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## Factors Associated with Subjective Quality of Life of Adults with Autism Spectrum Disorder: Self-Report vs. Maternal Reports

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### Abstract

We examined factors related to subjective quality of life (QoL) of adults with Autism Spectrum Disorder (ASD) aged 25 to 55 ( $n = 60$ ), using the World Health Organization Quality of Life measure (WHOQOL-BREF). We used three different assessment methods: adult self-report, maternal proxy-report, and maternal report. Reliability analysis showed that adults with ASD rated their own QoL reliably. QoL scores derived from adult self-reports were more closely related to those from maternal proxy-report than from maternal report. Subjective factors such as perceived stress and having been bullied frequently were associated with QoL based on adult self-reports. In contrast, level of independence in daily activities and physical health were significant predictors of maternal reports of their son or daughter's QoL.

### Keywords

Autism spectrum disorder; Subjective quality of life; WHOQOL-BREF domains; Self-report; Maternal report

### Introduction

Subjective quality of life (QoL) represents a multidimensional construct defined by the World Health Organization as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL Group 1995, p. 1405). Consistent with this multidimensional conceptualization, measures of subjective QoL usually include physical, psychological and social domains (Danckaerts et al. 2010). When extended to individuals with autism spectrum disorder (ASD), subjective QoL provides an opportunity to understand the extent to which adults with ASD are satisfied with various domains of their life, and measurement of subjective QoL enriches more traditional approaches to understanding outcomes during adulthood (Renty and Roeyers 2006). Given that QoL for

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individuals with ASD is often an important treatment outcome (Gerber et al. 2011) and improving their QoL is a main objective of many interventions and social services, it is critical to accurately assess the subjective QoL of adults with ASD and to identify factors associated with a favorable QoL.

Emphasizing the multidimensional nature of the QoL construct, Schalock (2004) identified eight domains from the literature on QoL in the general population and applied them to individuals with developmental disabilities: interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, and human and legal rights. In the general population, subjective QoL is measured by self-reports capturing personal appraisal of these life domains. However, for individuals with ASD, this measurement strategy poses special challenges as many with this diagnosis have impairments in communication and/or cognitive functioning. A number of studies have addressed the issue of reliability and validity of QoL self-report scores by individuals with ASD, mainly by examining the level of agreement between their self-report and parental reports. Sheldrick and colleagues (2012) reported that self-report from adolescents with ASD was more highly correlated with parental proxy-report (i.e., parental reports of how they think their child would respond to questions) than with parents' own report (i.e., parental reports of how they evaluate their child's QoL). However, a recent study showed that the intra-class correlations (ICC) coefficients between adolescents' self-report and parental proxy-report were low for some subjective QoL scales including self-perception, autonomy, and parent relations (Clark et al. 2015). Reviewing past literature on the use of subjective QoL measures with children and youth with ASD, Ikeda and colleagues (2014) concluded that there were large discrepancies between self-reports and parental proxy-reports, with self-reported QoL being more favorable than parental proxy-reports in most domains. Similar findings were reported with subjective QoL scale scores for children with ADHD (Klassen et al. 2006), and for adolescents with ASD (Shipman et al. 2011).

However, no past studies have focused on self-reports versus parent-proxy reports of QoL in adults with ASD. Adulthood is a life stage when it is normative for individuals to be autonomous and independent from their parents in life choices and preferences. Yet many adults with ASD continue to depend on their family for support, and for some parental reports are the only way to assess the subjective QoL of the adult. Thus, research on convergence or divergence of subjective QoL appraisal by adults with ASD and their parents is needed. This is the focus of the first aim of the present study.

The second aim of this study is to examine predictors of subjective QoL for adults with ASD. This aim is particularly important given the need to identify modifiable predictors of subjective QoL in order to develop treatments and services that effectively improve QoL in individuals with ASD throughout the life course. There is a growing body of research on the relationship between the subjective QoL of individuals with ASD and their behavioral profiles, including autism symptoms, behavior problems, and adaptive behavior. In general, autism symptoms and behavior problems have been found to be negatively associated with subjective QoL in children with ASD as rated by their parents, indicating that greater behavioral impairment is associated with poorer subjective QoL (de Vries and Geurts 2015; Gerber et al. 2008; Ikeda et al. 2014; Kuhlthau et al. 2010). Further, specific subdomains of

subjective QoL have been associated with relevant subscales of autism traits. For instance, greater impairments in children's social cognition and social communication were shown to be associated with parental reports of lower QoL scores in the social functioning subscale (de Vries and Geurts 2015). In contrast, past research on adults with ASD found no significant association between autism characteristics and subjective QoL (Chiang and Wineman 2014; Kamp-Becker et al. 2010), whereas adaptive behavior and executive functioning were found to be positively correlated with subjective QoL in adults on the autism spectrum (de Vries and Geurts 2015; Ikeda et al. 2014; Kamp-Becker et al. 2010).

