ORIGINAL ARTICLE

Analysis of the knowledge and satisfaction with applied behavior analysis as treatment for autism spectrum disorder in parents with affected, with healthy children and childless adults

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AbstractOBJECTIVE: Applied Behavior Analysis (ABA) is an evidence-based approach for the treat-
ment of Autism Spectrum Disorder (ASD). Erroneous beliefs deriving from a reductive
conception of ABA partly explain the delay in the spread of ABA treatments in Italy. Never-
theless, an increasing number of parents have been choosing this treatment. The purpose
of this survey is to investigate beliefs about ABA, the degree of satisfaction regarding ABA
treatments, and the sources of information used to choose the treatment.

DESIGN: The sample included 109 Italian participants: 67 parents of children with ASD, 19 parents of healthy children and 23 adults without children. Participants have been invited to complete an online questionnaire. Socio-demographic data was also collected, along with information on the sources consulted to choose a treatment and on the satisfaction for ABA treatments.

RESULTS: Participants agree that ABA is an approach of choice that intervenes on socially significant skills, while they do not agree with several reductive and stereotypical statements related to it. Regarding the sources, most parents with children with ASD choose the consultation with other parents who live or have lived the same experience. Finally, although the majority of participants rate ABA treatments positively, findings proved that parents of children with ASD appreciate ABA treatments more than the other two groups. **CONCLUSION:** There is a broad agreement among participants in correctly identifying the distinctive features of ABA. This data indicates a certain diffusion of correct knowledge and a lower adherence to reductive concepts. The direct experience of applying ABA treatment information is more accessible compared to the past, the tendency to seek advice from other parents of children with ASD remains. The results of the survey enable us to give concrete indications for training and dissemination activities.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopment disorder characterized by specific deficits in different areas of behavior, social communication, and interaction that emerge in the early developmental period and determine a significant impairment of personal, social, educational and, later, occupational functioning (American Psychiatric Association 2013; Bartakovičová et al. 2019; Maye et al. 2017). The phenotypical expression of the deficit is varied, thus determining a heterogeneous phenomenological continuum. The diagnosis requires a specialist assessment based on behavioral symptoms: in fact, laboratory and/or instrumental investigations cannot reliably confirm a clinical suspicion since no specific biological biomarkers for this disorder have been identified to date (Di Pasquale 2016).

As far as treatment is concerned, several publications have documented the effectiveness of behavioral approaches (McPhilemy & Dillenburger 2013; Odom *et al.* 2010; Reed 2016). In particular, starting from a relevant study conducted by Lovaas (1987), multiple investigations have supported the effectiveness of Applied Behavior Analysis (ABA) (Doehring *et al.* 2014; Lai *et al.* 2014; Larsson 2013; Peters-Scheffer 2011; Reichow 2012; Salomone *et al.* 2016; Wong *et al.* 2015).

ABA is a broad term that includes a series of instructional approaches, which range from structured ones, such as the Discrete Trial Training (DTT; Lovaas 1987), to more naturalistic ones, like Pivotal Response Training (PRT; Koegel *et al.* 2016). Each of them relies upon techniques and procedures derived from learning principles and aims at developing or modifying socially relevant behaviors. All ABA-oriented instructional approaches are rigorous from a methodological standpoint and contemplate precise standards for clinical practice.

ABA was developed around the early Sixties in the US. In Italy, its spread began around the second half of the Seventies; however, despite the strong evidence of effectiveness, conflicting and adverse opinions among clinicians remained numerous throughout the years (Truzoli 2011). Moreover, even though the Italian Society of Child Neuropsychiatry indicated ABA as the treatment of choice for ASD (SINPIA 2005), the availability of ABA treatments within the Italian Healthcare System is still unsatisfactory. Currently, in Italy, the notion of ABA as the gold standard treatment for ASD is spreading and the knowledge of the distinctive features of these approaches is gradually improving. However, that does not imply that the general population is familiar with the peculiarities of the ABA approaches, although we can hypothesize that those who have to deal with people with ASD, professionally or personally, might easily acquire such information.

