

Original Article

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Gender differences in psychosocial function and self-reported health status in late-diagnosed autistic adults: results from the FACE-ASD national cohort

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Abstract

Background. While adult outcome in autism spectrum disorder (ASD) is generally measured using socially valued roles, it could also be understood in terms of aspects related to health status – an approach that could inform on potential gender differences.

Methods. We investigated gender differences in two aspects of outcome related to health-status, i.e. general functioning and self-perceived health status, and co-occurring health conditions in a large multi-center sample of autistic adults. Three hundred and eighty-three participants were consecutively recruited from the FondaMental Advanced Centers of Expertise for ASD cohort (a French network of seven expert centers) between 2013 and 2020. Evaluation included a medical interview, standardized scales for autism diagnosis, clinical and functional outcomes, self-perceived health status and verbal ability. Psychosocial function was measured using the Global Assessment of Functioning scale.

Results. While autistic women in this study were more likely than men to have socially valued roles, female gender was associated with poorer physical and mental health (e.g. a 7-fold risk for having three or more co-occurring physical health conditions) and a poorer self-perceived health status. Psychosocial function was negatively associated with depression and impairment in social communication. Half of the sample had multiple co-occurring health conditions but more than 70% reported that their visit at the Expert Center was their first contact with mental health services.

Conclusions. To improve objective and subjective aspects of health outcome, gender differences and a wide range of co-occurring health conditions should be taken into account when designing healthcare provision for autistic adults.

Introduction

Autism spectrum disorder (ASD, hereafter referred to as autism) is a frequent and often serious neurodevelopmental disorder (Lai, Lombardo, & Baron-Cohen, 2014). Co-occurring mental and physical health conditions are frequent in autistic persons – herein we will use identity-first language to refer to autistic people – and are associated with poor functional outcomes and a generally poor quality of life (Lai et al., 2019; Mason et al., 2018; Weir, Allison, Warrier, & Baron-Cohen, 2021).

Having socially valued roles (e.g. living independently and being employed or studying, being married or a parent) is often used to define 'good' adult outcome in autistic people (Mason et al., 2021a). According to Mason et al. (2021a) meta-analysis, one in five autistic persons will have a 'good' adult outcome (i.e. living independently and being employed/studying) and one in four people a 'fair' adult outcome (i.e. living independently or being employed/student).

Although for many having meaningful social roles could have positive effects on wellbeing and quality of life (Mason et al., 2018; McCauley, Pickles, Huerta, & Lord, 2020b; Moss, Mandy, & Howlin, 2017), some autistic persons may find social roles challenging as they can result in increased negative experiences (e.g. loss of employment, social isolation, failed



relationships, sexual abuse), poorer mental health and a reduced quality of life (Howlin, 2021; Lounds Taylor, 2017; Moss et al., 2017; Pecora, Hancock, Mesibov, & Stokes, 2019). Besides, some of the typical adult experiences – based on socio-cultural norms, roles and expectations in the general population such as finding a job, living in relationship or becoming parent – are not necessarily central or meaningful for every autistic individual and may therefore not be adequate markers of adult outcome in this population (Howlin, 2021).

Good mental health generally contributes to objective (e.g. impact of health status on functional outcome) and subjective (e.g. self-perceived health status and perceived impact on well-being) aspects of adult outcome (Lounds Taylor, Adams, & Bishop, 2017; McCauley et al., 2020b; Park et al., 2019). However, these associations could depend on the level of social support (Bishop-Fitzpatrick et al., 2016). Aligning with this, depressive symptoms in autistic people diagnosed during early childhood often peak in early adulthood in relation to increased social expectations and challenges but also less support from providers (McCauley, Elias, & Lord, 2020a). This could be particularly true for late-diagnosed autistic young adults who achieved positive outcomes without receiving any formal support from transition or mental health services.

Self-reported gender is a prominent facet of a person's identity influencing the experience of autism. According to the 'female autism phenotype' (i.e. a behavioral expression of autism that could be more common in women; Hull et al., 2020), while autistic women have similar core autistic symptoms compared with men, they also tend to report poorer mental and physical health and a reduced quality of life (Brugha et al., 2016; Dubreucq & Dubreucq, 2021; Hull et al., 2020; Taylor & DaWalt, 2020; Tint et al., 2018). Given autistic women tend to report more often than men to be involved in a relationship or to be a parent (Power et al., 2013; Schöttle, Briken, Tüscher, & Turner, 2017), this could be related to the impact of gendered social, norms, roles, pressures and expectations on a person's wellbeing and sense of identity (Dubreucq & Dubreucq, 2021; Kanfisz, Davies, & Collins, 2017).

