



The Characteristics and Results of Parent Training Interventions in Children with Autism Spectrum Disorder: A Systematic Review

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Abstract

Background: The role of parents in taking care of children with Autism Spectrum Disorder (ASD) is critical. This systematic review aimed to investigate the characteristics and results of parent training interventions for autistic children.

Methods: All relevant studies were searched using Boolean operators such as "AND" and "OR" with the keywords such as "Autism Spectrum Disorders," "Autism," "Autistic disorder," "Asperger syndrome," "Rett's syndrome," "Childhood disintegrative disorder," "Non-specific pervasive disorder", Parent*, Education*, train*, teach*, indoctrinate*, and instruct* in electronic databases such as PubMed, Scopus, Google Scholar, Cochrane Library, Science Direct, Web of knowledge, and also via manual searching in relevant journals, checking the reference list of articles, expert contact, and grey literature from 1 Jan 2000 to 30 Feb 2020. The retrieved studies were screened and reviewed then quality assessed by CONSORT checklist. The qualitative data were analyzed using content analysis method.

Results: Eventually, 53 articles were considered in which 1758 parents with autistic children participated. Overall, 49 studies were conducted in high-income countries, 19 at home, 25 in training centers, 14 carried out only in training way, 39 in training along with practices and assignments, 30 individual interventions, and 21 in groups. Moreover, the effectiveness of interventions was studied in both parents and children groups. The results for parents show direct and indirect favorable impacts of interventions on them. The results for the children indicate direct and indirect favorable effects of the parents-based interventions on the child and the symptoms of their disorder.

Conclusion: According to the included studies, parents-based training interventions significantly impact parents and their children's behavior.

Keywords: Autism spectrum disorder; Effectiveness; Interventions; Parents training; Systematic review



Introduction

Autism spectrum disorder (ASD), introduced by Leo Connor (1894-1981), has always been one of the most challenging psychiatric disorders in scientific communities since 1943. The American Psychiatric Association has identified main characteristics in diagnosing ASD according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as difficulty with social communication and interaction demonstrated as defects and delays in language, speaking with an abnormal tone or rhythm using a singsong voice or robot-like speech, failing to understand and respond to someone, conservation, not expressing emotions besides appearing unaware of others' feelings, and making minor, none or inconsistent eye contact, facial expression, and body language (1). Epidemiological studies show a dramatic increase in the number of families suffering from ASD globally. According to the United States Centers for Disease Control and Prevention (CDC), in 2008, about 1 in 88 children aged 8-10 had been diagnosed with ASD (2). The prevalence of autism in the world is less than 1%, with a higher prevalence in high-income countries (3). Moreover, the previous edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) estimated the incidence of this disorder as 2 to 5 cases per 10,000 people (4).

Besides the high prevalence of ASD, diagnosis, training, and maintenance of children with ASD have consequences that may affect almost all aspects of a family; naturally, it is a bitter and unexpected moment for parents to know their child is diagnosed with autism (5). Parents with autistic children experience more anxiety and lower quality of life than those with mentally disabled children without ASD, cerebral palsy, and normal children (6-9).

Despite extensive research on the treatment and control of behavioral disorders, there are limited options for improving ASD-related symptoms (10). Several indefinite factors have been suggested in ASD etiology; therefore, researchers believe ASD is a multifactorial disorder caused by several

common factors (11). One option is applied behavior analysis (ABA) therapy based on theories of learning and operational conditioning (12). Another intervention is central response therapy (PRT), which involves a more natural behavioral approach that targets incentives and specific skills (13). As a result of the multi-facility of ASD, available therapies and training methods are very diverse. Kalyva (14) describes more than 20 available training methods in his book entitled "Autism: Educational and Therapeutic Approaches". However, most interventions are costly, time-consuming, and not accessible; thus, today, there is a need to introduce less costly parents-based interventions (15). Parent education interventions have been effective in improving children's disruptive and maladaptive behaviors, socialization, and daily life skills (16, 17). Systematic and proper parents-based training with positive effects is remarkable in two perspectives: first, they help parents to cope with their child's disorder, slightly reducing their inner negative feelings; second, by educating and assisting their child and seeing some minor progress, parents will be enlightened with hope for future (18, 19). Review studies similar to the current study have been conducted on parent education interventions examining a specific age range, specific consequences of interventions, etc. Literature review on training interventions of parents with ASD children suggests that these interventions can be considered complementary and even a suitable alternative for other interventions. Therefore, the present study intends to review systematically the parents-based training interventions in ASD.

