Childhood Diagnoses in Individuals Diagnosed With Autism in Adulthood

Eya-Mist Rødgaard

University of Copenhagen

Kristian Jensen

Université de Montréal

Kamilla Woznica Miskowiak

University of Copenhagen

Laurent Mottron (✉ laurent.mottron@gmail.com)

Université de Montréal <https://orcid.org/0000-0001-5668-5422>

Short report

Keywords: Autism, adult, comorbidity, late diagnosis

Posted Date: July 19th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-708676/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Abstract

Autism is a developmental condition, where symptoms are expected to occur in childhood, but a significant number of individuals are diagnosed with autism for the first time in adulthood. Here we use the National Danish Patient Registry to investigate diagnoses given in childhood among those that are diagnosed with autism in adulthood (N = 2199). We found that most childhood diagnoses were given after the age of 12, and attention-deficit hyperactivity disorder, affective disorders, anxiety, and stress disorders were the most prevalent childhood diagnoses. However, 69% of males and 61% of females with adult autism diagnoses had not received any of the included diagnoses before the age of 18. In most cases, the late autism diagnosis is therefore unlikely to be explained by either misdiagnosis or diagnostic overshadowing. This result is at odds with the prevailing notion that autistic symptoms tend to diminish with age. Therefore, further research is warranted to examine how early signs of autism may have manifested among these individuals, and how similar they are to autistic people diagnosed earlier in their development. Milder to moderate cases of psychiatric conditions that have been solely treated by family physician or school psychologists may not be fully included in our dataset.

Introduction

According to diagnostic criteria(1), symptoms of autism must appear in childhood, but there are also individuals who are diagnosed with autism for the first time during adulthood. This has led researchers to hypothesize a “lost generation” of autistic individuals whose autism symptoms were not identified in childhood(2). It is relevant to question why the autism condition, which should have manifested across contexts during childhood, might have been missed until adulthood. It has been suggested that factors such as high IQ, female gender and camouflaging behaviours may hinder an early identification of the condition(3, 4).

Studies of autism diagnosed in adulthood generally report a high frequency of comorbid psychiatric diagnoses(5-9). Another hypothesis therefore is that autism symptoms in childhood were mistaken as symptoms of other conditions(5, 10) such as attention-deficit hyperactivity disorder (ADHD)(11, 12) or obsessive-compulsive disorder (OCD)(13) due to symptom overlap. It is also possible that both conditions were present, but due to diagnostic overshadowing, the autism symptoms were attributed to the other condition and no autism diagnosis was given(14, 15).

Although numerous studies have investigated previous psychiatric diagnoses among individuals diagnosed with autism as adults, most of these studies did not investigate *when* previous diagnoses were given, i.e. in childhood or relatively shortly before the autism diagnoses well into adulthood. Here, we specifically investigate childhood deviation in individuals who were diagnosed with autism in adulthood. We used a Danish national health registry to investigate which diagnoses these individuals were given in childhood, and thus whether misdiagnosis and diagnostic overshadowing might explain why autism can have gone undiagnosed throughout childhood.

Method

Data was retrieved from the Danish National Patient Registry (DNPR), which contains information about all diagnoses given within the Danish hospital sector (in-patient and out-patient) from 1994 to 2018. The DNPR is connected to the Danish Central Person Registry, allowing diagnoses given to the same individual at different times to be linked. Access to the registries were obtained through the Danish Health Data Authority. To ensure that the available data covered all relevant diagnoses given in childhood, we excluded individuals born before January 1, 1993. Our autism population thus consisted of individuals born between January 1, 1993 and December 31, 2000 who were diagnosed with autism (ICD-10 codes F84.0, F84.1, F84.5, F84.8, F84.9) at age 18 or later (1312 males, 887 females). We calculated the percentage of males and females that had received one of the psychiatric or neurological diagnoses shown in Figure 1 before the age of 12, as well as before the age of 18. The ICD-10 codes used for each diagnosis are shown in Supplementary Table S2. The diagnoses were chosen based on what previous studies have found in populations diagnosed with autism in adulthood, as well as diagnoses as which autism might be misclassified due to symptom overlaps. The data was extracted on August 24, 2020.

Results

The childhood prevalence (0-17 years of age) of each selected diagnosis among those diagnosed with autism in adulthood is shown in Figure 1a. 69% of males and 61% of females had not been registered with any of the selected diagnoses before their 18th birthday. Since autism symptoms would be expected to occur in early childhood, we also investigated how often the selected diagnoses were given before the age of 12. This is shown in Figure 1b. 84% of males and 91% of females had not been registered with any of the selected diagnoses before their 12th birthday.