According to Lai, Anagnostou, Wiznitzer, Allison, and Baron-Cohen (2020), support for autistic adults should be strengths-based, person-centered and should aim at maximizing the individual's potential, minimizing barriers and optimizing the person-environment fit. This includes early diagnosis, improving social communication, coping with sensory experiences, treating co-occurring physical health and mental health conditions, encouraging family support and reducing stigma (Howlin, 2021; Lai et al., 2020; Mason et al., 2021a).

In France, based on the above findings, the need to improve early diagnosis, to treat co-occurring health conditions and to offer personalized strengths-based care for autistic individuals led the Ministry of Research and the Ministry of Health to support the development of a national network of Expert Centers for ASD, coordinated by the foundation FondaMental since 2012 (<http://www.fondation-fondamental.org>; see Henry et al. (2015) and Schürhoff et al. (2015) for a description of Expert Centers in other conditions such as bipolar disorder or schizophrenia).

This paper presents data on objective (i.e. general functioning and socially valued roles) and subjective (i.e. self-perceived health status) aspects of adult outcome and co-occurring health conditions from a large national multi-centric non-selected sample of 383 autistic adults and no co-occurring intellectual disability

(ID). The main aims of this study were to examine the relationship between health status and general functioning and potential gender differences in adult outcome. We made the following research hypotheses:

- 1) Although good mental health usually contributes to better adult outcome (Brugha et al., 2016; Lord et al., 2022; McCauley et al., 2020a, 2020b; Park et al., 2019), we hypothesized that general functioning would be positively associated with depression in a sample composed of late-diagnosed autistic adults (i.e. who may have been confronted to challenges in early adulthood but received less support from providers; Bishop-Fitzpatrick et al., 2016; McCauley et al., 2020a). We also hypothesized that general functioning would be negatively associated with impairment in social communication.
- 2) According to the literature reviewed above (Brugha et al., 2016; Dubreucq & Dubreucq, 2021; Hull et al., 2020; Taylor & DaWalt, 2020; Tint et al., 2018), we hypothesized that there would be gender differences in aspects of adult outcome related to health status (i.e. comparable objective outcomes but poorer mental and physical health and poorer self-reported health status in autistic women).
- 3) While associations between verbal ability or female gender and co-occurring health conditions can vary according to sample characteristics (e.g. age and sample composition; Day, McNaughton, Naples, & McPartland, 2020; McCauley et al., 2020b), given the nature and age of our sample (i.e. late-diagnosed autistic adults) we made the hypothesis that female gender and verbal ability – two factors linked to compensation (Bargiela, Steward, & Mandy, 2016; Hull et al., 2020) – would be associated with more co-occurring physical and mental health conditions.
- 4) Finally, we hypothesized that people reporting first contact with psychiatric services at the visit at the expert center would have fewer co-occurring health conditions than those with a psychiatric history (Fusar-Poli, Brondino, Politi, & Aguglia, 2022).

Material and methods

Study population

The FondaMental Advanced Centers of Expertise for ASD (FACE-ASD) cohort is made up of participants assessed in a French network of seven Expert Centers for ASD without co-occurring ID (Créteil, Bordeaux, Grenoble, Versailles, Marseille, Caen, Strasbourg). Participants are referred to these centers by their general practitioner or psychiatrist who remains in charge of routine care and treatment, or they are self-referred. The criteria for inclusion in the cohort were: (i) diagnosis of autism (DSM-5; APA, 2013); (ii) age above 18 years; (iii) without co-occurring ID (i.e. IQ > 70). The exclusion criteria were: (i) inability to read or speak French; (ii) non-willingness to give informed consent. However, the present study was restricted to data collected at baseline for participants with a confirmed diagnosis of autism.

During the evaluation, a systematic and comprehensive clinical, functional and cognitive assessment is performed to confirm the diagnosis and establish the individual's strengths and weaknesses, autonomy, and occupational level (online Supplementary Table S1). Follow-up is planned to last for 3 to 5 years. At the end of each evaluation, a detailed evaluation report is sent to

the patient and the referring physician along with a personalized care program including the rationale for pharmacological and psychosocial treatment recommendations. Psychosocial treatment includes psychoeducation, cognitive remediation, cognitive behavioral therapy, social skills training, peer-support interventions, supported employment and supported parenting. The relevant Ethical Review Board (CPP- Est IV) approved the appraisal protocol on 18 June 2019. All participants gave their informed consent.