Methods

Designed and conducted in 2020, the current systematic review, which is a part of Azeri Blue Buddies: Interdisciplinary Longitudinal Autism Researches (ABBILAR), has been prepared according to the systematic reviews guidelines in

"Systematic reviews to support evidence-based medicine" book (20).

Search strategy

Databases such as PubMed, Scopus, Google Scholar, Cochrane Library, Science Direct, and Web of Knowledge were searched using keywords such as "Autism Spectrum Disorders," "Autism," "Autistic disorder," "Asperger syndrome," "Rett's syndrome," "Childhood disintegrative disorder," "Non-specific pervasive disorder," Parent*, Education*, train*, teach*, indoctrinate*, and instruct* from 1 Jan 2000 to 30 Feb 2020 (appendix 1). The keywords were combined using Boolean operators of "AND" and "OR". Several valid journals were searched manually to identify and cover more published articles. After excluding the articles inconsistent with the inclusion criteria, reference lists of selected articles were searched to enhance the reliability of the paper identification and find additional articles. Gray literature search was also done through the European Association for Gray Literature Exploitation (EAGLE) and the Healthcare Management Information Consortium (HMIC) databases.

Inclusion and exclusion criteria

Inclusion criteria:

- Parents with ASD children
- Studies with parent training based interventions
- Parents without ASD child and any interventions
- Reduction of ASD-related problems for parents and their children
- Studies in English

Exclusion criteria:

- Interventions with targets other than parents such as children and teachers
- Unconventional and common interventions for parents (without regular protocols) in different centers
- Parents with a child having ASD combined with other disorders such as ADHD
- Irrelevant outcomes such as parent's comments about presented training

- Observational or non-interventional studies
- Survey studies
- Studies using assessment tools

Quality assessment

Reporting quality of all extracted articles was assessed by two evaluators using the consolidated standards of reporting trials (CONSORT) checklist. This checklist was selected due to its specificity in evaluating interventional studies, particularly clinical trials and its translation and validation in Persian to evaluate the articles (21). The CONSORT assessment tool is one of the most important and applicable tools in evaluating clinical trials introduced as an international standard reporting assessment for clinical trials by a group of clinicians, statisticians, and epidemiologists in the mid-1990s. The latest version of CONSORT contains 37 items to evaluate six main points, including title, abstract, introduction, materials and methods, results, discussion and other information, each including different subsections (22). Any disagreements were resolved by discussion and in consultation with an expert.

Data extraction

First, three data extraction forms were designed manually in Word software: one for inserting the general specifications of articles, one for interventions' information and results, and one for a description of interventions. Next, the data of three articles were extracted experimentally using these forms to resolve possible deficiencies in the initial forms. Two independent reviewers conducted data extraction. Extracted information in form 1 (Appendix 2: articles specifications) includes: the author's name and the publication year, the country where the study was conducted, the study location (home and training centers), study type, participant's demographics. Form 2 (Appendix 3: intervention specifications) includes the author's name and the publication year, brief title of the intervention (Appendix 4: full details of interventions), type of intervention, the electronic/technology methods for intervention (email, internet, designed programs, games, soft-

ware), duration of intervention and follow-up, intervention methods (group or individually), evaluation tools, results, statistical significance in results (Yes/No) and overall effectiveness of the intervention (If all measures significantly improved (quite effective), if some of the measures significantly improved (somewhat effective) and if none of the measures had improved (ineffective), the ambiguous cases were identified in consultation with the research team). The extracted information in Form 3 (details of the intervention) include the author's name, publication year and details of interventions.

About the effectiveness of the studies measurement, the overall results and indicators examined in each study are divided into three categories based on an agreement between two members of the research team: "absolute effective" (studies in which the indicators improved significantly and the researchers confirmed the certainty of the result), "partially effective" (cases in which the indicators improved insignificantly or slightly, and researchers confirmed the effectiveness of studies with uncertainty), and "non-effective" (cases where the indicators improved and researchers confirm the ineffectiveness of studies).