Among the erroneous beliefs on ABA historically widespread in Italy we encounter the following: ABA treatments do not allow an actual, deep, learning process since they are based upon procedures of reinforcement and punishment, which determine a mechanical learning that lacks an effective acquisition of meaning (cfr. Tzanakaki *et al.* 2012); they induce stress in parents and pay scarce attention to the individual features of each child; lastly, they only act on behaviors that are not relevant for social interaction. Actually, ABAoriented approaches allow the development of complex behaviors and skills, such as language and social skills, without evidence of an increase in stress in parents (Iadarola *et al.* 2018; Kuravackel *et al.* 2018; Strauss *et al.* 2012).

Another critical issue lies in the process of choice of treatment undertaken by the parents of children with ASD. In this respect, it should be highlighted that parents tend to make this choice by themselves (Keenan *et al.* 2010) and often base their own decision on unreliable sources, especially when an efficient and effective support from the Healthcare Services is lacking (Dillenburger 2011). Previous international research has documented that the most common sources of information guiding such choice are experiential and anecdotal (Green *et al.* 2006; Green 2007). Recent studies confirmed these findings and pointed out how the absence of precise medical advice leads to autonomous decisions (McPhilemy & Dillenburger 2013; Tzanakaki *et al.* 2012).

To sum up, literature has shown that the choice of treatment for children with ASD is often based on erroneous beliefs rather than evidence-based principles. Therefore, further research on this issue is of utmost importance (Denne *et al.* 2017).

In light of these considerations, the purpose of this paper is: a) to investigate the knowledge and beliefs regarding ABA in a sample of parents with children affected by ASD, with healthy children and without children and to point out eventual discrepancies; b) to test the degree of satisfaction regarding ABA approaches; and c) to examine the sources of information used by parents of children with ASD in order to choose their treatment.

MATERIAL AND METHODS

Participants

Eligible participants included parents of children and young people with a diagnosis of ASD (Group I), parents of children and young people without any diagnosis (Group II), and childless adults (Group III). Group I participants live the direct experience of raising a child with ASD; which is not the case for Group II; Group III subjects have indirect experience with volunteer activities in the field or have followed theoretical introductory modules to ABA.

<u>Materials</u>

The questionnaire was adapted from Denne *et al.* (2017) and consisted of 13 questions (reported in

Annex 1). With respect to the items included in the British questionnaire, the following changes have been made:

- The first item of the British questionnaire was deleted since it was deemed unsuitable for the Italian reality, where the Health authority offer ABA treatments and such treatments are included in the SINPIA guidelines (2005);
- Items 5 and 9 have been modified to make them more consistent with the Italian reality and more understandable, but without substantially changing what was asked;
- We added an item (number 12) investigating the acknowledgement of the effectiveness of ABA in improving socially significant behaviors, such as interpersonal relationships and language. ASD symptoms, in fact, often determine a significant impairment in social, educational and occupational functioning;
- We introduced a 13th item to examine the satisfaction with ABA treatments.

The proposed items broadly referred to ABA, without specifying the precise type of treatment (such as Discrete Trial Training - Lovaas 1987, or Pivotal Response Training – Koegel *et al.* 2016), since it is common for parents to use this acronym. Moreover, most websites providing parents and careers with information and support on ASD tend to adopt this term (Denne *et al.* 2017). The questionnaire investigates knowledge and beliefs related to the objectives and characteristics of the ABA, and the possible repercussions within the household.

For each of the 13 items of the questionnaire, each participant was asked to indicate their degree of agreement or disagreement on a 5-point likert scale (1 = strongly agree, 2 = agree, 3 = do not know, 4 = disagree, and 5 = strongly disagree). Consequently, the higher the score, the higher the disagreement. The 13-item questionnaire had a maximum possible score of 65 and the lowest possible score was 13.

