

**ONTARIO PHYSICIANS' PERCEIVED COMPETENCY WHEN PROVIDING CARE
FOR INDIVIDUALS WITH ASD**

by

Golnaz Ghaderi

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Arts (M.A.) in Applied Psychology

The Faculty of Graduate Studies
Laurentian University
Sudbury, Ontario

© Golnaz Ghaderi, 2017

THESIS DEFENCE COMMITTEE/COMITÉ DE SOUTENANCE DE THÈSE
Laurentian Université/Université Laurentienne
Faculty of Graduate Studies/Faculté des études supérieures

Title of Thesis Titre de la thèse	ONTARIO PHYSICIANS' PERCEIVED COMPETENCE WHEN PROVIDING CARE FOR INDIVIDUALS WITH ASD	
Name of Candidate Nom du candidat	Ghaderi, Golnaz	
Degree Diplôme	Master of Arts	
Department/Program Département/Programme	Psychology	Date of Defence Date de la soutenance July 27, 2017

APPROVED/APPROUVÉ

Thesis Examiners/Examineurs de thèse:

Dr. Shelley Watson
(Supervisor/Directeur(trice) de thèse)

Dr. Cynthia Whissell
(Committee member/Membre du comité)

Dr. Nicole Yantzi
(Committee member/Membre du comité)

Dr. Virginie Cobigo
(External Examiner/Examineur externe)

Approved for the Faculty of Graduate Studies
Approuvé pour la Faculté des études supérieures
Dr. David Lesbarrères
Monsieur David Lesbarrères
Dean, Faculty of Graduate Studies
Doyen, Faculté des études supérieures

ACCESSIBILITY CLAUSE AND PERMISSION TO USE

I, **Golnaz Ghaderi**, hereby grant to Laurentian University and/or its agents the non-exclusive license to archive and make accessible my thesis, dissertation, or project report in whole or in part in all forms of media, now or for the duration of my copyright ownership. I retain all other ownership rights to the copyright of the thesis, dissertation or project report. I also reserve the right to use in future works (such as articles or books) all or part of this thesis, dissertation, or project report. I further agree that permission for copying of this thesis in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis work or, in their absence, by the Head of the Department in which my thesis work was done. It is understood that any copying or publication or use of this thesis or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that this copy is being made available in this form by the authority of the copyright owner solely for the purpose of private study and research and may not be copied or reproduced except as permitted by the copyright laws without written authority from the copyright owner.

Abstract

The current document is a manuscript-based thesis investigating the overall perceived knowledge, competency and experiences of Ontario physicians when diagnosing and treating individuals with Autism Spectrum Disorder (ASD). A growing body of literature has revealed that physicians often do not feel comfortable providing care for patients with ASD due to lack of education, training, exposure, and interest working with this population. However, there has been a recent shift in the literature focusing on identifying factors that enhance the healthcare system for patients with ASD as well as barriers that physicians encounter when diagnosing and treating these individuals. Therefore, the first paper included in this thesis is a mixed-methods analysis of physicians' perceived knowledge and competency in terms of diagnosis and treatment of ASD. Despite their high perceived knowledge regarding the diagnosis and treatment of ASD, medical practitioners expressed their needs for further education and training regarding ASD. The second paper included is also a mixed-methods analysis examining factors that hinder and facilitate physicians' abilities to provide appropriate care for individuals with ASD. Descriptive statistics, paired-samples T-tests, repeated measures ANOVA, and chi-square analyses were used to analyze the results of a questionnaire and thematic analysis was used to analyze the semi-structured interviews. Recommendations for improving the healthcare and educational systems as well as implications for enhancing physicians' knowledge, competency and experiences are discussed.

Keywords

The following could be used to describe this thesis entitled "Ontario Physicians' Perceived Competency When Providing Care For Individuals With ASD": autism spectrum disorder,

developmental disability, medical practitioners, mixed methods, Ontario, perceived knowledge, perceived competency, barriers, challenges, facilitators, diagnosis, treatment, and services.

Acknowledgments

I would first like to thank the physicians who took the time out of their busy schedules to participate in this study. I am grateful to have had the opportunity to meet such incredible and caring professionals who shared their experiences in order to contribute in the field, and ultimately make a difference in the lives of individuals with ASD.

To my supervisor, Dr. Shelley L. Watson, thank you for your support and mentorship throughout my master's education. I am grateful for all the learning opportunities that you have provided me with, which has allowed me to grow as a student and as a researcher. With your guidance, support, and supervision, I was able to broaden my knowledge and skills, and more importantly, to present at many conferences speaking about my research which is my passion. You held my hands when I was hopeless, you showed me the path when I felt lost, and you were patient when I felt overwhelmed. I feel privileged to have had the opportunity to work with an amazing professional, researcher, and supervisor like you. I have learned a tremendous amount from you and I am thankful for working with you.

I would also like to thank my committee members, Dr. Cynthia Whissell and Dr. Nicole Yantzi, for their incredible feedback. I have learned tremendously from working with you both and I am grateful of such a supportive, knowledgeable, and positive committee.

I would like to thank my family for their support throughout my degree-I would not be able to be where I am in life without your unconditional love and support. To my best friend and my life partner, Sean Bowers, thank you for your support and encouragement throughout my education- you have played a tremendous role in my success. I would also like to make a special mention to Kelly Coons for her continued help with my thesis. I feel privileged to have you as my close friend, whom I look up to as a professional and as an intelligent individual.

