



Contents lists available at ScienceDirect

Pratiques psychologiques

journal homepage: www.elsevier.com

Clinical psychology

Maternal adjustment: A longitudinal study of transactional variables and quality of life in the year following a child's autism diagnosis

Ajustement maternel : une étude longitudinale des variables transactionnelles et de la qualité de vie au cours de l'année suivant le diagnostic d'autisme d'un enfant

Gwendoline Desquenne-Godfrey ^{a,*}, Aude De Gaulmyn ^b, Catherine Doyen^b,
Valérie Vantalon^c, Lisa Ouss ^d, Romain Taton^e, Antoine Rosier ^e,
Emilie Cappe ^a

^a Université Paris Cité, laboratoire de psychopathologie et processus de santé, 71, avenue Edouard-Vaillant, 92774 Boulogne-Billancourt, France

^b Groupe hospitalier universitaire de Paris, psychiatrie et neurosciences, 26, boulevard Brune, 75014 Paris, France

^c Centre d'excellence InovAND, hôpital universitaire Robert-Debré, 48, boulevard Sérurier, 75019 Paris, France

^d Hôpital universitaire Necker-Enfants-Malades, 149, rue de Sevres, 75015 Paris, France

^e Centre ressources autisme Normandie Seine Eure, 4, rue Paul-Eluard, 76300 Sotteville-lès-Rouen, France

ARTICLE INFO

Keywords:

Autism
Diagnosis
Mothers
Adjustment

ABSTRACT

Introduction: Receiving an official diagnosis can be an emotional experience for parents of autistic children and generate a need for psychosocial adjustment.

Objective: The aim of the study was to assess the perception of mothers of autistic children regarding their level of stress, control over their child's development, satisfaction regarding social support, family functioning, coping strategies, and impact on quality of life, in the year following their child's diagnosis.

Method: Thirty-one mothers of autistic children were recruited through diagnosis centres and completed a set of questionnaires measuring the targeted variables three times: a month after the diagnosis, six months after, and a year after.

Results: Results showed no significant evolution of the level of perceived stress, perceived control over the child's development, perceived family functioning, coping strategies, and impact on quality of life over the year post-diagnosis. However, a significant decrease in perceived satisfaction regarding social support was observed during the assessed period.

Discussion: Results are discussed in relation to the existing literature on the topic, which contains inconsistent data and needs to be broadened, and to other factors which could have influenced them. Specifically, the decrease in perceived satisfaction regarding social support should be investigated. Indeed, the appointments related to the diagnostic assessments may provide access to professional support, which would be less available at the end of the process. Recommendations are made for further studies and clinical applications of the results.

* Corresponding author.

E-mail addresses: gwendoline.desquenne@hotmail.fr (G. Desquenne-Godfrey), a.degaulmyn@ghu-paris.fr (A. De Gaulmyn), c.doyen@ghu-paris.fr (C. Doyen), valerie.vantalon@aphp.fr (V. Vantalon), lisa.ouss@aphp.fr (L. Ouss), romain.taton@ch-lerouvray.fr (R. Taton), antoine.rosier@ch-lerouvray.fr (A. Rosier), emilie.cappe@u-paris.fr (E. Cappe).

<https://doi.org/10.1016/j.prps.2026.06.001>

Received 21 October 2025; Accepted 1 June 2026

Available online xxx

1269-1763/© 2026 Société Française de Psychologie. Published by Elsevier Masson SAS. All rights are reserved, including those for text and data mining, AI training, and similar technologies.

R É S U M É

Mots clés :
Autisme
Diagnostic
Mères
Ajustement

Introduction : Recevoir un diagnostic officiel peut être une expérience chargée émotionnellement pour les parents d'enfants autistes et engendrer un besoin d'ajustement.

Objectif : L'étude visait à évaluer la perception des mères d'enfants autistes concernant leur stress, leur sentiment de contrôle sur le développement de l'enfant, leur satisfaction à l'égard du soutien social, leur fonctionnement familial, leurs stratégies de coping, et leur qualité de vie, au cours de l'année post-diagnostic.

Méthode : Trente et une mères d'enfants autistes ont été recrutées via des centres de diagnostic et ont complété des questionnaires mesurant les variables ciblées à trois reprises : un mois après le diagnostic, six mois après, et un an après.

Résultats : Les résultats n'ont montré aucune évolution significative du niveau de stress perçu, du sentiment de contrôle sur le développement de l'enfant, du fonctionnement familial perçu, des stratégies de coping, ou encore de la qualité de vie au cours de l'année post-diagnostic. Cependant, une diminution significative de la satisfaction perçue à l'égard du soutien social a été observée durant la période évaluée.

Discussion : Les résultats sont discutés en lien avec la littérature existante, laquelle présente des données inconsistantes et mérite d'être approfondie, ainsi qu'en lien avec d'autres facteurs susceptibles de les avoir influencés. Spécifiquement, la diminution de la satisfaction perçue concernant le soutien social devrait être examinée. En effet, les rendez-vous liés au diagnostic peuvent apporter un soutien professionnel, moins disponible à la fin du processus. Des recommandations sont formulées pour des futures recherches et applications cliniques.

1. Introduction

In the DSM-5 and the ICD-11, autism spectrum disorder (ASD) is characterised by a persistent deficit of communication and social interactions as well as repetitive behaviours and restricted interests (APA, 2013, 2022; WHO, 2022). Following the recommendations of several studies on autistic people's preferences and their families', the terms "autism" and "autistic person" are used in this article (Bureau, 2023; Geelhand et al., 2023; Keating et al., 2023; Kenny et al., 2016).

1.1. Parental wellbeing

For parents of autistic children, daily life can generate more fatigue (Seymour, Wood, Giallo, & Jellett, 2013), stress (Craig et al., 2016), anxiety and depression (Fourcade, Kruck, & Rogé, 2019) than for parents of neurotypical children. These challenges are all the more present when the clinical signs are severe (Brei, Schwarz, & Klein-Tasman, 2015) and associated with behavioural and emotional difficulties (Craig et al., 2016; Scibelli et al., 2021), lower adaptive skills (Karst & Van Hecke, 2012), or comorbidities such as an intellectual disability (Scibelli et al., 2021) or an attention deficit hyperactivity disorder (Schiltz et al., 2022). These difficulties appear to affect mothers even more than fathers (Jones, Totsika, Hastings, & Petalas, 2013; Patel, Rivard, Mello, & Morin, 2022; Rattaz, Loubersac, Michelon, Picot, & Baghdadli, 2023). An explanation could be that the responsibility of daily life adaptations and administrative procedures frequently falls on them (Beaud & Quentel, 2011; Tehee, Honan, & Hevey, 2009).

In France, recommendations have been established regarding the diagnosis of autism (HAS, 2018). However, parents still report facing many challenges between the first observations and the announcement of the official diagnosis. Indeed, on top of daily difficulties, the journey towards the diagnosis can bring additional stress and fatigue, with a plethora of unsatisfactory consultations with untrained professionals, long administrative procedures, and a feeling of helplessness (Leblé, Cosquer, Mezghiche, Cazard, & Joussemme, 2021; Mercuriali & Yvon, 2020; Moh & Magiati, 2012).

When the diagnosis is finally given, parents can express disappointment related to the loss of time and stress related to the implications of autism and the future (Leblé et al., 2021; Martins, Bonito, Andrade, Albuquerque, & Chaves, 2015; Patel et al., 2022). Some parents also express relief after receiving a diagnosis from competent professionals. A lot of them are aware of their child's difficulties before the official diagnosis, but this step strengthens the legitimacy of their worry, lowers the feeling of guilt, gives solid arguments against criticism, and gives direction for care providers. Even if some parents remain doubtful about the diagnosis, the process within expert centres is often found satisfactory. However, the lack of support in accessing care post-diagnosis often causes dissatisfaction (Cappe et al., 2024; Jacobs, Steyaert, Dierickx, & Hens, 2020; Leblé et al., 2021).

