

A Descriptive Study of The Diagnosis and Symptomatology of A Sample of Autistic Children in The Klang Valley Region of Malaysia

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ABSTRAK

Kertas ini mengkaji diagnosis dan simptom satu sampel kanak-kanak autistik di Lembah Kelang, Malaysia. Lima puluh pesakit autistik yang mengunjungi Unit Psikiatri Remaja dan Kanak-Kanak (Pusat Perubatan Universiti Malaya, Kuala Lumpur) dalam jeda sepuluh minggu disoal selidik dengan menggunakan Skala Penilaian Autisme Kanak-Kanak (CARS). Keputusan kajian menunjukkan bahawa pesakit secara umumnya adalah lelaki (92%) dan dari beberapa bangsa berlainan. 80% daripada pesakit mengalami autisme sederhana dan 20% mengalami autisme serius. Daripada sampel tersebut hanya 35% tidak mengalami komorbiditi, di mana penyakit hiperaktif dan kurang daya tumpuan (ADHD) merupakan komorbiditi yang paling biasa. Tidak ada perbezaan signifikan dalam tahap autisme di antara pesakit dengan peristiwa antenatal dan/atau perinatal rumit, dan pesakit dengan pengalaman antenatal dan/atau perinatal biasa. Akhirnya, 30% daripada kanak-kanak autistik tidak terlibat dalam apa-apa jenis terapi. Keputusan kajian ini dibincangkan dari segi sistem kepercayaan bangsa berlainan di Malaysia. Implikasi bagi rawatan penyakit yang berbeza-beza di negara-negara membangun juga dipertimbangkan.

INTRODUCTION

Autism spectrum conditions are clinical disorders of a variety of causes and variable prognoses which manifests in markedly abnormal social interaction, communication ability, patterns of interest and patterns of behaviour. By definition, autism must manifest in delays in 'social interaction, language as used in social communication, or symbolic or imaginative play' with an onset prior to 3-years of age (American Psychiatric Association, 1994). Often, impairments in social interaction, communication and behaviour are accompanied by cognitive deficits ranging from mild to profound (Wing, 1997).

Individuals with autism tend to have difficulty learning from experience and modifying their behaviour to accommodate new situations (Bryson & Smith, 1998). Although some autistic adults are able to find successful employment and benefit from structured training programmes

(Persson, 2000), many others are unable to cope with the unpredictability of the social world. Indeed, many adult autistics remain dependent on family or friends for most of their lives.

The reported prevalence of autism varies considerably between countries and has shown large changes in a relatively short period of time. In the developed world, there has generally been an increase in the number of children identified with autism (see Bax, 1994; Filipek et al., 1999; Honda, Shimizu & Rutter, 2005; Shattuck, 2006). Thus, the prevalence of autism has increased from 4.5 per 10,000 in the mid-1960s (Lotter, 1966) to 4-5 per 10,000 in the 1970s (e.g., Wing & Gould, 1979), 2.5-16 per 10,000 in the 1980s (e.g., Bohman, Bohman, Björck & Sjöholm, 1983; Cialdella & Mamelle, 1989) and 5-31 per 10,000 in the 1990s (e.g., Arvidsson et al., 1997; Baron-Cohen et al., 1996; Honda et al., 1996). The sex ratio in such studies is typically 3-4:1 boys to girls (Bryson & Smith, 1998).

The variability in reported prevalence estimates has been attributed to new diagnostic techniques, increased public awareness about autism and population demographic characteristics. However, there remains a great deal of debate within the literature over the existence of autism 'epidemic' as well as the possible contributing factors (Kidd, 2002). Both those who agree and disagree that there is an 'epidemic' nevertheless agree that the impact of autism on patients, families, school systems and the community requires a great deal of assistance from society as a whole.

Outside the United States, Europe and Japan, generally little is known about the prevalence and epidemiology of autism (Daley, 2002). This is particularly true in the developing world, where a lack of resources, manpower and expertise has meant that autism has not received the same level of coverage and research as in developed nations. In Malaysia, for example, prevalence estimates and epidemiological studies on autistic children are still lacking, despite the existence of the National Autism Society in Malaysia (NASOM), a non-governmental, welfare organisation established in 1986.