More specifically, once you logged into Google forms, the initial section presented information about the purpose of the survey, the administration and use of the data and informed consent. Only after providing informed consent was it possible to complete the questionnaire. Immediately after the questionnaire followed this question: "Are you a parent of a child diagnosed with Autistic Spectrum Disorder?" If not, information was collected on gender, age, residence, educational qualifications, profession, and whether or not they had children. In case of a positive answer, the following three questions were asked:

In looking for a treatment for my son/daughter, I relied on: (multiple answers possible)

Available scientific knowledge Internet websites Other parents \Box Associations

□ Advice from medical specialists

□ Other:

Has your child followed an ABA program in the past or is he currently following an ABA program? □ Yes

□ No

Would you personally recommend to others the opportunity for ABA treatment?

□ Yes

🗆 No

□ Don't know

Afterwards, we collected personal data both of the parent (parental relationship, age, residence, educational qualification, and profession) and of the child (sex, age, school attendance, and diagnosis).

<u>Procedure</u>

An online questionnaire has been prepared which could be accessed through a reference link. Participation in the study was voluntary. The questionnaire was anonymous and could only be completed after giving informed consent. A mandatory answer to each question was provided; otherwise it was not possible to proceed with the compilation.

Participants were recruited primarily by email. Several support groups and associations were contacted, including national associations for parents of children and adolescents diagnosed with ASD, volunteers working in such associations even with children without any diagnosis, and students of the Bachelor of Science and Technique of Psychiatric Rehabilitation as a subgroup that should be particularly sensitive to the issue and relatively trained on the treatment of autism.

Statistical analysis

Cronbach's alpha was calculated from the questionnaire. We applied the χ^2 test on contingency tables, Fisher test, Mann-Whitney test, and one-way ANOVA and Tukey HSD Post-hoc Test depending on the characteristics of the data used and the type of comparison implemented.

RESULTS

109 participants enrolled in the study. With regard to Group I (Parents with children with ASD), 43 (64.2%) mothers and 24 (35.8%) fathers participated in the research; Group II (Parents of children without an ASD diagnosis) included 19 participants (17.4%), 14 of which were mothers (73.7%); and Group III (Adults without children) included 23 subjects (21.1%), 22 of which were females (95.7%). The 67 parents with children diagnosed with ASD (61.5% of total participants) had a mean age=43.6 (SD=7.15; range 28.7–59.6); the

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	Educational qualifications					Professional area						
Group	Middle school	High school	Univ. Degree	Post Graduate	Health	Educa- tional	Clerical	Factory worker	Freelance	Student	Unem- ployment	
I	3 (4.5%)	32 (47.8%)	26 (38.8%)	6 (8.9%)	7 (10.4%)	7 (10.4%)	31 (46.3%)	8 (11.9%)	9 (13.4%)	0	5 (7.5%)	
II	0	6 (31.6%)	7 (36.8%)	6 (31.6%)	5 (26.3%)	2 (10.5%)	8 (42.1%)	0	3 (15.8%)	0	1 (5.3%)	
III	0	10 (43.5%)	10 (43.5%)	3 (13%)	2 (8.7%)	5 (21.7%)	3 (13.1%)	0	2 (8.7%)	9 (39.1%)	2 (8.7%)	

Tab. 1. Frequency (and percentage) of educational qualifications and professional area for the three groups

19 parents with children without any diagnosis (17.4% of total) had a mean age=44.7 (SD=6.05; range 35.0–59.6); and the 23 adults without children (21.1% of total) had a mean age=32.3 (SD=12.44; range=21.6-64.3). With respect to age, significant differences emerge between the three groups ($F_{(2)}$ =17.358, *p*<0.0001); in particular, Group III is significantly younger than both Group I (Tukey HSD Post-hoc Test: p<0.0001) and Group II (Tukey HSD Post-hoc Test: p<0.0001). No significant differences emerge between Group I and Group II (Tukey HSD Post-hoc Test: p=0.87). This is reasonable since 39.13% of Group III is represented by students attending university courses in the Healthcare field, whose personal objectives are still focused on personal training. As far as the place of residence is concerned, 51 Group I participants live in the city and 16 in the province; in Group II 12 subjects live in the city and 7 in the province; while among Group III participants 16 live in the city and 7 in the province. No statistically significant difference between the three groups was found: $\chi^2_{(2)} = 1.37$; p = 0.5.

