

# Handling the Psychological Distress of Parents of Children with Autism Spectrum Disorders: Feasibility of Group Work Approach

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## Abstract

Autism Spectrum Disorders are pervasive developmental disorders affecting many children today. Parenting a child with special needs, such as children with autism, is very taxing, as they need intensive and life-long intervention in diverse areas. This paper is an attempt to assess the need of those parents of children with autism and to develop an intervention programme to take care of the psychosocial issues. The study had two phases. In the first phase 120 parents of children with autism spectrum disorders were interviewed using a semi structured interview schedule and GHQ 28. In the second phase, an intervention module was prepared and implemented with 20 parents. The results show that the mean psychological distress was significantly higher for mothers compared to fathers. The scores on subscales show that mothers have higher level of somatic symptoms, anxiety and insomnia, social dysfunction and depression compared to fathers. The pre and post analysis of the group intervention shows that there is a drop in the

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level of distress and increase in the awareness on child's illness in parents after the group intervention. The findings show that addressing parental needs in a group setting can be very effective and beneficial in helping parents reduce their distress levels and hence making them better equipped to look after their child with a disability like autism.

**Keywords:** Autism, parent intervention module, psychological distress, group work

## Introduction

Child rearing and caring are considered as the most fulfilling responsibilities any parent has. Parenting is a skill, which can have significant impact on the cognitive, emotional and social development of children. Generally, parents have dreams about their children even before they are born. When the child turns out to have disability of any kind, the parents are disappointed. Autism Spectrum Disorders are pervasive developmental disorders affecting many children today (Rutter, 1978; Schopler, 1978). The term Autism Spectrum Disorder (ASD) is intended to include the entire spectrum of autism, which include childhood autism, atypical autism, Asperger's syndrome and pervasive developmental disorder unspecified. Autism is a diagnosis which is long lasting and probably lifelong. Taking care of children with this illness is hence continuous and tiresome.

Parenting young children with pervasive developmental disorder engenders unique sustained stressors, which have been termed "burden of care" (Pakenham, K., Samios, C., & Sofronoff, K, 2005). One specific source of stress for parents is the children's uneven developmental progress in which delays and accelerations of adaptive functioning may exist side by side.

Surveys among members of families with a family member with have found a rise in depression, stress and anxiety (Fleischmann, 2005). Caregivers of a child with autism often experience helplessness, feelings of inadequacy and failure, anger, shock, guilt, frustration, and resentment (Higgins et al, 2005). Longitudinal data suggests that families do not experience a single stressor; rather

they experience a pile-up of demands (Pakenham et al, 2005). These studies show that social support is very important in combating depression and stress (Fleischmann, 2005).

Thus, parenting young children with autism spectrum disorders have always been a great challenge for many parents. To care for their child with special needs, these parents need enormous support and guidance. Many studies have been conducted by different professionals to establish that parents of children with autism are at greater risk of developing depression, and other stress-related problems.

In recent years the group therapy has been used extensively for therapeutic and psycho-educational purposes under many diverse theoretical frameworks. Psycho-educational groups have been emphasized as a means of enhancing family coping and increasing involvement in the treatment of a variety of medical and psychiatric disorders (Van Noppen, 1994, Tynes, L., C. Salins, W. Skiba, D. K. Winstead, 1992). The natural tendency of parents to discuss child-rearing problems with other parents can be channeled into a constructive process through group discussion facilitated by professional leadership and appropriate goals (Arnold, 1978, C.A Mitchell, 2008). Parents share with one another coping strategies they have found helpful, suggest alternative frameworks for understanding events, and sometimes provide tangible and intangible support for a member in the midst of a crisis. In view of this, there is an increasing demand to develop and examine the feasibility of a planned and structured intervention programme for parents and its efficacy in bringing a change in their coping strategies, psychosocial conditions and there by involving them in a better way in taking care of their children. As there are no such studies in the Indian scenario, the present study is an attempt in that direction.

## **Method**

This particular study had two phases. First phase was to assess the needs of the parents of children with autism and the second phase

to develop and implement an intervention programme for the parents.