Table of Contents

Thesis Defense Committee ii

Abstract iii

 Keywords iii

Acknowledgement v

Table of Contents vi

List of Tables ix

List of Appendices x

Chapter 1: Introduction 1

Characteristics of ASD 2

The prevalence Rate of ASD 5

The Etiology of ASD 7

The Diagnostic Process of ASD in Primary Care Setting 9

Modified Checklist for Autism in Toddlers (M-CHAT) 11

Autism Diagnostic Observation Schedule (ADOS)..... 12

Childhood Autism Rating Scale (CARS) 13

DSM-5 13

Treatment and Intervention 14

Medications 14

Early Intensive Behavioural Intervention (EIBI) 16

Cognitive Behaviour Therapy (CBT) 17

Families of Individuals with ASD 18

Challenges in the diagnosis and treatment of ASD 20

Delay in the Diagnosis of ASD 21

Lack of Knowledge Regarding the Diagnosis and Treatment of ASD 23

Lack of Competency and/or Interest in Diagnosis and Treatment of ASD 23

Screening Tools 24

Purpose 25

Rationale 26

Research Questions 27

Methodology	27
<i>Participants</i>	28
<i>Phase 1: The Healthcare Professional Questionnaire</i>	29
<i>Phase 2: Semi-Structured Interview</i>	30
Ethical Considerations	31
Conclusion and Overview of Subsequent Chapters	31
“In Medical School, You Get Far More Training on Medical Stuff than Developmental Stuff”: Perspectives on ASD from Ontario Physicians	32
Abstract	33
Medical Practitioners’ Perspective	35
Methods	37
<i>Participants</i>	37
<i>Materials</i>	38
<i>Analysis</i>	40
Results	41
<i>“I know a little about it”: Perceived Knowledge Regarding the <u>Diagnosis</u> of ASD</i>	41
<i>“I don’t actually do it and I have never actually seen it”: Perceived Knowledge Regarding the <u>Treatment</u> of ASD</i>	44
<i>“I am a family doctor, and I treat people as a family doctor”: Physicians’ Perceived Competency Regarding the <u>Diagnosis and Treatment</u> of ASD</i>	46
Discussion	48
Limitations	50
Conclusion and Implications	51
References	54
Autism Spectrum Disorder Knowledge, Training and Experience: Ontario Physicians’ Perspectives about What Helps and What Does Not	59
Abstract	60
<i>Challenges in Providing Care</i>	62
<i>Facilitators</i>	63
Methods	64
<i>Participants</i>	65

<i>Materials</i>	65
<i>Analysis</i>	67
Results	69
<i>“There was no particular focus on ASD”: Barriers in Providing Care for ASD</i>	
<i>Individuals</i>	69
<i>“I definitely see a lot of ASD in my practice”: Facilitators in Providing Care for</i>	
<i>Individuals with ASD</i>	72
Discussion	76
<i>Limitations</i>	79
Conclusion and Implications	80
References	82
Chapter 4: Conclusion	88
Summary of Findings	88
Considerations and Recommendations for Future Research	91
Knowledge Translation	94
Clinical Implications	95
Conclusion	97
References	99

List of Tables

Table 1: Participant Demographic Characteristics.....	29
---	----

List of Appendices

Appendix A: Laurentian University Research Ethics Board Approval.....	125
Appendix B: Health Care Questionnaire.....	126
Appendix C: Semi-Structured Interview Guide for Medical Practitioners.....	137

Chapter 1: Introduction

Individuals with Autism Spectrum Disorder (ASD) demonstrate a wide range of impairments in communication and social function, as well as repetitive behaviours and restricted interests (Devlin & Scherer, 2012). According to the Centers for Disease Control and Prevention (CDC; 2014), approximately 1 in 68 children is diagnosed with ASD. Parents of children with ASD have raised concerns regarding the delay in diagnosis of ASD (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010), medical practitioners' knowledge about diagnosis and treatment of ASD (Carbone, Behl, Azor, & Murphy, 2010), and lack of social support due to a paucity of financial and medical resources (Glazzard & Overall, 2012). Health care professionals play an important role in the identification and treatment of children with ASD. Nonetheless, research shows that many health care providers do not feel comfortable in both the assessment and diagnosis of ASD (Rhoades et al., 2007), perhaps contributing to the delays in diagnosis. Furthermore, researchers have discussed several barriers (e.g., lack of education and training) that physicians experience when providing care for this population, especially in areas such as being able to diagnose and treat ASD (Daniels, Halladay, Shih, Elder, & Dawson, 2014; Fenikilé, Ellerbeck, Filippi, & Daley, 2015). In addition to challenges, several facilitators (e.g., working in a multidisciplinary team) have been identified that enhance the diagnostic and treatment processes for both physicians as well as individuals with ASD (Major, Peacock, Ruben, Thomas, & Weitzman, 2013). This thesis further investigates the perceived levels of knowledge and competency of health care professionals regarding the diagnosis and treatment of ASD in Ontario, as well as challenges and facilitators that physicians experience when providing care for this population.

The following literature review demonstrates the importance of studying medical practitioners' roles in the diagnosis and treatment of ASD, as well as both barriers and facilitators that physicians experience when providing care for this population. First, this literature review provides a summary of the characteristics, prevalence rate, and etiology of ASD. Second, some of the most common diagnostic tools that are used by diagnosticians, as well as treatment and intervention programs that are commonly implemented in clinical settings are explored. Third, the concerns and challenges that families of individuals with ASD experience when receiving diagnosis and treatment for their children are discussed. Finally, the challenges faced by medical practitioners in the diagnosis and treatment of ASD are discussed. Each of these components provides a rationale for the proposed study.

Characteristics of ASD

ASD is a heterogeneous neurodevelopmental disorder that affects the normal development of cognitive, social, language, and behavioural skills (Guthrie, Swineford, Nottke, & Wetherby, 2013; Walsh, Mulder, & Tudor, 2013). According to the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorder (DSM-5; APA, 2013), which is the most recent and commonly used diagnostic manual by healthcare professionals, in order for individuals to be diagnosed with ASD, they have to exhibit two core symptom domains: social-communication and restricted as well as repetitive behaviour and interests (McPartland, Reichow, & Volkmar, 2012).

