



# Quality of life in autism spectrum disorder

Mandy Roy<sup>1,2\*</sup> and Wolfgang Dillo<sup>1</sup>

\*Correspondence: [m.roy@asklepios.com](mailto:m.roy@asklepios.com)



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<sup>1</sup>Department of Psychiatry, Socialpsychiatry and Psychotherapy, Hannover Medical School, Hannover, Germany.

<sup>2</sup>Department of Psychiatry and Psychotherapy, Asklepios Klinik Nord, Langenhorner Chaussee 560, 22419 Hamburg.

## Abstract

**Background:** It is well known that individuals with autism spectrum disorders (ASD) show impairments in areas such as social interaction and flexibility and often are without employment and partnership. But little is known about their quality of life. Therefore it was aim of our investigation to find out how they sense their quality of life in adulthood.

**Subjects and Methods:** 32 adults with an ASD (18 female, 14 male adults, average age: 38.4 years) were asked about their quality of life via the 36 item short form health survey (SF-36). Mean values of our study-sample were compared to the reference mean values of the general German population.

**Results:** In our population study quality of life in adults with ASD was reduced in the sectors vitality, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning and mental health.

**Conclusions:** Our individuals with ASD show a global reduction in their sensed quality of life. This finding emphasizes the need for more therapeutic and integrative interventions supporting them.

**Keywords:** Autism spectrum disorder, Asperger syndrome, autism, quality of life

## Introduction

Autism Spectrum Disorders (ASD) are neurodevelopment disorders, that comprise impairments in social competence, communication and flexibility as well as special interests [1]. In the DSM-IV Asperger Syndrome (AS) is a subgroup of ASD, in contrast to childhood autism, in which symptoms have an onset prior to age 3 years and there is usually no clinically significant delay in language and cognitive development in AS [1]. According to the DSM-5 [2], individuals with an assured DSM-IV diagnosis of an AS shall now be classified as ASD. Prevalence of ASD is estimated to be approximately 0.76% [3] with a sex ratio of 3-4 males:1 female [4].

Social competence and flexibility are important qualities for succeeding both in private and professional life. Investigations have shown that many persons with ASD are without employment despite having a high-level school leaving certificate and completed training/university studies [5]. They often live without a partner and also suffer from psychiatric comorbidities such as depression and anxiety disorders [5]. These factors might lead to a dissatisfaction in individuals with an ASD. On the other hand it is well known, that special interests are of

great importance for persons with ASD also in adulthood [6] and maybe they largely support their subjective individual well-being, compensating the described deficits.

Thus, we do not know, how individuals with ASD sense their quality of life (QoL).

There don't exist a consistent concept of QoL, in some cases it is considered as a measure of well-being, in others it is used as an indicator of health [7]. According to the World Health Organization (WHO), QoL is defined as the individual's perception of one's position in life in the context of the culture and value system, and in relation to one's goals, expectations, standards and concerns [8]. Dijkers emphasizes the idea of QoL as life satisfaction [9]. Malkina-Pykh and Pykh define QoL as a measure of how positively or negatively we perceive our lives [10], thereby they propose the three essential domains of built environment (where one lives, e.g. house, surrounding, infrastructure), social environment (friends, family, education level, health) and economic environment including money and employment-situation.

Nevertheless, despite the heterogeneity of definition, there seems to be the agreement concerning QoL, that it is subjective

and can only be understood from an individual perspective [11].

There are only few studies about how adult persons with autism value their QoL. Potvin et al. [12] found a poorer QoL concerning physical and psychosocial health in children with high-functioning autism compared to typically developing peers, both rated by themselves and by their parents. Kamp-Becker et al. investigated the QoL in 42 predominantly male children and adolescents and showed that it was lower than in healthy controls [13]. Thereby self-reported scores were significantly higher than proxy-reported scores by parents. A study in young Taiwanese adults with ASD demonstrated lower scores in QoL concerning physical health, psychological health as well as in social relationships and showed lowest quality of life in the social relationship domain [14]. Another investigation in adolescent females with ASD showed a lower QoL as compared to their typically developing peers [15]. Van Heijst and Geurts conducted a meta-analysis about studies of QoL in autism and also investigated it in a sample of 24 elderly people with autism (53-83 years) [16]. They ascertained a reduced QoL in individuals with autism including their own sample in elderly age, but most other study-groups were teenagers or young twens. Pisula et al. [17] showed a negative correlation between QoL and stronger autistic traits in a non-clinical sample of 154 adults aged 19-38 years.