## **Phase 1**

A descriptive research design was adopted for the first phase. The universe consisted of parents of children who attend the Child and Adolescent Psychiatry unit's In-patient and Out-patient (OP) services of NIMHANS. The sample size was 120. The following tools were used for data collection:

### **Semi Structured Interview Schedule Consisting of 2 Parts**

#### **a. Demographic Profile of Respondents**

This was prepared by the researcher to elicit personal data profile of the respondent. It covered areas like age, sex, educational and occupational details of the parents and socio demographic and clinical details of children.

#### **b. Semi Structured Interview Schedule**

The schedule consisted of open ended as well as close ended questions constructed by the researcher to elicit information pertaining to psychosocial needs of parents involved in the care of children with Autism Spectrum Disorders. The purpose of the semi structured interview schedule was ultimately to develop an intervention package.

#### **(1) General Health Questionnaire (GHQ-28 item version; Goldberg, 1979)**

The 28 items version was used in the present study. The tool has 4 subscales: 1) somatic symptoms, 2) anxiety and insomnia, 3) social dysfunction and 4) severe depression. It has been recommended as a screening measure for psychological distress (Banks, 1983). This scale was administered to measure the psychological distress of parents of children with autism spectrum disorders.

## **Phase 2—Development of Intervention Module and Intervention**

Based on the psychosocial needs elicited through the semi structured interview schedule, a group intervention module was prepared and using this as a guideline the group intervention was conducted. The intervention programme had 6 modules. The group sessions thus included the following topics: What is Autism, Stress among Parents and Coping with Stress, Importance of training in autism, Social Support, The National Trust Act, and the services available for children with autism in India. Following the intervention, a post assessment with the same research tools was done and feedback about the group intervention was obtained.

## **Results and Discussion**

### **Phase I**

The major finding of phase I of the study is as follows: Total number of parents interviewed was 120, both parents were interviewed (102) for 51 children (73.9%), for 10 children, only mothers were the respondents (14.5%), for 8 children, only fathers were the respondents (11.6%).(Table No: 1 & Figure No.1).

The Majority of parents had only partial awareness about their child's illness, thus emphasizing the need for psycho education. Awareness about the benefits and facilities available for children with autism were found to be poor in parents. Majority felt that meetings with other parents of autistic children having similar kind of problems will be beneficial in sharing their feelings and getting emotional support from them. Some parents felt that they will be able to get more innovative ideas and information about training their child with special needs from other parents as they are also sailing in the same boat.

The results obtained from the GHQ 28 shows that the mean psychological distress was significantly higher for mothers (8.11) compared to fathers (4.15), ( $p < 0.05$ ). The scores on subscales show that mothers have a higher level of somatic symptoms ( $t = 2.46$ ,  $p < 0.05$ ), anxiety and insomnia ( $t = 2.78$ ,  $p < 0.05$ ), social dysfunction ( $t = 2.40$ ,  $p < 0.05$ ) and severe depression ( $t = 3.52$ ,  $p < 0.05$ ) compared

to fathers. The mean psychological distress is significantly higher for mothers compared to fathers. (Table No: 2). Parenting a child with a disability can produce great stress and a sense of imbalance in the family system. There is evidence that autism has some negative impact over the family and that the burden of care falls largely upon the mothers (Factor et al., 1998). One study by (Moes et al. 1992) compared the stress profiles of mothers and fathers of children with autism. The results showed that mothers of autistic children experienced more stress than fathers, suggesting that this result was a consequence of different responsibilities assigned to child rearing for each parent.

Psychological distress was higher for mothers compared to fathers. The scores on subscales show that mothers have higher level of somatic symptoms anxiety and insomnia, social dysfunction and severe depression compared to fathers. This result is supported by studies done by (Bristol, Gallagher, & Schopler, 1988; Wolf, Noh, Fisman, & Speechley, 1989). Their studies have shown that mothers experience greater distress in parenting a child with autism than fathers do. Mothers of children with autism suffer restrictions on their personal time and freedom, may endure loss of self - esteem because they view themselves as having "failed" in their parenting role, and report feelings of depression, anger, fatigue and tension (De Myer, 1979; Holroyd, 1974; Wolf et al., 1989; K. Giannoulise et al., 2004).

