



Research paper

Caregiving Affliction: A Comparison Study on the levels of Depression and Anxiety Among Parents of Autistic Children during Pre and Post Therapeutic Intervention

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ARTICLE INFO	ABSTRACT
<i>Article history</i> Received 22 February 2024 Revised 15 March 2024 Accepted 16 March 2024 Published 21 March 2024	Introduction: Parenting a young child with ASD requires a higher level of family adaptive functioning compared to parenting typically developing children. It has been discovered by researchers that parents of children with ASD are under more stress than typical parents, increasing evidence indicates that intervention can also have positive effects on parent and family functioning, which in turn can enhance child outcomes. Purpose: This study examined the effect of intervention strategies, care barriers and support services on the chronic stress and anxiety levels of parents with autistic children and also compares the depression, stress and anxiety among those parents before and after therapeutic intervention. Method: In this study a total of 20 parents with children (age-2-5 yrs) with ASD were taken as samples. Depression, Anxiety, Stress Scale, DASS 42 (Loviband, 1995) to measure three negative conditions, such as depression, anxiety and stress. Result: Before receiving therapeutic care, the parents of children with autism spectrum disorders scored higher on despair, anxiety, and stress. After six months of therapeutic intervention, the data reveals a small reduction in all three of these characteristics in the group of twenty parents. Conclusion: The current study concludes that stress, worry, and sadness are prevalent in parents of autistic children. All three variables showed a discernible decline after six months of therapy: stress dropped from 20.89 to 17.67, anxiety dropped from 13.61 to 11.89, and depression fell from a mean of 19.67 to 16.11.
<i>Keywords</i> <ul style="list-style-type: none">• Autism Spectrum Disorder• Psychological health• Therapeutic intervention	

1. Introduction

According to Jorrol & Happe (2003), autism spectrum disorder (ASD) is a developmental disability that is characterised by impairments in language, cognitive,

and social behaviour. ASD is a multifaceted developmental disorder characterised by ongoing difficulties with speech, nonverbal communication, social interaction, and restricted/repetitive behaviours. Researchers have discovered that parents of children with ASD are under more stress than typical parents. Stress levels for these parents are elevated by stigmas such as unfavourable social reactions and opinions of others. Parents experience shock when their child is initially diagnosed with ASD. They must



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quickly adapt to a new position as the parents of an extraordinary child and change how they view themselves to handle these new obligations. The difficult behaviours that parents typically exhibit—such as restless nights, disorderly eating patterns, self-harming actions, tantrums, etc.—can also contribute to their stress. Parents experience increased stress due to financial responsibilities such as treatment expenditures and medical support. Understandably, being a carer and the duty of parenting can lead to stress.

Thus, parenting a young child with ASD requires a higher level of family adaptive functioning compared to parenting typically developing children. Parents of children with ASD participate in recognizing developmental challenges, scheduling developmental assessments and diagnostic evaluations with experts, and collaborating with a multidisciplinary group to execute early intervention strategies. Parents who are extremely stressed, overwhelmed, or lacking resources may be less inclined to start intervention for their children or may struggle to actively participate in the learning process essential for early ASD intervention. On the other hand, parents who receive adequate support and are prepared to acquire new knowledge and adjust will probably have the most positive results. The potential benefits of early autism intervention for supporting parents are just starting to be realized, but increasing evidence indicates that intervention can also have positive effects on parent and family functioning, which in turn can enhance child outcomes. Positive parent traits or experiences have the potential to enhance intervention outcomes, counteracting the negative effects of parental stress on the process. Limited research has focused on factors related to parents that can help interventions succeed, even though there is some indication that positive parent expectations lead to better outcomes for children. Family adaptive functioning is a larger concept that goes further than just looking at how a single parent functions, it is an expansion of the idea of adaptive functioning for an individual, focusing on their ability to perform necessary skills for daily living, like dressing, eating, following rules, staying safe, and forming relationships.