Site selection and training

All seven sites in France were already actively involved in the treatment of autistic people, as well as in research on autism or psychiatric rehabilitation. Each Expert Center has agreed and been trained to use the same package of assessment tools. Clinical team members have monthly group meetings to monitor quality control, to ensure a good inter-rater reliability and to provide training in new therapeutic interventions. During these meetings, clinical cases of potential autism with or without potential co-occurring health conditions (e.g. depression) are also discussed to minimize case ascertainment differences between sites. Case ascertainment procedures are described in online Supplementary Table S4.

Data collection

Screening visit

Social responsiveness is evaluated with the parent-reported and self-reported Social Responsiveness Scale- 2nd version (Constantino and Gruber, 2012; Cronbach's alpha = 0.94–0.96; Stordeur, Boele, Peyre, Delorme, and Acquaviva, 2019). Self-reported autistic symptoms are measured using Ritvo Autism-Asperger Diagnostic Scale (Picot et al., 2021).

Diagnostic evaluation

The diagnostic evaluation includes: (i) the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994; Rutter, Lecouteur, & Lord, 2011) to investigate the developmental history and the informant-reported past and current autistic symptoms; (ii) the Autism Diagnostic Observation Schedule-2nd version (ADOS-2; Lord et al., 1989; Lord, Rutter, DiLavore, & Risi, 2015) for current autistic symptoms. When ADI-R is not realizable (e.g. parents not available to participate in the evaluation), the Asperger Syndrome Diagnostic Interview (Gillberg, Gillberg, Råstam, & Wentz, 2001) is used alternatively to investigate informant-reported autistic symptoms with one of the person's close relatives other than parents (e.g. the partner).

Medical and cognitive evaluation

General information on education, social outcome, co-occurring mental and physical health conditions and healthcare services utilization is recorded. A medical interview by a trained psychiatrist (DSM-5 criteria) and the Diagnostic Interview for Genetic Studies (DIGS, Nurnberger et al., 1994) are used to record co-occurring mental health and physical health conditions. Intellectual quotient is measured using the Wechsler Adult Intelligence Scale-4th edition (WAIS-IV; full scale and subscales; verbal comprehension index for verbal ability and perceptual reasoning index for non-verbal ability; Wechsler, 2011).

Adult outcome in relation to health status

Health is defined as a 'state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity' (WHO, 2014). Health encompasses both objective (e.g. impact of health status on functional outcome) and subjective outcomes (e.g. self-perceived health status and perceived impact on wellbeing). We therefore measured two aspects of health status that can be associated with adult outcome: clinician-rated general functioning and self-perceived health status.

General functioning: General functioning was measured using the Global Assessment of Functioning scale (GAF; Startup, Jackson, and Bendix, 2002). While GAF is not commonly used in autism, its simplicity, its generic nature (i.e. not related to a specific diagnostic group) and its good psychometric properties – in particular in contexts where raters are adequately trained – supported its selection as a measure of functional outcome. As socially valued roles may not be appropriate benchmarks in autism (Howlin, 2021), raters were also told to consider impairment only in outcomes participants identified as desirable for them (e.g. work for some people but not for others). Given concerns have been raised about GAF validity and reliability in routine clinical contexts (Aas, 2010), regular meetings and training sessions for raters were organized to ensure a good inter-rater reliability.

Self-perceived health status: Self-perceived health status was measured using the self-report EQ-5D-DL scale (score ranging from 0 to 100; five domains including self-care, mobility, pain/discomfort, anxiety/depression and ability to perform everyday activities; Johnson, Coons, Ergo, and Szava-Kovats, 1998).

Statistical analysis

Data are presented as the mean and s.d. for continuous variables and number and percentage for categorical variables. For comparison between groups, χ^2 or Fisher exact test was used for categorical variables Spearman's correlation test, Kruskal-Wallis rank sum test or linear model ANOVAS for continuous variables. Univariate significance *p* values were computed, and covariates significant at the 10% level were included in a multivariable logistic regression model. Age, gender, education and verbal ability were forced in the final model as confounding factors. The first question was to investigate the correlates of adult outcome. Psychosocial function (GAF continuous score) was retained as the predictor for the first multivariate analysis and self-perceived health status as the predictor for the 2nd multivariate analysis. The second question was to determine whether there would be gender differences in adult outcomes in univariable analyses. The third question was to investigate the correlates of co-occurring health conditions. Considering that most of the sample (>80%) had at least one co-occurring health condition, we retained respectively having three or more physical health conditions and having three or more mental health conditions as the predictors for the 3rd and the 4th multivariable analyses. The fourth question was to determine whether people reporting first contact with psychiatric services at the visit at the expert center (>70%) differed from those with past psychiatric history (i.e. inpatient or outpatient care). Thus, we retained reporting first contact with psychiatric services at the visit at the Expert Center as the predictor for the fifth multivariate analysis. *p* values < 0.05 were considered significant. All statistical analyses were performed using R (R Foundation for Statistical Computing, Vienna, Austria; <https://www.R-project.org/>; R Core Team, 2015).