In the previous version of the DSM (i.e., DSM-IV-TR), ASD was categorized under the Pervasive Developmental Disorders (PDDs) umbrella (APA, 2000). Most of these disorders are present early in life and co-occur with other medical conditions as well as mental health problems (APA, 2000). Many individuals with ASD exhibit a wide range of secondary

behaviours that are simultaneously present with the core symptoms of ASD. Individuals with ASD often experience comorbid conditions such as Attention Deficit Hyperactivity Disorder (ADHD), intellectual disabilities, epilepsy (Matson & Konst, 2015), as well as anxiety or other phobic disorders (Murray et al., 2014).

Based on the DSM-IV-TR, there are three possible diagnoses of ASD, which are Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDDNOS). These disorders are set in a hierarchal manner based on the severity of symptoms manifested by each disorder. For instance, based on the DSM-IV-TR, autistic disorder entails the highest number of symptom manifestations across all three areas of social, communication, and restricted repetitive behaviours areas; however, a diagnosis of Asperger's disorder only requires expression of at least two symptoms from the social and clinically important delays in their cognitive development during the first three years of life (APA, 2000). Accordingly, individuals with Asperger's disorder do not exhibit any significant delays in their development of language acquisition (Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012).

According to the DSM-IV-TR, in order for individuals to be diagnosed with autistic disorder, they must show impairments in at least two forms of social impairments such as "lack of social or emotional reciprocity" (APA, 2000, p. 75); at least one impairment in communication such as delay or total lack of the development of spoken language; and, at least one impairment in the form of restricted and stereotyped patterns of behaviour, interests, and activities such as "persistent preoccupation with parts of objects" (p.75). In addition, the symptoms of delay or abnormal functioning in either social interaction, social communicative language, or symbol or imaginative play before the age of three years must be present for the proposed diagnosis. With regard to the diagnosis of Asperger's disorder, individuals must exhibit

deficits in at least two areas of social interaction such as “marked impairment in the use of multiple non-verbal behaviours such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction” (p. 84). They also must show restricted repetitive and stereotyped behaviour, interests, and activities in one of the forms such as “persistent preoccupation with parts of objects” (p.84). More importantly, in order for individuals to be diagnosed with Asperger’s Disorder, they should not exhibit significant delays in language, cognitive, or age-appropriate self-help skills development (APA, 2000).

The revision made in the diagnosis of ASD from the DSM-IV-TR to DSM-5 meant changes in the categorization of the disorder. In other words, the DSM-5 uses ASD because a single category rather than a spectrum of autism disorders such as Autistic Disorders and Asperger’s disorder is recognized (Freeman, Chronin, & Candela, 2002; Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012). Moreover, the diagnoses of Asperger’s disorder, Autistic Disorder and PDDNOS were replaced with a single category of ASD (Tsai & Ghaziuddin, 2014). The diagnosis of ASD in the DSM-5 no longer includes the subtypes and the age of onset. In addition, the three core symptom domains in the diagnostic criteria have been reduced to two: social-communication as well as restricted and repetitive behaviour and interest (McPartland, Reichow, & Volkmar, 2012).

Alongside the changes for the diagnosis of ASD in the DSM-5, new specifiers including the presence of intellectual disability, structural language impairment, known medical/genetic or environmental/acquired conditions, other neurodevelopment, mental, or behavioural disorder, and catatonia have been added. These specifiers allow diagnosticians to determine whether ASD symptoms are present concurrently with the symptoms of other disorders. The specifiers also allow clinicians to better organize treatment plans for individuals affected with ASD (Luc,

2013).

The changes from the DSM-IV-TR to DSM-5 with regard to the diagnosis of ASD have raised many concerns among mental health and medical care professionals (Luc, 2013; Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012c; Tsai & Chaziuddin, 2014). As Luc (2013) argued, many of these concerns are regarding those who received a diagnosis based on the DSM-IV-TR, who will lose their ASD diagnosis due to the changes in the DSM-5. As a result, concerns have been raised that they will not receive necessary services in terms of medication, funding and treatment. Maenner and colleagues (2014) also looked at the implications of the revised diagnostic criteria for ASD in the DSM-5 with regard to estimating the prevalence of the disorder. These authors predicted that the prevalence rate of ASD would be smaller based on the DSM-5 than the DSM-IV-TR. As a result of such changes, the threshold of symptoms in the DSM-5 is much higher than the DSM-IV-TR, which can potentially lead to less diagnosis of ASD (Maenner et al., 2014).

The Prevalence Rate of ASD

For the past two decades, many studies have reported various prevalence rates for both Pervasive Developmental Disorders (PDD) and ASD, with an average of 69.5 per 10,000 (Baird et al., 2000; Tsai, 2014). From 2010 to 2013, 24 epidemiology studies have reported 78.4 per 10,000 as the prevalence rate of ASD and PDD (Tsai, 2014). Tsai (2014) claims that one of the factors contributing to such a discrepancy in the estimates of prevalence rates of ASD is due to different definitions used by the researchers. That is, in the DSM-5, there is no specific requirement for the presence of minimum number of symptoms manifested under the criterion A (i.e., “Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history”; APA, 2013, p.50). Nonetheless, the

criterion B in the DSM-5 for ASD requires manifestation of at least two symptoms under “B. Restricted, repetitive patterns of behaviour, interest, or activities, as manifested by at least two of the following, currently or by history” (APA, 2013, p.50). These changes in diagnosis of ASD from the DSM-IV-TR to DSM-5 have led to many controversies among professionals. For example, due to lack of clarity in diagnostic criteria of ASD in the DSM-5, it is up to the clinician’s discretion as to whether they choose to require one, two, or three symptoms from criterion A in order to make the diagnosis of ASD (Frances, 2013). In addition, there are some clinicians who do not use the DSM-5 and still refer to the DSM-IV-TR in order to make a diagnosis of ASD. Consequently, such variations in diagnosis of ASD result in drastic inconsistencies in reporting the prevalence rates of ASD (Frances, 2013; Tsai, 2014).

