Increased Perceived Stress is Negatively Associated with Activities of Daily Living and Subjective Quality of Life in Younger, Middle, and Older Autistic Adults

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Abstract

Few studies have examined self-reported perceived stress in autistic adults. Existing studies have included relatively small, predominantly male samples and have not included older autistic adults. Using a large autistic sample (*N*=713), enriched for individuals assigned female at birth (59.3%), and spanning younger, middle, and older adulthood, we examined perceived stress and its associations with independence in activities of daily living and subjective quality of life (QoL). Perceived stress for autistic adults designated male or female at birth was compared to their same birth-sex counterparts in a general population sample. In addition, within the autistic sample, effects of sex designated at birth, age, and their interaction were examined. Regression modeling examined effects of perceived stress in autistic adults on independence in activities of daily living and domains of subjective QoL after controlling for age, sex designated at birth and household income. Autistic adults reported significantly greater perceived stress than a general population comparison sample. Relative to autistic adults designated male at birth, those designated female at birth demonstrated significantly elevated perceived stress. Perceived stress contributed significantly to all regression models, with greater perceived stress associated with less independence in activities of daily living, and poorer subjective QoL across all domains—Physical, Psychological, Social, Environment and Autism-related QoL. Findings are contextualized within the literature documenting that autistic individuals experience heightened rates of adverse life events and increased exposure to minority stress.

Keywords: activities of daily living, autism, adulthood, perceived stress, subjective quality of life

Lay summary

This study looked at self-reported perceived stress in a large sample of autistic adults. Autistic adults reported more perceived stress than non-autistic adults. Autistic individuals designated female at birth reported higher stress than autistic individuals designated male at birth. In autistic adults, greater perceived stress is related to less independence in activities of daily living and poorer subjective quality of life.

Introduction

Stress is implicated in an array of poor health outcomes (Thoits, 2010). Detrimental impacts of stress on health include immune system dysfunction (Glaser & Kiecolt-Glaser, 2005), cardiovascular disease (Kivimäki & Steptoe, 2018), depression (Slavich & Irwin, 2014) and anxiety (Juruena et al., 2020). Stress can be operationalized in different ways. Stress may be measured via biological assays, such as levels of skin conductance or the stress hormone cortisol. Alternatively, stress may be defined by life experiences (e.g., having experienced a natural disaster or a major negative life event such as the death of a loved one or loss of a job and income) or by the life-roles one assumes (e.g., pregnancy-related stress, caregiver stress). Further, stress may be quantified based, not on a particular event or role per se, but instead based on an individual's report of how stressful they evaluate the relevant event or role to be.

There is a growing literature on the impacts of stress in autism spectrum disorder (ASD); however, studies have employed different operationalizations of stress. A number of studies have examined self-reported experiences of stress and have demonstrated elevated stress in autistic individuals. For instance, studies have shown autistic adults show elevated stress assessed via the Stress subscale of the Depression, Anxiety Stress Scales (DASS; Henry & Crawford, 2005) (George & Stokes, 2018; Park et al., 2019), a metric that more nearly approximates generalized anxiety, as opposed to stress. Other studies have used the Stress Survey Schedule (SSS; Groden et al., 2001), asking autistic individuals to rate the level of stress they would experience when encountering certain events (e.g., being near bright lights, waiting in line, having a conversation). These studies have shown autistic females report higher levels of stress in response to events involving sensory stimuli and personal contact, relative to autistic males, and older autistic adults report greater stress than their younger counterparts for all domains except exposure to sensory

stimuli and personal contact (Gillott & Standen, 2007; McGillivray & Evert, 2014). Research has also examined lifetime exposure to major stressors and perceived severity of those stressors using the Stress and Adversity Inventory for Adults (STRAIN; Slavich & Shields, 2018), showing autistic adults reported greater stress responsivity overall, and in particular greater severity of stress in response to stressors characterized by change, humiliation, and physical danger (Moseley et al., 2021).

Unlike the self-reported measures of stress used above, stress may also be defined more broadly, without reference to or consideration of any particular life event or role and without inquiring about specific experiences. This more global measure of stress queries an individual's appraisal of how stressful their everyday life is and how equipped they assess themselves to be to handle that everyday stress. This last conceptualization of stress is referred to as perceived stress. Perceived stress may be a particularly important metric of stress to employ in understanding the experiences and impacts of stress in ASD, given that relative to neurotypical individuals, autistic individuals may experience everyday life differently and may therefore identify different stimuli and events as stressors. For example, the core features of ASD include challenges in navigating social situations, sensory processing differences, and discomfort with transitions and novel situations. Thus, as a metric of stress, perceived stress allows for research that privileges the global autistic experience of stress, rather than presuming that certain stimuli or events may be sources of stress for autistic individuals.

Literature examining perceived stress to date has shown that compared to neurotypical adults, autistic adults report higher levels of perceived stress (Bishop-Fitzpatrick, Minshew, et al., 2017; Hirvikoski & Blomqvist, 2014; McLean et al., 2021), and the higher levels of perceived stress in autistic adults are associated with reduced social functioning (Bishop-

Fitzpatrick, Smith DaWalt, et al., 2017). Furthermore, greater perceived stress is linked to poorer subjective QoL (Bishop-Fitzpatrick, Smith DaWalt, et al., 2017) in autistic adults, unlike neurotypical adults, when controlling for age, sex and IQ (Bishop-Fitzpatrick et al., 2018). Additionally, higher levels of perceived stress in autistic adults worsened the association between poor sleep quality and diminished subjective quality of life (McLean et al., 2021). Finally, one study examining a small sample of autistic adults (N=60; autistic female: n=14) found sex differences in perceived stress in autistic adults, with autistic females reporting elevated levels of perceived stress relative to autistic males (Hong et al., 2016), a finding that parallels sex differences in perceived stress reported for the general population (Cohen & Janicki-Deverts, 2012).

A small body of research suggests perceived stress may serve as a target for therapeutic intervention in autistic adults. A randomized controlled trial showed that, compared to autistic adults assigned to a waitlist condition, those who received dog-assisted therapy reported decreased perceived stress at follow-up timepoints relative to baseline (Wijker et al., 2020), and autistic adults assessed before and after a twelve-week intervention utilizing acceptance and commitment therapy reported a significant reduction in perceived stress (Pahnke et al., 2019).

To advance our understanding of perceived stress in autistic adults, the current study examined potential relationships between perceived stress and activities of daily living and subjective quality of life (QoL) in a large sample of autistic adults spanning young, middle and older adulthood. We sought to replicate findings in the extant literature on perceived stress that has documented higher perceived stress in autistic adults relative to non-autistic adults, and that has shown elevated perceived stress in autistic adults is negatively associated with overall subjective QoL. We also sought to extend the existing literature, examining potential links

between perceived stress and activities of daily living and subjective QoL across multiple domains—Physical Health, Psychological Health, Environment, Social Relationships, and Autism-related QoL—while controlling for key, potentially confounding, variables: sex designated at birth, age, and a metric of socioeconomic status.

We hypothesized that autistic adults would show elevated perceived stress relative to a comparison general population sample, and that autistic adults designated female at birth would report greater levels of perceived stress relative to autistic adults designated male at birth. We further predicted that after accounting for effects of sex designated at birth, age, and socioeconomic status, heightened levels of perceived stress would predict lower independence in activities of daily living, and poorer subjective QoL across all measured domains in autistic adults.

Methods

Participants

Participants were recruited via Simons Powering Autism Research and Knowledge (SPARK; The SPARK Consortium, 2018) Research Match. All participants took part in a broader online study of adult development and outcomes in ASD and were provided $25 for completing study procedures. 713 adults (59.3% female) ranging in age from 18.17-83.33 years (M=38.47, SD=13.60) were included in analyses reported here.

