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Research Paper

Prevalence of Symptoms of Autism among 2-5 Year-Old Children in Bihar, India

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ABSTRACT

Autism spectrum disorder, a lifelong condition has been characterized with impairments in social life and in communication, both verbal and non-verbal. An early diagnosis for ASD with a reliable and valid tool is both desirable and essential for developing assistant tools and therapies. This paper presents an approach for checking prevalence of severity in symptoms through the Childhood Autism Rating Scale-2 Second Edition. The method used in this study is of descriptive research where the data was already collected and the researchers analysed, studied and interpreted according to the established score measures. The findings showed that 60.6% of the participants were in the mild-moderate autism spectrum range, while 34.6% were in the severe range. It was also found that boys were more prone to have autism than girls. The dominant result was that girls who were showcasing symptoms of autism were most likely to be in the mild-moderate range and in the severe range, while only two participants in the non-autistic range were girls. The study concludes that there can be more variables added to the study including receptive language and expressive language, sensory processing measure and domicile of participants.

Autism spectrum disorder (ASD) is a developmental and neurological disorder that has severe effects on an individual's ability to interact with others, and communicate appropriately. Individuals with autism have difficulties in social interactions and show repetitive and restricted patterns of behavior, interest and activities which may vary in severity across the continuum. They have trouble in linking words with their meanings, do not like changes in an already established routine and will act in unexpected, abnormal ways. They exhibit verbal and nonverbal communication delays and problems. They have poor eye contact, do not respond to name calling, and speak slowly. A diagnosis of autism

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can be made as early as 18-24 months of age because it is during this time that characteristics pertaining to the age start showing, distinguishing typical development from atypical development or delayed development.

An article published in the Times of India highlighted a recent finding that Bihar along with other states that fall on the low Socio Demographic Index (SDI) reported more number of cases related to mental disorders in children and adolescents (Nezami, 2020). Parents of children suffering from neuro-developmental disorders often face stigma from society which becomes internalized and leads to psychological burden. The stigma of diagnosis is one of the most observable of all, where researchers found that much of the stigma is attributed to fear, guilt, blame, denial and shame. There are many tools that are available in the field to make an appropriate diagnosis of autism in a child. These formal assessments are preferred by clinicians and professionals since they are more structured to meet the diagnostic criteria required. Some of these tools include the Childhood Autism Rating Scale (CARS), Indian Scale for the Assessment of Autism (ISAA), Gilliam Autism Rating Scale (GARS) and Modified Checklist for Autism in Toddlers (M-CHAT). Understanding these screening tools give the picture that diagnosis can be different when one uses different tools to find out if their child is in the autism spectrum.

CARS-2 identifies individuals with autism, based on direct observation from clinical psychologists. It differentiates between autism and deficits in cognition, and the second edition of this tool is more responsive to individuals that are in the high-functioning end of the spectrum. The CARS was first published in 1988, in alignment with the DSM III criteria, which has four levels from 1-4 based on observations from clinicians and corresponding information from parents or teacher reports. A total CARS score may range from a low of 15 to a high of 60, which represents the child's placement on a continuum. If a child obtains a lower score, the child is found to exhibit fewer autistic behaviors and if the child obtains a higher score, then they are found to exhibit more autistic behaviors. Ratings in this scale are not just based on frequency of behavior but also on duration, intensity and peculiarity (Bhatia, 2022). This research paper will therefore, focus on the screening tool Childhood Autism Rating Scale- Second Edition to understand the prevalence of severity in autism among 2-5 year old children in the state of Bihar on the basis of the widely accepted use of CARS-2 and its reliability and validity across many studies.

REVIEW OF LITERATURE

In a study titled "Global prevalence of autism: a systematic review update" researchers found that approximately 1 out of 100 children are diagnosed with autism spectrum disorder around the world (Zieden et al., 2022). Adding on to this fact is that there have been consistent findings that suggest that the female to male ratio of prevalence in autism is 1:4. The studies discussing gender differences talk about the gender stereotypes that are absorbed by children with autism through the process of camouflaging, wherein one internalizes gendered social conventions to mask differences. A study investigating the reasons for the 1:4 ratio explains that females might be underdiagnosed due to differing symptom presentation. A lot of the times, males show more of the autistic behaviors that trigger clinical evaluation such as aggression and hyperactivity (Halladay et al, 2015). While there has not been much success in finding out the cause or causes of symptoms, most investigators agree that a fundamental disturbance of the central nervous system is involved. A research led by Narendra K Arora from the INCLEN Trust International found that one in eight Indian children lives with a hearing impairment, speech and language disorder, autism spectrum disorder and intellectual disability (Goecker, 2018).