Data Analysis

Researchers analyzed data using content analysis, which is a method for identifying, analyzing and reporting themes within the text widely used in text data analysis (18, 19).

Two researchers conducted data coding. The steps of data analysis and coding were as follows: Familiarity with the text of extracted data (several rounds of information study to immerse in the text), identification and extraction of primary codes (related data with primary codes), theme identification (placement of primarily extracted codes in related themes), reviewing and completing identified themes, naming and defining themes (choosing a name for each category of similar codes based on content), and ensuring the reliability of the extracted codes and themes (reaching an agreement between the two coders by discussing and resolving issues). Descriptive data were analyzed and reported manually with

descriptive statistics (percentage, frequency, mean).

Results

Of 1830 articles found from the aforementioned databases and other resources, 730 were deleted due to duplication, and 987 articles were excluded after screening titles/abstracts. After full-text review, 60 articles were excluded because of inconsistency with the inclusion criteria. Finally, 53 articles were included (Fig.1) (The characteristics and details of the studies are provided in Appendix 2-4. Interested readers may contact the corresponding author directly to get access to them).

The country where the study was conducted:

Out of 53 papers, only seven were conducted in low-income countries (e.g., Bangladesh) and medium-income countries (e.g., Turkey, China, Thailand and Jordan). Forty-six articles were conducted in high-income countries (e.g., United States, Canada, United Kingdom, Netherlands and Australia), of which 37 were conducted in the United States. Division of countries was based on the 2018 World Bank statistics.

The study location: The studies were divided into two types (at home and in training centers) based on interventions' location; 19 studies were conducted at home, 25 in training centers, and 9 in both home and training centers.

Participants' number: Overall, 1758 parents participated in the studies, of which 1420 were in the experimental group, and 338 were in the control group. **Training protocols:** Finally, 53 protocols were extracted, including various training such as social skills training (13 studies), comprehensive training of ASD (12 studies), behavioral training and management of incompatible behaviors (11 studies), cognitive training (9 studies), sleep health-related training (4 studies), nutrition-related training (2 studies) and toilet-using-related training (2 studies). In addition, in 11 studies, some routine and conventional training were provided for control groups in the centers due to ethical considerations. However, the control group did not receive any special training in other studies.

