

Editorial

Need for Epidemiological Work on Autism in India

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The Poona Psychiatrist Association Oration of the Indian Association of Child and Adolescent Mental Health, 2005 delivered by Professor Savita Malhotra drew our attention to autistic disorders.¹ Autism is a serious, lifelong developmental disability characterized by significant impairments in reciprocal social interactions and communication skills, as well as a restricted/repetitive pattern of interests and/or behaviors. During the 1960s, it was generally assumed that autism was a rare seriously handicapping disorder, usually associated with intellectual disability and constituted a condition that was qualitatively distinct from variations in social and communicative competence within the normal range.¹⁻³ Both genetic and epidemiological research findings have forced a change in concept as a result of the evidence that autistic like abnormalities are common and often occur in individuals with normal intelligence, particularly in first degree relatives of individuals with autism.³ The heritability or underlying genetic liability of autism spectrum disorder is about 90% - the highest figure among all multi-factorial child psychiatric disorders. Twin data also show that the genetic liability extends well beyond the traditional core diagnosis of autism to include a wide spectrum of autistic-like disorders (autism spectrum disorders: ASD).³

There are good epidemiological data indicating that the true incidence of ASD is likely to be of the order of 30-60 cases per 10,000 as compared with the original estimate of 4 per 10,000 made some four decades ago.² A recent study has reported the prevalence of childhood autism to be 38.9 and for ASDs to be 116.1 per 10,000.⁴ In large part the variation in estimates is because of the combination of better ascertainment and a broadening of the diagnostic concept.²⁻⁴ A true rise in the incidence of autism also cannot be ruled out. However, despite strong claims made about the possible role of measles mumps rubella (MMR) vaccine in relation to the causation of autism, there is no convincing evidence in support of this hypothesis. In particular, the rate of ASD shows no particular association with either the stopping or starting of MMR and there is no change over time in the pattern of association between ASD and either bowel disturbance or developmental regression.⁵ The evidence with respect to a possible association with Thimerosal, a preservative in some vaccines, is much more limited but, again there is no supporting epidemiological evidence of a casual association.³

There are no specific community-linked studies on prevalence or incidence of autism or ASD in India.⁶ This is a serious gap because these disabling disorders can no longer be considered rare, with the more recent estimates placing the prevalence rate among children at about 1%,⁴ which is quite similar to that of schizophrenia and bipolar disorder in adults. Prevalence studies are of value in planning diagnostic and intervention services. Detailed epidemiological studies incorporating disability measurement will help identify the need for a range of services in health, education and social care. Longitudinal studies can generate and test etiological hypotheses for autism.

It is about time that a multi-site study with sound methodology on prevalence of ASD is mounted in India. To improve reliability of estimates there is a need for agreed and shared tools and definitions in prevalence and incidence studies and for designs that are not reliant on local system of case ascertainment that may exhibit educational and other biases⁴. Hence, there is also a need to develop an instrument with high fidelity to ICD-10/DSM-IV description/criteria, as the currently available instruments like Autism Diagnostic Interview – Revised,⁷ Autism Diagnostic Observational Schedule,⁸ and Childhood Autism Rating Scale⁹ are not specifically keyed to these criteria.

REFERENCES

1. Malhotra S. Autism: an experiment of nature. *J Indian Assoc Child Adolesc Ment Health* 2006; 2:9-17
2. Williams JG, Higgins JPT, Brayne CEG. Systematic review of prevalence studies of autism spectrum disorders. *Arch Dis Child* 2006; 91:8-15.
3. Rutter M. Aetiology of autism: findings and questions. *J Intellectual Disability Res* 2005; 49: 231-238.
4. Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D et al. Prevalence of disorders of the autism spectrum in a population cohort of children in south Thames: the Special Needs and Autism Project (SNAP). *Lancet* 2006; 368:210-215.
5. Honda H, Shimizu Y, Rutter M. No effect of MMR withdrawal on the incidence of autism: a total population study. *J Child Psychol Psychiatry* 2005; 46:572-579.
6. Malhotra S, Vikas A. Pervasive developmental disorders: Indian scene *J Indian Assoc Child Adolesc Ment Health* 2005; 1(3):5
7. Lord C, Rutter M, Goode S, Heemsbergen J, Jordan H, Mawhood L, et al. Autism Diagnostic Observation Schedule: a standardized observation of communicative and social behaviour. *J Autism Developmental Disord* 1989; 19:185-212.
8. Lord C, Rutter M, Le Couteur A. Autism Diagnostic Interview - Revised: a revised version of diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *J Autism Developmental Disord* 1994; 24:659-685.
9. Schopler E, Relchler RJ, Renner BR. The Childhood Autism Rating Scale (CARS). Los Angeles, CA: Western Psychological Services, 1986.