Results

Three hundred and eighty-three autistic persons were recruited from the FACE-ASD network. They had been included in this cohort study between 2013 and 2020. All participants were diagnosed with autism in adulthood, during the evaluation at the expert centers. Participants were mostly men (262; 68.4%) with a mean age and a mean age of diagnosis of 28.1 (s.d. = 10.9) years. The overall IQ was 108.4 (s.d. = 19.6) and the mean ADOS-2 social communication score was 10.9 (s.d. = 4.5). Baseline sample characteristics are presented in Table 1 (see online Supplementary Table S2 for a presentation by gender).

Overall functioning

Two hundred and sixty-nine participants (82.5%) had high school education and 202 (64.3%) had tertiary education. Participants were mostly single (208; 79.7%), unemployed (232; 72.5%) and had no children ($n = 221$; 86.3%). They had mild to moderate functional impairment (GAF-F = 57.6; s.d. = 9.4). Eighty-five participants (33.5%) met the criteria for good functional outcome.

Co-occurring health conditions

Participants had on average 2.9 [s.d. = 2.4; (0–10); median = 3.00] co-occurring mental health and 2.5 [s.d. = 1.9; (0–9)]; median = 2.00) physical health conditions. Approximately half of the sample had three or more co-occurring mental health or physical health conditions (respectively 53.3 and 49.4%). The most frequent co-occurring conditions were anxiety disorder ($n = 227$; 73.2%), depression (lifetime; $n = 151$; 49%; current, $n = 87$; 27.3%), sleep disorders (53.4%), gastro-intestinal problems ($n = 150$; 45.7%) and rheumatology/autoimmune conditions ($n = 137$; 41.5%). The visit at the Expert Center was the first contact with mental health services for most participants (232; 73.4%). Seventy-three participants (23%) reported a history of psychiatric hospitalization. Data on co-occurring health conditions and healthcare services utilization are shown on Table 1.

Correlates of clinician-report general functioning

Table 2 shows a multivariable analysis of the correlates of psychosocial function. Psychosocial function was best predicted by the absence of depression, impairment in social communication and verbal ability.

Gender differences in adult outcome

Table 3 presents the univariable gender differences in adult outcome. Compared to men, autistic women reported more often to be a parent, to have previous contact with mental health services and to have co-occurring mental health conditions (eating disorders, self-harm behaviors and history of suicide attempt) and a general poorer quality of life.

Correlates of self-perceived health status

Table 4 shows a multivariable analysis of the correlates of self-perceived health status. Self-perceived health status was negatively associated with the female gender.

Correlates of co-occurring health conditions

Table 5 presents the results of a multivariate analysis on the correlates of having three or more co-occurring physical health conditions. Having three or more co-occurring physical health conditions was best predicted by female gender, higher verbal abilities and social communication impairments. Table 6 presents the results of a multivariate analysis on the correlates of having three or more co-occurring mental health conditions. Having three or more co-occurring mental health conditions was only predicted by verbal ability.

Correlates of having first contact with psychiatric services

Those reporting that the visit to the expert center was the first contact with psychiatric services did not differ significantly from the other participants. The results are shown on online Supplementary Table S3.

Discussion

Main findings

To our knowledge, this study is the first to examine the correlates of two aspects of adult outcome related to health status, i.e. general functioning and self-perceived health status, in a national multi-center sample of late-diagnosed autistic adults and no co-occurring ID. One third of the sample reported ongoing depression and half of the sample reported three or more co-occurring mental and physical health conditions. Contrary to expectations from our first hypothesis, general functioning was negatively associated with co-occurring depression. We found however as expected a negative association between general functioning and impairment in social communication. Our 2nd hypothesis was supported by the results. Although we found no gender differences in objective markers of outcome (e.g. social communication impairment or verbal ability), autistic women in this study were more likely to have socially valued roles than men (significant association for being parent; trends for significance for tertiary education and intimate relationships). Female gender was associated with poorer physical and mental health (e.g. a 7-fold risk for having three or more co-occurring physical health conditions) and poorer self-perceived health status. Supporting our 3rd hypothesis, the verbal ability was associated with higher risk for having three or more co-occurring physical health conditions. Contrasting with our 4th hypothesis, autistic persons reporting first contact with psychiatric services did not differ from those with past psychiatric history.

