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ORIGINAL PAPER

Quality of Life in Immigrant Parents of Children With Autism Spectrum Disorder: A Comparison With Parents From the Host Culture

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Abstract

Objectives Studies conducted on families of children with autism spectrum disorder (ASD) indicate that the period following the child's diagnosis can be challenging, especially for immigrant families. Indeed, they tend to have additional difficulties in accessing and using ASD diagnosis and early intervention services. To date, few studies have contrasted the experiences of immigrant and native families.

Method During the period following their child's ASD diagnosis, 104 immigrant and Canadian-born mothers and fathers completed the Beach Center FQOL Scale and provided ratings of perceived support.

Results Immigrant families were less satisfied with their FQOL than Canadian-born parents, but no gender differences were observed. However, gender and immigration-status related patterns emerged with respect to the relative importance and satisfaction levels across dimensions of FQOL. Additionally, fewer immigrant families reported having access to external support, a predictor of FQOL, than Canadian families.

Conclusion Although no statistically significant gender differences emerged, patterns in the data suggest that each parent may benefit from different services. Overall, these findings highlight the importance of developing programs that take into account parents' gender and cultural background and provide means of developing external support networks.

Keywords Autism spectrum disorder · Family quality of life · Parenting · Immigrant families

Early childhood can be a particularly stressful time in a family's life because it entails multiple adjustments and potential role conflicts (Williford et al. 2007). This period may be especially difficult for parents of a child with ASD, a situation which introduces additional stressors and adjustment challenges (Baker-Ericzen et al. 2005; Blacher and McIntyre 2006; Mugno et al. 2007). The diagnosis itself may be experienced as a shock, but also launches a demanding process in which parents must research and request access to professional support and services to promote the child's well-being and development (Poirier and Goupil 2008; Roth et al. 2016). Families of children with ASD face more difficulties in various spheres of life (e.g., in terms of finances, mental health, social relationships, employment), and greater challenges in accessing diagnostic and intervention services for their child than those of children with any other condition (Brookman-Frazee et al. 2012; Families Special Interest Research Group of the International Association for the Scientific Study of Intellectual and Developmental Disabilities [FSIRG-IASSIDD] 2012). Indeed, the defining symptoms and features of ASD, such as communication and behavioral difficulties, as well as associated characteristics such as sleep or eating problems, can be a substantial source of stress and fatigue among family members (Cappe et al. 2014; Hodgetts et al. 2013; Hoffman et al. 2008). Among immigrant families, these issues may be compounded by a lack of familiarity with their host country's healthcare system, language barriers, or different beliefs regarding ASD (FSIRG-IASSID 2012; Klingner et al. 2009; Magaña et al. 2013). To date, the majority of studies on ASD have focused on White,

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English-speaker and affluent families, with data on parents' perspective being primarily collected among mothers (Daley and Sigman 2002; Davis and Carter 2008; FSIRG-IASSIDD 2012). Thus, a number of families and family members (e.g., fathers) are not well represented in the literature.

Despite evidence that families of children with ASD may experience heightened mental health risks during the early childhood period, relatively few studies have examined family adjustment during this period specifically (Brookman-Frazee et al. 2012; Dabrowska and Pisula 2010). Studies on this topic have to date tended to focus on parenting stress (Dabrowska and Pisula 2010; McStay et al. 2014). There has also been growing momentum in the field to examine the positive aspects of caring for a child with ASD and factors that may exert a beneficial influence on families' quality of life (Meral et al. 2013; Schlebusch et al. 2017; Vasilopoulou and Nisbet 2016). In keeping with this new focus, the concept of family quality of life (FQOL) provides a means of investigating and assessing the experience of families of a child with a given condition or disability, in order to maximize protective factors (Brown et al. 2003; Dunst and Bruder 2002; Park et al. 2003; Summers et al. 2005).

FQOL is said to be present when a family perceives that all family members' needs are met, enjoy their family life, and are able to participate in activities that are important to them within their community (Park et al. 2003; Turnbull et al. 2007). There has been a growing awareness of the importance of including family-focused measures in program evaluation and in studying services provided to families (Brown et al. 2003; Dunst and Bruder 2002; Park et al. 2003; Summers et al. 2005). Thus, construct of FQOL can serve as an indicator of the impact of policies and initiatives on the family unit (Hoffman et al. 2006; Park et al. 2003). This concept stems from quality of life (QOL), which refers to a person's appraisal of their situation (The World Health Organization Quality of Life Group [WHOQOL] 1994) and includes dimensions such as emotional, physical and material well-being, interpersonal relationships, and personal growth (Hoffman et al.2006; Schalock et al. 2002). However, a person's perception of these dimensions, and thus their satisfaction with their QOL or FQOL, is shaped by their culture, values, and expectations (WHOQOL 1994). Assessing FQOL enables service providers to adapt their offerings to each families' priorities and needs.

During the post-diagnosis period, families experience a range of negative emotions such as denial and anger (Corcoran et al. 2015). Furthermore, the complexity of a child's ASD diagnosis and the many changes (e.g., social, economic) it entails can alter family members' roles and responsibilities and, in turn, their adjustment (Gardiner and Iarocci 2012; Petalas et al. 2012). Living with a child with ASD has substantial impacts on family life, namely on parents' well-being, personal life (marital, social, professional, leisure), and interactions with each other and on the family's income and resources (Brookman-Frazee et al. 2012; Donaldson et al. 2011).

On an economic level, mothers of children with ASD frequently experience employment-related challenges such as recurring absences or an inability to hold full-time employment (Gray 2002). Additionally, the child will require a range of professional interventions and services specific to ASD or to co-occurring physical or mental health conditions (Matson and Nebel-Schwalm 2007; Parellada et al. 2013; Roth et al. 2016). Even in regions where free or subsidized supports are available to families of children with ASD, lengthy waiting periods and insufficient public resources entail that some families will elect to pay out of pocket for services by private providers (Sharpe and Baker 2007). These substantial expenses incurred by the family may impact all family members' standard of living. Higher divorce rates have been observed in families of children with ASD relative to the general population; this could further exacerbate social and economic difficulties (Blacher and McIntyre 2006). Furthermore, these families may experience social isolation. For instance, parents may feel that their parenting skills are being judged negatively by others and may restrict their social activities and outings to avoid this scrutiny (Corcoran et al. 2015).

Despite these challenges to family life, parents and other family members report positive effects of having a child with ASD. For instance, having experienced the challenges associated with ASD, individuals report having developed a more compassionate understanding of persons with disabilities (Bayat 2007; Gray 2006). They may also find that this experience has brought their family closer together and made them a better person (Bayat 2007; Kayfitz et al. 2009). Finally, they also report having re-examined their priorities in a positive manner and developed a more positive appreciation of life (Gray 2006; Myers et al. 2009).

