ORIGINAL ARTICLE

The primary caregiver's stress: its correlation with the chronological and diagnostic age of children with autism spectrum disorder

Zeenaf Aslam[1]*, Mansoor Ghani[1], Samina Manzoor[1], Saeed Ur Rahman[2], Asdia Aslam[2], Anila Sumreen[1], Afshan Mehvish Naz[1], Asma Batool[3]

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ABSTRACT

Background and Objective: Autism is a neurodevelopmental and heterogeneous disorder that affects people of all ages; also known as autism spectrum disorder (ASD). Nurturing these children puts a tremendous burden on the primary caregivers. It may be due to some compelling reasons, including existential concerns to unknown etiology of autism and lack of understanding of its nature. The aim of the study was to evaluate the stress level in the primary caregivers and its relationship with child's chronological and diagnosis age.

Methods: This cross-sectional study included 96 primary caregivers (mothers, fathers, siblings, and grandparents) of children diagnosed with ASD reporting at government and nongovernment institutes of Lahore city. The childhood autism rating scale was used to confirm the diagnosis of autistic children. The parent stress scale was used to evaluate stress levels in primary caregivers.

Results: The mean age of the autistic children was 5.1 ± 2.5 years, while the mean age at the time of diagnosis was 3.2 ± 1.1 years. The mean stress score was recorded as 52.3 ± 7.3, with the range of 36.0-70.0. No correlation (r = 0.015) was observed between stress score of primary caregivers and duration after diagnosis of autism in these children. However, negative associations (r = -0.044) were seen between primary caregiver's stress and child's chronological age.

Conclusion: The majority of primary caregivers indicated bearing a significant level of stress, especially in managing the child in earlier years after diagnosis. Appropriate education, counseling, and rehabilitation services may play an important role in reducing the anxiety and stress over time in caregivers as the child's age increases.

Keywords: Stress, autism, chronological age, diagnostic age, autism spectrum disorder.

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Correspondence to: Zeenaf Aslam
*Institute of Nursing (ION), University of Health Sciences, Lahore, Pakistan.
Email: zeenafaslam@uhs.edu.pk
Full list of author information is available at the end of the article.

Introduction

Autism is a chronic and complex psychological disorder in children. It is characterized by distress in the social use of verbal and nonverbal communication, language impairment, and repetitive or stereotypic behavior patterns in children. These types of behavior result in operative limitations in social, educational, and occupational performances. Autism is also termed as a pervasive developmental disorder that is indicated by distinct patterns of interests, peculiar behavioral presentations, language deficits, and developmental delays (DDs). Therefore, it is known as autism spectrum disorder (ASD). Autism prevalence rate reached 60 out of every 10,000 births which are about to be 1.9/1,000 (1:59) children with the rates increase in the United States, which represents a 120% increase in diagnoses since 2002.[1] According to the Autism Society of Pakistan, there is no reliable data for the cases of ASD in Pakistan, but the affected population is snowballing. However, South Asian development bodies indicated 350,000 cases of ASD in Pakistan.[2] DD is a discerned delay in developmental skills, including gross and fine motor skills, speech, and language skills. In addition to primary ASD diagnosis, the child has some comorbid conditions such as developmental, psychiatric, neurological, and other medical disorders.[3] Children diagnosed with ASD have symptoms that vary from moderate to severe. All of these children

have some degree of impairment in their communication skills, social interactions, and behaviors. The symptoms of autism begin in early childhood at the age of 2-3 years with compromised social-communicative behaviors. The Center for Disease Control has defined the following signs and symptoms of ASD that may vary among children. No response before the age of 12 months to be named, no references to objects of 14 months' interests, no 18-month play, avoidance of eye contact and the will to be alone, delayed speech and language ability, and repeating words or phrases.[4] The core attributes of ASD are difficulties in the area of verbal communication, uneven cognitive functioning, impaired social interaction, and behavioral problems.[5,6] Moreover, autistic children may self-injure and show elevated irritability which has been distinguished as a critical source of primary caregiver's anxiety, stress, and depression.[7,8]

