

Mapping impact of psycho-education programme on psychological well-being of parents with an autistic child

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ABSTRACT

Autism is a neuro-developmental disorder that first appears after two years and generally follows a steady course without any diminution. Autism falls under the category of pervasive developmental disorder. The characteristics of autism are the main cause of stress for parents and make it difficult to deal with the situation effectively and efficiently. Therefore, the aim of this study was to assess the impact of psycho-educational programme on the psychological well-being of parents with an autistic child. Present study is a mixed method study with a total of 76 parents were selected and assessed on two measures namely: Parental Stress Scale by Berry and Jones (2013) and Psychological Well-being Scale by Diener (2009). A psycho-education programme was implemented for a period of four months wherein, a brief introduction was given to the parents about autism, teaching aids were developed and real life problems were also discussed in detail. The results of the study shows that the stress level was significantly high (M=43.7) among parents and showed serious discomfort (M=14.8) on the scores of psychological well-being before intervention. The scores were seen to improve significantly after the intervention where high stress level dropped down (M= 34.4) and parents reported moderate malaise (M=35.7) on the scores of psychological well-being. Present study can be helpful for counselors, special educators as it becomes easy for them to help parents to overcome problems they are facing.

Keywords: *Autism, Psycho-educational Programme, Psychological Well-being, Parental Stress*

Research in this area is not a new concept but so far it has been focusing on development, education/ rehabilitation programmes for special children. The fact that families and parents especially mothers as chief caregivers, also undergo continuous and tremendous stress and face difficulties in coping/ bringing up their children. Hence proper training and interventions help parents to use more effective way of coping. Most parents have high level of stress, especially mothers, hence they need to have proper counselling so that they can overcome the stress that they are undergoing and lead a happy life.

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Objectives

1. To assess the level of stress of parents of autistic child.
2. To examine psychological well-being of the parents of autistic child.
3. To develop a psycho-education programme for the participants on the basis of aforementioned variables.
4. To expose the participants to the psycho-education programme. (Phase II Intervention)
5. To see the impact of the psycho-education programme on participants in relation to their parental stress and psychological well-being. (Phase III Post-Intervention)

METHODOLOGY

Research Design

Study used a pre-post study design.

Participants

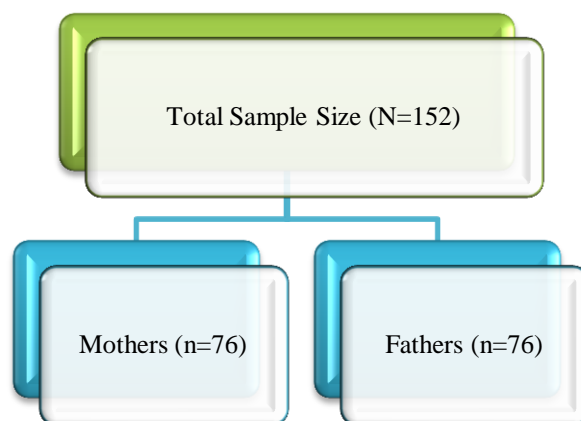


Figure 1: Sample Distribution

Purposive Sampling technique was used for selecting the participants from special schools. Figure 1 illustrates the sample distribution for the present study, a total of 76 parents that is 76 mothers and 76 fathers of already diagnosed autistic children were assessed on the parameters of parental stress scale and psychological well-being. Sample for the present study were residing in Jaipur city and only those parents were approached who fulfilled the inclusive criteria.

Inclusive Criteria

1. Only parents of autistic children (6-15 years) were taken.
2. Only those parents having income between 35,000 to 1,50,000 per month.
3. Only those parents who are not exposed to any other program will be selected

Measures

1. **Parental Stress Scale:** It is a self-report scale containing 18 items devolved by Berry and Jones (2013) representing pleasure or positive themes of parenthood (emotional benefits, self-enrichment, personal development) and negative components (demands on resources, opportunity costs and restrictions). Respondents are asked to agree or disagree with items in terms of their typical relationship with their child or children and to rate each item on a five-point scale. The 8 positive items are reverse scored so that possible scores on the scale can range between 18-90. Higher scores on the scale

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indicate greater stress. The scale is intended to be used for the assessment of parental stress for both mothers and fathers and for parents of children with and without clinical problems. The Parental Stress Scale demonstrated satisfactory levels of internal reliability (.83), and test-retest reliability (.81).

