

Clinical and demographic features of 76 children with autism spectrum disorders at a centre in Pakistan.

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Abstract

Objective: To study the clinical and demographic features of children

Study Design: Descriptive cross-sectional.

Place and Duration of Study: Autism Resource Centre (ARC), Rawalpindi from Jan 2013 to Apr 2018.

Methodology: Seventy six consecutive children with Autism Spectrum Disorder (ASD) were studied for the ages and individuals involved in first recognition, first consultation, diagnosis and referral to ARC. The other study parameters included gender, consanguinity, family history, socio-economic status, and parent's education. The clinical features and severity of ASD was assessed according to the Childhood Autism Rating Scale (CARS).

Results: A total of 76 children with ASD were examined. The median age at first recognition was 29 months, at first consultation it was 30 months, at diagnosis it was 36 months and at referral to ARC it was 42 months. Clinical psychologists, therapists and paediatricians were the most frequently involved people. There was an average delay of one year between the first consultation and referral to ARC. The male to female ratio was 4.4:1. Consanguinity was observed in 33 (43.4%) of the children. Three children had another affected sibling with ASD. Half of the children were from the affluent class while two third of the parents were professionals having good education. The severity of ASD showed that 13 (17%) children had borderline features, 50 (66%) had mild to moderate ASD while 13 (17%) had severe ASD.

Conclusion: Most of the children with ASD were recognized within the first three years of age but there was an average delay of one year before they could reach a specialist care centre. Clinical psychologists, therapists and paediatricians were the most important in recognition of the child's problem. ASD was seen four times more commonly in the males. Majority of the children belonged to the affluent and well educated parents. Most of the children (66%) had mild to moderate ASD.

Key words: Autism spectrum disorders, ages, consanguinity, socio-economic status, severity of disease, Pakistan

Introduction

Autism Spectrum Disorders (ASD) are characterized by failure to communicate, poor social interaction, and repetitive behavior. The symptoms usually appear in the first two to three years of life [1]. The highest prevalence of ASD is reported from the US where 16.9/1000 (1:59) children aged eight years are affected [2]. The disorder is reported at fairly high frequency from all races and ethnic groups [3]. However, no population based data are available from Pakistan but the prevalence is not expected to be different from the rest of the world.

Like many other developing countries autism is a neglected health issue in Pakistan and the level of awareness amongst the health professionals and the public is low [4]. The children with ASD are generally lumped together with the other learning disabilities. There are only a few places in the big cities where specialized care is available [5]. Autism Resource Centre (ARC) Rawalpindi is one such facility that is working since 2011 under the umbrella of Autism Society of Pakistan. It is a non-profit organization that provides services for diagnosis and management of children with ASD [<http://autismpak.com/new/>]. This cross-sectional study on the baseline clinical and demographic profile of children with ASD is the first its kind from Pakistan.

Methodology

This descriptive cross-sectional study of 76 consecutive children with ASD was conducted at the Autism Resource Centre (ARC) Rawalpindi from Jan 2013 to Apr 2018. ARC works under the umbrella of Autism Society of Pakistan (ASP) that is a non-profit non- governmental organization with a National charter to work for children with ASD. ARC is funded through donations by individuals and a few corporate organizations.

ARC Rawalpindi is equipped with facilities for the diagnosis and management of children with ASD. It has three separate branches including Ali Rafay Early Intervention Centre for the very young children, Amin Remedial School for the slow learners who are unable to make to the mainstream schools, and Nadeem Rehab Centre for the older children who were unable to get adequate early intervention. The professional staff of ARC comprises a core group of 30 qualified therapists special educationists, speech and language pathologists, clinical psychologists, occupational therapists and physiotherapists. In addition each child also has its teacher aid.

The study was approved by the Ethical Review Committee of the ASP Board of Directors. An informed consent was also obtained from the parents (usually the mothers) of the children with ASD.

The assessment of the children was made by experienced clinical psychologists using Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-V) criteria [1]. The children with incomplete documentation were excluded. Each mother of the child was interviewed as per the study questionnaire comprising information on the age of the child and the individuals involved in first recognition, consultation, diagnosis, and referral to ARC. The information on gender,

consanguinity, family history, socio-economic status, and parent's education was also recorded. Each child was examined for developmental milestones, eye contact, speech, repetitive movements, behavioral issues, socialization and schooling. History of any medication was also recorded. The severity of ASD was assessed according to the Childhood Autism Rating Scale (CARS) as borderline (Score 15-29.5), mild to moderate (Score 30-36.5) and severe (Score > 37) [6].