In general, the initial diagnosis of ASD affects the mothers and families. The literature indicates that obtaining a diagnosis is a difficult and frustrating phase for families. The parents of autistic children, who have been diagnosed at an earlier age, require respite care and exceptional family support frequently.[9,10] The child's age has also been linked with the greater indices of clinical anxiety and depression in the primary caregivers or the parents.[11] Parents of children who had been diagnosed for 1 to <2 years reported a higher caregiving burden than others (<1 and ≥2 years since diagnosis). Moreover, it has been observed that primary caregivers, especially the mothers, get frustrated due to unawareness of behavioral issues appearing in child with ASD at the age of 2 years than a healthy child.[12]

After careful review of the literature regarding the impacts of ASD on primary caregivers, it has been found that no such correlational study has been conducted in Pakistan. Currently, primary caregivers are facing stressful psychological issues, such as stress due to maladaptive behaviors of their autistic child, misdiagnosis, and improper access to healthcare facilities. These behavioral problems in young children with ASD also interfere with parental efforts in pursuing their daily living activities. Late diagnosis is also coupled with elevated stress in the parents of elder children as compared to younger children. This study was, therefore, designed with the aim to assess the level of stress among primary caregivers and its relationship with duration after diagnosis and child's age at the time of diagnosis.

Methods

A descriptive cross-sectional study was carried out in the Department of Pediatrics at three institutes in Lahore: Developmental and Behavioral Unit of Children's Hospital and the Institute of Child Health (CHC&ICH), Water and Power Department Authority Teaching Hospital, and Global Institute for Autism Special Education, Mind and Behavioral Sciences, for a period of 6 months from July 15, 2020 to December 15, 2020. Ethical approval was obtained from the Institutional Review Board of CHC&ICH. A nonprobability purposive sampling was used. Primary caregivers spending minimum 8 hours with their autistic children, who were diagnosed according to Diagnostic and Statistical Manual of Mental Disorders-V-TR criteria (APA, 2005) for the last 6 months and autism index (AI) score of ≥30 were selected.[13] The primary caregivers with chronic uncontrolled disorders or already having psychiatric illness or having more than one child with a disability were excluded.

The childhood autism rating scale was used to check AI. The standardized structured scale consists of domains 1-14 assessing behavior problems and domain 15 rating the general impression of autism. Each domain is scored on a scale ranging from 1 to 4 and higher scores are associated with the severity of impairment. Total scores range from 15 to 60. Scores ≤30 indicate non-autistic, 30-36.5 indicate mild to moderate autism, and 37-60 indicate severe autism.[14]

Demographic data consisted of five following questions: primary caregiver's relationship with the child, primary caregiver's age, education, profession/occupation, and child's age. The parental stress scale (PSS) to assess parental stress for mothers and fathers of children with and without clinical problems was used to ascertain the stress level in caregivers.[15] The PSS consists of 18 items rated on a Likert scale. To compute the parental stress score, items 1, 2, 5, 6, 7, 8, 17, and 18 were reversely scored as follows: (1 = 5), (2 = 4), (3 = 3), (4 = 2), and (5 = 1). The overall possible scores on the scale ranged from 18 to 90. All research instruments were forward and backward translated in Urdu version via a committee of bilingual experts and pilot tested (Cronbach's alpha = 0.728) among 10 participants for reliability. Written informed consent was obtained from all participants prior to conducting the study. Participants participated voluntarily. Confidentiality of data was ensured.

Statistical analysis

The data were entered into Statistical Package of the Social Sciences version 23.0 and were analyzed by using its statistical package. Descriptive statistics were presented and performed as mean (± SD) and frequency and percentage were given for the child and primary caregiver's characteristics. Pearson's correlation was used to determine the association of stress in primary caregivers with duration after the diagnosis of disease and child age at the time of diagnosis. *p*-value ≤ 0.05 and a 95% confidence interval at a 5% margin of error (1.96) were considered statistically significant.

Results

Total participants of the study were 96 and the response rate was 100%. Table 1 shows the descriptive statistics (mean ± SD) of the primary caregivers - the autistic child and PSS. Overall, the mean age of primary caregivers was 34.2 ± 7.0 years. Mean age of the child with autism was 5.1 ± 1.8 years, while the mean age at the time of diagnosis was 3.2 ± 1.1 years. Mean duration after diagnosis of disorder was 1.9 ± 1.4 years. The PSS was used to determine the stress level among primary caregivers. Overall, the possible scores on the scale ranged from 18 to 90. The higher the score, the higher the measured level of parental stress. The mean stress score was 52.3 ± 7.3, with the range of 36.0-70.0, which indicates a moderate stress level among the primary caregivers.