The sample was composed of "independent" autistic adults, as designated by SPARK. "Independent adults" are individuals ≥18 years of age who do not have a court-appointed legal guardian and who can therefore consent for themselves. Given these SPARK criteria for "independent adult" status, participants were unlikely to have a co-occurring intellectual

disability. Additionally, as part of a medical history questionnaire collected in the current study, no participant reported intellectual disability as a past or current diagnosis.

To be included in analyses here, a self-disclosed community-based diagnosis of an autism spectrum disorder provided by a medical/clinical professional was required. SPARK does not independently confirm diagnoses; however, SPARK partners with and recruits from expert autism clinical sites, in part, to increase the likelihood that participants have a professional autism spectrum diagnosis (The SPARK Consortium, 2018). Additionally, a study examining a sample of 254 SPARK participants, including "independent" adults, confirmed an autism spectrum diagnosis in 98.8% of the sample using electronic medical records (Fombonne et al., 2021). The study concluded that the validity of disclosed autism spectrum diagnoses, including self-disclosed diagnoses, were independently confirmed with "high confidence" (Fombonne et al., 2021). Consistent with the self-disclosed clinical diagnoses of participants in the current study, 94.5% of the sample (*n*=674) met screening criteria (total scores of >65) on the Autism Spectrum Quotient-Short Form (AQ-28; Hoekstra et al., 2011).

Demographic characteristics of the sample are presented in Table 1. The study was approved by The George Washington University Institutional Review board and followed procedures in accordance with the Declaration of Helsinki.

Measures

Perceived stress

The Perceived Stress Scale (PSS; Cohen et al., 1983; Cohen & Williamson, 1988) is one of the most commonly used instruments for the measurement of perceived stress, and has been implemented in neurotypical (Ezzati et al., 2014; Tan et al., 2020) and autistic samples (Bishop-Fitzpatrick, Minshew, et al., 2017; Bishop-Fitzpatrick et al., 2018; Wijker et al., 2020).

In its initial deployment, the PSS was comprised of 14 items (Cohen et al., 1983). The 14-item scale showed adequate reliability (Cronbach's alpha=.84-.86). The measure was also correlated with life-event impact scores (*r*=.24-.49), which to some degree assesses the subjective assessment of stress, and therefore supports the construct validity of the PSS (Cohen et al., 1983). Moreover, the PSS was a better predictor of health-related outcomes than were life-event scores, which probed the number of negative life events (derived from the Unpleasant Events Schedule (Lewinsohn & Talkington, 1979)), and the respondents' rating regarding the impact of the relevant aversive events.

A modified version of the PSS, comprised of 10 items (Cohen & Williamson, 1988), has shown reliability and validity comparable to the 14-item PSS (Roberti et al., 2006). The current study employed the 10-item PSS. Broadly, the 10-item PSS demonstrates good internal consistency reliability (Cronbach's alpha=0.78-0.98) (Cohen & Janicki-Deverts, 2012; Cohen & Williamson, 1988). Further, and of particular relevance to the current study, within a sample of autistic adults without co-occurring ID, the PSS has shown good internal consistency reliability (Cronbach's alpha=.87) (Bishop-Fitzpatrick, Minshew, et al., 2017). For details on prior empirical studies that have utilized the PSS in autistic adult samples, see Table 2.

The PSS forms a unidimensional scale of global perceived stress. Participants responded to each item on a 5-point Likert scale (ranging from 0=Never to 4=Very Often). Total scores range from 0-40, with higher scores indicating greater levels of perceived stress. In the current study, Cronbach's alpha for the PSS was 0.89. In all analyses, the PSS was used as the independent variable.

Activities of daily living

Participants' independence in the performance of activities of daily living was assessed using the Waisman Activities of Daily Living (W-ADL; Maenner et al., 2013). The W-ADL is comprised of 17-items answered on a 3-point Likert scale (0=Does not do at all; 1=Does with help; 2=Independent, or does on own). W-ADL items were summed to generate a total score ranging from 0 to 34, with higher scores indicative of greater independence in activities of daily living. The W-ADL has high internal reliability (Cronbach's alpha=0.81; Bishop-Fitzpatrick et al., 2017) and has demonstrated robust reliability over time, with weighted kappas ranging from 0.92 to 0.93 (Maenner et al., 2013). The W-ADL mean item score served as a dependent variable in analyses reported here.

Subjective quality of life

Subjective quality of life (QoL) was assessed via the Abbreviated World Health Organization Quality of Life (WHOQOL-BREF; The WHOQOL Group, 1998), and the Autism Spectrum Quality of Life (ASQoL; McConachie et al., 2018) questionnaires. The WHOQOL-BREF is a 26-item assessment focusing on four domains of subjective QoL: Physical Health (7 items), Psychological Health (6 items), Social Relationships (3 items), and Environment (8 items). Two additional items query general health and global QoL. Participants responded to each item on a 5-point Likert scale. A score was generated for each of the four domains by summing respective item responses. Analyses reported here used the mean item score for each of the four domains (range 1 to 5), with higher scores reflecting better subjective QoL.

The ASQoL was developed through engagement with autistic adults to formulate "autism-specific" subjective QoL items to be administered in conjunction with the WHOQOL-BREF (McConachie et al., 2018). The ASQoL consists of nine items answered on a 5-point Likert scale (1=Not at All/Never, 5=Totally/Always). An ASQoL score is calculated by

averaging responses to the initial eight survey items. A final ninth item, which asks about 'autistic identity,' is not included in the calculation of the ASQoL score. Mean scores range from 1 to 5, with higher scores reflecting better subjective QoL. In analyses reported here, the ASQoL mean score was used as a dependent variable.

Data Analysis

To contextualize perceived stress in the current sample of autistic adults, we compared mean PSS scores in our sample to those scores collected from a large sample of adults from the general population. In 2009, the 10-item PSS was administered to 4,000 adults in the United States (Cohen & Janicki-Deverts, 2012). Using two one-sample *z*-tests, we compared PSS mean scores in autistic females and males in the current sample with those of females and males, respectively, in the aforementioned general population sample.

To evaluate potential sources of perceived stress heterogeneity within the autistic sample, a 2 × 2 Analysis of Variance (ANOVA) examined effects of sex designated at birth (female vs. male), age group (younger [18-39 years; n=421] vs. older [40-83 years; n=292] adults) and a sex × age interaction.

To probe relationships between perceived stress and the outcomes of interest, multiple linear regression analyses were employed. These analyses investigated contributions of perceived stress to subjective QoL (WHOQOL-BREF Physical Health, Psychological Health, Social Relationships, and Environment domain scores; ASQoL total score) and daily living skills (W-ADL total score) after accounting for potentially influential covariates, including age, annual household income, and sex designated at birth. Additionally, the regression between perceived stress and psychological QoL was rerun omitting one of the items from the psychological QoL domain ("How often do you have negative feelings, such as blue mood, despair, anxiety,

depression?") due to its content overlap with an item on the PSS ("In the last month, how often have you felt nervous and stressed?") in order to confirm that findings remained unchanged by this item's omission. Corrections for multiple comparisons in the regression models were made using the Bonferroni method, and regression results surviving the adjusted *p*-value (.05/6=.0083) were considered statistically significant.

Results

One-sample *z*-tests revealed that compared to general population adult females (*M*=16.14, *SD*=7.56) and males (*M*=15.5, *SD*=7.44), autistic females (*M*=23.96, *SD*=7.07) and males (*M*=21.13, *SD*=7.61) reported significantly elevated levels of perceived stress (females: *z*=6.18, *p*<.0001; males: *z*=4.19, *p*<.0001). See Figure 1.

