Qual Life Res (2014) 23:1859–1868
DOI 10.1007/s11136-014-0635-6

Impact of autism in adolescents on parental quality of life

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Accepted: 21 January 2014

Abstract

Purpose To study the impact of autism spectrum disorders (ASDs) on parental quality of life (QoL) at adolescence using the parental–developmental disorders-quality of life scale (Par–DD-QoL).

Methods One hundred and fifty-two mothers of adolescents with ASD completed Par–DD-QoL. This scale assesses the following dimensions: emotional, daily disturbance and global QoL. This cross-sectional study uses a subset of data collected at the final time of a follow-up study (EpiTED cohort).

Results A polytomic regression identified an increase in aberrant behavior scores as the major independent risk factor for parental QoL. The identified protective factors were the increase in daily living, communication and object cognition scores and a higher number of siblings.

Conclusions Those results suggest that there is a negative effect of externalizing behaviors and a protective effect of adaptive skills, communication and object cognition on parental QoL. Study limitations and implications are discussed.

Keywords Parental quality of life · Autism spectrum disorders · Risk factors · Adolescents · Cohort

Abbreviations

QoL	Quality of life
ASD	Autism spectrum disorders
Par–DD-QoL	Parental–developmental disorders-quality of life

Introduction

Autism Spectrum Disorders (ASD) are neurodevelopmental disorders characterized by impairments in socialization and communication [1, 2], which are particularly severe and long-lasting when compared to other types of developmental disorder [3]. ASD might have a negative impact not only on the person's Quality of Life (QoL), but also on the family QoL, as in chronic diseases [4–6]. Given the impact of ASD on family functioning, there is an awareness of the need to study the impact of ASD on family, especially parent's QoL. Regrettably, few studies have specifically addressed the impact of ASD in terms of QoL.

Quality of life is a multidimensional concept, broader than health and well-being, covering multiple domains such as relational, psychological and physical aspects, including aspects related to specific health status/condition [7]. Some studies have focused on one aspect of parental QoL, i.e., psychological state or physical health. In a meta-analysis, parents of children with autism had more

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psychiatric disorders than parents of children with typical development or another diagnosis [8]. Parents of children with autism also experienced more stress [9, 10], more impairment in physical activity and social relationships and a worse overall perception of their QoL [8, 11]. In a recent study [12], caregivers of children with autism rated their health as poor compared to caregivers of typically developing children. Moreover, having a child with ASD has an impact on economic and professional fields [13].

In the multifactorial model developed by Bruchon-Schweitzer [14] and based on Lazarus' transactional definition of stress [15], QoL is influenced by factors present before the stressful event (such as personality traits or environmental factors) and by transactional variables (perceived stress, perceived control, perceived social support and coping strategies). In families of children with ASD, the level of impairment in QoL is likely to be moderated by several variables such as socioeconomic status, social support, parental and child characteristics and coping strategies [7, 11, 16–18]. The programs or the interventions proposed to the children also play a crucial role in parents' QoL. For example, programs based on cognitive behavioral approaches aim to increase short-term parental skills and to strengthen their coping capacities [19, 20]. Parental response to the programs varies according to their feelings about their child's disorder, interventions' effectiveness or life events [21–23]. Social support and inclusion into an ordinary school setting also seem to have an impact on parental QoL [9, 24]. As regards the child's characteristics, studies have shown that parental QoL is impacted by several factors related to their child with ASD such as symptom severity and challenging behaviors [9, 25]. These variables can be considered as protective or risk factors [26] and some of them may interact. For example, the families of children with more impairments may be less likely to receive social support, which might increase the risk of psychological difficulties for parents [9]. In order to facilitate a collaborative approach, in which families are integral members [10], it is crucial to better understand the factors that might predict parental QoL.