The potential for improving parent and family functioning through early autism intervention is just starting to be recognized, with increasing evidence indicating that positive effects on parents can also lead to better outcomes for children. Though the

benefits of early autism intervention for parents are still largely unknown, mounting research (discussed in the next sections) indicates that intervention's good effects on parent and family functioning may even further enhance child outcomes. Parents who contact with professionals in the healthcare and educational sectors firsthand witness the effects of the intervention. Indirect effects of ASD treatments are also felt by parents when their children exhibit problematic behaviours or make slower-than-expected developmental progress. This is especially true for children receiving services. But parents also have a significant role in family adaptive functioning, which refers to the strategies families use to promote the best possible outcomes for their children with ASD. A parent's stress levels, and psychological health have an impact on their capacity to do adaptive tasks. Consequently, there is a transactional process by which parents influence and are influenced by ASD interventions for their offspring. As a result, it is anticipated that over time, parents of ASD children would experience a decrease in stress and anxiety. The goal of this study is to compare the stress and anxiety levels of parents of children with ASD before and after therapeutic intervention.

2. Review of Literature

Past studies show that parents of children with ASD experience higher levels of stress, depression, and anxiety compared to other parents.

Hart (2003) found that children with ASD exhibit significant learning and behavioral problems, leading to greater stress, anxiety, and depression among their parents. Her study involved 71 parents of children with ASD and 40 in a control group, with ASD parents reporting significantly higher levels of emotional distress.

Rao et al. (2009) investigated the effects of high-functioning autism (HFA) on parental stress, sibling adjustment, and family function. The study, which included parents of 15 children with HFA and 15 control children, discovered that parents of HFA children are much more stressed, which is directly related to the children's features. The study also found that improved intellectual functioning in HFA children does not alleviate the burden of parenting. Thus, treatment programs should target parental stress in order to improve results for both the kid and their family.

Rezendes et al. (2011) investigated the relationship between parental anxiety/depression and child behaviour difficulties in children with autism spectrum disorders (ASDs), with an emphasis on parenting stress and self-efficacy as mediators. Using a sample of 134 mothers, the study discovered that parenting stress mediates the association between child behaviour problems and low parenting self-efficacy, which in turn partially mediates the relationship between parenting stress and increased anxiety/depression. The findings show how stress and self-efficacy affect parental mental health in households with children with ASD.

Alafeeq et al. (2012) investigated depression and anxiety among parents and carers of autism spectrum disorder children. The study had 100 parents/caregivers, 50 cases, and 50 controls. He found that autism is connected with increased load and stress for the affected child's parents/caregivers. The demands of the impairment increase the overall incidence of depression and anxiety among parents/caregivers.

Silva et al. (2012) measured stress in parents of children with ASD using the Autism Parenting Stress Index (APSI) with a sample of 274 children under six. The APSI, which has a Cronbach's alpha of .827, identifies areas where parents need support. Parenting stress in the autism group was four times higher than in the typical group and double that of the developmental delay group. Three key factors impacting stress were identified: core deficits, co-morbid behavioral symptoms, and co-morbid physical symptoms.

Aliaj (2013) investigated the degree of stress, anxiety, and depression in moms of autistic, Down syndrome, and usual development children in Albania. In this study, he included moms with children with autism (n=30), mothers with children with Down syndrome, and mothers with children with average development (n=30). The study's findings reveal that moms of children with Down syndrome have higher levels of stress, anxiety, and depression than mothers of children with autism spectrum disorder or mothers of children with average development.

Soltanifar et al. (2015) investigated parental stress in mothers and fathers of children with ASD in Iran. The study included 42 couples with children ages 2 to 12 who were diagnosed with ASD. Using the Childhood Autism Rating Scale (CARS) and the Parenting Stress Index (PSI), the study discovered a

positive relationship between stress levels and the severity of the disease, with fathers of more severely afflicted children suffering more stress. Mothers reported significantly higher stress levels than fathers across all PSI subscales. These findings emphasise the emotional demands of parents in developing effective treatment techniques for ASD children.

Davis (2015) investigated the link between parental stress and behavioural issues in families with children with autism spectrum disorders (ASD). The study, which included 39 parents who participated in a Mindfulness-Based Stress Reduction (MBSR) intervention, discovered that common child behaviour concerns such as concentration problems, language difficulties, and externalising behaviours were associated with higher parental stress. Specifically, "not answering when spoken to" and "temper tantrums" were substantially associated with parental stress and predicted changes in stress levels throughout intervention. According to the study, therapies that target these problematic behaviours can help to reduce parental stress.

Bonis et al. (2016) investigated the stress levels of parents of children with autism. His goal is to investigate the elements that influence parents' stress levels. He discovered that parents of children with ASD experience higher levels of stress than other groups of parents.

