

Health-related quality of life in adolescents and young adults with high functioning autism-spectrum disorder

Gesundheitsbezogene Lebensqualität bei Jugendlichen und jungen Erwachsenen mit Autismus-Spektrum-Störung

Abstract

Aim: Over the last years, health-related quality of life (HRQOL) has emerged as an important measure not only in somatic medicine but also in psychiatry. To date, there are only few reports on HRQOL in patients with autism-spectrum disorder (ASD). This study aimed at studying HRQOL in ASD patients with an IQ >70, using a self-report HRQOL questionnaire with cross-cultural validity.

Methods: In this cross-sectional study, twenty-six male adolescents and young adults with the diagnosis of Asperger Syndrome, high functioning autism and atypical autism were evaluated, using the German version of the WHOQOL-BREF HRQOL questionnaire.

Results: Mean WHOQOL-BREF global scores were 60.6 (SD \pm 26.1), mean WHOQOL-BREF subscale scores were 70.1 (SD \pm 19.1) for the domain "physical health", 61.5 (SD \pm 21.9) for the domain "psychological health", 53.8 (SD \pm 23.5) for the domain "social relationships" and 67.9 (SD \pm 17.4) for the domain "environment". Compared to a reference population of healthy controls, our sample scored significantly lower in three of four WHOQOL-BREF domains. In comparison to a reference sample of individuals with schizophrenia spectrum disorder (SSD), HRQOL of our sample was significantly better in all domains except for the "social relations" domain. There was a significant association between HRQOL and the Vineland Adaptive Behavior Scales domain "daily living skills", but not with age, IQ, or ADOS-G summary scores.

Conclusion: Overall self-reported HRQOL in patients with high functioning ASD seems to be lower than in healthy individuals, but better than in patients with SSD. Also, higher HRQOL was associated with better daily living skills. This interrelationship should especially be accounted for in the design and application of treatment programmes for individuals with ASD, as it is of importance for the level of self-perceived HRQOL.

Keywords: autism, autism-spectrum disorder, health-related quality of life, schizophrenia-spectrum disorder, WHOQOL-BREF

Zusammenfassung

Zielsetzung: In den vergangenen Jahren hat sich die gesundheitsbezogene Lebensqualität (gbLQ) als wichtige Zielgröße nicht nur in der somatischen Medizin, sondern auch in den psychiatrischen Fächern etabliert. Bisher liegen nur wenige Studien zur gbLQ von Patienten mit Autismus-Spektrum-Störung (ASS) vor. Ziel dieser Studie war die Erfassung der gbLQ von Patienten mit ASS mit IQ >70 aus Patientenperspektive unter Verwendung eines international eingesetzten und validierten gbLQ-Instruments.

Methodik: 26 männliche Jugendliche und junge Erwachsene mit den Diagnosen Asperger-Syndrom, High Functioning Autismus oder Atypischer Autismus wurden in einem querschnittlichen Design mithilfe der deutschen Version des WHOQOL-BREF, einem Fragebogenverfahren zur Erfassung der gbLQ, untersucht.

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Ergebnisse: Der durchschnittliche Wert im WHOQOL-BREF betrug 60,6 (SD \pm 26,1). Die mittleren Werte in den WHOQOL-BREF-Subskalen waren 70,1 (SD \pm 19,1) für die Domäne „Körperliche Gesundheit“, 61,5 (SD \pm 21,9) für die Domäne „Psychische Gesundheit“, 53,8 (SD \pm 23,5) für die Domäne „Soziale Beziehungen“ und 67,9 (SD \pm 17,4) für die Domäne „Umwelt“. Verglichen mit Gesunden lagen die Ergebnisse der von uns untersuchten Population in drei von vier WHOQOL-BREF-Subskalen signifikant niedriger. Im Vergleich zu Patienten mit Schizophrenie-Spektrum-Störung (SSS) war die gbLQ der von uns untersuchten Population in fast allen Domänen (Ausnahme: Domäne „Soziale Beziehungen“) besser. Es zeigte sich eine signifikante Assoziation zwischen gbLQ und der Domäne „Lebenspraktische Fertigkeiten“, jedoch nicht mit Alter, IQ oder den Summenwerten im ADOS-G.