Another important point is that parental QoL is likely to change across life as a function of their children's age. Studies on parental satisfaction with services and providers showed a higher rate of dissatisfaction among parents of adolescents as compared to parents of children or adults with ASD [27–29]. Those results suggest that, as in typical development, adolescence is a critical period for persons with ASD and raises specific issues. The parents of adolescents, even if they have many years of experience and have had a longer time than parents of young children to develop coping strategies, seem to increase their level of demand toward the services proposed to their children and to express greater concern about the future.

Those results show that parents of children with ASD report a negative overall perception of their QoL at several levels and suggest that QoL might be particularly impaired at some period of life such as adolescence. In the present study, we chose to explore parental QoL in a population of adolescents with ASD. Our primary objective was to determine the factors associated to an impaired QoL in parents of adolescents with ASD, among which the adolescent's characteristics (symptom severity, adaptive behaviors, psychological development, challenging behaviors), the amount of weekly interventions and parental socioeconomic status. A second objective was to verify the psychometric properties of the parental QoL scale used in the present study.

Methods

Participants and procedure

The participants were the biological parents of 152 adolescents with an ASD, followed up in the French project of EpiTED cohort [30], which examines changes in 152 children over a 10-year period. One hundred and fifty-two mothers (100 %) and 13 fathers (8.5 %) took part in the study. Only the Par–DD-Qol scales completed by mothers were included in the analyses, because the sample size of fathers was insufficient, which did not allow comparison across groups. These adolescents were recruited from 46 autism evaluation clinics, and all of them had an ICD-10-based diagnosis of autism [2], confirmed by autism diagnosis interview-revised (ADI-R; [31]). Experienced psychologists individually assessed children using a standardized protocol.

For this cross-sectional study, we only used a subset of data collected during the third time point of the EpiTED follow-up. The parental QoL was collected only at this point.

The Local Human Subjects Protection Committee approved the research protocol, parents provided informed consent for all children, and assent was obtained from adolescents when possible.

Outcome measures: quality of life

Parental–developmental disorder-quality of life was used to assess the impact of ASD on parental QoL on the following dimensions: emotional, daily disturbance and global QoL. It is a QoL questionnaire for a specific use in populations with chronic disabilities. This was adapted from the Par–ENT-QoL, a simple and validated French self-administered questionnaire used in the general population with chronic ear, nose and throat (ENT) infections

[32]. The Par–DD-QoL adapted from the Par–ENT-QoL proved to be appropriate for parents who have children with ASD or other developmental disorders, because they are chronic conditions which have an impact on family QoL. Par–DD-QoL contains 17 questions, each rated by parents on a 5-point Likert scale. The first 15 questions concern the intensity of the difficulties encountered by parents, the sixteenth their frequency and the last one the global parental QoL. There are two sub-scores, emotional score (ES as the sum of Q1–Q6, Q13 and Q14) and daily disturbances score (DDS as the sum of Q7–Q11, Q15 and Q16), and a global score (sum of the previous two scores). The scores linearly transformed range from 0 to 100, 0 being the best and 100 the worst, assuming equal weights on each domain. The Par–DD-QoL scale was validated in a population of 590 parents (256 fathers and 334 mothers) for 349 children having developmental disorders (218 with ASD, and the others with intellectual disabilities without ASD), and also in a sample of 208 children and adolescents with severe chronic diseases (cystic fibrosis, epilepsy, congenital malformation) recruited in pediatric clinics [24, 33]. The validation study using factor analysis and test retest confirmed two QoL dimensions and showed a good internal consistency, with a Cronbach's α coefficient between 0.7 and 0.8.

