

Stress and Coping Styles in Mothers of Children with Autism Spectrum Disorder

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ABSTRACT

Background: Children with autism spectrum disorder (ASD) require well-balanced care and a comprehensive therapeutic approach. Mental health problems often go unnoticed in mothers of children with ASD due to the focus on training for the children. The presence of stress and depressive symptoms in mothers can interfere with the quality of care and therapy given to the child. The present study aimed to assess the quality of life, coping styles, and symptoms of depression, anxiety, and stress in mothers of children with ASD. **Methods:** This study recruited thirty mothers of children with ASD, to whom Depression, Anxiety and Stress Scale (DASS 21), WHO Quality of Life Scale (WHOQOL-BREF), and COPE Inventory were administered. **Results:** Results indicated the presence of depressive and anxiety symptoms and impaired quality of life among the mothers. Despite this, they exhibited positive coping styles. **Conclusion:** As part of a comprehensive intervention for children with ASD, there is also a need to address the psychological distress and coping styles of mothers.

Key words: Anxiety, autism spectrum disorder (ASD), coping styles, depression, quality of life, stress

Key messages: The mothers of children with ASD are vulnerable to develop symptoms of depression and anxiety. They are also more likely to have an impaired quality of life. Hence, it is of paramount importance to focus on their mental health needs, in order for the mothers to be able to efficiently deliver behavioral interventions to children with ASD.

In India, it has been estimated that more than two million people might be affected by autism spectrum disorder (ASD),^[1] with a pooled percentage prevalence of 0.11 (1–18 year age group) in the rural areas and 0.09 (0–15 year age group) in the urban areas.^[2]


ASD involves persistent impairments in language, social skills, and daily life activities, which persist throughout

the lifespan. Approximately two-thirds of children with ASD are unable to live independently, and only 1% can achieve any degree of personal autonomy as adults, which imply a high workload and ongoing concern for the caregiver.^[3] These factors may affect the way the parents deal with the child and possibly create a rift in the relationship between the family members.

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How to cite this article: Selvakumar N, Panicker AS. Stress and coping styles in mothers of children with autism spectrum disorder. Indian J Psychol Med 2020;42:225-32.

Access this article online	
Website: www.ijpm.info	Quick Response Code 
DOI: 10.4103/IJPSYM.IJPSYM_333_19	

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Submitted: 17-Aug-2019, **Revised:** 24-Sep-2019, **Accepted:** 12-Mar-2020, **Published:** 25-Apr-2020

The preponderance of deficits, variability in ASD severity and functioning, and the lifelong nature of the condition complicate service planning and necessitate prioritization to address the expressed needs and individualized care at different life stages.^[4,5]

The caregiving process often requires additional physical, emotional, social, and financial resources.^[6] Parents of children with neurodevelopmental disorders have the additional responsibility of giving focused inputs for overcoming the deficits in the child, along with the usual child-rearing practices. This often makes the parents experience excess pressure and a sense of inadequacy about their parenting skills. This can result in parental stress if the parents' perceptions of the demands of their parental role exceed their coping resources, without being able to restore an equilibrium through the usual methods and strategies.^[7]

The stress experienced by parents of children with ASD, which reaches clinically significant levels in 77% of the cases,^[8,9] has been found to be greater than the stress of parents with children with typical development.^[10-14] The levels of parental stress also exceed the stress of parents with children with other neurodevelopmental disorders, such as specific learning disorders, intellectual disabilities, Down syndrome, cerebral palsy, externalizing behaviors, or attention deficit hyperactivity disorder.^[15-18]

Parents play an important role in the overall development of a child with a disability. Rahman *et al.* (2016) have established the feasibility and acceptability of the parent-mediated intervention for ASD in India.^[19] Mental health difficulties in parents can impair their involvement in such interventions. The severity of the core features of autism has been found to be related to parenting stress^[20] and maternal psychopathology symptoms.^[21] Specifically, self-isolated/ritualistic and repetitive behaviors are associated with poorer parent outcomes and the mothers' anxiety and depression.^[22] The problems of children with ASD seem to affect different domains of parenting stress. Parental distress is predicted by behavioral and emotional problems in the children, whereas stress related to a dysfunctional parent-child relationship is associated with daily living, communication skills, and cognitive abilities.^[23] Based on a review of 133 studies, behavioral problems of children with ASD, particularly externalizing problems, were found to be linked to parental stress.^[24]