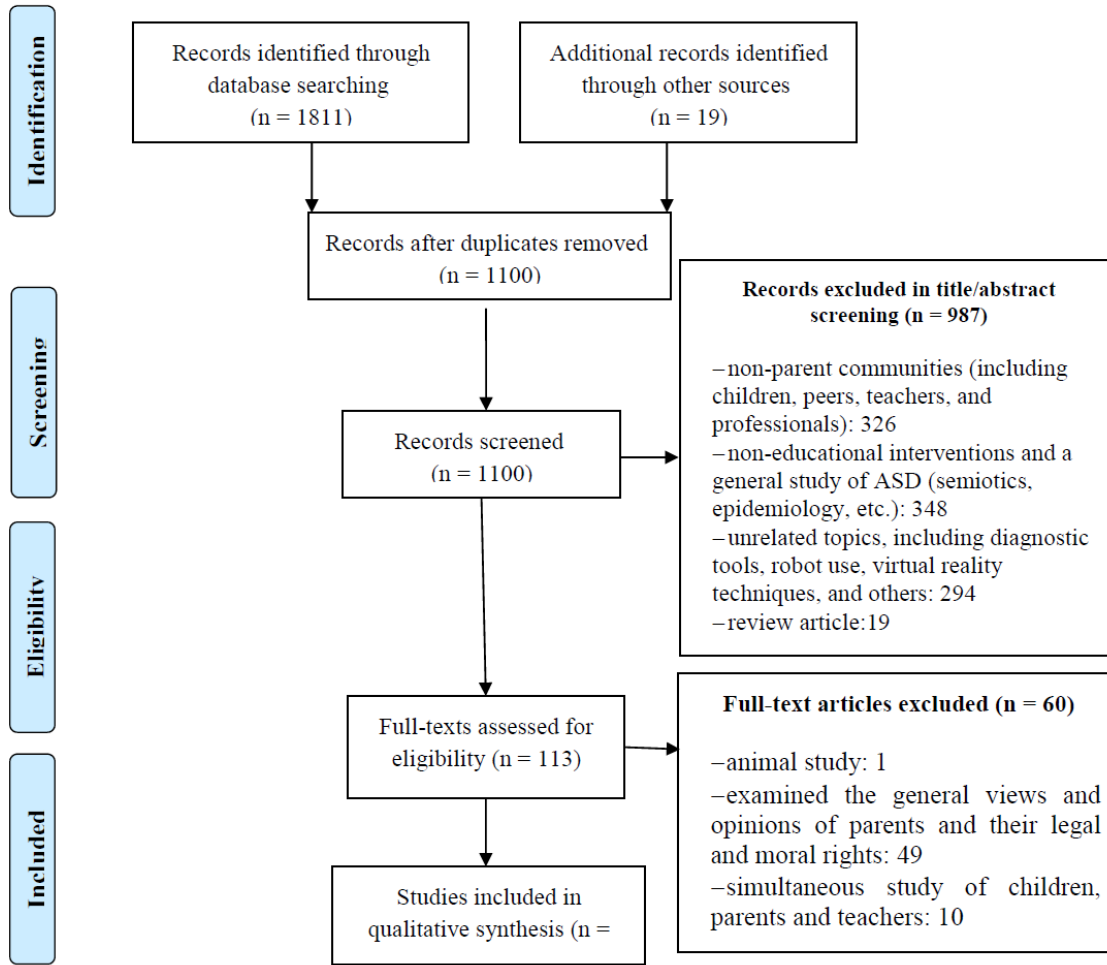


Fig. 1: Searches and inclusion process

Technology use: Using and not using training technologies such as the internet, tablets, laptops, smartphones, were also evaluated. In 38 studies, some kinds of training technologies were used, but in 15 studies, no technology was used. The electronic devices used in the studies included voice recorders, camcorders, training clips, cameras, according to the needs and structure of the interventions.

Intervention type: The types of interventions can be divided into two groups of only training and mixed training (training along with practice). Only 14 studies were devoted to only training through holding workshops and sessions, and 39 studies implemented their interventions in the form of training along with practice.

Intervention duration: Including a period ranging from 1 to 100 wk, 43 studies referred to intervention duration. In general, the studies that lasted less than ten weeks were only training, and studies with practice-based interventions had durations between 10 to 30 weeks.

Follow-up period: The evaluation of the existence of a follow-up period and its duration showed that 17 studies had a follow-up period, while 36 studies lacked it. The follow-up period varied from 2 wk to 18 months. However, most follow-up courses were between 1 to 6 months.

Duration of intervention sessions: With a range of 10 min to 5 h, the duration of each intervention session was indicated in 42 studies.

The length of sessions in most interventions ranged from 60 to 120 min.

Intervention method: The method of interventions can be divided into two types of individual and group training. Accordingly, 30 interventions were performed individually, 21 in groups and two both individually and in groups.

Evaluation instruments: The evaluation tools were tests and questionnaires used before, during and after the intervention implementation. Most studies used valid tools; otherwise, researcher-based tools were used. Tools for assessing the

level of stress in parents and the Vineland scale were used the most.

Study results: The results of the studies vary according to the type of intervention and target behaviors. Regarding the main objective of the current study, two general groups (parents and children) could be influenced by the training. Therefore, the following conclusions can be presented based on study results:

A) Results on parents: This includes the direct and indirect favorable impacts of interventions on parents (Fig. 2).