In contrast with FQOL research in the field of intellectual and developmental disabilities, relatively few studies have examined FQOL in ASD, particularly in the early childhood period following the child's diagnosis (Rivard et al. 2017). However, some studies have identified several factors associated with lower or higher satisfaction with FQOL families of children with disabilities including ASD. For instance, access to family-centered professional supports, social support and household income have been identified as predictors of FQOL among families of children with ASD or other disabilities (Mello et al. 2018; Meral et al. 2013). While some studies indicate higher FQOL among fathers than mothers others find comparable FQOL in both parents (Mello et al. 2018; see also McStay et al. 2014;

Wang et al. 2006). Additionally, studies examining cultural factors suggest that satisfaction with FQOL may vary as a function of families' country of origin (Meral et al. 2013; see also Cohen et al. 2014). To date, potential differences in the perception of FQOL between immigrant and native families during the post-diagnosis period have yet to be investigated, despite the fact that cultural differences may impact FQOL and its predictors, and could account for discrepant results across studies (e.g., Alshamri 2016).

Improving QOL is often one of the factors motivating individuals to immigrate to a new country (DeJong 2000). Indeed, prospective immigrants generally hope to improve the financial situation, safety, employment, or physical and psychological well-being of all family members (Nussbaum 2007). However, this transition may also be a source of stress and adjustment difficulties (Parkhomenko 2016), as well as dissatisfaction due to a gap between expectations and reality (Mähönen et al. 2013; Ward et al. 2001). Immigrant families' QOL is indeed correlated with the congruence between what they had anticipated and their actual experiences in their host country, particularly in terms of their physical and psychological health and their socioeconomic status (Bayram et al. 2007; Belizaire and Fuertes 2011; Parkhomenko 2016). Having a child with a disability may compound these negative effects of immigration on families' well-being. The period that follows a child's diagnosis may be especially stressful in this respect, as it entails demands stemming from multiple roles: in addition to being parents, mothers and fathers must also act as therapists and case managers for their child at the same time as they adjust to the norms and customs of their host country. Additionally, immigrant families of children with ASD are more likely to have a poor social support network and a lower socioeconomic status, and may also face additional difficulties in accessing assessment and intervention services for their child (Klingner et al. 2009; Mandell et al. 2009; Söderström 2014). In Canada, immigrants comprise 21% of the population; this proportion has been on the increase (Statistics Canada 2017). Despite the fact that this group is represented proportionally in services for individuals with ASD, cultural minority groups are under-represented in the literature, such that the extant body of research does not accurately represent all families (Gardiner and French 2011; FSIRG-IASSIDD 2012). Including immigrant families from diverse backgrounds in ASD research will help to better describe their experiences and understand their needs, and by extension develop socially valid intervention programs (Cohen and Miguel 2018; Wolery and Garfinkle 2002).

An earlier study by our group examined parenting stress during the post-diagnosis period, as families waited for services from a public provider (Millau et al. 2016). In contrast to what was suggested by the extant literature on this topic, Canadian parents reported higher stress levels than immigrant parents. These findings may be attributable to the focus of the instrument used to study stress, the Parenting Stress Index (PSI; Abidin 1995). The PSI assesses stress related to parenting skills, such as parental distress and dysfunctional parent–child interactions, but does not account for other stressful situations or life events. In immigrant families, the constructs of the PSI may represent a fraction of parents' overall stress, as other stressors (e.g., acculturation-related or economic) are present in addition to parenting a child with ASD (Millau et al. 2016). Another element that could explain these apparent discrepancies in the literature may be the coping strategies adopted by families in response to their child's diagnosis.

Coping strategies refer to the cognitive and behavioral efforts deployed by individuals in order to manage the adaptation challenges of a stressful event (Lazarus and Folkman 1984; Lazarus 2006). This process relates to the personal, cultural, and contextual aspects of the situation (Lazarus 2006). Parents of children with ASD may resort to less effective coping strategies (e.g., avoidance, self-criticism, negative emotions) than parents of typically developing children or children with intellectual disabilities (Montes and Halterman 2007; Lai et al. 2015; Piazza et al. 2014). Parents who use emotion-focused coping strategies may experience higher stress than those who adopt problem-focused strategies; mothers are more likely than fathers to use emotion-focused strategies (Dabrowska and Pisula 2010). Parents of children with ASD of European origin are also more likely than Asian parents to use emotion-focused coping strategies (Lin et al. 2008; Luong et al. 2009). These findings suggest that mothers and fathers, as well as members of different cultural groups, may adopt different coping strategies, which could in turn impact their respective experiences of parenting stress and FQOL.

In keeping with the emerging focus on family-centered assessments and interventions, an in response to a need to better document the experiences of underrepresented groups (e.g., fathers, cultural minorities, and immigrants) in ASD, the present study sought to investigate FQOL in immigrant mothers and fathers. Because immigrant families experience peculiar difficulties associated with immigration and with the pivotal moment in their child's ASD service trajectory, it is important to promote the development of services suited to their unique situation. The assessment of their overall experience and needs as a family unit, through the construct of FQOL, may thus be a starting point in adapting interventions to their needs.

The primary goal of the present study was to document the FQOL of immigrant parents of children with ASD and to compare it to that of Canadian parents with a comparable socioeconomic status, while examining potential gender-related differences. A secondary objective of the study was to examine the sources and perceived levels of external support by immigrant and Canadian parents.

Method

Participants

The data examined in the present study were collected as part of a larger investigation of the effectiveness of early intervention services provided in the suburbs of Montréal. In order to be eligible to participate in this larger study, families had to have a child who had been officially diagnosed with ASD and be on a waiting list for services at a regional rehabilitation center. Of the 277 participating families whose FQOL was assessed, 36 (13%) were immigrant families. Among these, 29 families could be paired with participating Canadian-born families on the basis of annual household income. Therefore, 58 families were included in the sample for the present study. In 12 instances, the child's father was absent at the time of data collection or had declined to participate, such that only the mother completed the FQOL measure; for the remaining 46 families, both parents responded to the questionnaire. Thus, data from 104 participants, that is, 58 mothers and 46 fathers, an equal number of which were born in Canada or had immigrated to Canada, were analyzed. Children were aged 39 months ($SD = 11.7$) on average.

The immigrant families who participated in the study had emigrated from the Maghreb region of North Africa (29%), Central or Eastern Africa (21%), Latin America (21%), the Middle East (13%), Eastern Europe (12%), and China (4%). Approximately half (48%) of families reported an annual income in the CAD 10,000 to 29,999 range, which is below the poverty threshold for Canada (an annual household income between CAD 30,000 and 35,000, depending on the size of the household). On the opposite end of the spectrum, 13.5% of families' incomes exceeded CAD 90,000. Additional information on parents' income and level of education are provided in Table 1.

