

Prevalence of autism in children born to Somali parents living in Sweden: a brief report

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In a geographical area of Stockholm, with a relatively large Somali immigrant population, parents as well as teachers in special schools and staff at habilitation centres have raised concerns over whether children with a Somali background are over-represented in the total group of children with autism. The aim of the study was, therefore, to investigate the prevalence of autism in children with parents from Somalia, living in Stockholm county, and to compare the prevalence in children of Somali background with that in the non-Somali group. We reviewed the records of 17 children (13 males, four females), born between 1988 and 1998 (age range 7–17y) and with a Somali background, who had a diagnosis of autistic disorder or pervasive developmental disorder not otherwise specified (PDDNOS) and were registered at either of the two autism habilitation centres for school-aged children. The prevalence of autistic disorder or PDDNOS was found to be three to four times higher than in the non-Somali group (0.7% vs 0.19%). All children also had learning disability.* Our findings warrant further investigations of possible aetiological factors behind the increased prevalence of autistic disorders in children of Somali origin found in this area in Sweden.

See end of paper for list of abbreviations.

*North American usage: mental retardation.

Autism is a developmental disorder with multiple aetiologies.¹ It is regarded as a spectrum, including autistic disorder, Asperger syndrome, and pervasive developmental disorder not otherwise specified (PDDNOS). Many individuals, particularly those with the most severe and 'classic' variants of autistic disorder, also exhibit a low level of general cognitive functioning.

In some children the underlying aetiology can be demonstrated, such as when a specific syndrome or a neurological condition is diagnosed, including tuberous sclerosis, fragile X syndrome, or Moebius syndrome. However, at present, despite a thorough medical investigation, a definite medical condition can be identified only in a minority of children with autism.^{1,2} Genetic factors are very important,^{3,4} although the exact genetic mechanisms are currently not known. Several susceptibility genes have been discussed, and some cases are clearly due to (or are partly caused by) specific mutant genes.⁵ The rate of autism is much higher in monozygotic twins than in dizygotic twins, and the condition is more prevalent in males.¹

Idiopathic autism is a very challenging condition for parents. Along with genetic aspects, several other explanations have been discussed, including the influence of diet, intestinal inflammation, and vaccination. In a geographical area of Stockholm, with a relatively large Somali immigrant population, many parents of Somali children have refrained from letting their child be given the measles, mumps, and rubella (MMR) vaccine because of the controversial (and now refuted) link between MMR vaccination and autism.⁶ In that specific area of Stockholm, vaccination frequency was 69.5% in 2005, and 71% in 2006, in comparison to about 95% in most other areas in Stockholm.⁷ In this area in the northwestern part of Stockholm, parental concern about the risk of vaccination coincides with concerns from teachers and autism assessment teams about a seemingly higher than expected proportion of Somali children having autism.

Against this background, we set out to investigate the prevalence of autism in children with parents from Somalia, living in Stockholm county (with a total population of about 1.8 million people and about 20 000 births per year during the studied birth-year period), and to compare the prevalence in children of Somali background with that in the non-Somali group of children in the same area. Our hypothesis was that the prevalence of autism in the group of children with Somali background was higher than in children with other ethnicities.

Method

In the county of Stockholm, school-age children (age range 7–17y) who have been given a diagnosis of autistic disorder or PDDNOS according to DSM-IV,⁸ in conjunction with learning disability are referred for intervention and follow-up to one of two autism habilitation centres ('north' and 'south').

TARGET POPULATION

The target population consisted of all children aged 7 to 17 years (birth years 1988–1998) and living in the county of Stockholm in November 2005 ($n=253\ 002$).

CHILDREN OF SOMALI BACKGROUND

Children of Somali background were those who were either born in Somalia or born in Sweden, with both parents born abroad and at least one parent coming from Somalia, as defined by the Swedish Central Bureau of Statistics.⁹ In

November 2005, this group consisted of 2437 7- to 17-year-olds. Children with a Somali background constituted 0.96% (2437/253 002) of the total child population born during 1988 to 1998 in the county.

