#### **ORIGINAL PAPER**



# Dyadic Effect of Coping on the Perceived Impact of ASD of Children on Parental Quality of Life: Report from the ELENA Cohort

Leïla Brillet<sup>1,2</sup> · Marianne Peries<sup>1</sup> · Christelle Vernhet<sup>1</sup> · Cécile Rattaz<sup>1</sup> · Cécile Michelon<sup>1</sup> · Amaria Baghdadli<sup>1,2,3,4</sup> · Cécile Rattaz<sup>1</sup> · Cécile Michelon<sup>1</sup> · Amaria Baghdadli<sup>1,2,3,4</sup> · Cécile Rattaz<sup>1</sup> · Cécile Michelon<sup>1</sup> · Amaria Baghdadli<sup>1,2,3,4</sup>

Accepted: 15 December 2021 / Published online: 7 January 2022

© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022

#### **Abstract**

Autism spectrum disorder (ASD) has a significant impact on the quality of life (QoL) of families. This study aimed to examine, for parents of children with ASD, the dyadic effect of each parent's coping strategy on the perception of the impact of ASD on their QoL. In total, 164 couples completed self-report questionnaires, including the Par-DD-QoL, to evaluate the parental perception of QoL. Results from the actor-partner interdependence model showed that, in addition to the effect of the mothers' and fathers' emotion-focused coping on their own perception of QoL, the mothers' emotion-focused coping plays a key role in the fathers' perception of QoL. These findings suggest that both parents of children with ASD would benefit from couple-focused interventions.

 $\textbf{Keywords} \ \ \text{Autism spectrum disorder} \cdot \text{Parents} \cdot \text{Dyads} \cdot \text{Coping} \cdot \text{Perception of the impact on quality of life} \cdot \text{Actor-partner interdependence model}$ 

#### Introduction

Autism spectrum disorder (ASD) is an early-onset neurodevelopmental disorder in children characterized by a combination of persistent deficits in communication and social interactions across a range of settings and restricted and repetitive behaviors, interests, or activities (American Psychiatric Association, 2013). This long-lasting disorder, with a prognosis that is often more severe than for other

The members of the ELENA study group are listed in acknowledgments section.

- Amaria Baghdadli rech-clinique-autisme@chu-montpellier.fr
- Centre de Ressources Autisme Languedoc-Roussillon et Centre d'Excellence Sur Les Troubles Neuro-Développementaux, CHU Montpellier, Montpellier, France
- University of Medecine, Montpellier, France
- Université Paris-Saclay, UVSQ, Inserm, CESP, Team DevPsy, 94807 Villejuif, France
- Centre de Ressources Autisme Languedoc-Roussillon et Centre d'excellence sur l'Autisme et les Troubles Neuro-développementaux, CHU Montpellier, 39 Avenue Charles Flahault, 34295 Cedex 05 Montpellier, France

neurodevelopmental disorders, has a major impact on the quality of life (QoL) of the entire family (Cappe et al., 2009). QoL is defined as an "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 [...] is related to physical health, psychological state, social relationships, and personal beliefs" (Group, 1994). Studies have shown that parents of children with ASD express more psychological distress (Estes et al., 2009; Pisula, 2007) and perceive a greater negative impact on their QoL than those of children with other disabilities or chronic diseases (Bourke-Taylor et al., 2012; Tung et al., 2014).

It has been shown that the impact of ASD on parents' QoL may vary according to not only their child's clinical characteristics (including the severity of ASD, social-adaptive difficulties, and associated psychiatric disorders) (Baghdadli et al., 2014, 2019; Vernhet et al., 2019; Rattaz et al., 2017). (Baghdadli et al., 2014; Eapen & Guan, 2016; Khanna et al., 2011; Pozo et al., 2014; Tung et al., 2014; Vasilopoulou & Nisbet, 2016), but also their own sociodemographic characteristics, including their educational level or professional status (Cappe et al., 2018), as well as transactional processes, such as their stress and coping



strategies (Benson, 2010; Cappe et al., 2011; Dardas & Ahmad, 2015; Smith et al., 2008; Vernhet et al., 2019).

Coping strategies correspond to the set of "cognitive and behavioral efforts, constantly changing, to manage specific internal and/or external demands that are evaluated as consuming or exceeding one's resources" (Lazarus & Folkman, 1984). Two dimensions of coping strategies have been proposed (Folkman & Lazarus, 1980): the problem-focused strategy (which consists of acting on the problem causing the distress) and the emotion-focused strategy (which aims to manage the emotional distress associated with the problem). A third strategy is frequently mentioned in the literature in the form of seeking social support (Greenglass, 1993).

A number of studies have found significant links between coping strategies of parents of children with ASD and their QoL (Benson, 2010; Cappe et al., 2011; Dardas & Ahmad, 2015; Smith et al., 2008; Vernhet et al., 2019). The use of problem-focused strategies is generally associated with a better QoL, whereas the use of emotion-focused strategies (notably avoidance-escape) is associated with a poorer QoL.

Furthermore, parents of children with ASD each have to cope with their child's developmental difficulties, and may have different coping strategies. As soon as the diagnosis is communicated to the parents, they begin a process of readjustment and adaptation that is more or less symmetrical and interdependent (Altiere & von Kluge, 2008; Pisula & Kossakowska, 2010). The parental couple, as a unit, constitutes a dyad within which a privileged network of social interactions is formed, and the characteristics and behaviors of one member of the dyad may affect the life of the other (Kenny & Cook, 1999). The notion of dyadic coping (Bodenmann, 1997) was proposed to recognize the influence of the thoughts, emotions, and actions of the partners in a dyad on each other. Dyadic coping is defined as the efforts of one or both partners to manage stressful events and the tensions experienced by one (individual stress) or both partners (dyadic stress). Dyadic models therefore appear to be relevant for understanding the impact of individual coping strategies used within the parental dyad on the QoL of each member.

Several studies on the dyadic effects of coping strategies have focused on patient-caregiver dyads in the context of chronic illness. For example, research conducted with couples in which one partner is chronically ill has shown that the coping strategies used by one partner have an impact not only on him or herself, but also on the other partner (Lafaye et al., 2014). It has been shown that the nature of the coping strategy used by ill people can have a direct impact on the QoL of their caregivers in various contexts, such as cancer (Baumstarck et al., 2016; Hamidou et al., 2018) or serious mental illness (Boyer et al., 2017). These studies have shown that in couples in which one member is ill, the use of strategies, such as positive thinking or problem solving, are likely

associated with a better QoL, whereas those based on avoidance or the search for social support are likely a risk factor for a poorer QoL (Baumstarck et al., 2016, 2018; Boyer et al., 2017; Hamidou et al., 2018). However, the results are contradictory concerning the direction of the influence of the use of social support on QoL.