The data were analyzed by Microsoft Excel 2013. The frequencies of occurrence with means/medians and the ranges for the study variables were calculated.

Results

A total of 76 children with ASD were studied. This included 49 (64.5%) children from the early intervention centre, 17 (22.4%) from the remedial school, and 10 (13.2%) from the rehab centre. All of the children belonged to the twin cities of Rawalpindi and Islamabad.

Table 1 summarizes the ages and the individuals involved at first recognition, first consultation, diagnosis and referral to ARC. The median age at first recognition was 29 months (range 6-58 months) and mostly the parents were the first to recognize the problem (67%). The median age at first consultation was 30 months (range 6-84 months). Paediatricians and clinical psychologists were the most frequently consulted for the problem. The median age at diagnosis was 36 months (range 17-96 months) and the diagnosis was mostly made by clinical psychologists and paediatricians. The median age at referral to ARC was 42 months (18-168 months). Clinical psychologists and therapists were the most frequently involved people for referring the children to ARC while the paediatricians were the least represented. There was an average delay of one year between the first consultation and referral to ARC.

The results of various demographic features are summarized in Table 2. The male to female ratio was 4.4:1. Consanguinity was observed in 33 (43.4%) children. Three (3.9%) children had another affected sibling with ASD and two out of these three had consanguineous parents. Nearly 50% of the children were from the affluent class and only 8% belonged to the poor socio-economic group. Two thirds of the parents were professionals having good education.

The presenting features are summarized in Table 3. There were 33 children who had never been to a school, 11 (14.5%) had gone to a special school while 32 (42.1%) had dropped out of the mainstream schools. The severity of ASD based on the CARS scoring showed that 13 (17.1%) children had borderline features of ASD, 50 (65.8%) had mild to moderate ASD while 13 (17.1%) had severe ASD (Table 3). There were 22 (28.9%) children on regular antipsychotic drugs, 6 (7.9%) were taking antiepileptics, 6 (7.9%) were taking various other medicines and the remaining 43 (56.6%) were not on any medication.

Discussion

Autism is a neurodevelopmental disorder of children that is typically characterized by failure to communicate and repetitive behaviour [1]. Most of the symptoms of autism stem from these two fundamental defects. Although it is not possible to completely get rid of autism but its symptoms can be managed by behaviour modification therapy to the extent that the child can go to a mainstream school [7]. The therapies for autism give best results when these are started early in life. Therefore recognition of autism at an early stage is of fundamental importance.

ASD is an early-onset disorder. This cross-sectional study of a fairly large number of children with ASD shows that the median age at first recognition (30 months) is not different from what is reported in the literature [8]. In fact these findings are better than those reported from the Middle Eastern countries [9,10]. There was an average delay of one year between diagnosis and referral of the child to ARC. The delay in early intervention can be minimized by creating awareness amongst the health care providers especially the paediatricians [4,11]. This can be achieved through mass media, educational seminars and workshops.

The cause of autism is not well known but the widely held view is that some underlying genetic abnormalities may be triggered by environmental factors [12]. The role of genes, when present, is often precipitated by consanguinity [13]. The frequency of consanguinity in children with ASD in this study (43%) is significantly lower than in the rest of the Pakistani population [14,15]. Studies from the Middle East, where consanguinity is common, also do not show a higher frequency of consanguinity in the children affected by ASD [10,16]. These findings do not support the causative role of any recessive genes in the commonly found ASD in these populations.

Autism is reported to be more frequent in the affluent class of people [17], however, it may be due to the difficulties in accessing diagnostic and therapeutic services by the children from low-income families [18,19]. In this study, in spite of substantial fee subsidy, the representation from the lower-income group remains low while half of the children were from the upper middle or the upper class. Similarly two thirds of the children were born to parents with good education and a profession. The socioeconomic status and parental education of the study children with ASD is significantly better than the Pakistani population at large [20]. A better awareness amongst the educated parents may be a significant factor in over representation by the children with educated parents [21]. A study from Sweden with quality health care services for all also found no excess of ASD among children of high socioeconomic status [22]. It appears that there may be a tendency for the educated families and those with better financial resources to seek a diagnosis of ASD [23,24]. This raises an important issue as to what should be done to identify the undiagnosed and undetected children with ASD from the poor socio-economic and the less well educated segment of the population? There is a need to conduct a population based survey for making an estimate of the children with ASD in all segments of the population. There would also

be a need to develop cost effective service delivery for the underprivileged families having children with ASD.

