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Original article

# Adaptation and quality of life of parents with a child with autism spectrum disorder: A comparative exploratory study between France, French-Speaking Belgium and Quebec

## *Processus d'ajustement et qualité de vie des parents d'un enfant ayant un trouble du spectre de l'autisme : une étude exploratoire comparative entre la France, la Belgique francophone et le Québec*

É. Cappe[a,*,1], A. Pedoux[a,2], N. Poirier[b,2], N. Downes[a,3], N. Nader-Grosbois[c,4]

[a] *Laboratoire de psychopathologie et processus de santé (LPPS – EA4057), institut de Psychologie, université Paris Descartes – Sorbonne Paris Cité, 71, avenue Édouard-Vaillant, 92100 Boulogne-Billancourt, France*
[b] *Département de psychologie, université du Québec à Montréal, laboratoire de recherche sur les familles d'enfants présentant un TSA, CP 8888 Succursale Centre-Ville, Montréal, H3P 3C8, Canada*
[c] *Institut de recherche en sciences psychologiques, université Catholique de Louvain, place du Cardinal Mercier 10, B-1348 Louvain-la-Neuve, Belgium*

* Corresponding author.
*E-mail address:* emilie.cappe@parisdescartes.fr (É. Cappe).

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ABSTRACT

Raising a child with autism spectrum disorder (ASD) entails significant stress levels that impact parent's quality of life. The aim of this study is to explore parental adaptation between parents in France, French-speaking Belgium and Quebec. A total of 87 parents replied to questionnaires and self-rating scales to assess: (1) information about their child and family situation; (2) perceived stress (ALES-vf); (3) perceived social support (QSSP); (4) perceived control (CLCS); (5) coping strategies (WCC-R) and (6) quality of life (specific scale). The results show that French children with ASD are diagnosed later and attend less school than their counterparts in French-speaking Belgium and Quebec. French parents are more likely to perceive their current situation of having a child with ASD as a loss compared to their prior situation. They can count on more people, but tend not to seek social support. This study highlights the importance of considering environmental and contextual variables to understand parental stress and quality of life.



*Mots clés :*
Trouble du spectre de l'autisme (TSA)
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RÉSUMÉ

*Problématique de recherche.* – Avoir un enfant qui présente un trouble du spectre de l'autisme (TSA) est source de stress et perturbe considérablement la qualité de vie des parents. En effet, en raison des besoins spécifiques de l'enfant, les parents font face à de nombreux défis quotidiens, impliquant nécessairement une réorganisation de la structure familiale. Les parents sont ainsi plus susceptibles de rencontrer des difficultés d'ajustement, résultant d'interactions dynamiques et interdépendantes entre les variables transactionnelles et socio-environnementales. Il existe par ailleurs des différences en termes d'interventions, de scolarisation et d'inclusion sociale des personnes ayant un TSA entre la France, la Belgique francophone et le Québec. L'objectif de cette étude était d'explorer les différences de processus d'ajustement entre parents français, belges francophones et québécois.

*Méthode.* – Au total, 87 parents ont répondu à des questionnaires évaluant : (1) les informations socio-biographiques ; (2) le stress perçu (ALES-vf) ; (3) le contrôle perçu (CLCS) ; (4) le soutien social perçu (QSSP) ; (4) ; (5) les stratégies de coping (WCC-R) et (6) la qualité de vie.

*Résultats.* – Les résultats indiquent plusieurs différences significatives entre les parents. En moyenne, les enfants en France sont diagnostiqués plus tardivement qu'en Belgique francophone et au Québec. Ils bénéficient également de temps de scolarisation hebdomadaire moins importants. Les parents français perçoivent davantage leur situation comme une perte. Leur réseau de soutien social est plus élargi bien qu'ils aient moins recours à la recherche de soutien social lorsqu'ils sont confrontés à une situation stressante en lien avec les difficultés de leur enfant.

*Limites.* – Les principales limites de cette étude sont la petite taille des échantillons, mais aussi et surtout leur défaut de représentativité de la population. En effet, les participants n'ont pas été choisis au hasard. Ils ont été recrutés via des appels à participation. Les parents qui répondent à ce type de sollicitation sont généralement très motivés, dynamiques, voire très engagés dans la cause de l'autisme. Pour ces différentes raisons, les résultats et conclusions de cette étude sont donc à considérer avec précaution.
*Conclusion.* – Cette étude met en évidence qu'élever un enfant ayant un TSA est source de stress et de différentes difficultés au quotidien. Il est essentiel de comprendre comment les différentes cultures perçoivent le TSA et quels services de soutien sont mis à leur disposition. En effet, les professionnels devraient davantage considérer les besoins, le parcours d'intervention et de scolarisation afin de soutenir la perception de contrôle sur l'évolution de l'enfant, le coping centré sur le problème et la qualité de vie des parents dans plusieurs domaines. De ce fait, cette recherche révèle l'importance de mieux considérer le rôle des variables socio-environnementales et contextuelles dans l'étude du stress et de la qualité de vie chez les parents.


## 1. Introduction

Autism spectrum disorder (ASD) (American Psychiatric Association, 2013) is considered a neurodevelopmental disorder affecting around 1% of the world's population (Fombonne, 2012). It can be defined as a "persistent impairment in reciprocal social communication and social interaction (criterion A), and restricted, repetitive patterns of behavior, interest or activities (criterion B)" (APA, 2013, p. 53). Parents of children with ASD face daily challenges trying to respond to the specific needs of their child, which often result in the reorganization of the family unit (Turnbull, Poston, Minnes, & Summers, 2007).

