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**Aging and autism: Do measures of autism symptoms, co-occurring mental health conditions, or quality of life differ between younger and older autistic adults?**

**Running title:** Age, symptoms and QoL in autistic adults

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## **Abstract**

Previous research has indicated that autistic adults experience higher rates of co-occurring mental health difficulties and poorer quality of life (QoL) than their non-autistic peers. Little is known, however, about these aspects in older age or whether younger and older autistic adults experience similar patterns. This cross-sectional study investigated potential age-related effects on autism symptoms, self-reported mental health and QoL in younger and older autistic adults (n=79, aged 19-71 years) compared to a non-autistic control group (n=57) matched for gender, age and IQ. Results showed that autistic adults had higher levels of self-reported autism symptoms and poorer QoL than controls. There were no significant age effects on autism symptoms or on most self-rated mental health symptoms. However, significantly more autistic adults in the younger versus older group scored above the clinical threshold for anxiety, somatoform disorders and eating disorders. Older autistic adults rated social QoL as significantly better than younger autistic adults; there was no significant age difference in the control group. Self-reported QoL was best predicted by self-ratings of severity of depressive symptoms in both groups. Further research is needed to track autism and co-occurring mental

health symptomatology across the lifespan, so that service provision can be tailored accordingly.

*Keywords:* Autism spectrum disorder, adults, mental health, quality of life, aging

## **Lay Summary**

Young autistic adults have reported more psychological difficulties and poorer quality of life (QoL) than the general population. We investigated whether these difficulties continue into older age. Autism symptoms and mental health problems were common in autistic adults, with no difference between age groups, except for anxiety, physical and eating problems. Although QoL was poorer in both younger and older autistic compared to non-autistic adults, older autistic adults reported better social QoL than those who were younger.

## **Introduction**

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition, yet much of the research to date has focused on children, adolescents, and young adults. Establishing the mental health needs, wellbeing, and profiles of autism symptoms in older autistic adults is clearly important for service development and delivery. The aim of the current paper was to examine age-related differences between younger and older autistic adults, on self- and clinician-rated autism symptoms, self-reported mental health, and quality of life (QoL).

Until recently, only a limited number of papers - mainly case studies, online surveys, mini-reviews or discussion papers (Mukaetova-Ladinska, Perry, Baron, & Povey 2012; Ruggieri Gómez, Martínez & Arberas, 2019; Wise, 2020) - addressed autism-related difficulties in older age (usually defined as age 50 years plus; Roestorf et al., 2019). These have been supplemented by some longitudinal studies examining age-related differences in autistic adults diagnosed in

childhood (e.g., see Mason et al., 2021) and group studies examining age effects in autistic individuals predominantly diagnosed in adulthood (Happé et al., 2016; Lever & Geurts, 2018). However, although studies about aging in autism are increasing, research in this area is still limited. (Mason, Stewart, Capp & Happé, 2022; Tse et al., 2021).

To our knowledge, only one study has examined age-related effects on autism symptoms in older autistic adults. Lever and Geurts (2018) reported a non-linear relationship between age and self-reported autism symptoms in a sample with a wide age-range (19-79, mean=46 years). Results showed that older (53-79 years) autistic adults reported more autism symptoms than younger (19-40 years) autistic adults; middle-aged (40-53 years) autistic adults reported more symptoms than either group. In contrast, a longitudinal study of individuals diagnosed in the 1960's and 70's (Howlin, Moss, Savage & Rutter, 2013), that included some participants aged 50+, found that autism symptoms decreased significantly with age (from mean age 26 years to mean age 46 years). The findings of cross sectional studies are also mixed.. Happé et al. (2016) reported higher self-rated autism symptoms with greater age in a group of 94 adults (aged 18-55, mean=30 years) attending an autism diagnostic clinic; Autism-Spectrum Quotient (AQ; Baron-Cohen et al., 2001) scores increased by 2.19 points with every decade. Using the same measure, however, Bishop and Seltzer (2012) reported no significant associations between age and self-reported autism symptoms in autistic adults (n=65 aged 18-52 years). Taken together, there is some suggestion that autistic traits may change over time, yet to date, studies have focused more on adults in middle age than those who are older.

Autistic adults report high rates of co-occurring mental health conditions. The estimated prevalence of current mental health problems is over 50% in the majority of clinical and community-based studies of autistic adults (e.g., Buck et al., 2014; Roy, Prox-Vagedes,

Ohlmeier, & Dillo, 2015; Stuart-Hamilton & Morgan, 2011). Co-occurring mental health conditions are diverse, but anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), and obsessive-compulsive disorder (OCD) are common (Hollocks et al. , 2019; Lugo-Marín et al., 2019). A handful of studies has examined age-related effects on mental health conditions in older autistic adults and results are somewhat conflicting. Totsika, Felce, Kerr and Hastings (2010) and Lever and Geurts (2016) found fewer mental health conditions in older (n=87, aged 50-90 years and n=48, aged 55-79 years, respectively) compared to younger (n=194, aged 18-49 years and n=124, aged 19-54 years, respectively) autistic adults. Roy et al. (2015) reported the opposite pattern, with higher rates in older (n=24, aged 40-62 years) than younger (n=26, aged 20-39 years) autistic adults. In a recent study, Uljarević and colleagues (2020) found no significant difference in anxiety or depression between adults in three age bands (20-39 years, n=97; 40-64 years, n=70; 65-80 years n=11). Younger adult studies have reported no significant relationship between age and co-occurring psychiatric conditions (Mazurek, 2014; Moss et al., 2015). However, in a recent meta-analysis of studies across the lifespan, including those with autistic children and older adults, Lai and colleagues (2019) reported lower rates of ADHD, but higher rates of depression, bipolar disorder and schizophrenia with increasing age.

It is worth noting that there is a great deal of variability in prevalence rates of mental health conditions among non-autistic older people (Blazer, 2009). Although some statistics suggest lower rates of mental health problems in later-life, this may be related to how samples are selected, differences in symptom presentation, and reluctance among older adults to disclose mental health difficulties (Bryant, Jackson & Ames, 2008). A recent report found that 15% of older people received help for a mental health condition (AgeUK, 2019;

[https://www.ageuk.org.uk/globalassets/age-uk/documents/policy-positions/health-and-wellbeing/ppp\\_mental\\_health\\_england.pdf](https://www.ageuk.org.uk/globalassets/age-uk/documents/policy-positions/health-and-wellbeing/ppp_mental_health_england.pdf)).