Table 1 Participants' demographic information

	Immigrant		Canadian-born	
	Mothers *n* (%) 29 (100)	Fathers *n* (%) 23 (100)	Mothers *n* (%) 29 (100)	Fathers *n* (%) 23 (100)
Annual household income (CAD)				
10,000–29,999	14 (48.28)	11 (47.83)	14 (48.28)	11 (47.83)
30,000–49,999	3 (10.34)	2 (8.70)	3 (10.34)	2 (8.70)
50,000–69,999	5 (17.24)	4 (17.39)	5 (17.24)	4 (17.39)
70,000–89,999	2 (6.90)	2 (8.70)	2 (6.90)	2 (8.70)
90,000 or more	4 (13.79)	3 (13.04)	4 (13.79)	3 (13.04)
Missing information	1 (3.45)	1 (4.35)	1 (3.45)	1 (4.35)
Educational background				
Incomplete high school	5 (17.24)	2 (8.70)	8 (27.59)	4 (17.39)
High school or professional	7 (24.14)	3 (13.04)	6 (20.69)	8 (34.79)
Post high school	6 (20.69)	4 (17.39)	8 (27.59)	6 (26.09)
University (1st degree)	7 (24.14)	7 (30.43)	4 (13.79)	1 (4.35)
University (2nd, 3rd degree)	4 (13.79)	7 (30.43)	1 (3.45)	0 (0)
Other or missing information	0 (0)	0 (0)	2 (6.90)	4 (17.39)
Employment				
Full-time worker	8 (27.59)	14 (60.86)	11 (37.93)	15 (65.21)
Part-time worker	3 (10.34)	2 (8.70)	5 (17.24)	0 (0)
Freelance or contract worker	1 (3.45)	0 (0)	1 (3.45)	2 (8.70)
Homemaker	14 (48.28)	4 (17.39)	10 (34.48)	4 (17.39)
Unemployed	0 (0)	0 (0)	0 (0)	2 (8.70)
Student	1 (3.45)	1 (4.35)	1 (3.45)	0 (0)
Other	2 (6.90)	2 (8.70)	1 (3.45)	0 (0)
Birth country				
North America (Canada)			29 (100)	23 (100)
North Africa (Maghreb region)	9 (31.03)	6 (26.09)		
Central and West Africa	6 (20.69)	5 (21.74)		
Latin America	6 (20.69)	5 (21.74)		
Middle East	4 (13.79)	3 (13.04)		
Eastern Europe and Russia	3 (10.34)	3 (13.04)		
China	1 (3.45)	1 (4.35)		

Procedures

This study protocol was approved by the Joint Research Ethics Board for Public Rehabilitation Centers for Persons with Intellectual Disabilities and ASD in Québec. Families who met the inclusion criteria were invited to participate in the study by a research assistant from the rehabilitation center. Following this first contact, a research assistant met with prospective participants and explained to them the goals of the study, as well as the nature of their involvement and the practices that would be employed to protect their confidentiality if they decided to participate. Those who wished to enroll in the study indicated their free and informed consent by signing a consent form. Parents then completed the sociodemographic questionnaire and the Beach Center FQOL Scale in the presence of the research assistant. Taken together, these two assessments took approximately 20 min to complete.

Measures

Sociodemographic questionnaire

In order to provide indicators of socioeconomic status and ethnic diversity in the study sample, participating families completed a questionnaire based on that employed by Rivard et al. (2014). This instrument consisted of 19 questions regarding the child's diagnosis, comorbid conditions, and siblings, as well as parents' place of birth, native language, marital status, employment, income, and education. Additional items prompted parents to rate the presence of an external support network on a 0 (*not at all*) to 3 (*a lot*) and to specify their primary source of external support, if any.

FQOL assessment

Families' QOL was measured with the Beach Center FQOL Scale (Hoffman et al. 2006). This self-report measure asks parents to rate their satisfaction with, and priorities regarding, various aspects of family life. The Beach Center instrument was selected for this study because of its speed and ease of administration, and because it was used and validated in various countries: China, several European countries, Australia, Israel, Nigeria, Saudi Arabia, the United States, and French Canada (e.g., Alshamri 2016; Rivard et al. 2017; Balcells-Balcells et al. 2010; Brown et al. 2006; Jokinen 2008; Meral et al. 2013; Parpa et al. 2016; Svraka et al. 2011). The scale consists of 25 items for which respondents rate their satisfaction on a 5-point scale (1 = *very dissatisfied* to 5 = *very satisfied*). These items make up five subscales: Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-related Support. In addition to their satisfaction with each item, respondents also rate the degree to which a given aspect of family life is important to them on a 5-point scale. Thus, for an item such as "My family members have friends or others who provide support", parents would first rate the degree to which this social support is important to them, then the degree to which they are satisfied with their social support. The original, English language version of the scale presented good psychometric properties: its internal consistency was Cronbach's α = 0.94 and 0.88; test–retest reliability was between 0.60 and 0.77 for satisfaction ratings, and between 0.41 and 0.82 for importance ratings. For the present study, a French translation of this instrument that was previously validated on a sample of 452 French-speaking Canadian parents of children with ASD (Rivard et al. 2017) was adopted. This translation presented excellent internal consistency across the entire scale and acceptable consistency within its five subscales, Cronbach's α = 0.90 and 0.72–0.82, respectively.

Data Analyses

Descriptive statistics were computed on the following demographic information: household income, education, employment, country of origin, and social support. Analyses of variance (ANOVAs) were used to examine differences in FQOL as a function of origin (Canadian or immigrant) and gender (mother, father) for total scores on the FQOL importance and satisfaction scale and for each of the five subscales. Additionally, chi squared tests of independence were used to assess the relationship between categorical FQOL levels and perceived support on one hand, and parents' origin or gender on the other hand.

Results

FQOL Total Scores: Satisfaction Ratings

Table 2 presents participants' overall satisfaction as a function of gender and immigration status. Average FQOL was 3.72 across the study sample as a whole. More

Table 2 Parents' total and subscale FQOL satisfaction scores as a function of immigration status and gender

Subscale	Immigrant *M* (*SD*)			Canadian-born *M* (*SD*)			All Parents *M* (*SD*)		
	Mothers	Fathers	Both	Mothers	Fathers	Both	Mothers	Fathers	Both
Family Interaction	3.31 (0.90)	3.17 (0.85)	3.25 (0.88)	3.50 (0.66)	3.65 (0.73)	3.56 (0.69)	3.40 (0.78)	3.41 (0.83)	3.41 (0.80)
Parenting	3.90 (0.69)	3.87 (0.62)	3.88 (0.66)	3.68 (0.82)	3.77 (0.64)	3.72 (0.74)	3.79 (0.76)	3.80 (0.63)	3.80 (0.70)
Emotional Well-being	3.49 (0.82)	3.45 (0.84)	3.49 (0.82)	3.62 (0.68)	3.77 (0.66)	3.69 (0.67)	3.57 (0.79)	3.63 (0.76)	3.59 (0.75)
Physical/Material Well-being	3.84 (0.87)	3.81 (0.74)	3.83 (0.82)	4.04 (0.60)	4.08 (0.60)	4.06 (0.59)	3.94 (0.75)	3.95 (0.69)	3.95 (0.72)
Disability-related Support	3.57 (0.96)	3.62 (0.88)	3.58 (0.91)	4.12 (0.50)	4.05 (0.48)	4.09 (0.49)	3.85 (0.81)	3.82 (0.73)	3.84 (0.78)
Overall FQOL Scale	3.63 (0.61)	3.58 (0.59)	3.60 (0.58)	3.80 (0.59)	3.87 (0.51)	3.83 (0.48)	3.71 (0.54)	3.73 (0.59)	3.71 (0.55)

FQOL family quality of life

precisely, approximately 10% of families reported being *very dissatisfied* (1) to *dissatisfied* (2), 63% were neutral (3 = *neither satisfied nor dissatisfied*), and 27% were either *satisfied* (4) or *very satisfied* (4–5) overall.

