Behavioral predictors of Subjective Quality of Life in Young High-Functioning Adults with Autism Spectrum Disorder (ASD).
Abstract

This study was conducted to assess subjective quality of life and to distinguish predictors of quality of life in young adults with autism spectrum disorder (ASD). Young adults with ASD enrolled in higher education were compared to control students without ASD with respect to quality of life, executive functioning, motivation performance, social anxiety, emotion regulation, stress coping abilities, ASD symptoms, adaptive functioning, and self-reflection. Young adults with ASD reported lower subjective quality of life than control peers and showed higher impairment in all of the above-mentioned areas. Within the ASD group, low initiative taking, high internalizing problems, and high negative tension in social situations predict lower quality of life. Together, these findings indicate that deficits in the stress regulation system lead to lower subjective quality of life in young adults with ASD, despite their high functioning.

*Keywords:* young adults, students, autism spectrum disorder, high-functioning, predictors of subjective quality of life
The number of publications on Quality of Life (QoL) in individuals with autism spectrum disorder (ASD) has grown rapidly over the last few years. Important aspects of quality of life are interpersonal relationships and social activities, and exactly those factors are often affected in the lives of individuals with ASD (Bauminger & Kasari, 2000). ASD is a neurodevelopmental disorder in the category of pervasive developmental disorders and is characterized by a very heterogeneous pathology. Clinical features of ASD are reflected in three domains; that is qualitative impairments in social interactions, qualitatively impaired verbal and non-verbal communication, and restricted range of interests (Rutter et al., 2008).

Despite the growing interest in quality of life of individuals with ASD, few studies have been done with young adults diagnosed with this condition. This is remarkable since the transition phase from adolescence into young adulthood is particularly difficult for individuals with ASD (Adreon & Durocher, 2007). Not only do young adults move out of their parents’ houses, but in this phase of their lives it is also very important to have relationships and to become self-sufficient in everyday life. The basis for later adult life and the individual’s functioning within society is laid in the transition phase from adolescence into adulthood.

The small body of literature concerning young adults with ASD and quality of life mostly concerns broad outcome in terms of living condition and independency. In a long-term follow-up study, Billstedt, Gillberg, and Gillberg (2011) measured quality of life in 120 young adults diagnosed with ASD in childhood. The researchers found that the majority of the individuals with ASD needed support in the areas of occupational and recreational activities. It was also found that the subjects with ASD
were often unable to give their subjective point of view regarding quality of life.

When studying quality of life, a distinction can be made between objective and subjective elements. Objective measurements of QoL entail social, economic, and health indicators (Costanza et al., 2005), while subjective measurements focus on the personal experience of these indictors. Subjective well-being is a term for the importance of a ‘perceived need’ and the degree to which that perceived need is being met. Subjective well-being is often used as a proxy for quality of life in the literature (Costanza et al., 2005). A good outcome in terms of quality of life is often described as the development of a normal social life and independence by adulthood (Billstedt, Gillberg & Gillberg, 2011). For individuals with ASD, their subjective quality of life might be different than typically developing individuals (Plimley, 2007). It is for example very important to include subjective measures when measuring quality of life in individuals with ASD, since knowing social rules does not imply that a child with ASD can use these social rules appropriately. Solely asking objective questions would therefore miss the aim of measuring how the individual with ASD evaluates the perceived need.

It should be noted that in the study by Billstedt et al., (2011) severe mental retardation was found (SMR= IQ < 50) in almost half of the subjects in the ASD group (46%), which implicates that these findings cannot be generalized to high-functioning individuals within the upper ranges of the autism spectrum. The term ‘high-functioning’ is often used for individuals with a disability having a normal to above average IQ (IQ>85). Knowledge about high-functioning individuals with ASD is scarce. Young high-functioning adults with ASD have high intelligence, but may still have problems in the social, communicative, and behavioral domains. In one study by Renty & Roeyers (2006), quality of life in high-functioning adults with ASD
was studied. It was found that an available supportive social network is related to quality of life in adults with ASD. The authors found that quality of life is more strongly linked to the perception that support is available than to the effects of the actual supporting behaviors. Taken together, these studies suggest that more research should address subjective quality of life in high-functioning individuals with ASD. Measuring the subjective quality of life in young adults with ASD will give insights into the importance these young adults give to fulfilling each of the human needs relative to young adults without ASD.

