ORIGINAL ARTICLE

Clinical characteristics and demographic profile of children with Autism Spectrum Disorder (ASD) at child development clinic (CDC), Penang Hospital, Malaysia

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ABSTRACT

Objective: To explore socio-demographics and clinical characteristics of children with Autism Spectrum Disorder (ASD) at Child Development Clinic (CDC), Penang Hospital.

Study design: A record review study of 331 children with ASD attending CDC, Penang Hospital from September 2013 to April 2017.

Results: Out of 331 children with ASD, 82.5% were males, 17.5% females, with male to female ratio of 4.7:1. Mean age at consultation was 5 years and 6 months (SD 31.68 months) with age range from 19 months to 18 years and 4 months. 85.8% were term infants with normal birth weight. History of speech regression was noted in 14.8%, epilepsy and genetic disorders in 9.4% and 5.7% respectively. Sleep problems was reported in 29.3%, dietary issues 22.1%, challenging behaviour 24.2% and ADHD 14.2%. Mean age of the father and mother at birth was 33.6 and 31.6 years respectively.

Conclusion: In this study, we report a higher male to female ratio and mean age at referral with some similar rates of neurodevelopmental and medical comorbidities and relatively younger parental age with higher parental education levels.

KEY WORDS:
Children, Autism Spectrum Disorder, Clinical characteristics

INTRODUCTION

Based on the American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-5), diagnostic criteria for Autism spectrum disorders (ASD) include persistent deficits in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behaviour, interests or activities.[1]

Prevalence rate for ASD is increasing over the years. Early estimates of prevalence of ASD range widely from 0.7 per 10000 to 72.6 per 10000 with a median estimate of 13 per 10000 children.[2] The Centre for Disease Control and Prevention released new data on the prevalence of ASD in the United States in March 2014[3] in which, 1 in 68 children, 1 in 42 boys and 1 in 189 girls were identified as having ASD. There is no local epidemiological study on ASD prevalence is available in Malaysia.[4] However, based on a feasibility study on the use of Modified Checklist for Autism in Toddlers (M-CHAT) among children of 18 to 36 months of age in child health clinics by Ministry of Health Malaysia in 2006, the prevalence of ASD in Malaysia was reported to be approximately 1.6 in 1000.[4]

Prevalence data on ASD in Malaysia is essential to form the basis on planning and establishing intervention and education options for children with ASD. With the increasing numbers of children diagnosed with ASD each year, there is a growing need for trained clinicians, early intervention centres and schools in addition to occupational, speech therapists and clinical psychologists. Many recent studies underline the importance of early identification and of tailoring individual intervention programs to improve outcomes in ASD.[5]

This study aimed to explore the socio-demographics and clinical characteristics of children with ASD at child development clinic (CDC), Penang Hospital. It is a pilot study involving children with ASD who were referred to a regional CDC.

MATERIALS AND METHODS

Study design and setting

This is a record review study done at CDC, Penang Hospital from September 2013 until April 2017. The CDC at the Paediatric Department in Penang Hospital was established in September 2013 and serves as the only tertiary referral centre for children with developmental disabilities for the northern region of Malaysia providing comprehensive assessments using standardised, specific assessment tools. Referrals were from paediatricians from government and private hospitals and family medicine specialists from health clinics in Penang, Kedah, Perlis and northern Perak.

Participants

A total of 331 children were diagnosed to have ASD at CDC, Penang Hospital during the study period and all of them were included in the study. Their ages ranged from 1 year up to 18 years. All children with the diagnosis of ASD were included in this study; children without diagnosis of ASD were excluded from study. All patients were reviewed by a Developmental Paediatrician. Diagnosis of ASD is based on Diagnostic and Statistical Manual of Mental Disorder 5th edition (DSM 5) classification.