As seen in Table 2, Canadian parents had higher overall satisfaction ratings compared to immigrant parents, however this difference did not attain significance. Additionally, 35% of Canadian parents' reported being satisfied with their FQOL (4–5), compared to 19% of immigrant parents. In contrast, 15% of immigrant parents reported being dissatisfied (1–2) overall, compared to 4% of Canadian parents. The relation between FQOL and immigration status was significant, $\chi^2(1, N = 58) = 5.797$, $p = 0.016$.

As shown in Table 3, mothers' and fathers' overall scores did not differ. Overall scores denoted satisfaction with FQOL (4–5) for 26% of fathers and 28% of mothers; 12% of mothers and 7% of fathers reported being dissatisfied (1–2). FQOL levels were not significantly associated with parents' gender, $\chi^2(1, N = 58) = 0.510$, $p = 0.475$.

Gender and immigration status did not interact. However, Canadian fathers tended to have higher FQOL compared to Canadian mothers, whose satisfaction was in turn higher than that of their immigrant counterparts. The lowest levels of FQOL were observed among immigrant fathers.

FQOL Subscale Scores: Satisfaction Ratings

Across the entire sample, average satisfaction levels with the five dimensions of FQOL assessed by the instrument's subscales ranged between 3.40 (Family Interaction) and 3.95 (Physical/Material Well-being). Immigrant fathers had the lowest scores on the Family Interaction subscale, whereas the highest levels of satisfaction were observed for Disability-related Support among Canadian mothers.

Canadian families reported significantly higher satisfaction with Family Interaction compared to immigrant families. The same pattern of differences was observed for the Disability-related Support subscale. Canadian parents also reported higher satisfaction with Emotional Well-being and Physical/Material Well-being, but these differences were not significant. Conversely, immigrant parents had slightly, but not significantly, higher satisfaction ratings for Parenting compared to Canadian parents. No gender differences were noted on any of the subscales. Additionally, gender and immigration status did not interact for any of the subscales.

FQOL Total and Subscale Scores: Importance Ratings

Table 4 shows the results of analyses of variance carried out on importance ratings. For overall importance ratings, there were no main effects of immigration status or gender, nor did these factors interact. At the subscale level, however, immigrant parents rated the Parenting dimension as significantly more important than Canadian-born parents; no other differences attained significance. However, as seen in Table 5, different patterns emerged across groups of parents with respect to which dimensions of FQOL they considered

Table 3 Analyses of variance examining differences in satisfaction ratings based on immigration status and gender

Subscale	Immigration status			Gender			Immigration status*gender		
	F	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2
Family Interaction	4.455	0.037	0.042	0.002	0.964	0.000	0.861	0.356	0.008
Parenting	1.308	0.255	0.013	0.045	0.832	0.000	0.156	0.694	0.002
Emotional Well-being	2.265	0.135	0.022	0.128	0.721	0.001	0.358	0.551	0.004
Physical/Material Well-being	2.752	0.100	0.027	0.003	0.957	0.000	0.072	0.789	0.001
Disability-related Support	11.18	0.001	0.100	0.009	0.925	0.000	0.174	0.677	0.002
Overall FQOL	3.400	0.068	0.033	0.019	0.891	0.000	0.222	0.639	0.002

Table 4 Analyses of variance examining differences in importance ratings based on immigration status and gender

Subscale	Immigration status			Gender			Immigration status*gender		
	F	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2
Family Interaction	0.126	0.724	0.001	0.265	0.608	0.003	0.977	0.326	0.011
Parenting	4.736	0.032	0.052	0.222	0.638	0.003	0.005	0.944	0.000
Emotional Well-being	0.055	0.815	0.001	0.000	0.990	0.000	0.909	0.343	0.010
Physical/Material Well-being	0.214	0.645	0.002	0.000	0.994	0.000	0.486	0.488	0.006
Disability-related Support	0.008	0.928	0.000	0.002	0.964	0.000	1.190	0.278	0.013
Overall FQOL	0.735	0.393	0.008	0.081	0.776	0.001	1.316	0.255	0.015

Table 5 Parents' total and subscale FQOL importance scores as a function of immigration status and gender

Subscale	Immigrant *M* (*SD*)			Canadian-born *M* (*SD*)			All Parents *M* (SD)		
	Mothers	Fathers	Both	Mothers	Fathers	Both	Mothers	Fathers	Both
Family Interaction	4.66 (0.44)	4.70 (0.52)	4.68 (0.47)	4.71 (0.36)	4.41 (0.65)	4.56 (0.54)	4.69(0.39)	4.54 (0.83)	4.62 (0.50)
Parenting	4.50 (0.53)	4.57 (0.58)	4.53 (0.55)	4.25 (0.45)	4.17 (0.77)	4.21 (0.62)	4.37 (0.50)	4.35 (0.83)	4.36 (0.60)
Emotional Well-being	4.13 (0.74)	4.33 (0.87)	4.23 (0.80)	4.37 (0.82)	4.02 (0.81)	4.19 (0.82)	4.25 (0.78)	4.16 (0.95)	4.21(0.81)
Physical/Material Well-being	4.55 (0.76)	4.67 (0.53)	4.61 (0.66)	4.72 (0.42)	4.53 (0.72)	4.63 (0.59)	4.64 (0.60)	4.16 (0.95)	4.62 (0.62)
Disability-related Support	4.57 (0.93)	4.77 (0.50)	4.67 (0.77)	4.77 (0.36)	4.50 (0.81)	4.64 (0.62)	4.67 (0.69)	4.63 (0.86)	4.65 (0.69)
Overal FQOL Scale	4.49 (0.56)	4.61 (0.50)	4.55 (0.53)	4.56 (0.34)	4.34 (0.60)	4.45 (0.48)	4.53 (0.45)	4.46 (0.80)	4.49 (0.50)

FQOL family quality of life

Table 6 Availability and sources of external support

	Immigrant *n* (%)	Canadian-born *n* (%)
Presence of support		
No support	14 (48.3)	5 (17.2)
A little support	8 (27.6)	16 (55.2)
Moderate support	3 (10.3)	5 (17.2)
A lot of support	4 (13.8)	2 (6.9)
Missing information	0 (0)	1 (3.4)
Source of external support[a]		
Extended family	5 (33.3)	11 (47.8)
Close family	2 (13.3)	3 (13.0)
Friends	1 (6.7)	2 (8.7)
Hired help	2 (13.3)	1 (4.3)
Missing information	5 (33.3)	6 (26.1)

[a] Percentages for this item were computed relative to the number of parents who reported having access to some support (from "a little support" to "a lot of support"), $n = 15$ for immigrant families and $n = 23$ for Canadian families

most important, and their satisfaction towards these. Immigrant mothers rated Family Interaction as the most important aspect of FQOL; this was also the dimension for which they reported the lowest level of satisfaction. In contrast, Canadian parents had higher levels of satisfaction on the subscales that reflected the most important aspects of FQOL for them, namely Disability-related Support for mothers and Physical/Material Well-being for Canadian fathers. For immigrant fathers, Disability-related Support was also rated as having the highest importance and was associated with moderate levels of satisfaction. Emotional Well-being was rated as least important by all groups but Canadian mothers, for whom Parenting was considered less important.

