



## Preliminary Results of the Effects of a Psychoeducational Program on Stress and Quality of Life Among French Parents of a Child With Autism

Émilie Cappe, Naomi Downes, Sophie Albert-Benaroya, Julie Allard Ech-Chouikh, Aude de Gaulmyn, Lydia Luperto, Valérie Caron, Elisabeth Roussel, Romain Taton, Carol Sankey

### ► To cite this version:

Émilie Cappe, Naomi Downes, Sophie Albert-Benaroya, Julie Allard Ech-Chouikh, Aude de Gaulmyn, et al.. Preliminary Results of the Effects of a Psychoeducational Program on Stress and Quality of Life Among French Parents of a Child With Autism. *Focus on Autism and Other Developmental Disabilities*, 2021, 36 (3), pp.176-186. 10.1177/1088357620986946 . hal-04505218

**HAL Id: hal-04505218**

**<https://hal.science/hal-04505218>**

Submitted on 18 Mar 2024

**HAL** is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

**Article title:** Preliminary results of the effects of a psychoeducational program on stress and quality of life among French parents of an autistic child

**Full name, affiliated institution and contact information of each author**

**Emilie Cappe\***, Professor, Ph.D., Université de Paris, Laboratoire de Psychopathologie et Processus de Santé (UR 4057), 71 avenue Edouard Vaillant, F-92100 Boulogne-Billancourt, France, Tél : +33 (0)1 76 53 30 80, E-mail: emilie.cappe@u-paris.fr

**Naomi Downes**, Psy.M., Université de Paris, Laboratoire de Psychopathologie et Processus de Santé (UR 4057), 71 avenue Edouard Vaillant, F-92100 Boulogne-Billancourt, France, Email: downesn@tcd.ie

**Sophie Albert-Benaroya**, Psy.M., Université de Paris, Laboratoire de Psychopathologie et Processus de Santé (UR 4057), 71 avenue Edouard Vaillant, F-92100 Boulogne-Billancourt, France, Email: benaroya.sophie@neuf.fr

**Julie Allard Ech-Chouikh**, Psy.M., Centre de Ressources Autisme Centre-Val de Loire, CHRU Bretonneau de Tours, 2 Boulevard Tonnellé, 37000 Tours, France, Email: j.allard-ech-chouikh@chu-tours.fr

**Aude De Gaulmyn**, Ph.D., Service de Psychiatrie de l'enfant et de l'adolescent I08, GHU Paris Psychiatrie et Neurosciences, Centre Hospitalier Sainte-Anne, 1 rue Cabanis, 75014 Paris, France, Email: A.DEGAULMYN@ch-sainte-anne.fr

**Lydia Luperto**, Psy.M., Centre Ressources Autisme Île-de-France, 6 Cour Saint-Éloi, 75012 Paris, Email: l.luperto@craif.org

**Valérie Caron**, Ph.D., Centre Expert Autisme Limousin, CHU de Limoges, 2 Avenue Martin Luther King, 87000 Limoges, Email: valerie.caron1@uqtr.ca

**Roussel Elisabeth**, Psy.M., Service de Psychopathologie de l'Enfant et de l'Adolescent, Hôpital Bichat-Claude Bernard AP-HP.Nord – Université de Paris, Policlinique Ney Jenny Aubry, 124 Boulevard Ney, 75018 Paris, France, Email: [eroussel.psy@gmail.com](mailto:eroussel.psy@gmail.com)

**Romain Taton**, Ph.D., Centre de Ressources Autisme Normandie Seine-Eure, Centre Hospitalier du Rouvray, 4 rue Paul Eluard, 76300 Sotteville-lès-Rouen, France, Email: [Romain.TATON@ch-lerouvray.fr](mailto:Romain.TATON@ch-lerouvray.fr)

**Carol Sankey**, Ph.D., Université de Paris, Laboratoire de Psychopathologie et Processus de Santé (UR 4057), 71 avenue Edouard Vaillant, F-92100 Boulogne-Billancourt, France, Email: [c.sankey@gamil.com](mailto:c.sankey@gamil.com)

\* **Contact author:** Cappe Emilie

## **Additional information and acknowledgments**

### **Contribution of each author**

EC: Principal investigator of the study, established the research collaborations with partner clinical services, developed the research protocol, participated in recruiting participants, collecting and analyzing data, writing and proofreading of the article. ND: Participated in the writing and proofreading of the article. SAB: Participated in the data processing. CS: Participated in recruiting participants and collecting data. The other authors participated in recruiting participants.

### **Acknowledgements**

This study has received funding from the *Caisse Nationale de Solidarité pour l'Autonomie (CNSA)* through the call for projects "Autism 2014" proposed by the *Institut de Recherche En Santé Publique (IRES-P)*. The authors would like to thank all the parents who agreed to participate in the study, as well as the psychologists, educators, health managers, doctors and department

heads who contributed to the implementation of the program and the smooth running of the research project through the associated clinical services. They also would like to thank Mrs. Rousseau and Bourassa from the *Centre Intégré Universitaire de Santé et de Services Sociaux de la Mauricie et du Centre du Québec* (CIUSSS MCQ).

