

# Quality of Life in Parents of Young Adults with ASD: EpiTED Cohort

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## ABSTRACT

The impact of ASD on parental QOL was evaluated in the EpiTED cohort study at early adulthood. Two third of parents of young adults with ASD (66.7%) reported that their QoL was at least moderately altered. The perceived impact of ASD on parental QoL was related to the young adults' level of adaptive skills, as well as to symptom severity and the presence of challenging behaviors, which appeared to be the main risk factor. The study of change between adolescence and early adulthood showed that parents whose children had a decrease in challenging behaviors perceived a decreased impact on their QoL. These results argue for the importance to propose specific interventions to target associated challenging behaviors in ASD.

*Keywords* Parental QoL, Autism, Young adult, Cohort.

## INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong condition, potentially impacting the parental Quality of Life (QoL) in a persistent manner. It has been shown that parental QoL was particularly impacted in ASD (see Eapen and Guan, 2016, for a review), which may be related to unmet needs, smaller social support networks, or associated challenging behaviors (Craig et al. 2016; Davis and Carter 2008; Schieve et al. 2007). This impact can be moderated by several variables, including the person's cognitive and socio-adaptive profile, symptom severity and associated challenging behaviors (Baghdadli et al. 2014; Ingersoll and Hambrick 2011). Parental QoL is also likely to change across life as a function of their child's age. Entering adulthood is in particular a critical period for people with ASD, often associated with changes in the type of living, schooling and services (Taylor and Seltzer 2010). However, most studies on QoL focus on parents of young children, and there are very few studies about the transition from adolescence to adulthood in ASD and its impact on parental QoL.

Little is known about aging in autism spectrum disorder (Happé and Charlton 2011). With respect to adaptive skills, a poor outcome was described in a majority of cases, with few people attaining independence (Baghdadli et al. 2012; Billstedt et al. 2007). The diagnostic criteria and the educational approaches have considerably changed since people were included in these follow-up studies and the outcome of such groups may tell us little about the likely outcome of children with ASD diagnosed nowadays (Happé and Charlton 2011). However, increasing deficits in adaptive behaviors over time were also found in people with ASD who had good cognitive abilities (Pugliese et al. 2015). Regarding autism symptoms, some studies reported general improvements in many symptoms areas (Howlin et al. 2013; Seltzer et al. 2003), as well as improvement in sensory abnormalities (Kern et al. 2006) with increasing age. Overall, there might be a decrease in autism symptomatology over age, but adaptive deficits persist and sometimes increase with age. For those reasons, most adults with ASD still need a consistent support in their daily life, partially or totally assumed by the parents.

Moreover, many parents face significant life adjustments when their child grows older. Transition periods have been reported as a time of confusion and stress for families of people with developmental disabilities (Davies and Beamish 2009; Neece et al. 2009). Higher levels of caregiver burden in ASD were evidenced at adolescence and adulthood, with an association between burden and unmet needs in domains such as social relationships and mental health problem (Cadman et al. 2012). Another important issue when entering adulthood is that a large number of adults with autism remain without appropriate services and effective interventions (Barnard et al. 2001; Gerhardt and Lainer 2011; van Heijst and Geurts 2014). In a study about parental satisfaction, we found a

lower global satisfaction at adolescence as compared to childhood and adulthood, and the parents expressed greater concern about the future at this period of life (Rattaz et al. 2014). McStay et al (2014) found a stable level of stress and family QoL but less support from professionals at adolescence. In a study focusing on the transition period out of the educational system between 16 and 21 years old (McKenzie et al. 2016), parents reported higher perceived distress after their child's transition out of school. Parents also worry about what will happen to their children when they are not around to care for them anymore, and this might impact their quality of life in a significant manner (Eaves and Ho 2008; van Heijst and Geurts 2014). A few studies showed an improvement in maternal well-being when their child becomes adult (Lounds et al. 2007), as well as a decrease in depression and anxiety in parents of adolescents and adults compared to parents of children, but the levels of stress remained the same (Pozo and Sarriá 2015). As regards the potential factors related to parental QoL at adulthood, Boehm et al (2015) reported that a higher family QoL was related to lower frequency of challenging behaviors, lower support needs, and higher strength of parental religious faith in a sample of young adults with autism or intellectual disability.

