

## Effective Coping Strategies for Stress in Parents of Autistic Children: A Training Module

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### ABSTRACT

The purpose of the study is to determine the level of stress and different coping mechanisms used by parents of children with Autism Spectrum Disorder on pre-training and post-training tests. A researcher-developed training module was used to impart training to enhance the coping mechanisms used by parents to reduce their level of stress. A sample of 100 parents of one child with Autism Spectrum Disorder was taken. They were administered on Parental Stress Index and Family Crisis Oriented Personal Evaluation Scales (F-COPES). The study utilized a quantitative approach, using Means, Standard Deviation and t –test in analysing data. Results reveal that parents of autistic children differed significantly on coping strategies and level of stress after the training.

**Keywords:** *Family, Coping Mechanism, Social Support, Parental stress*

**P**arenting a child is demanding and challenging for all parents, and when a child has a disorder, the demands and challenges are extravagant. It is hard to imagine how parents and siblings cope when the problem is autism which is one of the most devastating and least understood mental disorders of childhood.

Autism was first introduced to medical literature by Leo Kanner, a former child psychologist at Johns Hopkins University, in 1943. According to Coleman (1989, p.3), Kanner chose the word “autistic” because the children had in common an “extreme aloneness from the beginning of life and an anxious, obsessive desire for the preservation of sameness.” The author observed that in the previous decade, the parents were blamed for the illness of their child in the theories of mental illness. It was surmised that the disorder must be caused by faulty nurturing on the part of the parents (Sanua, 1986), especially the mother, hence the term “refrigerator mother” because there were no physical abnormalities. Luckily, now autism is understood as a neurological syndrome and autistic symptoms are recognized as the final pathway with which the brain

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expresses a great variety of lesions and malfunctions of the infant central nervous system (Coleman, 1989).

Autism Spectrum Disorder, also known as ASD, is extremely complex and has a wide range of symptoms. ASD is categorized in the Diagnostic and Statistical Manual of Mental Disorders, IV ed. (DSM-IV) as a pervasive developmental disorder. An individual diagnosed with autism may communicate verbally or nonverbally, they may follow restricted and repetitive routines as well as exhibit restricted motor mannerisms (American Psychological Association [APA], 2000, p. 72). Children who are diagnosed with ASD are very interested in friendships but lack the social skills to develop these relationships and are unable to relate to peers. The population often displays atypical sensory related behaviors such as excessive rocking, spinning and twirling in order to self-stimulate. Another aspect of the autism diagnosis can be sound sensitivity. Children who are diagnosed with ASD may be observed covering their ears or wearing a headset to drown out unwanted sounds (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Behavioral symptoms are also recognized in children diagnosed with autism including hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behaviors and temper tantrums (APA, 2000, p. 72).

The autism spectrum ranges from low to high with some symptoms being more extreme than others and because of the wide range of manifestations, this disorder varies greatly. ASD is typically diagnosed in children by the age of three where difficulties are recognized in the area(s) of social interaction, language for communication, and/or restricted, repetitive, and stereotyped patterns of behavior (MacFarlane & Kanaya, 2009).

### ***Parental Stress***

Parental stress is regarded as an intricate set of non-specific, persistent and major challenges associated with taking care of their child i.e. one of parents' most important roles. There is still no consensus on the conceptualization of this phenomenon despite a significant amount of data on stress in parents of children with disabilities (Perry, 2004).

Parental stress can lead to parents experiencing higher levels of stress than average when the difficulties of parenting exaggerate due to increased situational demands of challenging child behaviors (Theule, Wiener, Rogers, & Marton, 2011). Parental stress can have damaging effects to the parent's health, their interactions within the family, and intensifying the conditions that caused parental stress to increase, in the case of parenting a child with a disability. Parenting stress is based on the exclusive experiences of each parent. Parents' idealizations about what is "normal" influence the response to emotional distress and anxiety (Deater-Deckard, 2004). Every parent has a different set of expectations about their child's capabilities and when these expectations are not met, the ability to adjust to the child is affected. A child's development and their future outcomes are shaped by a psychologically powerful relationship i.e. the parent-child bond. Parents experience stress that is qualitatively different than other types of life stressors

when this bond is strained, but is not separated from the other stressors that parents deal with in their lives.

### *Coping Strategies*

Coping is an important aspect in the grieving process when presented with an autism diagnosis. Coping compliments the family's acceptance process. "The grieving process associated with the birth of a child with disabilities is complicated by the parents' grieving the death of the "expected" baby while at the same time trying to accept the "imperfect" baby. Even though they have the joy of being able to hold and love their baby, their life is suddenly and drastically changed" (Hooyman & Kramer, 2006, p. 200). One way parents can cope with the stress of autism is by networking with other families who have been affected by the disorder.