**Ethical statement**

This study received a favorable ethical opinion from *the Comité Consultatif sur le Traitement de l'Information en matière de Recherche dans le domaine de la Santé (CCTIRS)* and the *Conseil pour l'Évaluation éthique des Recherches En Santé (CERES, N° IRB: 20135400001082)* and an authorization from the *Commission Nationale de l'Informatique et des Libertés (CNIL)*.

Preliminary results of the effects of a psychoeducational program on stress and quality of life  
among French parents of an [autistic](#) child

Abstract

Introduction: The objective was to evaluate the impact of a psychoeducational program on the stress and quality of life of parents [with an autistic](#) child.

Methods: Twenty parents attended a shortened version of the program (SV group) and 15 others a complete version (CV group). An assessment of perceived stress, [parenting](#) stress and, quality of life was performed before (T0), after (T1), and 6 months after the program (T2). Parental satisfaction was measured at T1.

Results: Parents in the CV group appeared to be significantly less stressed and there was a significant improvement in certain areas of their quality of life (relationship with the child, psychological well-being, [and](#) personal fulfillment). No significant effects were observed in the SV group. Both groups highly appreciated the program.

Conclusion: These results confirm the need to offer support to parents after receiving a diagnosis of [autism](#) for their child.

Key Words: Autism Spectrum Disorder, [Parenting stress](#), Quality of Life, Psychoeducation,

Program Evaluation

[February 6<sup>th</sup>, 2020](#)

Preliminary results of the effects of a psychoeducational program on stress and quality of life among French parents [of an autistic child](#)

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder of early and chronic onset with a prevalence of 1% in the population. [It is](#) characterized by various deficits in communication and social interaction, [as well as](#) the presence of restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association [APA], 2013). In France, it is estimated there are between 600 000 and 700 000 [autistic](#) people (Secrétariat d'Etat auprès du Premier Ministre chargé des Personnes handicapées, 2018). ASD can lead to significant disability in various spheres of development (APA, 2013). [Individuals on the autism spectrum present different abilities and difficulties that vary depending on their environment or period of their life \(APA, 2013\).](#) Nevertheless, [these](#) children have the same basic needs as any other child, in addition to specific needs related to their disability and the very nature of [autistic](#) symptoms. For example, [autistic](#) children [may](#) require a highly structured daily routine adapted to their sensory sensitivities. The education of [an autistic](#) child is, therefore, more difficult than that of a [typically developing](#) child (Anonymous, 2016): parents [may](#) face numerous demands including vigilant parenting, time pressure, important investments, delays concerning healthcare [services, as well as a constant need to provide adjustments and support whilst raising their child](#) (Woodgate, Ateah, & Secco, 2008). Moreover, parents of [an autistic](#) child experience higher levels of stress than parents of children [with](#) other developmental disorders (Eisenhower, Baker, & Blacher, 2005). [Parenting stress has mainly been linked to autism symptom severity and challenging behaviors presented by autistic children \(Yorke et al., 2018\).](#) Research also shows that [a parent's](#) quality of life can be impaired (Vasilopoulou & Nisbet, 2016). [Nevertheless, despite challenges they may face, many parents identify various strengths among their children \(Carter et al., 2015\), and react to adversity by forming a more positive outlook \(McConnell, Savage, Sobsey & Uditsky, 2015\).](#)

French parents [require](#) information regarding the disorder, schooling, child development, parenting tips, and care services [to be](#) better adapted to their [autistic](#) child as well as their situation (Anonymous, 2016). Many parent-training programs have been developed to address these needs [and](#) offer support after diagnosis ([Bearss, Burell, Stewart, & Scahill, 2015](#)). Parent-training programs vary in terms of frequency, duration, session format, and [use](#) of media ([Bearss et al., 2015; Schultz, Schmidt, & Stichter, 2011](#)). They may focus on offering [either](#) information, [genuine parental training, or](#) psychological and social support. [Most programs](#) combine [these](#) multiple areas of intervention. [Even though certain programs have shown their effectiveness with benefits including decreased stress and improved quality of life \(for a review see Anonymus, 2019a\),](#) many present methodological limits (lack of direct measures of stress and quality of life, lack of pre-intervention or long term evaluation, small sample size or homogeneity of the sample, non-matching of groups, absence of [a](#) control group, [tools](#) lack [a](#) description of psychometric properties). Finally, evaluations do not necessarily show significant post-intervention impact [or](#) any long-term impact ([for a review see Kuhaneck, Madonna, Novak & Pearson, 2015](#)). [Some programs do offer booster sessions, three to six months after the program, to check in with parents, address new questions, and offer new resources \(e.g., Derguy, Poumeyreau, Pingault, & M'bailara, 2018\).](#)

In France, parental support is still far from being available to everyone. It was only recently that the French National Authority for Health first recognized [the important role of families for the care of autistic children and adolescents, as well as the necessity of parent-professional partnerships as cited by the best practice guidelines](#) (HAS, 2012). These guidelines also highlight the repercussions of [autism](#) on families in conjunction with the need to provide appropriate support to parents.

