Sociodemographic and clinical profile of children with autism spectrum disorders – An observational study from a tertiary care hospital

Bilal Ahmad Bhat, Arshad Hussain, Wasim Qadir, Shabir Ahmad Dar

Abstract:
BACKGROUND: In spite of advances in assessment and management of patients with autism spectrum disorders (ASDs) in the west, developing countries including India are lagging far behind in child psychiatry, let alone ASDs. The aims of our study were to find the sociodemographic and clinical profile of children with ASDs in a child psychiatry clinic of a tertiary care hospital.

MATERIALS AND METHODS: A semi-structured questionnaire was used to record the sociodemographic status. The diagnosis of ASDs was made on the basis of both 4th Edition, Text Revision and 5th Edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR and DSM-V), after a thorough clinical assessment. Intelligence quotient was assessed by a clinical psychologist. Descriptive statistical analysis was done and presented as frequencies and percentages.

RESULTS: A total of 55 patients were diagnosed with ASDs. Most of the patients were <9 years with 52.73% in 4–7 years’ age group and 21.82% in 7–9 years’ age group. Males (78.18%) outnumbered females. About 52.73% belonged to nuclear family, and 63.63% were from rural background. Nearly 70.91% were staying at home. About 87.27% with ASDs as per DSM-IV-TR met the DSM-V symptom criteria for ASDs, whereas 12.73% met DSM-V symptom criteria for social communication disorder.

CONCLUSION: Almost 10.4% of children and adolescents with psychiatric disorders were having ASDs. Only 3% of our cases were receiving inclusive education, and about 70% of cases were staying at home. Nearly 87.27% of DSM-IV-diagnosed ASDs retained the DSM-V diagnosis of ASDs. Comorbid intellectual disability was frequently seen in children with ASDs.

Keywords: Autism spectrum disorders, intellectual disability, social communication disorder

Autism spectrum disorders (ASDs) are a group of neurodevelopmental disorders in which there is impaired development in social, communicative, and cognitive abilities. Although these disorders are usually detected in early childhood, the time at which these disorders are diagnosed is much later than the time of onset of these disorders. In addition, there may be a long duration between the acknowledgment of early symptoms and signs of these disorders by parents and the diagnosis of these disorders. This is further complicated by the fact that there are no early signs of ASDs which are specific to these disorders, making it hard to recognize and diagnose these disorders at early stage. The five disorders in the category of ASDs in the Diagnostic and Statistical Manual of Mental Disorders 4th Edition, Text Revision (DSM-IV TR) are autism, childhood disintegrative disorder (CDD), Rett’s disorder, Asperger’s syndrome (AS), and pervasive developmental disorder-not otherwise specified (PDD-NOS). ASDs

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are characterized by deficits in reciprocal social interaction and communication and unusual and repetitive stereotypic behavior.[8] Although a certain set of behaviors define ASDs, the children suffering from it may exhibit these behaviors in any combination with variable degree of severity.[8] In previous studies, autistic disorder, AS, and PDD-NOS were difficult to differentiate from each other with overlapping criteria for AS and autistic disorder, and a consistent distinction between the different ASDs is uncommon.[19,21] For the DSM-V, instead of these DSM-IV subtypes, there is only one category of ASDs in which the neurodevelopmental symptoms are seen on a continuum ranging from mild to severe expression.[12] The prevalence of ASDs has been shown to increase progressively since 1985, with an estimate ranging from 0.07% to 2.64%.[13-15] A combination of many factors including greater awareness in the public, diagnosis at lower age, better ascertaining of cases, substituting diagnosis, and changes in the diagnostic models and corresponding diagnostic criteria have been attributed to these prevalence changes of ASDs.[13] However, an estimate of 0.6%–0.7% or one child in about 150 children can be confidently derived from the recent studies on prevalence of ASDs.[15] Toddlers at risk of ASDs are not uncommon in India as a recent study found that between the age groups of 16 and 24 months, 5.5% were at risk.[16] In addition, siblings of children with ASDs should be routinely screened for the presence of these neurodevelopmental disorders as the prevalence of ASDs in siblings of Indian children with ASDs in a recent study was 4.97%.[17] Being a complex neurodevelopmental disorder and in the absence of biologic markers, ASDs are diagnosed based on behaviors instead of medical tests and require the examining clinician to have unique skills and experience in identifying those behavioral phenotypes.[18] It is believed by many researchers that the shared social impairment is the hallmark feature of the ASDs that distinguish them from other childhood disorders.[19-21]

Although the beneficial effects of early diagnosis and intervention have been demonstrated by evidence, the opportunity for specialized services is missed by many children with ASDs.[22-24] For the children suffering from these disorders and their caregivers to be benefitted, it is essential to diagnose ASDs as early as possible.[22] Moreover, diagnosis is also essential to get an access to services and specially designed intervention programs. In addition, providing appropriate information to parents will make them more intelligent and informed consumers of services on behalf of their child.