### 1.1. Impact of child's symptoms on quality of life and parental adjustment

Many studies have focused on parental experience, psychological adaptation and the impact of ASD on the parent's quality of life (Gray, 2006; Vasilopoulou & Nisbet, 2016). Generally, parents of children with ASD present higher levels of stress than parents with neurotypical children or children with different types of neuro-developmental disorders (Hayes & Watson, 2012). As a consequence, their quality of daily life is more affected (Baghdalli, Pry, & Michelon, 2014). In fact, having a child with ASD considerably modifies parents' social relationships, family life and the couple's relationship (Baeza-Velasco, Michelon, Rattaz, Pernon, & Baghdadli, 2013; Cappe, Wolff, Bobet, & Adrien, 2012), often giving parents a more negative impression of their parental capacities (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Moreover, parental practices are often judged by problem behaviours displayed by the child, which often leads to parents avoiding public places and thus to encounter social and emotional isolation (Paquet, Chatenoud, & Cappe, 2014). This is not to mention parents who must abandon their job to take care of their child's needs due to limited treatment availability in France (Cappe et al., 2012). Parents are confronted with considerable repercussions on their physical and mental health, affecting many areas of their daily lives and their ability to adjust to a variety of factors (Cappe et al., 2012).

### 1.2. Factors of parental adjustment

Research has highlighted a number of factors affecting the perceived stress and quality of life of parents of children with ASD. These include individual factors related to the characteristics of ASD and the specific needs of the child (Benson, 2006; Hastings, 2002), as well as contextual factors and those related to psychosocial (stable or transactional) variables (Boyd, 2002; Bromley, Hare, Davison, & Emerson, 2004; Dunn et al., 2001). The limited material resources, employment difficulties, child's characteristics and lack of respite, lead to parental distress and decrease their quality of life (des Rivières-Pigeon & Courcy, 2014a). Other studies highlight the effects of perceived social support and coping strategies. The more parents of children with ASD perceive social support, the lower their level of distress (Boyd, 2002; Bromley et al., 2004). However, the more emotion-focused coping strategies they employ, the higher their level of distress (Dunn et al., 2001). These strategies are indeed less effective and less adaptive in terms of emotional regulation (Pottie & Ingram, 2008).

To date, multiple empirical studies conducted with parents of children with ASD in France (Cappe, É., Wolff, M., Bobet, R., & Adrien, J.-L. (2011); Cappe et al., 2012, Quebec (des Rivières-Pigeon, Courcy, & Dunn, 2014b; Author et al., 2014) and in French-speaking Belgium (Nader-Grosbois and Cappe, 2014), have yet to be compared in order to reveal the intercultural and environmental effects, and the various treatment options available among these French-speaking countries. At a time when government recommendations are encouraging professionals from these three countries to support parents (Fédération Wallonie-Bruxelles, 2016; Ministère de la Santé et des Services Sociaux [MSSS], 2003; Ministère de la Santé et des Services Sociaux [MSSS], 2017; Secrétariat d'État auprès du Premier ministre chargé des Personnes handicapées, 2018), it seems essential to compare these three contexts in order to identify the positive factors related to parental adaptation (Philip, 2014).

### 1.3. A variety of contexts and treatments

The prevalence rate of Autism in France is 1 per 150 children (Haute Autorité de santé, 2012), resulting in it becoming a major public health issue (Favre, 2012). Despite the government's recommendations, the implementation of successive "Autism plans" (*Plans Autisme*) (2005–2007, 2008–2010, 2013–2017) and clinical practice recommendations (Haute Autorité de santé, 2012), care services remain unequal and specialized structures are scarce. However, intervention provided to people with ASD and their families can vary depending on the professional's perspective and the structure it is offered in. Mainstream schools are more accommodating since the law of 11 February 2005 was established on the equal rights, opportunities, participation and citizenship of people with disabilities. Nevertheless, the National Consultative Ethics Committee (*Comité Consultatif National d'Ethique*) denounced certain shortcomings in the education and schooling of people with ASD (Comité Consultatif National and d'Éthique – [CCNE], 2007). It is estimated that 50% of children with ASD remain deprived of any form of schooling (Collectif Autisme, 2011), whilst 20% are educated in mainstream schools, either in a mainstream class that has an inclusive setting, as defined in the article 24 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), or in a special educational needs class reserved specifically for students with ASD or cognitive disabilities, and 30% attend specialist provisions, mostly part-time. Since September 2014, special needs classes have been introduced in nursery schools, enabling young children under 6 years of age with ASD to go from special needs schools to inclusive education settings without a one-to-one assistant (Ministère de l'Éducation Nationale, de l'Enseignement Supérieur et de la Recherche [MENESR], 2014). However, the division of care services by age still causes many discontinuities in treatment and generates stress for finding suitable long term care services (Cappe et al., 2012).

In French-speaking Belgium, approximately 70,000 families are confronted with autism (Veereman et al., 2014). Reference centres are set up by the National Institute for Health and Disability Insurance (*Institut National d'Assurance Maladie-Invalidité*) for ASD screening, which can take up to 8 months on a waiting list (Parlement Wallon, 2017). In the French-Speaking Belgian system, different authorities of the various provinces are responsible for institutional policy, making access to offers and services difficult for families (Conseil Supérieur de la Santé, 2013). In spite of this, care services are extensive and there is a continuity of treatment for people with ASD from the age of 8 years old until 18 years

old (Conseil Supérieur de la Santé, 2013). Before the child is 8 years old, specific early intervention services are often proposed to families. Whereas in adulthood, the continuity of treatment proves to be quite complicated. Regarding education, French-speaking Belgium has a more pragmatic approach: school is compulsory from 6 to 18 years old, including intervention focused on educational, cognitive-behavioral and developmental methods. The Individual Learning Plan (*Plan Individuel d'Apprentissage*) is required to be developed by teachers in collaboration with families to promote personalized care. In mainstream schools, integration is implemented by special education teachers working in classrooms either on a full or part time basis. Since 2009, the Ministry of Education (*Ministère de l'Education*) has also institutionalized a network of TEACCH Classes, aiming to create special education teaching based on the TEACCH method. Nevertheless, this intervention remains limited due to the lack of professionals trained in this method (Fédération Wallonie-Bruxelles, 2016). From this observation emerged the need to develop a "Transversal Autism Plan" (*Plan Transversal Autisme)*, inspired by the recommendations of the Autism Plan (*Plan Autisme*) and the HAS (2012) in France, and advocated by parent associations (Fédération Wallonie-Bruxelles, 2016).

