UNIVERSITÉ DU QUÉBEC À MONTRÉAL

EXPÉRIENCE DES PARENTS ISSUS DE L'IMMIGRATION AYANT UN ENFANT AVEC UN TROUBLE DU SPECTRE DE L'AUTISME : STRESS PARENTAL, QUALITÉ DE VIE FAMILIALE ET PERCEPTIONS DU TROUBLE DU SPECTRE DE L'AUTISME

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DÉDICACE

« *C'est dans notre famille qu'on*
trouve nos meilleurs soutiens. »
Félicité de Genlis

À toutes les familles qui ont un enfant
avec un TSA et qui se battent au
quotidien pour le soutenir.

À ma famille qui a été d'un soutien
inimaginable.

AVANT-PROPOS

Cette thèse est composée de trois articles documentant l'expérience des familles issues de l'immigration ayant un enfant avec un trouble du spectre de l'autisme (TSA).

Le premier article de cette thèse, intitulé « *Parenting stress in immigrant families of children with an autism spectrum disorder: a comparison with families from the host culture* » a fait l'objet d'une présentation au 22e congrès de l'Internationnal Association for Cross-Cultural Psychology (IACCP) et est publié à titre de chapitre de livre. Il décrit les différences de stress parental entre des parents issus de l'immigration et des parents québécois, durant la période suivant le diagnostic de leur enfant et pendant l'attente de service.

Le second article quant à lui compare la qualité de vie familiale des parents issus de l'immigration et des parents québécois, toujours dans la période particulièrement difficile qui est celle faisant suite au diagnostic. Il s'intitule « *Family quality of life in immigrant families of children with autism spectrum disorder : a comparison with families from the host culture* » et a été soumis en juin 2018 au *Journal of child and familiy studies*.

Enfin, le troisième article de cette thèse : « *Immigrant families' perception of the causes, first manifestations, and treatment of autism spectrum disorder* » est une étude qualitative visant à documenter les perceptions des parents issus de l'immigration quant à leur perception des causes du TSA, quant aux premiers symptômes perçus chez leur enfant, ainsi que leurs priorités de traitement. Cet article a été accepté en mai 2018 pour publication au *Journal of child and familiy studies*.

Ces trois articles visent à dresser un portrait de l'expérience des parents issus de l'immigration, mais également à mettre en avant les différences selon le genre du parent.

Dans le cadre de cette thèse, chaque article commence par une introduction permettant de le mettre en contexte. Les trois articles sont suivis d'une discussion générale abordant entre autres les limites de la recherche, les apports cliniques et les perspectives de recherches futures.

Les deux premiers articles proviennent d'une même banque de données issue d'un projet de grande ampleur visant à évaluer la qualité des services (Rivard, Lépine, Mercier et Morin, 2015). Ainsi, il est possible qu'il y ait certaines redondances qui sont nécessaires à la compréhension des articles indépendamment du contexte de cette thèse.

TABLE DES MATIÈRES

LISTE DES FIGURES

LISTE DES TABLEAUX

LISTE DES ABRÉVIATIONS, DES SIGLES ET DES ACRONYMES

ABA	Applied Behavior Analysis (analyse appliquée du comportement)
APA	American Psychological Association
ASD	Autisme Spectrum Disorder
CDC	Center for Disease Control and Prevention
CRDITED	Centre de réadaptation en déficience intellectuelle et troubles envahissants du développement
DI	Déficience intellectuelle
DSM	Manuel diagnostique et statistique des troubles mentaux
FQoL	Family quality of life (qualité de vie familiale)
ICI	Intervention comportementale intensive
ISP	Indice de stress parental
TSA	Trouble du spectre de l'autisme

RÉSUMÉ

Les études rapportent que les familles ayant un enfant avec un trouble du spectre de l'autisme (TSA) et qui sont issues de l'immigration présentent plus de difficultés dans l'accès, l'utilisation et l'adhésion aux services d'intervention offerts à leur enfant (Cho et Gannotti, 2005; Klingner, Blanchett et Harry, 2009; Mandell et Novak, 2005). En effet, elles sont confrontées à plusieurs barrières telles que la langue, les différences quant aux perceptions de ce qui cause le TSA et de la façon dont on devrait intervenir et le manque de familiarité avec le système de santé du pays d'accueil (Barrio, 2000; Gardiner et French, 2011; Liptak *et al.*, 2008). Tous ces éléments peuvent avoir un impact, non seulement sur l'accès aux services, mais aussi sur leur collaboration avec les professionnels, notamment en termes d'implantation des interventions proposées. Les études en TSA soulignent l'importance de la prise en charge précoce pour un meilleur diagnostic chez l'enfant et un meilleur bien-être des familles (Eikeseth, Klintwall, Jahr et Karlsson, 2012; Eldevik *et al.*, 2009). Ainsi, il est important de documenter les éléments entravant ce processus, mais aussi les éléments facilitateurs de celui-ci. Aussi, les pères sont peu représentés dans les recherches sur les familles ayant un enfant avec un TSA, comparativement aux mères (Davis et Carter, 2008). Afin de proposer des aides adaptées aux besoins des pères et des parents issus de l'immigration, il est essentiel de mieux comprendre leur expérience. Le présent projet s'inscrit dans cette perspective et vise à dresser le portrait de l'expérience des pères et mères issus de l'immigration et de la comparer aux parents québécois.

Les résultats de cette étude sont présentés sous la forme de trois articles. Le premier article avait pour objectif d'analyser et de comparer le stress parental de 41 parents (24 mères et 17 pères) issus de l'immigration à celui de 41 parents québécois (24 mères et 17 pères). Cet article s'intéresse également aux différences selon le genre des parents. Les résultats indiquent que les parents québécois ont un niveau de stress parental plus élevé que les parents issus de l'immigration, plus particulièrement les pères québécois présentent un stress parental plus élevé que toutes les mères et que les pères issus de l'immigration.

Le deuxième article compare la qualité de vie familiale (FQoL) de 52 parents issus de l'immigration (29 mères et 23 pères) à celle de 52 parents québécois (29 mères et 23 pères) dont l'enfant a reçu un diagnostic de TSA et avant qu'ils ne reçoivent des services. Les résultats indiquent que les familles issues de l'immigration rapportent une moins bonne satisfaction de leur FQoL que les parents québécois.

Enfin, le troisième article a pour objectif de documenter la perception de 45 parents issus de l'immigration (28 mères et 17 pères) concernant les causes, leur perception quant aux premiers symptômes du TSA perçus chez leur enfant, et les interventions et traitements à favoriser selon eux. Les causes les plus souvent citées par les parents sont les causes environnementales (alimentation, vaccins). Concernant les premiers symptômes perçus, les parents nomment majoritairement les problèmes de langage. On observe des différences selon le genre, concernant les priorités de traitement. Alors que les mères favorisent l'orthophonie, la priorité des pères est le soutien scolaire.

Les résultats de ces trois articles permettent de souligner l'importance de développer des services de soutien aux familles et qu'ils soient adaptés à leur situation. Ces services de soutien devraient inclure des services d'information sur le TSA, les causes et les traitements afin d'augmenter les connaissances des parents. Il est également nécessaire que ces services offrent des stratégies visant la réduction du stress parental et l'augmentation de la qualité de vie familiale. De plus, des formations dédiées aux professionnels devraient être offertes afin de les sensibiliser aux défis et difficultés rencontrés par l'ensemble des membres de la famille et à les sensibiliser à l'intervention culturellement sensible.

Mots clés : trouble du spectre de l'autisme, culture, familles issues de l'immigration, pères, stress parental, qualité de vie familiale.

ABSTRACT

Studies report that immigrant families of children with Autism Spectrum Disorder (ASD) have greater difficulty accessing, using and adhering to intervention services offered to their child (Cho & Gannotti, 2005; Klingner, Blanchett & Harry, 2009; Mandell & Novak, 2005). Indeed, they face several barriers such as: language, differences in perceptions regarding the causes of ASD and intervention approaches, as well as lack of familiarity with the health system of the host country (Barrio, 2000; Gardiner & French, 2011; Liptak et al., 2008). All of these elements can have an impact not only on access to services, but also on the collaboration with professionals, particularly in terms of the implementation of the proposed interventions. Studies on ASD emphasize the importance of early intervention for a better prognosis for the child and for the well-being of the family (Eikeseth, Klintwall, Jahr & Karlsson, 2012; Eldevik et al., 2009). Thus, it is important to document the elements hindering this process, but also the factors that facilitate it. Also, fathers are poorly represented in research on families with children with ASD compared to mothers (Davis & Carter, 2008). In order to offer support tailored to the needs of fathers and parents of immigrant backgrounds, it is essential to better understand their experience. From this perspective, the current project aims to portray the experience of first-generation immigrant fathers and mothers in comparison to Quebec parents.

The results of this study are presented in the form of three articles. The first article aims to analyze and compare the parental stress of 41 parents (24 mothers and 17 fathers) of immigrant origin to that of 41 Quebec parents (24 mothers and 17 fathers). This article is also interested in the differences in gender functions of parents. The results indicate that Quebec parents have a higher level of parental stress than parents of immigrant background. More specifically, Quebec fathers were found to have higher parental stress than all mothers and fathers of immigrant background.

The second article compares the family quality of life (FQoL) of 52 parents of immigrant background (20 mothers and 23 fathers) to that of 52 Quebec parents (29 mothers and 23 fathers) whose child was diagnosed with ASD before they receive services. The results indicate that families of immigrant background report lower FQoL satisfaction than Quebec parents.

Finally, the purpose of the third article is to document the perception of 45 parents of immigrant background (28 mothers and 17 fathers) about the causes, their perception of the first symptoms of ASD in their child, and the interventions and treatments that are available and that should be prioritized in their opinion. The causes most often cited by parents are environmental causes (e.g., food, vaccines). Concerning the first symptoms that were perceived, parents mainly name language difficulties. With regard to the priority treatments and interventions, a gender-based difference can be observed. While mothers favor speech therapy, fathers tend to favor school support.

The results of these three articles highlight the importance of developing support services for families that are adapted to their situation. These support services should include information services on ASD, causes and treatments to increase parent knowledge. It is also necessary for these services to offer strategies aimed at reducing parental stress and increasing the family quality of life. In addition, training courses for professionals on immigration-related issues should be offered to raise awareness of the challenges and difficulties faced by all family members and families as a whole.

Keywords: autism spectrum disorder, cultural beliefs, fathers, immigrant families, parental stress, family quality of life.

INTRODUCTION

Partout dans le monde, on retrouve des disparités culturelles et ethniques dans l'accès et l'utilisation des services d'éducation et de santé de qualité pour les personnes ayant un trouble du développement tel que le trouble du spectre de l'autisme (TSA; Klingner, Blanchett et Harry, 2009; Magaña, Lopez, Aguinaga et Morton, 2013; Mandell, Listerud, Levy et Pinto-Martin, 2002). Dans les pays occidentaux où l'on observe davantage la présence de services basés sur les données probantes[1], ces disparités persistent et des études révèlent que les familles issues de l'immigration ont un parcours d'accès aux services plus difficile, engendrant d'importantes conséquences sur leur santé physique et mentale (Dyches, Wilder, Sudweeks, Obiakor et Algozzine, 2004; Flores et al., 2002; Mandell et Novak, 2005). Au Québec, la politique À part entière : pour un véritable exercice du droit à l'égalité, mentionne que les besoins des personnes assujetties aux préjugés et en situation de vulnérabilité doivent être une priorité (Office des personnes handicapées du Québec, 2009). Parmi ces personnes en situation de vulnérabilité, les familles issues de l'immigration ayant un enfant avec un TSA doivent faire face à la fois aux défis liés à l'immigration et l'intégration à la culture d'accueil, en plus de ceux liés à la situation de leur enfant (Klingner et al., 2009; Magaña et al., 2013; Mandell et al., 2002). Les familles dont l'enfant présente un TSA cumulent plusieurs difficultés sur les plans de leur situation familiale, économique et sociale, de leur emploi, de leur santé physique et mentale, et ce, bien plus que les familles ayant un enfant avec tout autre handicap (Baker-Ericzen, Brookman-Frazee et Stahmer, 2005; Blacher et McIntyre, 2006; Corcoran, Berry et Hill, 2015; Hastings et

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[1] Notamment l'intervention comportementale intensive (ICI), dont l'efficacité est soutenue par de nombreuses recherches. L'ICI est répertoriée par plusieurs organisations nationales comme une pratique exemplaire pour les jeunes enfants atteints de TSA et est inclue dans les guides de pratique de ces organisations. C'est le cas au Québec où l'ICI est offerte par les services publics.

Johnson, 2001; Rivard, Terroux, Parent-Boursier et Mercier, 2014). Ces difficultés seraient exacerbées dans le cas des familles issues de l'immigration (Cho et Gannotti, 2005; Klingner et al., 2009; Mandell et Novak, 2005). La littérature scientifique indique que le stress des familles, leur santé physique et mentale peuvent affecter leur implication dans le traitement (Strauss et al., 2012). Certaines études mettent en évidence que plus les familles sont impliquées dans le traitement de leur enfant, plus les effets sur l'enfant sont prometteurs (Crockett, Fleming, Doepke et Stevens, 2005; Strauss et al., 2012, 2013; Vasilopulou et Nisbet, 2016). En ce sens, la recherche en TSA s'oriente de plus en plus vers la compréhension du vécu, des besoins et des attentes des familles afin de leur proposer des services adaptés et de maximiser leur implication et la collaboration entre les parents et ces services d'intervention (Meral, Cavkaytar, Turnbull et Wang, 2013; Schlebusch, Dada et Samuels, 2017). Les groupes les plus vulnérables tels que les familles issues de l'immigration ou celles étant plus défavorisées sur le plan économique sont sous-représentés dans les recherches (IASSID, 2012). C'est également le cas des pères qui participent moins aux recherches que les mères (Davis et Carter, 2008). Afin de mieux répondre aux besoins de ces parents, il est important de s'intéresser à leur expérience et ceci en s'intéressant à différents aspects de cette expérience (Gardiner et French, 2011; Hughes, Valle-Riestra et Arguelles, 2008; Welterlin et LaRue, 2007).

0.1 Définition et prévalence du trouble du spectre de l'autisme

Selon les dernières études menées aux États-Unis et au Canada, le taux de prévalence du trouble du spectre de l'autisme (TSA) aurait augmenté de manière considérable cette dernière décennie (Centers for Disease Control and Prevention [CDC], 2017; Institut national de santé public au Québec [INSPQ], 2017). Il s'agit du trouble neurodéveloppemental qui a la plus forte incidence avec une prévalence de 1/59 chez les enfants (CDC, 2017). Les garçons sont quatre fois plus touchés par ce trouble que les filles (CDC, 2017). Le taux de prévalence du TSA et la symptomatologie sont relativement homogènes entre les cultures (CDC, 2017). Au Québec, les études épidémiologiques réalisées avec des données scolaires indiquent que le taux de prévalence du TSA est de 1/101 dans les écoles (Noiseux, 2014). Ce diagnostic se caractérise par des atteintes dans les domaines de la communication et des interactions sociales, ainsi que par la présence de comportements restreints et stéréotypés (American Psychological Association [APA], 2013a). Ces symptômes se présentent sur un continuum de sévérité allant d'une atteinte légère à sévère. Chacun de ces niveaux de sévérité se distingue par le degré de soutien requis (APA, 2013a). Aussi, les études indiquent une prévalence importante des troubles concomitants (ex. : déficience intellectuelle, trouble du déficit de l'attention) chez les enfants ayant un TSA (INSPQ, 2017).

0.2 Les familles d'enfants présentant un TSA

La famille est un système composé d'au moins deux personnes, qui accomplissent chaque jour différentes fonctions en lien avec les responsabilités familiales (Poston, Turnbull, Park et al., 2003; Turnbull et Aldersey, 2014). Parmi ces responsabilités, on retrouve notamment la santé affective, la socialisation, l'éducation, les soins quotidiens et le bien-être économique (Turnbull et Aldersey, 2014). En tant que système, la famille est sans cesse en évolution afin de s'adapter aux différents cycles de vie et aux défis rencontrés, engendrant ainsi des changements dans les fonctions familiales (Turnbull et Aldersey, 2014). Cette adaptation dépend des caractéristiques de la famille, des caractéristiques individuelles de chaque individu qui la constitue et des défis particuliers (Poston et al., 2003; Turnbull et Aldersey, 2014). Les interactions familiales sont également influencées par ces caractéristiques et permettent l'accomplissement des fonctions familiales (Turnbull et Aldersey, 2014).

Le fait de vivre avec un enfant présentant un TSA est un des défis particuliers nécessitant des adaptations sur plusieurs dimensions familiales et à différents moments du cycle de vie (Chatenoud, Kalubi, Purdy, 2014; Gardiner et Iarocci, 2012; Pétales et al., 2012). En effet, les fonctions familiales et les interactions de tous les membres de la famille sont modifiées par ce diagnostic (Cappe, Chatenoud et Paquet, 2014; Gardiner et Iarocci, 2012; Turnbull, Turnbull, Erwin, Soodak et Shogren, 2011; Pétales et al., 2012). Parmi ces modifications, on peut retrouver : un temps supplémentaire accordé aux soins de l'enfant ayant un TSA, un temps plus restreint dans les activités de loisirs, des différences dans les pratiques parentales, un risque d'endettement et des changements concernant la carrière des parents (Hall et Graff, 2010; Jarbrink, 2007; Paquet, Chatenoud et Cappe, 2014; Sharpe et Baker, 2007). Les caractéristiques propres à la symptomatologie du TSA, par exemple les difficultés de communication ou comportementales, mais aussi les difficultés concomitantes telles que les problèmes de sommeil, d'alimentation ou encore l'agressivité peuvent engendrer un stress important et un épuisement chez les membres de la famille (Cappe et al., 2014; Hodgetts, Nicholas et Zwaigebaum, 2013; Hoffman, Sweeney, Lopez-Wagner et al., 2008). De manière générale, les études dressent un portrait pessimiste du vécu des parents ayant un enfant avec un TSA (Hastings et Johnson, 2001; Hoffman et al., 2008; Khanna et al., 2011). Ils sont confrontés à de nombreux défis, pouvant avoir des effets importants sur leur stress, leur qualité de vie et leur santé (Brookman-Frazee et al., 2011; Donaldson, Elder, Self et Christie, 2011; Karst et Van Hecke 2012, Mackintosh et al., 2012, Rivard et al., 2014). Les études sur le stress parental des parents d'enfant présentant un TSA mettent en lumière qu'entre 26 % à 85 % des parents dépassent le seuil clinique de stress parental (Ingersoll et Hambrick, 2011; Kayfitz, Gragg et Orr, 2010). L'accès aux services d'évaluation diagnostique, d'intervention précoce et de soutien aux familles est un des défis majeurs contribuant à la situation des parents (Brookman-Frazee et al., 2011; Granger, Des Rivières-Pigeon, Sabourin et Forget, 2012; McLennan, Huculak et Sheehan, 2008). Au Québec, l'augmentation des demandes de services de diagnostic et d'intervention occasionne des retards dans l'obtention de ceux-ci pouvant aller jusqu'à deux ans (Protecteur du citoyen, 2009, 2012). Cette période d'attente des services est exigeante pour les parents qui sont souvent seuls pour trouver l'information sur les ressources disponibles et pour faire les démarches d'obtention de ces services. Cela, en plus de devoir faire face au choc en lien avec l'annonce du diagnostic de leur enfant (Bitterman, Daley, Misra, Carlson et Markowitz, 2008; Brookman-Frazee et al., 2011; Granger et al., 2012; McLennan et al., 2008).

Plusieurs études révèlent que la satisfaction des parents quant aux services reçus pour leur enfant est influencée par les conditions d'accès à ces services (Barelds et al., 2009; Rivard, Lépine, Mercier et Morin, 2014). Ainsi, cette période est déterminante, non seulement pour l'évolution des services que recevra l'enfant, mais aussi pour la satisfaction des familles. Bien que cette étape soit reconnue comme étant éprouvante pour les familles et cruciale pour l'ensemble de la trajectoire des services, peu d'études se sont intéressées à l'expérience des parents et à leurs besoins durant cette période (parmi ces études voir celles de Mello et al., 2018, en révision; Rivard et al., 2014). De plus, les familles issues de l'immigration, celles ayant un statut socio-économique faible, mais aussi les pères, sont moins susceptibles de faire l'objet de recherche. Pourtant, ces populations sont les plus vulnérables, et sont plus enclines à obtenir des services de moindre qualité (Cho et Gannotti, 2005; Klingner et al., 2009; Mandell et al., 2002, 2009; Söderström, 2014).

0.3 Les parents issus de l'immigration ayant un enfant avec un TSA

Au Canada, on observe une augmentation de l'immigration des familles provenant de différentes régions du monde (Statistiques Canada, 2017). En 2016, le recensement canadien indiquait que 21,9 % de la population était issue de l'immigration, que le

Québec était l'une des quatre provinces accueillant le plus de nouveaux arrivants et que 91 % des personnes issues de l'immigration habitaient dans une région métropolitaine (Statistiques Canada, 2017). Dans la région métropolitaine de Montréal, les personnes issues de l'immigration représentent 23,4 % de la population (Statistiques Canada, 2017). Les données sociodémographiques d'une étude québécoise menée de 2009 à 2011 dans un centre de réadaptation en déficience intellectuelle et trouble envahissant du développement (CRDITED[2]) révèlent que plus de 20 % des familles recevant des services pour leur enfant ayant un TSA sont nés à l'étranger (Rivard et al., 2014). Ainsi, le taux de personnes issues de l'immigration nécessitant des services en TSA est proportionnel au taux de personnes issues de l'immigration dans la population générale.

Le fait d'immigrer dans un nouveau pays représente un défi particulier pour les familles. Être parent dans un contexte de double culture nécessite une adaptation qui est d'autant plus importante lorsque l'enfant présente des particularités développementales telles qu'un TSA (Rueda, Monzo, Shapiro, Gomez et Blacher, 2005). Les démarches d'accès aux services, déjà difficile pour les familles québécoises, représentent un défi supplémentaire pour les familles qui ne sont pas familières avec le fonctionnement du système de soin, ou celles ayant des barrières de langue, de culture ou de statut socio-économique (Klingner et al., 2009; Magaña et al., 2013; Mandell et Novak, 2005; Rivard, Millau, Morin et Forget, 2013). La littérature scientifique met effectivement en évidence des différences culturelles dans l'accès aux soins, dans l'obtention de traitements de qualité, dans le diagnostic des enfants et dans la qualité de vie des familles ayant un enfant présentant un TSA (Emerson, McConkey, Walsh et Felce, 2008; Fombonne, 2009; IASSID SIRG, 2012; Jones et al., 2011). Aussi, la perception des causes et des symptômes peut être différente selon la culture d'origine, ce qui peut affecter le délai de recherche de services, mais aussi la collaboration avec

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[2] Bien que le terme TSA ait remplacé le terme TED dans le DSM-5, l'appellation des CRDI n'a pas changé, ce qui explique qu'on utilise le terme CRDITED ici.

les professionnels lorsque ces services sont obtenus (Cho et Gannotti, 2005; Mandell et Novak, 2005; Ravindra et Myers, 2012). Le rôle complexe des valeurs culturelles et le statut social ont une influence sur l'adaptation des familles, nécessitant de développer et d'offrir des programmes qui soient adaptés à l'ensemble des familles d'enfants ayant un TSA (Barrio, 2000; Gardiner et French, 2011). Actuellement, les travaux de recherche ne sont pas représentatifs de l'ensemble des familles ayant un enfant avec un TSA puisqu'ils concernent majoritairement les populations anglophones caucasiennes provenant de pays occidentaux (Al-Salehi, Al-Hifthy et Ghaziuddin, 2009; Dyches et al., 2004; Emerson, Fujiura et Hatton, 2007; Emerson et al., 2008). Afin d'avoir une meilleure connaissance du vécu des parents ayant un enfant présentant un TSA, il apparaît nécessaire d'orienter plus de travaux auprès des familles issues de minorités ethnoculturelles (Gardiner et French, 2011; IASSID, FSIRG; 2012), mais aussi auprès de familles ou de membres de la famille dont on a peu documenté l'expérience telle que les pères (Davis et Carter, 2008).

0.4 Les pères d'enfant ayant un TSA

De manière générale, la paternité est de plus en plus étudiée, due notamment à l'évolution du rôle des pères au sein de la famille, qui s'investissent davantage dans l'éducation des enfants (Cabrera, Tamis-LeMonda, Bradley, Hofferth et Lamb, 2000). Dans le domaine des TSA, les études documentant l'expérience des parents se sont majoritairement intéressées aux mères (Rivard et al., 2014). De plus, lorsque les pères sont inclus dans les recherches, on retrouve de petits échantillons, ce qui ne permet pas de généraliser les résultats (Rivard et al., 2014). Les résultats des quelques études comparant le stress parental ou la qualité de vie familiale selon la perspective des pères et des mères ne sont pas consistants; certaines études indiquent des différences entre les parents, d'autres révélant des scores similaires pour les pères et les mères (Davis et Carter, 2008; Hastings, 2003; Herring et al., 2006; Rivard et al., 2014). Les études sur les rôles parentaux indiquent que comparativement aux parents d'enfants ayant un développement typique, les pères d'enfant présentant un TSA auraient davantage un rôle traditionnel (soutien financier) alors que les mères seraient quant à elles plus centrées sur les soins de leur enfant (Courcy, 2014; Gray, 2003).

Les quelques études réalisées auprès des pères sur leur expérience indiquent que ceux-ci ont plusieurs préoccupations, notamment concernant l'avenir de leur enfant (Goulet, 2016; Hunt-Jackson, 2007; Isenhour, 2010). Malgré ces inquiétudes et les modifications familiales engendrées par les symptômes associés au TSA, les pères parviennent à identifier des éléments positifs de cette expérience tels que développer une plus grande patience, une meilleure compréhension des différences et un enrichissement personnel (Isenhour, 2010; Stehouwer, 2014). Ces études comportent de petits échantillons (entre 6 et 21 participants), il est donc difficile de généraliser les résultats à l'ensemble des pères d'enfants ayant un TSA.

La littérature, dans le domaine des TSA, documente en majorité les aspects difficiles tels que le stress, les difficultés d'accès aux services et les émotions négatives. Ces aspects sont nécessaires pour comprendre les difficultés rencontrées par les parents. Néanmoins, il est également primordial de s'intéresser aux facteurs soutenant une meilleure qualité de vie et d'avoir une vision plus complète du vécu des familles (Meral et al., 2013; Schlebusch et al., 2017).

La présente thèse vise à dresser un portrait du vécu des pères et mères issus de l'immigration et dont l'enfant présente un TSA, ceci à la suite de l'annonce du diagnostic et avant qu'ils n'obtiennent des services. À cette fin, la thèse se décline en trois articles, chacun s'intéressant à trois aspects complémentaires et importants du vécu de ces parents afin de pouvoir identifier leurs besoins en vue de développer des services adaptés.

Le premier article porte sur une analyse comparative du stress parental rapporté par des pères et des mères issus de l'immigration et des pères et des mères d'origine québécoise[3] caucasienne francophone. Le deuxième article vise à enrichir le portrait de ces familles en documentant la perception de la qualité de vie des familles (FQoL) selon ces parents. Cet aspect apporte une vision différente des besoins des parents. D'une part, le stress parental apporte une vision sur les difficultés parentales, d'autre part le FQoL permet d'identifier les éléments satisfaisants d'une famille. Le FQoL vise à déterminer les forces et les besoins des parents concernant la famille (ex. : besoin de soutien, les interactions familiales), alors que le stress parental documente et évalue leur stress concernant leur rôle de parent sans considérer la dynamique familiale.

Finalement, le troisième article de la thèse complète le portrait du vécu des parents issus de l'immigration à la suite de l'annonce du diagnostic de TSA chez leur enfant en documentant leurs perceptions concernant les causes du TSA de leur enfant, les premiers symptômes qu'ils ont perçus, et leurs priorités de traitements. Ces trois articles forment les trois premiers chapitres de la thèse et décrivent ensemble l'expérience des parents. Chaque article présente un contexte théorique en lien avec l'aspect de l'expérience des parents à l'étude, les objectifs de l'étude, la méthode, les résultats et la discussion. Le quatrième et dernier chapitre est une discussion générale des résultats de chacun des articles. Il est suivi d'une conclusion portant sur l'ensemble de la thèse.

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[3] Pour faciliter la compréhension des lecteurs internationaux, nous avons utilisé dans les trois articles le terme « canadien » plutôt que « québécois ». Afin d'être plus précis, le terme « québécois » est utilisé dans cette introduction ainsi que dans la discussion générale.

CHAPITRE I

PARENTING STRESS IN IMMIGRANT FAMILIES OF CHILDREN WITH AN AUTISM SPECTRUM DISORDER: A COMPARISON WITH FAMILIES FROM THE HOST CULTURE

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1.1 Abstract

Immigrant families of children with autism spectrum disorders (ASD) face significant challenges in accessing and using rehabilitation services appropriate for their child's disorder. Compared to families native to their host country, the stress experienced by these families in relation to their child's condition may be magnified by their immigrant status. This study compared self-reported parenting stress levels among 24 mothers and 17 fathers who had immigrated to Canada to income-matched, Canadian-born parents. Overall, Canadian-born parents tended to report higher stress levels than immigrant parents, but this may be primarily due to the high stress levels among Canadian-born fathers relative to immigrant fathers and mothers from both types of families. These findings highlight the necessity of using supplemental and specialized stress measures when focusing on immigrant families, for whom stress associated with the immigration process may compound or manifest separately from parenting stress. Cultural influences on the perception of ASD (its causes, treatment, and prognosis), children's place in the family, and parents' roles in childrearing may also impact stress.

Keywords: Autism spectrum disorder, parenting stress, immigrant families, early intervention services, acculturation

1.2 Résumé

Les familles issues de l'immigration ayant un enfant atteint de trouble du spectre autistique (TSA) sont confrontées à des difficultés considérables pour accéder aux services d'intervention pour leur enfant. Comparé aux familles originaires du pays d'accueil, le stress subi par ces familles peut être amplifié par leur statut d'immigration. Cette étude compare les niveaux de stress parental de 24 mères et 17 pères issus de l'immigration à celui de parents nés au Canada ayant le même revenu annuel. Les résultats indiquent que les parents nés au Canada ont un niveau de stress parental plus élevé que les parents issus de l'immigration. Ces résultats mettent en évidence la nécessité d'utiliser des mesures supplémentaires et spécialisées pour les familles issues de l'immigration, pour qui le stress associé au processus d'immigration peut se manifester indépendamment du stress parental. Les influences culturelles sur la perception du TSA (ses causes, son traitement et son pronostic), la place des enfants dans la famille et le rôle des parents dans l'éducation des enfants peuvent également influer sur le stress et avoir un impact sur les résultats.

Mots clés : Trouble du spectre de l'autisme, stress parental, familles issues de l'immigration, acculturation.

1.3 Introduction

Families of children with autism spectrum disorders (ASD) face several difficulties on a daily basis. Indeed, the symptoms associated with these diagnoses heighten the challenges of educating and caring for their child (Benson, 2006; Blacher & McIntyre, 2006; Davis & Carter, 2008; Freeman, Perry, & Factor, 1991). Furthermore, seeking out and obtaining appropriate health care and special education services and supports is especially problematic in the case of ASD (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008; Brachlow, Ness, McPheeters, & Gurney, 2007; Hayes & Watson, 2013; Kogan et al., 2008; Rivard, Lépine, Mercier, & Morin, 2014). As a result, these families have been shown to exhibit higher stress levels than the families of children with other conditions (e.g., Down syndrome, cerebral palsy; Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Blacher & McIntyre, 2006; Hayes & Watson, 2013; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Several family characteristics, such as being of a low socioeconomic status, undergoing an immigration process, or belonging to an ethnic or cultural minority, may intensify this stress. These situations may decrease families' access to, and usage of, services as well as increase their risk for social maladjustment and mental disorders (Bailey, Scarborough, Hebbeler, Spiker, & Mallik, 2004; Denney, Itkonen & Okamoto, 2007; Harry, 1992; Mandell & Novak, 2005; McManus, McCormick, Acevedo-Garcia, Ganz, & Hauser-Cram, 2009; Rivard, Millau, Morin, & Forget, 2013). Although the literature highlights the specific challenges faced by immigrant families of children with ASD, to date it lacks systematic comparisons between immigrant and nonimmigrant families. This study sought to address this gap by contrasting the stress levels of first-generation immigrant and Canadian-born parents whose children had recently been diagnosed with ASD and placed on a waiting list for early intervention services.

1.3.1 Parenting stress among families of children with ASD

Families of children with ASD experience greater mental health, employment, social, and marital challenges in comparison to the families of children with physical or intellectual disabilities (Baker-Ericzen et al., 2005; Blacher & McIntyre, 2006; Bouma & Schweitzer, 1990; Dumas, Wolf, Fisman, & Culligan, 1991; Hastings & Johnson, 2001; Holroyd & McArthur, 1976; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Olsson & Hwang, 2001; Sanders & Morgan, 1997; Wolf, Noh, Fisman, & Speechley, 1989). Unfortunately, these difficulties are widespread: one child out of every 68 receives an ASD diagnosis and this prevalence has been increasing continuously in recent years (Centers for Disease Control and Prevention, 2014). The stressors experienced by these families notably include delays in obtaining and confirming the child's diagnosis; seeking out and accessing appropriate services for both the child and the family; transitioning between daycare, kindergarten, and school (Osborne, McHugh, Saunders, & Reid, 2008). According to a recent study (Rivard, Terroux et al., 2014), between 54.1 and 60% of parents displayed clinically significant stress levels during the period following their child's diagnosis, as they were placed on a waiting list for services. These stress levels were notably influenced by mothers' education, the child's age, sex, and clinical profile, as well as waiting times for services.

1.3.2 Immigrant families of children with ASD

Immigrant families of children with ASD are doubly vulnerable to stress as they must tackle challenges inherent to their immigrant status (Berry & Sabatier, 2010; Berry & Sam, 1997; Thomas, 1995) alongside those of their child's condition (Cho & Gannotti, 2005; Klingner, Blanchett, & Harry, 2009; Mandell & Novak, 2005; Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005). Their task of locating services and collaborating with professionals is made more complex by language barriers and cultural differences in terms of, for instance, their intervention priorities and their perceptions and understanding of disabilities and mental health (Cho & Gannotti, 2005; Klingner et al., 2009; Mandell & Novak, 2005; Perry et al., 2011; Pituch et al., 2011; Welterlin & LaRue, 2007). Families of children with ASD who belong to ethnic or cultural minorities are indeed at a disadvantage in accessing quality services and with respect to their child's prognosis and their family's quality of life (Bailey et al., 2004; Emerson, McConkey, Walsh, & Felce, 2008; Fombonne, 2009; Families Special Interest Research Group of the International Association for the Scientific Study of Intellectual and Developmental Disabilities [FSIRG-IASSIDD], 2012; Jones et al., 2011; Rosenberg, Daniels, Law, Law, & Kaufmann, 2009).

These disparities may be explained by immigrants' difficulty navigating the health and social services system of their host country, obtaining reliable information, and expressing themselves in the host language (Liptak et al., 2008; Montes, Halterman, & Magyar, 2009; Mandell & Novak, 2005). Cultural variations in the perception of mental disorders and disabilities, prejudices toward mental disorders, and expectations for services may compound the impact of these hurdles (Barrio, 2000; Cho & Gannotti, 2005; Harry, Klingner, & Hart, 2005; Rivard et al., 2013). Indeed, minority families experience more discrimination, are less satisfied with the services that they receive, and have less positive relationships with professionals compared to majority families (Cho & Gannotti, 2005; Freedman & Boyer, 2000; Rosenberg et al., 2008; Samadi, McConkey, & Kelly, 2011, 2012).

