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LETTER TO THE EDITORS

Mind the gap: the inconceivable void in the epidemiology of autism spectrum disorders in Brazil

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Autism was once considered a rare neurological condition, documented through meticulous case reports of a severely impairing syndrome thought to occur in only a few of every thousand births. However, this perception has shifted dramatically over the past few decades. Our current understanding of autism encompasses a broader spectrum of severity and impairment, and epidemiological evidence now suggests that this condition is far more common than previously believed. This aligns with the early predictions of Leo Kanner, the child psychiatrist who first described autism in 1943: "These characteristics form a unique 'syndrome,' not heretofore reported, which seems to be rare enough, yet is probably more frequent than is indicated by the paucity of observed cases."[1]

Prevalence estimates of autism spectrum disorder (ASD) have consistently increased with each new report from the U.S. Centers for Disease Control and Prevention (CDC). In 2000, the prevalence was estimated at 1 in 150 children, but by 2010 it had risen to 1 in 68. The latest estimate from 2023 indicates that 1 in 36 U.S. children are diagnosed with ASD.[2] Estimates based on the U.K. Clinical Practice Research Datalink primary care database found a 787% increase in the incidence of autism diagnosis over 20 years – with the most significant increases in diagnostic rates observed among adults and females.[3] Contributing factors to this increase include increased awareness of ASD by health professionals and within communities, leading to improved detection, partly due to heightened media coverage and anti-stigma campaigns. However, and perhaps most importantly, the diagnostic criteria were broadened and the diagnostic thresholds were lowered. For instance, the transition from ICD-10 to ICD-11 and from DSM-IV to DSM-5 criteria consolidated various autism subtypes under a single category, allowing for recognition of a wider range of symptoms and severity levels. This change also allowed for the co-occurrence of ASD with other disorders (such as attention-deficit/hyperactivity disorder and intellectual disability) and likely contributed to this evolving scenario. There is ongoing debate about whether unidentified etiologic risk factors (as well as genetic and environmental components) have also contributed to this increase.[4] Recent research using data from the Swedish Twin Registry suggests weak evidence for substantial changes in these factors over time, finding no significant shifts in genetic or environmental factors related to ASD or autistic traits. This indicates that other factors may be contributing to the observed increase in prevalence.[5] Meanwhile, there is widespread public concern about the possibility of a global autism epidemic.

Another important question is whether the rapidly increasing numbers reported by the CDC and other surveillance institutes in a few countries apply to other regions of the world, including Brazil. For instance, a recent study using data from the Global Burden of Disease (GBD) [6,7] revealed that, although the total number of cases of autism and the associated burden has increased worldwide between 1990 and 2019, age-standardized prevalence and incidence rates have remained stable. However, this stability is misleading, reflecting an increasing incidence in high-income countries, where surveillance is better established, and a stable or decreasing incidence in low- and middle-income countries, where prevalence studies are scarce. In fact, the data are insufficient to determine whether country- or region-level variations are overshadowed by these estimates, making it crucial for all nations to implement surveillance efforts and conduct reliable prevalence studies for local contexts.

What is the current data on ASD epidemiology in Brazil? For the present letter, we reviewed the references of three recent meta-analyses on autism prevalence,[8-10] examined the data sources utilized by the GBD to construct country-level estimates, and consulted national experts in the field of epidemiology and neurodevelopmental disorders. To our surprise, we found only four prevalence studies conducted in Brazil, which provide the entirety of our current knowledge and inform higher-level meta-analytic estimates, such as the GBD. To dive into the strengths and weaknesses of these surveys, as well as the extent to which they represent the actual prevalence rates in our country, it is essential to outline the gaps we face in this matter.

Two studies stem from a population-based cohort in Pelotas, Rio Grande do Sul, which invited the mothers of all 4,231 babies born in 2004 to participate. In the fifth follow-up wave, 3,585 6-year-old children (84.7% of the original cohort) were evaluated for psychiatric disorders with the Development and Well-Being Assessment (DAWBA), which was administered in interviews with the children's mothers or caregivers according to both the ICD-10 and DSM-4-TR. An algorithm was used to estimate the probability of psychiatric disorders in children based on structured responses, while clinical raters independently assessed symptoms, impairments, and qualitative information. Clinical judgments were made by a child psychiatrist. Individuals from lower-income countries had a higher prevalence of any mental disorder than those from high-income families, and the prevalence of ASD reported in this study was 0.3% (10 cases). A limitation at the time of the fifth follow-up wave was that

the autism diagnoses were based solely on screening questions.[6] In the subsequent follow-up wave, when the children reached 11 years of age, the DAWBA was again administered, applying ICD-10 criteria and comparing them to those of the DSM-5. The prevalence at this point was 0.4%.[11,12]

The third study screened children in 55 schools in São Paulo and Porto Alegre, two major cities in Brazil. The final sample of 2,511 children aged 6 to 14 years old consisted of one randomly selected group and another group at high risk for psychopathology, defined as the presence of subthreshold symptoms or a positive family history of psychiatric disorders. The DAWBA was also used. The prevalence of autism was 0.2% in the random sample and 0.9% in the high-risk group. The overall mean prevalence was 0.6%. This study only assessed schools near the research centers, which could have led to bias. Furthermore, the random group, which is more representative of the general population, included fewer than 1000 individuals and only 2 cases of ASD. Autism was not contemplated with the oversampling procedure in either group, making the estimates highly uncertain.[13]

Although not included in the GBD, a study by Paula et al.[14] provided an important estimate of ASD prevalence in Brazil, focusing on the medium-sized city of Atibaia, São Paulo. The study population consisted of 1,470 children aged 7 to 12 years who were part of a Family Health Program. The Autism Screening Questionnaire was used for initial screening, followed by diagnostic assessments with the DSM-IV, the Schedule for Affective Disorders and Schizophrenia for School-Aged Children, and the Autism Diagnostic Interview-Revised (ADI-R). This study found a prevalence of 27.2 cases per 10,000 individuals (or 0.272%).[14]

This overview has revealed the limitations of the literature on ASD prevalence in Brazil. First, the estimates come exclusively from medium- and large-sized urban centers in two wealthier states (São Paulo and Rio Grande do Sul). Second, the time frame of the measures was narrow (2010 to 2015), thus providing no information on longitudinal patterns. Third, only one study used a standardized clinical interview designed for ASD diagnosis, such as the ADI-R. The other three studies, including the two phases of Pelotas cohort, based diagnosis on screening questions or a structured interview applied by lay interviewers, which limits diagnostic precision. These issues are not unique to our country. Challenges related to research methodology and limited access to diagnostic tools, such as the Autism Diagnostic Observational Schedule and the ADI-R, both of which require considerable time and expertise, are encountered globally.

Erskine et al. investigated global estimates of child and adolescent psychiatric disorders, i.e., the extent to which the prevalence studies represent the children and adolescents of the world.[15] The global coverage for ASD was 16.1%, but the figure was higher for high-income countries, with 34.59% coverage. In low- and middle-income countries, the coverage dropped to an alarming 1%. The understanding and detection of ASD have significantly evolved over the years, revealing a condition more prevalent than previously recognized. The uncertainty about ASD prevalence, as evidenced by data from the CDC and other epidemiological studies, shows the importance of awareness and comprehensive research. It also raises concerns about the lack of data worldwide. Our review of the available Brazilian prevalence studies highlights the critical need for greater research and surveillance efforts in different regions to inform public policy, as well as the need for specialized health care. Addressing these gaps will be essential to provide equitable care for all affected individuals and their families.

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