

MEDIATING ROLE OF ACCEPTANCE ON PARENTAL STRESS AND COPING AMONG PARENTS HAVING CHILDREN WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

Back ground: Autism Spectrum Disorder (ASD) is a lifelong heterogeneous neurodevelopmental condition which includes social and communication impairments and restricted stereotypical patterns of behavior and interests. This is considered as chronic condition and it requires multiple therapy procedures and Rehabilitation for improvement of the condition. Parental acceptance of children with disability is very significant as it effects the perception of the problem, and the way they adopt coping strategies to deal effectively with the problem of the child. Parents especially of children with ASD undergo lot of stress as it is a chronic condition associated with poor adaptive skills and behavioural problems which makes them feel more stressed. **Objectives:** To study the level of distress and coping strategies among parents of children with Autism Spectrum Disorder. **Methods:** Sampling method included purposive sampling. About 50 parents aged between 25 years to 50 years old, who is the primary care giver of children with Autism Spectrum Disorder, attending OP services from NIEPMD, Chennai were included in the study. Parents who are single and having any other chronic physical or mental illness were excluded from the study. The participants were approached individually and after obtaining informed consent, General Health Questionnaire (GHQ-12), Parental Acceptance Questionnaire (PAR-Q), and Coping Health Inventory for parents (CHIP) were administered. The data obtained were statistically analyzed to assess the level of distress of parents with disability, different coping strategies they adopt, and mediating effect of Acceptance on relationship between coping strategies and stress. **Results:** The results showed that the majority of the parents are found to have psychological distress and the rejection level was found to be mildly high than the acceptance level of the parents. There is negative relationship between coping strategies and level of distress among these parents having children with ASD. Further, it was also found that level of acceptance plays a significant mediating role and it affects the relationship between coping strategies and level of distress among the parents. **Conclusion:** The study highlighted the importance of identifying mental health issues among parents having children with ASD and it also signifies the importance of adopting strategies to enhance the Acceptance level and coping strategies while delivering intervention programs for parents having children with ASD.

Keywords: Autism Spectrum Disorder, Psychological distress, and Parental acceptance.

INTRODUCTION

Parents having child with disability undergo lot of stressors due to multiple challenges while rearing the child like facing stigma from the society, long term therapy procedures, and difficulty in accessibility of services. While the Parental stress among parents having children with disability has been well established, the stress among Parents having children with Autism Spectrum Disorder (ASD) has been more when compared to than those of with typical children and other disability. It has been reported that Parents of children with ASD have more stress compared to those with typical children and also than having children with Down Syndrome (A. dwska & E. Pisula., 2010, L. Abbeduto et al., 2004). Parents of children with Autism face many challenges as Autism remains undiagnosed late or until preschool years (Beauchesne & Kelley, 2004) and due to the associated symptoms such as impairment in social communication skills and restricted or repetitive behaviors (Gabriels, R. L., 2005). In a very recent study done by Dijkstra-de Neijis, L (2024), he has reported that Parents of children with ASD have more psychological distress and poor quality of life. Although there is no proven cure for autism, the treatment of Autism includes long term multiple therapy procedures to improve the overall functional status of the child by promoting development of communication, social, adaptive, behavioral, and academic skills as well as lessening maladaptive and repetitive behaviors. Troster H. and Lange S. (2019) have described the various demands of parents having children with ASD such as cooperating with the partner, strengthening parent child relationship, difficulty in maintaining social life, facing stigmatizing social reactions, managing problem behavior of the child, and fulfilling one's own need. Due to multiple challenges, they are prone to develop psychological disorders such as