Those results suggest that the impact of ASD on parental QoL is important and long lasting, and that parents face many new challenges when their children enter adulthood. However, there are very few studies about parental QoL at adulthood and the factors related to parental QoL at this period of life remain unclear. The goals of this study were to describe the perceived impact of ASD on parental QoL in the EpiTED cohort at early adulthood (T4 ; 18-23 years), and to examine the risk factors for an altered QoL as regards the adult's profile (cognitive and adaptive abilities) as well as the environment's characteristics (type of living, scholarship, social support, etc. Our secondary objective was to examine the changes in QoL from adolescence to early adulthood in the subgroup of parents who reported a decreased or increased impact on their QoL between adolescence (T3; 13-17 years) and early adulthood (T4; 18-23 years).

## **METHODS**

This research was approved by the Local Human Subject Protection Committee (CPP) and National Commission for Computing and Liberties (CNIL). All parents or tutors of subjects signed a consent form. EpiTED-cohort is recorded on AVIESAN Epidemiology-France portal.

### *Recruitment*

For this cross-sectional study, we only used a subset of data collected during the third and fourth time point of the EpiTED follow-up (Baghdadli et al. 2012). The EpiTED cohort was set-up in order to understand the heterogeneity of developmental trajectories among children with a diagnosis of Pervasive Developmental Disorder and the role of clinical, biological and environmental factors in their adaptive outcome. All the children included in the cohort had an ICD-10 based diagnosis of autistic disorder (WHO 1993) confirmed by autism diagnosis interviewed-revised ADI-R (Lord et al. 1994). In ICD-10 the use of “Atypical Autism” is equivalent to pervasive developmental disorder – not otherwise specified (PDD – NOS) using DSM-IV standards. They were followed during 15 years and were assessed four times (at 5, 8, 15 and 20 years on average, see flow chart in Figure 1). From 2000 to 2002, 219 of the original group was reassessed (time 2, T2). At time 3 (T3), between 2007 and 2009, 152 were re-assessed and between 2012 and 2015, 106 (time 4, T4). The parental quality of life was collected only at T3 and T4. The participants were the biological parents of 106 young adults with ASD, followed-up in the French project of EpiTED Cohort which examines changes in 106 children over a long lifespan period.

*[Place Fig 1 about here]*

### *Participants*

A description of the parents’ and young adults’ characteristics at time 4 is detailed in Table 1.

#### *Parents*

Participants consisted of the parents of young adults with ASD. The questionnaire was completed by mothers (68%), both parents (20%), fathers (10%) or tutors or guardians (2%). The two guardians were closely related to the families: the first one was the young adults’ brother, and the second one filled out the questionnaire by translating the parents’ responses, as the family did not speak French. Moreover, no differences were found between the respondents for the three QoL scores; for those reasons the analysis was performed by pooling all respondents. Mothers’ mean age was 51.8 years ( $\pm 4.4$  years) and fathers’ mean age was 55.1 years ( $\pm 6.8$  years).

#### *Young adults*

The young adults' mean age was 20.6 years ( $\pm 1.5$  years), the sex ratio was 6:1 (m:f). Most of the adults had a diagnosis of infantile autism (77.4%), and 15.1% a diagnosis of atypical autism. Eight children (7.5%) did not meet any more the criteria for an ASD diagnosis anymore. Language is functional in 50.9% of the young adults, absent in 31.2 % and limited to few words in 17.9%.

