



Impact of Autism Spectrum Disorders on Parental Quality of Life in Early Adulthood

Raffaz C., Michelon C., Baghdadli A.
Autism Resources Center, Montpellier, France



Background and objectives

Autism Spectrum Disorders (ASD) have a known impact not only on the person's Quality of Life (QoL), but also on the family QoL. This impact was shown to be moderated by several variables, including the person's cognitive and socio-adaptive profile, symptom severity and associated challenging behaviors. 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.

Objectives

- Describe the perceived impact of ASD on parental QoL in the EpiTED cohort at early adulthood (T4 ; 18-23 years)
- 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, etc.)
- Examine the changes in parental QoL from adolescence to early adulthood

PAR-DD-QOL

Adapted from the questionnaire PAR-ENT-QoL Exclusive property of PIERRE FABRE

From 1 (Not at all) to 5 (A lot)

Currently, due to your child's disorder, ...

- Are you worried?
- Are you more stressful than usual?
- Do you, in general, get impatient more easily?
- Do you feel annoyed?
- Does that affect your mood?
- Is the quality of sleep affected by any of the following: worry, stress, impatience, annoyance and loss of spirit?
- Do you have less time for others members of the family?
- Do you have to reduce your outings and leisure?
- Is your daily life disturbed by last minute changes?
- Is the quality of your outdoor or house work affected?
- Do you have any difficulty with planning your time schedule?
- Do you have to pay any fees?
- Do you feel incapacitated or powerless?
- Have his (or her) troubles any repercussions on your own health?
- Are his (or her) disorders a source of tension and misunderstanding within the family?
- Does your child wake you up during the night because of his (or her) disorders?
- Due to your child's disorder, would you say your Quality of Life is :
1 (Unchanged) to 5 (A lot worsened)

Acknowledgements

We wish to sincerely thank the participants and their families for their valuable and long-lasting collaboration and their confidence in our study. We also extend our thanks to the research teams for their support during the past 15 years. A special thought to Nathalie Fallourd, Camille Souche and Carolina Baeza-Velasco for their help with the data collection and to Colette Boy for her help with the literature review.

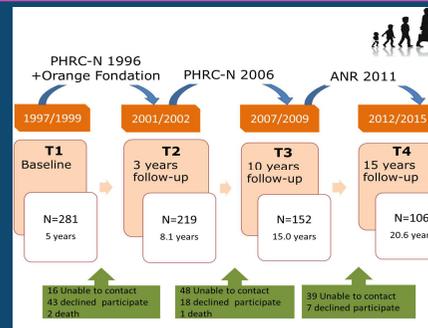
Methods

Design

Subset of data collected at the fourth time of a long term prospective follow-up study (EpiTED) of a population-based cohort diagnosed with ASD in childhood and followed into early adulthood.

Population

One hundred and six young adults participated at the fourth time of the cohort : 85% male, mean age of 20.6 years (± 1.5).



Results

Par-DD-QoL scores and associated variables

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. The impact of ASD on global parental QoL was significantly related to adaptive skills, symptom severity and aberrant behaviors. The Daily Disturbance Score (DDS) was also related to several environmental characteristics (scholarship, financial aid, protection measure).

Global QoL	<ul style="list-style-type: none"> Adaptive skills (Communication, Socialization, Daily living - Vineland ; p<0.003) Severity symptom (CARS; p<0.03) Aberrant behaviors (ABC1: irritability, ABC2: lethargy, ABC3: stereotypy, ABC4: hyperactivity; p<0.003)
Emotional	<ul style="list-style-type: none"> Aberrant behaviors (ABC1: irritability; p<0.001; ABC2: lethargy; p<0.01; ABC3: stereotypy; p<0.002; ABC4: hyperactivity; p<0.0001)
Daily Disturbances	<ul style="list-style-type: none"> Adaptive skills (Communication, Socialization, Daily living - Vineland ; p<0.003) Severity symptom (CARS; p<0.001) Aberrant behaviors (ABC1: irritability; p<0.001; ABC2: lethargy; p<0.01; ABC3: stereotypy; p<0.002; ABC4: hyperactivity; p<0.0001) Environmental Characteristics (Protection measures; p<0.04; scholarship p<0.002; financial aid; p<0.01) Verbal expressive language (p<0.01)

Predictors of parental QoL at early adulthood

Risk factors	Global QoL	Unit	OR*	CI 95%	p-value
ABC2 (Lethargy/withdrawal)	1 ^a	20	2.2	(1.2; 4.3)	<0.001
	2 ^v	20	1.7	(0.9; 3.1)	
ABC4 (Hyperactivity)	1	20	3.4	(1.7; 7.1)	0.04
	2	20	1.8	(0.9; 3.8)	
Emotional					
ABC1 (Irritable, uncooperative)	1	20	3.7	(1.8; 7.4)	0.0005
	2	20	2.5	(1.2; 5.3)	
Daily disturbance					
ABC4 (Hyperactivity)	1	20	4.3	(1.2; 10.7)	<0.001
	2	20	2.1	(0.8; 5.3)	
ABC2 (Lethargy/withdrawal)	1	20	2.4	(1.7; 10.7)	0.06
	2	20	1.7	(0.8; 5.3)	

*Adjusted Odds Ratio; ^a 1: High Impact vs. No impact; ^v 2: Moderate Impact vs. No Impact

As regards risk factors, the polytomous regression showed that externalizing behaviors appeared to be the main risk factor for a high impact of ASD on parental QoL at T4.

Questionnaire

The impact of ASD in young adults on parental QoL was assessed using a questionnaire completed by parents (Parental-Developmental Disorder-QoL scale; Par-DD-QoL). This scale assesses the following dimensions: emotional, daily disturbance and global QoL. For each dimension, higher scores indicated that the parent had greater difficulties related to the child's disorder.

Study of change 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 (N=54). The decreased impact on parental QoL was related to a decrease in irritability (ABC1), lethargy (ABC2), stereotypy (ABC3) and hyperactivity (ABC4). We also found that parents who perceived a decreased impact on their QoL were more often affiliated to a parental association.

	Decreased impact		Increased impact		P-value
	Mean	SD	Mean	SD	
A* ABC1 : Irritability/aggressiveness	-13.9	16.7	5.5	14.5	0.0001
A ABC2 : Lethargy/withdrawal	-7.7	17.8	13.6	17.4	0.0001
A ABC3 : Stereotypy	-9.1	21.7	6.1	21.8	0.015
A 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		

*A = |Value at 4 - Value at T3|

Conclusion

Results show that parental QoL was moderately or highly impacted in two third of parents, suggesting that the impact of ASD on families remains strong even when their children grow up. 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. Finally, the study of change in parental QoL between adolescence and adulthood showed that parents whose children had a decrease in challenging behaviors experienced a decreased impact on their QoL. The EpiTED study remains an active cohort and we plan to perform a fifth follow-up time from 2018 to 2019. Our objective in the future will be to study the role of psycho-social factors (for example stress, anxiety, coping, social support) on parental QoL.