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A retrospective chart study: The pathway to a diagnosis for adults referred for ASD assessment

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Abstract
Charts of 125 adults (18 to 82 years), referred to an autism expert team for Autism Spectrum Disorder (ASD) assessment, were reviewed to explore the pathway to an adulthood ASD diagnosis. The participants first contacted the mental health care clinic at a median age of 19 years (range 2 to 78 years). Men contacted the clinic slightly earlier than women. The main referral reasons were social problems, feelings of anxiety and mood disturbances. The most common earlier diagnoses were anxiety and mood disorders or psychosis-related disorders. These diagnoses were more common in women than in men. Surprisingly few differences emerged between those who finally received an ASD diagnosis and those who did not. However, those with an ASD diagnosis contacted the clinic a mean of 15 years earlier and less frequently received different former diagnoses, although the type of diagnoses did not differ. The diagnostic criteria that were prevalent during early childhood of these adults did not influence their diagnostic history. A quarter of these clients were known with social problems within the mental health care system, but ASD was not assessed. Hence, the current study shows that the pathways to an adulthood ASD diagnosis are very heterogeneous.

Keywords
autism, asperger, PDD-NOS, adults, chart review

Most people with Autism Spectrum Disorders (ASDs) receive their diagnosis during childhood. In some cases, ASDs are not recognized until adulthood. Three important

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developments account for a late diagnosis of ASD. First, when the adults were children, specific ASD diagnoses (like Asperger syndrome) were not broadly known. Second, it has been acknowledged only recently that ASD can be present among all possible intelligence levels (Baird et al., 2000). Third, earlier versions of the 'Diagnostic and Statistical Manual of Mental Disorders' (DSM) used more stringent criteria (see Wing and Potter, 2002). As a result, people who nowadays would meet current ASD criteria might have been previously misdiagnosed, not diagnosed at all, or obtained an earlier diagnosis that is no longer valid owing to changes in the diagnostic criteria (Coo et al., 2008; Shattuck, 2006).

Currently, adults increasingly receive ASD diagnoses, but some still remain undetected. Among an outpatient psychiatric population, 1.4% met ASD criteria, compared with 3.2% in an inpatient population (Nylander and Gillberg, 2001). Undiagnosed ASD patients had a former diagnosis of schizophrenia in 26% of the cases. Some schizophrenia characteristics overlap with ASD characteristics (e.g. Hurst et al., 2007).This is why the diagnostic criteria of the DSM-IV(TR) direct clinicians to schizophrenia as a differential diagnosis (American Psychiatric Association, 1994, 2000; see also schizotypal personality disorder and avoidant personality disorder in the DSM-IV(TR)). Furthermore, ASD can be accompanied by comorbid mood disorders, anxiety disorders, attention deficit hyperactivity disorder (ADHD) and personality disorders (Hofvander et al., 2009; Leyfer et al., 2006; Matson and Nebel-Schwalm, 2007).

In this paper we report the results of a chart review of 125 adults who received an ASD diagnosis in adulthood. We explore 1) the *reasons* for the first referral to the general mental health care system; 2) the *number* of former diagnoses; 3) the *type* of former diagnoses; 4) whether individuals that do receive an ASD diagnosis differ from those that did not receive an ASD diagnosis; 5) whether gender has an effect on time and type of former diagnosis; and 6) whether the changes in diagnostic criteria have an effect on time of diagnosis (Coo et al., 2008; Shattuck, 2006).

Methods

Participants

Retrospective chart reviews were conducted on 125 adults, who were seen between 1994 and 2006 for diagnostic evaluation by the autism expert team (AET) at a tertiary mental health care (MHC) clinic specialized in the assessment of ASD. The adults were diagnosed following an extensive diagnostic procedure, which included clinical (non-standardized) psychiatric interviews, thorough developmental and psychosocial history from one or both parents, guardians or another close relative, and an observation in the home or work environment of the client. All classifications were based on a consensus meeting by a team of professionals including a psychiatrist, psychologists, social worker and cognitive behavioural therapist. The pool of charts initially reviewed included adults with Autistic disorder (n = 27), Asperger syndrome (n = 28), or pervasive developmental disorder – not otherwise specified (PDD-NOS) (n = 50) as outlined by the DSM-IV(TR) (American Psychiatric Association, 1994; 2000) and adults who did not meet criteria for ASD (n = 20) but were referred to receive ASD assessment.

