Original Article

Association Between Autism Spectrum Disorder Severity and Mental Health of Care Givers

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ABSTRACT

Background: Autism spectrum disorder (ASD) is heterogenous in range of symptoms and severity of dysfunction. Diagnosis of ASD can lead to significant distress to the parents. The aim of our study was to assess the association between the severity of ASD and mental health of primary caregivers.

Materials and Methods: Children with ASD and their primary caregivers were recruited from the child psychiatry unit of a large tertiary children hospital in south India. Severity of ASD was assessed by Childhood Autism Rating Scale 1 (CARS-1) and repetitive behaviour by Repetitive Behaviour Scale - Revised (RBS-R). Among the caregivers, anxiety levels were assessed by Hamilton rating scale for Anxiety (HAM-A) and depression levels were assessed by Hamilton rating scale for Depression (HAM-D). Association was tested using Pearson correlation test.

Results: We recruited 100 children with ASD and their mothers (primary caregivers) in the study. The prevalence of anxiety and depression among mothers of children with ASD was 44% and 30% respectively. Statistically significant correlation was observed between CARS scores and HAM-A ($p=0.002$) and HAM-D ($p<0.001$) scores. Among the repetitive behaviours, self-injurious behaviour was found to be significantly associated with both anxiety ($p<0.001$) and depression ($p<0.001$) scores, while stereotyped ($P=0.002$) and compulsive ($p=0.004$) behaviours were associated with depression scores.

Conclusion: There is a significant association between severity of autism spectrum disorder and adverse mental health of primary caregivers. Further research is required to better understand the mediators of these outcomes.

Keywords: Autism Spectrum Disorder, Severity, Repetitive Behaviour, Primary Caregiver, Depression, Anxiety

Running Title: Mental health of caregivers in ASD

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Autism Spectrum Disorders (ASD) are characterized by abnormalities in reciprocal social interaction and presence of restricted repetitive behaviour. and restricted interests.[1] According to more recent updates from Center for Disease Control in the United Sates, 18.5 per 1000 children at 8 years of age had ASD.[2] However, the prevalence of ASD varies worldwide.[3] In a recent meta-analysis of four prevalence studies of ASD from India, pooled percentage prevalence was 0.11 [95% confidence interval (CI) 0.01–0.20] in children in rural areas aged 1-18 years, while the urban areas hada

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pooled percentage prevalence of 0.09 (95% CI 0.02–0.16) in children aged 0-15 years.[4] It more common in boys with a ratio of 4:1.[5]

Children with ASD present with associated language impairment and intellectual delay. Around half of those with ASD are reported to have significant intellectual delay due to many factors.[6]

Expectedly parents of children with ASD experience greater levels of stress compared to those with developmental disorders or physical illnesses.[7] Parents of children with ASD face uncertainties about the diagnosis, challenges in accessing, affording treatment and are often unsure of the future.[8] Studies have suggested that mothers experience greater levels of stress compared to fathers of children with ASD.[9] The stress perceived by the parents also depends on the type of coping mechanism they adopt in the process.

Even though many studies from India had assessed the severity of ASD through different tools,[10] and psychological distress among the primary caregivers,[11] only few studies have examined the association between these two factors. Hence, the aim of our study was to examine the association between repetitive behaviours and severity of ASD and anxiety and depression levels among the primary caregivers of these children with ASD.

MATERIAL & METHODS

Study site: The study was carried out at the outpatient department of the child psychiatry unit at a tertiary care paediatric centre in Chennai, south India. A cross-sectional descriptive study methodology was adopted for data collection. Institutional Ethics Committee (IEC) approval was obtained before the start of the study.

Study subjects: 100 consecutive children diagnosed as autism and their primary caregivers at-tending the outpatient department of the study site were recruited into the study based on the inclusion and exclusion criteria:

Inclusion Criteria: 1. Children aged less than 6 years; 2. Both gender; 3. Diagnosed with ASD based on International Classification of Diseases - 10 (ICD-10) diagnostic criteria; 4. Primary caregivers giving written informed consent

Exclusion Criteria: 1. Autism with co-morbid physical illness; 2. Co-morbidities with other pervasive neuro developmental disorders (Atypical autism, Rett's syndrome, Asperger's syndrome, Childhood disintegrative disorder, Pervasive Developmental Disorder -Unspecified)

Assessments: Demographic profile and illness variables: A semi-structured proforma was developed to collect the relevant socio-demographic variables and illness variables including the age at diagnosis.

