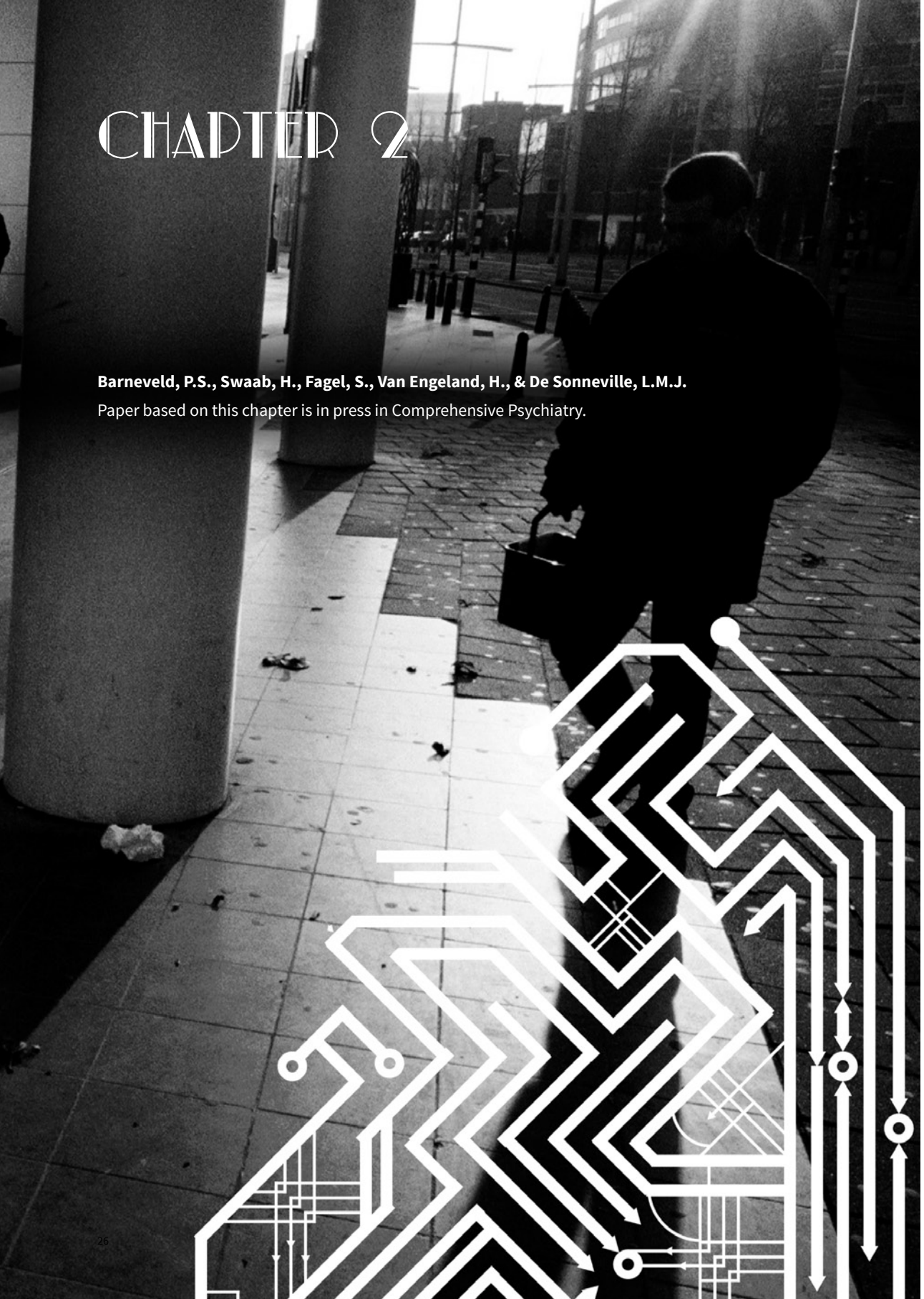
Growing up with autism spectrum disorders: outcome in adolescence and adulthood

Barneveld, P.S.



CHAPTER 2

Barneveld, P.S., Swaab, H., Fagel, S., Van Engeland, H., & De Sonneville, L.M.J.

Paper based on this chapter is in press in Comprehensive Psychiatry.

Quality of life: A case-controlled long-term follow-up study, comparing young high-functioning adults with autism spectrum disorders with adults with other psychiatric disorders diagnosed in childhood.

Abstract

Background: Long term outcome in childhood autism spectrum disorders (ASD) was evaluated by studying quality of life (QoL) in young adulthood in comparison to the outcome of other child psychiatric disorders.

Methods: In this follow-up study, objective and subjective QoL of 169 high-functioning (IQ>70) adults with ASD (19 to 30 years) was contrasted with QoL data of age matched adults diagnosed with attention deficit/hyper-activity disorder (*N*=85), disruptive behaviour disorders (*N*=83), and affective disorders (*N*=85) diagnosed during childhood. The mean follow-up period of the ASD patients was 13.9 years. Objective QoL included marital status, living arrangements, level of education, employment, and usage of mental health care. Subjective QoL included satisfaction concerning living arrangements, work or education, physical condition, partner relationship, social relation-ships, state of mind, and future perspective.

Results: QoL was more compromised in adults diagnosed with ASD in childhood than in adults with other psychiatric disorders in childhood. A relatively large proportion of the adults with ASD were single, few lived with a partner or a family and many of them were institutionalized. Adults with ASD had lower educational levels, relatively few had paid employment and many were social security recipients, as compared to the other psychiatric patients. In case the adults with ASD used medication, 47% used anti-psychotics. Re-garding the subjective QoL, the adults with ASD were less satisfied about their work or education, partner relationship, and future perspective than the other groups. Even when highly educated adults with ASD were compared to highly educated adults diagnosed with other childhood disorders, the QoL appeared to be more disadvantageous in adults with ASD.