There has been a lot of discussion on the rising prevalence of autism which suggests that directing more attention towards bringing a change in environmental factors instead of focusing on genetic-environmental factors that are long claimed to aggravate its symptoms is most important. These environmental factors include infectious diseases, certain foods, metals, phenols, plastics, vaccines, smoking and alcohol. An outward manifestation of a child does not indicate their autistic condition. Therefore, a psychological diagnosis is crucial in understanding the severity of the child in the autism spectrum disorder or whether or not the child even has autism. The diagnosis is usually made by a full patient history, physical examination, and neurological assessment.

Children who may have developmental delays might be found using screening techniques. The types of screening tools include those that are specialized to a condition (such as autism) or a domain (such as cognitive development, language, or gross motor abilities), as well as those that are more broad and cover a range of potential problems. An article calls attention to the crucial fact that a person's autism severity does not qualify or exclude them for therapy. However, assessing a patient's severity can assist medical staff understand how their autism symptoms change or worsen under different conditions. Teams can also be able to evaluate the efficacy of therapy through the scores received by the development screening tools (Elemy, 2022).

A study conducted by Coelho et al., (2020) found that CARS was a good predictive value in the development of children falling in the autism spectrum. While focusing on the domains, the researchers stated that the predictive value on imitation and personal relations was most evident. However, the limitations of CARS was seen in its predictive power in earlier development. According to the study, its ability to forecast development in those regions is reduced for early stages, at the time of diagnosis, and more obvious in the later development (Coelho et al., 2020).

Rationale
Many psychological aspects of autism have been studied around the world, however there are very few published studies related to the prevalence of autism in India, with none being from Bihar. Empirical research has shown that more and more children are being diagnosed with autism spectrum disorder but in comparison, there are very few parents equipped with all the knowledge associated with this disorder, to provide their children with the learning environment that these children require.

Therefore, with the significant lack of literature on this field, this study would allow researchers and psychologists to understand and explore the need of appropriate interventions for the range in severity of the symptoms among children with autism.

METHODOLOGY
Aims and Objectives
- To assess severity level of all children coming for detailed and descriptive assessment.
- To understand the prevalence of autistic symptoms and severity in children.

Research Design
The research employed a descriptive research design. The descriptive research was adopted for this study to investigate the severity of the symptoms of autism through scores collected by CARS-2. A descriptive research is defined as a method that discusses the characteristics

of the population or the phenomenon in focus. A quantitative observation allowed the researchers to focus on the values and scores collected through the psychological tests.

Participants

A heterogeneous group of 297 children aged between 2-5 years were selected for this study. The subjects were selected from Mainstream Foundation, a center for autism in Patna, Bihar. Purposive Sampling was employed as the method for determining the subjects of the study as per the inclusion criteria.

Inclusion Criteria
- Age group between 2-5 years
- Belong to any gender orientation
- Have been diagnosed with autism spectrum disorder

Exclusion Criteria
- Diagnosed with other neurological disorders
- Diagnosed with Intellectual disabilities

Research Instruments

Three measures were used in this study.
1. **General Assessment:** The demographic data of the subjects were gathered via a General Assessment Questionnaire for the parents. Through the form, questions for the subjects included details of the child's name, gender, age, nationality, date of birth, names of caregivers, state, district and domicile.
2. **Childhood Autism Rating Scale- Second Edition (CARS 2-ST):** The Childhood Autism Rating Scale is a 15-item rating scale that is empirically validated, objective and concise to help identify children with autism and distinguish them from other developmental disabilities. The clinician uses a 4- point scale to rate the individual and covers different aspects of the child's early development. A diagnostic classification method was developed by Schopler et al. (1995) in which CARS total scores between 15-29 indicate that a person has minimal to no symptoms of autism, whereas scores of 30 or above indicate that a person is "autistic." Scores above 30 are further broken down into "mild to moderate autism" (30 to 36.5) and "severe autism" (37 and higher).
3. **Microsoft Excel:** Excel, spreadsheet application was launched in 1985 by the Microsoft Corporation. It is a spreadsheet system that organizes data in rows and columns that can be manipulated through formulas, thus allowing the software to perform complex calculations on the data (Britannica, 2019).