Table 2 presents the frequency distribution of primary caregiver's relationship with the autistic child. Out of 96 primary caregivers, most of them (76, 79.2%) were mothers. The majority (*n* = 47, 49%) of primary caregivers have completed higher education, like masters/M. Phil. Degrees, etc., while fewer (23, 24.0%) had secondary high school/ vocational certifications. Only 22 (22.9%) primary caregivers had professional jobs/occupations, while most of them (74, 77.1%) were unemployed or had no professional job. Majority (*n* = 55, 57.3%) of the primary caregivers spent more than 14 hours with their autistic child.

Table 3 presents the correlational statistics between primary caregiver's stress and the age characteristics of the autistic child. Pearson's correlation test was applied and results revealed that no correlation was found between time duration after diagnosis and the stress in primary caregivers. Similarly, correlations between child's chronological age and the stress scores of the primary caregivers were weak and negative. However, stress scores showed a decreasing trend with the increase in the child's age.

Discussion

The primary caregivers or parents of a child with autism experience some exceptional challenges as compared to the parents of normal children. It includes the modification of routine activities and family dynamics because autistic children need extra attention from their parents.[16,17] In the current study, out of 96 participants, 76 (79.2%) mothers and 20 (20.8%) fathers with the support of grandparents were included. The overall mean age of the primary caregiver was 22-57 years (*M* = 34.2, SD = 7.0). In agreement with our findings, a study conducted by Sharabi et al.[18] reported that out of 107 participants, 61 mothers, aged 21-45 years (*M* = 34.04, SD = 5.73) and 46 fathers, aged 24-59 years (*M* = 37.91, SD = 6.67) were involved in the caregiving responsibilities of ASD children. Similarly, another phenomenological study

Table 1. *Descriptive statistics of the primary caregivers and autistic children (n = 96).*

Variables	Mean ± SD	Minimum	Maximum
Age of the primary caregivers	34.2 ± 7.0	22.0	57.0
Age of the autistic child	5.1 ± 1.8	2.50	9.00
Child's age at time of diagnosis	3.2 ± 1.1	1.10	7.20
Duration after diagnosis	1.9 ± 1.4	0.50	6.00
Stress score in primary caregivers	52.3 ± 7.3	36.0	70.0

Table 2. *Frequency distribution of the primary caregivers' characteristics (n = 96).*

Characteristics		Frequency	Percentage
Relationship	Mother	76	79.2
	Father with grandparents	20	20.8
Employment status	Yes	22	22.9
	No	74	77.1
Time (hours) spent with the child	8-10	9	9.4
	10-12	16	16.7
	12-14	16	16.7
	≥14	55	57.3
Educational status of the caregivers	Masters/M.Phil	47	49.0
	Graduation	26	27.1
	Secondary school/ vocational certification	23	24.0

Table 3. *Correlational statistics of the primary caregivers and age of the autistic child.*

Variables		Stress score
Duration after diagnosis (Diagnostic age)	*R*	0.015
	p-value	0.886
Child's age at diagnosis (Chronological age)	*R*	-0.044
	p-value	0.671

conducted in Karachi, Pakistan, explored that mothers are more conscious about the needs of their autistic children and engage in emotion-focused strategies as compared to fathers.[19]

Findings from the current study suggest that the mean child age at the time of diagnosis was 3.2 ± 1.1 years, with the range of 1.10-7.20 years. The mean age of ASD diagnosis is 18-24 months and children need to show several signs of autism before the age of 3 years. Parallel to these findings, studies conducted in Japan and Malaysia reported the mean age at ASD diagnosis being 7.2 ± 4.2 years and the mean age at the time of consultation ranged from 19 months to 18 years and 4 months (SD = 31.68 months), respectively.[20,21] Another study performed in Oman and Qatar reported contrasting results; 56% of the children with autism were diagnosed at the age of 7-14 years and only 4 cases received their diagnosis at the age of 1-4 years.[22]

The current study shows that a significant percentage (49.0%) of the participants had an higher education, i.e., masters and M.Phil. degrees, while the rest of the primary caregivers (27.1%) had a bachelor's degree or lower-level qualifications (24.0%). These findings are supported by another study conducted in the United Kingdom which concluded that children of a mother with higher studies make twice the rate of autistic children (1.5%; range = 1.1%-1.9%) as compared to mothers with a low level of education (0.7%; range = 0.5%-0.9%).[23] Although the literature reveals no potential link between the education level of mothers and the incidence of autism in their children, it may be speculated that the rate of early diagnosis and awareness about the symptoms of autism is higher in well-educated families.