Conclusion: Many studies have shown that QoL is threatened in psychiatric patients, but findings of this study indicate that young high-functioning adults diagnosed with ASD in childhood are at relatively high risk of poor QoL compared to other childhood psychiatric disorders.

Introduction

Children with autism spectrum disorders (ASD) are characterized by marked impairments in social interaction and communication as well as by restricted interests and repetitive behaviour. [1] These deficiencies increasingly hamper daily life functioning as demands for social relationships and independent living become larger and more prominent when growing older. [2] Reviews [3-6] of functioning in adulthood indicate that the prognosis of ASD is generally poor, albeit considerable heterogeneity in social outcomes. A minority of individuals with ASD live independently, few individuals have social and intimate relationships, and education and employment levels are low, even when general intelligence is within the normal range. [3-6] The majority of studies examining the outcome of childhood ASD, have compared the quality of life (QoL) of individuals with ASD to normally developing individuals [e.g.,7], or made comparisons between different subtypes of ASD. [e.g.,8,9] Whereas social development in ASD is specifically challenged, only a few studies have studied whether the outcome of individuals with ASD is less favourable than that of individuals with other child psychiatric disorders. A cross-sectional study of Lee et al examined QoL in a national American survey of 483 children with autism in comparison to the well-being of 6.319 children with attention deficit hyperactivity disorders (ADHD) and unaffected controls in the age range of 3 to 17 years.[10] Families with children with ASD reported more profound QoL effects than families of children with ADHD or typically developing children. Children with autism were more likely to miss school, more often repeated a grade and were less likely to participate in organized activities. In addition, Bastiaansen et al examined whether or not child psychiatric disorders have a different impact on QoL. [11] In this study of 6-to-18-year-old children referred for psychiatric problems to an outpatient child psychiatric clinic, children, their parents and attending clinicians reported on QoL indicators. Objective QoL indicators were examined, comprising living conditions, employment or school functioning, and social relationships. They reported that 28 children with ASD had fewer friends and received more special education than 107 children with ADHD or disruptive behaviour disorders, 57 children with mood disorders, 57 children with anxiety disorders, 22 children with other disorders, and 67 children without disorders. Besides objective outcome criteria, they also studied subjective QoL, involving the perspective of the child, parents and clinician of the child's physical, emotional, social, and school functioning. Across multiple raters, the subjective QoL appeared to be poorest in those areas of life that are most affected by the symptoms specific to the diagnosis; social functioning in children with ASD, school and social functioning in children with ADHD or DISR, and emotional functioning in children with anxiety and mood disorders. [11] Finally, Green et al examined the QoL of 20 11-to-19-year-old high-functioning adolescents with Asperger syndrome, alongside a comparison psychiatric group of 20 adolescents with Conduct disorders in a cross-sectional study. [12] The adolescents with Asperger syndrome showed severe impairments in social functioning as compared to the adolescents with Conduct disorders. They showed a profound lack of the ability for independent living and difficulties in social relationships, despite good cognitive ability and absence of significant early language delay. These findings suggest that the QoL of children and adolescents with ASD is more disadvantageous than for those with other childhood disorders. To date, there are no known follow-up studies that have investigated adult outcome on objective and subjective QoL of patients with ASD, as compared to patients with other psychiatric disorders diagnosed in childhood. Such a follow-up study would be worthwhile, since consequences for social functioning may become more prominent throughout the lifespan with increasing demands for personal independence. Since ASD is a condition in which there is, almost by definition, a profound impairment in social adaptation in adulthood, it can be expected that the QoL of individuals with ASD is worse compared to the QoL of individuals with other main child psychiatric disorders. This study therefore focuses on the severity of long-term consequences of ASD to a person's well-being (QoL), in comparison to groups of adults representing three main psychiatric disorders diagnosed in childhood; ADHD, disruptive behaviour disorders (DISR, i.e., Oppositional Defiant Disorders and Conduct Disorders), and affective disorders (AFF, i.e., mood and anxiety disorders).

There is a general consensus of factors related to late outcome in

ASD. Besides the development of early language skills before the age of 6, the most significant predictor of QoL appeared to be the level of intellectual functioning in ASD. As compared to ASD individuals with an IQ level beneath 70, those individuals with an IQ of at least 70 appeared to have a much better prognosis in adulthood. [3,13,14} However, above this cut-off IQ level outcome can be very variable and difficult to predict. [14,15] Whereas intelligence can be defined as the capacity to acquire and apply knowledge and deal effectively with the environment [16], a person's educational level is argued to reflect the realized potential, i.e. to constitute a more appropriate measure of the acquisition of knowledge and skills later in life. Because the influence of education on QoL in ASD is not examined so far, this will be done in the present study.

This study is about comparison of outcomes between psychiatric patients that were diagnosed in childhood or adolescence, specifically, QoL of adults diagnosed with ASD compared to adults diagnosed with other major psychiatric disorders. The focus is on the person's marital status, living arrangements, education, employment, and mental health care to portray the QoL in a large sample of young adults diagnosed with ASD in childhood as compared to age matched groups of adults with ADHD, DISR, or AFF, with exclusion of mutual co-morbidity of the respective disorders. Objective life conditions as well as the subjective life satisfaction will be examined. It is hypothesized that young adults with ASD will show a worse QoL profile when compared to adults diagnosed with ADHD, DISR, or AFF in childhood. In addition, it is expected that low-educated adults with ASD have poorer QoL when compared to high-educated adults with ASD. Comparisons of highly educated ASD individuals to other highly educated psychiatric patients will be explored.

