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Sense of Coherence and Resilience among Mothers of children with Autism Spectrum Disorder

Rosy Sandilya[1]; Richa Singh[2]

[1]Research Scholar, Department of Psychology, Vasanta College for Women, Rajghat, India

[2]Associate Professor, Department of Psychology, Vasanta College for Women, Rajghat, India

Corresponding Author Email: rosypsy.16@gmail.com

Abstract—Autism Spectrum Disorder (ASD) is a neuro-developmental condition generally characterized by deficits in sensory processing and social interaction along with a restricted and repetitive pattern of behavior and activities. Its symptoms includes limited eye contact, problem in forming and maintaining social relationships, challenges in understanding non-verbal communication, repetitive motor actions and words. Mothers of TDC equally face all the challenges but in a different way. Sense of Coherence is a protective factor for psychological health as it helps in understanding stressors by promoting emotional regulation. Resilience helps in balancing psychological strength and adaptability to the situation. In this study, 103 mothers having ASD child and 100 mothers of TDC were included using purposive sampling. Mothers having ASD child reported significantly higher level of SOC than mothers of TDC. However, both the groups also showed average level of resilience. Targeted interventions on SOC and resilience can help in significantly improving maternal well being and their responsibilities.

Keywords: Autism Spectrum Disorder, Typically Developing Children, Sense of Coherence, Resilience.

I. INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong neuro-developmental condition which is characterized by deficits in sensory processing and social interaction along with a restricted and repetitive pattern of behavior and activities (American Psychiatric Association, 2013). It includes the term “Spectrum” which acknowledges the complex and wide variation of the disorder.

Symptoms of ASD generally appear in the early childhood and vary in its type and severity. It is characterized by set of symptoms which includes limited eye contact, problem in forming and maintaining social relationships, challenges in understanding non-verbal communication. Individuals with ASD also exhibit repetitive motor actions such as hand flapping or rocking (Lord et al., 2020) and repetitive words on specific topics or object.

The cause of ASD still remains unclear, but it involves a dynamic interplay between genetic, neurobiological, and environmental factors. Genetic studies on twin and family by Tick, et.al.(2016) reveals an estimate of 70 to 90 percent heritability of ASD, indicating the role of genetic factor in its development. Brain imaging studies reveals neurobiological abnormalities such as increase in brain volume, deformities in cortical thickness and disrupted connectivity in brain regions (Lord et al., 2020) also contributes significantly to ASD. Indirectly, environmental factors such as advanced parental age, infections during pregnancy, and reactions with certain medications, nutritional factors and complications during the delivery of the child have been found to be associated with chances of ASD.

According to the World Health Organization (2023), it is estimated worldwide that 1 in 100 children are on the spectrum. The Centers for Disease Control and Prevention (CDC, 2023) reported 1 in 36 children are diagnosed with ASD. In India, there is limited awareness along with diverse cultural and linguistic settings. Despite of the above, ICMR-INCLEN, 2018 reports suggest a prevalence rate of 0.9% to 1.1% among children aged between 2 to 9 years. Also there are studies conducted in urban centers such as Delhi, Bangalore, and Mumbai have shown higher diagnosis rates of ASD compared to the rural areas, underlining the gap in approach to care giving (Daley et al., 2013).

Typically developing children are those who acquire the developmental milestones within their typical age range. Their physical development such as sitting, walking, playing, running, jumping, drawing and interacting with others grow steadily at

appropriate stages. TDC learn to think, to reason, to solve and understand the cause and effect relationship as they grow cognitively. They are not found to be deficit with social emotional reciprocity as they learn to form relationships along with expressing, managing and understanding one's own as well as others emotions by following the social norms. Typically developing children also show significant development in their language starting from babbling, forming words, making sentences, involving into conversations and understanding non-verbal cues too.

Parenting a child with ASD and a typically developing child is different. As a primary caregiver of the child, mostly the mothers face more challenges as compared to their fathers. Mothers of ASD child have to give more time, energy and attention to their child as they face problem in communicating as well as behaving in a typical way. Along with the care at home, they require to be dealt with different therapy sessions which require a lot of resources. These may put different types of pressures such as personal, emotional, social, professional as well as financial, which barricades their mental health.

In today's world where every situation is very competitive, mothers of TDC equally face all the challenges but in a different way. They need to train their children in such a way to achieve all the milestones coming from schools, skills, achievements and many more. But the stress these mothers face are more manageable as they have emotional support from family and society which considers the growth of their child could be at least considered at their usual pace.