The dyadic effects of coping have also been studied in the dyads of parents confronted with their child's serious illness. For example, research has been carried out on parents confronted with a diagnosis of cancer in their child (Compas et al., 2015; Van Schoors et al., 2019a, b). Compas et al. (2015) showed that disengagement coping strategies (including avoidance, denial, and wishful thinking) by the mothers of children with cancer were associated with greater depressive symptoms in the fathers after controlling for the fathers' coping strategies and sociodemographic variables. In their study, Van Schoors et al. (Van Schoors, et al., 2019a) found that the type of dyadic coping strategy was predictive of better perceived family adjustment by parents over time (in terms of financial, social, or overall family impact and satisfaction with internal family adjustment). Specifically, better communication concerning their stress predicted a smaller financial impact on these families. In other words, the more mothers or fathers shared their stress with their partner in the short term, the less they worried about the long-term financial consequences of the disease. In addition, an association was found between hostile negative dyadic coping (such as denigration, distancing, sarcasm, and minimization) and satisfaction with family adjustment. Thus, the more distance, mockery, or sarcasm a parent felt from their partner when talking about the illness, the lower was the perceived family adjustment. In another study, Van Schoors et al. (2019a, b) showed that positive dyadic coping (i.e., supportive dyadic coping, in which one partner supports the other in his/her coping efforts) and common dyadic coping (i.e., both partners participate in the coping process together) were associated with lower levels of perceived depression, anxiety, and stress and a more satisfying perceived marital relationship. On the contrary, negative dyadic coping, including hostile (i.e., support accompanied by distancing or sarcasm), ambivalent (i.e., support that is unwilling), or superficial (i.e., support that is insincere) dyadic coping (Bodenmann, 1997), were associated with more depression and a less satisfying marital relationship.

As the literature on chronic illnesses emphasizes the existence of dynamic interactions within a dyad that can modify QoL, it is important to explore these interactions between parents whose child has a chronic disorder, such as ASD, to gain a systemic understanding of their adaptations and support needs.

A study by García-López et al. (2016) showed an association between supportive dyadic coping of mothers and fathers and marital satisfaction for parents of children with



ASD, as well as psychological adjustment (i.e., their level of parental stress and psychological well-being) for each partner. The authors used an actor-partner interdependence model (APIM) that approaches the dyad, the couple of mother and father, as the unit of analysis (Cook & Kenny, 2016). This method allows for the study of interactions between dyad members (Cook & Kenny, 2016; Kenny, 2016).

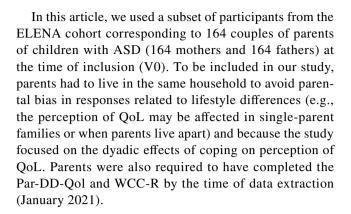
Studies that have examined the dyadic effects of coping strategies of parents of children with ASD remain scarce and none have examined the effects of these strategies on their QoL.QoL of parents of children with ASD is impacted by the child's disorder (Vasilopoulou & Nisbet, 2016) and the link between coping strategies and QoL in this population has been demonstrated (Vernhet et al., 2019). We hypothesized that coping strategies are interdependent on the perception of the impact of ASD on the QoL within the "mother–father" dyads.

Our objective was to study the dyadic effect of each parent's coping strategy (problem-focused coping, emotion-focused coping, and social-support seeking) on the perception of the impact of ASD on the emotional and daily disturbance of QoL of both parents in a sample of 164 "mother–father" dyads whose child has formally diagnosed ASD.

#### Methods

#### **Participants**

This cross-sectional study used data from the prospective, multicenter French cohort—ELENA—of children and adolescents with a confirmed diagnosis of ASD (Baghdadli et al., 2019). Almost 900 children were recruited into the ELENA cohort after parental consent by December 31, 2019. Inclusion criteria for the ELENA cohort were to be aged 2-16 years and diagnosed with ASD according to DSM-5 criteria. Children were diagnosed by a multidisciplinary team according to a standardized process, including the Autism Diagnostic Interview-Revised (ADI-R), the Autism Diagnostic Observation Schedule 2 (ADOS-2), the Vineland Adaptive Behavior Scale-II (VABS II), and psychometric tests to assess IQ (Wechsler, K-ABC II, PEP, or Brunet Lézine scales, depending on the child's level). There were no exclusion criteria for the ELENA cohort other than parental refusal. As part of the follow-up [i.e., at baseline (V0), 18 months after V0, 3 years, 4.5 years, and 6 years after V0], parents were asked to complete online selfquestionnaires to collect information on multiple variables, including socio-demographic and psychosocial variables, as well as data concerning the child's care and behavior in a standardized manner.



#### Measures

# Par-DD-QoL at the end of (Parental-Developmental Disorder-Quality of Life)

A self-administered questionnaire that explores the parental perception of the impact of ASD on the emotional and daily disturbance of OoL (Baghdadli et al., 2014). This instrument was tailored from the Parental Ear, Nose, and Throat-Quality of Life (Par-ENT-QoL), a validated French questionnaire used to study the QoL of the parents of children from the general population with chronic ear, nose, and throat (ENT) infections (Berdeaux et al., 1998). This scale was adapted to study the QoL of the parents of children with neurodevelopmental conditions, such as ASD (Baghdadli et al., 2014; Rattaz et al., 2017; Raysse, 2011). Each of the 17 items is rated on a five-point Likert scale and a global score can be calculated from two sub-scores: (i) emotional score (stress, anxiety, sleeping disorders, etc.); and (ii) daily life scores (family life, personal life, social life, professional life, etc.). The reliability of the Parent-Developmental Disorders-Quality of Life for each item was is excellent ( $\alpha > 0.82$ ) and the intra-class coefficient of the test/re-test 0.93 (Baghdadli et al., 2014; Raysse, 2011). The scores were linearly transformed to range from 0 to 100, 0 being the lowest impact on QoL and 100 the highest, assuming equal weights for each dimension.

### WCC-R (Ways of Coping Checklist)

This scale, inspired by Lazarus and Folkman's transactional model of stress created by Vitaliano et al. (1985), was translated and validated in French by Cousson et al. (1996). It is a self-questionnaire composed of 27 items to which the subjects answer using a four-point Likert scale. The scores obtained from the responses to the items are analyzed through three dimensions: a score that evaluates the coping focused on the problem, one that measures emotion-focused



coping, and one that assesses social-support seeking. This scale has good psychometric qualities. A factorial analysis conducted on the responses of 468 French adults made it possible to isolate the three domains explaining approximately 35% of the total variance. The internal consistency coefficients are very satisfactory (0.71 to 0.82) and the test–retest reliability coefficients at one-week intervals are highly adequate (+0.90, +0.84, and +0.75, respectively).

#### **Demographic and Clinical Characteristics**

The parents' age, education levels and socioeconomic status (SES) were extracted from the ELENA socio-demographic report à inclusion visit. Parental SES was scored as high (business owners, executives), middle (farmers, supervisors, skilled craftsmen), or low (farm workers, laborers, service employees, unemployed).

