in parents of



children with ASD in Turkey may be that they have little or no knowledge about EBPs. In fact, Orum-Cattik et al. (2021) found that families of individuals with ASD in Turkey could not explain what an effective practice or EBP means and did not have adequate knowledge about them. It should also be noted that there are a number of services and efforts for disseminating CAM treatments in Turkey. For instance, there are some newly opened graduate programs (e.g., Complementary and Alternative Medicine Master's or PhD Program at University of Health Sciences), clinics called as Complementary and Alternative Medicine Centers at public and private hospitals, and a number of formal meetings (e.g., 2nd International Traditional and Complementary Medicine Congress-2019) held by Ministry of Health. This indicates that doctors have a positive attitude to CAM treatments in Turkey, which contributes to dissemination of these practices among parents of children with ASD. Additionally, higher face validity of biological treatments by repetitive advertisements on television and internet promoting they are a miracle cure may strengthen or reinforce parents' belief that these treatments are effective. These treatments lack scientific evidence of effectiveness in treating core ASD symptoms (Dawson & Watling, 2000). Therefore, relying on ineffective treatments can, in turn, result in significant time and money wasted, poor eating habits, side effects such as tantrums, or busy lifestyle which can prevent the child with ASD from participating in necessary intensity of EBPs as well as interfering with the effectiveness of EBPs.

Even a small amount of time exploring whether a CAM treatment works can accumulate over time to large amount of lost time in terms of potential educational benefit (Travers, 2017). Thus, especially special educators must take some important steps. Firstly, they must avoid using unproven and ineffective pseudoscientific practices, adhere to an evidence-based approach as well as educating parents about EBPs and pseudoscientific practices. Second, they should try to respectfully investigate and understand the motivating operations, reinforcers, and decisions that parents make in CAM treatments use so that they can offer directions for parents. Finally, it is important for the educators to document the effectiveness of EBPs they use to the parents in such ways as collecting continuous data with fidelity and sharing them with the parents, which may positively influence parents' perceived effectiveness of these practices and, in turn, prevent them from trying CAM treatments.

In this study, the untried CAM treatments that most parents were unwilling to use were in energy therapies category. Furthermore, massage and auditory integration were the non-biological treatments with the highest lifetime usage in energy therapies, which is similar to the results of previous studies (Konuk-Sener & Karaca, 2020; Lindly et al., 2018;

Salomone et al., 2015). It should be noted that massage falls within the category of emerging practices according to the reports by NAC (2015) and NCAEP (2020), while the latter is considered as unestablished (NAC, 2015) or as emerging practice (NCAEP, 2020). Also, there are a number of literature analyses that found both practices are not supported by credible evidence (e.g., Barton et al., 2015). The result that responding parents started those practices upon recommendations from other families and special educators makes us think that professionals offer directions for parents without considering empirical evidence; families can share unreliable and incorrect information with themselves; and parents are faced with information pollution. Therefore, we think it is essential for professionals to advocate for parents of children with ASD, educate them about the effectiveness of these practices, and direct them to effective practices, EBPs.

It is interesting that the only category the average use of which increased compared to past was mind-body therapies, although most parents were unwilling to use them. This may be that because many treatments within this category are recent (Senel, 2010), parents who have access to them are trying new alternatives, whereas those with no access are unwilling to try them, which warrants future research. Psychotherapy had the highest lifetime use rate within this category, and one third of the parents reported willingness to use it. Recent popularity and familiarity of relationship-based practices in Turkey may be attracting parents' attention to psychotherapy (Koksal & Erciyes, 2021). This endorsement may also be due to parents' perceptions towards ASD or endeavor to deal with the symptoms of psychiatric disorders commonly seen in individuals with ASD (Lainhart & Folstein, 1994). Thus, future research may examine parental perception on etiology of ASD and its relationship with treatment choice. As to psychotherapy, future research should investigate parents' opinions and perceptions of effectiveness and improvement in their child's functioning.

Animal therapy was by far the most desired treatment by the responding parents. In fact, most parents were willing to try horse and pet therapy in future. Previous research showed that local consumer interest, availability, and accessibility of a treatment were among the most common reasons influencing parental decisions on the use of that treatment (Carlon et al., 2015). Considering that majority of the local governments in Turkey promote animal therapies as *free services to support cognitive and emotional well-being* and provide these therapies at no cost, it is highly probable that parents of children with ASD are encouraged to use them, which is supported by their textual comments.