A few studies have explored how contextual factors are related to subjective QoL of individuals with ASD. For example, greater perceived informal support (Renty and Roeyers 2006) has been shown to be associated with better subjective QoL in adults with ASD. Yet, contextual and environmental predictors of subjective QoL in individuals with ASD have been understudied to date, and questions remain regarding how both psychological and physical characteristics and life experiences may impact subjective QoL in individuals with ASD, especially in adulthood.

This study aims to advance understanding of subjective QoL in adults with ASD by addressing following research questions:

First, to what extent are self-reports from adults with ASD congruent with maternal- and proxy-reports with respect to the subjective QoL of adults with ASD?

Second, what factors are associated with the subjective QoL of adults with ASD? Specifically, we investigate predictors representing two domains, (1) psychological and physical characteristics and (2) life experiences of adults with ASD, and their associations with subjective QoL of adults with ASD.

## Methods

### Data and Sample

The participants in the present study drawn were from a large, longitudinal study of families of adolescents and adults with ASD (Seltzer et al. 2011). The study began in 1998 with 406 families of adolescents and adults with ASD who were then aged 10 years or older. In total, over the subsequent 15 years, 10 waves of data collection were conducted. The subjective QoL measures (WHOQOL-BREF) were collected during the 10th and last wave of the study, conducted in 2013 and 2014, that included 193 mothers and 67 adults with ASD.

There were 7 individuals with ASD who were interviewed but whose responses we determined not reliable enough to be included in the analysis based on a case by case review of interview observation notes and response patterns, and they were excluded from the present study. This resulted in a final analytic sample of 60 adults with ASD. These 60 mother-adult child pairs formed the sample for the present study. Data were collected from both the adults with ASD and their mothers through separate in-home face to face interviews that were focused on their perceptions of subjective QoL and daily life experiences.

About half of the individuals in the current sample (51.7%) were recruited from Wisconsin and the rest were recruited from Massachusetts. The average age of adults with ASD in the analysis was 32 years old (S.D. = 6.8), ranging from 25 to 55 years. Three-fourths (76.7%) were male, and nearly one-third (30.0%) had an intellectual disability. More than half (53.3%) of adults with ASD were living with their parents at home at the time of interview. Those who were not living with parents were in regular touch with their family members, as more than three quarters (79.3%) had weekly or more frequent contact with their families. Compared to non-participants (n = 133), adults who participated in the interview were relatively high functioning, indicated by lower levels of autism symptoms as measured by the ADI-R (Lord et al. 1994) and the SRS (Constantino & Gruber 2005) ( $p < .001$ ). Also, the percentage of adults with an intellectual disability was much lower among those who could be interviewed than the others in the longitudinal study (30% vs. 86%,  $p < .001$ ). Among mothers, more than half (58.3%) had a Bachelor's degree or higher levels of education, and about two-thirds (62.8%) were employed. The median annual household income was in the range of \$70,000 to \$80,000.

## Measures

**Outcome Variable: Subjective Quality of Life (QoL)**—Subjective QoL was measured using the WHOQOL-BREF, a shorter version of World Health Organization Quality of Life assessment, the WHOQOL-100 (Skevington et al. 2004) that is psychometrically similar to and correlates highly with domain scores on the longer version of the instrument (WHOQOL Group 1998; Skevington et al. 2004). It contains 26 items in total: 2 benchmark items measuring overall QoL and health and 24 items that were developed to measure four domains of subjective QoL: physical health, psychological health, social relationships, and environment. Each item is measured with a 5-point scale, with higher scores indicating higher levels of subjective QoL. The domain scores can be calculated to range between 4 and 20 to be comparable with the WHOQOL-100, or can be transformed to a scale 0 to 100. In this study, a scale score of 0 to 100 was used in the analysis.

For the present study, given that some participants required assistance in completing the WHOQOL-BREF items, several modifications were made to the instrument. First, when needed, additional words or sentences were used to help the adults better understand the meaning of the questions when they had difficulty understanding. For example, the question of “To what extent do you feel your life has meaning” was supplemented (when the adult asked for help in understanding the question) with “...your life is important or has purpose.” The question of “Are you able to accept your bodily appearance?” was supplemented with “Do you like how you look?” (A full listing of supplementary phrases are provided in an appendix.) Second, to provide adults with ASD with reference points of response categories (e.g., 1 very dissatisfied...5 very satisfied), the interviewers used response cards illustrated by faces with different emotional expressions corresponding to each written response category, from a frown (very dissatisfied) to a broad smile (very satisfied). Third, one of the social relations domain item “How satisfied are you with your sex life?” was dropped from the instrument due to privacy concerns. Scoring methods for the social relations domain were modified accordingly so that the 0 to 100 point scale would have same meaning as the original domain score. This scoring method was chosen so that the mean levels of subjective

QoL of adults with ASD in the current study could be compared with previous studies on subjective QoL of adults with ASD using the same WHOQOL-BREF measures (e.g., Jennes-Coussens et al. 2006; Kamp-Becker et al. 2010).