Interpretation of the results

Adult outcome

Participants' GAF mean score was also comparable to those reported by Cederlund, Hagberg, Billstedt, Gillberg, and Gillberg (2008) and Helles, Gillberg, Gillberg, and Billstedt (2017). One in four participants in this study were employed, one in five were in a romantic relationship and one in seven were parents. While the heterogeneity of previous samples, methods and reported outcomes limits the possibilities of comparisons between studies, the low proportion of people reporting to have socially valued roles in the present study concur with findings from other studies (Farley et al., 2018; Helles et al., 2017; Howlin & Moss, 2012; Power et al., 2013; Strunz et al., 2017).

Table 1. Sample characteristics

Gender	
Male [N (%)]	262 (68.4%)
Female [N (%)]	121 (31.6%)
Age	
Mean (s.d.)	28.1 (10.9)
[min-max]	[17-65]
Marital status	
Single	208 (79.7%)
In a couple	53 (20.3%)
Parenting status	
Non-parents	221 (86.3%)
Parents	35 (13.7%)
Vocational status	
Unemployed	232 (72.5%)
Employed	88 (27.5%)
Highest education level at the time of admission	
High school	269 (82.5%)
University	202 (64.3%)
Having two or more socially valued roles	37 (9.6%)
Global Assessment of Functioning (GAF)	
Mean score (s.d.)	57.58 (9.36)
[min-max]	[45-75]
Good adult outcome (GAF \geq 61)	85 (33.5%)
ADOS Total social communication	
Mean score (s.d.)	10.9 (4.5)
[min-max]	[3-21]
Social Responsiveness Scale (SRS)	
Mean score (s.d.)	94 (30)
[min-max]	[17-183]
EQ5D5L_SCORE	
Mean score (s.d.)	0.7 (0.2)
[min-max]	[0-1]
Empathy Quotient (EQ)	
Mean score (s.d.)	25.3 (11.1)
[min-max]	[7-65]
IQ total	
Mean score (s.d.)	108.9 (18.7)
[min-max]	[79-154]
Verbal IQ	
Mean score (s.d.)	117.2 (18.1)
Co-occurring mental health condition	
Mean score (s.d.)	2.9 (2.4)
[min-max]	[0-10]
Depression (lifetime)	
N (%)	151 (49%)

Depression (current)	
N (%)	87 (29.3%)
Self-harm	
N (%)	81 (29.3%)
History of suicide attempt	
N (%)	33 (12%)
Anxiety disorder	
N (%)	227 (73.2%)
ADHD	
N (%)	43 (15.1%)
Eating disorder	
N (%)	27 (8.8%)
Substance use disorders	
N (%)	53 (17.2%)
Sleep disorders	
N (%)	148 (53.4%)
Psychotic disorder	
N (%)	25 (8.3%)
Bipolar disorder	
N (%)	5 (1.7%)
Co-occurring physical health condition	
Mean (s.d.)	2.5 (1.9)
[min-max]	[0-9]
Epilepsy	
N (%)	12 (4%)
Otorhinolaryngology /Ophthalmology	
N (%)	238 (72.3%)
Cardiovascular conditions	
N (%)	51 (15.6%)
Pneumology/Allergic conditions	
N (%)	155 (47.3%)
Rheumatology/Dermatology/Autoimmune conditions	
N (%)	155 (47.3%)
Gastro-intestinal disorder	
N (%)	150 (45.7%)
Neurology	
N (%)	70 (21.7%)
Oncology	
N (%)	7 (2.1%)
Genetic conditions	
N (%)	17 (5.6%)

Gender differences in adult outcome

Compared with autistic men, autistic women in this study had similar impairments in social communication but had poorer subjective adult outcomes (i.e. increased self-harm and suicidal history; more co-occurring physical health conditions and a

Table 2. Linear regression on the correlates of general functioning

Predictors	Global Assessment of Functioning		
	Estimates	CI	<i>p</i>
(Intercept)	51.3693	38.8179–63.9207	<0.001
Rheumatology (Yes v. No)	1.0217	–2.3105 to 4.3539	0.548
Anxiety (Yes v. No)	–0.3898	–3.9344 to 3.1549	0.829
Depression (Yes v. No)	–3.8471	–7.0669 to –0.6272	0.019
Gastro-intestinal disorder (Yes v. No)	1.9938	–1.2533 to 5.2409	0.229
Age	–0.0414	–0.2030 to 0.1201	0.615
ADOS_2 social communication total score	–0.5766	–0.9768 to –0.1765	0.005
WAIS IV verbal ability	0.1555	0.0567–0.2544	0.002
Gender (Female)	–2.8474	–6.2411 to 0.5462	0.100
History of psychiatric hospitalization (Yes v. No)	–2.0429	–6.2479 to 2.1621	0.341
History of suicide attempt (Yes v. No)	1.0097	–3.8440 to 5.8635	0.683
Sleep disorder (Yes v. No)	–1.8032	–5.2155 to 1.6092	0.300
Observations	105		
<i>R</i> ²	0.317		

GAF, Global Assessment of Functioning.