To determine which factors influence subjective quality of life in young adults with ASD, several neuropsychological markers that are known to be influenced in ASD are studied. First, we focus on emotion regulation and stress-coping abilities, for individuals with ASD experience difficulties in processing their own emotions (Rieffe, Oosterveld, Meerum Terwogt, Mootz, van Leeuwen & Stockmann, 2011). Especially in stressful situations, the ability to manage affective arousal and emotion may improve quality of life. According to research by Rieffe et al. (2011), high-functioning children with ASD have a more fragmented emotion regulation than regularly developing peers. Emotion dysregulation includes difficulties in identifying and labeling feelings, difficulties in distinguishing feelings from the bodily sensations of emotional arousal, and a tendency to focus on external events rather than inner experiences. This cluster of cognitive and affective features has been described as the alexithymia construct (Hill, Berthoz & Frith, 2004). Secondly, in addition to regulating emotions, being able to regulate and monitor oneself in social situations might improve quality of life as well. Many adolescents with ASD are prone to social anxiety because of their difficulties with social interactions (Bellini, 2006). Some individuals with ASD desire having meaningful social relationships, but experience
worry and distress in social situations (Jobe & White, 2007). Their deficits in social
skills place young adults with ASD at risk for failing to obtain and maintain
relationships with fellow students (Adreon & Durocher, 2007). This inability to
reflect on one’s own social functioning may lead to social anxiety and may impact
daily life functioning in young adulthood. Thus, social anxiety might be related to
Quality of Life (QoL) in young adults with ASD. As social anxiety seems to be related
to ASD symptoms (Kuusikko et al., 2008), emotion regulation and coping
mechanisms in young adults with ASD may also be influenced by the degree of ASD
symptoms. More severe ASD symptoms may lead to higher social anxiety and lower
emotion regulation, stress and coping skills. The influence of ASD symptoms on
subjective quality of life should therefore be assessed. Thirdly, anxiety and mood
changes are features of internalizing problems. According to Christ and Reiersen
(2009), the most common co-morbid psychiatric difficulties in individuals with ASD
are symptoms of anxiety and depression. Since these symptoms have a high impact on
daily life, adaptive functioning should be taken into account when assessing quality of
life. A fourth factor, executive functioning (EF) may also contribute to QoL. The term
‘executive function’ is an umbrella term for functions such as planning, working
memory, impulse control, inhibition, initiation and monitoring of action (Rutter, et al.,
2008). Executive functions are important functions in dealing with challenges of
young adulthood, especially planning and flexibility are important for effective
transition phases in an individual’s life. Although results are mixed, previous research
showed impairments for these functions in students with ASD (Hill, 2004). Planning
is important for effective monitoring of own behavior and flexibility is important for
switching between different surroundings and demands. Since planning and mental
flexibility are impaired in young adults with ASD, this might affect their subjective
well-being in the transition phase from adolescent to young adult. Finally, many individuals with ASD show reduced interest in certain academic assignments when these are not within their range of interest. Motivation and drive seem to play a large role in their performance (Koegel, Singh, & Koegel, 2010). Motivation and drive might therefore predict quality of life in young adults with ASD.

In this study the subjective experience, or the degree to which a perceived need is being met and the importance of that perceived need, in young adults with ASD enrolled in higher education will be measured. The objective of this study is to identify factors that predict quality of life in young adults with ASD who are high functioning. Predictors include ASD symptoms, performance motivation and drive, executive functioning, social anxiety, emotion regulation and stress-coping abilities, and adaptive functioning. The research questions are as follows: (1) Are there differences in subjective quality of life between young adults with ASD and peers without ASD?; (2) What characteristics are predictive of quality of life in the ASD group? and (3) Are these characteristics well or less well developed in the ASD group compared to their peers without ASD? In other words, are these predictors strong or weak characteristics within this group?

To answer these questions, subjective quality of life in young adults with ASD participating in a special housing project will be measured. This housing project includes support in daily life and study-related issues for young adults with ASD, while they live together in groups of about 8 students. It is expected that these high-functioning young adults with ASD report lower quality of life than typically developing peers. Furthermore, we expect that low regulation capacities in the emotional, executive functioning, and stress domains, and low feelings of competence
in the social and internalizing domains lead to lower subjective quality of life in young adults with ASD.

**Method**

**Participants.** One hundred and fifteen students (100 men and 15 women) from universities throughout the Netherlands participated in this study. Of the total of 115 young adults that participated in this study, 85 belonged to the ASD group and 30 to the control group. Participants ranged in age from 18 to 28 years \((M=22.16, SD =2.33)\). Of the students in the ASD group, 75 were men (88%) and 10 were women (12%). Of the students in the control group, 25 were men (83%) and 5 were women (17%). No differences in sex distribution were found between the ASD and the control group, \(\chi^2(1, N=115) = .47, p=.49\). Young adults who are diagnosed with ASD and who were admitted to the Stumass programme were approached for participation in the study with help of the Stumass organization. Stumass is an acronym of ‘students with autism spectrum disorder’ and the goal of the organization is to reduce dropout rates and to increase independency among students with ASD. The coaches working at Stumass support students in daily living and in their studies, but also in participating in society. Stumass provides living homes with guidance in most cities in the Netherlands where universities and colleges are located. There are twenty-five Stumass houses in cities throughout the Netherlands. In these houses, each student is assigned a personal tutor, with whom he or she has weekly meetings to consult about personal and study-related issues. The study was approved by the medical ethics committee of Leiden University, according to the declaration of Helsinki. Students without ASD from several universities were approached through
mouth-to-mouth advertising and an information brochure. Students without ASD received a voucher worth of 10 Euros for their participation in the study.