Although many autistic adults experience a much poorer quality of life (QoL) than individuals in the general population, this is not invariably the case and some studies have found quality of life scores for autistic participants lie within the normative range (Moss, Mandy & Howlin, 2017; Oakley et al., 2021). Similarly, findings regarding the association between QoL and other factors vary, depending on the measures and sources of information involved (Moss et al., 2017). Overall, quality of life does not appear to be directly related to age (Howlin et al., 2013; Kim & Bottema-Beutel, 2019; Otsuka, et al., 2017; Renty & Roeyers, 2006; Totsika et al., 2010; van Heijst & Geurts, 2015). IQ has been reported as a significant correlate of QoL in some studies (higher IQ, more positive outcomes; Cederlund et al., 2008; Eaves & Ho, 2008; Howlin et al., 2013) but van Heijst and Geurts (2015) found no correlation between QoL and IQ in older autistic adults. Kim and Bottema-Beutel (2019) also reported no significant relationship with IQ, although higher QoL was correlated with better social functioning. Several studies have reported an association between poorer quality of life and more severe autism symptoms and/or co-occurring psychiatric conditions (Howlin et al., 2013; Mason et al., 2018; 2019; Moss et al., 2015; Oakley et al., 2021). However, other research (Heijst & Geurts, 2015; Kim & Bottema-Beutel, 2019) has failed to find a relationship between quality of life and autism symptom severity.

A recent survey of autistic adults identified research into mental health and quality of life as a major priority (Benevides et al., 2020). Nevertheless, existing data on factors associated with quality of life and mental health in autism are inconsistent and sometimes conflicting. This is due, at least in part, to wide heterogeneity in participant characteristics across studies and

variability in the assessment measures used. The relatively small numbers of older autistic participants (i.e., 50-60 years plus) also limits our knowledge about trajectories beyond middle age, and studies of older autistic adults are particularly important to allow better planning for their needs and wellbeing in later life. To this end, the present study investigated autism symptoms in younger and older autistic adults; we also compared self-reported mental health symptoms and QoL in younger and older individuals with and without an autism diagnosis. The study aims were to: (1) examine age-related differences in self- and clinician-rated autism symptoms, mental health symptoms and QoL, and (2) explore predictors of self-reported QoL, specifically IQ, self-reported autism symptoms and mental health symptoms, as a function of age.

## **Method**

### **Participants and procedure**

Using a cross-sectional design, we compared younger and older autistic adults with a non-autistic control group. Participants were 136 adults: 79 with a formal diagnosis of autism (mean age=44.96 years, SD=15.36, range 21-71 years) and 57 non-autistic controls (mean age=45.39 years, SD=17.36, range 18-74 years). Autistic adults were approached via 1) clinic and research databases hosted at the South London and Maudsley NHS Foundation Trust, King's College London and City, University of London, and 2) research advertisements circulated at King's College London and City, University of London. The control group was recruited via advertisements and research databases at King's College London and City, University of London. Ethical approval for the study was granted by the Psychiatry, Nursing and Midwifery Research Subcommittee at King's College London (Ref.: PNM/13/14-26) and by the Psychology Department Research Ethics Committee at City, University of London (Ref.: PSYETH(UPTD) 13/14 28).

Inclusion criteria for both groups were: age 18 years or older, full-scale IQ score >70 (measured by the Wechsler Abbreviated Scales of Intelligence-2<sup>nd</sup> edition; WASI-II, Wechsler, 2011) and English fluency sufficient to complete the measures. Additional inclusion criteria were applied for each group: a formal autism diagnosis by a clinician for the autism group, and no known current or past psychiatric diagnoses for the control group. Replicating previous studies (e.g., Totsika et al., 2010), the autism and control groups were divided into younger (19-48 years (n=38) and 18-49 years (n=30), respectively) and older (50-71 years (n=41) and 52-74 years (n=27), respectively) age groups.

As different recruitment methods can result in sampling artefacts, the recruitment sources of participants in the older and younger autism groups were examined. For those with available recruitment information, 47% of younger (n=18) and 41% of older (n=17) autistic adults were recruited through clinical settings; 53% of younger (n=20) and 59% of older (n=24) adults were recruited via adverts or research volunteer databases. Thus, the proportion of participants recruited from different sources was equivalent across the two autism age groups ( $\chi^2(1)=0.28$ ,  $p=.60$ ). Autistic participants were asked about the age at which they were initially diagnosed but many (56%) were unable to provide this information, or age of initial diagnosis was unclear from their supporting diagnostic reports because of the diversity of assessments conducted.

Among those participants whose age at first autism diagnosis was known (n=44; 58% of younger, 54% of older adults), mean age of diagnosis was 24.00 years (SD=8.72, range 6-42 years) in the younger autism group and 54.77 years (SD=7.08, range 40-70 years) in the older autism group.

The measures reported here were part of a larger battery lasting approximately three hours per session including breaks. For logistical reasons, one control and nine autistic participants were tested over two sessions, resulting in data on QoL and mental health and autism symptoms being collected between 15 and 28 months apart. Removing these participants did not affect most of the results reported below, but where it did, this is noted. Some of the participants from the community sample (n=26) had declined to take part in the majority of assessments, thus were not included in the relevant analyses. Participants were included if they completed, at least, IQ, self-reported QoL and anxiety/depression measures. Differences in sample size are noted in the results section. Information sheets were provided to all participants and written consent was obtained before the study took place. All participants were offered a gratuity in addition to reimbursement for their travel costs in thanks for their participation.

## **Measures**

### **Self- and clinician-rated autism symptoms**

Module 4 of the Autism Diagnostic Observation Schedule-2 (ADOS-2, Lord et al., 2012) was used to assess social interaction, communication and restricted and repetitive behaviors/interests, for participants in the autism group only; all assessors were trained to reach reliability. Although calibrated severity scores (CSS) have since been developed to provide estimates of autism symptom severity that are relatively independent of participant characteristics (Hus & Lord, 2014; Janvier et al., 2022) the CSS algorithm for Module 4 was not available when the study was planned.