depression and anxiety (Al-Farsi, O. A 2016., Cai, R. Y., 2020). In a review of study done by Bailey et al., (2007) on mothers of children with disability, higher ratings of depressive symptoms were attributed to children with autism or behavioral problems. Although the stress is overwhelming, it is not likely that all parents were not able to handle the stress, some of them were able to cope up well the situation in a positive optimal way. It depends upon the individual and the coping strategies they adopt to deal with the situation. Coping involves specific coping strategies and psychological resources to manage a stressful event or situation. It depends upon the wide variety of factors such as perception and interpretation of the event, individual personality characteristics, financial status, education etc. The other factors such as marital relationship and social support also determines the adjustment of mother having individuals with disability (Emerson, 2003 & Fazil, Wallace & Singh, 2004). It is reported in a study that social support was associated with better coping strategy such as mobilizing family to acquire social support (Vassiliki Ntre., et al., 2021) Coping strategies to deal with the situation can be active and passive. Active coping strategies is more action oriented such as approaching the problem and resolution while passive coping strategies were such as avoiding the problem, can be a mechanism to reduce stress on short term. Many studies have revealed the relationship between coping strategies and stress among parents with disability. Problem focused coping has been associated with more positive well-being including relationship adjustment with one's partner (Stoneman & Gavidia-Payne 2006), whereas avoidant coping strategies have been associated with psychological distress (Hastings et al., 2005). According to the systematic review by Vernhet and colleagues (2019), parents of children with ASD use less support and are more likely to

use avoidance strategies than parents of neurotypically developing children. It has been found that emotion focused coping as predictor for parental stress in parents of children with autism (Dabrowska, A., & Pisula, E. (2010). In the study done by Tway, Connolly, and Novak (2007), parents reported that support from families and close friends was frequently used as emotion-focused coping. Studies show that parents who use coping strategy such as active avoidance exhibit higher level of stress (Hastings RP, 2005) whereas active coping reduces the stress among parents of children with ASD (Wang J. ,2013). Even though it has been proved that coping ability affects the stress level, there are other multiple factors that would affect the relationship such as their self-efficacy, social support etc. and it has been also widely studied. Acceptance of uncomfortable thoughts and emotions and using decreased avoidance strategies were found to be helpful for parents with disability. It was found that parents who accepted the child and the disability could adjust positively to the situation (Heiman., 2002). MacDonald, Hastings, and Fitzsimons (2010) reported in the study that acceptance in relation to parenting was found to be mediating the relationship between child behavior problems and parental well-being. It has been found that wellbeing of mothers of children with ASD, acceptance acts as a mediator variable and it serves as an important factor for coping (J. A. Weiss et al., 2012). Hence, assessing the mediating effect of acceptance on stress and coping will pave a way to understand the significance of psychoeducating and resolving the conflict of the parents to accept the condition of child with ASD and to improve the overall wellbeing of parents having children with ASD. Even though, there are studies available which have studied the wellbeing of the Parents having children with disability, the studies on Parents having

children with ASD is very limited and hence this study would fill the research gap.

OBJECTIVES

Hence, this current study aimed to study the level of distress and level of acceptance and rejection among Parents of children with Autism Spectrum Disorder. The study also intended to study the mediating effect of Acceptance on relationship between coping strategies and level of distress.

HYPOTHESES

1. There will be significant level of distress among Parents of Children with ASD
2. There will be high level of Rejection compared to level of Acceptance among the Parents towards their children with Autism
3. There will be significant relationship between different types of coping strategies and the level of distress among the parents
4. The level of Acceptance and Rejection will mediate the relationship between Coping strategies and level of distress among Parents of Children with ASD.

METHODOLOGY

The present study included parents, both male and female aged between 25 years to 60 years old, who is the primary care giver of children with ASD, attending OP services from NIEPMD, Chennai. Parents of children with any comorbid disability other than intellectual disability and parents having more than one child with disability were excluded from the study. Parents having history of any other chronic mental illness or physical illness were also excluded from the study. After getting ethical clearance from the institution, the participants were approached individually and after obtaining informed consent, General Health Questionnaire (GHQ-12), Parental Acceptance Questionnaire (PAR-Q), and

Coping Health Inventory for parents (CHIP) were administered. The data obtained were statistically analyzed to assess the level of distress of parents with disability, different coping strategies they adopt, and mediating effect of Acceptance on relationship between coping strategies and stress.