Fazit: Die gbLQ von Patienten mit hoch funktionalem ASS scheint niedriger als die gesunder Menschen, jedoch besser als die von an SSS Erkrankten zu sein. Vor dem Hintergrund der Assoziation von guten lebenspraktischen Fertigkeiten und besserer gbLQ sollten erstere bei der Entwicklung von Therapieprogrammen berücksichtigt werden, da sie anscheinend für das Mass an selbstbeurteilter gbLQ von Bedeutung sind.

Schlüsselwörter: Autismus-Spektrum-Störung, gesundheitsbezogene Lebensqualität, Schizophrenie-Spektrum-Störung, WHOQOL-BREF

Background

Autism spectrum disorders (ASD) are complex neurodevelopmental disorders characterized by qualitative impairments in three domains: Social interaction, communication and repetitive, stereotyped behaviour. ASD can have a detrimental impact on the well-being of affected individuals: Studies show an increased prevalence of psychiatric comorbidity such as social anxiety disorder, depression, attention-deficit/hyperactivity disorder (ADHD) and oppositional-defiant disorder (ODD) [1], [2], [3] and there is also data documenting an increased burden upon the families of individuals with ASD [4], [5], [6]. The psychosocial impairment of individuals with ASD is also well-known [7]: Affected persons regularly experience severe difficulties especially in interpersonal relationships and often appear as solitary “cranks”, who tend to choose non-mainstream vocations, combined with frequent change of jobs. Furthermore, recent studies confirm, that as well in people with ASD and good cognitive abilities, their adaptive skills significantly stay behind their cognitive level, thus leading to considerable impairment in everyday life [8].

Over recent years, Health-related quality of life (HRQOL) has increasingly been considered as a relevant endpoint and outcome criterion in evaluating the effects of medical intervention and prevention measures. It resembles a multidimensional construct which includes emotional well-being, interpersonal relations, material well-being (such as financial status, employment and housing), personal development (i.e. education, personal competence and performance), physical well-being (health, activities of daily living and leisure), self-determination, social inclusion and human and legal rights [9]. Beside the individual's perception (self-reported HRQOL), HRQOL

studies also include external (e.g. parents' or teachers') perspectives (proxy-reported HRQOL) as well as objective indicators. While some studies on HRQOL in adults with ASD have been published in recent years [10], [11], [12], [13], [14], [15], many of the participants of these studies had severe intellectual disabilities. Only few studies used standardized, cross-culturally evaluated psychometric instruments with self-report versions and there is no study yet concerning a German population.

The psychosocial impairment in individuals with ASD is well established [16], [17], even in persons with good intellectual abilities [18], [19]. Studies in this population which focused on the social outcome (mostly defined by objective factors like educational attainment, independence or employment [20], [21], [22]) have demonstrated heterogenous findings, ranging from good to very poor outcomes [23]. Beyond studies that focus on objective outcomes, studies on the subjective contentment of patients are equally important. In current clinical psychiatric research, the subjective perspective on outcomes is of high relevance in the measurement of quality of life [24], [25]. Also, until now, only little is known about the relationship between potential influencing factors and outcome [26].

For these reasons, the aim of the present study was to evaluate HRQOL in young German adults with high functioning ASD, using the German version of a well-validated generic self-report HRQOL questionnaire: the World Health Organisation Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF) [27]. Additionally, a possible association between self-reported HRQOL and potential influencing factors like IQ, results in ASD-specific diagnostic tests and adaptive behaviour was analysed. The rationale for this was the hypothesis that e.g. a higher IQ and better adaptive behaviour might lead to better social relation-