Self-reported autism symptoms were measured using the Social Responsiveness Scale (SRS-2), a 65-item questionnaire assessing social awareness, social cognition, social communication, social motivation, and restricted interests and repetitive behavior (Bruni, 2014; Constantino &

Gruber, 2012). The SRS has good psychometric properties (See supplementary file). In the present data set (item scores available for n=97), Cronbach's alpha was .98 for total score, .97 for Social Communication and Interaction subscale score and .93 for Restricted Interests and Repetitive Behavior Subscale score of the SRS-2. Further information about the psychometric properties of these and all measures are provided in Supplementary Material 1.

### **Intellectual ability**

The Wechsler Abbreviated Scales of Intelligence-Second Edition (WASI-II, Wechsler, 2011) was used to obtain an estimate of IQ. It has four subtests (Vocabulary, Similarities, Block Design, and Matrix Reasoning) and provides an estimate of general intellectual ability (full-scale intelligence; FSIQ), verbal intelligence (VIQ) and performance intelligence (PIQ). In the current study, a cut-off score of >70 was set for recruitment, in order to meet the minimum cognitive requirements of other tasks in the study.

### **Demographic information**

The socio-demographic information and income categories in the "generic mental health UK" version of the Client Service Receipt Inventory (CSRI, Beecham & Knapp, 1992) were used to collect demographic information.

### **Self-reported mental health symptoms**

The Obsessive-Compulsive Inventory-Revised (OCI-R, Foa et al., 2002) was used to assess characteristics associated with obsessive-compulsive disorder (OCD). It comprises 18 items and six domains (washing, obsessing, hoarding, ordering, checking, and neutralizing; answers are rated on a 5-point Likert scale (0= not at all, 4=extremely). Psychometric properties of the instrument are good (see Supplementary Materials 1). With a cut-off score of possible clinical

diagnosis set as 21, 65.6% sensitivity and 63.9% specificity has been reported (Foa et al., 2002). A cut-off score of 29 has been suggested for autistic adults and reported to show sensitivity of 69% and specificity of 70% (Cadman et al., 2015). Therefore, in the current analyses different cut-off scores were used in the autism (cut-off 29) and control groups (cut-off 21). In the present data set (item scores available for  $n=132$ ), Cronbach's alpha was .93.

The Beck Anxiety Inventory (BAI, Beck & Steer, 1990; Fydrich, Dowdall, & Chambless, 1992) and Beck Depression Inventory-II (BDI-II, Beck, Steer, & Brown, 1996) were used to assess severity of self-reported anxiety and depression symptoms. Both comprise 21 self-report items rated on a 4-point scale (0=no impairment, 3=severe or substantial impairment); maximum score is 63. Scores  $\geq 8$  and 10, respectively, were considered clinically significant, in consensus with previous research with autistic adults (Lai et al., 2011; Moss et al., 2015). Both measures have good psychometric properties (see Supplementary Materials 1). In the present data set, Cronbach's  $\alpha$  was .91 for the BAI ( $n=131$ ) and .93 for the BDI-II ( $n=118$ ).

The Patient Health Questionnaire (PHQ, Spitzer, Kroenke, Williams, & PHQ Primary Care Group, 1999) was used to assess a range of symptoms related to: depression, anxiety, panic disorder, harmful use of alcohol, somatoform and eating disorders. Items are assessed on a 3- or 4-point Likert scale (e.g., "not bothered" to "bothered a lot") or with yes/no answers, and cut-offs are specified to indicate clinical thresholds for possible co-occurring conditions. The questionnaire has good psychometric properties (see Supplementary Materials 1). In the present data set (item scores available for  $n=128$ ) internal consistency was mainly acceptable to good, with Cronbach's alpha scores of .68 for somatoform symptoms, .74 for eating-related difficulties, and .91 for depressive and anxiety symptoms. The alcohol abuse subscale showed

an alpha of .43, which is below the acceptable cut-off; hence results for this subscale should be interpreted with caution.

Self-reported Attention-Deficit/Hyperactivity Disorder (ADHD) symptoms were tested using the ADHD-Self-Report Scale Symptom Checklist (ASRS-v1.1, Kessler et al., 2005; 2007). It has 6 items rated on a 5-point Likert scale from “never” to “very often”. Scores are calculated by counting items rated over a specific point (e.g., if they occur more than “sometimes”); a score of four or more is considered to indicate presence of ADHD. The test has good psychometric properties (see Supplementary Materials 1); Cronbach’s alpha in the present dataset (n=134) was .77, indicating acceptable internal consistency.

### **Self-reported Quality of Life (QoL)**

The World Health Organization Quality of Life Assessment (Skevington, Lotfy, & O’Connell, 2004; WHOQOL-BREF, WHOQOL Group, 1998) was used to assess QoL. It is a 26-item self-assessment scale consisting of four domains of QoL: physical (e.g., mobility, energy and fatigue), psychological (e.g., negative/positive feelings, self-esteem), social (e.g., personal relationships and social support), and environment (e.g., financial resources, transport and home environment). There are two additional items assessing an individual’s overall perception of quality life and general health and in the present study we combined scores on these two items to create a “global” QoL score. Answers are rated on a 5-point Likert scale (e.g., 1 “very dissatisfied” to 5 “very satisfied”). Higher scores indicate better QoL. The WHOQOL-BREF has good psychometric properties (see Supplementary Material 1). In the present data set (n=136), internal consistency values were acceptable, with Cronbach’s alpha of .79 for global, .87 for physical, .87 for psychological, .75 for social relationships and .84 for environment

domain. The more recent adaptation of the WHOQOL-BREF (the ASQoL McConachie et al., 2018) was not available at the time the present study began.

### **Statistical analysis**

Data were analyzed with SPSS version 26. Parametric tests were employed for statistical analysis where applicable. Homogeneity of variance was measured using Levene's test. Normality of data distribution was checked with the Kolmogorov-Smirnov test, Shapiro-Wilk test, histograms, Q-Q plots and examination of skewness and kurtosis scores. Bootstrap analysis was performed to test whether the results were robust against deviations from parametric assumptions (Chong & Choo, 2011), when at least three of the above indicators suggested deviation from the normal distribution. The 95% mean difference confidence intervals obtained from the bootstrap test are reported alongside such cases to support outcomes of the test statistic. All bootstrap tests were based on 1000 samples. Conservative *p* values were not used since analyses were exploratory (Field, 2018; Rubin, 2017).

