



Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study



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Summary

Background Asperger's syndrome in adulthood is frequently associated with depression, but few studies have explored the lifetime experience of self-reported suicidal ideation and suicide plans or attempts in this clinical group. We aimed to assess this prevalence in a clinical cohort of patients in the UK.

Method In a clinical cohort study, we undertook a retrospective analysis of clinical survey data from adults newly diagnosed with Asperger's syndrome at a specialist diagnostic clinic between Jan 23, 2004, and July 8, 2013, in England. Patients completed a self-report questionnaire before clinical assessment, recording lifetime experience of depression, suicidal ideation, and suicide plans or attempts, along with self-reported measures of autistic traits and empathy. We compared the rate of suicidal ideation in the sample with published rates of suicidal ideation in the general population and other clinical groups. We also assessed associations between depression, autistic traits, empathy, and likelihood of suicidal ideation and suicide plans or attempts.

Findings 374 adults (256 men and 118 women) were diagnosed with Asperger's syndrome in the study period. 243 (66%) of 367 respondents self-reported suicidal ideation, 127 (35%) of 365 respondents self-reported plans or attempts at suicide, and 116 (31%) of 368 respondents self-reported depression. Adults with Asperger's syndrome were significantly more likely to report lifetime experience of suicidal ideation than were individuals from a general UK population sample (odds ratio 9.6 [95% CI 7.6–11.9], $p < 0.0001$), people with one, two, or more medical illnesses ($p < 0.0001$), or people with psychotic illness ($p = 0.019$). Compared with people diagnosed with Asperger's syndrome without depression, people with Asperger's syndrome and depression were more likely to report suicidal ideation ($p < 0.0001$) and suicide plans or attempts ($p < 0.0001$).

Interpretation Our findings lend support to anecdotal reports of increased rates of suicidal ideation in adults with Asperger's syndrome, and depression as an important potential risk factor for suicidality in adults with this condition. Because adults with Asperger's syndrome often have many risk factors for secondary depression (eg, social isolation or exclusion, and unemployment), our findings emphasise the need for appropriate service planning and support to reduce risk in this clinical group.

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Introduction

The autism spectrum is a set of heterogeneous neurodevelopmental conditions, characterised by difficulties in social communication and unusually restrictive and repetitive behaviours and interests.¹ Although the term autism spectrum disorder is widely adopted, autism spectrum condition avoids the negative overtones of the disorder label, while recognising autism as a medical diagnosis for which individuals need support. Asperger's syndrome is a subgroup on the autism spectrum,² showing core symptoms in the absence of language delay or intellectual disability. A clinical diagnosis is often delayed until about 11 years of age,³ or even into adulthood,^{4–6} compared with the average age of 5 years for a diagnosis of classic autism. Transition into adulthood for people with Asperger's syndrome is often accompanied

by a lack of support services⁷ and poor outcomes in terms of health and social difficulties,^{8,9} quality of life, achievement of occupational potential,¹⁰ social exclusion and isolation,^{9,11} and high rates of depression.^{12,13}

Depression is a risk factor for completed suicide, and more than 90% of people who die by suicide have depression.¹⁴ In view of the evidence for high incidence of poor outcomes and depression in adults with Asperger's syndrome, these individuals might be at particular risk of experiencing suicidal ideation and suicide plans or attempts. However, very few studies have explored suicidality in this group. Suicidal ideation is anecdotally reported to be very common in people with Asperger's syndrome, especially in adolescence and early adult life. According to Gillberg,¹⁵ suicidal acts in Asperger's syndrome are anecdotally reported to be quite frequent

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from the onset of puberty, and can be associated with a preoccupation with death, a reaction to stress associated with a depressive disorder, social isolation, low self-esteem, or feelings of social exclusion.