For the current study, we conducted a new validation of the Par–DD-QoL scale into our sample of parents, again using factor analysis procedures. According to our study objectives, the data analysis methods were designed to compare the Par–DD-QoL factor structure derived in our ASD sample with factor solutions from Raysse study [33] and to confirm the emotional and daily disturbance subdimensions. We performed factor analyses with varimax rotation using 17 items of Par–DD-QoL. The results of the analyses suggested a two-factor model that accounted for 95 % of the total variance. The first factor explained 82.5 % of the total variance, and the second factor explained 12.5 %. Good internal consistency reliability was observed for two dimensions. Cronbach's α coefficient was >0.82 for each dimension. Following these analyses, we calculated scores for two sub-dimensions of QoL: (1) ''emotional'' (2) ''daily disturbances''. For each dimension, higher scores indicated that the parent had greater difficulties related to the child's disorder. Finally, we computed a Global score from the sum of the two sub-dimension scores. Higher scores indicated greater disruption for the parent, that is, a lower QoL.

Predictor measures

Sociodemographic data and parental social class (high, middle or low) were obtained from medical records. An overall measure of weekly special interventions (in specialized settings and regular classrooms) was calculated by adding up the hours per week spent at each facility (this record was prepared with parents during the Vineland interview).

Associated medical conditions, such as epilepsy, congenital, chromosomal or genetic abnormalities and perinatal condition, were recorded from the medical reports.

Symptom severity (childhood autism rating scale: CARS) and expressive speech were assessed based on observational data from video clips performed in adolescence [34]. Expressive speech was scored using three levels: (a) spontaneous, functional speech with sentences, (b) speech including at least five different words and (c) use of fewer than five words.

Adaptive behaviors were assessed using the three subscales of the Vineland adaptive behavior scale: communication (COM), daily living skills (DLS) and socialization (SOC) [35]. Given that the adaptive level can be expressed either as standard score or as developmental age (DA), we chose developmental age (months) to improve comparability across tests.

Behavioral problems were evaluated using four behavioral domains (BD) of the aberrant behavior checklist or ABC [36]: BD (I): irritability, aggressiveness; BD (II) social withdrawal, passiveness; BD (III): stereotypy and self-injury and BD (IV): hyperactivity and lack of cooperation. Scores were reduced to a scale of 100 in order to make comparisons between the four domains.

Because no single test could be used to evaluate the development of a large sample throughout the years covered, psychological development was assessed in two functional areas, object-related cognition functioning (OC) and person-related cognition functioning (PC), using multiple sources of information [30, 37]. Each area was interpreted as a developmental age, which was then translated into scales (OC and PC) ranging from 1 to 204 months with 6-month intervals. OC was assessed using the Brunet–Lezine eye–hand coordination domain when the child's developmental age (DA) was below 36 months, and in the other cases the "Block Design" from the WPPSI-R/WISC-III-R/WISC-IV. PC was assessed using items linked to joint attention, imitation, symbolic play and theory of mind [38, 39].

Statistical analyses

The Par–DD-QoL scores did not have a Gaussian distribution; therefore, these scores were divided into three categories (no impact, moderate and high impact) according to terciles identified in a sample of 208 individuals with severe chronic diseases [33]. The links between Par–DD-QoL scores and clinical and social variables were investigated with Spearman's rank order correlation or Mann–

Whitney or Kruskal–Wallis test. Pairwise comparisons were made using the Bonferroni post hoc test. Polytomic logistic regressions were performed to compare outcome measures in parents according to their child's characteristics. The linearity of the relationships between Par–DD-QoL scores and independent variables was tested. Only variables significantly associated with Par–DD-QoL in the univariate analysis were included in the model (with the highest p value) and in the case of collinear variables. The significance level used was 5 %. Statistical analyses were performed using SAS version 9.2 (SAS Institute, Cary, NC, USA).

Results

A description of participants and their child's characteristics are shown in Tables 1 and 2.

Comparison with the severe chronic disease (Table 3)

Interestingly, the emotional and global scores did not differ significantly from those obtained in a severe chronic disease sample. However, the Daily Disturbances Score (median = 42.9, IntQ = 31.4; 60) was significantly higher than in the severe chronic disease sample (median = 38.6, IntQ = 28.6; 51.4), $p = 0.03$.