1.2. Model of adjustment

Considering the challenges related to daily life with an autistic child and to the diagnosis procedure, a parental and specifically maternal adjustment is often needed. This process can be described using the multifactorial, integrative, transactional model by Bruchon-Schweitzer (2002), based on the original transactional model by Lazarus and Folkman (1984). It illustrates adjustment mechanisms through transactional processes, which can be defined as the interaction between the environment and the cognitive, behavioural, emotional and physiological perception of this environment.

According to this model, in a potentially threatening situation, an individual makes a primary assessment. Perceived stress is the transactional process defined as the perception of the situation as consuming or exceeding the available resources to face it (Bruchon-Schweitzer & Boujut, 2021; Lazarus & Folkman, 1984). Hayes and Watson's (2012) meta-analysis indicates that parents of autistic children generally perceive higher levels of stress than parents of typically developing children. Besides, Yorke et al.'s (2018) systematic review and meta-analysis suggests that the more severe the autism symptoms, the higher the parental stress.

Perceived stress interacts with other transactional processes resulting from the secondary assessment of personal and social resources such as perceived control and perceived social support. On the one hand, perceived control is the feeling of being capable of managing the situation which has been assessed as stressful (Bruchon-Schweitzer & Boujut, 2021; Lazarus & Folkman, 1984). For parents of autistic children, this transactional process can be assessed specifically in terms of perceived control over the child's development (Cappe et al., 2011). The literature on this variable is limited. However perceived parental self-efficacy regarding the autistic child is a close construct and Brennan, Ward, Tomeny, and Davis's (2024) systematic review on this variable indicates that severe autism symptoms are associated with lower perceived parental self-efficacy. On the other hand, perceived social support is defined as the interaction between the help received and the satisfaction perceived towards it, in relation with the needs and expectations (Bruchon-Schweitzer & Boujut, 2021; Lazarus & Folkman, 1984). Gao and Drani's (2025) systematic review suggests that parents of autistic children have a high need for informative, practical, and emotional support, which is rarely met.

Considering the primary and secondary assessments, the person facing the aversive situation develops coping strategies, which aim to manage, reduce, or simply tolerate the situation. The main categories of coping strategies are focused on the problem (to increase the resources or problem solve), on the emotion (to regulate the emotional discomfort linked to the situation), and on social support seeking (to obtain sympathy or help) (Bruchon-Schweitzer & Boujut, 2021; Lazarus & Folkman, 1984). Parents of autistic children use these strategies to face the challenges they encounter in relation to their children's difficulties (Cappe et al., 2011). In their systematic review, Vernhet et al. (2019) noted that parents of autistic children use more avoidance (inefficient emotion-focused strategy) and less social support seeking than parents of typically developing children.

In this study, although it does not appear in the original model, perceived family functioning was included as a transactional process reflecting the perception of interactions in the family environment. Indeed, research in autism has shown this variable to be significantly correlated with factors involved in adjustment mechanisms (Desquenne-Godfrey, Downes, & Cappe, 2023). Family functioning refers to regular interactions among family members constituting a system (Watzlawick, 1972). According to Olson's model (2011), it includes three dimensions: cohesion (attachment between members of the system), flexibility (ability to adjust rules and roles as needed), and communication (which allows adaptation of cohesion and flexibility depending on the needs).

In Bruchon-Schweitzer's model (2002), quality of life can be considered as an outcome of the adjustment mechanisms. WHO (1993) defines it as "an individual's 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" (p. 153). It interacts with the transactional processes, in that it results from their action but can also have a retroactive effect on them. Cappe et al. (2011) specifically defines the quality of life of parents of autistic children through seven domains: relationships with autistic child, family and couple relationships, psychological well-being, personal fulfilment, daily activities, professional activities and relationships, and social activities and relationships. Turnage and Conner (2022), in their review, noted that quality of life for parents of autistic children was lower than for parents of typically developing children. Besides, more severe autistic symptoms appear to be linked to a lower quality of life.

1.3. Maternal adjustment post-diagnosis

The official diagnosis of an autistic child is often seen as a turning point for the parents, with implications for the future, continuous and new challenges, but also a sense of relief and requalification in the parental role (Jacobs et al., 2020; Leblé et al., 2021; Patel et al., 2022). It marks the start of a new step in their journey, which leads to wonder how parental adjustment mechanisms based on the transactional model evolve in the period closely following the diagnosis.

Some studies have focused longitudinally on variables of the transactional model to understand parental adjustment following the diagnosis of an autistic child. In Rattaz et al.'s study (2023), stress levels decreased in the three years following it. Regarding perceived control, no study focusing on the evolution post-diagnosis was found. Regarding perceived social support, McGrew and Keyes (2014) observed an increase a year after diagnosis. On the contrary, Dai et al. (2024) did not report any evolution post-diagnosis. Considering problem-focused coping strategies, McGrew and Keyes (2014) observed a decrease a year after diagnosis. On the contrary, Rattaz et al. (2023) did not observe any change three years after diagnosis. They also did not note an evolution in social support seeking. Considering emotion-focused strategies, McGrew and Keyes (2014) did not observe any change a year after diagnosis. Three years after diagnosis, Rattaz et al. (2023) observed a decrease. Regarding perceived family functioning, Herring et al. (2006) noted a significant positive correlation between the assessment at diagnosis and a year after diagnosis. Finally, regarding general quality of life satisfaction, Dai et al. (2024) observed an increase a year after diagnosis.

To our knowledge, no other published article so far has focused on the evolution of these variables over time, following the diagnosis of an autistic child. The current literature on this topic seems therefore quite limited. In addition, for the variables on which more than one longitudinal article are published such as perceived social support (Dai et al., 2024; McGrew & Keyes, 2014), problem-focused coping strategies (McGrew & Keyes, 2014; Rattaz et al., 2023), and emotion-focused coping strategies (McGrew & Keyes, 2014; Rattaz et al., 2023), results are inconsistent. These discrepancies could be due to methodological or contextual differences, but are difficult to interpret without more data and studies.

To investigate further this research question, the aim of this study was to assess the perception of mothers regarding stress, control over the development of the child, satisfaction regarding social support, family functioning, coping strategies, and impact

on quality of life in the year following the diagnosis of their autistic children. Even though the initial focus of the study was parental adjustment, the difficulty in recruiting fathers led to a shift towards maternal adjustment. It seemed like a relevant transition considering that mothers often bear the responsibility of daily life adaptations and administrative procedures (Beaud & Quentel, 2011; Tehee et al., 2009).

Although receiving the official diagnosis can be emotionally charged and have implications for the future, it often marks the end of a long and difficult journey and aims to guide parents towards appropriate care (Cappe et al., 2024; Leblé et al., 2021; Mercuriali & Yvon, 2020; Moh & Magiati, 2012; Patel et al., 2022). In that sense, the levels of perceived stress, ineffective emotion-focused coping strategies, unbalanced family functioning, and impact on quality of life were expected to decrease during the year post-diagnosis. On the contrary, the levels of perceived control over the development of the child, perceived satisfaction regarding social support, effective problem-focused and social support seeking coping strategies, and balanced family functioning were expected to increase.

2. Method

This research was designed and conducted as part of a larger doctoral project.

2.1. Population

Originally, 138 parents (mothers and fathers) of autistic children were contacted through four diagnosis centres mainly around Paris, in France. Other diagnosis centres had been approached but the ongoing COVID-19 pandemic led to difficulties in building research partnerships and therefore a recruitment bias limiting the generalisation of the findings to the whole of France. To participate, parents had to be fluent in French (1) and have a child between 2 and 10 years old (2) diagnosed with ASD approximately one month before the beginning of their participation (3). The age range was chosen considering that signs of autism are clearer from 18 months (HAS, 2018) and the mean age of diagnosis in France is around 5 (Rattaz et al., 2022). The child had to live with them at least part of the time (4). They were asked to participate in the study at three different points in time: one month after their child's diagnosis (T0), six months after T0 (T1), and one year after T0 (T2). These time points allowed for an ethical yet rapid assessment of parental adjustment and its evolution throughout the first year following the diagnosis. The short amount of time between the diagnosis and the required participation led to difficulties in recruitment, emphasised by the COVID-19 sanitary crisis.

