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Survey of autism spectrum disorder in Chandigarh, India

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***Background & objectives*: Prevalence of autism spectrum disorder (ASD) has been reportedly on the rise in western literature. However, accurate data from India are not available. The present study was planned to assess the community-based prevalence of ASD in Chandigarh, India.**

***Methods*: This study was a two-stage survey of representative child population of Chandigarh using stratified random sampling technique, covering 8820 children between the ages 1.5 and 10 yr. Proportionate population from urban (82.3%), rural (4.3%) and slum area (13.4%) were included in the study and screened using Chandigarh autism screening instrument (CASI). Thirty two children scored above cut-off, of whom two had shifted to other places before they could be assessed and 30 were assessed in detail. Detailed assessment was done using Autism Diagnostic Interview–Revised and Childhood Autism Rating Scale-2; diagnosis was made according to the Diagnostic and Statistical Manual-5. Nineteen were diagnosed with ASD.**

***Results*: Of the 8451 children screened between the age group of one and a half to 10 yr, 19 (10 boys and 9 girls) were diagnosed as ASD, thus the prevalence of ASD was found to be 2.25 per 1000 (0.69-5.19, 95% confidence interval) children in Chandigarh. No child below the cut-off on the screening instrument was diagnosed as ASD.**

***Interpretation & conclusions*: The results suggest that the prevalence of ASD in Chandigarh was in tandem with other reports from across India and was lower than western countries.**

Key words Autism - autism spectrum disorder - child development disorder - community survey - prevalence - screening

Autism spectrum disorder (ASD) is a disorder that becomes apparent in early childhood and has lifelong consequences. Prevalence estimates are available mostly from developed nations, and the prevalence of ASD has been increasing with each successive report of the Centers for Disease Control and prevention (CDC); the most recent report of the CDC puts a prevalence of ASD as 1:54 children[1]. In the USA or other developed nations, most of the studies are either done from schools or data collected from health registries. In these countries, health registries are maintained meticulously, and school enrolment is better than developing countries, which makes it easier to estimate the prevalence. One of the reasons for increasing prevalence of pervasive developmental disorders (PDD) is increased awareness and better diagnostic abilities of medical professionals and parents.

There are many hurdles in finding the prevalence of PDD in developing nations like India. In India, neither the health registries are maintained nor is health insurance mandatory. Due to the large population, there is poor access to healthcare, especially in remote and rural areas. Hence, even if parents have any concerns

related to their child's development, they are unable to get the required intervention. Moreover, there is poor awareness regarding ASD among health professionals[2]. In a study from Pakistan, poor awareness of early signs of autism among healthcare professionals was reported, which was attributed the delay in diagnosing ASD[3].

Another source of ASD prevalence data is screening of school children, as is done in many other countries[4]. However, the enrolment rate for children with disability is low as per the Ministry of Statistics and Program Implementation; National Sample Survey Organization, Government of India, have reported that only 11 per cent of children with intellectual disability attended school[5]. Many parents prefer keeping a child with special needs at home due to limited special education facilities, lack of awareness, distance from school and pessimism[6]. In most of the regular schools, teachers do not have adequate skills to identify ASD children. In a study from the USA, early childhood pre-service teachers were found to have misconceptions and lacked knowledge about inclusion of ASD[7].

Moreover, the parents are either unable to identify or refuse to acknowledge that their child has a disability. In a study from North Wales, parents reported that they were not able to make sense of their child's behaviour[8]. It may take upto three years after the first visit to health professionals to get the diagnosis of autism[9]. Even when pointed out by teachers or doctors, parents may disregard it.

Further, ASD prevalence reports from developing countries are scarce and possible reasons could be inadequate trained human resources and lack of availability of a short, simple and sensitive low cost screening instrument. Hence, this study was undertaken to find out prevalence of ASD among 1.5-10 yr old children in the community in the city of Chandigarh, India.

Material & Methods

The present study was carried out in Chandigarh, a city in north India by the department of Psychiatry, Government Medical College and Hospital, Chandigarh. Ethical approval was obtained from the Institutional Ethics Committee. Written informed consent was also taken from all the participants at screening stage and assent of children above seven years was taken before conducting the interview.