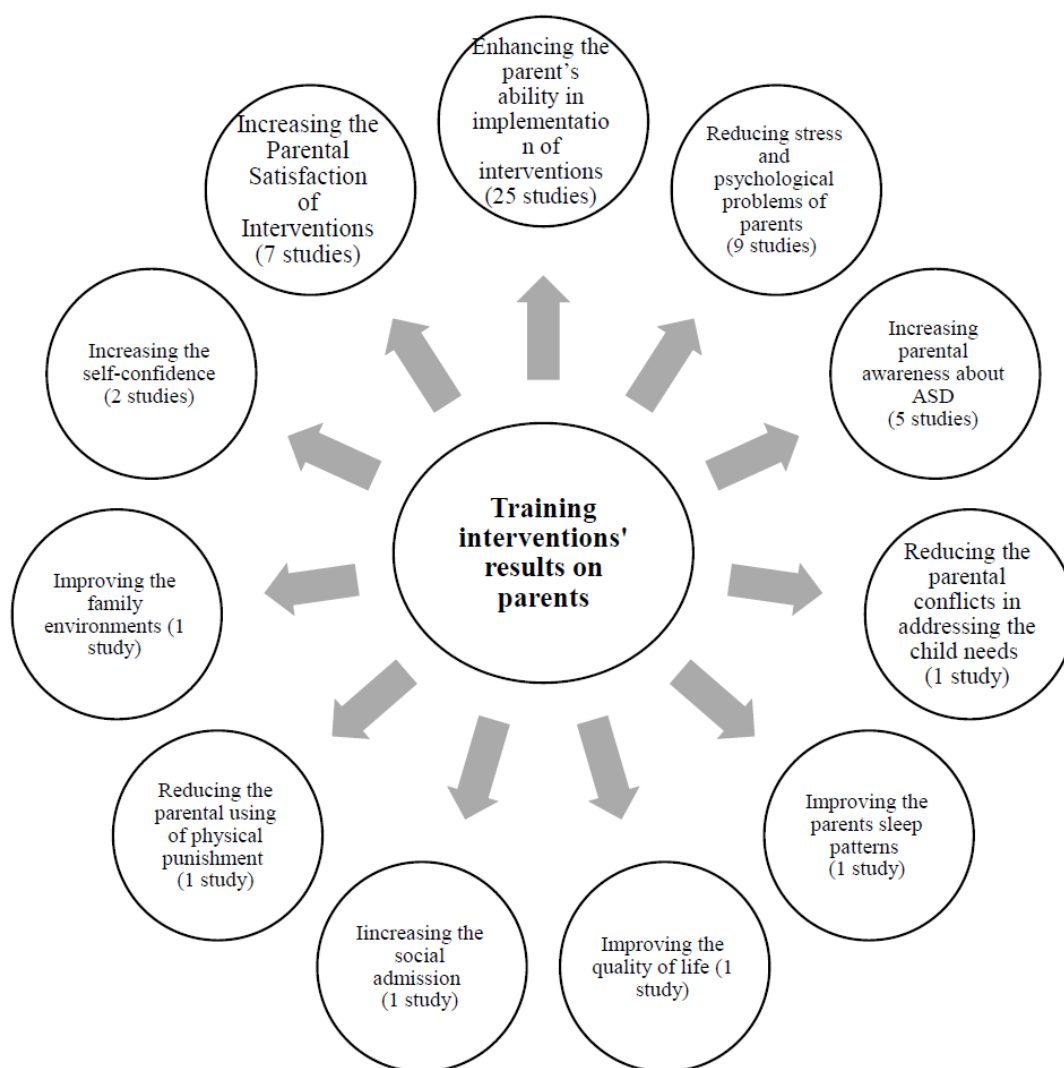


Fig. 2: Training interventions results for parents

B) Results on children: It includes direct or indirect favorable effects of the parents-based interventions on the child and symptoms of their disorder. The intervention results for children can be categorized into two areas according to the ASD syndromes in DSM-5:

1- Disturbance in social interactions: Results of 21 studies demonstrated some improvement in social relationships and interactions in children. However, two studies showed no significant effect on improving children's social skills. There were contradictory results in language and communication skill development in children; six studies reported positive results, but three studies

did not show positive effects of training to enhance children's language skills.

2- Restrictive and repetitive behaviors and activities: Results from 17 studies indicated that parent-based training interventions had a positive effect on restrictive and repetitive behaviors of children, including sleep patterns, nutrition-related behaviors, stereotypical movements, small and large movements, stimulation and hyperactivity. However, the results of 3 studies showed no significant effects on these behaviors.

Training protocols: The extracted training protocols comprise 7 different sections, as presented in Fig. 3.

