



King's Research Portal

DOI:

[10.1177/1362361315604271](https://doi.org/10.1177/1362361315604271)

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Russell, A. J., Murphy, C., Wilson, E., Gillan, N., Brown, C., Robertson, D. M., ... Murphy, D. GM. (2016). The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: A clinic report. *Autism*, 20(5), 623-627. <https://doi.org/10.1177/1362361315604271>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: A clinic report

Autism
2016, Vol. 20(5) 623–627
© The Author(s) 2015
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1362361315604271
aut.sagepub.com



Ailsa J Russell¹, Clodagh M Murphy^{2,3}, Ellie Wilson^{2,3}, Nicola Gillan², Cordelia Brown¹, Dene M Robertson^{2,3}, Michael C Craig^{2,3}, Quinton Deeley^{2,3}, Janneke Zinkstok^{2,3}, Kate Johnston^{2,3}, Grainne M McAlonan^{2,3}, Deborah Spain^{2,3} and Declan GM Murphy^{2,3}

Abstract

Growing awareness of autism spectrum disorders has increased the demand for diagnostic services in adulthood. High rates of mental health problems have been reported in young people and adults with autism spectrum disorder. However, sampling and methodological issues mean prevalence estimates and conclusions about specificity in psychiatric co-morbidity in autism spectrum disorder remain unclear. A retrospective case review of 859 adults referred for assessment of autism spectrum disorder compares International Classification of Diseases, Tenth Revision diagnoses in those that met criteria for autism spectrum disorder ($n=474$) with those that did not ($n=385$). Rates of psychiatric diagnosis ($>57\%$) were equivalent across both groups and exceeded general population rates for a number of conditions. The prevalence of anxiety disorders, particularly obsessive compulsive disorder, was significantly higher in adults with autism spectrum disorder than adults without autism spectrum disorder. Limitations of this observational clinic study, which may impact generalisability of the findings, include the lack of standardised structured psychiatric diagnostic assessments by assessors blind to autism spectrum disorder diagnosis and inter-rater reliability. The implications of this study highlight the need for careful consideration of mental health needs in all adults referred for autism spectrum disorder diagnosis.

Keywords

autism spectrum disorders, psychiatric co-morbidity

Introduction

Autism spectrum disorder (ASD) is a life-long neurodevelopmental disorder characterised by deficits in social communication and social interaction across contexts and restricted, repetitive patterns of behaviours, interests and activities (Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-V); American Psychiatric Association (APA), 2013). ASD has been reported to affect approximately 14.67 cases per 1000 of children aged 8 years in the United States (Center for Disease Control and Prevention, 2014). The 3rd National Adult Psychiatric Morbidity Survey established ASD to be present in approximately 1% of the adult population in England (Brugha et al., 2011) with the authors highlighting the numbers of cases without intellectual disability living undetected in the community. ASD is associated with significant healthcare

costs (Buescher et al., 2014). Increasing awareness of adults with ASD has led to evolving demand for services, but research guiding health service provision is limited. Changes in UK government legislation (i.e. the 2009 Autism Act (HM Government, 2009) and the 2010/2014 Autism Strategies (Department of Health, 2010; HM Government, 2014)) recommend need-led services for people with ASD. This is likely to include mental health needs as psychiatric

¹University of Bath, UK

²Kings College London, UK

³South London and Maudsley NHS Foundation Trust, UK

Corresponding author:

Ailsa J Russell, University of Bath, Claverton Down, Bath BA2 7AY, UK.
Email: a.j.russell@bath.ac.uk

co-morbidity in people with ASD is common (Hofvander et al., 2009), particularly attention deficit hyperactivity disorder (ADHD) (Gargaro et al., 2011; Johnston et al., 2013), anxiety disorders (White et al., 2009), obsessive compulsive disorder (OCD) (Russell et al., 2005) and depression (Kim et al., 2000). A large proportion of studies have focused on young people with ASD (e.g. White et al., 2009), and developmental issues pertinent to mental health conditions mean the findings may not have relevance for adults with ASD. Other studies have been disorder specific (e.g. Russell et al., 2005) or potentially subject to sample bias by considering co-morbidity rates in already diagnosed clinic referrals (e.g. Joshi et al., 2013). Hofvander et al. (2009) considered a pooled sample of consecutive referrals to two clinics specialising in adult diagnosis of childhood-onset disorders. Although lacking a suitable comparison group, the authors found high rates of psychiatric co-morbidity particularly anxiety (50%) and mood (53%) disorders, ADHD (43%) and psychotic disorders (12%), leading the authors to conclude that clinical attention to a wide spectrum of psychiatric problems in adults with ASD is of importance. In addition to considering prevalence issues, investigating specificity of co-morbid mental health problems in adults with ASD is also of relevance to clinical service delivery. Furthermore, those seeking diagnostic assessment of possible ASD but who do not have ASD may have other mental health problems. Hence, we investigated the diagnoses given (ASD and otherwise) to adults referred to a national tertiary clinic for assessment of possible ASD to (1) consider the prevalence of a broad range of mental health conditions in adults diagnosed with ASD and (2) identify any differences in co-morbidity between adults with and without an ASD diagnosis.

Method and measures

Participants

Clinical assessments of 937 adults (>18 years old) referred to a national specialist clinic for assessment of possible ASD between April 2003 and September 2011 (8.5-year period) were retrospectively reviewed. The clinic is a national referral centre and over the course of the study may have received referrals from regions/areas with no care pathway for diagnostic assessment of autism in adults as well as highly complex referrals from regions with already specialised services seeking additional support. Individuals with suspected or confirmed intellectual disability were not included in this study in order to reduce the number of confounds and increase the likelihood that any findings in relation to mental health co-morbidity might be autism-specific. Research consent was not available for 73 individuals, no diagnosis was recorded for 1 participant and gender information was absent in 4 cases. Thus, the final sample included 859 participants (645 (75%) male). Clinical referrals were made by general practitioners (GPs) or consultant psychiatrists via extra-contractual commissioning arrangements, indicating sufficient local

concerns to warrant specialist assessment. All referrals were assessed within a standardised format.

Ethical approval was conferred by the local research ethics committee (12/LO/07990).

Diagnostic assessment

Multidisciplinary clinical assessment typically lasted 5–6 h and included neuropsychiatric assessment, social needs, screening questionnaires of psychiatric co-morbidity (anxiety and depression (Hospital Anxiety and Depression Scale), OCD (Obsessive Compulsive Inventory-Revised), ADHD (Berkley Adult ADHD Self Report Rating Scale), ASD (Autism Spectrum Quotient)) and gold-standard, validated ASD assessments; the Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994) where patients consented to parental interview and the Autism Diagnostic Observation Schedule-Generic (ADOS-G) (Lord et al., 2000). The ADI-R was completed for 492 (57.3%) participants and the ADOS for 282 (33.9%). The ADOS was primarily used to supplement diagnostic information by using a standardised tool when no informant was available to complete the ADI-R. Information gathered during the assessment process was reviewed in a multi-disciplinary meeting and ASD diagnosis confirmed via clinical consensus. Diagnoses were made by consultant psychiatrists with expertise in ASD and made according to International Classification of Diseases, Tenth Revision (ICD-10R) research criteria, except ADHD, which, in keeping with UK guidelines, was diagnosed using Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV).

Results

Of the 859 adults, 474 (55.2%) were diagnosed with ASD and 385 (44.8%) were not. There were significant between-group differences in gender and age; ASD males $N=372$ (78.4%), non-ASD males $N=273$ (70.9%), $\chi^2=6.511$ (degree of freedom (d.f.)=1), $p=0.011$; ASD mean age=30.59 (standard deviation (s.d.)=11.18) years, non-ASD mean age=33.54 (s.d.=12.13) years; $t=3.66$ (d.f.=851), $p<0.001$, 95% confidence interval (CI) 1.36–4.52.