*[Place Table 1 about here]*

### *Measures*

*Parental - Developmental Disorder – Quality of Life (Par-DD-QoL)* was used to assess the impact of ASD on parental QoL on the following dimensions: Emotional, Daily Disturbance and Global QoL (Baghdadli et al. 2014). It is a QoL questionnaire for 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 ENT (Ear, Nose and Throat) infections (Berdeaux et al. 1998). 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 (Baghdadli et al. 2014; Raysse 2011). Par-DD-QoL contains 17 questions, each rated by parents on a 5 - point Likert scale. The questionnaire begins with the sentence: “because of child’s disorders, do you feel...”. The first fifteen questions concern the intensity of the difficulties encountered by parents, the sixteenth their frequency and the last one the global parental quality of life. 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 2 scores). Good internal consistency reliability was observed for 2 dimensions. Cronbach’s alpha coefficient was greater than 0.82 for each dimension (Baghdadli et al. 2014; Raysse 2011). The scores linearly transformed range from 0 to 100, 0 being the best and 100 the worst, assuming equal weights on each domain.

*Adaptive Behaviors* were assessed using the three sub-scales of the Vineland Adaptive Behavior Scale (VABS): Communication (COM) which involves the skills required for receptive, expressive, and written language, Daily Living Skills (DLS) which includes the practical skills that are needed to take care of oneself and contribute to a household, and Socialization (SOC) which pertains to those skills needed to get along with others (Sparrow et al. 1984). The VABS is a semi-structured interview which was administered to parents.

Scores derived from this instrument have a mean of 100 and a standard deviation of 15 with a Cronbach  $\alpha$  coefficient of 0.92. Age equivalent scores and standard scores were obtained for each domain. In the present study the measures are expressed in age equivalents (months) to improve comparability across tests.

*Aberrant Behavior Checklist (ABC)* (Aman et al. 1985), the ABC is a 58-item behavior rating scale used to measure behavior problems across four domains: irritability (ABC1), lethargy/withdrawal (ABC2), stereotypy (ABC3), hyperactivity (ABC4). Items are rated on a 4-point Likert scale (ranging from 0 [not at all a problem] to 3 [the problem is severe in degree]), with higher scores indicating more severe problems. The ABC was shown to have sound psychometric properties with high internal consistency among subscales (mean  $\alpha$  = 0.91), excellent test-retest reliability (mean  $r$  = 0.98), acceptable interrater reliability (mean  $r$  = 0.63), and moderate correlations with measures of adaptive behavior (mean  $r$  = 0.60) (Aman et al., 1985). Scores are reduced to a scale of 100 in order to make comparisons. Thresholds have been created to facilitate the description of the four clusters. The scores indicate low (<20), medium (20-40) and high (>40) levels of aberrant behaviors.

*Symptom severity* (Childhood Autism Rating Scale: CARS) and expressive speech were assessed based on observational data from video clips performed at adolescence (Schopler et al. 1988). The CARS consists of 15 items intended to measure the presence and severity of ASD. The child is rated on each item based on the clinician's observation of the child's behaviour throughout the evaluation as well as on the parent's report. The CARS includes items on socialization, communication, emotional responses, and sensory sensitivities. The CARS classifies a child as having mild, moderate, or severe autism, or no autism, with a cut-off of 30 for the presence of autism.

*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.

*Environmental variables* were assessed using a parental questionnaire. It contains several variables (1) about parents: age, age at the child's birth, being affiliated to a parental association, number of children, socio-economical status scored as high (business owners, professionals, executives), middle (farmers, supervisors, skilled craftsmen), or low (farm workers, laborers, and service employees), marital status (married, divorced, single), educational level (No qualifications, Elementary education, Secondary education, Higher level), professional situation (employment, unemployment, retirement, at home), financial aid (Yes/No), training on autism (Yes/No), and (2) about young adults: scholarship in mainstream schools (Yes/No), specialized service (Yes/No), type of living (with the parents or in a specialized center), protection measures (tutelage).

*Medical variables* were assessed using a parental questionnaire about health conditions (psychiatric disorder, epilepsy, diabetes, metabolic disorder, cardiac disorder, asthma, gastric reflux, renal illness, arterial hypertension) and functional disorders (gastrointestinal disease, sleeping disorder).