Methods

Procedure and participants

This study is part of a longitudinal study, designed to monitor the cognitive and social-emotional development of patients, referred during 1984 to 2004, to the Department of Child and Adolescent Psychiatry at the University Medical Centre Utrecht, the Netherlands. The study was approved by the medical ethics committee (number 05-319/K) and written informed consent was obtained according to the declaration of Helsinki. Patients who were diagnosed with ASD, ADHD, DISR, or AFF and reached the young adult age (19 to 30 years of age) were approached for participation in the follow-up study during 2007 to 2010. The DSM-diagnoses of the patients in this study were based on full agreement between two board-certified psychiatrists. Semi-structured DSM-focused interviews, observations, medical records, and structured questionnaires (Child Behavior Checklist and Teacher's Report Form) were included in the diagnostic process.

Criteria for inclusion were (1) age between 19 to 30 years, (2) no axis II DSM-diagnosis of mental retardation (IQ<70) in childhood, and for the comparison groups (3) no co-morbid ADHD, DISR, or AFF disorder on Axis I of the DSM-III, DSM-III-R or DSM-IV that were customary at the time of referral. A total of 396 patients diagnosed with ASD in childhood were suitable candidates for follow-up. They were sent a letter informing them about the aims of the study and asking them to participate. A total of 169 (43%) adults (141 male, 28 female) diagnosed with ASD at a mean age of 9.80 (SD 3.73) years participated in this study, whereas 227 adults refused participation or could not be traced despite thorough search procedures involving family doctors and local government registration files. The ASD group consisted of 20 patients diagnosed in childhood with autistic disorder (299.00), 18 with Asperger's disorder (299.81) and 131 with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS, 299.80). Mean age at follow-up was 23.70 (SD 3.33) years, the mean follow-up period was 13.90 (SD 4.44) years.

With regard to the comparison groups, after exclusion of co-morbid DISR or AFF, 85 ADHD patients were matched on age and the group consisted of 77 adults who were diagnosed in childhood with ADHD of the combined subtype (314.01), seven adults with the predominantly inattentive subtype (314.00) and one adult with the predominantly hyperactive-impulsive subtype (314.01). In addition, after exclusion of co-morbid ADHD or AFF, 83 patients with DISR were matched on age of which 61 adults were diagnosed in childhood with ODD (313.81), 10 with CD (312.81) and 12 with other disruptive behaviour disorders (ICD9/10 diagnosis 312.xx). Finally, after exclusion of co-morbid ADHD or DISR, 85 patients diagnosed with AFF in childhood were matched on age, 48 of them with a mood disorder (15 adults with depressive disorder 296.xx, and 33 adults with dysthymic disorder 300.40) and 37 with an anxiety disorder (300.xx or 309.21).

No differences in age were found between the adults with ASD, ADHD, DISR, or AFF (p=.983). The gender distribution differed by group (ASD: 83% male, 17% female; ADHD: 88% male, 12% female; DISR: 70% male, 30% female; AFF: 38% male, 62% female) (p<.001).

Materials

Objective QoL

The questionnaire developed for this study to administer objective life conditions, consisted of questions about the patients' marital status, living arrangements, highest educational qualification, employment, mental health care, and medication usage. The questionnaire covers customary domains of QoL. [e.g.,13] The level of education of the patients was reported on the basis of the SOI-2006 (Standaard Onderwijs Indeling [Standard Classification of Education]; see Central Bureau for Statistics) [17], which is based on the ISCED (International Standard Classification of Education; see UNESCO). [18] Low educational qualifications are defined by the level of education that fits in the categories 'Soi 1. Pre-primary education', 'Soi 2. Primary education', and 'Soi 3. Upper secondary education'. The last type of education is designed to prepare students for entering the labour market or as a preparation for further education. High educational qualifications are defined by the level of education that fits in the categories 'Soi 4. Upper secondary education' and higher levels. These types of education are aimed at specialisation with a certain field of knowledge by the acquisition of a specific profession with a direct entry into the labour market or higher professional studies with bachelor's or master's programs, doctoral studies and post-doctoral tracks. The inquiry is a self-report questionnaire, but patients could also be assisted by parents or caregivers to complete the questionnaire. ASD patients needed more assistance to answer the questions (67% self reports) than patients with ADHD (69%), DISR (82%), or AFF (92%) (p<.001).

Subjective QoL

A composite rating on a 6-point scale (1=very dissatisfied, 6=well satisfied) of life satisfaction was based on questions concerning satisfaction about living arrangements, work or education, physical condition, having or not having a partner and social relationships, the state of mind (general mood), and future perspective (life prospects).

Statistical analysis

Descriptive statistics were used to characterize the objective and subjective QoL (patients' marital status, living arrangements, education, employment, and mental health care) of all groups.