Childhood Autism Rating Scale 1 (CARS-1): CARS-1 was developed by Eric Schopler, Robert J. Reichier and Barbara Rochen Renner.[12] It has 15 items. Each is rated as 1 - 4 with higher scores indicating worse outcome. Total score 15 to 60, minimum score of 30 for a diagnosis of autism. Average reliability is 0.71 with good inter-rater reliability and internal consistency. Scoring pattern is as follows: 15 – 29.5 = Non autistic; 30 – 36.5 = Mild to moderately autistic; 37 – 60 = Severely autistic.

Repetitive Behaviour Scale - Revised (RBS-R): RBS-R is a 44 items questionnaire for differential identification and scoring of discrete varieties of repetitive behaviours.[13] The score that best de-scribes severity of the problem behaviour in the previous month is recorded. The RBS-R consists of six sub-scales including: stereotyped behaviour, self-injurious behaviour, compulsive behaviour, routine behaviour, sameness behaviour, and restricted behaviour. Behaviours are rated on a four-point scale.

Hamilton rating scale for Anxiety (HAM-A): It was devised by Max Hamilton in 1959.[14] It is used to assess anxiety and as a tool to evaluate recovery from anxiety. The HAM-A probes 14 parameters, each item is scored on a 5-point scale, ranging from 0=not present to 4=severe. Scoring is as follows: 0-13 = Normal; 14-17 = Mild anxiety; 18-24 = Moderate anxiety; and >25 = Severe anxiety.

Hamilton rating scale for Depression (HAM-D): It was devised by Max Hamilton in 1960.[15] It is used to assess depression and to evaluate the severity of depression in adults. It is said to be the gold standard in assessing depression on clinical grounds. The original version consisted of 17 items (HSRD-17), the recent version consists of 21 questions. Respondents are classified based on the following scoring: Scoring patterns: 0-7 = Normal; 8-13 = Mild Depression; 14-18 = Moderate Depression; 19-22 = Severe Depression; and ≥ 23 = Very Severe Depression

Statistical analysis: All the statistical analysis was done use SPSS 16.0. Descriptive statistics, such as frequencies and mean with SD, was used to analyze the data. Chi-square test was used to find associations between categorical variables and Pearson correlation was used to examine correlation between continuous variables. Statistical level of significance was set at $p<0.05$.

RESULTS

Socio demographic and clinical profile of the primary caregivers and children with autism are presented in Table 1 and Table 2. All the primary caregivers were mothers. The average time spent by them in taking care of their children with autism was 19.4 ± 3.16 hours per day including the time when either the child or parent was asleep. We observed that the prevalence of mild to moderate autism in the study population was 74% while 26% accounts for severe autism.

Table 1. Socio-demographic and clinical profile of the primary caregivers (N = 100)

Variable	**Mean ± SD; N (%)**
Age (in years)	28.8 ± 3.7
Education	
Uneducated	5 (5)
Secondary	19 (19)
Higher secondary	30 (30)
Graduate	46 (46)
Occupation	
Unemployed	82 (82)
Laborer	5 (5)
Clerical	13 (13)
Family type	
Joint	68 (68)
Nuclear	32 (32)
Number of children	
1	59 (59)
2	37 (37)
3	4 (4)
HAM-A	6.1 ± 8.7
HAM-D	8.8 ± 10.7

HAM-A – Hamilton rating scale for Anxiety; HAM-D – Hamilton rating scale for Depression

Among the primary caregivers, 30% had depression, with mild, moderate and severe depression accounting for 10%, 16% and 4% respectively. We observed 44% of the primary caregivers have anxiety of which 12% have mild, 17% have moderate and 15% have severe anxiety.

We found no statistically significant correlation between family type and anxiety ($p = 0.826$) and depression ($p = 0.059$) scores of primary caregivers. Significant association was observed between duration of illness in the children with autism and anxiety ($p = 0.033$) and depression ($p<0.001$) scores among primary caregivers **(Table 3)**.

Table 2. Demographic and clinical profile of the children with autism (N = 100)

Variable	Mean ± SD; N (%)
Gender	
Male	84 (84)
Female	16 (16)
Age at diagnosis (in months)	37 ± 5.13
Type of schooling	
Not in school	19 (19)
Special school	30 (30)
Regular school	51 (51)
CARS score – Total	34.7 ± 4.1
CARS score – Classification	
Mild to moderate	74 (74)
Severe	26 (26)
RBS-R	
Stereotyped behaviour	68 (68)
Self-injurious behaviour	31 (31)
Compulsive behaviour	65 (65)
Ritualistic behaviour	62 (62)
Sameness behaviour	95 (95)
Restricted behaviour	95 (95)

CARS – Childhood Autism Rating Scale; RBS-R – Repetitive behaviour scale – Revised
SD - Standard Deviation; N- number

