Health and Marital Adjustments of Parents of Children with Autism-Impact of Functional Skills Intervention Program

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ABSTRACT:

The aim of the study was to examine the impact of intervention program of functional skills of autistic children on the health and marital adjustments of their parents. A total sample of one twenty parents of autistic children who were in the age group of 5 to 10 years attending special schools in Bangalore city was identified through purposive sampling technique. Self-structured scales on health adjustment and marital adjustment developed by the investigator were used to collect the data from the respondents. The pre and post method with an intervention programme was employed for the present study. The data was analysed using t-test. The pre-test data for both experimental and control groups showed that parents of children with autism had low health and marital adjustments. The influence of intervention program showed that there were significant improvement in both the health and marital adjustments of parents of experimental group. However, for the control group, there were not significance in the pre-test and post-test scores of the health and marital adjustments.

Keywords:

Children with autism, Functional skills, Health Adjustment, Marital Adjustment

INTRODUCTION:

Children with autism are those with a complex neurobehavioral condition that includes impairments in social interaction and developmental language and communication skills combined with rigid, repetitive behaviours (WebMD, 2018). Symptoms can range from mild to severe and often change over time (Copeland, 2018). It typically appears during the first three years of life. Some children show signs from birth. Others seem to develop when they are 18 to 36 months old. However, it is now recognized that autism symptoms exhibit when social demands exceed their capabilities. It knows no racial, ethnic, or social boundaries and it does not cause because of the family income, lifestyle, or educational levels. There is a great range of abilities and characteristics of children with autism. They are

very sensitive and sometimes may be greatly in pained by sounds, touches, smells, or sights that seem normal to other typically developing children (WebMD, 2018).

Children with autism have social interaction and communication problems such as difficulties in normal back-and-forth conversation, reduced sharing of interests or emotions, difficulty in making eye contact, challenges in understanding facial expressions and gestures, trouble making friends and interacting with typically developing children and other people around them, etc. (Copeland, 2018). Further, they also have restricted and repetitive patterns of behaviours, interests or activities like repeated body movements (such as finger-flicking, rocking and hand-flapping), playing with toys in an unusual way (such as lining up cars or flipping objects, flicking a rubber band or twirling a piece of string), speaking in a unique way (such as using odd patterns or pitches in speaking, echolalia), often prefer to have a daily routine so that they know what is going to happen every day (Nation Autism Society, 2016).

Due to all these issues, children with autism face challenges in performing the daily living skills which is also known as functional skills. Functional skills are the skills that an individual requires to master before they can truly develop independence (Webster, 2017). It includes self-care skills, functional academic skills, pre vocational skills, social skills and community living skills (Learning, 2003). Many children with autism experience challenges acquiring these skills needed for independent functioning, including those needed for home life, employment, and participation in community events (Hendricks & Wehman, 2009).

Parents of children with autism find it difficult and embarrassing especially when other people around them do not understand their issues and their child shows unusual behaviours in public such as inappropriate touching or invading other people's space, flapping hands or spinning around, being fascinated with a particular item, etc. When parents feel stressed and unable to cope these problems, their own health can be at risk (Brazier, 2016), and this in turn affects their health and marital adjustments.

Raising a child with autism is a challenging task for all the parents. These child-related challenges are associated with increased levels of parenting stress (Hayes & Watson, 2013), and poor physiological health (Dykens & Lambert, 2013) in parents of children with autism. According to the family systems perspective, stressors in a family subsystem affects the functioning of other subsystems (Cox, Paley, & Harter, 2001); high child-related challenges within the parenting subsystem may thus lead to high couple conflict within the marital subsystem. In addition, marital satisfaction is related to both parenting stress and child behaviour problems, where parents with low marital satisfaction reported higher parenting stress and child behaviour problems (Robinson & Neece, 2015).

