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**Title:** “An ecological exploration of individual, family, and environmental contributions to parental quality of life in autism”

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## **Abstract**

The aim of this study was to assess the respective weight of individual and environmental factors on quality of life (Qol) of parents of children with autism spectrum disorders (ASD). Few studies have investigated both individual and environmental predictors of Qol but to our knowledge, none of them has considered the child's and parents' characteristics, family context and services available in the same design. Participants were 115 parents (73 mothers and 42 fathers) of children with ASD aged from 3 to 10 years. Hierarchical regression analyses were conducted to investigate predictors of parental Qol among child-related, parent-related and environmental factors. Findings indicate that a higher Qol is associated with a good quality of interaction in marital and parent-grandparents dyads, no family medical history and access to psycho-educational interventions for the child, regardless of child's developmental quotient, comorbidity, parent sex and working time. This final model best fits the data and explains 31.5% of the variance of parents' Qol. This study highlights that it is crucial to consider both individual and environmental variables as potential protective factors of parental adjustment. An ecological approach seems to be relevant to understand which parenting resources should be targeted in support programs.

Keywords : autism spectrum disorders (ASD); quality of Life; parents; environmental factors; individual factors; ecological approach

## 1. Introduction

Children with Autism Spectrum Disorders (ASD) have communication and social deficits that can impact parents' functioning and daily life. Caregivers have often costs and special needs in marital, financial, social and professional areas (Derguy, Michel, M'Bailara, Roux, & Bouvard, 2015; Fletcher, Markoulakis, & Bryden, 2012). Mothers and fathers of children with ASD experience higher level of stress (Baker-Ericzen & Brookman-Frazer, 2005; Dabrowska & Pisula, 2010; Estes et al., 2009; Johnston et al., 2003; Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004). In the same way, they reported higher alteration of their QoL than parents of typically developing children (Allik, Larsson, & Smedje, 2006; Khanna et al., 2010; Kheir et al., 2012; Lee, 2009; Pisula & Porębowicz-Dörsmann, 2017; Yamada et al., 2012) and those of children with other neurodevelopmental disorders (Lee, 2009; Mugno, Ruta, D'Arrigo, & Mazzone, 2007a).

While many studies have focused on identifying predictors of negative outcomes - particularly the parental stress - (e.g. Derguy, M'Bailara, Michel, Roux, & Bouvard, 2016) there are fewer and heterogenous data on what determines a good parental QoL (McStay, Trembath, & Dissanayake, 2014). However, addressing this issue is particularly crucial in the case of ASD because it is a lifelong disorder and it has no cure. Hence, a better understanding the predictors of QoL is an important challenge to improve parenting programs.

Most previous studies have focused on children related factors. Regarding demographic variables, there is no consensus about the impact of the child age: McStay et al. (2014) did not show any significant difference while others reported either a positive (L A Dardas & Ahmad, 2014b; Mugno et al., 2007a) or a negative correlation (Kousha, Attar, & Shoar, 2016) with parental QoL.

As regards to clinical variables, negative associations between parental QoL and autism severity have been shown (Baghdadli, Pry, Michelon, & Rattaz, 2014; É. Cappe, Poirier, Sankey, Belzil, & Dionne, 2017; McKeachie, Moffat, Johnstone, & Fletcher-Watson, 2017). In the same way, high scores of challenging behavior and developmental delay are associated with low scores of parental QoL and well-being (Baghdadli et al., 2014; Nuske, Hedley, Tseng, Begeer, & Dissanayake, 2017; Samadi & McConkey, 2012). Finally, children's comorbidities and communication problems are associated with a low QoL (Garrido, Carballo, Franco, & García-Retamero, 2015; Zablotsky, Anderson, & Law, 2013).

As far as parents' characteristics are concerned, some studies have reported differences between mothers and fathers on QoL, with mothers having lower scores (Dabrowska & Pisula, 2010; Ji et al., 2014; Kheir et al., 2012; Mugno et al., 2007a; Yamada et al., 2012), while others did not show any differences (L A Dardas &

Ahmad, 2014a, 2014c; Hastings, 2003). Then, Qol is positively associated with several socio-economic factors such as family income, parents' education level and the working time (e.g. Favero-Nunes & Gomes, 2010; Hatton & Emerson, 2009; Parish, Seltzer, Greenberg, Floyd, & Taylor, 2004; Yamada et al., 2012).