Parents with a Somali origin were asked by a letter, with information written in Swedish and Somali, to let one of the authors (MBO) have access to their child's records from the habilitation centre. All records of children in the age group with a Somali background, who were registered at either one of the two habilitation centres and who had a diagnosis of autistic disorder or PDDNOS, were reviewed, and their status as regards Somali background was determined. All records were scrutinized regarding antenatal, perinatal, and postnatal data, medical information, and data from the assessment supporting the diagnosis of autism. Two of the authors (MBO and EF) made certain that DSM-IV criteria for autistic disorder or PDDNOS were met in all individuals registered as having autistic disorder or PDDNOS.

The study was approved by the regional ethics committee in Stockholm.

Results

PREVALENCE RATES

A total of 501 children (0.2% of the total child population, with a male:female ratio of 3:1) had a diagnosis of autistic disorder or PDDNOS and were registered at either of the two habilitation centres for children with autistic disorder or PDDNOS in Stockholm in 2005. Seventeen (13 males, four females, population-adjusted male:female ratio 3.3:1) of the 501 children with autistic disorder ($n=14$) or PDDNOS ($n=3$; 3.4% of all with autistic disorder or PDDNOS) had a Somali background. Fifteen of these were registered at the north centre and two at the south centre.

The minimum prevalence of autistic disorder or PDDNOS was 0.7% (17 of 2437; 95% confidence interval [CI] 0.37–1.03) among children with a Somali background. Among the children with a non-Somali background the corresponding prevalence was 0.19% (484 of 250 565; 95% CI 0.18–0.21; $p<0.001$).

GENERAL DATA

Data from records revealed that most of the children (13 of 17) had three or more siblings. One female had a brother (not in the study group) with autism and learning disability. One male with autism and learning disability had two non-study-group siblings with learning disability (but no autism) and yet another male with autism and learning disability had a non-study-group sibling with autism. Six of the 17 children with autistic disorder or PDDNOS were the parents' first-born child. In all children, except one, both parents had a Somali origin. One child had a father from another country on the Horn of Africa.

Information on the time of arrival in Sweden was mostly not given in the records. In one case it was mentioned that the mother moved to Sweden during pregnancy.

Consanguinity was reported in the records for three individuals, parents being first cousins for one child and second cousins for another; a more remote relationship was declared for the third. This information had not regularly been requested during assessments. All 17 children had been born in Sweden. Gestational ages could be identified in the

available records for 15 of the 17 children; all these were born at term. Available data demonstrated that one child had been born small for gestational age and had had mild hypoglycaemia, one had had mild asphyxia, and one had suffered from mild respiratory distress.

DEVELOPMENTAL DATA

Most (14 of 17) of the children had presented signs of arrested development, mainly in the progression of speech and language, at an age of about 12 to 24 months. For one child developmental deviation was reported at an age of about 6 months, and for two children information was lacking. Learning disability, assessed with the Griffiths scales in most of the children, or strongly clinically suspected, were reported for 16 of the 17 children. One child was reported to have a borderline intellectual functioning but attended a special school for children with learning disability. Profound hyperactivity was reported in at least 13 of the 17 children. This hyperactivity was described as 'tears down the visiting room' or 'constantly touching everything'. One child had a congenital bilateral deafness but no other symptoms or signs pertaining to a specific syndrome. One child had epilepsy, but it was not possible from available records to identify the type. General motor function was not a problem in most of the children; only one child who also had bilateral deafness had delayed motor development.

Discussion

Our hypothesis that the prevalence of autistic disorder or PDDNOS was increased in children with a Somali background living in Sweden was confirmed. The prevalence was threefold to fourfold that in children of non-Somali origin living in the county (0.7% vs 0.19%). At the habilitation centres, children from Somalia constituted 3.4% (17 of 501) and the rate of Somali children in the county was 0.96% (2437 of 253 002).