Study population: Chandigarh is a planned city which was developed after independence of India and is situated in north India. The city is divided into sectors and villages. A few urban slums have also come up over the years. As per the 2011 Census of India, the total population of Chandigarh was 1,055,459 (projected figure 1,080,753 in 2014)[10], with 117,953 (120,680 in 2014) children in the age range of 0-6 yr. By using population proportion to size technique, the study population was selected. Children from 1.5-10 yr of age from the general population were included in the study.

Sample size: Sample size was calculated using OpenEpi[11] for unknown prevalence, with finite population correction. Sample size calculated was 8227, and by taking a two per cent iteration rate in data, we decided to take a sample of 8400.

As per 2011 the census of Chandigarh, 91.3 per cent population resides in urban area, 2.7 per cent in rural area and six per cent in slum areas. Stratified random sampling technique was used to screen similar proportion of sample from urban sectors, rural area and slums area.

Screening instrument: Chandigarh autism screening instrument (CASI) was developed with the objective of screening the general population for ASD by multipurpose health workers. It is a 34-item questionnaire developed in Hindi with dichotomous (Yes/No) responses which can be applied on children 1.5-10 yr of age to assess their behaviour. A score of 10 as cut-off had sensitivity of 89.16 per cent, specificity of 89.13 per cent, positive predictive value (PPV) of 67.89 per cent and negative predictive value of 96.96 per cent[12].

Study design: This was a cross-sectional two-stage study carried out in the city of Chandigarh. All the children living in a defined area were included in the study. Door-to-door survey was carried out for screening the population of Chandigarh for ASD by research workers who were postgraduates in psychology. They were provided training in community survey, how to approach the household and how to engage the population. This was done using role play and modelling. Research workers were asked not to go alone and be in a team to ensure their safety, as some people behaved in a hostile or inappropriate manner. They were also asked to carry their identification cards. Reliability of the research workers was assessed by re-applying CASI in five per cent of the random cases in community by first author during initial two months.

Inclusion criteria were consent given by parents for children in the age group of 1.5-10 yr. There were no exclusion criteria.

Children above cut-off on CASI were evaluated in detail by a psychiatrist and a paediatrician either in hospital or at their respective homes if they were unable to come. These persons were not blind to the status of the children while performing detailed evaluation.

Stage I- Community screening: Data were collected over a period of two years and six months (April, 2015-September, 2017) by research workers. For urban population, the city was stratified into three parts: North, South and Central part, to have equal number from whole of the city, and further four sectors were selected from each part by computer-generated random number table. Five villages and two slums were randomly selected from the list available with the city Municipal Corporation. Every successive house was surveyed starting from a random number, taken from a random number table. From the urban area, it was decided to survey 7500 population from each sector selected for the study. From each identified house, consent was taken. In area where defense personnel were living, an application was given to their office and permission taken. In rural and slum areas, the village *Sarpanch* or colony *Pradhaan* was contacted and was explained the need and methodology to conduct the study.

From each selected house, information about the number of persons living in the house, their gender and age to find out if there were children in the age range of 1.5-10 yr was collected. Though ASD can be diagnosed early, the mean age of diagnosis was reported up to10 yr previously[13]. Hence, the age group of 1.5-10 yr was decided upon for the present study.

In case the house was found locked, the information regarding number of residents, children along with their ages and their availability was collected from their neighbours. Wherever children between ages of 1.5 and 10 yr were present, CASI was filled after taking the consent from either parent or primary caregiver (usually grandmother or aunt). If mothers were unavailable at the time of interview, the visit was rescheduled. After obtaining consent, CASI was administered by research workers. The questions were asked to the parent or primary caregiver pertaining to child's observable behaviour. If the child scored above cut-off *i.e.,*10 on CASI, the child was evaluated in detail either in the hospital or at home in case the child was bedridden or parents showed inability to come to the hospital. In case parents declined the consent during the first visit for completing CASI, parents were contacted again after two weeks. A house was considered as non-participant after three visits over a period of one month.

