

Parents of Children with Autistic Spectrum Disorder (ASD) as Co-therapists: The Therapists' View

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Studies on the evaluation by therapists of parental behavior towards their children with Autistic Spectrum Disorder (ASD) and towards the therapists of their children are scarce. They are necessary, however, for enabling parents to become co-therapists. The present study's purpose was the evaluation by therapists of the behavior of parents towards their children, of their relationship to therapists, and therapy outcome. The sample consisted of 178 parents of 89 children (72 boys) with ASD, who underwent intensive early intervention at a day centre for developmental disabilities. The professional team completed a questionnaire, separately for the mother and father, evaluating the parental attitude towards their children and towards the therapists. The behavior of parents was less satisfactory than expected. The fathers had difficulties in understanding their child's problems, and had unrealistic expectations; mothers' behavior towards their children and therapists was better than the fathers'. Mothers had difficulty mostly in the management of the child's behavior, and did not do well with feeding. It might be difficult for every parent to become co-therapist. Understanding the child's difficulties by the mother, adequate handling of feeding and homework, were statistically significant in the good outcome of therapy.

Keywords: Autistic Spectrum Disorder (ASD), parents, co-therapists, stress, expectations, collaboration, homework

Introduction

The management, of the children with ASD by their parents, has drawn the interest of clinicians and researchers for a long time (Davis & Carter, 2008; Miranda, Mira, Berenguer, Rosello, & Baixauli, 2019;

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Solomon & Chung, 2012). It was initially considered that autism was the result of poor parental handling of the child (Kanner, 1949; Bettelheim, 1967). Bettelheim (1967), in his book “*The Empty Forest*”, claimed that detached and cold parents were responsible for their child’s autistic behavior. These theories do not stand anymore. More recent views consider that autism is a multi-factorial disorder contributing it to both genetic and environmental factors. Often the problems start in the early development of the brain, as early as the third month of pregnancy. Recent studies have focused on how to help parents become competent in dealing with their children’s difficulties. Ambition of the therapists and parents has been the development by parents of skills that will systematically guide them to be equal partners in the therapeutic management of their children (Burrell & Borrego, 2012; Edwards, Brebner, McCormack, & Macdougall, 2016; Kalyva, 2013). Basic factors that influence the collaboration between parents and therapists are: early diagnosis and beginning of therapy, the parent’s mental state (level of stress and anxiety), and available programs to help them develop behavior management skills.

Early Diagnosis and Beginning of Therapy

The importance of early diagnosis and early beginning of therapy is widely accepted. It is important because it reduces anxiety and times spent by the parents seeking different services (Bonis, 2016). Early start of therapy reduces difficulties of inappropriate handling. Programs such as Early Start Denver Model (ESDM) for children with autism (Rogers & Dawson, 2010) and Pivotal Response Treatment (PRT) for autism (R. L. Koegel & L. K. Koegel, 2006) are widely used. Studies such as those by Vivanti et al. (2014) and Colombi et al. (2018) have verified the importance of the Early Start Denver Model. A meta-analysis study by Fuller, Oliver, Vejnoska, and Rogers (2020) had interesting findings. It involved 12 studies which met strict criteria and included 640 children ages nine months to five years (average 2, 51 years), from five different countries. These studies showed that in comparison to other programs the children in the ESDM programs made more gains in cognition and language but there was no difference in autism symptoms, social communication, adaptive functions, and repetitious behavior.

Mental State of Parents (Stress)

The diagnosis of ASD in a young child has an intense effect on the psychological and physical state of the parents. Stress, sadness, despair, and physical symptoms have been observed even in cases of mild autism. Stress particularly in the mothers of ASD children has been found at every level of autism. It has been found in parents of high functioning children (Pisula & Dörsmann, 2017; Zhou, Liu, Xiong, & Xu, 2019), in parents before the diagnosis of ASD (Des Champs et al., 2019) and in parents of infants (Davis & Carter, 2008).

In the study by Davis and Carter (2008), it was found that delays in children’s development were associated with parental stress. Furthermore, problems in regulating the children’s behavior were linked to mother’s stress while externalizing problems were linked to stress of the father. Similar results showed the study by Miranda et al. (2019). Mothers’ stress was linked to their children’s behavior problems, while there was no association with coping strategies and social support.