The purpose of this research was to evaluate the effects of a psychoeducational support program offered to French parents after their child's diagnosis of ASD (Stipanivic, Couture, Rivest, & Rousseau, 2014). We measured the effect on stress, quality of life, and satisfaction with the program. Two versions of the program were compared: a complete version (CV) for parents who benefited from 5 collective workshops and individual follow-up, and a shortened version (SV) for parents who only took part in 5 collective workshops. The latter version did not include an individual follow-up due to a lack of human resources in some clinics.

## Method

### Presentation of the evaluated program

The “*Au-delà du TED: des compétences parentales à ma portée*” (Beyond PDD: parenting skills within my reach) program was developed in 2004 in Quebec. This psychoeducational program is both therapeutic and educational (Stipanivic et al., 2014). It offers parents of an autistic child information, as well as psychological and social support. The general objective of this program is to enable parents to recognize, develop, and update their parenting skills (Stipanivic et al., 2014). In France, implementation and evaluation of this program began in 2013 in association with six clinical centers. Satisfactory results regarding the program's implementation in France have been shown (Anonymous, 2020a; Anonymous, 2020b; Anonymous, 2019b; Anonymous, 2019c).

This program is for parents with a child diagnosed with ASD under the age of eight. It offers five bi-monthly meetings of 2½ hours, with groups of 6 to 10 parents (Stipanivic et al., 2014). It is facilitated by two autism specialists (two psychologists in France) who have received training for this program. Each workshop addresses a different theme and has specific objectives (for more details see: Stipanivic et al., 2014): “discovering the child's unique nature”, “respecting one's adaptation process”, “developing a positive relationship and effective communication”,



“understanding education strategies adapted to a child with ASD”, “acting positively upon one’s parental role”. The program suggests parents should also benefit from an individual follow-up with an educator between each workshop. This will help them understand and apply the discussed recommendations in a home environment. The objective of these individual follow-ups is to make sure parents have understood the contents of different workshops, as well as verify they are adapted to the parent’s and child’s needs and daily lives. The educator must also ensure the parent has understood and completed home exercises. If necessary, they can provide support whilst parents practice these exercises. At each meeting, the educator follows instructions provided in a handbook. They also evaluate on a specific grid whether objectives have been achieved. Finally, they check whether the parent requires additional information about the contents of the program.

This structured program includes three guidebooks to support management and participation: the facilitator’s handbook helps psychologists roll out activities and follow the program’s objectives, the participant’s handbook contains documents given throughout the workshops, and the educator’s handbook helps educators support parents’ efforts in-between workshops. The program is driven by various intervention and educational strategies (theoretical lectures, group and pair discussions, individual exercises, clinical vignettes and testimonials, practical and situational exercises, homework, visual material, self-evaluation) to provide relevant knowledge, sharing of experiences and implementation within the group and at home (Stipanovic et al., 2014).

## **Participants**

To participate in the program, parents had to be French-speaking and commit to attending every workshop. Their children had to be diagnosed with ASD. The diagnosis had to be established by a child psychiatrist, according to international classification criteria for the autism

spectrum disorder phenotype (American Psychiatric Association, 2003, 2013). One or more ASD diagnostic evaluations were used during the screening process as recommended by the French National Authority for Health (HAS, 2018). Criteria for non-inclusion consisted of a parent with an unstable mental health disorder, known by clinicians or declared by parents, involvement in another parental intervention, or the presence of a sibling with a mental health disorder or disability.

## Measures

Parents completed a standardized self-report questionnaire (Anonymous, 2011) to gather socio-biographical characteristics of the autistic child, as well as information about the parent's family and personal situation.

