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Quality of Life in Families of Young Children with Autism Spectrum Disorder

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Author Note

Portions of this work were presented at the 2017 AIDD and 2018 INSAR annual meetings. This research was supported by grants from the Montérégie Health Agency and the Québec Ministry of Health and Social Services to Céline Mercier and Méline Rivard. The authors wish to thank the CRDITED Montérégie-Est and its staff for their support, as well as all the families who participated in this study. The authors also thank Lauren Hammond, whose assistance was invaluable in preparing this manuscript.

Abstract

The present study investigated family quality of life (FQOL) as experienced by 493 mothers and fathers (295 families) of young children with autism spectrum disorder (ASD) prior to receiving early intervention services in the province of Québec. These families were most satisfied with their physical and material well-being and least satisfied with their family interactions. Children's level of functioning across various standardized and subjective measures, were positively associated with parents' FQOL. In both parents, family characteristics associated with financial and personal resources were also linked to FQOL. The child's age and the number of children were associated with mothers' FQOL. Overall, these findings provide a portrait of ASD-related stressors and resources relevant to both parents during the early childhood period.

Keywords: family, parenting, quality of life, early childhood, autism spectrum disorder

Quality of Life in Families of Young Children with Autism Spectrum Disorder

The extant literature on families of children with autism spectrum disorder (ASD) paints a relatively pessimistic picture of parents' health and well-being, but also of their employment, social, and conjugal situations (e.g., Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005). An increasing number of studies highlight the positive impacts of having a child with ASD on the family (e.g., Gray, 2006; Kayfitz, Gragg, & Orr, 2009; Montes & Halterman, 2007; Myers, Mackintosh, & Goin-Kochel, 2009). However, there remain inequalities in access to health, social, and education services in ASD, as well as stigma toward ASD, that create challenges in family functioning, interactions within the family unit, and family members' well-being and ability to participate in various activities in their community (e.g., work, socialization; Corcoran et al., 2015; Karst & Van Hecke, 2012). These various aspects of family functioning are encompassed within the concept of family quality of life (FQOL), which refers to the extent to which a family's needs are met, its members enjoy life together, and have the opportunity to engage in activities as other families (Turnbull et al., 2000).

Quality of life (QOL) is a multidimensional concept that includes individuals' emotional, material, and physical well-being as well as their interpersonal relationships and social inclusion, personal development, self-determination, and disability-related rights (e.g., Special Interest Research Group on Quality of Life, 2000). FQOL specifically relates to the QOL dimensions of family dynamics, the experience of having a family member with a disability, and family-oriented services or policies (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). This concept has become a topic of growing interest for research in intellectual and developmental disabilities (IDD; Schalock et al., 2002), particularly as a means of demonstrating the impact of

policies, programs, or treatments (Hoffman et al., 2006). Furthermore, whereas the focus of research on families' outcomes has historically focused on negative experiences such as stress, caregiver burden, etc., FQOL takes into account the positive and negative dimensions of families' experiences (for a review, see Gardiner & Iarocci, 2012).

Large-scale studies of FQOL with respect to IDD have been conducted in several countries (for a review, see Meral et al., 2013). In contrast, however, research on FQOL in ASD, particularly in early childhood, remains scarce. To date, the studies in this field that examined families' well-being have primarily focused on parenting stress and its correlates (e.g., McStay, Trembath, & Dissanayake, 2014a; Rivard, Terroux, Parent-Boursier, & Mercier, 2014); comparably few have examined quality of life (QOL) in families whose child has been diagnosed with ASD. A systematic review by Vasilopoulou and Nisbet (2016) found only 12 high-quality studies reporting QOL in families of children (0–18 years) with ASD. Eapen and Guan (2016) identified additional studies, although none used family-centered measures of QOL. In both reviews, QOL in families of children with ASD is lower than in those of typically developing children and of children with any other disability; lower QOL was generally observed in mothers. However, none of these studies focused on the early childhood period and, specifically, the moment when families receive a diagnosis for their child, a pivotal experience for parents. Yet, families of young children recently diagnosed with ASD may be especially susceptible to poor FQOL: in addition to the role balancing act common to all parents of young children (e.g., Williford, Calkins, & Keane, 2007), the acceptance of the recent diagnosis may act as a catalyst for a more comprehensive and radical re-examination of the family's functioning and goals (e.g., Corcoran et al. 2015).