Par–DD-QoL scores and teenagers' characteristics (Table 4)

When we compared parents perceiving a high or moderate impact versus no impact of disease on their QoL, we observed that the impact of ASD on parental QoL (on the three Par–DD-QoL scores) was related to daily living skills, communication, socialization, OC and PC scores. High aberrant behavior scores (BD I, II, III and IV) and a high CARS score were also associated with a higher impact on the three scores of QoL ($p < 0.001$). When comparing parents perceiving a high impact on their QoL to those perceiving no impact, an elevated intervention time was linked to higher emotional ($p = 0.01$) and daily disturbance scores ($p = 0.03$). It should be noted that there was a positive correlation between the intervention time and severity of autism measured with CARS ($r = 0.2$; $p = 0.04$). A lower number of siblings was associated with a lower emotional score ($p = 0.04$), and an earlier diagnosis was associated with an increased global score ($p = 0.04$).

Moreover, psychoactive treatment and a worse expressive language were linked to higher Par–DD-Qol scores. It must be noted that all adolescents treated (46 %) with psychoactive drugs had higher scores of aberrant behavior than untreated adolescents (54 %), $p < 0.01$. A diagnosis of infantile autism versus atypical autism was related to a higher impact on daily disturbance score of parental QoL.

Table 1 Parents' characteristics

Parents' characteristics	Median	IntQ*
Parents' age		
Mother	46	(42; 49.5)
Father	49	(44; 52)
Children number	2	(2;3)
	N	%
Marital status		
Married	97	63.8
Single	32	21.1
Remarried or cohabiting	13	8.6
Other	10	6.6
Mother's professional situation		
Employed	92	60.9
House women	45	29.8
Long illness/disability	7	4.6
Unemployed	4	2.6
Retiree	2	1.3
Parental leave	1	0.7
Father's professional situation		
Employed	116	84.1
Housemen	1	0.7
Long illness/disability	7	5.1
Unemployed	7	5.1
Retiree	7	5.1
Parents' SES**		
Low	69	45.4
Middle	29	19.1
High	54	35.5

* IntQ: (Q25–Q75); ** parents' socioeconomic status (SES), scored as high (business owners, professionals, executives), middle (farmers, supervisors, skilled craftsmen) or low (farm workers, laborers and service employees)

Chronological age, age at first intervention, gender, epilepsy, socioeconomic status and parental age were not significantly linked to the Par–DD-QoL scores.

Risk factors for impact of ASD on parental QoL (Table 5)

The polytomic regressions showed that externalizing behaviors appeared to be the main risk factors for a high impact of ASD on parental QoL. A high ABC IV score (hyperactivity) significantly increased the risk for parents to perceive a high impact on their QoL (vs. no impact) for the three Par–DD-QoL scores. In addition, a high ABC I score (irritability) increased the risk for parents to perceive a high impact on their global and emotional QoL.

Table 2 Teenagers' characteristics

Adolescents' characteristics	Mean	SD
Chronologic age	15	1.6
	Median	IntQ*
CARS total score	33	(26.5; 39.5)
Adaptive behaviors (VABS) (month)		
Communication	25	(15; 76)
Socialization	24	(13.5; 56)
Daily living skills	44.5	(29; 80.5)
Cognition (month)		
Object	48	(27; 111)
Person	27	(09; 78)
Total intervention (h/week)	31.35	(29.7; 33)
Aberrant behaviors checklist (ABC)		
BD I (irritable, uncooperative)	15.6	(6.7; 37.8)
BD II (lethargy, withdrawal)	25	(14.6; 37.5)
BD III (stereotypy, self-injury)	23.8	(9.5; 42.9)
BD IV (hyperactivity)	22.9	(8.3; 41.7)
	N	%
Verbal expressive language		
Functional language	72	47.4
Words	28	18.4
Mute	52	34.2
Epilepsy		
Presence	26	17.1
Diagnosis		
Infantile autism	121	79.6
Atypical autism	31	20.4

SD standard deviation

* IntQ (Q25–Q75)

Conversely, an independent functioning and cognitive abilities were protective factors. The increase in the Vineland daily living skills decreased the risk for parents to perceive a moderate impact on their global QoL (vs. no impact), but it did not decrease the risk for a high impact. The increase in the Vineland communication skills decreased the risk for parents to perceive an impact on their daily disturbances score (vs. no impact). The increase in object-related cognition decreased the risk for an impact on emotional score.