The Appraisal of Life Events Scale (ALES) was developed by Ferguson, Matthews, & Cox (1999) to measure the notion of “primary appraisal” and dimensions of perceived stress (loss, threat, and challenge) as described by Lazarus and Folkman (1984). Faced with a difficult situation, the individual reacts and mobilizes resources to adapt within a reasonable amount of time. One same event can be perceived differently by individuals: some may perceive it as a loss compared to their previous situation (e.g., redefining their parental role) or as a threat to their future (e.g., giving up employment and social activities). Other individuals may perceive the event as a challenge with the possibility of benefitting from the situation (e.g., redefining their priorities in life). The ALES was adapted and validated into French (ALES-vf) by Anonymous (2017) to assess the perceived stress of being a parent of an autistic child. There are no other measurements of this type available in French. Firstly, the participant is invited to briefly describe how being a parent of an autistic child can be a source of stress in their daily lives. Then, they must indicate the extent to which 16 adjectives best describe their current experience as a parent of an autistic child, on a six-point Likert scale ranging from 0 for “not at all” to 5 for “very

much so”. The 16 adjectives are related to the three dimensions of stress. This 16-item scale calculates three scores that reflect if the parent perceives their experience as a “threat” (e.g., worrying, frightening;  $\alpha = .86$ ), a “loss” (e.g., painful, pitiful;  $\alpha = .87$ ), or a “challenge” (e.g., enjoyable, stimulating;  $\alpha = .89$ ) (Anonymous, 2017). The higher the scores, the more the individual perceives his experience as described.

The French-language short form of the [Parenting Stress](#) Index (ISP-FB, Abidin, 1995; Bigras, LaFrenière & Abidin, 1996) is the most widely used measurement in research and clinical settings. [It](#) evaluates [parenting stress](#) depending on the way [parents](#) perceive their child’s characteristics, their characteristics, as well as their interaction with [their](#) child. The ISP-FB consists of 36 items, rated using a six-point Likert scale ranging from 1 for “strongly disagree” to 5 for “strongly agree”, and is divided into three subscales labeled “parental distress”, “parent-child dysfunctional interaction” and “difficult child”. The parental distress subscale score ( $\alpha = .87$ ) assesses the effect of personal factors associated with parenting on a parent’s level of distress (e.g., “I feel trapped by my responsibilities as a parent”). A high score reflects [the](#) parent’s adjustment difficulties that [negative](#)ly impact the parent-child relationship. The parent-child dysfunctional interaction subscale score ( $\alpha = .80$ ) determines to what extent parents feel their child does not meet their expectations. It also assesses whether parent-child interactions fail to reinforce them as a parent (e.g., “My child rarely does things for me that make me feel good”). A high score means parents view themselves as either being abused or shunned by the child, or feel alienated from them. The difficult child subscale score ( $\alpha = .85$ ) determines how difficult it is to manage certain child behaviors (e.g., “My child seems to cry or fuss more often than most children”). Parent’s [s](#) difficulty to manage their child’s behavior is reflected by a higher score. Also, the ISP-FB yields a total stress score related to parental function ( $\alpha = .91$ ). A high score represents higher parenting stress.

The Quality of Life Scale for Parents of a Child with ASD (EQVPTSA) was used to assess the impact of the disorder on different areas of [a parent's](#) daily life (Anonymous, 2011). This is one of the only measurements of quality of life specifically adapted to the context of [autism](#) that is available in French. It assesses the impact of the child's [autism](#) on [a parent's](#) daily life. This scale includes 102 items, rated on a [four-point](#) Likert scale ranging from 0 “completely disagree” to 3 “completely agree”. [Each](#) item starts with “Because of my child's ASD and/or care and education...”. It calculates a general quality of life score ( $\alpha = .78$ ) and seven sub-scores: daily activities (e.g., “I have to plan and organize everything in advance”;  $\alpha = .91$ ), professional activities and relationships (e.g., “I rearranged my work hours”;  $\alpha = .76$ ), social activities and relationships (e.g., “I do not host at my home people I am not very familiar with”;  $\alpha = .92$ ), family and couple activities and relationships (e.g., “We limit our family outings”;  $\alpha = .86$ ), activities and relationships with the child with ASD (e.g., “My relationship and emotional ties with my child are limited”;  $\alpha = .76$ ), psychological well-being (e.g., “I have lost confidence in myself”;  $\alpha = .90$ ), personal fulfillment (e.g., “My life has become enriched”;  $\alpha = .86$ ). The higher the score, the more the child's disorder causes difficulties for the parent in that particular domain.

The Parent Evaluation Inventory (PEI) of Kazdin, Siegel, and Bass (1992) is a 19-item measure allowing a global score and two sub-scores. [The first sub-score](#) “perceived progress” includes 11 items (e.g., “What did you learn that changed the way you react to your child?”). [It](#) aims to assess whether parents feel they have made progress in their parental role thanks to participating in the program. [The second sub-score](#) “program's acceptability” includes eight items (e.g., “Are you happy to have participated in the program?”). [It](#) measures whether parents found the program to be appropriate, interesting, and stimulating. The answers were rated from 1 to 5 with an intermediary answer of 3 corresponding to a neutral or moderate assessment. [The](#)

PEI has shown good levels of reliability and validity and can discriminate among treatments and reactions (e.g., Kazdin, 2000).