The scarce empirical evidence available (just four studies^{8,16–18}) suggests that suicidal ideation and attempts are common in individuals with autism spectrum conditions. First, parent-reported rates of suicidal ideation and attempts are significantly higher for children with autism (14%) than for typically developing children (0.5%).¹⁶ Second, the rate of suicidal ideation and attempts in 102 young people with autism spectrum conditions and comorbid anxiety was 11%.¹⁷ Third, in a small community sample of 42 adults with Asperger's syndrome, the rate of suicidal ideation was 40% and the rate of suicide attempts was 15%.⁸ Finally, in 26 adult psychiatric patients diagnosed with autism spectrum conditions, 30.8% presented with suicidal ideation and two had died by suicide.¹⁸ However, the lifetime experience of suicidal ideation and suicide plans or attempts in a large sample of adults with Asperger's syndrome, how it compares with other clinical groups, and what risk factors (particularly depression) are associated with suicidality in adults with Asperger's syndrome, is unclear from these studies.

The Cambridge Lifespan Asperger Syndrome Service (CLASS) is a specialist diagnostic clinic established in 1999 with charitable funding because the UK National Health Service (NHS) did not recognise the clinical needs of adults seeking late diagnosis of possible Asperger's syndrome. The clinic provides a diagnostic service to adults in recognition that many adults with possible Asperger's syndrome but born before 1994 (when Asperger's syndrome was finally recognised in the Diagnostic and Statistical Manual of Mental Disorders IV¹⁹ and the WHO International Classification of Diseases 10²⁰) would have been missed. In 2011, the clinic became part of the Cambridgeshire and Peterborough NHS Foundation Trust, following the UK Parliament's Autism Act (2010) and the UK Department of Health's Autism Strategy (2011), making the provision of such clinics a statutory requirement. Because existing gold standard diagnostic instruments for autism spectrum conditions (the Autism Diagnostic Interview—Revised²⁰ and the Autism Diagnostic Observation Schedule²¹) miss up to 50% of adults with a diagnosis of Asperger's syndrome or high-functioning autism²² because they were designed to detect autism spectrum conditions in childhood, the CLASS clinic developed a diagnostic tool for adults, called the Adult Asperger Assessment.²³ This test is based on (but is more stringent than) the criteria in the Diagnostic and Statistical Manual of Mental Disorders IV.¹⁹ We analysed survey data from a large clinical cohort of people with Asperger's syndrome to compare rates of suicidal ideation with known rates in the general population and other clinical groups, and explore risk factors for

suicidal ideation and suicide plans or attempts (ie, depression and self-reported autistic symptoms) in this population.

Methods

Participants

Between Jan 23, 2004, and July 8, 2013, the CLASS clinic in Cambridge, UK, routinely administered a patient screening questionnaire before appointments to all individuals newly diagnosed with Asperger's syndrome. Diagnoses were made on the basis of a face-to-face interview by an expert clinician, who used both the Adult Asperger Assessment²³ and clinical judgment, with input from an informant (usually a parent) who knew the patient in their early childhood when possible. We identified participants from the CLASS clinic database.

Ethics approval for the study to migrate anonymised clinic data into the Cambridge University Autism Research Centre for research purposes was granted by the Cambridge University Psychology Research Ethics Committee, with approval by the Cambridgeshire and Peterborough NHS Foundation Trust Research and Development Office.

Assessment

All patients were required to complete a self-report patient screening questionnaire before being invited for further clinical assessment. Relevant questions were “have you ever been diagnosed with depression?”, “have you ever felt suicidal?”, and “if yes, have you ever planned or attempted suicide?”. Patients posted the questionnaire back in a freepost envelope before the appointment. The responses to these questions were entered into a clinic database with the demographic details and diagnostic outcome of each patient. These data were gathered as part of the routine practice of the clinic. If patients reported any lifetime experience of suicidality or depression, it was explored further during a face-to-face clinical assessment interview.