Discussion

The presence of childhood diagnoses of psychiatric or neurological disorders may explain why autism has not been diagnosed throughout childhood, e.g. due to misdiagnosis or diagnostic overshadowing. The present data showed that only 31% of males and 39% of females were registered as having received any of the diagnoses shown in Figure 1 before the age of 18, and even fewer were registered with any of the diagnoses before the age of 12 (16% of males and 9% of females). In these cases, the late autism diagnosis may be attributed to misdiagnosis or overshadowing. Similarly, there may have been a recategorization of diagnoses, such that symptoms that are now classified as autism would previously have been categorized as another condition, e.g. intellectual disability(16). However, the remaining majority of late autism diagnoses likely have other explanations. Some individuals may not have exhibited signs of autism to a degree that has caused a thorough diagnostic evaluation to be initiated. Recent evidence suggests that the threshold for receiving an autism diagnosis has been lowered through the last decades(17), which may also explain why a person that did not meet the criteria in childhood can get a diagnosis later in life.

Some researchers have hypothesized the concept of camouflaging, describing coping strategies used to hide autism symptoms and maintain an appearance of normal social functioning(4). Studies of camouflaging have suggested that the coping behaviour requires an intense effort(4), which may eventually cause distress to a degree where a psychiatric evaluation is initiated, leading to a late autism diagnosis(18). Alternatively, it is possible that stressors experienced later in life (such as increased social and executive requirements during the transition from adolescence to adulthood) may exacerbate latent subclinical traits and trigger a late onset of a phenotype that resembles autism. There have been concerns about the validity of the camouflaging construct and suggestions that further research is needed to operationalize it and differentiate it from other constructs(19). Specifically, it is relevant to strengthen the validity of the distinction between camouflaged symptoms and absence of symptoms, in order to elucidate to which extent camouflaging contributes to individuals with an adult autism diagnosis not being diagnosed in childhood.

We found high incidences of ADHD, mood disorders, and anxiety before the age of 18, which is consistent with previous studies of comorbidity in individuals diagnosed with autism in adulthood(5-9, 20). Incidences before the age of 12 were considerably lower, showing that most of the pre-autism diagnoses were given in adolescence. Sex differences of childhood prevalence were generally in the same direction as sex differences among the general population (Supplementary Table S1). We found a high incidence of stress disorders before the age of 18, particularly among females, whereas previous studies have either not reported rates of stress disorders(5-7) or only reported rates specifically for post-traumatic stress disorder(8, 9).

The fraction of individuals who did not receive any of the investigated diagnoses in childhood was slightly higher than what has previously been reported. Rydén & Bejerot (2008)(8) found that 53% of those diagnosed with autism as adults had received psychiatric care in childhood. This difference might be attributed to changes in the autism population over time, or differences in which diagnoses were included. It is also possible that the difference can be ascribed to the fact that the DNPR only contains diagnoses given in the hospital system, while some individuals may have received childhood psychiatric care in the primary healthcare sector, e.g. for conditions such as depression or anxiety(21).

Limitations

The present results are based on records of autism diagnoses and cannot inform about how the diagnoses correspond to a “true” autism condition. Because our data only contains diagnoses given within the hospital sector, some individuals with an adult autism diagnosis may not be included if they were diagnosed and treated exclusively by their primary physician or a psychiatrist in private practice. However, since diagnostic assessment for autism in adults is complicated by several factors(2), diagnoses not conducted by specialist teams might have insufficient validity and could introduce false-positive diagnoses if included. Investigated childhood diagnoses also do not include those given by school psychologists or primary physicians. However, problems that are managed solely by a primary

physician or school psychologist (e.g. milder cases of anxiety or depression) are likely less pronounced than the cross-context challenges that would be expected due to autism.

Conclusion

Most individuals receiving an autism diagnosis in adulthood did not receive any of the investigated psychiatric diagnoses. In such cases, the late autism diagnosis cannot likely be explained by misdiagnosis or overshadowing. Further research is warranted to investigate how autism manifested in childhood in these individuals, whether they might have benefited from access to support, and whether cases of autism that only reach a clinical threshold in adulthood are biologically distinct from their childhood counterparts.

Abbreviations

ADHD: Attention-deficit hyperactivity disorder

DNPR: Danish National Patient Registry

Declarations

Ethics approval and consent to participate

Data in the Danish national health registries are anonymized and the use of these registries for research does not require ethics approval. Our analysis protocol was approved by the University of Copenhagen, Faculty of Social Sciences.

Consent for publication

Not applicable

Availability of data and materials

The aggregated count data described in this manuscript are included in the supplementary material. The raw data in the Danish National Patient Registry cannot be shared. Researchers can apply for access to the raw data through the Danish Health Data Authority.

Competing interests

KWM declares having received consultancy fees from Lundbeck A/S and Janssen-Cilag A/S in the past three years. EMR, KJ, and LM declare no conflicts of interest.

Funding

EMR was supported by grants from the Ivan Nielsen Foundation and the Sofie Foundation. KWM is supported by the Lundbeck Foundation and the Weimann Foundation. LM was supported by a grant from

Brain Canada (MIRI2015-3736). The funding bodies were not involved in designing or conducting the study, nor in writing the manuscript.

