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Development

Epidemiological Surveys of Autism Spectrum Disorders

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Introduction

Since the first epidemiological survey of autism performed in 1966 in the UK[1], many epidemiological surveys of autism have been conducted worldwide in order to estimate the prevalence of autism spectrum disorder (ASD) in human populations and to identify factors associated with variation in that prevalence.

Subject

Prevalence studies estimate the proportion of participants affected with ASD in a given population, at one point in time. Prevalence estimates are needed to help plan services and devise appropriate health and education policies. Prevalence studies can also contribute to evaluating risk factors associated with ASD, and they may be repeated over time to detect secular changes in the incidence of ASD.

Problems

Investigating ASD at the population level is challenging since, in the absence of valid biomarkers, the diagnosis of ASD relies on complex and time-consuming clinical procedures. Diagnostic

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concepts and criteria have evolved continuously making it more difficult to compare study results over time. In addition, age at diagnosis varies and not all children have equal access to diagnostic services, leaving some children undiagnosed and difficult to identify in population surveys. Finally, large samples required to provide the necessary precision are more difficult and costly to acquire.

Research Context

We updated a review of all surveys of ASD performed from 1966 to 2023.[2] We only included studies with a sample size >5,000 and with a professional confirmation of the ASD diagnosis in participants. The 163 identified surveys were conducted in 38 countries. Half of them were published since 2013; 140 were performed in 27 high-income countries (as defined by the World Bank) and none in low-income countries. Some regions of the world (South America, Africa, Central Asia) have no or very limited data. The median size of surveyed populations was 69,000 (interquartile range (IQR): 15,668-312,728), and the median age of participants was 8.0 years (IQR: 6.5-9.6).

There is high heterogeneity in the methodology employed in surveys in terms of case definition and ascertainment. Definitions of ASD have relied on variable diagnostic criteria from Kanner's and Rutter's criteria, to ICD-9/10/11 and to DSM-III/IV/5. Confirmation of case status was also variable with some studies relying on existing educational or health diagnoses while others performed in-person evaluations to confirm the diagnosis. Case identification strategies also varied with studies of large registries or databases passively relying on existing recorded diagnoses while other studies employed more pro-active screening approaches, including screening normal schools in order to detect yet undiagnosed children. In the latter group, survey protocols vary in whether they include parents, teachers, and subjects with ASD as participants and rely on variable screening instruments and diagnostic confirmation procedures.

Thus, no agreed-upon formula exists for planning and conducting a survey, and there is no standardization of autism survey methodology. Each survey has unique design features that account for the specific educational and health services infrastructure and policies for children with disabilities in the local region or country. In light of this methodological heterogeneity, comparisons of prevalence of estimates across studies must therefore be made with caution.

Key Research Questions

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1. What are the current estimates for the prevalence of ASD among children?
2. What are the correlates of ASD in prevalence studies?
3. Are there meaningful time or place differences in ASD prevalence?

Recent Research Results

1. Prevalence of ASD was significantly higher in more recent studies, in studies performed in high-income as opposed to middle-income countries, in those using more recent diagnostic criteria (ICD-10/11 and DSM-IV/5) and in surveys focusing on school age children. To summarize results, we restricted our analysis to 41 surveys performed since 2018 in 19 high-income countries (total population: 27.5 million children; median age: 8 years). Prevalence estimates ranged from 0.2% to 2.76% (IQR: 0.76%-1.56%) with a median prevalence estimate of 1.15%. This figure of 1.15% is a conservative lower-bound estimate for current ASD prevalence among children ages four to 12 living in high-income countries.[2] A plausible range is 1%-2%. An interactive global autism prevalence map is publicly available.[3]

2. Over time, there was a marked increase in prevalence as indicated by a significant correlation between prevalence and year of publication ($P < .001$).[2,4,5] The proportion of participants without intellectual disability (ID) significantly increased over time as well ($P < .001$); in recent studies, the median proportion of individuals without ID was 62.1% (IQR: 53%-76%).

Across 135 surveys, the median male:female ratio was 4.1:1 (IQR: 3.1-4.8); there was no significant change over time in the male preponderance in surveys and a 4:1 sex ratio (translating in about 80% males in samples) is a robust feature of ASD epidemiological profile.

Prevalence was lower in surveys including preschoolers or teenagers and adults due to the low sensitivity of case ascertainment in these age groups. Thus, estimates derived from school age samples are least biased.[4]

Adult surveys are still scarce. Pioneering studies performed in England in adults living in typical households or in supported accommodations reported a prevalence of 1.1% with no variation across different age bands.[6,7] A recent study on the Medicaid US adult population aged 18 and older provided a prevalence estimate of 0.95% in 2019, with a figure approaching 1.8% among

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18-24 year-olds but remaining less than 0.5% among individuals aged ≥45 years illustrating strong cohort and age effects found in adult samples.[8]

In the US, prevalence has been typically lower in underserved groups due to social inequalities in access to services although this trend has abated recently.[9] However, in surveys performed in countries with universal healthcare systems, ASD is usually not associated with family socio-economic status, parental education or race/ethnicity.