Malakar et al. (2018) examined the levels of stress, anxiety, and depression experienced by parents of children diagnosed with ADHD and autism. One hundred parents from Kolkata—fifty men and fifty women—with children under the age of ten were involved in the study. The two groups of parents' stress, anxiety, and depression levels differed significantly, according to the results.

Bilai et al. (2018) investigated stress, anxiety, and depression in moms of children with autism spectrum disorder. The DASS-42/scale was employed to gather data. They discovered that, with regard to marital status, education level, occupation, and number of siblings, there was no statistically significant difference in the stress levels of the experimental group and the control group.

Estes et al. (2019) examined the effect of early autism intervention on parents and family functioning. They discovered a reciprocal link between the success of kid interventions and parent well-being. Parental involvement is beneficial for effective interventions, such as high-intensity EIBIs that apply naturalistic developmental and

behavioural principles. Well-supported parents are more likely to use interventions successfully, which improves the results for their kids.

Zhou et al. (2019) looked at emotional issues among moms of kids with autism spectrum disorder (ASD), concentrating on the relationship between the kids' primary symptoms and the moms' socioeconomic status (SES). 180 moms in Chang Sha, China were surveyed, and the results showed that 80.2% and 72.5% of the mothers, respectively, reported having anxiety and depression symptoms. While SES had no effect on anxiety symptoms, it did have some effect on depressive symptoms, with higher depression levels being associated with lower levels of education. One important component was the child's level of autistic symptoms; milder symptoms offered some protection against depression and anxiety in the mother. Reducing mother emotional discomfort may be aided by improving children's primary symptoms.

Hence, the above literatures reveal that elevated levels of stress, anxiety, and depression among parents whose children have autism spectrum disorder (ASD). These levels in parents will be compared in this study before and after their child has received six months of therapy. Whereas the current study aims to identify parents who are at risk of chronic stress and enhance intervention options by investigating the impact of care barriers and support services on parental stress.

3. Methodology

3.1 Aim

To assess the effect of intervention strategies, care barriers and support services on the chronic stress levels of parents with autistic children.

3.2 Objectives of the Study

- To measure the depression, stress and anxiety of the parents of children with Autism who have not started any therapeutic intervention.
- To measure the depression, stress and anxiety level of parents of children who had attended therapeutic intervention for at least 6 months.
- Compare the depression, stress and anxiety among those parents before and after therapeutic intervention.

3.3 Hypothesis of the Study

H1 The level of depression, stress and anxiety will decrease comparatively in parents with children with autism after therapeutic intervention.

3.4 Sample

In this study a total of 20 parents with children with autistic spectrum disorder were taken as samples. The age range of the autistic children has been taken within 2-5 years.

3.5 Procedure

The institution in which the study was conducted with parents of children with autistic spectrum disorder is Odisha Speech and Hearing Centre, Bhubaneswar, Odisha. The first meeting was held with the director of the clinic. Parent questionnaires and the purpose of the study were explained in detail. Once the study was explained in detail and signed permission for the work, we started the study. A selection of 20 parents had been made for the current study of whose children have just been diagnosed with autism. The selection of the parents was done randomly from the Therapy Center. Then we administered DASS 42 to those 20 parents. After the administration of DASS 42, their children started therapeutic intervention. DASS 42 was again administered to those 20 parents after receiving at least 6 months of therapeutic intervention of their child.

3.6 Tools Used

The instruments used in this study is Depression, Anxiety, Stress Scale (Loviband, 1995). This is an instrument designed to measure three negative conditions, such as depression, anxiety and stress. Completion of this instrument is realized through self-report. Each of the persons involved in the study read all written statements and chooses a number from 0 to 3, each of the numbers takes a certain value. Number 0 - the statement read does not suit me at all to me, number 1 is right for me sometimes, number 2 is right for me in a considerable number of cases or in the best of times, and the number 3 has best fit me most of the time. The questionnaire contains a total of 42 questions and intends to measure the emotional state of an individual. The results are determined by taking these measures: stress/anxiety/depression

normal, easy, moderate, severe, and extremely – severe.

DASS score interpretation was done according to the following table:

Meaning	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely severe	28+	20+	34+

4. Results & Discussion

Before and after receiving therapeutic intervention, each of the 20 parents whose children had autism and were involved in the study had self-scored twice for depression, stress, and anxiety.