The number of participants was 41 at T0 (37 mothers, 4 fathers), 35 at T1 (32 mothers, 3 fathers), and 32 at T2 (31 mothers, 1 father). The loss of participants was due to medical issues, lack of time, or loss of interest in the study. Because of the difficulty to recruit fathers and the loss of participants reducing the number of fathers to 1 in the longitudinal sample, the focus of the study shifted towards mothers' experience. Therefore, the only father who participated throughout the whole study was excluded. In the end, 31 mothers (22.46% of the parents initially contacted), with a mean age of 37.18 years old ($SD = 6.03$, 95% CI [35.15, 39.41]) at T0, signed a consent form and participated in the three points of measurement. Sociodemographic data are available in Table 1.

During their participation, each mother was asked to refer to her autistic child diagnosed one month before T0. These children were 5 girls and 26 boys with a mean age of 5.55 years ($SD = 2.30$, 95% CI [4.73, 6.39]) at T0. Among the 31 children, 3 were diagnosed with ASD "requiring support", 13 with ASD "requiring substantial support", and 15 with ASD "requiring very substantial support", using the ADOS-2 (Lord et al., 2012) among other tools. Sociodemographic data are provided in Table 2.

2.2. Procedure

As mentioned, mothers were recruited to participate in the study one month after the diagnosis of their child (T0), six months after T0 (T1), and one year after T0 (T2). In reality, the mean time between diagnosis and T0 was 40.45 days ($SD = 16.72$, 95% CI [34.65, 46.32]), the mean time between T0 and T1 was 190.48 days ($SD = 19.54$, 95% CI [184.36, 198.64]), and the mean time between T1 and T2 was 200.65 days ($SD = 27.34$, 95% CI [191.20, 210.09]). Finally, the mean time between diagnosis and T2 was 431.58 days ($SD = 32.09$, 95% CI [419.87, 441.93]), meaning a little over a year and two months. The measurement times could not be followed strictly due to personal and professional constraints of mothers.

At each assessment time, mothers were asked to fill out several questionnaires online or by phone. These options allowed a wider sample of mothers to participate. Of the 31 mothers, 24 responded online and 7 by phone. The questionnaires provided an assessment of perceived stress, perceived control over the child's development, perceived social support, coping strategies, impact on quality of life, and perceived family functioning.

2.3. Assessment tools

Firstly, mothers were asked about sociodemographic information. Afterwards, self-reported scales were used. The large number of items participants were required to complete may have contributed to participant attrition and increased the risk of response fatigue bias.

Table 1
Mothers' sociodemographic data at T0.

	<i>n</i> = 31
Age (years)	
Mean	37.18
Standard deviation	6.03
Confidence interval (95%)	[35.15, 39.41]
Relationship status (<i>n</i>)	
In a relationship	23 (74.19%)
Not in a relationship	8 (25.81%)
Region of France (<i>n</i>)	
Paris region	29 (93.55%)
Other	2 (6.45%)
Education level (<i>n</i>)	
Secondary education	16 (51.61%)
One year of higher education	1 (3.23%)
Two years of higher education	5 (16.13%)
Three years of higher education	1 (3.23%)
Four years of higher education	1 (3.23%)
Five years of higher education	4 (12.90%)
More than five years of higher education	3 (9.67%)
Professional activity (<i>n</i>)	
Full time	12 (38.71%)
Part time	7 (22.58%)
At home	9 (29.03%)
Job seeking	2 (6.45%)
Long term sick leave	1 (3.23%)

Table 2
Autistic children and siblings' sociodemographic data at T0.

	<i>n</i> = 31
Age (years)	
Mean	5.55
Standard deviation	2.30
Confidence interval (95%)	[4.73, 6.39]
Gender (<i>n</i>)	
Girl	5 (83.87%)
Boy	26 (16.13%)
Autism severity (<i>n</i>)	
Requiring support	3 (9.67%)
Requiring substantial support	13 (41.94%)
Requiring very substantial support	15 (48.39%)
Living arrangement (<i>n</i>)	
With both parents	23 (74.19%)
Only with their mother	8 (25.81%)
Number of siblings (<i>n</i>)	
Zero	6 (19.35%)
One	10 (32.26%)
Two	9 (29.03%)
Three	4 (12.90%)
Four	1 (3.23%)
Five	1 (3.23%)
Number of siblings with a disability or chronic disease (<i>n</i>)	
Zero	28 (90.32%)
One	3 (9.68%)

To assess perceived stress, the Perceived Stress Scale (PSS-10) from Cohen, Kamarck, and Mermelstein (1983), translated in French by Bruchon-Schweitzer (2002) and validated by Bellinghausen, Collange, Botella, Emery, and Albert (2009) among employees was used. This scale contains ten five-point Likert scales reflecting two dimensions. The first is the perception of emotional overflow ($\alpha = 0.85$). The higher the score, the more the person feels overwhelmed by their emotions. The second dimension is perceived personal efficacy ($\alpha = 0.80$). The higher the score, the more ineffective the person feels coping with the situation.

To assess perceived control over the child's development, an adaptation of the Cancer Locus of Control Scale (CLCS) was used. It was created and validated by Pruyn et al. (1988) and translated into French and validated by Cousson-Gélie (1997) and Kolec (2000) in the field of physical health. From these versions, Cappe et al. (2011) created an adaptation and validated it among parents of autistic children. One subscale of this adaptation was used in this study: perceived control over the child's development.

It includes six four-point Likert scales ($\alpha = 0.65$). The higher the score, the more the person feels they can influence their autistic child's development.

To assess perceived social support, the Questionnaire de Soutien Social Perçu (QSSP, Perceived Social Support Questionnaire) from Koleck (2000), adapted and validated by Cappe et al. (2011) among parents of autistic children, was used. Specifically, only the subscale assessing satisfaction regarding perceived social support was used. The respondent is asked to assess the level of satisfaction on four six-point Likert scales corresponding to different aspects of social support ($\alpha = 0.82$). The higher the score, the more satisfied the person is with perceived social support.

To assess coping strategies, the Ways of Coping Checklist (WCC-R) from Vitaliano, Russo, Carr, Maiuro, and Becker (1985), translated in French and validated by Cousson-Gélie, Bruchon-Schweitzer, Quintard, Nuissier, and Rascle (1996), and adapted and validated by Cappe et al. (2011) among parents of autistic children, was used. It contains twenty-five four-point Likert scales reflecting three dimensions: problem-focused strategies ($\alpha = 0.76$), ineffective emotion-focused strategies ($\alpha = 0.73$), and social support seeking strategies ($\alpha = 0.76$). For each subscale, the higher the score, the more the person uses the coping strategy.

To assess the impact on quality of life, the Parents of Autistic Children Quality of Life Scale created and validated by Cappe et al. (2011), was used. It contains 99 four-point Likert scales reflecting a global score ($\alpha = 0.78$) and seven dimensions: daily activities ($\alpha = 0.91$), professional activities and relationships ($\alpha = 0.76$), social activities and relationships ($\alpha = 0.92$), family and couple activities and relationships ($\alpha = 0.86$), parent-child activities and relationship ($\alpha = 0.76$), psychological well-being ($\alpha = 0.90$), and personal fulfillment ($\alpha = 0.86$). For each dimension, the higher the score, the more the quality of life of the parent of an autistic child is impacted.

To assess perceived family functioning, the Family Adaptability and Cohesion Evaluation Scales (FACES IV) by Olson (2011), translated and validated in French by Desautels, Lapalme, Touchette, and Pauzé (2016) among parents of the general population and families in crisis, was used. It includes sixty-two five-point Likert scales reflecting eight dimensions. Cohesion is assessed through the subscales of balanced cohesion ($\alpha = 0.85$), disengagement i.e. unbalanced low cohesion ($\alpha = 0.72$), and enmeshment i.e. unbalanced high cohesion ($\alpha = 0.64$). Flexibility is assessed through the subscales of balanced flexibility ($\alpha = 0.74$), rigidity i.e. unbalanced low flexibility ($\alpha = 0.66$), and chaos i.e. unbalanced high flexibility ($\alpha = 0.76$). For both balanced scales, the higher the score, the more balanced the family functioning is perceived. For the unbalanced scales, the higher the score, the more the person perceives their family functioning as unbalanced. Furthermore, the quality of communication within the family is assessed ($\alpha = 0.89$). The higher the score, the more the person perceives family communication to be of good quality. Finally, satisfaction regarding family functioning ($\alpha = 0.92$) is assessed. The higher the score, the more satisfied the person is with their family functioning.

