Factors affecting age at presentation of Autism Spectrum Disorders: A descriptive survey from a child mental health clinic at Lady Ridgeway Hospital

DMA Dahanayake, YM Rohanachandra, GS Wijetunge

Background
Early diagnosis of autism is important since Early Intensive Behavioural Interventions improves outcome. Age at presentation to child psychiatry services in Sri Lanka and the factors determining it have not been established. These would be useful in planning service provision. The objective of this study was to assess the patterns and factors affecting age at presentation of children with autism to a child mental health clinic at Lady Ridgeway Hospital.

Method
All patients diagnosed as having autism registered at a child mental health clinic at Lady Ridgeway Hospital from January to December 2013 were included. Data was collected retrospectively from clinic records.

Results
Half of the participants had presented at the age of 3 years or less. Speech delay was the commonest presenting complaint (58.5%). Age at presentation showed a significant association with the nature of the presenting symptoms, with children who had speech delay presenting at an earlier age (p=0.02). There was no significant association between age at presentation and gender of the child, parental education level, income or whether the child was living with extended family.

Conclusion
Speech delay is the commonest reason for children with autism to be brought to health services, and it may prompt early presentation. Education about other symptoms may further help to ensure early presentation.

Key words: autism, speech delay, age at presentation

Introduction
Autism was first described by Kanner in 1943. His original description of symptoms in 11 children included inability to relate to others, speech difficulties and unusual, repetitive activities (1). In order to make a diagnosis, the ICD-10 Classification of Mental and Behavioural disorders require the presence of abnormalities in all of the following three areas, namely social interactions, communication, and restricted, repetitive behaviours (2), which is in keeping with the pattern originally described by Kanner.

It is now understood that autism is a neuro-developmental disorder with neuroanatomical and neuroimaging studies revealing abnormalities in several brain areas (3). Studies have shown focal disruption of cortical laminar architecture in children with autism, suggesting that brain irregularities in autism may have prenatal origins (4).

It is estimated that the prevalence of autism in the United States of America is 1 in 68 children (5). A study done in a semi-urban setting in Sri Lanka revealed a prevalence of 1.07% or 1 in 93 children (6). The burden of disease of autism has been shown to be significant with effects on both the affected individuals and their families (7).

Autism has no known prevention or cure at present. Behavioural therapies are the mainstay of treatment, with Early Intensive Behavioural Intervention (EIBI) being one of the more well-established therapies. Research suggests EIBI has promise in the modification of core symptoms of autism (8). Early intervention is important since this facilitates neuroplasticity, with resultant improvement in symptoms and level of functioning (9). This is likely to improve the quality of life and reduce the burden of disease. Thus, early detection of autism is of paramount importance. But, despite studies indicating that behaviours predictive of autism can be seen in children as young as 12 months (10), most children are not diagnosed until after three years of age (11). The most common presentation is with speech delay (12). In Sri Lanka too, speech delay is reported as the most common reason for presentation of children with autism to child mental health services (13). There appears to be a low degree of awareness about other manifestations of autism, which might cause delay in presentation to services (13).

The age at diagnosis of autism has been shown to be associated with several factors. These include education and health system resources (14,15), ethnicity (16), income, symptoms such as severe language deficits, hand
flapping, toe walking, and sustained odd play (17) and the sex of the child (18). However, in contrast to international findings, research from Sri Lanka to date has not reported any association between the age at presentation and factors such as the presenting symptoms and parental level of education or occupation. In addition, the role of other associated factors such as the sex of the child, family income and whether the child was living with nuclear or extended family, has not been explored in the Sri Lankan population. The elucidation of factors associated with age at presentation to medical care in Sri Lanka is important in terms of developing services and also for designing public awareness campaigns, screening guidelines and professional education programs. Presentation at a younger age would hasten early diagnosis and thereby offer the affected individuals earlier access to behavioural interventions.

Methods

This is a retrospective study, based on clinic records of all children who presented to a child mental health clinic at Lady Ridgeway Hospital for Children during the year 2013. The records of all children who presented to this clinic during the year 2013, who were diagnosed to be suffering from autism, were included in the study. Each child had been interviewed by a consultant psychiatrist, and the diagnosis was made based on the criteria of the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM IV) (19). Data for the study was collected retrospectively, using a specifically designed data extraction form. Outcomes of interest included information on age at presentation, gender, presenting symptoms, level of education of parents, monthly family income and whether the child was living with the extended family or not.

Data was analysed using SPSS 19th version statistical software package. Associations between age at presentation and individual presenting symptoms, parental education level, parent’s occupation, living circumstances and gender of the child was assessed using chi square statistics.

Ethical approval was obtained from the ethical review committee at Lady Ridgeway Hospital for Children, Colombo.