STATISTICAL ANALYSIS & STUDY DESIGN

Data was analysed using Statistical Package for Social Sciences (SPSS 20). Descriptive statistics was done to find the frequency percentage of level of distress and level of Acceptance. Pearson Correlation was used to find the relationship between coping strategies and psychological distress. The mediation analysis was done to assess the mediating effect of Acceptance on the relationship between coping and psychological distress.

RESULTS

Table-1: Frequency of level of distress of parents having children with ASD.

	Frequency	Percent	Cumulative percent
Typical	19	38.8	38.8
Distress	8	16.3	55.1
Severe psychological distress	22	44.9	44.9
Total	49	100.0	100.0

Table 1 shows the level of distress of parents having children with ASD. Out of 49 parents, 22 (44.9%) parents were found to be having severe psychological distress and 19 (38.8%) parents shown to have evidence for distress whereas 8 (16.3%) were considered as typical. Hence, the results have revealed that majority of the parents have distress.

Table-2: Frequency of level of acceptance shown by parents towards their children with ASD.

	Frequency	Percent	Cumulative percent
Acceptance	21	42.9	42.9
Rejection	28	57.1	57.1
Total	49	100.0	100.0

Table 2 shows level of acceptance among parents having children with ASD. It was found that out of 49 parents with ASD, 21(42.9%) parents with ASD were considered to have acceptance and 28 (57.1%) parents with ASD shown to have evidence for rejection. The rejection level was found to be mildly high than the acceptance level of the parents.

Table-3: The coefficient of correlation obtained between coping strategies and level of distress among Parents of Children with ASD

Variables	Coping strategies
Family integration	-.546**
Social support	-.572**
Understanding medical situation	-.508**

****.** Correlation is significant at 0.01 level (2-tailed).

Table-3 shows coefficient of correlation obtained between coping strategies and level of distress among parents at 0.01 level of significance. The correlational analysis indicated that there is a moderate negative relationship between coping strategies and distress levels among these parents. Specifically, family integration ($r = -.546$), social support ($r = -.572$), and understanding the medical situation ($r = -.508$) all showed significant negative correlations with distress. These findings suggest that better the coping strategies adopted, it influences the level of distress highlighting the importance of these strategies in mitigating distress among parents of children with ASD.

Table-4: The mediating effect of Acceptance on relationship between Coping strategies and level of distress.

Effect	Label	Estimate	S.E.	95% Confidence Interval		Z	P	% Mediation
				Lower	Upper			
Indirect	a × b	0.4321	0.0774	0.280	0.5842	5.582	< .001	18.73
Direct	C	2.1715	0.1605	1.933	2.5461	13.533	< .001	81.27
Total	c + a × b	2.3046	0.1627	1.986	2.6231	14.166	< .001	100.00

Table 4 : shows the mediating effect of Acceptance on relationship between coping strategies and level of distress among parents of children with ASD using a 95% confidence interval. The indirect effect (a × b) had an estimate of 0.4321 (SE = 0.0774), with a confidence interval ranging from 0.280 to 0.5842, and was statistically significant (Z = 5.582, $p < .001$), indicating that level of Acceptance significantly mediates this relationship. The mediation percentage for the indirect effect was 18.73%. Conversely, the direct effect (c) was also substantial and statistically significant with an estimate of 1.8725 (SE = 0.1605) and a confidence interval from 1.558 to 2.187 (Z = 11.666, $p < .001$), accounting for 81.27% of the total effect. The total effect (c + a × b) combined both direct and indirect effects, with an estimate of 2.3046 (SE = 0.1627) and a confidence interval from 1.986 to 2.6231, and was statistically significant (Z = 14.166, $p < .001$), representing 100% of the effect size. Thus, while coping strategies significantly affect the level of distress among these parents, level of Acceptance plays a significant mediating role with both direct and indirect effects contributing to the overall impact.