2.4. Analysis

For each participant, less than 5% of the data was missing (Srijan & Rajagopalan, 2024). Within the collected data, the missing information from the self-reported scales was replaced with the mean of the items from the same subscale and from the same participant, as recommended by Fox-Wasylyshyn and El-Masri (2005).

To conduct the analysis, IBM SPSS Statistics was used. Considering the small sample size and the unsatisfactory distribution of the data, non-parametric tests were conducted. Specifically, to assess the evolutions of all the variables, the Friedman test was used. In order to conduct a sensitivity analysis for a Friedman test with three repeated measures ($n = 31$, $df = 2$), statistical power was set at 80% ($\beta = 0.20$), in line with conventional recommendations in social sciences (Cohen, 1988). According to this analysis, the study design allowed the detection of a global effect corresponding to Kendall's $W = 0.16$, meaning moderate and large longitudinal effects. Smaller effects may not be identified. In case of significative result on the Friedman test, the Wilcoxon matched pairs test was planned as a post-hoc analysis.

3. Results

Results are displayed in Table 3. The chosen significance threshold was $P < 0.05$.

Fig. 1 illustrates the results regarding traditional transactional processes. Contrary to what was expected, no significant evolution was observed over the three points in time for both subdimensions of perceived stress (emotional overflow and perceived personal efficacy), for perceived control over the child's development, and for the different coping strategies (problem-focused strategies, emotion-focused strategies, and social support seeking). However, a significant moderate evolution was noted for perceived satisfaction regarding social support. With further analysis, the Wilcoxon test showed a significant decrease between T0 and T1 ($Z = -3.72$, $P < 0.001$), but not between T1 and T2 ($Z = 1.46$, $P = 0.15$). The general decrease between T0 and T2 was significant ($Z = -3.64$, $P < 0.001$). This result highlights a decrease in satisfaction regarding social support perceived by mothers of autistic children six months after the diagnosis, maintained a year after the diagnosis. This evolution is contrary to the hypothesised increase in perceived satisfaction regarding social support.

Fig. 2 illustrates the results regarding perceived family functioning. Contrary to what was expected, no significant evolution was observed over the three points in time for seven of the subscales: balanced cohesion, disengagement, enmeshment, balanced flexibility, rigidity, chaos, and satisfaction regarding family functioning. However, a significant evolution was noted for the communication subscale. The effect size was small. With further analysis, the Wilcoxon test showed a significant decrease between T0 and T1 ($Z = -2.80$, $P < 0.01$), but no significant difference between T1 and T2 ($Z = 1.59$, $P = 0.11$). The general decrease between T0 and T2 was not significant ($Z = -0.90$, $P = 0.37$). This result highlights a decrease in the quality of family

Table 3
Evolution of the scores of mothers of autistic children on the different scales over time.

	T0		T1		T2		Friedman test		
	M (SD)	Mdn (IQR)	M (SD)	Mdn (IQR)	M (SD)	Mdn (IQR)	$\chi^2(2)$	P	Kendall's W
Perceived stress									
Emotional overflow	16.42 (5.80)	16 (8)	16.94 (5.66)	18 (9)	16.52 (5.13)	17 (8)	0.98	0.61	0.02
Perceived personal efficacy	9.97 (2.94)	10 (3)	9.29 (2.64)	9 (3)	9.74 (3.08)	10 (4)	0.52	0.77	0.01
Perceived control									
Over the child's development	13.92 (2.94)	14 (3)	14.35 (3.29)	16 (4)	14.35 (2.73)	15 (3)	0.13	0.94	0.00
Perceived social support									
Satisfaction	14.19 (5.28)	16 (6)	10.32 (2.93)	11 (4)	10.97 (3.62)	12 (5)	20.30	< 0.001**	0.33
Coping strategies									
Problem-focused strategies	30.53 (5.91)	30 (7)	29.97 (6.51)	30 (7)	29.95 (6.77)	30 (7)	1.25	0.54	0.02
Emotion-focused strategies	23.79 (5.34)	25 (8)	22.00 (6.86)	23 (10)	21.31 (5.10)	21 (5)	4.43	0.11	0.07
Social support seeking	22.72 (5.28)	23 (7)	21.83 (6.79)	23 (10)	23.14 (5.67)	23 (8)	3.38	0.19	0.06
Perceived family functioning									
Balanced cohesion	29.06 (4.46)	30 (5)	27.57 (5.13)	28 (4)	28.39 (4.32)	28 (6)	2.06	0.36	0.03
Disengagement	17.06 (3.94)	16 (5)	16.85 (2.95)	16 (5)	16.89 (5.00)	17 (7)	1.25	0.54	0.02
Enmeshment	16.84 (5.60)	16 (8)	15.69 (5.85)	14 (9)	17.46 (5.71)	17 (7)	2.32	0.31	0.04
Balanced flexibility	25.55 (4.84)	25 (7)	25.27 (5.07)	26 (5)	25.39 (4.58)	26 (7)	0.12	0.94	0.00
Rigidity	19.48 (6.13)	19 (9)	18.73 (6.51)	18 (8)	18.19 (5.84)	18 (9)	1.61	0.45	0.03
Chaos	15.58 (4.81)	17 (6)	15.47 (5.12)	16 (8)	15.90 (4.97)	16 (7)	1.56	0.46	0.03
Communication	40.71 (6.91)	42 (9)	38.07 (7.49)	39 (7)	39.90 (6.66)	39 (10)	6.56	0.04*	0.11
Satisfaction	33.65 (9.15)	33 (12)	33.33 (8.74)	32 (10)	33.66 (8.47)	33 (10)	0.90	0.64	0.02
Impact on quality of life									
General impact	136.89 (54.27)	140 (58)	130.65 (61.46)	144 (88)	126.13 (59.44)	130 (76)	3.59	0.17	0.06
Daily activities	31.86 (12.14)	32 (17)	30.29 (13.71)	34 (21)	30.68 (13.56)	32 (20)	1.47	0.48	0.02
Professional activities and relationships	6.70 (5.44)	6 (8)	6.48 (6.55)	3 (11)	4.77 (4.57)	3 (7)	4.33	0.12	0.07
Social activities and relationships	29.46 (15.24)	31 (20)	26.61 (17.46)	26 (31)	25.92 (15.12)	27 (22)	3.32	0.19	0.05
Family and couple activities and relationships	27.84 (13.92)	29 (15)	26.24 (14.07)	29 (22)	26.11 (15.23)	27 (20)	3.62	0.16	0.06
Parent-child activities and relationship	6.94 (4.56)	8 (7)	6.71 (4.71)	6 (8)	5.34 (5.17)	6 (7)	3.88	0.14	0.06
Psychological well-being	22.90 (12.57)	21 (16)	22.39 (12.37)	21 (13)	20.74 (12.91)	22 (17)	1.32	0.52	0.02
Personal fulfilment	7.94 (5.15)	9 (8)	8.67 (5.25)	8 (7)	9.13 (5.25)	9 (8)	1.63	0.44	0.03

M: Mean; SD: Standard Deviation; Mdn: Median; IQR: Interquartile range.

* $P < 0.05$.

