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Quality of life of French Canadian parents raising a child with autism spectrum disorder and effects of psychosocial factors

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Abstract

Purpose This study aimed to investigate the quality of life of parents of a child with autism spectrum disorder in Quebec.

Methods Seventy-seven participants completed a questionnaire with socio-biographic information and five self-assessed scales, to measure perceived stress, social support and control, coping strategies, and quality of life.

Results Perception of their child's autonomy level, of the severity of the disorder, of the family's income, as well as changes in their professional or familial organization influenced parents' quality of life. Perceiving their situation as a threat predicted poor quality of life, whereas satisfaction of social support predicted good quality of life. In addition, parents who used problem solving and support-seeking coping strategies had a better relationship with their child, whereas those who used more emotion-centered coping strategies struggled. Lastly, parents who felt they had the power to contribute to their child's development were more satisfied and less disturbed.

Conclusions Beyond the parents' actual situation, our results underscore the importance of paying attention to their own perception of the situation in order to provide them with appropriate support.

Keywords Autism spectrum disorder · Parents · Quality of life · Psychosocial variables

Introduction

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders [1], features of autism spectrum disorder (ASD) include persistent impairment in reciprocal social communication and social interaction, and restricted, repetitive patterns of behavior, interests, or activities. Prevalence of ASD approaches 1% and it is diagnosed four times more often in boys than in girls [1]. Since 2000–2001, there has been an average increase of 17% in ASD prevalence within the French Canadian population. In 2015–2016, prevalence reached 142 for 10,000 in Quebec, which means one child out of 70 was diagnosed with ASD. There were great regional variations: regions near Montreal had a prevalence three to four times higher than peripheral regions and sex ratio was 5:1 boys for a girl [2].

Symptoms are present from early childhood and limit or impair not only everyday functioning [1], but also hamper family quality of life [3, 4]. The quality-of-life construct offers the possibility to take an integrative and multifactorial approach, to capture a person as a whole [5]. Several studies have shown that characteristics of children with ASD and their parents, as well as environmental elements, have a significant impact on families' quality of life [6]. While they could help fill the gaps in our current knowledge regarding this population, studies with a multidimensional approach remain scarce [7–12].

Difficulties encountered by children with ASD affect all areas of parents' daily lives [4, 13–15]. The child requires specific care, which disrupts everyday life organization

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[16–18] and reduces the time dedicated to the couple [19, 20], family, and siblings [21–23]. Indeed, parents spend, on average, 1000 h more per year than an ordinary family, caring for and educating their child with ASD [17]. In the absence of respite services, this life organization affects parents' professional [19, 23–28], occupational [29], and social activities [23, 30, 31], as well as their physical and mental health [6, 15, 20, 24, 32–37]. For instance, mothers' renunciation to career prospects and/or fathers' overinvestment of professional activities are frequent [25]. Several parents report having little or no spare time for themselves, due to the energy required to care for their disabled child [23, 31]. Furthermore, parents refrain from taking part in social activities, out of fear they have to live the stigma of their child's invisible disability [23]. Parents therefore tend to value leisure activities that do not require public exposure [23, 30]. Moreover, it can be difficult for all family members to undertake ordinary activities together and be available for relatives [23]. Research on conjugal relationships shows that parents of a child with ASD are more likely to face marital conflicts on a daily basis, including tension and irritability with the partner [19, 20]. Lastly, it seems that mothers express more somatic complaints [32, 34] and experience more psychological distress than fathers [33–35, 37].

Children with ASD demonstrate behavioral specificities, such as sleep disorders, dietary inflexibilities, stereotyped behaviors, angry outbursts, and absence of social reciprocity, that impact the family's quality of life [4, 38]. More precisely, the child's sleep disorders affect parents' sleep quality and duration, resulting in irritability and impatience in their interactions with their child [39]. Dietary inflexibilities also generate several issues, for instance, cooking different meals for each family member [23, 40]. Other distinctive characteristics may impair families' quality of life, such as stereotyped behaviors, angry outbursts, and absence of social reciprocity [4, 24, 32, 36, 41]. Des Rivières-Pigeon et al. [19] reported that 56% of parents in their sample refrained from engaging the family in social activities, because of these behavioral specificities. In addition, lack of social reciprocity, behavioral disorders, and severity of symptoms can, in some cases, adversely affect mother–child relationship and attachment [42]. Parents' psychological distress and physical health are also linked to the severity of ASD symptoms, to its comorbidities, and to the child's age and behavioral disorders [32, 43, 44], even though some studies do not find that severity of autistic symptoms and parents' quality of life are linked [13, 14, 41].