Zissi and Barry (2006), after reviewing studies from 1970 to 2006 on factors affecting the mental health and quality of life of parents of children with ASD, reported that these were related to various factors that included: (a) the socio-economic status of the family, the type of the family, the severity of autism and access to therapeutic services; and (b) socio-psychological processes such as characteristics related to understanding autism, mental resilience, attitude towards disability, and quality of bonding.

There are studies however that show different results. Appropriate announcement of the diagnosis of ASD with clear information and support brings usually relief to parents (Crane, Chester, Goddard, Henry, & Hill, 2016). Parent counseling, behavior management programs and friends seem to help reduce anxiety and stress and prepare the parents to be more involved in their child's therapy intervention (Drogomyretska, Fox, & Colbert, 2020, Spain et al., 2017).

Parent Educational Programs

Education and support for parents of children with ASD is considered very important in the process of parents becoming actively involved in their child's difficulties. Various methods to assist parents to become co-therapists have been developed in recent years in several countries (Garbacz, McIntyre, & Santiago, 2017; Hodgetts, Zwaigenbaum, & Nicholas, 2015; Leadbitter et al., 2018).

There is, however, less knowledge on the quality of parent education programs. Dawson-Squibb, Davids, Harrison, Molony, and De Vries (2020), reviewing 32 education programs outside the US found diversity among them. A large proportion 86.4% of those surveyed described positive results to the objectives of the programs and only two of the programs were reported as negative. However, the quality of the programs was only 27% satisfactory and on evidence based research.

The Therapist's View

The basic factors that influence active participation of parents, e.g., early diagnosis and therapy, mental state of parents, and education and support of parents are well researched. For parents to become co-therapists, however, is not a simple process. Little is known, regarding how to best engage and support the parents. In a study by Centles, Nicholas, Jack, McKibbon, and Szamarti (2019), it is stated that defining concerns about the child and the disorder, informing the self (which involves interacting with deferent information sources), and adapting emotionally, these three processes and their continuous interaction account for parents' evolving readiness and motivation. This is still on a theoretical basis. Practical recommendations of the cooperation of parents with the therapists of their children have been under-searched. Also, in most surveys, it is the parents who answered the questionnaires. We need studies that will take into consideration the views of the therapists. Such studies may add guilt to already long suffering parents. Nevertheless, there cannot be real cooperation unless we examine the issues from the therapist's point of view as well. In most investigations, informant is usually the mother. Bearing in mind that, in recent years, fathers have been actively involved in the therapeutic intervention of their children; there is a need to include them as well. An important question to be answered is: Are all parents able to become co-therapists? The present study was the first step towards answering this question. It involved evaluation, by the team of therapists of a Day Centre, of the behavior of parents (mother and father) towards their children with ASD, their cooperation with therapists and the relation of these factors with the outcome of the children's therapy. In subsequent studies, more practical ways of involving parents in therapy will be investigated.

Hypotheses

The following hypotheses were raised:

1. All parents are able to become co-therapists.
2. There is no difference between fathers and mothers in their behavior towards their children.
3. The collaboration between parents and therapists is satisfactory.

Materials and Methods

Sample

The sample consisted of 178 individuals who were the parents of 89 children (72 boys and 17 girls) with ASD. The average age of children at admission was 40 months (3.33 years) and the average duration of intervention was 41 months (3.44 years).

The professional team of 11 therapists from all specialties took part in the study: psychologists, speech language therapists, occupational therapists, social workers, and a special education teacher. All therapists worked with the children and remained the same during all the years of operation of the Centre. Each child received individual or group intervention from at least five therapists. The therapists met once a week for one hour, and filled out a questionnaire for each child. The evaluation was done separately for the mother and father. The therapists answered the questions with “Yes” or “No”; there was no gradation of the answers. One answer was considered valid when 90% of therapists agreed. Some questions required looking up to the therapists’ notes in the files of the children. The task of completing the questionnaires by the group of therapists lasted one year.

It was very difficult to find a suitable questionnaire in the literature, so we had to create our own. The questionnaire covered the following sections: (1) Demographics; (2). Evaluation by the therapists of co-occurring difficulties with autism; (3) Child care by parents; (4) Emotional attitude of the parents; (5) Management of child’s difficulties; (5) Collaboration with therapists; and (6) Outcome of intervention.