Measures. The assessment battery included individually administered psychological tests and self-report questionnaires as well as observant-completed questionnaires. Quality of life was assessed with the in Dutch translated Quality of Life Questionnaire (QoL-Q; Schalock & Keith, 1993). According to Plimley (2007) and Renty & Roeyers (2006), the QoL-Q is a reliable and accurate tool for determining subjective quality of life in individuals with ASD. The QoL-Q has good psychometric properties with a test-retest coefficient of .87 and with a Cronbach’s alpha of .90 for the total scale (Schalock & Keith, 1993). No data exist on the reliability and validity for the Dutch version of the QoL-Q, but it is assumed to be comparable to the original version. The questionnaire yields data regarding overall QOL, consisting of scores from four subscales: satisfaction, competence/productivity, empowerment/independence, and social belonging. Each subscale contains 10 items, scored on a 3-point Likert-scale. An example of a question is ‘How much fun and enjoyment do you get out of life?’ with answer possibilities ‘lots’, ‘some’ and ‘not much’. The QoL-Q comprises 40 questions and a higher score represents a higher level of overall quality of life.

ASD symptoms were measured with the Social Responsiveness Scale for Adults (SRS-A, Constantino & Todd, 2005). The SRS consists of 65 questions that map the social shortcomings of the adult. The self-report version was administered to all participants and the observant/informant version to somebody close to the participant (family member, partner, or personal tutor). The questionnaire comprises the scales social awareness, processing social information, competence in reciprocal
social communication, social cognition, social communication, social motivation and autistic mannerisms and gives a total score. The SRS subscale scores give an index of severity of social deficits in the autism spectrum with higher scores indicating more ASD traits. Internal consistency was found to be highly acceptable with a Cronbach’s alpha of .95 in parents of children with ASD (Constantino & Todd, 2005) and the overall test-retest reliability (Pearson’s r) for the SRS was found to be .64. An example of a question is ‘I am oversensitive to sounds, textures, or scents’ with answer possibilities on a four-point scale ranging from ‘not true’ to ‘almost always true’.

Performance motivation and drive were assessed with the Dutch Performance Motivation Test for adults (PMT; Hermans, 1970). This scale measures performance motivation and personality traits that define productivity and attitude towards work. The questionnaire consists of 90 questions that load on the three different subscales performance motivation, positive performance anxiety and negative performance anxiety. According to the COTAN, reliability of the PMT is sufficient. An example of a question is ‘When I find myself in a difficult situation, I feel…’ with answer possibilities ‘very insecure’, ‘insecure’ and ‘secure’. Answer possibilities are different for each question.

Executive functioning was assessed with the Dutch version of the American Behavior Rating Inventory of Executive Function for Adults (BRIEF-A; Isquith, Guen Kenworthy, 2000). Based on the original BRIEF, the BRIEF-A for adults is composed of 75 items with nine scales: inhibit, self-monitor, plan/organize, shift, initiate, task monitor, emotional control, working memory, and organization of materials. Higher ratings are indicative of greater perceived impairment in executive functioning. The reliability of the BRIEF for children has been estimated with a
Cronbach’s alpha for internal consistency ranging from .80 to .98. Also, reliability based on test-retest is high for as well the scales and the indexes (Gioia, Isquith, Guy & Kenworthy, 2000). An example of a question is ‘I have trouble sticking to the subject’ with answer possibilities on a three-point Likert-scale; ‘never’, ‘sometimes,’ or ‘often’.

Social anxiety was assessed with the adolescent-version of the Scale for Interpersonal Behavior (SIB; Arrindell, de Groot & Walburg, 1984). This scale measures the degree of anxiety in adolescents in practicing new skills and the degree to which these skills are actually performed. The SIB has four subscales; expression of negative feelings, expression of own insecurity and inadequacy, making yourself known and expressing positive feelings. The items of the SIB are rated on two dimensions; the tension dimension (how much tension one experiences in social situations) and the frequency dimension (how many times the individual finds oneself in the social situation). The SIB exists of 50 items that need to be rated two times: once along the tension dimension and once along the frequency dimension. Research indicates that the SIB is a valid and reliable questionnaire, the reliability coefficients are on average far above .7 and a clear relationship exists with constructs like social fear and shyness (Bijlstra & Oostra, 2000). An example of a question is ‘Approach someone to get to know him/her’ with answer possibilities ranging from ‘totally no tension experienced’ to ‘much tension experienced’ and ‘never occurs’ to ‘always occurs’.

To assess emotion regulation, the Dutch Bermond-Vorst Alexithymia Questionnaire (BVAQ; Bermond & Vorst, 1993) was administered. Alexithymia refers to a dysfunction in emotional awareness. The questionnaire consists of 40 questions that refer to the subscales verbalization, identification, analysis, fantasy life,
and emotionalizing. The higher the score, the more the subject is alexithymic. The reliability of this questionnaire is .85 and the questionnaire is proven valid in samples of Dutch students (Vorst, & Bermond, 2001). An example of a question is ‘If I’m upset, then I know whether I am anxious or angry’ with response possibilities on a five-point scale from ‘fully applicable’ to ‘entirely not applicable’.

To assess stress-coping abilities, the Dutch Utrechtse Coping List (UCL, Schreurs & van de Willige 1988) was administered to all participants. This scale measures coping and problem solving in adults and is comprised of seven scales that measure coping ability; active coping, palliative coping, avoiding, social support seeking, depressive-regressive coping, expression of negative emotions, and comforting ideas. The UCL has sufficient reliability; Cronbach’s alphas range from 0.64 to 0.82 (Schreurs, Van de Willige, Tellegen & Brosschot, 1988). The UCL consists of 47 questions. An example of a question is ‘Generally, I mull over the past’ with four response options from ‘rarely or never’ to ‘very often’. Higher scores on the subscales indicate that the coping style is used more often.