Materials Required

Scoring Sheet
Pen/ Pencil
Paper

Procedure

The participants were selected via the Purposive Sampling method mentioned above. In order to proceed with the research, initial interactions were done with the parents to establish rapport and trust. After informing them about the study, its implications and the possible results, the parents signed an informed consent form for participation in the study and

allowing the data on their children to be used for the research paper. They were then given a general assessment questionnaire to collect demographic details of the participants.

The psychologist then conducted the CARS-2 assessment, where the parents were asked a number of questions related to the behaviors of their child in order to find out the severity of the symptoms. After the data had been collected, the analysis of the results was done through Microsoft Excel. The researchers then represented this information in tables and charts that helped them to draw personal conclusions.

RESULTS

The participants of the study were 297 children (44 girls and 253 boys). The higher the scores in CARS, the more is the presence of autistic features in the child. The highest and the lowest scores on CARS were 20 and 50 respectively.

Figure 1.
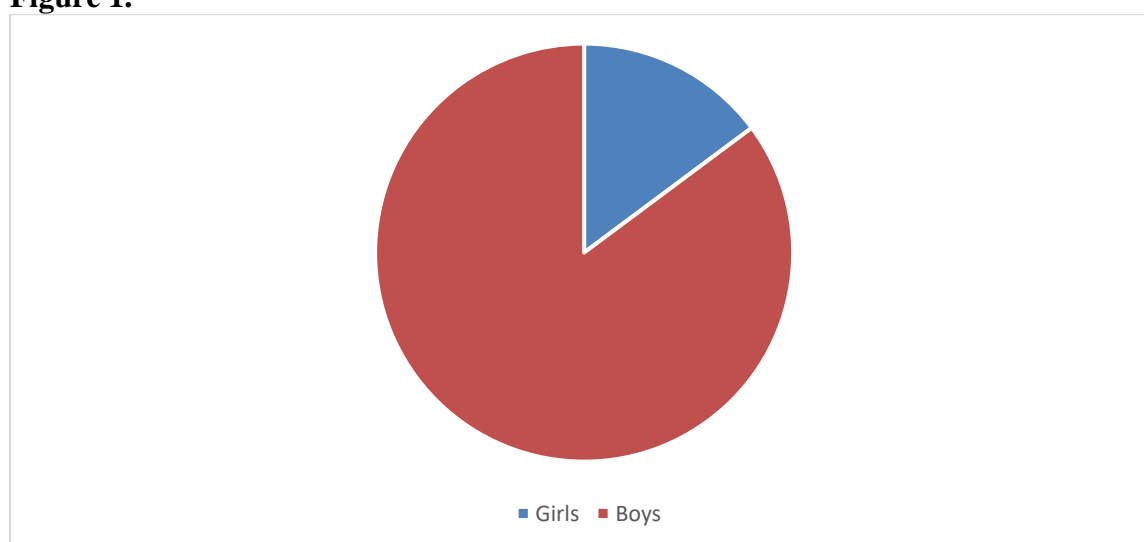
Note: Percentage of boys and girls participating in the study diagnosed with ASD

Table 1 Severity levels of all the participants

CARS-2	Minimal to None (15-29)	Mild-Moderate (30-36.5)	Severe (37 and higher)
Number	14	180	103
Percentage	4.71%	60.60%	34.6%

Table 2 Severity levels of Autism in boys

CARS 2	Minimal to None (15-29)	Mild-Moderate (30-36.5)	Severe (37 and higher)
Number	12	156	85
Percentage	4.04%	52.52%	28.6%

Table 3 Severity levels of Autism in girls

CARS-2 GIRLS	Minimal to None (15-29)	Mild-Moderate (30-36.5)	Severe (37 and higher)
Number	2	24	18
Percentage	0.67%	8.08%	6.06%

DISCUSSION

The purpose of the study was to see the prevalence of the range of symptoms in autism among 297 children in the north-eastern state of Bihar by using the CARS-2 ST. The study was carried out with the greater aim of bringing awareness to this field and to bring about representation of Autism spectrum disorder in smaller cities and villages that do not have access to the best health care services provided in the country. Table 1 highlights the findings that out of the total 297 participants who were administered the CARS-2 test, 4.71 % had scores below 30. This means that 14 children of the total number of participants were in the non-autistic range. 60.60% of the total participants had scores between 30-36.5. These scores indicate that 180 participants had mild-moderate autism. The rest of the participants, i.e., 103 of the 297 participants had scores between 37 and 60. This points to the fact that 34.6% of children fell in the range of severe autism.