In Quebec, nearly 80,000 people are reportedly affected by ASD, a figure that is constantly increasing (Poirier & Cappe, 2016). For many years, psychoeducational care and the partnership between parents and professionals have been encouraged. Indeed, since 2003, the publication entitled "An Act for the Future" ("*Un geste porteur d'avenir*") allowed the reorganization of health and social services aimed at adapting specialized services to children and their families by proposing a program of Intensive Behavioral Intervention (*programme d'Intervention Comportementale Intensive*; *ICI*) to all children under 5 diagnosed with ASD (MSSS, 2003). However, accessibility to the ICI program remains a concern. In fact, the waiting time to benefit from it can vary from 4 to 24 months according to the Rehabilitation Centres for Intellectual Disabilities and Pervasive Developmental Disorders (*Centres de Réadaptation en Déficience Intellectuelle et en Troubles Envahissants du Développement*) (Dionne, Joly, Paquet, Rivard, & Rousseau, 2012). Nevertheless, all Quebec children have access to primary and secondary education services, full-time, from the eligible age of 4 (for children with disabilities) until they are 21 years old (Poirier & Cappe, 2016). Thus, whatever the degree of severity of the ASD, all these children benefit, according to their needs, from some form of schooling (mainstream or special needs) decided by the school boards. In contrast to figures collected in Europe, nearly 85% of students with ASD have access to mainstream schools (Poirier & Cappe, 2016). However, access can occasionally remain restricted, even in this system (Chamak, 2016; Protecteur du citoyen, 2012).

In conclusion, ASD treatment and its impact on families is influenced by societal and intercultural differences depending on how ASD is perceived and understood (Ravindran & Myers, 2012). Thus, there are differences between France, French-speaking Belgium and Quebec regarding interventions, schooling and social inclusion of individuals with ASD. The objective of this study is therefore to explore the differences between French, French-speaking Belgian, and Quebec parents, with regards to contextual, socio-demographic and adjustment processes in order to better understand their reality.

## 2. Method

### 2.1. Sample and procedure

In total, the sample consists of 87 French, French-speaking Belgian and Quebec parents divided equally in each group ($n = 29$). Recruitment was carried out from 2012 to 2014 through different appeals for voluntary participation distributed to a parents' association, a self-help group, a professional organisation with two specialised centres and a specialised clinic. Each participant freely agreed to take part in the study. Finally, for the purpose of this study, participating parents were matched by sex, age, family status and socio-economic status.

### 2.2. Measures

#### 2.2.1. Evaluation of socio-biographical characteristics

A specific questionnaire was designed by Cappe, 2009 to collect socio-biographical information about the child with ASD and their parents (Appendix A). Part of the questionnaire concerns the

characteristics of the child with ASD, another part involves parental characteristics and the family situation. Two subscales from this questionnaire are also used to assess the level of satisfaction and need regarding the received care services.

*2.2.2. Perceived stress: ALES-vf*

ALES-vf is a French adaptation of Ferguson, Matthews, and Cox (1999) Appraisal of Life Events Scale (ALES) (Cappe et al., 2017). ALES-vf has been validated with French, Quebec and French-speaking Belgian parents with children with ASD. Firstly, parents describe how the presence of ASD of their child can potentially become a source of stress in their daily lives. The parent then evaluates, on a Likert scale, to what extent each of the adjectives corresponds to their current situation, resulting in either one of the three following sub-scores: experience perceived as a threat (e.g.: threatening, fearful, worrying, hostile, frightening and terrifying); experience perceived as a loss (e.g.: painful, depressing, pitiful and intolerable); experience perceived as a challenge (e.g.: enjoyable, challenging, stimulating, exhilarating, informative and exciting). Folkman & Lazarus (1985) defined the threat dimension as being related to the potential for harm, while the loss dimension is linked to the harm affecting health, friendships, or self-esteem. Meanwhile, the challenge dimension seems to be similar to the concept of eustress, which seems to refer to beneficial stress (Seyle, 1974). This dimension concerns the potential for gain and growth mastery. For example, parents could perceive giving up their job to take care of their child with ASD either as a threat to their social status, a financial loss, or rather as an opportunity to become closer to their child. The higher these scores, the more the individual judges his experience as either a threat, a loss, or a challenge. All three dimensions show good internal coherence (Cappe et al., 2017).

*2.2.3. Perceived control: CLCS*

The Cancer Locus of Control Scale (CLCS) (Pruyn et al., 1988) is a scale originally designed to assess specific beliefs of control in cases of chronic, severe and cancerous diseases. This scale was translated into French by Cousson-Gélie (1997), then validated and adapted by Cappe, 2009 to target the population of this study. A factor analysis of this adaptation revealed a factorial structure similar to that found by Cousson-Gélie (1997) with good internal consistency. Each parent interviewed must express their degree of agreement to 17 proposals on a Likert scale which produces the following three sub-scores:

- perceived control about the onset of ASD: The higher the score, the more parents view themselves as the cause of the ASD of their child;
- perceived control over the evolution of the child's development: The higher the score, the more parents think they can employ strong control over their child's ASD;
- religious beliefs about the onset of ASD: The higher the score, the more parents attribute "irrational" causes to the onset of ASD.