In addition to the adult self-report, the same WHOQOL-BREF instrument was administered to each adult's mother reflecting two different perspectives: how *she feels* about the QoL of her adult child with ASD (maternal report), and how *she thinks her adult child with ASD feels* about his/her own QoL (maternal proxy-report). The domain scores of these two WHOQOL-BREF measurement approaches were used to examine the extent to which the domains of QoL were congruent among the mother's own perception, her proxy perceptions for her adult child, and the independent self-perception of adults with ASD, and as dependent variables in separate regression models predicting subjective QoL.

**Independent Variables: Characteristics of Adults with ASD**—We selected six independent variables for the regression models to reflect personal and contextual dimensions of adults with ASD: psychopathology, level of independence in daily activities, physical health, personality (extraversion), perceived stress, and the experience of being bullied.

Psychopathology was measured by the *Adult Behavior Check List* (ABCL; Achenbach and Rescorla 2003), using the T-score of total problems in the analysis. The internal consistency (Cronbach's  $\alpha$ ) of the ABCL total score was .892. The ABCL assesses emotional difficulties common in the general population. We selected this measure because it is a developmentally appropriate assessment of psychological symptoms experienced by adults. In a follow-up analysis, we examined whether substituting the ADI-R for the ABCL resulted in a different pattern of predictors; the results did not differ (data available from authors) so the ABCL was retained as the measure of psychological symptoms.

To measure the degree of *independence in daily activities*, the Waisman-Activities of Daily Living scale (W-ADL; Maenner et al. 2013) was used. W-ADL consists of 17 items covering the level of independence in typical daily activities such as self-care, meal preparation, and household tasks. Each item was rated on a 3-point scale (0 does not do at all, 1 does with help, 2 independent), and summed up to create a total score. The internal consistency (Cronbach's  $\alpha$ ) of the W-ADL was .815.

The *physical health status* of adults with ASD was rated on a 4-point scale: 0 poor, 1 fair, 2 good, and 3 excellent. For this study, a dichotomous variable was created and used, reflecting whether adults with ASD had good/excellent health (= 1) or poor/fair health (= 0). Considerable previous research has provided evidence of the validity of such health ratings (for a review, see Idler & Benjamini 1997).

The personality trait of *extraversion* was measured using the two extraversion scale items from the Ten Item Personality Inventory (TIPI; Gosling et al. 2003). Each item was rated on a 7-point scale, 1 = disagree strongly to 7 = agree strongly, and the average of the two items was taken as a measure of extraversion. The internal consistency (Cronbach's  $\alpha$ ) of the

extraversion scale was .791. ABCL, W-ADL, physical health, and extraversion were measured via maternal report.

Two variables collected directly from adults with ASD were used in the study to measure life experiences. The experience of *being bullied* was measured by two questions, “Have you ever been teased or bullied?” and “(if yes) How often did this happen?” The response category for the second question was: 1 time, 2 times, 3 times, 4 times, and 5 times or more. Of those who responded to have ever been bullied, the majority (70%) reported they had been bullied five times or more. Based on these results an ordinal variable was created indicating frequent experience of being bullied: 0 = have never been bullied, 1 = have been bullied one to four times, 2 = have been bullied five times or more.

The *perception of stress* was measured using items from the Perceived Stress Scale (PSS; Cohen et al. 1983). Of 10 original items, four items that were considered relevant to adults with ASD were collected: upset over the unexpected, feeling “stressed,” difficulty in coping, and being angered over the uncontrollable. Each item was rated by the adult on a 5-point scale, 0 = never to 4 = very often, and the mean score of the four items was used in the study. The internal consistency (Cronbach’s  $\alpha$  of the perceived stress scale was .760.

## Data Analysis

First, we present psychometric comparisons among the three assessment methods (adult self-report, maternal proxy-report, and maternal report). To evaluate the reliability of the data obtained from the different reporters, alpha reliabilities were presented and compared with similar data from the standardization of the WHOQOL-BREF. To evaluate the validity of the different reporters, we examined the level of agreement by comparing the mean scores from adult self-report, maternal report, and maternal proxy-report on the WHOQOL-BREF domains. Additionally, the correlations among the three sets of scores were compared using the approach presented in Lee and Preacher (2013). Finally, to identify factors that influence the subjective QoL of adults with ASD, separate multiple regression analyses were conducted with the four domain scores of the WHOQOL-BREF for each assessment method as dependent variables.

## Results

### Descriptive Findings

Descriptive statistics of study variables are presented in Table 1, for the whole sample and divided by gender.