A number of indicators would suggest that the prevalence of autism has increased in Malaysia in recent years. For example, persons with autism referred to NASOM by government hospitals and private practitioners appeared to have risen towards the late 1990s (NASOM, 2002). Moreover, the particular cultural context in Malaysia, in particular traditional belief systems, may intersect with various aspects of help-seeking behaviours related to autism (cf. Tan, 2005). There remains, however, a lacuna in the research literature in developmental disorders in Malaysia, despite autism offering researchers a rich topic for research (Daley, 2002).

Clearly, a systematic approach to the study of autism in developing nations like Malaysia is required sooner rather than later. This is important because it will determine the response to autism diagnosis, care and response by individuals, organisations and governments. The present study was one attempt to add to the literature by documenting the characteristics of children diagnosed with autism in Malaysia. This includes demographic variables, symptomatology, severity of autism, comorbidities and treatments sought by parents of autistic children.

METHODS

Participants

The participants of this study were a cross-sectional sample of clinical patients who visited the Adolescent and Child Psychiatry Unit at the University Malaya Medical Centre in Kuala Lumpur. The unit was established in 1999 and is involved in the provision of mental health care services for adolescents and children in the Klang Valley region of Malaysia. Patients with autism, mental retardation, epilepsy, and other developmental disorders closely related to mental retardation are eligible to receive services through the Adolescent and Child Psychiatry Unit. Eligibility is determined on the basis of diagnostic parameters without financial or ethnic stipulations.

Only patients who consistently visited the unit over a 10-week period, and whose medical records were complete, were interviewed in the present study. Informed consent for the interview and data collection was obtained from patients' parents. The final sample consisted of 50 patients ranging in age from 3-20 years ($M=7.90$, $SD=3.53$). The majority of the sample was male (92%), which is much higher than the sex ratio reported in developed nations (Bryson & Smith, 1998). In terms of ethnicity, 38% of the sample was Indian, 34% were Chinese, 24% were Malay, and 4% were of other ethnic backgrounds. Socio-economic status data was not systematically collected, but the sample was relatively diverse in terms of economic circumstances.

Measures

Patient demographic data and illness history were obtained from their medical records. Patient symptomatology was assessed using the Childhood Autism Rating Scale (CARS; Schopler, Reichler, DeVellis, & Daly, 1980; Schopler, Reichler & Renner, 1988). CARS is a widely-used, standardised instrument specifically designed to aid in the diagnosis of autism for use with children as young as 2 years of age. CARS consists of 15 items drawn from 5 prominent systems for diagnosing autism, and covers characteristics, abilities or behaviours of the autism spectrum (Relationships with people, Imitation, Emotional Response, Body use, Object use, Adaptation to change, Visual response, Auditory response, Near-receptor response, Anxiety, Verbal communication, Nonverbal communication, Activity level, Intellectual inconsistency, and General impression).

Each item is rated on a 7-point scale (1-4 with $\frac{1}{2}$ points), and a total score is computed by summing the individual ratings. A score below 30 is considered to indicate the absence of autism; a score of 30 or greater the presence of autism, with 30-36.5 considered mild/moderate autism, and 37 or greater considered severe autism. The psychometric properties of CARS, both reliability (e.g., Perry & Freeman, 1996; Schopler et al., 1988) and validity (e.g., Eaves & Milner, 1993; Perry & Freeman, 1996), are good. The scale was administered in English, as no validated Bahasa Melayu (Malay) version of the scale is currently available (for discussions of limitations, see Discussion).

Procedure

All patients' data was collected between early 2004 and early 2006. Although a sampling frame analysis was not conducted, we are fairly confident that these data are representative of patients who visited the Adolescent and Child Psychiatry Unit. After observing the patient and examining relevant information from parent and medical reports, an experimenter trained in the use of CARS and fluent in English rated the patient on each of the 15 CARS items. Using a 7-point scale, the experimenter indicated the degree to which the patient's behaviour deviated from that of a normal child of the same age. The scale took approximately 30 minutes to administer, and parents were debriefed following the procedure.

RESULTS

Symptomatology

The age of initial diagnosis of autism in patients ranged from 2 to 11 years ($M=4.62$, $SD=1.96$). The initial presenting complaints were delayed speech (94%), poor social interaction (36%), abnormal, stereotyped or repetitive behaviour (30%), poor eye contact (24%), overly active or restlessness (22%), developmental delay (14%), no response to calling (4%), and poor school performance (2%). In terms of severity of autism as measured by CARS, the majority of patients were found to have mild/moderate autism (80%), whereas 20% were considered to be severely autistic.