Despite the controversies about the prevalence rate of ASD, many researchers (e.g., Matson et al., 2012c; Mayes, Black, & Tierney, 2013; Mcpartland, Reichow, & Volkmar, 2012; Tsai, 2014; Worley & Matson, 2012) have found that on average, between 35 to 45 percent of individuals who met the DSM-IV-TR diagnosis of ASD, will no longer meet the diagnostic criteria based on the DSM-5. Young and Rodi (2013) reported that 57.1% of individuals who received the diagnoses of autistic disorder (AD), Asperger’s disorder, and PDDNOS based on the DSM-IV-TR, did not receive a diagnosis based on the DSM-5 criteria. They also noted that most of the individuals who did not meet the DSM-5 criteria were those with Asperger’s disorder and PDDNOS (i.e., high-functioning individuals). Mayes and colleagues (2013) also found that 16% of children who were previously diagnosed with AD and 90% with PDDNOS would not receive a diagnosis according to the DSM-5. As a result of such discrepancies in diagnosis, these studies have shown a decrease in the prevalence rate of ASD (Mayes et al., 2013; Young & Rodi, 2013).

On the other hand, there are many other studies that have investigated the prevalence rate of ASD and have reported an increase in the number of individuals who are diagnosed with autism (Autism Speaks, 2015; Rice et al., 2010; Skuse, 2012; Tsai & Ghaziuddin, 2014). For instance, based on Autism Speaks (2015), in the past two decades, there has been an increase in the number of children who receive the diagnosis and treatment for ASD. Tsai (2014) stated that the modifications in diagnostic criteria as well as parents', healthcare professionals' and the general public's elevated awareness in the identification of autism among children are potential factors contributing to the increase in prevalence of ASD. Despite such changes in diagnostic systems and individuals' awareness regarding ASD, research shows scattered estimates in the prevalence of ASD (Tsai, 2014). For instance, the very first study investigating the epidemiology of ASD was done by Kanner (1943), and reported 4.5 per 10,000 children between the ages of 8 to 10 in England had ASD. Other population-based studies reported an increase in the number of individuals with ASD. Baron-Cohen and colleagues (2009) reported the occurrence of ASD in UK to be as high as 157 per 10,000; Kim and colleagues (2011) reported prevalence rate of 264 per 10,000 in Asia; Blumberg and colleagues (2013) reported 200 per 10,000 as an estimate of ASD in the US; and Ouellette-Kuntz and colleagues (2014) reported an increased prevalence rate, ranging from 9.7% to 14.6%, among individuals between the ages of 2-14 years. Ultimately and most recently, according to the Centers for Disease Control and Prevention (CDC; 2014), approximately 1 in 68 children is diagnosed with ASD.

The Etiology of ASD

Individuals with ASD show a wide range of impairments in communication and social functions, as well as repetitive behaviours and restricted interests (Devlin & Scherer, 2012). As Devlin and Scherer (2012) discussed, the onset of ASD is before the age of three years and more

prevalent among males than females with a ratio of approximately 4:1. Although there have been controversies regarding the etiology of ASD, there are studies looking at genetics and environmental risk factors leading to ASD. Twin studies investigating genetics as a risk factor have found 65% to 95% concordance rates among monozygotic twins versus 3% to 8% among dizygotic twins (Boyd, Odom, Humphreys, & Sam, 2010; Volker & Lopata, 2008). Despite the elusive nature of ASD, there is a growing body of research supporting genetics as a major cause of ASD. Research shows that some of the genetic factors are mutations and structural variation in number of genes (Abrahams & Geschwind, 2008). For instance, Bölte (2014) identified some of the genetic variables found to be responsible for the pathology of ASD are chromosomal rearrangement and dysregulation in DNA methylation. Abrahams and Geschwind (2008) also suggested that children with siblings who have ASD are at a 2% to 6% higher risk of having ASD in comparison to those with typically developing siblings (Newschaffer et al., 2007). In addition, 10% of individuals with ASD have other genetic conditions such as fragile X syndrome, tuberous sclerosis or Rett syndrome (Anagnostou & colleagues, 2014).

Besides genetics as a potential risk factor for ASD, researchers have investigated the neurodevelopmental processes of children with ASD in relation to their immune system. For instance, abnormal levels of autoantibodies, immunoglobulins, and inflammatory cytokines have been found in the peripheral blood and cerebral spinal fluid of children with ASD (Croonenberghs et al., 2002; Molloy et al., 2006; Zimmerman et al., 2005). Nonetheless, as Newschaffer and colleagues (2007) declared, the relationship between dysregulation in the immune systems of children with ASD is still unclear and more research is required in order to demonstrate such an association.

As discussed previously, the environment also plays a role in the etiology of ASD. Some

environmental risk factors are metals such as lead and mercury, maternal chronic exposure to solvents, as well as prenatal exposure to alcohol, smoking, and illicit drugs (Goines & Ashwood, 2013; Newschaffer et al., 2007). For instance, Anagnostou and colleagues (2014) discuss that environmental influences, such as perinatal effects that are shared by twins are more likely to cause ASD compared to genetic factors. More importantly, Aronson, Hagberg, and Gillberg (1997) indicated that alcohol could be a direct risk factor in ASD by playing a role as a teratogen, or could influence individuals through genetic vulnerability to ASD. Researchers have also found that individuals who are exposed to heavy metals such as lead and mercury during critical early developmental period often exhibit impairments in their behavioural and intellectual disabilities (Selevan et al., 2003; Winneke, 2011). Research indicates that the interplay between environment and genetics plays a substantial role in the etiology of ASD (Goines & Ashwood, 2013; Lai, Lombardo, & Baron-Cohen, 2014). For instance, those who are genetically predisposed to ASD would respond to environmental risk factors such as infection or exposure to toxics inappropriately. As a consequence of exposure to environmental influences during the early developmental period, an individual's nervous and immune system can be severely affected (Goines & Ashwood, 2013). Therefore, this chain of events could lead to ASD, as well as the neurological and behavioural implications exhibited by these individuals (Goines & Ashwood, 2013). In addition, maternal and paternal reproduction age, biological factors such as germline mutation, especially in fathers, and gestational factors such as complications during pregnancy are other risk factors to be considered (Lai et al., 2014).