Children clinical characteristics were collected from the ELENA inclusion visit. Symptoms severity was measured using the Calibrated Severity Score (CSS) of Autism Diagnosis Observation Schedule-2 (ADOS-2) (Lord et al., 2012). The intellectual level was estimated for each child using ageappropriate tests to take into account the variability of skills among children by age (Howlin et al., 2014). A performance IO was calculated if a standardized test could be administered [Wechsler scales (Wechsler, 2002, 2003, 2014a, b) or K-ABC II (Kaufman & Kaufman, 2004)]. A developmental age was estimated from developmental scales if the child could not understand the test instructions [Brunet Lézine-Revised (Brunet et al., 1997) or PEP-3 (Schopler et al., 2004)] and a developmental quotient was calculated according to Stern's formula (Stern, 1912) by dividing the developmental age score by the chronological age  $\times$  100. The adaptive skills were assessed with the Vineland Adaptive Behavior Scale, Second Edition (VABS-II) (Sparrow et al., 2005).

### **Statistical Analysis**

Descriptive analyses (such as means, standard deviations, frequencies, and percentages) were computed to describe the demographic and clinical characteristics of the mothers and fathers and to describe the clinical characteristics of their child. Paired comparisons using paired T-tests, Mc Nemar's test, or Stuart Maxwell's test, as appropriate, were performed to determine, first, the difference in characteristics between the mothers and fathers and second, the differences in coping strategies (problem-focused coping, emotion-focused coping, and seeking social support) and the perception of the impact of ASD on parental QoL between the mothers and fathers. Pearson's correlations were calculated to test the non-independence of these continuous variables among the mothers and fathers.

We used the APIM to assess the dyadic effects of the three coping strategies on the perception of the impact of ASD on parental QoL. The outcome variable was the perception of the impact of ASD on parental QoL. The predictor variables are the three coping dimensions: problemfocused coping, emotion-focused coping and social-support seeking. This model assumes that the scores within the same dyad are not independent but more similar than the scores of two individuals who are not in the same dyad. First, the distinguishability of the dyad (mother and father) was confirmed using a likelihood-ratio test between models with and without distinguishable members. Then the APIM was assessed using structural equation modeling (SEM) with a maximum likelihood estimation, which is recommended for distinguishable dyads. A separate APIM was fitted for each combination of dyadic coping subscales and the perception of the impact of ASD on parental QoL. No missing data for coping strategies or parental perception of QoL variables was reported. For this study, the actor effect was the impact of a person's coping strategy on his or her own perception of QoL. The partner effect was the impact of each person's coping strategy on his or her partner's perception of QoL. The k ratio was calculated to assess the magnitude of the partner effect to the actor effect. The 95% confidence intervals of k were calculated using Monte Carlo sampling. A k ratio of 1 (couple model) implies that both the actor and partner have a relatively equal pattern from the coping strategies to their perception of QoL, whereas a k ratio of -1 implies that the actor and partner have opposite patterns. A k ratio of 0 (actor or partner only model) implies that the independent variable affects only the actor's or the partner's outcome.

Unstandardized coefficients for actor and partner effects are presented with their standard error (SE). All p values < 0.05 were considered statistically significant. Statistical analyses were performed using SAS enterprise guide v7.13 and R software v3.6.3. The APIMs were generated using the lavaan-R package for fitting the SEM.

### **Results**

In total, 164 dyads (mothers/fathers) were studied. The characteristics of the parents and children are presented in Table 1.

The fathers were significantly older [40.8 years  $(SD \pm 7.7)$ ] than the mothers [37.7 years  $(SD \pm 6.1)$ , p<0.001], had a higher socioeconomic level than the mothers (34.8% of fathers with a high SES versus 16.5% of mothers, p=0.004), but a comparable level of education to that of the mothers (p=0.29).

In approximately 80% of cases, the child with ASD was a boy and the mean age of the children with ASD was 5.8 years (SD $\pm$ 3.4). In our sample, the ASD severity index estimated with the ADOS was moderate (M=7.0, SD $\pm$ 1.9).



Table 1 Demographic characteristics of mothers, fathers (n = 164 dyads), and their children with ASD

Demographic variable		Mothers $(n = 164)$	Fathers $(n = 164)$	p value
Parents				
Age, mean (SD)		37.67 (6.10) <sup>a</sup>	40.75 (7.71)	< 0.001
Educational level, n (%)	Elementary education	$0 (0)^{e}$	1 (0.62) <sup>b</sup>	0.29
	Secondary education (high school)	55 (34.59)	64 (39.51)	
	Higher level (college/graduate school)	104 (65.41)	97 (59.88)	
Socio-professional category, n (%)	Low SES	85 (53.80)	71 (44.10)	0.004
	Middle SES	47 (29.75) 34 (21.12)		
	High SES	26 (16.46) <sup>f</sup>	56 (34.78) <sup>c</sup>	
Child				
Gender, n (%)	Boys	129 (78.66)		
	Girls	35 (21.34)		
Age, mean (SD)		5.80 (3.39)		
Autism severity—CSS (ADOS-2), mean (SD)		7.02 (1.94) <sup>h</sup>		
Cognitive level (Best Estimate IQ), mean (SD)		73.19 (28.20) <sup>g</sup>		
Adaptative behaviors (Vineland-II), mean (SD)	Communication SS	71.66 (15.04)		
	Daily living skills SS	73.82 (12.13)		
	Socialization SS	70.54 (10.86)		
Number of siblings, n (%)	1	36 (21.95)		
	2	83 (50.61)		
	≥3	45 (27.44)		

<sup>&</sup>lt;sup>a</sup>1 missing data

**Table 2** Comparison of Par-DD-QoL scores and WCC-R scores by fathers and mothers

	Fathers Mean (SD)	Mothers Mean (SD)	Score difference <sup>a</sup>	p value
Par-DD-Qol score	50.30 (16.04)	56.21 (16.80)	- 5.91 (15.17)	< 0.001 <sup>b</sup>
WCC-R: problem-focused coping	29.43 (5.42)	30.96 (5.30)	- 1.54 (5.66)	$0.001^{b}$
WCC-R: emotion-focused coping	21.80 (5.62)	22.95 (5.58)	- 1.14 (6.34)	$0.017^{b}$
WCC-R: seeking social support	19.73 (5.62)	21.96 (5.76)	- 2.23 (5.84)	< 0.001 <sup>b</sup>

<sup>&</sup>lt;sup>a</sup>Fathers' score-mothers' score

# Matched Comparison of the Perception of the Impact of ASD on QoL and Coping Scores Between Fathers and Mothers

The comparison between each parent's perception of the impact of ASD on their QoL and the coping strategies they implemented is presented in Table 2. The results suggest

that the mothers perceived a greater negative impact of ASD on their QoL than the fathers ( $p \le 0.001$ ). In addition, the mothers appeared to implement more coping strategies than the fathers for all three coping categories: problem-focused coping (p = 0.001), emotion-focused coping (p = 0.017), and seeking social support (p < 0.001).



