

Impact of Short Term Psycho Educational Intervention in Developing Knowledge and Awareness of Parents Having Autistic Children

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Abstract

Background: Autism is a behaviorally defined disorder having significant impairments in social interactions and facial processing. Recent findings suggested that, the information from research is not been properly disseminated to parents of person with autism spectrum disorders (ASD). Therefore the aim of the present study was to evaluate the effectiveness of constructed psycho educational intervention in developing knowledge and awareness of parents of children with autism spectrum disorders.

Methods: Participants in this quasi experimental study comprised of 23 families were selected from Al-Basma and Alragaa center for mentally handicapped children at ShebinElkom and Tantacity, Egypt. They were pre and post assessed with psycho-education sheet developed by the researchers. The intervention was conducted in 8 sessions, twice weekly for a period of 30 days and one hour per session followed by post assessment.

Results: Significant results were found between pre $0.34906 + 1.67$ compared with $0.3549 + 1.72$ in post assessment data and $t = -38.21$ and $P < 0.05$. Also, there was no significant difference between the socio-demographic and personal characteristics of target sample and their level of knowledge and awareness in the pre and post assessment data.

Conclusion and Recommendation: The findings were indicated the beneficial effect of psycho-educational intervention in developing parents' knowledge and awareness regarding the nature of autism spectrum disorders, dispelling their misconceptions, and meeting their needs about referral resources in the community. Therefore, further researches in the field of therapeutic intervention for autistic children with involvement of their families are recommended.

Keywords: Autism Spectrum Disorders, Psycho Education Intervention, Parents of Autistic Children

Introduction

The autism spectrum disorders are more common in the pediatric population. Autism spectrum disorder (ASD) is characterized by deficits in social interactions and communication skills, as well as the presence of stereotypic and repetitive behaviors (DMS-IV-TR; American Psychiatric Association [APA] [1]. Currently in the United States, 1 out of every 110 children has an ASD diagnosis (Autism and Developmental Disabilities Monitoring [ADDM]). Recent reports suggest that the prevalence of autism in the Arab world ranges from 1.4 cases per 10,000 children in Oman to 29 per 10,000 children in the United Arab Emirates Al-Farsi, Al-Sharbati and Eapen [2, 3]. While these rates are lower than those of the developed world, which are 39 per 10,000 for autism and 77 per 10,000 for all forms of autism spectrum disorders (ASD), it does not necessarily mean the condition is less prevalent in the Arab world.

This wide range of prevalence points to a need for earlier and more accurate screening for the symptoms of autism. The earlier the

disorder is diagnosed, the sooner the child can be helped through treatment interventions. . Parents are usually the first to notice unusual behaviors in their child. In some cases, the baby seemed "different" from birth, unresponsive to people or focusing intently on one item for long periods of time. Research has shown that parents are usually correct about noticing developmental problems, although they may not realize the specific nature or degree of the problem.

Families of children with ASD are currently being studied across Western and non-Western cultures [4-7]. Results indicate that the disorder influences many family variables [8,5,7]. Children with ASD also may not be able to abide by all of the local customs because of the symptoms of the disorder. Having a child with autism can severely disrupt family life. Parents may experience emotional stress, anxiety, fear and guilt [9]. They may have to rearrange their way of life to accommodate their child, and problems such as the absence of language and behavioral difficulties are likely. Parents provide the main developmental context for their preschool child, yet they often feel ignored by professionals involved in diagnosis and treatment.

A resounding theme across ASD studies conducted globally is that mothers, who generally serve the role of primary caregiver, are significantly affected by their children's ASD diagnosis [8,4,7]. Regardless of maternal employment situations, mothers of children with ASD reported high levels of stress, few opportunities for respite, and high demands for being the primary teacher to children with ASD [8,4,7]. The majority of mothers felt that sacrifices made for the child with ASD led to remediation of ASD symptoms [8].

Many aspects of development in autism will be different from those found in normally developing children or in those with other developmental disorders.