Bold values refer to values significant at $p < 0.05$.

worse self-perceived health status). This pattern of outcome concurs with previous findings (Hull et al., 2020; Kassee et al., 2020; Kölves, Fitzgerald, Nordentoft, Wood, & Erlangsen, 2021; Weir et al., 2021). Autistic women in this study were more likely than men to have socially valued roles. While this concurs with some studies (Strunz et al., 2017; Tint et al., 2018), this is in contrast with other studies that reported no gender differences in adult social outcome (DaWalt et al., 2020; McCauley et al., 2020b; Myers, Davis, Stobbe, & Bjornson, 2015) or greater difficulties for autistic women to maintain tertiary education positions over time (Taylor, Henninger, & Mailick, 2015).

Several factors could contribute to this pattern of gender differences. First, gendered social norms roles, expectations and pressures can have an impact on a person's sense of identity and wellbeing (e.g. social pressures related to motherhood considered by some autistic women as stress-triggering and a daunting life experience; Kanfisz et al., 2017). Second, while autistic women are more likely to be involved in a relationship or parent than autistic men, they also report challenges related to these socially valued roles (e.g. increased risk for sexual or domestic abuse; Bargiela et al., 2016; Pecora et al., 2019; peripartum depression, feelings of social isolation in the postnatal period, or communication difficulties with perinatal health providers; Pohl, Crockford, Blakemore, Allison, & Baron-Cohen, 2020). Third, compared with autistic men, autistic women often report more unmet needs related to their mental health concerns, to vocational services and to reproductive health issues; Brugha et al., 2016; Dubreucq & Dubreucq, 2021; Taylor & DaWalt, 2020; Tint & Weiss, 2018). Aligning with this, autistic women are more likely to be undiagnosed or misdiagnosed than autistic men even in epidemiological studies (Brugha et al., 2016; Loomes, Hull, & Mandy, 2017).

Another potential explanation to these gender differences could be that autistic men, presumed to have poorer social function, are more often referred to expert centers, whereas only autistic

women with severe social communication impairments are referred. Autistic women in this study were more likely to report previous contact with psychiatric services compared with autistic men. Aligning with this, some studies suggested that autistic women may be more likely than men to receive alternative prior psychiatric diagnoses that are no longer present after autism diagnosis, possibly delaying their access to diagnosis and adequate support from mental health services (Brugha et al., 2016; Fusar-Poli et al., 2022; Kentrou, Oostervink, Scheeren, & Begeer, 2021; Leedham, Thompson, Smith, & Freeth, 2020; Loomes et al., 2017).

Factors associated with general functioning

Aligning with previous studies on adult outcome (Lounds Taylor et al., 2017; McCauley et al., 2020b; Park et al., 2019), good mental health, low impairments in social communication and verbal ability (i.e. verbal knowledge and verbal reasoning) were associated with better general functioning.

Contrasting with Fusar-Poli et al. (2022), autistic adults who reported first contact with mental health services at the visit at the expert center – the majority of the sample – did not differ from those with previous psychiatric history. This suggests that autism remains under-detected and that the current healthcare service provision does not meet the needs of autistic people (Lai et al., 2019; MacManus, Bebbington, Jenkins, & Brugha, 2016; Weir et al., 2021). Efforts should therefore be made to improve the access to early diagnosis and to adequate healthcare, i.e. the provision of the standardized diagnostic evaluation, treatment of co-occurring health conditions and strengths-based psychosocial treatment to optimize the person-environment fit and to improve social inclusion (Lai et al., 2019).

Co-occurring health conditions

In line with Lai et al. (2014), most of the participants (76.2%) reported at least one co-occurring mental health condition and more than 50% reported multiple co-occurring mental health

Table 3. Gender differences in adult outcome (univariate)