<sup>&</sup>lt;sup>b</sup>2 missing data

<sup>&</sup>lt;sup>c</sup>3 missing data

<sup>&</sup>lt;sup>d</sup>4 missing data

e5 missing data

<sup>&</sup>lt;sup>f</sup>6 missing data

g 19 missing data

<sup>&</sup>lt;sup>h</sup>23 missing data

<sup>&</sup>lt;sup>b</sup>Paired student test

Table 3 Correlation between the Par-DD-QoL scores and WCC-R scores of mothers and fathers

	1	2	3	4	5	6	7	8
1. Fathers' par-DD-QoL score	_							
2. Mothers' par-DD-QoL score	0.574**	_						
3. Fathers' problem-focused coping	-0.093	-0.052	_					
4. Mothers' problem-focused coping	-0.027	-0.101	0.444**	_				
5. Fathers' emotion-focused coping	0.434**	0.131	-0.054	0.115	_			
6. Mothers' emotion-focused coping	0.340**	0.469**	-0.069	-0.091	0.360**	_		
7. Fathers' seeking social support	0.033	0.003	0.496**	0.239**	0.268**	0.054	_	
8. Mothers' seeking social support	0.07	0.059	0.237**	0.399**	0.170*	0.15	0.475**	_

<sup>\*</sup>p<0.05, \*\*p<0.01

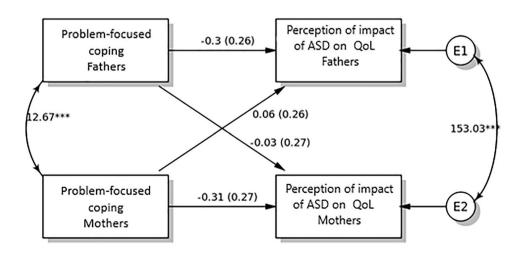
#### **Correlations**

Correlations between the perception of the impact of ASD on the fathers' and mothers' QoL and coping are presented in Table 3. The mothers' perception of the impact of ASD on their QoL was significantly related to their own emotion-focused coping (r = 0.444, p < 0.01). The fathers' perception of the impact of ASD on their QoL was also significantly related to their own emotion-focused coping (r = 0.434, p < 0.01), as well as to the mother's emotion-focused coping (r = 0.340, p < 0.01). Finally, the perceptions of the impact of ASD on the fathers' and mothers' QoL significantly correlated with each other (r = 0.574, p < 0.01).

## Impact of Coping Strategies on Parental Perception of QoL

Three APIM analyses were carried out to test the impact of coping strategies (problem-focused coping, emotion-focused coping, and seeking social support) on the perception of the impact of ASD on QoL for the mothers and fathers.

Fig. 1 Problem-focused coping: the actor and partner effects as predictors of the perceived impact of ASD on QoL. APIM with distinguishable dyads regression model. \*\*\*p < 0.001



# Impact of Problem-Focused Coping on the Perception of the Impact of ASD on QoL

The first APIM model examined actor and partner effects of problem-focused coping on the perception of the impact of ASD on QoL (Fig. 1). For both the mothers and fathers, problem-focused coping was not significantly associated with the perception of the impact of ASD on their QoL (for mothers,  $\beta$ =0.308, SE=0.275, p=0.262; for fathers,  $\beta$ =-0.301, SE=0.257, p=0.242). Similarly, both partner effects were found to be non-significant when predicting the perception of the impact on QoL from problem-focused coping among the mothers ( $\beta$ =-0.03, SE=0.269, p=0.921) and fathers ( $\beta$ =0.056, SE=0.257, p=0.831) (Table 4).

# Impact of Emotion-Focused Coping on the Perception of the Impact of ASD on QoL

The results of the APIM for the impact of emotion-focused coping on the perception of the impact of ASD on QoL are presented in Fig. 2. For both the mothers and fathers, emotion-focused coping was significantly associated with



the perception of the impact of ASD on their own QoL (for mothers,  $\beta = 1.46$ , SE=0.22, p<0.001; for fathers,  $\beta = 1.02$ , SE=0.21, p<0.001). Only the partner effect was found to

be significant when predicting the perception of the impact of ASD on QoL from emotion-focused coping among the fathers ( $\beta$ =0.61, SE=0.21, p<0.01). The mothers'

Table 4 APIM parameter estimates for the impact of problem-focused coping, emotion-focused coping, and social-support seeking on the perceived impact of ASD on QoL

	Impact of problem-focused coping on the perceived impact of ASD on QoL			Impact of emotion-focused coping on the perceived impact of ASD on QoL			Impact seeking social support on the perceived impact of ASD on QoL		
	β	SE	p value	β	SE	p value	β	SE	p value
Actor effect									
Mothers	-0.308	0.275	0.262	1.457	0.222	< 0.001	0.216	0.258	0.404
Fathers	-0.301	0.257	0.242	1.022	0.210	< 0.001	-0.002	0.253	0.994
Partner effect									
Mothers	-0.027	0.269	0.921	- 0.128	0.221	0.561	- 0.097	0.265	0.715
Fathers	0.056	0.262	0.831	0.607	0.211	0.004	0.195	0.246	0.429

The statistically significant actor effects are indicated in bold  $\beta$  unstandardized coefficients, SE standard error

Fig. 2 Emotion-focused coping: the actor and partner effects as predictors of the perceived impact of ASD on QoL. APIM with distinguishable dyads regression model. \*\*p<0.01, \*\*\*p<0.001

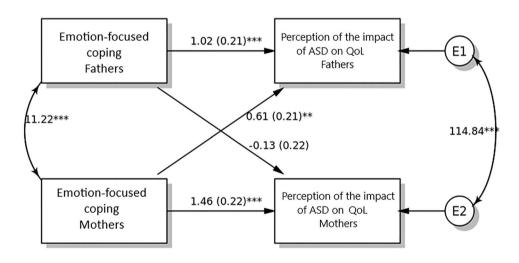
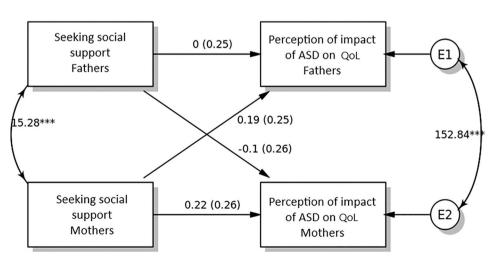


Fig. 3 Seeking social support: the actor and partner effects as predictors of the perceived impact of ASD on QoL. APIM with distinguishable dyads regression model. \*\*\*p<0.001





perception of the impact of ASD on QoL was not affected by the fathers' emotion-focused coping ( $\beta = -0.13$ , SE=0.221, p=0.561) (Table 4).

Concerning the dyadic patterns, the value of the k ratio for the mothers was -0.09 [95% CI (-0.38, 0.2)] and 0.59 [95% CI (0.05, 1.13)] for the fathers. Thus, the actor-only model is plausible for mothers, whereas the couple model is plausible for fathers.

# Impact of Seeking Social Support on the Perception of the Impact of ASD on QoL

The final APIM examined actor and partner effects of seeking social support on the perception of the impact of ASD on QoL among the mothers and fathers (Fig. 3). For both the mothers and fathers, actor effects and partner effects were found to be non-significant when predicting the perception of the impact of ASD on QoL from seeking social support (Table 4).

### **Discussion**

The results of the present study highlight some important observations concerning the dyadic effect of each parent's coping strategy on the perception of the impact of ASD on the QoL of both parents in a sample of 164 "mother-father" dyads.