Finally, regarding environmental factors, previous study suggested that marital support was positively associated with Qol and well-being in mothers (Benson & Kersh, 2011; McStay et al., 2014). With regard to the social network, perceived social support is negatively associated with Qol in parents (Ji et al., 2014; Khanna et al., 2010). The parental Qol could be also impacted by services available for the child. Indeed, psychological well-being of mothers are more important when the child is schooled (Baghdadli et al., 2008). In addition, studies have failed to reach consensus on whether the diagnosis precocity have a positive or a negative impact on parental Qol. Indeed Ji et al. (2014) reported a better parental Qol with an early diagnosis while Kousha et al. (2016) showed the opposite. This difference in results may be due to the difference in children's age between studies and/or the diversity of caregivers interviewed in the first study (mothers, fathers, grandparents, aunts).

While there are a number of identified factors of parental Qol, some disagreements between studies remain and several limitations could be raised.

So far, very few studies have investigated both individual and environmental predictors of Qol (Kousha, Attar, & Shoar, 2015; e.g. McStay et al., 2014) but to our knowledge, none of them have considered the child's and parents' characteristics, family context and services available in the same design. However, Belsky's model (1984) emphasises that one's parenthood must be analysed "in context", taking into account various proximal and distal factors as the parent's personal characteristics (e.g. personality traits), the child's personal characteristics (e.g. sex, presence of a disability) and contextual characteristics (e.g. family and marital relationships, care services). This model justifies the relevance of adopting an ecological approach, which takes into account environmental factors as differences among countries' health policies. Actually, there are very few studies on quality of life predictors have been conducted among a sample of French parents. It is very important to fill this gap, especially since there are real differences in services context in France (Chamak & Bonniau, 2013). For example, the situation of schooling for children with ASD in France is still far below national and international targets (Convention on the Rights of Persons with Disabilities, 2006). In 2011, 65% of French teachers surveyed believe that the place of a child with autism is in a specialized institution (OpinionWay survey for "le Collectif Autisme" conducted March 17, 2011). This last point justifies the relevance of adopting an ecological approach, which takes into account environmental factors.

Moreover, previous studies do not often use the same measure of quality of life. Indeed, while QoL is a multidimensional concept many studies have evaluated only some of its aspects such as, Health-Related Quality of life (HRQoL) (e.g. Khanna et al., 2010) or Family Quality of life (FQoL) (e.g. Gardiner & Iarocci, 2015). Indeed, the first one is related to an individual's health or disease status, the second one refers to the QoL of members of the whole family (e.g. unmet needs, their life together). Therefore, QoL is an important measure of individual well-being and is not only health or family-related. QoL is defined as « *individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns* » (The WHOQOL Group, 1995 p.1405). Subjectivity and four dimensions characterize this concept: physical health, psychological health, social relationship and, environment. Studying parents' whole QoL could help us to better understand those aspects of life that extend beyond health such as for example education, marital relationships and the social environment.

Finally, the low rate of fathers' participation in previous studies is another important issue. Indeed, so far, very few studies on the specific topic area of parents' quality of life have included fathers (e.g. Latefa A. Dardas & Ahmad, 2015; Mugno, Ruta, D'Arrigo, & Mazzone, 2007b). As a result, our understanding of the experience of fathers is limited and cannot be generalized from data on mothers (Johnson & Simpson, 2013).

To overcome the previously identified limitations, the present study adopt an ecological approach based on Belsky's model of parenting which has already shown its relevance to understand the experience of parents of children with an ASD (Derguy et al., 2016). Our main objective is to examine the joint impact of individual factors (children-related and parent-related factors) and environmental factors (family environment, services, working time) on both mothers' and fathers' QoL. According to the World Health Organization, we are interested in the quality of life of the parent as a multidimensional and subjective concept (The WHOQOL Group, 1995).

We hypothesized that:

- Both individual and environmental factors would be associated with parents' quality of life.
- The association of individual and environmental factors would better explain parental quality of life than the individual variables alone.