The mean of the W-ADL was 27.7 indicating that adults were able to carry out most daily activities either independently or with some help. The average number of daily activities they could do independently was 12.4 (out of 17). The mean of the ABCL total problems score was 57.8. While the majority of adults (75.9%) were in the normal range, about one-sixth (17.2%) were in the clinical range of the ABCL, signifying elevated psychological problems. Three-fourths (75.0%) of the adults were in good or excellent health. The mean item score of extraversion for the whole sample was 4.0, the mid-point of the scale, but the sample members were evenly distributed across the scale, and women with ASD were



reported to be more extraverted than males (4.9 vs. 3.7,  $p < .05$ ). The mean of the Perceived Stress Scale for the whole sample was 1.7, suggesting that on average, adults with ASD felt stressed sometimes each month. While about a quarter of adults (26.7%) reported they either never or almost never felt stressed, one-tenth reported feeling stressed fairly often or frequently each month. Women with ASD reported higher levels of perceived stress than men (2.2 vs. 1.5,  $p < .05$ ). As for the lifetime experience of having been bullied, whereas about one in six (17.5%) reported they had never been bullied or teased, more than a half (57.9%) reported they had been bullied five times or more. The others (24.6%) reported less frequent bullying experiences, between one and four times. There was a different pattern of bullying reported by men and women. Whereas more women than men reported never having been bullied (31% never for women vs. 14% never for men), all of the women who ever were bullied experienced mistreatment five or more times. In contrast, about one-third of the men who ever were bullied reported this experience between one and four times and two-thirds five times or more.

### **Psychometric Comparison of Three Assessment Methods of Subjective quality of Life**

Table 2 presents the internal consistency (Cronbach's  $\alpha$ ) of the scales of WHOQOL-BREF domains from the three assessment methods used in the current study.

The internal consistency for the adults with ASD was good for all four domains ( $\alpha$ s ranged from .71 to .82), suggesting that adults with ASD rated their subjective QoL in consistent and reliable ways. Additionally, mothers' proxy-report and mothers' self-report showed similarly good internal consistency reliability ( $\alpha$ s ranged from .74 to .88, and from .70 to .87, respectively).

Table 2 also shows data from Skevington et al. (2004) that reported internal consistency of the WHOQOL-BREF administered to 11,830 adults in the US and internationally. The data were from the WHOQOL-BREF field trial (mean age of participants = 45, ranging from 12 to 97) from 23 countries including the US. In this large data set,  $\alpha$ s ranged from .68 to .87. Thus, the reliability of the WHOQOL-BREF in the present sample of adults with ASD and their mothers is similar to that of the general adult population in the US and internationally.

Table 3 shows mean scores of WHOQOL-BREF domains using the three different assessment methods (adult self-report, maternal proxy-report and maternal report) and their correlations.

With one exception, mean scores from adult self-report of subjective QoL did not differ from means based on maternal proxy-report or maternal report. The exception was for the social relationships domain, where adults with ASD reported higher levels of satisfaction than maternally-reported ratings ( $t = 2.77$ ,  $df = 58$ ,  $p < .01$ ).

Pearson correlations were significantly higher between adult self-report and maternal proxy-report than between adult self-report and maternal report for the physical health ( $p < .001$ ), psychological health ( $p < .05$ ), and social relationship ( $p < .01$ ) domains. For the environment domain, the correlation between adult self-report and maternal proxy-report was not statistically different from the correlation between adult self-report and maternal

report. The correlations between both types of maternal reports and adult self-report were highest in the physical health domain, and lowest in the psychological health domain.

Intraclass correlations (ICC) are also presented in Table 3 to show the degree of absolute agreement between adult and maternal reports, or within-group (family) homogeneity. The pattern of ICC is similar to that of the Pearson correlations, confirming that there is greater agreement between adult self-report and maternal proxy-report than between adult self-report and maternal report.

### Predictors of Subjective Quality of Life

The second aim of this study was to investigate the factors that predicted subjective QoL in adults with ASD. A series of regression analyses were conducted to predict WHOQOL-BREF domain scores, and the results are presented in Table 4.

Overall, the six predictors in the regression models explained variations in subjective QoL domains well. Model  $R^2$  ranged from .34 to .68, indicating that a substantial amount of variance in subjective QoL domains is explained by the predictors. However, a different set of factors emerged as significant predictors of subjective QoL, depending on the assessment method (adult self-report, maternal proxy-report, and maternal report).

**Adult Self-Report**—When QoL was rated directly by the adult with ASD, two factors consistently predicted all four domains of subjective QoL – perceived stress and the experience of frequently being bullied. Adults with higher levels of perceived stress or with frequent experiences of being bullied reported lower levels of subjective QoL than those with lower levels of perceived stress or with fewer bullying experiences. Being extraverted was a positive predictor of the psychological health and the social relationship domains. Good health was a positive predictor of the psychological health domain only. Level of independence in daily activities and psychopathology were not significant predictors of any subjective QoL domains based on adult self-report.

