



Stability and Change in Diagnosis of Autism Spectrum Disorder Over Time Among Toddlers

Selvakumar L^{1*}, Prahbjot Malhi² and Pratibha Singhi²

¹ Assistant Professor, Department of Pediatrics, Saveetha Institute of Medical and Technical Science, Chennai, Tamil Nadu, India

² Professor, Department of Paediatrics, Post Graduate Institute of Medical Education and Research, Sector 12, Chandigarh, India

*Corresponding e-mail: skselvak1@gmail.com

ABSTRACT

Objective: To assess the diagnostic stability of autism spectrum disorder in children less than three years. **Material & Methods:** Twenty children (16 boys, 4 girls) with a diagnosis of autistic disorder and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) at age of 3 years or less as per DSM IV criteria and who had attained an age of 4 to 5 years were recruited from Pediatric Outpatient services. A Multi-disciplinary evaluation was done at diagnosis and follow up assessment was done around 4-5 years of age. Childhood Autism Rating Scale (CARS) used to assess symptom severity. **Results:** At Time 1, at the mean age of 2.4 (SD=4.94) years, 15 (75%) children were diagnosed as autistic and 5 (25%) children with PDD-NOS. At time 2, at the mean age of 3.9 (SD=9.49) years, 16 (80%) children were diagnosed with autism disorder and 2 (10%) children were diagnosed with PDD-NOS, and 2 (10%) children were found to be off the ASD spectrum. Looking at specific ASD diagnosis, the diagnostic stability of an Autistic Disorder was 12/15 (80%) and PDD-NOS was 0/5 (0%). Only 2 children went off the spectrum and 4 children developed the full symptoms at Time 2. **Conclusion:** The present study supports that a reliable diagnosis of autism can be made in children which would stand over time provided that expert clinicians are available. However, continued work is needed for the development of reliable and valid diagnostic tools.

Keywords: Autism spectrum disorders, Stability of diagnosis, Very young children, DSM-IV, Childhood Autism Rating Scale (CARS)

INTRODUCTION

Autism spectrum disorders (ASD) are behavioral developmental disorders which are characterized by impairment in social interaction, disordered communication and restricted and repetitive activities manifested prior to 3 years of age [1]. In most cases, autism has an onset in infancy with a delay in speech and social development, the most typical presenting concern [2]. The Recent surveys suggest that the rate for all forms of PDDs are around 30 per 10,000 but more recent surveys suggest that the estimate might be as high as 60 per 10,000 [3]. While parents typically report concerns in the first year of life, many children do not receive diagnoses until much later. Retrospective studies of home videotapes suggest that deficits are present as early as 3 to 8 months of age in infants who are later diagnosed with autism [4,5].

There has been growing emphasis on early identification and early intervention which is associated with better prognosis, including improved language, adaptive functioning, social relationships and fewer maladaptive behaviors [6,7]. The issue of diagnostic stability in the field of autism spectrum disorders (ASD) has become an increasing focus of research and several studies have demonstrated that early diagnosis of autism made by expert clinicians remain relatively stable 2 to 22 years after initial diagnosis [8-10].

Early and accurate diagnosis of ASD also enables families to learn about their child's developmental challenges, cope with care giving demands, seek appropriate services and obtain genetic counselling [11]. Early detection and diagnosis also means that the delays and the resulting distress that families often face when trying to obtain a diagnosis for their

child, possibly as a result of having to deal with the child's impairments in communication, difficult behaviors, social isolation, difficulties in self-care and lack of understanding are avoided or minimized [12]. Early diagnosis enables professionals to learn about the developmental trajectories of ASD in the early years and to identify predictors of outcome [13]. It may also be cost-effective because late identification means that expensive treatment programs may be needed for secondary behavior problems that could have been prevented or at least treated more effectively and at lower costs during the preschool years [14]. For these and other reasons, the stability of core symptoms of ASD and concomitant behavior problems and syndromes across time has become a topic of considerable interest. Keeping this in view, the aim of the study was to examine the stability and variability in the diagnosis of Autistic Disorder (AD) and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) as per the DSM IV criteria ASD made in children before age 3 years.

MATERIAL AND METHODS

Participants

The subjects in the study included 20 children in whom a diagnosis of autistic disorder and PDD-NOS was made at age 3 years or less. All children were recruited after obtained informed consent from the Outpatient services of the Department of Pediatrics, Post Graduate Institute of Medical Education and Research, Chandigarh. The inclusion criteria for all children were a chronological age of 3 years or less at the time of first assessment, the absence of metabolic or genetic disorders, and absence of sensory or motor impairment and who had attained an age between 4 to 5 years. The detailed description of the sample is presented in Table 1.