The 2 × 2 ANOVA revealed a main effect of sex designated at birth for PSS total score, with autistic females reporting higher perceived stress relative to autistic males (autistic females: *n*=423, *M*=2.40, SD=0.71; autistic males: *n*=290, *M*=2.12, SD=0.76; *F*(1,709)=23.58, *p*<.001, ηp^2=.03), but neither a significant main effect of age group (18-39: *n*=421, *M*=2.31, SD=0.75; 40-83: *n*=292, *M*=2.25, SD=0.73; *F*(1,709)=0.84, *p*=.36, ηp^2=.001), nor a significant interaction between age group and sex designated at birth (*F*(1,709)=0.46, *p*=.50; ηp^2=.001).

Results of multiple linear regression analyses are reported in Table 3 and Figure 2. An evaluation of covariates revealed that, with the exception of Social Relationships, sex designated at birth contributed significantly to all domains of subjective QoL, with autistic adults designated female at birth reporting lower subjective QoL compared to those designated male at birth. Age contributed significantly to the model of activities of daily living, with older age associated with greater independence in activities of daily living. Age also significantly contributed to models of Physical Health, Social Relationships, and Autism-related QoL, with older age associated with

lower subjective QoL in these domains. Household income significantly contributed to all models, with higher household income associated with greater independence in activities of daily living and higher subjective QoL across all five domains.

After accounting for the significant effects of sex designated at birth, age, and household income, Bonferroni-corrected results revealed that perceived stress contributed significantly to the models for activities of daily living and to all metrics of QoL. Specifically, perceived stress was significantly associated with less independence in activities of daily living (β=-0.17, t=-4.54, p<.001, ΔR^2=.03, adjusted R^2=.07), and with lower Autism-Related QoL (β=-0.69, t=-20.98, p<.001 ΔR^2=.34, adjusted R^2=.45), as well as lower QoL for all four WHOQOL-BREF domains: Physical Health (β=-0.68, t=-19.64, p<.001 ΔR^2=.31, adjusted R^2=.42), Environment (β=-0.60, t=-18.74, p<.001 ΔR^2=.28, adjusted R^2=.42), Psychological Health (β=-0.69, t=-24.32, p<.001 ΔR^2=.44, adjusted R^2=.47), and Social Relationships (β=-0.48, t=-14.30, p<.001, ΔR^2=.22, adjusted R^2=.24). Thus, effect sizes demonstrated small (W-ADL), medium-to-large (WHOQOL Social Relationships), and large (ASQoL and the WHOQOL Physical Health, Psychological Health and Environment domains) effects of perceived stress on daily living skills and subjective QoL.

Additionally, after rerunning the regression examining links between perceived stress and psychological QoL (omitting a single item from the latter measure due to its content overlap with a PSS item), findings for this model remained substantively unchanged. Specifically, after removal of this item, and after accounting for effects of sex designated at birth, age, and household income, perceived stress was significantly associated with lower Psychological Health (β=-0.64, t=-21.32, p<.001 ΔR^2=.38, adjusted R^2=.41).

Discussion

The current study aimed to advance the understanding of perceived stress and its potential associations with activities of daily living and subjective QoL in autistic adults. In a large sample, spanning young, middle and older adulthood, we present robust findings, consistent with the extant literature (Bishop-Fitzpatrick, Minshew et al., 2017; Hirvikoski & Blomqvist, 2014; McLean et al., 2021), that autistic adults report higher perceived stress relative to non-autistic adults, and autistic adults designated female at birth evince higher perceived stress relative to autistic adults designated male at birth (Hong et al., 2016). The findings reported here also extend the literature, showing that after controlling for sex designated at birth, age, and total household income, perceived stress in autistic adults is significantly associated with less independence in activities of daily living and lower subjective QoL across all measured domains—Physical Health, Psychological Health, Environment, Social Relationships, and Autism-related QoL.

We found autistic adults designated female and male at birth reported significantly elevated perceived stress relative to females and males, respectively, in a large general population sample (Cohen & Janicki-Deverts, 2012). These results are in accord with research reporting autistic adults show higher levels of perceived stress compared to neurotypical adults (Bishop-Fitzpatrick, Minshew et al., 2017; Hirvikoski & Blomqvist, 2014; McLean et al., 2021). Consistent with broader findings on perceived stress in the general population (Cohen & Janicki-Deverts, 2012), autistic adults designated female at birth reported significantly higher levels of perceived stress compared to those designated male at birth. The sex differences reported in the current study are in accord with a study with a considerably smaller study of 60 autistic adults (female, n=14), which found that compared to autistic males, autistic females self-reported greater levels of perceived stress (Hong et al., 2016).

After accounting for the effects of sex designated at birth, age and total household income, and subsequent to correcting for multiple comparisons, perceived stress contributed significantly to all models: greater levels of perceived stress predicted less independence in activities of daily living and lower subjective QoL. To date only one other study has examined effects of self-reported perceived stress on independence in activities of daily living (Bishop-Fitzpatrick, Minshew, et al., 2017). Unlike the current study, this earlier study did not find that perceived stress contributed significantly to activities of daily living. Of relevance to the null finding reported in the prior study, we note that the relatively small effect size for the relationship between perceived stress and activities of daily living in our sample is likely due to ceiling effects on the W-ADL in autistic adults without co-occurring intellectual disability. Consistent with this interpretation, just over a third of participants in the current sample (34%, *n*=244) scored the maximum value on the W-ADL. Of note, the prior study (Bishop-Fitzpatrick, Minshew, et al., 2017) had a sample size of 40 autistic participants, and 90% of the sample was male. Given the current study's finding of ceiling effects on the W-ADL in a much larger sample of autistic adults, it is plausible that the previous study was not powered to detect effects of perceived stress on independence in activities of daily living in a sample without co-occurring intellectual disability.

The current study further found that higher perceived stress was associated with poorer subjective QoL for the ASQoL and all four WHOQOL domains: Physical Health, Psychological Health, Environment, and Social Relationships. These findings converge with literature indicating that greater levels of perceived stress in autistic adults are associated with overall lower subjective QoL (Bishop-Fitzpatrick, Smith DaWalt, et al., 2017; Bishop-Fitzpatrick et al., 2018). Distinct from previous studies showing links between perceived stress and a composite

metric indexing *overall* subjective QoL in autistic adults, the current study's large sample size permitted us to examine each subjective QoL domain separately. These findings suggest that perceived stress is closely related to subjective quality of life across the board, rather than being related only to selective aspects of quality of life.

Among the strengths of the current study are its statistical power and rigor. The sample size in the current study is greater than 10 times the largest sample size in the literature to date on self-reported perceived stress in autistic adults. Additionally, the current study's sample was enriched for individuals designated female at birth, an understudied population in autism research: the number of adults designated female at birth in the current study is more than 30 times the largest number of female participants included in the literature on perceived stress in autistic adults. Furthermore, the large overall sample size of the current study permitted the examination of specific domains of subjective QoL, rather than examining overall subjective QoL (as done in the prior studies to date) while controlling for key confounding variables and correcting for multiple comparisons. The sample's composition, spanning young, middle and older adulthood, allowed us to probe for age differences, and the enrichment for autistic individuals designated female at birth afforded statistical power to further probe sex, and sex by age interactions. The majority of the limited research to date examining subjective QoL in autistic adults has studied those in early to middle adulthood (Geurts et al., 2021). In contrast, in the current study, 21% of autistic adults were aged ≥50 years, helping to bridge the gap in our knowledge of older autistic adults.