The Diagnostic Process of ASD in Primary Care Settings

Parents are usually the first people who detect abnormal behavioural signs in their children with ASD. For instance, they may notice that their children do not make eye contact, do not

respond to their names, or show fixated and repetitive patterns of behaviours (Anagnostou et al., 2014; Autism Speaks, 2015). Researchers have also found signs of behavioural warnings for ASD, which assist diagnosticians to identify related symptoms among young children and toddlers, including delay or impairment in social behaviours (e.g., smiling and looking at faces), restricted and repetitive behaviours (e.g., repetitive play with objects and repetitive movements), as well as coordination of verbal and nonverbal behaviours (Boyd et al., 2010). Other signs of behavioural warning are unusual exploration of objects at 12 months, rotating or spinning objects between the ages of 18 and 24 months, as well as deficits in development of receptive and expressive language skills at the age of 30 to 36 months (Morgan et al., 2008; Ozonoff et al., 2008).

There is a distinct variability in expression and severity of symptomatology of ASD between and within individuals over time. That is, there is no one individual with ASD who exhibits the same symptoms or characteristics (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). As Ozonoff and colleagues (2010) stated, children with ASD often exhibit two distinctive patterns of behavioural signs including “early onset” and “a regressive pattern” (p. 256). The former refers to the onset of behavioural symptoms as early as one year of age; and, the latter refers to the regressive patterns of development. In other words, these children often lose communication and social skills between the ages of 16 to 20 months (Ozonoff et al., 2010).

To better capture the behavioural and developmental trajectories of ASD in early childhood, Bryson and colleagues (2007) systematically looked at the appearance of the symptoms of ASD among nine high-risk six-month old infants (i.e., infants with a sibling with autism). In this study, they used the Autism Observation Scale for Infants (AOSI), the Autism Diagnostic Observation Schedule (ADOS), DSM-IVTR and the Autism Diagnostic Interview-

Revised (ADI-R) to assess the infants' cognition, early gestures, language and temperament at the ages of 6, 12, 18, 24 and 36 months. The results of the study demonstrated that although some of the children did not show atypical behavioural, temperamental, or cognitive symptoms of ASD at 6 months of age, and for some, 12 months of age, all children were diagnosed with ASD by the age of 36 months. More importantly, all infants in this study illustrated typical social engagement (e.g., eye contact), temperament, and average cognitive functioning prior to 18 months of age; however, the symptoms of ASD gradually manifested between the ages of 12 to 18 months (Bryson et al., 2007). The results of the study highlight the variability in the symptomology of ASD. Due to such, it is crucial for diagnosticians to employ a multi-disciplinary approach in order to gather thorough and comprehensive information regarding the history of social, communication, behavioural, and cognitive development of an individual with a suspected diagnosis of ASD (Keenan et al., 2010).

Modified Checklist for Autism in Toddlers (M-CHAT)

There are several specific and valid screening tools that are used to assess children's symptoms with suspected diagnosis of ASD. For example, the Modified Checklist for Autism in Toddlers (M-CHAT), which is a modified version of the CHAT, was designed to screen for the symptoms of ASD along the entire spectrum. The MCHAT is one of the widely used instruments by practitioners to screen for the symptoms of ASD among children as young as 18 months of age (Wright & Poulin-Dubois, 2012). The M-CHAT assessment tool is a quick and highly sensitive measure including 23 likert-type behavioural questions filled out by medical practitioners and parents (Allison et al., 2008). For the purpose of the M-CHAT, parents are asked to answer *yes* or *no* to the measuring items regarding the presence of symptomatic behaviours as warning signs for ASD. The questions included in the M-CHAT are regarding

whether the infant engages in social interactions, maintains eye contact, imitates, engages in repetitive and pretend play, and uses eye contact or gestures to ask for help (Wright & Poulin-Dubois, 2012). Robins (2008) found that the M-CHAT has a high positive predictive value (PPV) and Kleinman and colleagues (2008) reported PPV of 0.65 for children who were at low risk for ASD, and 0.76 for those who were at high risk for ASD. Therefore, these studies provide evidence for the sensitivity and validity of the M-CHAT in screening for symptoms and warning signs of ASD between the ages of 18 to 24 months old.

Autism Diagnostic Observation Schedule (ADOS)

Another widely used diagnostic assessment tool is the Autism Diagnostic Observation Schedule (ADOS). The ADOS is a semi-structured observational instrument that evaluates “social interaction, communication, play and imaginative use of materials for individuals who may have autism” (Lord et al., 2000, p. 205). For instance, examiners offer communication opportunities in order to prompt a variety of interchanges (Lord et al., 2000; Molloy et al., 2011). The ADOS includes 4 modules that can be used with individuals as young as one year old to adults. These modules are designed to assess individuals at different developmental and language stages, as well as those with no expressive or receptive language (Le Couteur, Haden, Hammal, & McConachie, 2008). Molloy and colleagues (2011) looked at the validity of ADOS classifications of ASD in comparison to the final diagnoses of the disorder. They found that the ADOS has low specificity as individuals with diagnoses other than ASD could meet the cut off for an ASD diagnosis, which can mislead diagnosticians. In other words, there is an overlap between the scores of, for example, children with ASD and Specific Language Impairment (SLI) on communication items, because the ADOS evaluates continuous characteristics in different domains. In such cases, children with a potential diagnosis of ASD who have other

developmental disabilities may not receive a valid diagnosis solely based on the ADOS.

Therefore, the ADOS has been recommended as a complementary measuring tool employed by multidisciplinary teams alongside other assessment tools (Gotham, Risi, Pickles, & Lord, 2007; Molloy et al., 2011).