Table 1 Baseline data

Characteristic	ASD group (N=20)
Chronological age (Months)	28.75 (4.94)
Residence (% Urban)	95
Family structure (% Nuclear)	65
M: F ratio	03:01
DQ	59.30 (14.62)
Severely retarded (%)	35
CARS	34.64 (3.66)
Severely Autistic (%)	29.4

Childhood Autism Rating Scale (CARS) [15]

The CARS is an observational measure used to assess the symptom severity of autism. It is the most widely used behavioral rating system. It includes 15 item measuring domains such as emotional response, imitation, body use, relating to people, object use, adaption to change, visual response, listening response, fear or nervousness, touch taste and smell response, verbal communication, nonverbal communication, activity level, intellectual response, and general impression.

Each scale is scored on a seven-point Likert scale, ranging from normal to severely abnormal based on observations of the child's behavior. The total score is computed by adding the 15 items (possible range from 15 to 60). Children scoring less than 30 are designated as non-autistic. Scores 30 to 37 are designated as mild to moderate autism whereas children scoring more than 37 are designated as severely autistic. The CARS was score is based on the observation of the child and parental information. Test-retest reliability for CARS (presented in the CARS manual) is 0.88.

Developmental Profile II (DP II) [16]

The DP II is a 186 items inventory which assesses the child's developmental status from birth to 9½ years. It assesses the developmental status in five developmental domains namely physical, social, self-help, academic, and communication. Each sub-scale produces a developmental age that is subtracted from the chronological age. The resulting "months differential" is compared with a cut off that reveals whether children are advanced, normal, borderline or delayed in their development. The academic scale of the DP II can be converted into an IQ score by dividing the academic age by chronological age and the product multiplied by hundred. The DP II has been used by several authors in India to assess the child's developmental functioning. The DP II was used to assess the IQ of the ASD children in this study.

Procedure

All the children enrolled in the study according to the inclusion criteria were evaluated with a detailed clinical history, clinical and neurological examination, visual assessment and auditory evaluation and IQ assessment. An informed consent was obtained prior to enrolment in all cases. Twenty children with a diagnosis of autistic disorder as per the DSM-IV criteria were enrolled over 1 year. These children were evaluated using the CARS and Developmental Profile II (DP-II). Two clinicians with expertise in the field of autism and related developmental disorders arrived at the clinical diagnosis. At Time 2, the children were seen again by the two clinicians and the procedure was similar to that at Time 1. The symptoms severity was measured by CARS. All statistical analysis was performed using the SPSS software for windows platform. Descriptive statistics like Means and Standard deviations were calculated. The extent of agreement between Time 1 diagnosis (before age 3) and time 2 diagnosis (between ages 4 to 5) were compared. Percentages were used to indicate how many of the children retained the same diagnosis and how many had either lost the diagnosis or changed the diagnosis at Time 2.

RESULTS

At Time 1, among the 20 children, 15 were diagnosed with autistic disorder and the remaining 5 children as PDD-NOS. Of the 15 children with an initial diagnosis of autism, 12 (80%) retained the same diagnosis of autism at follow-up. Whereas among the remaining 3 children, 2 received PDD-NOS diagnosis, and one child did not receive autism spectrum diagnosis at follow-up. Of the five children with an initial diagnosis of PDD-NOS, 4 were diagnosed with autistic disorder and one child moved off the spectrum. None of the children with an initial diagnosis of PDD-NOS retained the same diagnosis. Overall, 18 of the 20 children (90%) remained within the autism spectrum from age below 3 years to an age between 4 to 5 years and 2 children moved off the spectrum. Among these 18 children with ASD 16 were autistic and 2 were PDD-NOS. So, the overall diagnostic stability of an ASD diagnosis was 18 out of 20 (90%), the diagnostic stability of an autistic disorder was 12 out of 15 (80%) and the diagnostic stability of a PDD-NOS diagnosis was 0 out of 5 (0%). Only 2 children went off the spectrum, and 2 children developed milder symptoms and 4 children developed the full syndrome at time 2 (Figure 1).