2. Psychological Well-Being Scale (PWB)

It was defined as a parental global well-being and it was developed by Diener (2009). To assess the overall psychological well-being, it consisted of eight items that described important aspects of human functioning ranging from positive relationships, to feelings of competence, to having meaning and purpose in life. Each item was answered by using 7-point Likert, a self-report scale which indicate the point at which a person agrees or disagrees with each statement (7 Strongly agree, 6 Agree, 5 Slightly agree, 4 Mixed or neither agree nor disagree, 3 Slightly disagree, 2 Disagree, 1 Strongly disagree). Scores were ranged from 7 (Strong Disagreement with all items) to 56 (Strong Agreement with all items).

Procedure

Phase-I: Pre-Intervention

First of all, 100 parents fulfilling the inclusive criteria were approached and given the selected measures of the present study. Out of these parents, there were a few dropouts and the final sample for the study was 76 parents (N=152). These parents were exposed to psycho-education programme.

Phase-II: Intervention

1. Planning and development of Psycho- Education Programme

- Activities were developed and the various strategies to deliver the same were decided with the help of experts and educators.
- Preparation of audio visual aids (charts, posters, pamphlets, presentations etc.)

2. Implementation of Programme

Psycho-education program was implemented for a period of 3 months, 4 days a week and included following sessions (Figure2):



Figure 2: Themes Covered in Psycho-education Programme

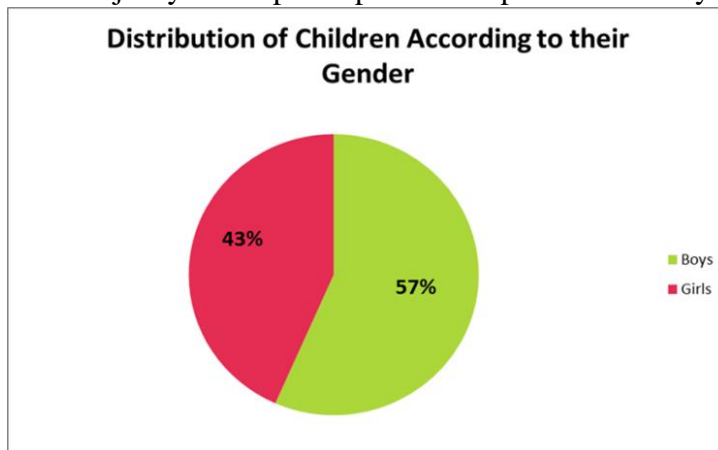
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Phase-III (Post-Intervention)

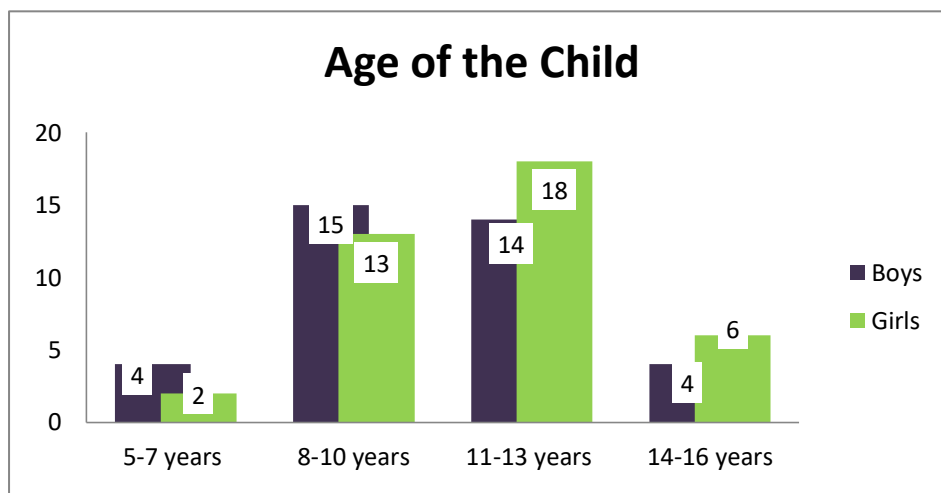
After exposure to psycho-education programme, once gain the participants were assessed on the same measures in order to see the relative difference in score and effectiveness of the programme

RESULTS & DISCUSSIONS

The pie chart shows that the majority of the participants were parents of a Boy Child (57%).