Presence and Availability of External Support

Table 6 presents information regarding families' external support network. Almost half of immigrant families reporting not having access to external support, whereas this proportion was much lower among Canadian respondents. However, fewer Canadian than immigrant families reported having a lot of external support. The relation between families' external support network and immigration status was significant, $\chi^2(1, N = 58) = 8.081$, $p = 0.044$.

Among the immigrant families who reported having access to external support, a third indicated that this support network consisted of relatives (i.e., the child's grandparents and the extended family). Among Canadian families, almost half received support from relatives. Other sources of support are outlined in Table 6.

Discussion

Families of children with ASD face numerous challenges (Baker-Ericzen et al. 2005; Blacher and McIntyre 2006; Mugno et al. 2007), which may be even greater in the case of immigrant families (Fombonne 2009; Klingner et al. 2009; Magaña et al. 2013). The period following the child's diagnosis has been described as a stressful, crucial point in families' trajectory, yet relatively few studies have examined the needs of families at this moment (Mello et al. 2018). Indeed, the impact of having a child with ASD on family life has typically been studied through the lens of parenting stress (Dabrowska and Pisula 2010; McStay et al. 2014). While this indicator may highlight important difficulties faced by parents, it tends to focus on parenting skills and negative perceptions and thus does not provide a complete portrait of their experiences. The study of FQOL provides an overview of a family's situation that encompasses its strengths as well as areas where support may be needed. To our knowledge, this study is the first to compare FQOL in mothers and fathers of children with ASD in immigrant and native families during the post-diagnosis period.

The levels of overall satisfaction observed in the entire study sample indicated that despite going through a difficult period in their family's trajectory (i.e., waiting for services following the child's diagnosis), the majority of respondents did not have a negative appraisal of their FQOL. Indeed, despite the high levels of stress experienced in this period (Millau et al. 2016; Rivard et al. 2014), participants had neutral to positive satisfaction ratings on average. Thus, the measure of FQOL can also highlight positive aspects of the experiences of families of children with ASD, for instance as families develop coping strategies that favorably impact their FQOL.

Although no statistically significant differences as a function of immigration status emerged in overall satisfaction levels, Canadian parents tended to report higher average satisfaction levels, while immigrant parents were four times more likely to report being dissatisfied with their FQOL. Support from members of the extended family was previously identified as a predictor of FQOL among parents of children with ASD (Meral et al. 2013). Social support has also been found to promote resilience and adaptation among young immigrants (Masten 2004). In the present study, immigrant parents were almost three times more likely than native Canadians to report not having access to external support. These results are consistent with those of earlier studies highlighting the risk of social isolation in immigrant parents, in particular when members of their extended family are absent (Klingner et al. 2009; Mandell et al. 2009; Söderström 2014). Outreach, information, and coaching programs offered to families of children with ASD would benefit from the inclusion of members of the extended family in order to bolster their ability to support parents. Indeed, including other family members is an approach that has proven to be effective for other psychosocial intervention programs, and is consistent with the values of many immigrants' culture with respect to the overall involvement of the extended family and its role in rearing children (Barrio 2000; Klingner et al. 2009). Additionally, group-based information programs provide immigrant families with opportunities to form and develop a new social support network in the host country.

It should be noted that the first step in this investigation, which focused on parenting stress, had indicated that immigrant families experienced less stress than their Canadian counterparts (Millau et al. 2016). The observation of a different pattern of results for FQOL may be due to the relatively narrow scope of the stress measure (i.e., stress associated with the role of parent). These new data pertaining to FQOL in a broader sense provide nuance to these earlier findings. Specifically, they indicate that immigrant families, while reporting lower parenting stress, do not necessarily experience greater well-being and satisfaction with their family dynamics than families native to the host culture.

Canadian-born and immigrant parents differed with regards to their satisfaction with several aspects of their FQOL. First, Canadian families were more satisfied with the support they received in relation to their child's disability. This observation is consistent with the literature reporting that immigrant families may have difficulty gaining access to services (Klingner et al. 2009; Söderström 2014). Having access to family-centered professional supports has been identified as a predictor of FQOL (Meral et al. 2013; Wang et al. 2006). Through local contacts or their knowledge of the organizations that comprise the human and social services system, Canadian families may obtain more external support during the waiting period compared to immigrant families. It would thus be important to provide and promote services that inform immigrant families of resources that are available to them.

Second, Canadian parents reported greater satisfaction with Family Interaction aspects of FQOL compared to immigrant parents. However, this was also the subscale on which Canadian parents indicated the lowest levels of satisfaction. Having a child with ASD directly affects interactions among family members, for instance due to the communication deficits that are inherent to ASD (Gardiner and Iarocci 2012; Petalas et al. 2012). Fathers' typical roles and responsibilities may shift as a function of their child's ASD and alter their experience of fatherhood (Donaldson et al. 2011; Lyons et al. 2010) and interactions with family members. In addition to adjusting to the child's diagnosis, immigrant families must also adapt to the culture and values of their host country. This could pose additional strains on family interactions among this population. Finally, a study suggested that mothers' employment may correlate positively with scores on Family Interaction (Mello et al. 2018); immigrant mothers in the present sample were more likely than Canadian mothers to be homemakers.

The only dimension of FQOL on which immigrant families reported higher satisfaction than Canadian families related to the Parenting subscale. The fact that a larger proportion of immigrant mothers were homemakers, and may thus be able to spend more time with the child, could be an influential factor. Indeed, items assessing this aspect of FQOL pertain to having time to care for, educate, and support children (e.g., "Adults in my family have time to take care of the individual needs of every child"). Similarly, Canadian parents had higher scores on the Parent-Child Dysfunctional Interaction dimension of parenting stress assessed in an earlier study (Millau et al. 2016). Parents who experience stress in their interactions with their child may also be less satisfied with their parenting.