## 2. Methods

### 2.1. Participants and procedures

All study participants were recruited in diagnosis and treatment centers, parents' associations and schools. Education and health professionals sent out an information letter and a consent form to the participants. Then, parents received an email with a link to access to the questionnaires. The parents completed the "online" questionnaires on LimeSurvey software (LimeSurvey Project Team & Schmitz, 2012). When both the father and mother of the child participated, it was specified that they had to complete all the questionnaires individually and according to their own experience and feelings. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and consistent with the 1964 Helsinki Declaration and its later amendments, or comparable ethical standards. Moreover, an independent protection committee (Comité de Protection des Personnes Sud-Ouest et Outre Mer III) prospectively approved the research. Informed consent was obtained from all individual participants included in the study.

The sample included 115 parents of 78 children aged from 3 to 10 years. The mean age of the children was 6.3 years ( $SD=2.3$ ) and the sample included 63.5% of mothers ( $N=73$ ) and 36.5% of fathers ( $N=42$ ). In 64.4% of cases, both parents of the child participated (37 couples) and 94.7% of parents resided together in the family home. Regarding services available, ASD diagnosis was confirmed on average at 50.7 months. The child's diagnosis was made by a child psychiatrist using the Autism Diagnostic Interview - Revised (Le Couteur et al., 1989; Lord, Rutter, & Le Couteur, 1994) or/and the Autism Diagnostic Observation Schedule (Lord, Rutter, DiLavore, & Risi, 1999). The child psychiatrist who made the diagnosis (ASD and comorbidities) was the one who told parents about the study and gave them the authors' contact. All of the children met the diagnostic criteria for ASD according to APA (American Psychiatric Association, 2003, 2013). Only 64% of children were enrolled in school and 70% had access to psychoeducational interventions. Finally, only 23% of parents received a formal support from a professional (in group or in individual session). Demographic data are presented in Tables 1 and 2.

TABLES 1, 2

### 2.2. Measures

#### 2.2.1. Outcome measure

Qol was measured with the WHOQOL-BREF, a short version of the WHOQOL-100. This instrument consists of 26 items, subdivided into four domains: physical, psychological, social relationships and environment. The 26 questions are scored using a five point Likert scale. It has a good acceptability and satisfactory validity with parents of children with ASD (Cronbach alphas between 0.67 and 0.84) (L A Dardas & Ahmad, 2014d). In our sample, the Cronbach's alphas for the total scale have showed a good internal consistency ( $\alpha = 0.83$ ). In this study our analyses are performed only on the total score of Qol as proposed by Dardas et Ahmad (2014a, 2014c).

### 2.2.2. Individual predictors

This category of predictors refers to “the individual characteristics of the parent” and “the individual characteristics of the child” areas in Belsky's model of parenting (Belsky, 1984).

Firstly, age, sex and marital status were considered as individual characteristics of the parent.

Secondly, age and sex were considered as the individual characteristics of the child. We collected information about functioning in children with ASD: developmental quotient (DQ) and the presence of comorbidities.

DQ was calculated as follows:  $(DA/CA)*100$ , where DA is the child's developmental age (in months) and CA the child's chronological age (in months). The child's developmental age was measured by a psychologist specialised in ASD, with the psychoeducational profile (Schopler, Lansing, Reichler, & Marcus, 2008) or the Wechsler Preschool and Primary Scale of Intelligence (WPPSI; Wechsler, 2004). The psychoeducational profile was used to evaluate cognitive development of children with language impairment. When the child had a good level of language (expressive and receptive), the WPPSI was preferred. In this study, the DQ was used as a proxy for intellectual disability. Finally, we evaluated comorbidities through the presence of others neurodevelopmental disorders according APA criteria (American Psychiatric Association, 2013). A child psychiatrist made the diagnosis of comorbid disorder(s). This variable has two modalities (0: absence; 1: presence).

### 2.2.3. Environmental predictors

This category of predictors refers to “the environmental influences of stress and support” area in Belsky's model of parenting (Belsky, 1984).