	N (%)		p value
	Men (N = 262)	Women (N = 121)	
Parents			0.008
No	171 (91.4%)	74 (79.6%)	
Yes	16 (8.6%)	19 (20.4%)	
University			0.083
No	82 (39.2%)	30 (28.6%)	
Yes	127 (60.8%)	75 (71.4%)	
In couple			0.087
No	167 (88.4%)	76 (80%)	
Yes	22 (11.6%)	19 (20%)	
Employed			1
No	22 (28.2%)	13 (28.9%)	
Yes	56 (71.8%)	32 (71.1%)	
First contact with mental health services			0.012
No	46 (21.9%)	38 (35.8%)	
Yes	164 (78.1%)	68 (64.2%)	
History of suicide attempt			0.001
No	171 (92.9%)	72 (78.3%)	
Yes	13 (7.1%)	20 (21.7%)	
History of psychiatric hospitalization			1
No	162 (76.8%)	82 (77.4%)	
Yes	49 (23.2%)	24 (22.6%)	
Sleep disorder			0.217
No	91 (50%)	38 (41.3%)	
Yes	91 (50%)	54 (58.7%)	
Eating disorder			<0.001
No	198 (97.1%)	82 (79.6%)	
Yes	6 (2.9%)	21 (20.4%)	
Self-harm injury			<0.001
No	145 (79.2%)	51 (55.4%)	
Yes	38 (20.8%)	41 (44.6%)	
Substance use disorder			0.787
No	166 (82.2%)	90 (84.1%)	
Yes	36 (17.8%)	17 (15.9%)	
	Mean (s.d.)		
EQ-5D5L	0.8 (0.2)	0.6 (0.2)	<0.001
ADOS total social communication	11.1 (4.3)	10.4 (4.9)	0.302
WAIS IV verbal ability	116.9 (17.8)	117.6 (18.8)	0.636

Bold values refer to values significant at $p < 0.05$.

conditions. The mean number of co-occurring mental health conditions was comparable with the findings of Joshi et al. (2013) in a middle-aged sample of autistic people without co-occurring ID.

Table 4. Linear multivariable regression on the correlates of self-perceived health status (EQ5D)

Predictors	Self-perceived health status (EQ5D_SCORE)		
	Estimates	CI	p
(Intercept)	0.8204	0.5227–1.1181	<0.001
Age	0.0004	–0.0035 to 0.0043	0.843
ADOS_2 social communication total score	–0.0046	–0.0138 to 0.0046	0.323
WAIS IV verbal ability	0.0002	–0.0021 to 0.0025	0.874
Gender: Female	–0.1657	–0.2495 to –0.0819	<0.001
Observations	108		
R ² /R ² adjusted	0.309/0.247		

Bold values refer to values significant at $p < 0.05$.

Table 5. Logistic regression on the correlates of having three or more co-occurring physical health conditions

Predictors	Three or more co-occurring physical health conditions		
	Odds Ratios	CI	p
(Intercept)	0.00	0.00–0.01	0.003
Age	1.01	0.93–1.09	0.896
GAF	1.03	0.97–1.11	0.340
WAIS IV verbal ability	1.06	1.02–1.11	0.008
Gender: Female	6.81	1.75–36.78	0.011
In relationship: (Yes v. No)	0.73	0.11–5.49	0.743
Parenting status: (Yes v. No)	1.24	0.13–14.22	0.856
Tertiary education: (Yes v. No)	1.16	0.26–4.97	0.842
History of psychiatric hospitalization: (Yes v. No)	0.69	0.13–3.93	0.665
History of suicide attempt (Yes v. No)	1.95	0.20–27.16	0.574
ADOS_2 social communication total score	1.24	1.07–1.48	0.008
Observations	88		
R ² Tjur	0.307		

GAF, Global Assessment of Functioning. Bold values refer to values significant at $p < 0.05$.

Having three or more co-occurring mental health conditions was positively associated with verbal knowledge and reasoning – two domains related to higher insight into autism-related challenges and poorer mental health (Livingston & Happé, 2017; Livingston, Colvert, Bolton, & Happé, 2019; McCauley et al., 2020a).

The high frequency of co-occurring physical health conditions in autistic people in this study concurs with recent meta-analyses (Rydzewska, Dunn, & Cooper, 2021; Weir et al., 2021). In line with these studies, we found that the female gender was associated with a 7-fold risk for having three or more co-occurring physical health conditions. Aligning with Kólves et al. (2021), we found no

Table 6. Logistic regression on the correlates of having three or more co-occurring mental health conditions

Predictors	Three or more co-occurring mental health conditions		
	Odds Ratios	CI	p
(Intercept)	0.04	0.00–1.91	0.03
Age	1.02	0.97–1.09	0.599
GAF score	0.99	0.93–1.06	0.812
WAIS IV verbal ability	1.03	1.00–1.06	0.026
Gender: (Female)	1.49	0.60–3.85	0.398
In relationship: (Yes v. No)	2.16	0.36–18.70	0.432
Parenting status: (Yes v. No)	0.21	0.02–1.35	0.117
Tertiary education: (Yes v. No)	0.79	0.26–2.28	0.674
History of psychiatric hospitalization(Yes v. No)	2.25	0.68–9.15	0.211
History of suicide attempt: (Yes v. No)	5.98	1.02–115.03	0.102
Observations	133		
R ² Tjur	0.264		

GAF, Global Assessment of Functioning.