Although the proportion of immigrant families is continually increasing in countries traditionally populated by predominantly White individuals[4], research in the field of ASD has generally focused on White, English-speaking families (Daley & Sigman, 2002; FSIRG-IASSIDD, 2012). The susceptibility to the negative consequences of a child's ASD diagnosis has been well documented among minority families (Gardiner & French, 2011; Klingner et al., 2009; Mandell & Novak, 2005). However, the

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[4] For instance, immigrants make up 20.6% of the population of Canada and 22.6% of the population in the greater Montréal area (Statistics Canada, 2012).

relationship between parents of children with ASD's immigrant status and stress levels has yet to be examined. Understanding how these families' situations influence their stress and overall quality of life is crucial to better addressing their needs (Gardiner & French, 2011).

1.3.3 Cultural differences in parental roles

In addition to these concerns, it should be noted that culture influences family structure and parental roles. This may, in turn, affect how parents experience their child's condition. For instance, in traditional views of gender roles, fathers provide instrumental, financial, and disciplinary support and are therefore less present in the child's day-to-day life. For instance, Hofferth (2003) reported that Black fathers spent less time with their children and exercised greater control over them than did White fathers. Thus, investigations of immigrant parents' stress must also take into account cultural differences regarding mothers' and fathers' respective responsibilities and contact with their child who has ASD.

1.3.4 Objectives

This study sought to examine the impact of migrant status on the stress levels of mothers and fathers whose child has ASD. To this end, the stress of parents who had immigrated to Canada was compared to that of parents born in this country. To the extent that mothers and fathers may experience their child's condition and immigration-related stressors differently, the impact of gender on parenting stress was examined alongside the impact of immigrant status.

1.4 Method

1.4.1 Participants

This study was conducted in Québec, a Canadian province in which services for children and adults with ASD are provided by public institutions called rehabilitation centers. These centers provide free specialized supports and rehabilitation services to any individual with a confirmed ASD diagnosis. All participants were enrolled in a broader research project assessing the effectiveness of a rehabilitation center's services (see Rivard, Terroux et al., 2014). Among the initial population that completed the parenting stress measure (118 families), 24 families consisted of first-generation immigrant (i.e., born outside of Canada) parents. In all cases, the child's mother and father were living together at the time of the study. However, for seven of these families, the father did not complete the parenting stress measure (see Table 1.1) because he was either unwilling or unavailable to participate directly in the study. These immigrant families were paired with 24 income-matched, Canadian-born families who had been recruited in the context of the same project. In order to maintain comparable samples, we omitted from statistical analyses the data from Canadian-born fathers who were paired to an immigrant family for which the father's demographic and stress information were missing. Thus, a total of 48 families were analyzed in this investigation (24 immigrant mothers and 24 Canadian-born mothers; 17 immigrant fathers and 17 Canadian-born fathers).

1.4.2 Measures

Parenting stress was assessed with the French version of the Parenting Stress Index Short Form (PSI/SF; Abidin, 1995; Bigras, LaFrenière, & Abidin, 1996). The PSI/SF is a self-report stress measure for parents of children aged between 3 months and 10 years. Responses are based on a five-point Likert scale. The instrument's 36 items are distributed across three subscales: Parental Distress, Parent-Child Dysfunctional Interactions, and Difficult Child. Scores on each subscale range between 13 and 65 points, yielding total scores between 36 and 180 points for the entire scale. Higher scores correspond to greater stress levels, with the authors recommending 90 points as a clinical cutoff. As a whole, the PSI/SF exhibits excellent internal consistency (Cronbach's $\alpha = .91$ for the entire scale; .40–.63 for its subscales) and good test-retest reliability ($r = .84$ for the entire scale; .68–.85 for its subscales; Abidin, 1995). The linguistic and semantic equivalence of the French translation to its original was verified through a conventional back-translation process. The French version was standardized on a sample of 377 mothers whose age, ethnicity, and socioeconomic status was comparable to the normative sample for the original version (Bigras et al., 1996).

1.4.3 Procedure

Prior to collecting data, the research team explained to family members the goals of the study, the scope of their participation, and the steps that would be taken to preserve their confidentiality. Those who elected to participate signed a consent form. Data collection took place while families were on the waiting list for early intervention services provided by the participating rehabilitation center. During a meeting with the parents, a research assistant administered several measures including the PSI/SF and a demographic questionnaire. When one of child's parents was unable to attend this meeting, the other parent was encouraged to given him or her a copy of each form and return it to the researchers by mail.

1.4.4 Analyses

Descriptive statistics were computed for the following demographic information: household income, education, employment, and ethnicity. A 2 (Migrant status) x 2

(Gender) related-samples factorial ANOVA was conducted for total parenting stress scores and for each of the three PSI/SF subscales. These ANOVAs only included the data from mothers that could be paired with corresponding responses from the child's father. In light of prior findings of superior stress among fathers compared to mothers in a Canadian-born sample (Rivard, Terroux et al., 2014), these ANOVAs were followed up by planned contrasts that used paired-samples t-tests to compare Canadian-born men's scores to those of the three other subgroups. Fisher's exact test was used to compare the proportion of participants within each subgroup of the entire sample who exceeded the clinical cutoff for stress according to their total scores. The level of significance was set to .05 for all analyses.

1.5 Results

1.5.1 Demographic information

Demographic information from participants both groups are displayed in Table 1.1. The majority of immigrant parents had annual household incomes ranging between CAN$10,000 and $29,000, the lowest income category. Because immigrant and non-immigrant families were paired on the basis of income, these proportions were also observed among Canadian-born parents. Immigrant fathers were more likely to be employed full time and less likely to stay at home than their Canadian-born peers. This pattern was reversed among mothers: compared to Canadian-born mothers, fewer immigrant mothers worked full time and more stayed at home. Immigrant fathers and mothers with a college or university degree were considerably more numerous than Canadian-born parents with the same educational attainment. Most of the immigrant families had come from the Maghreb region (Algeria, Morocco, and Tunisia) and Latin America.

1.5.2 Total stress levels

Mothers' and fathers' results on the PSI/SF are presented in Tables 1.2 and 1.3, respectively. Regarding total scores, only a significant main effect of migrant status was found, with Canadian-born parents reporting higher stress levels than their immigrant peers, $F(1,16) = 4.506$, $p = .050$. The main effect of gender and the interaction between migrant status and gender were not significant, $F(1,16) = 1.606$, $p = .223$ and $F(1,16) = 1.841$, $p = .194$, respectively. Planned comparisons indicated that Canadian-born fathers' stress scores were significantly higher than those of Canadian-born mothers, $t(16) = 2.149$, $p = .047$, immigrant fathers, $t(16) = 2.372$, $p = .031$, and immigrant mothers, $t(16) = 2.761$, $p = .014$. Thus, the main effect of migrant status may be partially driven by Canadian-born fathers' high total stress scores. When examining the proportion of parents for whom total scores exceeded the clinical cutoff, no differences were found between immigrant (76.47%) and Canadian-born (94.2%) fathers, $p = .168$, or between immigrant (79.2%) and Canadian-born (95.8%) mothers, $p = .094$.

1.5.3 Scores on the PSI/SF subscales

As with total scores, only a significant main effect of migrant status was observed for the Parental Distress subscale, with Canadian-born parents reporting higher levels of distress than their immigrant peers, $F(1,16) = 11.817$, $p = .003$. The main effect of gender and the interaction between migrant status and gender were not significant, $F(1,16) = 1.025$, $p = .326$ and $F(1,16) = 0.793$, $p = .386$. Canadian-born fathers' parental distress scores did not differ from those of Canadian-born mothers, $t(16) = 1.300$, $p = .212$, but were significantly higher than both immigrant fathers', $t(16) = 2.720$, $p = .015$, and immigrant mothers' scores, $t(16) = 3.414$, $p = .004$.

A similar pattern of results was observed for the Parent Child Dysfunctional Interaction subscale, with only the main effect of migrant status attaining significance, $F(1,16) = 6.045$, $p = .026$. The main effect of gender and the interaction between migrant status and gender were not significant, $F(1,16) = 2.646$, $p = .123$ and $F(1,16) = 0.546$, $p = .462$. According to planned contrast analyses, Canadian-born fathers' scores on this subscale did not differ from those of Canadian-born mothers, $t(16) = 0.093$, $p = .927$, immigrant fathers, $t(16) = 1.611$, $p = .127$, or immigrant mothers, $t(16) = 1.297$, $p = .213$.

For the Difficult Child subscale, however, a different pattern of group differences emerged. There was a main effect of gender, $F(1,16) = 7.114$, $p = .017$. The main effect of migrant status and the interaction between migrant status and gender did not attain significance, $F(1,16) = 0.904$, $p = .356$, and $F(1,16) = 4.205$, $p = .057$, respectively. Canadian-born fathers' scores on this subscale significantly exceeded those of Canadian-born mothers, $t(16) = 2.891$, $p = .011$, and immigrant mothers, $t(16) = 2.161$, $p = .046$, but not those of immigrant fathers, $t(16) = 1.771$, $p = .096$.

1.6 Discussion

To the best of our knowledge, this study was the first to compare the stress levels reported by parents of children with ASD according to their migrant status. The literature on families of children with ASD reports elevated stress as a result of the child's diagnosis as well as additional challenges for immigrant families. This study compared immigrant and Canadian-born parents' stress at a crucial point in their trajectory within public services, that is, after their child's diagnosis but prior to receiving services.

The high stress levels noted across the entire sample is consistent with other studies examining the families of children with ASD (Baker-Ericzen et al., 2005; Blacher &

McIntyre, 2006; Rivard, Terroux et al., 2014). In fact, the mean total stress score (117.04) and the overall proportion of participants (87.8%) whose score was at or above the clinical cutoff exceeded previously documented levels. For instance, the proportion of families experiencing clinically significant stress levels varies between 26 and 85% across studies (Ingersoll & Hambrick, 2011; Kayfitz, Gragg, & Orr, 2010). The rates of clinically significant stress were comparable across genders and may be attributable to three characteristics of the present study: the moment at which data were collected, families' socioeconomic status, and waiting times for services.

Data were collected during the period following the child's diagnosis, as the families were placed on a waiting list for early intervention. This period was previously found to be particularly stressful for the parents of young children with ASD (Cox et al., 1999; Davis & Carter, 2008; Osborne et al., 2008). Because immigrant and Canadian-born parents were paired in terms of annual household income, lower-income families (less than $29,000 per year) were overrepresented in the final sample. These families are less likely to receive early intervention services and display greater psychological distress, higher stress, and less positive parenting than families with a higher socioeconomic status (Bailey et al., 2004; Bakermans-Kranenburg, Van IJzendoorn, & Kroonenberg 2004; Denney et al., 2007; McManus et al., 2009). Furthermore, the length of the waiting period to obtain public services, which may be up to 2 years in the province of Québec, is in itself source of stress (Québec Ombudsman, 2009; Rivard, Terroux et al., 2014). Given these waiting times and provided they have the financial means to do so, families may turn to private clinics to obtain early intervention services for their child. Low socioeconomic status families cannot afford private care and must thus endure the stress of long waiting periods during which their child is not receiving the services that he or she needs.

The primary goal of this study was to ascertain whether immigrant mothers and fathers experienced higher stress levels than Canadian-born parents of children with ASD. To date, the literature on this topic suggests that given the additional challenges faced by first-generation immigrants in general, immigrant parents whose child has ASD are likely to experience higher stress levels than parents native to their host country. The additional difficulties faced by immigrant parents of children with ASD have been documented elsewhere (Cho &Ganotti, 2005; Klingner & al, 2005). Indeed, the social, cultural, and economic adjustment required of immigrant families are compounded by difficulties associated with their child's diagnosis, namely in terms of gaining access to ASD services and related to their child's behavioral and developmental particularities. Moreover, language barriers, a lack of familiarity with the health care system, as well as cultural differences with respect to values, expectations, and perception of the child's diagnosis can be major obstacles to gaining access to services and collaborating with professionals. Because these many potential difficulties, the original hypothesis underlying this study was that immigrant families would report higher stress levels than families native to their host country. In actuality, the immigrant families who participated in the present study tended to show lower levels of stress compared to their Canadian-born peers. Several factors may account for this unexpected result: the type of measures used, parents' status with respect to accessing specialized services, several characteristics of participating immigrant families, or cultural differences in the perception of parental roles or understanding of ASD.

Regarding the potential impact of measure selection, the unexpected finding of lower stress among immigrants may be attributable to the specific nature of the stress scale adopted for this study. Indeed, the PSI/SF measures parenting stress exclusively, without accounting for other stressful life circumstances or events (Abidin, 1995). It may thus fail to fully capture the stress experienced by immigrant parents. This speculation finds support in a study by Emmen et al. (2013) that tested a minority family stress model among immigrant mothers of typically developing children aged between 5 and 16 years. The authors found that (1) acculturation stress was linked to socioeconomic status and (2) was correlated with fewer positive parenting experiences, and (3) that general psychological distress levels were uncorrelated to acculturation stress. They inferred that stress pathways may differ between immigrant and majority families. Thus, investigations into the challenges faced by immigrant families may require the use of specific measures of acculturation stress, as well as gathering information on their immigration history and their experience of integration in the host culture, including discrimination in order to assess the full complexity of their stress process. Unfortunately, no such data were collected in this study.

Another possible explanation for the fact that immigrant mothers and fathers did not display higher stress levels than their Canadian-born peers may be related to their interactions with the rehabilitation center. At the time of the study, these families were awaiting services from, and therefore in contact with, the regional rehabilitation center. Yet one of the most frequently reported difficulties faced by immigrant families of children with special needs relates to the accessibility of such services (FSIRG-IASSID, 2012; Haack, Gerdes, & Lawton, 2014; Jones et al., 2011; Klingner et al., 2009; Welterlin & LaRue, 2007). Although they had yet to receive services, the mothers and fathers enrolled in this study had been able to have their child diagnosed and had secured a place on a waiting list for early behavioral intervention. Their situation may therefore not be representative of immigrant families in general. Some of the demographic characteristics of these parents, namely their high level of education, may have facilitated their access to services. Indeed, approximately half of immigrant parents in this study had obtained an undergraduate (bachelor's) or graduate (master's or doctoral) degree. A study by Goldyne (2013) reported that families whose immigration experience is positive (i.e., without acculturation stress) are more oriented toward the host culture. They are thus more likely to have access to social support and information about resources available to parents. Given their high education levels, the immigrant families who participated in the present study may therefore have a generally more positive immigration experience, which could also facilitate their access to services. Moreover, cultural differences in families' attitudes and coping strategies could account for these findings. For instance, Blacher and McIntyre (2006) report that Latin American families present more positive attitudes toward their child with disabilities. Thus, culture-specific values regarding disability, along with attitudes toward stress, may contribute to the fact that the immigrant parents in this study did not present elevated stress levels compared to Canadian-born families in spite of facing additional challenges,.

The observation of higher stress levels among Canadian-born fathers compared to their immigrant peers and mothers is consistent with findings by Rivard, Terroux et al. (2014). Using the PSI/SF, these authors also noted higher total stress scores and a higher proportion of clinically significant stress among fathers (*M* = 118.35, 60.6%) than mothers (*M* = 112.38 and 54.1%). The fact that Canadian-born fathers reported higher stress levels than their immigrant peers may be due to cultural differences in the perception of paternal roles and fathers' level of involvement with their children. As a function of fathers' culture, these may have translated into varying levels awareness of their child's atypical behaviors and development, and thus concerns about his or her future and parenting stress. For instance, in some cultures the father tends to be seen as an authority figure who is responsible for the family's financial security (Al-Krenawi & Graham, 2000). Fathers' involvement in child-rearing also varies greatly in terms of intensity and task sharing across cultures. Canadian-born fathers may not be perceived exclusively as breadwinners and may be expected to participate more directly in their child's daily life. For instance, we noted that they three times more likely to stay at home in the present study. This greater proximity to their child may translate into an increased awareness of his or her atypical behaviors and development, thereby eliciting more concerns about the child's future and higher levels of parenting stress. More generally, the lower stress levels observed among immigrant families may be due to cultural differences in terms of their expectations and norms for children, which may extend to how the child's behavioral and emotional difficulties are perceived.

1.7 Limitations

As a preliminary exploration of the relationship between parenting stress and immigrant status, the present study was not without limitations. First, the stress measure cannot be considered culture-free: although translated versions normed among other cultural groups (e.g., Hispanic cultures) were available, the Québec French version was used for this study. Its content validity was assessed within, and therefore influenced by, the predominant culture in Québec. As such, the items used to assess stress may not be sufficiently sensitive to parenting stress as it is experienced and expressed in immigrant families' native cultures. The study sample was also relatively small and not necessarily representative of immigrant families of children with ASD. It namely excluded families who had not be referred to services or sought to obtain these on their own. Highly educated and low-income parents were also overrepresented. These sampling issues are due to the fact that the research project from which these data were obtained was not designed for an in-depth examination of immigrant families. For this same reason, additional information regarding families' immigration history, reasons for immigrating, acculturation stress, and coping strategies were not collected. Future studies would benefit from gathering this type of information in order to better examine parenting and acculturation stress as they relate to the immigration process. In this respect, two ongoing projects are specifically investigating immigrant families' 1) perception of ASD symptoms, treatment, and prognosis; 2) expectations toward parental support services; and 3) perceptions of service delivery. In light of some of the limitations encountered in the present study, these projects will further examine variables relating to immigration conditions, acculturation, and cultural differences in parental roles and conceptualizations of ASD.

1.8 Conclusion

This study demonstrates that the families of children with ASD generally experience high stress levels. In fact, participants reported stress levels in excess of what had been observed among this population, which may be attributable to their comparably lower income. Financial difficulties may exacerbate the stress of having a child with ASD. Contrary to what had been hypothesized, immigrant parents did not display higher total stress levels than their Canadian-born peers. Such findings do not necessarily indicate that immigrant parents do not experience heightened stress. Rather, it may be that a measure of parenting stress such as the PSI/SF does not capture the presence of additional sources of stress. Additionally, these results suggest that stress levels may also be related to families' characteristics and status with respect to gaining access to services. Through these observations, this study highlights important considerations for future research and clinical applications. First, the high levels of stress noted here in both native and immigrant families and their possible relation to household income suggest that families placed on a waiting list for services could benefit from less resource-intensive parental support programs. Second, research on immigrant families' experiences would benefit from additional information about immigration history, acculturation stress, social support, and culturally-based perceptions of parental roles and ASD, as well as from the selection of psychological measures normed for use among these groups. These precautions would support a broader understanding of these families' complex situation and pave the way for solutions.

1.9 Tables

Table 1.1 Demographic characteristics of immigrant and canadian-born parents

	Immigrant N=41		Canadian-born N=41	
	Mothers *n* (%)	Fathers *n* (%)	Mothers *n* (%)	Fathers *n* (%)
Family income				
$10,000-29,999	12 (50)	9 (52.9)	12 (50)	9 (52.9)
$30,000-49,999	3 (12.5)	1 (5.8)	3 (12.5)	1 (5.8)
$50,000-69,999	5 (20.8)	4 (23.5)	5 (20.8)	4 (23.5)
$70,000-89,999	1 (4.1)	1 (5.8)	1 (4.1)	1 (5.8)
$90,000 and above	3 (12.5)	2 (11.7)	3 (12.5)	2 (11.7)
Level of education				
Incomplete secondary degree	4 (16.6)	1 (5.8)	7 (29.1)	4 (23.5)
Secondary or vocational degree	5 (20.8)	2 (11.7)	5 (20.8)	5 (29.4)
Postsecondary	5 (20.8)	3 (17.6)	6 (25)	4 (23.5)
Undergraduate	7 (29.1)	6 (35.3)	3(12.5)	0 (0)
Graduate	3 (12.5)	5 (29.4)	1 (4.1)	0 (0)
Other or missing information	0 (0)	0 (0)	2 (8.3)	4 (23.5)
Employment				
Full-time work	8 (33.3)	12 (70.5)	9 (37.5)	9 (52.9)
Part-time work	3 (12.5)	1 (5.8)	4 (16.6)	0 (0)
Freelance or contract work	0 (0)	0 (0)	1 (4.1)	1 (5.8)
At home	10 (41.6)	1 (5.8)	8 (33.3)	3 (17.6)
Other (e.g., student)	3 (12.5)	3 (17.6)	2 (8.3)	4 (23.5)
Birth Country				
North Africa (Maghreb)	8 (33.3)	5 (29.4)		
Latin America	5 (20.8)	4 (23.5)		
Central & West Africa	4 (16.6)	3 (17.6)		
Middle East	3 (12.5)	2 (11.7)		
Other (Haiti, China)	2 (8.3)	1 (5.8)		

Table 1.2 Mothers' total and subscale scores on the parenting stress index short form

	Immigrant *M* (*SD*)	Canadian-born *M* (*SD*)	Total *M* (*SD*)
Parental Distress	38.92 (10.19)	43.63 (5.89)	42.21 (14.29)
Difficult Child	35.45 (10.62)	33.83 (8.46)	34.64 (9.53)
Parent-Child Dysfunctional Interaction	38.08 (6.24)	40.54 (5.57)	39.31 (5.98)
Total stress	112.46 (22.84)	123.13 (26.58)	115.36 (19.74)

Table 1.3 Fathers' total and subscale scores on the parenting stress index short form

	Immigrant *M* (*SD*)	Canadian-born *M* (*SD*)	Total *M* (*SD*)
Parental Distress	37.94 (10.22)	46.76 (9.95)	42.35 (10.89)
Difficult Child	37.47 (10.97)	45.35 (15.60)	41.61 (13.87)
Parent-Child Dysfunctional Interaction	35.17 (6.74)	40.06 (7.18)	37.61 (7.29)
Total stress	110.59 (24.92)	128.65 (22.23)	119.62 (23.05)

1.10 References

Abidin, R. R. (1995). *The Parenting Stress Index* (3rd ed.). Odessa, FL: Psychological Assessment Resources.

Bailey, D., Scarborough, A., Hebbeler, K., Spiker, D., & Mallik, S. (2004). *National early intervention longitudinal study: Family outcomes at the end of early intervention.* Menlo Park, CA: SRI International.

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. doi:10.2511/rpsd.30.4.194.

Bakermans-Kranenburg, M. J., Van IJzendoorn, M. H., & Kroonenberg, P. M. (2004). Differences in attachment security between African-American and White children: Ethnicity or socio-economic status? *Infant Behavior and Development, 27,* 417–433. doi:10.1016/j.infbeh.2004.02.002

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

Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of Autism and Developmental Disorders,* 36, 685–695. doi: 10.1007/s10803-006-0112-3

Berry, J., & Sam, D. (1997). Acculturation and adaptation. In J. W., Berry, M.H. Segall, & C. Kagitçibasi (Eds.), *Handbook of Cross-Cultural Psychology* (Vol. 3, pp. 291–326. Boston, MA: Allyn & Bacon.

Berry, J. W., & Sabatier, C. (2010). Acculturation, discrimination, and adaptation among second generation immigrant youth in Montreal and Paris. *International Journal of Intercultural Relations, 34,* 191–207. doi: 10.1016/j.ijintrel.2009.11.007

Bigras, M., LaFreniere, P. J., & Abidin, R. R. (1996). *Indice de stress parental: manuel francophone en complément à l'édition américaine* [Parental Stress Index: French-language manual to supplement the American edition]. Toronto, Canada: Multi-Health Systems.

Bitterman, A., Daley, T. C., Misra, S., Carlson, E., & Markowitz, J. (2008). A national sample of preschoolers with autism spectrum disorders: Special education services and parent satisfaction. *Journal of Autism and Developmental Disorders, 38,* 1509–1517. doi: 10.1007/s10803-007-0531-9

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. doi:10.1111/j.1365 2788.2005.00768.x.

Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46,* 722–730. doi:10.1002/1097-4679(199011)46:6\722:AID JCLP2270460605[3.0.CO;2-6.

Brachlow, A. E., Ness, K. K., McPheeters, M. L., & Gurney, J. G. (2007). Comparison of indicators for a primary care medical home between children with autism or asthma and other special health care needs: National Survey of Children's Health. *Archives of Pediatrics & Adolescent Medicine, 161,* 399–405. doi: 10.1001/archpedi.161.4.399

Centers for Disease Control and Prevention (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. *MMWR Surveillance Summaries, 63*(2), 1–21.

Cho, S.-J., & Gannotti, M. E. (2005). Korean-American mothers' perception of professional support in early intervention and special education programs. *Journal of Policy and Practice in Intellectual Disabilities, 1,* 1–9. doi: 10.1111/j.1741-1130.2005.00002.x

Cox, A., Klein, K., Charman, T., Baird, G., Baron-Cohen, S., Swettenham, J., ... Wheelwright, S. (1999). Autism spectrum disorders at 20 and 42 months of age: Stability of clinical and ADI-R diagnosis. *Journal of Child Psychology and Psychiatry, 40,* 719–732. doi: 10.1111/1469-7610.00488.

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. doi: 10.1007/s10803-007-0512-z.

Denney, M. K., Itkonen, T., & Okamoto, Y. (2007). Early intervention systems of care for Latino families and their young children with special needs: Salient themes and guiding implications. *Infants and Young Children, 20,* 326–335. doi: 10.1097/01.IYC.0000290355.77911.78

Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality, 2,* 97–110. doi:10.1080/ 09362839109524770.

Emerson, E., McConkey, R., Walsh, P., & Felce, D. (2008). Intellectual disability in a global context. *Journal of Policy and Practice in Intellectual Disability, 5,* 79–80. doi: 10.1111/j.1741-1130.2008.00151.x

Emmen, R. A., Malda, M., Mesman, J., van IJzendoorn, M. H., Prevoo, M. J., & Yeniad, N. (2013). Socioeconomic status and parenting in ethnic minority families: Testing a minority family stress model. *Journal of Family Psychology, 27,* 896–904. doi: 10.1037/a0034693

Families Special Interest Research Group of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (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. doi: 10.1111/jar.12078

Freeman, N. L., Perry, A., & Factor, D. C. (1991). Child behaviors as stressors: Replicating and extending the use of the CARS as a measure of stress: A research note. *Journal of Child Psychology and Psychiatry, 32,* 1025–1030. doi: 10. 1111/j.1469-7610.1991.tb01927.x.

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

Freedman, R. I., & Boyer, N. C. (2000). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health & Social Work, 25,* 59–68. doi: 10.1093/hsw/25.1.59

Gardiner, E., & French, C. (2011). The relevance of cultural sensitivity in early intervention. *Exceptionality Education International, 21*(3), 34–49.

Goldyne, D. A. (2013). *Parenting and acculturation stress among Latino immigrants: Does perceived spousal support moderate the effects on parenting self-efficacy?*

(Doctoral dissertation, Fielding Graduate University). Retrieved from http://gradworks.umi.com/35/88/3588510.html

Haack, L. M., Gerdes, A. C., & Lawton, K. E. (2014). Conducting research with Latino families: Examination of strategies to improve recruitment, retention, and satisfaction with an at-risk and underserved population. *Journal of Child and Family Studies, 23*, 410–421. doi: 10.1007/s10826-012-9689-7

Harry, B. (1992). *Cultural diversity, families and the special education system: Communication and empowerment.* New York, NY: Teachers College Press.

Harry, B., Klingner, J. K., & Hart, J. (2005). African American families under fire: Ethnographic views of family strengths. *Remedial and Special Education, 26,* 101–112. doi: 10.1177/07419325050260020501

Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorder*s, *31*, 327–336. doi:10.1023/A:1010799320795

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*, 629–642. doi: 10.1007/s10803-012-1604-y

Hofferth, S. L. (2003). Race/Ethnic Differences in Father Involvement in Two-Parent Families Culture, Context, or Economy? *Journal of Family Issues, 24*, 185–216. doi: 10.1177/0192513X02250087

Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal of Mental Deficiency*, *80*, 431–436.

Ingersoll, B., & Hambrick, D. Z. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5, 337–344. doi:10.1016/j.rasd.2010.04.017

Jones, E. W., Hoerger, M., Hughes, J. C., Williams, B. M., Jones, B., Moseley, Y., … Prys, D. (2011). ABA and diverse cultural and linguistic environments: A Welsh perspective. *Journal of Behavioral Education*, *20*, 297–305. doi: 10.1007/s10864-011-9138-5

Kayfitz, A. D., Gragg, M. N., & Orr, R. R. (2010). Positive experiences of mothers and fathers of children with autism. *Journal of Applied Research in Intellectual Disabilities*, 23, 337–343. doi: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.

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*, *122*(6), e1149-e1158.

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E.(2008). Disparities in diagnosis and access to health service for children with autism: Data from the national survey of children's health. *Journal of Developmental & Behavioral Pediatrics, 29,* 152–160. doi: 10.1097/DBP.0b013e318165c7a0

Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11,* 110–115. doi: 10.1002/mrdd.20061

McManus, B. M., McCormick, M. C., Acevedo-Garcia, D., Ganz, M., & Hauser-Cram, P. (2009). The effect of state early intervention (EI) eligibility on EI participation among children with special health care needs. *Pediatrics*, *124* (Supplement 4), 368–374. doi: 10.1542/peds.2009-1255G

Montes, G., Halterman, & Magyar, C. I. (2009). Access to and satisfaction with school and community health services for US children with ASD. *Pediatrics, 124* (Supplement 4), 407–413. doi: 10.1542/peds.2009-1255L

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. doi:10.1186/1477-7525-5-22.

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers with intellectual disability. *Journal of Intellectual Disability Research*, *45*, 535–543. doi:10.1046/j.1365-2788.2001.00372.x.

Osborne, L. A., McHugh, L., Saunders, J., & Reid, P. (2008).A possible contra-indication for early diagnosis of autistic spectrum conditions: Impact on parenting stress. *Research in Autism Spectrum Disorders*, *2*, 707–715. doi:10.1016/j.rasd.2008.02.005.

Perry, A., Cummings, A., Dunn Geier, J., Freeman, N., Hughes, S., Managhan, T., … Williams, J. (2011). Predictors of outcome for children receiving intensive behavioral intervention in a large, community-based program. *Research in Autism Spectrum Disorders*, *5*, 592–603. doi: 10.1016/j.rasd.2010.07.003

Pituch, K. A., Green, V. A., Didden, R., Lang, R., O'Reilly, M. F., Lancioni, G. E., & Sigafoos, J. (2011). Parent reported treatment priorities for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *5,* 135–143. doi: 10.1016/j.rasd.2010.03.003

Québec Ombudsman (2009). *Special Ombudsman's Report on Government Services for Children with Pervasive Developmental Disorders.* Retrieved from http://www.protecteurducitoyen.qc.ca/fileadmin/medias/pdf/rapports_speciaux/REPORT_TED-tr-rev.pdf.

Rivard, M., Lépine, A., Mercier, C., & Morin, M. (2014). Quality determinants of services for parents of young children with autism spectrum disorders. *Journal of Child and Family Studies*. Advance online publication. doi: 10.1007/s10826-014-0041-2

Rivard, M., Millau, M., Forget, J., & Morin, D. (2013). L'influence des facteurs culturels dans l'application des programmes découlant de l'analyse appliquée du comportement [The influence of cultural factors in the implementation of applied behavior analysis-based programs]. *Revue francophone de clinique comportementale et cognitive, 18,* 33–46.

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. doi: 10.1007/s10803-013-2028-z

Rosenberg, R. E., Daniels, A. M., Law, J. K., Law, P. A., & Kaufmann, W. E. (2009). Trends in autism spectrum disorder diagnoses: 1994–2007. *Journal of Autism and Developmental Disorders, 39,* 1099–1111. doi:10.1007/s10803-009-0723-6

Rueda, R., Monzo, L., Shapiro, J., Gomez, J., & Blacher, J. (2005). Cultural models of transition: Latina mothers of young adults with developmental disabilities. *Exceptional Children, 71,* 401–414. doi: 10.1177/001440290507100402

Samadi, S. A., McConkey, R., & Kelly, G.(2011). The information and support needs of Iranian parents of children with autism spectrum disorders. *Early Child Development and Care, 182,* 1439–1453. doi: 10.1080/03004430.2011.616931

Samadi, S. A., McConkey, R., & Kelly, G. (2012). Enhancing parental well-being and coping through a family-centred short course for Iranian parents of children with an autism spectrum disorders. *Autism, 17,* 27–43. doi: 10.1177/1362361311435156

Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behavior Therapy, 19*(4), 15–32. doi:10.1300/J019v19n04_02.

Statistics Canada (2012). *2011 Census of Canada.* Ottawa, ON: Statistics Canada.

Thomas, T. N. (1995). Acculturative stress in the adjustment of immigrant families. *Journal of Social Distress and the Homeless, 4,* 131–142. doi: 10.1007/BF02094613

Welterlin, A., & LaRue, R. (2007). Serving the needs of immigrant families of children with autism. *Disability & Society, 22,* 747–3760. doi: 10.1080/09687590701659600

Wolf, L., Noh, S., Fisman, S., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders, 19,* 157–166. doi:10.1007/BF02212727.

CHAPITRE II

QUALITY OF LIFE IN IMMIGRANT PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: A COMPARISON WITH PARENTS FROM THE HOST CULTURE

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2.1 Abstract

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. The present study investigated family quality of life (FQOL) and perceived external support in 104 parents of children with autism spectrum disorder (ASD) during the period following the child's diagnosis. Specifically, data from mothers and fathers in both immigrant and Canadian-born families were compared. Results indicated that Canadian-born parents reported higher overall satisfaction with their FQOL, specifically the Parenting and Disability-related Support dimensions. Additionally, fewer immigrant families reported having access to external support, a predictor of FQOL, than Canadian families. 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

2.2 Résumé

Des études menées auprès de familles ayant un enfant atteint de trouble du spectre autistique (TSA) indiquent que la période suivant le diagnostic de l'enfant peut être difficile, en particulier pour les familles issues de l'immigration. En effet, elles ont tendance à avoir des difficultés supplémentaires pour accéder et utiliser les services de diagnostic et d'intervention précoce du TSA. À ce jour, peu d'études ont comparé l'expérience des familles issues de l'immigration à celle des familles de la culture d'accueil. La présente étude s'intéresse à la qualité de vie familiale (FQOL) ainsi qu'au soutien externe perçu chez 104 parents d'enfant ayant un TSA à la période suivant l'annonce du diagnostic. Plus précisément, les données des mères et des pères issus de l'immigration ont été comparées aux parents canadiens. Les résultats indiquent que les parents nés au Canada sont globalement plus satisfaits de leur FQOL, en particulier aux sous-échelles « soutien relié au handicap » et « parentalité ». De plus, les familles issues de l'immigration ont moins de soutien externe, un des prédicteurs de la FQOL, que les familles canadiennes. Bien qu'il n'y a pas de différences significatives en fonction du genre, certaines différences permettent de faire des recommandations pour les services offerts aux deux parents. Ces résultats mettent en lumière la nécessité de développer des programmes dédiés aux familles qui tiennent compte de la culture et du genre des parents.