A total of 992 people were registered as clients between 1994 and 2006 by the AET From this group we selected 125 charts with the following inclusion criteria: 18 years or older when

ASD assessed; no longer receiving treatment from the AET; and inclusion of a report with official DSM diagnoses.

The included participants were 2 to 78 years when they first contacted a general MHC provider and were aged 18 to 82 years when they were diagnosed (Table 1). Hence, they contacted the general MHC providers between 1950 and 2006. We divided the participants in three DSM-age groups according to the prevalent diagnostic tradition when these adults were around 3 to 10 years of age, as ASD diagnoses are most often determined within this age range (Shattuck et al., 2009). The first category (n = 54) included those individuals that were between 3 and 10 years of age before 1980, prior to the publication of the DSM-III (American Psychiatric Association, 1980). The second category (n = 62) ranged from 1980 to 1994, when the DSM-IV was published, which included Asperger syndrome and PDD-NOS for the first time. The participants in the third category were those that were 3 to 10 years after 1994 (n = 9).

The participants were predominately male and most of them had no diagnosis of an intellectual disability (Table 1). Of the 125 participants, 105 received an ASD diagnosis (autistic disorder n = 27; Asperger syndrome n = 28; PDD-NOS n = 50) and 20 adults did not meet ASD criteria.

Procedure

Charts were reviewed for the following information: age when receiving the ASD diagnosis or, in the non-ASD group, age when ASD diagnosis was ruled out; gender; presented problems in their first contact with general MHC providers; age at the time of their first contact with general MHC providers; diagnosis by the AET; former diagnoses in the time period between the first contact with the MHC system and the AET diagnosis; and comorbid diagnoses along the ASD diagnosis made by the AET. We gave a specific code for each problem type and the diagnoses on two of the DSM-IV(TR) axes (axis I and axis II). Axis I consists of all clinical disorders and Axis II consists of all personality disorders and intellectual disabilities. Statistical analyses

We used non-parametric Mann-Whitney U tests (for gender and ASD versus non-ASD), a non-parametric Kruskal-Wallis tests (to compare the DSM-age groups) and chi-square tests for a two-way contingency table (to test the relationship between AET diagnosis and DSM-age groups).

Results

In the total sample the median age of the first contact with the general MHC system was 32 years. Forty-nine percent contacted the MHC system before they reached adulthood (median 9 years). These adults received their ASD assessment a mean of 17 years later. The other 51% contacted the MHC system in middle adulthood (median 29 years). They were assessed for ASD approximately 7 years later. Reasons for referral to the MHC system included social problems, mood disturbances and anxious feelings (Table 1). Fifty-seven percent of the participants did not receive an axis I diagnosis in the past. Those who did receive an earlier axis I diagnosis most often received the following diagnoses: mood disorder, anxiety disorder, or psychoses related disorders. Axis II diagnoses were present in 44% of the participants. Most common was the diagnosis of an intellectual disability (30%), while 14% of the participants received a personality disorder as diagnosis.