Table 1: Review of HRQOL studies in individuals with ASD

	Author	Sample	Questionnaire/Method	Results
Proxy-reported HRQOL	Saldaña et al. (2009) [10]	- 74 adults with AS, ASD and PDD - Mean age: 24.6 [SD 5.8, range 18.4–40.1] yrs	- Items from the Comprehensive Quality of Life Questionnaire (ComQoL) - HRQOL assessment by family	- HRQOL results only available for 25 individuals - Objective HRQOL outcome was extremely poor - Objective indicators of HRQOL such as social networks differ highly from subjective estimation
	Gerber et al. (2008) [12]	- 30 adults with PDD in different residential settings - Mean age: 39.9 [range 24–62] yrs	- Inventaire de Qualité de Vie en Milieu Résidentiel (IQVMR) - HRQOL assessment by family and staff	- HRQOL was good - Staff-reported HRQOL was higher than family-reported HRQOL
	Eaves & Ho (2008) [11]	- 48 adults with ASD - Mean age: 24 [range 19–31] yrs - IQ >50 in 50% of participants	- Telephone interview - Global outcome score (1–10 scale, higher values = better HRQOL)	- Parents rated HRQOL 5.2 - Combination of IQ and autistic symptoms score at age 11 predicted outcome
Self-reported HRQOL	This study	- 26 adults with ASD - Mean age: 21.6 [SD 3.4, range 17–28] yrs - Mean IQ: 99.3	World Health Organisation Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF)	- HRQOL in all domains lower than healthy reference sample - Association between HRQOL and daily living skills, but not between HRQOL and IQ or severity of autism
	Jennes-Coussens et al. (2006) [13]	- 12 adults with AS - 13 healthy adults (CG) - Age range: 18–21 yrs	World Health Organisation Quality of Life Assessment-Brief Version (WHOQOL-BREF)	Lower social and physical HRQOL in the AS group
	Renty & Roeyers (2006) [14]	- 58 adults with ASD - Mean age: 28.3 [range 18–53] yrs - Mean IQ: 103	Quality of Life Questionnaire (QOL-Q)	Association between HRQOL and social support, but not between HRQOL and severity of autism symptoms
	Persson (2000) [15]	- 7 male adults with autism - Mean age: 32.3 [range 20–50] yrs - IQ: mental retardation	- Adult and Adolescent Psycho-Educational Profile (AAPEP) - Longitudinal study evaluating the TEACCH program	TEACCH increases independence and other skills, indicating improved quality of life

Abbreviations: AS=Asperger syndrome, ASD=Autism-spectrum disorder, CG=Control group, HRQOL=Health-related quality of life, PDD=Pervasive developmental disorder

ships and better coping with ASD-caused limitations, thus positively influencing HRQOL. In respect to the results of previous studies (see Table 1), we hypothesized that – in comparison to healthy controls – self-reported HRQOL in individuals with high-functioning ASD is lower, especially in the domain of “social relationships”. Furthermore, it was hypothesized that HRQOL in individuals with ASD was impaired comparable to individuals with severe psychiatric disorders like schizophrenia.

In respect to the relatively small sample size we examined the relationship between HRQOL and influencing factors in an exploratory data analysis.

Methods

Participants

For this cross-sectional study, we contacted 46 adolescents and young adults with the diagnosis of either Asperger Syndrome (AS), high functioning autism (HFA) or atypical autism (AA) (all male, mean age: 21.2 years) by mail during June 2008. Twenty-six individuals participated in the study (mean age 21.6, range 17–28 years). All patients had been extensively diagnosed at the outpatient clinic of our institution (department of child and adolescent psychiatry, tertiary referral centre for ASD) in the previous seven years.

The diagnostic classification was made according to the standardized criteria of the International Classification of Diseases, 10th revision (ICD-10) and comprised diagnostic categories F84.0, F84.1 and F84.5. The expression of autistic symptoms was assessed by the German version of the Autism Diagnostic Observation Scale-Generic (ADOS-G) [28] and a semi-structured ASD-specific parent interview (German version of the Autism Diagnostic Interview-Revised (ADI-R) [29]. The ADOS-G is a semi-structured, standardized assessment of communication, social interaction, play, and imagination designed for use in diagnostic evaluation of individuals with a suspected diagnosis of ASD. The ADOS-G encompasses four modules with different activities to observe behaviour in participants of particular developmental and language levels: ranging from those without expressive language to verbally fluent, from profound mental retardation to cognitively high-functioning children and adults. Activities are designed to provide planned opportunities to elicit autistic behaviors. The ADOS-G has shown an inter-rater reliability of 0.84 and both a sensitivity and specificity of 0.95. In this study, only modules 3 and 4 were used. The ADOS-G was administered by an examined clinician (IKB) who had completed research training and met standard requirements for research reliability [30]. Comorbidity was diagnosed by the attending psychologist/physician according to the ICD-10 criteria using the German version of the diagnostic interview of psychiatric disorders for children (Kinder-DIPS) [31]. The Kinder-DIPS is a structured interview that enables both lifetime and current diagnoses of externalizing behavior disorders, elimination