The conditions or resources that maximize FQOL in families of individuals with disabilities have received considerable attention and remain a central concern for research in this field (Gardiner & Iarocci, 2012; Meral et al., 2013). Several authors have applied the Double ABCX model of family adaptation (McCubbin & Patterson, 1983) to examine outcomes such as caregiver stress and FQOL in ASD (e.g., Manning et al., 2011; Stuart & McGrew, 2009). This model has proved instrumental in accounting for variables highlighted as risk or protective factors, i.e., associated with more negative or positive family outcomes and adjustment, respectively. According to this model, the child's diagnosis represents a stressor with which families must cope. Within this framework, several child characteristics have been identified as additional stressors which compound the family's adaptation difficulties. Among these are the presence of problem behaviors (internalizing and externalizing; see Hall & Graff, 2012; McStay et al., 2014a; Pozo, Sarria, & Brioso, 2014), autism symptom severity (e.g., Stuart & McGrew, 2009; Schlebusch et al., 2017; but see e.g., McStay et al., 2014a), and low levels of adaptive or intellectual functioning (see Gardiner & Iarocci, 2015). Additional stressors and demands beyond the child's diagnosis may affect the family, such as marital difficulties, financial strain, or service access difficulties. However, families also possess resources that could moderate the impact of these stressors on the family and its ability to cope. Some of these resources are internal to the family, such as strong relationships within the family or financial means (e.g., income and employment; see Schlebusch et al., 2018; Vasilopoulou & Nisbet, 2016, Wang et al., 2004). Social support has emerged as an important external family resources, and has indeed been identified as a positive factor in FQOL studies (e.g., Meral et al., 2013, Stuart & McGrew, 2009; Vasilopoulou & Nisbet, 2016). Additionally, families vary in how they appraise and cope with various stressors,

including their child's diagnosis and difficulties; this, in turn may impact their outcomes (e.g., Manning et al., 2011; Pisula & Kossakowska, 2010; Stuart & McGrew, 2009).

There is inconsistent evidence regarding the respective levels of stress or FQOL experienced by each parent (see Vasilopoulou & Nisbet, 2016 for a review). However, whether or not absolute they differ in terms of mental health outcomes, mothers and fathers may nevertheless experience the various stressors associated with their child with ASD's diagnosis, such as symptom severity or challenging behaviors, differently (e.g., Baker-Ericzén, et al., 2005, Pozo et al., 2014; Rivard et al., 2014). They may also perceive and benefit differentially from the families' internal and external resources such as social support, income, etc. (e.g., Pozo et al., 2014). There is also evidence that mothers and fathers tend to deploy different coping strategies (Gray, 2003; McStay, 2014a). Some of these differences in parents' experience of their child's ASD may relate to their role in the family and typical interactions with the child (e.g., Gray, 2003).

The Present Study

To the best of our knowledge, no studies to date have examined FQOL in early childhood (0 to 5 years) following diagnostic evaluation, using an instrument specifically developed to assess FQOL. Furthermore, with one exception focusing on families of adolescents (Baghdadli et al., 2014), none have done so in French-speaking populations. Understanding how these families experience the various dimensions of FQOL and identifying potential risk (stressors) or protective factors (resources) would assist in the development and provision of interventions that are most relevant to families at this stage of the ASD services trajectory. Improving parents' FQOL could help them better care for their child, which would result in better outcomes for the family as a whole. To this end, the present study assessed FQOL and its determinants in a large sample

of families whose child had been diagnosed with ASD using a French version of the Beach Center FQOL scale (Redacted for blind review, 2017).

The objectives of the present study were to 1) report on, and compare, mothers' and fathers' of young children with ASD's family quality of life at a critical moment in their trajectory, i.e., when they requested services from a public rehabilitation center following their child's diagnosis but prior to receiving any form of intervention, and 2) identify potential risk factors (stressors) as well as protective factors (resources) among children's characteristics or associated with families' socioeconomic (internal) characteristics and social (external) support in relation to FQOL during this period.

Methods

Participants

A total of 295 families agreed to participate in the study. Of these, 4 (1.4%) did not make an appointment for an intake interview or complete any of the measures or questionnaires following their initial enrollment. Another 14 families (4.7%) did not complete or return by mail the primary study instrument (the BEACH FQOL scale). Thus, the final sample consisted of 278 families of preschool-aged children with ASD for a total of 493 parents, of whom 271 (52.7%) were mothers and 222 (47.3%) were fathers. Specifically, of the 277 families interviewed, 216 of these provided FQOL data for both parents (i.e., 432 parents); of the remaining 61 families, 6 and 55 had data regarding only the father's or mother's FQOL, respectively. Parents' demographic characteristics are summarized in Table 1. Seventy-six (27.4%) of the 277 children in the study sample were only children. Of the children with ASD with at least one sibling, 33 had a sibling diagnosed with either ASD (25), some other developmental or learning disability (19), or both (19). Preliminary analyses indicated that the presence of one or both conditions in a sibling

did not have a main effect on FQOL or interact with other factors. Therefore, families in which more than one child had a disability were included in subsequent analyses.