DISCUSSION

The results have revealed that there is significant level of distress among parents of Children with ASD which is in line with the previous literature that Parents of children with ASD have more distress due to reasons such as difficulty especially in handling the behaviour pattern of the child which has been reported in a recent study done by Miranda, A., Mira., et al., (2019) and deficits in social and communication domain. In a study done by Omar Al-Farsi (2016), caregivers of children with Autism have high levels of stress, anxiety, and depression compared to parents with intellectual disability and typically developing children. It also has been reported in a study done by Ciara Padden (2017) that Parents of children with ASD not only experience higher level of stress but also poorer health than parents of typically developing children. In a very recent study done by Taleha Shahbaz et al., (2023), stress level of 144 parents of children with ASD were assessed and it reported that especially Mothers experienced higher level of stress and it correlated with symptoms of autism. The current study also revealed similar findings in line with the previous findings that majority of them had higher level of psychological distress. Even though, the person experience stress, the way an

individual cope is significantly important for the person to overcome the stress and maintain their wellbeing. Hence, as the study intended to study the coping mechanism adopted by the parents, CHIP inventory was used to study the coping mechanisms of parents having children with ASD as the condition of Autism is considered as a chronic condition. *In this study, most of the Parents had better coping mechanism which might be due to the reason that most of them included in our study were literates and belongs to middle socio-economic status. They are also aware of the condition of the child since they are seeking services already for their children and hence these factors might have amplified the coping mechanism in a better way in the current study.*

The current study showed that relationship between different coping domains such as family integration ($r = -.546$), social support ($r = -.572$), and understanding the medical situation ($r = -.508$) have significant negative correlation with psychological distress (*Joseph Awwad Bawalsah 2016; Ana Miranda et al., (2019)*). *In a study done by Sharabi, A., and Marom-Golan, D. (2018), it was reported that different sources of informal social support from the family, friends, and partner reduce stress, foster engagement, and mediate and moderate wellbeing. This finding well corroborates with finding of the current study which revealed that social support and family integration was negatively correlated with distress level of the parents. The findings corroborated with the study done by Joseph Awwad Bawalsah (2016) in which he concluded significant and positive correlation between levels of stress and coping strategies.* Our study also have found that the acceptance level mediates the relationship between coping strategies and stress. The similar findings were highlighted in other similar previous studies. In a study done by Lloyd, T., & Hastings, R. P. (2008),

acceptance was negatively associated with maternal anxiety, depression and stress such that mothers who were generally more accepting reported fewer psychological adjustment problem. In a study done by Elaine E. MacDonald et al., (2009), his findings have revealed that Acceptance level mediates the impact of behavioural problems on parental stress, anxiety, and depression and it also serves as positive predictor of parent's perceptions associated with raising their child with disability. This finding clearly proves the effect of parental acceptance on mental well-being of the parents. In another study done by Heiman T. (2002), he conducted interview with the parents and majority of them have expressed the need for optimistic outlook, realistic view and acceptance of the disability. These findings highlighted the importance of knowing the parent's insight and acceptance level towards their child which would help us to implement intervention programs to improve the parent's attunement towards their child's condition which indeed will also help to maintain their mental well being.

CONCLUSION

The study have concluded that Parents of Children with ASD have significant level of distress which had significant negative relationship with coping strategies they adopt. The study also highlighted the significance of Acceptance level of the parents towards their children with ASD that mediated the relationship between coping strategy and distress. This study gave the understanding that while planning interventions for the children, the focus should also be aimed to improve the mental well being of the parents, decrease their stress by using appropriate strategies and also to improve the level of acceptance. The factors such as increasing their social support and family integration, and making them to understand the condition of the child would serve a lot in the programs

of rehabilitation and intervention.

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