*2.2.4. Perceived social support: QSSP*

The Perceived Social Support Questionnaire (Koleck, 2000) was adapted and validated by Cappe, 2009, showing a good internal coherence. It consists of four questions assessing the main forms of social support: emotional, informational, self-esteem, and material. For each question, the parent indicates how many people they can count on in each situation, and then ranks their satisfaction with the support they receive on a Likert scale. Two sub-scores of perceived social support can then be obtained: the availability score and the satisfaction score. The higher the availability score, the more parents can count on a large number of people. The higher the satisfaction score, the more parents are satisfied with the help they obtained by those around them.

*2.2.5. Coping strategies: WCC-R*

The Ways of Coping Checklist (WCC-R) (Vitaliano, Russo, Carr, Maiuro, & Becker, 1985) is a revised adaptation of the WCC by Folkman and Lazarus (1988). This scale has been translated into French by Cousson-Gélie, Bruchon-Schweitzer, Quintard, Nuissier, & Rasclen, (1996), then adapted and validated by Cappe, 2009 to the target population of this study, presenting an overall good internal consistency. The instructions and the scoring system were modified to evaluate the different coping strategies used

by parents of a child with ASD. Firstly, the parents are asked to describe a recent stressful situation related to the child's autism, and then pinpoint their level of agreement for 27 proposals on a Likert scale. Three sub-scores are then calculated, corresponding to the strategies found in the model of Lazarus and Folkman (1984). High scores among the "problem-focused coping" (e.g.: "Just took things one step at time", "Stood my ground and fought for what I wanted") and "emotion-focused coping" (e.g.: "Blame myself", "Hoped a miracle would happen") scales suggest a more frequent use of these strategies, and a high "Seeking social support" (e.g.: "Talked to someone to find out about this situation", "Got professional help and did what they recommended") score suggests that the parent is seeking more help from their family or social network to cope with the situation.

### 2.2.6. *Quality of life*

A quality of life scale, specifically designed for parents of children with ASD, was used to assess the impact and consequences of ASD on various domains of daily life (Cappe, 2009; Cappe et al., 2012). Parents offer their extent of agreement for 102 situations on a Likert scale. An overall score and seven sub-scores can then be obtained which correspond to the following quality of life domains: (1) daily activities; (2) professional activities and relationships; (3) social activities and relationships; (4) family and couple activities and relationships; (5) activities and relationships with the child with ASD; (6) psychological well-being; (7) personal fulfillment. For each of these sections, the higher the score, the more the child's ASD causes difficulties for the parent in that particular domain; and vice versa, the lower the score, the less the disorder has an impact on that domain.

**Table 1**
Socio-biographical information of parents.

| | France | Quebec | French-speaking Belgium | *N* | $\chi 2$ or *F* | *p* |
|---|---|---|---|---|---|---|
| Total number of parents[a] | 29 | 29 | 29 | 87 | | |
| Gender | | | | | .24 | .88 |
| Number of mothers | 25 (86.21%) | 23 (82.14%) | 25 (86.21%) | 73 (86.21%) | – | – |
| Number of fathers | 4 (13.79%) | 5 (17.86%) | 4 (13.79%) | 13 (15.12%) | – | – |
| Average age | 42.55 (4.2) | 40.62 (7.31) | 40.59 (6.14) | 41.25 (6.02) | .01 | .37 |
| Relationship status: in a couple | 28 (96.55%) | 25 (86.21%) | 28 (96.55%) | 81 (93.10%) | 3.22 | .19 |
| Average number of dependent children[b] | 1.17 (0.85) | 1.07 (0.53) | 1.48 (1.05) | 1.23 (0.8) | 1.84 | .16 |
| Career changes | 26 (89.66%) | 21 (72.41%) | 17 (60.71%) | 64 (74.42%) | 6.36 | .04 |
| Employment[c,*] | | | | | 9.34 | .05 |
| Unemployed | 9 (23.08%) | 6 (20.69%) | 11 (42.31%) | 26 (30.95%) | – | – |
| Part time | 13 (44.83%) | 7 (24.14%) | 9 (34.62%) | 29 (34.52%) | – | – |
| Full time | 7 (24.14%) | 16 (55.17%) | 6 (23.08%) | 29 (34.52%) | – | – |
| Health problems | 8 (27.59%) | 14 (48.28%) | 11 (37.93%) | 33 (37.93%) | 2.64 | .27 |
| Health problems that affect daily lives | 7 (24.14%) | 6 (20.69%) | 8 (27.59%) | 21 (24.14%) | 9.91 | .27 |
| Health problems considered to be related to having a child with ASD | 6 (20.69%) | 7 (24.14%) | 5 (17.24%) | 18 (20.69%) | 3.91 | .42 |
| Income perceived as being sufficient | 15 (51.72%) | 17 (60.71%) | 13 (52%) | 45 (54.88%) | .59 | .75 |
| Special allowances perceived as being sufficient[d] | 9 (36%) | 8 (33.33%) | 7 (28%) | 24 (32.43%) | .38 | .83 |
| Member of an association[e] | 21 (72.41%) | 16 (57.14%) | 13 (44.83%) | 50 (58.14%) | 4.55 | .09 |
| Member of a support group[f] | 5 (17.24%) | 3 (10.34%) | 5 (21.74%) | 13 (16.05%) | 1.28 | .62 |
| Parental needs average score | 34.96 (52.98%) | 30.31 (45.93%) | 29.25 (44.31%) | 31.51 (47.74%) | 1.44 | .24 |
| Parental satisfaction average score | 18.14 (43.18%) | 19.28 (45.9%) | 18.11 (43.13%) | 18.51 (44.07%) | .55 | .56 |

[*] $p = .053$.