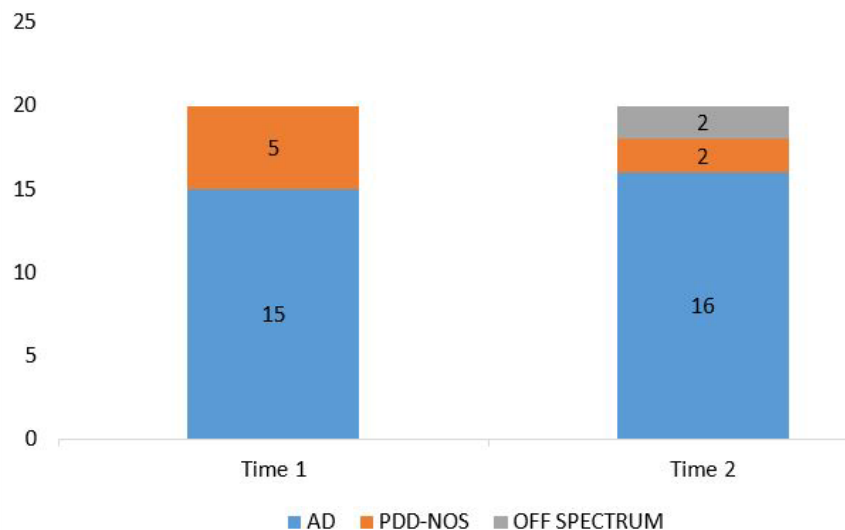


Figure 1 Diagnostic stability between Time 1 and Time 2

At Time 1, 15 (75%) children were diagnosed as having Autistic Disorder (AD) and 5 (25%) children with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). The median age of the children with an ASD diagnosis was 29 months (SD=4.94) at Time 1, and there were 16 boys and 4 girls the youngest child who was diagnosed before age 3 was 20 months old (Table 2).

Table 2 Mean scores on measures at Time 1 and Time 2

Tools	Time-1		Time-2		t	P (2-tailed)
	Mean	S. D	Mean	S. D		
IQ	59.3	14.62	55.17	17.75	1.214	0.24
CARS	34.64	3.66	29.57	7.37	3.331	0.005*

The mean IQ at Time 1 was 59.30 (SD=14.62) and 55.17 (SD=17.75) at Time 2. There were no significant differences ($t=1.2$, ns) between Time 1 and time 2. The mean CARS score of the cases at Time 1 was 34.64 (SD=3.66) and 29.57 (SD=7.37) at Time 2 which is statistically significant ($p=0.005$) between Time 1 and Time 2.

DISCUSSION

Autistic disorder is the most severe form of a spectrum of related disorders. At an estimated prevalence of 1 in 150 [17,18], the ASD is among the most common forms of severe developmental disability. There is increasing demand for diagnostic assessment of very young children. However, unique challenges exist in applying current diagnostic guidelines for ASD to children under the age of 2 and 3 because standard criteria of the DSM IV and ICD-10 are difficult to apply to this age group. The general consensus is that symptoms tend to remain relatively stable over time without the use of effective, evidence-based intervention. Landa, et al. [19] found that the children with autism displayed clear symptoms at 14 months and continued to evince these symptoms at 36 months.

At Time 1 evaluation, 11 children had mild to moderate autistic features and 5 children had severe autistic features. At Time 2 evaluation, children with mild to moderate autistic features had decreased from 11 to 8 and an improvement was noticed in severe autistic features also. Based on the CARS, children with mild to moderate autism had a significantly higher mental age compared to the individuals with severe autism. This finding raises the possibility of a relationship between mental ability and severity of autism by suggesting that individuals with higher mental abilities are perceived or indeed reveal less autistic symptomatology than individuals with lower mental abilities. This improvement can also be attributed to parental education and subsequent early intervention after Time 1 diagnosis as many parents enrolled children for speech therapy and in play schools. The unique challenges of evaluating ASD symptoms in younger children require the diagnostic process to be led by a clinician experienced in developmental disabilities assessment in this age group. Notably, many of the early behaviors associated with ASD overlap with those associated with language delay and intellectual disability [20].

Similar to previous studies [9,13,21-23] this study also suggests that it is possible to make a clinical diagnosis of an autistic spectrum disorder in children aged below 3 years with 90% accuracy. Specific diagnosis of autism was found to be somewhat less reliable but was nonetheless made with 80% accuracy (12 of the 15 children diagnosed with autism at an age below 3 years retained their original diagnosis at time 2 assessment and two children were moved from a diagnosis of autism). Infants and toddlers differ from preschool-aged children in the nature of their social relationships, cognitive and communicative processes, learning characteristics, and daily routines.

It is noteworthy that only 2 children moved off the spectrum, one who was initially diagnosed as autistic disorder and the other with PDD-NOS. Movement off the spectrum may reflect true improvement over time-based on maturation, intervention, or over-diagnosis at age less than 3. Our findings are consistent with those of other studies which have found that clinical diagnosis of autistic spectrum disorders at the age of 2 is reliable and stable [21,22] and those children who remain within the autistic spectrum continue to show significant impairments [23] Also consistent with other studies, a diagnosis of Autistic Disorder was more likely to persist than a diagnosis of PDD-NOS. In our study stability of the PDD-NOS diagnosis was much lower than in previous studies where low stability has been associated either with true PDD-NOS cases being missed at Time 1 or true autism cases being classified initially as PDD-NOS [24,25].

CONCLUSION

The present results provide evidence that the diagnosis of autism in younger children can be made with Indian autistic children with reliability which would be standing over time. However, continued work is needed for the development of reliable and valid diagnostic tools to make more accurate and earlier diagnoses of autism in younger children.

DECLARATIONS

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Author's Contribution

This study done as a part of my MD thesis under the guidance of Dr. Prabhjot Malhi and Dr. Prathiba Singhi.

Conflict of Interest

The authors and planners have disclosed no potential conflicts of interest, financial or otherwise.

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