Children with autism experience the world in a different way and an understanding of such underlying differences is essential. Parents (and grandparents) who have prior experience of rearing children often find that tried and tested strategies prove ineffective for the child with autism. New parents may feel inadequate and family conflicts may result from the well-meaning advice of other family members.

Bristol and identifies some factors that appear to contribute to the stresses associated with living with a child with autism. In addition to the social isolation and distress that may result from the birth of a child with any disability, the social, communication and behavioral manifestations of autism often produce a lack of understanding from the general public, and the parents' handling of the child may be criticized, with suggestions that the child is 'naughty' or 'spoilt'. Particularly high levels of parental stress are associated with factors outside the family, such as a lack of help and support, as well as with factors relating to the child [10]. Families who receive support from relatives, friends and other parents seem to cope best. Participation in family support schemes is also associated with lower levels of parental stress [11].

Parent-training programs are now used worldwide to increase the communication skills of children with ASD [12-15]. Evidence is also emerging for the efficacy of the Picture Exchange Communication System (PECS; and the Treatment and Education of Autistic and Communication Related Handicapped Children program (TEACCH) for treating ASD in various cultures [16-20]. The use of advanced technology is also contributing to the treatment practices of children with ASD [21]. Although treatment options are becoming available in various countries, accessibility to these treatments remains a challenge especially for parents living in developing countries.

Providing psychoeducation to parents of children with autism is based on attachment theory, developed by John Bowlby, Psycho educational treatment and parent support programs are some treatment approaches that can be applied to develop awareness of parents and public about any medical as well as psychiatric disorders. Also psycho-educational treatment can be applied to cases with social communicative, and behavioral problem. Parent education concerning ASD is one component of treatment programs occurring outside of the United States. For example, researchers reported that parent-training programs occurring in India and China included a psychoeducational component for parent participants [22, 14].

These sessions educated parents on the facts and misconceptions concerning an ASD diagnosis. Results indicated that parents felt a sense of empowerment following the sessions. Some parents

reported that the psychoeducational sessions were the most useful of all treatment sessions [14]. The psycho-educational treatment as it based on behavioral strategies are amongst the best evaluated for children with autism and it appears that such treatments are most effective if they involve parents and are implemented early in the child's development. Moreover, educating parents on ASD may be a necessary component of parent-training sessions in countries where there is a lack of public awareness concerning the disorder.

Significance of the Study

Learning that a child has a chronic illness or disability can be devastating for many parents, especially those without an extended support system. Having a child with autism can severely disrupt family life. Parents may experience emotional stress, anxiety, fear and guilt as they often have a number of confusions and misconceptions about ASD. The increase in prevalence rates for the disorder suggests that Parent-training treatment models can increase the communication skills of children with ASD. Also, the information from research is not been properly disseminated to parents of person with ASD's. Hence, parents need timely basic education about the condition and its long-term effects, also they need information on management, coping skills, and understanding the reasons of child's behavior. With this objective in mind, This study aims at evaluating "the effectiveness of constructed psychoeducational intervention for parents of children with autism spectrum disorders." More specifically the main objective of the study is to Assess level of parents' knowledge and awareness' regarding Autism, test the efficacy of psychoeducation program in dispelling the misconceptions regarding the condition and developing their awareness about the available services and programs for the parents as well as children with ASD's.

Participants and method

Research Design

In the present study, a Quasi experimental design was adopted for evaluating the effectiveness psychoeducational intervention with pre and post assessment.

Participants

To achieve the aim of the study, parents of 23 autistic children were recruited from Al-Basma and Alragaa center, which are Non-Government Organization for Intellectually handicapped children at Shebin Elkom and Tantacity, Egypt. The children were thirteen boys and 10 girls, aged between 3 and 12.5 years, and first diagnosed between 3 and 7 years. All the children lived at their home, attended the center, and spent 6 hours. In respite care.

The Sociodemographic & personal Characteristics of the target parents sample

Concerning age, the majority (78.26%) of father sample were in the age group 36-45 years, compared with 52.17% of mother in the same age group, about half of the mother sample 47% were in age group 25-35 years while only 17% of father were in the same age group compared with only 4.3% of fathers were in 40 -50 age group.