Patients were also screened before their appointment with the Empathy Quotient,²⁴ a self-report questionnaire that quantifies individual differences in empathy. Scores range from 0 to 80, with highest scores suggesting greatest empathy. Empathy Quotient scores can show sex differences (with typically developing women on average scoring higher than typically developing men), and individuals with autism on average scoring lower than typically developing men.²⁴ 80% of patients with Asperger's syndrome score less than 30 on the Empathy Quotient, compared with 12% of the general population.²⁴

Patients were asked to complete the Autism Spectrum Quotient questionnaire, which measures the degree to which an adult with average or above-average intelligence has cognitive-behavioural traits associated with autism.²⁵ Scores range from 0 to 50, with highest scores suggesting most autistic traits. The Autism Spectrum Quotient has consistently showed higher

	16–24 years	25–34 years	35–44 years	45–54 years	55–64 years	65–74 years	Missing	Total
Men (n=256)								
Suicidal ideation	60% (53/89)	60% (44/73)	72% (34/47)	70% (23/33)	75% (6/8)	0 (0/1)	0 (1/252)	64% (161/252)
Suicide plans or attempts	28% (25/89)	33% (24/73)	37% (17/46)	33% (11/33)	14% (1/7)	0 (0/1)	0 (1/250)	32% (79/250)
Depression	30% (27/91)	35% (25/71)	28% (13/46)	30% (10/33)	25% (2/8)	0 (0/1)	0 (1/251)	31% (78/251)
Women (n=118)								
Suicidal ideation	66% (29/44)	64% (21/33)	89% (25/28)	75% (6/8)	100% (1/1)	0 (0/1)	0 (0/115)	71% (82/115)
Suicide plans or attempts	39% (17/44)	39% (13/33)	46% (13/28)	50% (4/8)	100% (1/1)	0 (0/1)	0 (0/115)	42% (48/115)
Depression	22% (10/45)	32% (11/34)	46% (13/28)	50% (4/8)	0 (0/1)	0 (0/1)	0 (0/117)	33% (38/117)
All adults (n=374)								
Suicidal ideation	62% (82/133)	61% (65/106)	79% (59/75)	71% (29/41)	78% (7/9)	0 (0/2)	0 (1/367)	66% (243/367)
Suicide plans or attempts	32% (42/133)	35% (37/106)	41% (30/74)	37% (15/41)	25% (2/8)	0 (0/2)	0 (1/365)	35% (127/365)
Depression	27% (37/136)	34% (36/105)	35% (26/74)	34% (14/41)	22% (2/9)	0 (0/2)	0 (1/368)	32% (116/368)

Data are n/N (%), for which n is number of respondents who answered yes to the survey question and N is number of respondents who answered the survey question.

Table 1: History of depression, suicidal ideation, and suicide plans or attempts in individuals diagnosed with Asperger’s syndrome, stratified by age group and sex

	16–24 years	25–34 years	35–44 years	45–54 years	55–64 years	65–74 years	Missing	Total
Men (n=78)								
Suicidal ideation	81% (22/27)	76% (19/25)	85% (11/13)	100% (10/10)	100% (2/2)	0 (0/0)	1% (1/78)	83% (65/78)
Suicide plans or attempts	41% (11/27)	44% (11/25)	31% (4/13)	50% (5/10)	50% (1/2)	0 (0/0)	1% (1/78)	42% (33/78)
Women (n=38)								
Suicidal ideation	89% (8/9)	82% (9/11)	92% (12/13)	100% (4/4)	0 (0/0)	0 (0/0)	0 (0/37)	89% (33/37)
Suicide plans or attempts	56% (5/9)	64% (7/11)	62% (8/13)	75% (3/4)	0 (0/0)	0 (0/0)	0 (0/37)	62% (23/37)
All adults (n=116)								
Suicidal ideation	83% (30/36)	78% (28/36)	88% (23/26)	100% (14/14)	100% (2/2)	0 (0/0)	1% (1/115)	85% (98/115)
Suicide plans or attempts	44% (16/36)	50% (18/36)	46% (12/26)	57% (8/14)	50% (1/2)	0 (0/0)	1% (1/115)	49% (56/115)

Data are n/N (%), for which n is number of respondents who answered yes to the survey question and N is number of respondents who answered the survey question. A female patient who reported depression but provided no information about suicidal ideation is not included.