Thus it was our aim to investigate the QoL in adults with ASD with a broad range of age. We wanted to find out if their QoL is also sensed as reduced as in children and adolescents. This is important for understanding, how they subjectively sense their living situation, if they suffer from the negative circumstances of their life as described above (e.g. unemployment, no partnership) or if they are satisfied in their life due to having another weighting of values, for example enjoying their special interests. Understanding their subjective feeling of well-being is an important first aspect for an approach of supporting them according to their real needs.

## Methods

### Subjects

We included 32 adults with a diagnosis of ASD (18 female, 14 male adults, range of age: 22- 50 years, mean: 38.4 years, standard deviation: 7,9 years), who were recruited from our German outpatient clinic for ASD. Their characteristics are listed in [Table 1](#).

### Assessment of ASD

ASD in adulthood was diagnosed using a self-developed, semi-structured interview (Diagnostic interview: Asperger syndrome in adulthood) [5] that thoroughly assessed the criteria for AS in patients according to DSM-IV criteria and was used in previous studies [5,6,18,19]. According to the DSM-5 [2], individuals with an assured DSM-IV diagnosis of an AS shall now be classified as ASD.

After a general section focusing on medical anamnesis (somatic, psychiatric, and social histories, including childhood development), the interview continues with a special section

**Table 1. Characteristics of ASD-patients.**

No.	Sex	Age	AQ	EQ
1	female	35	47,00	16,00
2	female	32	38,00	11,00
3	female	46	44,00	20,00
4	female	46	46,00	11,00
5	female	31	46,00	11,00
6	female	22	39,00	20,00
7	female	37	42,00	11,00
8	female	46	46,00	24,00
9	female	39	44,00	3,00
10	female	50	46,00	10,00
11	female	45	39,00	27,00
12	female	28	47,00	6,00
13	female	49	43,00	10,00
14	female	29	43,00	2,00
15	female	45	42,00	9,00
16	female	40	33,00	27,00
17	female	50	39,00	27,00
18	female	29	43,00	10,00
19	male	38	42,00	9,00
20	male	29	38,00	8,00
21	male	39	39,00	14,00
22	male	44	36,00	17,00
23	male	28	34,00	7,00
24	male	46	33,00	19,00
25	male	49	34,00	20,00
26	male	45	33,00	22,00
27	male	43	39,00	15,00
28	male	42	33,00	25,00
29	male	31	42,00	15,00
30	male	34	44,00	7,00
31	male	37	47,00	14,00
32	male	25	43,00	7,00

involving AS that includes the following items with respect to childhood and adulthood: social interaction and communication (e.g. friendships with/relationship to/interest in peers, and being a loner and suffering from loneliness); special interests (e.g. spending leisure time, and interest in specific objects/topics); stereotypic behavior (e.g. rituals, and reaction towards disturbances of rituals); and other characteristics (e.g. clumsiness, and sensitivity towards noises/smells/tactile stimuli). Additionally, eye contact, mimicking expressions, speech melody, "mirroring" of affections, and clumsiness were observed during the interview. The interview was conducted by the same experienced investigator and had a duration of approximately 90 minutes. If available, diagnosis of ASD was complemented by information from personal/telephone interviews, or in written form from observers during childhood and/or adulthood, such as partners, friends, parents, or siblings. In some cases, school reports were consulted. The diagnosis of ASD was only confirmed if DSM-IV criteria were

clearly fulfilled based on clinical judgment and available information during the interview.

Additionally, we used the two self-rating scales “Autism-spectrum quotient” (AQ) [20] and “Empathy quotient” (EQ) [21]. The AQ is a scale for quantification, in which the score of a person is assessed on a continuum from normality to autism; a higher score indicates more pronounced autistic traits. The EQ is a scale for estimating an individual’s ability to empathize, thereby a higher score indicates stronger empathy. Baron-Cohen suggested a cut-off of  $\geq 32$  points for the AQ and  $\leq 30$  points for the EQ. In our sample of adults with ASD all scored above the cut-off of the AQ and below the cut-off of the EQ.

No adult with ASD had a mental retardation, as tested by a German multiple-choice word recognition test for the measurement of intelligence (“Mehrfachwahl-Wortschatz-Intelligenztest MWT-B”, Lehrl 1993).

All participants gave informed consent after the procedure had been explained. Approval for this study was given by the Ethics Committee of Hannover Medical School.

