



## **Stress, adjustment and coping pattern in parents of children with Autism**

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### **Abstract**

The present study is an exploratory study which aims to assess the stress, coping and adjustment pattern in parents of children with autism. The sample consisted of 20 parents. The tools used in the present research were a semi-structured interview schedule that aided in the process of data collection and to probe into relevant areas. A parent stress index questionnaire was used to assess the stress experienced due to child characteristics, parent characteristics and other life stresses. A coping checklist was used to study the coping styles adopted. A structured interview schedule was used to assess the adjustment level of the parents. The results indicated that the parents experienced stress due to certain characteristics of their child namely, adaptability, demandingness and inability to positively reinforce parent. Also parents felt incompetent at handling their child and felt isolated. The coping styles adopted their child and isolated. The coping styles adopted by the subjects varied, as certain coping styles were preferred over the others. Results also indicated that a large number of parents were maladjusted and in need of professional assistance.

**Keywords:** adjustment pattern, coping style, stress and autism

### **Introduction**

Autism has attracted a remarkable degree of interest and concern from clinicians and researchers alike, more so in recent times. Autism is a neurodevelopment disorder characterized by early onset (before 3 years old) of significant impairment in social interaction and communication and stereotyped behaviors. Parents of children with developmental disabilities face challenges placing them at risk for high levels of stress, adjustment and coping problems. Parenting a child with autism may pose additional stressors related to the child's challenges in communicating, difficult behaviors, social isolation, difficulties in self-care, and lack of community understanding. Several studies reported increased psychological distress, including depression, anxiety, and components of stress, such as decreased family cohesion and increased somatic complaints and burnout, among parents of children with autism and related autism spectrum disorders (ASDs) in comparison to parents of typically developing children or parents of non autistic children with mental retardation or other developmental disabilities.

Stress was used to refer to the stimulus event of sufficient severity to produce disequilibrium systems (family systems).

Coping refers to a person's efforts to manage the internal and external demands of the person – environment transaction that is viewed as taxing and exceeding a person's resources (Folkman and Lazarus, 1984). The study tries to assess the coping styles of the parents. Also the effectiveness of these coping styles to deal with the burden is taken under consideration.

Adjustment refers to the continual process by which living organism maintains balance between its need and the circumstances that influence the satisfaction of these needs.

### **Objectives**

The present study was undertaken keeping in mind the following objectives.

1. To study the stress faced by parents in bringing up an autistic child. The stress could be due to certain qualities displayed by the child that make it difficult for parents to fulfill their parenting roles or dimensions of parent functioning or other life stresses.
2. To study the adjustment pattern of the parents to these stressors.
3. To assess and study the coping strategies adopted by the parents as primary caregivers of the child with the autism. Autism is limiting in behavioural, cognitive and emotional aspects, these leads to a lot of dependence on the caregiver by the child. The effectiveness of coping to a great deal determines the management of the child by the caregivers. Hence it was of interest to see how the caregivers dealt with these demands.

### **Methodology**

The present study is an exploratory study which aims to elicit qualitative data on the stress, coping and adjustment pattern in parents of autistic children. The methodology for the study has been employed to gather rich data to reach a wide understanding of the stresses faced by parents of autistic children, how they cope with the problem and have adjusted to the present situation. The present study uses both qualitative methods using semi-structured interview and theme analysis as well as quantitative methods using objective tools.

### **Sample**

The sample for this study comprised of 20 parents identified

as primary caregivers for the child with autism. Families studied for this research were lower class, middle class and upper class. The sample was taken of educated parents, who have been in touch with mental health professionals due to their child's illness. Incidental sampling was used to select participants who were ready and willing to be part of this study.

**Criteria**

**Inclusion Criteria for Child**

Child age 3 to 17 years.  
Diagnosed as Autistic as per ICD 10 classification.

**Inclusion Criteria for Parents**

Parents who have been in touch with mental health professionals  
Parent actively involved in taking care of the child

**Exclusion Criteria for Child**

Any Co morbid Diagnosis  
Any organic illness

**Exclusion Criteria for Parents**

Divorced parent.  
Parent with any major physical or mental illness.  
More than one disabled child.