The child's characteristics and his/her disorder fail to account for all parents' disturbances. Other factors, including environmental factors or personal parental characteristics are also involved [5]. First of all, parents who experience more stress have a poorer quality of life [14, 15]. Their well-being also greatly depends on their personal and social resources: some studies show that feeling efficient in the education of a child with ASD [24, 45], having a positive and optimistic view of the situation, feeling responsible for it, and in control [12, 46–49], as well as being able to count on a supporting and helping social network [4, 12, 24, 41, 45, 46, 50, 51] are associated with a better quality of life. Lastly, several studies investigating coping strategies in parents of a child with ASD showed that those centered on emotion are linked with a poorer quality of life [4, 52] and negative affects [50, 53–57]. Conversely, those centered on solving the problem or seeking social support seem more efficient [8, 54–56]. Yet, Lai and Oei [57] point out that many studies report significant links between emotion-centered strategies and well-being, but much fewer between problem-solving strategies and well-being.

Study objectives

Several studies have been carried out with French Canadian parents [19, 26, 27, 58], but none of them has taken into account psychosocial variables, such as perceived stress, perceived control, perceived social support, and coping strategies. Thus, the purpose of this study was to examine the effects of child and parents' personal characteristics, environmental characteristics, as well as psychosocial variables on the quality of life of French Canadian parents of a child with ASD. We used an integrative, multifactorial model based on a transactional approach of stress [59, 60] which takes into account subject–environment interactions and considers that an individual does not passively suffer the aversiveness of a stressful situation, but instead actively develops perceptual-cognitive, emotional, and behavioral strategies to cope with it. According to this model, quality of life is considered as an adaptive outcome influenced by personal history and transactional psychosocial variables (i.e., perceived stress, perceived control, perceived social support, and coping strategies).

Methods

Participants

Overall, 77 parents participated in this study: 71 mothers, five fathers, and one individual of unspecified gender. They were, on average, 40.49 years old ($SD=6.29$; $Min=29$ and $Max=56$). They were recruited through a private clinic specialized in ASD (46.5%), by the psychologist in charge of children's follow-up, as well as through a call for participation posted on the "*Fédération Québécoise de l'Autisme*" website ($n=53.5\%$).

At the time of recruitment, most parents lived with a partner (85.6%). They worked full-time (45.5%) or part-time (33.8%). The child's difficulties had led more than two-thirds of participants (70.1%) to experience changes in their professional activity. Moreover, 45.6% had changed the way they organized family life with their partner. They had on average one other child, in addition to their child with ASD ($M=1.31$; $SD=0.57$; $Min=0$ and $Max=3$). A little less than half the parents (46.8%) reported physical or psychological health problems. Among them, 45% felt that these were quite, or very disturbing. Furthermore, 56.8% of those who reported health problems indicated that these were linked to their child's difficulties. The family's annual income was inferior to $80,000 for 48.1% of participants. Nevertheless, most of them (68.1%) thought their income was sufficient to fulfill the needs of their child with ASD.

Their children (87% boys and 13% girls) were, on average, 9.62 years old ($SD=3.47$; $Min=2.16$ and $Max=18.17$): 14.3% were under 6 years of age, 27.3% between 6 and 9, 33.8% between 9 and 12, and 24.7% over 12. According to their parents, almost two-thirds of children (61%) presented associated disorders and 53.9% took medication. On average, children had been diagnosed at the age of 4.36 years ($SD=2.06$; $Min=1.58$ and $Max=12.33$); 35.1% under 3, 44.6% between 3 and 6, and 20.3% over 6. Again according to their parents, 22.4% were as autonomous as most children of their age, 38.2% less autonomous, 25% a lot less autonomous, and 14.5% totally dependent on adults for their daily activities. In addition, most children had acquired diurnal (83.1%) and nocturnal (80.5%) toilet training. Most of them had access to oral language (87%). One-third (32.5%) used an alternative communication system, based on pictograms, images, and/or signs (e.g., PECS, Baby signs, LSQ). Overall, most parents (88.2%) felt their child had disturbing behaviors.

Materials

We asked each participant to fill out a questionnaire containing usual socio-biographic data, in order to assess personal characteristics, as well as the way they perceive their child's difficulties. In addition, we used five self-assessment scales, which had previously been validated with a population of French parents of a child with ASD [61–64].

Perceived stress

The French adaptation of the Appraisal of Life Events Scale (ALES; [64, 65]) was built to operationalize the notion of "primary evaluation" and the dimensions of perceived stress (threat, loss, and challenge) described by Lazarus and Folkman [60]. The French adaptation [64] has satisfactory psychometric properties. This scale includes 16 items consisting in adjectives that describe how parents perceive their situation. Each item is rated on a 5-point Likert scale, ranging from 0 ("not at all") to 5 ("extremely"). Three scores can be calculated. The "experience perceived as a threat" score ranges from 0 to 30, the "experience perceived as a loss" score ranges from 0 to 20, and the "experience perceived as a challenge" score ranges from 0 to 30. For all three scores, the higher the score, the more parents perceive their situation as a threat, a loss, or a challenge. In our sample, there was a good internal consistency for these three factors, with Cronbach alphas of 0.84, 0.86, and 0.84, respectively.