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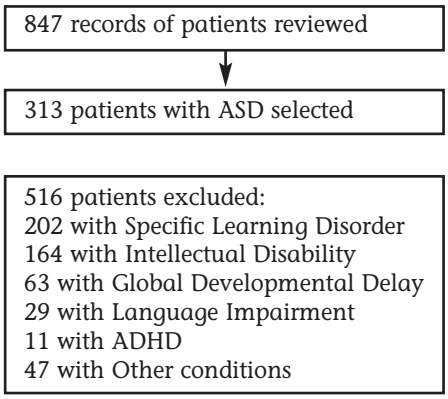
Study instrument and procedure
Data collection was done on a self-constructed data form which includes details of birth; namely gestation and birth weight, family history of neurodevelopmental disorders and other medical or neurodevelopmental diagnosis. Parent details including parental age at conception and education level were also included.

A total of 847 records of all patients seen were reviewed; 313 children had diagnosis of ASD and all these children were included in the study.



Ethics statement
Consent was not taken from any patient as all data was obtained from the medical records of patients. Patient confidentiality and anonymity was maintained as no private details were included in data form. Each patient data was numbered from 1 to 331. Ethics approval was obtained from the Malaysian Medical Research and Ethics Committee (NMRR-16-1084-31391-IIR).

Data analyses
Descriptive analysis was conducted for all variables using Microsoft Excel. Continuous variables were presented as mean and SD while frequency and relative frequencies were listed for categorical variables.

RESULTS

Demographic profiles of children with ASD
Table I shows the demographic profiles of these children. Of the total of 331 patients, 273 (82.5%) were male sand 58 (17.5%) were females. Male to female ratio was 4.7:1. The mean age at first visit to CDC was 5 years and 6 months (Standard Deviation (SD): 31.68 months) with ages at presentation ranging from 19 months to 18 years and 4 months.

Chinese patients formed the largest majority at 151, making a total of 45.6%, followed by Malay patients at 134 (40.5%) and Indian patients at 46 (13.9%). The services in our centre were mainly utilised by children from the Penang Island, total number of 189 or 57.1%. The remaining 21.5% were from the mainland of Penang, 19.3% from Kedah while 1.2% and 0.9% came from Perak and Perlis respectively.

Clinical characteristics of children with ASD
Table II outlines the clinical characteristics of children with ASD seen at CDC. A large majority of patients (85.8%) were term infants and most had normal range of birth weight. Among patients who were preterm, late preterm infants formed a bigger number as compared to moderate and very preterm in this cohort. History of speech regression was noted in 14.8% while epilepsy and confirmed genetic disorders were found in 9.4% and 5.7% respectively. Approximately fifteen percentage of the cohort had other medical diagnoses which include common childhood conditions like bronchial asthma and eczema, congenital heart disease like ventricular and atrial septal defect, congenital upper airway malformations and gastro-oesophageal conditions requiring surgery among others. As the numbers of each condition were small with less likelihood of being directly related to ASD, they have been grouped together under 'Others'. Sleep problems reported by parents, which include sleep onset difficulties and frequent night waking were seen in 97 children (29.3%) while dietary issues which included dietary restrictions and food rigidity was seen in 73 children (22.1%). Twenty-four point two percentages were reported to have challenging behaviour while 14.2% also had a diagnosis of ADHD. Most of the referrals to CDC, Penang Hospital were from other paediatric general/subspecialty clinics in the hospital (52.2%), other specialty clinics in the hospital (10.3%) followed by general paediatric clinics from other government hospitals in the northern region (21.3%).

Parental characteristics
The mean age of fathers and mothers during conception was 33.6 years (S.D = 5.09 years) and 31.6 years (S.D =4.99 years) respectively. Majority of both parents were within age range of 31-35 years (47.1%).The number of fathers and mothers aged between 36-40 years were 78 (23.6%) and 49(14.8%), ages 41-45 years were 27 (8.2%) and 15 (4.5%) and ages 46-50 years were 5(1.5%) and 1(0.3%). Majority of the parents (38.7% of fathers and 41.1% of mothers) are degree holders with many holding Master's degree. 27.8% of fathers and 25.7% of mothers are diplomas or certificates holders, while 29% of fathers and 31.7% of mothers had completed secondary education. 3.6% of fathers and 1.2% of mothers had completed primary education. There was no data available on the educational status of three fathers and one mother.