Adults diagnosed with ASD: 115 (24.3%) were diagnosed with childhood autism, 212 (44.7%) with Asperger's syndrome, 100 (21.1%) with atypical autism and 47 (9.9%) with pervasive developmental disorder (PDD)-unspecified. Additionally, 275 (58%) received one or more co-morbid psychiatric diagnoses (mean number of co-morbid diagnoses 0.89 (s.d.=0.95), min=0, max=4 (median of 1), 165 (34.8%) received no co-morbid diagnoses and 34 (7.1%) were recommended further assessment. There were no significant gender differences in frequency or type of co-morbid psychiatric diagnosis in the ASD group. There were significant differences in the frequency of diagnosis of OCD across ASD subtypes. OCD was diagnosed in 23

Table 1. Psychiatric co-morbidity in individuals assessed for possible ASD in adulthood.

	ASD group, N (%)	Non-ASD group, N (%)	χ^2 (d.f.), p ^{**}	UK Adult Psychiatric Morbidity Survey 2007 ¹¹	ASD Group and UK Survey ¹¹ χ^2 (d.f. = 1), p ^{**}	Non-ASD group and UK Survey χ^2 (d.f. = 1), p ^{**}
ADHD	46 (9.7)	39 (10.1)	ns	2.3%	ns	Ns
Specific phobia	2 (0.4)	2 (0.5)	ns	All phobias: 1.4%	581.68 ***	333.26***
Agoraphobia	19 (4)	7 (1.8)	ns			
Social phobia	59 (12.4)	47 (12.2)	ns			
Panic disorder	1	0	ns	1.1%	ns	
Generalised anxiety disorder	56 (11.8)	46 (11.9)	ns	4.4%	52.04***	45.08***
OCD	85 (17.9)	51 (13.2)	*3.50(1)	1.1%	603.77***	330.21***
Any anxiety disorder	186 (39.2)	127 (32.9)	*3.58(1)			
PTSD/acute stress reaction	2	0	ns	3%	10.73***	
Depressive episode	75 (15.8)	49 (12.7)	ns	2.3%	259.44***	141.17***
BPAD	4 (0.8)	5 (1.2)	5.760 (2)			
Any mood disorder	95 (20)	86 (22.3)	ns			
Specific personality disorder	4 (0.8)	8 (2.0)	ns	0.7% (antisocial, borderline personality disorders)	ns	8.82**
Psychotic disorder	10 (2.1)	16 (4.1)	ns	0.4%	24.12***	82.22***
Schizophrenia	6 (1.2)	9 (3.2)	ns			
Schizotypal disorder	4 (0.8)	7 (1.8)	ns			
Alcohol dependence	3 (0.6)	10 (2.5)	5.686 (2)	5.9%	23.44***	7.37**
Drug dependence	1	5 (1.2)	ns	3.4%	14.61***	5.07*
Eating disorder	1	0	ns	1.6%	5.72*	
Tic disorder	7 (1.4)	1	ns			
Genetic condition	6 (1.2)	6 (1.5)	ns			

ASD: autism spectrum disorder; d.f.: degree of freedom; ADHD: attention deficit hyperactivity disorder; ns: not significant; OCD: obsessive compulsive disorder; PTSD: post-traumatic stress disorder; BPAD: bi-polar affective disorder.

*p < 0.05; **p < 0.01; ***p < 0.001.

(20%) of adults also diagnosed with childhood autism, 44 (20.7%) of those with Asperger's syndrome and in 18 (12%) adults with PDD-unspecified ($\chi^2=8.705$ (d.f.=3), $p=0.033$).

