Social support and links to quality of life among middle-aged and older autistic adults

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Abstract

Social support has a positive impact on quality of life (QoL) in neurotypical older adults and young autistic adults, but the association for older autistic adults is unclear. Autistic adults ($n = 388$; mean age = 40–83 years) were recruited via Simons Powering Autism Research for Knowledge (SPARK) Research Match. Participants completed questionnaires online querying demographic information, depression, and anxiety symptomatology, QoL (physical, psychological, social, environmental, and autism-specific) and social support (instrumental, subjective, and social interactions). Regression analyses examined whether different aspects of social support contributed to models explaining each domain of QoL. Models explaining QoL were significant. Subjective social support significantly contributed to the models for all aspects of QoL; social interactions contributed to the models for Physical and Psychological QoL, whereas instrumental support contributed to models for social, environmental and autism-specific QoL. Social support is an important contributor to the QoL of middle-aged and older autistic adults, after accounting for demographic factors and depression. Further studies are required to understand whether age-related changes in social support and QoL are the same for autistic as non-autistic older adults in order to identify and implement appropriate support.

Lay abstract

Social support can take many forms, such as practical help, time spent socially with others, or the satisfaction with personal relationships. Social support is known to affect quality of life (QoL) in both non-autistic older and autistic young adults. QoL reflects how satisfied an individual is with their life either overall or in a certain area. We know little about middle-aged and older autistic adults' experiences of social support or QoL. In this study, 388 adults aged 40–83 years old, completed online questionnaires asking about background such as age and sex, depression and anxiety symptoms, QoL (physical, psychological, social, environmental, and autism-specific), and different types of social support. Even after taking into account background, depression, and anxiety, social support was important for individuals' QoL. To our knowledge this is the first paper to examine the relationship between social support and QoL in middle-aged and older autistic adults. Improving social support may have a significant impact on the QoL of older autistic adults. Future studies should examine whether age-related changes in social support (size, content, and arrangement of social networks) that are common in non-autistic aging, also occur among older autistic adults.

Introduction

There is extensive literature describing the positive impact of social support on mental and physical health and on quality of life (QoL) in the general population and those with psychiatric disorders (Brookes et al., 2012; Campos et al., 2014; Chachamovich et al., 2008). Social support is

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often described as a supportive social network. However, it is multidimensional and reflects access to interpersonal resources including social interactions, perceived emotional support, and practical or instrumental support (Kelly et al., 2017; Sahin et al., 2019; Tyler, 2006). High overall social support has been shown to have both direct and indirect positive effects on mental and physical health outcomes. Direct effects link increased social support with reduced depression, suicidal thoughts, and time to mortality; whereas indirect effects may act by reducing depression or stress, which in turn positively impacts QoL, mood, and suicidality (Holt-Lunstad et al., 2010; Pan et al., 2020; Sahin et al., 2019). Research has shown that as individuals reach later life, subjective social support reduces, and this reduction has a significant negative impact on mood and suicidality (Hybels et al., 2011; Pan et al., 2020). Given that difficulties in social communication and interactions are a core diagnostic feature of autism spectrum disorder (ASD), it has been questioned whether the impact of variable levels of social support is the same for autistic versus non-autistic individuals (Hedley et al., 2017). To date, few studies have examined social support among autistic adults, and to our knowledge, no study has examined social support among middle-aged or older autistic adults.

Studies examining social support among autistic adolescents and young adults have identified lower rates of overall subjective social support compared to comparison groups of both neurotypical individuals and those with specific reading disability (Bishop-Fitzpatrick et al., 2018; Humphrey & Symes, 2010). In a sample of 41 autistic young and middle-aged adults (mean age = 30 years), subjective support from friends was rated as low compared to both attention-deficit hyperactivity disorder (ADHD) and neurotypical comparison groups, but no differences were observed for ratings of support from family or a significant other (Alvarez-Fernandez et al., 2017). Given the potential buffering effects associated with good social support in the general population, low social support could be an added risk for already poor QoL outcomes for autistic adults (Bennett et al., 2005; Jennes-Coussens et al., 2006; Kamio et al., 2012; Kamp-Becker et al., 2010; van Heijst & Geurts, 2014) compared to neurotypical individuals. Subjective QoL can be defined as the individual's perception of their satisfaction with life within the context of their own society and value system, and relating to the expectations and concerns of the individual (Harper & The WHOQOL Group, 1998). As such, QoL (rated subjectively by the individual) is often used as a relevant outcome measure across different cultures, societies, and groups, including autistic individuals (Burgess & Gutstein, 2007).

Examining the association between social support and psychosocial and health-related outcomes in young and middle-aged autistic adults (mean age = 24 years), Bishop-Fitzpatrick and colleagues (2018) found a positive

association between subjective social support and overall QoL. However, the source and type of social support may also impact results. Greater perceived social support from family and friends (but not significant others) was associated with higher mental health–related QoL among autistic adults (mean age = 31 years; Khanna et al., 2014). An examination of the different components of social support suggests that perceived informal support (e.g. support from friends or relatives) and number of unmet formal support needs (number of domains where support is needed but neither informal nor formal support from professionals is available) were (respectively positively and negatively) associated with overall QoL (Renty & Roeyers, 2006). A further study found that more tangible material support was associated with lower depression among autistic adults (Hedley et al., 2017). In contrast, perceived support by having someone to talk through problems or having people available to share activities had no effect on depression in this sample. It remains unclear to what extent the type of social support impacts different aspects of mental health or QoL among autistic adults.