Table 1 shows the frequency and percentage of the degree, profession, and place of residence.

Educational level was medium-high; and the three groups do not differ in their qualifications: $\chi^2_{(3)}=1.81$, p=0.61. The three groups of participants do not differ in the profession as well: $\chi^2_{(6)}=10.33$; p = 0.11.

With regard to the diagnosis, parents of children with ASD report for 47 children (70.2%) a diagnosis of Autism Spectrum Disorder, for 8 children (11.9%) Asperger's Syndrome and for 12 children (17.9%) High Functioning Autism Spectrum Disorder. It is evident that, since DSM 5 provided only one diagnostic category, i.e. the Autism Spectrum Disorder, which was able to group all the disorders classified by categories in the DSM-IV R, some diagnoses indicated by parents were made before the publication of DSM 5. 82% (n = 55) of children with ASD are male; 12 are female; and the mean age was 11.3 years (range 3-22.1; SD=6.07). 53 children with ASD attend school, while 14 do not.

Analysis of questionnaire responses

The questionnaire was examined for internal consistency (Cronbach, 1951) and the correlation between all 13 items produced Cronbach's alpha=0.83. The correlation between the 13 items and the total score of the questionnaire produced Cronbach's alpha=0.74.

Initially, the frequencies of the responses to the 13 items were calculated for each of the three groups of participants.

Table 2 shows the item response frequencies for each parent/adult group.

The Fisher exact probability test was used to test any differences in the questionnaire responses among the three groups. Significant differences emerge in item 6 ("The focus of ABA programmes is on increasing positive behaviour rather than on behaviour problems"; Fisher test: *p*=0.02); 8 ("*ABA is based on a highly struc*tured curriculum that every child has to follow"; Fisher test: *p*<0.0001); 9 ("Children who have been taught using" ABA methods often learn mechanically, without a real understanding"; Fisher test: p<0.004); and 10 ("ABA places pressure on family life"; Fisher test: p<0.002). With reference to this item, Group II shows more uncertainty, reflected by more "Don't know" answers. A possible explanation is that these subjects tend to associate ASD with behavioral disturbances and do not know what kind of behavior ABA interventions are able to target, nor the features of ABA treatments. Moreover, they seem to suffer more from the stereotype that ABA results in a mechanical learning and tend to assume that having to follow an ABA treatment is a source of stress.

More specifically, Group I participants recognize ABA as an individualized treatment (items 1 and 8); as an approach of choice (items 2 and 5); as a treatment that intervenes on necessary and socially significant skills (items 3 and 12). Furthermore, they do not agree with reductive and stereotypical statements about ABA treatments (items 4, 6 and 9). The greatest uncertainty emerges with regard to items 5, 7 and 11. As far as the item 5 is concerned ("ABA is an approach chosen by parents who want to provide their children with the best treatment"), it should be noted that 10 parents with children with ASD do not have active ABA treatment. As regards item 7 ("Once you start on an ABA program, it is very difficult to reduce or stop the program"), the uncertainty might derive from absence of actual experience with ABA discontinuation; while regarding item

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Tab. 2. Frequency of responses to the 13 items of the questionnaire for the three groups of participants

ltem	Groups	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
	I	54	11	0	1	1
		3	10	5	1	0
	III	10	10	3	0	0
	I	15	34	14	3	1
		2	9	7	1	0
	111	6	6	5	5	1
	<u> </u>	24	33	6	3	1
		4	9	4	2	0
	Ш	4	10	4	5	0
	I	1	9	5	34	18
	II	1	1	7	6	4
		0	3	3	8	9
	I	8	34	20	2	3
		2	9	8	0	0
		1	7	11	3	1
	I	43	18	0	5	1
	II	2	6	8	3	0
		10	9	2	1	1
	I	3	8	30	23	3
	II	0	3	9	7	0
	III	1	3	9	10	0
	I	6	2	3	8	48
		0	3	10	2	4
		0	2	4	8	9
	I	3	6	6	12	40
		1	2	8	5	3
		2	2	3	7	9
	I	2	10	8	38	9
0		1	2	10	4	2
		2	2	2	10	7
	I	4	22	33	5	3
1		3	5	8	2	1
		4	7	7	5	0
	I	46	11	6	2	2
2		5	6	7	1	0
		12	7	3	0	1
	I	48	9	7	1	2
3	!	5	7	5	2	0
J.		7	12	3	0	1