**Maternal Proxy-Report**—When subjective QoL was based on maternal proxy-reports, the adult's level of independence in daily activities was a significant predictor of three QoL domains – physical health, psychological health, and social relationships. Mothers who rated their child with ASD as being more independent in daily activities reported that their adult child would assess his or her own subjective QoL more favorably in those domains. Also, adults' perceived stress was significantly associated with three subjective QoL domains based on maternal proxy-report: physical health, psychological health, and environment. Similar to adult self-report, extraversion was a significant and positive predictor of the psychological health and the social relationship QoL domains when proxy-rated by mothers. In contrast, the experience of being bullied frequently was significantly associated with only the physical health and psychological health QoL domains in maternal proxy-report, but not with the social relationship or environment domains. Good health was a significant predictor of the physical health domain only. The level of psychopathology of adults with ASD did not predict any subjective QoL domain using maternal proxy-report ratings.



**Maternal Report**—When subjective QoL was based on maternal reports, similar to maternal proxy-report, the level of independence in daily activities was a significant predictor of three QoL domains – physical health, psychological health, and social relationships. Mothers rated their adult child as having higher levels of subjective QoL when they were more independent in daily activities. Good health was a significant predictor of the QoL domains of physical health and psychological health, and the level of psychopathology of adults with ASD was significantly associated with the physical health QoL domain using the maternal report ratings. Extraversion was a positive predictor of the social relationship domain, but perceived stress was significantly associated only with the environment domain. Notably, being bullied was a significant predictor of only one subjective QoL domain using maternal report ratings, namely psychological health.

## Discussion

The concept of subjective QoL is an important, yet understudied, facet of overall outcomes for adults with ASD, and better understanding of how to reliably measure subjective QoL and the factors that predict it is needed. This study aimed to expand our understanding of subjective QoL in adults with ASD, first by examining the reliability of subjective QoL measures self-reported by adults with ASD and second, by investigating the factors that predict subjective QoL in adults with ASD. Overall, adults with ASD in this study reported relatively high levels of subjective QoL. Their mean WHOQOL-BREF domain scores were comparable with individuals without disabilities in the general population (Jennes-Coussens et al. 2006; Skevington et al. 2004), and above the threshold of good subjective QoL (Skevington et al. 2004).

Consistent with a previous finding that focused on adolescents with ASD (Sheldrick et al. 2012), adult self-report of subjective QoL was more congruent with maternal proxy-report than with maternal report. Correlations of WHOQOL-BREF domain scores between adult self-report and maternal proxy-report ranged from modest to high, and adult self-report ratings were as reliable (i.e., internally consistent) as both types of maternal ratings. Further, there were no significant mean differences between adult self-report and maternal proxy-report in any of the four domains of the WHOQOL-BREF. The only significant difference between adult self-report and maternal proxy report was with respect to the social relationship domain, where maternal ratings were lower. This implies that mothers are good reporters of their adult child's subjective QoL, although they may perceive the subjective QoL of their adult child with respect to social relationships as poorer than their son or daughter's self-perception. That there was the most agreement in the environmental domain and the least agreement in psychological health domain also suggests that mothers may have more difficulty interpreting the internal or intrapersonal aspects of QoL of their adult child with ASD.

This study also examined predictors of subjective QoL of adults with ASD, and explored the factors that had significant impacts on subjective QoL across the three different assessment methods. Results of regression analyses revealed a number of pertinent findings. First, different sets of factors played important roles in predicting levels of subjective QoL based on adult self-report and both types of maternal reports (self and proxy-reports). In both types

of maternal reports, adults' level of independence in daily activities was a significant predictor of three of four domains of subjective QoL (the physical health, psychological health, and social relationship domains). In adults' own self-report, however, it was stress related variables – having experienced frequent bullying and levels of perceived stress – that predicted all four domains of subjective QoL. In contrast to mothers' ratings, level of independence in daily activities did not predict any domain of subjective QoL as self-rated by the adult with ASD. Additionally, the health status of the adult played a more significant role in predicting physical health and psychological health in maternal reports than in adult self-reports.

Thus, overall, the findings reported herein suggest that from the mother's perspective, whether it is her own or her proxy perception, observable characteristics of adults with ASD such as health status and level of independence in daily activities played key roles in evaluating the subjective QoL of their adult child with ASD. For the adults themselves, on the other hand, intrapersonal factors such as perceived stress or past experience with being bullied were the critical elements in appraising their own QoL. Notably, psychopathology was the factor that contributed the least to any domain of subjective QoL from either the adults' own perspective or that of their mothers.