Perceived control

The French adaptation of the Cancer Locus of Control Scale (CLCS [66]; French validation: [67]) was originally designed for patients suffering from cancer, to measure their feeling of control over the disease. This scale was adapted to our study's situation, in order to determine the feeling of control parents have over their child's situation (for more details concerning this adaptation, see [62]). Respondents had to indicate their degree of agreement with each of the 17 items on a 4-point scale ranging from 0 ("totally disagree") to 3 ("totally agree"). This adaptation has satisfactory psychometric properties [62], and gives three scores of perceived control. The first reflects "perceived control over the onset of the disorder" (internal causality attribution score) and ranges from 0 to 15. The higher the score, the more parents feel responsible for the onset of their child's disorder. The second score reflects the parents' "perceived control over the child's development." It ranges from 0 to 18: a higher score meaning that parents feel they can help their child to develop, either with their own resources, or with external resources. Lastly, the third score reflects "irrational beliefs regarding the disorder" and ranges from 0 to 9. The higher the score, the more the parent puts the onset of the child's disorder and his/her development down to "irrational" causes. Internal consistency for these three factors within our study sample was good, with Cronbach alphas of 0.72, 0.64, and 0.70, respectively.

Perceived social support

We also used the French Perceived Social Support Questionnaire (QSSP; [68]), which assesses the availability (number of people) and quality (level of satisfaction regarding the assistance obtained) of perceived social support. First, the participant has to tick every category of people (colleagues, friends, family, professionals) that provide him/her with emotional, informative, esteem, and material or financial supports and specify the number of people for each category. Second, he/she has to rate his level of satisfaction regarding the support obtained on a

6-point Likert scale, ranging from 0 (“very unsatisfied”) to 5 (“very satisfied”). Thus, one can calculate two scores. The first can be obtained by adding up the number of people cited: the higher the score, the greater the number of people the parent can rely on for help. The sum of the satisfaction scores for the four types of supports reflects “satisfaction regarding social support” and ranges from 0 to 20. The higher the score, the more parents are satisfied with the help they get from their circle. Internal consistency for these two factors within our study sample was good, with Cronbach alphas of 0.80 and 0.60, respectively.

Coping strategies

The French adaptation of the Ways of Coping Checklist—Revised (WCC—R [69]; French validation: [70]) allowed us to assess the coping strategies participants used to face stress, whether focused on problem solving (e.g., efforts, action plan), emotion (e.g., avoidance, guilt, disengagement), and search for social support (e.g., informative, financial, emotional). Instructions for this scale were adapted to the study situation, in order to assess the coping strategies parents used to face the stress induced by their child’s ASD [62]. The parent had to rate his/her degree of agreement with each of the 27 propositions, on a 4-point Likert scale ranging from 0 (“no”) to 3 (“yes”). This scale allowed us to compute three scores of coping. The “problem-solving coping” and “emotion-focused coping” scores range from 0 to 27, and the “social support seeking” score ranges from 0 to 21. For all three scores, the higher the score, the more parents use problem-solving, emotional, or social support-seeking coping strategies. Internal consistency for these three factors within our study sample was good, with Cronbach alphas of 0.80, 0.80, and 0.74, respectively.

Quality of life

Lastly, quality of life was assessed using a scale developed for parents of children with ASD [61, 62], which allows an evaluation in seven areas: (1) “daily life activities” ($\alpha = 0.92$); (2) “professional relationships and activities” ($\alpha = 0.75$); (3) “social relationships and activities” ($\alpha = 0.94$); (4) “family and couple relationships and activities” ($\alpha = 0.91$); (5) “relationships and activities with the child with ASD” ($\alpha = 0.80$); (6) “psychological well-being” ($\alpha = 0.92$) ; and (7) “personal fulfillment” ($\alpha = 0.85$). The parent is invited to give his/her degree of agreement for each of the 102 propositions, using a 4-point Likert scale ranging from 0 (”totally disagree”) to 3 (“totally agree”). In this scale, scores reflect the intensity of repercussions of the child’s difficulties on parents’ lives: higher scores reflect stronger repercussions and thus poorer quality of life.