Two-way ANOVA was used to investigate the effect of study group (autism vs control) and age group (younger vs older) on outcome measures (autism symptoms, QoL). Significant interactions were followed up with analysis of simple main effects. Spearman's or Pearson's correlation coefficient was used to measure associations. Multiple regression analyses were only conducted for global QoL scores in study groups separately (as the effect of study group might exaggerate the effect of autism symptoms) and solely with variables that had significant correlation with the outcome variable included as possible predictors. Forward stepwise method was used in all regression analyses, results of which were confirmed using backward elimination method to identify all significant predictors. Categorical data were tested using either log-linear analysis, Pearson's Chi Square statistic or Fisher's exact test.

## **Results**

### **Demographic information**

[Insert Table 1 about here](#)

Table 1 shows the demographic variables and group effects. Results of two-way ANOVA and three-way log-linear analyses showed that groups were well-matched, except for age (as planned) and total years of education, with younger adults having slightly more years of education than older adults.

### **Self- and clinician-rated autism symptoms**

[Insert Table 2 about here](#)

Differences in ADOS scores (available only for the autism group), for younger versus older autistic adults, were not statistically significant (see Table 2).

[Insert Table 3 about here](#)

Two-way ANOVA showed a significant main effect of group (autism vs control) on subscale and total SRS scores. The main effect of age was not significant, nor was the interaction of age by participant group. Autistic adults reported more autism symptoms than adults in the control group, regardless of age (Table 3).

### **Self-reported mental health symptoms**

Individuals who scored above the suggested clinical cut-off for at least one mental health condition were rated as having significant symptoms of co-occurring mental health symptoms. When there was more than one measure available assessing similar mental health symptoms (e.g., anxiety and depression), those who met the cut-off score on at least one measure were allocated to the "with co-occurring mental health symptoms" group.

Insert Figure 1 about here

Figure 1 outlines the percentages and numbers of individuals, by age group, meeting cut-off criteria for self-reported mental health symptoms. Rates of mental health problems in the autism and control groups were not directly compared as inclusion criteria for the control (but not autism) group included having no known psychiatric diagnosis; nevertheless, some control participants did score above clinical cut-off on the mental health questionnaires (see Figure 1). Within the autism group ( $n=76$ ), there was no difference between younger and older autistic groups in the proportions meeting cut-off for mental health symptoms, ( $\chi^2(1)=3.63, p=.06$ ). When examining each condition separately, significantly more younger than older autistic adults scored above the suggested cut-offs on the anxiety ( $\chi^2(1)=4.40, p=.04$ ), eating disorder ( $\chi^2(1)=6.85, p=.009$ ) and somatoform disorders ( $\chi^2(1)=6.85, p=.009$ ) scales. There were no significant differences between younger and older groups in the proportions meeting clinical cut-off criteria on measures of depression ( $\chi^2(1)=3.65, p=.06$ ), OCD ( $\chi^2(1)=2.61, p=.11$ ), ADHD ( $\chi^2(1)=0.19, p=.67$ ) or alcohol abuse (Fisher's exact,  $p=.48$ ). Removing the 10 participants with data collected across two temporally distant sessions resulted in a significant effect of age in the autism group for depressive symptoms ( $\chi^2(1)=5.95, p=.01$ ; younger age = more depression symptoms).

### **Self-reported Quality of Life (QoL)**

Separate two-way ANOVA analyses were conducted to test the influence of group (autism vs control) and age (younger vs older) on the WHOQOL global QoL score and each of the domains: physical health, psychological health, social relationships and environment.

All four domain scores and the global score on the WHOQOL displayed the same pattern of significant effects, with one exception: study group showed a main effect, with self-reported QoL being significantly lower in the autism compared to control group, but age and age by group effects were not significant. The only exception was a significant interaction effect of age by group for QoL social relationships domain score (Table 3, Figure 2). In the autism group, older adults reported significantly better social relationships QoL than younger adults ( $F(1,132)=7.58, p=.007, \eta_p^2=.05$ ), whereas there was no significant difference by age in the control group ( $F(1,132)=3.32, p=.07, \eta_p^2=.03$ ).

### **Correlates of self-reported QoL: age, intellectual level, severity of self-and clinician-rated autism symptoms, OCD, anxiety and depression**

To reduce the chance of Type 1 error due to multiple comparisons, associations and predictors of global QoL only were examined in the following analyses.

**Insert Tables 4 & 5 about here**

Age and intellectual level were not significantly related to global QoL score either in the autism or control group. Exploratory analysis (reported in Supplementary Materials 2) suggested a possible curvilinear relationship between age and QoL in the whole sample, which appeared to be driven by the autistic adults having somewhat better QoL in older age. While ADOS Total scores were not significantly correlated with the global QoL score in the autism group (control participants did not receive the ADOS), self-reported autism symptoms on the SRS were significantly and negatively related to QoL in both groups. Severity of self-reported mental health symptoms (see Table 4) was also significantly and negatively correlated with global QoL scores in both the autism and control groups (Table 5).

## **Predictors of self-reported QoL: severity of self-reported autism symptoms, OCD, anxiety and depressive symptoms**

Separate multiple linear regression analyses were conducted to explore significant predictor/s of global QoL domain scores in the autism (n=76) and control (n=52) groups. Self-reported mental health severity scores that were significantly correlated with the global QoL domain score were included as possible predictors. For the autism group, a multiple linear regression analysis was run to predict global QoL score based on severity scores of self-reported autism symptoms, OCD, anxiety and depression. A significant regression equation was found ( $F(1,74)=59.81, p<.001$ ) with an  $R^2=.45$ . The only significant predictor of global QoL score was self-reported depressive symptoms ( $\beta=-.67, p<.001$ ; higher QoL=lower depression score).

Similarly, for the control group, a multiple linear regression analysis was run to predict global QoL score based on severity scores of self-reported autism symptoms, OCD, anxiety and depression. A significant regression equation was found ( $F(1,50)=12.98, p<.001$ ) with an  $R^2=.21$ . The only significant predictor of global QoL score was self-reported depressive symptoms ( $\beta=-.45, p<.00$ ; higher QoL=lower depression score). Age was not entered into either regression because it was not significantly correlated with global QoL in the autism or control groups.

## **Discussion**

This study examined self- and clinician-rated autism symptoms, mental health and wellbeing in intellectually able younger and older autistic adults compared to their non-autistic peers. No significant effect of age, examined either categorically or dimensionally, was found for self-reported autism symptoms or for observer-rated autism symptoms on the ADOS-2. The present results support previous reports of no association between age and self-reported autism

symptom severity (e.g., Bishop & Seltzer, 2012), but contrast with longitudinal and cross-sectional findings that suggest an age-related reduction in autism symptoms around middle adulthood (e.g., Howlin et al., 2013; Lever & Geurts, 2018).