Pakistan is a developing country of over twenty million population. The awareness about disorders like ASD is on the rise but the limited resources, lack of Government funding, and no health insurance pose a challenge for providing expensive management options. Autism Resource Centre (ARC), Rawalpindi was established on self-help basis. It is providing facilities for the diagnosis and management of ASD under one roof to a large number of children. Over the past few years ARC has evolved as a sustainable model for providing quality services to such children. With adequate funding such model facilities can also be expanded to the other parts of the country.

Conclusion

The recognition of ASD was made fairly early (median age 30 months) but there was an average delay of one year between the first consultation and referral to a specialized centre. Clinical psychologists, therapists and paediatricians were the most important in recognition of the child's problem. The disorder was seen four times more commonly in the males. Consanguinity, though observed in 43% of the study children, was less common than that reported in the rest of the population. Majority of the children belonged to the affluent and well educated parents and there was minimal representation from the less well developed segment of the population. Majority of the children (66%) had mild to moderate ASD.

Table 1. Recognition of 76 children of Autism Spectrum Disorders with reference to the ages and the individuals involved.

	1st	%	1st	%	Diagnosis	%	Referral to	%
	Recognition		Consultation				ARC	
Age (months)	29 (6-58)		30 (6-84)		36 (17-96)		42 (18-168)	
Self	51	67.1					3	3.9
Peers	3	3.9						
GP			9	11.8				
Psychiatrist			6	7.9	11	14.5	3	3.9
Clinical Psychologist			15	19.7	31	40.8	13	17.1
Paediatrician			27	35.5	14	18.4	3	3.9
Therapist			11	14.5	13	17.1	16	21.1
Others	22	28.9	8	10.5	7	9.2	38	50.0
Total	76	100.0	76	100.0	76	100.0	76	100.0

Table 2. Demographic features of 76 children with Autism Spectrum Disorders and their parents at the time of admission to ARC Rawalpindi.

<i>Features</i>	<i>Category</i>	<i>Number (n=76)</i>	<i>%</i>
<i>Gender</i>	Male	62	81.6
	Female	14	18.4
<i>Consanguinity</i>	1 st Cousins	26	34.2
	Relatives	7	9.2
	Biradri (Clan)	5	6.6
	Unrelated	38	50.0
<i>Family History</i>	None	73	96.1
	Yes	3	3.9
<i>Socioeconomic Status</i>	Poor	6	7.9
	Lower Middle	15	19.7
	Middle	18	23.7
	Upper Middle	27	35.5
	Upper	10	13.2
<i>Mother's Education</i>	None	2	2.6
	Matric (O levels)	6	7.9
	Intermediate (A levels)	6	7.9
	Bachelor	16	21.1
	Professional	46	60.5
<i>Father's Education</i>	None	1	1.3
	Matric (O levels)	4	5.3
	Intermediate (A levels)	2	2.6
	Bachelor	10	13.2
	Professional	59	77.6

Table 3. Clinical features of 76 children with Autism Spectrum Disorders at the time of admission to ARC Rawalpindi.

<i>Features</i>	<i>Category</i>	<i>Number (n=76)</i>	<i>%</i>
<i>Developmental Milestones</i>	Delayed	37	48.7
	Normal	39	51.3
<i>Eye Contact</i>	Good	36	47.4
	Poor	24	31.6
	None	16	21.0
<i>Speech</i>	Good	16	21.1
	Poor	35	46.0
	None	25	32.9
<i>Repetitive Movements</i>	None	10	13.2
	Occasional	16	21.1
	Frequent	50	65.8
<i>Behavioral Issues</i>	None	1	1.3
	Occasional	20	26.3
	Frequent	55	72.4
<i>Socialization</i>	None	32	42.1
	Occasional	35	46.1
	Frequent	9	11.8
<i>Schooling</i>	None	33	43.4
	Special School	11	14.5
	Mainstream drop out	32	42.1
<i>Severity of ASD</i>	Borderline (CARS 15-29.5)	13	17.1
	Mild to Moderate (CARS 30-36.5)	50	65.8
	Severe (CARS >37)	13	17.1

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