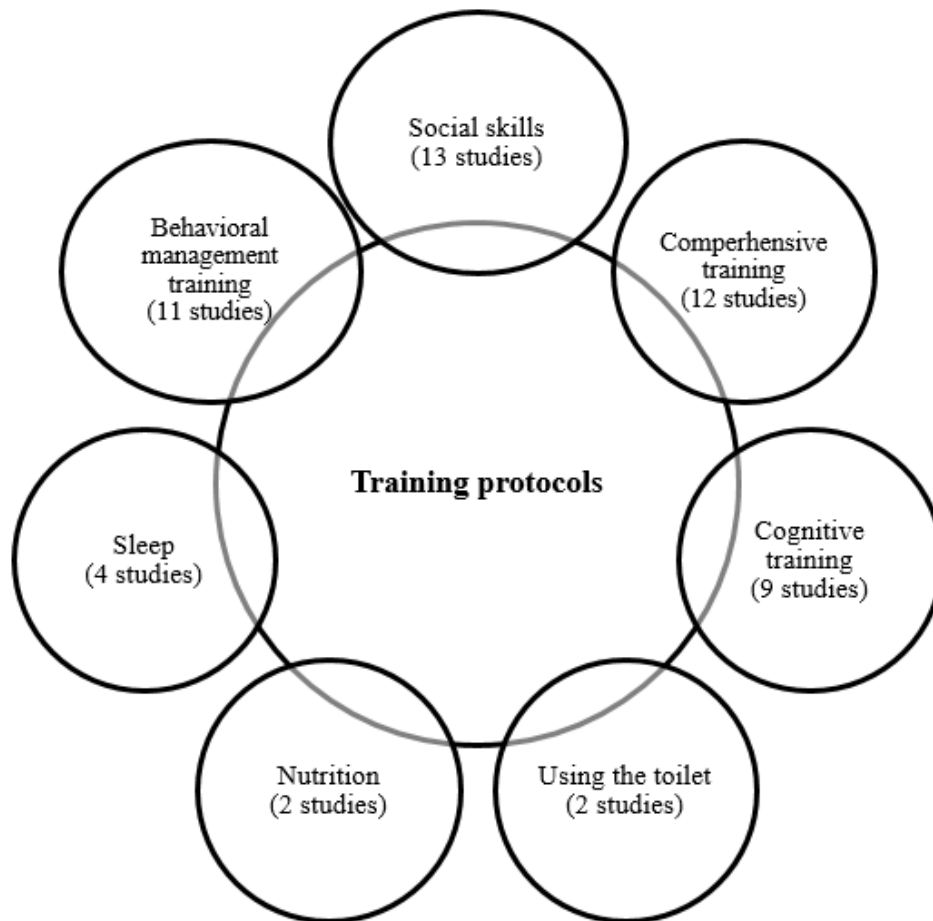


Fig. 3: Training protocols

The effectiveness of interventions based on the studied variables (country's income, intervention location, intervention type, intervention method,

technology use, intervention duration, follow-up period and protocols) is shown in Table 1.

Table 1: Results of parent training-based interventions based on the studied variables

<i>Variables</i>	<i>Variable level</i>	<i>Number of interventions in each variable level</i>	<i>Number of effective interventions *</i>	<i>Effectiveness (%)**</i>
Country	High-Income Countries (HICs)	46	36	78/26
	Low and middle-income countries (LMICs)	7	3	42/85
Intervention location	Training centers	25	21	84
	Home	19	16	84/21
	Mixed	8	7	87/5
	Not identified	1	1	100
Intervention type	Education	14	11	78/57
	Mixed (training and education)	39	33	84/61
Intervention method	Individual	30	27	90
	Groups	21	16	76/19
	Mixed	2	2	100
Technology use	Yes	37	32	86/48
	No	16	13	81/25
Interventions duration	week≤10	17	14	82/35
	11≤week≤30	23	20	86/95
	31≤week≤50	2	1	50
	week≥51	1	0	0
	Unknown	10	9	90
Follow-up period	week≤5	3	2	66/6
	6≤week≤15	9	6	66/6
	16≤week≤30	3	2	66/6
	week≥31	5	4	80
Protocols	Unknown	33	28	84/8
	Social skills	13	12	92/3
	Comprehensive training	12	10	87/5
	Management of incompatible behaviors	11	10	90/9
	Cognitive training	9	5	55/5
	Sleep-related training	4	4	100
	Nutrition-related training	2	2	100
Toilet-using-related training	2	2	100	

*Based on results of Appendix 3
 ** Number of Interventions/ Number of effective interventions

Interventions in HICs were more effective than LMICs. However, the effectiveness of the interventions did not differ much regarding the location. The interventions using technology were more effective. Additionally, the effectiveness of educational interventions was less than the com-

bined interventions. Nutrition, sleep, and toilet training protocols were more effective than others.