#### *Statistical analysis*

Descriptive statistics at time 4 were made using means and standard deviations or median and Inter-Quartile (25th-75th Quartile) for quantitative variables and proportions for categorical at the three times of the follow up. None of the continuous variables, tested with the Shapiro-Wilk test, had a normal distribution. The Par-DD-QoL scores did not have a Gaussian distribution, therefore, these scores were divided into 3 categories (no impact, moderate and high impact) according to terciles identified in a sample with severe chronic diseases (Baghdadli et al. 2014). "No impact" corresponds to a QoL score less than 40, "Moderate impact" corresponds to a QoL score between 40 and 57 and "High impact" corresponds to a score higher than 57.

For the first part of analysis, links at time 4 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. Factors predictive of parental quality of life were identified using polytomous logistic regressions analysis. 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 in the case of collinear variables).

For second part of analysis, the study of change was realized only on the sample of parents who perceived a decreased impact (for example high impact at T3 and moderate impact at T4) or increased impact (for example no impact at T3 and moderate impact at T4) on their QoL, using a generalized Mac Nemar test and the pondered kappa. To study the change in aberrant behaviors (ABC 1, 2, 3, 4) and adaptive behaviors (communication, socialization, daily living skills), the difference  $\Delta$  (Delta) between the scores at the two collection time points (T3 and T4) was calculated:  $\Delta$  (Variable) = (Variable value at T4) – (Variable value at T3). The effects of  $\Delta$ ABC scores or  $\Delta$ Vineland scores on changes in parental QOL global score were then analysed.

For polytomous logistic regression, the odd ratio (OR) and associated two-side 95% Wald type confidence intervals (CiS) were computed. To assess the predictive ability of the model, concordance rate between predicted and observed responses was calculated. The alpha-to-enter was set at 0.2 and alpha-to-exit was set at 0.10. The significance of adding or removing a variable from multivariate models were determined by



the maximum likelihood ratio test. The goodness-of-fit of the models was assessed using the Hosmer and Lemeshow test.

The significance level used was 5%. Statistical analyses were performed using SAS version 9.3 (SAS Institute, Cary, North Carolina).

## Results

### *I. Parental QoL at early adulthood (T4)*

#### *a. Par-DD-QoL scores and adult's / environmental characteristics at T4*

At T4, 38.1% of parents perceived a high impact of ASD on their QoL, 28.6% a moderate impact and 33.3% no impact. As regards subdomain scores, the daily disturbance QoL was highly impacted in 41.9% of parents, moderately impacted in 31.4% of parents, and not impacted in 26.7% of parents. There was a high impact on emotional QoL for 41% of parents, a moderate impact for 27.6% of parents, and no impact in 31.4% of parents.

The univariate analysis shows that the impact of ASD on global parental QoL was significantly related to adaptive skills (the three Vineland scores), symptom severity (CARS) and aberrant behaviors (the four ABC scores) (see Fig. 2). The adults whose parents report a high impact on their global QoL have lower adaptive skills (between 19 and 39 months in median at the three Vineland scores;  $p < .005$ ), higher symptom severity (CARS median score = 37.5;  $p < .02$ ), and higher ABC scores (between 31 and 38 in median at the four ABC scores;  $p < .0001$ ). The Daily Disturbance Score (DDS) was related to the same variables as global parental QoL but also to several environmental characteristics (scholarship, financial aid, protection measure) and verbal expressive language (see Fig. 2). The adults whose parents have an altered DDS have lower adaptive skills (between 13.5 and 38 months in median at the three Vineland scores;  $p < .0001$ ), higher symptom severity (CARS median score = 38;  $p < .0001$ ), higher ABC scores (between 31 and 42 in median at the four ABC scores; ABC1 and ABC4 =  $p < .0001$ ; ABC2 and ABC3 =  $p < .001$ ) and less expressive language. As regards environmental variables, most of these adults did not benefit from a scholarship (88.6%), a higher percentage of them was under guardianship (63.6%) and more parents benefited from a financial aid (86.4%). The link between benefiting from a financial aid and the DDS score might be explained by a strong collinearity between having a financial aid and the adaptive deficit measured at the Vineland scale. In fact, the attribution of a financial aid is largely dependent on the young adults' adaptive skills. For this reason, we decided not to include the variable financial aid in the multivariate model. The Emotional Score (ES) was significantly related to the 4 aberrant behaviors scores