Parents of children with ASD engage certain coping mechanisms in order to tide through the various phases of development. The previous research has evaluated the role of coping styles employed by caregivers as a protective and remedial mechanism. Parental coping

styles and the presence of social support in relationship with developmental disabilities can impact the level of parental distress.^[23] Higher levels of problem-focused coping and lower levels of emotion-focused coping were generally associated with better maternal wellbeing, regardless of the level of symptomatology of the children with ASD.^[24] On the other hand, parenting stress was negatively correlated with the engagement coping and social functional support reported by the mothers.^[7]

Quality of life (QOL) is defined as an individual's perception about his/her position in life in the context of their culture and value system in relation to their objectives, expectations, standards, and concerns.^[25] Due to high-stress levels and associated psychiatric comorbidities, caregivers of children with ASD tend to have a poor QOL.^[26] The presence of parental psychopathology and stress can impair the quality of inputs given, thereby hindering progress in the child with ASD. As the role of parents is crucial in the process of development, an understanding of the mental health difficulties, quality of life, and coping styles of parents can give a better understanding of the possible barriers in the process of change. With this background, the current study was planned. Lack of acceptance and awareness are again factors which can hinder the initiation and progress in training. In order to understand this further, the investigators also explored the differences between the maternal estimate and the actual social age of the child. This study extends earlier research by examining the mental health of caregivers of children with ASD. In the Indian setting, limited research has been carried out exploring the coping styles and resultant quality of life of mothers of children with ASD. Thus, the present study aimed to evaluate the coping styles, quality of life, and presence of depressive, anxiety, and stress symptoms in mothers of children with ASD.

MATERIALS AND METHODS

The study protocol was approved by the Institutional Human Ethics Committee (IHEC).

Participants

The sample for this study was selected by consecutive sampling from the psychiatry outpatient department of a tertiary care hospital in south India. The sample was selected from mothers of children (age range of children: 3 to 15 years) who had approached the outpatient department either on their own or through a referral from school, workplace, or other medical professionals for the purpose of assessment and diagnosis. The diagnosis of ASD was made based on (1) clinical interview and detailed evaluation by a qualified psychiatrist and (2) assessment score

obtained on Childhood Autism Rating Scale (CARS) by a qualified clinical psychologist. For assessing the severity of deficits in social functioning, the Vineland Social Maturity Scale (VSMS) was also administered.

Materials

Depression, anxiety, and stress scale (DASS 21)^[27] is a 42-item questionnaire to assess symptoms of depression, anxiety, and stress among various populations, age-groups, and clinical and nonclinical respondents. DASS includes three self-report scales designed to measure the negative emotional states of depression, anxiety, and stress. The reliability and validity of the DASS have been established in clinical and nonclinical populations^[28,29] DASS has been manually translated into Tamil and back-translated into English for determining the linguistic validity of the translated version. This version has been used in a previous study^[30] and the inter-rater reliability was found to be high [$\kappa = 0.68$ ($P < 0.001$), 95% CI (0.504, 0.848)]. As the primary language of the participants in the present study was Tamil, the Tamil version of DASS was used.

WHO quality of life scale (WHOQOL-BREF)^[25] is a measure of QOL, which could be reliably used across different cultures. It brings forth the person's perception of life with regard to his/her cultural background and taking into consideration his/her personal goals and standards. It covers four domains: physical, psychological, social, and environmental. The brief version, consisting of 26 items, was used for the present study. The mean scores are calculated separately for each of the four domains.

COPE inventory^[31] is a multidimensional coping inventory to assess the different ways in which people respond to stress. It consists of 60 items, divided into 13 scales (four items in each scale), which measure conceptually distinct aspects of coping, namely, active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support, seeking of emotional social support, positive reinterpretation and growth, acceptance, denial, turning to religion, focus on and venting of emotions, behavioral disengagement, and mental disengagement. The participants were instructed to respond to a series of statements, based on how they would react when experiencing stress. These statements described various coping strategies using a 4-point scale: 1 = "I usually do not do this at all," 2 = "I usually do this a little bit," 3 = "I usually do this a medium amount," and 4 = "I usually do this a lot." Possible values for each coping scale ranged from 0 to 12, with a higher score indicating greater use of that coping strategy. Cronbach's alpha reliability coefficients for the coping scales ranged from 0.56 to 0.88.