Although there are centers dedicated to these children in different parts of India, it is very unfortunate that we do not have any specialized center for these children in Kashmir. Our department of psychiatry started a child psychiatry clinic in May 2014, and the present study was carried out in the same center as a preliminary study with an aim to find the sociodemographic and clinical profile of children with ASDs.

### Materials and Methods

This was a cross-sectional observational descriptive study which was conducted among the patients attending the outpatient service of the child psychiatry clinic of Postgraduate Department of Psychiatry, Government Medical College, Srinagar, over a period of 1½ year, from February 2015 to June 2016. In this clinic, all the diagnoses are made after a thorough clinical assessment and later confirmed by consultant in-charge of the clinic. This study was approved by the institutional ethics committee. Children of both sexes and age 1–16 years, whose parent/guardian gave the consent and who were diagnosed with ASDs as per DSM-IV-TR, were included in the study. Written informed consent from the parent/guardian was taken in a simple and easily understandable unambiguous language. A semi-structured questionnaire consisting of age, sex, residence, family type, and occupation was used to record the sociodemographic status of the children attending the clinic. All the children who were diagnosed with any type ASD as per DSM-IV-TR during the study period were subjected to a thorough clinical assessment for ASDs based on DSM-V criteria. Intelligence quotient (IQ) was assessed by a clinical psychologist. The data about various parameters were entered into Microsoft Excel. Descriptive analysis was carried out using Statistical Package for the Social Sciences version 20.0. Continuous data were represented as mean and standard deviation. Categorical data were represented in the form of frequencies and percentages. Chi-square was used as a test of significance. \( P < 0.05 \) was considered as statistically significant.

### Results

This study included 55 children and adolescents with ASDs. The mean age of our study population was 6.50 ± 3.06 years, with a minimum age of 2 years and a maximum of 16 years. Of these 55 children and adolescents, 7 (12.73%) patients were in 1–3 years’ age group, 29 (52.73%) patients were in 4–6 years’ age group, 12 (21.82%) patients were in 7–9 years’ age group, 3 (5.45%) patients were in 10–12 years’ age group, whereas 4 (7.27%) patients were in 13–16 years’ age group. Males outnumbered females by an approximate ratio of 3.6:1 with 43 (78.18%) males and 12 (21.82%) females. Twenty-nine patients (52.73%) belonged to nuclear family, whereas 26 (47.27%) belonged to joint families. Thirty-five patients (63.63%) were from rural background, whereas 20 (36.37%) were from urban background. Thirty-nine patients (70.91%) were not bilingual.
involved with a particular occupation and were staying at home. Thirteen patients (37.14%) were attending a special school/crèche, whereas 3 of our patients (5.45%) were students [Table 1].

Among the DSM-IV-TR categories of ASDs, autism was the most frequent diagnosis occurring in 34 (61.82%) patients, followed by PDD-NOS which occurred in 17 patients (30.91%). Asperger’s disorder was found in 3 patients (5.45%), and 1 patient (1.82%) had Rett’s syndrome. Forty-eight children (87.27%) with ASDs as per DSM-IV-TR met the DSM-V symptom criteria for ASDs, whereas 7 children (12.73%) met DSM-V symptom criteria for social communication disorder (SCD). Six children (10.91%) with PDD-NOS and 1 child (1.82%) with Asperger’s disorder under DSM-IV-TR did not meet the DSM-V criteria for ASDs and were diagnosed as SCD [Table 2].

Comorbid intellectual disability (ID) was present in 47 (85.45%) individuals. Mild ID (IQ = 50–70) was present in 19 (34.55%) cases, moderate ID (IQ = 35–49) in 14 (25.45%) cases, severe ID (IQ = 20–34) in 11 (20%) cases, and profound ID (IQ < 20) in 3 (5.45%) cases [Table 3].

Discussion

ASDs, a group of neurodevelopmental disorders, is a clinically manifested behavioral syndrome that usually presents in early childhood.[25] The core symptoms of ASDs include absent or abnormal reciprocated interpersonal and emotional interactions, impaired language and communication, and repetitive/stereotypic pattern of behavior.[7] Populations worldwide are affected by this condition.[26] The current burden of ASDs worldwide is implicit. Since the year 2000, most of the studies conducted across the globe have shown an estimate prevalence of 62/10,000 for all ASDs.[27] Indian research on ASDs has been largely confined to hospital settings or selective settings for autistic children.[28‑31] Our study was also limited to hospital settings only. Out of 529 patients who visited our clinic during the study period, 55 (10.4%) patients were diagnosed with ASDs. Studies from India and other countries in the subcontinent and west have also found lower proportion with ASDs among the children visiting child psychiatry outpatient.[32‑33] One reason for a higher rate of ASDs in our study could be that our clinic is the only facility in our state of Jammu and Kashmir (J and K) for the assessment and management of such patients due to which many such patients are brought to our clinic. Another reason could be the awareness generated by our department about ASDs through regular seminars and print and mass media and thus increased referral of such patients from doctors and the general public to our clinic.