Poor QoL among autistic people has been reported in specific domains such as physical health (Kamp-Becker et al., 2010; Khanna et al., 2014) or psychological and social aspects (Kamio et al., 2012), as well as in overall QoL (Bennett et al., 2005; Bishop-Fitzpatrick et al., 2018; van Heijst & Geurts, 2014). However, it is worth noting that not all autistic people report poor QoL (Oakley et al., 2021). QoL has been reported to vary within the autistic population and across domains of QoL; therefore, caution may be needed when considering group-level comparisons (Oakley et al., 2021). Better subjective QoL among younger autistic adults is associated with factors such as having good social and practical (professional or family) support (Kamio et al., 2012; Leader et al., 2021; Mason et al., 2018; Renty & Roeyers, 2006), being employed (Mason et al., 2018), having better sleep quality (Leader et al., 2021), and better daily living skills (Kamp-Becker et al., 2010). However intelligence quotient (IQ), age, or severity of autistic traits have been found to not be associated with QoL (Kamp-Becker et al., 2010; Leader et al., 2021; van Heijst & Geurts, 2014). Therefore, these findings suggest that both greater interpersonal social support and practical (instrumental, tangible, and material) support can have independent positive impacts on QoL for autistic young adults. Whether different aspects of social support similarly impacts QoL among middle-aged and older autistic adults has not yet been explored.

This study sought to examine social support and its associations with QoL among middle-aged and older autistic adults (40+ years of age) for the first time. We hypothesized that social support would be associated with self-reported QoL, even after accounting for variables, such as demographic, physical health, anxiety, and depression. We explored whether the pattern of associations was

the same or different for aspects of QoL. Owing to the limited previous literature examining QoL and social support in middle-aged and older autistic adults, we characterized the data by decades (reporting data for those aged 40–49 years; 50–59 years, etc) and explored the data for possible age-effects.

Methods

Participants

Participants were recruited online via Simons Foundation Powering Autism Research for Knowledge (SPARK; SPARK Consortium, 2018) Research Match. All participants took part in a broader online study of adult development/aging of 40+-year-old autistic adults and were compensated $25 for their time. The study was approved by the local institutional review board and followed procedures in accordance with the Declaration of Helsinki. Accordingly, all participants provided informed consent. Four-hundred and thirty-eight people began the survey, with 413 completing the World Health Organization Quality of Life Instrument and 394 completing the Duke Social Support Index (DSSI). Participants who completed both measures were included in the analysis; therefore, the sample analysed here represented 388 autistic individuals aged 40–83 years. For details see Table 1.

The sample was composed of 'independent' autistic adults as designated by SPARK. These adults can consent for themselves and thus are unlikely to have a co-occurring intellectual disability. Moreover, none of the participants in this study reported intellectual disability as a prior medical diagnosis on their health history questionnaire. In order to be included in the SPARK registry, participants were required to have self-disclosed a diagnosis of ASD given by medical/clinical professionals. To further validate the ASD clinical diagnosis information provided, 387 of the 388 participants completed the 28-item self-report Autism spectrum Quotient-28 (AQ28; Hoekstra et al., 2011). Scores > 65 are considered to be above the cut-off indicating a positive screen for ASD. In the current sample 97.4% of participants scored more than 65.

Measures

Demographic information and health conditions. Participants provided detailed demographic information including age, race, ethnicity, sex assigned at birth, and presence of physical health conditions. As health conditions are known to have a significant negative impact on QoL (Raggi et al., 2016; Skevington & McCrate, 2012), the number of physical health conditions that likely affect activities of daily living were coded and summed for each participant and used as a variable in analyses. Health conditions coded as affecting activities of daily living included chronic pain,

fibromyalgia, multiple sclerosis, chronic obstructive pulmonary disorder, and various forms of arthritis. Age, sex assigned at birth, and physical health conditions were included as covariates in the analyses, as they have been shown to impact QoL. QoL associations with sex assigned at birth and physical health seem to be consistent across autistic and non-autistic populations. However, age–QoL associations may be linear among autistic people, rather than quadratic as generally observed in non-autistic populations.