disorders, depressive disorders, anxiety disorders, phobias, OCD, eating disorders, specific learning disabilities according to DSM-III-R/ICD-10. The interview is available both as a parent/proxy version and as a self-report version. Kappa coefficients are between 0.60 and 0.82 and Y-coefficients range from 0.74 and 0.94, while re-test reliability (Cohen’s Kappa) lies between 0.50 and 0.89. Until now, the Kinder-DIPS has not been employed in studies in children with ASD. In this study, the Kinder-DIPS was used to make lifetime diagnoses. Additionally, in one patient the clinical diagnosis of Tourette’s syndrome was made according to ICD-10 diagnostic criteria. The adaptive behaviour was assessed by the Vineland Adaptive Behavior Scales (VABS) [32]. This is a 297-item interview-based tool assessing adaptive behaviour in three domains: communication (receptive, expressive and written), daily living skills (personal, domestic and community), and socialisation (interpersonal relations, play and leisure time and coping skills). The VABS is sensitive to the severity of impairment in ASD [7], [8], [33]. For intellectual testing, the respective age-appropriate German version of the Wechsler Intelligence Scales was applied [34], [35].

Materials

The World Health Organisation Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF) has been designed for the assessment of subjectively perceived HRQOL in adults with physical or mental disorders and in healthy adults. The instrument can be used for research or for quality assurance in outpatient, day-care or inpatient care settings. The WHOQOL-BREF is only available as a self-report version. HRQOL is evaluated in the following domains: “Physical health” (e.g. physical pain, medical treatment), “psychological health” (e.g. negative feelings, ability to concentrate), “social relationships” (e.g. social support, personal relationships) and “environment” (e.g. access to health services, transport). WHOQOL-BREF results are expressed on the following scores: an overall score (range 0–100, with higher numbers indicating better HRQOL) and domain scores (range 0–100; with higher numbers indicating better HRQOL). For the German version of the WHOQOL-BREF, age-specific values from a reference sample (n=2055) are available for an age range from 18 to 85 years. Worldwide field studies and clinical studies have shown that the questionnaire differentiates very well between individuals with and without impaired health and between individuals with physical and mental health problems (e.g. schizophrenia, depression). The internal consistency (Cronbach’s Alpha) for the WHOQOL-BREF subscales ranges from $\alpha=0.57$ to $\alpha=0.88$ [27].

For the exploratory analysis of the influencing factor “severity of autistic symptoms”, the ADOS data from modules 3 and 4 were taken together (“emphatic or emotional gestures”, “communication of own affect” and “responsibility” were omitted, because they are included

in module 4 only). A sum score of all ADOS-items (not only algorithm items) was then calculated.

Procedure

A copy of the German version of the WHOQOL-BREF questionnaire, a sociodemographic data form and an informed consent form were sent to the patients by mail, accompanied by a letter explaining the purpose of the study.

Individuals willing to participate in the study sent back the completed questionnaires and forms to our clinic. The study was approved by the Institutional Review Board. Patients gave written informed consent for study participation.