Discussion

Out of 1830 articles, 53 were included, conducted mainly in HICs. In addition, the efficacy of studies in HICs was estimated as 26.68%, which is higher than those of LMICs (42.85%). Almost half of the interventions were carried out in the child's home. Additionally, 30 studies were estimated with 90% effectiveness in individual form, 21 with 76.19% effectiveness in group form, and in mixed form, the effectiveness was significant. In the LMICs, especially among those with lower socioeconomic levels, the presence of a stranger at home (even as a therapist) is not accepted; therefore, most studies in LMICs were conducted in training centers (23-31).

In most studies (37 articles), a variety of technologies was used. For example, in most studies where parents were asked to practice assignments, clips and educational pictures were provided as templates; or in cases where communication between the educator and the parent was essential, calls were made through telecommunication applications like Skype. In some cases, to assess the parent's performance and feedback besides providing corrective feedback and appropriate solutions, they were asked to take a picture of their interactions and behaviors with the child at certain times of the day. The effectiveness percentage of studies using technology was 86.48%, which was higher than others (81.25%). This finding is important from two perspectives: first, considering the increasing use of technology and cyberspace, access to the internet, smartphone, camcorder and video can be possible; second, considering the context and culture of families in underdeveloped countries, it is likely that the acceptance of a stranger at home may be problematic; therefore, by using technology, we can benefit in some cases, such as protocols training, observation of home milieu and intervention results' assessment (31, 32).

Only 14 articles held workshops and training forms; participants in this short-term training model do not perform a specific practice and only listen to the trainer. However, this training

model has some benefits. For example, it can be used if the teaching protocol's goal is increasing knowledge and awareness (31, 33). Ideally, when the parents' training is practical with using facilities such as video clips, their training and outcomes would have more significant improvement (16). In the current study, the effectiveness percentage of mixed education (84.61%) was higher than only training method (78.57%). Additionally, following the combination of the two models can lead to benefits from both models.

The intervention duration ranged from 1 to 100 wk with a non-constant session duration fluctuating from 10 min to 5 hours. Most of the studies were conducted with 10 to 30 sessions and had the highest percentage of efficacy (86.95%). The follow-up period varied from 2 wk to 18 months, with most studies ranging from 6 to 15 weeks. A child's state in terms of ASD severity can be determined based on DSM-5, interventions, and the level of parent's knowledge and awareness. Studies focused on providing practical parenting training ranged from 10 to 30 wk, with a session duration between 60 and 120 min. The existence of a follow-up period and its duration can also be influenced by the importance of the study results as well as the access to the research. Therefore, if there are no constraints in various studies, a follow-up period of 3 to 6 months will increase the number of studies with reliable results (34).

Finally, 30 studies were estimated with 90% effectiveness in individual form, 21 with 76.19% effectiveness in group form, and in mixed form, the effectiveness was significant. Given the extensive ASD symptoms and categories, the homogeneity of the training members can be considered as an essential criterion. The subject of training protocols is also important; for example, several studies focused on the use of toilet or behavioral problems during sleep in children with ASD. If needed to present these training as a group, they should be grouped by parental screening and according to their needs. In general, given the benefits of group-based education, including cost and time saving, as well as the strong theory (e.g., the social learning theory of Albert

Bandura (35)), well-organized group-based training would be more productive.

Another finding is the extracted results from included articles categorized into two categories: results for parents and results for the child. The most frequent result for parents was parental skills' improvement during various interventions (in 25 studies). This finding is important because most interventions in ASD focused directly on the child by a trainer or expert (36). Each child with ASD has unique characteristics and lives in a unique environment in which the family as a whole and parents have the highest levels of interaction and cognition. Therefore, it seems desirable to emphasize the role of parents in teaching and directing the children.