| Table 1: Sociodemographic profile (n=55) | \(\chi^2\) | \(P\) |
|---|---|---|
| Age (years) | | |
| 1-3 | 7 (12.73) | 41.273 | 0.0001 |
| 4-6 | 29 (52.73) | | |
| 7-9 | 12 (21.82) | | |
| 10-12 | 3 (5.45) | | |
| 13-16 | 4 (7.27) | | |
| Sex of patient | | |
| Male | 43 (78.18) | 17.47 | 0.0001 |
| Female | 12 (21.82) | | |
| Family type | | |
| Nuclear | 29 (52.73) | 0.164 | 0.686 |
| Joint | 26 (47.27) | | |
| Residence | | |
| Rural | 35 (63.63) | 4.09 | 0.04 |
| Urban | 20 (36.37) | | |
| Occupation | | |
| Student | 3 (5.45) | 63.33 | 0.0001 |
| Crèche | 4 (7.27) | | |
| Special school | 9 (16.36) | | |
| Nil | 39 (70.91) | | |

| Table 2: Autism spectrum disorders - clinical profile |
|---|
| \(n\) (%) |
| DSM-IV-TR diagnosis | | |
| Autism | 34 (61.82) | | |
| PDD-NOS | 17 (30.91) | | |
| Asperger’s disorder | 3 (5.45) | | |
| Rett’s syndrome | 1 (1.82) | | |
| Total | 55 (100) | | |
| DSM 5 diagnosis | | |
| ASD | 34 (61.82) | | |
| SCD | 11 (20.0) | | |
| ASD | 2 (3.63) | | |
| SCD | 1 (1.82) | | |
| Total | 48 (87.27) | | |
| SCD | 6 (10.91) | | |
| SCD | 1 (1.82) | | |
| Total | 7 (12.73) | | |
| Total | 55 (100) | | |

ASD=Autism spectrum disorder, SCD=Social communication disorder, PDD-NOS=Pervasive developmental disorder not otherwise specified, DSM=Diagnostic and Statistical Manual, DSM-IV-TR=DSM of Mental Disorders 4th Edition, Text Revision

| Table 3: Comorbid mental retardation and intelligence quotient in autism spectrum disorders (n=55) |
|---|
| Intelligence quotient | Number of patients (%) |
| Mild MR (IQ=50-70) | 19 (34.55) |
| Moderate MR (IQ=35-49) | 14 (25.45) |
| Severe MR (IQ=20-34) | 11 (20) |
| Profound MR (IQ<20) | 3 (5.45) |
| Total | 47 (85.45) |

MR=Mental retardation, IQ=Intelligence quotient

About 65% of children with ASDs in our study were below 6 years with about 53% in the age group of 4–6 years. Our results are consistent with other studies.
from India and abroad which have reported the mean age of presentation 3.5–4.5 years. A thorough review on early diagnosis of ASDs revealed that many children with ASDs in the 1st year of their life exhibit some recognizable problems in social interactions. The current knowledge about developmental difficulties among children with ASDs has made it possible to identify the condition very early in their life for a substantial proportion. Despite the growing awareness of ASDs and our ability to identify the signs of ASDs early in life, studies have found that these children do not receive a diagnosis until they have attained a school age. This is further complicated by paucity of trained professionals for the diagnosis of ASDs. In an attempt to develop a screening instrument to screen ASDs on a large scale in North Indian Hindi-speaking population by multipurpose health workers, Arun and Chavan found Chandigarh Autism Screening Instrument to be a valid instrument but suggested to evaluate its usefulness in a larger community study. Although the early diagnosis of ASDs is critical for many reasons, the most important reason is to start early intervention in these children to improve their functioning as these may be more effective with younger children. There is an evidence, suggesting that early interventions enhance long-term prognosis, and as a child gets older, these interventions yield diminishing results. Many studies have found that the functional gains associated with early intervention will result in significant cost savings to both families of children with ASDs and the settings in which they are served. To provide consensus guidelines on evaluation and management of ASDs in children in India, Dalwai et al. recommended that a definitive diagnosis is not necessary for commencing intervention which should begin as early as possible targeting core features of ASDs with intervention being specific, evidence based, structured, and appropriate to the developmental needs of the child. They further recommended that management of these children should be provided through interdisciplinary teams, coordinated by the pediatrician.