Mots clés: Trouble du spectre de l'autisme, qualité de vie familiale, parentalité, familles issues de l'immigration

2.3 Introduction

Early childhood can be a particularly stressful time in a family's life because it entails multiple adjustments and potential role conflicts (Williford, Calkins, & Keane 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, Brookman-Frazee, & Stahmer, 2005; Blacher & 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 & 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, Baker-Ericzén, Stadnick, & Taylor, 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, Chatenoud, & Paquet, 2014; Hodgetts, Nicholas, & Zwaigebaum, 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, Blanchett, & Harry, 2009; Magaña, Lopez, Aguinaga, & Morton, 2013). To date, the majority of studies on ASD have focused on White, English-speaker and affluent families, with data on parents' perspective being primarily collected among mothers (Daley & Sigman, 2002; Davis & 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 & Pisula, 2010). Studies on this topic have to date tended to focus on parenting stress (Dabrowska & 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, Cavkaytar, Turnbull, & Wang, 2013; Schlebusch, Dada, & Samuels, 2017; Vasilopoulou & 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, Anand, Fung, Isaacs, & Baum, 2003; Dunst & Bruder, 2002; Park et al., 2003; Summers et al., 2005).

2.3.1 Family Quality of Life (FQOL)

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, Summers, Lee, & Kyzar, 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, Anand, Fung, Isaacs, & Baum, 2003; Dunst & 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, Marquis, Poston, Summers, & Turnbull,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.

2.3.2 Impact of an ASD diagnosis and FQOL

During the post-diagnosis period, families experience a range of negative emotions such as denial and anger (Corcoran, Berry, & Hill, 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 & Iarocci, 2012; Pétales, Hastings, Nash, Hall, Joannidi, & Dowey, 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., 2011; Donaldson, Elder, Self, & Christie, 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 & 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 & 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 & 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, Gragg, & Orr, 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, Mackintosh, & Goin-Kochel, 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, Mestari, Terroux, Mello, & Bégin, 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 (Author, 2018; Meral et al., 2013). While some studies indicate higher FQOL among fathers than mothers others find comparable FQOL in both parents (Author, 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, Holloway, Domínguez-Pareto, & Kuppermann, 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).

2.3.3 Immigrant families of children with ASD

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, Leinonen, & Jasinskaja-Lahti, 2013; Ward, Bochner, & Furnham, 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, Thorburn, Demirhan, & Bilgel, 2007; Belizaire & 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 & 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 & Miguel, 2018; Wolery & Garfinkle, 2002).

The present article represents the second step in a study comparing the experiences of immigrant families with those of Canadian families (i.e., the host culture) of children with ASD and examining links with parents' gender. The first step of this study examined parenting stress during the post-diagnosis period, as families waited for services from a public provider (Author, 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 in the study, 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 (Author, 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.

2.3.4 Coping Strategies

Coping strategies refer to the cognitive and behavioral efforts deployed by individuals in order to manage the adaptation challenges of a stressful event (Lazarus & 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 & Halterman, 2007; Lai, Goh, Oei, & Sung; 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 & Pisula, 2010). Parents of children with ASD of European origin are also more likely than Asian parents to use emotion-focused coping strategies (Lin, Tsai & Chang, 2008; Luong, Yoder, & Canham, 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 family quality of life.

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.

2.3.5 Objectives

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.

2.4 Method

2.4.1 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 2.1.

2.4.2 Measures

2.4.2.1 Sociodemographic questionnaire

In order to provide indicators of socioeconomic status and ethnic diversity in the study sample, participating families complete a questionnaire based on that employed by Authors (2015). 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.

2.4.2.2 FQOL assessment

Families' QOL was measured with the Beach Center FQOL Scale (Hoffman, Marquis, Poston, Summers & Turnbull, 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, various European countries, Australia, Israel, Saudi Arabia, the United States, and French Canada (e.g., Alshamri, 2016; Author, 2017; Balcells-Balcells, Giné, Guàrdia-Olmos, & Summers, 2010; Brown et al., 2006; Jokinen, 2008; Meral et al., 2013; Parpa et al., 2016; Svraka, Loga, & Brown, 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 $\alpha = .94$ and .88; test-retest reliability was between .60 and .77 for satisfaction ratings, and between41 and .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 (Author, 2017) was adopted. This translation presented excellent internal consistency across the entire scale and acceptable consistency within its five subscales, Cronbach's $\alpha = .90$ and .72-.82, respectively.

2.4.3 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 minutes to complete.

2.4.4 Statistical 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.

2.5 Results

2.5.1 FQOL total scores: satisfaction ratings

Table 2.2 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 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 2.2, 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, $\chi^2(1, N = 58) = 5.797, p = .016$.

As shown in Table 2.3, 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, $\chi^2(1, N = 58) = 0.510, p = .475$.

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.

2.5.2 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.

2.5.3 FQOL total and subscale scores: importance ratings

Table 2.5 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 2.4, different patterns emerged across groups of parents with respect to which dimensions of FQOL they considered 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.

2.5.4 Presence and availability of external support

Table 2.6 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, $\chi^2(1, N = 58) = 8.081, p = .044$.

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 2.6.

2.6 Discussion

Families of children with ASD face numerous challenges (Baker-Ericzen et al., 2005; Blacher & 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 (Author, 2018). Indeed, the impact of having a child with ASD on family life has typically been studied through the lens of parenting stress (Dabrowska & 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 (Author, 2016; Author, 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 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 (Authors, 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 & Iarocci, 2012; Pétales 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, Leon, & Roecker Phelps, 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 (Author, 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 stage of this investigation (Author, 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 (Authors, 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 & 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.

2.7 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 & 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.

2.8 Conclusion

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 implementing changes to reduce their social isolation. Additionally, the development of family-centered services may be especially beneficial to the well-being of families during this period of their child's development. Possible initiatives to promote FQOL in immigrant families of children with ASD could include the implementation of support groups, parenting skills coaching programs, and information sessions on services available to them. These would provide family with opportunities to broaden their social and support networks, to increase their access to professional support, and to maximize their involvement in their child's early intervention services.

2.9 Tables

Table 2.1 Participants' demographic information

	Immigrant (*N*= 52)		Canadian-born (*N*=52)	
	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)		

Table 2.2 Parents' total and subscale FQOL satisfaction scores as a function of immigration status and gender

	Immigrant *(N=52)* *M* (*SD*)			Canadian-born (*N=52*) *M* (*SD*)			All Parents *(N=104)* *M* (*SD*)		
Subscale	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)

Note. FQOL = Family quality of life.

Table 2.3 Analyses of variance examining differences in satisfaction ratings based on immigration status and gender

	Immigration Status			Gender			Immigration Status * Gender		
Subscale	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2
Family Interaction	4.455	.037	.042	.002	.964	.000	.861	.356	.008
Parenting	1.308	.255	.013	.045	.832	.000	.156	.694	.002
Emotional Well-being	2.265	.135	.022	.128	.721	.001	.358	.551	.004
Physical/Material Well-being	2.752	.100	.027	.003	.957	.000	.072	.789	.001
Disability-related Support	11.18	.001	.100	.009	.925	.000	.174	.677	.002
Overall FQOL	3.400	.068	.033	.019	.891	.000	.222	.639	.002

Table 2.4 Parents' total and subscale FQOL importance scores as a function of immigration status and gender

	Immigrant (*N*=*52*) *M* (*SD*)			Canadian-born *(N=52)* *M* (*SD*)			All Parents (*N*=*104)* *M* (*SD*)		
Subscale	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)
Overall 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)

Note. FQOL = Family quality of life.

Table 2.5 Analyses of variance examining differences in importance ratings based on immigration status and gender

	Immigration Status			Gender			Immigration Status * Gender		
Subscale	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2
Family Interaction	.126	.724	.001	.265	.608	.003	.977	.326	.011
Parenting	4.736	.032	.052	.222	.638	.003	.005	.944	.000
Emotional Well-being	.055	.815	.001	.000	.990	.000	.909	.343	.010
Physical/Material Well-being	.214	.645	.002	.000	.994	.000	.486	.488	.006
Disability-related Support	.008	.928	.000	.002	.964	.000	1.190	.278	.013
Overall FQOL	.735	.393	.008	.081	.776	.001	1.316	.255	.015

Table 2.6 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		
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)

Note. [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.

2.10 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. Retrieved from: 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. doi: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. doi: 10.1111/j.1365-2788.2010.01350.x.

Barrio, C. (2000). The cultural relevance of community support programs. *Psychiatric Services, 51*, 879–884. doi: 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. doi: 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. doi: 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. doi: 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. doi: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. doi: 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. doi: 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. doi: 10.1023/A:1024931022773

Cho, S. J., & Gannotti, M. E. (2005). Korean-American Mothers' Perception of Professional Support in Early Intervention and Special Education Programs. *Journal of Policy and Practice in Intellectual Disabilities, 2,* 1-9. doi: 10.1111/j.1741-1130.2005.00002.x

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. doi: 10.1111/jir.12016

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. doi: 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. doi: 10.1111/j.1365-2788.2010.01258.x.

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. doi: 10.1016/j.ridd.2014.10.047

DeJong, G. F. (2000). Expectations, gender, and norms in migration decision-making. *Population Studies,* 54, 307-319. doi: 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. doi: 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. doi: 10.1177/001440290206800305

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

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. doi: 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. doi: 10.1080/1366825021000008639

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

Harry, B. (1992). *Cultural diversity, families and the special education system: Communication and empowerment*. New York, NY: Teachers College Press.

Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorders, 31,* 327–336. doi:10.1023/A:1010799320795

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. doi: 10.1111/j.1741-3737.2006.00314.x

IASSID Families Special Interest Research Group (FSIRG; 2012). *Families supporting a child with intellectual or developmental disabilities: the current state of knowledge.* Position Paper

Jokinen, N. S. M. (2008). *Family quality of life in the context of aging and intellectual disability*. (Doctoral dissertation, Graduate Division of Educational Research). University of Calgary, Alberta, Canada.

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. doi: 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: Guilford Press.

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. doi: 10.1007/s10826-009-9323-5

Mackintosh, V. H., Goin-Kochel, R. P., & Myers, B. J. (2012). What do you like/dislike about the treatments you're currently using?: A qualitative study of parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 27,51–60. doi: 10.1177/1088357611423542

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. doi: 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, doi: 10.1080/00207594.2012.662278

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child, & Adolescent Psychiatry*, *41*, 1447-1453. doi: 10.1097/00004583-200212000-

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. doi: 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. doi : 10.1016/j.ridd.2006.08.001

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. doi: 10.1007/s10803-014-2178-7

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. doi: 10.1177/154079691303800403

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. doi: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. doi: 10.1016/j.rasd.2009.01.004

Nussbaum J.F., (2007). Life span communication and quality of life. *Journal of Communication. 57*, 1-7. doi: 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. doi : 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. doi: 10.1046/j.1365-2 788.2003.00497.x

Parkhomenko, D. (2016). *Quality of Life and Migration Experiences among Russian Speaking Immigrants to the United States of America* (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. 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. doi: 10.1016/j.rasd.2011.07.015

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. doi: 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. doi: 10.1007/s10803-013-2028-z.

Rodrigue, J., Morgan, S., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology, 19*, 371–379. doi: 10.1207/s15374424jccp1904_9

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.

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 Information, 40*, 457–470. doi: 10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.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. doi: 10.1007/s10803-017-3102-8

Sharpe, D. L. et Baker, D. L. (2007). Financial issues associated with having a child with autism. *Journal of Family and Economic Issues, 28*, p. 247-264. doi: 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. doi: 10.1080/09687599.2013.848783

Special Interest Research Group on Quality of Life Quality of Life: Its Conceptualization, Measurement and Application. A Consensus Document. International Association for the Scientific Study of Intellectual Disabilities.

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. doi: 10.1352/0047 6765(2002)040,0457:CMAAOQ.2.0.CO;2.

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. doi: 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. doi: 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. doi: 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. doi: 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. doi: 10.1080/00207411.1994.11449286

CHAPITRE III

IMMIGRANT FAMILIES' PERCEPTION OF THE CAUSES, FIRST MANIFESTATIONS, AND TREATMENT OF AUTISM SPECTRUM DISORDER

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3.1 Abstract

Compared to families from their host country, families from immigrant backgrounds who have a child with autism spectrum disorder (ASD) tend to experience greater difficulties in accessing, using, and complying with intervention services for their child. This disparity may be partially accounted for by cultural differences in how families perceive the causes and symptoms of ASD as well as their treatment priorities. The present study sought to document these perceptions in immigrant families living in a Canadian city. Forty-five parents from Latin America, Africa, Western and Eastern Europe, the Caribbean, East Asia, and the Middle East participated in a semi-structured interview. These data were examined qualitatively through thematic analysis to first document all parents' perceptions, then to contrast mothers' and fathers' responses, and finally to examine common themes as a function of country of origin. The most frequently mentioned causes of ASD were environmental factors such as vaccines and diet. Moreover, some participants did not know the cause of their child's ASD. The majority of parents cited the absence of speech as one of the first symptoms noted in their child. Priorities for intervention varied: mothers tended to prioritize speech therapy, whereas fathers favored support in school. Taken as a whole, these findings highlight the need to implement informational programs for these families.

Keywords: Autism spectrum disorder, parenting, perception, immigrant families, cultural beliefs

3.2 Résumé

Les études rapportent que les familles ayant un enfant avec un trouble du spectre de l'autisme (TSA) et issues de l'immigration présentent plus de difficultés dans l'accès, l'utilisation et l'adhésion aux services d'intervention offerts à leur enfant. Les différences culturelles concernant la perception des causes, des symptômes des TSA ainsi que les priorités de traitement pourraient expliquer une partie de ces difficultés. L'objectif général de cette étude est de documenter la perception des causes, les premiers symptômes perçus, et les priorités de traitement chez des familles issues de l'immigration, habitant à Montréal, dont l'enfant présente un TSA. Quarante-cinq parents habitant dans une métropole canadienne et originaires d'Amérique-Latine, du Maghreb, d'Amérique du Nord, d'Europe, d'Afrique, des Caraïbes, d'Asie, et du Proche-Orient, ont complété une entrevue semi-structurée. Ces données ont été examinées qualitativement au moyen d'une analyse thématique. Premièrement, pour décrire les perceptions de tous les parents, dans un second temps pour faire ressortir les différences en fonction du genre des parents et finalement en fonction du pays d'origine. Les causes les plus fréquemment mentionnées sont celles en lien avec des facteurs environnementaux tels que les vaccins et l'alimentation. La majorité des parents ont cité l'absence de langage comme l'un des premiers symptômes constatés chez leur enfant. Les priorités d'intervention sont différentes en fonction du genre : les mères ont tendance à privilégier l'orthophonie, alors que les pères privilégient le soutien à l'école. L'ensemble de ces résultats mettent en évidence la nécessité de mettre en œuvre des programmes d'information pour ces familles.

Mots clés : trouble du spectre de l'autisme, parentalité, perceptions, familles immigrantes, croyances culturelles

3.3 Introduction

Autism spectrum disorder (ASD) is a developmental disorder characterized by impairments in social communication and restricted, stereotypical behavior patterns (American Psychiatric Association [APA], 2013). The most recent prevalence studies conducted in the United States indicate that it affects one child out of every 68 (Centers for Disease Control and Prevention, 2014). Despite the relatively homogeneous prevalence and symptomatology of the disorder across the globe, there are ethnic and cultural differences with respect to the accessibility and quality of care, children's prognosis, and family quality of life (Families Special Interest Group de l'International Association for the Scientific Study of Intellectual Disabilities [IASSID SIRG], 2012; Fombonne, 2009; Klingner, Blanchett, & Harry, 2009; Magaña, Lopez, Aguinaga, & Morton, 2013). This indicates that the extant knowledge base regarding ASD may not be representative of all families' situations (IASSID SIRG, 2012). Indeed, 90% of psychological research has recruited participants from wealthy, Westernized, and industrialized nations (Nielsen, Haun, Kärtner, & Legare, 2017). This is also the case for ASD research, in which a majority of samples to date have consisted of White, English-Speaker individuals from industrialized countries (IASSID SIRG, 2012). A few studies have reported that ethnic minority families experience greater challenges in obtaining a diagnosis and gaining access to services for their child (Klingner et al., 2009; Mandell, Listerud, Levy, & Pinto-Martin, 2002). Given the importance of early diagnosis and intervention for the child's optimal prognosis and for family quality of life, this places these families at a disadvantage (Eldevik et al., 2009; Virués-Ortega, 2010).

In the Canadian province of Québec, where the present study was conducted, families may wait up to two years to obtain a diagnosis; waiting periods for intervention may be even longer (Québec Ombudsman, 2009, 2012). Since the 20th century, this province has experienced several important waves of immigration. Nowadays, 20.6%

of the Canadian population consists of first-generation immigrants, that is, individuals who immigrated to the country (Statistiques Canada, 2011). A similar proportion is noted among families seeking rehabilitation services in specialized centers for ASD. Thus, staff and therapists at these centers must not only be responsive to the characteristics and needs of families of children with ASD, but also possess the cultural competence to work with families of a different background. Barriers related to language and socioeconomic status, but also culturally-based perceptions of ASD could explain some obstacles to accessing diagnostic and intervention services (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015; Magaña, Parish, & Son, 2015; Montes & Halterman, 2011). Specifically, how families perceive the causes of ASD, its early manifestations, and the effectiveness of treatments may influence their compliance with recommended intervention practices, as well as the moment at which they begin to seek out services (Ravindran & Myers, 2012). Our study therefore sought to document the perceptions of 30 immigrant families living in a Québec metropolis regarding their causal attributions of ASD, the first symptoms they noted in their child, and their priorities for intervention. Where waiting times for an ASD diagnosis are long, as is the case in Québec, any additional delays in seeking intervention services could have significant consequences for a child's prognosis (Virués-Ortega, 2010). A better understanding of immigrant families' perceptions of ASD could help prepare them for this stage in their care and services trajectory.

Several studies have highlighted cultural differences in the detection and interpretation of ASD symptoms (Burkett et al., 2015; Mandell & Novak, 2005; Mandell et al., 2009). Norms with respect to child development vary across cultures, which could in turn influence how families perceive and interpret deviations from normative behavior (Mandell & Novak, 2005). These perceptions could influence what a parent notices and interprets as deficient or as cause to consult a professional. This, in turn, could have an impact on the timing of the child's diagnosis and enrollment into an early intervention program. For instance, Indian families tend to take note of social deficits, rather than a language delay, whereas the reverse is true of English-Speaker, White families (Mandell & Novak, 2005). Furthermore, some behaviors that are considered ASD-specific symptoms in Westernized cultures may not be perceived as deviant within other cultures. For instance, in some Asian cultures, children may be expected to express respect for adults and authority figures by not establishing direct eye contact. Thus, depending on the context in which this behavior is observed, gaze avoidance in a child might not be readily interpreted as a symptom of ASD (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). Additionally, cultural differences in the perception of child development and disability could affect the perceived severity of symptoms. For instance, although their children presented more severe symptoms as per the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2012), Latin American mothers reported fewer developmental problems and ASD symptoms than their non-Latin counterparts (Blacher, Cohen & Azad, 2014). Differences in the perception of the severity of symptoms, or in the interpretation of certain signs as symptoms, could impact the child's diagnosis (Kalb et al., 2012; Liptak et al., 2008).

Families of children with ASD generally experience important delays in obtaining a formal diagnosis. Studies have shown that members of racial, ethnic, or cultural minorities face additional challenges and delays in gaining access both to this diagnosis and to services (Burkett et al., 20015; Grinker, Yeargin-Allsopp, & Boyle, 2011; Liptak et al. 2008; Magaña et al., 2012, 2013). For instance, African American children are diagnosed on average a year and a half later than their European American counterparts and are five times more likely to be misdiagnosed (Mandell et al., 2009). Latin American children are diagnosed two and a half years later and are six times more likely to receive non-evidence-based treatments (Blacher et al., 2014; Magana et al., 2013; Palmer, Walker, Mandell, Bayles, & Miller, 2010). On the one hand, a portion of the diagnosis delays noted in immigrant families could be related to perceptions of the child's ASD symptoms (Liptak et al. 2008). On the other hand, such delays are generally consistent with those observed in this population with respect to accessing health care services in general (Kalb et al., 2012; Liptak et al., 2008). Obtaining a diagnosis is an essential step in receiving appropriate and high-quality services, such that delays in the former affect access to the latter. The importance of early intake and intervention for children's outcomes and families' well-being has been well documented (Eikeseth, 2009; Eldevik et al., 2009). It is therefore crucial to better understand how immigrant families perceive the symptoms, causes, and treatment of ASD in order to better guide them toward appropriate services and ensure that their needs are met in a timely manner (Magana et al., 2013; Palmer et al., 2010; Zuckerman, Lindly, & Sinche, 2016).

Studies to date indicate that ASD is a neurodevelopmental condition that is partially genetic in origin (APA, 2013). However, available evidence does not yet permit the clear identification of the specific causes of this condition. Because of this lack of consensus and unequivocal information, parents in search of answers may develop their own belief system with respect to the etiology of their child's diagnosis; these beliefs are influenced by their cultural background (Gona et al., 2015). These differences in causal attribution may, in turn, lead to cultural variations in family practices, in the understanding of mental illness and disability, in stigma or prejudice toward mental illness, as well as in parents' expectations for, and response to, services (Barrio, 2000; Harry, Klingner, & Hart, 2005). Immigrant families are exposed to beliefs stemming from their native culture as well as the predominant culture of their host country. It is therefore possible that these families would hold Westernized beliefs, namely in a genetic origin of ASD, alongside beliefs consistent with their native culture's values and traditions.

Most of the studies on families' perceptions of the causes of ASD have been conducted in Westernized countries, among White, English-Speaker populations. In studies that included participants of all backgrounds, ethnic or cultural minority groups tended to be under-represented such that comparisons between, for instance, immigrant and native families could not be performed. A study by Selkrirk et al. (2009) among 255 American families indicated that the majority (72.7%) of them attributed ASD to a genetic cause, while 30.1% said they did not know the origin of the disorder. In another study in the United States, 38% of participants listed five causes of ASD (Goin-Kochel, Mire, & Dempsey, 2015). In that study, the most frequently mentioned causes involved genetic factors (41.6%), followed by external factors (pollution, vaccines, or viruses; 22.1%).

A few studies have been conducted among families of backgrounds other than White, European, and English-Speaker. For instance, families of African origin are more likely to believe in physical factors, such as diet or medication during pregnancy (Burkett et al., 2015; Gona et al., 2015). In addition to these biomedical beliefs, some Kenyan families believed that ASD was due to evil spirits or sorcery (Gona et al., 2015). Several families in Latin America traced ASD to a religious cause (Hughes, Valle-Riestra, & Arguelles, 2008; Skinner, Skinner, & Bailey, 2001). For example, they might perceive a child with developmental disorders as a divine gift and opportunity to grow as parents (Hughes et al., 2008; Skinner et al., 2001). Conversely, some families in Asian cultures perceive having a child with ASD as divine punishment (Dysches et al., 2004). Thus, parents' attributions of their child's ASD is strongly influenced by their culture's beliefs. These factors must therefore be taken into account in developing awareness and information programs (Magana et al., 2013).

How families conceptualize the origins of ASD in their child may influence their priorities for treatment, the expectations they have for interventions, and their compliance with proposed treatments (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010; Lipstein, Brinkman, & Britto, 2012; Yeh, Hough, McCabe, Lau & Garland, 2004). For instance, families who believe that their child's condition stems from biomedical causes will tend to request medical treatments (Ravindran & Myers, 2012). Families who attribute the disorder to vaccines will instead favor diet-based interventions (e.g., eliminating dairy or gluten) or chelation (i.e., the removal of heavy metals, such as mercury, from the organism; Levy & Hyman 2003). Similarly, families who attribute ASD to religious or spiritual causes will be more likely to turn to their family and religious community, rather than external professionals, for treatment (Guilamo-Ramos et al., 2007).

Families who entertain several, distinct beliefs with respect to the causes of ASD, or are exposed to dual cultures, may be likely to combine different forms of treatment for their child. For instance, Taiwanese families of children with ASD may choose to supplement the educational and behavioral treatments offered by an ASD service center with spiritual rituals such as readings from Buddhist scripture or changing the child's first name (Shyu, Tsai, & Tsai, 2010). This dual response stems from these families ascribing to a biomedical interpretation of the causes of ASD, and thus favoring educational approaches, while also applying practices consistent with their traditional, religious beliefs (Dyches et al., 2004). Similarly, a study conducted among Indian immigrants to the United States indicated that they tended to combine traditional approaches from their native culture (e.g., yoga, Ayurveda, and homeopathy) with practices more common in North America, such as speech and language therapy and early intensive behavioral intervention (EIBI, Ravindran & Myers, 2012). This combination of traditional and Western approaches was also noted in Kenyan families (Gona et al., 2015).

In addition to cultural differences, gender and parental roles may also influence the perception of the causes of ASD and of its symptoms and, in turn, expectations and decisions regarding treatment. Potential differences in parents' perceptions as a function of gender may be relevant to the timing and process of a family's search for services and their subsequent compliance with recommended interventions (Ravindran & Myers, 2012). It should be noted that mothers tend to be the participating parent in ASD studies, whereas fathers are less well represented in samples (Braunstein, Peniston, Perelman, & Cassano, 2013; Davis & Carter, 2008). Studies specifically comparing mothers and fathers in the field of ASD have tended to focus on parenting stress. These studies have yielded mixed results to date: some reported no difference between mothers' and fathers' stress levels (Davis & Carter, 2008; Hastings, 2003), others reported higher stress in mothers (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Herring et al., 2006). One consistent finding across these studies is that parents of children with ASD report higher stress compared to parents of children with any other condition (Baker-Ericzen et al., 2005; Blacher & McIntyre 2006; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). The manifestations of ASD that are most salient to mothers and fathers, or are perceived as priorities for intervention, could be a function of their respective gender, roles and interactions with the child (e.g., Pleck & Masciadrelli, 2004). For instance, fathers of children with Down syndrome tended to focus on their external roles (i.e., employment) and did not address their expectations or role performance as fathers, whereas mothers viewed their parental role as a challenge and expressed concern regarding ability to be a good mother (Pelchat & Lefebvre, 2003). Additionally, mothers were more likely to express confidence in their child's adaptive functioning potential. This study therefore suggested that there may be differences in how parents perceive their respective roles in the family and, as a result, differences in parental involvement and response to a child's disability. To the extent that parental roles may be influenced by a culture's values and these two factors may influence when parents seek out treatment, which approaches they select, and their compliance with services, further documenting the role of culture and gender-based roles would enhance our understanding of parents' treatment decisions.

The overarching goal of this study was to describe immigrant families' perceptions of their child's diagnosis to ultimately inform efforts to adapt information, support, and coaching programs for this population. To this end, three specific objectives were delineated: 1) to document parents' perceptions of the causes of ASD, 2) to identify the first symptoms reported by parents and for which they requested that their child be assessed, and 3) to examine these parents' treatment priorities, that is, which interventions they believe are most important for their child and their family. For each objective, the themes present in responses were examined as a function of parents' gender and region of origin.

3.4 Method

3.4.1 Participants

Thirty first-generation immigrant families participated in this study. These families were recruited through two rehabilitation centers serving Montréal and its suburbs. Participants were either on a waiting list for services or had received services from the center; in all cases, they had received a formal diagnosis of ASD for their child. For 15 of these families, both the mother and the father participated; for 13 families, only the mother completed the interview, and in two families only the father participated. Thus, a total of 28 mothers and 17 fathers (*N* = 45) were enrolled in the study.

The average age of the child with ASD in the participating families was 4 years and 1 month (range: 2 years to 6 years and 8 months). Participants had been established in Québec for over 16 years (14.3%), between 11 and 15 years (11.9%), between 6 and 10 years (38.09 %), or for less than 5 years (35.71%). With respect to region of origin, 42.23% of participants were from Latin America, 22.23% from the Maghreb, 8.88% from Western Europe, 8.88% from African, 6.66% from Eastern Europe, 6.66% from the Caribbean and 2.22% from Asia and the Middle East. Additional information regarding these parents' income, level of education, and country of origin as a function of gender is presented in Table 3.1.

3.4.2 Procedure

The protocol for this study was reviewed and approved by the ethics committee for student research projects at the Université du Québec à Montréal and the Joint Research Ethics Board for Public Rehabilitation Centers for Persons with Intellectual Disabilities and ASD in Québec. Families that met inclusion criteria for this study (i.e., first-generation immigrant parents with a young child, seven years old and under, diagnosed with ASD) were first contacted by a research assistant employed by the participating rehabilitation center. The assistant introduced the research protocol and mentioned the inclusion criteria and goals of the study. Following this presentation, the families who wished to participate scheduled an appointment to complete the interview. Parents signed a form indicating their informed consent prior to beginning the interview.

Three research assistants, all students enrolled in a doctoral psychology program, completed the interviews. Participants chose the venue (i.e., their home or the rehabilitation center) and moment (i.e., day and time) for the interview. Only one family requested that the interview be carried out at the rehabilitation center. For visits in the homes of the remaining 29 families, a research assistant offered to look after the children while the parents completed the interview with another assistant. Following Patton's (2001), recommendations, an interview guide was created and all assistants underwent training to ensure they would be follow a consistent procedure during the interview. The interviews were videotaped and subsequently transcribed by research assistants. Families could complete the interview in French, English, or Spanish, according to their preference. Of the 30 interviews, one was conducted in Spanish by a bilingual research assistant whose native language was Spanish, while another was conducted in both French and English by a bilingual research assistant. These two interviews were transcribed and translated by these same bilingual research assistants. The remaining 28 interviews were conducted in French and transcribed by Francophile assistants.

3.4.3 Measures

Families participated in a semi-structured interview that consisted of 12 open-ended questions and lasted approximately 90 minutes. Four questions were based on Kleinman's (1978) questionnaire and served to investigate participants' perceptions of ASD as it related to their culture (e.g., "According to you, what would be the cause of your child's difficulties?"). The remaining eight questions served to collect information about each family's culture of origin (e.g., "How are your child's difficulties perceived in your native culture?"); the circumstances under which they immigrated to Canada (e.g., "Why did you immigrate to Québec?") and the treatments they would prioritize for their child (e.g., "What kind of treatment or intervention do you think your child should receive?"). These were based on the interview schedules adopted by Cho and Ganotti (2005) and Samadi et al. (2013). At the end of the interview, families were encouraged to supply additional comments if they so desired. Four researchers with an expertise in qualitative analysis, ASD, and/or cross-cultural psychology reviewed the full interview schedule prior to it being pre-tested with a family. In addition to the interview questions, participants completed a sociodemographic questionnaire based on Rivard et al.'s (2015) that collected information such as income, ethnicity, and years lived in Québec.

3.4.4 Data analysis

Interview transcripts were analyzed based on an analysis method proposed by Mucchielli (see l'Ecuyer, 1990). According to this method, categories and subcategories are first identified upon reading the transcripts. Then, each unit of meaning within these transcripts is classified into the relevant category or subcategory (where appropriate). In order to minimize bias in this content analysis process, the present study adopted a triangulation approach. Specifically, two researchers trained in qualitative data analysis independently generated categories and subcategories based on a first transcript. They then met to discuss these and produce an initial coding grid. This first grid was tested on a different transcript and modified, as a result of this initial coding attempt. Three successive versions of the coding grid were thus created and tested, each time on a different transcript. Revisions could include the addition of new categories (or subcategories), the relabeling of existing categories, or the merging of categories. These revisions were carried out by the two researchers who created the original grid. The third version was then reviewed by an expert in qualitative analysis who was not otherwise involved with the present study or otherwise affiliated with the research team. A final version of the coding grid was produced based on this independent expert's feedback. Two research assistants trained in content analysis then applied the final coding grid to all interview transcripts. As needed, these assistants could propose new categories or subcategories that emerged upon reading additional transcripts. In such cases, these additions to the coding grid were discussed with the principal investigator and the other research assistant. To further ensure the rigor of these analyses, interrater reliability was computed on 13% of the interviews, and was found to be $\kappa = 0.81$. Once all transcripts were coded, the percentage of respondents who mentioned elements falling within each (sub)category were counted in order to identify the most frequently mentioned items.

3.5 Results

Data analyses examined participants' responses according to the three following perceptions: 1) causes of ASD, 2) first symptoms noted by parents, and 3) priorities for intervention. For each of these research objectives, data are first presented for the study sample as a whole, then examined as a function of participants' gender and region of origin. With respect to the latter aspect, it should be noted that the number of participants associated with each region varied considerably (see Table 3.1).

3.5.1 Causal attributions of ASD

Participants' attributions of the causes of ASD in their child could be organized into seven distinct categories: 1) environmental (42%), 2) unknown (40%), 3) pregnancy-related (37.7%), 4) genetic (26.6%), 5) medical (13%), 5) spiritual or religious (11%) and 7) emotional (10%). Table 3.2 presents the categories and subcategories for each of these with representative excerpts from interview transcripts. Of these categories, the most frequently mentioned category, environmental causes, included diet (20%), vaccines (17.7%), and other factors such as pollution. One participant said that "other immigrants who arrived also have autistic children, so we wondered if this wasn't due to a wholesale change in diet", while another said "At some point, vaccines became a nuclear bomb. There are ten or twelve of them all at once. The child is well and healthy, but is taken ill after the vaccine." Parents mentioned that the causes of ASD were unknown almost as often as they did environmental factors, saying for instance that "it's hard to say: if professionals who are looking into this issue cannot say for sure, who am I to say?"

The third category of factors related to the prenatal or perinatal factors such as: medical complications during pregnancy or childbirth (gestational diabetes, use of forceps to deliver the child) in 20% of instances, stress or depression in the pregnant mother (8.8%), or artificial means of conception such as in vitro fertilization (8.8%): "we sort of went against nature, if you will, because we had in vitro. Sometimes, we wonder if something happened."

Genetic factors, the fourth category, was mentioned by over a fourth of participants. Parents also linked ASD to medical factors, such as the occurrence head trauma or childhood illnesses that required the use of medication, "He became ill during my trip to Columbia. After the trip, he was like a different child."

Finally, some parents mentioned religious or spiritual causes: "I strongly believe in the spiritual component. It's a hypothesis, let's say that autistic children are... spirits."

Some parents also attributed the child's ASD to his or her experiencing emotional difficulties, such feeling detached from one of the parents: "When he was one year old, I started working... We took him to day care, he was very young, I thought that had something to do with it (...) because he needed me."

Participants could list multiple causes of ASD. This was the case for 21 participants (46.67%); on average, participants mentioned 1.83 (*SD* = 1.04) causes.

3.5.1.1 Differences between mothers and fathers

As can be seen in Figure 3.1, mothers and fathers' opinions regarding the causes of ASD tended to differ. Indeed, for fathers the most frequent type of causal attribution related to environmental factors (58.8%), whereas this was less frequently mentioned by mothers (32%). Among the subcategories of environmental factors, the most frequently mentioned cause was diet for fathers (29.4%), whereas it was vaccines among mothers (17.8%). The latter subcategory was the second most frequently cited environmental factor among fathers (17.6%). Finally, 11.7% of fathers mentioned other environmental factors such as pollution or air quality. One participant explained how the transition from natural, organic foods in their African diet to non-organic foods containing casein and gluten may have been a factor: "In Africa, they eat natural foods (...) because in gluten-free, casein-free diets there is a lot, a lot of organic things (...) in our opinion this [North American food] also plays a role in the disease." Another parent said that they believed that "there is something in our North American environment, maybe in the food or in the environment itself."