Of the autistic patients, only 36% were free of comorbidities. Attention deficit hyperactivity disorder (ADHD) was observed in 46%, mental retardation in 22%, behavioural problems in 6%, congenital deafness, epilepsy, severe astigmatism, and tics and glucose-6-phosphate dehydrogenase (G6PD) deficiency in 2% of autistic children, respectively. A small number of patients also showed a combination of comorbidities (ADHD and mental retardation, 2%; ADHD and behavioural problems, 2%; ADHD, behavioural problems and mental retardation, 4%; ADHD and congenital deafness, 2%; ADHD and epilepsy, 2%, and; mental retardation and epilepsy, 2%).

Patient History

Out of the 50 patients, just under half (48%) had experienced antenatal and/or perinatal complications. Normal antenatal and perinatal history refers to absence of significant illness in mothers during pregnancy, full term spontaneous vaginal delivery and the absence of significant illness throughout first week of life. There were no significant differences between severity of autism in those with complicated antenatal and/or perinatal events and those with uneventful antenatal and perinatal experience ($\chi^2=242.40$, $p>0.05$). A small number of patients (2%) had a sibling with autism or Golden har syndrome, and 4% had a cousin with autistic symptoms.

Education

Among autistic children aged between 7 and 18 years, 45% were attending 'normal' schools, 29% were in special schools, 23% were in special classes and the remaining were not schooling. Of those enrolled in 'normal' schools, only 3% passed school exams (although only just) and 7% were severely autistic.

Therapy and Medication

Of the total sample, 70% were undergoing non-pharmacological therapy or early intervention programmes. This typically involved intervention or enrolment in NASOM programmes for autistics (e.g., speech therapy). Forty-six percent were prescribed with medication, mainly for behavioural problems and hyperactivity. Forty percent were receiving both therapy and medication.

DISCUSSION

The results of this study raised a number of interesting results, which are considered in turn. First, in terms of ethnicity, it is notable that 38% of the present sample was Indian, despite Indians only comprising some 10% of the Malaysian population. The percentage of patients who were Chinese appeared to be representative of the larger population, but Malays were somewhat under-represented. The over-representation of Indians may have its roots in Indian parental sensitivity to social behaviours (Kakar, 1981), where the child-rearing style of Indian mothers is often indulgent and protective (Saraswathi & Pai, 1997). Thus, parents who are more socially and emotionally connected with their children may be alerted to the unusualness of an impaired child, which in turn may lead to greater help-seeking behaviour. In addition, some researchers have suggested that Indians 'know' autism: for different historical, medical and political reasons, autism may have been placed on the Indian map (Daley, 2004; Daley & Sigman, 2002), and this may have been transported to Malaysia with the migration of Indians during the colonial period.

By contrast, the relative under-representation of Malays may have been due to their greater likelihood of seeking traditional healthcare for symptoms of autism. Within Malay communities, witchcraft and possession by spirits are regarded as common causes of mental illness, and these beliefs may have an effect on the likelihood of patients to seek help. In general, treatment defaulting rate is high among people who attribute the cause of mental illness to supernatural powers (Mubarak, 2003, 2005), and this may help explain why Malays are less likely to seek medical care for autistic symptoms. Moreover, Malay parents may also demand greater adherence to social norms and obedience, which may lead them to dismiss or deny signs of problematic child behaviour. Nevertheless, it should be highlighted that the over-representation of Indians and under-representation of Malays may have rather been an artefact of the sampling location. We would, therefore, urge more systematic investigations of the prevalence of autism not just in the Klang Valley, but in Malaysia more generally.

Secondly, the sex ratio of autistic patients in the present sample was weighted in favour of boys (just over 9:1). This is much higher than the incidence reported in other studies in developed nations, where the ratio is much closer to 3-4:1 (Bryson & Smith, 1998). One possible explanation for this finding is a potential bias in the sampling. Although every possible effort was taken to ensure that the sample reflected a cross-section of patients who visited the Adolescent and Child Psychiatry Unit, it is possible that the sex bias reflects a bias in recruitment. A different explanation is that the beliefs systems of Malaysians may influence perceptions of mental illness causation and help-seeking behaviour (Razali, Khan & Hasanah, 1996). Given the significant level of gender-role stereotyping in Malaysia (cf. Othman, 2001), where boys are more strongly valued and shown preference in terms of education and welfare, it may be the case that parents are more concerned with developmental instability in boys.