Analysis

In order to avoid unnecessary duplication of information, strongly correlated subscores were merged into a single subscore. According to Cohen [71], a correlation inferior or equal to 0.30 is weak, one between 0.30 and 0.50 is moderate, and one superior to 0.50 is strong. Thus, quality-of-life subscores regarding “daily life activities,” “professional activities and relationships,” “social activities and relationships,” and “psychological well-being” were merged into a single score named “quality of life” ($\alpha = 0.89$), ranging from 0 to 249, for these subscores were strongly correlated (Table 1). Quality-of-life subscores, regarding “activities and relationship with the child with ASD” ($\alpha = 0.80$) and

Table 1 Correlation matrix between the subscores of the quality-of-life scale

	DLA	PRA	SRA	FRA	RAC	PWB	PF
Daily life activities (DLA)	1						
Professional relationships and activities (PRA)	0.57***	1					
Social relationships and activities (SRA)	0.82***	0.56***	1				
Family relationships and activities (FRA)	0.78***	0.59***	0.74**	1			
Relationships and activities with the child with ASD (RAC)	0.25*	0.13	0.29*	0.40***	1		
Psychological well-being (PWB)	0.62***	0.51***	0.57***	0.66***	0.43***	1	
Personal fulfillment (PF)	−0.21	−0.23*	−0.09	−0.15	0.26*	0.05	1

DLA daily life activities, *PRA* professional relationships and activities, *SRA* social relationships and activities, *FAR* family relationships and activities, *RAC* relationships and activities with the child with ASD, *PWB* psychological well-being, *PF* personal fulfillment

*$p < 0.05$

**$p < 0.01$

***$p < 0.001$

"personal fulfillment" ($\alpha = 0.85$) were examined separately, for correlations with other quality-of-life subscores were weak to moderate (Table 1). Similarly, subscores "experience viewed as a threat" ($\alpha = 0.84$) and "experience viewed as a loss" ($\alpha = 0.86$) of the ALES were very strongly correlated ($r = 0.75$, $p < 0.001$) and were therefore merged into a single subscore "experience viewed as a threat and a loss" ($\alpha = 0.84$), ranging from 0 to 50.

We carried out variance analyses (Fisher–Snedecor F), followed by post hoc tests, to assess the effects of children and parents' personal characteristics on quality of life. We also carried out correlations, followed by multi-variable linear regressions. We tested two regression models for each of the three dependent variables (DV): independent variables (IV) that were significantly correlated with the DV at a threshold of 0.01 were included in the first model, then those that were correlated with the DV at a threshold of 0.05 were added to the second model [72, 73]. This allowed us to highlight the links and predictive weights of perceived stress, perceived control, perceived social support, and coping strategies on quality of life.

Results

Table 2 presents the means and standard deviations of participants' subscores for the different assessment scales.

Results show that the way parents perceived their child's difficulties had a significant effect: quality of life varied according to the presence of associated disorders ($F(1, 75) = 7.38$, $p < 0.01$, $\eta^2 = 0.09$) and the child's autonomy level ($F(3, 72) = 11.31$, $p < 0.001$, $\eta^2 = 0.32$). Whether the child took a course of medication and his/her autonomy level influenced the "relationships and activities with the child with ASD" score ($F(1.74) = 7.54$, $p < 0.01$, $\eta^2 = 0.09$ and $F(1, 72) = 3.49$, $p < 0.05$, $\eta^2 = 0.13$, respectively) (Table 3).

Having undergone professional changes linked to the child's disorder significantly affected quality of life ($F(1, 75) = 14.11$, $p < 0.001$, $\eta^2 = 0.16$), and so did having experienced changes in the organization of family life with their partner ($F(1, 66) = 4.04$, $p < 0.05$, $\eta^2 = 0.06$). In addition, the family's annual income and the way it was perceived to respond to the child's specific needs, significantly affected quality of life ($F(1, 75) = 10.19$, $p < 0.001$, $\eta^2 = 0.12$ and $F(1, 70) = 7.82$, $p < 0.01$, $\eta^2 = 0.10$, respectively) (Table 4).

As for the analysis of links (Table 5), our results revealed moderate significant positive correlations between quality-of-life subscore and the following subscores: "experience viewed as a threat and a loss" of perceived stress ($r = 0.43$, $p < 0.001$) and "emotion-focused" of coping strategies ($r = 0.36$, $p < 0.01$). Weak significant negative correlations were noted between "quality of life" and "feeling of control regarding the evolution of the child's development" of perceived control ($r = -0.23$, $p < 0.05$), and "satisfaction of support" of social support ($r = -0.28$, $p < 0.05$).