Several studies have also reported that parents of children with developmental disabilities experience significantly lower levels of marital satisfaction and higher rates of divorce and separation (Breslau & Davis, 1986; Bristol, Gallagher, & Schopler, 1988; Gath, 1977; Hodapp & Krasner, 1995; Kasak, 1987; Singhi, Goyal, Pershad, Singhi, & Walia, 1990; Witt, Riley, & Coiro, 2003); these could be because raising a child with disability has negative effects on marriage in some families (Risdal & Singer, 2004). Among the whole

family members, parents are the one who is most affected by the child's disorder. Parents of children with autism have low quality of life and this can lead to more depression, anger, anxiety, and marital discord (Mills, 2014). They also describe themselves as "burned out," "exhausted," and "stressed out," due to their extensive caregiving responsibilities (Doig, McLennan, & Urichuk, 2009). Thus an attempt has been made to examine the impact of intervention program of functional skills of autistic children on the health and marital adjustments of their parents.

METHODOLOGY:

Objectives:

The objectives of the study were to assess the following:

1. The impact of intervention program on the health adjustment of parents of children with autism
2. The impact of intervention program on the marital adjustment of parents of children with autism

Sample:

A total of one-twenty parents of children with autism were identified as sample for the present study through purposive sampling techniques. They were identified from several special schools catering to the educational needs of children with autism in Bangalore city. Out of one-twenty, sixty parents were considered as experimental group based on their willingness to participate in the intervention program and remaining sixty of them were identified as control group.

Tool used:

Five point Likert type rating scales on health and marital adjustments were developed by the investigator to assess the health and marital adjustments of the parents of children with autism before and after the intervention program. The response options given to the respondents were "Never", "Rarely", "Sometimes", "Often" and "Always" in which positive items were given a score of 1,2,3,4 and 5; whereas, negative items were reverse scored. The description of tools is given below:

Sl. No.	Tools	Positive items	Negative items	Total number of items
1	Health Adjustment	5	7	12
2	Marital Adjustment	5	9	14

Method:

The pre- test, post-test method with an intervention program was adopted for the present study.

Pre-test:

Directory on the list of special school were prepared by the investigator by collecting addresses and contact information of various special schools located in the city of Bangalore through online and from different websites. With the help of this directory, the investigator conducted a survey within the city of Bangalore. A letter stating the purpose of the study was given to the school principal to seek the permission for conducting the present study. After the permission was sought from the principal, the investigator interacted with the parents and briefed them about the objectives and process of the study. Then, established rapport with parents and gave them assurance that data obtained from them will be kept confidential. Data was collected from those parents who gave the consent to participate the study by administering the developed health and marital adjustments tools.

Intervention Program:

The ASSURE model developed by Forest (2015), was adopted in developing the intervention module of educating the parents on the techniques of teaching functional skills to children with autism as well as to effectively carry out the intervention program (IP).
The abbreviation of ASSURE is given below:

"A" stands for **Analyze the Learner Characteristics;**

"S" stands for **State Objectives**

The second **"S"** means **Select, Modify, or Design Materials;**

"U" stands for **Utilize Materials**

"R" is **Require Learner Participation**

"E" is **Evaluation**

The objective of the intervention program was to train the respondents on the techniques of teaching functional skills to their autistic children and also to help them understand the need and importance of functional skills. The intervention program was conducted by the investigator for only the respondents of experimental group for a period of four months and lasted for three hours per session with tea break in between. During the intervention program, the investigator addressed various topics using different teaching strategies and techniques such as power point presentations, flash cards, video clips, picture cards, puzzles, models, worksheets, lectures, posters, story-telling, lego blocks, group

discussions, role play, hands on experience, etc. Topics covered during the intervention program are given in table 1.