Stage II- Detail evaluation of screen positive cases: All the CASI-positive children were assessed for features of ASD, and physical examination was carried out. ASD assessment was conducted using Autism Diagnostic Interview–Revised (ADI-R)[14] and Childhood Autism Rating Scale (CARS)-2[15]. Diagnosis was made on the basis of diagnostic criteria of Diagnostic and Statistical Manual (DSM)-5[16]. First author (PA) carried out all the detailed evaluations of screen positive children.

Paediatric assessment was done on a semi-structured proforma by the paediatrician. Details of antenatal, neonatal, developmental history and medical history were noted, and physical examination including stigmata, systemic examination and hearing assessment was carried out. For the subjects who were evaluated at home, health records and previous evaluation by a paediatrician at any hospital were referred to. All the children assessed at home were undergoing treatment in tertiary care hospitals, and adequate health records having all the necessary information were available with the parents. Complete clinical assessment of each child took about 3-3.5 h.

Control group: To find out false-negative cases on the screening instrument, the sample size was calculated. Since variability of data was not known, a confidence level of 99 per cent and a precision of five per cent were used that gave a number of 666. Hence, 672 children below cut-off on CASI were evaluated. The children in the control group were age and sex matched who were taken by using random number table from the same locality from where children above cut-off on CASI were taken. The clinical assessment of controls was done by an independent psychiatrist for symptoms of ASD and making a diagnosis according to the DSM-5. Psychiatrist was given specific training in performing paediatric physical examination for a period of 15 days. Previous health records were checked in addition to physical examination. All the children had adequate health records like immunization details, height, weight, birth and obstetric history. The assessment was done at their respective homes as most of the parents refused to visit the hospital and no incentive was paid for the hospital visit.

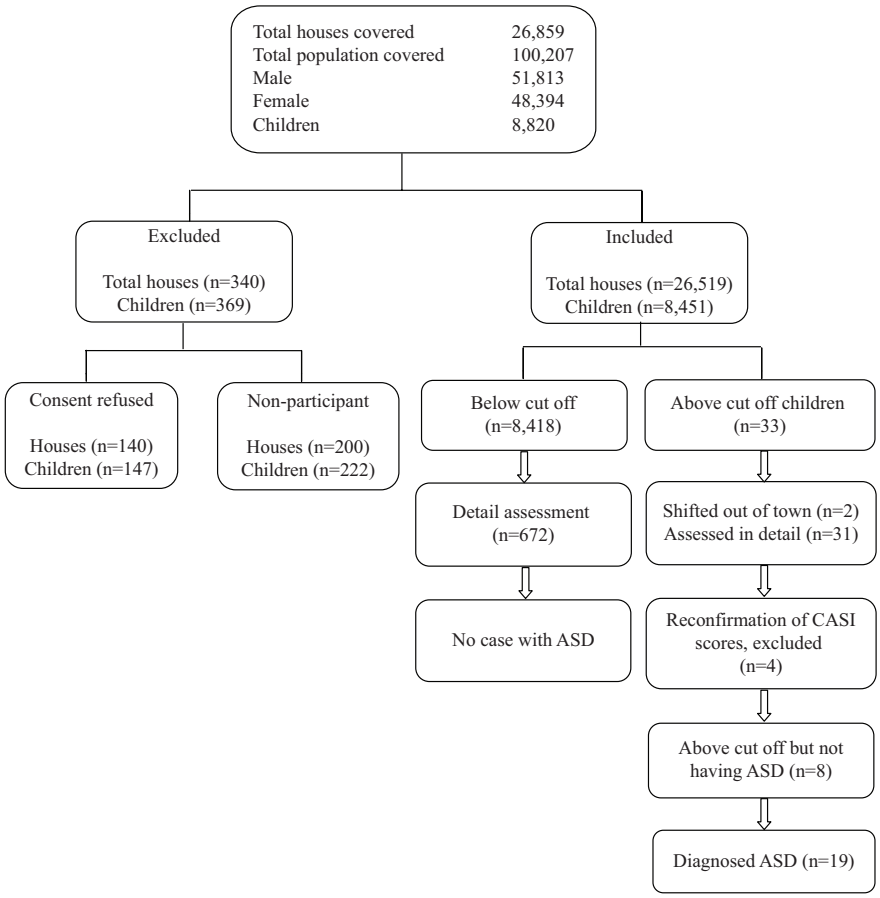

Figure. Flowchart of population covered.