Graph 1: Distribution of Children According to their Gender



Graph 2: Age of the Child

Graph 2 depicts the age of the child who were a part of the current research. With the data above it is clear that the most of the participants fell in the age groups of 11-13 years (42%) followed by 8-10 years (36%). Also, the least number of participants belonged to the age group 5-7 years with only 7.8% of the total. The major reason for the same could be lack of awareness on autism and late diagnosis of this neurological disorder.

Table 1: Mean, Standard Deviation & t-value of Parents on the Scores on Indicators of Parental Stress Pre-Intervention (N=152)

Sub Scale	Fathers		Mothers		t	p
	Mean	S.D	Mean	S.D		
Stress	46.90	8.31	44.30	7.66	2.80**	0.01

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Table 1 reveals that there is a significant difference in the stress levels of mothers and fathers as the calculated 'z' value ($z=2.80, p<.01$) is higher than the tabulated value at .01% level of significance.

Table 2: Psychological wellbeing of Parents Pre- Intervention (N=152)

Items	SA(%)	A(%)	SLA(%)	M/NA(%)	SLD(%)	D(%)	SD(%)
I lead a purposeful and a significant life	05	08	17	20	05	10	35
People respect me	68	12	10	05	05	00	00
My social relationship is supportive and satisfying	20	09	16	25	15	12	03
I am engaged and interested in my daily activities	02	03	08	05	12	15	55
I am contributing to the happiness and well-being of others	10	05	10	15	05	05	50
I am a competent and capable in the activities that are important to me	05	03	02	04	03	13	70
I am a good person and live a good life	06	04	18	52	04	08	08
I am hopeful about my future	00	00	02	08	05	15	70

Note. SA = strongly agree, A = Agree, SLA = slightly agree, M/NA = Mixed or neither agree nor disagree, SLD = slightly disagree, D =Disagree, SD = strongly disagree.

Table 2 concluded that, the small percent (5%, 2%, 10%, 5%, 6%, 0%) of studied parents strongly agree about they lead a purposeful and a significant life; they engaged and interested in their daily activities; they contributing to the happiness and well-being of others, they are competent and capable in the activities that are important to them; they feel that they are good persons and live a good life; they are hopeful about their future, while 20% of them strongly agreed that their social relationships are supportive and satisfying, 68% of them strongly agreed that people respect them.

Table 3: Mean, Standard Deviation & t-value of Parents on the Scores on Indicators of Parental Stress Post-Intervention (N=152)

Sub Scale	Fathers		Mothers		t	p
	Mean	S.D	Mean	S.D		
Stress	32.54	7.83	37.65	7.32	3.09**	0.01

Table 3 shows the Mean, S.D and z- value scores of Parental Stress Scale post intervention and the data reveals that there is a significant difference in the stress levels of mothers and fathers as the calculated 'z' value ($z=3.09, p<.01$) is higher than the tabulated value at .01% level of significance.

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Table 4: Psychological wellbeing of Parents Post-Intervention (N=152)

Items	SA(%)	A(%)	SLA(%)	M/NA(%)	SLD(%)	D(%)	SD(%)
I lead a purposeful and a significant life	10	15	23	25	05	12	10
People respect me	75	11	04	05	05	00	00
My social relationship is supportive and satisfying	43	13	14	18	10	02	00
I am engaged and interested in my daily activities	12	04	09	16	12	15	32
I am contributing to the happiness and well-being of others	12	04	32	11	05	05	31
I am a competent and capable in the activities that are important to me	43	16	07	05	16	01	12
I am a good person and live a good life	10	08	16	61	05	00	00
I am hopeful about my future	34	29	12	12	03	10	00

Note. SA = strongly agree, A = Agree, SLA = slightly agree, M/NA = Mixed or neither agree nor disagree, SLD = slightly disagree, D =Disagree, SD = strongly disagree.

Table 4 shows the change in the level of psychological well-being of parents. It is evident that there has been a positive shift in areas of hope, happiness, respect and a better future

MAJOR FINDINGS & CONCLUSION

Raising a child with autism can be a stressful experience for parents especially when left unmanaged and make their life very hard, usually they are left alone to face the stressful challenge of raising a child with autism. In addition, they are also concerned with communication, education and related services, relationships with professionals and the independence of the child and his/her future concerns.