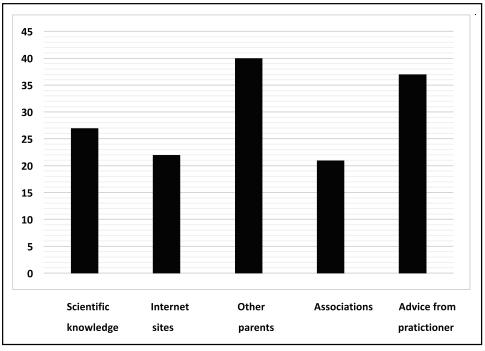


Fig. 1. Sources used to choose the treatment for children with ASD

11 ("*ABA can be used successfully with older children and teenagers*"), since many parents have started ABA treatment early, they may be doubtful about the effectiveness of a late-start treatment. The answers to item 10 ("*ABA places pressure on family life*") are substantially consistent with the results of other research (see Strauss *et al.* 2012).

Group II participants, however, recognize ABA as an individualized treatment (item 1); as an approach of choice (items 2 and 5); as a treatment that affects necessary and socially significant skills (items 3 and 12); and do not agree with reductive and stereotypical statements about ABA treatments (items 4, and 9). There are, however, discrete areas of uncertainty in several items (for example, items 6: "The focus of ABA programmes is on increasing positive behaviour rather than on behaviour problem"s; 8: "ABA is based on a highly structured curriculum that every child has to follow"; 9: "Children who have been taught using ABA methods often learn mechanically, without a real understanding"; and 10: "ABA places pressure on family life"). This probably stems from the fact that these parents have neither direct experience nor specific training on the subject.

Group III participants also recognize ABA as an individualized treatment (items 1 and 8); as an approach of choice (item 2); as a treatment that intervenes on necessary and socially significant skills (items 3 and 12); and disagree with reductive and stereotypical statements about ABA treatments (items 4, 6 and 9). Items 5, 7 and 11 show greater uncertainty. The uncertainty around item 5 (*"ABA is an approach chosen by parents who want to provide the best treatment for their children"*) may arise from the fact that participants do not have children; while regarding item 7 ("Once you start on an ABA programme, it is very difficult to reduce or stop the programme") it may have never been thought about. The answers to item 11 ("ABA can be used successfully with older children and teenagers") may be affected by the fact that the need for early intervention is often emphasized in education and training. The answers to item 10 are substantially consistent with the results of other research (see Strauss *et al.* 2012).

The answers to item 13 (*"In general, I consider ABA treatments positively"*) are more detailed: see paragraph "Analysis of satisfaction with ABA treatments".

In summary, the responses largely reflect the subjective experience and socio-demographic characteristics of the three groups of participants.

Group I was then asked the above-mentioned three questions.

With respect to the sources used to choose treatment for their children (*"When searching for treatment for my child, I based myself on*"), the answers are shown in Figure 1.

The largest number of responses (n = 40) concerned the consultation of other parents living or having lived the same experience; followed by advice provided by specialists physicians in the field (37 responses); 27 subjects referred to available scientific knowledge; 22 searched for information from websites; and 21 looked for information from associations.

With respect to the question: "*Has your child followed or is currently following an ABA program*?", 57 children (85%) have followed or are following an ABA treatment, and 10 (15%) have not. Compared to the reasons why 10 children have not had ABA treatment, it should

be noted that five were quite old (19.4, 22, 22.1, and 28.5 years old) and therefore probably did not have the opportunity to access ABA treatment; two were 3 and 3.3 years old, and therefore probably had an early diagnosis but did not start ABA treatment yet.