Insert Table 1 about here

At the time of the study, the participating families had requested services for their child from a public rehabilitation center for intellectual disabilities and ASD. To be eligible to receive services from this center, children must be diagnosed with ASD by an independent multidisciplinary team following Québec's provincial guidelines. This team included either a psychologist or pediatrician and, at the time of the study, applied the criteria in the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV-TR; American Psychiatric Association, 2000). The children in question were aged 28-64 months ($M = 45.9$, $SD = 7.3$) at intake; 220 (79.4%) were male.

Measures

Intake interview. The semi-structured intake interview included a range of sociodemographic and background questions querying characteristics such as parents' marital status, the child's siblings (number, age, and diagnoses), annual household income, parents' level of education and employment status, parents' country of origin and native language, and use of childcare services (provider type and hours per week) for the child with ASD. Table 1 presents details on these data. Parents were also asked to rate their child's overall functioning as a holistic score on a scale from 1 (lowest) to 100 (highest). These subjective ratings were included in the present study to examine whether parents' appraisal of the child's difficulties related to FQOL and to more specific or objective assessments of various aspects of the child's functioning. Parents were also asked to what extent a support network was available to them and they relied upon this support network (from 0 = *no* to 3 = *a lot*) – for the purpose of this study, responses to these two

items were averaged to form an indicator of level of perceived support. The nature of the support received from this network was left intentionally vague to include perceived emotional, financial, logistical, etc. support. Parents also indicated who was included in this support network (e.g., family members, friends, or neighbors, community resources).

Beach Center FQOL scale. The Beach Center Family Quality of Life Scale (Hoffman et al., 2006) was used to assess FQOL. A French translation of this scale was validated on the cohort of families described in the present study (Redacted for blind review, 2017). This self-report measure asks parents to rate the degree to which they are satisfied with various aspects of their family's life using a scale of 1 (*very dissatisfied*) to 5 (*very satisfied*). Some versions of this instrument also include importance ratings for these same items. The scale consists of 25 items comprising five subscales: Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-related support. These subscale scores and an average, global score, were used in the present study. Overall, the instrument was found to have acceptable to excellent internal consistency across subscales and overall, as well as satisfactory test-retest reliability and convergent validity (Hoffman et al., 2006). The French version generally replicated the original scale's factor structure and had excellent internal consistency at the whole scale level ($\alpha = .90$) and acceptable to good internal consistency across subscales ($\alpha = .72-.82$; Redacted for blind review, 2017).

Intellectual quotient. The French version of the Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III; Wechsler, 2002) was administered by a research assistant who held an undergraduate degree in psychology, had two years of experience in administering the instrument with this population, and was supervised by a psychologist. The full scale intellectual quotient (FSIQ), an overall score, was examined in this study. The WPPSI-III was validated

among children with and without developmental disabilities, and has demonstrated good to excellent internal consistency (.86–.97) and test-retest reliability (.84–.92; Wechsler, 2002).

Adaptive behaviors. The French version of the Parent/Primary Caregiver Form for ages 0–5 years of the Adaptive Behavior Assessment System-II (ABAS-II; Harrison & Oakland, 2003) was completed by parents to measure participants' adaptive behavior. This tool targets 10 adaptive skills within the three Conceptual, Social and Practical domains recognized by the AAIDD (Schalock et al., 2010). This form of the instrument includes 241 items, with 22 to 27 items focusing on each skill within the three domains. The General Adaptive Composite (GAC) score was used in the present study. The ABAS-II has demonstrated excellent internal consistency (.98–.99) and test-retest reliability (.90), as well as good convergent validity (.70–.84) with the Vineland Adaptive Behavior Scale (VABS; Sparrow, Cicchetti, & Balla, 2005).

Severity of autism symptoms. Autism symptom severity was measured using the French version of the Childhood Autism Rating Scale (CARS, Schopler, Reichler, & Rochen-Renner, 1988). This self-administered measure requires a parent or professional who knows the child well (e.g., a teacher) to rate 15 areas of the child's behavior in comparison to typically developing children. Total scores, as used in the present study, range between 15 and 60, with higher scores indicating more severe autism symptoms. This instrument has been found to have excellent internal consistency (.94) and good test-retest reliability (.88), interrater reliability (.71), and criterion validity (.84).