Statistical analyses did not indicate gender-based differences in parents' satisfaction with FQOL overall or on any of the subscales. While mothers' and fathers' average satisfaction ratings were similar, it should be noted that almost twice as many mothers as fathers reported being dissatisfied to some degree. This observation is consistent with other studies finding higher FQOL among fathers (e.g., McStay et al. 2014). Inasmuch as employment may be predictive of FQOL among mothers (Mello et al. 2018), the fact that over 41% of mothers, versus 17% of fathers, did not work outside the home could account for some mothers' dissatisfaction.

In the present study, gender and immigration status did not interact significantly. However, Canadian fathers tended to have higher FQOL than immigrant fathers or mothers in either group. Some studies have shown that the more fathers experience risk factors for stress, the less they are likely to deploy effective personal and family coping strategies and thus improve their FQOL (Dardas and Ahmad 2015). Additional, immigration-related stressors experienced by immigrant fathers may account for their lower FQOL compared to their Canadian counterparts.

An examination of the importance ratings provided by parents throughout the FQOL scale indicate that immigrant and Canadian-born families may prioritize different aspects of family life. Immigrant families rated Family Interaction and Disability-related Support as most important, whereas Disability-related Support and Physical/Material Well-being were considered more important by Canadian parents. These results suggest that early intervention services provided to immigrant families should be family-centered, involve all family members (i.e., parents, siblings, and other relatives involved in the child's life), and include goals pertaining to relationships within the family. To the extent that both immigrant and Canadian families rated supports relating to their child's ASD as important, it remains important to continue to promote evidence-based early intervention services. However, it is also critical to address the issue of waiting lists for these services so that families may benefit from professional services sooner. This would not only support an optimal prognosis for the child, but could also facilitate families' QOL during the post-diagnosis period.

Limitations

One of the major limitations of the present study is its small sample size, which limited the statistical power of analyses and the generalization of results. A larger sample would also have supported more fine-grained comparisons between immigrant families from different countries or regions, and thus provide a more in-depth understanding of culturally-based differences in FQOL. Additionally, no data were collected regarding the circumstances under which the sampled parent had immigrated Canada, how long they had resided in Canada, and whether other family members had immigrated with them. These are a factor in acculturation stress (Mähönen et al. 2013; Parkhomenko 2016; Ward et al. 2001) as well as quality of life (Bayram et al. 2007; Belizaire and Fuertes 2011; Parkhomenko 2016), and could also impact FQOL. Finally, the majority of a sample had a low income, which has been shown to negatively affect FQOL, such that some of the findings noted in the present study may not generalize to more affluent families.

Overall, the findings of the present study corroborated, and expanded upon, extant data on the difficulties faced by immigrant families of children with ASD. Relatively few studies have examined families' experience of FQOL during the stressful post-diagnosis period, during which they await services. As indicated by Families Special Interest Research Group of the IASSID (2012), the literature may not be representative of the whole of families of children with ASD. The present study examined the situation of an especially vulnerable population, that is, of low-income families, half of which had immigrated to Canada. Although their overall FQOL levels were neutral, some of the findings underscored the importance of investigating means of alleviating their social isolation. Additionally, future studies should assess the social validity and efficacy of family-centered services during this period of their child's development. In particular, it would be pertinent to explore means to help families broaden their social and support networks, facilitate their access to professional support, and in promote their involvement in their child's early intervention services. With these goals in mind, future work should assess the implementation and impact of approaches such as support groups, parenting skills coaching programs, or information sessions on available services on FQOL.

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Author Contributions M.M.: Analyzed the data, and wrote the paper. M.R.: participated in the design and writing of the study, collaborated in the writing of the paper. C.M.: participated in the interpretation of findings, collaborated in the writing, translation, and editing of the final manuscript.

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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 studies involving human participants were in accordance with the ethical standards of two institutional research committees (the University du Québec à Montréal and the Joint Research Ethics Board for Public Rehabilitation Centers for Persons with Intellectual Disabilities and ASD in Québec) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

References

Abidin, R. R. (1995). *Manual for the parenting stress index*. 3rd ed. Charlottesville, VA: Pediatric Psychology Press.

Alshamri, K. H. (2016). *Family quality of life for families of children with intellectual disability in Saudi Arabia* (Doctoral dissertation). Western Sydney University. http://researchdirect.uws.edu.au/islandora/object/uws%3A40063.

Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, *30*, 194–204. https://doi.org/10.2511/rpsd.30.4.194.

Balcells-Balcells, A., Giné, C., Guàrdia-Olmos, J., & Summers, J. A. (2010). Family quality of life: Adaptation to Spanish population of several family support questionnaires. *Journal of Intellectual Disability Research*, *55*, 1151–1163. https://doi.org/10.1111/j.1365-2788.2010.01350.x.

Barrio, C. (2000). The cultural relevance of community support programs. *Psychiatric Services*, *51*, 879–884. https://doi.org/10.1176/appi.ps.51.7.879.

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, *51*, 702–714. https://doi.org/10.1111/j.1365-2788.2007.00960.x.

Bayram, N., Thorburn, D., Demirhan, H., & Bilgel, N. (2007). Quality of life among Turkish immigrants in Sweden. *Quality of Life Research*, *16*, 1319–1333. https://doi.org/10.1007/s11136-007-9249-6.

Belizaire, L. S., & Fuertes, J. N. (2011). Attachment, coping, acculturative stress, and quality of life among Haitian immigrants. *Journal of Counseling & Development*, *89*, 89–97. https://doi.org/10.1002/j.1556-6678.2011.tb00064.x.

Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioral disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual and Developmental Disability*, *50*, 184–198. https://doi.org/10.1111/j.1365-2788.2005.00768.x.

Brookman-Frazee, L., Baker-Ericzén, M., Stadnick, N., & Taylor, R. (2012). Parent perspectives on community mental health services for children with autism spectrum disorders. *Journal of Child and Family Studies*, *21*, 533–544. https://doi.org/10.1007/s10826-011-9506-8.

Brown, R. I., MacAdam-Crisp, J., Wang, M., & Iarocci, G. (2006). Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, *3*, 238–245. https://doi.org/10.1111/j.1741-1130.2006.00085.x.

Brown, I., Anand, S., Fung, A. W. L., Isaacs, B. J., & Baum, N. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities*, *15*, 207–230. https://doi.org/10.1023/A:1024931022773.

Cappe, E, Chatenoud, C., & Paquet, A. (2014). Les caractéristiques des personnes ayant un TSA et des autres membres de la famille influençant l'adaptabilité familiale [Characteristics of persons with autism spectrum disorder and order family members that influence family adaptability]. In C. Chatenoud, J.-C. Kalubi, & A. Paquet (Eds.) *La famille et la personne ayant un trouble du spectre de l'autisme: comprendre, soutenir et agir autrement* (pp. 51–69). Québec, QC: Éditions Nouvelles.

Cohen, S. R., Holloway, S. D., Domínguez-Pareto, I., & Kuppermann, M. (2014). Receiving or believing in family support? Contributors to the life quality of Latino and non-Latino families of children with intellectual disability. *Journal of Intellectual Disability Research*, *58*, 333–345. https://doi.org/10.1111/jir.12016.