The 14-item evaluation grid of the workshops was developed and validated by Gagnon in 1998 (as cited by Naud & Sinclair, 2003). It allowed parents to evaluate workshops, particularly their content (e.g., “The topic of the meeting is interesting”), resources (e.g., “The activities promote learning”), management (e.g., “The facilitator promoted active participation”), atmosphere (e.g., “I feel like I am part of the group”), impact (e.g., “I learned a lot of useful information today”), and overall satisfaction (“Overall I am happy with the meeting”), on a five-point Likert scale, ranging from 1 “completely disagree” to 4 “completely agree”. High scores reflect a high sense of satisfaction.

## Procedure

Six clinical facilities participated in the research and offered the program to parents who met the inclusion criteria. Due to limited human resources among certain partner centers, a shortened version of the program (5 group workshops without the individual follow-up) was offered. This was to provide parental support adapted to the facilities’ organizational and logistical possibilities. The partner centers had the choice to implement the shortened or complete version (5 group workshops with 5 individual follow-ups). Among the six partner facilities, two were able to offer the complete version (CV) and four offered the shortened version (SV) of the program. Parents voluntarily participated in the program. Yet, it is important to note that they did not have the choice between either version of the program. Chief physicians, physicians, and psychologists provided contact information of parents corresponding to inclusion criteria. These parents were then contacted by one of the researchers who presented the project and invited them to participate. All participants in the sample gave their informed consent to take part in the study. Parents who could not find time to participate in the program were offered the possibility to join

the [study](#) by integrating a control group. Nevertheless, the constitution of this group did not succeed.

Parents completed the ALES-vf, ISP-FB, and EQVPTSA across three time periods: at the beginning of the study (T0: 15 days before the beginning of the program), at the end of the program (T1: 3 months after T0) and 6 months after T1 (T2). After each workshop, they [also](#) completed the evaluation grid assessing the meeting. [At T1, the PEI scale was assessed.](#)

### **Data analysis**

Data [was](#) normally distributed (Lilliefors test for each condition:  $p > .20$ ), so we were able to use parametric statistics. [First, the  \$\chi^2\$  test was used to compare socio-biographical data between the two groups at T0. \[This was\]\(#\) to verify that parents participating in both versions presented similar profiles. \[Then Student's  \\$t\\$ -test for independent samples was conducted\]\(#\) to compare the means of the two groups at T0. \[This was\]\(#\) to ensure both groups had similar \[stress\]\(#\) levels and quality of life \[when they were included.\]\(#\) \[Finally, the Fischer-Snedecor  \\$F\\$ -test \\(repeated measures ANOVA\\) measured\]\(#\) the evolution between T0, T1, and T2 in both groups. The EQVPTSA “professional activities and relationships” sub-score was not retained in the analyses given the large number of non-employed participants.](#)

### **Results**

Our results show [the parent's perception of](#) 1) the effects of a complete and a shortened version of the program on stress and quality of life levels and 2) their progress and level of satisfaction regarding the program. [All findings are from self-report measures.](#)

### **Socio-biographical information of parents and their child**

Table 1 presents all socio-biographical data. Overall, 35 parents participated in the study, 15 [from 6 different](#) CV groups, and 20 from 4 different SV groups. For the SV sample, [the smallest group consisted of 4 parents and the largest of 8 parents. For the CV sample, the smallest group was](#)

composed of 4 parents and the largest of 5 parents. Most parents lived together as a couple.

Among these parents, more parents in the CV group were satisfied with the distribution of childrearing and household tasks within the couple compared to the SV group,  $\chi^2 (1, N = 35) = 6.03, p < .05$ . A higher proportion of children were verbal in the SV group compared to the CV group,  $\chi^2 (1, N = 35) = 12.15, p < .001$ . More parents in the CV group, compared to the SV group, reported that their child lacked autonomy,  $\chi^2 (1, N = 35) = 4.10, p < .05$ . Finally, the majority of parents considered care services to be adapted to their child's needs. But more parents of the CV group were satisfied with these given care services, compared to the SV group,  $\chi^2 (1, N = 35) = 4.10, p < .05$ .

### **Differences between the two groups before entering the program**

Before participating in the program, parents in the CV group and SV group had on average, similar levels of perceived stress, parenting stress, and quality of life. Except for the “parent-child dysfunctional interaction” sub-score of the ISP-FB scale and the “activities and relationships with the child with ASD” sub-score of the EQVPTSA scale that were significantly higher for parents in the CV group (see Table 2).

### **Evolution of stress and quality of life**

Following the program, the results obtained at ALES-vf showed parents in the CV group perceived their situation as less of a threat and more a challenge (see Table 3). Concerning the threat sub-score, this effect was immediate since the post-hoc tests showed a decrease from period T0 to T1 (see Table 3). In addition, the results obtained at the ISP-FB showed a general decrease in parenting stress (overall score) among these parents: they were less stressed 6 months after the program than before participating (see Table 3). Stress generated by dysfunctional interactions with their child also decreased (see Table 3).