These variables accounted for 24.1% of variance in the "quality-of-life" score ($F(4, 72) = 7.02$, $p < 0.001$) (Table 6). However, only the subscores "experience viewed as a threat and a loss" of perceived stress ($\beta = 0.27$, $t = 2.29$, $p < 0.05$), "emotion-focused" of coping strategies ($\beta = 0.23$, $t = 2.16$, $p < 0.05$) , and "satisfaction of support" of social support ($\beta = -0.23$, $t = 2.22$, $p < 0.05$) had significant predictive weights.

On the one hand, the "activities and relationship with the child with ASD" score was moderately positively correlated with the subscores "experience viewed as a threat and a loss" of perceived stress ($r = 0\ .34$, $p < 0.01$), and "emotion-focused" of coping strategies ($r = 0.42$, $p < 0.001$). On

Table 2 Means and standard deviations of the participants' subscores for the different assessment scales ($N = 77$)

	Min	*Max*	*M*	*SD*
ALES—Experience perceived as a threat and a loss	0	50	20.52	10.51
ALES—Experience perceived as a challenge	0	29	14.96	6.41
CLCS—Feeling of control over the onset of the disorder	0	10	1.74	2.35
CLCS—Feeling of control regarding the evolution of the child's development	5	18	14.61	2.48
CLCS—Irrational beliefs regarding the disorder	0	8	1.10	1.81
QSSP—Availability of social support	2	54	18.21	12.41
QSSP—Satisfaction of social support	2	20	13.27	3.47
WCC—Problem-solving coping strategies	6	27	17.65	4.98
WCC—Emotion-focused coping strategies	0	27	11.75	5.87
WCC—Seeking social support coping strategies	0	21	14.05	4.42
Relationships and activities with the child with ASD	0	17	7.36	3.95
Personal fulfillment	0	26	9.51	5.24
Quality of life	5	221	117.47	47.56

Min minimum, *Max* maximum, *M* mean, *SD* standard deviation

Table 3 Means (*M*) and standard deviations (*SD*) for the three subscores of quality of life according to the child's characteristics

	Relationships and activities with the child with ASD							Personal fulfillment					Quality of life					
	N	*M*	*SD*	*F*	*p*	η^2	*Post hoc*	*M*	*SD*	*F*	*p*	η^2	*M*	*SD*	*F*	*p*	η^2	*Post hoc*
Age group																		
< 6 yrs	11	7.27	3.29	0.51	0.68	0.02	–	11	7.21	0.34	0.79	0.01	118.64	28.30	0.62	0.6	0.02	–
6–9 yrs	21	7.67	4.14					9.14	3.23				128.48	37.57				
9–12 yrs	26	6.65	3.72					9.27	5.81				109.5	53.58				
> 12 yrs	19	8.05	4.5					9.37	5.2				115.53	57.57				
Age of diagnosis[a]																		
≤ 3 yrs	26	7.04	3.89	0.2	0.82	0.01	–	9.23	6.67	1.33	0.27	0.04	124.08	43.18	0.72	0.49	0.02	–
3–6 yrs	33	7.7	4.51					9.18	4.53				109.03	49.97				
> 6 yrs	15	7.4	2.8					11.67	3.5				116.73	51.36				
Course of medication[b]																		
Yes	35	8.54	3.61	7.54	0.008**	0.09	–	10.29	5.24	1.84	0.18	0.02	128.07	45.84	3.82	0.05	0.05	–
No	41	6.17	3.89					8.66	5.24				107.34	46.41				
Related disorders																		
Yes	47	7.94	3.78	2.59	0.11	0.03	–	9.49	4.93	0.00	0.97	0.00	128.77	48.39	7.38	0.008**	0.09	–
No	30	6.47	4.1					9.53	5.78				99.77	41.03				
Autonomy[b]																		
None	11	10	3.69	3.49	0.02*	0.13	1 > 4	7.18	4.42	2.39	0.76	0.09	158.82	43.6	11.31	0.000***	0.32	1 > 3
A lot less	19	7.84	3.15					10.53	4.91				133.32	44.94				1 > 4
Less	29	7.31	3.94					8.55	3.97				114.52	35.68				2 > 4
As much	17	5.35	4.18					11.71	6.71				75.12	38.84				3 > 4

*$p < 0.05$

**$p < 0.01$

***$p < 0.001$

[a] Three data missing for this variable

[b] One data missing for these two variables

the other hand, this same subscore of quality of life was weakly to moderately negatively correlated with the subscores "experience viewed as a challenge" of perceived stress ($r = -0.43$, $p < 0.001$), "feeling of control regarding the evolution of the child's development" of perceived control ($r = -0.28$, $p < 0.05$), and "problem solving" of coping strategies ($r = -0.35$, $p < 0.01$) (Table 5). These variables accounted for 31.3% of "activities and relationship with the child with ASD" score variance ($F(5, 71) = 7.93$, $p < 0.001$) (Table 6). Nevertheless, only the subscores "emotion-focused" of coping strategies ($\beta = 0.29$, $t = 2.80$, $p < 0.001$) and "experience viewed as a challenge" of perceived stress ($\beta = -0.27$, $t = -2.51$, $p < 0.05$) had significant predictive weights.