Second, across assessment methods, single variables emerged as salient factors for specific domains of subjective QoL. For instance, being bullied frequently was a significant predictor of the psychological health domain for all three sources of subjective QoL ratings. Being extraverted was a significant predictor of the social relationship domain across all three sources of subjective QoL ratings, and perceived stress was a significant predictor of the environment domain in adult self-report and both types of maternal reports. Thus, for three of the four domains of the WHOQOL-BREF, single factors (being bullied, extraversion, perceived stress) emerged as significant predictors, with convergence across adults' self-reports, mothers' perceptions of their adult child's appraisals, and mothers' own appraisals of subjective QoL. It is notable that these factors have not frequently been included in past research on adults with autism. Thus, future research might profitably include measures of exposure to bullying, ratings of stress, and the personality characteristic of extraversion in addition to more typically-included measures of autism symptoms, functional independence, and cognitive abilities.

Third, across domains and across assessment methods, the proportion of variance in subjective QoL that was accounted for by the set of predictors was substantial, ranging from one-third to over two-thirds of the variance in the WHOQOL-BREF measure. This, along with high levels of reliability, suggests that subjective QoL is an outcome that can be validly investigated alongside of traditional adult outcomes for adults with ASD.

One limitation of the present study is that families of the individuals in the sample had been participating in research for almost 15 years at the time of data collection, making them a select group, possibly representative of subsamples of families with greater resources and motivation. Also, although about one-third of these adults had an intellectual disability, many more of those adults in the larger sample had intellectual disability and more significant autism symptoms such that they were not able to participate in the subjective

QoL interview. Consequently, the resulting sample of individuals with ASD in this analysis was relatively high functioning with lower ASD symptomatology. Because of this sample selection, the findings of this study may not be generalizable to all adults on the spectrum.

Further, with a relatively small sample size, this study was limited in exploring the broader range of potential predictors that might impact subjective QoL of adults with ASD. Future studies with larger sample sizes could expand the conceptual model further by incorporating additional antecedents of subjective QoL including social and economic resources, normative social outcomes and objective measures of QoL.

Notwithstanding these limitations, the current study contributes to the understanding of subjective QoL of individuals with ASD, first by focusing on adults with ASD, a group that has been understudied, and second by investigating correlates of subjective QoL not just in the domain of autism related symptoms but also incorporating measures of the adult's own life experiences.

The results of the present study have a number of important implications for improving the subjective QoL of adults with ASD, specifically with regard to life stress related variables that emerged as salient predictors of subjective QoL. Specifically, the finding that a history of being bullied five or more times and greater perceived stress were associated with poorer self- and maternally-reported subjective QoL in adults with ASD has important implications for practice. New research suggests that between half and three quarters of individuals with ASD are victims of bullying (e.g., Cappadocia et al. 2012; Schroeder et al. 2014; Sterzing et al. 2012). The finding of the present research that a history of frequent bullying in childhood or adolescence is associated with poorer subjective QoL in adulthood underscores the need to reduce bullying by intervening early in the course of bullying and creating a better and more accepting environment for individuals with ASD, particularly in inclusive settings in schools where much bullying occurs. In addition, the finding of the present study that greater perceived stress is associated with poorer self-reported subjective QoL across a number of domains aligns with recent research that indicates that adults with ASD report higher levels of perceived stress and stressful life events than healthy volunteers (Bishop-Fitzpatrick 2015; Bishop-Fitzpatrick et al. 2015; Hirvikoski and Blomqvist 2015) and that greater perceived stress and exposure to stressful life events predict poorer social functioning in high-functioning adults with ASD (Bishop-Fitzpatrick 2015; Bishop-Fitzpatrick et al. 2015; Sterzing et al. 2012), suggesting an emerging pattern of association between stress and social outcomes in this population. Stress reduction may thus be a pertinent target for interventions that aim to improve adult outcomes and subjective QoL.

This study also has implications for future research attempting to measure subjective QoL in adults with ASD. When an adult can respond to subjective QoL questions, self-report would be the preferred approach. However, if the adult cannot self-report, our data suggest that parental proxy report is a better method than parental report. Similarly, in a clinical setting, it would be important for clinicians to attempt to ask the adult with ASD for self-reports of his or her subjective QoL, but if this is not possible, parental proxy report is the preferred second choice.

In conclusion, the results reported herein indicate that adults with ASD are able to reliably report their own subjective QoL, and that high perceived stress and frequent bullying are salient predictors of poorer subjective QoL in this population. As an extension of the literature on adult outcomes in ASD, the results from the present study indicate that these adults with ASD experience relatively good subjective QoL in terms of physical health, psychological health, social, and environmental indicators. The findings of the present study highlight the resilience of individuals with ASD in adulthood, especially in the context of family support. Nonetheless, given findings that frequent bullying and high perceived stress predict poorer subjective QoL in this population, our results underscore the need for interventions and services that target bullying and perceived stress in individuals with ASD across the life course.

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**Table 1**

Descriptive Statistics of Independent Variables (n = 60).