Consistent with the previous research on caregiver coping styles,^[32,33] the following four of the original 13 scales were selected as predictor variables in the main analysis for the present study: positive reinterpretation and growth, religious coping, mental disengagement, and behavioral disengagement. Positive reinterpretation and growth involves reframing a problem in a positive light or restructuring a stressful situation in positive terms (e.g., "I look for something good in what is happening"). Religious coping refers to turning to faith for support (e.g., "I put my trust in God"). Mental disengagement refers to efforts to distract self from thinking about the problem (e.g., "I turn to work or other substitute activities to take my mind off things"). Behavioral disengagement involves reducing one's efforts to deal with a particular stressor (e.g., "I give up the attempt to get what I want"). As the primary language of the participants was Tamil, this scale was translated into Tamil and back-translated into English for determining the linguistic validity of the translated version.

Procedure

The researcher was trained in the administration of the questionnaires and conducted five interview sessions under the supervision of a clinical psychologist, following which data collection for the present study was started.

The researcher explained the purpose of the study and assured confidentiality to the mothers of children with ASD, and written informed consent was taken. DASS, WHO-QOL questionnaire, and COPE Inventory were then administered to the mothers. The average time taken for the administration of the tools was 25 min. Following the assessment, mothers who were assessed to have high levels of depression, anxiety, or stress symptoms were referred to the psychiatry outpatient department for detailed evaluation by a psychiatrist and for planning further management of the same.

Analyses

Statistical Package for Social Sciences-Version 19 b (SPSS-19) was used for the analyses. The data was found to be normally distributed. Descriptive statistics was used for the analysis of data obtained from the sociodemographic sheet, DASS, and COPE. Independent sample *t*-test was used to determine the difference between the maternal social age estimate and the actual social age of the child. Pearson product-moment correlation was used to test the relationship between the different domains of quality of life and the relationship between levels of depression, anxiety, and stress with QOL and maternal social age estimate.

RESULTS

Sociodemographic characteristics

The sample consisted of thirty mothers of children with ASD. Ninety percent of the mothers were homemakers. All the mothers were literate, with 50% being graduates, and 50% had completed 10 years of formal school education. The mean age of the mothers at the time of childbirth was 25.40 years (SD = 2.95).

The mean score of autism severity was 30 (SD = 3.99), indicating a mild level of ASD. The mean duration of schooling of the children was 2.57 (SD = 1.87) two years. The sociodemographic details are presented in Table 1. History of feeding difficulty was present in 36.6% of the children.

Social age and maternal estimate

The mean social quotient of the children was 51.86 (SD = 29.0), indicating mild disability of social functioning. When the maternal estimate of the child's social age was explored, eight (27%) had overestimated and four (13%) had underestimated the child's social age by 1 year. Independent sample *t*-test indicated that there was no significant difference between the mean maternal estimate of the child's social age (M = 38.4; SD = 16.92 months) and the mean actual social age [(M = 41.37; SD = 24.94 months), *t* (29) = 0.087]. There was no significant correlation between the maternal estimate of the child's social age and the severity of the mothers' depressive ($r = -.185$, $n = 30$, $P = 0.329$), anxiety ($r = -.233$, $n = 14$, $P = .215$), or stress ($r = -.134$, $n = 14$, $P = .479$) symptoms.

Depression, anxiety, and stress symptoms

It was found that 60.4% of the mothers had depressive symptoms, among whom 42.9% reported mild-to-moderate depressive symptoms, while 16.5% had severe depressive symptoms. In addition, 46.2% of the mothers were found to have anxiety, among whom 16.5% exhibited severe anxiety [Table 2].

Quality of life

Among the various domains of QOL, mothers perceived the highest level of QOL in the environmental domain, with a mean score of 73.5, and the psychological domain was the lowest at 65.6. The physical and social relationship domains were intermediate, with mean scores of 72.5 and 69.6, respectively. There was a significant correlation between the domains of QOL. It was also found that the level of QOL in all the domains was negatively correlated with the severity of stress and depressive symptoms [Table 3].

Coping styles

The major coping styles adopted by the mothers included active coping, positive reframing, planning, acceptance, and religious coping [Table 4].

DISCUSSION

The earliest phase of the child's life was a period of relative normalcy and social cohesion. In the second phase, the child's behaviors began to disrupt the everyday social order, but parents viewed these unexpected behaviors as temporary. In the third phase, parents' observations in public situations, along with assessments of others, led to a qualitative shift in which

Table 1: Sociodemographic characteristics (n=30)

Variable	n	%
Age (Mean±SD)	6.5±4.5 yrs	-
Gender (Male)	25	83.5
Consanguinity present	9	30
Autism Severity		
Mild	14	46.7
Moderate	14	46.7
Severe	2	6.7
Education		
Not attending	7	23.1
Attending school	22	75.9
Special education	17	56.1