[a] A parent from Quebec did not provide their gender.

[b] Two French-Speaking Belgian parents did not specify the number of dependent children.

[c] Three French-Speaking Belgian parents did not declare their employment status.

[d] Among the 85 parents receiving special allowances, 11 (3 French, 4 French-speaking Belgian and 4 Quebec) did not specify whether it was sufficient.

[e] One parent from Quebec did not specify whether they were a member of an association.

[f] Six French-speaking Belgian parents did not indicate whether they were part of a support group.

*2.2.7. Data analysis*

Pearson's Chi-squared tests were used to test for independence among the parent groups and their socio-biographical characteristics. F-tests were carried out to test the different effects between the three groups of parents (French, French-speaking Belgian, Quebec) in terms of quality of life and transactional processes.

## 3. Results

### 3.1. Socio-biographical information

Table 1 presents all the socio-biographical data of the parents for the three groups.

Parents are on average 41 years old (*Mdn* = 42 years, *Min* = 28 years and *Max* = 56 years, *SD* = 6.02). The majority of participants were mothers ($n = 73$) and lived in a couple ($n = 81$). At the time of recruitment, 26 parents had no professional activity; 29 worked part-time and 26 full-time. The results reveal that French parents are significantly more likely to experience professional changes due to their child's ASD (89.66%, $\chi 2 = 6.36$, $p < .05$). Regarding the socio-economic level, just over 50% of parents ($n = 45$) estimated their income as being sufficient to support their child. Although the majority of parents in the total sample received special allowances for children or adults with disabilities ($n = 73$), two-thirds of them reported that these transfers were insufficient to support their child ($n = 50$).

More than one-third of parents also reported having health problems ($n = 33$). Among them, 21 parents felt that these health problems disturbed (moderately or highly) their daily lives and 18 said that they were related to the autism of their child.

Finally, more than half of the parents surveyed were part of an association or organization defending autism rights ($n = 50$).

French parents express greater material, financial and social needs compared to other parents ($M_{\text{France}} = 52.98$ [$SD = 18.15$] > $M_{\text{Quebec}} = 45.93$ [$SD = 21.79$] > $M_{\text{Belgium}} = 44.31$ [$SD = 21.69$]), but the difference is not significant ($F(2,84) = 1.44$, $p > .05$). Finally, parents show almost identical levels of satisfaction with available care services regarding treatment, child development, parent-professional relationships, support, active listening, reactions, and information provided concerning ASD ($M_{\text{Quebec}} = 45.90$ [$SD = 11.53$] > $M_{\text{France}} = 43.18$ [$SD = 9.3$] > $M_{\text{Belgium}} = 43.13$ [$SD = 13.14$], $F(2,84) = 0.55$, $p > .05$).

Table 2 presents all the socio-biographical data of the children for the three groups.

In total, there were 87 children, 68 being male. The average age was about 9 years and 9 months (*Mdn* = 9 years and 7 months, *Min* = 26 months and *Max* = 21 years and 9 months, *SD* = 4 years and 3 months old). Among these, 19 were under 6 years old; 20 between 6 and 9 years; 18 between 9 and 12 years and 30 between 12 and 18 years. The majority of children lived with the interviewed parent ($n = 79$); seven had parents with joint custody and one child lived with the other parent. The average age of children at the time of diagnosis was approximately 4 years and 5 months old (*Mdn* = 3 years and 9 months, *Min* = 20 months and *Max* = 12 years and 11 months, *SD* = 24 months). French children are significantly more likely to be diagnosed later, with an average detection age of 5 years and 8 months (*Mdn* = 58 months, *Min* = 30 months and *Max* = 12 years 11 months, *SD* = 15.46 months), compared to French-speaking Belgian and Quebec children ($F(2,81) = 6.66$, $p < .05$). The majority received the first intervention before 6 years old: 28 children before 3 years old and 38 between 3 and 6 years. In this sample, 30 parents experienced interruptions in the care of their child. Furthermore, more than half of all children were followed in the public health and social service ($n = 50$); the average waiting time being 14 months (*M* = 14 months, *Min* = 0 and *Max* = 121 months, *SD* = 20.44). However, French children are significantly more likely to receive private care services (75.86%, $\chi 2 = 8.81$, $p < .05$), compared to French-speaking Belgian and Quebec children. Just over three quarters of the parents believe that the care services provided are adapted to their child's needs.

In regards to inclusion, the majority were integrated into school ($n = 72$) and did not differ significantly in terms of mainstream school enrolment, despite French children having a significantly lower average weekly school time than French-speaking Belgian and Quebec children ($M_{\text{France}} = 18$ hours [$SD = 8.71$], $M_{\text{Belgium + Quebec}} = 30$ hours, $F(2, 67) = 12.97$, $p < .05$). Among the parents, 46 perceived their child's school as being adapted.