Table 2: Suicidal ideation and suicide plans or attempts in people diagnosed with Asperger’s syndrome who reported a history of depression, stratified by age and sex

	Obsessive-compulsive disorder	Eating disorder	Attention-deficit hyperactivity disorder	Tourette’s syndrome	Borderline personality disorder	Dyspraxia	Dyslexia
Men (n=256)	3 (1%)	1 (0%)	2 (1%)	1 (0%)	0	3 (1%)	2 (1%)
Women (n=118)	1 (1%)	1 (1%)	2 (2%)	0	1 (1%)	1 (1%)	1 (1%)
Total (n=374)	4 (1%)	2 (1%)	4 (1%)	1 (0%)	1 (0%)	4 (1%)	3 (1%)

Table 3: Number of patients with comorbid diagnoses, stratified by sex

mean scores in those with autism spectrum conditions than in typically developing individuals.^{25–27} 80% of patients with Asperger’s syndrome score 32 or higher on the Autism Spectrum Quotient, compared with only 2% of the general population.²⁵ Empathy Quotient and Autism Spectrum Quotient scores were fed into the Adult Asperger Assessment electronically, before the assessment, providing guidance to the clinician about how to gather evidence for symptoms causing impairment in functioning. Because the Empathy Quotient and Autism Spectrum Quotient are collected before the

appointment, they also serve as a confirmation that the referral is likely to be an appropriate use of clinic time, because each appointment takes up to 3 h.

We identified comparison samples from the general population, general medical population, and psychiatric population through searches of Medline, PsycINFO, and Google Scholar for reports published between Jan 1, 1995, and Sept 20, 2013, with the general search term “suicid*” in combination with search terms for each disorder (eg, “ADHD”, “autism”). To be eligible for inclusion, studies had to include self-report questions on the lifetime experience of suicidal ideation in adult men and women between 16 and 75 years of age.

Statistical analyses

We anonymised data in Microsoft Excel 2010 and analysed the results in PASW Statistics version 18.0. We used Pearson’s χ^2 tests to explore associations between sex, depression, and suicidal ideation and suicide plans or attempts, and to compare lifetime experience of suicidal ideation in the present sample with that of other

clinical groups. We calculated odds ratios (ORs) and 95% CIs as a measure of effect size. We used Bonferroni-corrected independent samples *t* tests to compare Autism Spectrum Quotient scores, Empathy Quotient scores, and age between participants who reported depression, suicidal ideation, or suicide plans or attempts.

Role of the funding source

The funders had no role in the study design, data collection, analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and final responsibility for the decision to submit for publication.

Results

374 adults attending the CLASS clinic were diagnosed with Asperger's syndrome between Jan 23, 2004, and July 8, 2013. Informants were available for 355 (95%) participants. The mean age at diagnosis was 31.5 years (range 17–67, SD 10.9) and 87 (23%) participants were in full-time education at the time of assessment.

256 (68%) respondents were men. Seven (2%) participants did not complete the question about suicidal ideation, six (2%) did not complete the question about depression, and nine (2%) did not complete the question about planned or attempted suicide. About a third of respondents had a lifetime experience of self-reported history of depression; about two-thirds had lifetime experience of suicidal ideation; and about a third had planned or attempted suicide (table 1). Lifetime experience of depression ($p=0.787$), suicidal ideation ($p=0.164$), and suicide plans or attempts ($p=0.06$) did not differ significantly between men and women (table 1). Individuals with a history of depression (table 2) were more likely to report suicidal ideation (OR 4.3, 95% CI 2.4–7.7; $p<0.0001$) and more likely to report suicide plans or attempts (OR 2.4, 95% CI 1.5–3.8; $p<0.0001$) than were those without any history of depression. A small number (all <2%) of patients had any comorbid diagnoses (table 3). Individuals who reported suicide plans or attempts had significantly higher Autism Spectrum Quotient scores than those who did not (table 4). Empathy Quotient scores and ages did not differ between individuals who did or did not report suicide plans or attempts (table 4). Patients with self-reported depression or suicidal ideation did not have significantly higher Autism Spectrum Quotient scores, Empathy Quotient scores, or age than did those without depression or suicidal ideation (table 4).