Executive functioning. At the time of this study, a validated French translation of a measure of challenging behavior adapted for use with this population was not available. However, the rehabilitation center routinely administered the Behavior Rating Inventory of Executive

Function – Preschool (BRIEF-P; Gioia, Espy & Isquith, 2003), which assesses several problematic behaviors that could be observed by caregivers. The 63-item scale which was completed by a parent or other caregiver who knew the child well. Respondents rated the frequency with which the child displayed problematic behaviors such as over the course of the past 6 months. For the purposes of the present study, the Global Executive Composite (GEC), an overall score, was used. The BRIEF-P has demonstrated good to excellent internal consistency (Cronbach's $\alpha = .80-.90$ by parents, $.90-.97$ by teachers). The GEC in particular has very high reliability ($r = .95$ and $.97$) and high test-retest reliability ($r = .90$ and $.88$; Gioia et al., 2003).

Socioaffective competencies. The Social Competence and Behaviour Evaluation scale (SCBE; Lafrenière & Dumas, 1996), known as the Profil Socio-Affectif in French (PSA; Lafrenière, Dumas, Capuano, & Dubeau, 1992) was used as an additional measure of behavioral difficulties (specifically, in domains such as externalizing behaviors, internalizing behaviors, and social competence). Respondents, typically preschool teachers, must rate the frequency with which the target child (aged 2.5–6 years) displays a range of behaviors related to social competence and emotional regulation. The full scale includes 80 items comprising the Externalizing Behaviors, Internalizing Behavior, Social Competence domains and, taken together, General Adaptation. In the present study, the latter overall score was analyzed. In a sample of Québec children, the PSA presented high internal consistency (Cronbach's $\alpha = .79-.91$), interrater reliability ($r = .72-.89$), and test-retest reliability ($r = .70-.87$; Lafrenière et al., 1992).

Procedure

The research protocol for this study was reviewed and approved by the ethics board overseeing rehabilitation centers for persons with ID and ASD in Québec. Participating families were

recruited within the context of a larger program evaluation initiative that examined a regional rehabilitation center's early intervention services. All families who were on the waiting list to early intervention for their child diagnosed with ASD were eligible to participate. The only exclusion criterion for participation in these services, and thus the present study, was the presence of a degenerative disease; families of children who presented a degenerative disease were eligible to receive specialized services from a different organization and were thus not recruited. A member of the research team, accompanied by a case manager from the center, first met with families to invite them to join a longitudinal study tracking children with ASD and their families beginning in early childhood. Research assistants visited the families who provided informed consent to participate. During these sessions, while parents were completing the various questionnaires, a research assistant administered a test of intellectual functioning to the child in another room. During this data collection period, an employee of the rehabilitation center administered measures of adaptive behaviors, severity of autism symptoms, and executive function to parents. They also oversaw the completion of a measure of socioaffective competencies by the child's daycare or preschool teacher (or another caregiver, as applicable).

Statistical Analyses

Preliminary analyses using the Missing Values Analysis package (SPSS) were conducted on missing data to verify that these did not constitute a pattern. Little's Missing Completely At Random (MCAR) test on FQOL and its correlates did not attain significance, $\chi^2(366) = 389.77, p = .188$. With the exception of data related to single-respondent families (e.g., missing FQOL or sociodemographic information for one parent), more than 5% of data were missing were socioaffective competencies (12.6% missing) and symptom severity (5.4%). Missing data for the former indicated that the study team was unable to coordinate with the child's preschool or daycare teacher to complete this measure.

For the first objective, analyses of variance (ANOVAs) were used to examine mothers' and fathers' FQOL within the same family as a function of gender and subscale (i.e., dimensions of FQOL). Inasmuch as parents' ratings were correlated (i.e., nonindependent), gender was treated as a within-dyad factor for the 216 dual-respondent families. Post hoc tests using Tukey's method were used to compare FQOL across subscales.

The second objective was addressed through a data reduction approach followed by multiple regression. First, the relations between variables identified as potential risk and protective factors and overall FQOL levels were assessed for mothers and fathers separately through Pearson's (binary or interval/ratio variables) correlations, and Spearman's rank correlations (ordinal variables). For these analyses, two categorical variables were dummy-coded to reflect their conceptualization as potential family resources: being in a single- or dual-parent household (marital status) and being employed outside the home or not (employment). Prior to multiple regression, data were inspected for multicollinearity: no variance inflation factors exceeded 2.5 (range: 1.10-2.39). However, some significant intercorrelations were observed between the independent variables, e.g., between household income and each parent's employment status ($r = .327$ and $.413$) and between measures of IQ, AB, autism symptoms, and executive functioning ($r = .404$ -.634). Such associations were expected at a conceptual level. Therefore, correlates of FQOL were entered into a principal component analysis using the Varimax rotation method with the specification that components with eigenvalues exceeding 1 be retained in the final solution. Mothers' and fathers' FQOL were then separately regressed on the resulting component scores. For these analyses, missing values were imputed using the Estimation-Maximization (EM) method (Tabachnik & Fidell, 2012). However, the observed patterns of results were also replicated when cases with missing values were omitted in a listwise fashion.