Adaptive functioning was assessed with the Adult Self report (ASR, for Ages 18-59) and an informant/observant version of this questionnaire, i.e. the Adult Behavior Checklist (ABCL; Achenbach & Rescorla, 2006). An informant who is close to the subject completed the ABCL. We looked at the syndrome scales anxious/depressed; withdrawn; somatic complaints; thought problems; attention problems; aggressive behavior and rulebreaking behavior and the internalizing, externalizing and total problems scale. A higher score on a subscale indicates higher levels of problem behavior. The ASR consists of 123 items and the ABCL has exactly the same questions, but is used to report on others. Internal consistency alpha ranges from .87 to .93 (McKinney & Milone, 2012). The reliability of the ASR and ABCL
questionnaires is very high; statistically significant test–retest correlations with $p<0.1$ have been found (Achenbach & Rescorla, 2006). An example of a question is ‘I am worried about my future’ with answer possibilities on a 3-point scale from ‘not true’ to ‘very true or often true’.

Procedure. Young adults living in Stumass houses were invited to participate in the study by an information letter, provided by their personal tutors. Students signed an informed consent form and the questionnaires were sent to their Stumass houses. The young adults filled in the questionnaires in about two sessions of sixty minutes and were guided by the attending tutor at that moment. Their personal tutors were asked to fill in the observant versions of SRS-A and the ASR. To guarantee anonymity, all young adults received a participant number. Only the research team had an overview of details about the participants, the tutors could not access personal information about the young adults. The students in the control group were recruited by the researcher. Students attending different universities in the provinces Noord Holland and Zuid Holland were asked to participate in the study. They were given an information letter and upon agreement, the questionnaires and informed consent were sent to their homes. Each student was also asked to let someone close fill in an observant version of two questionnaires. Completing the questionnaire took roughly one and a half hour for the control participants. The control participants received the reward when they had returned the completed questionnaires to the university of Leiden.

Statistical analyses

A multivariate ANOVA was performed to test group differences on the subtests and total score of the Quality of life questionnaire (QoL). One-way
ANOVA’s were performed to test group differences on the subtests and total score of the SRS-A (observant version), PMT, BRIEF-A, SIB, BVAQ, UCL and the ABCL.

To distinguish significant behavioral predictors of subjective QoL in young high-functioning adults with ASD, a regression analysis was performed. Predictors on which the ASD group and the control group significantly differed were put into the regression analysis; in order to see which variables best predict quality of life specifically for the ASD group. No total scores were entered into the regression since these are merely summaries of the subscales. The following subscales were entered into the regression; of the SRS-A (observant version) the subscales social communication, social motivation and autistic mannerisms; of the PMT the subscales performance motivation, positive fear of failure and negative fear of failure; of the BRIEF the subscales inhibition, cognitive flexibility, emotion regulation, initiative taking, working memory, planning/organising and orderliness; of the SIB the subscales tension while expressing negative feelings, tension while expressing insecurity, tension while making oneself known and tension while expressing positive feelings; of the BVAQ the subscales verbalizing and identifying emotions; of the UCL the subscales active coping, avoidance, depressive-regressive coping, and comforting ideas; and of the ABCL the subscales internalizing problems, aggressive behavior, attention problems, thought problems, somatic complaints, withdrawn and anxious/depressed. The method used for the regression was forward entering. With forward entering, only predictors that significantly add something to the model are entered in the regression. In this forward model, the criterion for entering the predictor in the regression equation is that $F$ should be smaller than 4.

Effect sizes are represented with Cohen’s $d$. Cohen’s $d$ is an objective and standardized measure of the magnitude of the observed effect. The effect size is
calculated by dividing the difference between the means of the groups by the standard deviation. As a guide for the interpretation of effect sizes, Cohen (as cited in Gliner, Leech, & Morgan, 2007) considered effect sizes of .2 standard deviations to be small, effect sizes of about .5 standard deviations to be medium, and effect sizes of .8 standard deviations or higher to be large.

Results

In the final analyses, 85 subjects from the ASD group and 30 subjects from the control group participated. Three subjects were removed from the ASD group prior to analysis, due to missing data. These students did not complete more than half of the questionnaires, due to lack of time. As some subjects in the ASD group did not fill in all the questions correctly, some questionnaires could not be scored and therefore participation numbers varied among analyses.

Quality of life

Mean scores and standard deviations for the ASD (N=82) and the control group (N=29) on the subtests of the Quality of Life questionnaire are provided in Figure 1. A multivariate significant group difference between the ASD and the control group was found, $F(4, 107)=16.49, p<.001$. When looking at the univariate tests, several significant differences were found. First, it was found that the ASD group scores significantly lower than the control group on the subtest satisfaction, $F(1,110)=40.06, p<.001$. Second, it was found that the ASD group scores significantly lower than the control group on competence, $F(1, 110)=23.13, p<.001$. Third, it was found that the ASD group scores significantly lower than the control group on independence, $F(1, 110)=39.18, p<.001$. Fourth, it was found that the ASD group
scores significantly lower than the control group on social belonging, $F(1,110)=30.03$, $p<.001$. Finally, a significant difference was found between young adults with ASD and the control group on total quality of life score, $F(1,110)=59.42$, $p<.001$. Young adults with ASD ($M=85.57$, $SD=11.65$) score lower on quality of life than control students ($M=103.76$, $SD=8.47$).