Finally, the increase in hours of intervention received by adolescents increased the risk for their parents to perceive a high or moderate impact on their emotional QoL. Moreover, parents with at least two children had a lower risk for a high or a moderate impact on their emotional QoL.

Discussion

Despite the increasing interest in QoL of people with disabilities, studies have only recently begun to focus on individuals with ASD. Moreover, as QoL pertains not only to individuals but also to their family system, few researches have tried to identify aspects of family QoL. In this sample, we explored the impact of ASD on parental QoL in adolescence using a validated scale, Par–DD-QoL.

Findings of this study support the assertion that life satisfaction as perceived by parents is related to their children's characteristics and to the interventions they receive. Our results suggest that the increase in autism severity predicts decreased parental QoL [9, 40]. We also found that parental QoL decreases when aberrant behaviors such as irritability, lethargy, stereotypy and hyperactivity increases [41]. As in previous studies [42, 43], life satisfaction, as perceived by proxy respondents, decreases when independent functioning (extrapolated in our study from the results of the Vineland and cognition scales, and the assessment of language) decreases. We also detected a relationship between the decrease in Par–DD-QoL scores and the use of psychopharmacotherapy, whereas Kamp-Becker et al. [43] found no significant difference, hypothesizing that under successful psychopharmacotherapy symptoms should have been improved, raising QoL to a level equal to that of those who are not in need of medication. However, when testing the link between the use of psychopharmacotherapy and parental QoL while controlling for aberrant behavior, we found that adolescents treated with drugs had more challenging behaviors and that the alteration in parental QoL was an effect of challenging

Table 3 Comparison of Par–DD-QOL scores between our sample and another with severe chronic diseases

PAR–DD-QOL	ASD ($n = 152$)		Severe chronic diseases ($n = 208$)		p value[a]
	Median	Q25–Q75	Median	Q25–Q75	
Global score	46.7	(36; 60.7)	44.7	(36.7; 57.3)	NS
Emotional score	47.5	(37.5; 65)	50	(40; 62.5)	NS
Daily disturbance score	42.9	(31.4; 60)	38.6	(28.6; 51.4)	.03

Raysse [11]

[a] Mann and Whitney test

Table 4 Univariate analysis between teenager's characteristics and Par–DD-QoL scores

