A Study to Assess Caregiver Burden in Parents of Children with Autism Spectrum Disorder

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ABSTRACT

BACKGROUND

Autism is one of the most demanding types of disorders in terms of caregiver's intervention. A significant amount of distress is always associated with a long term, pervasive intervention and attention given by the care giver. The above scenario leads to depression, adjustment disorder along with suicidal tendencies among the care givers leading to poor prognosis of the disease progress in children and emergence of stress related mental illness in the care givers. Pro-active assessment, diagnosis and management of the above among the care givers might be beneficial for both the child and the care giver along with other family members.

METHODS

This study was conducted in the special schools of Kancheepuram from December 2019 to February 2020. The cross-sectional study aimed to assess caregiver burden and the variations of burden with varying social and language development in parents of children with ASD (Autism Spectrum Disorder). A total of 60 parents whose children were diagnosed to have Autism Spectrum Disorders were assessed to scale the caregiver burden using Burden Assessment Schedule, and semi structured socio-demographic questionnaire.

RESULTS

Majority of the caregivers showed an impact on multiple areas of life. 59 % of the caregivers showed significant impact on wellbeing with 84 % feeling depressed and anxious. Lack of appreciation for care was seen in 85 % of the caregivers. Relationship with others was very much impacted in about 14 % of the caregivers. Perceived severity of illness was impacted in 53 % population.

CONCLUSIONS

Bringing up a child with an autism spectrum disorder is a significant chronic stressor sufficient to disrupt various areas of an adult life and also to cause mental illnesses. Early recognition and management of burden is of immense value in the wellbeing of the caregiver, more importantly in the prognosis of the child's disorder.

KEYWORDS

Autism Spectrum Disorder, Caregiver Burden Assessment, Caregiver Burnout

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BACKGROUND

Autism is a complex neurodevelopmental disorder recognised by significant impairment in social interaction, communication and the presence of restricted learning activity and repetitive behaviours or interests.[1,2] It has been estimated that more than 2 million people might be affected by ASD in India. The incidence of the disorder along with the stress associated with the same is found to be increasing in number and severity worsened by the negative effects of the disorder.[3,4]

The caregivers of children with autism face numerous challenges and many studies reported increased psychological distress including depression.[5-8] However, factors reported related to caregiver depression were children's behaviour problems, early onset of autism, low functioning of patients, inadequate social support that caregivers received, caregivers suffering from comorbid conditions or disability.[9,10] Furthermore, factors relating to caregiver burden were severity of patient's symptoms, number of life problems of caregiver and low level of support that caregiver received.[11] Numerous research studies have identified many problems associated with caring children with autism which depends on many risk factors including gender of caregiver, amount of time spent caring for children, marital status, parental education and also on the caregivers' quality of life as an impact of behavioural problems of children with autistic disorder.[12,13,14]

A care giver is defined as the person who fulfils the need of physical and psychological wellbeing of a diseased or disordered individual.[15] Caregiver burden is defined as parents' perceptions of stressors related to providing on-going care for their adult children diagnosed with ASD (Lazarus & Folkman, 1984). In order to understand and guide the caregiver to cope and to improve their overall quality of life, this research has assessed the subjective burden among family caregivers of autistic children.

METHODS

1. CARS - Childhood Autism Rating Scale

A CARS score of; or = 33 (sensitivity = 81.4 %, specificity = 78.6 %; area under the curve = 81 %), as suggested for diagnostic use in Indian populations has good inter-rater reliability (ICC- Intraclass Correlation Coefficient = 0.74) and test-retest reliability (ICC = 0.81). Besides the adequate face and content validity, CARS has demonstrated good internal consistency (Cronbach's alpha = 0.79) and item-total correlation. It has high concordance rate with the reference standard, ICD (International Classification of Diseases) - 10 diagnosis (82.52 %; Cohen's kappa = 0.40, p = 0.001) in classifying autism. A 5-factor structure explained 65.34 % of variance.

2. Burden Assessment Schedule Instrument

The inter-rater reliability between the interviewers has Kappa 0.80. The instrument has 20 items rated on a 3-point scale, marked 1 - 3[16] with a combination of qualitative and quantitative methods. It assesses 5 factors: Impact on wellbeing, on marital relationships, on relationships with others, appreciation of care, perceived severity of illness. The instrument may be able to predict burnout in persons caring for a chronically mentally ill person. Measuring both subjective and objective burden, the BAS (Burden Assessment Schedule) will be sensitive enough to detect early symptoms of burnout.