Only 22 (22.9%) primary caregivers had professional jobs/occupations at the time of the study, while 74 (77.1%) were unemployed or had no professional jobs. In agreement with our findings, a systematic review conducted at the Memorial University of Newfoundland concluded with a critical summary that it is least possible for both parents to continue their jobs with structuring their long-term responsibility for the child with autism in school years and beyond. Loss of job has a substantial impact on family income as well.[24] In economically constrained countries, like Pakistan, joblessness and lack of resources may be taken as other stressful factors for the parents, while the government fails to provide any support to such families.

In the present findings, the mean stress score in the primary caregivers was 52.3 ± 7.3, with a range of 36.0-70.0, which indicates a significantly higher stress level among the primary caregivers. Similar results were concluded by another study conducted in Gujrat, Pakistan, where most parents reported severe levels of perceived stress (171, 68%) as compared to moderate (76, 30.3%) and only mild (4, 1.6%) levels.[25] Similarly, correlations between child's age at the time of diagnosis and parental stress were weak negative (r = -0.044), resulting in a decreased level of stress with the increase in child's age after diagnosis of disease. The present statistics are opposed by a longitudinal study conducted in WA, USA, where a nonsignificant ($p > 0.05$) association between child's age and parental stress resulting in a high level of stress consistently across 6 months even in 16-20 months of their child age was noted.[10] Our findings of lower stress with an increasing child age may be attributed to successful rehabilitation services with better coping by both parents and children with ASD.

With the passage of time, the primary caregivers learn to live according to their child's condition, hence the adaptation phenomenon prevails. Similar findings were inferred by another study where the parents of children with a shorter duration after diagnosis displayed stronger emotions as compared to the extended postdiagnosis period.[26]

The noteworthy aspect of this study was that the caregivers reported no financial or social support from the government, while private nongovernment organizations working for the cause also have a long way to go to support such families in factuality.

Conclusion

In conclusion, the primary caregivers of a child with autism face a high level of stress with inadequate financial and social support for their autistic children. Timely diagnosis of the disorder is a prerequisite to early access for preliminary intervention, as well as to yield effective adaptation strategies by the primary caregivers. Counseling services and continued support programs for these families are necessary across many disciplines, such as medicine, nursing, occupational therapy, and psychiatry, especially in countries like Pakistan.

Limitations of the study

The study was based on participants from autism management centers in Lahore city only. The findings may not be generalized as significant variations from region to region and city to city prevail. Another limitation was the small sample size. A cross-sectional study design can be biased because the participant's mood or recent behavior of the autistic children could have influenced their interpretation of stress.

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List of Abbreviations

ASD	Autism spectrum disorder
CHC&ICH	Children's Hospital Complex and The Institute of Child Health
DD	Developmental delay
PSS	Parental stress scale

Conflict of interest

None to declare.

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Ethical approval

Ethical approval for the study was obtained from the Institutional Review Board of Children's Hospital and The Institute of Child Health Lahore, Pakistan, on 24-02-2020 vide Letter No. IRB # 102/20.

Authors' contribution

ZA (principal author): Acquisition of data, drafting of manuscript, and intellectual input to manuscript.
MG: Conception and design of study and intellectual input to manuscript.
SM and AS: Important intellectual input with critical revision.
SUR and AA: Acquisition of data.
AMN and AB: Analysis and interpretation of data.
ALL AUTHORS: Approval for the final version of the manuscript to be published.

Authors' Details

Zeenaf Aslam[1], Mansoor Ghani[1], Samina Manzoor[1], Saeed Ur Rahman[2], Asdia Aslam[2], Anila Sumreen[1], Afshan Mehvish Naz[1], Asma Batool[3]

1. Institute of Nursing (ION), University of Health Sciences, Lahore, Pakistan
2. Faisalabad Medical University, Allied Hospital, Faisalabad, Pakistan
3. Multan College of Nursing, Ibne-Sina-Hospital Multan, Pakistan

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