Results

Mothers' and Fathers' Perceptions of Family Quality of Life

Table 2 presents mothers' and fathers' mean satisfaction ratings on each subscale of the Beach Center FQOL scale and their total scores across the 216 dual-respondent families. Within the same family, mothers' and fathers' overall FQOL scores were positively correlated, $r(214) = .52, p < .001$ with each other; correlations between each parent's subscale scores ranged between $r = .415$ (Parenting) and $.474$ (Family Interaction). When each parent's subscale scores were entered in a 2 (Parent) x 5 (Subscale) ANOVA, there was neither a main effect nor an interaction involving the Parent factor, $F(1,215) = 0.01, p = .923, \eta_p^2 < .001$, and $F(4,860) = 1.11, p = .350, \eta_p^2 = .005$, respectively. FQOL significantly varied across subscales, $F(4,1104) = 33.23, p < .001, \eta_p^2 = .110$. Post hoc tests supported the following ordering of dimensions, from highest to lowest satisfaction: Physical/Material Well-being, Disability-related Support, Emotional Well-being, Parenting, and Family Interaction. With the exception of Emotional Well-being and Parenting, which did not differ from each other, $t(276) = 0.444, p = .660, d = 0.03$, all other pairwise comparisons were significant, all $t(276) \geq 2.19, p \leq .029, d = 0.13$ to 0.75 . This pattern of differences between FQOL subscale means was also obtained when including single-respondent families and using an averaged response for dual-respondent families; these results are therefore not presented here.

Insert Table 2 about here

Child- and Family-Related Covariates of FQOL

Descriptive statistics for child and family characteristics and their correlations with mothers' and fathers' overall FQOL are depicted in Table 3. With respect to child characteristics, significant associations between both parents' FQOL and children's adaptive behavior, executive

functioning difficulties, autism symptom severity, and holistic ratings of functioning were observed. Children's age was only correlated with mothers' FQOL, whereas IQ and socioaffective competencies only related to fathers' FQOL. With respect to family characteristics, number of children was linked to mothers', but not fathers' FQOL. Household income, mothers' employment¹, and perceived social support were associated with higher FQOL for both parents, but either parent's level of education and type of household (single- or dual-parent) were not.

The principal component analysis conducted on significant correlates of FQOL (in either or both parents) yielded three components, which accounted for approximately 55% of variance in scores. The rotated factor solution is depicted in Table 4. The first component consisted of all standardized tests of the child and the holistic rating of child functioning provided by the child's parents. The second component described some family resources: it included household income, mothers' employment outside the home, and perceived social support. The third component consisted of the number of children and the age of the child with ASD. Regressions using these components as independent variables and each parent's FQOL as dependent variables are shown in Table 5. In mothers, all three components were significant; for fathers, only the first two were significant.

Insert Tables 4 and 5 about here

Discussion

The first goal of this study was to report on FQOL among parents of young children recently diagnosed with ASD and prior receiving early intervention. Overall, parents' satisfaction

¹ Families in which the mother worked vs. did not work outside the home were compared in terms of key variables in this study. Unsurprisingly, families in which the mother worked (full- or part-time) had significantly higher income. However, there were also several significant differences of note in terms of children's characteristics: children of working mothers tended to have higher IQ and AB, as well as less severe symptoms and less pronounced executive functioning problems; their parents also perceived their global level of functioning as being higher.

with their FQOL was relatively neutral (i.e., 3.66–3.70 on a scale of 1 to 5, $M = 3.65$). Mothers' and fathers' FQOL ratings within the same family were also highly correlated across all subscales and overall (but see Pozo et al., 2014). Other studies among parents of children with ASD and/or IDD and with the Beach Center FQOL scale have thus far identified FQOL levels between 3.5–4 among families of children with ASD in Turkey (Meral et al., 2013); South Africa (Schlebusch et al., 2017), Canada (Gardiner and Iarocci, 2015), Australia (McStay et al., 2014a), and the United States (Eskow et al., 2011). Previous studies either found no differences in FQOL between mothers and fathers of children with various disabilities (e.g., Wang et al., 2006) or noted higher FQOL in fathers (e.g., McStay et al., 2014a; see Vasilopoulou & Nisbet, 2016, for an overview). In the present study, there were no salient differences between mothers' and fathers' reported FQOL levels.