Variables	Mean (s.d.) [range] / %			Difference M vs. F
	All	Males (n=46)	Females (n=14)	
W-ADL	27.7 (4.8) [14, 34]	27.7 (5.1) [14, 34]	27.5 (3.8) [21, 34]	t = 0.11
ABCL Total problems score	57.8 (6.1) [47, 81]	58.1 (6.6) [47, 81]	57.1 (4.4) [51, 66]	t = 0.53
normal range	75.9%	72.7%	85.7%	Chi-sq = 1.60
borderline range	6.9%	9.1%	0.0%	
clinical range	17.2%	18.2%	14.3%	
physical health				Chi-sq = 3.10
poor/fair	25.0%	19.6%	42.9%	
good/excellent	75.0%	80.4%	57.1%	
personality: extraversion	4.0 (1.7) [1, 7]	3.7 (1.8) [1, 7]	4.9 (1.2) [3, 7]	t = -2.19*
perceived stress	1.7 (0.9) [0, 4]	1.5 (0.8) [0, 4]	2.2 (0.9) [0, 4]	t = -2.31*
frequency: being bullied in lifetime				Chi-sq = 6.18*
never	17.5%	13.6%	30.8%	
one to four times	24.6%	31.8%	0.0%	
five times or more	57.9%	54.5%	69.2%	

W-ADL Waisman-Activities of Daily Living scale, ABCL Adult Behavior Check List

\* p &lt; .05

**Table 2**

Internal Consistency (Cronbach's  $\alpha$ ) for WHOQOL-BREF Domains

	N	Physical health	Psychological health	Social Relationships	Environment
Adult self-report	60	0.71	0.82	0.78	0.79
Maternal proxy-report	60	0.83	0.86	0.74	0.85
Maternal report	60	0.81	0.78	0.70	0.87
US samples <sup>a</sup>	159	0.87	0.87	0.69	0.84
WHO whole sample <sup>a</sup>	11830	0.82	0.81	0.68	0.80

<sup>a</sup> (Skevington et al. 2004)

**Table 3**

Comparison of Mean WHOQOL-BREF Domains Scores and Correlations among Adult Self-Report, Maternal Proxy-Report and Maternal Report

	Adult self-report	Maternal proxy-report	Maternal report
<i>Mean QoL domain scores<sup>a</sup></i>			
Physical health	73.3 (15.7)	73.4 (18.7)	72.1 (17.6)
Psychological health	69.5 (18.8)	68.8 (18.5)	66.5 (16.1)
Social Relationships	71.2 (26.9)*	67.2 (23.4)	60.2 (24.1)*
Environment	77.4 (15.6)	74.5 (18.3)	75.6 (18.1)
<i>Pearson Correlations with adult self-report WHOQOL-BREF domains</i>			
Physical health <sup>b</sup>	--	.729***	.486***
Psychological health <sup>b</sup>	--	.368**	.161
Social Relationships <sup>b</sup>	--	.544***	.283*
Environment	--	.524***	.395**
<i>Intraclass Correlations (ICC) with adult self-report WHOQOL-BREF domains</i>			
Physical health	--	.721***	.486***
Psychological health	--	.371**	.159
Social Relationships	--	.536***	.260*
Environment	--	.515***	.392**

\* p < .05,

\*\* p < .01,

\*\*\* p < .001

<sup>a</sup> Standard deviations are presented in the parenthesis.

<sup>b</sup> The correlation between adult self-report and maternal proxy-report was significantly greater than the correlation between adult self-report and maternal report (p < .05).

**Table 4**

Multiple Regression Models Predicting WHOQOL-BREF Domain Scores from Adult Self-Report, Paternal Proxy-Report and Maternal Report