Differences between diagnostic groups on the objective and subjective QoL measures were analyzed using chi-square (X^2) tests (categorical data), or multivariate, or univariate analyses of variance (ANOVA's) (ordinal data). To examine the influence of level of education on QoL, similar group comparisons between adults with QoL of low (SOI 1-3) and high (SOI 4-7) education were performed using X^2-tests. When significant differences were found, differences in distributions of the QoL variables of highly educated adults with ASD versus highly educated adults with ADHD, DISR or AFF were tested by X^2-analyses. For the X^2-tests, adjusted residuals were calculated in order to identify which category is over- or under-represented in the specific diagnostic category, compared to the expected frequency based on data of the total psychiatric sample. The adjusted residual is distributed according to the standard normal distribution and when it has a magnitude greater than 1.96, the corresponding category is considered a major contributor to the significance. [19] For the ANOVA's, simple contrast analyses were computed to determine whether the QoL measures differ significantly between the ASD group and comparison groups. Alpha was set to 0.05 and partial eta squared (η_p^2) was computed to estimate effect sizes (weak effect: ηp^2~0.03; moderate: ηp^2~0.06; large: $\eta p^2 \geq 0.14$). [20]

Results

QoL of adults with ASD as compared to adults with ADHD, DISR or AFF.

Marital status

The majority (88%) of the adults with ASD was single, 4% of the adults had a relationship, and 8% were married or cohabiting. This distribution was significantly different in the comparison groups ($X^2(6)=39.552$, p<.001) with

singles being over-represented (z=5.8) in the ASD group, and under-represented in the DISR (z=-3.6) and AFF groups (z=-3.2). Conversely, adults who were married or cohabiting were under-represented (z=-5.2) in the ASD group, but over-represented in the DISR group (z=3.2) and in the AFF group (z=3.0) (Table 1).

Living arrangements

The largest proportion (45%) of the adults with ASD lived with their parents or other family members and 21% were institutionalized (supported or residential living). Twenty-seven percent of the adults with ASD lived self-reliant (independent living), and 7% lived with a partner or a family (partner and children). This distribution was significantly different in the adults with ADHD, DISR, or AFF ($X^2(9)=75.420$, $p<.001$). Within the ASD group, adults who were institutionalized (z=5.6) were over-represented, whereas those were under-represented in the DISR (z=-2.2) and AFF (z=-2.8) groups. In contrast, adults living with a partner or family were under-represented (z=-5.7) in the ASD group, but over-represented in the DISR (z=3.6) and AFF (z=3.2) groups (Table 1).

Highest educational qualification

The highest qualification was primary education for 20% of the adults with ASD and lower secondary education for 17% of the adults with ASD. The majority (55%) completed upper secondary education, only 3% post-secondary non-tertiary education, and 5% completed the first stage of tertiary education (Table 1). This distribution differed by group ($X^2(12)=24.768$, p=.016). The mean level of the highest educational qualification differed significantly by group ($F(3,399)=3.949$, p=.009, η_p^2=.029). The highest educational level was significantly lower in the ASD group (M=3.57, SD=1.00) compared to the DISR group (M=3.86, SD=.80) (p=.026) and the AFF group (M=3.98, SD=.95) (p=.001). There were no group differences between the ASD and ADHD (M=3.71, SD=.90) group.

Employment

Most of the adults with ASD had paid employment (49%), but 36% of the adults with ASD were social security recipients. Fifteen percent of the adults with ASD had employment related training. The distribution of current employment situations differed by group ($X^2(6)=27.189$, $p<.001$). The adults with paid employment were under-represented in the ASD group (z=-3.9), whereas the social security recipients were over-represented (z=4.8) when compared to the other groups (Table 1). For those adults with paid employment, the number of hours of paid employment did not differ by group (p=.055).

Table 1. Objective quality of life of adults with autism spectrum disorders (ASD) as compared to adults with attention deficit/ hyperactivity (ADHD), disruptive behaviour (DISR), and affective disorders (AFF). * $p\leq0.05$

	ASD	%	z	ADHD	%	z	DISR	%	z	AFF	%	z
MARITAL STATUS	*N*=16			*N*=81			*N*=83			*N*=82		
Single	143	88.3	5.8*	58	71.6	-0.2	47	56.6	-3.6*	48	58.5	-3.2*
Relationship	6	3.7	-1.9	6	7.4	0.3	8	9.6	1.2	7	8.5	0.8
Married, cohabiting	13	8.0	-5.2*	16	21.0	0.0	28	33.7	3.2*	27	32.9	3.0*
LIVING ARRANGEMENTS	*N*=165			*N* =83			*N* =79			*N*=84		
Self-reliant	45	27.3	-0.2	18	21.7	-1.4	17	21.5	-1.4	34	40.5	2.9*
With partner or family	11	6.7	-5.7*	18	21.7	0.3	28	35.4	3.6*	28	33.3	3.2*
With parents or other family members	74	44.8	1.3	43	51.8	2.3*	31	39.2	-0.3	20	23.8	-3.6*
Institutionalized	35	21.2	5.6*	4	8.9	-1.9	3	3.8	-2.2*	2	2.4	-2.8*
HIGHEST EDUCATIONAL QUALIFICATION	*N*=157			*N*=82			*N*=79			*N*=85		
SOI 2. primary education	31	19.7	3.6*	8	9.8	-0.8	5	6.3	-1.8	6	7.1	-1.7
SOI 3. lower secondary education	26	16.6	-0.8	20	24.4	1.7	14	17.7	-0.1	13	15.3	-0.8
SOI 4. upper secondary education	87	55.4	-0.8	46	56.1	-0.4	49	62.0	0.8	51	60.0	0.5
SOI 5. post-secondary non-tertiary education	5	3.2	-2.0*	4	4.9	-0.6	9	11.4	2.1*	7	8.2	0.9
SOI 6. First stage of tertiary education	8	5.1	-0.3	4	4.9	-0.3	2	2.5	-1.3	8	9.4	1.8
EMPLOYMENT	*N*=159			*N*=82			*N*=80			*N*=84		
Paid employment	78	49.1	-3.9*	57	69.5	1.8	59	73.8	2.7*	52	61.9	0.2
In training	24	15.1	-0.4	12	14.6	-0.4	11	13.8	-0.6	18	21.4	1.5
Social security recipient	57	35.8	4.8*	13	15.9	-1.8	10	12.5	-2.5*	14	16.7	-1.6
MENTAL HEALTH CARE												
N=161	*N*=161			*N*=82			*N*=83			*N*=85		
None	100	62.1		52	63.4		44	53.0		45	52.9	
None, but counselling in the past	27	16.8		14	17.1		23	27.7		19	22.4	
Counselling	24	14.9		13	15.9		13	15.7		16	18.8	
Hospitalized	10	6.2		3	4.2		3	3.6		5	5.9	
TYPE OF MEDICATION	N=55			N=40			N=20			N=30		
Psycho stimulants	11	20.0	-4.0*	34	85.0	6.7*	10	50.0	0.9	4	13.3	-3.4*
Anti depressives	10	18.2	-1.6	2	5.0	-3.5*	6	30.0	0.5	19	63.3	5.3*
Anti psychotics	26	47.3	5.1*	4	10.0	-2.5*	2	10.0	-1.6	3	10.0	-2.0*
Anxiety stabilizers	5	9.1	0.8	0	0	-2.0*	1	5.0	-0.4	4	13.3	1.6
Remaining	3	5.5	1.5	0	0	-1.3	1	5.0	0.7	0	0	-1.0