Analysis of ABA treatment satisfaction

In general, recommending a treatment (or Service) to other people is an indication of their satisfaction with the treatment (or Service). In turn, satisfaction is an index of perceived quality (De Ambrogio, 2000). With this in mind, the question "Would you personally recommend to others the opportunity for ABA treatment?" has been included: 57 participants answered; 2 answered No, while 8 "Don't know". Comparing the answers to the previous question with those to question 13: In general, Group I assess ABA treatments positively (Very agree or agree=57; Don't know=7, and Disagree or very disagree=3), no significant differences emerge from the Fisher test (p=0.99). This supports the consistency of Group I participants' responses, and confirms their substantial acceptance of the ABA approach. However, comparing the answers to question 13 of those who followed an ABA treatment and those who did not, significant differences emerge in the Mann-Whitney test (U=471.5; z=4.13; p<0.0001). Having had direct experience of the application of an ABA intervention probably made it possible to evaluate its effectiveness in practice.

Finally, even if the majority of participants (n = 88, 80.7%) positively evaluate ABA treatments, comparing the answers to question 13 among the three groups, significant differences emerge: Group I, median=1 (Strongly agree); Group II, median=4 (Disagree); Group III, median=3 (Don't know); Kruskal-Wallis test: $\chi^2_{(2)}$ = 15.33, *p*<0.0001. Overall, participants with children with ASD appreciate ABA treatments more than the other two groups.

DISCUSSION

To our knowledge, this is the first survey carried out in Italy, aimed at investigating knowledge and beliefs about ABA treatments for ASD in a heterogeneous group of participants and the degree of satisfaction and the sources used to look for treatment in parents of children with ASD.

We have highlighted the appropriateness of the knowledge and the similarities and differences between the groups. Firstly, an important element is that all groups widely agree on the consideration of ABA as an individualized treatment; as an approach of choice; as a treatment that intervenes on socially significant skills; and do not agree with reductive statements and stereotypes about ABA approaches. This data is positive and indicates a certain degree of knowledge and a lesser adherence to reductive concepts, often derived from theoretical non-behavioral models. In particular,

statements regarding program rigidity or mechanical learning seem to have less grip, especially in parents with children with ASD who have undergone such treatments. The significant disagreement of Group I regarding parents' additional burden (stress) highlights how the initial commitment required to develop some skills to manage problematic behaviors and promote functional ones positively affects the behavior of the children and leads to a reduction of perceived stress. Certainly, the need to educate themselves, often through parent training, and the commitment to relate to children with ASD according to behavioral principles, can be challenging at first. Therefore, during the early stages of parent training, it may be useful to inform parents about how behavior is expected to change. The results regarding the item "ABA can be used successfully with older children and teenagers" indicates a discreet disagreement between the groups, suggesting that the applicability of ABA across the lifespan is not widely known. For this reason, it would be important to highlight it in dissemination and training activities. We reported some areas of uncertainty, with Group II presenting more "Don't know" answers. As highlighted above, while for Groups I and III the greatest uncertainty is recorded for item 5, 7 and 11, for Group II the greatest uncertainty concerns items 6, 8, 9 and 10. While Group I participants with some direct or indirect experience of ABA treatments do not present uncertainty about items related to the main characteristics of ABA and the effects on the family load; parents with healthy children - who probably only know ABA thanks to dissemination activities related to ASD - are uncertain about such fundamental items and the repercussions on family load. These results suggest the need to emphasize these aspects in ABA's dissemination activities properly.

As for the appreciation of ABA treatments, parents with children with ASD evaluated them more positively than the other two groups; in addition, parents with children with ASD who have followed or are following an ABA intervention give a more positive assessment than parents with children with ASD who did not follow him. Having had a direct experience of applying an ABA intervention is probably the most important variable associated with this result. How people perceive ABA treatments seems an important element for the dissemination of an evidence-based approach; from this point of view, the role of parents with children with ASD can be relevant, also taking into account that parents tend to refer to other parents to seek treatment.