Sense of Coherence is defined as a global orientation that refers to person's capacity to perceive life as structured, predictable and meaningful which helps individuals to understand the sense of stressful situations and mobilize the internal and external resources of the individual. According to Aaron Antonovsky, it serves as a protective factor for psychological health as it helps in understanding stressors by promoting emotional regulation and use of adaptive coping strategies.

Parenting a child with ASD is a highly stressful situation in which one need to have stronger SOC. Higher SOC leads to have more resilience, better able to adapt, and buffer the burnout experience or psychological distress while facing emotional, physical and social challenges. High SOC can make mothers believe they have the skills to handle their child and also help in finding a purpose in their care giving to the child. Olsson and Hwang (2002), in their studies reported that higher SOC results in better emotional health and lower levels of stress and depression. Other studies by Ekas, Lickenbrock, and Whitman (2010) and Hassall, Rose, and McDonald (2005) found that SOC is a significant predictor of maternal adjustment, coping strategies and life satisfaction.

Mothers face a wide range of stressors including managing their child's behavioral difficulties, generating resources for their healthcare and educational systems and dealing with social stigma. Despite of these challenges, mothers show their resilient trait which helps them in balancing their psychological strength and adaptability to the situation in which they are. Resilience is defined as the ability to adapt positively in the face of adversity, stress, or trauma (Masten, 2001). It involves balancing mental health, finding meaning in care giving and coping effectively with demands. Studies show that mothers who are resilient are better able to buffer the psychological effects of stress. Mothers of children with ASD reported higher level of stress in comparison to mothers of TDC, and with greater resilience exhibits lower levels of depression and anxiety along with stronger emotional- well being (Hayes & Watson, 2013; Bekhet, Johnson & Zauszniewski, 2012). Personal attributes such as optimism, emotional regulation, and problem solving abilities are few factors contributing to resilience. Mothers with such attributes are more likely to perceive challenges as manageable and are active in seeking support (Kayfitz, Gragg& Orr, 2010).

II. HYPOTHESIS

- There will be significant difference in SOC among mothers of children with ASD and mothers of typically developing children.
- There will be significant difference in resilience among mothers of children with ASD and mothers of typically developing children.

III. METHOD

Sample- 203 mothers voluntarily participated in the study. Among them, 103 were the mothers of children having ASD (mean age of 34.89 years) and 100 were the mothers of typically developing children (mean age of 32.95 years). Mothers who had child with mild to moderate disability of ASD were included. Child having other disabilities and suffering from any other physical or psychological condition were excluded. The data was collected from mental health care institutions, NGOs in New Delhi using purposive sampling.

***Tools**:*

Sense of coherence scale: Hindi version by Gupta and Pandey (2013) was used for measuring the sense of coherence. It is a 26 item instrument which measure three dimensions of sense of coherence namely comprehensibility (10 items), manageability (9 items), and meaningfulness (7 items). The response alternatives are on semantic scale of 1 to 7 points. The alpha coefficient for overall scale is 0.82, for comprehensibility is 0.78, for manageability is 0.69 and for meaningfulness is 0.25.

Resilience Scale- This scale is developed by Lakshmi and Narain (2017) which measures high, average and low resilience. It has 30 items in which 26 are positive items and 4 are negative items. It measures resilience on 5 point Likert scale from strongly agree, agree, neutral, disagree to strongly disagree. Split-half reliability of this scale was 0.84 and concurrent validity is 0.86.

Procedure:

Mothers of children having ASD, mental health institutions and NGOs were contacted. Mothers coming for the session of their children were selected with the help of therapist. Purpose of the research was debriefed. After establishing rapport with each mothers consent was taken and questionnaires were filled with appropriate instructions. After questionnaires being filled, participants were thanked for their valuable support and time.

Mothers of typically developing children were selected by contacting them in schools and taking permission from the principal. During parent teacher meet purpose of the research was acknowledged to the parents. After establishing rapport, consent was taken and questionnaires were filled with appropriate instructions. Further the scoring was done and data was analyzed using suitable statistics.

IV. RESULT

The data obtained from both the groups were analyzed using SPSS software. Result revealed average level of SOC was reported by both the groups. Mothers having ASD child reported slightly higher level of SOC (M=114.5, SD= 20.27) as compared to the mothers of TDC (M=100.64, SD=17.64). However, the difference between both the groups showed a significant difference t (201) = 5.21, p = 0.00. This suggests that having ASD child results in higher level of sense of coherence in comparison to having TDC.