Mental health care

The majority of the adults with ASD (62%) did not receive any form of mental health care, but 17% of the adults had some counselling in the past. Fifteen percent of the adults with ASD received mental treatment, 6% were hospitalized (day treatment or fully committed to a specialized mental institution). There were no group differences considering mental health care (p=.622) (Table 1). For the adults who received any form of mental health care, the mean duration of the treatment (ASD: M=3.89, SD=4.14) did not differ by group (p=.603).

Considering medication treatments for mental problems, 20% of the adults with ASD were using medication, 15% of the adults with ASD were not using medication but used some in the past, and the majority (64%) was not using any medication. This distribution differed by group (p=.032), the adults who did not use any medication are over-represented in the DISR (z=2.1) group, but under-represented in the ADHD (z=-2.5) group. In this group the adults who were not using medication but used some in the past are over-represented (z=3.3). When the adults were using or used medication, the type of medication differed by group (X^2(12)=84.202, p<.001). Almost half (47%) of the adults with ASD used anti-psychotics and this type of medication is over-represented in the ASD group (z=5.1), while the usage of psycho stimulants was under-represented in this group (z=-4.0) (Table 1).

Subjective QoL

The adults with ASD were significantly less satisfied about their QoL than the adults with ADHD, DISR, or AFF (F(21,1083)=2.904, p<.001, η_p^2=.053). Group differences were found considering satisfaction of work or education, physical condition, partner relationships, and future perspective (Table 2). Considering work or education the adults with ASD were less satisfied than the ADHD adults (p=.006), DISR adults (p=.008), and AFF adults (p=.021). The adults with ASD were also less satisfied about their relationships with a partner than adults with ADHD (p=.027), DISR (p=.003), or AFF (p=.003). Finally, the adults with ASD were less satisfied considering their future perspective than the DISR adults (p=.016), and AFF adults (p=.029). In contrast, the adults with ASD were significantly more satisfied about their physical condition than adults with DISR (p=.013), and AFF (p=.036). No group differences were found in satisfaction of living arrangements, social relationships, and state of mind.

QoL of adults with ASD with low (SOI 1-3) versus high (SOI 4-7) educational qualifications.

No difference in mean age was found between the adults with ASD with low educational qualifications (ASD LOW) (M=23.81, SD=3.56), as compared to adults with ASD with high educational qualifications (ASD HIGH) (M=23.63, SD=3.19) (p=.743).

With respect to living arrangements differences were found (X^2(3)=23.029, p<.001). Within the ASD LOW group, self-reliant living adults were under-represented (z=-2.4), whereas institutionalized adults were over-represented (z=4.7). In contrast, in the ASD HIGH group, self-reliant living adults were over-represented but institutionalized adults were under-represented (z=-4.7). The distribution of current employment situations also differed by group (X^2(2)=18.208, p<.001). The adults with paid employment were under-represented (z=-3.2) in the ASD LOW group, whereas the social security recipients were over-represented (z=4.3). However, the social security recipients were under-represented in the ASD HIGH group (z=-4.3), whereas the adults with paid employment are over-represented (z=3.2). No group differences were found for marital status (p=.607), use of mental health care (p=.395), type of medication treatment (p=.185), and subjective QoL (p=.256).

QoL in high-educated adults with ASD versus high-educated adults with ADHD, DISR, and AFF.

The mean levels of high educational qualifications (p=.227) and age (p=.321) did not differ by group.

Marital status

The majority (87%) of the ASD HIGH adults was single, 5% of the adults had a relationship, and 8% were married or cohabiting. This distribution was significantly different in the comparison groups (X^2(6)=26.463, p<.001), with singles in the ASD HIGH group being over-represented (z=4.8) whereas those who were married or cohabiting were under-represented (z=-4.7) (Table 3).