![Figure 1](image)

**Figure 1.** Mean scores and standard deviations for the ASD and the control group on the subscales of the Quality of life Questionnaire (QoL-Q). Error bars are derived from the individual standard deviations for each group.

The effect size (cohen’s $d$) is 1.8. The mean total quality of life score of the ASD group deviates with about 1.8 standard deviation from the control group and this is a large effect size.

**ASD symptoms**

A significant difference between the ASD (N= 85) and the control group (N=30) was found on the subscales of social communication, social motivation,
autistic mannerisms, and total score of the Social Responsiveness Scale for adults—Observant version (SRS-O). In Figure 8, the mean scores and standard deviations for both groups on these subscales are shown. First, young adults with ASD scored higher on social communication indicating more problems than control students, $F(1,113)=56.09$, $p<.001$. Second, young adults with ASD scored higher on social motivation, indicating more problems than control students, $F(1,113)=61.80$, $p<.001$. Third, young adults with ASD scored higher on autistic mannerisms, indicating more problems than control students, $F(1,113)=35.13$, $p<.001$. Finally, young adults with ASD had a higher total score ($M=77.93$, SD=11.87), indicating more social problems than control students ($M=59.03$, SD=7.23), $F(1,113)=67.03$, $p<.001$.

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*Figure 2*. Mean scores and standard deviations of the significant differences between the ASD group and the control group on the subscales of the Social responsiveness scale (SRS). Error bars are derived from the individual standard deviations for each group.
Performance motivation and drive

A significant difference was found between the ASD \((N=84)\) and the control group \((N=30)\) on all three subscales of the Performance Motivation Test (PMT). First, it was found that young adults with ASD score significantly lower on performance motivation than control students, \(F(1,112)=8.34, p<.05\). Second, a significant trend was found; young adults with ASD score lower on positive fear of failure than control students, \(F(1,112)=3.82, p=.05\). Third, it was found that young adults with ASD score significantly higher on negative fear of failure than control students, \(F(1,112)=7.9, p<.05\). In Figure 2, the means and standard deviations of both groups are represented graphically.

![Graph](image)

**Figure 3.** Mean scores and standard deviations for the ASD and the control group on the subscales of the Performance Motivation Test (PMT). Error bars are derived from the individual standard deviations for each group.
Executive functioning

Significant differences were found between the ASD ($N=84$) and the control group ($N=30$) on all subscales and the total score of the Brief Inventory of Executive Functioning for adults (BRIEF-A). In Figure 3, the means and standard deviations for the ASD and the control group are provided. First, young adults with ASD scored higher on impairment in total executive functioning than control students, $F(1,112)=24.46, p<.001$. Second, young adults with ASD showed higher impairment on the subscale inhibition than control students, $F(1,112)=25.38, p<.001$. Third, young adults with ASD showed higher impairment on the subscale cognitive flexibility than control students, $F(1,112)=31.87, p<.001$. Fourth, young adults with ASD showed higher impairment on the subscale emotion regulation than control students, $F(1,112)=23.14, p<.001$. Fifth, young adults with ASD showed higher impairment on the subscale initiative taking than control students, $F(1,112)=45.68, p<.001$. Sixth, young adults with ASD showed higher impairment on the subscale working memory than control students, $F(1,112)=27.76, p<.001$. Seventh, young adults with ASD showed higher impairment on the subscale planning and organizing than control students, $F(1,112)=17.8, p<.001$. Eighth, young adults with ASD showed higher impairment on the subscale orderliness than control students, $F(1,112)=27.05, p<.001$. Finally, young adults with ASD showed higher impairment on the subscale behavior evaluation than control students, $F(1,112)=8.91, p<.05$. 
Figure 4. Mean scores and standard deviations for the ASD and the control group on subscales of the Brief Inventory of Executive Functioning (BRIEF). Error bars are derived from the individual standard deviations for each group.

**Social anxiety**

It was found that young adults with ASD ($N=85$) differ significantly from control students ($N=30$) on all subscales of the Scale for Interpersonal Behavior (SIB). In Figure 4, the means and standard deviations for both groups on the tension subscales of the SIG are given. First, young adults with ASD experience more tension than control students in social situations, $F(1,113)=26.65$, $p<.001$. Second, young adults with ASD experience more tension while expressing negative feelings than control students in social situations, $F(1,113)=18.21$, $p<.001$. Third, young adults with ASD experience more tension while expressing insecurities than control students in social situations, $F(1,113)=18.33$, $p<.001$. Fourth, young adults with ASD experience more tension while making themselves known than control students in social situations, $F(1,113)=14.57$, $p<.001$. Second, young adults with ASD experience more tension while expressing negative feelings than control students in social situations, $F(1,113)=18.21$, $p<.001$. Third, young adults with ASD experience more tension while expressing insecurities than control students in social situations, $F(1,113)=18.33$, $p<.001$. Fourth, young adults with ASD experience more tension while making themselves known than control students in social situations, $F(1,113)=14.57$, $p<.001$. Second, young adults with ASD experience more tension while expressing negative feelings than control students in social situations, $F(1,113)=18.21$, $p<.001$. Third, young adults with ASD experience more tension while expressing insecurities than control students in social situations, $F(1,113)=18.33$, $p<.001$. Fourth, young adults with ASD experience more tension while making themselves known than control students in social situations, $F(1,113)=14.57$, $p<.001$. Second, young adults with ASD experience more tension while expressing negative feelings than control students in social situations, $F(1,113)=18.21$, $p<.001$. Third, young adults with ASD experience more tension while expressing insecurities than control students in social situations, $F(1,113)=18.33$, $p<.001$. Fourth, young adults with ASD experience more tension while making themselves known than control students in social
situations, $F(1,113)=25.61, p<.001$. Finally, young adults with ASD experience more tension while expressing positive feelings than control students in social situations, $F(1,113)=21.1, p<.001$. Another interesting finding was that young adults with ASD ($M=2.84, SD=.5$) report being in all above-mentioned kind of stress-evoking social situations less often than control students ($M=3.31, SD=.46$), $F(1,114)=20.71, p<.001$.