**Table 2**
Socio-biographical information of the children.

| | France | Quebec | French-speaking Belgium | *N*=87 | $\chi^2$ or *F* | *p* |
|---|---|---|---|---|---|---|
| Average age (in years) | 10.13 (3.72) | 9.44 (4.45) | 9.87 (4.85) | 9.81 (4.32) | .18 | .83 |
| Male gender | 22 (75.86%) | 23 (79.31%) | 23 (79.31%) | 68 (78.16%) | .13 | .93 |
| Average age of diagnosis (in years) | 5.64 (2.92) | 3.84 (1.73) | 3.91 (1.29) | 4.46 (2.24) | 6.66 | .00* |
| Language level: verbal | 15 (51.72%) | 15 (51.72%) | 12 (41.38%) | 42 (48.28%) | 7.55 | .11 |
| Alternative communication system | 9 (31.03%) | 13 (44.83%) | 14 (48.28%) | 36 (41.38%) | 1.99 | .37 |
| Decreased autonomy | 28 (96.55%) | 28 (96.55%) | 27 (93.1%) | 83 (95.4%) | 3.54 | .74 |
| Challenging behaviours | 29 (100%) | 27 (93.10%) | 26 (92.86%) | 82 (95.35%) | 2.14 | .34 |
| Attends school | 23 (79.31%) | 23 (79.31%) | 26 (89.66%) | 72 (82.76%) | 1.45 | .48 |
| Attends a mainstream class | 8 (34.78%) | 15 (65.22%) | 15 (60%) | 38 (53.52%) | 4.93 | .44 |
| Average time at school per week (in hours) | 18.28 (8.71) | 33.91(5.21) | 26.29 (11.28) | 13 (16.05%) | 12.97 | .00** |
| Schooling perceived as being adapted to the child | 11 (47.83%) | 18 (78.26%) | 17 (73.91%) | 46 (66.67%) | 5.61 | .06 |
| Care services perceived as being adapted to the child | 25 (86.21%) | 21 (75%) | 17 (70.83%) | 63 (77.78%) | 1.99 | .37 |
| Waiting time (in months) for public care | 18.33 (29.76) | 14.56 (10.86) | 10.17 (11.68) | 14.52 (20.44) | .56 | .57 |
| Benefit from public care | 18 (62.07%) | 19 (67.86%) | 13 (56.52%) | 50 (62.50%) | .69 | .71 |
| Benefit from private care | 22 (75.86%) | 11 (37.93%) | 15 (62.50%) | 48 (58.54%) | 8.81 | .01 |
| Mainstream leisure activities | 15 (51.72%) | 14 (48.28%) | 13 (44.83%) | 42 (48.28%) | .28 | .87 |
| Availability of leisure activities considered as insufficient | 27 (93.1%) | 18 (69.23%) | 24 (88.89%) | 69 (84.15%) | 6.53 | .03 |

* $p = .002$.
** $p = .000017$.

In terms of leisure time, French parents are significantly more likely to rate these services as insufficient compared to other parents (93.10%, $\chi 2 = 6.53$, $p < .05$).

### 3.2. Transactional Variables and Quality of Life results

The collected data from the transactional variables are presented in Table 3 and the quality of life data is shown in Table 4.

The results obtained from the perceived stress measure (ALES-vf), exhibit that parents perceive their experience as more of a threat ($M = 51.6$, $SD = 23.86$). French and French-speaking Belgian parents are significantly more likely to perceive their situation as a loss, compared to Quebec parents ($M_{\text{France+Belgium}} = 54.14 > M_{\text{Quebec}} = 40.17$, $F(2, 84) = 7.7$, $p < .05$); with the difference being more important for French parents ($d_{\text{obs/France}} = 17.42 > d_{\text{obs/Belgium}} = 10.52$).

The perceived control scale (CLCS), shows that most parents on average perceive more control over the evolution of their child's development ($M = 77$, $SD = 15.47$) and none of the subscale scores differed significantly between the three groups.

In terms of perceived social support (QSSP), French parents can count on significantly more people, compared to parents in French-speaking Belgium and Quebec ($M_{\text{France}} = 27.05 > M_{\text{Quebec+Belgium}} = 18.37$; $F(2.84) = 6.08$, $p < .05$), although there are significant interpersonal variations ($SD = 20.41$). The degree of satisfaction with the help provided by ones entourage does not vary significantly between the three groups.

Concerning coping strategies (WCC-R), parents generally use more problem-focused coping strategies ($M = 59.9$, $SD = 20.91$), than emotion-centred strategies ($M = 45.5$, $SD = 21.22$) or searching for social support ($M = 61.5$, $SD = 24.56$). French parents, however, made significantly less use of available social support ($M = 52.71$, $SD = 24.74$, $F(2, 84) = 5.87$, $p < .05$).

The impact of ASD on the quality of life of parents seems more important among French parents ($M = 54.04$, $SD = 14.26$), but there are no significant differences between the three groups. The parent's quality of life is more affected in daily activities ($M = 65$, $SD = 18.45$), followed by family and couple relationships and activities ($M = 54.13$, $SD = 17.22$), psychological well-being ($M = 51.75$, $SD = 18.73$), social

**Table 3**
Comparison of means (in percentage) of transactional variables' sub-scores between France. Quebec and French-Speaking Belgium.