First, our results indicate that the mothers perceive a greater impact than the fathers of their child's ASD on their QoL. This result is consistent with those of most previous studies (Mugno et al., 2007; Vasilopoulou & Nisbet, 2016; Yamada et al., 2012), although a few found there to be no difference in the QoL between the two parents (Dardas & Ahmad, 2014; Hastings, 2003). This result, however, needs to be interpreted in light of the fact that there are already gender differences in parents' ratings of QoL, whether or not they have a child with ASD, with mothers generally reporting a lower QoL than fathers (Chen et al., 2018; Lee et al., 2015). A possible explanation could be that mothers generally have a greater responsibility for the education of their children (Gray, 2003; Wang et al., 2011). Indeed, this appears to be the case in our study, in which the mothers were the most likely to have stopped working compared to fathers.

Second, we observed that the mothers implemented more coping strategies than the fathers, whether it was emotion-focused coping, problem-focused coping, or social-support seeking. Lee (2009) reported a similar result in their study, namely that the mothers of children with ASD used more coping strategies than the fathers to deal with stress. However, there is no consensus concerning these results, as several studies showed differences between mothers and fathers

in the use of coping strategies (Dabrowska & Pisula, 2010; Hastings et al., 2005; Luque Salas et al., 2017; Pozo et al., 2014), whereas others did not (Allik et al., 2006). Moreover, within the studies that observed a gender difference in the use of coping strategies, the results were contradictory. Thus, a systematic review (Vernhet et al., 2019) found that mothers used more emotion-focused coping (Dabrowska & Pisula, 2010; Luque Salas et al., 2017) and social-support seeking (Luque Salas et al., 2017) than fathers and that fathers used more problem-avoidance strategies than mothers (Luque Salas et al., 2017; Pozo et al., 2014). However, other studies have shown that mothers use problem-focused coping strategies more than fathers (Lee, 2009; Pozo et al., 2014). The lack of consensus on this issue may be explained by methodological biases, such as the timing of data collection. In the context of our study, our results can be explained by the fact that our data were collected at the time of inclusion of the children in the ELENA cohort, which coincides with the time of the communication of the diagnosis of ASD to their parents. We can therefore hypothesize that the fathers had not yet developed strategies to cope with their child's ASD at the time of diagnosis and that, conversely, the mothers had developed this type of strategy earlier, in a context in which they are the primary day-to-day providers of educational care to their children and are confronted with the chronic stress that this represents (Gray, 2003; Wang et al., 2011). Thus, it is possible that the fathers would mobilize more problem-focused coping strategies than the mothers at a distance from the diagnosis. It would be interesting to evaluate it in future studies using data collected at V2 (i.e., 3 years after inclusion) or V4 (i.e., 6 years after inclusion).

Third, the examination of the associations between emotion-focused coping and parental perception of the impact of ASD on QoL allowed us to identify "actor effects" (i.e., the association between the emotion-focused coping of a member of the dyad and his or her own perceived QoL). We observed that the more the mother used emotion-focused coping, the greater was the perceived impact of ASD on her QoL with the PAR-DD-QOL. We observed the same result for fathers, who perceived a greater impact of ASD on their QoL the more they used emotion-focused coping strategies. However, it is important to note that the items exploring "emotion-focused coping" in the questionnaire used in our study (Cousson et al., 1996; Vitaliano et al., 1985) were mainly related to avoidance strategies (e.g., "I tried to forget everything", "I thought of unreal or fantastic things to make me feel better") or self-blame (e.g., "I criticized or lectured myself", "I made myself feel guilty"). It has been suggested that these types of strategies are inappropriate and ineffective for coping with a stressful event for family caregivers of people with dementia (Li et al., 2012). This result corroborates other similar results in the literature, whether in "patient-caregiver" dyads (Baumstarck et al., 2018; Boyer



et al., 2017; Hamidou et al., 2018; Lafaye et al., 2014; Lazzarotto et al., 2019) or parents of children with ASD (Cappe et al., 2011), namely, a lower QoL when emotion-focused coping and, in particular, avoidance strategies are used.

Further concerning emotion-focused coping strategies, we observed a "partner effect" (i.e., the association between the emotion-focused coping of one member of the dyad and the perceived QoL of the other member). Thus, the more emotion-focused coping mothers used, the greater was the impact of the child's ASD on the fathers' perceived QoL. This result appears to be consistent with those of other studies reporting a partner effect in the literature. Indeed, in a study (Lafaye et al., 2014) describing partner effects in a context in which one of the partners has prostate cancer, it has been shown that the quality of the mental life (evaluated using the Short Form 12 (SF-12) scale and grouping together dimensions, such as vitality, social functioning, emotional state, and psychological health (Gandek et al., 1998)) of men was lower when their wives used emotion-focused coping. However, in our study, this partner effect was not observed, i.e., the fathers' use of emotion-focused coping was not significantly associated with the mothers' perceived impact of ASD on QoL.

Fourth, the examination of the associations between problem-focused coping and the perception of the impact of ASD on QoL for both the fathers and mothers did not identify either an actor or partner effect. This result was unexpected, given that this is hypothesized to be one of the most effective coping strategies for dealing with a stressor in parents of children with a neurodevelopmental disorder (Cappe et al., 2011; Dabrowska & Pisula, 2010; Smith et al., 2008). Our results can be explained by the fact that our data were collected at V0, i.e., at the time of diagnosis. It is indeed possible that parents have not yet developed these strategies to cope with their child's ASD, and that they develop them in the months following the communication of the diagnosis. It should be emphasized that, to be effective, problem-focused strategies must be adapted to the difficulties encountered. Communication of the diagnosis thus often allows the adaptation of care and support to the needs of children with ASD and their families. It is therefore likely that the effectiveness of problem-focused coping on the perception of parental QoL is only visible in the long term and that the impact of this type of coping strategy on the perception of the QoL of the parents in our sample cannot be observed at V0.

Finally, contrary to our expectations, the study of associations between coping strategies such as "social-support seeking" and parental perception of the impact of ASD on QoL, did not allow us to find any actor or partner effects. It is possible that the absence of significant results in our study is linked to the questionnaire used: the WCC-R. Indeed, the WCC-R is not specific to the evaluation of the perception of seeking social support. Studies that have shown a link

between social-support seeking and QoL (Baumstarck et al., 2016, 2018; Boyer et al., 2017; Hamidou et al., 2018; Lazzarotto et al., 2019) all used other tools (COPE Brief, Baumstarck et al., 2017; Muller & Spitz, 2003)).

One of the strengths of our study was the use of the APIM model to model interdependence in the dyadic relationship, insofar as a child's ASD diagnosis can be considered a dyadic stressor (Bodenmann, 1997) for his/her parents. However, as the APIM model is generally used in longitudinal designs (Cook & Kenny, 2016), it would be relevant in the future to use such a design. Another strength of our study, given its exploratory nature, was the sample size of children who all had a confirmed diagnosis of ASD. However, further research with larger sample sizes is needed to confirm our findings.