3. Proforma

We have used a semi structured socio-demographic questionnaire comprising of sociodemographic data of the child along with height and weight, birth and developmental milestones, presence of seizure disorder / episodes, temperament, co-morbid externalizing disorder, treatment and its duration, impression with severity of autism, details about the care givers including age, gender, socio-economic status, education status, occupation and relationship with the child, time spent with the child along with impression. This proforma was filled approximately in 50 - 60 minutes per patient.

This study was conducted in the special schools of Kancheepuram from December 2019 to February 2020. The cross-sectional study aimed to assess caregiver burden and the variations of burden with varying social and language development in parents of children with ASD. A total of 60 parents whose children were diagnosed to have autism spectrum disorders were assessed to scale the caregiver burden using Burden Assessment Schedule.

This study uses Pollak and Perlick (1991) method to identify primary caregiver.[17] According to this method, primary caregiver is one who satisfies 3 or more of the following 5 criteria

1. Spouse, parent or spouse equivalent.
2. Most frequent contact with patients.
3. Supports patient financially.
4. Most frequent collateral participant in the patient's treatment.
5. Is the person contacted in case of emergency?

This is a cross sectional observational study conducted among care givers of in-patients and out-patients attending Department of Psychiatry, Meenakshi Medical College Hospital and Research Institute, Enathur, Kanchipuram. Schools included: Adhura School for especially abled children, Kanchipuram. SSKV school which has a section for specially abled children, Kanchipuram. Sample period: February 2020 to March 2020. Sample size: 70. Sampling technique: Purposive / Selective sampling. Statistical analysis using descriptive statistics and Tests of significance (SPSS software).

Inclusion Criteria

1. Primary caregivers of cases of autism spectrum disorder diagnosed according to the International Classification of Diseases 10th edition (ICD 10) in effect at the time of the data collection.
2. Age of the parent: 20 to 50 years.

Exclusion Criteria

1. Parents of children with visual, hearing, or physical impairment.
2. Parents of children with cerebral palsy; childhood disintegrative disorder; Rett syndrome and severe intellectual impairment.
3. Parents with previous mental illness, substance dependence and severe physical illness.
4. Parents who do not consent to participate in the study.

Procedure

The study was approved by the Institutional Ethical Committee, Meenakshi Medical College Hospital and Research Institute, Kanchipuram, Tamilnadu. A written consent was obtained from all the participants. Sociodemographic details of the child and the caregiver was collected using a semi-structured proforma. All those who satisfied the inclusion and exclusion criteria were assessed on Childhood Autism Rating Scale to know the severity of autism. Caregivers of the selected cases were applied to "Caregiver Burden Schedule Scale" (Dr. Thara). Data collected was tabulated.

Statistical Analysis

Data was tabulated in Google sheets and statistical analysis was done. Means and proportions were calculated, describing the baseline characteristics. Chi square test was used to compare statistical difference in proportion with the above details. A p value of < 0.05 was considered statistically significant.

Ethical Considerations

Institute ethical committee approval and clearance was obtained before the study was started. Informed consent was obtained from all the patients in their own language, who participated in the study. No ethical issues were involved. The information of the patients was kept confidential.

RESULTS

Applying all the inclusion and exclusion criteria, the study population was 63 primary caregivers of children with autism spectrum disorder. The primary caregivers of 90 % of the sample were biological mothers. Their ages ranged from 25 - 52 years with mean age being 35.74. In our study 90 % of the primary caregivers were mothers. At least 90 % of them had completed high schooling. Most of the study participants were belonging to upper middle socio-economic status and were from a rural background. 95.4 % of the study population were married. 96 % belonged to Hinduism. 12 % of the caregivers had diabetes and / or hypothyroidism. None of them had any substance use. 82.5 % of the children with ASD in the study were boys. Their ages ranged from 3 to 18 years with a mean age of 8.64. 98 % of the children had mild to moderate degree of autism with a mean score of 32.3 on CARS. 33 % of them had history of epilepsy. Burden assessment schedule was used to assess impact in areas like impact on wellbeing, appreciation of care, impact on relationships with others, perceived severity of the illness. Impact on wellbeing was moderate to severe in 59 % of the caregivers. 56 % reported of exhaustion. Impact on physical health was severe in 15 % of the parents, while 33 % said it was moderate. 84 % of them reported of feeling depressed and anxious. 75 % felt frustrated about the child's improvement. Lack of appreciation for care was moderate to severe for 85 % of the caregivers. 30 % of them felt that their family or friends never appreciated the way she took care of the baby. Caregivers accepted that their ability to care enough for others in the family was very much affected in 33 % of them and to some extent in 44 % of them. Relationship with others was very much impacted in less than 14 % of the caregivers. Most caregivers were still trying to have a satisfying relationship with the rest of the family and friends. They still maintained a stable family.