The term coping generally refers to adaptive or constructive coping strategies, i.e. the strategies reduce stress levels. However, some coping strategies can be considered maladaptive, i.e. stress levels increase. Maladaptive coping can thus be described, in effect, as non-coping. Furthermore, the term coping generally refers to reactive coping, i.e. the coping response follows the stressor. This contrasts with proactive coping, in which a coping response aims to head off future stressors.

Researchers document the importance of understanding families' worldviews, values and spiritual beliefs and day-to-day priorities and concerns (King & et al, 2009). Because each family system is unique, each family may have different coping strategies. So, professionals need to know that what coping strategies are helping each family. One should not assume that any one specific strategy works well for all families. Professionals should identify family sources of support and promote the utilization of both formal and informal support systems.

Elizabeth Koehler, Xiao-Hua Zhou & Jeffrey Munson (2009) observed parents of children with developmental disabilities, particularly autism spectrum disorders (ASDs), are at risk for high levels of distress.

Also, Deborah C. Beidel (2009) conducted a study to investigate the impact of children with high-functioning autism (HFA) on parental stress, sibling adjustment, and family functioning. The results indicate parents of children with HFA experience significantly more parenting stress than parents of children with no psychological disorder, which was found to be directly related to characteristics of the children.

Furthermore, Gupta and Singhal (2004), in their study recognized families that have been successful in developing positive perceptions regarding raising a child with disability. It has been reported that families with a child with disability can and in fact do have positive perceptions which leads to a better quality of life for the family, and scope for maximizing the child's potential. Positive perceptions play a central role in the coping process and assist us in dealing with the traumatic and stressful event.

## Effective Coping Strategies for Stress in Parents of Autistic Children: A Training Module

The purpose of the present research was to study the impact of the training module on the level of stress and the type of coping mechanism employed by the parents of autistic children.

### OBJECTIVES

*In the present research the following objectives were formulated:*

- To assess the coping strategy of parents with autistic children.
- To assess the level of stress among parents of autistic children.
- To develop a training module for coping with stress in parents of autistic children.
- To see the effect of training module on the level of stress of parents of autistic children

### Hypothesis

*In the present research the following hypotheses were formulated:*

- There will be a significant effect of the training module on the level of stress in parents of autistic children.
- The parents of autistic children will differ significantly on coping strategies and level of stress after the training module.
- There will be an interactive effect of social support on coping strategies and level of stress on parents having autistic children.

### MATERIAL AND METHOD

#### *Design and Sample:*

In this study a sample of 100 parents of one child with ASD was taken. They were sourced from early intervention centres, specialist schools, autism associations and support groups in New Delhi.

#### **Instruments**

- **Parenting Stress Index – Short Form (Abidin, 1995)**

The PSI-SF is a self-reported questionnaire that yields an overall parenting stress viz. the norms for children in the ranging of one month to 12 years are developed by the author. The items of parenting stress (Abidin, 1995) is not designed to assess the stress that parents experience related to other life roles and life events. The PSI was originally used with parents who have at least fifth grade reading levels.

- **Family Crisis Oriented Personal Evaluation Scales (F-COPES: McCubbin, Olson, & Larsen, 1987).**

The F-COPES is a 30-item, self-report questionnaire used to assess ways that families cope with stress. The measure uses a 5-point Likert Scale with responses ranging from “strongly disagree” to “strongly agree.” There are five subscales: reframing, acquiring social support, mobilizing family to acquire and seek help, seeking spiritual support and passive appraisal. Higher scores indicate more positive coping and problem solving strategies during times of crisis.

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- **Effective Coping Strategies For Stress In Parents Of Autistic Children: A Training Module**

A training module was prepared in order to help the participants reduce their stress levels and enhance their coping mechanisms. The training modules comprised of four sessions namely:

- i. **Handling Emotions:** this session increased the awareness about the participant's emotions. The session was divided into two activities wherein first activity dealt with defining various emotions and helping the participants to identify different emotions felt by them. The second activity enabled the participants to be aware of other's emotions and to understand how others would feel by placing oneself in their situation thus, understanding and expressing empathy by the help of a situation based worksheet.
- ii. **Parenting Style:** this session enabled the participants to discuss about various facets of parenting and also helped them to reflect upon their parenting style.
- iii. **Self-Awareness on Stress:** this session enabled the participants to identify factors that contribute to stress and also recognize the internal and external stressors in one's own life. This was done with the help role plays. The participants also calculated their present stress level with the help of a "Stress- Prone Characteristic Questionnaire".
- iv. **Identifying Social Support:** this session let the participants identify importance and various sources of social support. The participants were asked to discuss about various situations where they felt a need of support from family/friends. Then the participants were asked to fill questionnaires on Perceived Social Support-Family and Perceived Social Support-Friends in order to have an idea of their sources of social support.