(ABC1 and ABC4 =  $p < .0001$ ; ABC2 and ABC3 =  $p < .01$ ). The young adults whose parents report an altered emotional QoL have higher ABC scores (between 42 and 52 in median at the four ABC scores). There was no effect of the parents' socio-economical and marital status, educational level, age of parent at birth of the child, number of siblings, and affiliation to a parental association. The young adults' health conditions or functional disorders, as well as their type of service and living did not either appear to be significantly related to parental QoL.

*b. Predictors of parental QoL at early adulthood*

The polytomic logistic regression showed that externalizing behaviors appeared to be the main risk factor for a high impact of ASD on parental QoL at T4. The risk for parents to perceive a high impact on their global QoL was multiplied by 2.2 (95 % CI = 1.2-4.3) when the young adults had a higher ABC2 score (lethargy/withdrawal) and multiplied by 3.4 (95 % CI = 1.7-7.1) when the young adults had a higher hyperactivity (ABC4) score as compared to parents who perceived no impact on their QoL. Regarding Emotional score (ES), the risk for parents to perceive a high impact on their QoL was multiplied by 3.7 (95 % CI = 1.8-7.4) - and by 2.5 for a moderate impact (95 % CI = 1.2-5.3) - when the young adult had a higher ABC2 score (lethargy/withdrawal) as compared to parents who perceived no impact on their QoL. Similarly, the adults whose parents had an altered Daily Disturbance score (DDS) were significantly more likely to have higher lethargy (ORa = 2.4, 95 % CI = 1.7-10.7) and hyperactivity (ORa = 4.3, 95 % CI = 1.7-10.7) scores.

*[Place Table 2 about here]*

*II. Study of change in parental QoL between adolescence and adulthood*

*a. Discordance and Concordance*

The second objective of the study was to examine if the perceived impact on parental QoL changed between adolescence and adulthood. In Table 3, the absence of significant results indicates that the proportion of parents who perceived a decreased or increased impact on their QoL between T3 and T4 remains stable over the five-year period. However, the concordance coefficient (kappa) between the two collection times is weak (Global QoL=0.34,  $p = .001$ ; ES=0.37,  $p < .0001$ ; DDS=0.45,  $p < .0001$ ). This result means that, if the global repartition remains the same over the two collection time points, the impact of ASD on QoL changed for many parents. For

example, among the parents who indicated that ASD did not alter their global QoL at T4, only 47% were found in the same category at T3, whereas 35% reported a moderate impact and 18% a high impact on their QoL at T3. Overall, among the 106 parents, 54 (52%) experienced a decreased or increased impact on their QoL over the five-year period.

*[Place Table 3 about here]*

*b. Study of changes in global parental QoL between T3 and T4*

The following analysis was conducted only on the subgroup of parents who perceived a decreased impact or increased impact on their global QoL over the 5 years period (discordant pairs, N = 54, see Table 3). We examined the effects of  $\Delta$ ABC scores and environmental variables on changes in perceived parental QoL. Parents whose children had a decrease in irritability (ABC1), lethargy (ABC2), stereotypy (ABC3) and hyperactivity (ABC4) between T3 and T4 experienced a significant decreased impact on their QoL (all  $p$ s < .01). As regards environmental variables, we found that parents who perceived a decreased impact on their QoL were more often affiliated to a parental association ( $p < .03$ ). Health conditions, functional disorders, changes in Vineland adaptive scores ( $\Delta$  communication,  $\Delta$  socialization and  $\Delta$  daily living skill) and changes in CARS scores were not significantly linked to the change of global QoL scores.