To assess environmental factors, we measured family context, services available for children and parents' working time. Firstly, we collected information on family functioning by using the SAFE (Systemic Analysis of the Family Environment) (Yingling, Miller, McDonald, & Galewaler, 1998) translated into French by Scaiola and Favez (Favez, 2010). The SAFE is a self-administered questionnaire developed on the basis of the Family Adaptation and Cohesion Scale (FACES III; Olson and Gorall, 2003; Vandeleur et al., 1999). For this study, we opted for a dimensional approach by using the "Interactive processes (IP)" sub-scores for the couple and the parent-grandparent dyad. Interactive processes concern communication, listening, understanding, cooperation, support and problem-solving methods. The higher the score, the better was the quality of IP. In the results reported by Yingling in 2004, the SAFE has good convergent validity. In our sample, the two subscales (marital IP and parent-grandparents IP) had a good internal consistency (alphas ranging from 0.87 to 0.91). Second, we evaluated the presence of a history of psychiatric and / or chronic diseases in parents but also in second-degree relatives (siblings, children's grandparents). This variable has two modalities (0: absence; 1: presence) and is based on the speech of the parent.

In addition, we collected the following four factors from the medical records of the child: age of child at diagnosis (in months), time since diagnosis (in months), whether the child had received psychoeducational interventions (no: 0 vs yes: 1), whether the child was in schooling (no: 0 vs yes: 1).

Finally, we collected the parent's working time (Unemployed: 0, Part-time: 1, Full-time: 2) to serve as indicator of income.

### *2.3. Data analysis*

Analyses were conducted with SPSS 20<sup>®</sup> Software (IBM Corp., 2011). First, we performed univariate linear regressions to test the association between the individual and environmental variables with parental QoL. According to our theoretical framework, hierarchical regression analyses were conducted in 4 steps by initially entering the child-related variables (step 1) and then adding, the parent-related variables (step 2), the family variables (step 3) and others environmental variables (step 4). To assess the joint influence of all factors, we incorporated all of the child-related, parent-related and environmental factors identified as significant in the first step ( $p < 0.05$ ). Among the variables, many are qualitative variables. To integrate them into the regression models, it was first necessary to create dummy variables with one category as the reference (Bressoux, 2010, p. 115).

We conducted a statistical power analysis for a moderate size effect ( $f^2 = 0.15$ ) with 8 predictors and a power of 0.8 (adequate power). A minimum of 88 participants (Soper, 2011) was required. For each analysis,

the reliability criteria were taken into account (Bressoux, 2010; Tabachnick & Fidell, 2012).

### 3. Results

First, the association between parents' QoI and each individual and environmental factor were explored with linear regression analysis. Our results showed that there is only one significant association between individual characteristics and parental QoI. The absence of comorbidity in children is associated with a good parental QoI ( $\beta = 0.27$ ; 95% CI, 1.93 to 11.56;  $p = 0.006$ ).

With regard to environmental factors, a good marital IP ( $\beta = 0.34$ ; 95% CI, 0.31 to 1.07;  $p = 0.001$ ), a good parent-grandparents IP ( $\beta = 0.46$ ; 95% CI, 0.55 to 1.26) and no family medical history of psychiatric and / or chronic diseases in parents ( $\beta = 0.32$ ; 95% CI, 3.21 to 12.32;  $p = 0.001$ ) are respectively associated with QoI. Regarding services and support, parents report a better QoI ( $\beta = 0.25$ ; 95% CI, 1.56 to 11.11;  $p = 0.010$ ) when their child received a psychoeducational intervention. Linear regression results concerning individual and environmental factors are presented in Tables 3 and 4.

Hierarchical regression analyses were conducted in 4 steps with all of the child-related, parent-related and environmental factors identified as significant in univariate regressions ( $p < 0.05$ ). Despite the lack of significant association, developmental quotient and parent's sex were added for their theoretical relevance regarding the research questions.

As shown in Table 5, DQ and comorbidities (child-related factors) were entered in the first step, with an overall model that was significant and accounted for 6% of the variance in parent's QoI,  $F(2, 113) = 4.53$ ,  $p = 0.013$ . Parent sex (parent-related factor) was entered in the second step. The overall model continued to be significant,  $F(3, 112) = 3.17$ ,  $p = 0.27$ , but the  $R^2$  variation was not significant ( $p = 0.48$ ). Marital IP, parent-grandparents IP and the absence of family medical history (family factors) were entered in the third step. The overall model was still significant,  $F(6, 109) = 8.30$ ,  $p < 0.001$ , and accounted for an additional 24% variance beyond the second model. Finally, the presence of psychoeducational intervention and parent working time were entered in the fourth step concluding to an overall significant model,  $F(8, 107) = 7.4$ ,  $p < 0.001$ , and accounted for an additional 4% variance beyond the third model. This final model explains 31.5% of the variance of parents' QoI.