Information about the parents was taken from the notes of the social workers. Intelligence of the child and the level of functionality of the child were taken from the files of the children. In the files was information for each child from the CARS, VINELAND, and RAVEN, and, in 32 children, there was information from the ADOS. Also, for each one of the children, there was a diagram of a special tool EDALFA created by the team of the Day Centre (Kotsopoulou, Georgiou, Gyftogianni, & Gyftogianni, Sakellari, Troupou, Florou, 2014), assessing the level of functioning of the child in seven sections: movement (gross, fine), cognition, language (receptive expressive), psychokinetic, everyday skills, play, and other.

Results

The Statistical Package Social Sciences (SPSS) was applied for the analyses. Descriptive statistics with frequency tables for percentages were used. To evaluate the association between different parameters χ^2 control was performed. The procedure followed was: statistical analysis, creation of tables and data in quantitative form, data procession and interpretation and description of results.

Table 1

Descriptive Statistics

Demographic characteristics

Children’s sample: 89 children (72 boys and 17 girls)

Admission treatment time: Mean in months : 41 (Range 18-137 months)

Parents sample: 84 fathers (5 no information available)—85 mothers (4 no information available)

Mean age : fathers 40.15 years old—mothers 34.82 years old

Age to the program: 40 months

Table 2

Descriptive Statistics

Level of parents education—Frequencies
Illiterate: 1 father—0 mothers
Primary School: 8 fathers—11 mothers
High School: 33 fathers—26 mothers
College/University: 29 fathers—31 mothers
Other: 10 fathers—13 mothers
Missing: 8 fathers—8 mothers

Table 3

Descriptive Statistics

Socioeconomic Level—Frequencies
Unemployment: 4 fathers—46 mothers
Self employee: 36 fathers—3 mothers
Clerical worker: 39 fathers—34 mothers
Other: 4 fathers—2 mothers
Missing: 6 fathers—4 mothers

Table 4

Descriptive Statistics

Level of functionality
Low functionality: 27 children
Middle functionality: 30 children
High functionality: 32 children

Table 5

Descriptive Statistics

Level of intelligence	
Clinic-Raven children's intelligence	2 very high
	18 average
	10 low average
	5 marginal
	12 mental retardation
	33 not assessable
	9 there was no information

Table 6

Descriptive Statistics

Co-occurring psychiatric problems—Percentages
Anxiety: 85.1%
Attention difficulties: 67%
Phobias: 39%
Aggression: 32%
Irritability: 77.5%

Table 7

Child Care

Percentages	Percentage (%)
Personal hygiene	59.65
Sleep program	40.4
Feeding	43.8

A large percentage of children did not have sleep program and a large percentage of parents had difficulty managing feeding difficulties.

Table 8

Parental Emotional Attitude

Percentages	Fathers (%)	Mothers (%)
Acceptance	33.7	56.2
Abuse	39.3	11.1
Neglect	52.8	32.9

The mothers' emotional attitude towards their children was better than the fathers.

Table 9

Managing Child Difficulties

Percentages	Fathers (%)	Mothers (%)
Understanding child's difficulties	24.7	43.8
Adjustment to the needs of the child	24.7	43.8
Realistic expectations	12.4	32.6

Both parents had unrealistic expectations.

Table 10

Collaboration With Therapists

Percentages	Fathers (%)	Mothers (%)
Compliance to therapist recommendations	27.0	52.8
Stability and consistency in attendance	55.1	85.4
Homework	14.6	46.1

Fathers had difficulty in complying with therapist's recommendations.

Table 11

Therapy Outcome

Frequencies (Numbers)	N
In progress	11
Good	31
Moderate	13
Unsatisfactory	15
We do not know	3
Interrupted	13
Missing of system	3
Total	89

Progress of the children was satisfactory (31 good, 13 moderate), 15 unsatisfactory, 13 interrupted, 3 missing, 3 we did not know at the time. (today we know. One of them did well, one moderately well and one left the province saying she will come back)

At this point, in the statistical analysis, Chi-square χ^2 independence control method was used, examining in more detail the answers to the questionnaire and how they relate to the gender of the parents and the outcome of therapy.

Gender

Table 12

Gender

Variables	Pearson Chi-Square	Asymp. Sig. (2-sided)
Hygiene	0.005	0.944
Sleep	0.839	0.360
Feeding	0,000	0.995
Acceptance	1.115	0.283
Absence of abuse	0.851	0.356
Absence of neglect	2.448	0.118
Difficulties understanding	1.407	0.236
Adjustment	1.267	0.260
Expectations	4.619	0.032
Compliance	3.348	0.067
Homework	12.519	0.002
Attendance	1.815	0.178

Only *expectations of the parents and homework* related with the gender, none of the rest of variables had any association with it.