*[Place Table 4 about here]*

## DISCUSSION

The first purpose of the current study was to examine QoL in parents of adults with ASD. Results show that parental QoL is moderately or highly impacted as a consequence of having a child with ASD in two third of parents, suggesting that the impact of ASD on families remains strong even when their children grow up and become young adults. Those results are congruent with the studies on parents of children and adolescents, who report a poorer quality of life compared to the general population (see Eapen and Guan, (2016), for a review). They suggest that parental QoL remains impacted in most families even when their children grow older. Similarly to the findings about parental QoL during childhood (Baghdadli et al. 2014; Beadle-Brown et al. 2009; Ingersoll and Hambrick 2011) and adulthood (Boehm et al, 2015), the perceived impact of ASD on parental QoL at adulthood was related to their children's characteristics, namely the level of adaptive skills, the severity of symptomatology and the presence of challenging behaviors. When examining the two sub-scores of the Par-DD-

QoL scale, we found that the daily disturbance score was related to the adult's adaptive skills but also to several environmental characteristics (scholarship, financial aid, protection measures). As regards scholarship, there might be a bias as it concerns adults who are attending university (a very small part of our sample), and who have therefore a high intellectual level. The lower impact on parental QoL might be more related to their children's cognitive and adaptive level than to scholarship per se. The other environmental variables that appear to be linked the parents' daily life were availability of financial aid and a protection measure for the adults with ASD, which is not surprising as both of them can be viewed as concrete supports for parents. The emotional score was related to aberrant behaviors, indicating that the presence of such behaviors has a particularly strong impact on parental psychological well-being (stress, anxiety, sleep problems, etc.), congruently with the literature review (Boehm et al. 2015; Ingersoll and Hambrick 2011; Lecavalier et al. 2006; McStay et al. 2014).

The polytomic regression demonstrated that challenging behaviors were the main risk factors for an impact on parental QoL, particularly the lethargy/withdrawal, irritability, and hyperactivity domains. Interestingly, the stereotypy domain did not appear as a risk factor at this point. This domain is strongly related to ASD, as the presence of stereotypies and repetitive behaviors are part of the diagnostic criteria (DSM-5), but it did not appear to significantly impact parental QoL. The behaviors that most impact parental QoL were the lethargy/withdrawal behaviors, probably because of their consequences on family life (limitations of daily activities and social participation) and the associated challenging behaviors such as irritability and hyperactivity. These results encourage taking into consideration associated behavior problems and ASD co-morbidities as suggested in the ESSENCE model developed by Gillberg (2010) and in the DSM-5, with interventions at several levels aiming the different co-morbidities or challenging behaviors (Baeza-Velasco et al. 2014).

Our second purpose was to study the changes in parental QoL from adolescence to adulthood. On the whole population, the proportion of parents who perceived a high impact, moderate impact or no impact on their QoL remained stable over the five-year period. However, this stability was specious because as the concordance study showed, more than half parents moved from one category to another between the two collection times (for example perceived no impact of ASD on QoL at T3 and a moderate impact at T4). Results showed that parents whose children had a decrease in challenging behaviors experienced a decreased impact on their QoL. These results are congruent with the data above, suggesting that, when entering adulthood, challenging behaviors are the strongest predictor of parental QoL (Boehm et al. 2015). Another interesting result is that parents who

experienced a decreased impact on their QoL were more likely to be affiliated to a parental association, which is a substantial form of social support. Many studies yielded the importance of social support in parental QoL (Cappe et al. 2011; Pozo et al. 2014), and because of the difficulties they encounter in their daily life, parents who report an impact of their child's disorders on their QoL are probably more likely to look for social support.

Overall, parental QoL at early adulthood appears to be mainly predicted by the presence of challenging behaviors whereas at adolescence parental QoL was also predicted by their children's adaptive level, namely the communication and daily living skills (Baghdadli et al. 2014). The results of the present study suggest that, when entering adulthood, the adaptive level does not play a protective role anymore in parental QoL. The impact of challenging behaviors on family life argues for the importance to propose specific interventions to target these behaviors. It is also crucial to provide parental training and guidance as parental involvement and knowledge was found to be one of the key factors that predicted parental satisfaction (Renty and Roeyers 2006).