We found that other therapies were the most common category among parents with lifetime use compared to the other categories. The most frequently used treatment within this category was play therapy. To our knowledge, only one



study included play therapy in CAM treatments list (Gibbard, 2005). The study, published in grey literature, found that almost one third of 176 participating parents used play therapy and 77.1% rated it as effective. However, more rigorous research on the effectiveness of play therapy needs to be conducted (Dube, 2020). Meanwhile, professional stakeholders may suggest empirically effective play-based practices such as Pivotal Response Training (PRT) or Joint Attention Symbolic Play and Emotion Regulation (JAS-PER) to those weighing in play-based practices.

16.46% of the overall sample tried, and subsequently, discontinued at least one CAM treatment for their children with ASD. Only three studies on CAM treatments use by parents of children with ASD investigated the treatments that parents chose to discontinue and their reasons for discontinuation (Bowker et al., 2011; Christon et al., 2010; Shepherd et al., 2018). The studies reported that parents discontinued a treatment when they believed the child was not benefitting and they could not afford it. Similarly, we found that parents discontinued the treatments due to high price which is followed by lack of progress in their child. It can be interpreted as most parents would have continued CAM treatments if they could have afforded them. Surprisingly, the number of the parents who reported discontinuation due to advice of professionals is lower than that of those indicating high price and lack of progress. However, we don't know whether these professionals actually recommended families not using CAM treatments and parents refused to rely on their testimonials, which is another topic for future research. Also, future researchers may investigate parents' expectations of CAM treatments, their opinions of which area of their child's functioning they felt was improved or decreased by those treatments, and disseminate the results in parent-friendly language so that they can place confidence when choosing a particular treatment.

Another important finding was that over half the parents reported unwillingness to use untried CAM treatments mainly due to recommendations from others, which was followed by cost and lack of empirical evidence. Regarding the empirical evidence, previous research reported it is not of primary importance to parents (Bowker et al., 2011; Green et al., 2006; Shepherd et al., 2018). On the other hand, parents who were willing to use untried CAM treatments, pointed out recommendations from regular and special education teachers as reasons for willingness. This result that special education professionals recommend empirically unsupported practices is consistent with those of other studies that found recommendations are a primary factor influencing parental-decision making (Hanson et al., 2007; Miller et al., 2012). Also, the current study that investigated an area currently unreported in the literature (reasons for willingness and unwillingness to use untried CAM treatments) evidently shows that empirical evidence seems to be a predominant factor in influencing parental-decision making regarding treatment usage. This highlights parents' need for direction and information about the empirical support and effectiveness of treatments. Thus, it is significant for service providers and special educators working with the parents of children with ASD to be well-informed of EBPs, pseudoscientific practices, and their distinctions. Sadly, Turkish pre-service special education teachers have superficial and limited knowledge on EBPs (Tekinarslan et al., 2018), and what is worse, special education teachers do not know what an EBP means (Ataş et al., 2021). Many pseudoscientific practices that no experimental studies have shown their effectiveness may be the topic of peer-reviewed articles in reputable journals and, as such, professionals, who are not typically trained for evaluating scientific rigor of an experiment, interpret that as these practices are supported by empirical evidence when none actually exists and suggest them to parents. It seems significant for professionals who are in the position to offer directions for parents to be continuously well-informed of EBPs given that empirical status and classification of EBPs are regularly updated. One way to support professionals could be that existing coursework or curricula within special education teacher preparation programs may, if not already, be improved to better prepare pre-service special education teachers to develop their knowledge and capacity of research evaluation, pseudoscientific practices, and EBPs. Also, although there are lots of international websites about EBPs (e.g., Autism Speaks) for individuals with ASD, professional stakeholders' access to credible and reputable sources of information regarding EBPs is difficult and limited in Turkey. Thus, it can be helpful to design user-friendly, high-quality, and up-to-date websites about empirically validated and unvalidated treatments, given that there can be professionals and parents who cannot read English.

In Turkey, individuals diagnosed with a disability can take up to 8h of free supportive education in special education and rehabilitation centers per month. However, many families of children with ASD are in low socio-economic status group in Turkey and many of them cannot send their children to schools on a regular basis (Karadag & Bilsin, 2016; Meral & Cavkaytar, 2015). Since their children with ASD cannot take enough advantage of educational benefits, families may be more inclined to use CAM treatments for them.