Among mothers, the most frequent type of causal attribution related to the pregnancy: 41.9% of mothers, compared to 21% of fathers, provided causes within this theme. The majority of mothers attributed ASD to medical problems during the pregnancy (22.6%), followed by stress (12.9%) and, finally, problems with conception (6.5%): "I was really nervous. I never had a pregnancy like Z.'s." In contrast, 10.5% of fathers mentioned medical problems and conception problems, but none suggested that the mother's stress could have been a factor. The second most common type of cause mentioned by mothers was genetic factors: 29% discussed genetic causes, compared to 15.6% of fathers: "something genetic, but I think it comes from his father's side."

There was fewer discrepancies between mothers' and fathers' rates of attribution of ASD to other themes, with the exception of emotional problems. None of the fathers mentioned this possibility, but 16.1% of mothers believed their child's disorder may be an emotional reaction to a disturbance or conflict within the family (e.g., estrangement of a parent). It should again be noted that parents could list multiple possible causes: some mentioned several of their hypotheses while also stating that they did not know the cause of their child's ASD. Thus, 42.1% of fathers and 35.8% said that they were unsure of what had caused the disorder.

3.5.1.2 Differences as a function of region of origin

Overall, the analysis of themes as a function of participants' country of origin suggested that there were no major regional or cultural differences across the sample. Indeed, as depicted in Table 3.5, several categories of causes were mentioned at similar rates across groups. However, a few noteworthy distinctions emerged. Environmental factors were most frequently mentioned by participants from Africa and the Near East: all participants in these two groups discussed one or more causes within this theme. They most often mentioned dietary factors (75% of participants from Africa and 100%

of those from the Near East). One parent explained: “diet, a chance… notably lactose, this or that lactose by-product. We looked a little bit online and saw that it is possible that, a change in diet… Because there are immigrants that came here who also have children with autism. So we thought it might be due to a wholesale change in diet.” Vaccines were also mentioned by parents: “There are a lot of factors that go into a diagnosis. However, vaccines seem like a perfectly logical explanation.” Among participants from Latin America, 60% mentioned pregnancy-related factors, as did 50% of participants from the Caribbean. For instance. A mother discussed complications arising during her pregnancy: “I was bedridden at home, I could not do anything (…) they found out I was diabetic (…) and I lost a lot of blood. Maybe that’s why.” In contrast, this category was mentioned by only 10 to 25% of respondents originating from other regions. Genetic factors were more likely to be mentioned by parents from Western Europe or the Near East (50% in both groups). Religious or spiritual causes were reported by participants from Western Europe (50%), Africa (50%), and Latin America (5%): “I strongly believe in the spiritual element. It’s a hypothesis, let’s say that children with autism are like spirits that come.”

3.5.2 First symptoms noticed by parents

The second goal of the study was to identify which symptoms first made parents aware of their child’s difficulties. Responses obtained to this portion of the interview (e.g. “How did you find out that your child might be having difficulties?”) could be organized into six categories. Table 3.3 lists these categories with sample excerpts from interview transcripts. The three most frequently reported categories were consistent with the symptoms described in the DSM-V (APA, 2013). A lack of, delay in, or particularities in speech were most often noticed by participants (48.8%): “because he didn’t speak” and “a language delay… he did not speak (…) until he was almost three.” Nonverbal communicative behaviors and stereotypical behaviors were each mentioned by 26.6% of parents. The nonverbal communicative behaviors subcategory included symptoms such as the lack of joint attention, eye contact, or gestures, or the fact that the child does not respond to his or her name: “he would not go ‘bye-bye’”, “he did not look, he did not point.” Restricted eating or difficulties with food and a lack of play were respectively mentioned by 6.6% of parents: “he did not want to eat, he would not eat like other children, I had to smash [the food]”, “mostly he never played.” A motor development delay was mentioned by 4.4% of parents: “She sat at 10 months, that’s already late. And then walking, she did that at 3 years and 3 months.” Finally, parents stated that the presence of behavioral problems such as tantrums was an early sign of their child’s difficulties by 2.2% of parents: “aggression, the screaming.” Parents also mentioned other, less specific elements that did not precisely correspond to symptoms of ASD (17%); these responses were categorized as “Other”. These included, for instance, comparisons with the child’s siblings or disagreement with their child’s diagnosis: “it was by comparing her to her twin sister.”

3.5.2.1 Differences between mothers and fathers

Mothers and fathers alike most often reported first noticing symptoms related to speech, but, as seen in Figure 3.2, did so in different proportions. Indeed, over half of mothers (57%) mentioned this sign, whereas only 35.3% of fathers did so. The second and third most reported symptoms were nonverbal communicative behaviors and stereotypical behaviors, respectively, for parents of both genders: “he started lining up his toys in a row”, “he avoided eye contact”, or “he would not respond to his name.”

The fourth and fifth categories differed as a function of participants’ gender. Indeed, 11.7% of fathers but only 3.6% of mothers said they noticed a lack of play. However, 7% of mothers noted a motor delay and 3.2% of them reported some form of behavioral problem, whereas none of the fathers mentioned such symptoms.

3.5.2.2 Differences as a function of region of origin

The symptoms that parents first noticed in their child varied as a function of region of origin. For instance, participants from the Caribbean and the Near East did not mention an absence of, or delay in, speech, but, as seen in Table 3.5, between 50% and 100% of families from other regions reported such symptoms. Additionally, participants from the Maghreb region mentioned symptoms within each category at high rates, indicating that they were concerned by several symptoms. Nevertheless, this group most often mentioned symptoms relating to nonverbal communicative behaviors (80%) and speech (50%). A similar tendency was noted among African participants, who mentioned these two categories 50% of the time. Finally, the lack of play was only reported by participants from Western European (25%) and Maghreb (20%) countries.

3.5.3 Treatment priorities

The third objective of the study was to examine what areas they believed were priorities for interventions with their child. They were asked what kind of help and treatment they believed would be important (e.g., "What type of treatment or intervention do you think your child should receive?") As seen in Table 3.4, five general types of treatment and support emerged from this analysis.

Speech and language therapy was the form of treatment most often mentioned as a priority by participants (35.5%): "speech therapy so he can speak." The second most frequent treatment was specialized support in school or at day care: "I too would like kindergarten, and then schools, to continue services." EIBI and behavior modification services were also said to be important by 24% of parents: "techniques to correct his behavior." Some participants (11%) mentioned natural treatments. These parents mentioned gluten-free or lactose-free diets, or the use of vitamins: "Because it seems that there are intestinal fungi (…) that could influence the brain and promote autism.

And with kefir seeds (…) it reduces pollution through toxins in the brain." Finally, 8% of parents stated that occupational therapy was important, while 6.6% of parents said they did not know what type of treatment would be most beneficial to their child: "At this time, we would take any kind of help that is offered, any kind."

3.5.3.1 Differences between mothers and fathers

Mothers and fathers had somewhat different priorities for interventions. Mothers' priorities fell within three themes: speech and language therapy, EIBI, and specialized support in school. These same categories were also priorities for interventions among fathers, but were mentioned at different rates. For mothers, speech and language therapy was the most frequently mentioned treatment (46.4%) but it came second for fathers (17.6%). Indeed, as illustrated by Figure 3.3, fathers were more likely to mention integration and support in school (35.3%), which was the third most frequently mentioned type of treatment for mothers (25%). EIBI came in second for mothers (32%) but third for fathers (11.7%). Natural treatments (special diets or vitamins) were mentioned as often as EIBI by fathers (11.7%) and at a similar rate by mothers (10.7%). Finally, 5.8% of fathers and 7% of mothers said they did not know what type of treatment should be given priority.

3.5.3.2 Differences as a function of region of origin

Speech and language therapy was the most frequently mentioned treatment across the sample as a whole, as well as among parents from Asia (100%), the Middle East (50%), and Africa (50%) specifically. As depicted in Table 3.5, specialized support in school or day care was a priority for more than half of Latin American participants (55%), a third of Eastern European parents (33.3%), and a quarter of Western European parents (25%). Parents from Western European countries (66.6%) and the North Africa and the

Middle East (50% in both groups) were most likely to mention EIBI. Only parents from Central and West African countries (100%) mentioned natural treatments.

3.6 Discussion

Immigrant families and fathers have historically been underrepresented in research on ASD. The present study specifically examine differences in parents' perceptions of the causes of ASD and its treatments, as well as early signs in children as based on their country of origin and gender. Some of the salient differences observed between groups could help to understand and the service trajectories and needs of these families.

The first symptoms of ASD that parents said they had noticed in their child are consistent with those listed in the DSM-5. Indeed, parents most often stated difficulties with verbal or nonverbal communication. Thus, parents' perceptions of symptoms was generally aligned with the current understanding of ASD within the scientific community with respect to symptoms, if not in relation to the causes of ASD. Previous research suggests that American families are more likely to notice language delays than problems with social skills (Coonrod & Stone, 2004; Mandell & Novak, 2005). Consistently with this observation, the Eastern European families in the present study only listed language-related symptoms. In addition, Western European parents also noted the absence of play, nonverbal communication deficits, and stereotypical behaviors.

The fact that a lack of play was primarily reported by fathers may be explained by differences in parental roles with respect to the development of play in their children. Indeed, some authors indicate that mothers' role towards their children is primarily focused on caregiving, whereas the paternal role is more closely associated with play (Pleck & Masciadrelli, 2004). This differentiation of roles would account for fathers being more likely to notice and mention play as a cause for concern in their child. A more in-depth understanding of fathers' perceptions as well as how they differ from mothers', could help guide screening and informational services for ASD. Indeed, if both parents do not perceive the same symptoms, or disagree on what might constitute a potential problem, the family may incur delays in seeking services for their child. Furthermore, the extant literature indicates that it is oftentimes difficult to involve fathers in research (Braunstein et al., 2013; Davis et Carter, 2008) as well as interventions concerning their child with a disability (Pelchat & Lefebvre, 2003). It is thus especially important that screening, informational, and support services be made relevant to both parents by targeting their respective priorities and needs. This may help increase fathers' participation, which could benefit the child's progress as well as the well-being of the family unit. Indeed, several studies indicate that family involvement is positively associated with children's outcomes (Strauss et al., 2012; Vasilopoulou & Nisbet 2016).

With respect to differences as a function of region of origin or culture, Latin American parents in the present study mentioned language delays, stereotypical behaviors, and nonverbal communicative behaviors deficits as early symptoms at a relatively high rate. This observation is inconsistent with the literature, which indicated that Latin American families noticed fewer symptoms of ASD in their child (Blacher et al. 2014). This discrepancy could be accounted for by the characteristics of the present study sample. For instance, fathers were included in the present study but not in Blacher et al.'s (2014) sample. In the latter, 11.6% of Latin American participants had at least a bachelor's degree, whereas 50% of those in the present sample had attained this level of education.

With respect to the potential causes of their child's ASD, parents most often mentioned environmental factors. This finding diverges from previous observations that White families were more likely to believe in a genetic origin of the disorder, which is the most frequently mentioned cause across studies (between 43% and 72% of mentions;

Goin-Kochel et al. 2015; Selkrik et al., 2009; Zuckerman et al., 2016). Participants in these studies also mentioned environmental factors, but at lower rates (between 19.2% and 27.3%) than in the present study. The responses of immigrant families in the present sample support the observation by Zuckerman et al. (2016) that families of non-White race/ethnicity tend to attribute ASD to in utero or post-natal exposure and that non-Hispanic White families were more likely to believe in genetic causes than Hispanic or African American families. Although the predominant causes of ASD reported by immigrant families in the present sample and the White, Western families of previous studies differed, both groups were equally likely to report not knowing the causes of the disorder or to list several hypotheses. Indeed, 38% of the participants in the present study said they did not know the origins of their child's condition, as did 30.1% of the participants in Selkrik's study (2009). The fact that a large number of families attributed ASD to environmental factors or unknown causes, or involved several possible causes, highlights a need for education and outreach on this topic. Causal attributions of their child's disorder could influence families' choice of treatment. It is also important for professionals in the field to be respectful of families' beliefs while also affording them access to the most accurate information available on the etiology of ASD. Parents who understand the causes of ASD may be more likely to comply with proposed interventions and services that are consistent with this conceptualization of the disorder.

It is noteworthy that all participants from African countries mentioned environmental factors such as diet or vaccines, which is consistent with previous studies conducted with similar populations (Burkett et al., 2015; Gona et al., 2015; Pitten, 2008). However, whereas the extant literature suggests the importance of religious explanations of ASD among Latin American families (Hugues et al. 2008; Skinner et al. 2001), this was not the case in those who participated in the present study. In fact, they were more likely to evoke causes linked to the pregnancy or environmental factors. There are several possible explanations for this discrepancy. First, it should be noted that participants were recruited from rehabilitation centers providing services to individuals with ASD and their families. They had therefore already received a diagnosis for their child and were either on a waiting list for services or had already begun receiving these from the center. Thus, they may have received information as part of the diagnostic process or through subsequent services that would influence their perception of the causes of ASD. Second, the characteristics of families in the present study may differ from those of previous research. Indeed, while the literature suggests that Latin American families experience difficulties in gaining access to services (Flores, Bauchner, & Feinstein, 1999; Klingner et al. 2009; Magana et al., 2013, 2012), the parents interviewed in this study had access to ASD services. As noted previously, the level of education of the immigrant families in the present study was higher than what was reported in other studies: this factor may influence access to services. Finally, it is possible that social desirability biases could have influenced participants' responses. To the extent that the majority of interviews (with one exception) were conducted by non-Hispanic White research assistants, participants may not have felt comfortable mentioning religious or spiritual beliefs.

Participants' responses suggest that they strongly valued educational treatments such as speech and language therapy, EIBI, and support in school. These results may be due to immigrant families' concern for their child's social integration. Indeed, the importance of their (typically developing) children's social and academic success to immigrant parents has been extensively documented in the literature (Kanouté, Vatz Laaroussi, Rachédi, Tchimou Doffouchi, 2008; Stevenson, Chen, Uttal, 1990) this may also apply specifically to children with ASD. This may also be attributable to the fact that, at the time of the study, parents had received a formal diagnosis for their child along with information on available services and the importance of early intervention. Another noteworthy aspect of parents' treatment priorities concerns their association with the symptoms of ASD they reported noticing early on. Other studies on treatment selection suggest that perceived causes generally influence parents' treatment decision

(Al Anbar et al., 2010; Lipstein et al., 2012; Yeh et al., 2004). In the present study, African families tended to attribute ASD to environmental factors and most often mentioned the use of natural treatments such as special diets or vitamins. This suggests a link between perceived causes and preferred interventions for these families, which is consistent with the literature (Levy & Hyman, 2003). However, this relationship is less clear among other groups. Indeed, for most other participants, priorities for intervention appeared to be more closely linked to the first symptoms they had noted in their child. For instance, Western European and Asian participants who attributed ASD to environmental or medical factors nevertheless prioritized speech and language therapy, consistently with their reports of language-related difficulties as symptoms of concern. Finally, several families mentioned a combination of interventions that included treatments consistent with their traditional beliefs (i.e., natural treatments) and others that aligned with the Westernized beliefs of their host country, namely speech and language therapy.

The findings of the present study have several implications for practice settings. First, it is important that service providers be aware of differences in families' perceptions of ASD as these relate to culture or gender, and that they be receptive to these beliefs in order to establish a dialogue and build trust. Second, it may be necessary to provide outreach and information programs that address the causes of ASD, its symptoms and their evolution, and available services. This information could be integrated into parental coaching programs, where families could see how proposed educational strategies relate to these facts on ASD. Furthermore, this type of program may also help families on a waiting list to services to develop appropriate strategies to cope with day-to-day life and reduce the chance that their child's symptoms will worsen during this period. If these programs are to be truly effective, they must be culturally relevant and take into account families' values, beliefs, and needs. Some possible cultural adaptations to these programs would include: availability in families' preferred language, respect of families' educational and social values and availability at times and locations that are appropriate for parents' lifestyle. Indeed, the findings of the present study suggest that social and education values may differ across cultures and ethnicities. In order to ensure the social validity of interventions, proposed initiatives should respect the values of those who will make use of these services. To this end, Klingner (2009) recommends that service providers learn about families' native culture, namely their language, religion, values, and behavioral norms, as well as how ASD is perceived within this culture. Furthermore, opening up training sessions, meetings, and other activities to the extended family and other members of a family's social support network would be consistent with the values of many immigrant families (Barrio, 2000; Harry, 1992).

This study presented several limitations. First, parents of each gender and from each region were not equally represented across the sample, which may reduce the representativeness and generalizability of findings. Similarly, for the purposes of interpretation, families' country or region of origin had to be used, albeit tentatively, as a proxy for their culture. It is clear that immigrant families hailing from the same region are not homogeneous with respect to their culture and values, and may not necessarily speak the same language or hold the same religious beliefs. Nevertheless, the limited sample size prohibited a finer-grained analysis of families' ethnic or cultural backgrounds. These sampling issues could be addressed through the use of different recruitment procedures in future studies. Additionally, parents were asked about the first symptoms they had noted in their child several years after he or she had been diagnosed with ASD. While this delay may have introduced some biases in their recollection, it is equally likely that it would have focused their attention on the early signs that were ultimately most relevant to their child's situation. It would be pertinent to ask similar questions upon families' first consultation with professionals, and to revisit this question as they progress in their service trajectory. Furthermore, recruitment through a center providing ASD services necessarily introduces some sampling biases in that families who have obtained access to these programs may not represent immigrant families as a whole, and specifically those who have the most difficulty accessing services (e.g., due to language or cultural barriers, or a lack of awareness of available options). Nevertheless, the present study was one of the few in Québec to specifically examine immigrant families of children with ASD. Its findings suggested that parents' culture and gender could influence their perceptions of the causes and first symptoms of ASD. These views and beliefs may affect families' participation in, and compliance with, available services. It is therefore important that factors such as culture and gender be taken into account when communicating with families, identifying their needs, and supporting them throughout service delivery.

3.7 Tables and figures

Table 3.1 Participants' demographic characteristics

	Mothers (*N*=28) *n* (%)	Fathers (*N*=17) *n* (%)
Family income		
10,000-29,999$	3 (10.7)	3 (17.6)
30,000-49,999$	7 (25)	7 (41.1)
50,000-69,999$	11 (39.3)	4 (23.5)
70,000-89,999$	3 (10.7)	1 (5.8)
90,000 or more	3 (10.7)	1 (5.9)
Other or missing information	1 (3.6)	1 (5.9)
Level of education		
Incomplete high school	4 (14.3)	1 (5.9)
High school	0 (0)	4 (23.5)
Post high school and professional	3 (10.7)	1 (5.9)
College (baccalaureate degree)	12 (42.8)	7 (41.2)
University (graduate degree)	3 (10.7)	3 (17.6)
Other or missing information	6 (21.4)	1 (5.9))
Region of origin		
Latin America	13 (46.4)	6 (35.3)
North Africa (Maghreb)	5 (17.8)	5 (29.4)
Central and West Africa	2 (7.1)	2 (11.7)
Western Europe	2 (7.1)	2 (11.7)
Eastern Europe and Russia	2 (7.1)	1 (5.9)
Caribbean	2(7.1)	1 (5.9)
Middle East	1 (3.6)	0 (0)
East Asia	1 (3.6)	0 (0)

Note: $N = 28$ for mothers, 17 for fathers.

Table 3.2 Coding grid with sample transcript excerpts illustrating categories of perceived causes of ASD

Categories	Subcategories	Sample excerpts
1.1 Environmental Factors	1.1.1 Diet	"I did my own research... some specialists say that diet plays a very important role."
	1.1.2 Vaccines	"Vaccines... Because the first years everything was perfect. His development was excellent, and then..."
	1.1.3 Other factors, e.g. pollution	"The environment, well, perhaps we don't know that in fact all the crud that we breath and then... it ends up getting into the brain."
1.2 Prenatal or perinatal factors	1.2.1 Complications during pregnancy or childbirth	"Because she had, during her pregnancy, she had diabetes" "I had complications while giving birth."
	1.2.2 Artificial means of conception	"We tried for 5 years, then I said well maybe it won't happen and we forced nature's hand."
	1.2.3 Stress or depression in the pregnant mother	"Maybe he felt our stress or depression."
1.3 Medical factors		"Well he fell on his head two or three times. I say that maybe this did something.
1.4 Genetic factors		"I think it's genetic. What I don't know, is from whose side it came or if it's the combination of both sides."
1.5 Emotional difficulties		"We left without his father. I left alone with his sister, and we spent two months there without seeing his father. Maybe he was too attached to his father."
1.6 Religious, spiritual causea		"What could we have done to God to... Well, also, speaking of God in the sense that He placed him into our care because we are able to take care of him."
1.7 Unknown causes		"I have been trying to think about the cause until now, and I sincerely do not know."

Table 3.3 Coding grid with sample transcript excerpts illustrating categories of symptoms first noticed by parents

Categories	Sample excerpts
2.1 Stereotypical behaviors	"He did hand motions like this [making flapping gestures]."
2.2 Speech: lack of, delay, or particularities	"I said there's something wrong because normally a child of his age should be able to say 'mommy thirsty'."
2.3 Nonverbal communicative behaviors: lack of or particularities	"He didn't look at us." "He didn't point."
2.4 Restricted eating or difficulties with food	"Let's say that eating was the difficulty that we noticed." "He was doing [engaging in] dietary restriction."
2.5 Lack of play	"He didn't play with his brother and sister."
2.6 Motor development delay	"When she was 10-11 months old, she didn't walk yet, she didn't crawl."
2.7 Behavioral problems	"Aggression and screaming."
2.8 Other	"It's by comparing him to his twin." "It was the regression."

Table 3.4 Coding grid with sample transcript excerpts illustrating categories of priorities for intervention

Categories	Sample excerpts
3.1 Specialized support in school or at day care	"We would like someone to come help, a specialized educator, but every day to help him." "I would say, someone who could work with her after school to reinforce what was addressed."
3.2 EIBI and behavior modification services	"Receiving EIBI."
3.3 Speech and language therapy	"Having a speech and language therapy service, because the child is unable to speak." "I would like to see a speech and language therapist."
3.4 Occupational therapy	"They need occupational therapy."
3.5 Natural treatments	"Vitamins, diets."
3.6 Unknown	"You know, I am not sure it can be treated. I do not know."

Table 3.5 Percentage of parents who mentioned each type of potential cause of ASD, each type of symptom of ASD, type of treatment as a priority for their child as a function of region of origin

	Western Europe $n = 4$	Eastern Europe $n = 3$	Latin America $n = 19$	Caribbean $n = 3$	West Africa $n = 4$	North Africa $n = 10$	Middle East $n = 1$	Asia $n = 1$
Causes of ASD								
Environment	50	45	45	0	100	20	100	0
Unknown	50	25	25	50	75	75	0	0
Pregnancy	25	60	60	50	25	10	0	0
Genetic	50	30	30	0	25	20	100	0
Medical	0	25	25	0	0	10	0	0
Emotional	0	10	10	50	0	10	100	0
Religious	50	5	5	0	50	0	0	0
Other	0	0	0	0	25	20	0	100
First Manifestation noticed								
Speech	50	100	50	0	50	80	0	100
Nonverbal communicativbehaviors	0	0	20	0	50	80	0	0
Stereotypical behaviors	0	0	30	0	0	50	100	0
Motor development delay	0	0	5	0	0	10	0	0
Restricted eating	0	0	0	50	0	20	0	0
Behavioral problems	0	0	0	0	0	10	0	0
Lak of play	25	0	0	0	0	20	0	0
Other	0	0	0	0	1	0	0	0
Treatment priority								
Speech therapy	25	0	40		50	30	100	100
Specialized support school	25	33	55		0	0	0	0
EIBI	25	66.6	10		0	50	100	0
Natural treatments	0	0	0		100	0	0	0
Occupational therapy	25	0	0		50	0	0	0
Unknown	0	0	5		0	0	0	0

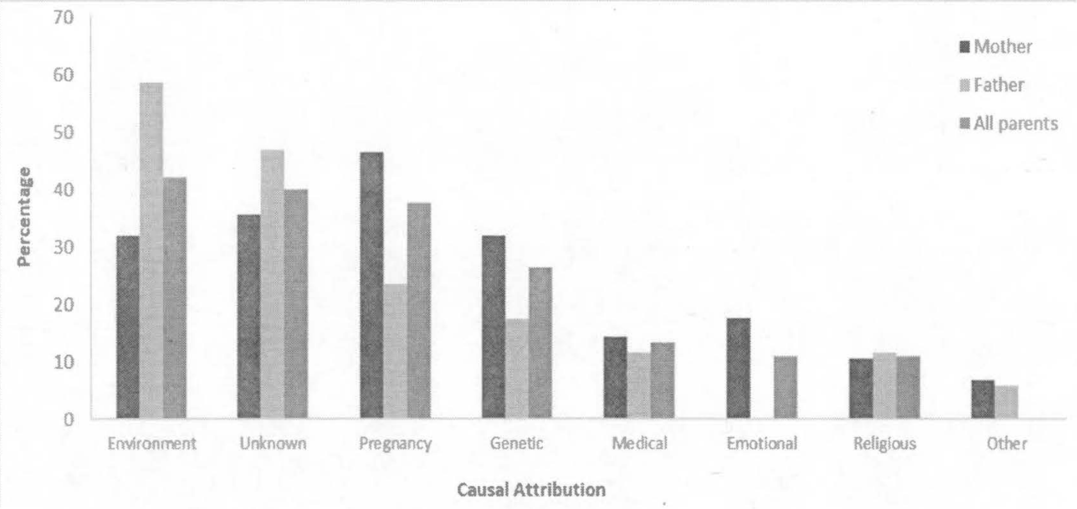

Figure 3.1 Percentage of all parents and of mothers and fathers who mentioned each type of potential cause of ASD in their child.

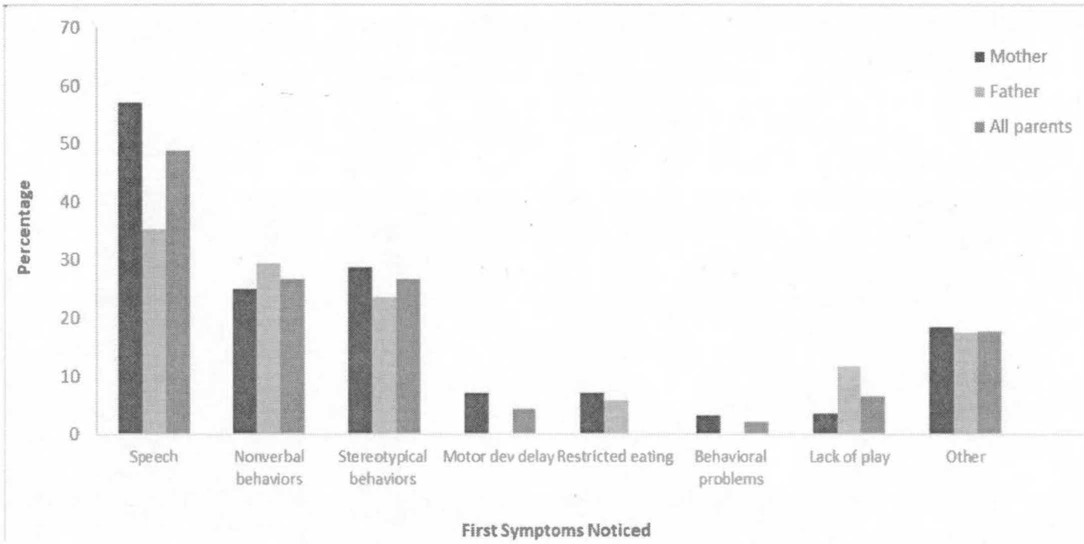

Figure 3.2 Percentage of parents who reported noticing each type of symptom of ASD in their child as a function of gender.

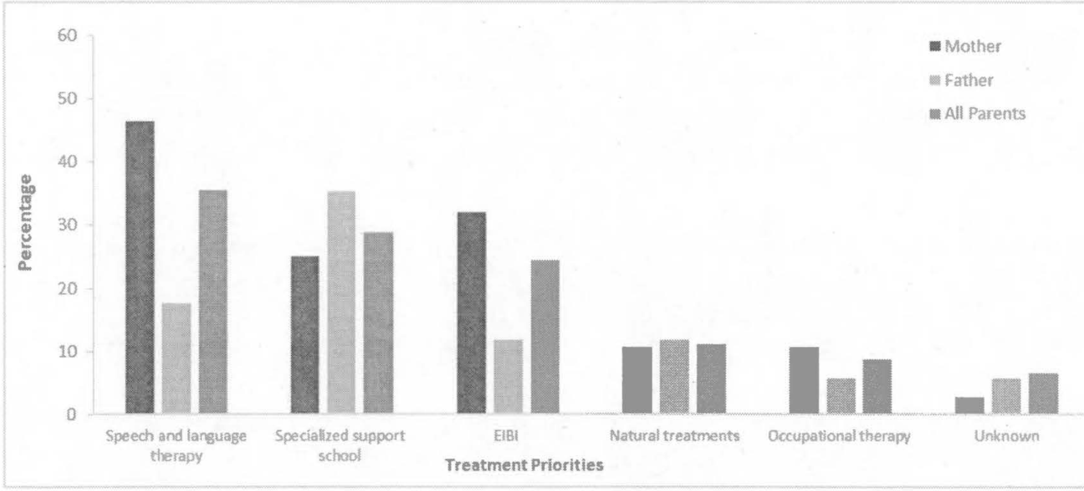

Figure 3.3 Percentage of parents who reported noticing identified each type of treatment as a priority for their child as a function of gender.

3.8 References

Al Anbar, N. N., Dardennes, R. M., Prado-Netto, A., Kaye, K., & Contejean, Y. (2010). Treatment choices in autism spectrum disorder: The role of parental illness perceptions. *Research in Developmental Disabilities, 31*, 817-828. doi: 10.1016/j.ridd.2010.02.007

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

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. doi: 10.2511/rpsd.30.4.194

Barrio, C. (2000). The Cultural Relevance of Community Support Programs. *Psychiatric services, 51*, 879-884. doi: 10.1176/appi.ps.51.7.879

Blacher, J., Cohen, S. R., & Azad, G. (2014). In the eye of the beholder: Reports of autism symptoms by Anglo and Latino mothers. *Research in Autism Spectrum Disorders, 8*, 1648-1656. doi: 10.1016/j.rasd.2014.08.017

Braunstein, V. L., Peniston, N., Perelman, A., & Cassano, M. C. (2013). The inclusion of fathers in investigations of autistic spectrum disorders. *Research in Autism Spectrum Disorders, 7*, 858-865. doi: 10.1016/j.rasd.2013.03.005

Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of Autism and Developmental Disorders, 45)*, 3244-3254. doi: 10.1007/s10803-015-2482-x

Centers for Disease Control and Prevention. (2014). Autism spectrum disorders: Data and statistics. *Retrieved November, 26*, 2014.

Cho, S. J., & Gannotti, M. E. (2005). Korean-American Mothers' Perception of Professional Support in Early Intervention and Special Education Programs. *Journal of Policy and Practice in Intellectual Disabilities, 2*, 1-9. doi: 10.1111/j.1741-1130.2005.00002.x

Coonrod, E. E. &Stone, W. L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants & Young Children, 17*, 258-268. doi: 10.1097/00001163-200407000-00007

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. doi: 10.1177/1744629515577876

Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38,* 1278-1291. doi: 0.1007/s10803-007-0512-z

Dyches, T. T., Wilder, L. K., Sudweeks, R. R., Obiakor, F. E., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of autism and developmental disorders, 34,* 211-222. doi :*10.1023/B:JADD.0000022611.80478.73*

Eikeseth, S. (2009). Outcome of comprehensive psycho-educational interventions for young children with autism. *Research in Developmental Disabilities, 30*, 158–178. doi: 10.1016/j.ridd.2008.02.003

Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2009). Meta-analysis of early intensive behavioral intervention for children with autism. *Journal of Clinical Child & Adolescent Psychology, 38*, 439-450. doi: 10.1080/15374410902851739

Flores, G., Bauchner, H., Feinstein, A. R., & Nguyen, U. S. (1999). The impact of ethnicity, family income, and parental education on children's health and use of health services. *American journal of public health, 89*, 1066-1071. doi: 10.2105/AJPH.89.7.1066

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

Goin-Kochel, R. P., Mire, S. S., & Dempsey, A. G. (2015). Emergence of autism spectrum disorder in children from simplex families: Relations to parental perceptions of etiology. *Journal of Autism and Developmental Disorders, 45,* 1451-1463. doi: 10.1007/s10803-014-2310-8

Gona, J. K., Newton, C. R., Rimba, K., Mapenzi, R., Kihara, M., Van de Vijver, F. J., & Abubakar, A. (2015). Parents' and professionals' perceptions on causes and treatment options for Autism Spectrum Disorders (ASD) in a multicultural context on the Kenyan Coast. *PloSOne, 10,* e0132729. doi: 10.1371/journal.pone.0132729

Grinker, R. R., Yeargin-Allsopp, M., & Boyle, C. (2011). Culture and autism spectrum disorders: The impact on prevalence and recognition. *Autism Spectrum Disorders,*112-136. doi: 10.1093/med/9780195371826.001.0001

Guilamo-Ramos, V., Dittus, P., Jaccard, J., Johansson, M., Bouris, A., & Acosta, N. (2007). Parenting practices among Dominican and Puerto Rican Mothers. *Journal of National Association of Social Workers, 52,* 17-30. doi: 10.1093/sw/52.1.17

Harry, B. (1992). *Cultural diversity, families and the special education system: Communication and empowerment.* New York: Teachers College Press.

Harry, B., Klingner, J. K., & Hart, J. (2005). African American families under fire: Ethnographic views of family strengths. *Remedial and Special Education, 26,* 101–112. doi: 10.1177/07419325050260020501

Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*, 231–237. doi: 10.1046/j.1365-2788.2003.00485.x

Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research, 50*, 874–882. doi: 10.1111/j.1365-2788.2006.00904.x

Hughes, M-T., Valle-Riestra, D., & Arguelles, M-E. (2008). The voice of Latino families raising children with special needs. *Journal of Latino and Education, 7*, 241-257. doi: 10.1080/15348430802100337

IASSID Families Special Interest Research Group (FSIRG; 2012). *Families supporting a child with intellectual or developmental disabilities: the current state of knowledge.* Position Paper

Kalb, L. G., Freedman, B., Foster, C., Menon, D., Landa, R., Kishfy, L., & Law, P. (2012). Determinants of appointment absenteeism at an outpatient pediatric autism clinic. *Journal of Developmental, & Behavioral Pediatrics, 33*, 685-697. doi: 10.1097/DBP.0b013e31826c66ef

Kanouté, F., Vatz Laaroussi, M., Rachédi, L., & Tchimou Doffouchi, M. (2008). Familles et réussite scolaire d'élèves immigrants du secondaire [Families and the academic success of immigrant high school students]. *Revue des sciences de l'éducation, 34*, 265-289. doi: 10.7202/019681ar

Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Annals of internal medicine, 88*, 251-258. doi : 10.7326/0003-4819-88-2-251

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: Guilford Press.

L'Écuyer, R. (1990). Méthodologie de l'analyse développementale de contenu [Developmental content analysis methods]. Québec: Presses de l'Université du Québec.

