

AUTISM

Epidemiology of Autism

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Introduction

Determining the prevalence of autism spectrum disorders (ASDs) and monitoring it over time is important to ensure the training of ASD diagnosticians, improve access to necessary interventions, and understand causal mechanisms of ASDs. We review the prevalence of ASDs and discuss the limitations and challenges in interpreting prevalence reports. We specifically consider factors contributing to variation in estimates and their change over time.

Problems

Because ASD is a behaviourally-defined disorder, determining its prevalence is more challenging than for a disorder where clear biological markers exist. The symptoms of ASD vary in severity and may present differently in children with a mixture of cognitive abilities.¹ Furthermore, how the data are gathered, analyzed and interpreted impacts the conclusions made regarding the prevalence of ASD.² Changes in societal awareness and the public health response also have an impact on prevalence estimates. As a result, there is controversy surrounding the prevalence of ASD, in particular whether the recent rise in reports of the disorder is due to a true increase in incidence or whether there are other factors that could be impacting estimates.

Key Research Results

ASDs and pervasive developmental disorders (PDDs) are often used interchangeably, and they are very similar in meaning. Based on current best estimates of the prevalence of ASD,^{2,3,4,5} rates derived from studies published in English in the last decade show that the current prevalence of autistic disorder is approximately 20-30/10,000, while the prevalence rate for all ASDs is approximately 90-120/10,000. Males consistently outnumber females by approximately 5:1 for broader ASDs. While these estimates are predominantly based on studies in North America and Northern Europe, a recent systematic review that included a wider representation of global prevalence estimates yielded similar figures.⁶ In all cases, prevalence figures as well as the population characteristics from which they were derived are highly variable. Prevalence rates for specific DSM-IV categories including Asperger's syndrome (AS) and childhood disintegrative disorders (CDD) have been more difficult to estimate because of the rarity of those disorders, especially CDD, or the lack of clear differentiation of the clinical phenotype within the spectrum of ASDs, especially for AS.

Research Context

The recent Centre for Disease Control and Prevention (CDC) reports indicate a clear rise in prevalence of ASDs in recent years. News reports and some stakeholder groups have called this an "autism epidemic," with the recent CDC estimates suggesting that 1 in 110 children 8 years of age have an ASD.⁷ When prevalence rates are considered against year of publication, there is indeed clear support for the claim for a rise in prevalence reported for autistic disorder over time.⁸ This pattern has caused much controversy because it has generated confusion as to whether the rise in prevalence can be equated with a rise in incidence. Prevalence is the proportion of individuals in a population who suffer from a defined disorder at any point in time, while incidence is the number of new cases occurring in a population over a period of time. Incidence does not include individuals already diagnosed or treated for the condition, only the new cases occurring during a certain time period. Prevalence is useful for estimating needs and planning services. In the case of the ASD prevalence reports, one cannot imply incidence from prevalence data because they require different methodologies and analysis.

The variation in prevalence estimates may be driven by a wide range of factors including:

Case definition: Differences in the way various studies defined ASDs and identified them make it difficult to compare between studies and report on the changes in prevalence over time. Relative to early studies in the 1960s and 1970s which used a narrow definition of autism, autism has

expanded into a broader class of ASDs. Unlike before, autism occurring without co-morbid mental retardation has also been recognized. The evolution of the case definition of autism into a spectrum disorder has created a challenge in examining prevalence rates between studies, especially over time.³

Diagnostic substitution and accretion: The modifications in the diagnostic criteria of autism to a spectrum disorder may be impacting more recent prevalence reports because it is possible that some of the cases which currently have an ASD diagnosis may not have received a diagnosis previously using older diagnostic criteria. More specifically, diagnostic substitution – when a case receives one diagnosis at one point and then later receives a different diagnosis – may be playing a role.⁹ For example, some cases may have received a diagnosis of mental retardation when they were younger, and then later received an ASD diagnosis because of the change in diagnostic criteria. It is also possible that some cases diagnosed with one disorder earlier in time may later acquire a co-morbid diagnosis that includes ASD, called diagnostic accretion. For example, other cases may have received a diagnosis of mental retardation when they were younger, and then later received a co-morbid diagnosis including autism.

Variability in study methods: Unique design features of different studies could have an impact on prevalence, making it particularly difficult to compare published rates over time. Some studies use pre-existing databases, such as service provider databases, special educational databases, or national registers to identify cases. Utilizing these databases to report prevalence excludes individuals who have the disorder but are not in contact with the agency maintaining the database. This results in an underestimation of the true prevalence. Another method used for case ascertainment includes a multi-stage approach, which involves a screening stage followed by a more in-depth diagnostic stage. The goal of the screening stage is to identify an exhaustive list of cases possibly affected with an ASD, leaving the comprehensive diagnostic assessment to the next stage. The number of data sources, the type of screening scale used, and the response rate influence the number of cases selected in the first stage, which then impacts the number of cases identified in the second stage. Even at the stage when participants are directly examined, assessments are conducted using various diagnostic instruments, ranging from a typical unstructured examination by a clinical expert to the use of a full battery of standardized measures.

Public health response, awareness and policy changes: Tracking prevalence has become a national priority in a few countries where such estimates are used in service planning and

development. In the U.S., research funding for autism, as well as the number of autism research grants, has increased steadily over the past decade.¹⁰ There is no doubt that increase in public awareness and access to services, and improved identification of autism in primary health care has contributed toward the increase in prevalence and may also account for regional variation within the U.S. Reports of the increasing prevalence of ASDs in research literature and in the media have helped to raise awareness in the general population, especially among parents of affected children. Parent groups have been discussing the rising rates of ASDs all over the U.S., Canada and many other nations. Government officials are taking notice of the public response, providing further impetus for awareness and identification efforts.

Conclusion and Implications

Current estimates for the prevalence of autistic disorder is 1/400 individuals,² and the prevalence of all ASDs combined is approximately 1/100 individuals. Additionally, comparisons of prevalence studies by year indicate a distinct trend of increasing rates of prevalence. However, whether this increase is the sign of a true ASD epidemic or not is subject to debate. Many factors can explain at least some of the reasons for increasing prevalence rates of ASD, such as changes in the diagnostic criteria for ASD included in the DSM and ICD over time, diagnostic substitution and accretion, and the variability in case ascertainment across studies. Affected families and advocacy groups have used the autism epidemic to improve the plight of individuals with ASD, which has led to the discussion of autism by governmental bodies, which regardless of the nature of the increase of ASD has been beneficial to those affected by it. In conclusion, it appears as though increasing rates of ASD can be explained by factors associated with the collection of data, and not necessarily by an actual increase in incidence although the latter possibility remains to be further investigated.

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