QoL. Subjective QoL was measured via the 26-item World Health Organization Quality of Life Instrument (WHOQOL-BREF; Harper & The WHOQOL Group, 1998) and the autism-specific quality of life measure (ASQOL; McConachie et al., 2018). The WHOQOL-BREF is an abbreviated version of the WHOQOL-100, designed for use across different cultures. The WHOQOL-BREF includes 24 items that probe four domains: Physical Health (7 items), Psychological Health (6 items), Social Relationships (3 items), Environmental Health (8 items), and two questions inquire about perceptions of overall QoL and health. Participants respond on a 5-point Likert-type scale (1 = very dissatisfied to 5 = very satisfied). The ASQOL asks nine additional questions regarding QoL for autistic individuals (McConachie et al., 2018). The ASQOL total score is computed by averaging the scores of the first eight items. The WHOQOL Disability module is often administered with the ASQOL; however, it was not administered here as many autistic individuals do not consider autism to be a disability and in order to reduce the demands of the overall survey. The four subscales from the WHOQOL-BREF and the ASQOL total score were used as dependent variables in the analyses. The WHOQOL-BREF has good internal consistency (Cronbach's alphas = 0.73–0.86 across domains), discriminant validity (when distinguishing 'ill' versus 'well' respondents, all domain p values < 0.001), and test–retest reliability (between $r = 0.66$ and $r = 0.87$). For the ASQOL, internal consistency (Cronbach's alpha = 0.82) and test–retest reliability (ICC = 0.76) were good (McConachie et al., 2018).

Social support. Social support was measured using the 23-item modified version of the DSSI (Koenig et al., 1993). The DSSI is comprised of three scales: the Social Interaction (SIS; 4 questions), Subjective Support (SSS; 7 questions), and Instrumental Support (ISS; 12 questions) Scales. The SIS inquires about the quality and quantity of social interactions (e.g. how often the respondent has attended a non-work-related gathering in the past week). The SSS probes the respondent's subjective sense of social support, including the quality of their close relationships (e.g. whether the respondent feels that they are listened to by their family/friends). The ISS provides an objective measure of social support, reflecting whether individuals obtain the support they need

Table 1. Descriptive statistics for measures by age group.

	Total, N = 388	40–49.9, N = 188	50–59.9, N = 118	60+, N = 82
Demographic				
Age, mean (SD)	52.19 (9.20) Range 40–83	44.61 (2.88)	54.33 (2.96)	66.47 (5.06)
Sex assigned at birth (m, f)	161, 277	66, 122	51, 67	44, 38
Number of health conditions affecting daily life, mean (SD)	0.20 (.465) Range 0–3	0.18 (.425) Range 0–2	0.23 (.513) Range 0–3	0.20 (.483) Range 0–3
[a]Race, count (White, African-American, Asian, Native American/ Alaska Native, Multiracial, Other)	316, 10, 7, 5, 39, 10	[b]White = 150, Non-White = 37	White = 96, Non-White = 22	White = 70, Non-White = 12
Ethnicity, count (Latinx, Not Latinx, Unknown)	26, 356, 6	13, 172, 3	9, 107, 2	4, 77, 1
Education, count				
No high school	2 (0.5%)	1 (0.5%)	0 (0%)	1 (1.2%)
Some high school	10 (2.6%)	6 (3.2%)	2 (1.7%)	2 (2.4%)
GED diploma	10 (2.6%)	7 (3.7%)	2 (1.7%)	1 (1.2%)
High school graduate	15 (3.9%)	11 (5.9%)	3 (2.5%)	1 (1.2%)
Trade/vocational school	19 (4.9%)	10 (5.3%)	5 (4.2%)	4 (4.9%)
Associate's degree	40 (10.3%)	21 (11.2%)	15 (12.7%)	4 (4.9%)
Some college	63 (16.2%)	31 (16.5%)	19 (16.1%)	13 (15.9%)
Baccalaureate degree	117 (30.2%)	56 (29.8%)	34 (28.8%)	27 (32.9%)
Graduate/professional degree	111 (28.6%)	44 (23.4%)	38 (32.2%)	29 (35.4%)
AQ scores, mean (SD)	86.57 (10.60)	86.65 (10.74)	86.62 (10.71)	86.30 (10.23)
Mean (SD) scores				
Physical QoL	3.22 (.858)	3.16 (.884)	3.22 (.847)	3.36 (.804)
Psychological QoL[c]	2.94 (.794)	2.87 (.809)	2.93 (.781)	3.14 (.755)
Social QoL	2.88 (.959)	2.85 (.980)	2.89 (.972)	2.92 (.900)
Environmental QoL	3.45 (.805)	3.40 (.819)	3.42 (.767)	3.61 (.817)
Autism QoL	2.98 (.829)	2.92 (.854)	2.98 (.822)	3.12 (.772)
Instrumental support scale	.554 (.304)	.578 (.319)	.527 (.307)	.537 (.258)
Subjective support scale	.611 (.390)	.594 (.402)	.605 (.374)	.657 (.387)
Social interaction scale	1.85 (.457)	1.85 (.465)	1.80 (.420)	1.91 (.487)
Depression score	11.29 (7.96)	11.95 (8.25)	11.52 (7.78)	9.43 (7.32)
Anxiety score[d]	13.94 (9.00)	15.19 (9.04)	13.69 (9.17)	11.45 (8.20)