Despite the strengths of our study, our results must be considered in light of a number of limitations. First, the crosssectional design of our study did not allow us to establish a causal link between coping strategies and parents' perceptions of the impact of ASD on their QoL. Thus, we do not know whether an individual's coping strategies actually influence his or her perception and that of his or her partner over time. Future studies should use a prospective longitudinal design to better test the direction of associations between the coping strategies implemented and parents' perceptions of the impact of ASD on their OoL. Another limitation of our study may have been a selection bias related to the fact that the individuals who volunteered to participate in the study had particular characteristics, as studies conducted in the general population generally involve those who are in better health. This may lead to a biased estimate of the perceived impact of ASD on the QoL by the parents of children with ASD and thus underestimate the dyadic effect of coping. In addition, our study sample likely included parents who had the motivation and time to participate in the study, which limits the generalizability of our results. Furthermore, the lack of the possibility to adjust for potential confounding factors, such as PSI and HAD scores or marital status, limits the interpretation of our results. In addition, we explored individual coping strategies to predict the perception of the partner of the impact of ASD on their QoL in parenting dyads, but did not directly explore the influence of dyadic coping (i.e., how both partners respond to a specific stressful event to reduce distress) (Revenson et al., 2005) on perceived QoL. It would be informative to use specific scales, such as the Dyadic Coping Inventory (Bodenmann et al., 2018), in future studies. Moreover, although the QoL of mothers appeared to be more affected by ASD than that of fathers in the ELENA cohort, we cannot conclude that there is a specific effect of ASD from the results of our study in the absence of a control group of parents of children with typical development. Finally, the use of self-administered questionnaires reduces the reliability of the measures and may also induce a desirability bias.



### **Conclusion and Clinical Implications**

Our finding that mothers perceive a greater negative impact of ASD on their QoL than fathers confirms that it is essential to consider the possibility that mothers and fathers of children with ASD have specific needs in terms of their QoL. This study shows that parents' perception of the impact of ASD on their QoL is not only related to their own coping strategies but also those used by their partner.

In addition, these results emphasize the need for parent education programs, which contribute to parent empowerment and might contribute to the improvement of QoL. It may be important for clinicians to take into consideration inter-individual differences in the way fathers and mothers react and cope with their child's ASD when accompanying parents following the diagnosis. Parents of children with ASD should receive couple-focused interventions to develop or strengthen their ability to cope together with their child's disorder and thus improve their perceived QoL.

Acknowledgments The members of the ELENA study group are Pr Amaria Baghdadli, Dr Catherine Chabaux, Dr Clarisse Chatel, Pr David Cohen, Dr Emmanuel Damville, Dr Marie-Maude Geoffray, Pr Ludovic Gicquel, Pr Renaud Jardri, Dr Thierry Maffre, Dr Alexandre Novo, Dr Roxane Odoyer, Dr Marie-Joëlle Oreve, Dr Didier Périsse, Pr François Poinso, Dr Julien Pottelette, Dr Laurence Robel, Pr Catherine Rolland, Dr Marie Schoenberger, Dr Sandrine Sonié, Pr Mario Speranza, and Dr Stéphanie Vespérini.

**Author Contributions** CV, LB and AB conceived the study, contributed to the collection, analysis, and interpretation of the data, and drafted the manuscript. AB is the PI of ELENA cohort. MP, CV, LB and AB analyzed and interpreted the data and critically revised it, with CR and CM. All authors read and approved the final version to be published.

**Funding** This work received support from PHRCN 2013 (Grant No. 13-0232), Caisse Nationale de Solidarité pour l'Autonomie (CNSA) (Grant No. 030319).

## References

- Allik, H., Larsson, J.-O., & Smedje, H. (2006). Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. *Health and Quality of Life Outcomes*, 4, 1. https://doi.org/10.1186/1477-7525-4-1
- Altiere, M. J., & von Kluge, S. (2008). Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies*, 18, 83–92. https://doi.org/10.1007/s10826-008-9209-y
- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (DSM-5®). *American Psychiatric Publication, Washington, 51*(13), 1–1. https://doi.org/10.1176/appi.pn.2016.7a7
- Baghdadli, A., Miot, S., Rattaz, C., Akbaraly, T., Geoffray, M.-M., Michelon, C., Loubersac, J., Traver, S., Mortamais, M., Sonié, S., Pottelette, J., Robel, L., Speranza, M., Vesperini, S., Maffre, T., Falissard, B., & Picot, M.-C. (2019). Investigating the natural

- history and prognostic factors of ASD in children: The multicEntric Longitudinal study of childrEN with ASD the ELENA study protocol. *BMJ Open*, *9*(6), e026286. https://doi.org/10.1136/bmjopen-2018-026286
- Baghdadli, A., Pry, R., Michelon, C., & Rattaz, C. (2014). Impact of autism in adolescents on parental quality of life. Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment. Care and Rehabilitation, 23(6), 1859–1868. https:// doi.org/10.1007/s11136-014-0635-6
- Baumstarck, K., Alessandrini, M., Hamidou, Z., Auquier, P., Leroy, T., & Boyer, L. (2017). Assessment of coping: A new French four-factor structure of the brief COPE inventory. *Health and Quality of Life Outcomes*, 15(1), 8. https://doi.org/10.1186/ s12955-016-0581-9
- Baumstarck, K., Chinot, O., Tabouret, E., Farina, P., Barrié, M., Campello, C., Petrirena, G., Hamidou, Z., & Auquier, P. (2018). Coping strategies and quality of life: A longitudinal study of high-grade glioma patient-caregiver dyads. *Health and Quality of Life Outcomes*, 16(1), 157. https://doi.org/10.1186/s12955-018-0983-y
- Baumstarck, K., Leroy, T., Hamidou, Z., Tabouret, E., Farina, P., Barrié, M., Campello, C., Petrirena, G., Chinot, O., & Auquier, P. (2016). Coping with a newly diagnosed high-grade glioma: Patient-caregiver dyad effects on quality of life. *Journal of Neuro-Oncology*, 129(1), 155–164. https://doi.org/10.1007/s11060-016-2161-6
- Benson, P. R. (2010). Coping, distress, and well-being in mothers of children with autism. *Research in Autism Spectrum Disorders*, 4(2), 217–228. https://doi.org/10.1016/j.rasd.2009.09.008
- Berdeaux, G., Hervié, C., Smajda, C., & Marquis, P. (1998). Parental quality of life and recurrent ENT infections in their children: Development of a questionnaire. *Quality of Life Research*, 7(6), 501–512. https://doi.org/10.1023/A:1008874324258
- Bodenmann, G. (1997). *Dyadic coping: A systemic-transactional view of stress and coping among couples: Theory and empirical findings* (p. 47). Revue Européene de Psychologie Appliquée.
- Bodenmann, G., Arista, L., Walsh, K., & Randall, A. (2018). Dyadic coping inventory (pp. 1–5). Springer International Publishing.
- Bourke-Taylor, H., Pallant, J. F., Law, M., & Howie, L. (2012). Predicting mental health among mothers of school-aged children with developmental disabilities: The relative contribution of child, maternal and environmental factors. *Research in Developmental Disabilities*, 33(6), 1732–1740. https://doi.org/10.1016/j.ridd.2012.04.011
- Boyer, L., Baumstarck, K., Alessandrini, M., Hamidou, Z., Testart, J., Serres, M., Arquillière, P., Auquier, P., Leroy, T., & Zendjidjian, X. (2017). Emotional intelligence and coping strategies as determinants of quality of life in depressed patient-caregiver dyads: An actor-partner interdependence analysis. *Comprehensive Psychiatry*, 74, 70–79. https://doi.org/10.1016/j.comppsych.2017.01.003
- Brunet, O., Lézine, I., & Josse, D. (1997). Brunet-Lézine révisé: Échelle de développement psychomoteur de la première enfance: manuel BLR-C. Etablissements d'Applications Psychotechniques.
- Cappe, E., Bobet, R., & Adrien, J.-L. (2009). Quality of life and adaptation processes in families with a child suffering from autistic troubles or the Asperger syndrome. *La Psychiatrie De L'enfant*, 52, 201–246.
- Cappe, E., Poirier, N., Sankey, C., Belzil, A., & Dionne, C. (2018).
  Quality of life of French Canadian parents raising a child with autism spectrum disorder and effects of psychosocial factors.
  Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation, 27(4), 955–967. https://doi.org/10.1007/s11136-017-1757-4
- Cappe, E., Wolff, M., Bobet, R., & Adrien, J.-L. (2011). Quality of life: A key variable to consider in the evaluation of adjustment