Authors' contributions

All authors contributed to the design of the study. EMR and KJ performed the analyses and drafted the manuscript. KWM and LM critically revised the manuscript. All authors read and approved the final manuscript.

Acknowledgements

Not applicable

References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®) Fifth Edition. Arlington, VA: American Psychiatric Publishing; 2013. 991 p.
2. Lai MC, Baron-Cohen S. Identifying the lost generation of adults with autism spectrum conditions. *Lancet Psychiatry*. 2015;2(11):1013-27.
3. Begeer S, Mandell D, Wijnker-Holmes B, Venderbosch S, Rem D, Stekelenburg F, et al. Sex differences in the timing of identification among children and adults with autism spectrum disorders. *J Autism Dev Disord*. 2013;43(5):1151-6.
4. Hull L, Petrides KV, Allison C, Smith P, Baron-Cohen S, Lai MC, et al. "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *J Autism Dev Disord*. 2017;47(8):2519-34.
5. Geurts HM, Jansen MD. A retrospective chart study: the pathway to a diagnosis for adults referred for ASD assessment. *Autism*. 2012;16(3):299-305.
6. Happe FG, Mansour H, Barrett P, Brown T, Abbott P, Charlton RA. Demographic and Cognitive Profile of Individuals Seeking a Diagnosis of Autism Spectrum Disorder in Adulthood. *J Autism Dev Disord*. 2016;46(11):3469-80.
7. Hofvander B, Delorme R, Chaste P, Nydén A, Wentz E, Stahlberg O, et al. Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*. 2009;10:9-35.
8. Rydén E, Bejerot S. Autism spectrum disorders in an adult psychiatric population: A naturalistic cross-sectional controlled study. *Clinical Neuropsychiatry: Journal of Treatment Evaluation*. 2008;5(1):13-21.
9. Underwood JFG, Kendall KM, Berrett J, Lewis C, Anney R, van den Bree MBM, et al. Autism spectrum disorder diagnosis in adults: phenotype and genotype findings from a clinically derived cohort. *Br J Psychiatry*. 2019;215(5):647-53.

10. Kentrou V, Oostervink M, Scheeren AM, Begeer S. Stability of co-occurring psychiatric diagnoses in autistic men and women. *Research in Autism Spectrum Disorders*. 2021;82:101736.
11. Kentrou V, de Veld DM, Mataw KJ, Begeer S. Delayed autism spectrum disorder recognition in children and adolescents previously diagnosed with attention-deficit/hyperactivity disorder. *Autism*. 2019;23(4):1065-72.
12. Mayes SD, Calhoun SL, Mayes RD, Molitoris S. Autism and ADHD: Overlapping and discriminating symptoms. *Research in Autism Spectrum Disorders*. 2012;6(1):277-85.
13. Paula-Perez I. Differential diagnosis between obsessive compulsive disorder and restrictive and repetitive behavioural patterns, activities and interests in autism spectrum disorders. *Rev Psiquiatr Salud Ment*. 2013;6(4):178-86.
14. Antshel K. Autism traits may be more prevalent in ADHD than previously reported. *Evid Based Ment Health*. 2014;17(3):83.
15. Griffiths DL, Farrell LJ, Waters AM, White SW. ASD Traits Among Youth with Obsessive-Compulsive Disorder. *Child Psychiatry Hum Dev*. 2017;48(6):911-21.
16. Polyak A, Kubina RM, Girirajan S. Comorbidity of intellectual disability confounds ascertainment of autism: implications for genetic diagnosis. *Am J Med Genet B Neuropsychiatr Genet*. 2015;168(7):600-8.
17. Arvidsson O, Gillberg C, Lichtenstein P, Lundström S. Secular changes in the symptom level of clinically diagnosed autism. *J Child Psychol Psychiatry*. 2018;59(7):744-51.
18. Aggarwal S, Angus B. Misdiagnosis versus missed diagnosis: diagnosing autism spectrum disorder in adolescents. *Australas Psychiatry*. 2015;23(2):120-3.
19. Fombonne E. Camouflage and autism. *J Child Psychol Psychiatry*. 2020;61(7):735-8.
20. Marriage S, Wolverson A, Marriage K. Autism spectrum disorder grown up: a chart review of adult functioning. *J Can Acad Child Adolesc Psychiatry*. 2009;18(4):322-8.
21. Munk-Jorgensen P, Ostergaard SD. Register-based studies of mental disorders. *Scand J Public Health*. 2011;39(7 Suppl):170-4.

Figures

Figure 1

Childhood prevalence (0-17 years) of diagnoses among males and females diagnosed with autism as adults. a) Diagnoses given before the age of 18. b) Diagnoses given before the age of 12.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [SupplementaryMaterial.docx](#)