In this study, we explored the association between lifetime CAM treatments use and a number of variables. Firstly, we found that CAM treatments use was associated with higher parental educational level. Although this result is consistent with some published studies (Akins et al., 2014; Bilgic et al., 2013; Hall & Riccio, 2012; Hanson et al., 2007;



Masri et al., 2020; Owen-Smith et al., 2015; Salomone et al., 2015; Wong & Smith, 2006), it differs from those of other studies (Granich et al., 2014; Harrington et al., 2006; Lindy et al., 2018; Wong 2009). Parents with higher educational level may have better access to internet and resources (i.e., more free time) to take advantage of social media parent support groups and researching. However, this result should be interpreted with caution because it does not mean that the parents with higher degrees are ignorant of scientific evidence. Indeed, this reflects their desire to find hope or cure and do whatever they can for their children. Secondly, existing research studies have shown mixed results relating to the association between family income level and CAM treatments use (Alnemary et al., 2017; Miller et al., 2012; Owen-Smith et al., 2015). In this study, we found no associations between these two variables. This finding was unexpected given that the main reported reason for discontinuation and unwillingness to use untried CAM treatments was that they were too expensive. Thirdly, we found that longer time since child's ASD diagnosis was associated with high levels of lifetime CAM treatments use. Although this result reflects that of Bilgic et al., (2013), Miller et al., (2012) found that the length of time since ASD diagnosis did not significantly contribute to parents' treatment choice for their children with ASD. It may be that increased length of time since diagnosis may cause a sense of frustration and helplessness, thus driving parents to try more CAM treatments for their children with ASD. The sunk cost fallacy (Fantino et al., 2003) can also be applied to the case of pursuing CAM treatments. In other words, parents continue or increase using these treatments because they invest much time, effort, and money in using CAM treatments, despite seeing little or no change in their child's overall functioning. Lastly, use of CAM treatments appeared to be associated with lower functioning of the child with ASD. Other researchers have found mixed results regarding the association between child's ASD severity and CAM treatments use (Hall & Riccio, 2012; Perrin et al., 2012; Salomone et al., 2015). For example, Hall & Riccio (2012) found that CAM treatments use was significantly correlated with greater severity of child's ASD symptoms, whereas Alnemary et al., (2017) reported no association between ASD severity and treatment use in general. However, it should be noted that we measured severity by parents' report, as such it may not be the severity of ASD core symptoms (e.g., social-communication impairments) that lead responding parents to choose CAM treatments, but instead, challenging behaviors in general. For example, one of the pilot parents in current study indicated that the main reason for using CAM treatments was to eliminate her child's stereotypical behaviors.

One strength of the current study was participants across all regions of Turkey responded to survey, thereby

increasing the generalizability of the results compared to previous studies. However, our participants were limited to those individuals who had internet access. Also, all the data relating to the children with ASD and the treatments were limited to parental reports. Despite these limitations, this study explored a wide range of areas regarding CAM treatments use by parents of children with ASD, investigated some areas currently unreported in the literature, thus advancing and contributing to existing literature.

In conclusion, the results of this study indicate that although CAM treatments use is common in parents of children with ASD, they consider them less effective than EBPs. The main reasons for starting CAM treatments were recommendations from professionals and non-professionals as well as internet research. Also, parents considered the cost and evidence-base as important for discontinuing and unwillingness to use untried CAM treatments. It is clear that the primary parental motive for using CAM treatments for their children with ASD was to improve their child's functioning. Furthermore, parent educational level, ASD severity, and the length of time since ASD diagnosis were associated with CAM treatments use. Finally, we think that limited or no access to quality and sufficient special education services may lead parents to use CAM treatments for their children with ASD. Further research needs to examine more closely the links between parents' access to EBPs and CAM treatments use. A reasonable way to tackle this issue, if any, could be to implement EBPs through effective service delivery models such as telehealth.

**Acknowledgements** We wish to gratefully acknowledge assistance provided by Avsar Ardic and Muharrem Koc. We are also grateful to all the respondents who participated in the study.

**Author contributions:** All authors contributed to the study conception and design. Material preparation and analyses were performed by Dincer Saral and Seray Olcay. Data collection was performed by all authors. The first draft of the manuscript was written by all authors and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Funding No funding was received for conducting this study. Correspondence concerning this article should be addressed to Dincer Saral, Hacettepe University, Beytepe Campus, Special Education Department, Ankara, Turkey, 06800. Electronic mail may be sent to [dincersaral@hacettepe.edu.tr].

#### **Declarations**

Compliance with Ethical Standards None.

**Conflict of Interest** The authors have no relevant financial or non-financial interests to disclose.

Ethical Approval Approval was obtained from the ethics committee of Hacettepe University (Ethics approval number: 2020/20-40). All



procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/ or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all parents included in the study.

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