| | France | Quebec | French-speaking Belgium | N = 87 | F | *p* | Eta$^2$ | Post-hoc |
|---|---|---|---|---|---|---|---|---|
| Perceived stress (ALES-vf) | | | | | | | | |
| Threat | 57.47 (25.05) | 43.56 (22.43) | 53.76 (22.59) | 51.6 (23.86) | 2.75 | .07 | .06 | |
| Loss | 57.59 (26) | 40.17 (23.32) | 50.69 (22.23) | 49.48 (24.7) | 3.9 | .02 | .08 | M(G1+G3) > MG2<br>M(G1) > MG2 |
| Challenge | 39.77 (23.75) | 47.93 (20.38) | 48.16 (28) | 45.29 (24.28) | 1.13 | .33 | .03 | |
| Perceived control (CLCS) | | | | | | | | |
| Perceived control over the appearance of their child's ASD | 10.34 (15.07) | 10.02 (15.32) | 9.48 (13.97) | 9.95 (14.63) | .02 | .97 | .00 | |
| Perceived control over the evolution of their child's ASD | 78.35 (14.65) | 75.86 (13.71) | 76.81 (18.15) | 77 (15.47) | .2 | .83 | .00 | |
| Religious beliefs | 6.51 (13.45) | 16.86 (23.87) | 12.2 (20.6) | 11.86 (20.02) | 1.99 | .14 | .04 | |
| Perceived social support (QSSP) | | | | | | | | |
| Availability | 27.05 (20.41) | 18.32 (13.04) | 18.42 (11.46) | 21.26 (15.83) | 3.04 | .05 | .07 | M(G1) > M(G2+G3) |
| Satisfaction | 24.27 (6.67) | 27.74 (4.85) | 25.88 (8) | 25.96 (6.71) | 1.98 | .14 | .04 | |
| Coping (WCC-R) | | | | | | | | |
| Problem-focused | 59.9 (20.91) | 65.9 (17.94) | 66.38 (18.81) | 64.06 (19.26) | 1.02 | .36 | .02 | |
| Emotion-focused | 46.74 (21.19) | 44.7 (21.59) | 45.05 (21.57) | 45.5 (21.22) | .07 | .93 | .00 | |
| Seeking social support | 52.71 (24.74) | 68.13 (24.28) | 63.13 (24.68) | 61.5 (24.56) | 1.98 | .04 | .07 | M(G1) > M(G2+G3)<br>M(G1) > M(G2) |

**Table 4**
Comparison of means (in percentage) of parent's quality of life sub-scores between France, Quebec and French-speaking Belgium.

| | France | Quebec | French-speaking Belgium | N = 87 | *F* | *p* | *Eta$^2$* |
|---|---|---|---|---|---|---|---|
| Overall score | 54.04 (14.26) | 49.55 (14.17) | 51.62 (12.88) | 51.74 (13.75) | .78 | .46 | .02 |
| Daily activities | 67.15 (18.81) | 64.49 (19.83) | 63.35 (17.06) | 65 (18.46) | .32 | .73 | .01 |
| Professional relationships and activities | 53.01 (27.78) | 42.1 (24.91) | 48.54 (33.19) | 47.88 (28.85) | 1.05 | .35 | .02 |
| Social relationships and activities | 52.82 (24.18) | 48.68 (21.39) | 53.15 (18.94) | 51.54 (21.45) | .38 | .68 | .01 |
| Family and couple relationships and activities | 57.14 (19.59) | 50 (18.07) | 55.25 (13.11) | 54.13 (17.22) | 1.35 | .26 | .03 |
| Activities and relationship with child with ASD | 38.92 (20.91) | 40.23 (18.42) | 38.75 (22.22) | 39.3 (20.35) | .04 | .96 | .00 |
| Psychological well-being | 54.83 (20.92) | 49.9 (15.31) | 50.51 (19.74) | 51.75 (18.73) | .59 | .55 | .01 |
| Personal fulfillment | 34.86 (21.99) | 33.84 (17.31) | 31.54 (23.79) | 33.42 (21) | .19 | .83 | .00 |

activities and relationships ($M = 51.54$, $SD = 21.45$), professional activities and relationships ($M = 47.88$, $SD = 28.85$), activities and relationships with the child with ASD ($M = 39.3$, $SD = 20.35$) and personal fulfilment ($M = 33.42$, $SD = 21$).

## 4. Discussion

The objective of this study was to explore the differences between French, French-Speaking Belgian and Quebec parents in terms of contextual and adjustment processes. Firstly, in terms of contextual and socio-demographic variables, the only significant difference found among parents concerned career changes due to their child's difficulties. Among the children, there were significant differences regarding the age when diagnosed, average school attendance, benefiting from private care services and the fact that their parents consider access to leisure activities as being sufficiently developed.

Data from the socio-demographic variables confirm that the disability associated with ASD creates socio-economic difficulties. For instance, three-quarters of parents report experiencing career changes because of the ASD, two-thirds did not work or only worked part-time when surveyed, and only half of parents perceive their income as sufficient to meet the needs of their child. We find that French parents are significantly more likely to perceive professional changes due to their child's ASD. International research explains these constraints as being related to access to care sometimes requiring parents to abandon their career (Rogier & Soete, 2014; Baker & Drapela, 2010; Kuhlthau et al., 2014; Myers, Mackintosh, & Goin-Kochel, 2009). Furthermore, more than one-third of parents surveyed reported having physical and/or mental health problems, and more than half felt that these problems were related to their child's autism. Health problems attributable to raising a child with ASD have already been recognized among English-speaking populations (Kuhlthau et al., 2014). Thus, the daily caregiving burden that the parents of this study experience can be questioned. Moreover, almost all parents in this study think that their child lacks autonomy and presents behaviours that disrupt everyday life. Literature shows that parents spend, on average, 1000 hours more per year than an ordinary family, caring for and educating their child with ASD (Järbrink, 2007). This information shows that the ASD generates a strain on the parents' daily life and confirms the necessity to offer parents respite time and care services adapted to their child's needs, if we want to avoid the risk of exhaustion among parents.