The overall quality of life of parents in the CV group did not seem impacted by the program. Nevertheless, there was a decrease [in](#) the negative impact of [autism](#) on their relationship with their child, their psychological well-being, and their fulfillment (Table 3).

Regarding the SV group, no significant change was found relevant to [the](#) parent's stress and quality of life (see Table 4).

### **Evaluation of parents' progress, and perceptions of the program and workshops**

The PEI scale showed that in both groups, parents seemed satisfied with the program (SV group:  $77.7 \pm 6.2$ , CV group:  $78.5 \pm 6.2$ , maximum score: 95). They gave the program a high acceptability score (SV group:  $41.6 \pm 8.1$ , CV group:  $41.6 \pm 4.4$ , maximum score: 55) and felt they had progressed (SV group:  $36.1 \pm 3.9$ , CV group:  $36.9 \pm 2.5$ , maximum score: 40).

Regarding the evaluation of each of the five workshops, parents of both groups seemed satisfied: they usually gave the maximum score to the evaluated sub-domains (see Table 5).

### **Discussion**

This program is offered to parents in the wake of a diagnosis. [A](#) pivotal moment where [parenting stress](#) is very high and quality of life seems degraded (Stuart & McGrew, 2009). The objective of this study was to evaluate the effects of this psychoeducational support program. Preliminary results showed a decrease in [parenting stress](#) (ISP-FB) and a positive change in parents' perception of parenting [an autistic](#) child (ALES-vf) [among](#) participants [of](#) the [program's](#) complete version (CV group). These parents experienced less stress related to their parenting role and perceived their parenting experience as less of a threat. [T](#)hey had a more positive view of their parenting experience, as they perceived it more as a challenge, [which](#) can bring certain benefits. No significant change in the overall quality of life was found for the CV group. However, the CV group showed a significant improvement in the quality of life areas of "relationship with the child with ASD", "psychological well-being" and "personal fulfillment".



This result is consistent with the literature, as several studies have already shown that parent-training programs improve parents' well-being (Minjarez, Mercier, Williams, & Hardan, 2013) and their relationship with their child (Ilg et al., 2018). Furthermore, previous research has shown positive results for programs delivered either via individual meetings or a combination of individual and group meetings (Schultz et al., 2011). An individualized approach allows for opportunities of personalized learning. However, group-based programs are more cost beneficial, as they can be offered to a greater number of parents (Bearss et al., 2015). The contribution of other parents during group-based programs also provides the added value of social support, which can improve parental well-being (Catalano, Holloway, & Mpofu, 2018). Thus, it seems important to offer support proposing both an individual approach to promote personalized learning, as well as a group approach to offer psychosocial support. Our results point in this direction, since the SV group, who benefited solely from group meetings, yielded no significant results.

It is important to note that before the program, interactions with the child were more complicated for parents who entered the CV group (sub-score "parent-child dysfunctional interaction" of the ISP-FB scale and sub-score "relationship with the child with ASD" of the EQVPTSA scale). This means the child's abilities did not match the parent's expectations, and interactions did not positively reinforce parents in their parenting role. Moreover, parents expressed difficulties interacting with their child (e.g., does not know how to interact or what activities interest the child, has the impression of not being competent). These differences could explain why observed effects were more pronounced among parents in the CV group. Moreover, receiving information and trying out new educational strategies may increase parents' awareness regarding their child's difficulties and thus increase their stress levels (Ilg et al., 2018). Individual follow-up included in the complete version of the program aims to help parents adjust to the

situation. Indeed, [this](#) individual follow-up could also have significant benefits [on](#) parents' stress and quality of life (Stipanivic et al., 2014). [In](#) this study, [parenting stress](#), perceived stress, and quality of life of parents in the SV group did not deteriorate: the shortened program yielded no significant pre-to-post evolution.

Consistent with the literature, [the](#) parent's level of satisfaction with the program was high in both groups, [regardless of program objectives and whether or not they were achieved](#) (McAleese, Lavery, & Dyer, 2014). Considering the distress parents experience during the post-diagnosis period (Stuart & McGrew, 2009), this result may reflect satisfaction [with being able to](#) take part in [such a](#) program, regardless of the program's characteristics. Moreover, when participants fill in questionnaires, they tend to minimize their dissatisfaction and are usually reluctant to express criticism (Fitzpatrick, 1991).