Before receiving therapeutic care, the parents of children with autism spectrum disorders scored higher on despair, anxiety, and stress Table 1 displays the level of stress, anxiety, and sadness experienced by parents of autistic children who have not yet begun the therapeutic intervention. It indicates that in those 20 parents, all three of these characteristics are very present. That is, parents of autistic children who have not begun therapeutic intervention show increased signs of stress, anxiety, and despair. It has been discovered that stress and depression go beyond anxiety. The graphical representation of depression, anxiety, stress among parents with children with autism is shown in figure 1. It shows that depression and anxiety is more among those parents than stress.

Table 1 DASS score of depression anxiety and stress of parents of autistic children pre-Therapeutic Intervention

Serial No	Depression	Anxiety	Stress	Serial No	Depression	Anxiety	Stress
1	19	15	24	11	23	14	20
2	25	14	26	12	12	9	18
3	18	9	15	13	23	16	25
4	13	7	15	14	26	17	28
5	9	10	14	15	15	16	20
6	24	16	21	16	21	15	22
7	18	15	17	17	25	16	24
8	22	17	20	18	20	12	21
9	14	9	16	19	11	7	15
10	27	18	30	20	13	9	18

The depression, stress, and anxiety scores of parents whose autistic children had received at least six months of therapeutic intervention are displayed in Table 2. The outcomes differed for each priest.

Throughout the testing phase, the parents were cooperative. Table 2 displays the level of stress, anxiety, and depression experienced by parents of autistic children who have been receiving therapeutic intervention for at least six months. After six months of therapeutic intervention, the data reveals a small reduction in all three of these characteristics in the group of twenty parents. It indicates that compared to their previous stress level (before to starting therapeutic intervention), parents who have started therapeutic intervention show slightly less depression, tension, and anxiety for their autistic kid. The results revealed that levels of depression and stress are found to be more than anxiety.

Table 2 DASS score of depression anxiety and stress of parents of autistic children post therapeutic intervention

Serial No	Depression	Anxiety	Stress	Serial No	Depression	Anxiety	Stress
1	12	10	15	11	20	11	18
2	20	18	22	12	10	7	15
3	15	9	15	13	18	13	20
4	11	7	12	14	20	14	24
5	9	7	14	15	13	14	16
6	20	13	19	16	18	13	18
7	15	12	15	17	23	14	20
8	19	13	18	18	13	8	16
9	12	8	15	19	8	5	9
10	22	14	26	20	10	7	16

Table 3 displays the distribution of the three parameters—anxiety, stress, and depression—among parents of autistic children. Out of 20 parents, it is shown that only 5% have no depression, 20% have mild depression, 30% have moderate depression, and 45% have severe depression. 20% of parents have mild anxiety, 20% exhibit moderate anxiety, and 50% exhibit severe anxiety. According to this table, 5% of parents report no stress, 35% report mild stress, 45% report moderate stress, and 15% report severe stress.

Table 3 Interpretation of percentage of parents having Depression, Anxiety and Stress before Therapeutic Intervention

	Normal	Mild	Moderate	Severe	Extremely Severe
Depression	1 (5%)	4(20%)	6(30%)	9 (45%)	0
Anxiety	2(10%)	4(20%)	4(20%)	10(50%)	0
Stress	1(5 %)	7(35%)	9(45%)	3(15 %)	0

After six months of therapy intervention, Table 4 shows the distribution of the three parameters—anxiety, stress, and depression—among the parents. Out of 20 parents, it demonstrates that only 5% have no depression, 40% have mild depression, 45% have moderate depression, and 10% have severe depression. 15% of parents report having mild anxiety, 55% report having moderate anxiety, and 5% report having severe anxiety. This table also reveals that 55% of parents experience mild stress, 25% experience moderate stress, and 5% experience severe stress.