![Figure 5](image.png)

**Figure 5.** Mean scores and standard deviations for the ASD and the control group on the tension subscales of the Scale for Interpersonal Behavior (SIB). Error bars are derived from the individual standard deviations for each group.

**Emotion regulation**

A significant difference between the ASD group ($N=81$) and the control group ($N=30$) was found on the subscales of verbalizing, identifying, and on total cognition of the Bermond-Vorst Alexithymia Questionnaire (BVAQ). First, young adults with ASD score higher on verbalizing emotions, indicating more problems, than control students, $F(1, 109)=6.92, p<.05$. Second, young adults with ASD score higher on identifying emotions, and again indicate more problems than control students,
Third, young adults with ASD ($M=66.46$, $SD=15.98$) score higher on total cognition, indicating more problems than control students ($M=55.9$, $SD=17.81$), $F(1,109)=8.98$, $p<.05$. In Figure 5, mean scores and standard deviations for both groups on the subscales of the BVAQ are shown.

**Figure 6.** Mean scores and standard deviations for the ASD and the control group on subscales of the Bermond-Vorst Alexithymia Questionnaire (BVAQ). Error bars are derived from the individual standard deviations for each group.

*Stress- coping abilities*

A significant difference between the ASD group ($N=83$) and the control group ($N=30$) was found on the subscales active coping, avoidance, depressive-regressive coping, and comforting ideas of the Utrechtse Coping list (UCL). First, young adults with ASD score lower than control students on active coping, $F(1,111)=23.24$, $p<.001$. Secondly, young adults with ASD score higher on avoidance than control students, $F(1, 111)=12.21$, $p=.001$. Third, young adults with ASD score higher on depressive-regressive coping than control students, $F(1,111)=26.96$, $p<.001$. Finally, young adults with ASD score lower on comforting ideas than control students, $F(1,$
111)=12.34, \( p<.001 \). In Figure 6, means and standard deviations for the subscales of the UCL are shown graphically.

![Graph showing mean scores and standard deviations for subscales of UCL](image)

<table>
<thead>
<tr>
<th>Subscale</th>
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<td>19,37</td>
<td>19,03</td>
</tr>
<tr>
<td>Avoiding</td>
<td>19,18</td>
<td>16,7</td>
</tr>
<tr>
<td>Social support seeking</td>
<td>12,73</td>
<td>13,87</td>
</tr>
<tr>
<td>Depressive-regressive coping</td>
<td>14,69</td>
<td>10,7</td>
</tr>
<tr>
<td>Expression of negative emotions</td>
<td>6,01</td>
<td>6,27</td>
</tr>
<tr>
<td>Comforting ideas</td>
<td>11,08</td>
<td>13,1</td>
</tr>
</tbody>
</table>

*Figure 7.* Mean scores and standard deviations for the ASD and the control group on subscales of the Utrechtse Coping list (UCL). Error bars are derived from the individual standard deviations for each group.

*Adaptive functioning*

Young adults with ASD \((N=85)\) significantly differ from control students \((N=30)\) on the subscales total problems, internalizing problems, aggressive behavior, attention problems, thought problems, somatic complaints, withdrawn and anxious/depressed, of the Adult Behavior Checklist (ABCL). In Figure 7, the means and standard deviations for both groups on these subscales are presented. First, young adults with ASD report higher internalizing problems than control students, \(F(1,113)=39.6, p<.001\). Second, young adults with ASD report higher total problems
than control students, $F(1,113)=34, p<.001$. Third, young adults with ASD report more aggressive problems than control students, $F(1,113)=4.88, p<.05$. Fourth, young adults with ASD report more attention problems than control students, $F(1,113)=35.13, p<.001$. Fifth, young adults with ASD report more thought problems than control students, $F(1,113)=8.26, p<.05$. Sixth, young adults with ASD report more somatic complaints than control students, $F(1,113)=4.57, p<.05$. Seventh, young adults with ASD report being more withdrawn than control students, $F(1,113)=24.11, p<.001$. Finally, young adults with ASD report higher feelings of anxiousness/depression than control students, $F(1,113)=21.55, p<.001$.

**Figure 8.** Means and standard deviations for the ASD and the control group on subscales of the Adult Behavior Checklist (ABCL). Error bars are derived from the individual standard deviations for each group.