As regards the educational level more than half of the father sample 52.17% were highly educated, compared with 39.13% of mothers at the same level of education, while an equal percent (21.73%) of father sample were at secondary and middle level of education compared with (56.25%) of the mother sample were at secondary and middle level while an equal percent (4.35%) of the

parents sample were at primary level of education.

Regarding occupation (87%) of the fathers' sample were working in professional occupation like doctor, teacher and accountant, compared with (69.6%) of mothers' sample as (26.09%) of mothers' sample were housewives compared with only 4.35% of fathers' sample working as lecturer in the university. Also, the majority (82.61%) of parents' sample had no relatives relationship compared with only (17.39%) had a relative relationship.

Concerning the Effect of autistic child on marital relation the results revealed that, nearly two- third (56.5%) of the sample has a positive attitude toward their autistic children compared with (43.5 %) of the sample thought that their children had a bad effect on their marital relation so, they report negative attitude toward them.

Measurements

Knowledge and awareness of target parents regarding ASD were measured by a developed questionnaire based on literature review, developed by the researchers and consists of two parts: The first part includes data of sociodemographic characteristics of parents and their autistic children. The second part includes a developed questionnaire assessing level of parent knowledge and awareness about autistic disorder.

Ethical consideration

An official permission was taken, from the director of the two centers. To conduct this study. The researchers explained the purpose of the research to all participants. Participants were asked for their permission to attend for the sessions according to the nominated schedule Furthermore, participants were assured that their participation in the study was voluntarily and that they could withdraw at any time.

The procedure

The study conducted into 3 phases as the following: Phase I: Pre assessment of parent knowledge and awareness about autistic disorder. Phase II: Implementation of psychoeducational intervention. The intervention was developed by the researchers based on review of related literature and conducted into eight sessions twice/week, -60 90 minutes for each. Phase III. This phase is concerned with applying the posttest assessment and evaluation of the intervention.

Components of the psychoeducational intervention

The program aims to help children through developing their parents' competence and confidence and helps parents to learn and share their experiences with and from other parents.

The description of psychoeducational intervention

The psychoeducational program works with a group of 23 parents at a time, over a period of one month. This duration appears to be long enough to boost confidence in parents having autistic children, yet short enough for parents to cope with the commitment of participating in the program. Considering the availability of the parents of children with ASD, sometimes both parents participated in the session and others one of them was involved. A weekly commitment is necessary, together with homework between the sessions.

The psychoeducational intervention addresses autism first because an explanation of the underlying deficits of autism helps parents understand the causes of their child's difficulties with communication

and behavior. Communication is addressed before behavior since many 'challenging behaviors' may result from difficulties with communication. The approach to behavior is functional and non-aversive, and includes communication- centered ways of approaching behavior. The program contents not only targeted the needs of parents living with child but also, covered children across the whole ASD and a resultant spread of developmental stages.

Content of sessions

The first week sessions (2 sessions) were used for identification, build trust and rapport relationship, and identification of parent experience with their children. All parents reported that their child's development was not as expected and that there was something 'different' in the way he or she behaved. The main problems identified were language, pointing and awareness, rituals and behavioral problems, eye contact, and sleep.

Examples of some of the mothers' responses regarding the identification of their child behaviors

Mother 1: When he was 3 months, he never look at my eye when I breastfeed, also when I was holding him he cries as something painful to him & it was difficult to understand what's going on . I never holding my son closely and I wish that it occurs.

Mother 2: When he was 18 months, something different was noticed but it was difficult because there was no language, and it was difficult to describe and understand. He didn't pay attention to anyone else. We started getting concerned because he wasn't responsive to shouting or things like that. We were concerned about his ritual behavior. He kept walking around the house in circles. The most difficult aspect is that he will not take no for an answer. He is black or white and never a grey area, all is yes and no.

Mother 3: He never pointed. He kept giggling when he became a toddler, he did giggle even when there was nothing happening.