Statistics

For statistical calculation, the Statistical Package for Social Sciences Version 17.0 (SPSS Inc., Chicago, IL, USA) was used. The tests were carried out using a significance level of 0.05 and two-tailed tests. Overall scores and domain scores for the WHOQOL-BREF were calculated according to the WHOQOL-BREF manual [27]. Differences between the means of the ASD sample and the healthy individuals/SSD reference sample were calculated using t-tests for independent samples. To estimate which variables predict HRQOL best, Pearson's correlation coefficient and a linear regression analysis with backward selection were calculated, complemented by Durbin-Watson testing. The WHOQOL-BREF summary score and the domain scores were used as dependent variable, while the full scale IQ, severity of autistic symptoms (ADOS-G summary score) and the adaptive behaviour (VBAS) were used as predictor variables.

Results

Study sample

Of 46 individuals contacted by mail, 26 individuals participated in our study and sent back the WHOQOL-BREF questionnaires and the socio-demographic data form (e.g. placement, education, family status). The response rate was 57% (26/46). The group of non-participants had the following diagnoses: AS (n=10), HFA (n=8) and AA (n=2). There were no statistically significant differences between the participating and non-participating groups concerning age ($p=0.759$), IQ ($p=0.310$) or severity of autistic symptoms ($p=0.770$). Table 2 displays the sample characteristics.

Patients had been diagnosed with the following lifetime psychiatric comorbidities: Obsessive-compulsive disorder (n=7; 26.9%), depression (n=2; 7.7%), dysthymia (n=1; 3.8%), enuresis (n=2; 7.7%), attention-deficit/hyperactivity disorder (n=2; 7.7%), specific phobia (n=2; 7.7%), oppositional-defiant disorder (n=1; 3.8%) and Tourette's syndrome (n=1; 3.8%). Seven patients (26.9%) received

psychopharmacotherapy (substances: risperidone, olanzapine, methylphenidate, duloxetine).

WHOQOL-BREF

The WHOQOL-BREF results for our sample are displayed in Table 3.

The highest HRQOL score was reached in the domain "physical health", followed by the domains "environment" and "psychological health". The lowest HRQOL score was found in the "social relationships" domain. When comparing the WHOQOL-BREF scores of our sample to a reference population of healthy individuals (male, age: 18–25 years) [27], the scores of the ASD patients were significantly (all $p<0.001$) lower in the domains "physical health", "psychological health", "social relationships" and in the overall score (Table 3).

In comparison with a WHOQOL-BREF reference population with schizophrenia-spectrum disorders (SSD) [27], ASD patients rated their HRQOL significantly better in the "physical health", "psychological health" and "environment" domain. In the "social relationships" domain, there was no significant difference in WHOQOL-BREF scores between both groups. As demonstrated in Table 3, the domain "social relationships" is the most impaired WHOQOL-BREF domain in our sample.

Concerning potential influencing factors, there was no significant association between WHOQOL-BREF overall scores and full scale IQ ($r=0.087$, $p=0.680$), ADOS-G summary score ($r=0.175$, $p=0.403$), and VABS total score ($r=0.372$, $p=0.080$). A significant association was found between the VABS domain "daily living skills" and the WHOQOL-BREF scales "physical health" ($r=0.434$, $p=0.039$), "psychological health" ($r=0.452$, $p=0.030$) and WHOQOL-BREF sum score ($r=0.515$, $p=0.012$).

A linear regression analysis with stepwise backward selection, including ADOS-G summary score, VABS domains and full scale IQ, attained significant explanation ($F=7.444$, $p=0.004$) and accounted for a sufficient amount of explained variance ($R^2=0.427$, adjusted $R^2=0.369$). Table 4 presents the final model, in which only two of the five influence factors are included. The overall HRQOL score was best predicted by the VABS domain "daily living skills" ($p=0.002$) in combination with the amount of autistic symptoms (ADOS-G sum-score) ($p=0.028$).

In the final model with these two independent variables (VABS domain "daily living skills", ADOS-G sum-score), we found tolerances of 0.89 for both variables, thus excluding colinearity. Durbin-Watson testing was used to rule out autocorrelation ($d=1.8$).

No significant difference in overall HRQOL was found between participants which received psychopharmacotherapy (n=7) and those who did not (n=19) ($p=0.900$).