## **Phase II**

The pre and post analysis of the group intervention shows that there is a drop in the level of distress in parents after the group intervention (Table No.3). Literature from the West reports that parent support groups are helpful in dealing with the psychological distress in parents. Support groups for parents give them opportunity to know that they are not the only ones experiencing a particularly stressful situation. In addition, they can get the most useful advice from others facing similar challenges and by using similar services and supports. It was found that there

is a change in the parental knowledge about the child’s illness and the governmental provisions available after the group intervention. These issues were focused in the group sessions.

The feedback obtained from the parents after the intervention showed that for 50% of the participants it was highly satisfactory; and for another 50%, satisfactory. 60% of the participants felt that the number of sessions were adequate.. All participants reported that the content of sessions, the number of participants and the language used were adequate and satisfactory for them (Table No. 4). A study by Probst (2001) corroborates this finding. In his study, it was found that a high proportion of parents evaluated the format of the group parent training positively and the mutual exchange of experiences between parents was rated as very helpful by almost all the parents.

**Conclusion**

The findings of this study shows that addressing parental needs in a group setting can be very effective and beneficial in helping parents reduce their distress levels and hence make them better equipped to look after their child with a disability like autism.

**Tables**

Table No. 1: Participants

Variable	Category	Frequency	Percentage
Participants	Father (Alone)	8	11.6
	Mother (Alone)	10	14.5
	Both	51	73.9
Total		69	100.00

Table No.2: Psychological Distress among parents

Variable		N	Mean	SD	df	t value	P value
Somatic symptoms	Mother	61	1.90	2.01	118	2.46	(p<0.05)
	Father	59	1.10	1.51			
Anxiety and insomnia	Mother	61	2.68	2.40	118	2.78	(p< .05)
	Father	59	1.59	1.87			
Social dysfunction	Mother	61	1.67	1.90	118	2.40	(p< .05)
	Father	59	0.91	1.53			
Severe depression	Mother	61	1.85	2.39	118	3.73	(p< .05)
	Father	59	0.54	1.31			
GHQ Total	Mother	61	8.11	7.30	118	3.52	(p< .05)
	Father	59	4.15	4.79			

Table No. 3: Psychological distress in parents before and after the group intervention (Pre and Post)

	Mean	N	SD	df	T	P value
PRGHQA	2.10	20	1.97	19	2.57	.019
POGHQA	1.40	20	1.84			
PRGHQB	3.05	20	2.39	19	1.99	.061
POGHQB	2.40	20	2.25			
PRGHQC	1.95	20	1.90	19	1.48	.154
POGHQC	1.50	20	1.79			
PRGHQD	1.65	20	2.23	19	1.37	.186
POGHQD	1.10	20	1.86			
PRGHQTotal	8.75	20	7.00	19	2.63	.016
POGHQTotal	6.40	20	6.48			

PRGHQA: Pre group somatic symptoms; POGHQA: Post group somatic symptoms; PRGHQB: Pre group anxiety and insomnia; POGHQB: Post group anxiety and insomnia; PRGHQC: Pre group social dysfunction; POGHQC: Post group social dysfunction; PRGHQD: Pre group severe depression; POGHQD; Post group severe depression.



Table No: 4: Feedback about the group intervention

	Category	N	%
Overall level of satisfaction	Highly Satisfactory	10	50
	Satisfactory	10	50
	Not satisfactory	0	0
<b>Total</b>		<b>20</b>	<b>100</b>
Adequacy of the number of sessions	Need more session	8	40
	Adequate	12	60
	Need less number of sessions	0	0
<b>Total</b>		<b>20</b>	<b>100</b>
Adequacy of the content of sessions	Adequate	20	100
	Not adequate	0	0
<b>Total</b>		<b>20</b>	<b>100</b>
Number of participants in a session	Adequate	20	100
	Need more number of people	0	0
	Need less number of people	0	0
<b>Total</b>		<b>20</b>	<b>100</b>
Comfort ability with the language used	Comfortable	20	100
	Not comfortable	0	0
<b>Total</b>		<b>20</b>	<b>100</b>

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