SD = standard deviation; QoL = quality of life; [a]Specific details of race are not provided by age group due to the small cell sizes and risk of identification; [b]N = 387 as one person missing from 40 to 49.9 group (n = 187); Group difference (between 40–49.9, 50–59.9, and 60+) are only noted on. [c]Psychological QoL mean score (F = 3.24, p = 0.040) and [d]anxiety score (F = 5.09, p = 0.007).

in everyday life (e.g. whether the respondent has family/ friends who will help them when they need help). Higher scores on the DSSI subscales reflect greater levels of social support. Subscales from the DSSI were used as independent variables of interest in the analyses. The 23-item DSSI, as well as an 11-item version of the questionnaire, were derived from a longer 35-item measure of social support (Landerman et al., 1989). Both the 23- and 11-item versions of the DSSI contain the SSS and SIS; however, only the 23-item DSSI contains a subscale querying instrumental support (i.e. the ISS; Koenig et al., 1993). In a study of community-dwelling older adults in Australia, the total score of the 11-item measure, which is comprised of a subset of items in the 23-item DSSI used here, demonstrated good concurrent and construct validity as well as good internal consistency (Cronbach's alpha = 0.77) and test–retest reliability (Goodger et al., 1999). Good internal reliability and construct validity has been demonstrated for the 4-item SIS (Cronbach's alpha = 0.80) and the 7-item SSS (Cronbach's alpha = 0.80) (Powers et al., 2004). The 23-item DSSI has shown good validity among both younger and older community-dwelling adults in China, with the subscales demonstrating good reliability, construct validity, and internal consistency (Cronbach's alpha ≥ 0.88; Pan et al., 2020) in evaluating social support (Jia & Zhang, 2012; Pan et al., 2020).

Items from the WHOQOL-BREF and DSSI were reviewed for potential overlap. One item was deemed similar across the two questionnaires, from the WHOQOL-BREF one question asks 'How satisfied are you with your personal relationships?' (contributing to the Social Relationships subscale) and one question from the DSSI asks 'How satisfied are you with relationships with family

and friends?' (contributing to the SSS). Mean scores for the Social Relationships subscale on the WHOQOL-BREF and the SSS on the DSSI were recalculated, excluding the relevant questions on each measure. Analyses were repeated to assure that results were not driven by the overlapping item.

Depression and anxiety symptomatology. Self-reported depression and anxiety symptomatology were measured so that their effects could be accounted for as covariates in analyses. Depression symptomatology was assessed using the 9-item Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001). Participants reported on the presence/frequency of depressive symptomatology on a 4-point Likert-type scale ('*Not at all*', '*Several days*', '*More than half the days*', and '*Nearly every day*'). Scores range from 0 to 27, with scores ≥10 indicating moderate or severe depression. Using a cut-off of ≥10, the PHQ-9 has been shown to have 88% sensitivity and specificity for major depressive disorder (Kroenke et al., 2001). The 7-item Generalized Anxiety Disorder scale (GAD-7; Spitzer et al., 2006) was used to quantify anxiety symptomatology. The GAD-7 probes the presence and severity of anxiety symptoms on a 4-point Likert-type scale ('*Not at all*', '*Several days*', '*More than half the days*', '*Nearly every day*'). Total scores range from 0 to 21, with scores ≥10 indicating moderate or severe anxiety. Using a cut-off of ≥10, the GAD-7 has shown good sensitivity (89%) and specificity (82%). The internal consistency of the GAD-7 was excellent (Cronbach's alpha = .92; Spitzer et al., 2006).

Community involvement: The studies were not designed or carried out with involvement from the autistic community.

Data analysis

Correlational analyses were used to examine the associations between variables of interest prior to regression analyses. Linear regression analyses were employed to identify the demographic and social support factors that explained variance in each QoL subscales in turn (Physical, Psychological, Social, Environmental, and ASQOL). In order to characterize QoL and social support in middle-aged and older autistic adults, means and standard deviations were reported for three age groups (40–49, 50–59, and 60+ years), and analyses of variance (ANOVAs) were performed to explore differences in these scores between the age groups.

Results

Correlational analyses

Correlational analyses were performed for all continuous variables of interest, to inform the inclusion of variables in the regression analyses. *Demographic and health variables*: Age correlated significantly with Psychological and Environmental QoL, with better QoL being associated with older age. The number of health conditions affecting daily functions correlated significantly and negatively with all QoL variables except Social QoL. *Mental health*: Depression and anxiety symptomatology correlated significantly with all five QoL subscales (Physical, Psychological, Social, Environmental, and ASQOL), indicating lower depression and anxiety ratings were associated with better QoL. *Social Support*: All three domains of social support (ISS, SSS, and SSS) correlated highly significantly and positively with all five QoL subscales, indicating better social support was associated with better QoL. See Table 2 for full details.

Regression analyses

Linear regression analyses were performed to explore the demographic and social support factors associated with each QoL subscale separately (Physical, Psychological, Social, Environmental, and ASQOL). Independent variables were entered in three steps. Step 1: sex assigned at birth, age, number of health conditions affecting daily life; Step 2: depression symptom score and anxiety symptom score; Step 3: ISS, SSS, and SIS scores from the DSSI.