Alongside these numerous strengths, are limitations that should be considered when contextualizing findings. In the current study, participants completed the WHOQOL-BREF and the ASQoL, but not the WHOQOL Disabilities module (WHODIS; Power et al., 2010). The

WHOQOL-DIS is described as an add-on module to the WHOQOL-BREF to assess subjective QoL in adults with physical or intellectual disabilities (Power et al., 2010). The ASQoL, in turn, is described as providing "autism-specific" items to be used alongside the WHOQOL-BREF and the WHOQOL-DIS (McConachie et al., 2018). The decision not to administer the WHOQOL-DIS was based on both conceptual and practical considerations. Conceptually, the WHOQOL-DIS is intended for use in adults with intellectual or physical disabilities. The current study included participants SPARK designated as "independent adults," meaning participants could consent for themselves, and so were unlikely to have a co-occurring intellectual disability. Additionally, prior to data collection, we did not know whether or how many autistic participants would report a physical disability that would make administration of the WHOQOL-DIS appropriate. These conceptual considerations were accompanied by the more practical, yet essential, concern of participant burden. The WHOQOL-BREF and ASQoL were administered as part of a broader battery of surveys investigating adult outcomes in ASD, and the decision to include these measures of subjective QoL but omit the WHOQOL-DIS also took into consideration the length of the overall survey battery.

The current study also relied on a short self-report survey to measure perceived stress. To advance and enrich our understanding of perceived stress in autistic adults, future studies should include metrics that capture the lived experience of everyday stressors and stress. For instance, future research might include qualitative interviews, in addition to questionnaire data. Research might also engage autistic adults as research partners to design probes using Cognitive Interviewing Techniques (Beatty & Willis, 2009) to gain knowledge concerning how autistic adults respond to questions on the PSS, and to illuminate key facets of the lived experience of everyday stress and its impacts on activities of daily living and subjective QoL for autistic adults.

The results reported here point to additional important directions for future research. Studies examining the effects of therapeutic interventions on perceived stress (Pahnke et al., 2019; Wijker et al., 2020) provide suggestive evidence that perceived stress may be a modifiable target for intervention. Prior studies have demonstrated associations between perceived stress and subjective QoL (Bishop-Fitzpatrick, Smith DaWalt, et al., 2017; Bishop-Fitzpatrick et al., 2018; McLean et al., 2021). The current study strengthens and extend these links. Taken together, the current and prior research suggest that interventions that decrease perceived stress may help improve subjective QoL in autistic adults, although this remains to be empirically verified.

It is critical to note that in addition to examining the potential for reducing perceived stress as a way to improve subjective QoL in autistic adults, it is critical to consider *external factors* that contribute to elevated levels of perceived stress and reduced subjective QoL in autistic adults. Autistic individuals may be vulnerable to a range of adverse life events, and these adversities are associated with elevated mental health difficulties and decreased life satisfaction (Griffiths et al., 2019). An accumulation of adverse life events, beginning in childhood, may help account for heightened perceived stress in autistic adults, with autistic adults reporting more trauma and demonstrating higher rates of post-traumatic stress disorder relative to adults in the general population (Haruvi-Lamdan et al., 2020).

As children, autistic individuals experience relatively high rates of physical (~1 in 5) and sexual (~1 in 6) abuse (Mandell et al., 2005), and as adolescents, autistic individuals are at elevated risk for sexual victimization (Ohlsson Gotby et al., 2018). In adulthood, autistic individuals designated female at birth and gender diverse autistic individuals, in particular, are at alarmingly elevated risk for physical and sexual abuse (Brown-Lavoie et al., 2014; Brown et al.,

2017). In younger autistic adults, cumulative experiences of trauma may contribute to elevated rates of mental health problems (Fuld, 2018; Taylor & Gotham, 2016).

In addition to physical and sexual abuse, autistic individuals are at elevated risk for bullying. Autistic youth experience higher rates of bullying compared to the general population (Cappadocia et al., 2012), and among autistic adolescents, experiences of bullying predict suicidality (Holden et al., 2020). Autistic adults also report higher incidences of bullying and harassment compared to neurotypical individuals (Weiss & Fardella, 2018), and autistic adults identify avoidance of bullying as a motivation for masking their autistic features (Cage & Troxell-Whitman, 2019). In addition, experiences of minority stress (Meyer, 2003), including social stressors such as stigma and discrimination may increase risk for developing mental health problems in autistic adults (Botha & Frost, 2020; Mitchell et al., 2021).

In addition to their neurominority (i.e., autistic) identity, autistic individuals may be more likely to possess other minority identities. Specifically, emerging evidence indicates that compared to non-autistic persons, diversity in gender identity and sexual orientation may be more common in autistic persons (Dewinter et al., 2017; George & Stokes, 2017; Warrier et al., 2020; Weir et al., 2021). The intersection of neurodiversity with gender and sexual diversity may increase minority stressors experienced by autistic individuals, and these added stressors in turn may contribute to elevated perceived stress. Consistent with this idea, compared to heterosexual autistic adults, autistic adults with a sexual minority identity (in a sample largely overlapping with the one described here) reported greater perceived stress, as well as overall poorer mental health and subjective QoL (McQuaid et al., 2021).

Advancing our understanding of adverse life experiences and experiences of minority stress and how these contribute to poorer mental health outcomes among autistic adults has been

identified as a high research priority by autistic stakeholders (Benevides et al., 2020), underscoring the importance of examining higher perceived stress and lower subjective QoL not simply within the autistic individual but rather as sequelae embedded within the broader context of individual-environment interactions.

References

Beatty, P. C., & Willis, G. (2009). Research synthesis: The practice of cognitive interviewing. In *SSRN* (Vol. 71, Issue 2). Oxford University Press. https://doi.org/10.1093/poq/nfm006

Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D., Hector, B. L., Morgan, L., Nebeker, L., Purkis, Y., Rankowski, B., Wittig, K., & Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*, *24*(4), 822–833. https://doi.org/10.1177/1362361320908410

Bishop-Fitzpatrick, L., Mazefsky, C. A., & Eack, S. M. (2018). The combined impact of social support and perceived stress on quality of life in adults with autism spectrum disorder and without intellectual disability. *Autism*, *22*(6), 703–711. https://doi.org/10.1177/1362361317703090

Bishop-Fitzpatrick, L., Minshew, N. J., Mazefsky, C. A., & Eack, S. M. (2017). Perception of life as stressful, not biological response to stress, is associated with greater social disability in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*(1), 1–16. https://doi.org/10.1007/s10803-016-2910-6

Bishop-Fitzpatrick, L., Smith DaWalt, L., Greenberg, J. S., & Mailick, M. R. (2017). Participation in recreational activities buffers the impact of perceived stress on quality of life in adults with autism spectrum disorder. *Autism Research*, *10*(5), 973–982. https://doi.org/10.1002/aur.1753

Botha, M., & Frost, D. M. (2020). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and Mental Health*, *10*(1), 20–34. https://doi.org/10.1177/2156869318804297

Brown-Lavoie, S. M., Viecili, M. A., & Weiss, J. A. (2014). Sexual knowledge and victimization in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *44*(9), 2185–2196. https://doi.org/10.1007/s10803-014-2093-y

Brown, K. R., Peña, E. V., & Rankin, S. (2017). Unwanted sexual contact: Students with autism and other disabilities at greater risk. *Journal of College Student Development*, *58*(5), 771–776. https://doi.org/10.1353/csd.2017.0059

Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders*, *49*(5), 1899–1911. https://doi.org/10.1007/s10803-018-03878-x

Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *42*(2), 266–277. https://doi.org/10.1007/s10803-011-1241-x

Cohen, S., & Janicki-Deverts, D. (2012). Who's stressed? Distributions of psychological stress in the United States in probability samples from 1983, 2006, and 2009. *Journal of Applied Social Psychology*, *42*(6), 1320–1334. https://doi.org/https://doi.org/10.1111/j.1559-1816.2012.00900.x

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, *24*(4), 385–396. https://doi.org/10.2307/2136404

Cohen, S., & Williamson, G. (1988). Perceived stress in a probability sample of the US. In S. Spacapam & S. Oskamp (Eds.), *The social psychology of health: Claremont Symposium on Applied Social Psychology*. Sage.