Outcome of Therapy

Table 13

Therapy Outcome

Variables	Pearson Chi-square	Asymp. Sig. (2-sided)
Intelligence	53.780	0.001
Socio-economic level	12.858	0.613
Level of function child	44.996	0.000
Occupational status father	41.586	0.020
Father educational level	13.561	0.969
Child gender	6.952	0.224
Occupational status mother	22.735	0.593
Mother educational level	22.907	0.293
Mother acceptance	9.642	0.086
Absence of mother abuse	4.772	0.444
Absence of mother neglect	4.721	0.451
Difficulties understanding mother	12.073	0.034
Mothers adjustment	4.137	0.530
Mothers expectations	8.423	0.134

Table 13 to be continued

Mothers compliance	4.430	0.489
Homework mother	19.312	0.036
Attendance mother	1.188	0.946
Feeding	12.102	0.033

The professional status of the father, the level of functionality of the child, the intelligence of the child, as well as understanding of the difficulties by the mother, homework by the mother and feeding were statistically significant in the good outcome of therapy.

Discussion

The results of the study in relation to the hypotheses set at the beginning: (a) All parents are able to become co-therapists; (b) There is no difference between fathers and mothers in their behavior towards their children; and (c) The collaboration between parents and therapists is satisfactory, showed the following:

Are all parents able to become co-therapists?

The behavior of the parents in the areas personal hygiene, stability and consistency of attendance and absence of abuse was within the average range. The area with the lowest scores was management of the child's difficulties (understanding and adjustment to the child's needs, and expectations for the future of the child).

In a study by De Pape and Lindsay (2015), which involved review of 31 articles, six stages that parents of children with ASD go through were identified: (a) before the formal diagnosis (a period of concern, worry and questions of what is happening to their child); (b) diagnosis: involving relief or grief, guilt or blaming others; (c) adjustment of the family to the child's behavior; (d) navigating the system: to find better services for their child; (e) empowerment of the parents (to take their child's fate on their hands with self teaching and development of strategies); and (f) moving forward (acceptance of the diagnosis and placing realistic targets such as for the child to become independent and later to find a job). At the Day Centre, we accept children very young (average age three years four months) and the parents are still at the stage (c) of acceptance and adjustment to the diagnosis, which explains perhaps the poor scoring of both parents in managing the children's difficulties.

Regarding the emotional attitude of parents towards their children (see table 8), the fathers scored low. There were even cases of abuse. The abuse was corporal; no cases of sexual abuse were recorded. Although, in the Greek culture, particularly in the provinces, mothers play the dominant role in bringing up the children with ASD (Kotsopoulos & Papadaki, 2012), the fathers of the present study exceeded the expectations. They often refused counseling and were negative to therapists' suggestions. The mothers' behavior, on the other hand, towards their children was better than the fathers' but still behind of what was expected. When a child is accepted at the Day Centre for therapy, to all mothers is offered counseling, by the social workers or the psychiatrists, weekly or every second week, according to their needs. Also, in regular spaces, meetings of the parents are arranged to discuss the child's progress. Furthermore, the targets of therapy as they come out hierarchically from the completion of EDALFA (Kotsopoulou et al., 2014) as well as, specific homework after the sessions, are given to each mother to work at home if and when they could. Despite all this, a number of mothers still had difficulties in understanding their child's problems, had unrealistic expectations and a few of them neglected and even abused their children. It seems not all parents are suitable to become co-therapists.

The expectations (see table 9) for the future of the child varied, being at times over positive and other times very dark. The importance of expectations of parents for the future of their children cannot be overestimated. Bush et al. (2017) assessed the relation between expectations of parents of 121 children with ASD aged four to seven, and their success in school. Seven tests and questionnaires were administered, considering at the same time parents, family, teacher and school. Substantial relationship was observed between the expectations of the parents and academic performance of the children. Thomas et al. (2017) studied the effect of psychopathology of 24 parents on their expectations for the future of their children. He assessed symptoms of psychopathology as well as the seriousness of the child's autistic symptoms. The study showed that parents with the most serious psychopathology and with children with severe autism had the lowest expectations. In the present study, the psychopathology of the parents was not assessed.