Physical QoL. Step 1: Demographic factors were significantly associated with physical QoL scores with sex assigned at birth (males reporting higher QOL than females) and number of health conditions contributing significantly to the model ($R^2 = .175$, $F = 26.90$, $p < .001$; age did not contribute significantly to the model). Step 2: Depression and anxiety symptomatology significantly contributed to the model, although only depression symptoms contributed significantly ($R^2 = .532$, $F = 85.87$, $p < .001$). Step 3: social support factors, specifically subjective support and social interaction contributed significantly to the model ($R^2 = .554$, $F = 58.22$, $p < .001$). Instrumental support did not contribute significantly to the model. See Table 3 for details.

Psychological QoL. Step 1: Demographic variables significant contributed to the model explaining Psychological QOL, with age and number of health conditions contributing significantly ($R^2 = .032$, $F = 4.43$, $p = .004$). Step 2: Mental health significantly contributed to the model, with only depression contributing significantly ($R^2 = .472$, $F = 67.67$, $p < .001$). Step 3: Social support further contributed to explaining Psychological QOL, with subjective support and social interaction contributing significantly to the model ($R^2 = .551$, $F = 57.54$, $p < .001$). Instrumental support did not contribute significantly to the model. See Table 4 for details.

Table 2. Correlation table showing associations between QoL subscales and variables of interest.

	Physical QoL	Psychological QoL	Social QoL	Environmental QoL	Autism-specific QoL
Age	$r = 0.088$	$r = 0.111*$	$r = 0.029$	$r = 0.103*$	$r = 0.093$
Number of health conditions affecting daily life	$r = -0.357**$	$r = -0.133**$	$r = -0.082$	$r = -0.226***$	$r = -0.161***$
Anxiety score	$r = -0.504**$	$r = -0.519***$	$r = -0.342***$	$r = -0.425***$	$r = -0.507***$
Depression score	$r = -0.670***$	$r = -0.687***$	$r = -0.485***$	$r = -0.544***$	$r = -0.591***$
Instrumental support scale	$r = 0.230***$	$r = 0.263***$	$r = 0.338***$	$r = 0.374***$	$r = 0.495***$
Subjective support scale	$r = 0.459***$	$r = 0.592***$	$r = 0.527***$	$r = 0.529***$	$r = 0.668***$
Social interaction scale	$r = 0.314***$	$r = 0.373***$	$r = 0.299***$	$r = 0.323***$	$r = 0.269***$

QoL = quality of life; $*p \leqslant .05$; $**p \leqslant .01$; $***p \leqslant .001$.

Table 3. Regression Analyses for the Physical Quality of Life subscale of the WHOQOL-BREF.

Predictor ($n = 384$)	Physical QoL		
	Std. Beta	Std. Error Beta	*t*-statistic
Step 1			
Sex	−.192	.082	−4.13***
Age	.073	.004	1.54
Number of health conditions affecting daily life	−.343	.086	−7.33***
Model summary	$R^2 = .175$; $F = 26.90$, $p < .001$		
Step 2			
Sex	−.144	.062	−4.01***
Age	−.013	.003	−0.353
Number of health conditions affecting daily life	−.244	.066	−6.79***
Anxiety Score	−.032	.005	−0.596
Depression Score	−.591	.006	−11.06***
Model Summary	$R^2 = .532$; $F = 85.87$, $p < .001$		
Step 3			
Sex	−.156	.062	−4.37***
Age	−.024	.003	−0.669
Number of health conditions affecting daily life	−.245	.065	−6.95***
Anxiety Score	−.041	.005	−0.784
Depression Score	−.504	.006	−8.74***
Instrumental Support Scale	−.069	.115	−1.70
Subjective Support Scale	.126	.101	2.74**
Social Interaction Scale Coded Mean	.100	.074	2.55*
Model Summary	$R^2 = .554$; $F = 58.22$, $p < .001$		

$*p \leqslant .05$; $**p \leqslant .01$; $***p \leqslant .001$; QoL = quality of life.

Social QoL. Step 1: Demographic variables did not significantly contribute to the model explaining Social QOL ($R^2 = .012$, $F = 1.55$, $p = .202$). Step 2: Mental health factors significantly contributed to the model explaining Social QOL, with depression and sex assigned at birth both contributing significantly ($R^2 = .249$, $F = 25.03$, $p < .001$). Step 3: Social support further contributed to explaining Social QOL. Instrumental support and subjective support scales contributed significantly, as well as depression and sex assigned at birth ($R^2 = .360$, $F = 26.36$, $p < .001$). The social interactions score did not contribute significantly to the model. See Table 5 for details.

Environmental QoL. Step 1: Demographic factors contributed a small but significant proportion to the model explaining Environmental QOL with sex assigned at birth (males reporting higher QOL than females) and number of health conditions contributing significantly ($R^2 = .084$, $F = 11.55$, $p < .001$). Step 2: Mental health (depression specifically) further contributed significantly to the model ($R^2 = .328$, $F = 36.83$, $p < .001$). Step 3: Social support contributed further to the model explaining Environmental QoL; instrumental support and subjective support scales contributed significantly ($R^2 = .420$, $F = 33.90$, $p < .001$).