Childhood Autism Rating Scale (CARS)

The Childhood Autism Rating Scale (CARS) is used to assess behavioural symptoms of ASD on 15 domains including relating to people, imitation, emotional response, body use, object use, adaptation to change, visual response, listening response, taste, smell, and touch response and use, fear or nervousness, verbal communication, nonverbal communication, activity level, level and consistency of intellectual response, and general impressions (Matson et al., 2010). The higher the score children attain in each domain, the more severe their impairments are in those domains (Chlebowski, Green, Barton, & Fein, 2010). According to Ventola and colleagues (2006), the sensitivity of the CARS is 0.89, which is an indicator of its validity in the diagnosis of ASD in children.

DSM-5

Lastly, the DSM-5 is a diagnostic manual that includes classification of mental disorders, and is used by mental health professionals across different clinical settings (APA, 2014). According to the DSM-5, in order for individuals to meet the criteria for ASD, they must exhibit symptoms in all three criteria of social-communication, as well as at least two symptoms in the restricted and repetitive criterion. Based on the DSM-5, individuals must exhibit symptoms of ASD from early childhood (Carrington, 2014). There have been many controversial studies with regards to the sensitivity (i.e., true positives) and specificity of the DSM-5 in the diagnosis of ASD. For instance, many researchers have argued that the changes made in criteria of ASD from

the DSM-IV-TR to DSM-5 have increased the sensitivity, but decreased the specificity of the diagnosis, especially for individuals who have high functioning ASD (Frazier et al., 2012; Heurta et al., 2012; Mattila et al., 2011; Taheri & Perry, 2012). On the other hand, Mayes and colleagues (2013) not only stated that these changes have had minimal effects on both the sensitivity and specificity of the DSM-5, but also recommended the DSM-5 as a diagnostic tool in the identification of ASD.

Treatment and Intervention

Research shows that there are promising intervention programs designed to improve the behavioural, social, communication, and cognitive skills of individuals with ASD. Some of the interventions recommended include medications, behavioural and developmental strategies, psychotherapy, motor and sensory interventions, assistive and adaptive technology, as well as motor and sensory interventions (Research Autism, 2014). Although there is no cure or ‘treatment’ for ASD, various approaches can treat some of the comorbid psychiatric conditions. Nonetheless, medications, behavioural interventions (e.g., Early Intensive Behavioural Intervention) and psychotherapy (e.g., cognitive behaviour therapy) are the most commonly used approaches in treating the symptoms of ASD. Due to the heterogeneity of ASD, intervention plans that are designed to address behavioural, developmental, and communication problems must be modified according to each individual’s needs (McLeod, Wood, & Klebanoff, 2015).

Medications

Research shows that prescription drugs are widely used in North America to treat the core and secondary symptoms of ASD (Hsai et al., 2014). Medication is often used in order to alleviate some of the maladaptive behavioural and mental health symptoms such as aggression, self-injurious behaviours, anxiety, and depression of individuals with ASD (Matson & Konst,

2015; Murray et al., 2014). Some of the medications that are commonly used are stimulants (e.g., methylphenidate, dexamfetamine), antidepressants (e.g., tricyclic antidepressant), antipsychotics (e.g., risperidone), and antiepileptics or mood stabilizers (Murray et al., 2014).

Hsai and colleagues (2014) found that antipsychotic drugs are the most commonly prescribed drugs for the treatment of ASD symptoms in both the childhood and adult population. For instance, Shea and colleagues (2004) studied the effectiveness of risperidone for the treatment of behavioural problems in children with ASD. These authors administered risperidone to 79 children with ASD in a 8-week study; results of the study showed that participants who took risperidone showed 64% improvement in the irritability score in comparison to the control group who took the placebo solution (Shea et al., 2004). Studies looking at the effectiveness of selective serotonin reuptake inhibitors (SSRIs) medications (e.g., citalopram and fluoxetine) on individuals who experience anxiety and depression indicate mixed results. Kolvezon, Mathewson, and Hollander (2006) found that SSRIs are valuable in medicating the core symptoms of many individuals with ASD who experience anxiety disorders. On the other hand, Hsai and colleagues (2014) declared that SSRIs have caused headache, nausea and sedation in the adult population. As a result of variability regarding the efficacy of pharmacological approach in treatment of ASD symptoms, caution and a thorough evaluation of symptoms are required prior to administration of any type of medications.

Although prescription drugs are commonly used among the ASD population, there are controversies among researchers and mental health professionals regarding the efficacy of such medications in lessening the symptoms of ASD. For instance, Hsai and colleagues (2014) mentioned that risperidone medication has metabolic side effects in children and adults with ASD. In addition, these authors discussed how stimulant drugs that are often used for individuals

with ASD who also have ADHD, cause sedation in many cases.

Early Intensive Behavioural Intervention (EIBI)

One of the most effective intervention programs that is considered to be the best practice for individuals with ASD is Early Intensive Behavioural Intervention (EIBI; Fava et al., 2011). EIBI is one of the main applications of applied behaviour analysis (ABA), which is a highly systematic method in teaching young children with ASD who are approximately five years old or younger (Reichow, Barton, Boyd, & Hume, 2012). The main principles of EIBI consist of discrete trial training, which is a particular teaching procedure, one on one adult to child ratio, and intensive behavioural intervention that ranges between 20 to 40 hours a week in different settings such as home or school. EIBI is a comprehensive program that focuses on reducing the core symptoms of ASD, and is delivered in a structured and predictable setting in order to promote generalization and maintenance. Treatment is then transferred to other natural settings such as a classroom and the community. EIBI includes various strategies that are used in accordance with children's challenging behaviours that impede their learning (Reichow et al., 2012).

Research shows that children who received EIBI treatment exhibited more adaptive behaviours, less severe symptoms, and better language skills (Eldevik et al., 2009; Perry et al., 2008; Reichow & Wolery, 2009; Rivard, Terroux, & Mercier, 2014). Moreover, Reichow and colleagues (2012) conducted a meta-analysis of studies looking at the effectiveness of EIBI in the treatment of children with ASD. They found that EIBI enhances adaptive behaviour, IQ, communication skills, expressive and receptive language, and everyday social and living skills. In addition, Fava and colleagues (2011) compared the efficacy of EIBI and eclectic interventions in treating children with ASD. The results of the study illustrated that children who received

EIBI interventions exhibited considerably improved socialization skills, decreased autism severity, improved social interaction, and better communication skills in comparison to children who received eclectic intervention.