Table 1 Descriptives

	Total sample (*n*=125)	ASD group (*n*=105)	Non-ASD group[a] (*n*=20)
Gender			
Male	89 (71%)	80 (76%)	9 (45%)
Female	36 (29%)	25 (24%)	11 (55%)
Age (years) diagnosis AET	32.0 (18–84)	31.0 (18–64)	35.5(19–84)
Comorbid diagnosis AET[c]			
No	85 (68%)	67 (64%)	18 (90%)
Yes	40 (32%)	38 (36%)	2 (10%)
No. of former diagnoses Axis I, 0/1/2/>2	71/34/17/5	66/22/14/5	5/12/3/0
Former diagnosis axis I			
Anxiety	15 (12%)	10 (10%)	5 (25%)
Mood	19 (15%)	14 (13%)	5 (25%)
Ext	3 (1%)	3 (3%)	0
Addict	2 (<1%)	2 (2%)	0
Psy	13 (10%)	9 (9%)	4 (20%)
MalAdapt	4 (3%)	3 (3%)	1 (5%)
Misc axis I[d]	6 (5%)	6 (6%)	0
Former diagnosis axis II			
IntDis[b]	37 (30%)	36 (34%)	1 (5%)[4]
Personality	18 (14%)	16 (15%)	2 (10%)
Age (years) at 1st contact	19.0 (2–73)	17.0 (2–62)	32.5 (14–73)
Reason for contact with MHC			
Anxiety	21 (17%)	14 (13%)	7 (35%)
Mood	25 (20%)	19 (18%)	6 (30%)
Ext	16 (13%)	15 (14%)	1 (5%)
Social	32 (26%)	27 (26%)	5 (35%)
Lang	5 (4%)	5 (5%)	0
Rep	4 (3%)	3 (3%)	1 (5%)
Psy	3 (1%)	2 (2%)	1 (5%)
School	9 (7%)	9 (9%)	0
Delay	14 (11%)	13 (12%)	1 (5%)
Misc[e]	34 (27%)	30 (29%)	4 (20%)
No. of reasons for contact, 1/2/>2	89/31/5	74/28/3	15/3/2

For dimensional measures the median (range) is given; for most categorical measures the absolute number (percentage) is given.
[a]The non-ASD group includes various diagnosis such as adaptation disorder (n=2); mood disorders (n=5); anxiety disorder (panic; n=3); personality disorder NOS (n=1), psychotic disorder NOS (n=1); schizophrenia (n=3); social phobia (n=2), IntDis (n=1); no ASD but also no other diagnosis given (n=3).
[b]For 16 of the individuals no information was available regarding intellectual status. However, there were also no clues in the chart that gave us any reason to believe that any of them were actually IntDis.
[c]The following comorbid diagnosis were given IntDis, personality disorder (n=1), anxiety (n=3), mood disorder (n=6), addiction (n=2), ADHD (n=1), psychotic characteristics (n=5), language disorder (n=2).
[d]Miscellaneous (Misc) refers to various disorders (e.g. paedophilia (n=2), sexually impulsive (n=1); eating disorder (n=2), attachment problems (n=1), learning disorder (n=1)).
[e]Miscellaneous (Misc) refers to several complaints that could not be fitted into one of the other categories (e.g., suicide attempt, dissociation, enuresis, weird behaviour NOS, no response to external stimuli, difficulties with sexual identity, homosexuality, sexually impulsive, headache, relational crises with partner, adjustment problems, sensitive to sounds, difficulties in organizing life, difficulties in rearing/upbringing, parents recently died, son diagnosed with Asperger syndrome).
Addict: addiction (or substance dependency), AET: autism expert team, ASD: Autism Spectrum Disorder, Delay: developmental delays, Ext: externalizing (aggression, oppositional, conduct disorder characteristics), IntDis: intellectual disability, Lang: language difficulties, MalAdapt: adaptation disorders, MHC: mental health care, Mood: mood disorders/complaints about mood, PDD: pervasive developmental disorder NOS, rep: repetitive behaviour (including OCD-like behaviour), Personality: personality disorder (all personality disorders including personality disorder NOS), Psy: psychotic characteristics (including schizophrenia and dissociative disorders), School: problems related to school, Social: social difficulties with peers.

Is there a difference between those who received an ASD diagnosis and those who did not?

As expected, the ASD group contacted the MHC system earlier, with a mean rank of 57.5, compared with 92.0 in the non-ASD group, $z = -3.91$, $p < .001$. However, the age of AET diagnosis did not differ, $z = -1.23$, $p = .22$ (ASD rank 61.3; non-ASD rank 72.2). Fifty-three percent of the ASD group contacted the MHC system before they reached adulthood (median 8.5 years), and only 20% of the non-ASD group contact the MHC before 18 years of age (median 16 years). There was also a difference of mean 10 years between the two groups when contacting the MHC system in adulthood (median ASD 26 years; non-ASD 37 years). The reasons for referral were diverse in both groups. Thirty-two percent of the participants with ASD received an axis I diagnosis. Axis II diagnoses were present in 51% of the participants, including a large number of intellectual disability diagnoses. Compared with the ASD group, the non-ASD group showed a higher number of earlier diagnoses, $\chi^2(3, n = 125) = 14.34$, exact $p < .005$. Seventy percent received an axis I diagnosis and 20% an axis II diagnosis. Although, groups did not differ in types of lifetime axis I diagnoses, a diagnosis of intellectual disability was less common in the non-ASD group than in the ASD group.