On the resilience scale the mean scores of mothers having ASD child (M= 96.01, SD = 19.74) were more than the mean scores of mothers of TDC (M= 93.59, SD= 18.49). Based on the mean scores, both groups showed average level of resilience. The difference between both the groups showed a non- significant difference t (201) = 0.90, p= 0.37. The result is graphically shown in Figure 1.

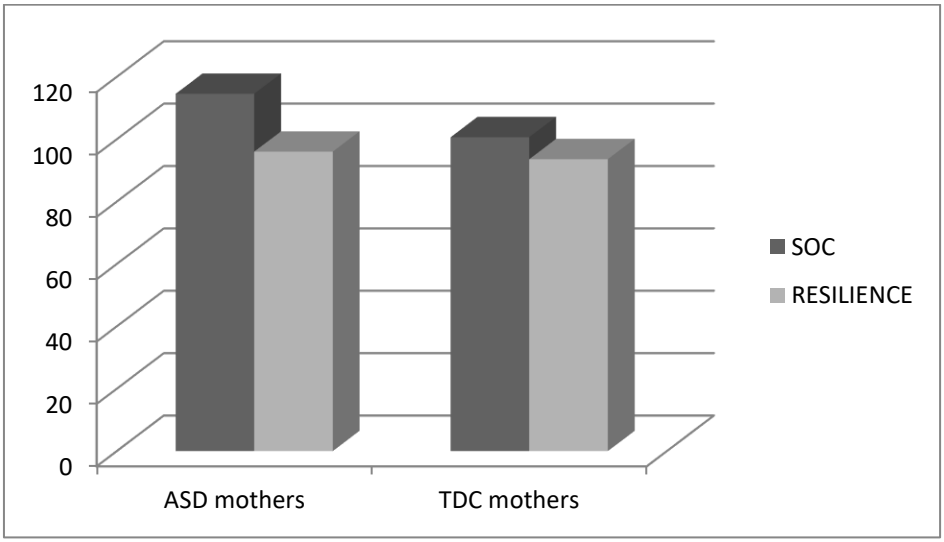

Figure 1: Mean of mothers of both the group on SOC and Resilience Scale.

V. DISCUSSION

This study seeks to investigate the impact of SOC and Resilience among mothers of children with ASD and mothers of TDC. The results revealed that the mothers of children with ASD scored higher level of sense of coherence as compared to mothers of TDC and the difference was found to be significant. Thus the first hypothesis i.e. *There will be a significant difference in SOC among mothers of children with ASD and mothers of typically developing children* is accepted. However, previous findings are in contradiction with the present finding. Olosson and Hwang (2002)examined that parents of intellectual disability including autism spectrum disorder reported lower level of SOC which was linked to higher level of parental stress and emotional problems. Another finding by Ekas and Whiteman (2011), also reported higher level of stress, lower SOC and improper psychological health among mothers of children with ASD. In conclusion, these prominent studies underscores the fact that mothers having ASD child are learning to manage and comprehend with their children by finding meaning in their care giving.

Further the results revealed that both the groups showed average level of resilience.Although the mean score of mothers having ASD was slightly more than the mean score of mothers of TDC, the difference between both the groups was not significant. Thus the second hypothesis which stated "*There will be significant difference in resilience among mothers of children with ASD and mothers of typically developing children"* gets rejected. Previous study by Smith et. al (2012) revealed that mothers who have children with ASD, have access to social networks and educational resources which makes them more resilient with better psychological adjustment.In another study by Bayat (2007) reported that parents of children having ASD generally face post trauma, which leads to have greater accumulation of emotional strength along with deeper relationships to find meaningfulness in the life, which are the signs exhibiting greater resilience.In conclusion these findings highlight the importance of being optimistic along with greater social support and availability of resources as the main source of impact on having greater level of SOC and Resilience.

VI. CONCLUSION

Psychological health of the mothers of children with ASD is mostly impacted by the challenging demands on care giving of the child. Having life experiences, good support systems, and able to cope helps in development of greater level of Sense of coherence which not only promotes the quality of care giving but also influences the way of perceiving and responding to stressors. Previous findings also support that many mothers of children with ASD tends to develop higher level of resilience in response to their adverse condition which helps them to find support by accepting it and nurture their personal growth as well. Encouraging SOC will help in promoting resilience, as SOC is significant predictor of resilience (Alon, 2009). Thus, targeted interventions on these factors can help in significantly improving maternal well being and their responsibilities.

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