Mother 4: There was a lot of bad behavior at the time. He also used to spin around. No sense of danger. He has gone through phases in terms of being physically aggressive. His behavior has been the most stressful.

Mother 5: I never saw her to reach and pick a toy up. If you gave her toy she would hold it but she never gets one independently. She did not sleep but cried until to sleep, and might start crying while she is sleeping and awake herself back again.

Teaching methods

The Program uses autism-specific materials includes the parent handout accompanies the various units covered during the group training sessions, providing factual information about autism prepared by researchers based on review of literature. Data show presentation for learned materials which supports all sessions, flip chart and overhead transparencies. Parents learn through role play, and sharing in the experiences and progress of the other parents with their children [23].

Results

Table 1 represents the distribution of the autistic children sample according to their sociodemographic & personal Characteristics. Concerning their age the results showed that about half of the sample (47. 82 %) were between 7-10 years compared with (39.13%) in

3-6 years age group and only (0.086%) were in 11- 12 age group.

Regarding sex, nearly two-third of children 56.5% were males while 43.5 % were females. As regarding their birth order, 78.26% of children were in first to third order compared with 21.74% were in fourth to fifth ranking order.

Table 1: Distribution of the autistic children sample according to their sociodemographic & personal Characteristics (N= 23)

Ch . variables	Frequency	
	No. 23	% 100
Age		
3-6	9	39.13
7-10	11	47.82
11-12	2	0.086
Sex		
Male	13	56.5
Female	10	43.5
Birth Order		
First to - third	18	78.26
Fourth to - five	5	21.74

Table 2 represents the One Way ANOVA analysis for the effect of the child birth order on the level of pre and post assessment of parents' knowledge and awareness. This table showed that there was a highly significant difference between total M (3.70) with F value =1.3 at P = .286 in pre assessment data compared with birth order mean of square 8.32 with F value = 5.28 and P = .005 in post assessment of parents' level of knowledge and awareness. P < 0.05

Table 2: One Way Anova Analysis for The Effect of The Child Birth Order on Level of Pre Assessment and Post Assessment Knowledge and Awareness

Ch. variables	Pretest assessment				Posttest assessment			
	Sum of square	Mean of square	F value	Sig.	Sum of square	Mean of square	F value	Sig.
Birth order	14.806	3.70	1.36*	.286	33.28	8.32	5.28	.005*

Table 3 shows the One Way ANOVA analysis of the effect of parents' level of education and occupation on their pre assessment level of knowledge and awareness. As regard to the level of mothers' education, the results showed that it has no significant relationship in their pre assessment of their knowledge level as F = (3.53) and (P = 7.008) with no significant difference. While, the total mean of fathers' education is 1.98 between and within the group of fathers' sample respectively with significance P= 0.027 compared with F value = 3.95 with total mean 8.15 & 2.067 between and within the group of mothers' sample respectively with significance difference between mothers and fathers as P = 0.24

Table 3: One Way Anova Analysis of The Effect of Parents' Level of Education & Occupation on Pre Assessment Evaluation of Parents' Knowledge And Awareness

Ch. variables	Father				Mother			
	Sum of square	M	F	Sig.	Sum of square	M	F	Sig.
Level of Education								
Between group	28.03	7.008	3.53	0.027	24.46	8.15	3.95	0.24
Within group	35.70	1.98			39.27	2.067		
Total	63.73				63.73			
Occupation								
Between group	16.73	8.37	3.56	0.048	15.97	7.98	3.34	0.056
Within group	47.000	2.35			47.77	2.39		
Total	63.73				63.74			

F is significant at the 0.05 level

Table 4: revealed the One Way ANOVA analysis of the effect of parents' level of education and occupation on posttest assessment evaluation of parents' knowledge and awareness. The results indicated that neither parents' level of education nor parent occupation had a significant difference in post assessment data evaluation of parents' knowledge and awareness. As regard the educational level of fathers and mothers F = 1.22 with 3.3 & 2.695 mean of square for fathers' sample respectively and the significance = 0.337 compared with F = 1.75 with mean of square 4.41 & 2.54 of mothers' sample and value of significance = 0.189.