Based on nine studies, the interventions reduced parental stress and psychological problems such as depression and anxiety. Studies have shown that diagnosis of ASD imposes extra pressures on parents and other family members (37, 38); therefore, the results can be helpful.

Increased parental satisfaction from interventions and their outcomes on the child was one of the most frequent results cited in 7 studies. Contributing to resolving child's problems, especially when the result of the efforts is evident, parents experience positive emotions and get optimistic about the future. Parents with autistic children were more likely to cooperate with teachers and participate in counseling sessions (39). Thus, by involving parents in the training courses, they can avoid negative emotions such as feelings of guilt, anxiety and disappointment towards the future. Accordingly, another significant result was a decrease in parental stress, mentioned in other studies (40).

Another frequent result for parents mentioned in 5 studies is increased knowledge and awareness on ASD. ASD identification is the first step in helping autistic children; therefore, in most educational protocols, at least one entire session was provided to introduce ASD and its features. Due to advantages such as time and cost-saving, education is necessary but insufficient. In the present study, the effectiveness rate of this type of intervention was less than the mixed type. Neverthe-

less, it is possible to get the advantages of both models simultaneously by combining the two models. In addition, quality of life, general conditions of the family milieu, interaction with other family members and friends, social acceptance, self-confidence and parental sleep patterns had improved, besides reduction of physical punishment, negative emotional feedback, feeling of loneliness, body complaints, and social deprivation.

Regarding the impact on children, results were summarized in two general aspects according to the DSM-5 criteria: social relationships and behaviors, and restrictive and repetitive activities. The results for children also indicate the desirable effects of parents' training, especially in social and behavioral skills. However, for more complex cognitive skills such as language teaching, the results were contradictory and less effective. Notably, these results were reported when parents were educating their children; however, the effectiveness of the training by parents compared to ones provided by specialists was equal in different centers (41, 42).

Protocols were comprised of seven aspects: social skills, general education, teaching and management of incompatible behaviors, cognitive training, sleep-related training, nutrition-related training and toilet-using-related training. The frequency of these protocols was 11, with an effectiveness percentage of 90.9. The protocols related to cognitive education (language skills and community attention) with a relatively high frequency (9 protocols) had the lowest level of effectiveness (55.5%). The results of the studies were controversial. For example, one study (43) indicated a significant effect of pivotal response treatment (PRT) training on improving the language skills of autistic children, while another study (44) showed no significant effect. Using different evaluation tools, characteristics of autistic children, and their different levels of verbal intelligence are the possible causes of such results (44). One study on autistic children with high levels of verbal intelligence showed that language-related teaching is effective (45).

Based on the results of the literature review and our best knowledge, the present study systematically and comprehensively examines the characteristics and results of parent training interventions in children with ASD for the first time. However, the present study had several limitations. First, the number of studies in each variable/level (Table 1) was not the same (for example, based on intervention duration, for week \leq 10, there were 17 studies, but for week \geq 51, there was only one study). In addition, due to the limited search in only English and Persian, it is possible that several studies in other languages were not included. Another limitation was that meta-analysis of the studies was not possible due to the type and nature of the reports.

Conclusion

The importance of designing and implementing interventions based on parents' training in ASD is becoming more evident. Studies have reported significant results for both parents and children. Notably, various aspects examined in this study could be used to create an appropriate protocol for parent training. The mixed interventions (both at home and in the centers and both individual and group) that used technology and performed within the range of 11 to 30 wk were suggested in the development of training protocols. Therefore, setting new protocols will be a higher priority during this period. The more effective protocols were operational with a clearly defined variable of the training goal. The effectiveness of protocols related to sleep hygiene, nutrition and toilet use was fully estimated. Therefore, while developing new protocols, target behaviors must be carefully selected and defined to base the appropriate intervention.

Ethical considerations

Ethical issues (Including plagiarism, informed consent, misconduct, data fabrication and/or falsification, double publication and/or submission,

redundancy, etc.) have been completely observed by the authors.

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Conflict of interests

None.

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