DISCUSSION

This study included 331 children with ASD diagnosed at a tertiary care centre within a 3 ½ year period and involved almost 40% of total referrals. To our knowledge there are no other publications reviewing the prevalence or clinical characteristics of children with ASD in a Child Development Clinic or general paediatric clinic in Malaysia at the time of this study.

Male to female ratio in our study was 4.7:1 which is a little higher than the commonly cited male to female ratio of 4:1. In a meta-analysis of prevalence studies conducted since the introduction of the DSM-IV and the ICD-10 by Loomes et al., the true male-to-female ratio in children with ASD is found to be closer to 3:19.[7]

Table I: Socio demographic characteristics of children with ASD at CDC, Penang Hospital

Characteristics	No. of patients n = 331	Percentage (%)
Gender		
Male	273	82.5
Female	58	17.5
Age at diagnosis		
< 2 years	3	0.9
2 - 3 years 11/12	102	30.8
4 - 6 years 11/12	139	42.0
7 - 11 years 11/12	79	23.9
> 12 years	8	2.4
Race		
Malay	134	40.5
Chinese	151	45.6
Indian	46	13.9
Origin (State)		
Penang : Island	189	57.1
Penang : Mainland	71	21.5
Kedah	64	19.3
Perak	4	1.2
Perlis	3	0.9

Table II: Clinical characteristics of children with ASD at CDC, Penang Hospital

Characteristics	No. of patients (%) n = 331
Term	
Total	284 (85.8)
Low birth weight (< 2.5kg)	14
Normal birth weight (2.5kg – 4kg)	251
High birth weight (> 4kg)	6
Weight unknown	13
Preterm	
Total	45 (13.6)
Very preterm (<32 weeks)	9
Moderate preterm (32-34 weeks)	9
Late preterm (34-37 weeks)	25
Preterm but unknown gestation	2
Unknown (term or preterm)	2
History of speech regression	49 (14.8)
Epilepsy	31 (9.4)
Sleep problems	97 (29.3)
Dietary problems	73 (22.1)
Challenging behaviour	80 (24.2)
ADHD	47 (14.2)
Genetic disorders	
Confirmed	19 (5.7)
Suspected	3
Other medical disorders	50 (15.1)

In this study the mean age was higher than that reported by few other studies but close to reported mean of 5.92 years by J.V.S. Kommu et al. in a study reviewing clinical characteristics of 200 children with ASD in a tertiary child psychiatry clinic in India.[8] The mean age at presentation in our cohort may not correlate well with age at which parents had significant concerns regarding the development of their children. Some parents sought diagnosis and treatment later hoping that their children will improve with time, while some children in this cohort have been diagnosed with ASD by child psychiatrists or paediatricians prior to presentation to our clinic. This information has not been recorded in our review. Age at first diagnosis is important as research has shown that early recognition and initiation of early intervention results in optimal outcome.[9] Majority of the children in our cohort were seen between 3 years to 3 years and 11 months (21.5%).This is similar to findings in J.V.S. Kommu et al (2017).There is a need to look into the severity of ASD and age at diagnosis in further studies in this cohort as it has been shown that children with less severe ASD symptoms and higher functioning abilities are diagnosed at later ages.[10]

Recent research has identified the importance of comorbidity research in ASD in diagnosis and management.[11,12,13] Mannion et al., examined the frequency of current comorbid diagnosis, comorbid psychopathology, sleep problems and gastrointestinal symptoms in children and adolescents with ASD.[14] In their study, 46.1% of children and adolescents with ASD had a comorbid psychological or medical diagnosis while 10.1% of them had epilepsy. In our study, other psychological comorbidities like Obsessive Compulsive Disorder and anxiety disorders were not studied as these conditions are generally managed by child psychiatrists. Frequency of comorbid ADHD was 14.2% while medical disorders were 15.1% which makes a total of 29.3%, a little lower than the findings in Mannion's study. However, 9.4% of children in our cohort had epilepsy, which is almost similar to what was found in the previous study. There have been reports of new cases of epilepsy appearing in the post-adolescent period. period. Billstedt et al., found that none of their patients developed epilepsy after the age of 20 years.[15] In our study, all children with epilepsy were diagnosed and treated prior to review at CDC and there were no new cases of epilepsy in previously well children with ASD. Only 5.7% of children with ASD in our cohort had a confirmed genetic disorder which is slightly less than the number quoted in other papers. In a review by Duchan and Patel, it was found that only 10% of ASD can be directly attributed to an underlying genetic condition and single-gene defects are rare within the broader autism phenotype.[16] They conclude that it is more likely that a unique set of genetic polymorphisms may determine the susceptibility of an individual to ASD.