Dewinter, J., De Graaf, H., & Begeer, S. (2017). Sexual orientation, gender identity, and romantic relationships in adolescents and adults with autism spectrum disorder. *Journal of*

Autism and Developmental Disorders, *47*(9), 2927–2934. https://doi.org/10.1007/s10803-017-3199-9

Ezzati, A., Jiang, J., Katz, M. J., Sliwinski, M. J., Zimmerman, M. E., & Lipton, R. B. (2014). Validation of the perceived stress scale in a community sample of older adults. *International Journal of Geriatric Psychiatry*, *29*(6), 645–652. https://doi.org/10.1002/gps.4049

Fombonne, E., Coppola, L., Mastel, S., & O'Roak, B. J. (2021). Validation of autism diagnosis and clinical data in the SPARK cohort. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-05218-y

Fuld, S. (2018). Autism spectrum disorder: The impact of stressful and traumatic life events and implications for clinical practice. *Clinical Social Work Journal*, *46*(3), 210–219. https://doi.org/10.1007/s10615-018-0649-6

George, R., & Stokes, M. A. (2017). Gender identity and sexual orientation in autism spectrum disorder. *Autism*, *22*(8), 970–982. https://doi.org/10.1177/1362361317714587

George, R., & Stokes, M. A. (2018). A quantitative analysis of mental health among sexual and gender minority groups in ASD. *Journal of Autism and Developmental Disorders*, *48*(6), 2052–2063. https://doi.org/10.1007/s10803-018-3469-1

Geurts, H. M., Charlton, R. A., & Bishop, L. (2021). Ageing when being autistic. In M. Putnam & C. Bigby (Eds.), *Handbook on Ageing with Disability* (pp. 148–157). Routledge.

Gillott, A., & Standen, P. J. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities*, *11*(4), 359–370. https://doi.org/10.1177/1744629507083585

Glaser, R., & Kiecolt-Glaser, J. K. (2005). Stress-induced immune dysfunction: Implications for

health. *Nature Reviews Immunology*, *5*(3), 243–251. https://doi.org/10.1038/nri1571

Griffiths, S., Allison, C., Kenny, R., Holt, R., Smith, P., & Baron-Cohen, S. (2019). The Vulnerability Experiences Quotient (VEQ): A study of vulnerability, mental health and life satisfaction in autistic adults. *Autism Research*, *12*(10), 1516–1528. https://doi.org/10.1002/aur.2162

Groden, J., Diller, A., Bausman, M., Velicer, W., Norman, G., & Cautela, J. (2001). The development of a stress survey schedule for persons with autism and other developmental disabilities. *Journal of Autism and Developmental Disorders*, *31*(2), 207–217. https://doi.org/10.1023/A:1010755300436

Haruvi-Lamdan, N., Horesh, D., Zohar, S., Kraus, M., & Golan, O. (2020). Autism spectrum disorder and post-traumatic stress disorder: An unexplored co-occurrence of conditions. *Autism*, *24*(4), 884–898. https://doi.org/10.1177/1362361320912143

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology*, *44*(2), 227–239. https://doi.org/https://doi.org/10.1348/014466505X29657

Hirvikoski, T., & Blomqvist, M. (2014). High self-perceived stress and poor coping in intellectually able adults with autism spectrum disorder. *Autism*, *19*(6), 752–757. https://doi.org/10.1177/1362361314543530

Hoekstra, R. A., Vinkhuyzen, A. A. E., Wheelwright, S., Bartels, M., Boomsma, D. I., Baron-Cohen, S., Posthuma, D., & van der Sluis, S. (2011). The construction and validation of an abridged version of the Autism-Spectrum Quotient (AQ-Short). *Journal of Autism and Developmental Disorders*, *41*(5), 589–596. https://doi.org/10.1007/s10803-010-1073-0

Holden, R., Mueller, J., McGowan, J., Sanyal, J., Kikoler, M., Simonoff, E., Velupillai, S., & Downs, J. (2020). Investigating bullying as a predictor of suicidality in a clinical sample of adolescents with autism spectrum disorder. *Autism Research*. https://doi.org/10.1002/aur.2292

Hong, J., Bishop-Fitzpatrick, L., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2016). Factors associated with subjective quality of life of adults with autism spectrum disorder: Self-report versus maternal reports. *Journal of Autism and Developmental Disorders*, *46*(4), 1368–1378. https://doi.org/10.1007/s10803-015-2678-0

Juruena, M. F., Eror, F., Cleare, A. J., & Young, A. H. (2020). The role of early life stress in HPA axis and anxiety. In Y.-K. Kim (Ed.), *Anxiety Disorders: Rethinking and Understanding Recent Discoveries* (pp. 141–153). Springer Nature. https://doi.org/10.1007/978-981-32-9705-0_9

Kivimäki, M., & Steptoe, A. (2018). Effects of stress on the development and progression of cardiovascular disease. *Nature Reviews Cardiology*, *15*(4), 215–229. https://doi.org/10.1038/nrcardio.2017.189

Lewinsohn, P. M., & Talkington, J. (1979). Studies on the measurement of unpleasant events and relations with depression. *Applied Psychological Measurement*, *3*(1), 83–101. https://doi.org/10.1177/014662167900300110

Maenner, M. J., Smith, L. E., Hong, J., Makuch, R., Greenberg, J. S., & Mailick, M. R. (2013). Evaluation of an activities of daily living scale for adolescents and adults with developmental disabilities. *Disability and Health Journal*, *6*(1), 8–17.

Mandell, D. S., Walrath, C. M., Manteuffel, B., Sgro, G., & Pinto-Martin, J. A. (2005). The prevalence and correlates of abuse among children with autism served in comprehensive

community-based mental health settings. *Child Abuse & Neglect*, *29*(12), 1359–1372. https://doi.org/10.1016/j.chiabu.2005.06.006

McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the validity of a quality of life measure for autistic people. *Journal of Autism and Developmental Disorders*, *48*(5), 1596–1611. https://doi.org/10.1007/s10803-017-3402-z

McGillivray, J. A., & Evert, H. T. (2014). Exploring the effect of gender and age on stress and emotional distress in adults with autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities*, *33*(1), 55–64. https://doi.org/10.1177/1088357614549317

McLean, K. J., Eack, S. M., & Bishop, L. (2021). The impact of sleep quality on quality of life for autistic adults. *Research in Autism Spectrum Disorders*, *88*, 101849. https://doi.org/https://doi.org/10.1016/j.rasd.2021.101849

McQuaid, G. A., Gendy, J., Lee, N. R., & Wallace, G. L. (2021). Comparison of mental health and subjective quality of life in sexual minority versus heterosexual autistic adults. *PsyArXiv*. https://doi.org/https://doi.org/10.31234/osf.io/qrxed

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin*, *129*(5), 674–697. https://doi.org/10.1037/0033-2909.129.5.674

Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. *British Journal of Developmental Psychology*. https://doi.org/10.1111/bjdp.12350

Moseley, R. L., Turner-Cobb, J. M., Spahr, C. M., Shields, G. S., & Slavich, G. M. (2021). Lifetime and perceived stress, social support, loneliness, and health in autistic adults. *Health Psychology*, *40*(8), 556–568. https://doi.org/10.1037/hea0001108

Ohlsson Gotby, V., Lichtenstein, P., Långström, N., & Pettersson, E. (2018). Childhood neurodevelopmental disorders and risk of coercive sexual victimization in childhood and adolescence - a population-based prospective twin study. *Journal of Child Psychology and Psychiatry*, *59*(9), 957–965. https://doi.org/10.1111/jcpp.12884