There are several limitations to the present study. First, the data presented here consist of a subset of a much larger study, which aims at studying the developmental trajectory of ASD (EpiTED Cohort). Therefore, there is some potential bias linked to the fact that the observations were not collected at random. However, 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. Secondly, the attrition rate at each stage of the cohort follow-up was on average 20%, but patients lost at T2, T3 or T4 had similar characteristics at T1 as the followed-up patients for age, autistic degree, adaptive behaviours, presence of speech, parent' socio-economic status, epilepsy, congenital or chromosomal abnormalities. Thirdly, the use of the CARS as an indication of autism severity can be criticized. We chose this tool as, when the first collection time began in 1997, there was no other existing tool to measure autism severity. We took several precautions to minimize the potential bias (double blind cotation, same three investigators for the 106 patients at T4). Finally, it would have been interesting to have more information about other parental variables which might be related to QoL such as coping, depression and parental stress, and to include them in the multivariate model. These variables were not collected in the EpiTED cohort, but will be included in the new French cohort study we are currently working on (ELENA cohort).

## CONCLUSION

The present study focuses on the impact of ASD on parental QoL during a particularly crucial period, the transition from adolescence to early adulthood. As in childhood, the perceived impact on parental QoL was related to the young adult's adaptive level and symptomatology severity. These results show that having a child with ASD has long term effects on the parents' QoL, with several implications on their daily life but also on their emotional well-being. As regards risk factors, our results suggest that parental QoL at this period was mainly predicted by the presence of challenging behaviors in their children. For parents who experienced a loss in QoL between adolescence and adulthood, these changes were mainly due to the increase in challenging behaviors in their children. This crucial and long-term impact of challenging behaviors on parental QoL argue for the importance to propose specific interventions to prevent challenging behaviors and to target these behaviors when they occur, as well as to provide social support to families. Research on parental QoL at adulthood is rare, and we plan to conduct future studies on this topic with the same cohort growing older, in a longitudinal perspective.

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Table 1 Parents' and young adults' characteristics)

<b>Parents' characteristics (n=106)</b>		
<i>Marital status</i>		<b>%</b>
	Married	63
	Single	30
	Remarried or cohabiting	7
<i>Parents' SES</i>		<b>%</b>
	Low	50.5
	Middle	22.8
	High	26.7
<i>Training on autism</i>	Yes	22
<i>Affiliated to a parental association</i>	Yes	38.1
<i>Number of siblings</i>	Median (IntQ)	
	2 (2;3)	
	Mother	Father
<i>Parents' age (year)</i>	Median (IntQ)	Median (IntQ)
	52 (48;55)	55(50;59)
<i>Study level</i>	<b>%</b>	<b>%</b>
	No qualifications	1.9
	Elementary education	11.7
	Secondary education (high school)	40.8
	Higher level (college /graduate school)	45.6
<i>Professional situation</i>	<b>%</b>	<b>%</b>
	Employed	54.5
	House women or men	22.8
	Long illness/disability	7.9
	Retired	4
	Unemployed	10.9
<b>Young adult characteristics</b>	Median (IntQ)	
<i>Vineland (month)</i>		
	Communication	29.5 (16;91)
	Socialization	24.0 (9;73)
	Daily Living Skills	49.5 (30;95)
<i>Autism degree (CARS total score)</i>	35 (25.5;42)	
<i>Aberrant behaviors checklist (ABC)</i>		
	ABC1 (irritability, uncooperative)	17.8 (4.4;33.3)
	ABC2 (lethargy, withdrawal)	27.1 (12.5;45.8)
	ABC3 (stereotypy)	23.8 (9.5.;47.6)
	ABC4 (hyperactivity)	17.7 (8.3;37.5)
<i>Scholarship</i>	<b>%</b>	
	Yes	19.8
<i>Educational level</i>		
	Without qualification	83.8
	Vocational/technical school	5.7
	High school diploma	7.6
	College / University	2.3
<i>Protection measures (tutelage)</i>	Yes	63
<i>Specialized service</i>	Yes	82.1

\*IntQ= (Q25; Q75);\*\* Parents' socio-economic status (SES), scored as high (business owners, professionals, executives), middle (farmers, supervisors, skilled craftsmen), or low (farm workers, laborers, and service employees).