In another study reviewing children and adolescents with ASD, it was found that sleep problems persist throughout age and span from early childhood through adolescence. Sleep problems reported in this study include difficulties in falling asleep, getting enough sleep on a regular basis and daytime sleepiness.[17] Mannion et al., found that 80.9% of participants presented with sleep problems. Prevalence of sleep problems among children with ASD are reported to be 50 to 80% as compared to typically developing children whose reported prevalence ranges from 30 to 50% (18). In our study, only 29.3% were reported to have sleep problems during clinical review at presentation to CDC. This is likely due to under reporting and could be contributed by limited awareness and knowledge by parents and caregivers regarding sleep health. In another study done in CDC Penang Hospital, where 124 children with ASD aged between 4 to 12 years old were recruited and parents were interviewed on Children's Sleep Habits Questionnaire (CSHQ), results showed higher prevalence of sleep difficulties at 63.7% (unpublished data)

Among the risk factors for ASD that are frequently studied, are maternal and paternal ages at delivery. In our cohort, the majority of parents were between ages 31-35 years with only 9.7% of fathers and 5.5% of mothers aged 41 and above. It is known that the maternal age at the time of conception and delivery may be associated with an increased risk for the child developing ASD.[16] A retrospective study of all singleton children born at Kaiser Permanente in California over a 4-year period showed that the risk of a child having ASD increased significantly with each 10-year increase in maternal age and paternal age.[19] The parents in our sample were mostly degree or diploma/certificate holders with less than 4% who have only completed primary education. Higher parental education can contribute to increased awareness leading to early referral and intervention. The association between parental age and education and age at referral is another area which could be reviewed in future studies.

Another risk factor that has been identified is low birth weight and/or low gestational age. In our cohort, only 45 (13.6%) were preterm, of which the majority were late preterm while only 14 (4.2%) had low birth weight. The risks of having ASD are greater for infants born preterm (birth before 37 gestational weeks) or with low birth weight (less than 2500g). It is likely that these children may have other medical conditions that also predisposes them to ASD.[20, 21]

This study had some limitations which could be addressed in future studies. This sample was obtained from one tertiary centre reviewed by a single developmental paediatrician, with no control group, making generalisation of the results inaccurate. Management and intervention was not addressed in this study. All children with ASD at this centre were referred to occupational and speech therapy services in the nearest government hospital and appropriate school placement and targeted intervention were discussed and planned with parents. Some parents opted for intervention at private centres while many attended early intervention programmes by non-governmental organizations locally. Information in this area will be useful in planning resources for intervention in the future. Other additional data which may confer benefit in future studies would include details on age at first parental concern and diagnosis made and follow up of this cohort till secondary school years.

CONCLUSION

Diagnosis of ASD in children affects patients, family and the community at large. Knowledge of ASD is crucial for health professionals as its prevalence is increasing globally. This paper is a pilot study reviewing clinical characteristics of a cohort of children with ASD managed in a tertiary centre. It is hoped that this study can contribute data to encourage a large scale national registry and resource allocation with programme planning in the future.

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Compliance with Ethical Standards: Ethics approval obtained from Malaysian Medical Research and Ethics Committee. (NMRR ID: 31391). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Consent was not taken from any patient as all data was obtained from medical records of patients and private details were not included. Each data collection sheet was numbered from 1 to 331, with no names or identity card included.

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