Pahnke, J., Hirvikoski, T., Bjureberg, J., Bölte, S., Jokinen, J., Bohman, B., & Lundgren, T. (2019). Acceptance and commitment therapy for autistic adults: An open pilot study in a psychiatric outpatient context. *Journal of Contextual Behavioral Science*, *13*, 34–41. https://doi.org/https://doi.org/10.1016/j.jcbs.2019.04.002

Park, S. H., Song, Y. J. C., Demetriou, E. A., Pepper, K. L., Norton, A., Thomas, E. E., Hickie, I. B., Hermens, D. F., Glozier, N., & Guastella, A. J. (2019). Disability, functioning, and quality of life among treatment-seeking young autistic adults and its relation to depression, anxiety, and stress. *Autism*, *23*(7), 1675–1686. https://doi.org/10.1177/1362361318823925

Power, M. J., Green, A. M., & Group, T. W.-D. (2010). Development of the WHOQOL disabilities module. *Quality of Life Research*, *19*(4), 571–584. https://doi.org/10.1007/s11136-010-9616-6

Roberti, J. W., Harrington, L. N., & Storch, E. A. (2006). Further psychometric support for the 10-Item version of the perceived stress scale. *Journal of College Counseling*, *9*(2), 135–147. https://doi.org/https://doi.org/10.1002/j.2161-1882.2006.tb00100.x

Slavich, G. M., & Irwin, M. R. (2014). From stress to inflammation and major depressive disorder: A social signal transduction theory of depression. *Psychological Bulletin*, *140*(3), 774–815. https://doi.org/10.1037/a0035302

Slavich, G. M., & Shields, G. S. (2018). Assessing lifetime stress exposure using the Stress and Adversity Inventory for Adults (Adult STRAIN): An overview and initial validation.

Psychosomatic Medicine, *80*(1), 17–27. https://doi.org/10.1097/PSY.0000000000000534

Tan, S. L., Jetzke, M., Vergeld, V., & Müller, C. (2020). Independent and combined associations of physical activity, sedentary time, and activity intensities with perceived stress among university students: Internet-based cross-sectional study. *JMIR Public Health and Surveillance*, *6*(4), e20119–e20119. https://doi.org/10.2196/20119

Taylor, J. L., & Gotham, K. O. (2016). Cumulative life events, traumatic experiences, and psychiatric symptomatology in transition-aged youth with autism spectrum disorder. *Journal of Neurodevelopmental Disorders*, *8*(1), 28. https://doi.org/10.1186/s11689-016-9160-y

The SPARK Consortium. (2018). SPARK: A US cohort of 50,000 families to accelerate autism research. *Neuron*, *97*(3), 488–493. https://doi.org/10.1016/j.neuron.2018.01.015

The WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, *28*(3), 551–558. https://doi.org/DOI: 10.1017/S0033291798006667

Thoits, P. A. (2010). Stress and health: Major findings and policy implications. *Journal of Health and Social Behavior*, *51*(1_suppl), S41–S53. https://doi.org/10.1177/0022146510383499

Warrier, V., Greenberg, D. M., Weir, E., Buckingham, C., Smith, P., Lai, M. C., Allison, C., & Baron-Cohen, S. (2020). Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nature Communications*, *11*(1), 1–12. https://doi.org/10.1038/s41467-020-17794-1

Weir, E., Allison, C., & Baron-Cohen, S. (2021). The sexual health, orientation, and activity of autistic adolescents and adults. *Autism Research*, *14*(11), 2342–2354.

https://doi.org/https://doi.org/10.1002/aur.2604

Weiss, J. A., & Fardella, M. A. (2018). Victimization and perpetration experiences of adults with autism. *Frontiers in Psychiatry*, *9*(MAY), 203. https://doi.org/10.3389/fpsyt.2018.00203

Wijker, C., Leontjevas, R., Spek, A., & Enders-Slegers, M.-J. (2020). Effects of dog assisted therapy for adults with autism spectrum disorder: An exploratory randomized controlled trial. *Journal of Autism and Developmental Disorders*, *50*(6), 2153–2163. https://doi.org/10.1007/s10803-019-03971-9

Table 1. Participant characteristics and mean self-report ratings

Construct	*N*=713
Age, years	
Mean (SD)	38.47 (13.60)
Median (Range)	36.08 (18.17-83.33)
Sex designated at birth, *n* (%)	
Female	423 (59.3%)
Male	290 (40.7%)
Gender Identity*	
Gender diverse	74 (10.4%)
Cisgender	638 (89.6%)
Race and Ethnicity, *n* (%)	
*Race**	
Asian	9 (1.3%)
Black/African-American	15 (2.1%)
More than one Race	70 (9.8%)
Native American/Alaska Native	8 (1.1%)
White	594 (83.7%)
Other	14 (2.0%)
*Ethnicity**	
Latinx	63 (8.9%)
Not Latinx	634 (89.5%)
Unknown	11 (1.6%)
Household Income, *n* (%)	
<$20,000	257 (36.0%)
$20,001-$35,000	132 (18.5%)
$36,000-$50,000	96 (13.5%)
$51,000-$65,000	39 (5.5%)
$66,000-$80,000	56 (7.9%)
$81,000-$100,000	38 (5.3%)
$101,000-$130,000	37 (5.2%)
$131,000-$160,000	26 (3.6%)
$161,000+	32 (4.5%)
Current employment and/or educational enrollment,* *n* (%)	
Currently employed, not enrolled in educational program	307 (43.4%)
Currently enrolled in educational program, not employed	57 (8.1%)
Currently employed and enrolled in educational program	62 (8.8%)
Not employed or enrolled in educational program	281 (39.7%)

Autism Spectrum Quotient-28, Total Score	
Mean (SD)	84.32 (11.58)
Median (Range)	85.0 (47-112)
Met Autism Spectrum Quotient-28 Screening Criteria, *n* (%)	
Yes	674 (94.5%)
No	39 (5.5%)
Perceived Stress Scale, Total Score	
Mean (SD)	22.81 (7.42)
Median (Range)	23.0 (1-40)
Waisman Activities of Daily Living, Item Score	
Mean (SD)	1.78 (0.28)
Median (Range)	1.88 (0-2)
WHOQOL-BREF-Physical Health, Item Score	
Mean (SD)	3.29 (0.87)
Median (Range)	3.33 (1-5)
WHOQOL-BREF-Psychological Health, Item Score	
Mean (SD)	2.96 (0.84)
Median (Range)	3.0 (1-5)
WHOQOL-BREF-Social Relationships, Item Score	
Mean (SD)	3.01 (1.01)
Median (Range)	3.0 (1-5)
WHOQOL-BREF-Environmental Health, Item Score	
Mean (SD)	3.46 (0.81)
Median (Range)	3.46 (1-5)
Autism Specific Quality of Life, Item Score	
Mean (SD)	3.11 (0.84)
Median (Range)	3.12 (1-5)

Note: WHOQOL-BREF=Abbreviated World Health Organization Quality of Life Questionnaire.

*Gender identity, *N*=712; Race, *N*=710; Ethnicity, *N*=708; Complete data for both currently enrolled in educational program and currently employed, *N*=707.