The training was imparted in the form of workshops. The participants were divided in to four groups. Four workshops were conducted in the span of four days i.e. one session each day for each group. Each session lasted for about two hours.

### ***Procedure***

All data were gathered using face-to-face interviews at the early intervention centres, specialist schools, autism associations and support groups. The interviewer administered the Parenting Stress Index – Short Form, the F-COPES to each parent in random order. After the tests were administered on the parents, the training was imparted in the form of workshops. Then the experimenter again administered the Parenting Stress Index – Short Form to the participants in order to gauge the effect of training module on the stress levels of the participants. The participants were welcomed to contact the experimenter for any questions or concerns regarding the experiment.

## RESULTS

The purpose of the present research was to study the impact of the training module on the level of stress and the type of coping mechanism employed by the parents of autistic children. For this purpose, a sample of 100 parents of autistic children were selected, after administering the parental stress scale, the range was within clinically significant stress to normal levels of stress. Data was analysed both with the help of descriptive and inferential statistics. Mean and Standard deviation were calculated. Inferential Statistics such as t-statistics was applied to compare the two groups and to see the relationship between various measures like stress and coping mechanism.

In table 4.1 percentages of cases showing different types of coping mechanism in the pre and post training test are presented. It showed that, 42% of the cases used social support, 18% of the cases used spiritual support, 14% of the cases used reframing and 13% of the cases used mobilising help from the family and passive appraisal as their coping mechanism in pre-training tests whereas 61% of the cases used social support, 12% of the cases used spiritual support, 10% of the cases used reframing, 9% of the cases used mobilising help from the family and 8% of the cases used passive appraisal as their coping mechanism in post-training test.

*Table 4.1: Percentage of cases showing type of coping mechanism used in pre and post training test (N=100)*

Coping Mechanism	Percentage in Pre-Training Test	Percentage in Post-Training Test
<b>Social Support</b>	42%	61%
<b>Spiritual Support</b>	18%	12%
<b>Reframing</b>	14%	10%
<b>Mobilising help from family</b>	13%	9%
<b>Passive Appraisal</b>	13%	8%

In Figure 4.3 and 4.4, percentages of cases showing levels of stress that is, low, normal, high and clinically significant on pre and post-tests respectively. It was observed that level of stress was reduced in post-test. Summary results of t-statistics for level of stress among pre training and post training tests are presented in table 4.4 and in table 4.5, results of types of coping mechanism for both pre training test and post training test are reported respectively.

*Table 4.2, Mean and S.D's for the level stress for both pre and post- training test (N=100)*

Level of Stress	Mean (N=100)	Standard Deviation (N=100)
Pre- Test	97.04	22.40
Post-Test	64.73	17.32

*Table 4.3, Mean and S.D's for the types of coping mechanism for both pre and post- training test (N=100)*

Coping Mechanism	Pre-Training Test		Post-Training Test		t-value
	Mean	S.D	Mean	S.D	
<b>Social Support</b>	30.33	8.88	37.90	8.73	<b>4.31</b>
<b>Spiritual Support</b>	25.79	8.53	27.74	8.04	1.66
<b>Reframing</b>	24.69	9.12	30.35	8.87	<b>4.44</b>
<b>Mobilising help from family</b>	24.98	8.72	28.65	2.26	<b>2.88</b>
<b>Passive Appraisal</b>	24.17	8.82	25.51	8.69	1.08

*Table 4.4: Showing mean, and t-value on the level of stress among pre training and post training tests (df=99)*

Stress Scores	MEAN	S.D	t- value
PRE- TRAINING	97.04	22.40	11.41
POST- TRAINING	64.73	17.32	

It can be seen from the table that the t-value of level of stress i.e. 11.41 was observed to be significant at 0.05 level, indicating that the mean scores of pre training test (mean=97.04) was higher as compared to post training test (mean=64.73).

*Table 4.5: Showing mean, and t-value on the coping mechanism among pre training and post training tests (df=99)*

Coping Mechanism Scores	MEAN	S.D	t- value
PRE- TRAINING	25.99	9.38	<b>2.91</b>
POST- TRAINING	30.03	10.23	

The above table denotes the scores of coping mechanism on pre-training and post-training tests. The t value of 2.91 signifies significant difference exists between the two at 0.05 significance level. This implies that training aid was able to enhance the coping mechanisms of the participants.