Table 2: Sample characteristics

Characteristics	No.	%	Mean	SD
Sex				
Male	26	100		
Female	0	0		
Age (yrs)				
			21.6 (range 17–28)	3.4
Best estimate diagnosis				
Asperger syndrome	14			
High functioning autism	8			
Atypical Autism	4			
IQ				
Verbal IQ			107.5	19.2
Performance IQ			90.6	18.9
Full scale IQ			99.3	17.7
Placement				
With parents/ relatives	19	73		
Institutional	5	19		
Independently	2	8		
Education				
Primary school	10	38		
Secondary school	12	46		
High school	4	16		
Employment				
Currently in school or training	8	31		
Currently employed	11	42		
Currently unemployed	7	27		
Family status				
Married/Close partnership	1	4		
No close partnership	25	96		
Psychopharmacotherapy				
Yes	7	27		
No	19	73		

Table 3: WHOQOL-BREF results (overall score and domain scores) of our sample in comparison with reference samples of healthy individuals and SSD patients

Domain	ASD patients			Healthy individuals (N=124)		SSD patients (N=98)	
	Mean	SD	Range	Mean	SD	Mean	SD
Physical health	70.1	19.1	10.7–92.9	87.2***	13.6	58.5**	17.7
Psychological health	61.5	21.9	8.3–87.5	79.1***	14.0	52.0*	19.5
Social relationships	53.8	23.5	0–91.7	74.9***	17.5	50.9	26.5
Environment	67.9	17.4	34.4–100	71.2	13.6	59.3*	18.8
Overall	60.6	26.1	0–100	75.5***	16.4	50.8	23.2

Annotations: ***: $p < 0.001$; **: $p < 0.01$; *: $p < 0.05$

Abbreviations: ASD=Autism-spectrum disorder, SSD=Schizophrenia-spectrum disorder

Table 4: Results of the linear regression analysis

Criteria variables	Dependent variable (WHOQOL-BREF overall score)	
	Beta	p
ADOS-G summary score	0.425	0.028
VABS domain score "daily living skills"	0.653	0.002

Discussion

The main finding of our study can be summarized as follows: Compared with young healthy adults, the HRQOL of adolescents and young adults with ASD appears to be lower. This result is in line with one of the few studies that include individuals with high-functioning autism [13]. In contrast, another comparable study found satisfying levels of HRQOL in a sample of 58 adults with high-functioning autism [14]. Albeit, they detected an association between HRQOL and social support that could not be replicated in our study.

Generally, the comparison of our results with other studies (Table 1) is hampered by the small number of studies on HRQOL in young adults with ASD. Moreover, there are considerable differences in patient population (e.g. diagnoses, mean age, age range, IQ, setting), design, treatment, HRQOL assessment (proxy vs. self-report) and outcome measures, which make a comparison difficult. The study best comparable to ours is the report of Jennes-Coussens et al. [13], who used the WHOQOL-BREF to evaluate young adults with Asperger syndrome and found lower HRQOL in the domains „social relationships“ and „physical health“, compared with healthy controls. Our findings are in line with theirs, but additionally show impairment for the domain „psychological health“ and the overall score. The detriment of the „social relationships“ domain reflects a core symptom of ASD, the qualitative impairment in social interaction. The impaired scores in the „psychological health“ domain, which encompasses items like negative emotions or the capacity to enjoy life, may reflect our sample's comorbid psychiatric disorders (e.g. depression). Rather unexpected are the low scores on the „physical health“ domain, as physical impairment is no key component of ASD. Here, it can be hypothesized, that the item composition of this domain, including items like „How satisfied are you with your ability to perform your daily living activities?“ or „How satisfied are you with your capacity for work?“ reflects not only physical health, but also the ability to participate in everyday life – which is certainly reduced in ASD patients [8].

When comparing our results with those of HRQOL studies in children with ASD, there are some similarities: Individuals with ASD seem to have lower HRQOL than healthy controls [36], [37]. In comparison with other psychiatric disorders, results are inconsistent: While Lee et al. found HRQOL in children with ADHD to be better than in those with ASD [36], Kamp-Becker et al. [37] found better HR-

QOL in children with ASD when compared to a sample of inpatient and outpatient children with Axis-I-psychiatric disorders [38].