Results

Demographic details

Records of 137 children who had presented to the clinic in 2013, were examined. A majority (83.9%, n=115) were males, and 50% (n=69) had been brought to the clinic by their parents/guardians at the age of 3 years or less. The age of presentation to this clinic ranged from 1 to 12 years (Figure 1).

With regards to residence, 58.9% (n=80) of participants were residing with their nuclear families, while 39.3% (n=54) lived with extended families including grandparents and/or aunts, uncles, cousins and stepsiblings. Data regarding parental education was available for 75.9% (n=104) children. Of these, only one mother has not had any formal education and 45.2% (n=47) had been educated up to or less than grade 10. Thirty eight point five percent (n=40) of mothers had done G.C.E. (Advanced Level) examination and 14.4%
Factors affecting age at presentation of Autism Spectrum Disorders

(n=15) had completed higher education (degrees/diplomas). Fifty four point eight percent (n=57) of the fathers had been educated up to or less than grade 10, with 26% (n=27) and 18.3% (n=19) having done G.C.E. (Advanced Level) examination and having had higher education, respectively.

The monthly family income was mentioned in the clinic records of 72.9% (n=100) of the patients. Of these families, 28% (n=28) had a monthly income exceeding Rs. 50,000 with 36% (n=36) having an income between Rs. 20,000 to Rs. 50,000. Twenty nine percent (n=29) had an income between Rs. 10,000 to Rs. 20,000 whereas 7% (n=7) of the families had an income less than Rs. 10,000 per month.

Presenting symptoms

Speech delay was the commonest reason that these children were brought to the child mental health clinic, accounting for 58.5% (n=80) of the presentations (Figure 2). Up to 26.5% (n=36) had exhibited behavioural problems at home and/or at school. Only 4.2% (n=6) presented with abnormalities in social interactions, while restricted and repetitive behaviours accounted for 3.1% (n=4) of the main complaints.

Factors associated with age at presentation

There was a significant association between age at presentation and the nature of the presenting symptoms. Children with speech delay presented at a significantly earlier age (p=0.02), compared to children presenting with other symptoms.

There were no significant associations between the sex of the child, parental education level, monthly family income and age at presentation to the clinic. Age at presentation was also not significantly associated with whether the child was living with his/her extended family or not.

Discussion

Age at presentation of autism to mental health services

Among this sample, 50% of children first presented to the clinic at the age three years or younger. In a previous Sri Lankan study, 48.4% of participants had contact with mental health services by the age of 3 years (13), which is comparable with our findings. International findings are similar – a study in Pennsylvania reported a mean age at diagnosis of 3.1 years (18).

Gender

Our sample consisted of 83.9% male patients, with a male to female ratio of around 5:1, which is higher than the expected ratio of 3:1 to 4:1 (21). This could reflect a true incidence of higher prevalence, or maybe due to confounding factors such as cultural norms, which may determine the likelihood of parents bringing male or female offspring to mental health services.

Presenting symptoms

Speech delay was the commonest reason for presentation
of children with autism spectrum disorder to mental health services, in this study. Another study from Sri Lanka reported similar results – speech delay was the commonest concern expressed by parents (82.4%) (13). Speech regression accounted for 6.3% of presentations, similar to previous Sri Lankan findings (13).

Although abnormalities in social interactions and restricted and repetitive behaviours account for the remaining core symptoms of autism, these did not figure prominently as presenting complaints in our study. Only 4.2% presented with abnormalities of social interactions and 3.1% were brought to mental health services due to restricted and repetitive behaviours. Lack of knowledge and limited importance assigned to social interactions in children may have influenced our findings (13). Further, differences among ethnicities in interpreting abnormalities in social interactions may influence time of presentation, and this may have contributed to our findings (22).

Factors affecting age at presentation

There was a significant association between the age at presentation and speech delay, compared to other presenting complaints. Children with speech were significantly more likely to present to services at an earlier age. This is similar to international findings, which reports that children with severe language impairment receive a diagnosis of autism an average of 1.2 years earlier than those without such symptoms (17). However, a previous Sri Lankan study did not find any such significant association (13).

Although our study did not find any significant difference between gender and age at diagnosis, previous studies have shown that females with autism tend to be diagnosed later than male patients (18). Previous research suggests that children from less affluent socio-economic backgrounds may be diagnosed later than their more affluent counterparts (17). This was not supported by the current study – there was no statistically significant difference between age at presentation and monthly family income. This discrepancy might result from true differences in the samples, or might be influenced by the availability of free health care services in Sri Lanka, thus reducing the importance of income as a determinant of health seeking behaviour. Previous work also suggests that residency in rural areas, sustained odd play, contact with multiple primary care physicians and having an affected sibling, may lower the age at diagnosis (17, 21). We did not explore these factors in the current study.