On the other hand Concerning occupational effect in post assessment data as F = 2.16 with mean of square 5.47 and 2.53 of fathers' sample and significance = 0.141 compared with F = 3.75 and mean of square 8.41 and 2.24 respectively in mothers' sample and significance was 0.041 (F > 0.05).

Table 4: One Way Anova Analysis of The Effect of Parents' Level of Education & Occupation on Posttest Assessment Evaluation of Parents' Knowledge and Awareness

Ch. Variables	Father				Mother			
	Sum of square	M	F	Sig.	Sum of square	Mean of square	F	Sig.
Level of Education								
Between group	13.143	3.29	1.22	0.337	13.39	4.41	1.75	0.189
Within group	48.50	2.695			2.54			
Total	61.65				61.65			
Occupation								
Between group	10.95	5.47	2.16	0.141	16.82	8.41	3.75	0.041
Within group	50.70	2.53			44.83	2.24		
Total	61.65				61.56			

F is significant at the 0.05 level

Figure (1) showed the difference between pre and post assessment evaluation of parents' level of knowledge and awareness of autism as the results of the current study revealed that there was a highly significant difference between pre $M= 0.34906 \pm 1.67$ Compared with $M=0.3549 \pm 1.702$ in post assessment data and $t = -38.21$ as $P<0.05$

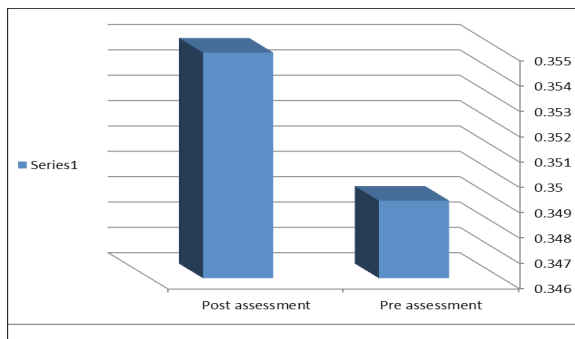


Figure 1: Difference between pre assessment and post assessment evaluation of parents' level of knowledge and awareness of autism

Significant level at 0.05

Discussion

Parenting a child with autism is a very complex task. Many of the developmental milestones that come natural to typically developing children require the parent's special attention in the case of autism. This study was concerned with: helping children through developing their parents' competence, confidence, knowledge, and awareness about the nature of their illness.

Regarding the effectiveness of the psychoeducational interventions on developing parents' knowledge and awareness, the results of the present study revealed that the psychoeducational intervention is effective in developing parents' knowledge about the nature of autism including definition, causes, signs and symptoms and treatment interventions as well as developing their awareness on behavioral and communication problems related to autistic disorder. Similar results was found by Barlow, Powell and Gilchrist, who evaluated the effectiveness of an intervention for parents of children with disabilities in a controlled study focusing on parents' self-efficacy, psychological well-being and perceptions of change in children's sleeping, eating and mobility, and greater attention needs to be paid to the psychological wellbeing of parents caring for children with disabilities.

This was supported by Mukaddes et al., who evaluated the effectiveness of a TEACCH-based home program intervention for young children with autism. In this project they taught parents how to work with their preschool autistic children at home, focusing on cognitive, academic and prevocational skills essential to later school success. Children in the home program treatment group improved significantly more than those in the non-treatment control group. The authors suggested that home program intervention was effective in enhancing development in young children with autism through family involvement in psycho educational intervention which aids in developing parent knowledge and awareness on the disorder of their affected child.

Similarly the same finding was reported by Dunlap and Kay Bunton who they recommend that family members should be encouraged

to participate in all aspects of assessment, curriculum planning, instruction, and monitoring [24]. Parents and other family members very often have the most useful information about an individual's history and learning characteristics, so effective intervention and instruction should take advantage of this vital resource.