Table 2. Summary of empirical literature implementing self-report on the perceived stress scale (PSS) in autistic adult samples

Study	Participant groups, *Ns*	Age, years Mean (SD), Range	Sex designated at birth	Aims/Research questions	PSS version	Variables examined for relationships with PSS	Group differences	Relationships of other variables with perceived stress
(Hirvikoski & Blomqvist, 2014)	ASD=25 NT=28	ASD 34.08 (7.52) NT 32.64 (6.99)	ASD Female: 10 Male: 15 NT Female: 16 Male: 12	Examine perceived stress in ASD & associations between autistic features and facets of perceived stress	14-item PSS	Autism Spectrum Quotient (AQ)	Total PSS: ASD > NT PSS Distress subscale: ASD > NT PSS Coping subscale: ASD > NT	- Higher AQ score associated with greater total PSS score in ASD and NT - Higher AQ score correlated with PSS Distress and PSS Coping subscale scores in ASD and NT
(Hong et al., 2016)	ASD=60	ASD 32 (6.8) 25-55	ASD Female: 14 Male: 46	Probe factors associated with subjective QoL	10-item PSS	WHOQOL-BREF	N/A	Perceived stress: Female > Male - Perceived stress predicted all domains of subjective QoL, with higher perceived stress associated with lower subjective QoL

Study	Participant groups, *Ns*	Age, years Mean (SD), Range	Sex designated at birth	Aims/Research questions	PSS version	Variables examined for relationships with PSS	Group differences	Relationships of other variables with perceived stress
(Bishop-Fitzpatrick, Minshew, et al., 2017)	ASD=40 NT=25	ASD 24.20 (6.95) 18-44 NT 24.84 (3.69) 18-32	ASD Female: 4 Male: 36 NT Female: 4 Male: 21	Examine whether poor response to stress negatively impacts social functioning in ASD	10-item PSS	W-ADL Social Adjustment Scale-II (SAS-II)	Perceived stress: ASD > NT	- Greater perceived stress associated with greater social disability in ASD, as measured by the SAS-II - Perceived stress was not significantly associated with independence in activities of daily living, as assessed via the W-ADL
(Bishop-Fitzpatrick, Smith DaWalt, et al., 2017)	ASD=67	ASD 31.5 (6.7) 24-55	ASD Female: 21 Male: 46	- Investigate association of perceived stress with subjective QoL - Probe whether social and recreational activities moderate association between perceived stress and subjective QoL	10-item PSS	WHOQOL-BREF Social and recreational activities	N/A	- Greater perceived stress associated with lower subjective QoL - Recreational activities, but not social activities, moderated effects of perceived stress on subjective QoL

Study	Participant groups, *Ns*	Age, years Mean (SD), Range	Sex designated at birth	Aims/Research questions	PSS version	Variables examined for relationships with PSS	Group differences	Relationships of other variables with perceived stress
(Bishop-Fitzpatrick et al., 2018)	ASD=40 NT=25	ASD 24.20 (6.95) 18-44 NT 24.84 (3.69) 18-32	ASD Female: 4 Male: 36 NT Female: 4 Male: 21	- Investigate impacts of perceived stress on subjective QoL - Examine whether social support serves as a buffer in this association	10-item PSS	WHOQOL-BREF Interpersonal Support Evaluation List (ISEL)	Perceived stress: ASD > NT	- Higher perceived stress associated with lower subjective QoL in ASD but not NT - Social support did not moderate effect of perceived stress on subjective QoL for ASD or NT
(Pahnke et al., 2019)	ASD=10	ASD 49 (12), 25-65	ASD Female: 5 Male: 5	Pilot study to determine feasibility of acceptance and commitment therapy (ACT) with ASD adults and to assess its effects on perceived stress	14-item PSS	Effect of intervention examined: comparison of PSS at baseline, post-treatment and 3 months follow-up	N/A	- Significant reduction in perceived stress from baseline to post-treatment - No significant difference in perceived stress when comparing baseline to 3 months follow-up

Study	Participant groups, *Ns*	Age, years Mean (SD), Range	Sex designated at birth	Aims/Research questions	PSS version	Variables examined for relationships with PSS	Group differences	Relationships of other variables with perceived stress
(Wijker et al., 2020)	ASD=53 Intervention group=27 Control condition=26	ASD 18-60	ASD Female: 23 Male: 29	Randomized control trial exploring effects of animal assisted therapy (AAT) compared to waitlist condition on perceived stress and other variables in ASD adults	10-item PSS	AAT intervention or control condition	N/A	Those receiving AAT (but not those in control group) showed significant reduction in perceived stress from baseline to post-intervention
(McLean et al., 2021)	ASD=40 NT=24	ASD 24.2 (6.95) NT 25 (3.68)	ASD Female: 4 Male: 36 NT Female: 4 Male: 20	- Examine effects of perceived stress on subjective QoL in ASD - Explore whether being autistic moderates associations between perceived stress and sleep quality with subjective QoL	10-item PSS	WHOQOL-BREF Pittsburgh Sleep Quality Index (PSQI)	Perceived stress: ASD > NT	- Higher perceived stress was associated with lower subjective QoL - No interaction between perceived stress and group (ASD, NT) on subjective QoL - Compared to NT, ASD with high perceived stress and poor sleep quality reported worse subjective QoL

W-ADL =Waisman-Activities of Daily Living; WHOQOL-BREF=Brief version of the World Health Organization Quality of Life Scale.

Table 3. Quality of life and daily living skills ratings regressed onto age, sex designated at birth, household income, and perceived stress

	W-ADL					**Physical Health QOL**					**Psychological QOL**				
	B	SE	95% CI	β	*t*	B	SE	95% CI	β	*t*	B	SE	95% CI	β	*t*
Step 1:	R^2=0.05, *F*=11.96, *p*<.001					R^2=0.11, *F*=30.24, *p*<.001					R^2=0.04, *F*=8.91, *p*<.001				
Age	0.002	0.001	[.001, .004]	0.11	2.96*	-0.007	0.002	[-.011, -.002]	-0.11	-2.95*	-0.001	0.002	[-.005, .004]	-0.02	-0.40
Household Income	0.02	0.004	[.011, .029]	0.17	4.60**	0.08	0.01	[.06, 0.11]	0.23	6.38**	0.05	0.01	[.04, .08]	0.15	3.95**
Sex Designated at Birth	-0.001	0.02	[-.043, .040]	-0.002	-0.06	-0.38	0.06	[-.51, -.26]	-0.22	-6.07**	-0.18	0.06	[-.31, -.06]	-0.11	-2.84*
Step 2:	ΔR^2=0.03, ΔF=20.60, Δp<.001					ΔR^2=0.31, ΔF=385.82, Δp<.001					ΔR^2=0.44, ΔF=591.42, Δp<.001				
PSS Mean Score	-0.06	0.01	[-.09, -.04]	-0.17	-4.54**	-0.68	0.03	[-.74, -.61]	-0.58	-19.64**	-0.78	0.03	[-.84, -.71]	-0.69	-24.3**

	Social Relationships QOL					**Environment QOL**					**Autism Spectrum QOL**				
	B	SE	95% CI	β	*t*	B	SE	95% CI	β	*t*	B	SE	95% CI	β	*t*
Step 1:	R^2=0.03, *F*=7.71, *p*<.001					R^2=0.14, *F*=39.66, *p*<.001					R^2=0.11, *F*=30.01, *p*<.001				
Age	-0.01	0.003	[-.02, -.006]	-0.16	-4.12**	-0.003	0.002	[-.008, .001]	-0.06	-1.62	-0.01	0.002	[-.02, -.007]	-0.18	-5.00**

Household Income	0.05	0.02	[.02, .08]	0.12	3.10*	0.12	0.01	[.10, .15]	0.37	10.43**	0.10	0.01	[.073, .12]	0.27	7.60**
Sex Designated at Birth	0.04	0.08	[-.11, .19]	0.02	0.54	-0.11	0.06	[-.22, .002]	-0.07	-1.94	-0.21	0.06	[-.33, -.09]	-0.12	-3.44*
Step 2:	ΔR^2=0.22, ΔF=204.55, Δp<.001					ΔR^2=0.28, ΔF=351.35, Δp<.001					ΔR^2=0.34, ΔF=440.14, Δp<.001				
PSS Mean Score	-0.66	0.05	[-.75, -.57]	-0.48	-14.30**	-0.60	0.03	[-.66, -.54]	-0.55	-18.74**	-0.69	0.03	[-.75, -.62]	-0.60	-20.98**