Finally, "personal fulfillment" was moderately negatively correlated with the subscores "experience viewed as a challenge" of perceived stress ($r = -0.42$, $p < 0.001$), "problem solving" of coping strategies ($r = -0.48$, $p < 0.001$), and "seeking social support" of coping strategies ($r = -0.30$, $p < 0.01$) (Table 5). These variables accounted for 26.4% of the "personal fulfillment" score variance ($F(3, 73) = 10.09$, $p < 0.001$) (Table 6). Nevertheless, only the subscores "problem solving" of coping strategies ($\beta = -0.32$, $t = -2.6$, $p < 0.05$) and "experience viewed as a challenge" of perceived stress ($\beta = -0.27$, $t = -2.48$, $p < 0.05$) had significant predictive weights.

Discussion

The aim of this study was to assess quality of life of French Canadian parents of a child with ASD, with a particular focus on psychosocial factors. With regard to the child's characteristics, our results showed that parents who reported that their child had associated disorders or took a course of medication had a poorer quality of life. In this respect, the report of the National Excellence Institute for Health and Social Services [74] states that one-third of French Canadian children with ASD take a course of medication for one or several associated disorders. In our study, parents' quality of life varied with their perception of their child's level of adaptive functioning, with greater implications for parents

Table 4 Means (*M*) and standard deviations (*SD*) for the three subscores of quality of life according to the parents' characteristics

	Relationships and activities with the child with ASD						Personal fulfillment					Quality of life				
	N	*M*	*SD*	*F*	*p*	η^2	*M*	*SD*	*F*	*p*	η^2	*M*	*SD*	*F*	*p*	η^2
Working time																
No activity	16	6.63	3.84	0.47	0.628	0.01	7.75	4.28	1.21	0.302	0.03	119.62	48.03	3.67	0.693	0.01
Part-time	26	7.85	4.77				10.27	5.95				122.85	51.44			
Full-time	35	7.34	3.33				9.74	5.34				117.47	45.21			
Professional changes																
Yes	54	7.7	4.02	1.2	0.276	0.02	9.5	4.7	0.00	0.987	0.00	129.74	44.27	14.11	0.000***	0.16
No	23	6.61	3.75				9.52	6.47				88.65	43.08			
Changes within the parental couple[a]																
Yes	31	7.39	4.16	0.00	0.993	0.00	9.13	5.33	0.17	0.680	0.00	132.1	45.89	4.04	0.049*	0.06
No	37	7.38	4.05				9.65	5.01				109.65	45.89			
Yearly income																
< 80,000 ($)	37	6.95	3.86	0.8	0.375	0.01	8.54	4.9	2.46	0.121	0.03	134.46	42.87	10.19	0.002**	0.12
> 80,000 ($)	40	7.75	4.04				10.4	5.45				101.75	46.73			
Sufficient income[b]																
Yes	49	7.98	3.89	2.86	0.095	0.04	10.43	5.56	3.02	0.087	0.04	105.16	48.41	7.82	0.007**	0.1
No	23	6.35	3.66				8.13	4.45				136.96	36.37			
Health problems																
Yes	36	7.42	3.32	0.01	0.913	0.00	8.69	4.86	1.63	0.205	0.02	124.36	47.46	1.43	0.236	0.02
No	41	7.32	3.64				10.22	5.52				111.41	47.46			

*$p < 0.05$

**$p < 0.01$

***$p < 0.001$

[a] Nine data missing for this variable

[b] Five data missing for this variable

whose child was not autonomous. These data are in line with previous findings showing that the severity of the child's symptoms affects parents' stress levels [32, 75, 76] and that parents' concerns are linked to their child's social skills [77].

As to the parents' characteristics, our data showed that parents who had to reorganize their professional activities and to change the way they organized family life with their partner to care for their child had a poorer quality of life. This supports the findings of Courcy and des Rivières-Pigeon [58], who conducted a qualitative study with French Canadian parents, and showed that family–work balance was more difficult for parents of a child with ASD than for parents of a typically developing child. Moreover, several studies showed that a child with ASD requires specific care that disrupts family life [17, 18, 31]. Families' annual income and whether this income was perceived as satisfactory to fulfill the child's needs, also affected participants' quality of life. Parents with lower incomes experienced more difficulties and those who considered their income insufficient to respond to their child's needs had a poorer quality of life. The study of des Rivières-Pigeon et al. [19] carried out with French Canadian parents, reported similar findings. Studies examining populations of other nationalities confirmed the influence of the economic variable, associated to raising a child with ASD, on parental stress and quality of life (e.g., [77–79]).