** $P < 0.01$.

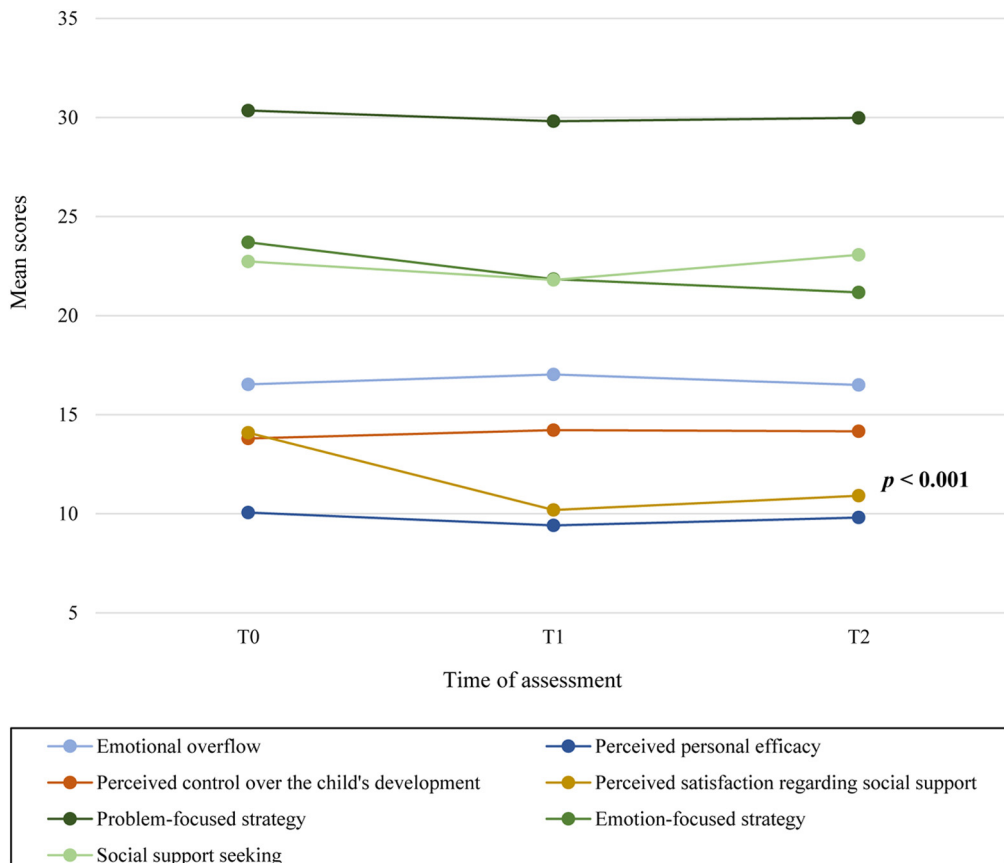


Fig. 1. Evolution of the mean scores of mothers of autistic children on scales assessing transactional processes over time.

communication perceived by mothers of autistic children six months after the diagnosis, which did not last until the assessment a year after the diagnosis. This evolution is contrary to the hypothesised increase in perceived family communication.

Finally, Fig. 3 illustrates the results regarding the impact on quality of life. Contrary to what was expected, no significant evolution was observed over the three points in time for the general scale and the seven subscales: daily activities, professional activities and relationships, social activities and relationships, family and couple activities and relationships, parent-child activities and relationship, psychological well-being, and personal fulfilment.

4. Discussion

The aim of the study was to assess the perception of mothers of autistic children regarding their level of stress, control over their child's development, social support, family functioning, coping strategies, and quality of life in the year following their child's diagnosis.

4.1. Discussion of the results

4.1.1. Significant evolutions in the year post-diagnosis

Contrary to what was expected, a decrease in maternal perceived satisfaction regarding social support was observed between the diagnosis and six months later, and was maintained a year after the diagnosis. This result suggests that mothers of autistic children were less satisfied with the social support they perceived six months after the diagnosis and a year after, compared to the time of the diagnosis. Better professional and personal support could be expected for mothers after the diagnosis, considering it is supposed to orientate them towards appropriate professional care and is known to provide a sense of legitimacy around their difficulties among friends and family (Jacobs et al., 2020; Leblé et al., 2021). Nevertheless, during the diagnosis process, parents have regular contacts with professionals who can support and guide them, both emotionally and practically. After the diagnosis, parents often report a lack of help in finding the suggested care, and struggle to do so (Chamak, 2020; Leblé et al., 2021). This could explain the reduction of perceived satisfaction regarding social support and is relevant to consider for clinical practices. More investigations should be conducted regarding this variable as this result is not in agreement with Dai et al.'s (2024) study, in which

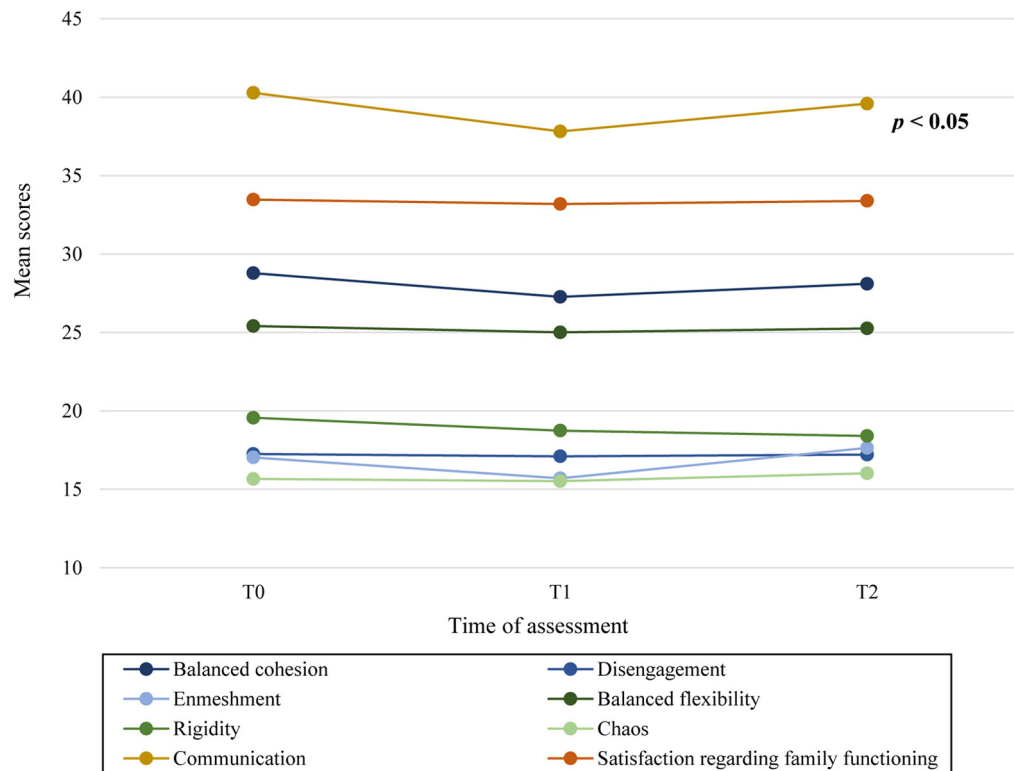


Fig. 2. Evolution of the mean scores of mothers of autistic children on scales assessing perceived family functioning over time.

no evolution was reported, or with McGrew and Keyes's (2014) study, in which an increase was noted a year after the diagnosis. It might be worth studying professional and personal support distinctively and maybe consider whether the children receive or not appropriate interventions during the year post-diagnosis.

Regarding perceived family communication, the noted evolution was also not the one originally expected. A significant decrease was observed between the time of the diagnosis and six months later, but not between six months and a year post-diagnosis. The general evolution over the assessed period was not significant. This result suggests that mothers of autistic children were less satisfied with the family communication they perceived six months after the diagnosis compared to the time of the diagnosis but not a year after. The official diagnosis does not appear to act as a communication tool within the family, fostering better agreement around autism. However, this temporary decrease is coherent with the idea that a diagnosis can modify family dynamics during a time period in order for the family to adjust and find a new balance (Andolfi, 1979; De Montigny & Beaudet, 1997). According to Olson and McCubbin (1982), the return to a balanced family functioning should occur approximately six months after a significant life event. This timeframe may depend on the specific circumstances. The evolution of family communication should be investigated further, in relation to other family functioning variables, but already highlights the importance of supporting families post-diagnosis.