*p<.01, **p<.001

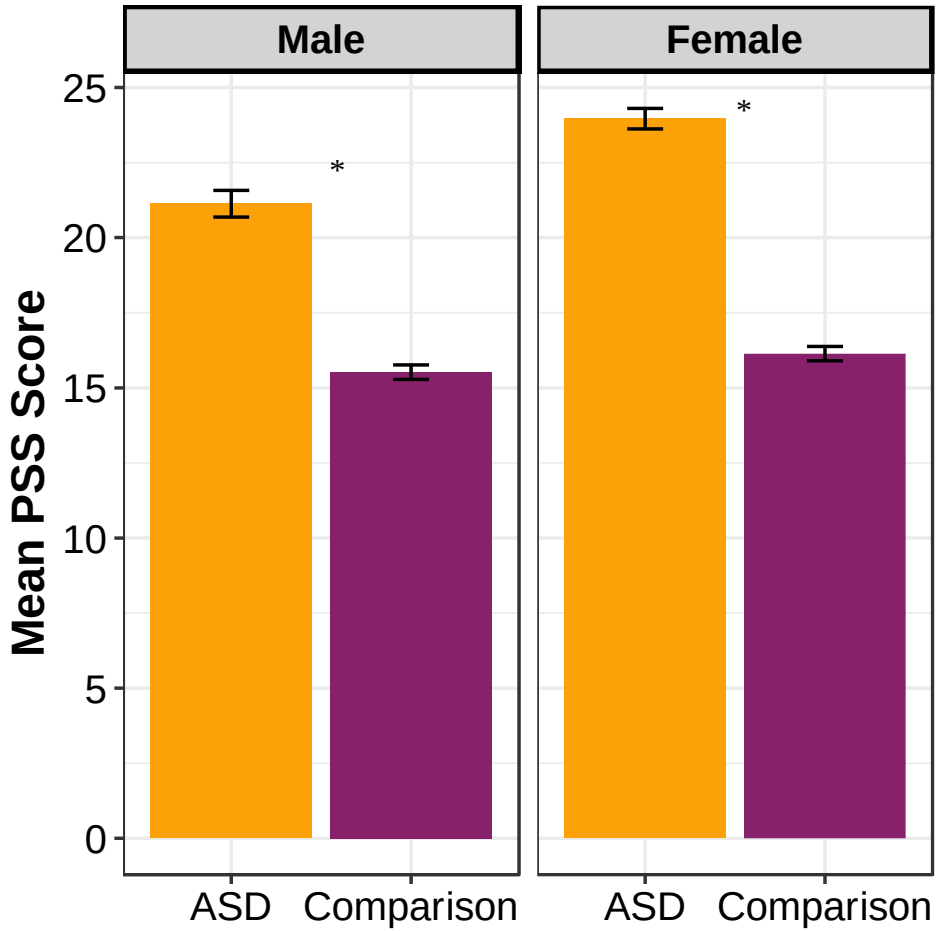

Figure 1. Mean 10-item Perceived Stress Scale (PSS) scores in current ASD sample and comparison general population data (Cohen & Janicki-Deverts, 2012), by sex designated at birth. Error bars represent standard error of the mean. *p<.0001

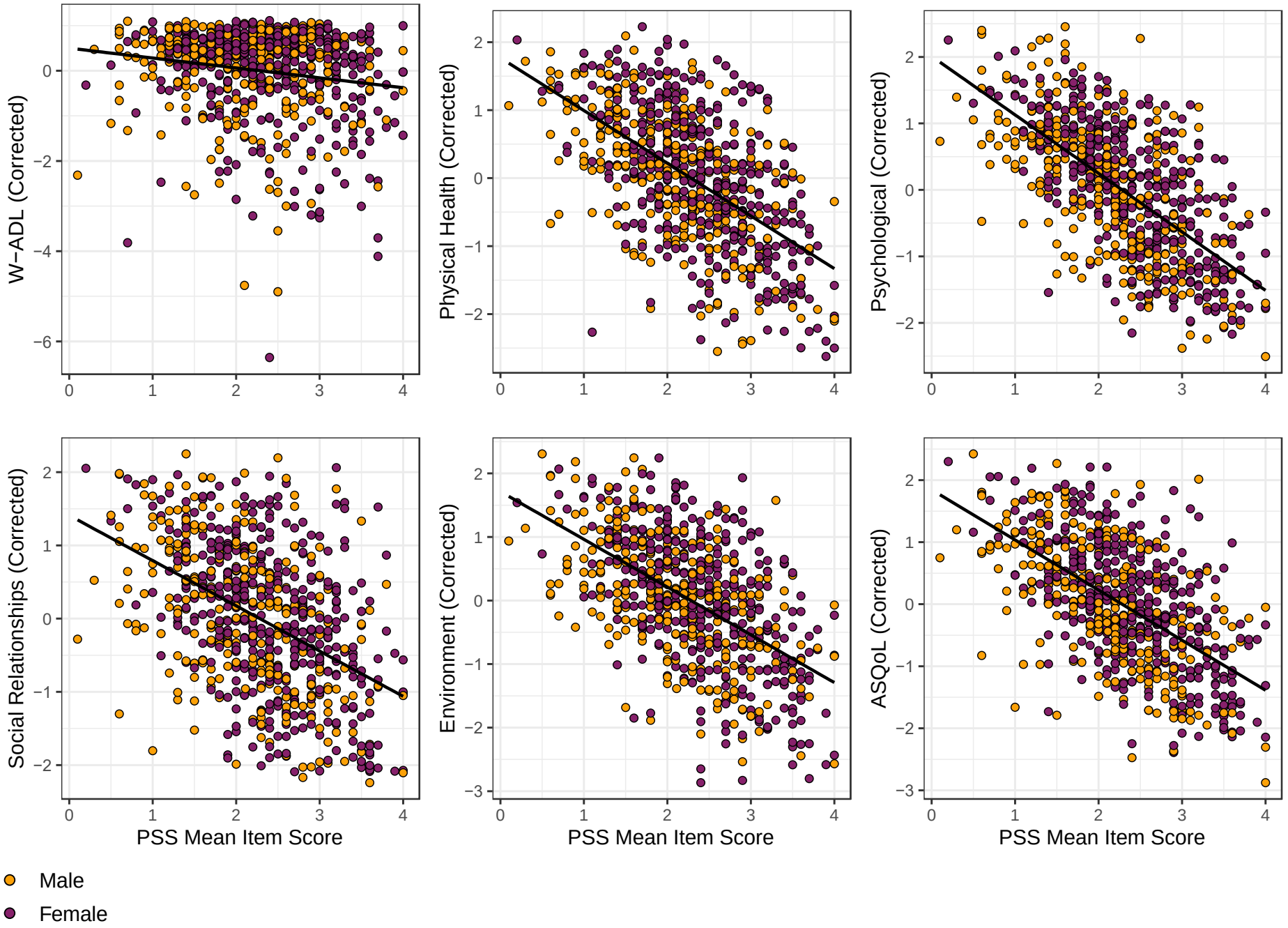
W−ADL (Corrected)
Physical Health (Corrected)
Psychological (Corrected)
Social Relationships (Corrected)
Environment (Corrected)
ASQoL (Corrected)
PSS Mean Item Score
PSS Mean Item Score
PSS Mean Item Score
Male
Female

Figure 2. Plots of Perceived Stress Scale (PSS) mean item scores and values for activities of daily living (W-ADL) and subjective quality of life (WHOQOL-BREF domains and ASQoL) after regressing out effects of sex designated at birth, age, and total household income.