Self-reported mental health difficulties were common in the autism group, with a substantial proportion of both age groups scoring above the suggested clinical cut-off scores for depression, OCD and ADHD. Younger and older autistic adults did not differ in the proportions meeting cut-off criteria for a mental health difficulty, although self-reported anxiety, somatoform and eating disorders were more common in younger than older autistic adults. However, if participants with long delays between assessments were excluded from the analysis, self-reported depressive symptoms were significantly higher in younger than older autistic adults. There are mixed findings in the literature on age and mental health (Lai et al., 2019), with some studies in groups without intellectual disability reporting fewer psychiatric symptoms in older compared to younger autistic adults (e.g., Lever & Geurts, 2016; Totsika et al., 2010), and others finding the opposite (e.g., Roy et al., 2015) or no significant association between age and co-occurring mental health difficulties (e.g., Mazurek, 2014; Moss et al., 2015; Uljarević et al., 2020). Future studies are needed with larger samples and greater statistical power to investigate the relationship between age and mental health problems in autistic adults.

Autistic adults had lower self-reported QoL than control adults across all domains, replicating the findings of several previous studies (Ayres et al., 2018; van Heijst & Geurts, 2015). Age had no significant association with any domain of QoL, in line with some previous research with older (e.g., van Heijst & Geurts, 2015; Totsika et al., 2010) and younger autistic adults (Howlin et al., 2013; Kim & Bottema-Beutel, 2019; Otsuka et al., 2017; Renty & Roeyers, 2006). However, there was a significant age by group interaction on the QoL social relationship

domain. Older autistic adults reported significantly better QoL in social relationships than younger autistic adults, whereas control adults showed no significant age effect. The absence of an age effect on subjective quality of life in the control group supports previous findings in similar age groups (Villas-Boas, Oliveira, Ramos, & Montero, 2019). This suggests that aging may affect different domains of QoL in different ways, and in different individuals (in keeping with the findings of e.g., Mason et al., 2018). More in-depth, qualitative work is needed to explore why age has different apparent relationships with social QoL in autistic and non-autistic adults.

Examination of the predictors of self-reported QoL was restricted to the global QoL score to minimize the chance of Type 1 error due to multiple comparisons, and because the QoL subscales were significantly inter-correlated in both autistic and control adults. Full-scale IQ was not related to self-reported QoL in either group, in line with a recent meta-analysis (Kim & Bottema-Beutel, 2019). In both autism and control groups, higher rates of self-reported autism symptoms, OCD, anxiety and depression were associated with poorer self-reported QoL, supporting previous findings (Howlin et al., 2013; Mason et al., 2018, 2019, Moss et al., 2015, Oakley et al., 2021; Totsika et al., 2010). Regression analysis also showed that severity of self-reported depression was the strongest statistical predictor of global QoL in both groups. Results were similar to those of recent studies (Kim & Bottema-Beutel, 2019; Oakley et al., 2021; van Heijst & Geurts, 2015), showing that neither IQ nor severity of self-reported autism symptoms, but rather rates of self-reported mental health symptoms (especially depression), predicted self-reported QoL in groups of younger and older autistic adults.

### **Methodological considerations**

The present work has several limitations that should be considered. Since analyses were exploratory, conservative *p* values were not used, but we attempted to reduce the risk of Type 1 errors by, for example, examining sub-scores only where total scores showed significant effects. However, overall, our relatively small sample sizes may have limited power to detect significant results, as reflected in effect sizes. Replication of the present results is needed with larger samples, and until then the findings should be interpreted with caution.

The cross-sectional design used may be subject to cohort effects, or survivor effects (where older participants effectively represent those who are still able to take part, whilst those with more complex profiles may be less able to do so), which are recognized as a potential problem for aging research in general (Tse et al., 2021). We sought to minimize bias in group selection by recruiting younger and older participants from similar sources. In addition, the groups were well matched for IQ and a proxy measure of socio-economic status (based on income level). The younger and older autism groups did not differ in ADOS scores or self-reported autistic trait levels. However, given the increased mortality rate at all ages in autism (Hwang et al., 2019), further examination of survivor effects in autism aging research is needed. The ideal future design would clearly be longitudinal, although given the urgent need for research on aging in autism, cross-sectional work is still of value in exploring possible age-related effects.

In this study the division of participants into older and younger adult groups was based on a cut-off age of 50, following the convention in autism aging research (Roestorf et al., 2019). Future longitudinal studies are needed to find out more about the mental health and QoL of autistic adults in their 70's and 80's. Also, the focus of the present study was on intellectually able adults (i.e., full-scale IQ>70), which should be taken into consideration when evaluating

the generalizability of these findings. Further research is needed on aging in autistic people with intellectual disability.

In terms of recruitment, we aimed to recruit a representative sample of control adults, and our recruitment information and adverts asked for adults without psychiatric diagnoses. However, we did not specifically screen for these or exclude any participants. In the autism group, by contrast, our advertising did not require absence of co-occurring psychiatric difficulties, since anxiety and depression are so common in autism that an unrepresentative autism sample would have resulted. Nevertheless, this approach did limit our ability to compare rates of mental health problems across groups.

We predominantly used self-report questionnaires, with the exception of the IQ measures and ADOS. While self-report may be considered more valid for QoL assessment, questionnaire measures of mental health would ideally be combined with clinician ratings from direct interview. Although Cronbach's alpha values in the present data set were acceptable for self-reported measures in general, the alpha value for the alcohol abuse subscale of the PHQ was below the acceptable cut-off, so the findings for this particular variable should be interpreted with caution.

A further limitation is the use of the ADOS total and domain scores to compare autism symptoms across age groups; the ADOS is primarily a diagnostic tool and not ideally suited to measure quantitative traits. As noted earlier, calibrated severity scores (CSS) are now available that are relatively independent of participant characteristics (Hus & Lord, 2014; Janvier et al., 2022). However, when the study was planned, the algorithm for Module 4 CSS scores was not available. There is still limited information on the use of the CSS with older adults, although

there is some suggestion that correlations with other autism measures are relatively low (Morrier et al., 2017).