### Questionnaire exploring Quality of life: SF-36

The 36 item short form health survey (SF-36) [22] is a frequently applied disease-unspecific self-reporting measure of quality of life regarding the previous 4 weeks. It comprises the 8 domains:

- vitality: rating concerning feelings of vitality and energy versus feeling tired and exhausted.
- physical functioning: extent of impairments in physical activities such as self-supply, walking, climbing up-stairs or stooping and lifting things.
- bodily pain : extent of bodily pain and its influence concerning daily activities.
- general health perception: rating of the own healthiness including the current condition, expectations concerning the future and resilience.
- physical role functioning: extent of impairments due to physical functioning concerning work and daily activities, leading to difficulties in managing activities.
- emotional role functioning: extent of impairment in daily

activities caused by emotional problems, such as being insufficient or less accurate.

- social role functioning: extent of impairment in social activities caused by physical or emotional problems.
- mental health: mental health including mood, fears and emotional control.

Answers are graded into a score of 2-6 options. Scores of each domain are added, several items have to be reversed before. Higher scores indicate a better sensed health-state. For comparisons between different populations, scores are then transformed into a scale value from 1-100. Reference scale values of the general German population exists.

### Data analysis

Mean values in every scale of the SF-36 were computed, the descriptive overview is listed in the results-section. Mean values of our study-sample with ASD were compared to the reference mean values of the general German population, differences were analyzed via T-Test. Analyses were performed using the software SPSS (Version 23.0 for Windows; IBM SPSS). Statistical significance was defined by a p-value of .05.

### Results

There were no significant differences between ASD-patients and the general German population concerning physical functioning. In the section bodily pain ASD-patients showed a lower functioning-value compared to the general German population. Physical role functioning, general health perception, vitality, social role functioning, emotional role functioning and mental health were highly significant lower in ASD compared to the German sample.

Mean values of each scale of the SF-36 of ASD-patients and the general German population as well as p-values of T-Tests are listed in **Table 2**.

Results of our investigation are also demonstrated in **Figure 1**.

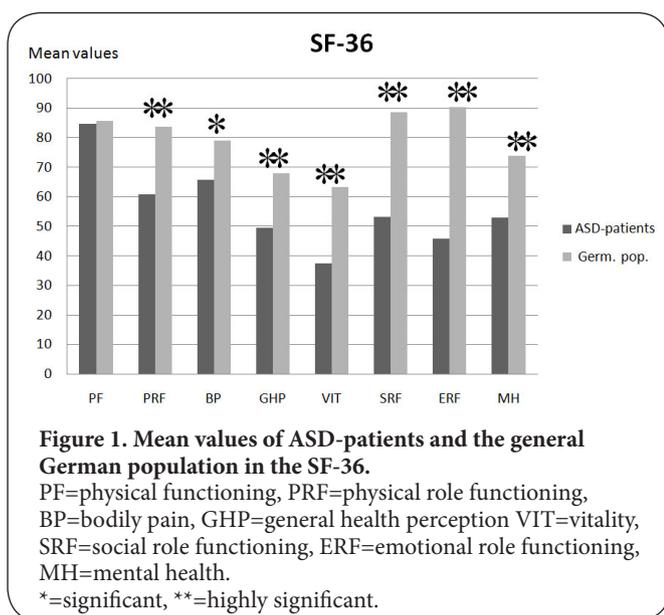
### Discussion

Several studies have described a reduction of QoL in children and young adults with ASD [12,14]. In this study we investi-

**Table 2. Means and standard deviations (SD) of each scale of the SF-36 of ASD-patients and the general German population.**

SF-36	ASD-patients			General German population			p-value
	n	mean	SD	n	mean	SD	
Physical functioning	32	84.69	13.79	2886	85.71	22.1	0.79
Physical role functioning	32	60.95	42.09	2856	83.7	31.73	<0.001
Bodily pain	32	65.74	29.47	2905	79.08	27.38	0.006
General health perception	32	49.41	22.33	2859	68.05	20.15	<0.001
Vitality	32	37.34	19.79	2876	63.27	18.47	<0.001
Social role functioning	32	53.13	28.39	2911	88.76	18.4	<0.001
Emotional role functioning	32	45.82	41.26	2855	90.35	25.62	<0.001
Mental health	32	53.00	21.84	2871	73.88	16.38	<0.001

Higher scores indicate a better sensed health-state. In the last column p-values of a t-Test are listed.



gated out how 32 adults with an ASD with a broad range of age (22-50 years) sense their QoL. For this purpose we used the 36 item short form health survey [22].

First, it is an important result that QoL seems to be globally reduced in all sectors in patients with ASD, except in physical functioning. This could be a hint for a relatively high suffering in their everyday life.