Parents were most satisfied with the dimension of FQOL relating to Material and Physical Well-being. The lowest rated aspect of FQOL related to Family Interaction. This is the opposite of what was observed by Meral et al. (2013) in Turkish families of children with ID or ASD. Additionally, previous samples of South African, Canadian (receiving services), and American (receiving or awaiting services) families tended to have relatively high scores on Family Interaction (rated lowest in the present sample), along with Physical/Material Well-being and Disability-related Support subscales, but to score lowest on Emotional Well-being (Eskow et al., 2011; Gardiner & Iarocci, 2015; Schlebusch et al., 2017). It should be noted that a large portion of Turkish families were below the poverty, if not hunger, thresholds (96% and 60%, respectively) according to Meral et al. (2013). In the present sample, 40% of families had an annual income below \$50,000 (c.f. 22.7% in the Canadian sample of Gardiner & Iarocci, 2012, where Physical/Material Well-being was rated relatively highly). However, in spite of their modest income,

parents in Québec had access to various government-funded material resources and services to support them in caring for their child. Furthermore, they would soon be offered early behavioral intervention for their child, at no cost to their family. This security may enable families in Québec to focus on non-financial impacts of ASD on their family. It may also account for the fairly high satisfaction with Disability-related Support relative to other FQOL dimensions, and in comparison to other samples also awaiting services (Eskow et al., 2011) or even receiving some form of intervention (Gardiner & Iarocci, 2015; Meral et al., 2013; Schlebusch et al., 2017). Finally, the atypically low ratings for Family Interaction may relate to the young age of children in this sample, which may entail different preoccupations than in families of older children. Participants in this study had yet to benefit from formal support and evidence-based interventions to, for instance, facilitate social communication or manage the child's challenging behaviors or symptoms. Parents of older children in previous studies may have developed effective strategies over time, as would those who were receiving ASD support services, and thus enjoy more satisfying interactions.

A second goal of the present study was to identify characteristics of children with ASD and their families that may act as risk (stressor) or protective (resource) factors. The component summarizing measures of child functioning and an examination of bivariate correlates indicated that various characteristics of the child directly associated to, or related to ASD, were linked to FQOL. These patterns were slightly more pronounced among fathers. Overall, parents reported higher FQOL if their child displayed less severe symptoms, fewer behavioral problems linked to executive function, more adaptive behavior, higher socioaffective competences (i.e., more behaviors associated with social competence, and fewer externalizing or internalizing behaviors), as well as a higher IQ. It should be noted that parents' subjective ratings of their child's overall

functioning were correlated with these standardized indicators and showed the highest correlations with FQOL. This rating could therefore provide an efficient means of identifying families at risk for poorer FQOL prior to more in-depth assessments of their stressors and resources.

Several family characteristics were linked to FQOL: these appear related to the family's financial and human capital. Indeed, social support outside the family and financial means may serve as protective factors (for similar findings, see Pozo et al., 2014). The primary source of support reported by most families was the child's grandparents, whom the literature indicates often provide emotional and instrumental support (e.g., financial or childcare assistance, advocacy) to parents of young children with ASD (Hillman, 2007). Both parents displayed higher FQOL when the mother worked outside the home. While mothers' employment is inextricably linked to income (itself predictive of FQOL), the possibility that many of the mothers who remained at home did so out necessity in order to care for their child with ASD (e.g., Gau et al., 2012; Montes & Halterman, 2008) was indirectly corroborated by children's characteristics. Indeed, children of mothers who did not work had more severe clinical profiles as measured by standardized tests (i.e., IQ, adaptive behaviors, executive function, symptom severity) and according to their parents' subjective assessment. However, other studies suggest that participating in paid employment outside the home may be linked to better mental health and QOL outcomes, particularly through increased opportunities for social support (see Bourke-Taylor, Pallant, Law, & Howie, 2012). In the present study, the factors determining mothers' employment status (e.g., choice, financial or familial necessity) were not assessed. To the extent that almost all fathers in the sample worked outside the home, no patterns emerged with respect to their employment situation.

Finally, at least in mothers, having an older child with ASD was associated with higher FQOL but having multiple children was associated with lower FQOL (see also Schlebusch et al.,

2017). The age effect may be in part explained by the ASD service delivery model implemented in Québec, where families may wait for up to 2 years following their child's diagnosis to receive early intervention services. Because these services are discontinued by age 6 and the current system must ensure that all children receive at least one year of intervention before kindergarten, families of younger children are given a lower priority unless their child presents a more severe clinical profile. However, the results of the present study suggest that age remains a factor after accounting for the child's functioning. An additional possibility is that families (and, specifically, mothers) of older preschool-aged children had more time to accept their child's diagnosis and adjust their day-to-day routines and expectations accordingly, but had yet to encounter hurdles associated with the school years reported in studies encompassing a broader age range (e.g., McStay et al., 2014b). The associations between FQOL and number of children may reflect the fact that a parent may experience stress or guilt when their child with ASD requires more of their time relative to their siblings, as noted by Corcoran et al. (2015). This dynamic may change as the child grows older and the family as a whole adjusts to the ASD diagnosis.