Table 2 records the data on the range of symptoms among the boys selected for the study. Out of the 253 boys, majority of them, i.e., 52.52% fell in the range of mild-moderate autism. 85 boys, i.e. 28.6% were severely autistic while only 12 out of the 253 boys showed minimal or no symptoms of autism.

Table 3 notes down the range of symptoms among the girls selected for the study. Out of the 44 girls, only 2 of them, i.e., 0.67% were in the non-autistic range showcasing minimal to no symptoms of autism. 8.08 % of the 44 girls were in the mild-moderate autism spectrum range. Only 18 out of 44 participants i.e., 6.06 % of girls were in the severe autism range.

On interpreting and describing the tables in detail, the researchers found that most of their participants fall in the mild to moderate autism range, with boys having a higher risk to be in the severe autism spectrum than girls with numbers of 85 and 18 respectively. This finding is supported by the Egyptian study conducted by El Baz et al., who found that boys are at a higher risk for autism in comparison to girls (El-Baz et al., 2011). It also highlights an important fact that out of all the girls that came in with symptoms of autism, only 2 out of 44 ended up being in the non-autistic range after the scoring was completed. From this data, we can make the inference that girls are more likely to show more obvious symptoms of autism that are rarely mistaken by their parents.

CONCLUSION

There has definitely been an increase in the number of children being identified as having ASD and this can be attributed to growing media attention and activism, extensive training by doctors and clinicians and increased accessibility of standard screening and diagnostic techniques for detecting ASD. This research study found that most of the children fell in the range of moderate and severe, and a research paper providing support to this fact based on the National Survey of Child Health, stated that after 2008, parents rated 41.7% of the cases in the Autism Spectrum Disorder as moderate or severe. (Press, 2015).

An Egyptian study on the risk factors of autism used CARS to find out the psychometric and clinical aspects of a cohort of 100 autistic children in Egypt. According to their findings, 57% of their cases had severe degree of autism, 28% had moderate degree of autism and 15% were mild cases (El-Baz et al., 2011). Similarly, a study on the risk factors of autism in Saudi Arabia used CARS to showcase severity of autism. In their study, 25% were found to be in the mild range, 41.6% in the moderate range and 33.3% fell in the severe spectrum of autism. These findings are also consistent with this study where the highest percentage of participants fell in the moderate range of severity with a percentage of 60.60%. Recently in

2017, Jack and Pelphrey found that those in the autism spectrum disorder, minimal verbal status and developmental regression have been substantially understudied (Stedman et al, 2018), which makes this paper on severity of autism extremely valuable.

Limitations

The limitation that the researchers found were that since the participants selected for the study were already showing some symptoms and features for autism spectrum disorder, therefore, the data that was collected did not have any children who were not showing autistic symptoms.

Recommendations and Scope

This study will allow the field of psychology and knowledge of neuro-developmental disorders get more awareness in Bihar, where there are still many stereotypes and stigmas attached to child and adolescent mental health and disorders. Understanding the range of autism and percentage of individuals in each of them will enable autism centers, psychologists and therapists to bring about better interventions and activities that will ultimately bring about a change in how they help individuals falling in mild –moderate autism and severe autism separately. The field of studies in autism is extremely vast, pertaining to the huge amount of data circling an autism tsunami in America. Similarly, in India the number of people being diagnosed with autism spectrum disorder are increasing manifold. CARS-2 ST is now become a very acceptable screening tool for diagnosis but this study can also be carried out using ISAA and other reliable screening tools for ASD.

Correlational studies can also be done to compare the severity in CARS-2 scores to the total scores in Sensory Processing Measure (SPM) test, to understand whether mild-moderate autism and severe autism always cause complete dysfunction.

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Conflict of Interest
The author(s) declared no conflict of interest.

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