Living arrangements

The majority (51%) of the highly educated adults with ASD lived with their parents or other family members and 8% were institutionalized. Thirty-five percent of the ASD HIGH adults lived self-reliant, and 6% lived with a partner or a

Table 2. Subjective quality of life of adults with autism spectrum disorders (ASD) as compared to adults with attention deficit/ hyperactivity (ADHD), disruptive behaviour (DISR), and affective disorders (AFF). * $p \leq 0.05$

SATISFACTION CONCERNING	ASD *N*=139	ADHD *N*=73	DISR *N*=77	AFF *N*=80	*F (3,365)*	*p*	η_p^2
Living arrangements	4.83 (1.12)	5.10 (10.2)	4.90 (1.20)	5.01 (1.03)	1.137	.334	.009
Work/education	4.25 (1.28)	4.75 (1.19)	4.73 (1.19)	4.66 (1.35)	3.945	**.009***	.031
Physical condition	4.59 (1.01)	4.70 (1.06)	4.19 (1.24)	4.26 (1.20)	4.061	**.007***	.032
Relationship partner	4.13 (1.37)	4.56 (1.29)	4.70 (1.44)	4.70 (1.28)	4.582	**.004***	.036
Social relationships	4.40 (1.22)	4.75 (1.10)	4.55 (1.27)	4.81 (1.21)	2.582	.053	.021
State of mind	4.47 (1.21)	4.78 (1.11)	4.39 (1.17)	4.54 (1.10)	1.655	.176	.013
Future perspective	4.41 (1.19)	4.68 (1.32)	4.82 (1.13)	4.77 (1.13)	2.673	**.047***	.021

Table 3. Objective quality of life of adults with autism spectrum disorders and high educational qualifications (SOI 4-7) (ASD HIGH) as compared to highly educated adults with attention deficit/hyperactivity (ADHD HIGH), disruptive behaviour (DISR HIGH), and affective disorders (AFF HIGH). * p≤0.05

	ASD HIGH	%	*z*	ADHD HIGH	%	*z*	DISR HIGH	%	*z*	AFF HIGH	%	*z*
MARITAL STATUS	*N*=97			*N*=53			*N*=60			*N*=66		
Single	84	86.6	4.8*	35	66.0	-0.4	32	53.3	-2.9*	38	57.6	-2.2*
Relationship	5	5.2	-0.8	3	5.7	-0.4	6	10.0	1.1	5	7.6	0.3
Married, cohabiting	8	8.2	-4.7*	15	28.3	0.7	22	36.7	2.4*	23	34.8	2.2*
LIVING ARRANGEMENTS	*N*=99			*N*=54			*N*=59			*N*=66		
Self-reliant	35	35.4	0.6	13	24.1	-1.6	16	27.1	-1.1	28	42.4	1.8
With partner or family	6	6.1	-5.3*	16	29.6	1.0	22	37.3	2.6*	24	36.4	2.6*
With parents or other family members	50	50.5	3.1*	24	44.4	1.0	20	33.9	-0.8	13	19.7	-3.6*
Institutionalized	8	8.1	2.6*	1	1.9	-0.9	1	1.7	-1.0	1	1.5	-1.2
EMPLOYMENT	*N*=98			*N*=52			*N*=58			*N*=66		
Paid employment	59	60.2		36	69.2		43	74.1		44	66.7	
In training	18	18.4		10	19.2		8	13.8		15	22.7	
Social security recipient	21	21.4		6	11.5		7	12.1		7	10.6	
MENTAL HEALTH CARE	*N*=98			*N*=54			*N*=60			*N*=66		
None	63	64.3		38	70.4		29	48.3		36	54.5	
None, but counselling in the past	16	16.3		8	14.8		20	33.3		13	19.7	
Counselling	16	16.3		7	13.0		10	16.7		13	19.7	
Hospitalized	3	3.1		1	1.9		1	1.7		4	6.1	
TYPE OF MEDICATION	*N*=55			*N*=40			*N*=20			*N*=30		
Psycho stimulants	8	28.6	-1.7	16	80.0	4.0*	8	53.3	1.1	3	13.6	-3.0*
Anti depressives	6	21.4	-1.9	2	10.0	-2.7*	6	40.0	0.4	16	72.7	4.3*
Anti psychotics	9	32.1	3.0*	2	10.0	-0.8	1	6.7	-1.0	1	4.5	-1.6
Anxiety stabilizers	3	10.7	1.3	0	0.0	-1.3	0	0.0	-1.1	2	9.1	0.7
Remaining	2	7.1	2.0*	0	0.0	-0.8	0	0.0	-0.7	0	0.0	-0.8

family. This distribution differed significantly from the highly educated adults with ADHD, DISR, or AFF ($X^2(9)=43.145$, $p<.001$). Within the ASD HIGH group, the adults who lived with their parents ($z=3.1$) or who were institutionalized ($z=2.6$) were over-represented, whereas those adults living with a partner or family were under-represented in the ASD HIGH group ($z=-5.3$) (Table 3).

Employment

Most of the high-educated adults with ASD had paid employment (60%), but 21% of the adults with ASD were social security recipients and 18% had employment related training (Table 3). The distribution of current employment situations did not differ by group ($p=.340$).

Mental health care

The majority of the high-educated adults with ASD (64%) did not receive any form of mental health care, but 16% of the adults had some counselling in the past. Sixteen percent of the highly educated adults with ASD received mental treatment, 3% were part-time or fulltime hospitalized. There were no differences with the comparison groups considering usage of mental health care ($p=.622$) (Table 3).

Considering medication treatments for mental problems, 15% of the highly educated adults with ASD were using medication, 14% were not using medication but used some in the past, and the majority (71%) was not using any medication. This distribution did not differ by group ($p=.496$). When the high-educated adults were using or used medication, the type of medication differed by group ($X^2(12)=42.554$, $p<.001$). Thirty-two percent highly educated adults with ASD used anti-psychotics and this type of medication is over-represented in the ASD HIGH group ($z=3.0$) (Table 3).