- in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation, 20(8), 1279–1294. https://doi.org/10.1007/s11136-011-9861-3
- Chen, P.-L., Tsai, Y.-L., Lin, M.-H., & Wang, J. (2018). Gender differences in health promotion behaviors and quality of life among community-dwelling elderly. *Journal of Women & Community Aging*, 30(3), 259–274. https://doi.org/10.1080/08952841.2017.1301170
- Compas, B. E., Bemis, H., Gerhardt, C. A., Dunn, M. J., Rodriguez, E. M., Desjardins, L., Preacher, K. J., Manring, S., & Vannatta, K. (2015). Mothers and fathers coping with their children's cancer: Individual and interpersonal processes. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association*, 34(8), 783–793. https://doi.org/10.1037/hea0000202
- Cook, W. L., & Kenny, D. A. (2016). The actor-partner interdependence model: A model of bidirectional effects in developmental studies. *International Journal of Behavioral Development*. https:// doi.org/10.1080/01650250444000405
- Cousson, F., Bruchon-Schweitzer, M., Quintard, B., & Nuissier, J. (1996). Analyse multidimensionnelle d'une échelle de coping: Validation française de la W.C.C. (Ways of Coping Checklist) = Multidimensional analysis of a coping scale: The French validation of the ways of coping checklist. *Psychologie Française*, 41(2), 155–164.
- Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research*, 54(3), 266–280. https://doi.org/10.1111/j.1365-2788. 2010.01258.x
- Dardas, L. A., & Ahmad, M. M. (2014). Quality of life among parents of children with autistic disorder: A sample from the Arab world. Research in Developmental Disabilities, 35(2), 278–287. https://doi.org/10.1016/j.ridd.2013.10.029
- Dardas, L. A., & Ahmad, M. M. (2015). Coping strategies as mediators and moderators between stress and quality of life among parents of children with autistic disorder. Stress and Health: Journal of the International Society for the Investigation of Stress, 31(1), 5–12. https://doi.org/10.1002/smi.2513
- Eapen, V., & Guan, J. (2016). Parental quality of life in autism spectrum disorder: Current status and future directions. *Acta Psychopathologica*. https://doi.org/10.4172/2469-6676.100031
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.-H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. Autism: the International Journal of Research and Practice, 13(4), 375–387. https://doi.org/10.1177/1362361309105658
- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 21(3), 219–239. https://doi.org/10.2307/2136617
- Gandek, B., Ware, J. E., Aaronson, N. K., Apolone, G., Bjorner, J. B., Brazier, J. E., Bullinger, M., Kaasa, S., Leplege, A., Prieto, L., & Sullivan, M. (1998). Cross-validation of item selection and scoring for the SF-12 health survey in nine countries: Results from the IQOLA project. *Journal of Clinical Epidemiology*, 51(11), 1171–1178. https://doi.org/10.1016/S0895-4356(98)00109-7
- García-López, C., Sarriá, E., Pozo, P., & Recio, P. (2016). Supportive dyadic coping and psychological adaptation in couples parenting children with autism spectrum disorder: The role of relationship satisfaction. *Journal of Autism and Developmental Disorders*, 46(11), 3434–3447. https://doi.org/10.1007/s10803-016-2883-5
- Gray, D. (2003). Gender and coping: The parents of children with high functioning autism. Social Science & Eamp; Medicine. https://doi. org/10.1016/S0277-9536(02)00059-X

- Greenglass, E. R. (1993). The contribution of social support to coping strategies. *Applied Psychology: An International Review*, 42(4), 323–340. https://doi.org/10.1111/j.1464-0597.1993.tb00748.x
- Group, W. (1994). Development of the WHOQOL: Rationale and current status. *International Journal of Mental Health*, 23(3), 24–56. https://doi.org/10.1080/00207411.1994.11449286
- Hamidou, Z., Auquier, P., Leroy, T., Barlesi, F., Salas, S., Chinot, O., & Baumstarck, K. (2018). Dyadic effects of coping strategies, time perspectives, and personality on the quality of life of cancer patients and their caregivers. *Psycho-Oncology*, 27(2), 590–599. https://doi.org/10.1002/pon.4553
- Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research*, 47(Pt 4–5), 231–237. https://doi.org/10.1046/j.1365-2788.2003.00485.x
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism: the International Journal of Research and Practice*, 9(4), 377–391. https://doi.org/10.1177/1362361305056078
- Howlin, P., Savage, S., Moss, P., Tempier, A., & Rutter, M. (2014). Cognitive and language skills in adults with autism: A 40-year follow-up. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 55(1), 49–58. https://doi.org/10.1111/jcpp.12115
- Kaufman, A., & Kaufman, L. (2004). Kaufman assessment battery for children (2nd ed.). Manual.
- Kenny, D. A. (2016). Models of non-independence in dyadic research. Journal of Social and Personal Relationships. https://doi.org/10. 1177/0265407596132007
- Kenny, D. A., & Cook, W. (1999). Partner effects in relationship research: Conceptual issues, analytic difficulties, and illustrations. *Personal Relationships*, 6(4), 433–448. https://doi.org/10.1111/j. 1475-6811.1999.tb00202.x
- Khanna, R., Madhavan, S. S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 41(9), 1214–1227. https://doi.org/10.1007/s10803-010-1140-6
- Lafaye, A., Petit, S., Richaud, P., Nadine, H., Baguet, F., & Cousson-Gélie, F. (2014). Dyadic effects of coping strategies on emotional state and quality of life in prostate cancer patients and their spouses. *Psycho-Oncology*. https://doi.org/10.1002/pon.3483
- Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping—Google Scholar. Springer Publishing Co Inc. https://scholar.google.com/scholar\_lookup?title=Stress%2C%20appraisal%2C%20and%20coping&author=RS.%20Lazarus&author=S.%20Folkman&publication\_year=1984
- Lazzarotto, S., Martin, F., Saint-Laurent, A., Hamidou, Z., Aghababian, V., Auquier, P., & Baumstarck, K. (2019). Coping with agerelated hearing loss: Patient-caregiver dyad effects on quality of life. *Health and Quality of Life Outcomes*, 17(1), 86. https://doi.org/10.1186/s12955-019-1161-6
- Lee, E.-J., Pieczynski, J., DeDios-Stern, S., Simonetti, C., & Lee, G. K. (2015). Gender differences in caregiver strain, needs for support, social support, and quality of life among spousal caregivers of persons with multiple sclerosis. Work (reading, Mass), 52(4), 777–787. https://doi.org/10.3233/WOR-152205
- Lee, G. K. (2009). Parents of children with high functioning autism: How well do they cope and adjust? *Journal of Developmental and Physical Disabilities*, 21(2), 93–114. https://doi.org/10.1007/s10882-008-9128-2
- Li, R., Cooper, C., Bradley, J., Shulman, A., & Livingston, G. (2012). Coping strategies and psychological morbidity in family carers of people with dementia: A systematic review and meta-analysis. *Journal of Affective Disorders*, 139(1), 1–11. https://doi.org/10. 1016/j.jad.2011.05.055