TABLES 3, 4, 5

### 4. Discussion

The main aim of this study was to identify the best predictors of parental QoL in ASD with an ecological approach by taking into account both individual and environmental predictors.

First, our results show that environmental factors play a major role in explaining the quality of life of parents. We underline the importance of considering the relationship within the couple and within the parent-grandparents dyad to better understand the parental adjustment. So far, these two factors have been evaluated in few researches and were discussed only in terms of marital satisfaction, family support or help given by grandparents (Benson & Kersh, 2011; Ji et al., 2014; Trute, 2003; Yamada et al., 2012). In our study, parental QoL seems to be determined by the quality of interactive processes used in the family: communication, listening, understanding, cooperation, support and problem-solving methods. Our results are in accordance with previous studies describing an association between ASD in children and difficulties of interaction and communication within the couple and the extended family (Brobst, Clopton, & Hendrick, 2009; Fletcher et al., 2012; Hastings, Thomas, & Delwiche, 2002; Higgins, Bailey, & Pearce, 2005; Katz & Kessel, 2002; Myers, Mackintosh, & Goin-Kochel, 2009; Ramisch, Onaga, & Oh, 2014; Volkmar, Paul, Rogers, & Pelphrey, 2014). Our paper highlights that a good quality of interaction implies to define and acknowledge the roles of each family member, an equal sharing and the absence of domination relationships (Favez, 2010). In case of ASD, the family members may have more difficulties in finding and keeping their places and the right distance, especially in a context of relationships being already fragile and conflicting (Beudin & Schneider, 2012).

Another protective environmental factor is the absence of family medical history of psychiatric and / or chronic diseases, as previously reported by Jones et al (2017). This result argues that a good mental and medical health in family is protective for the parental QoL as suggested by Jones et al. (2017). Mental and physical health problems in the family caregivers have been mentioned in several previous studies. It is unclear, particularly for mental health problems, whether there are due to genetic vulnerability or to the impact of everyday life with a child with autism. To address this issue, it would be interesting to evaluate the “Broad Autism Phenotype” (BAP) in parents, as a potential predictor of the parents' QoL. Indeed, parents with a BAP would be more likely to use poorer coping strategies and would have more difficulties using social support (Ingersoll & Hambrick, 2011). In this previous study, authors showed a positive association between BAP and stress in parents of children with autism. In a clinical perspective, it seems essential to better assess parental vulnerability by investigating more systematically family medical history (relatives and siblings) and the presence of social deficits in parents.

Second, it is also important to consider the presence of child's comorbidity because it is the only child-related individual factor associated with parental QoL. As in Zablotzky (2013), our results showed that a greater

number of co-occurring psychiatric disorders in the child were associated with a low parental QoL. In contrast, parental QoL was not related to the others characteristics of the child such as age, sex and developmental quotient. So far, many studies have focused on the association between the characteristics of the child's profile and parental adjustment, including QoL (Garrido et al., 2015; 2010; Øien & Eisemann, 2015; Suzumura, 2015). Unlike Suzumura (2015), we did not find a negative association between developmental quotient and QoL. These previous studies have used parents' self-report questionnaires to evaluate children's symptoms while our measures are based on a direct assessment. To what extent these tools are sensitive to parental adjustment and induce a bias in the assessment of children's symptoms remains unknown and might partly explain the association found by the other authors.

Finally, the access to psycho-educational interventions is another important factor associated with a good quality of life for the parent. In France, psychoeducational interventions are not systematic despite the recommendations of the government (Haute Autorité de Santé, 2012; Ministère des solidarités et de la santé, 2013). Indeed, there is a lack of trained professionals and funding in many cases. Thus, the gap between practices guidelines and reality can generate a feeling of frustration and helplessness in the parent and impact on one's well-being. More generally, the lack of available interventions often implies the reduction of the parents' working time, in order to be able to take care of their child. This last variable also emerged as associated with the quality of life in our study.