Are there gender differences?

Women were slightly older than men at the age of first contact with the general MHC system (rank 72.8 versus 59.0, $z = -1.94$, $p = .052$). Thirty-one percent of the women contacted the MHC system before adulthood (median 8 years) and 56% of the men (median 9 years). No differences were shown in the age of AET diagnosis or referral reasons, $z = -1.19$, $p = .24$ (women rank 69.1; men rank 60.6). The main two earlier axis I diagnoses (mood and anxiety) were similar in men and women. However, these diagnoses were more common in women (mood 31%; anxiety 22%) than in men (mood 9%; anxiety 8%, both $\chi^2 < .04$). No gender differences emerged in axis II disorders (women intellectual disability 22% and personality disorders 17%; men intellectual disability 36% and personality disorders 14%). However, we did see that women were more often known with an earlier diagnosis than men, $\chi^2(1, n = 125) = 5.44$, exact $p < .03$.

Is there an effect of diagnostic tradition?

A Kruskal-Wallis tests indicated no differences between the three DSM-age groups.

Discussion

The current results show that most adults with ASD were known within the MHC system before they received ASD assessment. The time between this first contact and ASD assessment ranged from 0 to 56 years (median 12 years). Those that finally received an ASD diagnosis contacted the MHC system at an earlier stage than the non-ASD group, but lifetime diagnoses were surprisingly less frequent in the ASD group. The types of earlier diagnoses and reasons for referral did not differ between these groups.

The current study confirmed a high prevalence of comorbid mood and anxiety disorders in ASD (Hofvander et al., 2009; Leyfer et al., 2006; Matson and Nebel-Schwalm, 2007). Psychotic disorders (10%) were reported less frequently than they were by Nylander and Gillberg (2001), who indicated schizophrenia as the main former diagnosis (26%).

However, we included only patients referred for ASD assessment, whereas in the aforementioned study a general population of patients was screened for ASD. ADHD was not a prevalent lifetime diagnosis either, despite clear indications of its comorbidity with ASD (Goldstein and Schwebach, 2004; Hofvander et al., 2009).

Almost one third of the patient group was known with an intellectual disability. After ASD was diagnosed 48% kept this diagnosis, which can be related to diagnostic substitution. (Coo et al., 2008; Shattuck, 2006). Only 14% had a lifetime personality disorder diagnosis, which is much lower than the previously found 62% after administering diagnostic interviews (Hofvander et al., 2009). However, we based our conclusion on charts. In the current sample none of the individuals had an earlier diagnosis of a schizoid personality disorder, which is remarkable, because in particular Asperger syndrome and schizoid personality disorders are often difficult to disentangle (Wolff, 1998).

Males with ASD were not identified earlier than females. Men contacted the general MHC system at slightly younger age, but this did not affect the time of ASD diagnosis. However, the age of first parental concern may be different from the time of the first contact with the general MHC system, and specific ASD categories may be affected differently by gender (Begeer, et al., submitted; Shattuck et al., 2009).

We found no influence of the diagnostic tradition on the pathway to the ASD diagnosis. However, it should be noted that our sample allowed us to study the introduction of the DSM III in 1980, but we did not have sufficient participants to study the influence of the introduction of the DSM-IV, which first included PDD-NOS and Asperger's syndrome as separate categories (American Psychiatric Association, 1994).

The present study did not include standardized clinical interviews for axis I and axis II disorders and intellectual disabilities, which is a limitation. The observed heterogeneity in the diagnostic pathways of adults with ASD and their late diagnosis might be related to mild symptoms, comorbid disorders and high intelligence. However, surprisingly, no specific red flags were found for ASD in the reviewed charts. The current findings do suggest that a younger age at first contact with the general MHC system and a smaller number of lifetime diagnoses increased the chance of an ASD diagnosis after extensive assessment.

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