Results

Out of the 26,859 houses which were selected for the study, 26,519 houses were included and the remaining 340 houses were excluded due to refusal to consent (n=140) and drop out (n=200). The study covered 100,207 population, out of which 51,813 were male (urban area: 47,141, rural area: 1426, slum area: 3246), 48,394 were female (urban area: 44,358, rural area: 1285, slum area: 2751) and 8820 were children between 1.5 -10 yr of age -7377 (82.3%) from urban areas, 342 (4.3%) from rural and 1101 (13.4%) were from the slum area (Figure).

Parents of 147 children (all from urban area) refused consent to participate in the study; parents of 222 children (218 from urban area and 4 from slum area) could not be contacted despite making three visits to their house and hence had to be excluded. High non-response rate is known to lead to non-response bias[17], but the non-response rate in the present study was lesser than 20 per cent and hence considered acceptable by most researchers.

A total of 8451 children between the ages 1.5-10 yr were screened using CASI. There were 52.8 per cent (n=4465) boys and 47.2 per cent (3986) girls. There were 82.3 per cent (6958) children from urban area, 4.3 per cent (364) from rural area and 13.4 per cent (1129) from slum area. Informants were only mother for 68.7 per cent (5805), only father for 11 per cent (926), both parents, two per cent (167) and care-givers for 18.4 per cent (1553) children.

A total of 8418 (99.61%) children scored below cut-off on CASI, while 33 (0.39%) children scored above cut-off on CASI (30 children from urban area and 3 children from slum area). Two children had shifted to another city, and 31 were assessed in detail. On reconfirmation of CASI scores by the first author, four children were excluded. Out of these four children, one child each had cerebral palsy and hypothyroidism. Eight children who had scored above cut-off on CASI and did not have ASD had severe neurological disorders. Only one child had mild intellectual disability; the rest had profound intellectual disability. Diagnosis of children was dystonic cerebral palsy, Segawa syndrome, mixed

cerebral palsy with quadriplegia, global developmental delay, corpus callosum agenesis, hydrocephalus with complete visual impairment, Tay-Sach's disease and mild intellectual disability.

Nineteen children were diagnosed with ASD. Detailed assessment was done using CARS-2 and ADI-R and diagnosis was made according to the DSM-5.

There were 10 boys (52.63%) and nine girls (47.36%) diagnosed as ASD. Children diagnosed as ASD were 23 months to 10 yr in age (mean=5.7 yr). All the children were living in urban area. Of the 19 children (Table), five required support and 14 required substantial support. CASI score ranged from 12 to 24 (mean=16.58). Prevalence rate for ASD in boys was 2.24 per 1000 and in girls was 2.26 per 1000; the total prevalence was 2.25 per thousand [95% confidence interval (CI) 0.69-5.19]. Prevalence rate among CASI positive was 57.57 per cent and among CASI negative was zero.

Table. Confirmed cases of autism spectrum disorder

Number of children	Urban
Age group (months)	
18-48	4
48-83	10
84-120	5
Gender	
Boys	10
Girls	9

Discussion

This was a population based study having a sufficient sample size and low non-response rate. In community-based studies, adequate sample size becomes important, more so in a disorder that is not commonly seen in the population. Fombonne[18] found a negative correlation of sample size with prevalence rates, *i.e.*, studies with smaller sample size reporting higher prevalence. In the present study, the prevalence of ASD was found to be 2.25 per 1000 (95% CI 0.69-5.19) or one in 450 children in Chandigarh in the age group of 1.5-10 yr. This prevalence rate is similar to other community-based reports on the prevalence of ASD from India[19-22], and the prevalence of ASD in these studies was reported between 0.05 and 0.36 per cent among children between one and 10 yr of age. These studies have been carried out from North (Himachal Pradesh, Raina *et al*[20]), South (Kerala, Poovathinal *et al*[19]) and East (Kolkata, Rudra *et al*[21]) of India, and one where sample was drawn from each region (Arora *et al*[22]).