With regards to follow-up services and interventions provided for children, firstly, it can be noted that children are diagnosed significantly later in France. However, the screening process in France has been making progress with earlier screening and shorter waiting times (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011b). Moreover, French participants benefit from private care services significantly more, which can be explained by the fact that despite the evolution of the screening process, access to public institutions remains limited and waiting times are long, suggesting a lack of special needs structures for people with ASD (Chamak & Bonniau, 2013). Nevertheless, it is important to note that this problem also exists in Quebec and Belgium, where care services are difficult to access and a lack of follow-ups when transitioning between different services generates stress, exhaustion and disrupts the social and economic condition of families (Chamak, 2016; Parlement Wallon, 2017; Protecteur du citoyen, 2012; Rogier & Soete, 2014; Sénéchal & des Rivières Pigeon, 2009). The literature reveals that the supply of public services remains insufficient and pushes parents towards more expensive private options (Leduc, 2012; cited by Chamak, 2016). Lastly, regarding mainstream leisure activities and mainstream education, it remains a difficult topic for all parents. Less than half of the children have access to leisure activities in a mainstream setting. Children did not differ significantly in regards to attending mainstream schools, but more children had access to them in Quebec and French-speaking Belgium. In Quebec, regardless of class level and the severity of the disability, it is required that children have access to some form of full-time education (COPHAN, 1999; Office des personnes handicapées du Québec, 1982). In France, the average time of schooling per week is significantly lower. This corresponds to the data collected by the Autism Collective (Collectif Autisme, 2011), which estimates that the majority of children enrolled in mainstream schools are accommodated mostly on a part-time basis. Despite the efforts being made in schooling, social inclusion obviously still needs to be encouraged.

The results concerning the transactional variables, on the one hand, show that French parents significantly perceived their experience as a loss. The literature suggests that these parents' experiences

could indeed be related to a loss or threat to their future, such as job loss, reduced social activities, or even discontinuity in the child's trajectory (Bobet & Boucher, 2005). On the other hand, parents on average perceived more control over the evolution of their child's development than feeling responsible for appearance of the ASD. Even if parents have traditionally been made to feel guilty under the influence of the psychodynamic approach, the findings of this study favour an evolution, which is certainly possible thanks to professionals further recognising and valuing parental skills (Philip, 2009), as well as a revision of diagnostic criteria which can change representations and reduce stigma (Chamak, 2011a).

As for support, French parents seem to be able to count on more people although the intergroup variability remains important. Thus, we are able to better understand the different results from the coping variable. French parents search significantly less for social support. This type of strategy is also known to be linked to a better quality of life (Pottie & Ingram, 2008). Moreover, parents with a low quality of life are unsatisfied with the help provided by their entourage and are turning to associations, reflecting the lack of reassurance provided by their social network as a result of their network failing to acknowledge the disability (Altiere & von Kluge, 2009; Baeza-Velasco et al., 2013; Chamak & Bonniau, 2013). Many studies suggest that French parents seek associations and organisations because they are unsatisfied with the support offered by their social network, notably by professionals and public authorities (Chamak & Bonniau, 2013). Meetings and exchanges with others in the same situation promotes de-stigmatization (Asen, 2002). Moreover, it is important to mention that some parents of children with intellectual disabilities do not always seek out family support to avoid disrupting the family dynamics (Guay & Thibodeau, 2002).

Finally, the results show that quality of life is most altered during daily activities, which is also supported by the scientific literature (Baghdalli et al., 2014). French parents are generally more affected in all domains, compared to other parents, although there is no significant difference. The lack of difference between the parents shows that the French system has progressed, in fact parents are on average satisfied with the services provided for their child. Nevertheless, French parents seem to express significantly more needs, thus indicating that the efforts made so far must be maintained.

In terms of limits, the size and composition of the sample of each parent group is still too small for these results to represent an overall reality. Coupled parents, mothers, and parent members of associations were overrepresented in our sample. In addition, the participants were not randomly chosen, they were recruited via calls for participation. Parents who respond to this type of call are generally very motivated, dynamic and often highly committed to defending autism rights. Thus, they are probably not very representative of the sample population. Moreover, the recruitment periods did not occur at the same time for the three groups, instead they were spread out over a two-year period, and the manner in which the data was collected did not provide enough insight with regards to the variety of treatments offered to the children and their families. Furthermore, seven children lived in joint care and one child did not live with the surveyed parent. Lastly, quantitative methods limits access to a more detailed analysis of parents experience. For these reasons, the results and conclusions of this study should be considered with caution. Therefore, this study should be replicated whilst taking these limits into account It would also be relevant to conduct an in-depth socio-economic survey to compare the service systems offered in these three countries and to highlight the similarities and differences, as well as the strengths and weaknesses among each of the three contexts.

## 5. Conclusion

Overall, French parents perceived their situation more significantly as a loss, and expressed greater needs than other parents and had a daily life more altered by the ASD. Parents of children with ASD express difficulties that arise from different cultural perceptions of disability and access to care (Ravindran & Myers, 2012). Nevertheless, contextual and environmental variables and their effects on parental adjustment are less studied in the scientific literature (Derguy et al., 2016). Evaluating these factors within a socio-ecological framework should make it possible to better understand adaptation problems issued from dynamic and interdependent interactions between the individual components (social, cultural, economic and temporal characteristics) (Bronfenbrenner, 1979), upon which it would be relevant to work on.

## Ethical approval

All procedures performed in the study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments. This study received the approval from the Ethics committee of the Psychological Sciences Research Institute of the Catholic University of Louvain (*Commission d'éthique de l'institut de recherche en sciences psychologiques de l'Université Catholique de Louvain*), as well as from the Institutional ethical committee for research with human beings of the University of Quebec in Montreal (*Comité Institutionnel d'Ethique de la Recherche avec Etres Humains de l'Université du Québec à Montréal*). At the time of recruitment (2012–2014), it was not necessary to obtain the opinion of an ethical committee to carry out the recruitment in France.

## Informed consent

Informed consent was obtained from all individual participants included in the study. Participation was voluntary and participants received no financial compensation for taking part in the study.

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## Disclosure of interest

The authors declare that they have no competing interest.

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## Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.psfr.2018.11.002.

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