Table 4. Regression Analyses for the Psychological Quality of Life subscale of the WHOQOL- BREF.

Predictor (n = 384)	Psychological QoL		
	Std. Beta	Std. Error Beta	t-statistic
Step 1			
Sex	−.049	.082	−0.964
Age	.109	.004	2.12*
Number of health conditions affecting daily life	−.134	.086	−2.65**
Model summary	$R^2 = .034$; $F = 4.43$, $p = .004$		
Step 2			
Sex	.008	.061	0.210
Age	.016	.003	0.405
Number of health conditions affecting daily life	−.023	.065	−0.609
Anxiety score	−.016	.005	−0.282
Depression score	−.670	.006	−11.81***
Model summary	$R^2 = .472$; $F = 67.67$, $p < .001$		
Step 3			
Sex	−.002	.058	−0.056
Age	.005	.003	0.143
Number of health conditions affecting daily life	−.022	.060	−0.629
Anxiety score	−.030	.005	−0.574
Depression score	−.482	.006	−8.34***
Instrumental support scale (ISS)	−.063	.107	−1.54
Subjective support scale	.303	.094	6.53***
Social interaction scale–coded mean	.102	.068	2.57**
Model summary	$R^2 = .551$; $F = 57.54$, $p < .001$		

*$p \leqslant .05$; **$p \leqslant .01$; ***$p \leqslant .001$; QoL = quality of life.

The social interactions score did not contribute significantly to the model. See Table 6 for details.

ASQOL. Step 1: Demographic factors contributed a small but significant amount to the model explaining ASQOL, with sex assigned at birth (males reporting higher QOL than females) and number of health conditions contributing significantly ($R^2 = .060$, $F = 8.03$, $p < .001$). Step 2: Mental health contributed further to the model with both depression and anxiety contributing significantly ($R^2 = .376$, $F = 45.51$, $p < .001$). Step 3: Social support contributed additional variance to the model explaining ASQOL; instrumental support and subjective support scales contributed significantly ($R^2 = .583$, $F = 65.64$, $p < .001$). The social interactions score did not contribute significantly to the model. See Table 7 for details.

To account for multiple comparisons, a Bonferroni correction was applied to the results. All final models remained significant after correction ($p < .01$). Analyses were repeated using the SSS and Social Relationships QoL scales recalculated to exclude the overlapping item. Results show the same pattern of associations, and models remained statistically significant suggesting that similarity between the items were not driving results (results not reported).

Data characterization

As there is currently little data describing how autistic adults describe their own experiences of social support and QoL, mean, and standard deviations for three age groups (40–49.9; 50–59.9; and 600+) are reported in Table 1. Differences between age groups for demographic information were examined. Few age-related differences were noted across the three groups. A significant age-group difference was observed only for the mean score for the Psychological WHOQOL-BREF subscale ($F = 3.24$, $p = .040$). Post hoc analyses demonstrated a significant difference between 40-year olds and those over 60, but no other group differences (Tukey HSD, Mean difference = −.264, $p = .032$). No other age-group differences in social support and QoL were observed (results not shown). No age-group differences were observed in AQ scores ($F = .05$, $p = .955$).

Discussion

This study supported the hypotheses and revealed significant associations between different aspects of QoL and social support in middle-aged and older autistic adults for the first time. In keeping with the literature from both non-autistic older adults and autistic young adults, better QoL

Table 5. Regression Analyses for the Social Quality of Life subscale of the WHOQOL- BREF.

Predictor ($n = 384$)	Social QoL		
	Std. Beta	Std. Error Beta	*t*-statistic
Step 1			
Sex	.066	.101	1.280
Age	.044	.005	0.844
Number of health conditions affecting daily life	−.090	.106	−1.749
Model summary	$R^2 = .012$; $F = 1.55$, $p = .202$		
Step 2			
Sex	.108	.089	2.38 *
Age	−.021	.005	−0.447
Number of health conditions affecting daily life	−.007	.094	−0.148
Anxiety score	.036	.007	0.529
Depression score	−.526	.008	−7.78***
Model summary	$R^2 = .249$; $F = 25.03$, $p < .001$		
Step 3			
Sex	.127	.083	2.96 **
Age	−.012	.004	−0.291
Number of health conditions affecting daily life	.001	.087	0.027
Anxiety score	.012	.007	0.194
Depression score	−.301	.008	−4.36***
Instrumental support scale	.115	.154	2.35*
Subjective support scale	.311	.136	5.61***
Social interaction scale coded mean	.032	.099	0.683
Model summary	$R^2 = .360$; $F = 26.36$, $p < .001$		

*$p \leqslant .05$; **$p \leqslant .01$; ***$p \leqslant .001$; QoL = quality of life.

Table 6. Regression Analyses for the Environment Quality of Life subscale of the WHOQOL- BREF.