Adults without ASD: 221 (57.4%) received one or more diagnoses other than ASD (mean number of diagnoses 0.89 (s.d.=0.95), min=0, max=5 (median=1)), 127 (32.9%) received no diagnosis and additional assessments were recommended for 34 (8.8%). There was a significant gender difference in diagnosis of a psychotic disorder (N male=9 (2.3%), 0 female, $\chi^2=3.781$ (d.f.=1), Fisher's exact $p=0.044$). There were no other significant gender differences in diagnosis in this group.

Differences between adults with and without ASD

There was no significant between-group difference in the number of psychiatric diagnoses (excluding diagnosis of ASD). However, there was a significant between-group difference in type of diagnosis (see Table 1); significantly

more adults with ASD were also diagnosed with OCD when compared with the non-ASD group. There was a trend towards a significant difference between the two groups in this study in terms of frequency of diagnosis of any anxiety disorder ($p=0.058$), bi-polar affective disorder ($p=0.056$) and alcohol dependence ($p=0.058$), with the latter two conditions more prevalent in adults without ASD.

Where there was congruence in the labelling and categorisation of mental health conditions, rates of co-morbidity were compared with general population data reported as part of the UK National Psychiatric Morbidity Survey (McManus et al., 2009). It was not possible to make certain comparisons, for example, collapsing the anxiety disorders into a single large group as data were not collated in this way for the purposes of the national survey. 'All phobias' were taken to include specific phobias, agoraphobia and social phobia grouped together.

In terms of the ASD group, there were significant differences between adults with ASD and general population data across a number of diagnostic categories (see Table 1) with 'all phobias', generalised anxiety disorder (GAD), OCD,

current depressive episode and psychotic disorders reported more frequently in adults with ASD. Post-traumatic stress disorder (PTSD), alcohol and drug dependence and eating disorders were more commonly reported in the general population sample. A similar pattern was observed in the adults without ASD when compared with the UK general population survey data (see Table 1).

Discussion

Our findings indicate high rates of clearly diagnosed mental health problems in a relatively large sample of individuals diagnosed with ASD in adulthood, primarily anxiety disorders, OCD, depression and ADHD. This is consistent with the findings of other studies (e.g. Hofvander et al., 2009) where a similar range of conditions was noted to be generally more prevalent in ASD than in general population clinical samples. When compared to a relevant psychiatric control group, that is, adults without ASD attending the same clinic, OCD was the single condition identified significantly more frequently in adults with ASD.

OCD and anxiety disorders, including agoraphobia, social phobia and GAD, and psychosis occurred in a greater proportion of adults with ASD when compared with rates from the UK national psychiatric morbidity survey (McManus et al., 2009). This was also observed in the adults without ASD suggesting that such difficulties, although common in ASD, may not be autism-specific. Comparison with the UK general population survey suggested that several conditions, for example, PTSD, alcohol and drug dependence and eating disorders, were under-represented in the referrals to the ASD clinic. It is possible that such conditions are more easily identifiable with clear care pathways in mainstream services. Of note, rates of ADHD were not significantly greater in the clinic sample when compared to general population data. It is possible that an associated specialist ADHD clinic within the same set of services meant many referrals were diverted away from the ASD clinic.

Our findings suggest that a significant proportion of adults referred for assessment of possible ASD do not meet ICD-10R diagnostic criteria for ASD, and also do not meet diagnostic criteria for other mental health problems. Thus, ASD diagnostic clinics need to consider a broad spectrum of mental health co-morbidity and onward care pathways for the majority of adults referred for assessment. This is consistent with the conclusions of Hofvander et al. (2009).

Our findings highlight the need for evidence-based, cost-effective community mental health services for adults with ASD. There is preliminary evidence that unmet needs arising from psychiatric co-morbidity in young adults with ASD increase the burden on both individual and carer(s) (Cadman et al., 2012). There is a need for accessible, evidence-based mental health care for adults with ASD including comprehensive assessments of possible ASD

and co-morbid mental health difficulties. There is evidence that psychological interventions adapted for adults with ASD can be effective (see Spain et al., 2014 for review) and this is promising in light of the high rates of OCD, mood and anxiety disorders in this group.