Table 4 Interpretation of percentage of parents having Depression, Anxiety and Stress after Therapeutic Intervention

	Normal	Mild	Moderate	Severe	Extremely Severe
Depression	1 (5%)	8(40%)	9(45%)	2(10%)	0
Anxiety	5(25%)	3(15%)	11(55%)	1(5%)	0
Stress	3(15 %)	11(55%)	5(25%)	1(5 %)	0

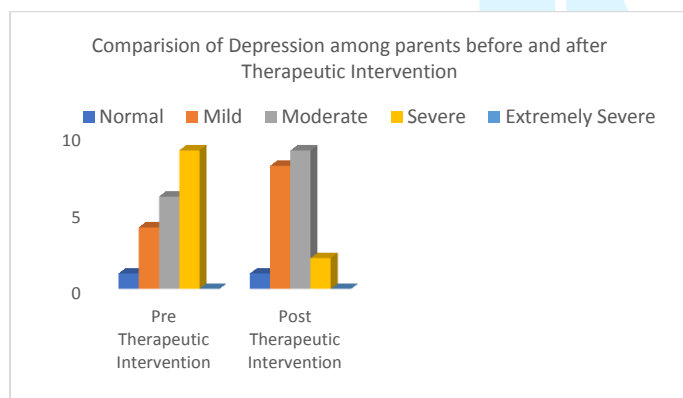


Fig. 1 Graphical Representation of the comparison of Depression levels among parents Pre and Post Therapeutic Intervention

Figure 4 compares the anxiety levels of 20 parents before and after a therapy intervention. It demonstrates that during six months of therapeutic intervention, the number of parents experiencing extreme anxiety decreased from ten to one. There are now 11 parents with moderate anxiety, up from 4 parents with severe anxiety. This could be because fewer parents with severe anxiety were present following therapeutic intervention. Three parents now have mild anxiety, compared to four before the six-month therapy session. After six months of therapeutic intervention, there are now five normal

parents instead of the previous two. This shows that anxiety has decreased in 20 parents following a 6-month therapy session.

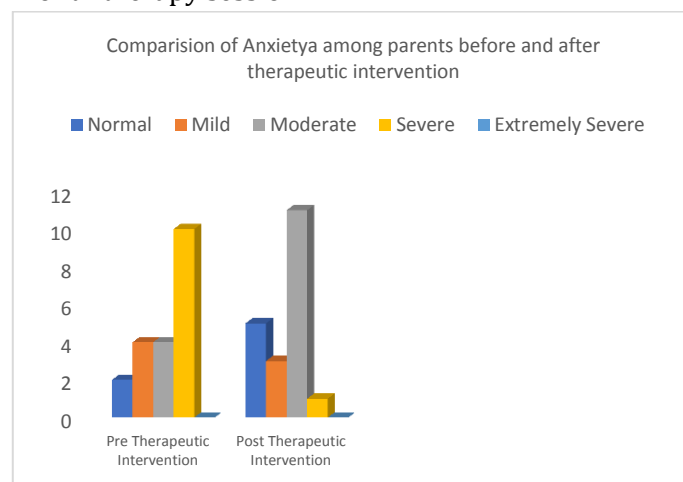


Fig. 2 Diagrammatic comparison of Anxiety among parents Pre and Post Therapeutic Intervention

Figure 5 compares the stress levels of 20 parents before and after a therapy intervention. It demonstrates how, following a six-month therapeutic session, parents experiencing extreme stress decreased from three to one parent. There are now five parents instead of nine who had moderate depression. After six months of therapeutic intervention, the number of parents with mild depression increased from seven to eleven; this increase may be the result of a decrease in parents with severe and moderate stress. After six months of therapeutic intervention, there are now three normal parents instead of the previous number of one. This indicates that stress levels among 20 parents had decreased following a 6-month therapy session.

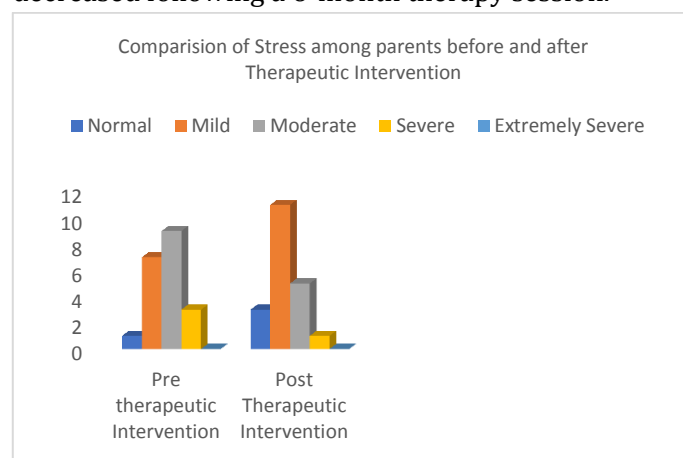


Fig. 3 Diagrammatic comparison of Stress among parents Pre and Post Therapeutic Intervention