**Research Tools Used**

The present research was carried out using the following tools:

- Semi-structured interview schedule.
- Parent Stress index (Abidin, 1995) <sup>[1]</sup>
- Coping checklist (Rao, Balakrishna and Prabhu, 1989).
- Structured Interview Schedule to study adjustment level.

**Procedure**

To begin with, the contact was made with different rehabilitation centre. As and when the patients meeting the criteria for the study were identified I would initiate an introduction. The parents fulfilling the criteria were approached and the nature of the study was explained to them. The consent of the parents regarding the data collection was taken and the parents were assured of confidentiality.

The data was collected in two sessions; both the sessions took place at the center. In the first session the nature of the study was explained to the parents. With their due consent the procedure of data collection was carried to the fore. The time taken in the first session varied between two to three hours. In the second session, which was scheduled according to the convenience of the subject, the subject was asked to provide information for the tools to be used. In the interview schedule on adjustment, the subject provided information for the questions. The coping checklist was given to the subject or the statements were narrated to the subject according to the will of the subject. Finally the parent stress index was given.

At the end of the second session, the subjects were thanked for their cooperation and willingness to provide information. The subjects were assured about the confidentiality and the appropriate use of the information obtained from them.

Each subject's responses to the tools used was scored and interpreted. Each case or subject was studied separately so that

the investigator could have a clear conception of the parent's stress, coping and adjustment. At the very end, a gestalt view was taken of all the cases and amalgamated to emulate what it's like to be a parent of an autistic child combining the data obtained qualitatively and quantitatively. In this manner the objectives of the study were fulfilled.

Every case would be analyzed in the same order. First the stress would be elicited, then coping strategies used by the subjects would be discussed and finally the adjustment of the subjects would be analyzed. The observations of each would also be discussed.

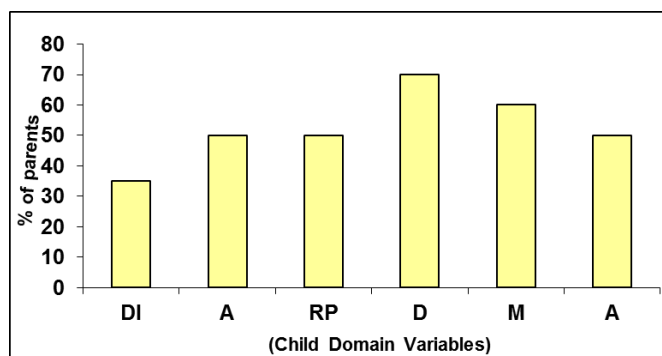
**Results and Discussion**

In the present study an attempt was made to assess the stress, adjustment and coping in parents of children with autism. The data was collected from 20 parents of children with autism by using parent stress index, coping checklist, semi-structured interview, adjustment interview. The group of parents comprised of eighteen mothers and two fathers with an age range of 26 yrs – 40 yrs and minimum educational qualification till 12<sup>th</sup>. The data have been collected and presented in tabular and Figical forms.

**Table 1:** Showing the percentage of parents of autistic children on the measure of various dimensions of child domain as a measure of parent stress index.

Variable	% of parents (Significant stress)
Distractibility	35
Adaptability	50
Reinforces Parents	50
Demandingness	70
Mood	60
Acceptability	50

Table 1 exhibits that children who display qualities like easy distractibility, inability to adapt, absence of positive reinforcement to parents, place too many demands on the parent, are moody and child is not as the parent hoped they would be. Such qualities make it difficult for parents to fulfill their parenting roles thereby contributing to the over-all stress in the parent child system.



**Fig 1:** Showing the % of parents of autistic children experiencing significant stress on the subscales in the child domain area on the parent stress index.