Levy, S. E., & Hyman, S. L. (2003). Use of complementary and alternative treatments for children with autistic spectrum disorders is increasing. *Pediatric Annals*, *32*, 685-691. doi: 10.3928/0090-4481-20031001-10

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health service for children with autism: Data from the national survey of children's health. *Journal of Developmental, & Behavioral Pediatrics*, *29,* 152–160. doi: 10.1097/DBP.0b013e318165c7a0

Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Medical Decision Making*, *32*, 246-258. doi: 10.1177/0272989X11421528

Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. (2012). *Autism diagnostic observation schedule: ADOS-2.* Los Angeles, CA: Western Psychological Services.

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. doi: 10.1352/1934-9556-51.3.141

Magaña, S., Parish, S. L., Rose, R. A., Timberlake, M., & Swaine, J. G. (2012). Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual and Developmental Disabilities*, *50*, 287-299. doi: 10.1352/1934-9556-50.4.287

Magaña, S., Parish, S. L., & Son, E. (2015). Have racial and ethnic disparities in the quality of health care relationships changed for children with developmental disabilities and ASD? *American journal on Intellectual and Developmental Disabilities*, *120*, 504-513. doi: 10.1352/1944-7558-120.6.504

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child, & Adolescent Psychiatry*, *41*, 1447-1453. doi: 10.1097/00004583-200212000-

Mandell, DS., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11*, 110-115. doi: 10.1002/mrdd.20061

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. doi: 10.2105/AJPH.2007.131243

Montes, G., & Halterman, J. S. (2011). White-Black disparities in family-centered care among children with autism in the United States: Evidence from the NS-CSHCN 2005–2006. *Academic Pediatrics, 11,* 297-304. doi: 10.1016/j.acap.2011.02.002

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. doi: 10.1186/1477-7525-5-22

Nielsen, M., Haun, D., Kärtner, J., & Legare, C. H. (2017). The persistent sampling bias in developmental psychology: A call to action. *Journal of Experimental Child Psychology*, *162*, 31-38. doi: /10.1016/j.jecp.2017.04.017

Palmer, R. F., Walker, T., Mandell, D., Bayles, B., & Miller, C. S. (2010). Explaining low rates of autism among Hispanic school children in Texas. *American Journal of Public Health, 100*, 270-272. doi: 10.2105/AJPH.2008.150565

Patton, M.Q. (2011). Qualitative research and evaluation methods (3rd ed.). Newbury Park, CA: SAGE.

Pelchat, D., Lefebvre, H., & Perreault, M. (2003). Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of child health care*, *7*, 231-247. doi : 10.1177/13674935030074001

Pitten, K. (2008). How cultural values influence diagnosis, treatment and the welfare of families with an autistic child. *Review Academic Journal*, *4*, 1-5. doi: 10.1177/1066480713476834

Pleck, J. H., & Masciadrelli, B. P. (2004). Paternal involvement by US residential fathers: Levels, sources, and consequences. In M. E. Lamb (Ed.), *The role of the father in child development* (pp. 222-271). Hoboken, NJ: John Wiley.

Québec Ombudsman (2009). *Looking towards greater continuity in delivery of services, approaches, and human relations: Study on government services for* *children with pervasive developmental disorders (PDDs)*. Québec, QC: Assemblée Nationale.

Québec Ombudsman (2012). *Services for young people and adults with a pervasive developmental disorder: From government commitment to cold hard facts.* Québec, QC: Assemblée Nationale.

Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies*, *21*, 311-319. doi: 10.1007/s10826-011-9477-9

Rivard, M., Lépine, A., Mercier, C., & Morin, M. (2015). Quality determinants of services for parents of young children with autism spectrum disorders. *Journal of Child and Family Studies, 24*, 2388-2397. doi: 10.1007/s10826-014-0041-2

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. doi: 10.1007/s10803-013-2028-z

Samadi, S. A., McConkey, R., & Kelly, G. (2013). Enhancing parental well-being and coping through a family-centred short course for Iranian parents of children with an autism spectrum disorder. *Autism*, *17*, 27-43. doi : 10.1177/1362361311435156

Selkirk, C. G., McCarthy Veach, P., Lian, F., Schimmenti, L., & LeRoy, B. S. (2009). Parents' perceptions of autism spectrum disorder etiology and recurrence risk and effects of their perceptions on family planning: Recommendations for genetic counselors. *Journal of Genetic Counseling*, *18*, 507-519. doi: 10.1007/s10897-009-9233-0

Shyu, Y. I. L., Tsai, J. L., & Tsai, W. C. (2010). Explaining and selecting treatments for autism: Parental explanatory models in Taiwan. *Journal of Autism and Developmental Disorders*, *40*, 1323-1331. doi: 10.1007/s10803-010-0991-1

Skinner, D.G., Correa, V., Skinner, M., Bailey, D.B. (2001). Role of Religion in the Lives of Latino Families of Young Children With Developmental Delays. *American Journal on Mental Retardation,106*, 297–313. doi: 10.1352/0895-8017(2001)106<0297:RORITL>2.0.CO;2

Statistiques Canada (2010). Immigration and Ethnocultural Diversity in Canada. Accessed via: http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-010-x/99-010-x2011001-eng.cfm

Stevenson, H. W., Chen, C., & Uttal, D. H. (1990). Beliefs and achievement: A study of Black, White, and Hispanic children. *Child development, 61,* 508-523. doi : 10.1111/j.1467-8624.1990.tb02796.x

Strauss, K., Vicari, S., Valeri, G., D'Elia, L., Arima, S., & Fava, L. (2012). Parent inclusion in early intensive behavioral intervention: The influence of parental stress, parent treatment fidelity and parent-mediated generalization of behavior targets on child outcomes. *Research in Developmental Disabilities, 33,* 688–703. doi:10.1016/j.ridd.2011.11.008.

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. doi: 10.1016/j.rasd.2015.11.008

Virués-Ortega, J. (2010). Applied behavior analytic intervention for autism in early childhood: Meta-analysis, meta-regression and dose-response meta-analysis of multiple outcomes. *Clinical Psychology Review, 30,* 387–399. doi: 10.1016/j.cpr.2010.01.008

Warren, Z., McPheeters, M. L., Sathe, N., Foss-Feig, J. H., Glasser, A. & Veenstra-VanderWeele, J. (2011). A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics, 127,* e1303–e1311. doi: 10.1542/peds.2011-0426

Yeh, M., Hough, R. L., McCabe, K., Lau, A., & Garland, A. (2004). Parental beliefs about the causes of child problems: Exploring racial/ethnic patterns. *Journal of the American Academy of Child, & Adolescent Psychiatry, 43,* 605-612. doi: 10.1097/00004583-200405000-00014

Zuckerman, K. E., Sinche, B., Cobian, M., Cervantes, M., Mejia, A., Becker, T., & Nicolaidis, C. (2014). Conceptualization of autism in the Latino community and its relationship with early diagnosis. *Journal of Developmental and Behavioral Pediatrics, 35,* 522. doi: 10.1097/DBP.0000000000000091

Zuckerman, K. E., Lindly, O. J., & Sinche, B. (2016). Parent beliefs about the causes of learning and developmental problems among children with autism spectrum disorder: Results from a national survey. *American Journal on Intellectual and Developmental Disabilities, 121,* 432-447. doi: 10.1352/1944-7558-121.5.432

CHAPITRE IV

DISCUSSION

Cette thèse doctorale a comme objectif l'étude de l'expérience des pères et des mères issus de l'immigration de première génération et ayant un enfant avec un TSA. La thèse est composée de trois articles qui s'intéressent chacun à un aspect particulier de cette expérience. Les deux premiers articles utilisent des données quantitatives pour comparer le stress parental et la qualité de vie familiale (FQoL) des parents issus de l'immigration à ces aspects chez des parents québécois ayant le même statut socio-économique. Le troisième article complète les deux premières études en étudiant, par le biais d'une étude qualitative, la perception des parents issus de l'immigration sur les causes du TSA de leur enfant, aux premiers symptômes perçus chez lui et aux traitements qu'ils privilégient. Ce quatrième chapitre présente une synthèse des résultats de chacun des articles et décrit les apports et les limites de la thèse. Des recommandations quant aux besoins de recherche futurs ainsi que des recommandations cliniques découlant des résultats et de la littérature sont proposées.

4.1 Le stress parental des pères et mères issus de l'immigration

Cette première étude est une analyse quantitative du stress parental de 82 parents ayant récemment eu un diagnostic de TSA pour leur enfant et étant en attente de services publics d'intervention précoce en centre de réadaptation en déficience intellectuelle et trouble envahissant du développement (CRDITED). Les objectifs de cette étude sont de documenter les différences de stress parental selon le genre du parent et de comparer le stress parental des parents issus de l'immigration à celui des parents québécois.

Les résultats de l'étude indiquent que 87 % de nos participants (toutes origines et tous genres confondus) dépassent le seuil clinique de stress parental. Ce résultat est concordant avec les données de la littérature qui indique un stress intense chez les familles ayant un enfant avec un TSA (Baker-Ericzèn *et al.*, 2005; Blacher et McIntyre, 2006; Rivard *et al.*, 2014). Toutefois, les résultats concernant le stress parental dans la population de notre étude sont particulièrement élevés comparativement aux études antérieures, dans lesquelles le pourcentage de participants dépassant le seuil clinique de stress parental oscille entre 26 % et 85 % (Ingersoll et Hambrick, 2011; Kayfitz *et al.*, 2010). La période dans laquelle se trouvent les parents au moment de la collecte de données (suite au diagnostic et en attente de service) ainsi que leur statut socio-économique (60,9 % ont un revenu familial annuel inférieur à 50 000 $) peut expliquer qu'autant de nos participants aient un stress parental dépassant le seuil clinique. Ce premier élément est important à prendre en considération par les intervenants. Cette période est documentée comme une période critique pour les parents (Davis et Carter, 2008; Osborne *et al.*, 2008; Mello *et al.*, 2018, en révision; Rivard *et al.*, 2014). Ainsi, il est important que les intervenants qui recevront les parents à la suite de cette période aient conscience de leur stress parental intense et de l'impact que celui-ci peut avoir sur leur disponibilité à mettre en place les interventions recommandées. Aussi, ces résultats indiquent l'importance d'identifier des alternatives pour pallier le manque de services et de soutien aux familles, suite au diagnostic de leur enfant.

Les analyses des effets du genre sur l'indice de stress parental global indiquent qu'il n'y a pas d'effet significatif. Toutefois, on peut souligner que les pères québécois ont un stress plus élevé que les trois autres groupes (mères québécoises et issues de l'immigration, pères issus de l'immigration). Lorsqu'on détaille les résultats aux sous-échelles de l'indice de stress parental, on observe que les pères québécois ont un stress significativement plus élevé que les pères et mères issus de l'immigration concernant l'échelle « détresse parentale » et un stress plus élevé que les pères issus de l'immigration concernant l'échelle « difficulté de l'enfant ». Ce résultat pourrait s'expliquer par des différences dans les rôles parentaux en fonction de la culture. En effet, les rôles parentaux sont influencés par la culture puisqu'il s'agit d'un construit social qui diffère d'une société à l'autre, mais aussi en fonction de l'époque (Constantin et Voicu, 2015; Pfau-Effinger, 2004). Dans la culture nord-américaine, les rôles parentaux tendent à être moins traditionnels, dans le sens où les pères s'impliqueraient davantage dans l'éducation de leur enfant (Cabrera *et al.*, 2000). Les rôles traditionnels peuvent être plus marqués dans certaines cultures. Par exemple, Hofferth (2003) explique que les pères originaires d'Afrique passeraient moins de temps avec leur enfant que les pères caucasiens. Cette différence de temps passé avec l'enfant pourrait expliquer que les pères québécois ressentent plus de stress concernant les difficultés de l'enfant. En effet, si effectivement ils passent plus de temps avec leur enfant, il est possible qu'ils aient plus conscience des difficultés de celui-ci.

Les résultats concernant les différences sur le stress parental selon le statut (issu de l'immigration vs origine québécoise caucasienne) vont à l'encontre de ce que nous pouvions supposer à la lumière des écrits existants (Klingner *et al.*, 2009; Magaña *et al.*, 2013; Mandell *et al.*, 2002). En effet, compte tenu des défis supplémentaires tels que les difficultés d'accès aux services que rencontrent les familles issues de l'immigration, nous nous attendions à un stress parental plus élevé chez ce groupe. Néanmoins, nos analyses indiquent que les parents québécois se perçoivent comme ayant un plus haut niveau de stress parental que les parents issus de l'immigration. Une étude menée par Emmen *et al.* (2013) auprès de mères d'enfants sans handicap, indique que le modèle de stress peut différer entre les familles issues de l'immigration et les familles issues de la culture d'accueil, notamment à cause de différentes sources de stress que celles-ci doivent affronter. Dans notre étude, seul le stress parental est mesuré. Ainsi, il est possible que nos participants issus de l'immigration aient en parallèle du stress parental déjà élevé, d'autres sources de stress telles que le stress financier et le stress d'acculturation. La multiplicité de ces différentes sources de stress peut ainsi ne pas se refléter dans les résultats concernant le stress parental, mais peut avoir un impact majeur sur d'autres aspects tels que le bien-être et la qualité de vie. En ce sens, il est nécessaire d'étudier d'autres dimensions du vécu des parents dans le but de dresser un portrait plus représentatif de leur réalité. Par exemple, la qualité de vie familiale est un concept permettant d'approfondir l'expérience de ces parents, en s'intéressant à l'impact du TSA de l'enfant sur la dynamique familiale.

4.2 La qualité de vie familiale des pères et mères issus de l'immigration

La seconde étude de cette thèse, présentée au chapitre II, est une analyse quantitative de la qualité de vie familiale (FQoL) de 104 parents d'enfants ayant un TSA à la période suivant l'annonce du diagnostic. Le premier objectif est d'étudier les différences de FQoL entre les parents issus de l'immigration (29 mères et 23 pères) et les parents québécois (29 mères et 23 pères). Le deuxième objectif est d'analyser les différences quant à la FQoL rapportée selon le genre du parent.

Tout d'abord, les résultats indiquent qu'en dépit du niveau de stress parental élevé rapporté par les parents pendant cette période (voir Chapitre I), ceux-ci ont une évaluation neutre de leur FQoL. Ce premier constat révèle que leur perception quant à leur qualité de vie familiale n'est pas totalement négative et qu'ils sont satisfaits de certains aspects de leur vie de famille. Cela permet de mettre en lumière un aspect moins pessimiste que le stress parental. L'échelle « bien-être physique et matériel » est l'échelle pour laquelle les parents (tous groupes confondus) ont donné les meilleurs scores de satisfaction. Ainsi, bien que la majorité des participants aient un revenu familial annuel inférieur à 50 000 $, ce n'est pas l'aspect de leur vie familiale dont ils sont le plus insatisfaits. Des études révèlent que le fait d'avoir un enfant ayant un TSA a modifié les priorités de vie des familles (Bayat, 2007; Gray, 2006). Il est ainsi possible que dans le cas de nos participants, leur situation financière ne soit pas perçue comme une difficulté majeure due à un changement de perception de leurs priorités après le diagnostic de leur enfant. De plus, contrairement à d'autres pays dans lesquels les services sont payants, au Québec, les familles sont avisées qu'elles recevront des services d'interventions basés sur les données probantes par le système public. Ainsi, même si elles attendent ces services, le fait de savoir qu'elles bénéficieront de ceux-ci peut amoindrir l'insatisfaction en lien avec le bien-être matériel.

Le premier objectif de l'étude était de documenter les différences entre les parents issus de l'immigration et ceux d'origine québécoise caucasienne. Nos résultats n'indiquent aucune différence significative sur l'échelle globale de satisfaction de FQoL entre ces deux groupes. Néanmoins, les parents québécois sont significativement plus satisfaits aux sous-échelles évaluant le « soutien en lien avec le handicap » et les « interactions familiales ». Le fait que les parents québécois obtiennent de meilleurs scores à la sous-échelle « soutien en lien avec le handicap » corrobore la littérature qui mentionne que les familles issues de l'immigration ayant un enfant avec un TSA ont plus de difficultés dans l'accès aux services et qu'elles sont plus isolées que les familles issues de la culture d'accueil (Cho et Gannotti, 2005; Klingner *et al.*, 2009; Mandell *et al.*, 2002; Söderström, 2014). En effet, les barrières de langues, de culture et l'absence des proches dans le pays d'accueil sont des éléments qui sont reliés à l'isolement que peuvent vivre les parents issus de l'immigration (Klingner *et al.*, 2009; Mandell *et al.*, 2002; Söderström, 2014). Les données de notre étude concernant le soutien reçu par les participants indiquent que les familles issues de l'immigration sont plus nombreuses que les familles québécoises à n'avoir aucune ressource de soutien. Le fait d'avoir peu de soutien, que ce soit de la part des professionnels, d'un réseau social ou de la famille, peut expliquer les différences de satisfaction de nos participants à cette sous-échelle. Le fait d'être parent issu de l'immigration entraîne des ajustements des rôles parentaux et de la vie familiale afin de s'adapter à la culture d'accueil. Ce faisant, les interactions familiales peuvent également être différentes des attentes des parents (Gervais, De Montigny, Azaroual et Courtois, 2009). En plus de ces modifications, les familles issues de l'immigration vivent aussi des modifications des interactions familiales engendrées par le diagnostic de leur enfant (Chatenoud, Kalubi et Paquet, 2014; Gardiner et Iarocci; 2012; Gervais *et al.*, 2009; Lyons *et al.*, 2010). Ces multiples ajustements peuvent créer un écart important avec le modèle familial de la culture d'origine, ce qui peut expliquer que les parents issus de l'immigration aient une moins bonne satisfaction que les parents québécois à l'échelle d'interaction familiale.

Notre deuxième objectif pour cette étude était de documenter les différences de satisfaction de la FQoL selon le genre. Nos résultats n'indiquent pas de différences significatives. Néanmoins, on peut souligner que les mères sont presque deux fois plus nombreuses que les pères à indiquer une insatisfaction de leur FQoL. L'emploi des mères peut expliquer les différences de satisfaction de FQoL qu'on observe entre les pères et les mères (McStay, Trembath et Dissanayake, 2014; Mello *et al.*, 2018, en révision). Dans notre étude, 41,38 % des mères sont sans-emploi, alors que les pères sont 17,39 %, ce qui peut contribuer à une plus grande insatisfaction de FQoL chez les mères.

Nos deux premiers articles et les résultats qui en découlent permettent de tirer plusieurs conclusions. Premièrement d'un point de vue clinique, nos résultats vont dans le même sens que la littérature concernant l'isolement des familles issues de l'immigration. La trajectoire de services, les démarches pour y avoir accès, mais aussi la satisfaction de ceux-ci sont des défis pour toutes les familles (Barelds *et al.*, 2009; Rivard *et al.*, 2014). Ces défis sont d'autant plus contraignants pour les familles issues de l'immigration qui ont des barrières telles que les différences de langues, l'absence de familiarité avec le fonctionnement du système québécois, l'isolement social (Klingner *et al.*, 2009; Magaña *et al.*, 2013; Mandell *et al.*, 2002). Il semble donc nécessaire de développer des services d'informations sur les services disponibles destinés aux familles issues de l'immigration afin de pallier le manque d'information sur les services québécois. De plus, nos résultats appuient les quelques études concernant cette période et indiquent la nécessité de mettre en place des services pour les familles dès l'annonce diagnostique. Le fait d'étudier différents aspects de l'expérience des familles est un apport permettant de mieux comprendre le vécu de ces familles. La mesure de FQoL a permis d'ajouter des nuances à la mesure de stress parental du premier article. En effet, il est important de connaître le niveau de stress parental, mais cette mesure seule ne permet pas d'identifier les besoins des familles. Cette seconde mesure aide à identifier les besoins des familles. Par exemple, on remarque que pour les familles issues de l'immigration il est important de développer des outils qui favoriseront l'amélioration des interactions familiales et le bien-être émotionnel puisqu'il s'agit des deux sous-échelles pour lesquelles elles sont le moins satisfaites. Ainsi, il est pertinent de récolter plusieurs types de données pour enrichir nos connaissances concernant le vécu des familles issues de l'immigration. Parmi ces différents moyens de récolter des données, l'analyse qualitative permet d'explorer davantage certains thèmes offrant une compréhension approfondie du vécu des familles.

La réalisation de ces études s'est développée par un processus de réflexions dynamique. En effet, le fait que la majorité des études en TSA dressent un portrait pessimiste des familles en s'intéressant particulièrement au stress nous a amenés à vouloir analyser une autre facette de leur expérience, soit la FQoL. À la suite de ces résultats, il nous a paru important d'ajouter une étude qualitative afin de pouvoir comprendre de manière plus profonde les éléments pouvant être un frein à l'accès des services ou encore à une bonne utilisation de ceux-ci. Pour répondre à cela et avoir un portrait plus approfondi de l'expérience de ces familles, l'étude des différentes perceptions qu'ont les familles sur le TSA nous a semblé importante.

4.3 Perceptions des causes, premiers symptômes perçus et priorités de traitement : le point de vue des familles issues de l'immigration

Le troisième et dernier article de cette thèse vise à documenter les perceptions de 45 parents (28 mères et 17 pères) concernant leurs croyances quant aux causes du TSA, les premiers symptômes perçus chez leur enfant et leur priorité de traitement. L'étude qualitative de ces perceptions est un apport important en termes de compréhension de l'expérience de ces familles. Les perceptions des causes du TSA ainsi que les premiers symptômes perçus par les parents dépendent de la manière dont le handicap et le développement de l'enfant sont appréhendés (Daley et Sigman, 2002; Harry, Kalyanpur et Day, 1999; Ravindra et Myers, 2012). Les conceptions du développement de l'enfant, mais aussi du handicap, varient ainsi selon les cultures et les époques (Rivard, Millau, Forget et Morin, 2013). Par exemple, l'évolution de la terminologie de trouble envahissant du développement (TED) à TSA est un exemple de variation en fonction des normes et des connaissances d'une époque (Rivard *et al.*, 2013). Les croyances quant aux causes, ainsi que les symptômes perçus par les parents, vont influencer leur choix de traitement, mais aussi leur adhésion avec les interventions proposées par les intervenants (Mandell et Novak, 2005; Welterlin et LaRue, 2007). Une meilleure compréhension de ces éléments permet d'approfondir la compréhension de ces familles et ainsi être utile pour mieux les rejoindre et répondre à leurs besoins. Pour répondre à cet objectif, les parents ont participé à une entrevue semi-structurée qui a ensuite été analysée selon l'analyse thématique de Mucchielli (voir l'Ecuyer, 1990).

4.3.1 Croyances quant aux causes des TSA

L'analyse des verbatims permet de faire émerger sept catégories de causes attribuées au TSA par les parents (voir Chapitre III pour les détails). Parmi ces catégories, celles nommées par le plus grand nombre de participants sont : les causes environnementales (alimentation, vaccins et pollution), les causes inconnues et les causes en lien avec la grossesse ou l'accouchement (conception par insémination, diabète de grossesse, stress, accouchement avec forceps). Ces résultats sont cohérents avec les études indiquant que les familles originaires d'Afrique ou d'Amérique latine sont moins susceptibles de croire aux causes génétiques que les familles caucasiennes (Zuckerman *et al.*, 2016). Ce premier résultat appuie la nécessité de promouvoir des services d'information sur le TSA pour les familles. En effet, les croyances que les familles ont quant aux causes du TSA peuvent avoir des effets importants sur la collaboration qu'elles auront avec les professionnels œuvrant dans les différents services. Ces perceptions sur les causes du TSA vont teinter l'interprétation que les parents ont des comportements et des symptômes de leur enfant (Dyches, Wilder, Sudweeks, Obiakor et Algozzine, 2004; Ravindra et Myers, 2012). Ces interprétations peuvent ainsi se différencier de celles proposées par les professionnels, et peuvent ainsi occasionner des difficultés d'adhésions aux interventions proposées (Dyches *et al.*, 2004; Jones *et al.*, 2011; Ravindra et Myers, 2012; Rivard *et al.*, 2013).

Concernant les différences en fonction du pays d'origine, bien que nos échantillons ne soient pas équivalents et représentatifs de chaque région, nous pouvons souligner quelques différences. Tout d'abord, les causes environnementales sont plus souvent mentionnées par les familles originaires d'Afrique, ce qui corrobore les résultats d'autres études menées auprès de cette population (Burkett *et al.*, 2015; Gona *et al.*, 2015). Ensuite, contrairement aux données de la littérature, les participants originaires d'Amérique latine sont peu à mentionner les causes religieuses. En effet, les résultats indiquent que plus de la moitié de ces participants mentionnent les causes en lien avec la grossesse ou l'accouchement et ce sont seulement 5 % de ces familles qui nomment des causes religieuses pour le diagnostic de leur enfant. Cette différence avec la littérature pourrait s'expliquer par le fait que les participants ont un niveau de scolarité plus élevé que ceux reportés dans les autres études (Hugues *et al.*, 2008; Skinner *et al.*, 2001). Aussi, la désirabilité sociale envers la personne menant l'entrevue est un biais possible pouvant expliquer la différence avec les données de la littérature.

Parmi les différences selon le genre, on peut souligner que les mères sont plus nombreuses que les pères à nommer des causes en lien avec la grossesse ou l'accouchement. Quant aux pères, ils nomment majoritairement les causes environnementales. Cette différence de perception entre les mères et les pères appuie la nécessité d'informer les parents sur les TSA, notamment par le biais de coaching parental. Dans le cadre d'atelier de coaching parental, il est nécessaire de tenir compte des différences de perceptions selon le genre du parent afin de répondre à leurs questionnements respectifs.

4.3.2 Premiers symptômes perçus

Les premiers symptômes perçus par nos participants peuvent être regroupés en six catégories. Les trois catégories principalement nommées sont : l'absence ou le délai de langage, la communication non verbale et les comportements stéréotypés. Ces catégories correspondent à la description des TSA selon le DSM-5 et l'intégration de ces aspects constitue une étape importante dans la compréhension du diagnostic par les familles. Notre étude n'indique pas de différences majeures dans la perception des premiers symptômes selon le genre. Par contre, on remarque certaines différences selon le pays d'origine. Par exemple, les familles originaires des Caraïbes ou du Proche-Orient ne mentionnent pas d'absence ou de retard de langage alors qu'entre 50 % et 100 % des familles provenant d'autres origines reportent ces symptômes. Une autre différence concerne l'absence de jeu qui est reporté uniquement par des familles originaires d'Afrique du Nord et d'Europe de l'Ouest. Rappelons que nous avons un petit échantillon et que le nombre de participants par pays n'est pas équivalent, ainsi il est impossible de généraliser ces résultats. Néanmoins, ces différences peuvent être des indicateurs d'une perception différente du développement du langage et du jeu en fonction des cultures.

4.3.3 Priorités de traitement

Les priorités de traitements mentionnées par les parents sont cohérentes avec les premiers symptômes perçus. Ainsi, l'orthophonie est le traitement le plus souvent nommé par les parents, suivi par le soutien à l'école et par l'intervention comportementale intensive (ICI). Ces résultats indiquent que les parents favorisent des traitements éducatifs. Cela peut s'expliquer par le fait que les familles issues de l'immigration accordent une grande importance à la scolarisation de leurs enfants. Des études menées auprès des familles issues de l'immigration ayant un enfant sans handicap indiquent que la réussite de la scolarisation de leur enfant représente un espoir d'une bonne intégration de celui-ci dans la société d'accueil (Gervais *et al.*, 2009; Kanouté *et al.*, 2008; Stevenson, Chen et Uttal, 1990). Ainsi, l'éducation et la réussite scolaire sont souvent valorisées et priorisées par ces familles. Il est ainsi probable que les parents aient les mêmes attentes en matière d'éducation pour leur enfant ayant un TSA.

Les traitements naturels tels que l'utilisation de régimes ou la prise de vitamines dans le but de diminuer ou d'enrayer les symptômes liés au TSA ont été nommés uniquement par les parents originaires d'Afrique centrale ou de l'Ouest. Ce résultat est cohérent avec les données de la littérature concernant les traitements privilégiés par ces familles (Burkett *et al.*, 2015; Gona *et al.*, 2015). Ces familles ont donc des croyances quant aux conséquences de l'environnement et de l'alimentation sur les comportements de leur enfant. Afin de garantir une bonne collaboration, les intervenants doivent considérer ces croyances et respecter le choix des familles, tout en expliquant l'état des connaissances pour promouvoir le maintien d'interventions comme l'ICI en parallèle des traitements naturels. L'ICI est majoritairement nommé par les parents originaires d'Europe de l'Ouest, d'Afrique du Nord et du Proche-Orient. Cela peut s'expliquer soit par le fait que l'ICI est un traitement qui correspond aux valeurs de ces parents, ou bien qu'ils sont plus informés sur les traitements et sur l'efficacité de l'ICI. En effet, l'ICI est le traitement recommandé par les guides de pratiques internationaux (APA, CAP, OPQ). L'efficacité de l'ICI, notamment sur la réduction des comportements problématiques, la diminution de la sévérité des symptômes du TSA, et l'amélioration des comportements adaptatifs, a été démontrée par de nombreuses études (Eldevik *et al.*, 2009; Kasari et Lawton, 2010; Makrygianni et Reed, 2010; Rivard, Morin, Mello, Terroux et Mercier, 2018; Rogers et Vismara, 2008; Virués-Ortega, 2010; Warren *et al.*, 2011) pouvant expliquer que ces familles favorisent ces traitements. De ce fait, l'information des parents sur les données probantes est nécessaire afin qu'ils puissent choisir d'adhérer ou non au traitement en ayant toutes les informations pertinentes. Les différences selon le genre indiquent que les mères priorisent majoritairement l'orthophonie alors que les pères sont plus nombreux à privilégier le soutien à l'école. Les pères orientent leurs attentes vers l'école et accordent de l'importance à la réussite scolaire. Quant aux mères, elles semblent favoriser la communication avec leur enfant.

Cette étude permet de mettre en avant des différences de perception selon la culture des parents, notamment concernant les causes que les parents attribuent aux TSA. Nos participants sont 46,67 % à avoir nommé plusieurs causes, et comparativement aux études menées auprès de familles nord-américaines, ils sont moins nombreux à évoquer des causes génétiques. Ainsi, l'information des parents, tant sur les TSA que sur les différents services disponibles au Québec à la suite du diagnostic, devrait être une priorité. De plus, il est également nécessaire que les personnes intervenantes auprès des familles aient connaissance de ces différentes perceptions et qu'ils soient respectueux des valeurs et croyances des familles, sans quoi la collaboration avec les familles ne sera pas favorable à l'évolution de l'enfant.

4.4 Les limites des études de la thèse

Les études de cette thèse présentent certaines limites qu'il est important de considérer pour l'interprétation des résultats, mais aussi pour suggérer des pistes de recherches futures. Premièrement, les échantillons de nos études ne permettent pas de généraliser les résultats à l'ensemble des populations visées ni de faire certaines analyses statistiques plus poussées. Toujours concernant le nombre de participants, il est important de rappeler que les groupes selon le pays d'origine ne sont pas équivalents et que les représentants de chaque pays sont peu nombreux. Concernant notre dernier article, le choix du devis représente une force sur le plan de la richesse de l'analyse, mais comporte la limite de l'absence de participants provenant de la culture d'accueil afin de comparer les perceptions respectives. Bien que des études similaires aient été menées auprès de familles nord-américaines, une comparaison avec des familles d'origine québécoise caucasienne aurait permis de confronter les perceptions des parents à la même période de la trajectoire. Aussi, dans nos études une et deux, les familles issues de l'immigration ont été appariées avec des familles d'origine québécoise caucasienne en fonction de leurs revenus. Bien que cela permette d'avoir des groupes comparables sur le plan socio-économique, on remarque que les groupes ne sont pas équivalents en ce qui concerne le niveau d'éducation. En effet, pour des revenus similaires, les familles issues de l'immigration ont un plus haut niveau de scolarisation que les familles québécoises. Cela met en évidence les difficultés rencontrées par les familles issues de l'immigration pour faire reconnaître leurs diplômes dans le pays d'accueil et pour pouvoir exercer leur métier d'origine (Côté, 2018).

4.5 Recommandations pour les recherches futures

Les différentes limites soulignées ainsi que les questionnements soulevés par nos résultats permettent d'identifier plusieurs besoins en matière de recherche future. De manière générale, et afin de combler le manque dans la littérature, il semble nécessaire de multiplier les recherches auprès des groupes sous-représentés dans les recherches soit les familles issues de l'immigration, mais aussi les pères.

Du point de vue de la méthode, des études similaires, mais ayant un plus grand échantillon, permettraient de confirmer nos résultats ou de développer une compréhension plus détaillée de l'expérience des parents issus de l'immigration. Aussi, afin de dresser des portraits plus complets selon les pays d'origine des familles, il serait intéressant de mener des recherches ayant des échantillons équivalents de participants par pays d'origine. Cela permettrait aussi de mieux comprendre l'impact des caractéristiques culturelles sur le stress parental, la FQoL, mais aussi sur les perceptions des familles face au TSA. En effet, les recherches en psychologie auprès de personnes issues de minorités culturelles indiquent l'importance de développer des modèles soulignant les différences entre groupes ethniques afin de pouvoir mettre en place des programmes adaptés à ces différences (Ortiz, 2013). Dans le but d'identifier les différentes sources de stress des parents issus de l'immigration et leur impact sur la FQoL et le stress parental, des études utilisant d'autres mesures telles qu'une mesure de stress d'acculturation et des données sur les circonstances d'immigration devraient être réalisées. En effet, les chercheurs en psychologie interculturelle[5] mentionnent la nécessité de s'intéresser à ces variables qui pourraient notamment expliquer les différences de réponses aux traitements, mais aussi les difficultés d'accès et d'adhésion à ces traitements (Kilbourne, Switzer, Hyman, Crowley-Matoka et Fine, 2006; Ortiz, 2013). Nos résultats indiquent un niveau de stress parental très élevé chez nos

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[5] Ici, nous faisons référence aux recherches en psychologie interculturelle, dans tous les domaines, pas uniquement en TSA.

participants. Afin de comprendre les processus en lien avec la gestion du stress, des recherches portant spécifiquement sur les stratégies d'adaptations au stress des parents ayant un enfant avec un TSA seraient pertinentes. Ces recherches devraient également s'intéresser aux différences de stratégie de gestion du stress efficace selon le genre des parents et de leur origine culturelle. Ce type de recherche serait une aide importante pour développer des services spécifiques visant la diminution du stress parental. Documenter le stress, la FQoL et les perceptions des parents durant toutes les étapes clés de la trajectoire de services (diagnostic, obtention des services, fin de services, entrée à l'école) apporterait un enrichissement des connaissances. En effet, les études sur la trajectoire des familles révèlent des défis majeurs et constants (Barelds, 2009; Little, 2003; Rivard *et al.*, 2014). La compréhension des besoins et attentes des familles à chacune des étapes permettrait l'amélioration des pratiques. Enfin, l'analyse qualitative des attentes et besoins des parents issus de l'immigration, mais aussi des pères, devrait être une promue pour augmenter leur implication dans l'intervention et garantir une meilleure collaboration. Sans une connaissance approfondie de leur expérience, mais aussi de leurs attentes, il est difficile de développer des services adaptés. Or, l'implication dans les services nécessite que ceux-ci correspondent aux attentes des parents (Gallimore et Goldenberg, 2001; Renty et Roeyers, 2006; Samadi, McConkey et Kelly, 2011, 2012).