One limitation of this study is the retrospective collection of data, relying on clinical notes that had not been intended for research. Only the autistic disorder or PDDNOS diagnoses for the Somali children were checked and reconfirmed. The data are therefore not complete and must be seen as preliminary. In addition, the study group was small, consisting of 17 children, assessed by different teams. However, 10 of them had been assessed at the same child neuropsychiatric unit in the county or this team had been consulted during the assessment, three of the children were assessed at other habilitation units in Sweden and the remainder were assessed by different neuropsychiatric/neuropaediatric teams in Stockholm. Assessments were performed similarly and all met criteria for autistic disorder or PDDNOS according to DSM-IV criteria. All 17 children and their parents had continued their contact for several years with the two habilitation centres that were exclusively aimed at children with autism-spectrum disorders in conjunction with learning disability.

Our clinical impression is that this group of Somali children constitutes a rather homogeneous group in the autism spectrum with regard to four characteristics: (1) the age at which the developmental deviation was noted (12–24mo); (2) the presence of a definite intellectual impairment in all 17 individuals, mostly of a moderate to severe degree; (3) the fact that motor function was not impaired, except in one

child; and (4) the fact that the activity level was exceptionally raised in the vast majority of the children.

The origins of the autistic disorder or PDDNOS in these children is not apparent. No definite perinatal or postnatal causes were revealed. Males dominated in the Somali population with autism, as in other groups of children with autism.

In our study group the children had both parents coming from Somalia, except for one child who had a father from a country near Somalia. The vast majority of the mothers had been settled in Sweden during the entire pregnancy. We had insufficient data about the number of mothers who had arrived in Sweden during pregnancy: only for one mother was this reported in the child's medical record.

All individuals had learning disability. This is a developmental disorder in which genetic background factors have a prominent role. Recessive inheritance has been especially demonstrated in severe learning disability.¹⁰ In many parts of the world, especially the Islamic countries, marriages between close relatives are common.^{11,12} In a previous study from Stockholm county,¹³ covering a population with a high rate of non-European/non-North American immigrants, the prevalence of severe learning disability was found to be 3.7 and 5.9 per 1000 respectively, in the European and in the non-European population.

Consanguineous marriages were assumed to be a factor of importance in the distribution of aetiologies of severe learning disability in that study. In the present study it was not possible to obtain information about consanguinity in most of the families, but this factor cannot be excluded as being of crucial importance. Differences between European and non-European groups of children with mental disabilities in the UK were studied by Akinsola and Fryers,¹⁴ also reporting more severe disabilities in the non-European group.

Increased prevalence rates of autism in children of immigrants of African origin have been previously reported in Sweden.^{15,16} Gillberg found a remarkably high prevalence in males from Uganda. In another study he discussed the possibility that some of the increased rate of autism in this sub-population of migrants to Sweden from Africa and other remote regions might be attributable to autism-spectrum conditions in the father rather than to the immigrant status of the mother. Several fathers of children in one of the studies were of Swedish descent. However, in the Somali sample reported in the present context there was no indication of such links.

Knowledge about genes linked to susceptibility for the development of autism and autism-spectrum disorders is increasing.¹⁷ McMahon et al. discuss the fact that there is currently no genetic test to determine the risk of autism, but it is possible that such tests may emerge in the near future. They also emphasize, like Gillberg and Coleman,¹ that autism represents complex, multifactorial conditions.

Recently, in a Norwegian study, Kanavin and collaborators¹⁸ reported that a 4-year-old male with autism, learning disability, and epilepsy, and with a Somali background, was found to have a metabolic disturbance, a defect in the degradation pathway of the amino acid L-isoleucine. The underlying gene defect could be detected. The authors were also able to identify this mutation in another two children from Somalia and Eritrea respectively.

The possibility of epigenetic factors operating in autism has been discussed by Zhao and colleagues,¹⁹ for example,

they concluded that disturbances in epigenetic modulations and regulations can lead to inappropriate expression or silencing of genes. It is hoped that our understanding of such mechanisms will increase in the future.

Conclusion

From a neuropaediatric/neuropsychiatric point of view, our findings warrant further investigations of possible aetiological factors behind the increased prevalence of autistic disorders in children with Somali origin. Yet, irrespective of aetiology, this group of children and their families need comprehensive habilitation measures and long-term support and follow-up.

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List of abbreviations

MMR	Measles, mumps, and rubella
PDDNOS	Pervasive developmental disorder not otherwise specified

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