Adults with Asperger's syndrome in this sample were more likely to report lifetime experience of suicidal ideation than were individuals from a general UK population sample (OR 9.6, 95% CI 7.6–11.9; $p<0.0001$)²⁸ or people with one medical illness (OR 5.8, 95% CI 4.6–7.4; $p<0.0001$),²⁹ two or more medical illnesses (OR 3.6, 95% CI 2.7–4.9; $p<0.0001$),²⁹ or psychotic illness (OR 1.3, 95% CI 1.0–1.7; $p<0.019$).³⁰ Adults with Asperger's syndrome were not more likely to

	Age (years)	Autism Spectrum Quotient score	Empathy Quotient score
Ideation			
Yes	32.1 (10.8)	38.0 (6.6)	17.6 (9.8)
No	30.3 (11.2)	36.6 (7.6)	15.9 (9.5)
Plans or acts			
Yes	31.4 (10.1)	38.7 (6.5)*	17.3 (10.1)
No	31.6 (11.4)	36.8 (7.2)*	16.9 (9.6)
Depression			
Yes	31.8 (10.3)	38.5 (6.8)	17.8 (10.5)
No	31.3 (11.3)	37 (7.1)	16.6 (9.4)

Data are mean (SD). * $p=0.011$.

Table 4: Mean age, Autism Spectrum Quotient score, and Empathy Quotient score, by outcome measure

	Prevalence	Population size	p value for comparison with present study
Adults with Asperger's syndrome (present study)	66.2%	367	..
General population (England) ²⁷	16.7%	7323	<0.0001
Adults with one medical illness ²⁸	25.2%	1901	<0.0001
Adults with two or more medical illnesses ²⁸	35.0%	406	<0.0001
Adults with psychotic illness ²⁹	59.3%	1048	0.019
Adults with cocaine or opioid dependence and attention-deficit hyperactivity disorder ³⁰	66.3%	92	0.99

Table 5: Comparison of prevalence of suicidal ideation

report lifetime experience of suicidal ideation than were people with both drug dependency and attention-deficit hyperactivity disorder ($p=0.99$; table 5).³¹

Discussion

Our findings of a 66% lifetime experience of suicidal ideation and a 35% lifetime experience of planned or attempted suicide supports the assertion that these occurrences are common in people with Asperger's syndrome. In our sample, the lifetime experience of suicidal ideation was more than nine times higher than in the general population in England,²⁸ and significantly higher than rates previously reported in other clinical groups with medical²⁹ and psychotic³⁰ illnesses (panel). People with Asperger's syndrome were significantly more likely to report suicidal ideation or plans or attempts at suicide if they also had depression. Individuals who planned or attempted suicide also had a significantly higher level of self-reported autistic traits than those who did not. Although determination of the direction of causation for this increase in risk is not possible, the fact that more people in this sample reported lifetime

Panel: Research in Context**Systematic review**

We identified articles by searching Medline, PsycINFO, and Google Scholar in September, 2013, with the general search term "suicid*" in combination with search terms for autism spectrum conditions (eg, "autism", "Asperger", etc). No age or date restrictions were applied to the search.

Interpretation

We identified four studies exploring suicidality in autism spectrum conditions. The few previous studies of suicidality in autism spectrum conditions have shown that these individuals are at high risk of suicidal ideation and behaviours. Only one study was done in adults with Asperger's syndrome, with no comparison sample, so the potential role of risk factors (eg, depression) or how the lifetime experience of suicidal ideation, plans, and attempts in adults with Asperger's syndrome compares with that of other clinical groups is not clear. We studied a unique cohort of individuals diagnosed with Asperger's syndrome as adults to explore their lifetime experience of suicidal ideation and plans or attempts by comparison with other clinical groups. In this first, large-scale clinical study, we noted that adults with confirmed Asperger's syndrome were significantly more likely to report lifetime experience of suicidal ideation than were individuals from a general UK population sample, or a sample with one, two, or more medical illnesses, or a sample with psychotic illness. Individuals with Asperger's syndrome were also significantly more likely to report suicidal ideation or plans or attempts at suicide if they also had depression. Those who planned or attempted suicide also had a significantly higher level of self-reported autistic traits than those who did not. Our findings support anecdotal reports of increased rates of suicidal ideation in adults with Asperger's syndrome, and identify depression as a significant risk factor for suicidality in these individuals. This study emphasises the need for more detailed studies into the triggers and experience of suicidal ideation, and the risk and protective factors for suicide plans and attempts in adults with Asperger's syndrome, to inform appropriate service planning and support to reduce risk in this clinical group.