Predictor measures	Global score				Emotional score				Daily disturbance score			
	1: No impact ($n = 49$)	2: Moderate impact ($n = 46$)	3: High impact ($n = 53$)		1: No impact ($n = 51$)	2: Moderate impact ($n = 39$)	3: High impact ($n = 58$)		1: No impact ($n = 33$)	2: Moderate impact ($n = 50$)	3: High impact ($n = 65$)	
	Median (IntQ)			p*	Median (IntQ)			p*	Median (IntQ)			p*
Adaptive behaviors (VABS)												
Daily living skills	71 (44; 95)	40.5 (28; 65)	32 (23; 64)	0.0001^{a}	71 (41; 98)	38 (24; 65)	33 (24; 64)	0.0001^{a}	86 (58; 102)	46 (31; 78)	32 (24; 50)	0.0001^{a}
Communication	57 (20; 104)	21 (13; 57)	18 (13; 38)	0.0001^{a}	57 (20; 104)	18 (12; 56)	20.5 (14; 40)	0.0001^{a}	87 (39; 108)	22 (16; 57)	17 (12; 40)	0.0001^{a}
Socialization	47 (23; 73)	20.5 (13; 49)	19 (10; 48)	0.0001^{a}	48 (23; 73)	20 (10; 55)	18.5 (11; 48)	0.0001^{a}	55 (34; 73)	22 (15; 49)	18 (10; 48)	0.0001^{a}
ABC												
BD** I (irritable/ uncooperative)	8.9 (2.2; 13.3)	21.1 (8.9; 33.3)	33.3 (15.6; 51.1)	0.0001^{b}	11.1 (4.4; 17.8)	15.6 (6.7; 28.9)	33.33 (15.6; 53.3)	0.0001^{d}	6.7 (2.2; 13.3)	14.4 (6.7; 31.1)	26.7 (13.3; 48.9)	0.0001^{b}
BD II (lethargy/ withdrawal)	18.75 (10.4; 27.1)	25 (10.4; 41.7)	31.25 (18.7; 47.9)	0.002^{c}	18.75 (10.4; 29.2)	22.9 (10.4; 35.4)	31.25 (18.7; 52.1)	0.002^{c}	20.8 (10.4; 29.2)	19.8 (10.4; 33.3)	29.2 (16.7; 43.75)	0.03^{c}
BD III (stereotypy/ self-injury)	19.1 (4.8; 28.6)	23.8 (9.5; 42.9)	38.1 (19.1; 52.4)	0.0001^{d}	19.05 (4.8; 28.6)	23.8 (9.5; 42.9)	38.1 (19.1; 52.4)	0.0001^{d}	14.3 (0; 19.05)	23.81 (14.3; 42.9)	33.33 (19.05; 47.6)	0.0001^{a}
BD IV (hyperactivity)	8.3 (4.2; 18.75)	22.9 (12.5; 39.6)	39.6 (22.9; 60.4)	0.0001^{b}	10.42 (4.2; 22.9)	25 (8.3; 45.8)	36.5 (22.9; 60.4)	0.0001^{b}	6.25 (4.2; 18.75)	16.7 (8.3; 31.25)	37.5 (22.9; 58.3)	0.0001^{b}
Cognition (month)												
Object	87 (45; 147)	39 (27; 93)	33 (27; 75)	0.0001^{a}	99 (45; 159)	33 (27; 81)	33 (27; 81)	0.0001^{a}	111 (57; 147)	48 (33; 141)	33 (27; 75)	0.0001^{b}
Person	75 (27; 117)	27 (9; 63)	21 (9; 51)	0.0001^{a}	63 (27; 117)	27 (9; 51)	24 (9; 51)	0.0001^{a}	87 (33; 117)	27 (21; 75)	21(9; 51)	0.0001^{a}
Autism degree												
CARS total score	29.75 (25.5; 34.5)	32.75 (26.5; 39.5)	37.5 (30.5; 44)	0.001^{c}	29.75 (25.5; 34.5)	33.5 (27; 41.5)	36 (30.5; 41)	0.004^{c}	27.25 (24.8; 31.3)	33.5 (28; 39)	37 (28.8; 43.8)	0.0001^{a}
Socioenvironmental data												
Total intervention (h/week)	29.7 (29.7; 33)	33 (29.7; 33)	33 (28.6; 33)	0.1	29.7 (26.4; 33)	30.7 (29.7; 33)	33 (29.7; 33)	0.01^{c}	29.7 (26.4; 33)	33 (29.7; 33)	33 (28.6; 33)	0.03^{c}
Siblings number	2.5 (2;4)	2 (2;3)	2 (2;3)	0.4	3 (2; 4)	2 (2; 3)	2 (2; 3)	0.04^{c}	2 (2; 3.5)	3 (2; 4)	2 (2; 3)	0.6
Age at first diagnosis (month)	43 (36; 53.5)	39 (30; 60)	36 (24; 48)	0.04^{c}	42 (36; 48)	39 (30; 60)	36 (30; 48)	0.3	39 (30; 48)	42 (36; 50.5)	36 (30; 60)	0.4
	%			p**	%			p**	%			p**
Verbal expressive language												
Functional	67.3	43.5	34	0.004	66.7	41	36.2	0.02	75.8	46	35.4	0.00035
Words	14.3	26.1	17		15.7	17.9	22.4		15.2	26	15.4	
Mute	18.4	30.4	49.1		17.6	41	41.4		9.1	28	49.2	
Drug use												
Presence	22.4	54.3	56.6	0.0007	25.5	56.4	53.4	0.003	21.2	34	64.6	0.00004
Diagnosis												
Infantile autism	71.4	78.3	86.8	0.2	70.6	76.9	87.9	0.08	60.6	82	86	0.01
Atypical autism	28.6	21.7	13.2		29.4	23.1	12.1		39.4	18	14	