Table 3. Correlation between CARS of the children with autism and HAM-A and HAM-D scores of the primary caregivers

	CARS - 1	
	correlation	**p**
HAM-A	0.313	0.002
HAM-D	0.422	<0.001

CARS – Childhood Autism Rating Scale; HAM-A – Hamilton rating scale for Anxiety; HAM-D – Hamilton rating scale for Depression

We found a statistically significant positive correlation between CARS scores among children with autism and HAM-A ($p = 0.002$) and HAM-D ($p<0.001$) scores among primary caregivers (Table 4). A significant positive correlation was observed between RBS-R domain 2 (self-injurious behaviour) and HAM-A ($p<0.001$) scores while no significant association between other domains and HAM-A scores. HAM-D scores are significantly associated with RBS-R domain 1 - stereotyped behaviour ($p = 0.002$), RBS-R domain 2 - self injurious behaviour ($p<0.001$) and RBS-R domain 3 - compulsive behaviour ($p = 0.004$).

Table 4. Correlation between RBS-R of the children with autism and HAM-A and HAM-D scores of the primary caregivers

RBS-R	HAM-A		HAM-D	
	correlation	p	correlation	p
Stereotyped Behaviour	0.195	0.051	0.312	0.002
Self-Injurious Behaviour	0.440	<0.001	0.512	<0.001
Compulsive Behaviour	-0.046	0.647	-0.287	0.004
Routine Behaviour	0.197	0.049	0.069	0.495
Sameness Behaviour	0.729	0.771	0.067	0.507
Restricted Behaviour	-0.142	0.158	0.015	0.885

RBS-R – Repetitive behaviour scale – Revised; HAM-A – Hamilton rating scale for Anxiety; HAM-D – Hamilton rating scale for Depression

DISCUSSION:

The aim of our study was to examine the association between the severity and repetitive behaviour among children with ASD and psychological impact such as anxiety and depression levels among their primary caregivers.

We found that severity of ASD was significantly associated with anxiety and depression levels among primary caregivers of children with ASD. Similar results were observed in previous stu-dies.[8, 16, 17] We observed that the prevalence of depression and anxiety among primary caregivers of children with ASD was lower when compared with some studies.9 For example, Olsson and Hwang found 50% of Swedish mothers have depression while 16% of them had severe depression.[18] Various factors could contribute to the lesser prevalence of depression in our study population including more resilience among the caregivers, less severe symptoms, limited understanding of the problem and better coping mechanisms.[9, 11]

Sameness behaviour and restricted behaviour were the most common symptom domains, both present in 95 % of the children in the study population. 60 to 70% of the study population children had stereotyped behaviour, compulsive behaviour, and ritualistic behaviour. Restricted, repetitive and stereotyped patterns of behaviour, interests and activities are among the core symptoms of autism.[19] One hypothesis suggests that repetitive behaviours are the result of a core deficit in attention. Given the high prevalence of motor deficits observed in ASDs alternative hypothesis suggests of abnormalities of the motor system may constitute the central mechanism underlying repetitive behaviours.[20]

Self-injurious behaviour was the least common symptom found in 31% of children in the form of hitting, biting, and scratching oneself. Similar result was observed in a population-based study where the prevalence of self-injurious behaviour was found to be 27.7%.[21] Children with ASD often exhibit externalizing behaviours at a higher rate than their typically developing peers.[22] Studies have shown that children's externalizing behaviour, including aggression, has a strong correlation with parenting stress.[23, 24]

Various studies have explored the factors predicting the anxiety and depression levels among primary caregivers of children with autism spectrum disorder. For example, lower household in-come has been found to be associated with depression among caregivers of children with intellectual and developmental disabilities.[25] Similarly, higher perceived stress among caregivers was observed with greater distance to treatment centers, poor transportation and children with co-morbid learning disability.[26] Social support, both formal and informal, was found to decrease stress and lead to better self-rated health among caregivers of children with ASD.[27]

The major limitations of the of the study are: 1. Single centre hospital based study; 2. Cross-sectional design of the study did not allow for observing the changes in the anxiety and depression levels among the primary caregivers with changes in the severity of ASD with treatment; 3. Only mothers the children with ASD was studied; 4. Economic and social support available and their impact were not studied; and 5. No control group of primary caregivers of children with chronic diseases with caregivers of ASD.

In conclusion, severity of illness and repetitive behaviours in children with ASD is associated with anxiety and depression levels among primary caregivers of children with ASD. Further research is needed to understand the influence of social support interventions that can reducing the mental health impact on primary caregivers of ASD.

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CONFLICT OF INTEREST

The authors have declared no conflict of interest with respect to the research, authorship,and/or publication of this article.

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