Co-operation Between Parents and Therapists

Regarding co-operation between parents and therapists (see table 10), the mothers on the whole did better than the fathers and, in two sections *expectations and homework*, the difference was statistically significant. The answer to the second hypothesis "there is no difference between fathers and mothers in their behavior towards their children" was negative. Negative were, also, the findings to the third hypothesis "The collaboration between parents and therapists is satisfactory". The fathers had difficulty complying with therapists' recommendations. A study by Kalyva (2013) examined the relationship between professionals of mental health and parents of children with ASD and the difference in their co-operation after reading the "Partnership Protocol", an international protocol on collaboration based on codes of ethics and written in simple language. Forty professionals participated, of ages 26 to 55 years and 40 parents (33 mothers and seven fathers) of the same ages. The results showed that the relationship between parents and professionals was problematic. Therapists complained about the demands of parents who were not keen to participate actively in the treatment of their children. The parents, on the other hand, blamed therapists for lacking interest in taking decisions for the future of their children, with them as equal partners. After reading the Partnership Protocol and agreeing on the type of cooperation, interpersonal relations and collaboration improved.

Outcome of Therapy

Considering all the variables examined (see table 12) intelligence of the child, level of functionality, and father's occupation, it had a relationship with positive outcome of therapy. These are factors that have been found in many studies to play a role in the positive outcome of therapy. In the present study, understanding by the mother of the child's difficulties, feeding management and homework were also related to good outcome of treatment. It is well known that 60% to 90% of the children with ASD have feeding difficulties (Bruns & Thompson, 2011). The symptoms range from dysphagia in infants (Kotsopoulou, Gasteratos, Gyftogianni, Gyftogiani, Troupou, 2012) to over picking later on (Beighley, Matson, Rieske, & Adams, 2013). Most of the parents (see table 7) had difficulties with feeding but when they managed well; it had a positive outcome to therapy. Home work and its relation to good outcome of therapy are interesting but not surprising. "Homework" means good working level of the child, good working relationship with the therapists, and absence of serious psychological or psychiatric problems of the parents, free time of the parents and adequate application of the professional recommendations. Mothers helped children mostly with homework. Homework is not always

helpful, if the parents are not careful it could create resistance and negative interaction. Nevertheless, it is important for positive outcome of therapy and should be studied in more detail.

Co-occurring to Autism Difficulties

According to therapists (see table 6), co-morbidity between autism and other difficulties was high. In three of them, anxiety (85%), irritability (77.5%), and attention difficulties (67%), it was very high. Most of the children had more than one co-occurring problem. This is not surprising as a number of studies have shown high prevalence of co-occurring difficulties in autism particularly with externalizing problems. In a study of 101 children (Salazar et al., 2015) aged 4.5-9.8 with ASD, 90.5% of the sample presented with the following difficulties: anxiety, phobias, depression, attention deficit hyperactivity disorder (ADHD), oppositional disorder and conduct disorder. A number of studies with older children and adolescents with ASD showed also high levels of psychiatric problems, e.g., depression and irritability (Andersen, Skogli, Hovik, Egeland, & Oie, 2015; Joshi et al., 2014, Mikita et al., 2015), as well as ADHD (Levy et al., 2010).

Conclusion

The answers to all three hypotheses were negative. Managing child's difficulties had the lowest scores for both parents. The mothers did better than the fathers. The fathers were not well informed about the disorder, and had unrealistic expectations about therapy; a number of them neglected and even corporally abused their children. The mothers' behavior overall and their cooperation with the therapists was acceptable. Management of feeding and homework were positively related to good outcome of therapy.

Recommendations

For the parents to become co-therapists and equal partners in decision-making about their child, the therapists have to understand the parents' mental state, to help them know the services available for their support, to encourage early start of therapy for the child, to develop or use educational programs for them and to try to understand the parents' attitude and expectations for their children. Educational programs such as CYGNET (Multi-professional Team of Autism of Bradford, 2002) as well as evidence based research educational programs (Sankey, Dergury, Clement, Ilg, & Cappe, 2019) could be used. Emphasis may be in understanding the father's attitude and encourage his participation in educational programs. More practical questions on decision-making and homework will be addressed in future studies.

The Contribution of the Study

Studies on the evaluation by therapists of parental behavior towards their children with ASD and towards the therapists of their children are scarce. They are necessary for enabling parents to become co-therapists. Parental understanding of the needs of their children and their expectations for the future play considerable role in enabling the parents to become co-therapists. Homework is important for positive outcome of therapy and should be encouraged.

Limitations of the Study

It was an empirical study. The questionnaire lacked detailed information. The large number of therapists made gradation to the answers to the questions of the questionnaire difficult.

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