Because of the typically impaired social interaction in ASD [1] it is obvious that sectors concerning social interaction and social competence are affected, such as social role functioning and emotional role functioning. Accordingly it could have been expected that our individuals recognize a great impairment in these areas. It is an important finding of our study, that individuals with ASD sense these impairments in a strong way as a reduction of QoL.

This may additionally contribute to their reduced mental health. But also common psychiatric comorbidities, such as depression and anxiety [5] can affect their mental health and worsen their QoL. Nonetheless, the finding of their low state of mental health emphasizes the need for sufficient therapeutic approaches.

Individuals with ASD seem to suffer from a reduced sensed physical functioning, too. It remains unclear, if this is a direct result of a physical impairment or an indirect consequence of the social and emotional suffering. There are some physical specifics that often occur in autism. They comprise motor impairment, such as hypotonia, apraxia [23] or reduced gross and fine motor skills [24] as well as gastrointestinal disturbances (diarrhea, constipation) and sensory processing problems (sound sensitivity, no sensitivity to pain) [25]. Thus, due to such phenomenons, individuals with ASD may feel impaired in their everyday physical functioning. Nevertheless, according to psychosomatic concepts [26], mental conflicts

can lead to physical reactions, too. Their impairments in social interactions can be reason for psychological stress in patients with ASD and therefore also physical impairments could develop. Maybe both factors contribute to the sensed reduction in physical functioning.

Our investigated individuals with AS also showed a reduced functioning due to bodily pain. A hyposensitivity to pain in persons with an ASD was frequently postulated, but more recent studies found no deviation in pain perception and some even showed a greater pain sensitivity [27-29]. McElhanon et al. for example found higher rates of gastrointestinal pain in autistic children [30]. An investigation of behavioral, vegetative and biochemical reactions towards a venepuncture in children with and without ASD revealed an enhanced heart rate and elevated plasma beta-endorphin despite a reduced behavioral reaction in autistic children compared to normotypic children, indicating a different mode of pain expression rather than an analgesia [31]. Our results could also be a hint for a greater pain sensitivity in some ASD-patients.

The low mean values in general health perception and vitality in our individuals with ASD may be a consequence of the already mentioned reductions in their physical and mental state and reflect once more the global extent of their impairments.

As explained in the introduction, the WHO defines the QoL as the individual's perception of one's position in life in the context of the culture and value system, and in relation to one's goals, expectations, standards and concerns [8]. Thus, our individuals with ASD obviously perceive their own position in their life as not satisfying and not fulfilling their goals and expectations.

According to this, QoL does not seem to improve across the lifespan of autistic individuals. As it is reduced in childhood and adolescence, it is still low in adulthood. Therefore living conditions for adults with ASD do not appear to be more comfortable, the demand for therapeutic support is obvious. Gal et al. could show that an intense preparation for the vocational world by a training with photography and a practical training period improved the perceived QoL in young adults [32]. After participating in a group cognitive behavioral therapy (CBT) or group recreational activity with 36 weekly 3-h sessions, adults with ASD also reported an increased QoL [33]. CBT included the five elements: structure, group setting, psycho-education about ASD, social training (e.g. practicing phone calls) and cognitive behavioural techniques (e.g. role-playing). Recreational activity intervention group comprised activities, participants would like to engage in, e.g. visiting museums or cinema.

### Limitations of the study

First, the results of our study are limited by the small number of participants.

In this study we still applied the DSM-IV criteria of an Asperger Syndrome and talk of an ASD because, according to

the DSM-5, individuals with an assured DSM-IV diagnosis of an AS shall now be classified as ASD [2].

We did not use the widespread diagnostic instruments ADI-R [34] and ADOS [35]. The ADI-R is based on information from parents concerning the childhood of the patients - but parents may not be available or adults do not wish to involve them. In agreement with Joshi et al. [36], we gave priority to consideration of the DSM- criteria via interview and clinical observation.

## Conclusions

QoL in adult individuals with AS is not only reduced in emotional and social areas, but also in those concerning physical well-being. Thus QoL seems to be globally reduced, reflecting the extent of suffering in ASD and emphasizing the need for therapeutic and integrative interventions.

## Competing interests

The authors declare that they have no competing interests.

## Authors' contributions

Authors' contributions	MR	WD
Research concept and design	✓	✓
Collection and/or assembly of data	✓	✓
Data analysis and interpretation	✓	✓
Writing the article	✓	✓
Critical revision of the article	✓	✓
Final approval of article	✓	✓
Statistical analysis	✓	✓

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