Cohen, S. R., & Miguel, J. (2018). Amor and social stigma: ASD beliefs among immigrant Mexican parents. *Journal of Autism and Developmental Disorders*, *48*, 1995–2009. https://doi.org/10.1007/s10803-017-3457-x.

Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders: a systematic review and meta-synthesis. *Journal of Intellectual Disabilities*, *19*, 356–366. https://doi.org/10.1177/1744629515577876.

Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research*, *54*, 266–280. https://doi.org/10.1111/j.1365-2788.2010.01258.x.

Daley, T. C., & Sigman, M. D. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *Journal of Autism and Developmental Disorders*, *32*, 13–23.

Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal on Autism and Developmental Disorders*, *38*, 1278–1291. https://doi.org/10.1007/s10803-007-0512-z.

Dardas, L. A., & Ahmad, M. M. (2015). For fathers raising children with autism, do coping strategies mediate or moderate the relationship between parenting stress and quality of life? *Research in Developmental Disabilities*, *36*, 620–629. https://doi.org/10.1016/j.ridd.2014.10.047.

DeJong, G. F. (2000). Expectations, gender, and norms in migration decision-making. *Population Studies*, *54*, 307–319. https://doi.org/10.1080/713779089.

Donaldson, S. O., Elder, J. H., Self, E. H., & Christie, M. B. (2011). Fathers' perceptions of their roles during in-home training for children with autism. *Journal of Child and Adolescent Psychiatric Nursing*, *24*, 200–207. https://doi.org/10.1111/j.1744-6171.2011.00300.x.

Dunst, C. J., & Bruder, M. B. (2002). Valued outcomes of service coordination, early intervention, and natural environments. *Exceptional Children*, *68*, 361–375. https://doi.org/10.1177/001440290206800305.

Families Special Interest Research Group of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (FSIRG IASSID; 2012). Families supporting a child with intellectual or developmental disabilities: The current state of knowledge. *Journal of Applied Research in Intellectual Disabilities*, *27*, 420–430. https://doi.org/10.1111/jar.12078.

Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research*, *65*, 591–598. https://doi.org/10.1203/PDR.0b013e31819e7203.

Gardiner, E., & French, C. (2011). The relevance of cultural sensitivity in early intervention. *Exceptionality Education International*, *21*, 34–49.

Gardiner, E., & Iarocci, G. (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities*, *33*, 2177–2192. https://doi.org/10.1016/j.ridd.2012.06.014.

Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability*, *27*, 215–222. https://doi.org/10.1080/1366825021000008639.

Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, *50*, 970–976. https://doi.org/10.1111/j.1365-2788.2006.00933.x.

Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the beach center family quality of life scale. *Journal of Marriage and Family*, *68*, 1069–1083. https://doi.org/10.1111/j.1741-3737.2006.00314.x.

Hoffman, C. D., Sweeney, D. P., Lopez-Wagner, M. C., Hodge, D., Nam, C. Y., & Botts, B. H. (2008). Children with autism: Sleep problems and mothers' stress. *Focus on Autism and Other Developmental Disabilities*, *23*, 155–165. https://doi.org/10.1177/1088357608316271.

Hodgetts, S., Nicholas, D., & Zwaigenbaum, L. (2013). Home sweet home? Families' experiences with aggression in children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *28*, 166–174. https://doi.org/10.1177/1088357612472932.

Jokinen, N. S. M. (2008). *Family quality of life in the context of aging and intellectual disability*. Alberta, Canada: University of Calgary. Unpublished doctoral dissertation.

Kayfitz, A., Gragg, M., & Orr, R. (2009). Positive experiences of mothers and fathers of children with autism. *Journal of Applied Research in Intellectual Disabilities*, *23*, 337–343. https://doi.org/10.1111/j.1468-3148.2009.00539.x.

Klingner, J. K., Blanchett, W. J., & Harry, B. (2009). Race, culture, and developmental disabilities. In S. L. Odom, R. H. Horner, M. Snell & J. Blacher (Eds.), *Handbook on Developmental Disabilities* (pp. 55–75). New York, NY: Guilford Press.

Lai, W. W., Goh, T. J., Oei, T. P., & Sung, M. (2015). Coping and well-being in parents of children with autismspectrum disorders (ASD). *Journal of Autism and Developmental Disorders*, *45*, 2582–2593. https://doi.org/10.1007/s10803-015-2430-9.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York, NY: Springer.

Lazarus, R. S. (2006). Emotions and interpersonal relationships: Toward a person-centered conceptualization of emotions and coping. *Journal of Personality*, *74*, 9–46. https://doi.org/10.1111/j.1467-6494.2005.00368.x.

Lin, C., Tsai, Y., & Chang, H. (2008). Coping mechanisms of parents of children recently diagnosed with Autism in Taiwan: A qualitative study. *Journal of Clinical Nursing*, *17*, 2733–2740. https://doi.org/10.1111/j.1365-2702.2008.02456.x.

Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast asian parents raising a child with Autism: A qualitative investigation of coping styles. *The. Journal of School Nursing*, *25*, 222–229. https://doi.org/10.1177/1059840509334365.

Lyons, A. M., Leon, S. C., Phelps, C. E. R., & Dunleavy, A. M. (2010). The impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles. *Journal of Child and Family Studies*, *19*, 516–524. https://doi.org/10.1007/s10826-009-9323-5.

Magaña, S., Lopez, K., Aguinaga, A., & Morton, H. (2013). Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities*, *51*, 141–153. https://doi.org/10.1352/1934-9556-51.3.141.

Mähönen, T. A., Leinonen, E., & Jasinskaja-Lahti, I. (2013). Met expectations and the wellbeing of diaspora immigrants: A longitudinal study. *International Journal of Psychology*, *48*, 324–333. https://doi.org/10.1080/00207594.2012.662278.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., & Shattuck, P. T. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, *99*, 493–498. https://doi.org/10.2105/AJPH.2007.131243.

Matson, J. L., & Nebel-Schwalm, M. (2007). Assessing challenging behaviors in children with autism spectrum disorders: A review. *Research in Developmental Disabilities*, *28*, 567–579. https://doi.org/10.1016/j.ridd.2006.08.001.

Masten, A. S., Burt, K. B., Roisman, G. I., Obradović, J., Long, J. D., & Tellegen, A. (2004). Resources andresilience in the transition to adulthood: Continuity and change. *Development and Psychopathology*, *16*, 1071–1094. https://doi.org/10.1017/S0954579404040143.

McStay, R., Trembath, D., & Dissanayake, C. (2014). Stress and family quality of life in parents of children with autism spectrum disorder: Parent gender and the double ABCX model. *Journal of Autism and Developmental Disorders*, *44*, 3101–3118. https://doi.org/10.1007/s10803-014-2178-7.

Mello, C., Rivard, M., & Terroux, A. (2018). Quality of life in families of young children with autism spectrum disorder at intake. Poster presented at the *2018 Annual Meeting of International Society for Autism Research*, Rotterdam, Netherlands.