In addition, although established cut-off scores were taken from the literature to estimate rates of mental health difficulties, only some of these measures have been specifically adapted for the autism population (Cadman et al., 2015). Common-methods variance may have inflated the correlation between self-reported QoL and self-reported mental health and autistic symptoms; it is interesting that the latter correlated significantly with QoL while researcher-rated ADOS scores did not. It is also important to note that QoL data were collected before the autism adaptation of the WHOQOL-BREF was published (McConachie et al., 2018).

Finally, the findings did not take into account possible differences between autistic participants diagnosed in childhood and those diagnosed as adults. Although individuals were asked to provide confirmation of clinical diagnosis, the data provided in these reports were very variable and did not necessarily specify age of initial diagnosis. Over half of the autistic participants did not know the exact age at which they were diagnosed and thus the estimate of average age of diagnosis is based only on individuals who were able to provide this information (likely to be those diagnosed relatively late).

## **Conclusion**

This study found no differences between younger and older autistic adults on autism trait measures, or overall QoL. Younger autistic adults reported more mental health problems than older autistic adults. Self-reported autism symptoms and co-occurring mental health difficulties were associated with poorer self-reported QoL in both age groups. Only QoL in social

relationships showed a group by age interaction, with relatively more satisfaction in older versus younger autistic adults only. Overall, self-rated depressive symptoms were the strongest predictor of QoL in both autism and control groups. Longitudinal studies are needed to elucidate developmental trajectories in autism-related difficulties, mental health and QoL in the older autistic population.

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## Tables

**Table 1. Demographics of age groups in the autism and control groups: Mean (SD)**

	Autism		Control		$F^\dagger$	$p$ -value	effect size: $\eta_p^2$
	Younger n=38	Older n=41	Younger n=30	Older n=27			
<b>Age (in years)</b>	31.03 (8.42) range:19-48	57.88 (6.22) range:50-71	30.90 (9.36) range:18-49	61.48 (6.35) range:52-74	1.70 <sup>group</sup> 463.50 <sup>age***</sup> 1.96 <sup>agexgroup</sup>	.20 <sup>group</sup> <.001 <sup>age</sup> .16 <sup>agexgroup</sup>	.01 <sup>group</sup> .78 <sup>age</sup> .02 <sup>agexgroup</sup>
<b>Gender ratio<sup>‡</sup> (M:F)</b>	29:9	32:9	15:15	17:10	-	.05	-
<b>VIQ</b>	107.97 (16.36)	111.12 (16.28)	111.87 (10.48)	108.85 (14.16)	0.10 <sup>group</sup> 0.001 <sup>age</sup> 1.43 <sup>agexgroup</sup>	.75 <sup>group</sup> .98 <sup>age</sup> .23 <sup>agexgroup</sup>	.001 <sup>group</sup> <.001 <sup>age</sup> .01 <sup>agexgroup</sup>
<b>PIQ</b>	113.18 (15.06)	114.34 (18.72)	114.27 (10.31)	105.67 (15.92)	1.96 <sup>group</sup> 1.88 <sup>age</sup> 3.24 <sup>agexgroup</sup>	.16 <sup>group</sup> .17 <sup>age</sup> .07 <sup>agexgroup</sup>	.02 <sup>group</sup> .01 <sup>age</sup> .02 <sup>agexgroup</sup>
<b>FSIQ</b>	111.05 (15.57)	112.85 (17.26)	112.10 (11.92)	105.93 (16.72)	1.17 <sup>group</sup> 0.65 <sup>age</sup> 2.15 <sup>agexgroup</sup>	.28 <sup>group</sup> .42 <sup>age</sup> .15 <sup>agexgroup</sup>	.01 <sup>group</sup> .01 <sup>age</sup> .02 <sup>agexgroup</sup>
<b>YoE</b>	16.39 (3.03)	15.24 (3.45)	16.73 (2.88)	14.93 (4.30)	<0.001 <sup>group</sup> 6.22 <sup>age*</sup> 0.31 <sup>agexgroup</sup>	.99 <sup>group</sup> .01 <sup>age</sup> .58 <sup>agexgroup</sup>	<.001 <sup>group</sup> .05 <sup>age</sup> .002 <sup>agexgroup</sup>
<b>Level of Income<sup>§</sup></b>	2.83 (1.71)	3.17 (1.56)	3.65 (1.42)	3.37 (1.50)	2.45 <sup>group</sup> 0.01 <sup>age</sup> 0.93 <sup>agexgroup</sup>	.12 <sup>dx</sup> .92 <sup>age</sup> .34 <sup>agexgroup</sup>	.03 <sup>group</sup> <.001 <sup>age</sup> .01 <sup>agexgroup</sup>

Autism: autism group; Control: non-autistic control group; VIQ: Verbal intelligence score; PIQ: Performance intelligence score; FSIQ: Full-scale intelligence quotient; YoE: Total years of education; Level of income is derived from the CSRI (ranges 1-5); <sup>†</sup>All  $df_{MS}=1$ ,  $df_{RS}=132$  (93 for Level of Income); <sup>‡</sup> $\chi^2(3)=7.93$ ; <sup>§</sup> $N=97$  (Younger and older autism  $n=29$  for each, Younger control  $n=20$ , Older control  $n=19$ ; <sup>group</sup>Main effect of study group; <sup>age</sup>Main effect of age group; <sup>agexgroup</sup>Interaction effect of age group by study group; \* $p<.05$ , \*\*\* $p<.001$ .

**Table 2. Autism symptom severity (on the ADOS) by age group: Mean (SD)**

		Younger autism n=32	Older autism n=34	<i>t</i>	df	<i>p</i>	<i>d</i>	95%CI
<b>ADOS</b>	<b>Total (max=22)</b>	9.25 (3.77)	9.26 (3.32)	-0.02	64	.99	.003	-1.76 – 1.73
	<b>Com. (max=8)</b>	2.97 (1.68)	2.97 (1.45)	-0.01	64	1.00	<.001	-.78 - .77 <sup>†</sup>
	<b>RSI (max=14)</b>	6.28 (2.81)	6.29 (2.60)	-0.02	64	.99	.004	-1.34 - 1.32
	<b>SBR (max=8)</b>	1.28 (1.20)	0.97 (1.09)	1.11	64	.28	.27	-.21 - .87 <sup>†</sup>
	<b>Imag. (max=2)</b>	0.97 (0.78)	1.00 (0.85)	-0.16	64	.88	.04	-.43 - .37

ADOS: Autism Diagnostic Observation Schedule; Com.: communication; RSI: reciprocal social interaction; SBR: stereotyped behaviours and restricted interests; Imag.: Imagination; <sup>†</sup>Bootstrap derived.

