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LETTER TO THE EDITOR

What is the True Prevalence of Autism Spectrum Disorders?

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There have been reports of dramatically increased rates of several child and adolescent psychiatric disorders in the last decade (Harpaz-Rotem & Rosenheck, 2004). Results show mounting frequencies for autism, bipolar disorder, anxiety disorder and attention deficit hyperactivity disorder. However, the disorders being the most intensely debated in this respect clearly are autism and other disorders of the autism spectrum (ASD). Not at least because, for a long time, autism was considered a very rare disorder, although some authors had pointed out the possibility of ASD being more common earlier (Gillberg et al., 1991). Studies published before the year 2000 showed a median prevalence rate of approximately 0.05 % for core autism and 0.19 % for the whole spectrum (Fombonne, 1999), whereas most studies published since the year 2000 indicate distinctly higher rates of about 0.2 % for core autism and 0.6 % for the autism spectrum (Fombonne, 2003). Despite consistently showing higher rates of ASD than in the past, the newer studies also vary substantially concerning the reported prevalences. The broad pattern of results seems to be a consequence of differing underlying study designs and assessment procedures. Nevertheless, owing to this lack of uniformity the pivotal question remains what the true rate of ASD is like: 0.5 %, 1 % or more? We are, of course, unable to answer this question, but would like to remind of and concisely summarize some fundamental issues closely related to it. Surprisingly, these are sometimes neglected, although they can be found in the existing literature.

Specificity

In epidemiological studies the sensitivity (proportion of true positives correctly identified) and specificity (proportion of true negatives correctly identified) of procedures and instruments are crucial. Particularly in face of low base rates of a disease in the general population, which applies for ASD. Regarding this, only a sensitivity and specificity close to 100 % can finally lead to reliable figures. Owing to the reports of significantly rising rates, the question of specificity has been discussed a lot in the context of the autism prevalence studies. However, careful diagnostic procedures have not been undertaken throughout. For instance, as far as the authors are aware, until today, only one study (Baird et al., 2006) has used the internationally accepted golden standard for final diagnosing autism spectrum disorders, which is the combination of a structured parent interview (Autism Diagnostic Interview-Revised) and a direct observation scale (Autism Diagnostic Observation Schedule). It is well established that these instruments together lead to highly specific classifications. Demands for high specificity are fulfilled here and the true rate of ASD is probably not lower than the reported figure of 1.16 % (UK population, South Thames, N = 56.946 children aged 9 to 10 years).

Sensitivity

The risk of lacking sensitivity in prevalence studies has been considered much less in the literature. This might be due to the fact that no fully validated screener suitable for population use is available yet (Williams & Brayne, 2006). Therefore, researchers often do not screen a complete population, but estimate the prevalence of ASD on the basis of a screening for high-risk individuals in a given population (e.g. children with special needs). Despite having certain advantages, this strategy indicates that the researchers must rely on previous diagnostic judgements by others. Especially, individuals with milder forms of ASD, such as pervasive developmental disorders not otherwise specified (PDD-NOS), who are not necessarily severely impaired and easily detected, might not get a label of needing special attention. Nevertheless, research has shown that the PDD-NOS diagnoses may form the largest subgroup of all ASD. Hence, there is a risk of prevalence underestimation, if populations are not screened entirely in the beginning. Indeed, studies where whole populations were screened have shown significantly higher rates than high risk sample screenings. For instance, a survey from Norway (Posserud et al., 2006) found high autism scores in 2.7 % of a general population sample using a screening questionnaire (Autism Spectrum Screening Questionnaire).

Cultural and regional differences

There is also the possibility of true regional prevalence differences. Because study designs have been incomparable across countries and regions, it is, at the moment, impossible to determine if such differences exist and whether they are minor or significant. We have recently gathered normative data for the German version of the Social Responsiveness Scale (SRS) in a sample of N = 838 preschool and school children aged 4 to 17 years (mean = 9.9, SD = 3.4). The SRS is a well validated questionnaire for assessing autistic traits in the general population (Constantino & Gruber, 2005). The parent-report values on the SRS in the German sample are comparable for girls (mean 22.8, SD 14.5)($z = .21$, $p = .84$) and boys (mean 25.3, SD 16.7)($z = .41$, $p = .68$) to the US standardization sample of N = 1081 (means 27.6 and 33.7; SDs 18.1 and 20.9)($z<.45$, $p>.32$). This may indicate rather minor cross-cultural differences regarding the distribution of autistic traits, at least in the Western world.

Drop-outs

Finally, reported prevalence rates could be biased by refusal to participate and other adverse effects. Unfortunately, it is unknown if participants and drop-outs are equal with regard to the occurrence of ASD. Future studies should therefore at least ensure that families declining participation in each stage can be presumed socio-economically homogeneous with the included sample. The latter seems advised as, for example, one study (Baird et al., 2006) reported that the rate of identified ASD cases among their participants was much lower for children of less educated parents.

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