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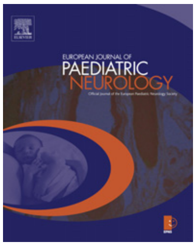

Original article

Observed prevalence of autism spectrum disorders in two Norwegian counties

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ABSTRACT

Background: The prevalence of autism spectrum disorders (ASD) has previously been reported to be increasing dramatically in European and non-European countries. No similar increase in prevalence rates has been documented in Norway to date. The current study reports on ASD prevalence rates in two Norwegian counties.

Methods: The population comprised 31 015 children, ages six to 12. Information about special needs services was provided by the school authorities and the public health service. Multiple search strategies were applied to identify children at risk of ASD or diagnosed with ASD. Hospital registers were searched and a mapping tool was used in all local schools.

Results: The total number of patients with ASD found in the population was 158. This gives a prevalence of 51 per 10 000 (95% CI, 0.43–0.59).

Conclusion: Compared with the previously reported prevalence of ASD in Norway, there has been almost a fourfold increase in the occurrence of childhood autism and a tenfold increase in the occurrence of all ASD groups. These findings have significant implications for designing and dimensioning appropriate intervention programmes for children with ASD and their families.

1. Introduction

Autism spectrum disorders (ASD) constitute a group of developmental disorders, emerging in childhood and characterised by pervasive deficits in social behaviour and interaction.[1] According to the International Classification of Diseases (10th edition (ICD-10)[2]) and the Diagnostic Statistical Manual (4th edition (DSM-IV)[3]), ASD includes childhood autism, atypical autism, Asperger's syndrome, disintegrative disorders and Rett syndrome. ASD is genetically and phenotypically heterogeneous with variable degrees of severity and symptomatology, and different outcomes.[4,5] However, the common denominator is that all manifestations can be characterised as devastating disorders in terms of co-morbidity,[6] outcome and impact on the family and society.[7]

Numerous epidemiological studies indicate that the prevalence of autism has risen markedly in recent decades.[8] Prior to 1980, reported prevalence was four to five per 10 000. However, during the 1990s and especially after 2000, prevalence rates have been reported as increasing dramatically.

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Some describe the rise as "epidemic".[9] The number of epidemiological surveys has been overwhelming and prevalence rates of more than 60 per 10 000 have been reported.[8] Furthermore, some authors consider these numbers to be conservative. Recently there have been reported prevalence rates in excess of 100 to more than 250 per 10 000.[10,11] If these figures are correct, society will be facing challenges in the medical as well as the educational system. Updated epidemiological data are essential to enable the health authorities to plan and develop health strategies, treatments and medical counselling services. Norway is a relatively small country (approximately 5 million inhabitants) with a well-organised health care system and reliable health registries that provide access to valid epidemiological information.

That being said, in contrast to other Western countries, the number of epidemiological studies of ASD in Norway has been rather modest. One Norwegian study from 1993[12] investigated the occurrence of autism in persons born between 1975 and 1991, reporting a prevalence of 5.5 per 10 000. Sponheim and Skjeldal[13] subsequently reported prevalence rates of 3.8 per 10 000 for childhood autism and 5.3 per 10 000 for ASD, based on the ICD-10 criteria. These studies generated debates because of their low prevalence rates compared with concurrent international research. Recently, a Norwegian study[14,15] reported, estimated ASD prevalence to range from 0.21 per cent to 0.87 per cent. The study aimed to identify all children with ASD, mapping a population of school children ranging in age from seven to nine in Bergen, Norway. A paper recently published reported an increase of high functioning ASD based on a prevalence estimate in a clinical sample in a geographical defined area: 0.35% of the childhood population 5–18 years.[16]

In the light of international research indicating a dramatic increase in the prevalence rate and the mixed results of the three Norwegian epidemiological surveys, the aim of the present study is to use multiple search strategies to estimate the prevalence of ASD in two Norwegian counties. Our objective is to identify children born between 1 January 1996 and 31 December 2002 who have been diagnosed with childhood autism or another ASD and to determine whether the prevalence of ASD has increased compared with findings from other Norwegian surveys.

2. Patients and method

2.1. *Study population*

This study is based on 31 015 children born between 1 January 1996 and 31 December 2002 and who reside in the counties of Oppland and Hedmark. The area has a population of about 374.359 inhabitants and consists of urban and rural areas alike. The region has a low rate of migration; all are included in the further analysis.

All children reported as eligible for special education and/or special care services were invited to participate in the study either through the school authorities (local schools) or the health care system (Child Habilitation Services (CHS) and Child and Adolescent Psychiatry (CAP) outpatient clinics).

Nine hundred and ninety-five children eligible for special education and/or special care services and therefore defined as at risk for ASD or with ASD, were identified in registers and by direct contact with the local schools. There was a high degree of overlap between children found in registers and children identified through feedback from parents.

Our working hypothesis was that all children with ASD would likely require some services, so it was reasonable to expect that we would find the ASD cases among the children receiving special education services.

2.2. *Procedures*

Two different strategies were employed to ensure that we found most of the children who either had ASD or were at risk for ASD. We used[1] patient records and[2] a mapping tool that was sent to all local schools in the region, targeting children eligible for special education and/or special care services

(1) Patient records

To identify children with ASD within the chosen age group, we thoroughly investigated patient records at CHS and CAP units. They keep records of clinically assessed children aged six to 12 with a variety of psychiatric and neurological diagnoses. These services have information about children with an established diagnosis of ASD and who are deemed eligible for special education, as well as information about children diagnosed with language and/or behavioural dysfunctions, the most common conditions that prompt referrals related to autism.

(2) Mapping autistic behaviour

The Social Communication Questionnaire (SCQ) was used to map autistic behaviour in the selected population. The instrument contains questions that focus on behaviours observed by the primary caregiver. The items are based on the Autism Diagnostic Interview, revised edition (ADI-r),[17] and correspond to the diagnostic criteria related to ASD and excerpted from the ICD-10. They have been modified so that they can be understood by parents without further explanation. The SCQ contains 40 questions that cover social interaction, language and communication, as well as repetitive/stereotyped behaviour. Each item is scored as either present or absent. Possible scores for verbal children range from 0 to 39, and for non-verbal children, from 0 to 33. These ranges of possible scores for verbal and non-verbal children are due to the exclusion of six language-based items for children without language. Our study applied the lifetime version, as the lowest age for inclusion in the study was six. The authors of SCQ reported that a cut-off score of 15 gave the highest sensitivity and specificity for identifying ASD. In this study, we used a cut-off $\geq$13 as the limit for inclusion. This has been justified in other studies which have shown that a cut-off score of 13 will ensure a lower rate of false negatives. Special mention is made of the highest functioning children with ASD.[18,19]

2.2.1. *Diagnostic assessment*

Two diagnostic instruments were used to assess autistic behaviour: the ADI-r and the Autism Diagnostic Observation Schedule (ADOS).[20] Both instruments standardise the collection of information for the diagnostic process in respect of autism.