4.6 Les forces et les apports des études de la thèse

Les contributions de la thèse sur le plan des connaissances dans le domaine du TSA et en termes de recommandations pour l'amélioration des pratiques sont multiples. Un des apports de la thèse est d'avoir favorisé la participation de familles sous représentées dans la littérature ainsi que celle des pères. Les études en TSA sont majoritairement réalisées auprès de populations anglophones, caucasiennes et ayant un bon revenu (Dyches *et al.*, 2004; Emerson *et al.*, 2008). Ainsi, nos études contribuent à dresser un portrait des familles peu représentées dans les recherches actuelles en TSA, mais aussi de documenter davantage l'expérience des pères. Le fait de comparer les résultats des pères et des mères sur plusieurs variables apporte des pistes de réflexion importantes concernant la pratique. Par exemple, la prise en considération du stress paternel et la mise en place d'outils spécifiques pour les aider à faire face à ce stress parental important. En effet, les études ayant essentiellement ciblé les mères, le stress parental des pères est moins reconnu. Nos résultats soulignent qu'il ne faut pas oublier cette variable dans la prise en charge des parents.

Dans le même ordre d'idées, le fait d'avoir des groupes équivalents (nombre et revenu) de parents issus de l'immigration et de parents québécois représente une force méthodologique. À notre connaissance, cette étude est la première qui compare le stress parental perçu et la FQoL de parents issus de l'immigration aux parents issus de la culture d'accueil dans la période critique suivant le diagnostic et en attente de service. L'ajout d'une étude qualitative sur la perception des familles issues de l'immigration permet de compléter les deux premières études en s'intéressant plus en profondeur à ce que perçoivent les familles et d'avoir une compréhension plus fine de leur expérience. La combinaison de données quantitatives et qualitatives représente une force du projet. Ce type de devis est recommandé dans les recherches menées auprès des familles issues de minorités culturelles (Blacher et Hatton, 2007; Ortiz, 2013).

4.7 Les recommandations cliniques résultant des études de la thèse

Les résultats de ces trois études nous permettent d'émettre plusieurs recommandations pour la pratique. Le soutien des parents sur différents aspects en lien avec le diagnostic de leur enfant pendant la période suivant le diagnostic et lorsqu'ils sont en attente de services est primordial, d'autant plus pour les familles issues de l'immigration qui sont confrontées à plusieurs difficultés. Ainsi, il est nécessaire de concevoir un modèle de soutien adapté à ces familles. L'adaptation culturelle des interventions et programmes en psychologie est de plus en plus mise en avant par la littérature scientifique (Bernal et Saez-Santiago, 2006; Haack *et al.*, 2014; Hall, Ibaraki et Huang, 2016; Hughes *et al.*, 2008; Ojeda, Flores, Meza et Morales, 2010; Ortiz, 2013). En 1996, Forehand et Kotchick[6] ont écrit un article qui soulignait l'importance que les formations parentales soient adaptées à la culture. Depuis, plusieurs chercheurs soulignent cette importance et plusieurs adaptations culturelles d'intervention parentale ont été réalisées (Castro, Barrera et Holleran-Steiker, 2010; Magana, Lopez et Machalicek, 2017; Valdez, Abegglen et Hauser, 2013; Valdez, Padilla, Moore et Magana, 2013). La prise en considération des aspects culturels dans la prise en charge psychologique est également soulignée par les guides de pratiques des associations de professionnels en psychologie telles que l'association américaine de psychologie (APA, 2013b, 2017). À la lumière de nos résultats, et en s'appuyant sur les guides de pratiques, sur les modèles conceptuels développés pour l'intervention culturellement sensible (voir entre autres : Bernal, Bonilla et Bellido, 1995; Bernal, Jiménez-Chafey et Domenech-Rodríguez, 2009), et sur les adaptations existantes dans le domaine des TSA (voir entre autres Magana *et al.*, 2017), nous proposons dans cette partie un modèle structurant les recommandations afin d'adapter les interventions pour les familles issues de l'immigration vivant au Québec ayant un enfant avec un TSA. Ce modèle (voir Figure 4.1) peut se diviser en quatre types de services répondant aux besoins majeurs découlant de nos résultats et des données de la littérature : 1) le soutien dans la trajectoire de services ; 2) l'information ; 3) le coaching parental ; et 4) le bien-être des familles. Afin que ces interventions soient efficaces, il est nécessaire de les adapter et de former les intervenants et les milieux à l'intervention culturellement sensible. C'est le cinquième point qui sera présenté dans cette partie.

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[6] Cet article ne concerne pas uniquement les formations parentales destinées aux parents d'enfants ayant un TSA, mais concerne les formations parentales en général. Il a été republié en 2016.

4.7.1 Le soutien dans la trajectoire de services

Comme démontré dans la littérature, les familles issues de l'immigration ont des difficultés d'accès aux services, ce qui peut avoir un impact sur le délai de prise en charge de leur enfant et de la famille. Ainsi, il serait pertinent que les familles soient accompagnées dans les démarches par un intervenant pivot suivant les familles dès les premiers soupçons, et ce, jusqu'à la fin des services. La désignation d'un intervenant pivot est d'ailleurs une des recommandations émises dans le rapport spécial du protecteur du citoyen (2015, p. 10) : « Que chaque usager entreprenant un parcours de services dans un contexte d'incapacités persistantes et significatives se voit assigner, dès le début de son parcours de services, un intervenant pivot responsable de coordonner ce parcours ». La continuité dans les services a été identifiée comme un élément important de la satisfaction des familles (Barelds, 2009). Actuellement, les familles interrogées sur leur satisfaction des services québécois mentionnent être insatisfaites de la continuité de ceux-ci (Protecteur du citoyen, 2015; Rivard *et al.*, 2014). Un soutien dans toutes les démarches apparaît d'autant plus important pour les familles issues de l'immigration qui ont des difficultés d'accès aux services (Liptak *et al.*, 2008; Montes, Halterman et Magyar, 2009; Thomas, Ellis, McLaurin, Daniels et Morrissey, 2007).

4.7.2 L'information

Un service d'informations contribuerait à l'amélioration des connaissances des familles sur les TSA, sur les services disponibles et sur les meilleures pratiques. Des études indiquent que le manque d'informations sur les TSA et sur les services contribue à l'exacerbation du stress des parents, mais aussi à une moins bonne satisfaction des services (Bligin et Kucuk, 2010; Renty et Roeyers, 2006; Samadi *et al.*, 2011). Comme le suggèrent Magana et ses collaborateurs (2017), ce type de formation devrait permettre aux parents de :

- Reconnaître les signes et les symptômes du TSA et comprendre les critères diagnostic ;
- Apprendre comment et vers qui obtenir de l'aide pour le diagnostic, pour les services pour l'enfant et la famille, et les services communautaires disponibles ;
- Connaître les subventions et autres services de soutien financier
- Apprendre les droits de l'enfant dans le système scolaire (ex : temps supplémentaire pour examen, services) ;
- - Apprendre aux parents comment expliquer l'autisme et les comportements de leur enfant aux autres membres de la famille ;
- Connaître les interventions fondées sur les données probantes et les sensibiliser sur les techniques et objectifs utilisés en ICI.

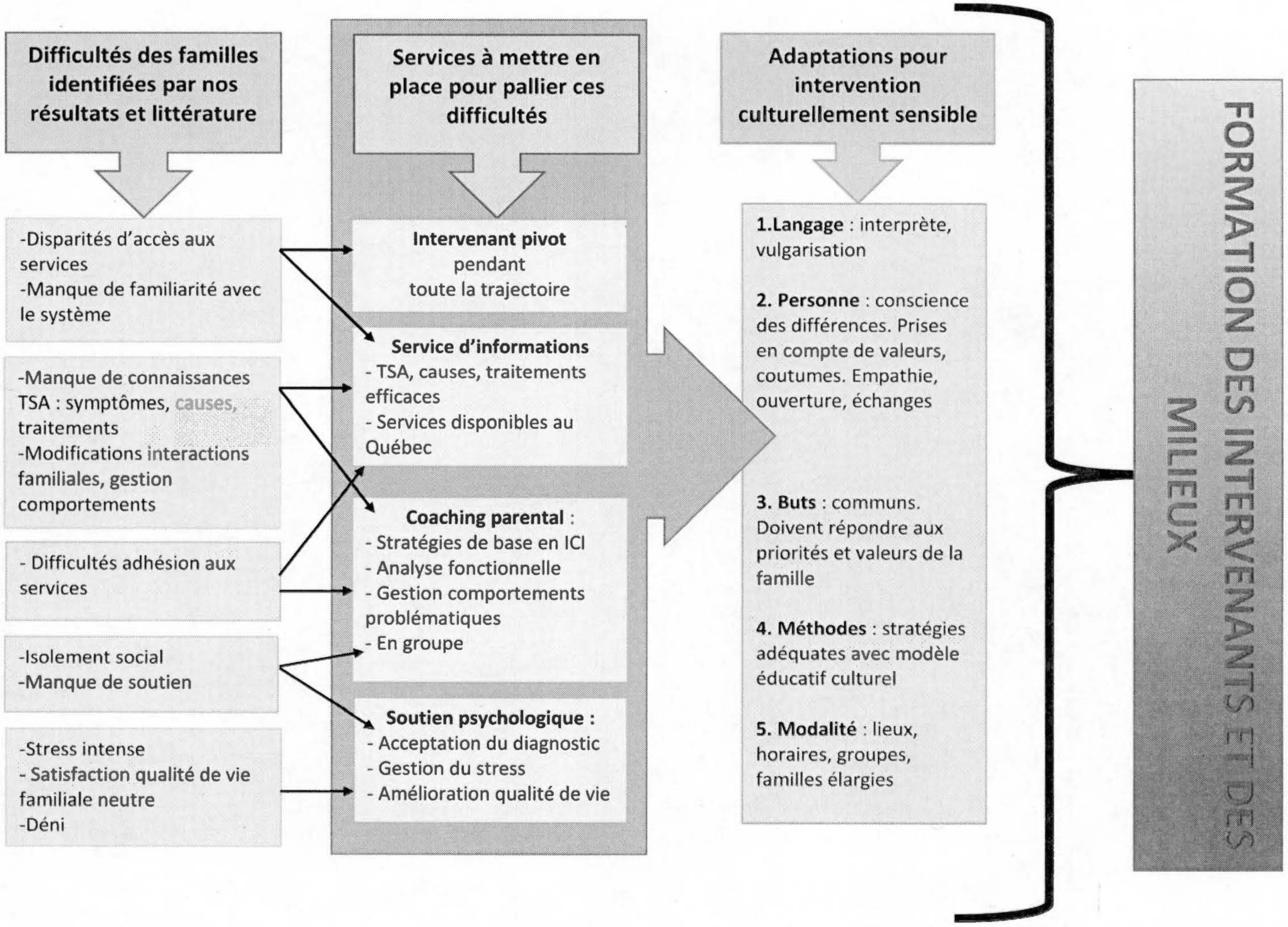

Figure 4.1 Modèle d'intervention répondant aux besoins des familles issues de l'immigration

Cette sensibilisation en amont des services d'ICI permettrait une meilleure compréhension du TSA et de l'ICI, ce qui favoriserait l'implication des parents. De plus, une connaissance des différents services et interventions offre la possibilité aux parents de choisir parmi les services disponibles ceux qui répondent le mieux à leur besoin et leurs valeurs. Ce type de service devrait être offert en groupe afin d'aider les familles à être moins isolées en rencontrant des parents vivant les mêmes difficultés. De plus, le format de groupe est reconnu comme étant un mode de dispensation ayant une bonne validité sociale auprès des familles issues de l'immigration (Barrio, 2000; Klingner *et al.*, 2009).

4.7.3 Le coaching parental

Le coaching parental, notamment dans la période d'attente des services, semble une solution pertinente pour pallier le manque de services et permettre aux parents d'obtenir de l'aide pour la gestion des comportements de leur enfant. Les études en TSA indiquent la nécessité de la prise en charge précoce, pour éviter que les symptômes se cristallisent (Eikeseth, Klintwall, Jahr et Karlsson, 2012; Eldevik *et al.*, 2009). La réalité des services au Québec entraîne des retards dans la mise en place de ces services, des programmes de coaching parental combleraient ce creux de services. De plus, le coaching parental permet d'augmenter l'efficacité parentale et l'autonomisation des familles pouvant ainsi avoir un impact sur leur bien-être (Leung, Sanders, Leung, Mak et Lau, 2003; Roberts, Mazzucchelli, Studman et Sanders, 2006). Ce type de services est déjà mis en place dans certains CRDITED, mais n'est pas encore systématique (ex. : ABC du comportement[7]). De manière générale, les programmes de coaching parental visent l'apprentissage : de l'analyse fonctionnelle des comportements problématiques; de stratégies pour améliorer les compétences de jeu et les compétences sociales de

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[7] Service d'entraînement aux habiletés parentales mis en place notamment au CRDITED de la Montérégie-Est.

l'enfant; de stratégie de réduction des comportements problématiques de l'enfant et de stratégies pour augmenter les comportements adéquats.

4.7.4 Le bien-être parental

Nos résultats, mais également de nombreuses études, indiquent un stress parental important chez les parents d'enfant ayant un TSA (Baker-Ericzen *et al.*, 2005; Blacher et McIntyre, 2006; Dabrowska et Pisula 2010; Rivard *et al.*, 2014). Bien que le coaching parental permette d'augmenter l'efficacité parentale, les études sur l'efficacité de ce type de services indiquent qu'ils n'ont pas toujours un impact sur la réduction du stress parental (Estes *et al.*, 2014; McConachie et Diggle, 2007; Smith, Buch et Gamby, 2000). Étant donné le niveau de stress élevé des familles, il est primordial de développer des solutions efficaces pour réduire ce stress. Pour cela, la mise en place d'un soutien psychologique ciblant le stress, les difficultés d'acceptation du diagnostic, et offrant des stratégies de gestion de stress[8] apparaît la solution nécessaire. Contrairement aux services d'informations et de coaching parental, par lesquels la modalité de groupe apparaît pertinente, ce service devrait être un service individuel pour que les familles puissent exprimer leur ressenti concernant leur situation. Cette thèse s'intéresse aux parents. Néanmoins, les autres membres de la famille, comme la fratrie, peuvent aussi être impactés par le diagnostic d'un frère ou d'une sœur. Il serait ainsi pertinent de leur offrir un service de soutien.

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[8] Stratégies basées sur les données probantes telles que les stratégies utilisées en Thérapie congrnitive et comportementale.

4.7.5 L'adaptation culturelle des services

Pour que l'ensemble de ces services soient efficaces auprès des familles issues de l'immigration, ils doivent être adaptés culturellement. En effet, les approches en psychologie interculturelle soulignent l'importance de proposer des moyens d'intervention adaptés aux différences culturelles afin que les interventions soient valides socialement (Klinger *et al.*, 2009). Des programmes adaptés à la culture permettent une amélioration de l'utilisation des services et une augmentation de la fréquentation de ces services (Dyches *et al.*, 2004; Klingner *et al.*, 2009; Rodriguez, 1986). Plusieurs dimensions sur lesquelles les interventions nécessitent une adaptation culturelle ont été identifiées dans la littérature, notamment par le langage, les personnes, le contenu, les buts, les méthodes et les modalités (Bernal, Bonilla et Bellido, 1995; Bernal et Sáez-Santiago, 2006; Harry, 2002; Klingner, 2009).

4.7.5.1 Le langage

Le langage est une barrière importante pour les parents issus de l'immigration. Il est donc nécessaire de proposer des services dans la langue maternelle des parents (interprètes ou intervenants bilingues). Cela permet de s'assurer que les interventions et informations soient comprises, mais aussi que les parents se sentent à l'aise d'intervenir pour poser des questions ou donner leur avis (Canadian Collaborative Mental Health Initiative, 2006; Klinger, 2009; Magaña, Lopez et Machalicek, 2017; Pumariega, Patel, Al-Mateen Charmi Patel, 2011). Des études indiquent que les patients ayant eu des services de psychologie dans leur langue maternelle par le biais d'interprètes se sentaient plus compris et montraient plus de motivation à revenir que ceux ayant reçu des services dans une autre langue (Pumariega, Patel, Al-Mateen Charmi Patel, 2011). Il est donc important de favoriser un meilleur climat et une meilleure compréhension en proposant des services dans la langue maternelle des familles qui le désirent.

4.7.5.2 Les personnes

Cette dimension fait référence à la collaboration entre les parents et les intervenants et aux compétences culturelles des intervenants (Bernal et Saez-Santiago, 2006). Pour avoir de bonnes compétences culturelles, l'intervenant doit prendre conscience de ses propres valeurs, être conscient et accepter celles des parents, comprendre et prendre connaissance des aspects en lien avec la culture des parents (normes, coutumes, langue, religion) et être capable d'adapter sa pratique au contexte culturel des parents (Bernal et Saez-Santiago, 2006; Harwood et Pachter, 1995; Klingner, 2009; Ravindran et Myers, 2012; Pumariega, Patel, Al-Mateen Charmi Patel, 2011). Afin de favoriser une bonne collaboration, les intervenants doivent établir un climat de confiance avec les parents. Pour ce faire, il est essentiel que les familles sentent que leurs croyances, valeurs et coutumes sont respectées et non jugées (Cho et Gannotti, 2005; Magaña *et al.*, 2017).

4.7.5.3 Les buts

Pour une optimisation des résultats des interventions sur l'enfant, il est important que les parents et les intervenants travaillent dans la même direction. Pour cela, ils doivent s'entendre pour établir des objectifs communs (Cho et Gannotti, 2005; Ravindran et Myers, 2012). Un service d'informations (tel que présenté précédemment) permettra aux familles d'ajuster leurs attentes en fonction des connaissances apprises sur le TSA et sur les interventions existantes. Il est primordial que les objectifs soient décidés conjointement dans un climat de confiance et qu'ils répondent aux attentes et valeurs des familles (Bernal et Saez-Santiago, 2006; Magaña *et al.*, 2017).

4.7.5.4 Les méthodes

L'adaptation des méthodes et stratégies est importante pour que les familles se les approprient et poursuivent au domicile les interventions proposées. Les équipes doivent avoir conscience que les interventions découlant de l'analyse appliquée du comportement (AAC), comme l'ICI, ont majoritairement été développées aux États-Unis et qu'elles ne répondent pas nécessairement aux valeurs de toutes les cultures (Jones *et al.*, 2011). Il est donc important de se questionner sur les procédures et stratégies à privilégier pour que les interventions proposées répondent aux valeurs des familles, tout en respectant les principes de l'ICI (Rivard, Millau, Morin et Forget, 2013).

4.7.5.5 Les modalités

Plusieurs éléments concernant les modalités de services peuvent et doivent être adaptés pour maximiser l'implication des familles. En effet, plusieurs stratégies en lien avec les modalités de services permettent d'augmenter la participation des parents : offrir un service de garde pour les enfants pendant les rendez-vous, faire des appels téléphoniques avant les rencontres, proposer des rencontres courtes, et tenir compte des moyens de transport disponibles pour les familles (Klingner, 2009; Magaña *et al.*, 2017; Snell-Johns, Mendez et Smith, 2004). L'horaire est également un élément très important. Par exemple, l'horaire proposé ne doit pas empêcher les familles pratiquant une religion de participer à leur culte. Enfin, le fait d'ouvrir les formations et ateliers à la famille élargie et aux personnes du soutien social de la famille peut être pertinent et rejoindre les valeurs de certaines familles.

Enfin, un dernier élément nécessaire à la réussite de ces interventions est la formation des intervenants. Dans le contexte de Montréal et de sa banlieue, il serait pertinent d'instaurer des formations présentant les moyens d'intervenir auprès de familles issues de l'immigration afin que les intervenants soient outillés. Ces formations devraient inclure la présentation des résultats des études portant sur les familles afin qu'ils aient une meilleure connaissance du vécu de ces parents et de leurs difficultés. La manière de travailler avec un interprète devrait également être présente. Finalement, ces formations devraient présenter les différentes dimensions nécessaires à l'intervention culturellement sensible (langage, personnes, buts, etc.), afin de favoriser une meilleure collaboration entre les familles issues de l'immigration et les intervenants.

CONCLUSION

En 2017, l'APA a réalisé de nouvelles lignes directrices pour la pratique dans un contexte multiculturel. Ce nouveau document a été conçu en vue de reconsidérer la diversité multiculturelle dans la pratique et la recherche en psychologie (APA, 2017). Cela indique la nécessite de se questionner sur les dimensions culturelles dans toutes les sphères de la psychologie. Dans le contexte multiculturel actuel au Québec, les milieux de pratiques et de recherche en TSA se doivent de se questionner sur les influences de la culture dans la prise en charge des enfants et des familles, et de faire évoluer leur pratique pour augmenter la validité sociale des services proposés afin de rejoindre l'ensemble des familles. Les dernières prédictions sur l'immigration au Canada prévoient qu'en 2036, 35 % de la population canadienne sera issue de l'immigration (Statistiques Canada, 2017). Quant au diagnostic de TSA, ils ne cessent d'augmenter ces dernières années, nécessitant de développer de plus en plus de solutions pour pallier à l'attente des services d'ICI. Ainsi, il est pertinent de développer des moyens d'intervention adaptés à toutes les familles.

Cette thèse doctorale a permis d'explorer l'expérience des parents issus de l'immigration ayant un enfant présentant un TSA et de la comparer sur certaines variables à l'expérience des parents québécois. Ce projet a permis de souligner des différences entre les parents issus de l'immigration et les parents québécois, mais aussi de mettre en avant certains points communs de leur expérience.

Les résultats de cette thèse et de nombreuses études actuelles en TSA appuient la nécessité de développer des services centrés sur les familles afin d'augmenter leur bien-être, leur implication dans les services et ainsi maximiser les progrès des enfants. Pour favoriser cette implication, la collaboration avec des organismes communautaires pourrait être une solution, permettant de rejoindre un maximum de familles, notamment celles issues de l'immigration.

APPENDICE A

QUESTIONNAIRE SOCIO DÉMOGRAPHIQUE

Ce questionnaire a pour but de dresser un portrait des participants en recueillant des informations générales. Il prend environ 15 minutes à compléter.
Toutes les données recueillies sont confidentielles et conservées sous clé dans un bureau de notre laboratoire de recherche à l'UQAM.

Date ____/_____/20____
Code (réservé à l'équipe de recherche)_____________

Informations complémentaires

1) **Diagnostic reçu** :

____
____
____
____
____

- Lieu de l'évaluation :____
____
____

- À quand remontent vos premiers soupçons quant à ce diagnostic ?__________
____

- De qui sont venus les premiers soupçons ?____________________________
____

- Quelles ont été vos démarches pour obtenir le diagnostic ?______________
____
____
____
____
____

- Durée d'attente avant de débuter le processus d'évaluation ? ______________
____
____

- Et avant l'obtention du diagnostic ?______________________________

2) **Autre(s) diagnostic(s) ou particularité(s) (diagnostic en santé mentale ou physique)?** ______________________________

3) **Recevez-vous des services** : oui / non
Si oui, quels types de services avez vous déjà reçus?
1)____
2)____
3)____
4)____
____
____
____
____

Lieux où ces services ont été offerts(CRDI,privé)
1)____
2)____
3)____
4)____
____

Quand avez vous obtenu ces services ?
1) de____/_____/ ____ à ______/____/_____
2) de____/_____/ ____ à _____/____/_____
3) de____/_____/ ____ à ____/____/_____
4) de____/_____/ ____ à ___/____/_____

Comment avez-vous été informé des services que vous pourriez recevoir ?
1)____
2)____
3)____
4)____

4) **Concernant les modalités de garde et de scolarisation** (entourez-la/les réponses qui vous correspondent)

Votre enfant est-il (ou a été) :

- en CPE
- en milieu familial
- en privé
- à la maison

Combien de temps (en mois ou années)? ____________________
À quelle fréquence? ____________________

- **Prématernelle (4 ans)?**
  classe régulière
  classe spéciale dans une école régulière
  école spéciale

Si oui, combien de temps (en mois ou années)? ____________________
À quelle fréquence? ____________________

- **Maternelle (5 ans)?**
  classe régulière
  classe spéciale dans une école régulière
  école spéciale

Combien de temps (en mois ou années)? ____________________
À quelle fréquence? ____________________

- **École Primaire?**
  classe régulière
  classe spéciale dans une école régulière
  école spéciale

Combien de temps (en mois ou années)? ____________________
À quelle fréquence? ____________________

5) La famille :

a. Entourez la réponse correspondant à votre famille :
- Famille nucléaire
- Recomposée
- Monoparental

b. Avez-vous parfois recours à des membres de votre famille, ami(es) ou gardiennes pour s'occuper de votre enfant lorsque cela est nécessaire?

Je fais appel à quelqu'un :
    Rarement
    Parfois
    Souvent
Des personnes sont disponibles :
    Rarement
    Parfois
    Souvent

Qui? : ____

6) Quel est votre revenu familial brut annuel?

10 000$ à 29 999$
30 000$ à 49 999$
50 000$ à 69 999$
70 000$ à 89 999$
90 000$ et plus

7) Quel est votre lieu de naissance (ville, province, pays) ?

- Mère : ____________________________
- Père : ____________________________

8) Depuis combien de temps êtes-vous au Québec ?
- Mère : ____________________________
- Père : ____________________________

9) Quel est votre statut au Canada ?

- Mère :
  - citoyen
  - résident permanent
  - visa de travail
  - visa d'étude
  - autre :
  - Ne souhaite pas répondre
- Père :
  - citoyen
  - résident permanent
  - visa de travail
  - visa d'étude
  - autre :
  - Ne souhaite pas répondre

10) Quelle est la langue parlée à la maison?

- Mère : ______________________________
- Père : ______________________________

11) Selon vous, votre niveau de français (parlé) est :

- Mère :
  - Très bon
  - Bon
  - Moyen/intermédiaire
  - Bas
  - Ne parle pas français
- Père :
  - Très bon
  - Bon
  - Moyen/intermédiaire
  - Bas
  - Ne parle pas français

12) Quelle est votre religion ?

____

____

13) **Quel est votre degré de pratique ?**
- très pratiquant
- pratiquant de temps en temps (certaines fêtes et coutumes)
- non pratiquant

14) **Quel est votre niveau de scolarité?** (Dernier niveau complété, précisez si au Canada ou dans votre pays d'origine)

- **Mère**
  - Études secondaires (non terminées)
  - Études secondaires (diplôme obtenu)
  - Études collégiales (CEGEP)
  - Universitaire (baccalauréat)
  - Études supérieures (maîtrise, doctorat)
  - Autres, précisez : ______________

- **Père**
  - Études secondaires (non terminées)
  - Études secondaires (diplôme obtenu)
  - Études collégiales (CEGEP)
  - Universitaire (baccalauréat)
  - Études supérieures (maîtrise, doctorat)
  - Autres, précisez : ______________

15) **Quel est votre statut d'emploi actuel? Quel type d'emploi ?**
(Entourez la case correspondante et inscrivez sur la ligne votre emploi)

- **Mère**
  - Salariée à temps plein____________________________
  - Salariée à temps partiel____________________________
  - Contractuelle____________________________
  - À la maison
  - Autres, précisez : ______________

- **Père**
  - Salarié à temps plein____________________________
  - Salarié à temps partiel____________________________
  - Contractuel____________________________
  - À la maison
  - Autres, précisez : ______________

16) À part__(nom de l'enfant)___ avez-vous d'autres enfants?

(1) oui
Nombre d'enfants au total : ________

(0) non

Si oui, a-t-il (ont-ils) un diagnostic d'autisme ou d'un autre trouble envahissant du développement?
(1) oui
(0) non

A-t-il (ont-ils) d'autres particularités du développement / apprentissage (p.ex. : TDAH, déficience intellectuelle, syndromes génétiques)
(1) oui
(0) non

Quel Diagnostic (s) ou problématique (s) : ___________________________

17) Autres précisions à apporter ?

____
____
____
____
____
____

APPENDICE B

CANEVAS D'ENTREVUE UTILISÉ POUR L'ARTICLE 3

Canevas entrevue article 3

Q1. Comment « a-t-on » réalisé que votre enfant pouvait avoir des difficultés ?

Q2. Selon vous quelles sont la(les) principales difficultés vécues par votre enfant ?

Q3. Quelle serait selon vous la cause à l'origine de ces difficultés ?

Q4. Quelles sont vos plus grandes craintes par rapport aux difficultés de x ?

Q5. Selon vous, qu'est-ce qui pourrait être fait pour aider les difficultés de votre enfant?

Q6. Jusqu'ici, avez-vous cherché de l'aide ?

Q7. En avez-vous reçu (quoi ?)? En êtes-vous satisfait ?

Q8. Quel genre de traitement ou intervention pensez-vous que votre enfant devrait recevoir ?

Q9. Pour quelles raisons avez-vous immigré au Québec ?

Q10. Aviez-vous des membres de votre famille ou des amis déjà installés au Québec ?

Q 11. Quelles sont leurs perceptions par rapport aux difficultés de votre enfant ?

Q 12. De façon générale quelles sont les perceptions de ces difficultés dans votre culture d'origine?

APPENDICE C

FORMULAIRE DE CONSENTEMENT DU PROJET DE RECHERCHE DONT LES DONNÉES ONT ÉTÉ UTILISÉES POUR L'ARTICLE 3

Formulaire d'information et de consentement des parents

Titre : Obstacles et facilitateurs dans l'accès au diagnostic et l'utilisation des services chez les familles issues de minorités ethnoculturelles dont l'enfant présente un trouble du spectre de l'autisme

Responsable(s) du projet :

Chercheure principale:

Professeure Mélina Rivard (Ph.D./Psy.D.)

Contact - rivard.melina@uqam.ca - (514) 987-3000 poste 5235

Université du Québec à Montréal, Case postale 8888, succursale Centre-ville, Montréal (Québec) H3C 3P8 Canada – local DS-5919.

Description de la recherche et objectifs:

Le multiculturalisme est un enjeu important au Québec. L'intervention auprès des jeunes ayant un trouble du spectre de l'autisme (TSA), l'est aussi. Pour les centres de réadaptation en déficience intellectuelle et troubles envahissants du développement (CRDITED), ces deux enjeux sont de taille en ce qui concerne les familles issues de l'immigration dont l'enfant présente un TSA : offrir un soutien adapté aux personnes se retrouvant en situation de double intégration, à la société d'accueil, en tant que famille émigrante et à la société civile, en vertu d'un handicap. Notre expérience clinique et de recherche nous indique qu'il est devenu important de documenter les facteurs menant à une trajectoire de services qui soit optimale pour ces familles. Cela en vue de développer des pistes de soutien pour celles-ci, de favoriser leur implication et ainsi de maximiser la réponse chez leur enfant aux interventions offertes. L'objectif général de ce projet est de documenter les obstacles et les facilitateurs vécus par les familles issues de l'immigration dont l'enfant présente un TSA, lors des services couvrant la période de la petite enfance (0 à 6 ans). Le premier objectif spécifique vise à dresser un portrait des obstacles et facilitateurs dans le processus menant à l'obtention du diagnostic de TSA.

Nature et durée de la participation

L'engagement dans la recherche entraine la participation des parents à deux séries de rencontre.

La participation du parent comprend une rencontre à l'été ou l'automne 2015 d'une durée d'environ 1h30 pour compléter les outils suivants:

1- Une collecte de données sociodémographiques (ex. : services reçus, diagnostic) de la famille *(déjà complété, dans le projet TC enfant)*;
2- Un questionnaire permettant d'évaluer la qualité des soins et la trajectoire des services du point de vue des familles *(ETAP)*
3- Une entrevue semi-structurée permettant de documenter les obstacles et les facilitateurs en lien avec le diagnostic.

La participation du parent comprend ensuite une deuxième rencontre à l'automne 2016 d'une durée d'environ 1h30 pour compléter les outils suivants:

1- Un questionnaire permettant d'évaluer la qualité des soins et la trajectoire des services du point de vue des familles *(ETAP)*
2- Un questionnaire sur les priorités d'intervention de la famille;
3- Une entrevue semi-structurée permettant de documenter les obstacles et les facilitateurs en lien avec les services en petite enfance.

La participation au projet de recherche implique également que les parents acceptent que l'équipe de recherche ait accès au dossier informatisé de l'enfant au CRDITED (le SIPAD) afin de documenter les différentes étapes sur la trajectoire de services et les plan d'intervention. Pour se faire, les chercheurs s'attarderont aux informations dans le dossier de l'enfant qui s'adressent à l'obtention du diagnostic (p.ex.: professionnels rencontrées, rapport d'évaluation) et à l'obtention des services d'intervention précoce (p.ex.: date des premiers contacts avec les centres, temps d'attente, date d'entrée dans les services d'intervention précoce, types de professionnels impliqués).

Endroit de la recherche :

Les entrevues auront lieu dans le domicile des familles. À leur convenance, elles pourront également avoir lieu au laboratoire de recherche de la chercheure à l'Université du Québec à Montréal.

Avantages pouvant découler de la participation à la recherche

Les avantages ne pourront profiter aux participants directement ou à court terme, mais ceux-ci pourront profiter à la population à l'étude en général. Nous savons dans un premier temps que les familles issues des minorités ethnoculturelles, particulièrement celles de première génération, disposent de peu de moyens pour s'orienter dans le processus d'accès et d'utilisation des services et qu'à ce titre, elles ont besoin de soutien pour exercer leur rôle dans l'accès aux services pour leur enfant. En ce qui a trait aux retombées sur les pratiques, le projet permettra de documenter plus précisément les moments et les lieux où les parents ont le plus besoin de soutien dans la compréhension et l'orientation dans les services.

Le projet devrait permettre aux intervenants, professionnels et gestionnaires de réfléchir aux façons d'offrir des services qui soient culturellement plus sensibles et adaptés aux enfants et aux familles. C'est à ce niveau que le projet risque d'avoir le plus de retombées directes pour induire des changements de pratique. Dans une perspective à plus long terme, les changements de pratique devraient permettre aux familles de collaborer de façon plus active aux programmes d'intervention proposés pour leur enfant. Il a le potentiel de pouvoir faire des recommandations pour pouvoir réduire les disparités d'accès aux services.

Risques et inconvénients pouvant découler de la participation à la recherche

Selon l'état actuel des connaissances, votre participation à cette recherche ne devrait causer aucun préjudice. Si des préjudices éventuels sont découverts en cours de projet, vous en seriez aussitôt informé et en assurera le suivi.

Retrait de la participation

La participation au projet est libre et volontaire. Le participant peut se retirer du projet en tout temps, sans craindre de préjudices quelconques. Un éventuel retrait du projet n'apporterait aucun changement aux services offerts par le CRDITED. Le retrait de la participation peut se faire en communiquant directement par téléphone ou par écrit avec le chercheur principal ou encore avec la coordonatrice.

En cas de désistement de la part du participant, tous les documents ou enregistrements liés à la recherche le concernant seront détruits.

Confidentialité

Pour garantir la confidentialité des données des familles participant à la recherche, un code sera attribué à chaque participant par l'assistant de recherche. Ainsi, chaque test ou questionnaire sera identifié par ce code sans jamais indiquer le nom de la personne.

Les données seront conservées sous clés dans le bureau de la chercheure principale à l'intérieur du laboratoire de recherche ÉPAULARD au pavillion Adrien Pinard de l'UQÀM.

Les données de la recherche seront détruites cinq ans après la fin du projet de recherche.

Responsabilités légales et professionnelles

En acceptant de participer à cette étude, le participant ne renonce à aucun de ses droits légaux, ni ne libère les chercheurs ou les institutions impliqués de leurs responsabilités légales et professionnelles.