Limitations

This study was limited to one child mental health clinic in Colombo, which is a limitation. However this clinic is part of a specialised hospital for children which serves as the national referral centre for paediatric care in Sri Lanka, and therefore children referred from many different parts of the country are seen in this clinic. The use of retrospective data extraction could also have led to errors and findings were limited to the information available in the records.

Conclusions

Several key findings emerge from this study. First, speech delay appears to be the commonest presenting symptom for children with autism, and it also significantly effects age of presentation to mental health services. Second, abnormalities in social interactions – a symptom which holds potential for early identification of autism – is overlooked by most parents. These are important findings that should be incorporated when planning and implementing public awareness campaigns in the future.

Declaration of interest

None declared

References

1. Kanner L. Autistic disturbances of affective contact. Nervous Child 1943; 2: 217-50.
2. World Health Organization. The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines. Geneva: World Health Organization; 1992.
3. Ecker C, Suckling J, Deoni SC et al. Brain anatomy and its relationship to behavior in adults with autism spectrum disorder: a multicenter magnetic resonance imaging study. Arch Gen Psychiatry 2012; 69(2): 195-209.
4. Stoner R, Chow ML, Boyle MP, et al. Patches of disorganizationin the neocortex of children with autism. N Engl J Med 2014; 370(13): 1209-19.
5. Centres for Disease Control and Prevention. Autism spectrum disorder: data and statistics. CDC. Available at www.cdc.gov/ncbddd/autism/data.html (accessed on 8 March 2015).
6. Perera H, Wijewardena K, Aluthwelage R. Screening of 18-24Month-old children for autism in a semi-urban community in Sri Lanka. J Trop Pediatr 2009; 55(6): 18-24
7. Baxter AJ, Brugha TS, Erskine HE, Scheuruer RW, Yos T, Scott JG. The epidemiology and global burden of autism spectrum disorders. Psychol Med 2014; 11: 1-13.
8. Reichow B, Barton EE, Boyd BA, Hume K. Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). Cochrane Database Syst Rev 2012; 10: CD009260.
9. Johnston MV, Ishida A, Ishida WN, Matsushita HB, Nishimura A, Tsuji M. Plasticity and injury in the developing brain. Brain Dev 2009; 31(1): 1-10.
Factors affecting age at presentation of Autism Spectrum Disorders

10. Osterlin J, Dawson G. Early recognition of children with autism: a study of first birthday home video tapes. J Autism Dev Disord 1994; 24(3): 247-57.

11. Mandell DS, Morales KH, Xie M, Lawer LJ, Stahmer AC, Marcus SC. Age of diagnosis among Medicaid-enrolled children with autism, 2001-2004. Psychiatr Serv 2010; 61(8): 822-9.

12. Chawarska K, Paul R, Klin A, Hannigen S, Dichtel LE, Volkmar F. Parental recognition of developmental problems in toddlers with autism spectrum disorders. J Autism Dev Disord 2007; 37(1): 62-72.

13. Perera H, Jeewandara KC, Guruge C, Seneviratne S. Presenting symptoms of autism in Sri Lanka: analysis of a clinical cohort Sri Lanka. Sri Lanka Journal of Child Health 2013; 42(3): 139-43.

14. Palmer R, Blanchard S, Jaen C, Mandell D. The association between school district resources and identification of children with autistic disorder. Am J Public Health 2005; 95(1): 125-30.

15. Mandell D, Palmer R. Differences among states in the identification of autistic spectrum disorders. Arch Pediatr Adolesc Med 2005; 159(3): 266-9.

16. Mandell DS, Listerud J, Levy SE, Pinto-Martin JA. Race differences in the age at diagnosis among Medicaid-eligible children with autism. J Am Acad Child Adolesc Psychiatry 2002; 41(12): 1447-53.

17. Mandell DS, Novak MM, Zubritsky CD. Factors associated with age of diagnosis among children with autism spectrum disorders. Pediatrics 2005; 116(6): 1480-6.

18. Begeer S, Mandell D, WijnkerHolmes B, et al. Sex differences in the timing of identification among children and adults with autism spectrum disorders. J Autism Dev Disord 2013; 43(5): 1151-6.

19. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 4th ed. Washington DC: APA; 1994.

20. Cuccaro ML, Brinkley J, Abramson RK, et al. Autism in African American families: clinical-phenotypic findings. Am J Med Genet B Neuropsychiatric Genet 2007; 144B(8): 1022-6.

21. Coo H, Ouellette-Kuntz H, Lam M, et al. Correlates of age at diagnosis of autism spectrum disorders in six Canadian regions. Chronic Dis Inj Can 2012; 32(2); 90-100.