Predictors of subjective well-being in young high-functioning adults with ASD

Finally, regression analyses were done to see which predictors are significant predictors of quality of life in young adults with ASD. The assumptions for linear
regression have not been violated. In the regression analysis, 78 young adults of the ASD group participated, as some subjects did not completely fill in all of the questionnaires. In predicting quality of life, the only independent variables to enter the regression were internalizing problems (ABCL), initiative taking (BRIEF), and negative tension while practicing new skills in social situations (SIB). The results of the regression indicated that the three predictors together explained 37.6% of the variance ($R^2=.40, F(1,74)=9.37, p<.05$). It was found that internalizing problems significantly predicts quality of life in young adults with ASD ($\beta=-.34, p<.05$), as did initiative taking ($\beta=-1.5, p=.001$) and tension while expressing negative feelings ($\beta=-3.79, p<.05$).

**Discussion**

In this study, subjective quality of life and predictors of quality of life in young adults with ASD were studied. First, it was found that young adults with ASD experience lower quality of life than control students. Although these young adults with ASD are very high functioning, as is reflected in their high academic level, subjective quality of life appears to be low in this group. This was shown in the effect size of 1.8. This is in line with research done by other research groups on objective quality of life; overall outcome in individuals with ASD is poor in terms of independency and isolation (Billstedt, Gillberg, & Gillberg, 2005; Engström, Ekström, & Emilsson, 2003; Renty & Roeyers, 2006) and adolescents with ASD report quality of life below the population mean (Shipman, Sheldrick, & Perrin, 2011). The finding that young adults with ASD appear to have lower subjective quality of life compared to control students implicates that young adults with ASD need support in this phase, notwithstanding their high intelligence and apparent good functioning. Based on national prevalence numbers of ASD in high school in 2007, it
is expected that roughly 1900 young adults with ASD attend higher education in the Netherlands (Boswijk, Breetvelt, & Mensink, 2007). Since individuals with ASD are preparing for adulthood in this developmental phase, risk for dysfunctioning and psychopathology rises with lower quality of life. Research conducted by Billstedt et al. (2005) pointed out that slightly less than one in five of all ASD cases shows deterioration in adolescence and this deterioration appeared to be permanent in 50% of the cases. When assessing and treating ASD, diagnosticians and clinicians should bear in mind that high-functioning does not imply higher quality of life in individuals with ASD and that these individuals need help, in spite of their high intelligence or normal appearance.

From all the behavioral predictors studied, three appeared to significant predictors of subjective quality of life in young high-functioning adults with ASD. Internalizing problems, initiative taking, and tension while expressing negative feelings in social situations best predicted subjective quality of life in young adults with ASD. Higher problems in these areas predict lower subjective quality of life in young adults with ASD. The variance in quality of life score explained by these three predictors is 38 %. Since this is a high explained variance, we conclude that these predictors predict quality of life very well.

*Negative tension (social anxiety)*

The significant contribution of experienced tension while expressing negative feelings in social situations in explaining quality of life in young adults with ASD suggests that high experienced tension while expressing negative feelings in social situations is a predictor of lower quality of life in young adults with ASD.
The finding in this study that young adults with ASD experience more tension in social situations and avoid these kind of situations more often than young adults without ASD suggests that young adults with ASD have problems with regulating their tension and internal feelings such as stress in social situations. Therefore, young high-functioning adults with ASD probably evoke social situations in daily life. This is especially stressful for young adults with ASD in higher education, since important social situations frequently occur while attending higher education. Hill, Berthoz, and Frith (2004) found that individuals with ASD are significantly more impaired in cognitive processing of emotions in social situations than controls. These findings suggest that difficulties with processing emotions in young adults with ASD lead to higher tension in social situations and corresponds to the finding in this study that young adults with ASD have trouble with identifying and verbalizing their own and others’ emotions. According to White, Ollendick, and Bray (2011), social anxiety is a frequent problem among high-functioning individuals with ASD. We hypothesize that past negative learning experiences and the increasing awareness of one’s own social difficulties in young adults with ASD may add to the social anxiety. Next to this, an altered stress system in individuals with ASD might add to the experience of tension in social situations. Previous research has suggested that children with ASD exhibit dysfunction of the HPA system by showing an exaggerated cortisol response to novel and threatening events (Corbett, Mendoza, Abdullah, Wegelin and Levine, 2006) and that an increased vulnerability to oxidative stress and a decreased capacity for methylation may contribute to the development and clinical manifestation of ASD (James, Cutler, Melnyk, Jernigan, Janak, Gaylor, & Neubrander, 2004). Secondly, we hypothesize that the higher tension experienced in social situations may lead to avoidance, lower assertiveness, and less initiative taking in young adults with ASD.
Initiative taking (executive functioning)