Table 5 shows the Mean and Standard Deviation of Stress, Anxiety, and Depression among 20 parents both before and after Therapeutic Intervention. This

table shows that following six months of therapeutic intervention, the mean value of depression decreased from 19.666 to 16.111. Prior to intervention, the standard deviation was 5.291; following intervention, it was 4.391. The anxiety mean value has also decreased; it was 13.611 before the therapy intervention and is now 11.888. Prior to the intervention, the standard deviation was 3.380; following it, it is now 4.638. After six months of therapeutic intervention, the mean value for stress has dropped from 20.888 to 17.666. Prior to intervention, the standard deviation was 4.625; following it, it was 3.622. It makes it evident that the therapeutic intervention significantly contributes to the parents' decreased levels of stress, anxiety, and sadness. Parents' levels of stress, worry, and depression must have decreased as a result of the child's improved behaviour, communication skills, and annoyances after the therapy intervention.

Table 5 Mean and Standard Deviation of Depression, Anxiety and Stress before and after Therapeutic Intervention

	Mean 1 (Before Therapeutic Intervention)	Mean 2 (After Therapeutic Intervention)	Standard Deviation 1 (Before Therapeutic Intervention)	Standard Deviation 2 (After Therapeutic Intervention)
Depression	19.67	16.11	5.291	4.391
Anxiety	13.611	11.888	3.380	4.638
Stress	20.888	17.666	4.625	3.662

Table 6 The 't' test value of Depression

Mean1 - Mean2	t	df	p value
3.55	+7.87	17	.0001

Table 7 The 't' test value of Anxiety

Mean1 - Mean2	t	df	p value
1.72	+1.87	17	.0394

Table 8 The 't' test value of Stress

Mean1 - Mean2	t	df	p value
3.22	+6.5	17	.0001

Data from the two participant groups were used to perform the student's "t" test. The depression "t" is shown in Table 6. The t-value ($t = 7.87$, $df = 17$) was found to be significant with a mean difference of 3.55. Prior to the therapeutic session, the parent group's mean score was 19.67; following the intervention, it was 16.11. As a result, there has been a noticeable and substantial decline in the parents' depression, indicating that the therapy intervention has been effective in assisting the parents in lowering their

depression levels. The findings validated the research premise, according to which parents of autistic children must get therapeutic intervention.

In Table 7, the anxiety "t" is displayed. The t-value ($t = 1.87$, $df = 17$) was found to be significant with a mean difference of 1.72. Prior to receiving therapeutic intervention, the parent group's mean score was 13.611, but following the intervention, it dropped to 11.888. As a result, the parents' anxiety has clearly and significantly decreased, indicating that the therapy intervention has been effective in assisting the parents in lowering their anxiety levels. The findings validated the research premise, according to which parents of autistic children must get therapeutic intervention.

Table 8 displays the "t" for Stress. A significant t-value ($t = 6.5$, $df = 17$) was found, indicating a mean difference of 3.22. Prior to the therapeutic intervention, the parent group's mean score was 20.888; following the intervention, it was 17.666. As a result, the parents' stress levels have clearly and significantly decreased, indicating that the therapy intervention has been effective in assisting the parents in lowering their stress levels. The findings validated the research premise, according to which parents of autistic children must get therapeutic intervention.

5. Conclusion

The current study concludes that stress, worry, and sadness is prevalent in parents of autistic children. According to this study, parents of kids who haven't started therapeutic intervention report having more of these problems than parents whose kids have been going to therapy for at least six months. In particular, stress and despair are more noticeable than worry. All three variables showed a discernible decline after six months of therapy: stress dropped from 20.89 to 17.67, anxiety dropped from 13.61 to 11.89, and depression fell from a mean of 19.67 to 16.11. This shows that parental stress, anxiety, and sadness can be considerably reduced with therapeutic approaches. Parental optimism and support are probable contributing factors to this decrease, as evidenced by improved child behaviour and communication.

6. Future Recommendations

To understanding the impact of stress, depression and anxiety felt by such parents, the current study can be

further proceeded to guide treatment and management intervention of children with autism. A strong desire of social support and family support is needed. There is need for community wise education programs to educate people and make awareness about Autism.

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