Predictor ($n = 384$)	Environmental QoL		
	Std. Beta	Std. Error Beta	*t*-statistic
Step 1			
Sex	−.143	.082	−2.86**
Age	.090	.004	1.81
Number of health conditions affecting daily life	−.218	.086	−4.41***
Model summary	$R^2 = .084$; $F = 11.55$. $p < .001$		
Step 2			
Sex	−.100	.070	−2.32*
Age	.018	.004	0.404
Number of health conditions affecting daily life	−.137	.075	−3.18**
Anxiety score	−.050	.006	−0.790
Depression score	−.470	.006	−7.35***
Model summary	$R^2 = .328$; $F = 36.83$, $p < .001$		
Step 3			
Sex	−.083	.067	−2.03*
Age	.024	.004	0.583
Number of health conditions affecting daily life	−.129	.070	−3.21***
Anxiety score	−.077	.005	−1.29
Depression score	−.263	.007	−4.00***
Instrumental support scale	.116	.124	2.50*
Subjective support scale	.253	.109	4.79***
Social interaction scale coded mean	.064	.079	1.42
Model summary	$R^2 = .420$; $F = 33.90$, $p < .001$		

*$p \leqslant .05$; **$p \leqslant .01$; ***$p \leqslant .001$; QoL = quality of life.

Table 7. Regression Analyses for the Autism Quality of Life scale.

Predictor (n = 384)	Autism QoL		
	Std. Beta	Std. Error Beta	*t*-statistic
Step 1			
Sex	−.156	.085	−3.09**
Age	.075	.005	1.49
Number of health conditions affecting daily life	−.151	.089	−3.01**
Model summary	$R^2 = .060$; $F = 8.03$, $p < .001$		
Step 2			
Sex	−.015	.070	−2.60**
Age	−.108	.004	−0.352
Number of health conditions affecting daily life	−.063	.074	−1.52
Anxiety score	−.156	.006	−2.54*
Depression score	−.454	.006	−7.36***
Model summary	$R^2 = .376$; $F = 45.51$, $p < .001$		
Step 3			
Sex	−.076	.058	−2.21*
Age	.003	.003	0.082
Number of health conditions affecting daily life	−.050	.061	−1.46
Anxiety score	−.195	.005	−3.84***
Depression score	−.151	.006	−2.70**
Instrumental support scale	.208	.107	5.34***
Subjective support scale	.385	.094	8.75***
Social interaction scale	.048	.014	0.177
Model summary	$R^2 = .583$; $F = 65.64$, $p < .001$		

$*p \leqslant .05$; $**p \leqslant .01$; $***p \leqslant .001$; QoL = quality of life.

was associated with greater social support. One of the unique features of this study was that it examined different aspects of QoL (physical, psychological, social and environmental, and autism-specific) as well as different aspects of social support (subjective, social interactions, and instrumental). Thus, this study allowed us to examine the unique patterns of associations between different aspects of QoL and different facets of social support and to examine associations in a group of middle-aged and older autistic adults.

In keeping with the hypotheses, social support was significantly associated with each aspect of QoL, even after accounting for demographic, health and mental health factors. The association between social support and each aspect of QoL varied by domain and magnitude (standardized Beta range = .100–.385). However, regression analyses also suggested distinct patterns of importance for different aspects of social support for each QoL measure. All components of QoL (physical, psychological, social relationships, environmental, and autism-specific) were associated with subjective social support and self-reported depression symptomatology. In addition, Physical and Psychological QoL were associated with the number and QoL interactions, whereas Social and Environmental QoL

were associated with instrumental support. Variance in ASQOL was additionally associated with anxiety symptomatology and instrumental support. It is worth noting that a large proportion of variance in QoL remained unaccounted for within each model. Despite demographic, mental and physical health and social support significantly contributing to the models, other, as yet unidentified, variables important for QoL are not included in the models.

These results demonstrate the importance of perceived or subjective social support for middle and older age autistic adults and are consistent with findings from previous studies of younger autistic adults. In one study, both perceived stress and perceived social support explained a significant proportion of the variance in overall QoL for young and middle-aged autistic adults (Bishop-Fitzpatrick et al., 2018). Other studies suggested that perceived support from family and friends or maternal support specifically are significantly associated with psychological, social and health-specific QoL for young autistic adults (Kamio et al., 2012; Khanna et al., 2014). However, not all studies find this pattern of associations. One study examining the impact of friendship on outcome variables found no association between number of friends and life satisfaction (although more friends was associated with lower

symptoms of anxiety and depression; Mazurek, 2013). It is worth noting that satisfaction with friendships (i.e. a subjective assessment of friendship quality) may be more important than the number of friends (i.e. a simple quantification of the number of friendships). To our knowledge only one study has examined the impact of both perceived and actual support on overall QoL in autistic adults. Support characteristics overall (perceived social support, received formal, and informal support) explained a significant proportion of the variance in overall QoL among younger autistic adults (Renty & Roeyers, 2006). However, post hoc analyses demonstrated that perceived informal support (akin to subjective social support in the current study) and unmet actual support needs were significantly associated with QoL, whereas received practical support was not in that sample. In this study, instrumental support significantly contributed to explaining the variance in Social, Environmental, and ASQOL. It is worth noting that the association between perceived social support and QoL is also recognized in the neurotypical aging literature (Hajek et al., 2016; LaRocca & Scogin, 2015; Sahin et al., 2019). In one study, perceived social support alone explained 22.1% of the variance in overall QoL, although other aspects of mental and physical health were not assessed (Sahin et al., 2019), perhaps overestimating the independent contribution of social support to QoL.