Subjective QoL

There appeared to be a significant difference concerning satisfaction about the QoL between the highly educated adults with ASD, ADHD, DISR, or AFF ($F(21,750)=2.394$, $p<.001$, $\eta_p^2=.063$). With respect to social relationships, the high-educated adults with ASD were less satisfied than those with ADHD ($p=.013$) and AFF ($p=.019$). In contrast, the high-educated adults with ASD were significantly more satisfied about their physical condition than adults with DISR ($p=.003$) (Table 4).

Table 4. Subjective quality of life of adults with autism spectrum disorders and high educational qualifications (SOI 4-7) (ASD HIGH) as compared to highly educated adults with attention deficit/hyperactivity (ADHD HIGH), disruptive behaviour (DISR HIGH), and affective disorders (AFF HIGH). * $p \leq 0.05$

SATISFACTION CONCERNING	ASD *N*=91	ADHD *N*=48	DISR *N*=56	AFF *N*=63	*F (3,254)*	*p*	η_p^2
Living arrangements	4.82 (1.11)	5.19 (0.98)	4.91 (1.07)	5.03 (1.00)	1.393	.245	.016
Work/education	4.42 (1.20)	4.94 (1.08)	4.79 (1.07)	4.76 (1.24)	2.585	.054	.030
Physical condition	4.65 (1.03)	4.54 (1.13)	4.05 (1.26)	4.30 (1.23)	3.503	.016*	.040
Relationship partner	4.24 (1.40)	4.75 (1.28)	4.66 (1.46)	4.76 (1.25)	2.548	.056	.029
Social relationships	4.52 (1.16)	5.00 (0.85)	4.68 (1.10)	4.94 (1.12)	2.957	.033*	.034
State of mind	4.64 (1.08)	4.88 (1.16)	4.46 (1.11)	4.62 (1.08)	1.208	.308	.014
Future perspective	4.59 (1.10)	5.02 (1.06)	4.84 (1.13)	4.92 (1.02)	2.071	.105	.024

Discussion

This follow-up study examined the specific impact of childhood ASD on QoL during young adulthood as compared to young adults who suffered from the other most prevalent psychiatric disorders in childhood; ADHD, DISR, and AFF disorders. Results showed that QoL of high-functioning adults diagnosed with ASD in childhood was more compromised than QoL of adults with other child psychiatric diagnoses. This applies for both objective and subjective QoL. In contrast with the outcome in adults with ADHD, DISR, or AFF, relatively many adults with ASD were single and only some of them were cohabiting or married. Most of the adults with ASD lived with their parents, relatively few lived with a partner or family and many of them were institutionalized. The highest educational level of the adults with ASD was significantly lower, relatively few had paid employment, and relatively many were social security recipients, as compared to adults with ADHD, DISR, and AFF disorders. When the adults with ASD were using or used medication, relatively many used anti-psychotics. The adults with ASD were less satisfied about their QoL than the adults with ADHD, DISR, or AFF disorders, they were less content about their work or education, partner relationships, and future perspective.

Several studies have shown that QoL in patients with psychiatric disorders is considerable poorer than that of typically developing individuals, but also comparable to or even poorer than that of physically ill patients, [e.g.,21,22] indicating that there is high risk of low quality of life in individuals with psychopathology. [11] Reviews reported that ADHD seriously compromises QoL, [e.g.,23,24] studies showed that patients with DISR had high rates of problems in social functioning [e.g.,25,26] and reviews also demonstrated poor QoL in patients with AFF. [e.g.,27,28,29,30] The current study revealed that ASD has a more profound negative effect on QoL in young adulthood than ADHD, disruptive, and affective disorders. Cross-sectional studies examining the relationship between the main psychiatric disorders and outcome in childhood and adolescence suggested that the QOL in ASD is more disadvantageous than in other psychiatric disorders, [10,12,21] this follow-up study showed the long-term negative impact of growing up with ASD on QoL in adulthood.

Although the objective characteristics of a patient's environment are important in evaluating QoL, the patient's subjective satisfaction of their life conditions is also essential, but these measures are not frequently used in QoL studies with ASD adults. Subjective QoL reflects the difference between the hopes and expectations of a person and their present experience. Making a judgement on satisfaction is a comparative activity and depends on one's experiences and judgements of what is typical and possible within one's situation. These might be limited in patients with ASD, since they typically lack the ability to judge their own behaviour. In addition, subjective QoL is influenced by the personal frame of reference that in ASD patients might run counter to generally accepted standards (e.g. less need for social interactions). Moreover, it is possible that psychiatric patients in general may lower their own standards to what would be objectively not desirable levels as a consequence of adaptation to life conditions. However, in this study the high-functioning adults with ASD appeared to be less satisfied about aspects of QoL than the adults with ADHD, DISR, or AFF disorders; they were less content about their work or education, partner relationships, and future perspectives. In contrast, the adults with ASD were more satisfied about their physical condition or well-being than adults with DISR and AFF disorders. This implies that ASD adults were not generally less content about their life conditions, but they were able to differentiate between different domains of subjective QoL.