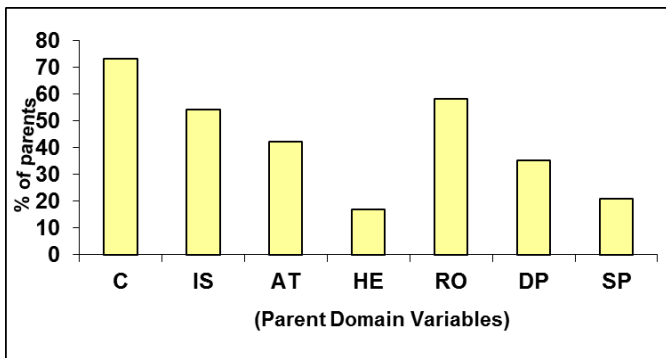
The Fig displays that parents experienced stress in the child domain area due to the child's inability to adjust to changes in his/her physical, social environment, the moody behaviour and

the demands the parent experiences the child as placing on them. Also the child is different from what they had expected; the child does not provide positive Reinforcement to the parents creating more stress.

**Table 2:** Showing the percentage of parents of autistic children on the various dimensions of parent domain as a measure of parent stress index.

Variable	% of parents (Significant stress)
Competence	60
Isolation	50
Attachment	25
Health	30
Role Restriction	50
Depression	25
Spouse	35

Table 2: Exhibits those sources of stress in the parent – child system that could be related to dimensions of parent’s functioning such as feeling incompetent, socially isolated, depressed, lack of support from spouse and experiencing the parental role as restricting their own identity.



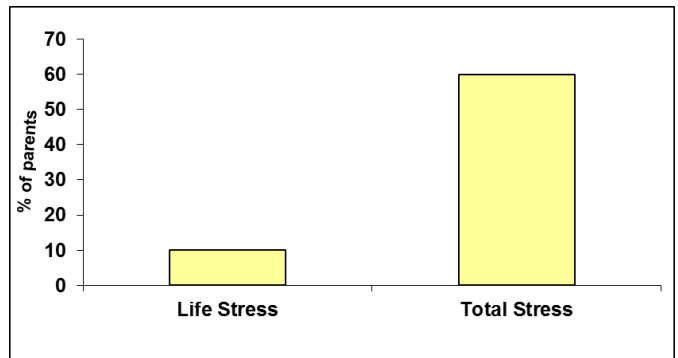
**Fig 2:** Showing the percentage of parents of autistic children experiencing significant stress in the parent domain on the parent stress index.

The Fig displays that parents experienced significant stress in the parent domain due to feelings of incompetence, and feeling controlled, dominated by their child’s demands and needs. They also tend to feel isolated from their peers, relatives and other emotional support systems.

**Table 3:** Showing the percentage of parents of autistic children experiencing stress in other situational areas and the total stress experienced.

	% of parents ( significant stress)
Life Stress	10
Total Stress	60

Table 3 exhibits the percentage of parents who find themselves in other stressful situational circumstances that are often beyond their control and that 60% of the parents are in need for professional assistance.

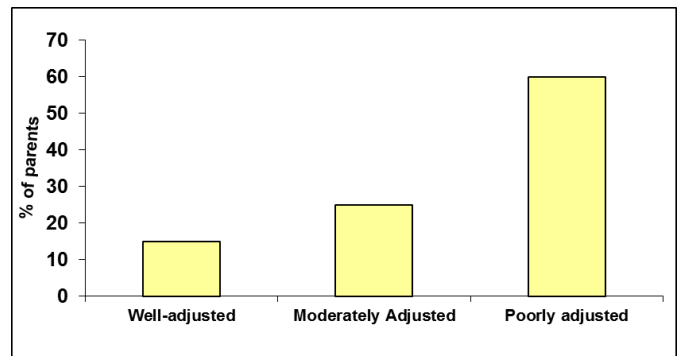


**Fig 3:** Showing the percentage of parents of autistic children experiencing significant stress thus amounting to a need for referral for professional assistance.

The Fig displays that 60% of the parents are in need for referral for professional assistance.

**Table 4:** Showing the percentage of parents of autistic children, who are well-adjusted, moderately adjusted and poorly adjusted.

Adjustment Level	% of parents
Well-adjusted	15
Moderately Adjusted	25
Poorly Adjusted	60



**Fig 4:** Showing the percentage of parents of autistic children with different levels of adjustment to the child’s condition.

The Fig displays that only 15% of the parents are well-adjusted while a majority 60%.