In addition, the more participants perceived their experience as a threat and a loss, the more it affected their quality of life. This result is in line with the literature that shows that parents who experience higher stress levels have a poorer quality of life [14, 15]. Conversely, participants who considered their experience as a challenge had less conflicting relationships with their child and were more content. This result is consistent with previous findings, underscoring the positive effects of parenting a child with ASD on the family's capacity for resilience [26, 80–82].

Moreover, it appeared that the more participants felt responsible for the manifestations of their child's disorder, the more they struggled. The literature provides evidence that the more parents contribute to their child's stimulation, the less psychologically disturbed they are and the better their relationship with their child is [12, 24, 35, 45–48, 83]. Our results go further, for parents who considered having the ability to help their child also had fewer difficulties in

Table 5 Correlation matrix between the three subscores of quality of life and subscores of perceived stress, perceived control, perceived social support, and coping strategies

	ALES—Threat and Loss	ALES—Challenge	CLCS—ASD onset	CLCS—Child's development	CLCS—Irrational beliefs	QSSP—Availability	QSSP—Satisfaction	WCC—Problem	WCC—Emotion	WCC—Seeking social support	Relationships and activities with the child with ASD	Personal fulfillment	Quality of life
ALES—Threat and Loss	1												
ALES—Challenge	−0.25*	1											
CLCS—ASD onset	0.07	0.04	1										
CLCS—Child's development	−0.42***	0.09	−0.04	1									
CLCS—Irrational beliefs	0.00	0.04	0.08	0.01	1								
QSSP—Availability	−0.07	0.21	0.21	0.11	−0.06	1							
QSSP—Satisfaction	−0.18	0.07	0.08	−0.05	0.24*	0.24*	1						
WCC—Problem	−0.23*	0.41***	0.04	0.17	0.26*	0.14	0.41***	1					
WCC—Emotion	0.37**	−0.21	0.16	−0.23*	0.10	−0.03	−0.04	−0.10	1				
WCC—Social support	−0.04	0.17	−0.06	0.06	0.19	0.31**	0.35**	0.49***	−0.06	1			
Relationships and activities with the child with ASD	0.34**	−0.43***	0.10	−0.28*	0.13	−0.04	−0.14	−0.35**	0.42***	−0.03	1		
Personal fulfillment	0.19	−0.42***	0.01	−0.18	−0.14	−0.17	−0.11	−0.48***	0.16	−0.30**	0.26*	1	
Quality of life	0.43***	−0.01	0.13	−0.23*	−0.07	−0.09	−0.28*	−0.05	0.36**	0.04	0.37**	−0.14	1

ALES—Threat and Loss experience perceived as a threat and a loss, *ALES—Challenge* experience perceived as a challenge, *CLCS—ASD onset* feeling of control over the onset of the disorder, *CLCS—Child's development* feeling of control regarding the evolution of the child's development, *CLCS—Irrational beliefs* irrational beliefs regarding the disorder, *QSSP—Availability* availability of social support, *QSSP—Satisfaction* satisfaction of social support, *WCC—Problem* problem-solving coping strategies, *WCC—Emotion* emotion-focused coping strategies, *WCC—Seeking social support* seeking social support coping strategies

$^{*}p < 0.05$

$^{**}p < 0.01$

$^{***}p < .0001$

Table 6 Synthesis of the multiple linear regressions carried out on the three quality-of-life subscores

Predicted variables	Model	IV	*ß*	*t*	*p*
Quality of life	Model 1[a]	ALES–Threat and Loss	0.34	3.12	0.003**
		WCC—Emotion	0.23	2.14	0.036*
	Model 2[b]	ALES—Threat and Loss	0.27	2.29	0.025*
		WCC—Emotion	0.23	2.16	0.034*
		CLCS—Child's development	− 0.07	− 0.63	0.533
		QSSP – Satisfaction	− 0.23	− 2.22	0.030*
Relationships and activities with the child with ASD	Model 1[c]	ALES–Threat and Loss	0.12	1.18	0.243
		ALES–Challenge	− 0.26	− 2.44	0.017*
		WCC – Problem	− 0.18	− 1.71	0.091
		WCC—Emotion	0.3	2.93	0.005**
	Model 2[d]	ALES–Threat and Loss	0.08	0.67	0.504
		ALES—Challenge	− 0.27	− 2.51	0.014*
		WCC – Problem	− 0.17	− 1.59	0.116
		WCC—Emotion	0.29	2.8	0.007**
		CLCS—Child's development	− 0.13	− 1.2	0.23
Personal fulfillment[f]	Model 1[e]	ALES—Challenge	− 0.27	− 2.48	0.015*
		WCC—Problem	− 0.32	− 2.6	0.011*
		WCC—Seeking social support	− 0.1	− 0.89	0.379