Although other studies reported that QoL can be very variable and difficult to predict in ASD populations with an IQ exceeding 70, [14,15] findings in this study showed that the level of education has an influence on QoL of adults with ASD without mental retardation. When a distinction was made between adults with ASD with low and high educational qualifications, relatively many adults with ASD with low educational qualifications lived institutionalized and were social security recipients. In contrast, relatively many adults with ASD with high education qualification lived self-reliant and had paid employment. No group differences were found concerning marital status and usage of mental health care. Remarkably, no differences considering subjective QoL were found between low- and high-educated ASD patients. Because of the variation in outcome between low- and high-educated adults with ASD, the differences of QoL were re-examined between a group of highly educated adults with ASD and groups of highly educated adults with ADHD, DISR, and AFF. In contrast with the high-educated adults with other major psychiatric diagnoses, relatively many adults with ASD were single and few were cohabiting or married. In addition, relatively few highly educated adults with ASD lived

with a partner or family and many lived with their parents or were institutionalized. The distribution of current employment situations and usage of mental health care did not differ by group. With respect to subjective QoL, the high-educated adults with ASD were less satisfied about their social relationships than those with ADHD or AFF. This indicates that even when highly educated adults with ASD were compared to highly educated adults diagnosed with the other main childhood disorders, the QoL remained to be more unfavourable in adults with ASD. This implies that high education is not a protective factor to QoL in ASD when compared to the QoL in other psychiatric disorders.

Outcomes of this study showed that a large percentage (47%) of adults with ASD were on anti-psychotics. Medication use itself, especially use of anti-psychotics, may influence QoL. Therefore, additional analyses were done to explore the differences in distributions of QoL indicators of adults with ASD who are using or used medication in the past (*N*=58) versus those who are not using any medication (*N*=104). Indeed, differences of both objective and subjective QoL were found. Differences were found with respect to living arrangements (p=.003), within the ASD group with medication, institutionalized adults were over-represented and, in the contrary, under-represented in the ASD group without medication. The mean level of the highest educational qualifications differed significantly by group (p=.003), this was significantly lower in the group of ASD adults with medication than those adults without medication. The distribution of current employment situations also differed by group (p<.001). Within the ASD group with medication, the adults with paid employment were under-represented and the social security recipients were over-represented. No group differences were found for marital status. Group differences were also found regarding subjective QoL indicators (p<.001). Within the ASD group with medication, the adults were less satisfied with respect to their work or education, physical condition, partner relationships, social relationships, state of mind, and their future perspective, when compared to the ASD group without medication. No group differences were found in satisfaction of their living arrangements. Moreover, within the group of ASD patients who used medication, the QoL indicators were compared between those who used anti-psychotics (*N*=26) and those who used other types of medication (*N*=29). However, no group differences were found, indicating that the usage of anti-psychotics has no specific influence on QoL. Nevertheless, a relation between medication usage and QoL in ASD was found. This might be explained by the medication use itself or the severity of symptoms and therefore the impact of the disorders on daily life functioning. In order to explore these hypotheses, we added comparisons between those ASD patients who use or used mental health care (*N*=61) and those who did not (*N*=100) and group difference were found. With respect to objective QoL indicators, the distribution of current employment situations differed by group (p<.001), within the ASD group with mental health care, the adults with paid employment were under-represented and the social security recipients were over-represented. No other group differences were found. However, group differences were found regarding subjective QoL indicators (p=.002). The adults within the ASD group with mental health care were less satisfied with respect to their work or education, social relationships, state of mind, and their future perspective, than those within the ASD group without mental health care. No group differences were found in satisfaction of their living arrangements, physical condition and partner relationships. In conclusion, besides the usage of medication, the usage of mental health care also did influence objective and subjective QoL. This might suggest that the severity of symptoms rather than medication use itself is a plausible explanation for compromised QoL in ASD and this should be verified in future research.

This study has a few limitations. The ASD diagnoses were not validated by the Autism Diagnostic Interview (ADI), since the subjects were diagnosed in the period between 1984 and 2004, and the Dutch translation of the ADI was not available until 2003. In addition, the exclusion of mentally retarded ASD patients and the large prevalence of PDD-NOS diagnoses limit the representativeness of the sample and, as such preclude generalizability to the whole autistic spectrum. In order to create pure comparison groups, mutual co-morbidity of the control patients in the period of their referral to the Department of Child and Adolescent Psychiatry were excluded. However, some of the patients might developed co-morbid disorders until the follow-up period. This may be a possible influencing factor for their QoL. More research is required to improve our understanding of relationships between QoL and other factors besides characteristics of the diagnosis itself, like the impact of symptom severity, social skills or social network factors. This study provides a first step in demonstrating poor QoL in ASD, but the next step should be to investigate the factors that lead to this outcome. Furthermore, the pathways to poor QoL might be distinctive in the different psychiatric groups and these should be

investigated comparatively. However, this study also has several strengths. This is the first study examining the long-term impact (follow-up period of almost 14 years) of ASD for QoL in adults, using no less that three age-matched comparison groups of patients presenting with the other major childhood psychiatric disorders. This approach enables to examine the specific impact of ASD on QoL, which is not possible when including only normally developing individuals as controls as is usually done in QoL studies. In addition, this study has a relatively large sample size. Finally, an important strength of the study is the exclusion of mutual co morbidity in the three psychiatric control groups, leaving very pure comparison groups.

In conclusion, although several studies suggested that psychopathology is generally associated with poor outcome, this study revealed that the QoL of young adults diagnosed with ASD in childhood is specifically more compromised than QoL in adults with other child psychiatric disorders. They are less likely to live independently, have less intimate relationships, have lower education levels and employment levels, and their subjective life satisfaction is lower, than adults diagnosed with ADHD, DISR, or AFF in childhood. Even when highly educated adults with ASD were compared to highly educated adults diagnosed with other childhood disorders, adults with ASD and high educational qualifications are at specific risk of poor QoL.

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