Harris and Handleman (2007) investigated whether the age and the cognitive functioning of children before and after receiving EIBI intervention would predict the outcome on enhancing the symptomology of ASD. These authors also measured the severity of ASD as well as IQ prior and after the intervention. After 35 to 45 hours of intensive intervention for one academic year, the authors found that children who received EIBI before the age of four years were more likely to be placed in inclusive educational settings in comparison to those who received intervention after the age of four years. Nonetheless, children who scored higher on an IQ test (e.g., the Stanford- Binet) at the time of intake and entered the intervention program after the age of four years were admitted to inclusive education placement after the intervention; children's IQ scores also increased significantly as a result of the EIBI. Therefore, the results of the study provide support for the effectiveness of the EIBI on the cognitive functioning of children with ASD, especially when they receive the intervention before four years of age (Harris & Handleman, 2007).

Cognitive Behaviour Therapy (CBT)

There is a growing body of research supporting the importance of CBT in treating psychiatric disorders among individuals with ASD. Sukhodolsky and colleagues (2013) conducted a meta-analysis study to systematically look at the evidence on the effectiveness of CBT for anxiety in children with ASD. Based on the review on eight randomized controlled studies, the authors found a significant impact of CBT on alleviating the symptoms of anxiety in children with ASD. Studies also show that people with ASD who received CBT exhibited less

anxiety and depressed mood symptoms, more adaptive social and behavioural characteristics, as well as enhanced cognition and emotional regulations (Lang et al., 2010; McGillivray & Evert, 2014; Spain et al., 2015; Sze & Wood, 2008; Wood, Fujii, Renno, & Dyke, 2014; Wood et al., 2015).

CBT has been shown to be successful in alleviating distressing mental health problems (e.g., anxiety, OCD, and depression) in individuals with ASD (Russell et al., 2013). For example, some of the components of CBT that are used in treating anxiety in individuals with ASD are externalizing symptomatic cognition, changing behaviour through raising awareness, and creating a list of anxiety provoking situations. The patients are then exposed to those anxiety-provoking situations in a hierarchical manner. Finally a therapist teaches the patient coping behavioural strategies such as relaxation and how to think rationally about the outcomes of such situations (Spain, Sin, Chalder, Murphy, & Happé, 2015). Nonetheless, there are different variables that could negatively affect the efficacy of CBT. For example, due to the nature of ASD, individuals are often unable to distinguish their thoughts and feelings, which can impede the outcome of CBT (Lang et al., 2010). In addition, some research has shown that individuals with below average IQ (i.e., < 70) or low cognitive ability do not benefit from CBT in comparison to those with the above average IQ (Taylor, Lindsay, & Willner, 2008). Willner (2005) stated that individuals with ASD who have below average IQ benefit from CBT strategies that teach self-management skills rather than those that focus on cognitive distortions. Given the intervention options discussed previously, it is also important to investigate the experiences of families of individuals with ASD when accessing services.

Families of Individuals with ASD

Studies show that parents of children with ASD experience stress due to lack of financial

and health care resources for children with ASD compared to children with other disabilities (Glazzard & Overall, 2012; Kogan et al., 2008). Perhaps, variability in the symptomology of ASD, as well as other comorbid conditions complicate the process of accessing services and agencies (Kogan et al., 2008). Glazzard and Overall (2012) also mentioned that parents reported lack of direction provided by health care professionals as to what the next step would be after receiving the diagnosis. For instance, a parent stated that,

What struck us was that after we received the diagnosis, there was no positive offer of support or therapy. It was left up to our family to research what would be best for our son and to work to put a team of therapists in place to help with his ASD. (Glazzard & Overall, 2012, p. 41)

The diagnostic process for ASD has been shown to cause stress among families of children with ASD (Howlin & Moore, 1997; Keenan et al., 2010; Wiggins et al., 2006). The diagnostic process of ASD often employs a multidisciplinary approach, in which parents' involvement plays an important role in the procedure; however, research shows that there are many parents who feel left out, as their views are not sufficiently included in the process (Keenan et al., 2010).

Additionally, researchers have found that parents reported frustration as they were provided with little information prior to and following the diagnosis; also, some parents stated that their children were misdiagnosed with ADHD or other disabilities. Therefore, these parents had to be self-reliant, and gain knowledge about the diagnosis of their children rather than relying on professionals guidance and support (Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor, 2012; Glazaard & Overall, 2012).

Many parents of children with ASD have reported a great deal of confusion, anger, and uncertainty while waiting for diagnosis for their children (Watson, Coons, Hayes, 2013; Wiggins

et al., 2006); however, receiving the diagnosis provided closure, and feeling of relief (Glazzard & Overall, 2012; Watson et al., 2013). Nonetheless, a delay in the diagnosis of ASD among children could lead to parental stress (Keenan et al., 2010).

Since early diagnosis is crucial in the effectiveness of intervention outcomes for children with ASD, Keenan and colleagues (2010) examined the diagnostic processes as well as issues with regard to future planning for these children. The results of the study showed that children, on average, received the diagnosis of ASD at the age of 4 years or older. More importantly, the authors found that the diagnosis took place approximately 16 months after the first referral. In addition, research shows that parents of children with ASD often receive the diagnosis for their children after the fourth visit with a medical professional (Siklos & Kerns, 2007). With regards to parents' experiences of diagnostic process, 49% of parents voiced their concerns regarding the duration and lack of professionalism in this process, and the rest reported that the information was not presented clearly to them. In addition, the majority of professionals reported that parents of individuals with ASD experience a great deal of stress when trying to receive a diagnosis for their child. Finally, 99% of parents and professionals agreed that the diagnostic process should be enhanced through increased support and guidance, plus the majority of the professionals and all of the parents stated that children's forward planning should be designed more comprehensively in order to address the needs of children with ASD (Keenan et al., 2010).