The significant contribution of the predictor ‘initiative to solve problems’ in explaining quality of life in young adults with ASD suggests that low initiative taking is a good predictor in explaining lower quality of life in young adults with ASD. The subscale initiative taking is part of the metacognition index of the BRIEF, and represents the extent to which an individual is able to independently perform tasks and monitor his own behavior. Since initiative taking is an important skill in certain situations, e.g., starting a new friendship, taking chances, and being appreciated by others, it is not strange that less initiative taking leads to lower quality of life in these high-functioning young adults with ASD. Lower initiative taking is especially inconvenient for university students, for whom independency is the norm. Students following higher education are asked to initiate their own study schedule, meetings with fellow students and to generalize study material to a broader field of knowledge. In this study, it has been found that young adults with ASD score lower than control students on all subscales of the executive functioning questionnaire. Other researchers have also found that individuals with ASD score lower in the executive functioning domain than controls (Hill, 2004). To date, little has been conducted on initiative taking in individuals with ASD. Some researchers (Gilotty, Kenworthy, Sirian, Black, & Wagner, 2002) suggest that difficulties in creatively generating new activities of individuals with ASD may be specifically related to the social deficits found in ASD. For example; not being able to come up with new ideas during free time. We hypothesize that the lower frequency of initiative taking and assertiveness in young adults with ASD is related to the high tension and stress they experience in new and challenging social situations. Subsequently, the lower initiative taking and higher feelings of tension in social situations because of the deficits in cognitive processing
lead to lower subjective quality of life in young adults with ASD. Deficits in cognitive processing are known in individuals with ASD and are confirmed in this study by the difficulties young adults with ASD experience with identifying and describing emotions. These difficulties might stem from a persistent failure of theory of mind or mentalizing (Hill, Berthoz, & Frith, 2004). Prove for this deficit in individuals with ASD has also been found in an fMRI study by Baron-Cohen, Ring, Wheelwright, Bullmore, Brammer, Simmons, & Williams (1999). According to the researchers, individuals with ASD activate the frontal temporal regions but not the amygdala in the brain when making mentalistic inferences in a fMRI task, in contrast to normal subjects who show increased activation in the superior temporal gyrus and the amygdala. Another explanation for the difficulties individuals with ASD experience with cognitive processing in social situations is the oxytocin dysfunction found in individuals with ASD (Hollander, Bartz, Chaplin, Phillips, Sumner, Anagnostou & Wasserman, 2007). So, deficits in cognitive processing and the stress system may contribute to problems found in initiative taking and higher feelings of tension in social situations for young high-functioning adults with ASD. To explore this further, more research should be carried out to the stress-regulation system in young adults with ASD. This can be done with physiological tests in combination with the observation of social skills. For example, it would be interesting to look at stress with heart rate monitor and skin conductance measures during social situations.

**Internalizing problems**

The significant contribution of the predictor ‘internalizing problems’ in explaining quality of life in young adults with ASD suggests that high internalizing problems is a good predictor in explaining lower quality of life in young adults with
ASD. Internalizing problems have consistently been found in previous research with high-functioning children with ASD (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000), and in students with autistic traits (Kanne, Christ & Reiersen, 2009). Kuusikko et al. (2008) found that high-functioning adolescents with ASD report higher internalizing symptoms than control students. They also found that these adolescents with ASD have higher social anxiety and that behavioral avoidance and evaluative social anxiety increase with age in the ASD group, whereas behavioral avoidance decreases with age in control participants. This is an interesting finding in light of the findings from the current study regarding social anxiety and initiative taking. These findings suggest that internalizing problems and social anxiety play a big role in the lives of young adults with ASD, and therefore in the way they feel about their lives. Young adults with ASD having internalizing problems in higher education puts them at risk for not being able to finish their studies, because of the comorbid problems. A young adult wrestling with depressive symptoms next to ASD symptoms may have extra trouble coping with demands like homework, compulsory class attendance and deadlines.

For clinical purposes, some practical implications of the findings will be provided here. First, targets for intervention for this group of young adults with ASD should focus on desensitization of social fears. Better understanding of social incentives, or cognitive processing, may lead to less tension and stress. Successful experiences in social situations may then lead to more initiative taking and self-confidence in young adults with ASD. Secondly, screening procedures for young adults with ASD while being diagnosed or entered in a special housing project like the Stumass project should aim at localizing specific problems like internalizing problems, difficulties in cognitive processing, and coping with stress. Individuals
with ASD should be treated for their internalizing problems, since these problems have a significant effect on their quality of life.

Some limitations may restrict the findings in this study. First, the QoL-Q has not been proven valid in Dutch samples for individuals with ASD to date. The questionnaires might not have been suitable for these young adults with ASD, since they were not made for this specific group. It was intended to overcome this problem by adding a control group to the study. Second, the young adults with ASD who participated in this study may have higher or lower levels of subjective quality of life than the students enrolled in the Stumass project that decided not to participate and young high-functioning adults with ASD not enrolled in the Stumass program. So, generalizations could be difficult since this is a very specific group of students with ASD. However, the power of this study is large given the high number of participants in the ASD group, and some young adults with ASD only just entered the Stumass program while participating in this study, so findings can be generalized to the larger population of students with ASD. In future studies, questionnaires may be adapted for this specific group of young adults with a pervasive developmental disorder to prevent drop-out.

Conclusions

Individuals with ASD have difficulties with transitions throughout their lives. Appropriate care for young adults with ASD would not only prevent educational failure and social marginalization, but it would also prevent the loss of talent. The findings in this study suggest that young adults with ASD have lower subjective quality of life compared to their peers and that extra attention should be given to internalizing problems, social anxiety, and regulation skills or executive functioning. Targeting these specific problems in young high-functioning adults with ASD will
make them more confident and enhance their competencies in daily life and in higher education.

References