	Physical Health	Psychological Health	Social relationships	Environment
<i>[Adult self-report]</i>				
good health (good/excellent = 1)	6.97 (4.14)	9.47 (4.73)*	-9.78 (7.71)	.38 (4.49)
W-ADL	.45 (.40)	-.03 (.46)	.91 (.73)	.13 (.44)
ABCL	-.40 (.31)	.30 (.36)	.27 (.57)	.00 (.34)
personality: Extravert	-.31 (.94)	2.68 (1.07)*	5.73 (1.76)**	.88 (1.02)
perceived stress	-8.01 (1.88)***	-6.46 (2.15)**	-9.60 (3.44)**	-8.00 (2.04)***
frequency: being bullied	-5.47 (2.30)*	-9.27 (2.63)**	-12.9 (4.18)**	-5.73 (2.49)*
constant	100.4	59.8	48.2	91.8
R <sup>2</sup>	.492	.494	.427	.375
<i>[Maternal proxy-report]</i>				
good health (good/excellent = 1)	13.5 (4.35)**	5.77 (4.88)	-1.35 (6.29)	8.58 (5.41)
W-ADL	1.16 (.42)**	1.46 (.48)**	1.78 (.61)**	.81 (.53)
ABCL	-.46 (.32)	-.36 (.37)	-.58 (.48)	-.66 (.41)
personality: Extravert	1.16 (.98)	2.75 (1.11)*	3.77 (1.43)*	.02 (1.23)
perceived stress	-7.03 (2.04)**	-5.20 (2.22)*	-5.65 (2.86)	-5.02 (2.46)*
frequency: being bullied	-5.95 (2.42)*	-6.32 (2.71)*	-3.42 (3.49)	-3.40 (3.03)
constant	72.6	51.4	50.8	96.5
R <sup>2</sup>	.613	.500	.409	.352
<i>[Maternal report]</i>				
good health (good/excellent = 1)	17.3 (3.68)***	11.4 (4.17)**	-9.35 (6.96)	10.9 (5.45)
W-ADL	1.46 (.36)***	1.26 (.41)**	1.94 (.68)**	.93 (.53)
ABCL	-.62 (.28)*	-.54 (.31)	-.80 (.53)	-.38 (.41)
personality: Extravert	.03 (.84)	1.25 (.95)	4.11 (1.58)*	-.51 (1.24)
perceived stress	-1.83 (1.67)	-1.24 (1.89)	1.86 (3.17)	-5.09 (2.48)*
frequency: being bullied	-3.13 (2.04)	-4.63 (2.31)*	1.84 (3.86)	-3.31 (3.03)
constant	62.3	57.5	36.1	78.8
R <sup>2</sup>	.680	.533	.359	.339

W-ADL Waisman-Activities of Daily Living scale, ABCL Adult Behavior Check List

\* p < .05,

\*\* p < .01,

\*\*\* p < .001

### Appendix

Comparison of original WHOQOL-BREF items and items used in the current study (supplementary comments used to help individuals with ASD to understand questions better were presented in brackets [supp:]).

WHOQOL-BREF original items	WHOQOL-BREF used in the current study
How would you rate your quality of life?	How would you rate your quality of life? [supp: <i>how well is your life going?</i> ]
How satisfied are you with your health?	How satisfied are you with your health? [supp: <i>physical or emotional</i> ]
To what extent do you feel that physical pain prevents you from doing what you need to do?	To what extent have you felt physical pain prevents you from doing what you need to do?
How much do you need any medical treatment to function in your daily life?	How much do you need any medical treatment to function in your daily life? [supp: <i>taking meds, physical devices</i> ]
How much do you enjoy life?	How much do you enjoy life?
To what extent do you feel your life to be meaningful?	To what extent do you feel your life is meaningful? [supp: <i>important or have purpose</i> ]
How well are you able to concentrate?	How well are you able to concentrate? [supp: <i>think or focus</i> ]
How safe do you feel in your daily life?	How safe do you feel in your daily life?
How healthy is your physical environment?	How healthy is your physical environment? [supp: <i>how much does your environment allow you to be healthy</i> ] [supp: <i>food, water, junk food, bugs</i> ]
Do you have enough energy for everyday life?	Do you have enough energy for everyday life?
Are you able to accept your bodily appearance?	Are you able to accept your bodily appearance? [supp: <i>do you like how you look?</i> ]
Have you enough money to meet your needs?	Have you enough money to meet your needs?
How available to you is the information that you need in your day-to-day life?	How available to you is the information that you need in your day-to-day life? [supp: <i>weather, bus schedule, TV stations, pharmacy</i> ]
To what extent do you have the opportunity for leisure activities?	To what extent do you have the opportunity for leisure activities? [supp: <i>having fun</i> ]
How well are you able to get around?	How well are you able to get around? [supp: <i>physically able to</i> ]
How satisfied are you with your sleep?	How satisfied are you with your sleep?
How satisfied are you with your ability to perform your daily living activities?	How satisfied are you with your ability to perform your daily living activities? [supp: <i>cooking, bathing, getting dressed</i> ]
How satisfied are you with your capacity for work?	How satisfied are you with your capacity for work? [supp: <i>ability to do work, feeling competent at job</i> ]
How satisfied are you with yourself?	How satisfied are you with yourself?
How satisfied are you with your personal relationships?	How satisfied are you with your personal relationships? [supp: <i>any type of relationships</i> ]
How satisfied are you with your sex life?	<b>Not asked.</b>
How satisfied are you with the support you get from your friends?	How satisfied are you with the support you get from your friends?
How satisfied are you with the conditions of your living place?	How satisfied are you with the conditions of your living place? [supp: <i>space itself</i> ]
How satisfied are you with your access to health services?	How satisfied are you with your access to health services? [supp: <i>doctor, dentist, psychiatrist/psychologist</i> ]

WHOQOL-BREF original items	WHOQOL-BREF used in the current study
How satisfied are you with your transport?	How satisfied are you with your transportation? <i>[supp: get a ride, call a cab, take a bus]</i>
How often do you have negative feelings such as blue mood, despair, anxiety, depression?	How often do you have negative feelings such as blue mood, despair, anxiety, depression?

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