3. The rising prevalence of ASD over time has sometimes been interpreted as evidence that the underlying population incidence of ASDs was increasing, fueling concerns about an autism "epidemic".[10] However, evaluation of secular changes in disease incidence or prevalence must be performed while holding constant methodological factors that contribute variance in prevalence estimates. Alternative explanations that could account for a change in prevalence must be systematically ruled out before a meaningful conclusion can be reached.[2]

Several studies have documented that the increase in prevalence reflected a mixture of factors. First, the concepts of ASD and its diagnostic criteria have been broadened in the last 50 years and studies have shown that prevalence estimates are strongly affected by the specific diagnostic criteria used by investigators.[2,4-5,10-11] Second, diagnostic substitution (or switching) occurred when new diagnostic concepts of ASD became familiar to health professionals and/or when access to early intervention services were made specifically contingent upon an ASD diagnosis. A high proportion of children previously diagnosed with "mental retardation", or ID or language disorders were subsequently re-diagnosed as having ASD.[12-15] Third, improvements in public awareness and access to diagnostic and intervention services have facilitated identification of children with ASD in surveys. Altogether, these changes have confounded the interpretation of time trends in prevalence[4,5,10,16] and thus far, no study could properly evaluate changes in underlying incidence after controlling for the effects of these extraneous factors.

The same difficulties arise for assessing geographical variation in prevalence. Cross-country comparisons are obscured by substantial differences in study methods. Nevertheless, everywhere it has been investigated, autism has been found. Initial surveys often identified more classic forms of severe ASD and reported low estimates. With time, and when more fully developed survey methods are deployed, prevalence in the neighborhood of 1% has been reported in countries as diverse as India[17], Qatar[18], Mexico[19], and China[20]. Based on available published data, there is no current evidence that there are countries with either very low or very

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high ASD rates, or that meaningful between-country variations in prevalence exist. By the same token, true differences could exist and remain undetected with present methodological limitations.

Investigators in worldwide studies have relied on the diagnostic concepts embodied in ICD/DSM and in the corresponding instrumentation (questionnaires, diagnostic tools), without difficulty or need to massively recalibrate the research and clinical instruments. Thus, it appears that the concept of autism has some universality even though it might be labelled and named differently in some cultures. Nevertheless, some minor adjustments in the wording of questions or the administration of tests are sometimes necessary to adjust to specific cultural contexts.[2,4]

Research Gaps

Monitoring the prevalence of ASD in different populations has become a public health objective in several countries. In the US, the surveillance of ASD has been performed by CDC since 2002 with bi-annual surveys of the population of children aged 8.[9,21] Comparable efforts initiated in Canada[22] and the European Union[23] have had a more limited impact.

Surveys of ASD among adults are needed as there is a growing number of adults with ASD whose needs are poorly understood and met.

Surveys are needed in countries (especially middle- and low-income countries) and world regions (Central Asia/Russia, South America, Africa) that still lack any epidemiological information about ASD.

Systematic cross-cultural comparisons of the ASD phenotype, of developmental trajectories and of lived experiences of people with ASD, their families and communities are also needed.

Future surveys would greatly benefit from incorporating genetic and biological data as well as planning for a long-term follow-up of the population-based sample of participants with ASD.

Conclusions

ASD is a neurodevelopmental disorder that is more common than once thought. The prevalence ranges from 1% to 2% with some countries having even higher rates. It affects 4 males for each female and is associated with intellectual disability in about 35-40% of the cases. ASD occurs in children from all social strata and racial/ethnic groups although social inequalities in health care

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delay diagnosis and intervention in underserved groups. The prevalence has increased over time, but it remains uncertain whether this reflects mostly artefacts of changing definitions and study methodologies as opposed to a genuine increase in the population incidence. There is no evidence that the prevalence of ASD is different across countries or that the expression and measurement of the ASD phenotype requires substantial culture-specific modifications. Epidemiological surveillance of ASD is increasingly contemplated by public health agencies.[2]

Implications for parents, Services and Policy

ASD is neurodevelopmental disorder with variable severity, emerging in the first 2 years of life but that is often recognized and diagnosed much later. It affects 1%-2% of school age children in most current surveys but there is a huge variability in the results of epidemiological surveys and several studies documented a prevalence higher than the 2% mark. Typically, 80% of children with ASD are males with no epidemiological evidence that this proportion has changed. Intellectual/learning disability now occurs in less than 40% of affected children. ASD occurs in all families and regions of the world, irrespective of familial background socio-demographic features. ASD is a lifelong condition that therefore also affects adults; however, the prevalence of ASD among adults has not been well documented yet. Surveys of adults with ASD are a priority. ASD occurs everywhere in the world and there is no evidence that it is either more rare or more frequent in any country, nor that its clinical manifestations vary according to the cultural context.[2]

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