4.1.2. Non-significant evolutions in the year post-diagnosis

Besides social support and family communication, none of the other studied variables around stress, control over the child's development, coping strategies, family functioning, and impact on quality of life, showed a significant evolution following the diagnosis. These results do not support the hypothesis of a better maternal adjustment post-autism diagnosis. As mentioned in the introduction, the literature on these adjustment variables over time after the diagnosis is both limited and inconsistent, providing little basis to interpret the findings. Although not significant, it is worth noting that a continuous decrease can be observed in ineffective emotion-focused coping strategies and in the impact on quality of life on the general scale and on the dimensions of professional activities and relationships, social activities and relationships, family and couple activities and relationships, and parent-child activities and relationship. The sensitivity analysis conducted to determine the effect size detectable with the available sample size indicated that small effects could not be detected. Therefore, it is possible that statistical type II errors occurred. With the limited sample, some existing evolutions might not have appeared significant. In addition, the recruitment bias of mainly living around Paris, but also of the ongoing pandemic, as well as the potential response bias and fatigue linked to the length of the questionnaires, could have influenced the results. Finally, other factors could be relevant to understand the evolution of the studied variables post-diagnosis, but the sample size did not allow for their consideration through subgroups simultaneously with the time variable.

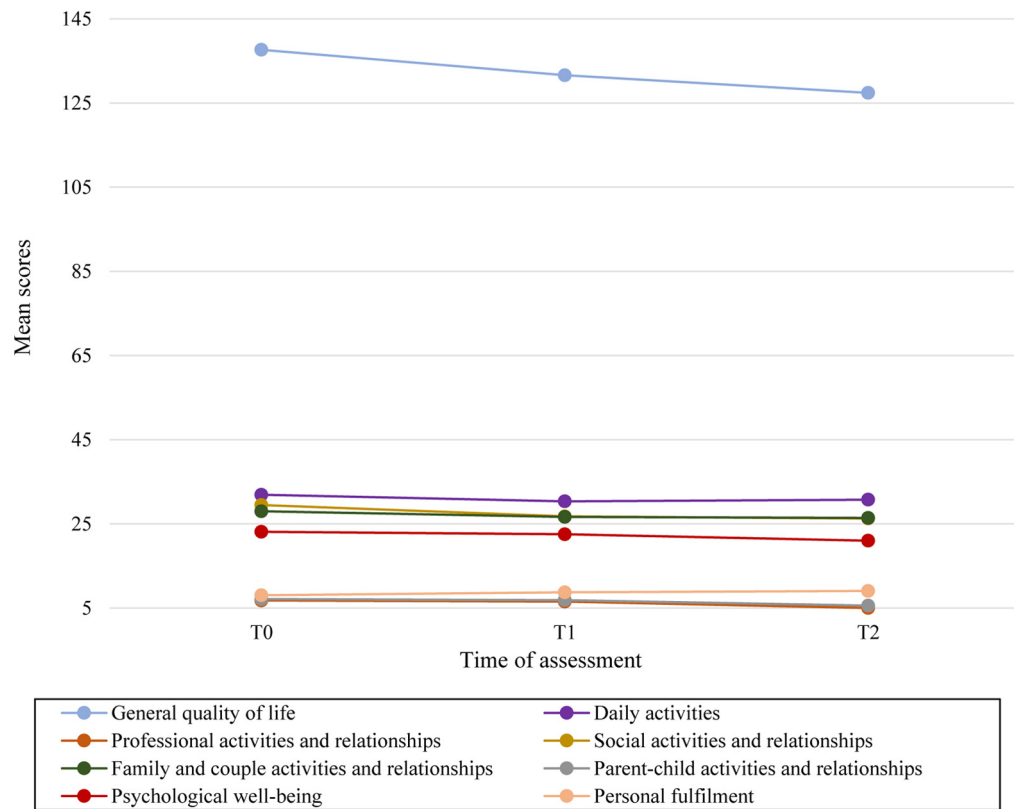


Fig. 3. Evolution of the mean scores of mothers of autistic children on scales assessing the impact on quality of life over time.

Firstly, in our study, the need for the variables to evolve in order to allow a satisfactory maternal adjustment was not considered in the initial levels assessed. According to the transactional model, the need for a person's adjustment depends on the primary assessment of the situation as being aversive and therefore stressful (Bruchon-Schweitzer & Boujut, 2021). The fact that the initial levels of maternal stress around the time of the diagnosis were not particularly low could suggest there was no significant need for them to evolve. Similarly, in the secondary assessment of the transactional model, the individual assesses the resources to face the situation (perceived control, perceived satisfaction regarding social support, and perceived family functioning). This assessment leads to coping strategies and to the outcome of the adjustment process, in this case the impact on quality of life (Bruchon-Schweitzer & Boujut, 2021). Depending on the initial level of these variables, the need for them to evolve to allow an optimal adjustment varies. Therefore, in future studies, creating subgroups of mothers of autistic children depending on the initial level of the variables involved in the adjustment mechanisms, could allow a better understanding of their evolution post-diagnosis, individually but also in relation to one another. Indeed, the variables included in the transactional model are not independent but interact together (Bruchon-Schweitzer & Boujut, 2021).

Secondly, in their journey towards the diagnosis some mothers will have already heard the term “autism”. The diagnosis might not be completely new to them, especially as they see the behaviour of their child every day (Leblé et al., 2021). Keeping this in mind, the level of knowledge and acceptance of the diagnosis before and after the assessments could be worth considering in future research to understand the evolution of the variables involved in maternal adjustment. In addition, the professional help they might receive from the diagnosis centre or somewhere else to cope with the diagnosis and the challenges of daily life would be relevant.

Thirdly, in our study, the clinical characteristics of the autistic children were not considered in relation to the evolution of the adjustment variables. During the year post-diagnosis, in addition to dealing with the news and its implications, parents still have to cope with the challenges of daily life with an autistic child. Indeed, having an autistic child can be associated with more fatigue (Seymour et al., 2013), stress (Craig et al., 2016), anxiety and depression (Fourcade et al., 2019) than having a neurotypical child. These challenges are more present when the clinical signs are severe (Brei et al., 2015) and associated with behavioural and emotional difficulties (Craig et al., 2016; Scibelli et al., 2021), lower adaptive skills (Karst & Van Hecke, 2012), or comorbidities such as an intellectual disability (Scibelli et al., 2021) or an attention deficit hyperactivity disorder (Schiltz et al., 2022). Besides, the clinical characteristics can vary with the person's age, compensation strategies, or professional interventions for the parents and the children themselves (APA, 2013, 2022). Therefore, during the year following the diagnosis, it would be worth studying the evolution of the adjustment variables while considering simultaneously the clinical characteristics of the autistic children and their evolution in relation to access to interventions or to the children's age.

In summary, the absence of evolution of most of the variables might be a reflection of the complexity of the adjustment mechanisms, in relation to other variables. The fact that no evolution of perceived stress was observed in our study could be explained by the original level of stress linked to the clinical characteristics of the child and to the diagnosis. Indeed, although parents often report feeling stressed around the time of the diagnosis, a lot of them also express relief as it marks the end of a difficult journey looking for answers (Leblé et al., 2021). An evolution might not have been needed or possible depending on the continuous factors causing stress. Similarly, the lack of evolution in coping strategies might depend on the need following the assessment of the situation as stressful or not (Bruchon-Schweitzer & Boujut, 2021). The resources like perceived control over the child's development and perceived family functioning were expected to increase after the diagnosis as it is a time when they receive answers and information, and are oriented towards appropriate interventions. However, again, an evolution might not be needed if the situation is not found stressful, if the level of perceived control and family functioning is satisfying to start with, or depending on the ongoing challenges being faced. Finally, regarding the impact on quality of life, the absence of evolution was unexpected as the diagnosis marks the end of an often-difficult journey (Leblé et al., 2021). Nevertheless, the absence of evolution of most variables is consistent with the absence of evolution in quality of life, as they are theorised to interact with one another (Bruchon-Schweitzer & Boujut, 2021).

4.2. Limits of the study

In our study, several limitations should be noted. Firstly, only a small number of parents agreed to participate, especially considering the loss of participants, which suggests a recruitment bias. The small sample size also limited the statistical analyses which could be conducted and made the results difficult to generalise. Besides, because of the sample, the focus of the study had to be shifted to only mothers. Secondly, regarding the way the responses were collected, although permitting responses online and by phone allowed participants with less means to participate, it might have created a response bias. Finally, the initial assessment of the adjustment variables was not considered as an indicator of the need for evolution in the study. In addition, no contextual factors (clinical characteristics, age at the time of the diagnosis, interventions, etc.) were considered in relation to the evolution of the variables.