About 78.18% in our study were males, and male-to-female ratio was 3.58:1. With regard to gender distribution in ASDs, studies have reported two consistent findings. First, male predominance for ASDs with an approximate sex ratio of four to one across the whole spectrum. Second, on average, females with ASDs identified clinically have lower intelligence than males with ASDs. Since there is an inverse relationship between symptoms of ASDs and IQ, intelligence acts as a potential confounding factor in studies on sex differences in ASDs, emphasizing the need to control for its effects. However, a bias for male predominance could not be ruled out in our study as the studies have found a gender-based differential help-seeking in childhood psychiatric disorders due to the importance given to boys in India.

The family characteristics showed that 52.73% of the families were of nuclear type. A high proportion of nuclear families in this study can be explained by the 2011 census of J and K which showed the occurrence of nuclear families as 73% and extended families as 13.5%. Majority of the patients (63.63%) belonged to rural area which can be explained by the overall rural and urban division of the population in our state of J and K, where the majority of the population still resides in rural areas.

In our study, we found that about 70% of children with ASDs were staying at home and rest were students with only about 5.5% of them in regular schools. As most of these children were in lower age group, it is expected many of these to be staying at home, but a number of ASD cases in a special school or regular school were low. Although international and national organizations are increasingly advocating inclusive education for students with disabilities globally, in many countries including India these children do not even attend schools, let alone a special one. It would be fair to state that most of the children with ASDs continue to be out of school or in inadequately equipped places.

With regard to DSM-IV-TR types of ASDs, about 62% of cases were autism and 31% cases were PDD-NOS. A review article on prevalence of ASDs, including autistic disorder, AS, PDD-NOS, and CDD found that, in comparison to autistic disorder and PDD-NOS, the prevalence for AS was much lower and that the CDD was a rarity as a disorder. The results of this review on epidemiological studies of ASDs are reflected in hospital based studies which have shown autistic disorder and PDD-NOS being diagnosed more frequently and Asperger’s disorder being diagnosed at a much lower rate whereas CDD diagnosed rarely. Almost 87.27% of our individuals who met DSM-IV-TR symptom criteria for ASDs also met the symptom criteria for DSM-V ASDs. A recent study on comparison of DSM-IV PDD and DSM-V ASD found that >90% of children with prior DSM-IV PDD meet DSM-V diagnostic criteria for ASD and SCD. A systematic review on effect of DSM-V criteria on individuals previously diagnosed as ASDs as per DSM-IV-TR concluded that between 50% and 75% of individuals will maintain diagnosis. Similar results were found in another study in which 30% of the ASDs sample did not meet DSM-V symptom criteria. Nearly 12.73% of ASD children with DSM-IV-TR diagnosis (10.91% with PDD-NOS and 1.82% with Asperger’s disorder) met DSM-V symptom criteria for SCD. Similar findings of PDD-NOS and Asperger’s disorder diverging from DSM-IV-TR diagnosis to SCD
have been shown in many studies.\textsuperscript{62-64} The divergence of these cases was mainly because they had relatively low levels of repetitive behaviors. About 85.45\% of our individuals had comorbid ID. A hospital-based study by Kalra et al. found that 95\% of children with ASDs had comorbid ID.\textsuperscript{28} Epidemiological surveys also indicate that approximately 70\% of ASDs have a significant ID.\textsuperscript{65,66} Even though there is a long-lasting belief that the vast majority of individuals with ASDs have a comorbid ID, the reports from recent research show that less than half of the individuals with ASDs have co-occurring ID.\textsuperscript{67,68} Thus, it is of fundamental importance that correct assessment of intellectual abilities in individuals with ASDs should be done so as not to underestimate their IQ which could affect their long-term outcomes and have a negative impact on their opportunities in everyday life.\textsuperscript{69}

\textbf{Conclusion}

About 10.4\% of children and adolescents with psychiatric disorders had ASDs with autistic disorder and PDD-NOS representing >90\% of these cases. Despite the growing global attention for inclusive education to these children, only 3\% of our cases were receiving inclusive education and about 70\% of cases were staying at home. Nearly 87.27\% of cases diagnosed with ASDs as per DSM-IV retained the DSM-V diagnosis of ASDs. Comorbid ID was frequent and seen in 85.45\% of these children.

\textbf{Limitations}

Our study should be viewed with the following limitations in mind: Due to its cross-sectional nature, changes over time cannot be discerned. The sample size was small. Only outpatient children and adolescents with ASDs were included which limit the generalizability of our results. Control group for comparison was not there, and the clinical information collected was little.

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\textbf{Conflicts of interest}

There are no conflicts of interest.

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