## **DISCUSSION**

Majority of parents go through immense amount of stress if their children have some kind of disabilities or any chronic health problems. It has been proved that parents of the children on the autism spectrum are the ones who experience the most stress of all.

The level of stress in parents of children with ASD is heightened due to various reasons. It is necessary to being able to cope with worries about the future, grief, and the tussle to be able to find and acquire proper services. There are some additional stressors being faced by parents of children with ASDs. Firstly, there exist ambiguity as to what caused their child to be autistic, sometimes there also exist a guilt caused by the sense of their inability or failed attempt to being able to do something that led to ASD in their child.

Second, social interaction is the core disability that is associated with ASDs. Parents desire for a loving and warm affiliation with their child. It is incomprehensible to discover that you have a child who does not like to be cuddled/held, or a child who does not make any eye contact. Parents pass through some pain and confusion while adapting the ways in which their child is comfortable.

Third, it does not matter what is the specific ASD diagnosis or IQ, frequent and intense tantrums to extreme rigidity and refusal to sleep as the few behaviour problems that children on the autism spectrum often have. Furthermore, entire family, siblings and marriage relationships are strained due to such behaviours.

Therefore the main aim of the present work was to see level of stress and coping mechanisms used by the parents of autistic children on pre-training and post-training tests. 100 autistic children's parents were administered on a number of tests Parental Stress Index and F-COPES.



## Effective Coping Strategies for Stress in Parents of Autistic Children: A Training Module

The first hypothesis stated that after the training there will be a significant difference among the level of stress on pre training and post training test. The data was analysed using percentage of cases that lie on the low, normal, high and clinically significant ranges of stress on both pre training and post training tests. This may be because of the fact that parents of autistic children are more stressed than parents of normal children and thus are not able to use coping mechanism effective in reducing level of stress. Thus, when the parents of autistic children were trained to enhance their coping mechanism and use it effectively the level of stress was reduced which was prominent in post training test. The results are consistent with the study by Sanders and Morgan which stated that comparison with parents of children with any other neurodevelopmental disabilities, it has been found that a higher level of stress and psychological distress is experienced by parents of children with ASD.

The second hypothesis states that the parents of autistic children will differ significantly on coping strategies and level of stress after the training module. The data was analysed using the percentage of cases that lie on different mechanisms of coping that is social support, spiritual support, reframing, mobilising help from family and passive appraisal and also using percentage of cases that lie on the low, normal, high and clinically significant ranges of stress on both pre training and post training tests respectively. The mean scores on level of stress were higher in pre-training test as compared to post-training tests.  $t$  - value was also found out to be significant indicating difference between the two groups. Even on the dimension of coping mechanism, the  $t$ -value obtained was found out to be significant. This dimension refers to the fact that in order to curb down their stress, parents adapt to different types of coping mechanisms.

The third hypothesis stated that there will be an interactive effect of social support on coping strategies and level of stress on parents having autistic children. The data was analysed using the percentage of cases that used social support as a coping mechanism to deal with their stress in pre- training and post-training tests. It was observed that using social support as a coping mechanism parents of autistic children could effectively deal with their stress as percentage of using social support as coping mechanism increased from 42% in pre-training test to 61% in post-training tests.

A positive finding observed from this sample was that higher the level of social support for the mothers of autistic children lesser the somatic problems and depressive symptoms (Gill & Harris, 1991). The prime investigator did not observe any fathers of autistic children while attending some local autism support group meetings. Most mothers specified that their social support largely came from other mothers whom they met at support groups or other related events. More support groups should be initiated to cater to the needs of the fathers of the autistic children.

Also, Krauss in his study observed that social support played a major role in lowering stress in mothers, however it was not observed to be a significant factor in lowering the stress levels of fathers of autistic children. Majority of the caregiver demands for children with disabilities are placed on the mothers is reflected by such findings.

## SUMMARY AND CONCLUSION

There has been an enormous increase in the number of children diagnosed with ASD; out of every 1000 children 6.7 are reported to have an ASD diagnosis. Few characteristics of ASDs are moderate to severe impairments in cognitive development, language development, repetitive behaviours and social interactions. It has been described as immensely stressful and full of psychological stress to parent a child with ASD. Some studies have now tried to understand the ways parents adapt in order to cope with the daily stressors of nurturing their children. To learn how parents deal with the regular hassles of raising a child with ASD and to recognise various techniques of coping employed by the parents of ASD children was the prime concern of this present study. Parenting a child with ASD is quite challenging. In comparison with parents of children with any other neurodevelopmental disabilities and typical children, it has been found that a higher level of stress and psychological distress is experienced by parents of children with ASD.

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