**Table 5:** Showing the percentage of parents of autistic children who are using a particular strategy of coping often.

	% of parents
Problem Solving	40
Distraction – Positive	0
Distraction – Negative	0
Acceptance	10
Faith/Religion	20
Social support	15
Denial	10

Table 5 Exhibits that parents tend to use problem solving often.

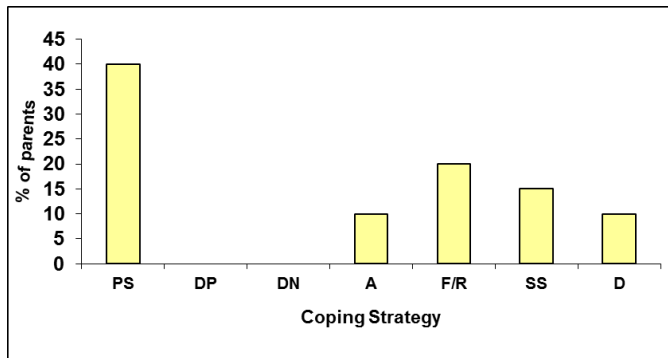


Fig 5: Showing the percentage of parents of autistic children who are using a particular strategy of coping.

Table 6: Showing the percentage of parents of autistic children who are using a particular strategy of coping moderately.

Strategy of coping	% of parents
Problem Solving	50
Distraction – Positive	90
Distraction – Negative	25
Acceptance	65
Faith/Religion	50
Social support	70
Denial	30

Table 6: Exhibits that parents tend to use Distraction positive, acceptance, social support and religion as a coping technique moderately.

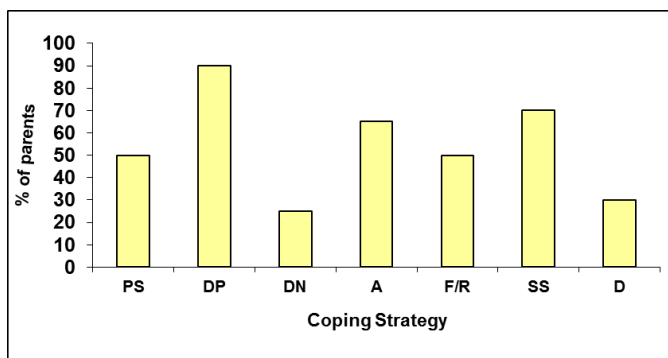


Fig 6: Showing the percentage of parents of autistic children who are using a particular strategy of coping.

The Fig exhibits that parents tend to use Distraction positive, acceptance, social support and religion moderately to deal with the situations.

Table 7: Showing the percentage of parents of autistic children who are using a particular strategy of coping rarely.

	% of parents
Problem Solving	10
Distraction – Positive	10
Distraction – Negative	75
Acceptance	25
Faith/Religion	30
Social support	15
Denial	60

Table 7: Exhibits those parents tend to rarely use distraction negative and denial as a strategy to cope with the demands of the situations.

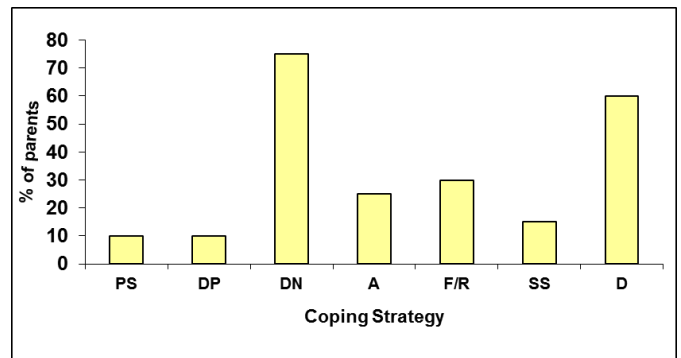


Fig 7: Showing the percentage of parents of autistic children who are using a particular strategy of coping rarely.

The Fig exhibits that parents tend to use Distraction negative and denial rarely to deal with the situations.

### Discussion

Autism presents a unique challenge to families. It takes the family several consultations to find someone who can guide them to a proper diagnostic process. Identification of stressful parent-child systems could function as an important part of preventive programs aimed at early identification and intervention.

