

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

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Background and objectives

Autism Spectrum Disorders (ASD) are lifelong neurodevelopmental conditions characterized by significant deficits in social and communication domains, as well as restrictive, repetitive behaviours, interests or activities (APA 2013). ASD have a known impact not only on the person's Quality of Life (QoL), but also on the family QoL, similar to chronic diseases. Quality of life is a multidimensional concept, broader than health and well-being, covering multiple domains such as relational, psychological and physical aspects (Fig. 1). 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.

Our primary objective is to compare evolution of QoL in parents of young adults with ASD between the ages of adolescence and early adulthood (T3 to T4).

Our second aim is to determine the factors associated with impaired QoL, considering the adolescent's characteristics (symptom severity, adaptive behaviors, psychological development, challenging behaviors), the amount of weekly interventions, and parental socio-economic status.



Figure 1: Quality of Life concept (Schallock, 2004)

Methods

Design: This cross-sectional study uses a subset of data collected at the fourth time of a long term prospective follow-up study of a population-based cohort diagnosed with ASD in childhood and followed into early adulthood : EpiTED cohort (Fig. 2). The participants had an ICD-10-based diagnosis of autism, confirmed by autism diagnosis interview-revised (ADI-R).

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), 77.4% met criteria for childhood autism, 15% for atypical autism and 7.6% are optimal outcome. 21% have a functional language and 55% use less than 5 words.

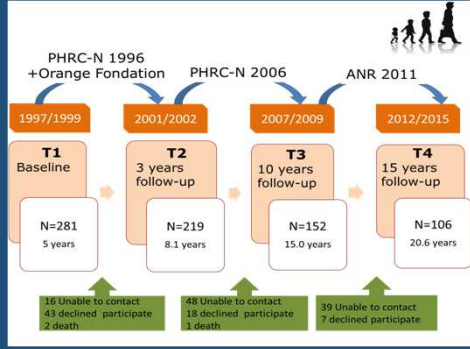


Figure 2: Flow chart of EpiTED Cohort

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). It contains 17 questions, each rated by parents on a 5 - point Likert scale. This scale assesses the following dimensions: emotional, daily disturbance and global QoL. This data was collected during the third and fourth point of follow-up (Fig. 2).

For each dimension, higher scores indicated that the parent had greater difficulties related to the child's disorder.

Results

The thresholds used for the Global score of QoL were established in a child population with chronic disease. At time 4, the parents report that their QoL is not altered for 33% of them, moderately altered for 28.5% and altered for 38.5%. Table 1 shows no overall significant difference between T3 and T4. However we observe some changes in the groups' distribution. QoL improves in some families and decreases in others, for example 53% of parents who were in the not altered group at T3 are in the moderately altered group at T4.

The univariate analysis identified multiple factors that play a role in parental QoL, such as intensity of autism symptoms, language level, behavioural disorders and adaptive functioning (table 2). Unlike some studies we found no link between the parental QoL and several characteristics of parents such as parental age at birth, social support, the level of training on autism and financial aid. Likewise for characteristics of children, such as epilepsy, type of interventions (schooling, specialized services).

At time 4, the main risk factors identified by multivariate analysis are behavioural disorders and the level of social adaptive skills already present at adolescence (T3). However, the intensity of autism symptoms and the language level have no impact on parental QoL. The model is adjusted on the chronological age.

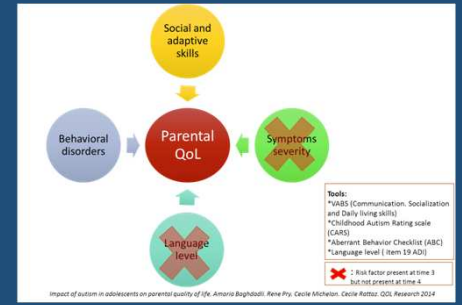
Table 1: Discordance analysis

| | at Time 4 | | | | | | Generalized Mc Nemar's test p_value |
|---------------------------|----------------|-------|---------------|-------|------------|-------|--|
| | 1. Not altered | | 2. Moderately | | 3. Altered | | |
| Global score | n | % col | n | % col | n | % col | NS |
| 1. Not altered | 16 | 47 | 16 | 53 | 2 | 5 | |
| 2. Moderately | 12 | 35 | 7 | 23 | 11 | 28 | |
| 3. Altered | 6 | 18 | 7 | 23 | 27 | 68 | |
| TOTAL | 34 | | 30 | | 40 | | |
| Daily living score | | | | | | | NS |
| 1. Not altered | 14 | 50 | 7 | 22 | 0 | . | NS |
| 2. Moderately | 6 | 21 | 16 | 50 | 11 | 25 | |
| 3. Altered | 8 | 29 | 9 | 28 | 33 | 75 | |
| TOTAL | 28 | | 32 | | 44 | | |
| Emotional score | | | | | | | NS |
| 1. Not altered | 18 | 56 | 12 | 41 | 6 | 14 | NS |
| 2. Moderately | 10 | 31 | 9 | 31 | 10 | 23 | |
| 3. Altered | 4 | 13 | 8 | 28 | 27 | 63 | |
| TOTAL | 32 | | 29 | | 43 | | |

Table 2: Univariate analysis at time 4

| Time 4 | 1. Not altered (n=35) | 2. Moderately (n=40) | 3. Altered (n=35) | p-value |
|---|---------------------------------|---------------------------------|--------------------------------|---------|
| Symptoms severity: CARS score | Median (IntQ) 28.5 (23.5;41) | Median (IntQ) 34.2 (25;41.5) | Median (IntQ) 37.75 (31;44) | 0.02 |
| Adaptive behaviours (VABS) | | | | |
| Communication | 56 (18;144) | 53.5 (17;95) | 19 (13.5;43) | 0.005 |
| Socialization | 34 (10;110) | 36 (13;83) | 13.5 (6.5;33.5) | 0.007 |
| Daily living skills | 62 (38;162) | 72 (37;130) | 38 (26;60.5) | 0.006 |
| Aberrant Behaviour Checklist (ABC) | | | | |
| BD I: irritable/uncooperative | 6.7 (0;20) | 17.8 (4.4;33.3) | 31.1(13.3;44.4) | <0.0001 |
| BD II: lethargy/withdrawal | 17.7 (4.2;29.2) | 31.2 (16.7;47.9) | 35.4 (20.8;58.3) | <0.0001 |
| BD III: stereotypy/self-injury | 14.3 (0;23.8) | 23.8 (9.5;52.4) | 38.1 (23.8;57) | <0.0001 |
| BD IV: hyperactivity | 7.2 (4.2;16.7) | 16.7 (8.3;31.3) | 33.3 (20.8;50) | <0.0001 |
| Verbal expressive language | % | % | % | |
| Functional | 54.3 | 66.7 | 37.5 | 0.08 |
| Words | 22.9 | 13.3 | 17.5 | |
| Mute | 22.9 | 20.0 | 45.0 | |

Figure 3: Multivariate analysis at time 4



Conclusion

These results suggest that there is a negative effect of externalizing behaviors (such as irritability, hyperactivity and lethargy) and a protective effect of adaptive skills (in particular the level of communication) on parental QoL. The impact of language level and the symptoms severity on parental QoL appears less important in the population of young adults with ASD compared to adolescents (T3). We can conclude that identification of risk and protective factors for parental could be used to suggest specific support to parents, including information and training about the management of externalizing behaviors. 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.

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