Table 2: Depression anxiety and stress levels of mothers

DASS Score range	Depression (%)	Anxiety (%)	Stress (%)
Normal	39.6	52.8	52.8
Mild	19.8	16.5	26.4
Moderate	23.1	13.2	16.5
Severe	9.9	9.9	0
Extremely Severe	6.6	6.6	3.3
Mean Score (±SD)	6.13 (±3.82)	4.0 (±3.38)	6.8 (±4.12)

DASS: Depression Anxiety Stress Scale

Table 3: Correlation between QOL and DASS scores

Domain	Depression	Anxiety	Stress
Physical	-0.38* ($P=0.037$)	-0.53** ($P=0.002$)	-0.45* ($P=0.014$)
Psychological	-0.73** ($P=0.001$)	-0.35 ($P=0.055$)	-0.69** ($P=0.001$)
Social	-0.53** ($P=0.003$)	-0.29 ($P=0.124$)	-0.51** ($P=0.004$)
Environment	-0.48** ($P=0.007$)	-0.32 ($P=0.083$)	-0.54** ($P=0.002$)

*Correlation is significant at 0.05 level (2-tailed). **Correlation is significant at 0.01 level (2-tailed). DASS: Depression Anxiety Stress Scale. QOL: Quality of Life

Table 4: Coping styles followed by mothers

Coping Style	n	%
Active coping	11	38.3
Positive reframing	11	38.3
Planning	9	38.3
Acceptance	12	36.65
Religion	10	38.3

parents began to perceive that there was a persisting problem interfering with their child's social and practical activities. In the fourth phase, parents grappled with developing their child's capacities to meet existing practical opportunities in the local society.

Caregivers of individuals with disabilities are at high risk for psychological distress because of the multiple stressors known to be associated with the caregiving role.^[34] In the current study, a majority of the children had mild severity levels of ASD as well as disability in social functioning, resulting in a delay in the development of social skills. This indicates the extent of increased workload and stress that mothers would experience as part of their caretaking role.

These findings are comparable to the previous research findings, which have also emphasized the long-standing stress experienced by the caregivers due to physical and emotional strain, lack of support from other family members, and gradual progress in the child, thereby making them more prone to mental health difficulties.^[35]

Only after awareness and acceptance that a child has ASD, the caregiver would proceed to the next stage of training and skill development. When a caregiver is unaware or refuses to accept the child's diagnosis of ASD, it results in a delay in the initiation and regularity of intervention. A majority (46.2%) of the mothers had correctly estimated their child's social age in the present study. Twenty percent of mothers had overestimated their child's social age by more than one and a half years and 6.6% of mothers had underestimated their child's social age by more than one and a half years. There was no significant correlation between this difference in the maternal estimate of the child's social age with the mothers' quality of life, depression, anxiety, or stress levels.

With regard to education and training, more than half of the children with ASD were attending special schools/training centers. These two factors, namely, the high percentage of mothers who correctly estimated their child's social age and placement in special schools/training centers, reflect the increased level of awareness among mothers about the child's deficits as well as the need for special training. This awareness was indicated in another study, where the major symptom identified by the majority of the parents was social difficulty among their children.^[36]

The high level of depressive and anxiety symptoms seen in the present study is consistent with the previous research, which has emphasized the long-standing stress experienced by caregivers due to physical and emotional

strain, lack of support from other family members, and a gradual deterioration in the child, which makes them more prone to develop a psychiatric illness.^[37] This is also reflected by higher levels of depressive and anxiety symptoms in caregivers assessed in similar studies.^[38] This implies that more attention has to be paid to the mental health of parents, particularly mothers, of children with ASD.

It was also found that almost half of the mothers in the study were experiencing stress. A study on parenting stress in mothers of children with ASD reported behavioral symptoms as the primary source of parenting stress for mothers. Mothers reporting more parenting stress had more depressive symptoms and lower levels of well-being.^[39]

QOL was found to be impaired, primarily in the psychological, social, and environmental domains. These findings are comparable to a study on the impairment of QOL in parents of children and adolescents with ASD that used the same scale. When compared to parents of healthy children, parents of children with ASD reported impairment in physical activity, social relationships, and worse overall perception of their QOL and health. The impairment of physical and psychological well being was more in mothers when compared to the fathers in the ASD.^[43] Parents of children with ASD experience a higher burden, probably due to a combination of environmental and physical factors. In the present study, all four domains of QOL had a negative correlation with depression and stress symptoms. This was similarly seen in a previous study on depression and QOL in mothers of children with ASD, where it was found that QOL had a negative association with depression.^[40]