Earlier studies from India have used various screening instruments and diagnostic criteria. In the studies by Poovathinal *et al*[19] and Raina *et al*[20], no proper diagnostic methods were used and diagnosis was made clinically by the neurologist in the first study and by a team in the second study. For screening of the population, Poovathinal *et al*[19] used a specifically designed screening instrument to assess developmental milestones and cognitive abilities, and Raina *et al*[20] used Indian Scale for Assessment of Autism (ISAA)[23]. ISAA was not developed for the purpose of diagnosis but for assessment of disability in autism. In both these studies, proper screening instruments and diagnostic methods were not used. In the study by Rudra *et al*[21], screening was done using social and communication disorder checklist and social communication questionnaire. Diagnosis was made using autism diagnostic observation schedule. In the study from Kolkata, the scales used were translated from western scales but were not used in Indian population earlier. In a study by Arora *et al*[22], all the children selected were evaluated in detail for nine neurodevelopmental disorders, and diagnosis was made using specific tools developed for ASD based on DSM IV TR. Moreover, there was considerable variability in prevalence rates from various sites.

In a study from Himachal Pradesh, a prevalence of 0.15 per cent (95% CI 0.15-0.25) was reported[20]. In this study, diagnosis was made on ICD-10 and DSM V TR. Another study from semi-urban community of Kerala which was conducted on the whole population (all ages) reported a prevalence of 0.1 per cent in the whole population, and in children below 10 yr of age, it was 0.36 per cent[19,24]. The diagnosis in this study was based on DSM IV TR; however, no diagnostic scale was used. The third study from India which was conducted on school children in Kolkata reported that prevalence of broad autism phenotype was 0.23 per cent and that of autism was 0.008 per cent[21]. Since the study was done on school children, it was not reflective of true prevalence as many children with disability do not attend schools. In all the previous studies from India, the prevalence rate is not as high as reported in western literature.

The recent CDC study[1] has reported a higher prevalence rate than the previously reported rates[25], but

it has inconsistency in between sites prevalence and the results indicate that the clinician may mention symptoms and not diagnose the child as autistic, but the CDC researcher finds enough criteria to diagnose autism[26]. This indicates that CDC researcher is over diagnosing autism by only counting the number of symptoms met, though autism is a clinical diagnosis. The same authors have also pointed that diagnosis was not made by direct observation in the CDC network that may be responsible for higher prevalence. Christensen *et al*[27] found lower prevalence of 13.4 per 1000 (30% lower) in four-year-olds in four sites out of 11 in ADDM network.

Kim *et al*[28] found a high prevalence of 264 per 10,000 in a general population sample in Korea. This study was done on children in regular school and special schools and two-third of cases were found in regular schools, unidentified and untreated. Similarly, in a study from Toyota City, Japan involving 12,589 children, an 11-fold increase in two decades was seen[29]. In this study, initial screening was done at 18 months, and more high functioning children were included. Prevalence rate of 181/10,000 in Toyota city was reported. Authors reported that the inclusion of high functioning subjects detected during infancy and the integrated process of screening led to higher rate of diagnosis. Baird *et al*[30] screened at risk or undetected cases and found prevalence of 116.1 per 10,000 for autism and other PDDs in South Thames.

In the present study, no child below cut-off on CASI screening (out of 672) was found to have ASD. This indicates that CASI is a sensitive instrument, a property that makes it a good screening instrument.

The study had adequate sample size, used a screening tool with high sensitivity and specificity, the final diagnosis was based on the use of standard diagnostic instrument and clinical interview by an experienced clinician. The study looked at the children below cut-off on screening tool to find out false-negative cases, and the non-response rate was much less. At last, the study used PPS method for sample size and stratified random sample technique to have representative sample from urban, rural and slum areas. Despite above mentioned strengths, the study had certain limitations. Diagnosis of ASD was made by a single clinician and intelligence testing of children below cut-off on screening instrument was not done. CASI negative children were not interviewed using ADI-R, only clinical evaluation was done. Prevalence in boys and girls was almost equal, which is contrary to the existing data. This indicates that some males may have been missed. Despite these limitations, this study adds valuable evidence to the existing body of literature and to the scanty data of prevalence of autism in India.

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***Conflicts of Interest*:** None.

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