* Post hoc test: a = 1 versus 2, 3; b = 1, 2, 3 versus 1, 2, 3; c = 1 versus 3; d = 3 versus 1, 2; ** p value chi-square test; other covariables were tested: age (years), age at first advice and first intervention (month), parents' SES, epilepsy and parents' age

Table 5 Polytomic logistic regression analysis of factors related to Par–DD-QoL score

Risk factors	Global score	Unit	ORa*	CI 95 %	*p* value
BD I (irritable, uncooperative)	1[a]	20	2.4	(1.1; 5.2)	<0.0001
	2[b]	20	1.7	(0.8; 3.55)	
BD IV (hyperactivity)	1	20	2.5	(1.3; 4.9)	0.035
	2	20	1.9	(0.95; 3.7)	
Daily living skills(month)	1	20	0.8	(0.6; 1.1)	0.09
	2	20	0.7	(0.5; 0.9)	
	Emotional score	Unit	ORa*	CI 95 %	*p* value
BD I (irritable, uncooperative)	1	20	2.2	(1.03; 4.9)	0.02
	2	20	1.1	(0.5; 2.55)	
BD IV (hyperactivity)	1	20	3.2	(1.6; 6.4)	<0.0001
	2	20	2.7	(1.3; 5.7)	
Cognition related to object (month)	1	10	0.9	(0.87; 1.02)	0.01
	2	10	0.9	(0.78; 0.95)	
Total intervention (h/week)	1	10	2.6	(1.1; 5.9)	0.04
	2	10	2.4	(1.06; 5.6)	
Sibling’s number	1	2	0.3	(0.15; 0.7)	0.006
	2	2	0.4	(0.2; 0.8)	
	Daily disturbance score	Unit	ORa*	CI 95 %	*p* value
BD IV (hyperactivity)	1	10	2	(1.4; 2.9)	<0.0001
	2	10	1.5	(1.01; 2.1)	
Communication (month)	1	20	0.7	(0.5; 0.9)	0.006
	2	20	0.7	(0.6; 0.9)	

* Adjusted odds ratio

[a] 1: High impact versus no impact

[b] 2: Moderate impact versus no impact

behaviors. Moreover, a paradoxical result in this study is that parents perceived more impact on their emotional QoL when their child benefited from more hours of specialized intervention. It may be possible that children received more hours of specialized intervention due to a worse parental QoL, but we did not record data that would allow us to determine whether the parents requested more services or help due to their lower QoL. It could also be assumed that intervention models are not sufficiently adapted to family needs. They focus on externalizing difficulties by providing more intervention hours to individuals with challenging behaviors, but they do not provide enough help to parents in order to regulate their child’s behavior and communicate better with him/her at home. We showed a positive correlation between the hours of intervention and severity of autism, as measured with the CARS, and when we controlled the effect of this severity, the link between hours of intervention and QoL was still observed. Thus, even if the benefit provided to children by a high intervention time is not questioned by our results, they suggest that parental concerns in adolescence seem to be particularly high, as found in previous studies [27, 28], and that greater intervention time does not meet all parental expectations and is not enough to improve their emotional QoL. This result confirms the need of support groups for parents.