Personnes-ressources

Pour toute plainte relative au projet de recherche, veuillez contacter le commissaire local à la qualité des services et aux plaintes en Montérégie : (450) 928-5149 ou par la poste à l'adresse suivante: 575, rue Adoncour, Longueuil (Québec), J4G 2M6.

Pour toute question relative à vos droits et recours ou par rapport à votre participation à ce projet de recherche, veuillez contacter Karoline Girard, coordonnatrice à l'éthique de la recherche pour le CÉRC/CRDITED au numéro suivant : 819 376-3984, poste 347 ou par courrier électronique : info@cerc-crdited.ca.

D'autres informations sur le projet

La chercheure principale répondra en tout le temps et au meilleur de sa connaissance à toutes les questions du participants à propos du projet de recherche. Il est possible de contacter le chercheur en tout temps par courriel au rivard.melina@uqam.ca, par téléphone au (514) 987-3000 poste 5235 ou par la poste : Université du Québec à Montréal, Case postale 8888, succursale Centre-ville. Local : DS-5919, H3C 3P8, Montréal (Québec) – Canada.

Je soussigné(e), [   ], reconnais avoir lu [ou avoir reçu la lecture] le présent formulaire et je comprends l'information qui m'a été communiqué pour que je puisse donner un consentement éclairé. On a répondu à toutes mes questions à mon entière satisfaction. J'ai disposé de suffisamment de temps pour réfléchir à ma décision de participer ou non à cette étude. Je comprends que ma participation à cette étude est entièrement volontaire et que je peux décider de me retirer en tout temps, sans aucune pénalité. Je consens volontairement à participer à cette étude.

1. ____________________	____________________	____________
Nom du parent	Signature du parent	Date

Téléphone:

Courriel:

2. ____________________	____________________	____________
Nom du parent	Signature du parent	Date

Téléphone:

Courriel:

____________________	____________________	____________
Nom du chercheur	Signature du chercheur	Date

APPENDICE D

CERTIFICAT D'APROBATION ÉTHIQUE DU PROJET DE RECHERCHE DONT LE DONNÉES ONT ÉTÉ UTILISÉES POUR L'ARTICLE 3

Centre intégré
universitaire de santé
et de services sociaux
de la Mauricie-et-
du-Centre-du-Québec
Québec

BUREAU INTÉGRÉ DE L'ÉTHIQUE
2700 boul. des Forges, bureau 302
Trois-Rivières (Québec) G8Z 1V2
Téléphone : 819-372-3133 poste 32303
Courriel : ciusssmcq_bureau_integre_de_lethique@ssss.gouv.qc.ca

Trois-Rivières, le 3 mai 2017

Madame Mélina Rivard
Université du Québec à Montréal
C.P. 8888, succ. Centre-ville
Montréal (Québec) H3C 3P8

PAR COURRIER ÉLECTRONIQUE

Objet : Suivi passif et renouvellement annuel au certificat d'éthique de la recherche pour le projet CÉRC-0208 : «Obstacles et facilitateurs dans l'accès au diagnostic et l'utilisation des services chez les familles issues de minorité ethnoculturelles dont l'enfant présente un trouble du spectre de l'autisme ».

Madame,

Le Comité d'éthique de la recherche conjoint en déficience intellectuelle et en troubles du spectre de l'autisme (CÉRC DI-TSA), a évalué la demande en titre le 3 mai 2017 en mode délégué. À cette fin, le *Formulaire de demande de renouvellement annuel du certificat d'éthique de la recherche* a été examiné.

Il me fait plaisir de vous informer que votre demande de renouvellement a été approuvée par le CÉRC DI-TSA.

Cette approbation suppose que vous vous engagiez à :

- respecter la décision du CÉRC DI-TSA;
- respecter les moyens relatifs au suivi continu figurant;
- conserver les dossiers de recherche pour une période couvrant minimalement la période de publication qui découlera de la recherche;
- respecter les modalités arrêtées au regard du mécanisme d'identification des participants à la recherche des établissements concernés par le projet, à savoir, la tenue à jour et la conservation de la liste à jour des participants recrutés pour les établissements qui pourront l'obtenir sur demande.

APPENDICE E

FORMULAIRE DE CONSENTEMENT DU PROJET DE RECHERCHE DONT LES DONNÉES ONT SERVI POUR LES ARTICLES 1 ET 2

FORMULAIRE DE CONSENTEMENT
PARENTS D'ENFANTS USAGERS DES SERVICES D'AIDE ÉDUCATIVE SPÉCIALISÉE

TITRE DU PROJET :
L'Offre de services spécialisés aux enfants âgés de 2 à 5 ans
qui présentent un trouble envahissant du développement (TED):
évaluation de la dispensation des services et de leurs effets

---

Vous êtes invités, à titre de parents, à participer à un projet de recherche ayant cours au Centre de réadaptation Montérégie-Est. Avant d'accepter de participer à ce projet, veuillez prendre le temps de comprendre et de considérer attentivement les renseignements qui suivent. Il est important que l'ensemble des informations contenues dans ce formulaire soit bien comprises. Ainsi, vous pouvez poser des questions en tout temps à la lecture de ce formulaire et pendant toute la durée du projet de recherche.

Chercheure principale :
Céline Mercier, Ph.D., département de médecine sociale et préventive, Université de Montréal, Équipe FQRSC « Déficience intellectuelle, troubles envahissants du développement et intersectorialité ».

Co-chercheure :
Mélina Rivard, M.Ps., candidate au doctorat en psychologie (Ph.D./Psy.D.), agente de programmation, de planification et de recherche au CRDI Montérégie-Est.

AGENTE DE RECHERCHE :
Claudel Parent-Boursier

Collaborateurs :
Sylvie Gladu, directrice des services professionnels au CRDI Montérégie-Est
Joanne Larose, conseillère-cadre au soutien spécialisé TED au CRDI Montérégie-Est
Annick Le Beau, psychologue au CRDI Montérégie-Est
Gilles Lemaire, coordonnateur des services TED 0-5 ans au CRDI Montérégie-Est

1.1 Description du projet de recherche

RÉSUMÉ ET OBJECTIFS

La recherche sur les programmes d'intervention précoce pour les enfants ayant un TED provient principalement jusqu'à maintenant d'études expérimentales, soit dans des milieux contrôlés, avec des critères de sélection des participants et ayant des ressources optimales. Très peu d'études se sont intéressées à évaluer l'application de ce type de programme «dans la vraie vie», à savoir, par exemple, son efficacité dans un système public. Aussi, les variables à l'étude dans ces projets de recherche s'adressent davantage à l'effet de l'intervention sur les comportements et l'apprentissage des enfants. À notre connaissance, peu d'études se sont intéressées à étudier les effets sur la qualité de vie des familles et aucune étude ne s'est penchée sur le soutien aux partenaires dans le suivi à ce type d'intervention.

Notre étude cherche ainsi à pallier à ces limites et à évaluer l'effet d'une offre de services spécialisés pour l'enfant et son système, soit sa famille et ses autres milieux de vie (partenaires). Cette étude vise à documenter et à évaluer l'efficacité de l'offre de services selon les trois volets développés par le CRDI Montérégie-Est: 1) le service d'adaptation et de réadaptation à l'enfant; 2) le service d'assistance éducative spécialisée à la famille; 3) le soutien spécialisé aux partenaires.

Ce formulaire de consentement concerne le volet service d'assistance éducative spécialisée à la famille.

MÉTHODE

Tous les parents dont les enfants sont nouvellement inscrits aux services d'aide éducative spécialisée du CRDI Montérégie-Est sont invités à participer à cette étude.

Les parents seront sollicités afin de participer à une entrevue d'une durée d'environ deux heures qui aura lieu dans un endroit de leur choix et à un moment qui leur convient le mieux. Cette entrevue permettra de remplir les formulaires de consentement, de remplir un questionnaire de type socio-démographique, de répondre à un questionnaire sur la qualité de vie de la famille et de répondre à un questionnaire sur la satisfaction des services.

De plus, nous désirons obtenir votre autorisation pour recueillir les informations obtenues dans le questionnaire sur le stress parental que l'équipe du centre de réadaptation vous a invité à répondre.

L'entrevue sera répétée lors de l'admission de l'enfant dans le programme de soutien ainsi, à son entrée au programme d'intervention comportementale intensive (ICI) l'année suivante ainsi qu'à sa sortie du programme ICI (après environ 12 mois).

NATURE ET DURÉE DE LA PARTICIPATION

Si vous acceptez de participer à ce projet de recherche :

1. Vous aurez une rencontre d'environ 2 heures avec un intervieweur ou une intervieweuse, membre de l'équipe de recherche. Lors de cette rencontre, nous vous poserons des questions générales sur votre enfant et sur les services. De plus, nous évaluerons votre satisfaction par rapport aux services reçus.
2. Avec votre autorisation nous consulterons les données quant au questionnaire sur le stress parental dans le dossier de votre enfant au CRDI Montérégie-Est.

Tel qu'indiqué précédemment, votre invitation à participer à l'étude se déroule sur une période de 2 ans.

1.2 Avantages pouvant découler de la participation

Vous n'obtiendrez aucun bénéfice personnel et direct suite à votre participation à cette recherche. Par contre, pour le CRDI Montérégie-Est, dont l'équipe clinique œuvrant auprès de votre enfant, les bénéfices de l'étude sont multiples. Elle permettra, par exemple, de documenter le fonctionnement des trois volets développés dans son offre de services spécialisés et d'en évaluer les effets. Éventuellement, cette étude jettera également des pistes pour adapter les pratiques et viser une meilleure individualisation des stratégies d'intervention. Elle permettra aussi à l'équipe de participer à l'avancement des connaissances en autisme et de faire partie du réseau scientifique.

De façon générale, cette étude permettra l'avancement des connaissances de façon à faire progresser la recherche et la clinique en TED. Entre autres, elle permettra la précision du profil des enfants ayant un TED quant à leurs caractéristiques individuelles (grand échantillon) et la possibilité de faire des liens entre ces différentes caractéristiques. Cette étude aura, finalement, comme bénéfice principal d'évaluer l'efficacité de l'ICI en milieu naturel et permettra de documenter les effets sur l'enfant, le degré de changement, les modalités qui semblent être les plus importantes, les obstacles et limites dans l'implantation, les effets sur la qualité de vie des parents et les effets sur le lien avec les partenaires.

1.3 Risques et inconvénients pouvant découler de la participation

Selon l'état actuel des connaissances, votre participation à cette recherche ne devrait vous causer aucun préjudice. Si des préjudices éventuels sont découverts en cours de projet, vous en serez aussitôt informés.

Bien que ce projet de recherche ne comporte vraisemblablement pas d'inconvénient ou de risque pour votre intégrité, il se peut que vous éprouviez un inconfort passager vis-à-vis certaines questions ou que vous trouviez l'entrevue longue ou certaines questions répétitives. Ce risque est compensé par le fait que vous pouvez en tout temps demander de faire une pause pendant l'entrevue, de demander à reprendre l'entrevue à un autre moment qui vous convient ou de refuser de répondre à certaines questions.

1.4 Compensation financière

Vous ne recevrez aucune indemnité compensatoire pour votre participation à ce projet de recherche.

1.5 Retrait de ma participation

Votre participation à ce projet de recherche est tout à fait volontaire. Vous êtes par conséquent tout à fait libre d'accepter ou de refuser d'y participer ou de répondre en partie aux propositions faites dans le cadre de l'étude. Advenant votre participation, vous êtes également libre, à tout moment, de mettre fin à votre participation à ce projet. Que vous décidiez de participer ou non à cette recherche ou d'interrompre votre participation ne changera en rien les services que votre famille reçoit actuellement ou que vous allez recevoir dans l'avenir du CRDI Montérégie-Est et ne vous causera aucun préjudice ou perte d'avantages auxquels vous avez normalement droit. En cas de désistement de votre part, vous pourrez en informer les chercheurs verbalement ou par écrit et, si vous le souhaitez, toutes les données recueillies dans le cadre de ce projet de recherche concernant votre participation seront détruites.

1.6 Confidentialité

Les données recueillies sont strictement confidentielles et ne seront utilisées que dans le cadre de ce projet. Un code alphanumérique sera utilisé pour colliger les données concernant votre enfant afin d'éviter l'utilisation de toutes données nominatives permettant de l'identifier. La liste maîtresse qui permet de faire le lien entre le nom du participant et son code alphanumérique sera conservée dans un endroit différent du test et des formulaires de dépouillement des dossiers. Cette liste des noms et numéros de même que les formulaires de consentement seront détruits cinq ans après la fin de l'étude de façon sécuritaire. De plus, les formulaires de consentement, les tests, les formulaires de dépouillement des dossiers, ainsi que la liste maîtresse seront gardés dans un classeur barré dans le bureau de la chercheure.

La mise en place et la gestion des banques de données informatisées seront sous la responsabilité de la chercheure principale, madame Céline Mercier. Ces banques de données informatisées seront conservées dans un répertoire informatique auquel madame Mercier ainsi que son équipe de recherche aura accès par mot de passe. Ces banques de données ainsi que tous les documents seront supprimés cinq (5) ans après la fin du projet de recherche.

Lorsque les résultats de cette étude seront diffusés (par exemple: publication dans une revue scientifique ou présentation à un congrès), aucun nom ne sera mentionné de quelque façon que ce soit.

Il se peut que certains organismes subventionnaires ou instances, tels que le comité d'éthique de la recherche, revoient les dossiers de recherche, et ce, dans le cadre de leur fonction de suivi ou d'évaluation.

Avec votre autorisation, une copie de ce formulaire de consentement sera versé au dossier de votre enfant (au CRDI Montérégie-Est) afin de permettre à l'intervenant responsable de savoir que votre enfant participe à ce projet et ainsi, éviter que vous soyez sollicités indûment à participer à d'autres projets de recherche.

Le projet a été soumis et approuvé par le Comité d'éthique de la recherche conjoint destiné aux centres de réadaptation en déficience intellectuelle et en troubles envahissants du développement (CÉRC/CRDI-TED) et ce dernier s'assurera du respect des règles éthiques, et ce, durant la durée complète du projet.

1.7 Clause de responsabilité

En acceptant de participer à cette étude, vous ne renoncez à aucun de vos droits ni ne libérez les chercheurs ou les institutions impliqués de leurs responsabilités légales ou professionnelles.

1.8 Questions concernant l'étude

Si vous avez des questions sur le projet de recherche, n'hésitez pas à les poser à l'intervieweur ou à l'intervieweuse dès maintenant. Si d'autres questions vous viennent au cours de la rencontre, vous pourrez également les poser.

1.9 Personnes-ressources

Si vous souhaitez poser des questions sur le projet, signaler un inconvénient associé à l'entrevue ou faire part de vos commentaires, vous pouvez en tout temps contacter

Mesdames :
Mélina Rivard, M.Ps., co-chercheure
(514) 771-3699
rivard.melina@courrier.uqam.ca

Céline Mercier, Ph.D., chercheure principale
(514) 259-2245 poste 247
cmercier.crld@ssss.gouv.qc.ca

Pour toute question relative à vos droits et recours ou sur votre participation à ce projet de recherche, veuillez contacter :

Madame Marlène Galdin
Coordonnatrice à l'éthique de la recherche pour le CÉRD/CRDI- TED
(819) 376-3984, poste 235
marlene_galdin@ssss.gouv.qc.ca

Pour toute plainte relative au projet de recherche, veuillez contacter

Madame Danièle Gagnon
Commissaire locale aux plaintes et à la qualité des services du CRDI Montérégie-Est
Centre jeunesse de la Montérégie
25, boulevard Lafayette
Longueuil (Québec) J4K 5C8
Tél.: (450) 928-5149 ou 1-800-347-8051
Daniele.gagnon@rrsss16.gouv.qc.ca

Si vous décidez de participer à ce projet de recherche, une copie de ce document vous sera remise.

1.10 Signatures

Nous, ______________________, ______________________ soussignés reconnaissons avoir lu le présent formulaire et comprenons l'information qui nous a été communiquée pour que nous puissions donner un consentement éclairé. L'équipe de recherche a répondu à toutes nos questions à notre entière satisfaction. Nous avons disposé de suffisamment de temps pour réfléchir à notre décision de participer ou non à cette étude. Nous comprenons que notre participation à cette étude est entièrement volontaire et que nous pouvons décider de retirer notre participation en tout temps, sans aucune pénalité. Nous consentons volontairement à participer à cette étude.

Je consens à participer à ce projet de recherche.

Nom du participant	Signature	Date
Nom du participant	Signature	Date

Je consens à ce qu'une copie du formulaire de consentement soit déposée au dossier de mon enfant.

Nom du participant	Signature	Date
Nom du participant	Signature	Date

J'autorise l'équipe de recherche à recueillir les données sur l'évaluation du stress parental.

Nom du participant	Signature	Date
Nom du participant	Signature	Date

Dans les trois années qui suivront la fin de cette étude, il est possible que les chercheurs souhaitent y donner suite, par exemple en recueillant des données sur l'intégration scolaire de ces enfants.

J'accepte d'être sollicité pour participer à une étude de suivi. Je comprends que je consens uniquement à ce qu'un membre de l'équipe de recherche communique avec moi pour m'inviter à participer à un projet de recherche. Je comprends que si je suis intéressé(e) à participer à ce projet, je recevrai l'information complète concernant ce projet, ce qui me permettra de donner ou non mon consentement libre et éclairé par écrit, le moment venu.

Nom du participant	Signature	Date
Nom du participant	Signature	Date

1.11 Formulaire d'engagement

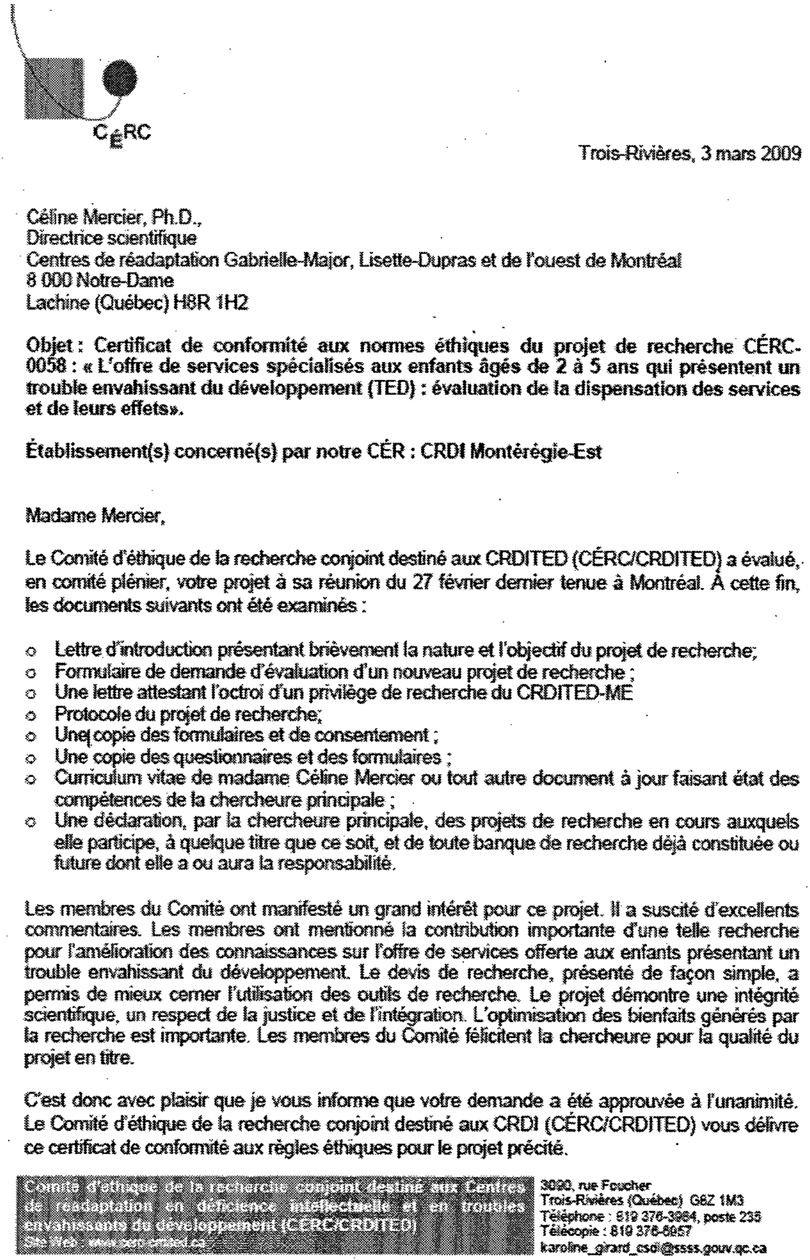
Je, soussigné-e, atteste avoir expliqué au participant tous les termes du présent formulaire, avoir répondu au meilleur de ma connaissance à ses questions et lui avoir souligné la possibilité de se retirer à tout moment du projet de recherche. Je m'engage à m'assurer que le participant recevra un exemplaire de ce formulaire d'information et de consentement.

Nom de l'intervieweur ou de l'intervieweuse	Signature	Date

APPENDICE F

CERTIFICAT D'APPROBATION ÉTHIQUE DU PROJET DE RECHERCHE DONT LES DONNÉES ONT SERVI POUR LES ARTICLES 1 ET 2

Certificat initial :



CÉRC

Trois-Rivières, 3 mars 2009

Céline Mercier, Ph.D.,
Directrice scientifique
Centres de réadaptation Gabrielle-Major, Lisette-Dupras et de l'ouest de Montréal
8 000 Notre-Dame
Lachine (Québec) H8R 1H2

Objet : Certificat de conformité aux normes éthiques du projet de recherche CÉRC-0058 : « L'offre de services spécialisés aux enfants âgés de 2 à 5 ans qui présentent un trouble envahissant du développement (TED) : évaluation de la dispensation des services et de leurs effets».

Établissement(s) concerné(s) par notre CÉR : CRDI Montérégie-Est

Madame Mercier,

Le Comité d'éthique de la recherche conjoint destiné aux CRDITED (CÉRC/CRDITED) a évalué, en comité plénier, votre projet à sa réunion du 27 février dernier tenue à Montréal. À cette fin, les documents suivants ont été examinés :

- Lettre d'introduction présentant brièvement la nature et l'objectif du projet de recherche;
- Formulaire de demande d'évaluation d'un nouveau projet de recherche ;
- Une lettre attestant l'octroi d'un privilège de recherche du CRDITED-ME
- Protocole du projet de recherche;
- Une copie des formulaires et de consentement ;
- Une copie des questionnaires et des formulaires ;
- Curriculum vitae de madame Céline Mercier ou tout autre document à jour faisant état des compétences de la chercheure principale ;
- Une déclaration, par la chercheure principale, des projets de recherche en cours auxquels elle participe, à quelque titre que ce soit, et de toute banque de recherche déjà constituée ou future dont elle a ou aura la responsabilité.

Les membres du Comité ont manifesté un grand intérêt pour ce projet. Il a suscité d'excellents commentaires. Les membres ont mentionné la contribution importante d'une telle recherche pour l'amélioration des connaissances sur l'offre de services offerte aux enfants présentant un trouble envahissant du développement. Le devis de recherche, présenté de façon simple, a permis de mieux cerner l'utilisation des outils de recherche. Le projet démontre une intégrité scientifique, un respect de la justice et de l'intégration. L'optimisation des bienfaits générés par la recherche est importante. Les membres du Comité félicitent la chercheure pour la qualité du projet en titre.

C'est donc avec plaisir que je vous informe que votre demande a été approuvée à l'unanimité. Le Comité d'éthique de la recherche conjoint destiné aux CRDI (CÉRC/CRDITED) vous délivre ce certificat de conformité aux règles éthiques pour le projet précité.

Comité d'éthique de la recherche conjoint destiné aux Centres de réadaptation en déficience intellectuelle et en troubles envahissants du développement (CÉRC/CRDITED)
Site Web : www.cerc-crdited.ca

3090, rue Foucher
Trois-Rivières (Québec) G8Z 1M3
Téléphone : 819 376-3984, poste 235
Télécopie : 819 376-6957
karoline_girard_csdi@ssss.gouv.qc.ca

Cette approbation suppose que vous vous engagiez à respecter les conditions et les modalités de recherche telles que présentées au CÉRC-CRDITED.

Cette approbation suppose que vous vous engagiez à :

- respecter la décision du CÉRC/CRDITED;
- respecter les moyens relatifs au suivi continu figurant au point 6 de la seconde section *du Guide de rédaction d'une demande d'évaluation d'un nouveau projet de recherche et modalités d'évaluation à l'intention des chercheurs* (CÉRC/CRDITED) et à utiliser les formulaires préparés à cette fin;
- conserver les dossiers de recherche pour une période couvrant minimalement la période de publication qui découlera de la recherche (voir le *Guide*, section II, point 5);
- respecter les modalités arrêtées au regard du mécanisme d'identification des participants à la recherche des établissements concernés par le projet, à savoir, la tenue à jour et la conservation de la liste à jour des participants recrutés pour les CRDI qui pourront l'obtenir sur demande.

La présente décision vaut pour une année (date d'échéance : 3 mars 2010) et peut être suspendue ou révoquée en cas de non respect de ces conditions. Je profite de cette occasion pour vous rappeler que le *Formulaire de demande de renouvellement* doit être rempli et expédier au CÉRC/CRDITED, 30 jours avant la date d'échéance du présent certificat d'éthique.

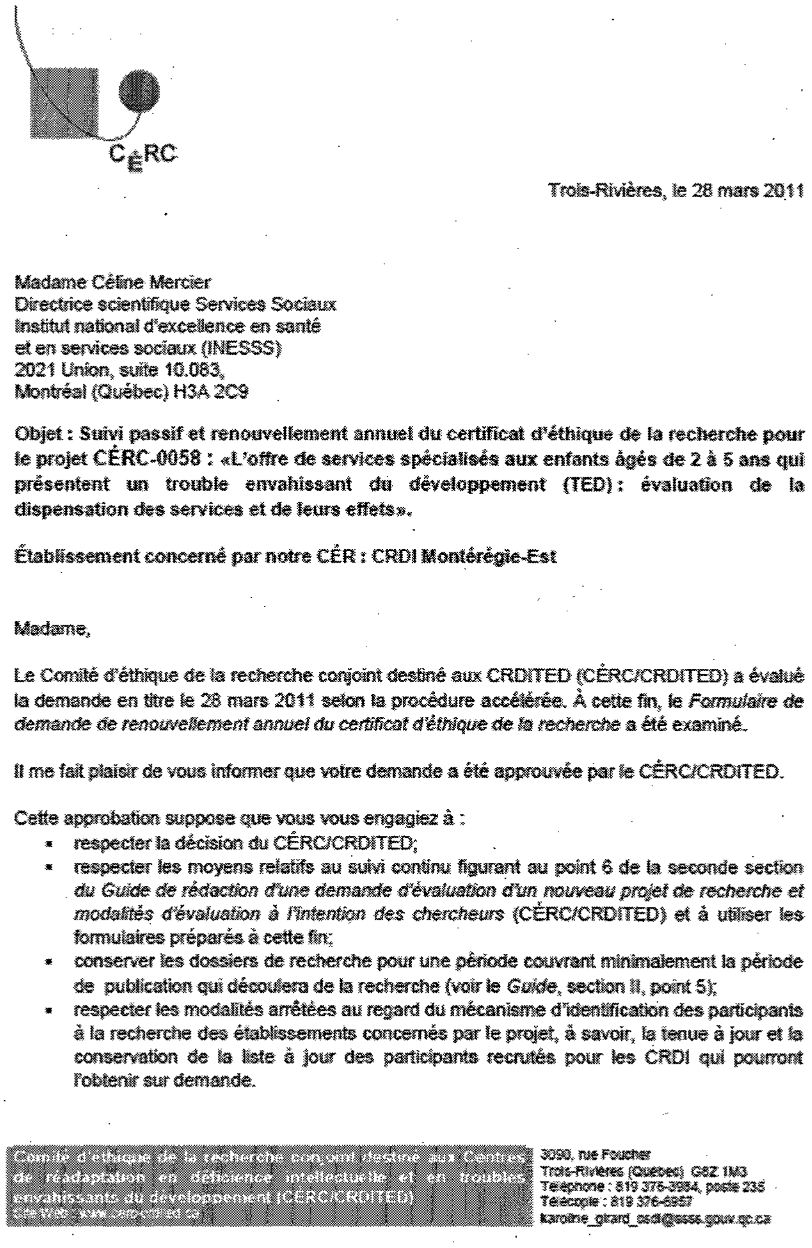
Pour toute question relative à ce certificat, n'hésitez pas à contacter M^{me} Karoline Girard, au bureau de coordination du CÉRC/CRDITED, au numéro 819 376-3984, poste 235.

Veuillez recevoir, madame Mercier, mes salutations distinguées.

Anne-Marie Hébert
Présidente du CÉRC/CRDITED

c. c. Sylvie Gladu, CRDI Montérégie-Es

Renouvellement du certificat :



CÉRC

Trois-Rivières, le 28 mars 2011

Madame Céline Mercier
Directrice scientifique Services Sociaux
Institut national d'excellence en santé
et en services sociaux (INESSS)
2021 Union, suite 10.083,
Montréal (Québec) H3A 2C9

Objet : Suivi passif et renouvellement annuel du certificat d'éthique de la recherche pour le projet CÉRC-0058 : «L'offre de services spécialisés aux enfants âgés de 2 à 5 ans qui présentent un trouble envahissant du développement (TED) : évaluation de la dispensation des services et de leurs effets».

Établissement concerné par notre CÉR : CRDI Montérégie-Est

Madame,

Le Comité d'éthique de la recherche conjoint destiné aux CRDITED (CÉRC/CRDITED) a évalué la demande en titre le 28 mars 2011 selon la procédure accélérée. À cette fin, le *Formulaire de demande de renouvellement annuel du certificat d'éthique de la recherche* a été examiné.

Il me fait plaisir de vous informer que votre demande a été approuvée par le CÉRC/CRDITED.

Cette approbation suppose que vous vous engagiez à :

- respecter la décision du CÉRC/CRDITED;
- respecter les moyens relatifs au suivi continu figurant au point 6 de la seconde section *du Guide de rédaction d'une demande d'évaluation d'un nouveau projet de recherche et modalités d'évaluation à l'intention des chercheurs* (CÉRC/CRDITED) et à utiliser les formulaires préparés à cette fin;
- conserver les dossiers de recherche pour une période couvrant minimalement la période de publication qui découlera de la recherche (voir le *Guide*, section II, point 5);
- respecter les modalités arrêtées au regard du mécanisme d'identification des participants à la recherche des établissements concernés par le projet, à savoir, la tenue à jour et la conservation de la liste à jour des participants recrutés pour les CRDI qui pourront l'obtenir sur demande.

La présente décision vaut pour une année (date d'échéance : **31 mars 2012**) et peut être suspendue ou révoquée en cas de non respect de ces exigences.

En terminant, je vous demanderais de bien vouloir mentionner, dans votre correspondance, le numéro attribué à votre demande par notre CÉR (CÉRC-0058).

Pour toute question relative à cette approbation, n'hésitez pas à contacter M^{me} Karoline Girard, au bureau de coordination du CÉRC/CRDITED, au numéro 819 376-3984, poste 235.

Veuillez recevoir, Madame, mes salutations distinguées.

Original signé
Anne-Marie Hébert
Présidente du CÉRC/CRDITED

c. c. Mme Sylvie Gladu, CRDI Montérégie-Est

BIBLIOGRAPHIE

Abidin, R. R. (1995). Manual for the Parenting Stress Index (3rd ed.). Charlottesville, VA: Pediatric Psychology Press.

Al Anbar, N. N., Dardennes, R. M., Prado-Netto, A., Kaye, K., & Contejean, Y. (2010). Treatment choices in autism spectrum disorder: The role of parental illness perceptions. *Research in Developmental Disabilities, 31*, 817-828. doi: 10.1016/j.ridd.2010.02.007

Al-Salehi, S. M., Al-Hifthy, E. H., & Ghaziuddin, M. (2009). Autism in Saudi Arabia: presentation, clinical correlates and comorbidity. *Transcultural Psychiatry*, *46*(2), 340-347. doi : 10.1177/1363461509105823

Alshamri, K. H. (2016). *Family quality of life for families of children with intellectual disability in Saudi Arabia* (Doctoral dissertation). Western Sydney University (Australia).

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

American Psychological Association. (2003b). Guidelines for providers of psychological services to ethnic, linguistic, and culturally diverse populations. Retrieved May 7, 2003. Repéré à http://www.apa.org/pi/oema/resources/policy/provider-guidelines.aspx

American Psychological Association. (2017). Multicultural guidelines: An ecological approach to context, identity, and intersectionality. Repéré à http://www.apa.org/about/policy/multicultural-guidelines.pdf

Bailey, D., Scarborough, A., Hebbeler, K., Spiker, D., & Mallik, S. (2004). *National early intervention longitudinal study: Family outcomes at the end of early intervention.* Menlo Park, CA: SRI International

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. doi:10.2511/rpsd.30.4.194

Bakermans-Kranenburg, M. J., Van IJzendoorn, M. H., & Kroonenberg, P. M. (2004). Differences in attachment security between African-American and White children: Ethnicity or socio-economic status? *Infant Behavior and Development, 27,* 417–433. doi:10.1016/j.infbeh.2004.02.002

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. doi: 10.1111/j.1365-2788.2010.01350.x.

Barelds, A., van de Goor, I., Bos, M., van Heck, G., & Schols, J. (2009). Care and service trajectories for people with intellectual disabilities: Defining its course and quality determinants from the client's perspective. Journal of policy and practice in intellectual disability, 6, 163–172. doi : 10.1111/j.1741-1130.2009.00224.x

Barrio, C. (2000). The cultural relevance of community support programs. *Psychiatric Services, 51,* 879–884. doi: 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*(9), 702-714. doi : 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*(8), 1319-1333.doi : 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*(1), 89-97. doi : 10.1002/j.1556-6678.2011.tb00064.x

Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of Autism and Developmental Disorders*, 36, 685–695. doi:10.1007/s10803-006-0112-3

Bernal, G., Bonilla, J., & Bellido, C. (1995). Ecological validity and cultural sensitivity for outcome research: Issues for cultural adaptation and development of psychosocial treatments with Hispanics. Journal of Abnormal Child Psychology, 23, 67–8. doi :10.1007/BF01447045

Bernal, G., Jiménez-Chafey, M. I., & Domenech Rodríguez, M. M. (2009). Cultural adaptation of treatments: A resource for considering culture in evidence-based practice. *Professional Psychology: Research and Practice, 40*(4), 361. doi : 10.1037/a0016401

Bernal, G., & Sáez-Santiago, E. (2006). Culturally centered psychosocial interventions. Journal of Community Psychology, 34(2), 121-132. doi : 10.1002/jcop.20096

Berry, J., & Sam, D. (1997). Acculturation and adaptation. In J. W., Berry, M.H. Segall, & C. Kagitçibasi (Eds.), *Handbook of Cross-Cultural Psychology* (Vol. 3, pp. 291–326. Boston, MA: Allyn & Bacon.

Berry, J. W., & Sabatier, C. (2010). Acculturation, discrimination, and adaptation among second generation immigrant youth in Montreal and Paris. *International Journal of Intercultural Relations, 34,* 191–207. doi: 10.1016/j.ijintrel.2009.11.007

Bigras, M., LaFreniere, P. J., & Abidin, R. R. (1996). *Indice de stress parental: manuel francophone en complément à l'édition américaine* [Parental Stress Index: French-language manual to supplement the American edition]. Toronto, Canada: Multi-Health Systems.