experience of suicidal ideation (66%) than were depressed (31%) is puzzling, and could suggest a different process for suicidal ideation in Asperger's syndrome than for other clinical groups. Alternatively, this finding might result from under-reporting of depression, perhaps because of alexithymia (difficulties verbally describing subjective emotional experience).^{32,33}

The lifetime experience of suicidal ideation reported in our clinic sample was higher than that noted in a previous small sample of adults with Asperger's syndrome living in the community (40%),⁸ and in a small sample of 26 adult psychiatric patients diagnosed with autism spectrum conditions (30.8%).¹⁸ This difference might be because individuals in our cohort had not been diagnosed with Asperger's syndrome until late in adulthood, with a mean age at diagnosis of 31 years compared with the usual average age of 11 years.³ Thus, many of these individuals had difficulties such as social exclusion, unfulfilled educational potential, difficulties with getting or keeping a job or being promoted, and difficulties with developing close relationships, which could have been exacerbated through lack of appropriate support throughout their lives. Delayed diagnosis in adulthood could possibly be another risk factor for suicidal ideation and plans or attempts in people with Asperger's syndrome.

Our study has several limitations. First, the sample only represents the population of people who reach adulthood without a diagnosis of Asperger's syndrome and who subsequently seek assessment. We do not know if these results can be generalised to the population who have Asperger's syndrome identified in childhood. We also cannot say anything about those adults who do not seek a diagnosis of Asperger's syndrome but who might be struggling, undiagnosed, in the community. Second, comparisons with other studies could not be closely matched for age, sex, or other risk factors. Nonetheless, the scale of the differences suggests that a significant difference would remain even these factors could be controlled for. The patient questionnaire used in the current study had not been previously validated for use in the current sample, and included both plans and attempts at suicide in the same question. Because lifetime experience of planning and attempting suicide were collapsed into one item of the patient screening questionnaire, disentanglement of these two related but distinct outcomes, or comparison with previously established rates in previous studies (in which these outcomes are recorded separately), was not possible. Future research could explore whether people with Asperger's syndrome are more likely to engage in suicide attempts without planning than are people in the general population or other clinical groups. Lifetime experience of depression, suicidal ideation, and suicide plans or attempts were all measured through a self-report questionnaire completed before the clinic assessment; whether this method led to underestimation or overestimation of these outcomes is not clear. However, all comparisons of suicidal ideation in other clinical groups also included similar self-report measures of the lifetime experience of suicidal ideation, to ensure that group differences were not confounded by differences in reporting methods.

More detailed studies are needed into the triggers and experience of suicidal ideation, the risk-promoting and protective factors for suicide plans and attempts in adults with Asperger's syndrome (such as age at diagnosis), and family history of suicide and aggression. In addition to the social factors known to predispose to depression, the cognitive profile of people with Asperger's syndrome might further increase the rate and risk of suicidality. For example, cognitive flexibility can be impaired, and might mediate some of the increased suicidality. On the basis of our findings, services should be alerted to the high lifetime risk of suicidal ideation and suicide plans or attempts, especially in individuals receiving a late diagnosis of Asperger's syndrome, in view of the substantial risk in this group.

Contributors

SC and PB did the literature search. SB-C conceived of the study and SC, PB, JR, and SB-C designed the study. SC and PB prepared the tables. PB, JR, MM, and SB-C collected the data. SC did the data analysis and interpretation. SC, PB, and SB-C wrote the report, and CA, JR, and MM critically revised the report. All authors approved the final submitted version.

Declaration of interests

We declare no competing interests.

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