#### *4.1. Limitations and perspectives*

This study has several limitations. First, the crossover design does not capture dynamically the issue of parental QoL and cannot lead to conclusions about causality. With regards to the variables evaluated, several require further consideration to analyse the determinants of QoL such as social network and support or coping strategies. The link between these variables and parental adjustment has already been demonstrated in the literature (Barker et al., 2011; Benson and Kersh, 2011; Cappe et al., 2011; Falk et al., 2014; Giallo, Wood, Jellett, and Porter, 2013; Ingersoll and Hambrick, 2011; Siman-Tov and Kaniel, 2011; Ji et al., 2014). Moreover, from the child's perspective, a more direct measure of behavioural disorders and the severity of the symptoms would have been of interest as previous studies have reported an association with parents' QoL in autism (Baghdadli et al., 2014; McKechnie et al., 2017; Samadi & McConkey, 2012). Therefore, our results should be interpreted with great caution.

Regarding our sample, it is important to take into account that only of French parents living in France were included. It is possible that the lack of services available in this country (Ministère des solidarités et de la santé, 2013) increases the weight of environmental factors in our analyses, compared to others countries where services are more developed. In addition, we cannot be totally sure that parents completed all the questionnaires individually even if they were explicitly asked to do so (during an individual telephone interview). Finally, some families were over-represented in the sample as both parents were enrolled in the study. We decided to consider a parent as a single statistical individual. Further research studying parental dyads by using the Actor and Partner Interdependence Model (Kenny, Kashy, & Cook, 2006) would be of interest. This is a specific model for the dyad that allows intra-dyadic analysis through a multilevel modeling approach and the concept of non-independence of the subjects (Kenny, Kashy and Cook, 2006).

In conclusion, parents of child with autism are a relevant sample to illustrate the Belsky's model of parenting. It appeared that the association of individual and environmental variables is essential to understand that parents' Quality of life is not only related to the child and parents characteristics but also to the resources available in the parents' environment. More precisely, this study highlights that family environment and psychoeducational interventions for child are decisive for parental quality of life. This finding is consistent with the literature on family quality of life (see for example: Zuna, Turnbull, & Summers, 2009) and it confirms the interest of a holistic and an ecological approach to understand parental well-being in ASD. This is particularly important not only for identifying parents' needs and risk situations but also for targeting the development of parenting resources and selecting relevant issues for the content of support programs (Derguy et al., 2015). In the future, it will be important to offer parent support programs that address both the child's profile and access to available environmental resources, especially child interventions and family interactions (between mothers, fathers, grandparents) (Øien & Eisemann, 2016).

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**Disclosure of interest**

The authors declare that they have no competing interest.

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Table 1. Sample characteristics (individual factors)

Variables	ASD ( $n = 115$ ) $M \pm SD$ or %
Parent sex, $n$ (%)	
	Female 73 (63.5)
	Male 42 (36.5)
Parent age (in years) [min–max]	38.40 $\pm$ 5.1 [29-59]
	Mothers 42.65 $\pm$ 13.60 [5-78]
	Fathers 44.92 $\pm$ 15.43 [4-70]
Marital Status	
	Couple 108 (94.7)
	Single 7 (5.3)
Child sex, $n$ (%)	
	Girl 18 (23.1)
	Boy 60 (76.9)
Child age (in years) [min–max]	6.30 $\pm$ 2.3 [3-10]
Developmental Quotient (DQ)	53.50 $\pm$ 21.88 [15-104]
Presence of comorbidities	38 (33.04)

*Note.* DQ = (Developmental age (in months) / Chronological age (in months)) \* 100

Table 2. Sample characteristics (environmental factors)

Variables	ASD ( $n = 115$ ) $M \pm SD$ or %
Family functioning (SAFE)	
Marital IP	24.72 $\pm$ 5.87 [6-30]
Parent-Grandparents IP	24.03 $\pm$ 6.12 [0-30]
Family medical history	47 (40.8)
Age of child at diagnosis (in months)	50.7 $\pm$ 24.2 [10-120]
Time since diagnosis (in months)	24.07 $\pm$ 29.5 [0-108]
Psycho-educational interventions, $n$ (%)	70 (92.10)
Child's schooling, $n$ (%)	64 (85.33)
Parent support, $n$ (%)	23 (22.11)
Parent working time (based on 35 hrs per week)	
Unemployed	38 (23.1)
Part-time	29 (25.2)
Full-time	48 (41.7)