### **Limitations and perspectives**

The first limitation of this study [is](#) the small sample size and absence of a control group, whose number at this stage is insufficient to form an acceptable statistical treatment. [Thus, the results of this study should be interpreted with great caution.](#) Moreover, most parents who participated [in](#) the study were mothers. Among parents who declined, some could not participate due to work or time constraints. [Other parents were forced to decline due to the](#) custody arrangements [of their autistic](#) child or their other children. These recruitment difficulties are similar to those that professionals encounter when they try to offer support to parents. Therefore, it seems important to take into account these constraints when offering interventions to provide support to as many parents as possible. [Among parents who agreed to participate in this study, only one parent withdrew from the program because of unexpected professional constraints.](#) Another difficulty was encountered in recruiting for the control group. [As](#) the number of participants [was](#) limited, [and the](#) majority dropped out before the end of the research. Since these

parents had no direct benefit from participating in [this](#) research, many left the study. One solution could be to offer a reward (money or material resources) at each assessment time to encourage them to [participate](#) until the end. Another way to solve this control group dilemma would be to carry out multiple single case studies (Barlow, Nock, & Hersen, 2009). [Furthermore](#), parent groups were established without being matched. Parents in both groups presented similar average levels of stress and quality of life at T0, but there were some significant differences [regarding](#) socio-biographical data. If these differences persist in the final sample, their impact on the effects of the program could be investigated. Similarly, intra-individual analysis could help identify profiles of parents who best respond to this program, [compared to](#) those who do not respond so well.

## Conclusions

To conclude, this study confirms the need to support parents after an [an ASD](#) diagnosis, [as well as in the](#) long term to preserve benefits produced by [this](#) program. [The](#) complete version of the program, including individual follow-up, appeared as the most efficient for this purpose.

[However, this program requires parents to be considerably involved. To participate parents must coordinate professional and family constraints to free up time. Professionals also need to find time to prepare and administer the program \(Anonymous, 2020b\). If limited time or human resources are an issue, self-guided psychoeducational programs or web-based resources should be offered instead \(Bearss et al., 2015\).](#) At the time of diagnosis, parents need to be given the necessary information to better understand their child, as well as offered support to get through this pivotal and distressing period in their lives. For the past several years, the French Government has encouraged the development of experimental programs [to guide](#) caregivers of [autistic](#) individuals. To meet these recommendations, various support programs have been developed for parents (Anonymous, 2019b). Thus, the program presented in this paper enriches

French provisions of parental support after a diagnosis. There are two types of parental programs that emerge in the literature (Bearss et al., 2015). Firstly, parent-mediated interventions teach parents specific techniques to target ASD symptoms, problem behaviors, and promote positive interactions. Secondly, there are parent support groups that increase parents' psychosocial support and their knowledge about ASD. [Parent support groups have](#) an indirect effect on the child. The "Beyond ASD: parenting skills within my reach" program falls within the category of the second type of intervention as mentioned above. Parent-mediated interventions are currently the most studied type of program ([Derguy et al.](#), 2018). Even though this [type of](#) program has clearly shown identified positive effects (Bearss et al., 2015), it may not be recommended for certain parents who [present](#) different needs (e.g., couple relationship difficulties, symptoms of depression) (Webster-Stratton & Reid, 2003). It is therefore essential to develop research aimed at evaluating the effects of parent support programs. Finally, it is important to keep in mind that parents need to be supported throughout their child's development, not only during the period following a diagnosis. [They](#) will be confronted with many challenges throughout their child's life, such as setting up their child's first care, facing discontinuity or reorganization of care services, accessing school, etc. Parental guidance must [therefore](#) be [offered](#) as quickly as possible after a diagnosis, or even after [parents express their](#) first concerns, and updated according to difficulties encountered throughout [a](#) child's life.

#### References

Abidin, R. R. (1995). Parenting Stress Index Professional Manual (3<sup>rd</sup> edition Short Form).

Odessa, FL: Psychological Assessment Resources.

[McAleese, A., Lavery, C., & Dyer, K. \(2014\). Evaluating a Psychoeducational, Therapeutic Group for Parents of Children with Autism Spectrum Disorder. \*Child Care in Practice\*, 20\(2\), 162–181.](#)

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders DSM-5* (5e éd.). Arlington, VA: American Psychiatric Publishing.

Barlow, D. H., Nock, M. K., & Hersen, M. (2009). *Single Case Experimental Designs: Strategies for Studying Behavior change*, third edition. London, England: Pearson.

Bearss, K. Burrell, T. L., Stewart, L. M., & Scahill, L. (2015). Parent Training in Autism Spectrum Disorder: What's in a Name? *Clinical Child and Family Psychology Review*, 18(2), 170–182.

Bigras, M., LaFrenière, P. J., Abidin, R. R. (1996). *Indice de stress parental : Manuel francophone en complément de l'édition américaine*. Toronto, ON: Multi-Health Systems.

Anonymous (2016). *Details omitted for double-blind reviewing*.

Anonymous (2011). *Details omitted for double-blind reviewing*.

Anonymous (2017). *Details omitted for double-blind reviewing*.

Anonymous (2020a). *Details omitted for double-blind reviewing*.

Catalano, D., Holloway, L., & Mpofu, E. (2018). Mental health interventions for parent carers of children with autistic spectrum disorder: Practice guidelines from a critical interpretive synthesis (CIS) systematic review. *International Journal of Environmental Research and Public Health*, 15, 341.