**Table 3. Self-reported autism trait scores (SRS-2) and QoL domain scores (WHOQOL-BREF) of age groups in autism and control group: Mean (SD)**

		Autism		Control		$F^\dagger$	$p$ -value	effect size: $\eta_p^2$
		Younger n=38	Older n=41	Younger n=30	Older n=27			
SRS-2 <sup>‡</sup>	<b>Total (max=90)</b>	72.89 (10.60)	70.17 (12.44)	46.96 (7.05)	46.19 (5.28)	208.31 <sup>group***</sup> 1.03 <sup>age</sup> 0.32 <sup>age<math>\times</math>group</sup>	<.001 <sup>group</sup> .31 <sup>age</sup> .58 <sup>age<math>\times</math>group</sup>	.62 <sup>group</sup> .01 <sup>age</sup> .002 <sup>age<math>\times</math>group</sup>
	<b>SCI (max=90)</b>	72.05 (10.79)	69.61 (12.25)	46.63 (6.62)	46.37 (5.92)	198.16 <sup>group***</sup> 0.61 <sup>age</sup> 0.40 <sup>age<math>\times</math>group</sup>	<.001 <sup>group</sup> .44 <sup>age</sup> .53 <sup>age<math>\times</math>group</sup>	.61 <sup>group</sup> .005 <sup>age</sup> .003 <sup>age<math>\times</math>group</sup>
	<b>RRB (max=90)</b>	73.03 (11.57)	69.88 (12.99)	49.15 (9.24)	46.44 (4.26)	160.75 <sup>group***</sup> 2.46 <sup>age</sup> 0.01 <sup>age<math>\times</math>group</sup>	<.001 <sup>group</sup> .12 <sup>age</sup> .91 <sup>age<math>\times</math>group</sup>	.56 <sup>group</sup> .02 <sup>age</sup> <.001 <sup>age<math>\times</math>group</sup>
WHOQOL-BREF	<b>Global (max=100)</b>	48.03 (21.66)	58.23 (26.61)	76.67 (17.60)	75.93 (13.84)	39.26 <sup>group***</sup> 1.64 <sup>age</sup> 2.19 <sup>age<math>\times</math>group</sup>	<.001 <sup>group</sup> .20 <sup>age</sup> .14 <sup>age<math>\times</math>group</sup>	.23 <sup>group</sup> .01 <sup>age</sup> .02 <sup>age<math>\times</math>group</sup>
	<b>Physical (max=100)</b>	56.86 (20.11)	64.20 (20.80)	82.86 (15.37)	80.56 (14.90)	43.57 <sup>group***</sup> 0.62 <sup>age</sup> 2.26 <sup>age<math>\times</math>group</sup>	<.001 <sup>group</sup> .43 <sup>age</sup> .14 <sup>age<math>\times</math>group</sup>	.25 <sup>group</sup> .005 <sup>age</sup> .02 <sup>age<math>\times</math>group</sup>
	<b>Psychological (max=100)</b>	45.40 (15.52)	55.39 (21.15)	70.97 (15.95)	72.68 (14.07)	50.95 <sup>group***</sup> 3.80 <sup>age</sup> 1.90 <sup>age<math>\times</math>group</sup>	<.001 <sup>group</sup> .053 <sup>age</sup> .17 <sup>age<math>\times</math>group</sup>	.28 <sup>group</sup> .03 <sup>age</sup> .01 <sup>age<math>\times</math>group</sup>
	<b>Social Relationships (max=100)</b>	40.13 (20.03)	52.44 (21.75)	74.72 (17.71)	65.12 (18.78)	46.83 <sup>group***</sup> 0.15 <sup>age</sup> 10.05 <sup>age<math>\times</math>group**</sup>	<.001 <sup>group</sup> .70 <sup>age</sup> .002 <sup>age<math>\times</math>group</sup>	.26 <sup>group</sup> .001 <sup>age</sup> .07 <sup>age<math>\times</math>group</sup>
	<b>Environment (max=100)</b>	58.47 (17.36)	64.10 (19.20)	74.48 (15.00)	76.39 (12.33)	24.00 <sup>group***</sup> 1.79 <sup>age</sup> 0.42 <sup>age<math>\times</math>group</sup>	<.001 <sup>group</sup> .19 <sup>age</sup> .52 <sup>age<math>\times</math>group</sup>	.15 <sup>group</sup> .01 <sup>age</sup> .003 <sup>age<math>\times</math>group</sup>

Autism: autism group; Control: non-autistic control group; SRS-2: Social Responsiveness Scale-2; SCI: Social Communication and Interaction; RRB: Restricted Interests and Repetitive Behaviour; WHOQOL-BREF: World Health Organization Quality of Life Assessment; <sup>†</sup>All  $df_{MS}=1$  and  $df_{RS}=129$  for SRS-2 and 132 for WHOQOL; <sup>‡</sup>Younger Control n=27; <sup>group</sup>Main effect of study group; <sup>age</sup>Main effect of age group; <sup>age $\times$ group</sup>Interaction effect of age group by study group; \*\* $p < .01$ , \*\*\* $p < .001$ .

**Table 4. Self-reported severity of OCD (OCI-R), anxiety (BAI) and depression (BDI-II) scores of age groups in autism and control group: Mean (SD)**

	Autism		Control	
	Younger n=37	Older n=39	Younger n=29	Older n=25
<b>OCI-R</b> (max=72)	26.89 (14.36)	22.72 (12.95)	7.10 (6.21)	7.44 (6.21)
<b>BAI</b> (max=63)	14.92 (9.55)	11.21 (8.69)	3.86 (3.81)	4.68 (7.30)
<b>BDI-II</b> (max=63)	18.16 (11.97)	13.74 (12.73)	4.21 (4.13)	4.48 (4.34)

Autism: autism group; Control: non-autistic control group; BDI-II: Beck Depression Scale-2; BAI: Beck Anxiety Scale; OCI-R: Obsessive-Compulsive Inventory-Revised.