Unfortunately, a direct comparison of HRQOL in children with ASD with HRQOL in young adults with ASD is not feasible, as there are no questionnaires which span the age range from childhood to adulthood. Therefore, it can only be speculated upon the relationship between those age groups in terms of HRQOL. On the one hand, it can be hypothesized that HRQOL in adults with ASD is lower than in children with ASD, as parental support decreases and impaired social skills (in contrast to healthy peers) might be perceived more intensively than in childhood. On the other hand, it can be assumed that – especially in well-fostered children – the fruits of social skills and behaviour training programs may be harvested in adulthood and thus lead to better HRQOL.

In the context of self-reported HRQOL, it has to be discussed how precise ratings are, as there may be a potentially limited ability of individuals with ASD to rate their HRQOL adequately: Several studies indicate a profound deficit in self representation in children and adolescents with ASD [39], [40], [41]. These impairments affect the identification of emotional states in other people as well as self-referential cognition [40], [42]. This lack of theory of mind might be an explanation for the discrepant results of self-report and proxy versions, as demonstrated by Johnson et al., who found youths with ASD to report significantly fewer autistic traits and more empathic features than their parents attributed to them [43].

However, while literature on this topic is still scarce, there are some hints that ASD patients have sufficient ability to rate their emotions appropriately. Hobson et al. argue, that the disability of self-reflection only concerns certain domains, e.g. children were found to be impaired in recognition and expression of embarrassment or shame, but were able to describe their own experiences of pride and (more rarely) guilt [44].

Finally, we did not find a significant association between IQ or ADOS-G scores and patients' HRQOL. The possible reasons for these findings – which are in line with those of Renty and Royers [14] – also point to some limitations of this report: The number of participants may have been too small for the detection of small and medium effects. Nevertheless, we found a significant correlation between HRQOL and the VABS domain „daily living skills“. This finding is of importance for therapeutic programmes and implies that – next to the autistic symptomatology – the daily living skills are of high relevance. The resulting autonomy in everyday life may be an important factor for

adults with high functioning ASD in respect to physical and psychological well-being.

There was no significant difference in HRQOL between individuals with and without psychopharmacotherapy. It can be hypothesized that especially patients with distinct psychiatric symptoms (negatively influencing HRQOL) have been prescribed medication. Under successful psychopharmacotherapy, symptoms should have improved, thus raising their HRQOL to a level equally to those who are not in need of medication.

Concerning the sample composition, there might have been a higher proportion of individuals with positively estimated HRQOL in the response sample, despite sociodemographic equivalence in comparison to the baseline sample.

ADI-R, ADOS-G and IQ data had been collected previous to this HRQOL study. As reports on stability of those data in the course of time are heterogeneous [23], [45], these data might not have reflected patients' current condition with highest precision and therefore might have caused imprecision in the calculations. Nevertheless, good daily living skills (as measured in the VABS) showed a predictive value for superior HRQOL in ASD patients.

Another possible limitation of our study lies in the psychiatric comorbidities in our sample, which may have influenced patients' HRQOL assessment. Then again, given the high rate of psychiatric comorbidity, our study population just represents the reality of psychopathology in ASD patients [1], [46].

Considering the clinical usefulness of HRQOL assessment in ASD patients, a main purpose could be longitudinal HRQOL measurement as a means to evaluate the effectiveness of therapeutic interventions. Additionally, high patient-reported HRQOL might help to explain lacking motivation for therapeutic interventions, as those patients do not feel the need to improve their (subjectively felt) satisfying condition [43].

Concerning future research directions in the field of HRQOL in patients with ASD, studies with larger samples, longitudinal design and more specifically designed psychometric instruments are required to evaluate HRQOL in this population comprehensively.

Conclusions

In our study, HRQOL in adolescents and young adults with ASD was lower than in healthy individuals and better than in patients with SSD. Also, higher HRQOL was associated with better daily living skills. This interrelationship should especially be accounted for in the design and application of treatment programmes for individuals with ASD, as it is of importance for the level of self-perceived HRQOL.

Notes

Conflicts of interest

None declared.

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