Concerning the Sociodemographic and personal characteristics of the autistic children, the current study demonstrated that the majority of the studied sample of autistic children (56.5%) were male, this result was supported by (NICHCY) Boyle and Baird who reported that autism occurs in four times as many boys as girls. This evidence is supported by nearly all researchers working in autistic disorders researches [25-27].

As regarding the birth order of the autistic children, the results revealed that the majority of them were the first or the second child the matter that is supporting the evidence of hereditary factors and genetic causes in developing autistic disorders this results supported by American Psychiatric Association and Centers for Disease Control [28-29].

Moreover, the results of the study indicated that the mean of the maternal age was 35.30 ± 5.07 which was the similar to the results obtained by Wolpert who reported that maternal age has an effect for inverted duplication of chromosome 15 which known as idic 15 [30]. These data supported by Wisniewski of the effect of parental age as well as well as extend the diagnosis to include children with both autistic disorder and isodicentric chromosome 15 [31]. So the finding of this study confirm the genetic linkage in autistic disorder the matter that as supported by many of recent biological research.

As regarding the impact of parental education and occupation on developing knowledge and awareness about autism, the finding of the present study revealed that education as well as occupation had no effect or significant difference in developing awareness for early detection of the autistic child. This was supported by Midence and O'neill who noted that there was no significant difference among parent occupation and educational level in early detection of the autistic child. Moreover, the comments of the parents who participated in the current study highlighted the need for early diagnosis and better understanding of the developmental problems in young children among health professionals, especially general practitioners [32]. Also, the invisible nature of autism makes it more difficult for parents to explain the nature of their child's behavioral problems or to accept the conclusion by themselves even in case of mother working as physician, the matter that was detected through the present study.

All of the participant families reported that they were able to detect early abnormalities in their child's development and this finding is consistent with Marcus who noted that 'parents usually suspect early on that their child has a significant developmental problem regardless their occupation or educational level. The 'feeling' that something was not right led parents to search for an explanation for their child's behavior, but if the diagnosis were incorrect then confusion, despair, blame and guilt could result. In turn, this may exacerbate parental stress and inability to cope [31]. Confusion over diagnosis also resulted in family difficulties to the extent of being isolated by other relatives and friends.

Furthermore, Norton and Drew have suggested that a disability is not often diagnosed during infancy and parents have to search for a reason for their child's problems until diagnosis is completed, the matter that was supported by the present study as majority of parents reported that diagnosis was made for their children between 3 to 7 years old [9].

Concerning the effect of autistic child on marital relationship the results revealed that the majority of parents have a positive attitude toward the presence of their autistic child this was supported by findings from other studies which noted that difficulties in marital relationship were not uncommon, and the diagnosis of a disability, including autism, can draw couples closer. Midence&O'neill and Cobb [32, 33].

Also the current study revealed that the birth order of the child affect significantly parents level of awareness to differentiate between normal and abnormal development of their children. As parents and grandparents who have prior experience of rearing children often find that tried and tested strategies proved ineffective for the child with autism On the other hand new parents may feel inadequate and family conflicts may result from the well-meaning advice of other family members. This was in the same line of the results obtained by Shields in his study of applying "The NAS Early Bird Program" with parents in early detection and intervention program for autism spectrum disorders. Furthermore, because families are so essential in the lives of people with autism, family support that helps strengthen the family system is regarded as a vital element in providing effective intervention for children with autism spectrum disorders.

Conclusion and Recommendation

The findings of the present study were indicated the beneficial effect of psycho-educational intervention in developing parents' knowledge and awareness regarding the nature of autism spectrum disorders, dispelling their misconceptions, and meeting their needs about referral resources in the community.

The psycho-educational intervention as it based on behavioral strategies are amongst the best evaluated for children with autism and it appears that such treatments are most effective if they involve parents and are implemented early in the child's development. Therefore, further researches in the field of therapeutic intervention for autistic children with involvement of their families are recommended. Also, it is highly recommended to construct a lot of governor institutional centers (at least one or two in each city in a big governorates) which enable parents to find a safe and suitable place for caring with their autistic children and application of counseling and rehabilitation interventions programs for the same population [34-44].

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