4.3. Implications for future research

Considering that the existing research on the longitudinal study of adjustment variables among parents of autistic children is limited and inconsistent, future research should continue to focus on that topic with larger samples and consider explicative qualitative data. The results of this study confirm the relevance of the studied variables for future research. New studies should focus on the experience of both mothers and fathers and consider the implications of contextual variables in this evolution. It would be worth engaging more personally with the participants in order not to lose them, even in quantitative protocols. The adjustment variables should also be analysed together longitudinally as variables related to one another. Furthermore, it could be relevant to add a time of measurement to the longitudinal studies before the official diagnosis in order to understand better the impact of the announcement of the diagnosis to the parents.

4.4. Clinical recommendations

Our study showed a significant decrease of perceived satisfaction regarding social support for our sample of mothers of autistic children. This decrease might be due to the fact that they receive satisfactory support during the diagnosis process but not after. This result confirms the importance of continued support for the parents after the diagnosis, maybe with follow up appointments or by helping them find appropriate supportive care providers after the diagnosis.

The results also showed a significant decrease in family communication within the first six months after diagnosis, though not between diagnosis and a year later. This highlights the need to support family communication during that period. It would be relevant for professionals to include several family members when announcing the diagnosis and to organise sessions aiming to explain the diagnosis and address its implications for family functioning in a systemic approach, regarding communication but also cohesion and flexibility as they are facilitated by communication.

Otherwise, our study did not indicate any evolution in the adjustment variables of mothers of autistic children. However, the initial levels of these variables should be considered and assessed in clinical settings, in order to understand the need for an intervention. Our study did not focus on a specific parental intervention, but in France, several programmes aiming to support parents of autistic children have been created and showed significant results, especially regarding a decrease in the levels of stress (Derguy & Cappe, 2019; Sankey, Derguy, Ilg, Clément, & Cappe, 2019). In diagnosis centres where this is not yet available, offering this type of parental intervention when needed could provide valuable support to families.

Author's contribution

The research was designed and conducted as part of the first author's doctorate without funding, under the supervision of the last author. The research protocol was approved by the Université Paris Cité ethics committee. All the other authors contributed by facilitating the recruitment of participants. All authors read and approved the final manuscript.

Disclosure of interest

The authors declare that they have no competing interest.

References

- American Psychiatric Association [APA]. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.) <http://doi.org/10.1176/appi.books.9780890425596>
- American Psychiatric Association [APA]. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.) <http://doi.org/10.1176/appi.books.9780890425787>
- Andolfi, M. (1979). *Family therapy: An interactional approach*. Jason Aronson Inc.
- Beaud, L., & Quentel, J.-C. (2011). Information et vécu parental du diagnostic de l'autisme II. Effets des troubles et qualité de vie. *Annales médico-psychologiques*, 169(2), 132–139. <http://doi.org/10.1016/j.amp.2010.12.010>
- Bellinghausen, L., Collange, J., Botella, M., Emery, J., & Albert, É. (2009). Validation factorielle de l'échelle française de stress perçu en milieu professionnel. *Santé publique*, 21(4), 365–373. <http://doi.org/10.3917/spub.094.0365>
- Brei, N. G., Schwarz, G. N., & Klein-Tasman, B. P. (2015). Predictors of parenting stress in children referred for an autism spectrum disorder diagnostic evaluation. *Journal of Developmental and Physical Disabilities*, 27(5), 617–635. <http://doi.org/10.1007/s10882-015-9439-z>
- Brennan, J., Ward, O. F., Tomeny, T. S., & Davis, T. E. (2024). A systematic review of parental self-efficacy in parents of autistic children. *Clinical Child And Family Psychology Review*, 27(3), 878–905. <http://doi.org/10.1007/s10567-024-00495-2>
- Bruchon-Schweitzer, M. (2002). *Psychologie de la santé : Modèles, concepts et méthodes*. Dunod.
- Bruchon-Schweitzer, M., & Boujut, E. (2021). *Psychologie de la santé : Concepts, méthodes et modèles*. Dunod.
- Bureau, R. (2023). *Envisager l'autisme sans trouble du développement intellectuel à l'âge adulte dans une perspective écologique : Des modèles aux interventions* [Thèse de doctorat, Université de Strasbourg] . <https://www.theses.fr/2023STRAG019>
- Cappe, E., Despax, J., Pedoux, A., Zylberberg, P., Chaste, P., De Gaulmyn, A., et al. (2024). Parental involvement and adjustment during the diagnostic evaluation of autism spectrum disorder at two diagnostic centers. *L'Encéphale*. <http://doi.org/10.1016/j.encep.2024.01.002>
- 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*, 20(8), 1279–1294. <http://doi.org/10.1007/s11136-011-9861-3>
- Chamak, B. (2020). Autisme et psychiatrie : Une histoire mouvementée. *Savoir - agir*, 52(2), 87–93. <https://doi.org/10.3917/sava.052.0087>
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Routledge <http://doi.org/10.4324/9780203771587>
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24(4), 385–396. <http://doi.org/10.2307/2136404>
- Cousson-Gélie, F. (1997). *L'évolution différentielle de la maladie et de la qualité de vie de patientes atteints d'un cancer du sein : Rôle de certains facteurs psychologiques, biologiques et sociaux* (Thèse de doctorat, Université Victor Segalen Bordeaux) .
- Cousson-Gélie, F., Bruchon-Schweitzer, M., Quintard, B., Nuissier, J., & Rasclé, N. (1996). Analyse multidimensionnelle d'une échelle de coping : Validation française de la WCC (Ways of Coping Checklist). *Psychologie française*, 41(2), 155–164.
- Craig, F., Operto, F. F., De Giacomo, A., Margari, L., Frolli, A., Conson, M., et al. (2016). Parenting stress among parents of children with neurodevelopmental disorders. *Psychiatry Research*, 242, 121–129. <http://doi.org/10.1016/j.psychres.2016.05.016>
- Dai, Y., Chen, M., Deng, T., Huang, B., Ji, Y., Feng, Y., et al. (2024). The importance of parenting self-efficacy and social support for family quality of life in children newly diagnosed with autism spectrum disorder: A one-year follow-up study. *Autism Research*, 17(1), 148–161. <http://doi.org/10.1002/aur.3061>
- De Montigny, F., & Beaudet, L. (1997). *Lorsque la vie éclate : L'impact de la mort d'un enfant sur la famille*. Éditions du Renouveau pédagogique.
- Derguy, C., & Cappe, E. (2019). *Familles et trouble du spectre de l'autisme*. Dunod <http://doi.org/10.3917/dunod.dergu.2019.01>
- Desautels, J., Lapalme, M., Touchette, L., & Pauzé, R. (2016). Validation de la version française du FACES IV auprès d'une population d'adolescents francophones issus d'un échantillon populationnel et clinique. *Thérapie familiale*, 37(1), 95–113. <http://doi.org/10.3917/tf.161.0095>
- Desquenne-Godfrey, G., Downes, N., & Cappe, E. (2023). A systematic review of family functioning in families of children on the autism spectrum. *Journal of Autism and Developmental Disorders*. <http://doi.org/10.1007/s10803-022-05830-6>
- Fourcade, C., Kruck, J., & Rogé, B. (2019). Chapitre 12. Le fardeau perçu chez les parents d'enfants avec un trouble du spectre de l'autisme : Approche quantitative et qualitative du vécu parental. In C. Derguy & E. Cappe (Eds.), *Familles et trouble du spectre de l'autisme* (pp. 177–190). Dunod <http://doi.org/10.3917/dunod.dergu.2019.01.0177>
- Fox-Wasylyshyn, S. M., & El-Masri, M. M. (2005). Handling missing data in self-report measures. *Research in Nursing & Health*, 28(6), 488–495. <http://doi.org/10.1002/nur.20100>
- Gao, X., & Drani, S. (2025). Social support experiences in parents of children with ASD: A qualitative systematic review. *SAGE Open*, 15(2) <http://doi.org/10.1177/21582440251336174>
- Geelhand, P., Papastamou, F., Belenger, M., Clin, E., Hickman, L., Keating, C. T., et al. (2023). Autism-related language preferences of French-speaking autistic adults: An online survey. *Autism in Adulthood: Challenges and Management*, 5(3), 275–288. <http://doi.org/10.1089/aut.2022.0056>
- Haute Autorité de Santé [HAS]. (2018). *Trouble du spectre de l'autisme — Signes d'alerte, repérage, diagnostic et évaluation chez l'enfant et l'adolescent* (Retrieved on 5th May 2025) . https://www.has-sante.fr/upload/docs/application/pdf/2018-02/trouble_du_spectre_de_lautisme_de_lenfant_et_ladolescent_recommandations.pdf
- Hayes, S. A., & Watson, S. L. (2012). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(3), 629–642. <http://doi.org/10.1007/s10803-012-1604-y>
- Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, 50(12), 874–882. <http://doi.org/10.1111/j.1365-2788.2006.00904.x>
- Jacobs, D., Steyaert, J., Dierickx, K., & Hens, K. (2020). Parents' views and experiences of the autism spectrum disorder diagnosis of their young child: A longitudinal interview study. *European Child & Adolescent Psychiatry*, 29(8), 1143–1154. <http://doi.org/10.1007/s00787-019-01431-4>
- Jones, L., Totsika, V., Hastings, R. P., & Petalas, M. A. (2013). Gender differences when parenting children with autism spectrum disorders: A multilevel modeling approach. *Journal of Autism and Developmental Disorders*, 43(9), 2090–2098. <http://doi.org/10.1007/s10803-012-1756-9>
- Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, 15(3), 247–277. <http://doi.org/10.1007/s10567-012-0119-6>
- Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., et al. (2023). Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation. *Autism Research*, 16(2), 406–428. <http://doi.org/10.1002/aur.2864>
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442–462. <http://doi.org/10.1177/1362361315588200>
- Koleck, M. (2000). *Rôle de certains facteurs psychosociaux dans l'évolution des lombalgies communes : Une étude semi-prospective en psychologie de la santé* (Thèse de doctorat, Université Victor Segalen, Bordeaux) .
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping*. Springer.
- Leblé, N., Cosquer, M., Mezghiche, L., Cazard, F., & Joussemme, C. (2021). Le vécu parental du parcours diagnostique dans l'autisme : Discussion autour d'une étude qualitative. *La psychiatrie de l'enfant*, 64(2), 149–167. <http://doi.org/10.3917/psyse.642.0149>

- Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. (2012). *Autism diagnostic observation schedule*. (second edition). Western Psychological Services.
- Martins, R., Bonito, I., Andrade, A., Albuquerque, C., & Chaves, C. (2015). The impact of the diagnosis of autism in parents of children. *Procedia, Social and Behavioral Sciences*, 171, 121–125. <http://doi.org/10.1016/j.sbspro.2015.01.097>
- McGrew, J. H., & Keyes, M. L. (2014). Caregiver stress during the first year after diagnosis of an Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, 8(10), 1373–1385. <http://doi.org/10.1016/j.rasd.2014.07.011>
- Mercuriali, G., & Yvon, D. (2020). Chapitre 25. L'impact de l'autisme sur les familles. In D. Yvon (Ed.), *À la découverte de l'autisme : Des neurosciences à la vie en société* (2^e ed., pp. 235–243). Dunod <http://doi.org/10.3917/dunod.yvon.2020.01.0235>
- Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 6(1), 293–303. <http://doi.org/10.1016/j.rasd.2011.05.011>
- Olson, D. (2011). FACES IV and the circumplex model: Validation study. *Journal of Marital and Family Therapy*, 37(1), 64–80. <http://doi.org/10.1111/j.1752-0606.2009.00175.x>
- Olson, D., & McCubbin, H. (1982). Circumplex model of marital and family systems. V. Application to family stress and crisis intervention. In H. McCubbin, A. Cauble, & J. Patterson (Eds.), *Family stress, coping, and social support* (pp. 48–68). Charles C Thomas.
- Patel, S., Rivard, M., Mello, C., & Morin, D. (2022). Parenting stress within mother-father dyads raising a young child with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 99, 102051. <http://doi.org/10.1016/j.rasd.2022.102051>
- Pruyn, J. F. A., Van Den Borne, H. W., De Reuver, R. S. M., De Boer, M. F., Bosman, L. J., & De Jong, P. C. (1988). The locus of control scale for cancer patients. *Tijdschrift Voor Sociale Gezondheidszorg*, 66, 404–408.
- Rattaz, C., Loubersac, J., Michelon, C., Geoffray, M.-M., Picot, M.-C., Munir, K., et al. (2022). Factors associated with age of diagnosis in children with autism spectrum disorders: Report from a French cohort. *Autism: The International Journal of Research and Practice*, 26(8), 2108–2116. <http://doi.org/10.1177/13623613221077724>
- Rattaz, C., Loubersac, J., Michelon, C., Picot, M.-C., & Baghdadli, A. (2023). Changes in mothers' and fathers' stress level, mental health and coping strategies during the 3 years following ASD diagnosis. *Research in Developmental Disabilities*, 137, 104497. <http://doi.org/10.1016/j.ridd.2023.104497>
- Sankey, C., Derguy, C., Ilg, J., Clément, C., & Cappe, É. (2019). Supporting parents of a child with Autism Spectrum Disorder: The French awakening. *Journal of Autism and Developmental Disorder*, 49(3), 1142–1153. <http://doi.org/10.1007/s10803-018-3800-x>
- Schiltz, H. K., McVey, A. J., Gonring, K., Haendel, A. D., Murphy, C., Van Hecke, A. V., et al. (2022). Examining differences in parenting stress, parenting efficacy, and household context among mothers of youth with autism and/or ADHD. *Journal of Child and Family Studies*, 31(3), 774–789. <http://doi.org/10.1007/s10826-021-02083-2>
- Scibelli, F., Fucà, E., Guerrero, S., Lupi, E., Alfieri, P., Valeri, G., et al. (2021). Clinical and individual features associated with maternal stress in young adolescents with autism spectrum disorder. *Autism Research*, 14(9), 1935–1947. <http://doi.org/10.1002/aur.2539>
- Seymour, M., Wood, C., Giallo, R., & Jellet, R. (2013). Fatigue, stress and coping in mothers of children with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(7), 1547–1554. <http://doi.org/10.1007/s10803-0121701-y>
- Srijan, S., & Rajagopalan, I. R. (2024). Best practices for handling missing data. *Annals of Surgical Oncology*, 31, 12–13. <http://doi.org/10.1245/s10434-023-14471-7>
- Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 34–42. <http://doi.org/10.1111/j.1468-3148.2008.00437.x>
- Turnage, D., & Conner, N. (2022). Quality of life of parents of children with Autism Spectrum Disorder: An integrative literature review. *Journal for Specialists in Pediatric Nursing*, 27(4), e12391. <http://doi.org/10.1111/jspn.12391>
- Vernhet, C., Dellapiazza, F., Blanc, N., Cousson-Gélie, F., Miot, S., Roeyers, H., et al. (2019). Coping strategies of parents of children with autism spectrum disorder: A systematic review. *European Child & Adolescent Psychiatry*, 28(6), 747–758. <http://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 Behavioural Research*, 20(1), 3–26.
- Watzlawick, P. (1972). *Une logique de la communication*. Éditions du Seuil.
- World Health Organisation, I. (2022). *International statistical classification of diseases and related health problems* (11th ed.). <https://icd.who.int/>
- World Health Organization [WHO]. (1993). Study protocol for the world health organization project to develop a quality of life assessment instrument (WHOQOL). *Quality of Life Research*, 2(2), 153–159. <http://www.jstor.org/stable/4034396>
- Yorke, I., White, P., Weston, A., Rafla, M., Charman, T., & Simonoff, E. (2018). The association between emotional and behavioral problems in children with autism spectrum disorder and psychological distress in their parents: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 48(10), 3393–3415. <http://doi.org/10.1007/s10803-018-3605-y>