Third, Malaysian parents appeared to have a poor understanding of autism and its symptoms. An anecdote from the study helps to illustrate this issue: 'poor school performance' was the presenting complaint of an 11-year-old child who was later diagnosed to have autism. This likely reflects the poor awareness on the part of parents concerning the importance of monitoring their children's development. This suggestion is further supported by the relatively high mean age (4.62 years) at which children were presented for psychiatric assessment in the present study. By contrast, abstracted record reviews in two studies in the West found the average age of recognition to be 14.9 months (Volkmar, Stier & Cohen, 1985) and 18.3 months (Siegel, Pliner, Eschler & Cohen, 1985). Parents should be able to detect delayed speech in a child beyond the age of 2 years, and the delayed help-seeking behaviour of Malaysian parents may reflect their poor understanding of autism in particular and mental health in general.

Further evidence of parents' poor awareness of autism and its intervention comes from the relatively high number of patients attending 'normal' schools. Given that most autistics in this scenario were finding it difficult to cope with the schooling process (e.g., examinations), it is worrying that more parents do not seek out specialist help at an earlier age. This is important because early intervention programmes can contribute to the improvement of autistic features (Klinger & Dawson, 1996; Serajee, Zhong & Mahbulul Huq, 2006). For example, some researchers have noted the advantages of intervention, for both child (Dawson & Osterling, 1997) and parents (Powers, 1992), before maladaptive patterns of behaviour and communication become firmly ingrained.

Nevertheless, the finding that the vast majority of autistic children were first diagnosed following delayed speech is consistent with the diagnosis of autism in developed nations (Kidd, 2002). In the majority of autism cases, the disorder first becomes apparent after a parent noticed the growing child is failing to use words to communicate. In a minority of cases, autism appears a developmental regression: parent's report that their child was growing normally, then regressed in language, behaviour, sociability, play or school performance (Tuchman, Rappin & Shinnar, 1991), which would also appear to be the case in the present study.

In the present study, we found that 2% of patients who were autistic also had a sibling that suffers from autism. Although this finding should be treated with caution, as this study was not primarily concerned with prevalence measures, it is noticeable that other studies have found that the rate of autism among siblings of an affected child is 3-6% (Rutter, 1999). This finding would seem to support the body of evidence indicating a genetic link in the predisposition to autism (Korvatska, Van de Water, Anders & Gershwin, 2002), although much work remains to be done in this respect.

In terms of therapy, just under half of parents in the present study were using some form of medication to treat their autistic child, which is generally in line with reported rates elsewhere (Green et al., 2000). Nevertheless, there may still be differences between the types of medication sought by parents in Malaysia, given the cultural differences discussed above. For example, Green et al. (2000) found that just over a quarter of parents were implementing special diets and just under half were using vitamin supplements, both of which were not observed in the present study.

In terms of limitations, it is worth pointing out that the instrument used for the diagnosis of autism in the present study may not have been appropriate in the local context. Although CARS has been widely used and validated in the West, research suggests that some items of CARS do not serve well as screening indicators in Eastern populations (e.g., Zhang, Wheeler & Richey, 2006). Although the use of CARS seemed appropriate the present case, it may have been that its use masked important cultural differences in autism presentation. Clearly, future work is needed to examine the validity and reliability of CARS in the diagnosis of autism with Malaysian samples.

The findings of this study have important implications for the treatment and care of autistic patients in the developing world. In contrast to developed nations, where research on the treatment, care and aetiology of autism has been an important and well-funded concern (e.g., Stokstad, 2001), knowledge about autism is still generally very poor in Malaysia. This may have an impact on the types of treatments sought by parents, and indeed on the presentation of children for assessment. Moreover, parents of autistic children in Malaysia still appear to be much less vocal than their counterparts in some developed countries. In the United States, for example, parent advocacy has been an important stimulant for research funding for autism (Stokstad, 2001). In the absence of such advocacy, it is important that governmental and non-governmental organisations take important steps to increase the public awareness of autism in order to facilitate earlier detection and provide the necessary care.

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