It was somewhat surprising that we did not find links between QoL perceived by parents and the age of their child at the beginning of interventions. Possible reasons are that many adolescents did not benefit from early interventions because there were not available and that early social support was not sufficiently focused on family needs and expectations. Considering that studies on adolescents with other developmental disorders showed that QoL worsened as the number of comorbid condition increased [44], it is interesting to note the absence of a significant link between Par–DD-R scores and the presence of epilepsy. The parents of adolescents with a diagnosis of infantile autism perceived significantly more impact on their QoL compared to those with a diagnosis of atypical autism. One reason could be that in this subgroup, children had more severe intellectual disability and consequently their parents could have greater concerns about their children's learning difficulties and adaptive behaviors. Moreover, children with atypical autism had more severe autistic behaviors than children with infantile autism. Parents reported less impact on their emotional QoL when there were more siblings, suggesting that this might counterbalance some of the negative effects of caring for a disabled child. This, as suggested by the study of family functioning [45], may have an influence on social support and coping among caregivers of children with autism. Finally, we found no link between QoL and parental socioeconomic status, perhaps indicating that social, economic and health policies as well as legislative reforms on support for disabled individuals and their families in France are of particular significance.

As in other studies [46], the polytomic regression demonstrated that challenging behaviors, notably hyperactivity and irritability, were the main independent risk factor for a high impact on the three parental QoL dimensions. As expected, an increase in cognitive and adaptive skills, possibly leading to a more independent functioning as measured by the Vineland daily living and communication scores, and cognition related to object score, was protective. In addition, a higher number of siblings seemed protective for the emotional Par–DD-QoL score, and we inferred that having another child without disability contributes to reinforce parental coping strategies and adaptation.

There are several limitations to the present study. First, the data presented here consists of a subset from a much larger study, in which the aim is to study the developmental trajectory of ASD (EpiTED cohort) [30]. Therefore, there is some potential bias linked to the fact that the observations were not collected at random. But given the high level of consistency with the other factor analysis studies of the Par–DD-QOL, we believe that this potential bias is limited at best. Second, the measurement of the interventions was a global one (number of weekly special interventions hours), and we can hypothesize that the type of interventions or parental satisfaction with the services [28] could have been a more valuable predictor of QoL. Third, only the impact of ASD on maternal QoL was analyzed, because very few fathers completed the questionnaires as they were often missing during the assessment of their child, the presence of only one parent being requested. There seems to be more impact on maternal QoL, as they more often stopped their professional activities and renounced their leisure activities [47] and for those reasons, we chose to study mothers' QoL. Finally, Parental QoL was collected only at the third time point of the EpiTED follow-up project, which does not allow a prospective analysis to be made. The reason for that was that QoL has been considered as especially relevant to conditions that are chronic such as ASD only recently. However, the follow-up of our cohort is still going on, and we are now collecting clinical and environmental variables at the adult age. This will allow us to compare the impact of ASD on parental QoL at adolescence and adult age, which might be especially relevant because several changes occur at that time (housing, type of interventions, etc.). The study of these changes will be the topic of a future article.

Conclusion

This is one of the rare studies on parental QoL in ASD in adolescence, using a standardized and specific instrument via the Par–DD-QoL scale. Our results suggest the consistency of this scale that could be used regularly in the future to assess the impact of ASD on emotional and daily life domains. A lower functioning level and higher aberrant behaviors scores are the main risk factors of a lower QoL among mothers.

Acknowledgments This study was supported by a grant from the Orange Foundation and the PHRC 1997 and 2007. We are extremely grateful to all the teenagers and their families who took part in this study, and the whole EpiTED Team.

Conflict of interest The authors have no conflict of interest to report.

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