Therefore, the aim of this study was to assess the impact psycho-education programme on the psychological well-being of parents with an autistic child.

The results of the present study clarify that parent stress regarding the child dependency are common among more than half of the participants under study that they feel concerned when they can't care for their child in addition to that they mentioned that autism is a disease that they can't deal with it and will suffer forever. This may be due to the fact that autism is considered a severely confounding disorder. Problems as absence of language, anti-social behaviors and tantrums are likely to manifest high levels of stress for parents caring autistic children for many years. Results of the present work is confirmed by Bristol who stated that, parents' stress results from child dependency and failure to understand an autistic child's language, both feels frustrated and the child can often show typical behaviour.

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Furthermore, the present study reveals that the majority of parents shows stress related to their child's future. They are worried because according to them their children did not live a normal life by far and how will they (parents) and the child will cope with the future, when things will be tougher and harder. Probable reason for the same could be that the majority of children need some or the other kind of assistance in performing the daily activity, few children with autism will never be able to live and work independently, in addition to that understanding the child with autism requires a great deal of time, routine, energy, and money which for a lot of parents is hard to manage. Furthermore, some even expected the siblings to bear the responsibility of the child after the parents could no longer do so. These findings are consistent with Shu et al. and Rivers et al. who reported that, parents of autistic children were concerned about their children's future, academics and daily living arrangements as well as their needs for social support. Concerning to stress about personal exhaustion, the result of the present study revealed that the majority of the parent suffers from personal exhaustion regarding caring for their child. They mentioned that the child condition affects their physical & mental health also, they become nervous while dealing with their child. Caring was exhausting for their parents symptoms like: constant crying and screaming made parents tense and led them to frequent arguments. These difficulties caused parents to retrospect their own abilities. This explanation is supported by Johnston who reported that autistic child's deficits are stressful for parents. Parents who lack in appropriate leisure skills often require constant structure of their time, a task not achievable to accomplish in the home environment, this is where intervention of social support comes in. Many families struggle with the additional challenges of getting their child to sleep through the night or eat a wider variety of foods. All of these deficits and behaviors are physically exhausting for parents and emotionally draining.

It is obvious from the results that small percent of studied parents strongly agreed about they lead a purposeful and significant life, they were engaged and interested in their daily activities, they actively contributed to the happiness and well-being of others, they are competent and capable in the activities that are important to them, they are good person and live a good life, they are hopeful about their children's future, while about quarter of them strongly agreed that their social relationships are supportive, satisfying and feel pessimistic about their children future, in addition to more than two third of them were strongly agree that people respect them. These results confirm the earlier findings, which report that parents of children with disabilities have more stress than parents of children without disabilities. This finding is supported by Abbeduto et al. who noticed that mothers of children with autism were more pessimistic about their children's future. Also, a study by Yirmiya et al., confirms that there was a strong evidence that parents of children with autism face a high level of stress. Meanwhile, this result was also in accordance with Watinikmat who investigated the prevalence of parental stress and psychological well-being among parents of children with autism and found that a high proportion of parents were stressed up and more than half of them showed poor psychological well-being .

The result of the present study clarifies that there is a highly statistical significant relation between awareness and psychological well-being among parents of children with autism. This could be due to the mothers who have a lack of awareness about autism suffering from negative psychological well-being and serious psychological discomfort. Parents did not initially report a concern about the children with autism because they accepted their behavior as a part of their age and did not consider it to be symptomatic of any particular disorder and it's attributed to their lack of awareness in society. In addition to the lack of awareness and

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believed myths of parents regarding make them not able to get expose of various remedial measures which could help them to bring improvement in the condition of the child.

Recommendations/Implications

Based upon the finding of the current study, the following recommendations can be deduced:

1. Counseling parents to enhance parents awareness about autism for modifying their behaviors and psychosocial skills.
2. Developing free educational resources about autism for parents at home, at school, with teachers and students about how to deal with autism.
3. Media awareness to help parents in prompt tolerance and understanding autism with a clear explanation.
4. There is a need for more research on parameters like coping strategies, subjective well-being, social stigma etc. of the parents/caregiver of children with autism.

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Conflict of Interest

The author declared no conflict of interests.

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