Limitations

One major limitation of this study is that the study sample did not include a comparison group of families of typically developing children, or families of children with ASD receiving services from a rehabilitation center. Thus, the patterns found in both parents across the various domains of FQOL and their associations with families' and children's characteristics must be interpreted tentatively and with reference to the unique situation of the families in the present sample. The moderate amount of variance in parents' FQOL (14%) explained by the regression analyses may underestimate what could have been observed with more targeted measures. For instance, while the measures of executive function and socioaffective competencies employed here

indeed assess caregivers' observations of various behavioral difficulties, these are not a direct replacement for established measures of challenging behavior in children with ASD. However, it is also possible that young children's characteristics associated with ASD's (e.g., symptoms, co-occurring intellectual disability) are not as salient as in older children, and thus not as impactful for FQOL (Gardiner & Iarocci, 2015). In addition to some of the documented stressors and resources, it would have been informative to assess other components of the ABCX model (McStay et al., 2014a), which may account for other portions of the variance in FQOL. For instance, additional information regarding parents' appraisal of their child's recent diagnosed disability and current situation, their perceptions of the adequacy of their internal and external family resources, and coping strategies should be examined in this population.

It should also be noted that data collection and storage arrangements between the research team and the participating rehabilitation center (whereby some raw data for some measures were not available to the research team) made it impossible to obtain an overall response rate for the study and prevented the computation of psychometric indicators that require data for individual items (e.g., Cronbach's α). With respect to the second point, although internal consistency could not be computed for each instrument within the study sample, the literature on these instruments suggests that these exhibit adequate psychometric properties across a range of populations.

Practical Implications

The information derived from this study could be instrumental in refining or developing family-centered interventions suited to the families of pre-school children with ASD. The presence of some of the risk or protective factors (e.g., severity of clinical profiles, external support

availability) noted in this study could be used as a conversation starter when working with individual families to identify their needs. At the organizational level, service providers could use FQOL data to evaluate and improve service offerings to meet the needs of the whole family. For instance, family interactions, the dimension of FQOL with which parents were least satisfied, could be targeted by programs aimed at supporting families in the post-diagnosis period, as they await direct intervention services for their child. In addition to enhancing FQOL, such programs would indirectly benefit the child through increased parental well-being and involvement (Strauss et al., 2012). External support (primarily from the extended family) was highlighted as an important resource. In keeping with a family-centered approach to interventions for ASD, service offerings could be expanded to include interventions that support other relatives, especially grandparents. Initiatives that help families thrive in the tumultuous period of early childhood, particularly as they adjust to their child's diagnosis and begin seeking assistance, could also provide a foundation for the continued resilience of these families through other transitional periods or challenges.

Research Implications and Future Directions

This study complements the body of research based on more focused measures, such as parenting stress or satisfaction with services, that are frequently used to evaluate EIBI programs. Additionally, these outcomes and FQOL have to date primarily been researched among mothers. In addition to shedding light on FQOL during a less-researched period of family life in ASD, and doing so on a fairly large number of mothers and fathers, the present study also marked the beginning of a longitudinal study of families extending into the child's school years. Therefore, FQOL data will become available for other key developmental periods and may shed light on shifting preoccupations and experiences, as well as risk and protective factors, in these families.

Conclusion

Early intervention programs typically focus on educating the child, improving his or her adaptive behavior, and reducing symptoms associated with ASD. However, the effectiveness of these programs is contingent on parents' involvement and their well-being (Strauss et al., 2012). In keeping with this family-focused intervention philosophy, the present study examined FQOL and its correlates in a large sample of families of young children recently diagnosed with ASD. Further investigations into this concept will be instrumental in developing interventions that recognize the importance of parents and other relatives in supporting individuals with disabilities (Turnbull et al., 2005), and, in ASD in particular, in maximizing the impacts of direct interventions on the child.

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Table 1

Participant Demographic Information (N = 277 Families)

	<i>N</i>	%
Family structure		
Nuclear	212	76.5
Step-parent	33	11.9
Divorced or single-parent	30	10.8
Missing	2	0.7
Annual household income		
Below \$29,999	60	21.7
\$30,000 to \$49,999	57	20.6
\$50,000 to \$69,99	53	19.1
\$70,000 to \$89,999	40	14.4
Over \$90,000	62	22.4
Missing	5	1.8
	Mothers	Fathers
Educational background	(<i>N</i> = 271)	(<i>N</i> = 222)
Some high school	41	41
High school	69	56
CEGEP ^a	85	54
Undergraduate	57	43
Graduate	15	20
Missing	4	8
Employment		
Full-time worker	108	170
Part-time worker	38	6
Freelance or contract worker	12	12
Homemaker	87	14
Unemployed	6	8
Student	4	2
Other	10	7

Missing	6	3
Origin		
Québec	228	187
Canada (other region) and United States	6	2
Latin America and Caribbean	11	8
Western Europe	3	5
Eastern Europe and Asia	7	8
Africa	15	15
Missing	1	5
Native language		
French	247	203
English	11	5
Other	13	12
Missing	1	2

^a In Québec, CEGEPs are general and vocational educational institutions that grant two- or three-year postsecondary degrees preparing students for university-level education or trades.