Limitations

Limitations include the absence of structured diagnostic instruments of co-morbidity and absence of inter-rater diagnostic reliability data. Findings may not be generalisable to all adults with ASD, including those with intellectual disability, those not referred to tertiary clinics or where ASD was diagnosed in childhood. However, neuropsychiatric/multi-disciplinary assessments were robust and included ICD-10R criteria and gold-standard ASD assessment.

Implications

Assessment of possible ASD in adults should include thorough diagnostic assessments including gold-standard assessments (ADI-R and ADOS), valid screening instruments and careful consideration of psychiatric co-morbidity both in the presence and absence of ASD.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

References

- American Psychiatric Association (APA) (2013) *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: APA.
- Brugha TS, McManus S, Bankart J, et al. (2011) Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry* 68(5): 459–466.
- Buescher A, Cidav Z, Knapp M, et al. (2014) The cost of autism spectrum disorders in the United Kingdom and the United States of America. *Journal of the American Medical Association of Pediatrics* 168(8): 721–728.
- Cadman T, Eklund H, Howley D, et al. (2012) Caregiver burden as people with autism spectrum disorder and attention-deficit hyperactivity disorder transition into adolescence and adulthood in the United Kingdom. *Journal of the American Academy of Child & Adolescent Psychiatry* 51(9): 879–888.
- Centers for Disease Control and Prevention (2014) Prevalence of autism spectrum disorder among children aged 8 years - Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR* 63(SS02): 1–21.
- Department of Health (2010) *Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England*. London: The Stationery Office Ltd.
- Gargaro B, Rinehart N, Bradshaw JL, et al. (2011) Autism and ADHD: how far have we come in the comorbidity debate? *Neuroscience and Biobehavioral Reviews* 35(5): 1081–1088.
- H.M. Government (2009) *Autism Act*. London: The Stationery Office Ltd.

- H.M. Government (2014) *Think Autism: Fulfilling and Rewarding Lives, the Strategy for Adults with Autism in England: An Update*. London: The Stationery Office Ltd.
- Hofvander B, Delorme R, Chaste P, et al. (2009) Psychiatric and psychological problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry* 9(35): 1–9.
- Johnston K, Dittner A, Bramham J, et al. (2013) Attention deficit hyperactivity disorder (ADHD) symptoms in adults with autism spectrum disorders. *Autism Research* 6(4): 225–236.
- Joshi G, Wozniak J, Petty C, et al. (2013) Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: a comparative study. *Journal of Autism and Developmental Disorders* 43: 1314–1325.
- Kim JA, Szatmari P, Bryson SE, et al. (2000) The prevalence of anxiety and mood problems among children with autism and Asperger syndrome. *Autism* 4: 117–132.
- Lord C, Risi S, Lambrecht L, et al. (2000) The Autism Diagnostic Observation Schedule – Generic: a standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders* 30(3): 205–223.
- Lord C, Rutter M and Le Couteur A (1994) Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders* 24: 659–685.
- McManus S, Meltzer H, Brugha T, et al. (eds) (2009) *Adult Psychiatric Morbidity in England 2007: Results of a Household Survey*. London: NHS Information Centre for Health and Social Care.
- Russell AJ, Mataix-Cols D, Anson M, et al. (2005) Obsessions and compulsions in Asperger syndrome and high-functioning autism. *British Journal of Psychiatry* 186: 525–528.
- Spain D, Sin J, Chalder T, et al. (2014) Cognitive behavior therapy for adults with autism spectrum disorders and psychiatric co-morbidity: a review. *Research in Autism Spectrum Disorders* 9: 151–162.
- White SW, Oswald D, Ollendick T, et al. (2009) Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review* 29: 216–229.