Meral, B. F., Cavkaytar, A., Turnbull, A. P., & Wang, M. (2013). Family quality of life of Turkish families who have children with intellectual disabilities and autism. *Research and Practice for Persons with Severe Disabilities*, *38*, 233–246. https://doi.org/10.1177/154079691303800403.

Millau, M, Rivard, M, Mercier, C., & Mello, C. (2016). Parenting stress in immigrant families of children with an autism spectrum disorder: A comparison with families from the host culture. In C. Roland-Lévy, P. Denoux, B. Voyer, P. Boski, W. K. Gabrenya Jr (Eds.), *Unity, diversity, and culture: Research and Scholarship Selected from the 22nd Congress of the International Association for Cross-Cultural Psychology* (pp. 312–319). Melbourne, Florida USA: IACCP. www.iaccp.org.

Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics*, *119*, e1040–e1046. https://doi.org/10.1542/peds.2006-2819.

Mugno, D., Ruta, L., D'Arrigo, V. G., & Mazzone, L. (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health and Quality of Life Outcomes*, *5*, 22 https://doi.org/10.1186/1477-7525-5-22.

Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, *3*, 670–684. https://doi.org/10.1016/j.rasd.2009.01.004.

Nussbaum, J. F. (2007). Life span communication and quality of life. *Journal of Communication.*, *57*, 1–7. https://doi.org/10.1111/j.1460-2466.2006.00325.x.

Parellada, M., Boada, L., Moreno, C., Llorente, C., Romo, J., Muela, C., & Arango, C. (2013). Specialty care programme for autism spectrum disorders in an urban population: A case-management model for health care delivery in an ASD population. *European Psychiatry*, *28*, 102–109. https://doi.org/10.1016/j.eurpsy.2011.06.004.

Park, J., Hoffman, L., Marquis, J., Turnbull, A. P., Poston, D., Mannan, H., & Nelson, L. L. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research*, *4*, 367–384. https://doi.org/10.1046/j.1365-2788.2003.00497.x.

Parkhomenko, D. (2016). *Quality of life and migration experiences among russian speaking immigrants to the United States of America* (Unpublished doctoral dissertation). The Chicago School of Professional Psychology.

Parpa, E., Katsantonis, N., Tsilika, E., Galanos, A., Sassari, M., & Mystakidou, K. (2016). Psychometric properties of the family quality of life scale in Greek families with intellectual disabilities. *Journal of Developmental and Physical Disabilities*, *28*, 393–405. https://doi.org/10.1007/s10882-016-9477-1.

Petalas, M. A., Hastings, R. P., Nash, S., Hall, L. M., Joannidi, H., & Dowey, A. (2012). Psychological adjustment and sibling relationships in siblings of children with autism spectrum disorders: Environmental stressors and the broad autism phenotype. *Research in Autism Spectrum Disorders*, *6*, 546–555. https://doi.org/10.1016/j.rasd.2011.07.015.

Piazza, V. E., Floyd, F. J., Mailick, M. R., & Greenberg, J. S. (2014). Coping and psychological health ofaging parents of adult children with developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, *119*, 186–198. https://doi.org/10.1352/1944-7558-119.2.186.

Poirier, N., & Goupil, G. (2008). Processus diagnostique des personnes présentant un trouble envahissant du développement au Québec: Expérience des parents [Diagnostic process for persons with a pervasive developmental disorder in Québec: Parents' experiences]. *Journal on Developmental Disabilities*, *14*, 19–28.

Rivard, M., Mercier, C., Mestari, Z., Terroux, A., Mello, C., & Bégin, J. (2017). Psychometric Properties of the Beach Center Family Quality of Life in French-speaking families with a preschool-aged child diagnosed with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, *122*, 439–452. https://doi.org/10.1352/1944-7558-122.5.439.

Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *44*, 1609–1620. https://doi.org/10.1007/s10803-013-2028-z.

Roth, B. M., Kralovic, S., Roizen, N. J., Spannagel, S. C., Minich, N., & Knapp, J. (2016). Impact of autism navigator on access to services. *Journal of Developmental & Behavioral Pediatrics*, *37*, 188–195. https://doi.org/10.1097/DBP.0000000000000261.

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Journal of Information*, *40*, 457–470. https://doi.org/10.1352/0047-6765(2002)0402.0.CO;2.

Schlebusch, L., Dada, S., & Samuels, A. E. (2017). Family quality of life of South African families raising children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*, 1966–1977. https://doi.org/10.1007/s10803-017-3102-8.

Sharpe, D. L., & Baker, D. L. (2007). Financial issues associated with having a child with autism. *Journal of Family and Economic Issues*, *28*, 247–264. https://doi.org/10.1007/s10834-007-9059-6.

Söderström, S. (2014). Lost in translation? Communication challenges in minority families' and healthcare workers' interactions. *Disability & Society*, *29*, 807–820. https://doi.org/10.1080/09687599.2013.848783.

Statistics Canada (2017). 2016 Census topic: Immigration and ethnocultural diversity. https://www12.statcan.gc.ca/census-recensement/2016/rt-td/imm-eng.cfm

Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., & Wang, M. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research*, *49*, 777–783. 10.1352/0047 6765(2002)040,0457:CMAAOQ.2.0.CO;2. https://doi.org/10.1111/j.1365-2788.2005.00751.x.

Svraka, E., Loga, S., & Brown, I. (2011). Family quality of life: Adult school children with intellectual disabilities in Bosnia and Herzegovina. *Journal of Intellectual Disability Research*, *1434*, 1–8. https://doi.org/10.1111/j.1365-2788.2011.01434.x.

Turnbull, A. P., Summers, J. A., Lee, S. H., & Kyzar, K. (2007). Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*, 346–356. https://doi.org/10.1002/mrdd.20174.

Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, *23*, 36–49. https://doi.org/10.1016/j.rasd.2015.11.008.

Wang, M., Summers, J. A., Little, T., Turnbull, A., Poston, D., & Mannan, H. (2006). Perspectives of fathers and mothers of children in early intervention programmes in assessing family quality of life. *Journal of Intellectual Disability Research*, *50*, 977–988. https://doi.org/10.1111/j.1365-2788.2006.00932.x.

Ward, C. A., Bochner, S., & Furnham, A. (2001). *The psychology of culture shock*. Hove England: Routledge.

The WHOQOL Group. (1994). Development of the WHOQOL: Rationale and current status. *International Journal of Mental Health*, *23*, 24–56. https://doi.org/10.1080/00207411.1994.11449286.

Williford, A. P., Calkins, S. D., & Keane, S. P. (2007). Predicting change in parenting stress across early childhood: Child and maternal factors. *Journal of Abnormal Child Psychology*, *35*, 251–263. https://doi.org/10.1007/s10802-006-9082-3.

Wolery, M., & Garfinkle, A. N. (2002). Measures in intervention research with young children who have autism. *Journal of Autism and Developmental Disorders*, *32*, 463–478. https://doi.org/10.1023/A:1020598023809.