Table 2

*Overall FQOL Scale and Subscale**Descriptives for Dual-Respondent Families*

Subscale	Mothers		Fathers	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Family Interaction	3.49	0.71	3.51	0.70
Parenting	3.65	0.78	3.69	0.71
Emotional Well-being	3.65	0.77	3.69	0.72
Physical/Material Well-being	3.91	0.727	3.94	0.64
Disability-related Support	3.71	0.79	3.81	0.77
Overall FQOL	3.66	0.58	3.70	0.58

Note. FQOL = Family Quality of Life.

Table 3

Children's Characteristics and Correlations With Parents' Family Quality of Life

	<i>M</i>	<i>SD</i>	Correlations with FQOL	
			Mothers	Fathers
Child's gender			-.07	-.07
Child's age at intake (years)	3.83	0.61	.17**	.07
Parents' holistic rating	58.85	14.99	.27***	.36***
Full-Scale Intellectual Quotient (WPPSI-III)	74.31	21.85	.03	.16**
General Adaptive Composite (ABAS-II)	66.83	14.90	.21**	.25**
Autism severity (CARS)	31.38	7.88	-.17**	-.29***
Socioaffective competencies (PSA)	41.77	8.47	.03	.15*
Global Executive Composite (BRIEF-P)	68.41	14.45	-.17**	-.26***
Type of household (single- vs dual-parent)			.06	.03
Number of children (<5) ^a	1.94	0.84	-.15**	-.11
Household income ^b			.11*	.16**
Father's education ^b			-.06	.06
Mother's education ^b			.03	.08
Father's employment (none vs. Full-/part-time)			.02	-.08
Mother's employment (none vs. Full-/part-time)			.12*	.14*
Perceived social support	1.56	0.94	.31***	.21**

Note. FQOL = Family Quality of Life (subscale scores: FI = Family Interaction, P = Parenting, EW = Emotional Well-being, PW = Physical/Material Well-being, DS = Disability-related Support), WPPSI-III = Wechsler Preschool and Primary Scale of Intelligence, ABAS-II = Adaptive Behavior Assessment System-II, CARS = Childhood Autism Rating Scale, PSA = Profil Socio-affectif, BRIEF-P = Behavior Rating of Executive Function – Preschool. ^a Only five families had more than four children; these excluded from the analysis. ^b Denotes an ordinal

variable for which Spearman's rank, rather than Pearson's, correlation coefficient is reported. * one-tailed $p < .05$, ** $p < .01$, *** $p < .001$.

Table 4

Principal Components Extracted from Correlates of Parents' FQOL

Variable	Component		
	Child Functioning	Family Resources	Children
Child's age at intake			-.71
Full-Scale Intellectual Quotient (WPPSI-III)	.76		
General Adaptive Composite (ABAS-II)	.78		
Autism severity (CARS)	-.83		
Socioaffective competencies (PSA)	.71		
Global Executive Composite (BRIEF-P)	-.49		
Parents' holistic rating	.68		
Number of children (<5)			.62
Household income		.70	
Mother's employment (none vs. Full-/part-time)		.71	
Perceived social support		.58	
Eigenvalue	3.19	1.80	1.15
R^2	.29	.16	.10

Note. Rotated solution as per the Varimax method. Loadings below .40 or are omitted. WPPSI-III = Wechsler Preschool and Primary Scale of Intelligence, ABAS-II = Adaptive Behavior Assessment System-II, CARS = Childhood Autism Rating Scale, PSA = Profil Socio-affectif, BRIEF-P = Behavior Rating of Executive Function – Preschool.

Table 5

Regression Analyses on Parents' Family Quality of Life Based on Child and Family Characteristics

Component	Mothers		Fathers	
	β	p	β	p
Child Functioning	.12	.029	.29	<.001
Family Resources	.24	<.001	.20	<.001
Children	-.26	<.001	-.11	.053
F	15.195	<.001	14.644	<.001
R^2	.14		.14	

Note. Component scores were computed such that a high value indicates a high level of functioning (e.g., less severe symptoms, higher levels of adaptive behavior), more family resources, and an older child.