Table 1: Topics Covered During the Intervention Program

Sl. No.	Topics covered	
1	**About Autism**	• Definition • Prevalence • Characteristics
2	**About Functional Skills**	• Meaning and types • Need and importance of functional skills to children with autism • Influence of functional skills of children with autism on parent's adjustment and life satisfaction.
3	**Self-care Skills**	• Brushing • Toileting • Washing hands • Bathing, etc.
4	**Functional Academic Skills**	• Concepts of alphabets • Concepts of numbers • Identify colours • Recognise shapes, etc.
5	**Vocational Skills**	• Envelopes making • Greeting Cards • Different kinds of flowers • Diya decoration • Pencil Box, etc.
6	**Social Skills**	• Making eye contact • Telling name • Making friends • Behaviours • Greeting others, etc.
7	**Community living skills**	• Following instructions • Using public transportation • Following rules in school • Know where to shop, etc.

In addition, respondents were taught how to use score cards to assess the progress of their children's performance in learning a specific skill. They were also taught how to use prompts if the child is not able to follow the steps while learning the skill. Home assignments were given to ensure that they begin to teach their child the skills by using the techniques that

they learnt during the program. Further, feedback was acquired from the respondents after each session of the intervention program.

Post-test:

After a gap of one month from the intervention program, post-test data was collected from the respondents of the experimental and control groups by re-administering both health and marital adjustments. This was done to assess the impact of intervention program in the health as well as marital adjustments of parents of children with autism.

Further, the data obtained was scored, tabulated and analysed using‘t’-test. Findings of the study are discussed under results and discussion:

RESULTS AND DISCUSSION:

Basic profile:

The socio-demographic information of the respondents and their children is discussed below. With regard to the age of respondents, majority of the respondents (74 per cent and 68 per cent) from both the experimental and control groups were from the age group of 31-40 years. Most of them from the experimental and control groups (52% and 62%) were graduates. Fifty-three per cent and fifty-five per cent of the mothers from both the experimental and control groups were home makers. Considering the income of the family, majority of the families from both the groups (52 per cent and 45 per cent) earned between Rs. 30,001/- and Rs. 50,000/- per month. The pre-post tests of health adjustment and marital adjustment of parents of children with autism for experimental and control groups are given in table 2 and table 3.

Table 2: Pre-Post Tests of Health Adjustment for Parents of Children with Autism (Experimental and Control Group)

DIMENSIONS OF HEALTH ADJUSTMENT	Experimental Group			Control Group		
	Pre-Test (60)	Post-Test (60)	Significance of t value	Pre-Test (60)	Post-Test (60)	Significance of t value
Health Adjustment related to oneself	12.50 ± 3.11	13.75 ± 2.68	2.3598*	12.85 ± 3.21	12.72 ± 2.64	0.2424^{NS}
Health Adjustment related to physical problems & emotions	12.17 ± 2.66	13.85 ± 2.08	3.8558**	12.28 ± 3.05	12.40 ± 2.84	0.2231^{NS}
Health Adjustment related to care given to their autistic child	11.33 ± 3.02	12.15 ± 2.98	1.4979^{NS}	11.50 ± 2.80	12.85 ± 3.18	2.4693*
Overall	36.00 ± 8.08	39.75 ± 7.04	2.7118**	36.63 ± 8.67	37.97 ± 8.02	0.8793^{NS}

** Significant at 1% level * Significant at 5% level NS Not significant

It is depicted from Table 2 that during pre-test, parents of children with autism from both experimental and control groups had low scores for all the three dimensions of heath adjustment i.e. 'health adjustment related to oneself, health adjustment related to physical problems and emotions, and health adjustment related to care given to their autistic child'. Research conducted by Allik, Larsson, and Smedje, (2006) also found that parents of children with autism especially mothers have poor mental and physical health. They are also at high risk for acute and chronic stress compared to parents of children with other developmental disabilities and parents of typically developing children (Bluth, Roberson, Billen, & Sams, 2013). This could be due to the unusual behaviour problems of the autistic child such as hyperactivity, self-injured, etc.