The study involved 20 parents of children with autism. The data obtained was analyzed to find out the stress experienced by these parents, the coping strategies that they employ and how well they had adjusted to their child’s difficulties. A significant percentage of parents are experiencing stress due to certain qualities of the child. Examining each of the dimensions, starting with the dimension of Adaptability it was noted (Table 1) that 50% of the parents responded that certain behaviors of their child such as preservation and inability to change from one task to another without emotional upset, overreaction to changes in routines and difficulty in calming the child once upset made the parenting task more difficult thereby contributing significantly to the stress they experienced in the parent – child system. Regarding the next dimensions of reinforcing parent, 50% of the parents do not experience the child as a source of positive reinforcement. The interactions between parent and child failed to produce good feelings in the parent about himself or herself. Absence of reinforcement from the child leads to experience of stress by the parents.

Moving onto the next dimensions of Demandingness 70% of the parents experienced the child as placing many demands upon them. They felt stressed when the child would be crying incessantly or physically hanging on to the parent and had difficulty in getting the child to comply to their demands.

On the dimension of Mood, 60% of the parents were stressed because the child would be unhappy, depressed, frequently crying or not displaying signs of happiness that they would either be unable to explain or understand.

Regarding the next dimension of Acceptability, 50% of the

parents felt that the child does not match the expectations they had for the child.

After assessing factors in the child domain that contribute to stress, next we focus on those factors that are sources of stress and may be related to dimensions of the parent functioning.

Regarding competence 60% of the parents feel incompetent at handling their child especially when they are in social situations which seem to be a great source of stress.

On the dimension of Role restriction, 50% of the parents feel that the parental role is restricting their freedom and frustrating them in their attempts to maintain their own identity. Parents felt controlled and dominated by their child's demands and needs and find it difficult to take time away for them, because they may feel unable to leave the child in the care of somebody else.

Regarding the next dimension of Isolation. 50% of the parents are under considerable stress as they feel that they are socially isolated from their peers, relatives and other emotional support systems

Moving on to the dimension of Attachment 25% of the parents reported an inability at observing and understanding their child's feelings or needs accurately. Which when observed during the session was either real or just perceived by the parents.

Regarding the presence of mental health problems 30% of the parents responded in such a way that was suggestive of the presence of significant depression in the parent. Parents reported guilt and unhappy feelings and difficulty in mobilizing the energy needed to fulfill parenting responsibilities as a result of which they were unable to respond assertively and with authority towards the child.

On the dimension of spouse support 35% of the parents felt that they were lacking the emotional and active support of the other parent in the area of child management.

Apart from child characteristics and parent characteristic, table III depicts that 10% of the parents earned a high life stress score. Thus implying that 10% of the parents find themselves in stressful situational circumstances that are often beyond their control, referring to the amount of stress that they are experiencing outside the parent child relationship. Since high life-stress scores tend to intensify the total stress that the parent is experiencing and thereby will affect the parent-child system.

Significant total stress was experienced by 60% of the parents at a level that indicates the need for referral for professional assistance.

A well-adjusted person is one who attempts to meet the demands of the environment the individual perceives and experiences a sense of general well being in relation to the environment. Looking at the adjustment pattern of the parents to the stressors (Table IV and Fig IV) it was observed that 15% of the parents of autistic children were well-adjusted while 25% were moderately adjusted and a majority i.e. 60% was poorly adjusted. Results indicated that parents of children with autism are reported to have difficulties in managing different environmental demands or adjusting under different circumstances. Parents reported difficulty in facing special situations; and in continuing in such a demanding situation. They felt that there was no harmony among different forces

within themselves or in their relationship with the wider community.

Next looking at the coping strategies adopted by the parents in order to cope with the difficulties felt. The effectiveness of coping to a great deal determines the management of the child by the parents. Hence it was of interest to see how the caregivers dealt with these demands.

Obtained scores on the coping checklist ranged from 29 to 41 indicating that the total score was on the average side. Also, the in depth analysis of the responses as can be seen from Table V and Fig v indicates that some coping strategies were preferred over others by the subjects. The overall coping scores of the subjects do not show very effective coping by the subjects. However, some diversity in the overall coping scores can be seen.