*Note.* SAFE: Systemic Analysis of the Family Environment, IP: Interactive processes

Table 3. Linear regression analyses with individual factors

			<i>Bêta</i>	Sig.	95% CI	$\Delta R^2$
Child-related	Sex	<i>Girl</i>	Ref	-	-	-
		<i>Boy</i>	-0.60	0.548	[-7.05, 3.76]	-0.006
	Comorbidity	Age	-0.09	0.380	[-1.54, 0.59]	-0.002
		DQ	0.08	0.448	[-0.66, 1.15]	-0.005
		<i>Presence</i>	Ref	-	-	-
	<i>Absence</i>	0.27	0.006*	[1.93, 11.56]	0.063	
Parent-related	Sex	<i>Woman</i>	Ref	-	-	-
		<i>Man</i>	0.10	0.322	[-2.39, 7.21]	<0.001
	Marital status	Age	0.03	0.740	[-0.38, 0.54]	-0.009
		<i>Couple</i>	-0.03	0.759	[-11.64, 8.52]	-0.009
		<i>Single</i>	Ref	-	-	-

Note. \*:  $p < 0.01$ ; DQ = (Developmental age (in months) / Chronological age (in months)) \* 100

Table 4. Linear regression analyses with environmental factors

		<i>Bêta</i>	Sig.	95% CI	$\Delta R^2$
Family context	Marital IP	0.34	0.001**	[0.31, 1.07]	0.11
	Parent-Grandparents IP	0.46	<0.001***	[0.55, 1.26]	0.20
	Family medical history (absence)	0.32	<0.001***	[0.33, 0.86]	0.16
Services available	Age of child at diagnosis	0.03	0.785	[-0.08, 1.11]	-0.01
	Time since diagnosis	-0.03	0.796	[-0.10, 0.08]	-0.01
	PI	0.25	0.010*	[1.56, 11.11]	0.05
	Child's schooling	-0.04	0.674	[-7.20, 4.68]	-0.01
	Parent support	-0.12	0.231	[-9.32, 2.27]	0.01
	Parent working time	0.23	0.022*	[-0.48, 5.93]	0.04

Note. \*\*\*:  $p < 0.001$ ; \*\*:  $p < 0.01$ ; \*:  $p < 0.05$ ; IP: Interactive processes; PI: Psychoeducational intervention

Table 5. Hierarchical Multiple Regression of predictors of parental quality of life

Variables	Model 1			Model 2			Model 3			Model 4		
	Bêta	Sig.	95% CI	Bêta	Sig.	95% CI	Bêta	Sig.	95% CI	Bêta	Sig.	95% CI
<b>Step 1: Child related factors</b>												
DQ	-0.11	0.259	[-0.16, 0.04]	-0.10	0.276	[-0.16, 0.05]	-0.04	0.594	[-0.12, 0.07]	-0.11	0.893	[-0.10, 0.09]
Comorbidity (absence)	0.27	0.004**	[2.16, 11.09]	0.27	0.005**	[2.00, 10.98]	0.08	0.373	[-2.35, 6.23]	0.10	0.243	[-1.71, 6.72]
<b>Step 2: Parent related factor</b>												
Parent sex				0.06	0.479	[-2.79, 5.91]	0.08	0.364	[-2.10, 5.68]	0.03	0.776	[-4.03, 5.38]
<b>Step 3: Family factors</b>												
Marital IP							0.19	0.034*	[0.03, 0.74]	0.18	0.040*	[0.02, 0.72]
Parent-Grandparents IP							0.36	0.000***	[0.37, 1.05]	0.32	0.000***	[0.30, 0.98]
Family medical history (absence)							0.22	0.013*	[1.10, 9.11]	0.20	0.018*	[0.82, 8.75]
<b>Step 4: Others environmental factors</b>												
Psychoeducational intervention (presence)										0.20	0.015*	[0.98, 8.89]
Working time										0.08	0.412	[-2.65, 6.40]
$\Delta R^2$		0.060			0.055			0.283			0.315	
F for change in $R^2$		4.527*			.503			12.424***			3.482*	

Note. \*\*\*:  $p < 0.001$ ; \*\*:  $p < 0.01$ ; \*:  $p < 0.05$ ; DQ = (Developmental age (in months) / Chronological age (in months)) \* 100; IP: Interactive processes