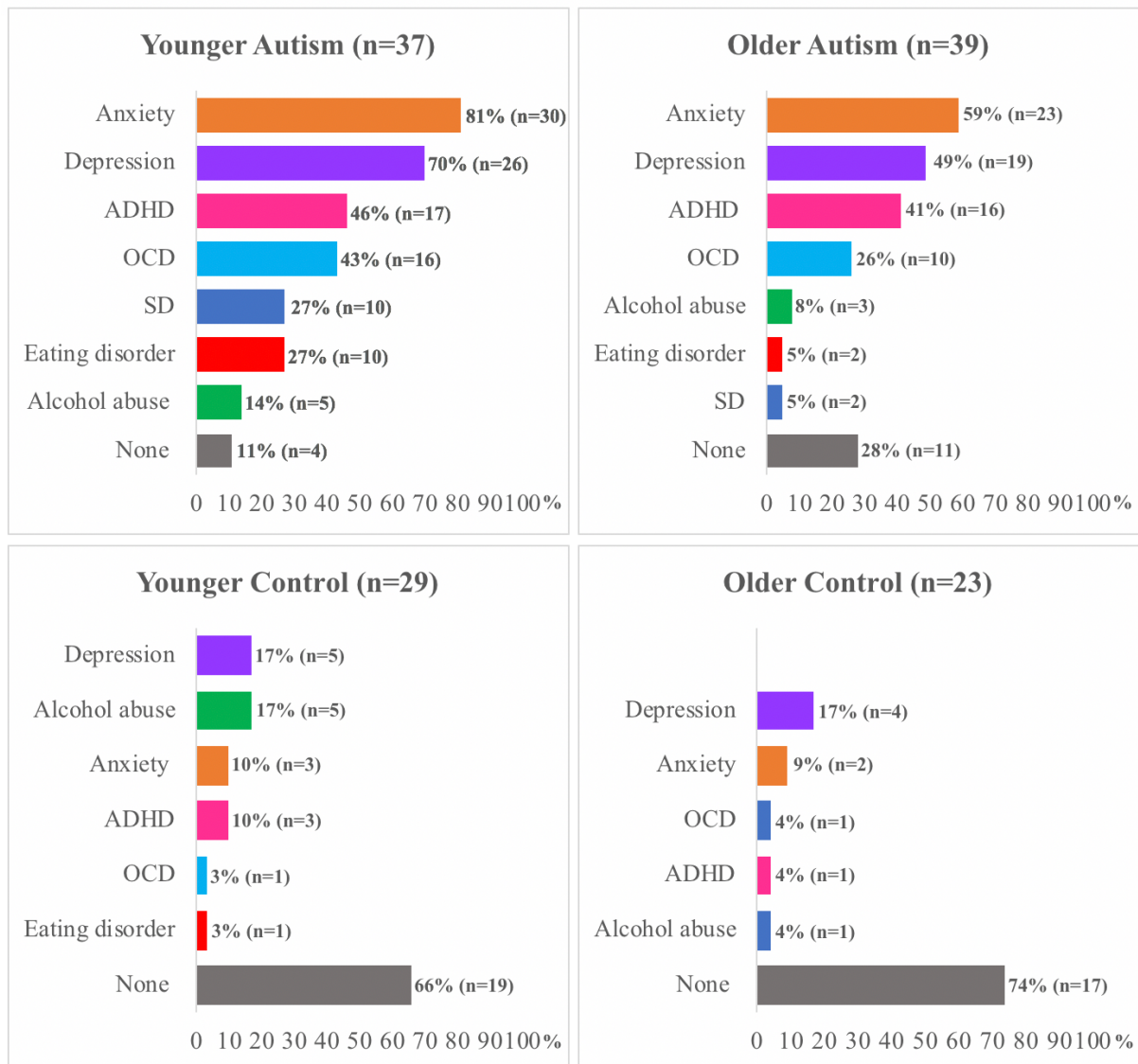
**Table 5. Associations between Global QoL score (WHOQOL-BREF) and total self- and clinician-rated autism symptoms (ADOS and SRS-2), OCD (OCI-R), anxiety (BAI) and depression (BDI-II) severity scores in autism and control groups**

		Age (in years)	FSIQ	ADOS	SRS-2	OCI-R	BAI	BDI-II
Global QoL	Autism	.15 <sup>†</sup> ( <i>p</i> =.20)	.03 ( <i>p</i> =.78)	-.18 ( <i>p</i> =.16) n=66	-.34** ( <i>p</i> =.002)	-.30** ( <i>p</i> =.007) n=78	-.50**** n=77	-.70**** <sup>†</sup>
	Control	-.15 <sup>†</sup> ( <i>p</i> =.27)	.04 ( <i>p</i> =.76)	N/A	-.36*** <sup>†</sup> ( <i>p</i> =.008) n=54	-.38*** <sup>†</sup> ( <i>p</i> =.004) n=54	-.40*** <sup>†</sup> ( <i>p</i> =.002)	-.54**** <sup>†</sup> n=56

Autism: autism group (n=79) unless specified, Control: non-autistic control group (n=57) unless specified; WHOQOL-BREF: World Health Organization Quality of Life Assessment; ADOS: Autism Diagnostic Observation Schedule; SRS-2: Social Responsiveness Scale-2; OCI-R: Obsessive-Compulsive Inventory-Revised; BAI: Beck Anxiety Scale; BDI-II: Beck Depression Scale-2; FSIQ: Full-scale intelligence score; <sup>†</sup>Spearman's rho; \*\**p* < .01, \*\*\**p* < .001.

## Figures

**Figure 1. Numbers and percentages<sup>†</sup> of younger and older adults with mental health conditions (as passing suggested cut-offs on the self-reported measures: OCI-R, BAI, BDI-II, ASRS-v1.1 and PHQ) in autism and control groups**



<sup>†</sup>Since some individuals had more than one co-occurring mental health condition, total percentages exceed 100 in some groups. Autism: autism group; Control: non-autistic control group; ADHD: Attention deficit and hyperactivity disorder; OCD: Obsessive-compulsive disorder; SD: Somatoform disorders; OCI-R: Obsessive-Compulsive Inventory-Revised; BAI: Beck Anxiety Scale; BDI-II: Beck Depression Scale-2; ASRS-v1.1: Attention-Deficit/Hyperactivity Disorder (ADHD)-Self-Report Scale Symptom Checklist; PHQ: Patient Health Questionnaire.

Figure 2. QoL in social relationships domain scores showing the interaction between study (Autism vs. Control) and age groups (Younger vs. Older)