The results reveal that 40% parents used problem solving as a coping style often, whereas 10% used it rarely and the 50% used it moderately. The results indicate that for some parents since their child's illness is an accepted truth, efforts are made to cope with various related problems in a planned and proper way. However, the extent to which the subjects are able to cope using problem solving differs and is related to the degree of the acceptance of the situation. Moving on to positive distraction it can be seen that this coping style was used moderately by 90% of the subjects and rarely by another 10% of the sample. This is suggestive of the fact that once the parents have accepted their child's illness, they find it useful to distract themselves by taking some time off from their routine work and indulging themselves in their hobbies. This way of positively distracting themselves from current stressors averts them from being overwhelmed by the emotions.

The next dimension to be studied was acceptance. Acceptance is a functional coping response, and in this a person who accepts reality of a stressful situation would seem to be a person who is engaged in an attempt to deal with the situation. Results indicate that 10% subjects seem to use acceptance as a coping strategy often, 65% subjects use it moderately and 25% of the subjects used it rarely. The results reveal that there is acceptance of the situation by all the subjects

Regarding the next dimension, religion, the results indicated that 20% of the subject used religion as a coping strategy often, whereas 50% used them moderately and only 30% used it rarely. One interesting finding was that most of the subjects responded positively when it came to 'praying to God'. With the help of the unstructured interview, it was found that most of them felt it was a way of ventilation and also it assured them of being heard. Although most of the subjects gained strength from belief in god yet they were not overly involved with the rituals. Next dimension studied was social support. The results indicate that 15% of the subjects used social support as a coping style often whereas 70% of them used social support moderately and the other 15% used it rarely. Social support is suggested to be an important factor in a family's coping ability. Informal support may be perceived to be more effective than formal support and in some cases use of community resources has been reported to be associated with increased maternal distress.

Last dimension to be studied is denial. The results revealed that 60% of the subjects used denial rarely, 10% used it often

and 30% used it moderately. Denial refers to the refusal of the truth or existence of a thing. Talking about denial in the present context, it is the denial of existence of a problem or a stressful situation.

After having discussed the various dimensions on the coping checklist, it can be seen that the coping strategies used by the subjects vary in the degree of their use. This can be attributed to various factors involved in coping. Coping mainly depends on attitude of parents and their knowledge of illness, past experiences with such a child, emotional reactions and advice offered by mental health professionals.

### Significance

Stress was found in the parents of children with autism. The stress could be attributed to certain behaviors of the child such as demandingness and moody behavior. Stress could also be due to the parents own functioning such as feelings of incompetence, isolation and role-restriction. Parents also felt that situational factors further aggravated the total stress experienced.

The coping style of the parents revealed the use of problem solving often. Occasionally to cope with the stress of the situation, they would also rely on distraction positive, social support for help.

A significant number of parents were found to be maladjusted requiring professional help.

### Limitations of the study

Although efforts were made to control extraneous factors certain limitations still existed which were unavoidable in the context of the research chosen. The total sample size of 20 was small, due to which the results of the study cannot be generalized. All aspects of stress, adjustment and coping have not been explored. Random sampling could not be done. Gender differences and differences between family structure, number of siblings, and education of parents could have been explored. The purpose for not finding these differences was due to lack of sufficient number of parents in each category. Efforts were made to minimize any bias that could affect the study.

Despite these limitations the study has successfully been able to assess the stress, coping and adjustment pattern in parents of children with autism.

### Conclusion

Thus stress on the family does have an impact on the child's mental health problem, to the extent that a circular relationship of cause and effect between family adversities and the child's mental health disorder was seen to operate.

To conclude, the illness of the child requires the family to organize itself to be available on a flexible, unpredictable schedule in order to respond to crisis as they occur, and to provide unlimited quantities of support and reassurance to allay the anxiety and emotional pain of the parents. The family must develop creative means of integrating the child within the community. The family must also develop appropriate expectations for the child whose development deviates significantly from the norm for his or her age group and who may be actively excluded from peer activities.

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