While, the post-test scores revealed that parents of children with autism from the experiment group had minimal improvement in their health adjustment in all the dimensions (i.e. from 12.50 ± 3.11 to 13.75 ± 2.68; from 12.17 ± 2.66 to 13.85 ± 2.08; and from 11.33 ± 3.02 to 12.15 ± 2.98). Overall, there was a highly significant difference between pre and post tests for all the dimensions of health adjustment of parents of children with autism with t-value of 2.7118**.

For the control group, the post-test scores revealed that there was a slightly significant improvement in the health adjustment related to care given to their autistic child at 5 % level. Overall, non-significance difference was observed between the pre- test and post-test of the parent's health adjustment.

Table 3 depicts that during pre-test, parents of children with autism from the experimental as well as control groups had low marital adjustment in all the three dimensions. Several studies have also reported that parents of autistic children have low marital adjustment (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Lee, 2009; Risdal & Singer, 2004; Robinson, et al., 2015). In addition, the stress of having a child with autism can negatively affect the couple relationship (Bluth et. al, 2013; & Meadan, Halle, & Ebata, 2010).

Table 3: Pre-Post Tests of Marital Adjustment for Parents of Children with Autism (Experimental and Control Group)

DIMENSIONS OF MARITAL ADJUSTMENT	Experimental Group			Control Group		
	Pre-Test (60)	Post-Test (60)	Significance of t value	Pre-Test (60)	Post-Test (60)	Significance of t value
Marital adjustment based on the child's disorder	14.92 ± 3.00	16.82 ± 2.37	3.8516**	15.53 ± 3.37	15.40 ± 2.88	0.3974^{NS}
Marital adjustment related to time spent with the spouse and in-laws	8.87 ± 1.94	10.60 ± 1.58	5.3593**	9.72 ± 1.89	9.98 ± 1.73	0.7864^{NS}

Marital adjustment related to caring of the autistic child and relation to spouse	16.20 ± 2.41	17.80 ± 2.05	9.6038**	16.83 ± 2.74	17.62 ± 2.21	3.8293**
Overall	39.98 ± 5.67	54.22 ± 4.81	14.8426**	42.08 ± 6.87	43.00 ± 5.48	0.8113^{NS}

** Significant at 1% level NS Not significant

The post-test data showed that after they attended the intervention program, parents from the experimental group had shown significant improvement in their marital adjustment in all dimensions. There were highly significant difference between the pre-test and post-test scores for all dimensions with the overall‘t’ value of 14.8426**. Increasing in the post test data of the marital adjustment of parents of children with autism clearly indicates that the intervention program on educating parents about the importance of functional skills and training them techniques of teaching functional skills to children with autism was effective.

For the control group, during the post-test, parents had nominal reduced in the ‘marital adjustment based on the child's disorder’, (i.e. from 15.53 ± 3.37 to 15.40 ± 2.88). A highly significance difference between pre-test and post-test of the ‘marital adjustment related to caring of the autistic child and relation to spouse’ was also observed with the‘t’ value 3.8293**.

A study by Finkel, Slotter, Luchies, Walton, and Gross (2013), supports the present study. They tested whether a novel 21-min intervention designed to foster the reappraisal of marital conflicts could preserve marital quality. Participants were 120 heterosexual married couples enrolled in an intensive 2-year study from the Chicago metropolitan area. Half of the couples were randomly assigned to receive the reappraisal intervention in Year 2 (following no intervention in Year 1); half were not. The study revealed that a 21 minutes writing intervention in which participants reappraised conflict in their marriage protected them against declines in marital quality over time. It also provided evidence that this effect was driven, at least in part, by a reduction in conflict related distress over time among participants in the intervention condition.

CONCLUSION:

Thus, it can be concluded that there is a need of intervention program in order to educate the parents about the importance of functional skills and train them techniques for teaching functional skills to their children with autism. Further, when parents learnt how to handle and teach these skills to their autistic child, there will be improvement in the child’s life: becoming independent, autonomy and self-reliant at home, school and community at large. This will help the child to gain employment opportunity which in turn improves the health and marital adjustments of the parents.

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