- Lord, C., DiLavore, P. C., Gotham, K., Guthrie, W., Luyster, R. J., Risi, S., & Rutter, M. (2012). Western psychological services (Firm) autism diagnostic observation schedule: ADOS-2. Western Psychological Services.
- Luque Salas, B., Yáñez Rodríguez, V., Tabernero Urbieta, C., & Cuadrado, E. (2017). The role of coping strategies and self-efficacy as predictors of life satisfaction in a sample of parents of children with autism spectrum disorder. *Psicothema*, 29(1), 55–60. https://doi.org/10.7334/psicothema2016.96
- Mugno, D., Ruta, L., D'Arrigo, V. G., & Mazzone, L. (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health and Quality of Life Outcomes*, 5, 22. https://doi.org/10.1186/1477-7525-5-22
- Muller, L., & Spitz, E. (2003). Multidimensional assessment of coping: Validation of the Brief COPE among French population. *L'encephale*, 29(6), 507–518.
- Pisula, E. (2007). A comparative study of stress profiles in mothers of children with autism and those of children with down's syndrome. *Journal of Applied Research in Intellectual Disabilities*, 20(3), 274–278. https://doi.org/10.1111/j.1468-3148.2006.00342.x
- Pisula, E., & Kossakowska, Z. (2010). Sense of coherence and coping with stress among mothers and fathers of children with autism. *Journal of Autism and Developmental Disorders*, 40(12), 1485– 1494. https://doi.org/10.1007/s10803-010-1001-3
- Pozo, P., Sarriá, E., & Brioso, A. (2014). Family quality of life and psychological well-being in parents of children with autism spectrum disorders: A double ABCX model. *Journal of Intellectual Disability Research*, 58(5), 442–458. https://doi.org/10.1111/jir.12042
- Rattaz, C., Michelon, C., Roeyers, H., & Baghdadli, A. (2017). Quality of Life in Parents of Young Adults with ASD: EpiTED Cohort. *Journal of Autism and Developmental Disorders*, 47(9), 2826– 2837. https://doi.org/10.1007/s10803-017-3197-y
- Raysse, P. (2011). *Troubles du développement de l'enfant et qualité de vie familiale* [These de doctorat, Montpellier 3]. http://www.theses.fr/2011MON30068
- Revenson, T. A., Kayser, K., & Bodenmann, G. (2005). Couples coping with stress: Emerging perspectives on dyadic coping. American Psychological Association.
- Schopler, E., Lansing, M., Reichler, R., & Marcus, L. (2004). Psychoeducational profile Third edition (PEP-3) (Pro-Ed ed.USA)
- Smith, L. E., Seltzer, M. M., Tager-Flusberg, H., Greenberg, J. S., & Carter, A. S. (2008). A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD. *Journal of Autism and Developmental Disorders*, 38(5), 876–889. https://doi.org/10.1007/s10803-007-0461-6
- Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (2005). Vineland-II: Survey forms manual; Vineland adaptive behavior scales; survey interview form and parent/caregiver rating form; a revision of the Vineland social maturity scale by Edgar A. Doll. Pearson Assessments.
- Stern, W. (1912). The psychological methods of intelligence testing (G. Whipple, Trans.). Warwick and York

- Tung, L.-C., Huang, C.-Y., Tseng, M.-H., Yen, H.-C., Tsai, Y.-P., Lin, Y.-C., & Chen, K.-L. (2014). Correlates of health-related quality of life and the perception of its importance in caregivers of children with autism. *Research in Autism Spectrum Disorders*, 8(9), 1235–1242. https://doi.org/10.1016/j.rasd.2014.06.010
- Van Schoors, M., De Paepe, A. L., Lemiere, J., Morez, A., Norga, K., Lambrecht, K., Goubert, L., & Verhofstadt, L. L. (2019). Family adjustment when facing pediatric cancer: The role of parental psychological flexibility, dyadic coping, and network support. Frontiers in Psychology. https://doi.org/10.3389/fpsyg.2019.02740
- Van Schoors, M., Loeys, T., Goubert, L., Berghmans, G., Ooms, B., Lemiere, J., Norga, K., & Verhofstadt, L. L. (2019). Couples dealing with pediatric blood cancer: A study on the role of dyadic coping. *Frontiers in Psychology*, 10, 402. https://doi.org/10.3389/ fpsyg.2019.00402
- Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 23, 36–49. https://doi. org/10.1016/j.rasd.2015.11.008
- Vernhet, C., Dellapiazza, F., Blanc, N., Cousson-Gélie, F., Miot, S., Roeyers, H., & Baghdadli, A. (2019). Coping strategies of parents of children with autism spectrum disorder: A systematic review. *European Child & Adolescent Psychiatry*, 28(6), 747–758. https://doi.org/10.1007/s00787-018-1183-3
- Vitaliano, P. P., Russo, J., Carr, J. E., Maiuro, R. D., & Becker, J. (1985). The ways of coping checklist: Revision and psychometric properties. *Multivariate Behavioral Research*, 20(1), 3–26. https://doi.org/10.1207/s15327906mbr2001\_1
- Wang, P., Michaels, C., & Day, M. (2011). Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal of Autism and Developmental Disorders*, 41, 783–795. https://doi.org/10.1007/s10803-010-1099-3
- Wechsler, D. (2002). Wechsler primary and preschool scale of intelligence. The Psychological Corporation.
- Wechsler, D. (2003). Wechsler intelligence scale for children–Fourth Edition (WISC-IV). The Psychological Corporation.
- Wechsler, D. (2014a). WISC-V: Administration and scoring manual. NCS Pearson, Incorporated.
- Wechsler, D. (2014b). WPPSI-IV, échelle d'intelligence de Wechsler pour enfants. ECPA.
- Yamada, A., Kato, M., Suzuki, M., Suzuki, M., Watanabe, N., Akechi, T., & Furukawa, T. A. (2012). Quality of life of parents raising children with pervasive developmental disorders. *BMC Psychiatry*, 12(1), 119. https://doi.org/10.1186/1471-244X-12-119

**Publisher's Note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