Bold values refer to values significant at $p < 0.05$.

association between suicidal history and the number of co-occurring physical health conditions.

Clinical implications

With replication, this study may have clinical implications. First, we found distinct patterns of associations when considering gender differences in objective (i.e. general functioning) and subjective aspects of health-related adult outcome (i.e. co-occurring mental health conditions and self-perceived health status). Aligning with findings from other studies (Brugha et al., 2016; Dubreucq & Dubreucq, 2021; Hull et al., 2020; Tint et al., 2018), while autistic women in this study were more likely to have social roles than autistic men, they also reported poorer health outcomes. This further supports the need to improve autistic women's access to diagnosis, to adequate treatment and more generally to service provision that could address their unique challenges and needs for care (e.g. provider training to the female autism phenotype or extra support in the domains of romantic relationships and reproductive health; Dubreucq & Dubreucq, 2021; Hull et al., 2020; Strang et al., 2020).

Second, co-occurring physical health conditions are common and are associated with poorer adult outcomes, but remain often under-detected and under-treated (Rydzewska et al., 2021; Weir et al., 2021). The barriers to seeking care include impairment in social communication, negative experiences with healthcare providers and healthcare providers' lack of knowledge about autism/about the female autism phenotype (Calleja, Islam, Kingsley, & McDonald, 2020; Dubreucq & Dubreucq, 2021; Mason et al., 2019; Tint & Weiss, 2018). Information and training on how to provide adequate care to autistic persons (e.g. improving providers' knowledge about autism, reducing barriers to communication of one's health needs) directed to healthcare providers are therefore needed (Calleja et al., 2020; Mason et al., 2021b, 2022; Weir et al., 2021).

Limits

This study has also a number of limitations. Although our network of Expert Centers for autism covers a large proportion of the French territory, it cannot be definitively asserted that it constitutes a representative sample of the French population of autistic people. Besides, given the discrepancy between highly frequent co-occurring health conditions in autistic adults and a healthcare utilization that does not differ from the general population (MacManus et al., 2016), non-epidemiological studies may be only representative of people who present to or are known to mental health services (Brugha et al., 2016). Moreover, the present sample is constituted of autistic persons diagnosed during adulthood, which may limit the extension of some results to other populations. Considering the criteria for defining adult outcome in autism, the cross-sectional nature of this study may be a limitation as the subjective aspects of adult outcome (e.g. self-perceived health status) refer to a process rather than an outcome and thus may vary over time. The use of the DIGS- an interview which has not been designed to guide the examiner on how to disentangle symptoms that could be due to autism from symptoms related to other neuro-developmental conditions- to screen for potential co-occurring health conditions is a substantial limitation as it may lead to artificial inflation of these conditions rates (Clark, Cuthbert, Lewis-Fernández, Narrow, & Reed, 2017; Reed et al., 2019). This limitation could be addressed through the implementation of the forthcoming revised WHO-SCAN interview. However, the monthly organization of meetings between clinical team members from all centers and the attention given to this issue in the case ascertainment procedure used by all sites might have reduced this risk. The absence of autistic individuals with co-occurring ID is another limitation, as it cannot be asserted that our results are also valid for this population. While socially valued roles may not be appropriate benchmarks in autism, our choice to define adult outcome using a measure of general functioning is a limitation as it limits the possibility to make direct comparisons with the results of other adult follow-up studies. While it cannot be asserted this definition, which relies mainly on a restricted health-related measure of functional outcome, is more valid than the usual definition of good adult outcome based on socially valued roles, raters were told to consider functional impairment only in outcomes participants identified as desirable for them. While concerns were raised about GAF's validity and reliability in routine clinical settings (Aas, 2010), the organization of regular training sessions/inter-rater meetings might have reduced this limitation. However, the implementation of more general measures of quality of life, commonly used and validated in autism (e.g. the WHO-QoL-Bref; Ayres et al., 2018) is needed.

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Author contributions. The authors had full access to the data in the study and take the responsibility for the integrity of the data and the accuracy of the data analysis. Dr Julien Dubreucq drafted the article and made the literature review. Mr Mohamed Lajnef conducted the statistical analysis. Dr Romain Coutelle, Dr Ophélie Godin, Pr Mario Speranza and Pr Marion Leboyer contributed to the interpretation of data and critically revised the article. All the authors were involved in the collection and analysis of the data. All authors contributed to and have approved the final manuscript.

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