Since information about treatments is more accessible than in the past, and in the light of the increased role that parents have in respect of intervention choices, it becomes important to deepen the role of parental beliefs in decision-making. Not being able to rule out that some parents with children with autism have been following specific courses or parent training, other studies may help to clarify whether more positive beliefs about ABA contributed to parents' intervention choices or whether exposure to ABA interventions may lead to more positive beliefs about ABA.

The study has some limitations. The sample size is not large, especially for two groups and certainly it would be appropriate to extend the research to other segments of the population. Moreover, some comments are speculative, but reasonable with respect to the characteristics of the participants in this survey. The survey, however, provides concrete suggestions for dissemination activities of training.

REFERENCES

- 1 American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders. 5th ed. Arlington (VA): Author.
- 2 Bartakovičová K, Keményová P, Siklenková L, Ostatníková D, Babinská K (2019). Sleep disturbances in children with autism spectrum disorder. Act Nerv Super Rediviva. 61(2): 41–48.
- 3 Cronbach LJ (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*. **16**(3): 297–334.
- 4 De Ambrogio U (2000). La rilevazione della qualità percepita (The detection of perceived quality) In: Ortigosa ER, editor. La valutazione di qualità nei servizi sanitari. (Quality assessment in health services). Vol 21. Milano: FrancoAngeli. ISBN: 978-8846421623.
- 5 Denne LD, Hastings RP, Hughes JC (2017). UK parents' beliefs about applied behaviour analysis as an approach to autism education. *Eur J Spec Needs Educ.* **32**(4): 543–555.
- 6 Dillenburger K (2011). The Emperor's new clothes: Eclecticism in autism treatment. *Res Autism Spectr Disord*. **5**(3): 1119–1128.
- 7 Di Pasquale D (2016). La diagnosi di autismo in età precoce (The diagnosis of autism at an early age). Psichiatria Oggi. XXIX(1): 100–107.
- 8 Doehring P, Reichow B, Palka T, Phillips C, Hagopian L (2014). Behavioral Approaches to Managing Severe Problem Behaviors in Children with Autism Spectrum and Related Developmental Disorders. *Child Adolesc Psychiatr Clin N Am.* **23**(1): 25–40.
- 9 Green VA (2007). Parental Experience with Treatments for Autism. J Dev Phys Disabil. 19(2): 91–101.
- 10 Green VA, Pituch KA, Itchon J, Choi A, O'Reilly M, Sigafoos J (2006). Internet survey of treatments used by parents of children with autism. Res Dev Disabil. **27**(1): 70–84.
- 11 Iadarola S, Levato L, Harrison B, Smith T, Lecavalier L, Johnson C et al. (2018). Teaching Parents Behavioral Strategies for Autism Spectrum Disorder (ASD): Effects on Stress, Strain, and Competence. J Autism Dev Disord. 48(4): 1031–1040.
- 12 Keenan M, Dillenburger K, Doherty A, Byrne T, Gallagher S (2010). The Experiences of Parents During Diagnosis and Forward Planning for Children with Autism Spectrum Disorder. J Appl Res Intellect Disabil. 23(4): 390–397.
- 13 Koegel, LK, Ashbaugh K, Koegel RL (2016). Pivotal Response Treatment. In: Lang R, Hancock TB, Singh NN, editors. Early Intervention for Young Children with Autism Spectrum Disorder. Switzerland: Springer International Publishing. ISBN: 978-3-319-30925-5, p. 85–112.