Table 2 Polytomic regression analysis of factors related to Par-DD-QoL scores

<b>Risk factors</b>	<b>Global score</b>	<b>Unit</b>	<b>ORa*</b>	<b>CI 95%</b>	<b>p-value</b>
<b>ABC2 (Lethargy/withdrawal)</b>	<b>1</b> <sup>a</sup>	20	2.2	(1.2 ; 4.3)	<0.0001
	<b>2</b> <sup>γ</sup>	20	1.7	(0.9 ; 3.1)	
<b>ABC4 (Hyperactivity)</b>	<b>1</b>	20	3.4	(1.7 ; 7.1)	0.04
	<b>2</b>	20	1.8	(0.9 ; 3.8)	
	<b>Emotional score</b>	<b>Unit</b>	<b>ORa*</b>	<b>CI 95%</b>	<b>p-value</b>
<b>ABC1 (Irritable, uncooperative)</b>	<b>1</b>	20	3.7	(1.8 ; 7.4)	0.0005
	<b>2</b>	20	2.5	(1.2 ; 5.3)	
	<b>Daily disturbance score</b>	<b>Unit</b>	<b>ORa*</b>	<b>CI 95%</b>	<b>p-value</b>
<b>ABC4 (Hyperactivity)</b>	<b>1</b>	20	4.3	(1.7;10.7)	<0.0001
	<b>2</b>	20	2.1	(0.8 ; 5.3)	
<b>ABC2 (Lethargy/withdrawal)</b>	<b>1</b>	20	2.4	(1.7;10.7)	0.06
	<b>2</b>	20	1.7	(0.8 ; 5.3)	

\*Adjusted Odds Ratio; <sup>a</sup> 1: High Impact vs. No impact; <sup>γ</sup> 2: Moderate Impact vs. No Impact

Table 3 Study of change between T3-T4

		at Time 4									Generalized Mc Nemar Test	
		1.No impact			2.Moderate impact			3. High impact				
at Time 3	<b>Global score</b>	n	% col		n	% col		n	% col		<b>p_value</b> NS	
	1.No impact	16	47%	stable*	16	53%	loss	2	5.0%	loss		
	2.Moderate impact	12	35%	gain	7	23%	stable	11	28%	loss		
		3. High impact	6	18%	gain	7	23%	gain	27	68%	stable	
	<b>Daily living score</b>											NS
	1.No impact	14	50%	stable	7	22%	loss	0	.			
	2.Moderate impact	6	21%	gain	16	50%	stable	11	25%	loss		
		3. High impact	8	29%	gain	9	28%	gain	33	75%	stable	
	<b>Emotional score</b>											NS
1.No impact	18	56%	stable	12	41%	loss	6	14%	loss			
2.Moderate impact	10	31%	gain	9	31%	stable	10	23%	loss			
	3. High impact	4	13%	gain	8	28%	gain	27	63%	stable		

\*(T4-T3)

Table 4 Comparison of the two groups of global parental QoL: aberrant behaviors and environmental variables

	Global QoL				P-value
	Decreased impact		Increased impact		
	Mean	SD	Mean	SD	
$\Delta^*$ ABC1 : Irritability/ aggressiveness	-13.9	16.7	5.5	14.5	0.0001
$\Delta$ ABC2 : Lethargy/ withdrawal	-7.7	17.8	13.6	17.4	0.0001
$\Delta$ ABC3 : Stereotypy	-9.1	21.7	6.1	21.8	0.015
$\Delta$ ABC4 : hyperactivity	-15.9	25.1	2.9	17.6	0.002
Affiliated to a parental association		%		%	
Yes		48		20.7	0.03
No		52		79.3	

\* $\Delta$  = (Value at T4 – Value at T3)