ALES—Threat and Loss experience perceived as a threat and a loss, *ALES—Challenge* experience perceived as a challenge, *CLCS—Child's development* feeling of control regarding the evolution of the child's development, *WCC—Problem* problem-solving coping strategies, *WCC—Emotion* emotion-focused coping strategies, *WCC—Social support* seeking social support coping strategies

*$p < 0.05$

**$p < 0.01$

[a] $R^2 = 0.210$, $F(2, 74) = 11.09$, $p < 0.001$

[b] $R^2 = 0.241$, $F(4, 72) = 7.02$, $p < 0.001$

[c] $R^2 = 0.309$, $F(4, 72) = 9.49$, $p < 0.001$

[d] $R^2 = 0.313$, $F(5, 71) = 7.93$, $p < 0.001$

[e] $R^2 = 0.264$, $F(3, 73) = 10.10$, $p < 0.001$

[f] Only one model was tested for this variable, for significant correlations were all above 0.01

their activities and relationship with him/her. Thus, parents' capacity to face their child's disorder depended on their feeling of parenting competence [84, 85]. Furthermore, our results showed that the more satisfied parents were with the support they got from relatives and professionals, the better their quality of life, which is also in line with the literature [86, 87]. This last point deserves particular attention when professionals implement interventions [88].

As regards coping strategies, our results showed that parents who focused on their emotions to face the situation struggled more to pursue their everyday activities and had a more disturbed relationship with their child with ASD. On the contrary, parents who used coping strategies that aim to solve the problem or seek social support had better relationships with their child and were more content. In this respect, several studies have reported that emotion-focused coping strategies are only efficient on the short-term, for redirecting internal tensions is necessary before taking action, but not on the long-term, for they divert attention from the problem and can lead to avoidance behaviors or denial [59]. Similar results can be found in the area of ASD, showing that emotion-focused coping strategies are linked to greater psychosocial difficulties for the parents, whereas problem-solving coping strategies are linked to more successful adaptation [8, 53–56, 62, 76, 89].

Limitations

This study has several limitations, including a recruitment bias. Parents were recruited through a private practice and an association, so our sample was not representative of all French Canadian parents of a child with ASD. In our sample, the unbalanced numbers of mothers and fathers did not allow us to assess the differences generally observed in the literature [48, 90]. In addition, we called on parents' perception for the evaluation of children's characteristics, with regards to behavior and development, and did not have more objective data from standardized evaluations, which could have complemented the existing data. However, it would be inappropriate to disqualify a person's subjectivity, *i.e.*, the internal and individual experience, when studying quality of life, which is by definition a subjective construct [5]. Lastly, studies investigating the situation of French Canadian parents are scarce [19, 26, 27, 58], and none had previously used a transactional approach. Thus, despite being based on a relatively small sample, our study provides valuable findings that can help develop and implement support tailored for this population's specific needs.

Conclusion and practical implications

In conclusion, this study provides further evidence to better understand adaptive psychosocial profiles of parents of a child with ASD in Quebec. Moreover, the results highlight the importance of providing interventions that aim to develop autonomy in the child, but also of considering the way parents perceive their situation and their child's difficulties, in order to give them appropriate support and information. Thus, the parents–professionals partnership should be based on appropriation of knowledge and self-determination, for it leads parents towards autonomy and fosters their confidence in their own resources [91]. In this respect, des Rivières-Pigeon et al. [19] recommend developing practical support measures for parents. As an example, they point to intensive behavioral interventions offered within the family environment. Sabourin et al. [92] mentioned that professionals who use this type of intervention play several roles: they deal with the child, give parents the tools they need for their interventions, and provide emotional support. Moreover, it is necessary to help parents feel and identify their emotions before they can solve problematic situations. Support programs for parents, aiming to develop cognitive restructuration strategies and problem solving, should be updated [62, 88]. Several such programs have been developed for French-speaking parents in Quebec [93, 94]. It is also important to take into account the parents' socio-economic situation, to make sure they do not end up in a precarious situation that could increase the family's difficulties. An ongoing comparative study including French, French Canadian, and French Belgian parents should, in the near future, allow us to improve our understanding of cultural contexts [95].

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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 Institutional ethical committee for research with human beings (CIEREH) of the University of Quebec in Montreal, as well as from the Ethical committee of joint research for the Centre for rehabilitation in intellectual disability and pervasive developmental disorder (CRDITED).

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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