Bitterman, A., Daley, T. C., Misra, S., Carlson, E., & Markowitz, J. (2008). A national sample of preschoolers with autism spectrum disorders: Special education services and parent satisfaction. *Journal of Autism and Developmental Disorders, 38,* 1509–1517. doi: 10.1007/s10803-007-0531-9

Blacher, J., Cohen, S. R., & Azad, G. (2014). In the eye of the beholder: Reports of autism symptoms by Anglo and Latino mothers. *Research in Autism Spectrum Disorders, 8,* 1648-1656. doi: 10.1016/j.rasd.2014.08.017

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. doi:10.1111/j.1365 2788.2005.00768.x.

Bilgin, H., & Kucuk, L. (2010). Raising an autistic child: Perspectives from Turkish mothers. *Journal of Child and Adolescent Psychiatric Nursing, 23*(2), 92-99. doi : 10.1111/j.1744-6171.2010.00228.x

Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46,* 722–730. doi:10.1002/1097-4679(199011)46:6\722:AID JCLP2270460605[3.0.CO;2-6

Brachlow, A. E., Ness, K. K., McPheeters, M. L., & Gurney, J. G. (2007). Comparison of indicators for a primary care medical home between children with autism or asthma and other special health care needs: National Survey of Children's Health. *Archives of Pediatrics & Adolescent Medicine*, *161*, 399–405. doi: 10.1001/archpedi.161.4.399

Braunstein, V. L., Peniston, N., Perelman, A., & Cassano, M. C. (2013). The inclusion of fathers in investigations of autistic spectrum disorders. *Research in Autism Spectrum Disorders, 7*, 858-865. doi: 10.1016/j.rasd.2013.03.005

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(4),* 533-544. doi: 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. doi: 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. doi: 10.1023/A:1024931022773

Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of Autism and Developmental Disorders, 45)*, 3244-3254. doi: 10.1007/s10803-015-2482-x

Cabrera, N., Tamis-LeMonda, C. S., Bradley, R. H., Hofferth, S., & Lamb, M. E. (2000). Fatherhood in the twenty-first century. *Child development*, *71*(1), 127-136. doi: 10.1111/1467-8624.00126

Cappe, É., Chatenoud, C., & Paquet, A. (2014). Les caractéristiques des personnes ayant un TSA et des autres membres de la famille influençant l'adaptabilité familiale. Dans C. Chatenoud, J-C. Kalubi et A. Paquet (dir), *La famille et la personne ayant un trouble du spectre de l'autisme. Comprendre, soutenir et agir autrement.* Montréal QC, Canada: Éditions Nouvelles, 51-69.

Castro, F. G., Barrera Jr, M., & Holleran Steiker, L. K. (2010). Issues and challenges in the design of culturally adapted evidence-based interventions. *Annual Review of Clinical Psychology*, *6*, 213-239. doi : 10.1023/B:PREV.0000013980.12412.cd

Centers for Disease Control and Prevention. (2014). Autism spectrum disorders: Data and statistics. *Repéré à https://www.cdc.gov/ncbddd/autism/data.html*

Chatenoud, C., Kalubi, J.-C. & Paquet, A. (2014). *La Famille et la personne ayant un trouble du spectre de l'autisme. Comprendre, soutenir et agir autrement.* Montréal, Québec : Éditions Nouvelles

Cho, S. J., & Gannotti, M. E. (2005). Korean-American Mothers' Perception of Professional Support in Early Intervention and Special Education Programs. *Journal of Policy and Practice in Intellectual Disabilities, 2*, 1-9. doi: 10.1111/j.1741-1130.2005.00002.x

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*(4), 333-345. doi : 10.1111/jir.12016

Constantin, A., & Voicu, M. (2015). Attitudes towards gender roles in cross-cultural surveys: Content validity and cross-cultural measurement invariance. *Social Indicators Research, 123*(3), 733-751. doi : 10.1007/s11205-014-0758-8

Coonrod, E. E. &Stone, W. L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants & Young Children, 17*, 258-268. doi: 10.1097/00001163-200407000-00007

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*(4), 356-366. doi : 10.1177/1744629515577876

Courcy, I. (2014). *Maternité en contexte d'autisme: les conditions matérielles et normatives de la vie de mères de jeunes enfants autistes au Québec* (Thèse de doctorat, Université du Québec à Montréal). Repéré à http://www.archipel.uqam.ca/6405/

Cox, A., Klein, K., Charman, T., Baird, G., Baron-Cohen, S., Swettenham, J., ... Wheelwright, S. (1999). Autism spectrum disorders at 20 and 42 months of age: Stability of clinical and ADI-R diagnosis. *Journal of Child Psychology and Psychiatry, 40,* 719–732. doi: 10.1111/1469-7610.00488

Crockett, J. L., Fleming, R. K., Doepke, K. J., & Stevens, J. S. (2007). Parent training: Acquisition and generalization of discrete trials teaching skills with parents of children with autism. *Research in developmental disabilities, 28*(1), 23-36. doi : 10.1016/j.ridd.2005.10.003

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. doi: 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.

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. doi : 10.1016/j.ridd.2014.10.047

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. doi: 10.1007/s10803-007-0512-z.

DeJong, G. F. (2000). Expectations, gender, and norms in migration decision-making. *Population Studies,* *54*(3), 307-319. doi: 10.1080/713779089

Denney, M. K., Itkonen, T., & Okamoto, Y. (2007). Early intervention systems of care for Latino families and their young children with special needs: Salient themes and guiding implications. *Infants and Young Children*, *20*, 326–335. doi: 10.1097/01.IYC.0000290355.77911.78

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*(4), 200-207. doi : 10.1111/j.1744-6171.2011.00300.x

Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality*, *2*, 97–110. doi:10.1080/ 09362839109524770.

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

Dyches, T. T., Wilder, L. K., Sudweeks, R. R., Obiakor, F. E., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of autism and developmental disorders, 34,* 211-222. doi :*10.1023/B:JADD.0000022611.80478.73*

Eikeseth, S. (2009). Outcome of comprehensive psycho-educational interventions for young children with autism. *Research in Developmental Disabilities, 30*, 158–178. doi: 10.1016/j.ridd.2008.02.003

Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2009). Meta-analysis of early intensive behavioral intervention for children with autism. *Journal of Clinical Child & Adolescent Psychology, 38*, 439-450. doi: 10.1080/15374410902851739

Emerson, E., Fujiura, G. T., & Hatton, C. (2007). International perspectives. *Dans S-L. Odom, R-H. Horner, et M-E. Snell, M-E. (dir.). Handbook of developmental disabilities.* Guilford press.

Emerson, E., McConkey, R., Walsh, P., & Felce, D. (2008). Intellectual disability in a global context. *Journal of Policy and Practice in Intellectual Disability, 5,* 79–80. doi: 10.1111/j.1741-1130.2008.00151.x

Emmen, R. A., Malda, M., Mesman, J., van IJzendoorn, M. H., Prevoo, M. J., & Yeniad, N. (2013). Socioeconomic status and parenting in ethnic minority families: Testing a minority family stress model. *Journal of Family Psychology, 27*, 896–904. doi: 10.1037/a0034693

Estes, A., Vismara, L., Mercado, C., Fitzpatrick, A., Elder, L., Greenson, J., ... & Dawson, G. (2014). The impact of parent-delivered intervention on parents of very young children with autism. Journal of autism and developmental disorders, 44(2), 353-365. doi : 10.1007/s10803-013-1874-z

Families Special Interest Research Group of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (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. doi: 10.1111/jar.12078

Flores, G., Fuentes-Afflick, E., Barbot, O., Carter-Pokras, O., Claudio, L., Lara, M., ... & Valdez, R. B. (2002). The health of Latino children: urgent priorities, unanswered questions, and a research agenda. *Jama*, *288*(1), 82-90. doi : 10.1001/jama.288.1.82

Flores, G., Bauchner, H., Feinstein, A. R., & Nguyen, U. S. (1999). The impact of ethnicity, family income, and parental education on children's health and use of health services. *American journal of public health, 89*, 1066-1071. doi: 10.2105/AJPH.89.7.1066

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

Forehand, R., & Kotchick, B. A. (2016). Cultural Diversity: A Wake-Up Call for Parent Training–Republished Article. *Behavior therapy*, *47*(6), 981-992.

Freeman, N. L., Perry, A., & Factor, D. C. (1991). Child behaviors as stressors: Replicating and extending the use of the CARS as a measure of stress: A research note. *Journal of Child Psychology and Psychiatry, 32,* 1025–1030. doi: 10. 1111/j.1469-7610.1991.tb01927.x.

Freedman, R. I., & Boyer, N. C. (2000). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health & Social Work, 25,* 59–68. doi: 10.1093/hsw/25.1.59

Gallimore, R., & Goldenberg, C. (2001). Analyzing cultural models and settings to connect minority achievement and school improvement research. *Educational Psychologist*, *36*(1), 45-56. doi : 10.1207/S15326985EP3601_5

Gardiner, E., & French, C. (2011). The relevance of cultural sensitivity in early intervention. *Exceptionality Education International, 21*(3), 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. doi: 10.1016/j.ridd.2012.06.014

Gervais, C., De Montigny, F., Azaroual, S. et Courtois, A. (2009). La paternité en contexte migratoire: étude comparative de l'expérience d'engagement paternel et de la construction de l'identité paternelle d'immigrants magrébins de première et de deuxième génération. *Enfances, Familles, Générations*, 11, 25-43. doi : 10.7202/044120ar

Goin-Kochel, R. P., Mire, S. S., & Dempsey, A. G. (2015). Emergence of autism spectrum disorder in children from simplex families: Relations to parental perceptions of etiology. *Journal of Autism and Developmental Disorders, 45,* 1451-1463. doi: 10.1007/s10803-014-2310-8

Goldyne, D. A. (2013). *Parenting and acculturation stress among Latino immigrants: Does perceived spousal support moderate the effects on parenting self-efficacy?* (Doctoral dissertation, Fielding Graduate University). Retrieved from http://gradworks.umi.com/35/88/3588510.html

Gona, J. K., Newton, C. R., Rimba, K., Mapenzi, R., Kihara, M., Van de Vijver, F. J., & Abubakar, A. (2015). Parents' and professionals' perceptions on causes and treatment options for Autism Spectrum Disorders (ASD) in a multicultural context on the Kenyan Coast. *PloSOne, 10,* e0132729. doi: 10.1371/journal.pone.0132729

Goulet, F. (2016). *Les rôles et les perceptions de pères d'enfants ayant un trouble du spectre de l'autisme* (Thèse de Doctorat, Université du Québec à Montréal). Repéré à https://archipel.uqam.ca/8923/1/D3085.pdf

Granger, S., des Rivières-Pigeon, C., Sabourin, G., & Forget, J. (2012). Mothers' reports of their involvement in early intensive behavioral intervention. *Topics in Early Childhood Special Education, 32*(2), 68-77. doi : 10.1177/0271121410393285

Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability, 27*(3), 215-222. doi: 10.1080/1366825021000008639

Gray, D. E. (2003). Gender and coping: the parents of children with high functioning autism. *Social science & medicine, 56*(3), 631-642. 10.1016/S0277-9536(02)00059-X

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

Grinker, R. R., Yeargin-Allsopp, M., & Boyle, C. (2011). Culture and autism spectrum disorders: The impact on prevalence and recognition. *Autism Spectrum Disorders,*112-136. doi: 10.1093/med/9780195371826.001.0001

Guilamo-Ramos, V., Dittus, P., Jaccard, J., Johansson, M., Bouris, A., & Acosta, N. (2007). Parenting practices among Dominican and Puerto Rican Mothers. *Journal of National Association of Social Workers, 52,* 17-30. doi: 10.1093/sw/52.1.17

Haack, L. M., Gerdes, A. C., & Lawton, K. E. (2014). Conducting research with Latino families: Examination of strategies to improve recruitment, retention, and satisfaction with an at-risk and underserved population. *Journal of Child and Family Studies, 23,* 410–421. doi: 10.1007/s10826-012-9689-7

Hall, H. R. & Graff, J. (2010). Parenting challenges in families of children with autism : A pilot study. *Issues in Comprehensive Pediatric Nursing,* 33 (4), p. 187-204. doi : 10.3109/01460862.2010.528644

Hall, G. C. N., Ibaraki, A. Y., Huang, E. R., Marti, C. N., & Stice, E. (2016). A meta-analysis of cultural adaptations of psychological interventions. *Behavior therapy*, *47*(6), 993-1014. doi : 10.1016/j.beth.2016.09.005

Harry, B. (1992). *Cultural diversity, families and the special education system: Communication and empowerment.* New York, NY: Teachers College Press.

Harry, B., Kalyanpur, M., & Day, M. (1999). *Building cultural reciprocity with families: Case studies in special education.* PH Brookes Publishing Company.

Harry, B., Klingner, J. K., & Hart, J. (2005). African American families under fire: Ethnographic views of family strengths. *Remedial and Special Education, 26,* 101–112. doi: 10.1177/07419325050260020501

Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47,* 231–237. doi: 10.1046/j.1365-2788.2003.00485.x

Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorders, 31,* 327–336. doi:10.1023/A:1010799320795

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*, 629–642. doi: 10.1007/s10803-012-1604-y

Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research, 50*, 874–882. doi: 10.1111/j.1365-2788.2006.00904.x

Hofferth, S. L. (2003). Race/Ethnic Differences in Father Involvement in Two-Parent Families Culture, Context, or Economy? *Journal of Family Issues, 24*, 185–216. doi: 10.1177/0192513X02250087

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. doi: 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*(3), 155-165. doi : 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*(3), 166-174. doi : 10.1177/1088357612472932

Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal of Mental Deficiency*, *80*, 431–436.

Hughes, M-T., Valle-Riestra, D., & Arguelles, M-E. (2008). The voice of Latino families raising children with special needs. *Journal of Latino and Education, 7*, 241-257. doi: 10.1080/15348430802100337

Hunt-Jackson, J. L. (2007). *Finding fathers'voices: Exploring life experiences of fathers of children with autistic spectrum disorders* (Doctoral dissertation, State University of New York at Buffalo). Repéré à https://search.proquest.com/openview/a35bb5533a7532becca4af85b59efe45/1?pq-origsite=gscholar&cbl=18750&diss=y

IASSID Families Special Interest Research Group (FSIRG; 2012). *Families supporting a child with intellectual or developmental disabilities: the current state of knowledge.* Position Paper

INSPQ, Institut National de santé public Québec. (2017). Surveillance du trouble du spectre de l'autisme au Québec (ISBN: 978-2-550-79621-3). Repéré à https://www.inspq.qc.ca/publications/2310

Ingersoll, B., & Hambrick, D. Z. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with

Isenhour, J. A. (2010). Experiences and Perceptions of Fatherhood Among Fathers With Sons Who Have Autism Spectrum Disorders. Appalachian State University, Boone, North Carolina (Doctoral dissertation, Appalachian State University).Repéréà https://libres.uncg.edu/ir/asu/f/Isenhour,%20Jeffrey_2010_Dissertation.pdf

Järbrink, K. (2007). The economic consequences of autistic spectrum disorder among children in a Swedish municipality. *Autism*, *11*(5), 453-463. doi: 10.1177/1362361307079602

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

Jones, E. W., Hoerger, M., Hughes, J. C., Williams, B. M., Jones, B., Moseley, Y., ... Prys, D. (2011). ABA and diverse cultural and linguistic environments: A Welsh perspective. *Journal of Behavioral Education, 20,* 297–305. doi: 10.1007/s10864-011-9138-5

Kalb, L. G., Freedman, B., Foster, C., Menon, D., Landa, R., Kishfy, L., & Law, P. (2012). Determinants of appointment absenteeism at an outpatient pediatric autism clinic. *Journal of Developmental, & Behavioral Pediatrics, 33,* 685-697. doi: 10.1097/DBP.0b013e31826c66ef

Kanouté, F., Vatz Laaroussi, M., Rachédi, L., & Tchimou Doffouchi, M. (2008). Familles et réussite scolaire d'élèves immigrants du secondaire [Families and the academic success of immigrant high school students]. *Revue des sciences de l'éducation, 34,* 265-289. doi: 10.7202/019681ar

Karst, J. S., & Van Hecke, A. V. (2015). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child Family Psychology Review, 15,* 247–277. doi: 10.1007/s10567-012-0119-6.

Kasari, C., & Lawton, K. (2010). New directions in behavioral treatment of autism spectrum disorders. *Current Opinion in Neurology*, 23, 137-143. doi : 10.1097/WCO.0b013e32833775cd

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. doi: 10.1111/j.1468-3148.2009.00539.x

Khanna, R., Madhavan, S. S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. Journal of Autism and Developmental Disorders, 41, 1214–1227. doi: 10.1007/s10803-010-1140-6.

Kilbourne, A. M., Switzer, G., Hyman, K., Crowley-Matoka, M., & Fine, M. J. (2006). Advancing health disparities research within the health care system: a conceptual framework. *American journal of public health, 96*(12), 2113-2121. doi : 10.2105/AJPH.2005.077628

Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Annals of internal medicine*, *88*, 251-258. doi : 10.7326/0003-4819-88-2-251

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: Guilford Press.

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*, *122*(6), e1149-e1158.

L'Écuyer, R. (1990). Méthodologie de l'analyse développementale de contenu [Developmental content analysis methods]. Québec: Presses de l'Université du Québec.

Leung, C., Sanders, M. R., Leung, S., Mak, R., & Lau, J. (2003). An outcome evaluation of the implementation of the Triple P—Positive Parenting Program in Hong Kong. *Family Process*, *42*, 95-108. doi: 10.1111/j.1545-5300.2003.00531.x

Levy, S. E., & Hyman, S. L. (2003). Use of complementary and alternative treatments for children with autistic spectrum disorders is increasing. *Pediatric Annals*, *32*, 685-691. doi: 10.3928/0090-4481-20031001-10

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E.(2008). Disparities in diagnosis and access to health service for children with autism: Data from the national survey of children's health. *Journal of Developmental & Behavioral Pediatrics*, *29*, 152–160. doi: 10.1097/DBP.0b013e318165c7a0

Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Medical Decision Making*, *32*, 246-258. doi: 10.1177/0272989X11421528

Little, L. (2003). Maternal perceptions of the importance of needs and resources for children with Asperger syndrome and non verbal learning disorders. *Focus on Autism and Other Developmental Disabilities*, 18, 258–267. doi : 10.1177/10883576030180040701

Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. (2012). *Autism diagnostic observation schedule: ADOS-2*. Los Angeles, CA: Western Psychological Services.

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(4)*, 516-524. doi: 10.1007/s10826-009-9323-5

Mackintosh, V. H., Goin-Kochel, R. P., & Myers, B. J. (2012). What do you like/dislike about the treatments you're currently using?: A qualitative study of parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 27,51–60. doi: 10.1177/1088357611423542

Magaña, S., Parish, S. L., & Son, E. (2015). Have racial and ethnic disparities in the quality of health care relationships changed for children with developmental disabilities and ASD? *American journal on Intellectual and Developmental Disabilities, 120*, 504-513. doi: 10.1352/1944-7558-120.6.504

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. doi: 10.1352/1934-9556-51.3.141

Magaña, S., Parish, S. L., Rose, R. A., Timberlake, M., & Swaine, J. G. (2012). Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual and Developmental Disabilities, 50*, 287-299. doi: 10.1352/1934-9556-50.4.287

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*(3), 324-333, doi: 10.1080/00207594.2012.662278

Makrygianni, M. K., & Reed, P. (2010). A meta-analytic review of the effectiveness of behavioural early intervention programs for children with autistic spectrum disorders. Research in Autism Spectrum Disorders, 4, 577-593. doi:10.1016/j.rasd.2010.01.014

Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11*, 110–115. doi: 10.1002/mrdd.20061

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child, & Adolescent Psychiatry, 41*, 1447-1453. doi: 10.1097/00004583-200212000-

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. doi: 10.2105/AJPH.2007.131243

McConachie, H., & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: A systematic review. *Journal of evaluation in clinical practice, 13*(1), 120-129. doi : 10.1111/j.1365-2753.2006.00674.x

McLennan, J. D., Huculak, S., & Sheehan, D. (2008). Brief report: pilot investigation of service receipt by young children with autistic spectrum disorders. Journal of Autism and Developmental Disorders, 38, 1192–1196. doi : 10.1007/s10803-007-0535-5

McManus, B. M., McCormick, M. C., Acevedo-Garcia, D., Ganz, M., & Hauser-Cram, P. (2009). The effect of state early intervention (EI) eligibility on EI participation among children with special health care needs. *Pediatrics*, *124* (Supplement 4), 368–374. doi: 10.1542/peds.2009-1255G

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. doi: 10.1007/s10803-014-2178-7

Mello, C., Rivard, M., & Terroux (2018). Quality of Life in Families of Young Children with Autism Spectrum Disorder. Manuscrit en révision

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. doi: 10.1177/154079691303800403

Montes, G., Halterman, & Magyar, C. I. (2009). Access to and satisfaction with school and community health services for US children with ASD. *Pediatrics, 124* (Supplement 4), 407–413. doi: 10.1542/peds.2009-1255L

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. doi: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. doi: 10.1016/j.rasd.2009.01.004

Nielsen, M., Haun, D., Kärtner, J., & Legare, C. H. (2017). The persistent sampling bias in developmental psychology: A call to action. *Journal of Experimental Child Psychology*, *162*, 31-38. doi: /10.1016/j.jecp.2017.04.017

Noiseux, M. (2014). Prévalence des troubles du spectre de l'autisme: la Montérégie en tête de peloton. Périscope, 47. Longueuil, Québec : Agence de la santé et des services sociaux de la Montérégie, Direction de la santé publique. Repéré à http://ex tranet.santemonteregie.qc.ca/depot/document/363 /PeriscopeTSA.pdf

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

Office des personnes handicapées du Québec (2009). La politique *À part entière : pour un véritable exercice du droit à l'égalité.* Repéré à https://m.ophq.gouv.qc.ca/loi-et-politiques/politique-a-part-entiere.html

Ojeda, L., Flores, L. Y., Meza, R. R., & Morales, A. (2010). Culturally competent qualitative research with Latino immi- grants. Hispanic Journal of Behavioral Sciences, 33, 184–203. doi: 10.1177/0739986311402626

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers with intellectual disability. *Journal of Intellectual Disability Research*, *45*, 535–543. doi:10.1046/j.1365-2788.2001.00372.x.

Ortiz, C., & Del Vecchio, T. (2013). Cultural diversity: Do we need a new wake-up call for parent training?. *Behavior Therapy*, *44*(3), 443-458. doi : 10.1016/j.beth.2013.03.009

Osborne, L. A., McHugh, L., Saunders, J., & Reid, P. (2008).A possible contra-indication for early diagnosis of autistic spectrum conditions: Impact on parenting stress. *Research in Autism Spectrum Disorders*, *2*, 707–715. doi:10.1016/j.rasd.2008.02.005

Palmer, R. F., Walker, T., Mandell, D., Bayles, B., & Miller, C. S. (2010). Explaining low rates of autism among Hispanic school children in Texas. *American Journal of Public Health*, *100*, 270-272. doi: 10.2105/AJPH.2008.150565

Paquet, A., Chatenoud, C., & Cappe, É. (2014). Les fonctions familiales. Dans C. Chatenoud, J-C. Kalubi et A. Paquet (dir), *La famille et la personne ayant un trouble du spectre de l'autisme. Comprendre, soutenir et agir autrement.* Montréal QC, Canada: Éditions Nouvelles, 51-69.

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. doi: 10.1046/j.1365-2 788.2003.00497.x

Parkhomenko, D. (2016). *Quality of Life and Migration Experiences among Russian Speaking Immigrants to the United States of America* (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. 10.1007/s10882-016-9477-1

Patton, M.Q. (2011). Qualitative research and evaluation methods (3rd ed.). Newbury Park, CA: SAGE

Pelchat, D., Lefebvre, H., & Perreault, M. (2003). Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of child health care*, *7*, 231-247. doi : 10.1177/13674935030074001

Perry, A., Cummings, A., Dunn Geier, J., Freeman, N., Hughes, S., Managhan, T., ... Williams, J. (2011). Predictors of outcome for children receiving intensive behavioral intervention in a large, community-based program. *Research in Autism Spectrum Disorders*, *5*, 592–603. doi: 10.1016/j.rasd.2010.07.003

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*(1), 546-555. doi : 10.1016/j.rasd.2011.07.015

Pitten, K. (2008). How cultural values influence diagnosis, treatment and the welfare of families with an autistic child. *Review Academic Journal*, *4*, 1-5. doi: 10.1177/1066480713476834

Pituch, K. A., Green, V. A., Didden, R., Lang, R., O'Reilly, M. F., Lancioni, G. E., & Sigafoos, J. (2011). Parent reported treatment priorities for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *5,* 135–143. doi: 10.1016/j.rasd.2010.03.003

Pleck, J. H., & Masciadrelli, B. P. (2004). Paternal involvement by US residential fathers: Levels, sources, and consequences. In M. E. Lamb (Ed.), *The role of the father in child development* (pp. 222-271). Hoboken, NJ: John Wiley.

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.

Poston, D., Turnbull, A. P., Park, J., Mannan, H., Marquis, J. et Wang, M. (2003). Family quality of life : A qualitative inquiry. *Mental Retardation,* 41 (5), p. 313-328. doi : 10.1352/0047-6765(2003)41<313:FQOLAQ>2.0.CO;2

Protecteur du Citoyen. (2009). Pour une meilleure continuité dans les services, les approches et les rapports hunains: *Rapport spécial du Protecteur du citoyen sur les services gouvernementaux destinés aux enfants présentant un trouble envahissant du développement.* Québec, QC : Auteur

Protecteur du Citoyen. (2012). Rapport special du protecteur du citoyen. *Les services aux jeunes et aux adultes présentant un trouble envahissant du développement : de l'engagement gouvernemental à la réalité.* Québec, QC :Auteur

Protecteur du Citoyen (2015). Rapport special du protecteur du citoyen: *L'accès, la continuité et la complémentarité des services pour les jeunes (0-18 ans) présentant une déficience intellectuelle ou un trouble du spectre de l'autisme.* Québec, QC : Auteur

Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies, 21*, 311-319. doi: 10.1007/s10826-011-9477-9

Renty, J., & Roeyers, H. (2006). Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents. *Child: Care, Health and Development*, *32*(3), 371-385. doi : 10.1111/j.1365-2214.2006.00584.x

Rivard, M., Lépine, A., Mercier, C., & Morin, M. (2014). Quality determinants of services for parents of young children with autism spectrum disorders. *Journal of Child and Family Studies*. Advance online publication. doi: 10.1007/s10826-014-0041-2

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*(5), 439-452. doi : 10.1352/1944-7558-122.5.439

Rivard, M., Millau, M., Forget, J., & Morin, D. (2013). L'influence des facteurs culturels dans l'application des programmes découlant de l'analyse appliquée du comportement *Revue francophone de clinique comportementale et cognitive, 18*, 33–46.

Rivard, M., Morin, M., Mello, C., Terroux, A., & Mercier, C. (2018). Follow-Up of Children With Autism Spectrum Disorder 1 Year After Early Behavioral Intervention. *Behavior modification.* Prépublication. doi : 10.1177/0145445518773692

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. doi: 10.1007/s10803-013-2028-z.

Roberts, C., Mazzucchelli, T., Studman, L., & Sanders, M. R. (2006). Behavioural family intervention for children with developmental disabilities and behavioural problems. *Journal of Clinical Child and Adolescent Psychology*, 35(2), 180-193. doi: 10.1207/s15374424jccp3502_2

Rodrigue, J., Morgan, S., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology, 19*, 371–379. doi: 10.1207/s15374424jccp1904_9

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. Journal of Clinical Child & Adolescent Psychology, 37, 8-38. doi:10.1080/15374410701817808

Rosenberg, R. E., Daniels, A. M., Law, J. K., Law, P. A., & Kaufmann, W. E. (2009). Trends in autism spectrum disorder diagnoses: 1994–2007. *Journal of Autism and Developmental Disorders*, *39*, 1099–1111. doi: 10.1007/s10803-009-0723-6

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*(3), 188-195

Rueda, R., Monzo, L., Shapiro, J., Gomez, J., & Blacher, J. (2005). Cultural models of transition: Latina mothers of young adults with developmental disabilities. *Exceptional Children, 71,* 401–414. doi: 10.1177/001440290507100402

Samadi, S. A., McConkey, R., & Kelly, G.(2011). The information and support needs of Iranian parents of children with autism spectrum disorders. *Early Child Development and Care, 182,* 1439–1453. doi: 10.1080/03004430.2011.616931

Samadi, S. A., McConkey, R., & Kelly, G. (2012). Enhancing parental well-being and coping through a family-centred short course for Iranian parents of children with an autism spectrum disorders. *Autism, 17*, 27–43. doi: 10.1177/1362361311435156

Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behavior Therapy*, *19*(4), 15–32. doi:10.1300/J019v19n04_02

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 Information, 40*, 457–470. doi: 10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.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. doi: 10.1007/s10803-017-3102-8

Selkirk, C. G., McCarthy Veach, P., Lian, F., Schimmenti, L., & LeRoy, B. S. (2009). Parents' perceptions of autism spectrum disorder etiology and recurrence risk and effects of their perceptions on family planning: Recommendations for genetic counselors. *Journal of Genetic Counseling, 18*, 507-519. doi: 10.1007/s10897-009-9233-0

Sharpe, D. L. et Baker, D. L. (2007). Financial issues associated with having a child with autism. *Journal of Family and Economic Issues*, 28 (2), p. 247-264. doi : 10.1007/s10834-007-9059-6

Shyu, Y. I. L., Tsai, J. L., & Tsai, W. C. (2010). Explaining and selecting treatments for autism: Parental explanatory models in Taiwan. *Journal of Autism and Developmental Disorders*, *40*, 1323-1331. doi: 10.1007/s10803-010-0991-1

Skinner, D.G., Correa, V., Skinner, M., Bailey, D.B. (2001). Role of Religion in the Lives of Latino Families of Young Children With Developmental Delays. *American Journal on Mental Retardation,106*, 297–313. doi: 10.1352/0895-8017(2001)106<0297:RORITL>2.0.CO;2

Smith, T., Buch, G. A., & Gamby, T. E. (2000). Parent-directed, intensive early intervention for children with pervasive developmental disorder. *Research in developmental disabilities*, *21*(4), 297-309. doi : 10.1016/S0891-4222(00)00043-3

Söderström, S. (2014). Lost in translation? Communication challenges in minority families' and healthcare workers' interactions. *Disability & Society, 29*(5), 807-820. doi : 10.1080/09687599.2013.848783

Special Interest Research Group on Quality of Life Quality of Life: Its Conceptualization, Measurement and Application. A Consensus Document. International Association for the Scientific Study of Intellectual Disabilities.

Statistiques Canada (2017). Thème du recencement 2016: Immigration et diversité ethnoculturelle. Repéré à https://www12.statcan.gc.ca/census-recensement/2016/rt-td/imm-fra.cfm

Stehouwer, L. R. (2014*). Living with " new normal: " Fathers blogged experiences of parenting a child with autism* (Doctoral dissertation , University of Guelph). Repéré à https://atrium.lib.uoguelph.ca/xmlui/handle/10214/8276

Stevenson, H. W., Chen, C., & Uttal, D. H. (1990). Beliefs and achievement: A study of Black, White, and Hispanic children. *Child development, 61,* 508-523. doi : 10.1111/j.1467-8624.1990.tb02796.x

Strauss, K., Mancini, F., Fava, L., & SPC Group. (2013). Parent inclusion in early intensive behavior interventions for young children with ASD: a synthesis of meta-analyses from 2009 to 2011. *Research in developmental disabilities, 34*(9), 2967-2985. doi : 10.1016/j.ridd.2013.06.007

Strauss, K., Vicari, S., Valeri, G., D'Elia, L., Arima, S., & Fava, L. (2012). Parent inclusion in early intensive behavioral intervention: The influence of parental stress, parent treatment fidelity and parent-mediated generalization of behavior targets on child outcomes. *Research in Developmental Disabilities, 33*, 688–703. doi:10.1016/j.ridd.2011.11.008

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. doi: 10.1352/0047-6765(2002)040,0457:CMAAOQ.2.0.CO;2.

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. doi: 10.1111/j.1365–2788.2011.01434.x

Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to care for autism-related services. *Journal of autism and developmental disorders, 37*(10), 1902-1912. doi : 10.1007/s10803-006-0323-7

Turnbull, A.P., Aldersey, H.M. (2014). Présentation générale du modèle des systèmes familiaux: de la conceptualisation à l'application. Dans C. Chatenoud, J-C. Kalubi et A. Paquet (dir), *La famille et la personne ayant un trouble du spectre de l'autisme. Comprendre, soutenir et agir autrement.* Montréal QC, Canada: Éditions Nouvelles, 51-69.

Turnbull, A. P., Turnbull, R., Erwin, J. E., Soodak, L. et Shogren, K. (2011). *Families, professionals, and exceptionality. Positive Outcomes through partnerships and trust*. Upper Saddle River : Pearson

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. doi: 10.1002/mrdd.20174

Valdez, C. R., Abegglen, J., & Hauser, C. T. (2013). Fortalezas Familiares Program: Building sociocultural and family strengths in Latina women with depression and their families. *Family process, 52*(3), 378-393. doi : doi.org/10.1111/famp.12008

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. doi: 10.1016/j.rasd.2015.11.008

Virués-Ortega, J. (2010). Applied behavior analytic intervention for autism in early childhood: Meta-analysis, meta-regression and dose-response meta-analysis of multiple outcomes. *Clinical Psychology Review, 30,* 387–399. doi: 10.1016/j.cpr.2010.01.008

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. doi: 10.1111/ j.1365-2788.2006.00932.x

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

Warren, Z., McPheeters, M. L., Sathe, N., Foss-Feig, J. H., Glasser, A. & Veenstra-VanderWeele, J. (2011). A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics, 127,* e1303–e1311. doi: 10.1542/peds.2011-0426

Welterlin, A., & LaRue, R. (2007). Serving the needs of immigrant families of children with autism. *Disability & Society, 22,* 747–3760. doi: 10.1080/09687590701659600

The WHOQOL Group (1994). Development of the WHOQOL: Rationale and current status. *International Journal of Mental Health, 23*(3), 24-56. doi : 10.1080/00207411.1994.11449286

Wolf, L., Noh, S., Fisman, S., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders, 19*, 157–166. doi:10.1007/BF02212727

Yeh, M., Hough, R. L., McCabe, K., Lau, A., & Garland, A. (2004). Parental beliefs about the causes of child problems: Exploring racial/ethnic patterns. *Journal of the American Academy of Child, & Adolescent Psychiatry, 43*, 605-612. doi: 10.1097/00004583-200405000-00014

Zuckerman, K. E., Sinche, B., Cobian, M., Cervantes, M., Mejia, A., Becker, T., & Nicolaidis, C. (2014). Conceptualization of autism in the Latino community and its relationship with early diagnosis. *Journal of Developmental and Behavioral Pediatrics, 35*, 522. doi: 10.1097/DBP.0000000000000091

Zuckerman, K. E., Lindly, O. J., & Sinche, B. (2016). Parent beliefs about the causes of learning and developmental problems among children with autism spectrum disorder: Results from a national survey. *American Journal on Intellectual and Developmental Disabilities, 121*, 432-447. doi: 10.1352/1944-7558-121.5.432