In keeping with studies in both younger autistic adults and non-autistic adults across adulthood, mental health factors such as presence of anxiety and depression symptoms were also associated with QoL (Chachamovich et al., 2008; Kamio et al., 2012; Layte et al., 2013; Mason et al., 2018, 2019). Previous studies have found that psychiatric comorbidities were associated with different aspects of QoL for young and middle-aged autistic adults (Kamio et al., 2012; Mason et al., 2018). For example, one previous study of autistic adults found that self-reported depression and anxiety symptoms were significantly associated with Physical, Psychological, and Environmental QoL, while Social QoL was only associated with depression symptoms (Mason et al., 2019). Studies in older neurotypical adults show a similar pattern of results, with mental health factors, and depression specifically (even at low levels), significantly impacting the QoL of older neurotypical adults (Chachamovich et al., 2008; Kisvetrova et al., 2021; Layte et al., 2013).

Sex assigned at birth contributed to the model explaining Physical and Environmental QoL. This reflected the finding that males reported higher Physical and Environmental QoL compared to females. This pattern of better self-reported QoL among males compared to females is frequently observed among neurotypical older adults (Campos et al., 2014; Gallicchio et al., 2007; Rollero et al., 2014 but see Kirchengast & Haslinger, 2008 for higher QoL in females).

There is little evidence of age-differences in QoL or social support measures among autistic adults in this study. This is somewhat discrepant from findings in non-autistic older adults. Previous research has suggested that non-autistic older adults may have better QoL compared to middle-aged adults, although in later old-age QoL has been shown to be reduced, possibly related to declines in health (Diehr et al., 2013; Raggi et al., 2016). One study has suggested that age-effects on QoL may be curvilinear with a person's QoL peaking in their late sixties and declining thereafter (Layte et al., 2013). Social support has also been shown to change with age among non-autistic adults, although the pattern of change is complex. Some studies suggest that the nature (friends vs family), but not the size, of social support networks may change with age, whereas other studies have shown increased social isolation with aging, and different trajectories at different age ranges (Czaja et al., 2018; Field & Minkler, 1988; van Tilburg, 1998). The results in this study suggest few age-effects, although it is unclear if this may reflect a different (less negative) pattern of age-effects for middle-aged and older autistic adults or some effect of sampling differences in either the recruitment of or diagnostic criteria applied to autistic adults of different ages. Ultimately, to answer these important developmental questions, longitudinal data during middle and older adulthood in ASD are needed in order to evaluate changes in QoL or social support, including evaluating the potential for both linear and nonlinear trajectories of change.

This study should be considered with certain strengths and limitations in mind. Caution should be used when considering results relating to ASQOL, as this measure was not administered alongside the Disability module of the WHOQOL-BREF. Furthermore, a recent paper has suggested that response to items on the ASQOL may differ by sex (Williams & Gotham, 2021), meaning that ASQOL results here relating to sex differences should be considered with caution. However, the WHOQOL-BREF has been validated for use with autistic adults (McConachie et al., 2018) and has evidence of good factor structure, fit and test–retest validity, meaning the results are likely to be robust. The models described here do not fully explain the variance in QoL, and future studies will need to consider and investigate additional contributing variables. The study relies on self-report online data, which may increase sampling bias. However, it is critically important to acknowledge that subjective QoL is based on an individual's perception and therefore self-report is not only appropriate, but also preferred, whenever possible. The cognitive demands of the survey and the participants' generally high education level suggest that this sample has abilities within the normal range or higher and, therefore, does not fully reflect the experiences of all autistic adults (e.g. those with co-occurring intellectual disability). The SPARK sample also has limited ethno-racial representation, although it has

been shown that self-disclosure of diagnoses in this sample is accurate (Fombonne et al., 2021). However, the sample also includes a large number of middle-aged and older autistic adults, particularly those assigned female at birth, both of which are under-studied groups. To our knowledge, this is the first study to examine the impact of social support on QoL among middle-aged and older autistic adults.

In conclusion, this study of 388 middle-aged and older autistic adults found that social support, in particular, subjective social support were associated with different aspects of QoL. Social support remained significantly associated with QoL even after accounting for the effects of demographic and health factors, and symptoms of anxiety and depression. Results suggest that different aspects of social support (instrumental, subjective, and social interactions) are important for outcomes for middle-aged and older autistic adults. Therefore interventions bolstering different forms and types of supports may cascade to benefit older autistic adults. Further longitudinal studies are required to explore the impact of common age-related changes, such as size, content, quality, and arrangement of social and other support networks on outcomes for autistic adults.

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