The previous research has evaluated the role of coping styles employed by caregivers as a protective and remedial mechanism. Parental coping styles and the presence of social support in relationship with developmental disabilities can impact the level of parental distress.^[23] An interesting finding in the present study is that the mothers had impaired QOL as well as high levels of depressive and stress symptoms. In spite of this, they predominantly followed positive coping styles. Problem-focused coping or active coping is the process of taking active steps to try to remove or circumvent the stressor and its effects. A positive attitude among the mothers was reflected through their employment of positive coping strategies. The least employed coping styles were substance use, denial, venting, and self-blame. Taylor, in 1983, had proposed a theory of cognitive adaptation which may help to interpret the results reported in this study. Among the factors that account for recovery from stressful events, two stood

out as particularly important: a search for meaning in the experience and an attempt to regain mastery over the situation.^[41] In support of this perspective, the present study indicates the use of the coping style of positive reframing for overcoming and adapting to their current difficult situation. Similarly, the previous research has also shown an inverse relationship between psychological stress and positive coping strategies, in which the use of positive reinterpretation and growth was associated with lower levels of depression and stress symptoms.^[33,42]

In the present study, religious coping was seen to be more commonly employed as compared to other coping styles. This is in line with the previous research in India in which caregivers reported that their religious practice gave them peace of mind and helped them to endure the caregiving situation^[43] and that the most common coping style used by mothers of children with intellectual disability was religious coping.^[44]

Limitations were present in the current study. The first limitation was that the sample size was small and restricted to hospital outpatient participants. A larger sample size and inclusion of a community-based sample could have improved the generalizability of the findings. The second limitation was that the psychological status of the mothers prior to the diagnosis of ASD and the presence of ongoing life stressors were not addressed. Third, the presence of comorbid attention deficit hyperactivity disorder (ADHD) in the children with ASD could have also influenced the current findings, as past research has shown that the presence of ASD with comorbid behavioral problems increases the level of parental stress.^[24] A fourth limitation was the cross-sectional study design. A longitudinal design could have tapped deficits across the lifespan. Future research can compare the severity of psychological distress with the duration after diagnosis of ASD and the life stage of the child (early childhood, later childhood, early adolescence), as the needs and parental expectations vary at each stage. In this context, yet another lacuna to be pointed out is the limitation of the tool used in the present study that assesses depressive, anxiety, and stress symptoms experienced within the period of one week prior to the interview, which could have been situational. A detailed clinical assessment would also be required to establish a diagnosis of depression and anxiety and offer treatment for the same. Future studies can also look into follow-up assessment after the implementation of appropriate psychoeducational interventions.

Nevertheless, the study results highlight the often-neglected difficulties and psychological distress encountered by the caregivers of children with ASD,

which require multi-modal interventions. The caregiver may not have the capacity to change the situation, but appropriate use of coping strategies will result in stress reduction and improved functioning, thereby resulting in a better quality of care. The role of parents, as well as persistence and consistency in parental engagement and training, is crucial for the overall development of the child. Research has indicated the effectiveness of a parent-mediated communication-focused intervention in ASD.^[29] Positive mental health among mothers is crucial for their adequate involvement and care delivery for children with ASD.

CONCLUSION

The present study indicates the presence of depressive, anxiety, and stress symptoms among the mothers of children with ASD, as assessed on the DASS 21. The QOL of the mothers was found to be impaired, as per assessment on the WHO-QOL. In spite of having high levels of symptoms of depressive, anxiety, and stress symptoms, the mothers predominantly adopted positive coping styles, namely, active coping, positive reframing, planning, acceptance, and religious coping.

The insights obtained from this study extend previous findings that mothers of children are at increased risk of developing psychiatric distress, a fact which frequently goes unrecognized and less addressed when planning the long-term management for children with ASD.

Promoting the best QOL possible for mothers of children with ASD requires significant time and attention to both individual- and family-based needs. For many of these families, substantial specialized care and resources are needed across the lifespan of the individual with ASD. The treatment process can include a component of addressing the parental stress, which in turn will help optimize treatment outcomes for the child and the family.^[19]

The implication of this study is to emphasize the role of mental health providers for adequate care delivery for the parents, along with the children with ASD. Regardless of the attitude or acceptance of the caregiving role, it is important to value and respect the individual mental health and coping styles of the parent. Comprehensive mental health care can include screening parents for psychological distress, psychoeducation regarding the appropriate use of coping styles for managing distress, peer support, and provision of support for parents of children with ASD.

Financial support and sponsorship
Indian Council of Medical Research.

Conflicts of interest

There are no conflicts of interest.

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