Perceived severity of illness was moderate to severely impacted in 53 % population. 49 % felt hopeless about the child's problem to some extent, while 13 % felt very much so. 64 % felt disturbed because of the child's unpredictable behaviour. 65 % felt that the child's disorder prevented them from looking for a job.

In our study, we found an increase in the burden with an increase in the severity of autism. But the caregiver was appreciated better when the severity of autism was higher.

DISCUSSION

Majority of autistic children are males (82.5 %), this result reflects the higher prevalence of ASD in males compared with females. This is also true in studies of David et al.[18] and Bromely et al.[19] Benjak et al.[20] Majority of the caregivers (90 %) were mothers. This result comes along with Nikmat et al[21] which finds that the majority of the gender of parents with autistic children (65.4 %) subjects was female (mother). About the caregiver age, majority of the study sample (68.2 %) is within (30 - 39) years old this finding is supported by Nikmat et al [21]. who showed that the finding (53.8 %) falling within (3140) years old, is major of age group for caregivers of autistic children. About the subjects' levels of education, the majority of the study sample were educated up to high school (31.75 %), up to graduation (26.98 %). These results did not correspond with Rhoades et al.[22] Who pointed out that (64 %) of caregivers with autistic children were at college degree. In addition, Hamlyn et al.[23] revealed that most of the autistic children caregivers were at college level (55.75). Allik et al.[24] stated that (64.5 %) of mothers with autistic children were at high school-education. Majority of the subjects' marital status (95.24 %) is married which is consistent with our culture; where both males and female tend to marry early and with study of Yuen et al.[25] who found that (90 %) of the caregivers with autistic children were married. The result of the data analysis showed that the majority of the monthly income of caregivers (63.49 %) were sufficient. But this finding could be biased because the sampling was mostly done from private special schools where poorer strata might hardly have enrolled, yet this finding agrees with Nikmat et al.[21] Montes et al. who reported that (50 %) of the sample were of a high level of household of monthly income. 96.83 % participant were Hindus and 3.17 % participants were from other religions. Though difference was statistically significant (p-value < 0.05), it reflects the distribution in the general population at large. 74.60 % participants were residing in a rural area, 15.87 were residing in suburban area and the remaining 9.52 % in the urban area. Though the difference was statistically significant, we opine that it only represented the general population distribution around the special school. This finding is inconsistent with a previous study done by Sahu et al.[26]

Impact on wellbeing was moderate to severe in 59 % of the caregivers, 84 % reported of feeling depressed and anxious. Lack of Appreciation for care was moderate to severe for 85 % of the caregivers. Relationship with others was very much impacted in less than 14 % of the caregivers. Perceived severity of illness was moderate to severely impacted in 53 % population. This result agrees with Tobing et al.[27] whose results indicate that the general mental health is mostly affected among the caregivers of children with ASD. The findings were consistent with Keller et al [28]. Whose findings reveal that (90.4 %) of caregivers with autistic children have highly significant burden and stress and (53.8 %) of the caregivers showed clinical disturbance in psychological wellbeing. Heiman[29] stated that when children were young, caregivers worry about whether they will be bullied at school or whether they will have any friend. As their children grow older, parents' concerns are toward prospects for independent living, employment opportunities and potential romantic relation.

According to the study of Lainhart[30] caregivers of autistic children had an increased rate of developing psychiatric disorder such as depression; this increased risk may be directly related to the burden of living with caring for an ASD children. Kogan et al.[31] elucidate that caregiver of a child with ASD suffered from feeling of isolation and depression.

Study showed an increase in the caregiver burden with an increasing severity of autism. The findings of this study were consistent with that of Nagaraju;[32] Nikmat et al.[21] and Sarkova et al.[33] Who reported that the severity of ASD children mostly effected on their caregivers' regard to psychosocial burden in future. Previous research has found child symptom severity to be the most reliable predictor of parenting stress.[34–37]

Limitations of the Study

Selecting sample from special schools might make the sample less representative of population at large. Parents might have minimalized the burden due to apprehension or embarrassment to answer honestly.

CONCLUSIONS

Early screening, diagnosis and management of stress related disorders in care givers of children with autistic spectrum of disorders is essential for better outcome in both the child and the primary caregiver. The above facilitates improve the quality of life for the entire family.

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