- 14 Kuravackel GM, Ruble LA, Reese RJ, Ables AP, Rodgers AD, Toland MD (2018). COMPASS for Hope: Evaluating the Effectiveness of a Parent Training and Support Program for Children with ASD. *J Autism Dev Disord.* **48**(2): 404–416.
- 15 Lai MC, Lombardo MV, Baron-Cohen S (2014). Autism. Lancet. 383(9920): 896-910.
- 16 Larsson EV (2013). Is applied behavior analysis (ABA) and early intensive behavioral intervention (EIBI) an effective treatment for autism? A cumulative history of impartial independent reviews. *Autism.* **27**(1): 168–1792.
- 17 Lovaas OI (1987). Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children. J Consult Clin Psychol. **55**(1): 3–9.
- 18 Maye MP, Kiss I, Carter AS (2017). Definitions and classification of autism spectrum disorders. In: Zager D, Cihak DF, Stone-Macdonald A, editors. Autism Spectrum Disorders: Identification, Education, and Treatment. New York: Routledge. ISBN: 9781138015708, p. 1–23.
- 19 McPhilemy C, Dillenburger K (2013). Parents' experiences of applied behaviour analysis (ABA)-based interventions for children diagnosed with autistic spectrum disorder. Br J Spec Educ. 40(4): 154–161.
- 20 Odom SL, Boyd BA, Hall LJ, Hume K (2010). Evaluation of comprehensive treatment models for individuals with autism spectrum disorders. J Autism Dev Disord. **40**(4): 425–436.
- 21 Peters-Scheffer N, Didden R, Korzilius H, Sturmey P (2011). A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with Autism Spectrum Disorders. *Res Autism Spectr Disord.* **5**(1): 60–69.
- 22 Reed P (2016). Interventions for Autism: Evidence for Educational and Clinical Practice. Chichester (UK): John Wiley & Sons. ISBN: 978-0-470-66991-4.
- 23 Reichow B (2012). Overview of Meta-Analyses on Early Intensive Behavioral Intervention for Young Children with Autism Spectrum Disorders. J Autism Dev Disord. 42(4): 512–520.
- 24 Salomone E, Beranová Š, Bonnet-Brilhault F, Briciet Lauritsen M, Budisteanu M, Buitelaar J et al. (2016). Use of early intervention for young children with autism spectrum disorder across Europe. *Autism.* **20**(2): 233–249.
- 25 SINPIA (2005). Linee Guida per l'autismo: Diagnosi e Interventi. (Guidelines for autism: Diagnosis and Interventions). Trento: Erickson. ISBN: 8879468278.
- 26 Strauss K, Vicari S, Valeri G, D'Elia L, Arima S, Fava L (2012). Parent inclusion in Early Intensive Behavioral Intervention: The influence of parental stress, parent treatment fidelity and parentmediated generalization of behavior targets on child outcomes. *Res Dev Disabil.* **33**(2): 688–703.
- 27 Truzoli R (2011). ABA e riabilitazione psichiatrica (ABA and Psychiatric rehabilitation). Milano: FrancoAngeli. ISBN: 978-8856841824.
- 28 Tzanakaki P, Grindle C, Hastings RP, Hughes JC, Kovshoff H, Remington B (2012). How and why do parents choose early intensive behavioral intervention for their young child with autism?. *Educ Train Autism Dev Disabil.* **47**(1): 58–71.
- 29 Wong C, Odom SL, Hume KA, Cox AW, Fettig A, Kucharczyk S et al. (2015). Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder: A Comprehensive Review. J Autism Dev Disord. **45**(7): 1951–1966.

Annex 1. Questionnaire on knowledge on ABA as a treatment for ASD and on satisfaction with ABA treatments

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
1. ABA is highly individualised and tailored to meet a child's needs					
2. ABA is relevant for children with autism in any Western culture					
3. ABA is simply trying to teach to children with autism the skills that all children need to learn					
4. ABA does not lead to proper learning because it is based on rewarding and bribing children to do things					
5. ABA is an approach chosen by parents who want to provide the best treatment for their children					
6. The focus of ABA programmes is on increasing positive behaviour rather than on behaviour problems					
7. Once you start on an ABA programme, it is very difficult to reduce or stop the programme					
8. ABA is based on a highly structured curriculum that every child has to follow					
9. Children who have been taught using ABA methods often learn mechanically, without a real understanding					
10. ABA places pressure on family life					
11. ABA can be used successfully with older children and teenagers					
12. ABA promotes socially significant behaviours, such as relationships with others or language					
13. In general, I rate ABA treatments positively					