Carter, E. W., Boehm, T. L., Biggs, E., Annandale, N. H., Taylor, C. E., Looock, A. K., & Liu, R. Y. (2015). Known for my strengths: Positive traits of transition-age youth with intellectual disability and/or autism. *Research and Practice for Persons with Severe Disabilities*, 40(2), 101–119.

McConnell, D., Savage, A., Sobsey, D., & Uditsky, B. (2015). Benefit-finding or finding benefits? The positive impact of having a disabled child. *Disability & Society*, 30(1), 29–45.

Anonymous (2020b). Details omitted for double-blind reviewing.

Derguy, C., Poumeyreau, M., Pingault, S., & M'Bailara, K. (2018). Un programme d'éducation thérapeutique destiné à des parents d'enfant avec un TSA : étude pilote de l'efficacité du programme ETAP. *L'encéphale*, 44(5), 421–428.

Eisenhower, A.S., Baker, B.L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behavior problems, and maternal well-being. *Journal of Intellectual Disability Research*, 49(Pt 9), 657–671.

Ferguson, E., Matthews, G., & Cox, T. (1999). The appraisal of life events (ALE) scale: reliability, and validity. *British Journal of Health Psychology*, 4, 97–116.

Fitzpatrick R. (1991). Surveys of patient satisfaction: Important general considerations. *British Medical Journal*, 302, 887–889.

Haute Autorité de Santé [HAS] (2012). *Autisme et autres troubles envahissants du développement : interventions éducatives et thérapeutiques coordonnées chez l'enfant et l'adolescent*. Saint-Denis La Plaine, France: HAS.

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. Recommandations de bonne pratique. Saint-Denis La Plaine, France: HAS.

Ilg, J., Jebrane, A., Paquet, A., Rousseau, M., Dutray, B., Wolgensinger, L., & Clément, C. (2018). Evaluation of a French parent-training program in young children with autism spectrum disorder. *Psychologie Française*, 63(2), 181–199.

Kazdin, A. E., Siegel, T. C., & Bass, D. (1992). Cognitive problem-solving skills training and parent management training in the treatment of antisocial behavior in children. *Journal of Consulting and Clinical Psychology*, 60(5), 733–747.

- Kazdin, A.E. (2000). Perceived Barriers to Treatment Participation and Treatment Acceptability Among Antisocial Children and Their Families. *Journal of Child & Family Studies*, 9(2), 157–174.
- Kuhaneck, H.M., Madonna, S., Novak, A., & Pearson, E. (2015). Effectiveness of interventions for children with autism spectrum disorder and their parents: A systematic review of family outcomes. *American Journal of Occupational Therapy*, 69(5), 1–14.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer.
- [Anonymous \(2019a\). Details omitted for double-blind reviewing.](#)
- Minjarez, M. B., Mercier, E. M., Williams, S. E., & Hardan, A. Y. (2013). Impact of pivotal response training group therapy on stress and empowerment in parents of children with autism. *Journal of Positive Behavior Interventions*, 15(2), 71–78.
- Naud, J., & Sinclair, F. (2003). *Eco-Famille : Programme de valorisation du développement du jeune enfant dans le cadre de la vie familiale*. Montréal : Chenelière/McGraw Hill.
- [Anonymous \(2019b\). Details omitted for double-blind reviewing.](#)
- [Anonymous \(2019c\). Details omitted for double-blind reviewing.](#)
- Secrétariat d'Etat auprès du Premier ministre chargé des Personnes handicapées (2018).  
L'autisme en 2018 : les chiffres clés. Retrieved from <https://handicap.gouv.fr/focus/l-autisme/strategie-nationale-pour-l-autisme-2018-2022/article/l-autisme-en-2018-les-chiffres-cles>
- Schultz, T.R., Schmidt, C.T., & Stichter, J.P. (2011). A review of parent education programs for parents of children with ASD. *Focus on Autism and Other Developmental Disabilities*, 26(2), 96–104.

- Stipanivic, A., Couture, G., Rivest, C., & Rousseau, M. (2014). Développement des modèles théoriques d'un programme destiné à des parents d'enfants présentant un trouble du spectre de l'autisme. *Journal on Developmental Disabilities*, 20(3), 19–29.
- Stuart, M., & McGrew, J.H. (2009). Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders*, 3(1), 86–97.
- 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.
- Webster-Stratton, C., & Reid, M. J. (2003). The incredible years parents, teachers and children training series: A multifaceted treatment approach for young children with conduct problems. In A. E. Kazdin & J. R. Weisz (Eds.), *Evidence-based psychotherapies for children and adolescents* (pp. 224-240). New York, NY: Guilford Press.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075–1083.
- Yorke, I., White, P., Weston, A., Rafla, M., Charman, Y., & 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.