Challenges in the diagnosis and treatment of ASD

Among medical practitioners, family physicians and pediatricians are often the first healthcare professionals who interact with children suspected of having ASD; hence, they play an important role in the early identification of ASD symptoms in the pediatric population (Self, Parham, & Rajagopalan, 2015). Healthcare professionals in the U.S. have been mandated to

utilize early developmental screening tools in order to identify developmental issues in children as young as 9 months of age (Self et al., 2015). For example, as part of the routine screenings, pediatricians are recommended to screen children's development at every well-child visit; also, they are required to attend to parents' concerns, attain a thorough developmental history at the 9, 18-, and 24- month visits, and administer an ASD-specific assessment during the 18-month child well-child visit (Self et al., 2015).

Delay in the Diagnosis of ASD

A growing body of research emphasizes the importance of early detection and intervention in lessening and regulating the symptoms of ASD (Charman & Baird, 2002; Crais et al., 2014; Rhoades et al., 2007). As discussed by Charman and Baird (2002), ASD can be reliably diagnosed as early as 2 years of age. Despite some evidence showing that ASD can be identified early in life (e.g., as young as one year of age; Ozonoff et al., 2010), professionals are often hesitant to make the diagnosis (Self et al., 2015). Nonetheless, parents of children with ASD have reported that, although their children showed signs of autism as early as six months of age, the diagnosis was not established until the age of 3 or 4 years (McMorris et al., 2013; Rhoades et al., 2007).

Although there are specific guidelines for medical practitioners to follow when making the diagnosis of ASD, there are many children with suspected diagnosis of ASD who do not receive the diagnosis until later in life (McMorris, Cox, Hudson, Liu, & Bebko, 2013). Depending on the symptomology of children with ASD, some may receive the diagnosis earlier than others. In other words, those who exhibit severe speech and language, as well as explicit behavioural impairments (e.g., hand flapping), tend to receive the diagnosis earlier than those who show less overt social and behavioural deficits (Crais et al., 2014; McMorris et al., 2013). Similarly,

another factor impeding the diagnosis of young children with ASD is the ongoing development of language, social and communication skills (Finke et al., 2010). For example, children as young as three years of age may exhibit deficits in their language development. Therefore, to identify the symptoms and make a valid diagnosis of ASD among young children, physicians have to look at other symptoms such as eye contact, stereotypic behaviours, engagement in joint attention activities, or conventional gestures (Finke et al., 2010). In addition, the diagnosis of children with ASD who have comorbid mental health problems is often delayed. The reason for the delay in diagnosis is that children with ASD who have anxiety disorders for example, exhibit exacerbated impairment in their social skills, which may in return complicate the diagnostic and treatment process (McMorris et al., 2013). In other words, children with ASD who have comorbid psychiatric or neurological problems are more likely to receive their ASD diagnosis later in life than those without comorbid problems because the comorbid symptoms often mask core symptoms of ASD.

Researchers have investigated possible explanations for the delay that often occurs in diagnosing most children with ASD. First, they found health care professionals, including pediatricians and family practitioners, often find it difficult to inform parents about the diagnosis of their children due to parents' strong emotional reactions (Rhoades et al., 2007). For instance, many pediatricians have reported their reluctance in 'scaring' parents with 'bad' news (Finke et al., 2010). Second, professionals hope that children's early symptoms will change as they grow older, and are often hesitant to label children due to potential negative consequences. Therefore, they use a 'wait and see' strategy (Finke et al., 2010; Rhoades et al., 2007). As a result of such factors, many children receive a diagnosis later in life.

Lack of Knowledge Regarding the Diagnosis and Treatment of ASD

In addition to concerns regarding the delay in diagnosis, parents of children with ASD have raised their dissatisfaction about medical practitioners' inadequate knowledge and expertise regarding the diagnosis of ASD, as well as providing proper medical care for such children (Carbone, Behl, Azor, & Murphy, 2010). In support of such findings, studies report that, for example, a significant number of American pediatricians lack expertise regarding ASD screening tools, which prevents them from detecting and assessing ASD in children (Brookman-Frazee et al., 2012; Dosreis et al., 2006). Other researchers have also stated that many pediatricians feel they do not receive ASD-specific training during medical school. More specifically, pediatricians reported that developmental pediatricians receive more training with regard to ASD than general pediatricians (Finke et al., 2010). Additionally, Brookman-Frazee and colleagues (2012) studied the community mental health (CMH) approach to diagnosis and treatment of ASD among children. The CMH clinics in the U.S deliver services to children with behavioural, psychiatric problems, as well as co-morbid psychiatric problems, especially among children with ASD. These authors found that many health care providers at the CMH clinics require more knowledge and training in diagnosing and providing care for children with ASD (Brookman-Frazee et al., 2012).

Lack of Competency and/or Interest in Diagnosis and Treatment of ASD

Despite the effort that most health care professionals put into providing care for all patients, many medical practitioners have reported feelings of incompetency when dealing with the ASD population. Due to perceived lack of knowledge and competency, a significant number of medical practitioners often overlook the symptoms of ASD (Crais et al., 2014; Rhoades et al., 2007). Research also shows that many pediatricians expressed their lack of interest toward

learning about ASD, and lack of competency dealing with this population (Finke et al., 2010). To demonstrate, one pediatrician stated that, “I don’t have the interest you have in autism. I read about autism to maintain basic competency” (Finke et al., 2010, p. 258). In addition, pediatricians reported lack of time, little knowledge of the tools, and lack of reimbursement as some of the barriers in further assessment of children with a suspected diagnosis of ASD (Dosreis et al., 2006). As a result of such obstacles, many pediatricians refer children of all ages to clinical specialists, and some agreed with a watch-and-wait strategy for children younger than 2 years old with suspected ASD. Therefore, it is important for medical doctors to endorse more regular screening for ASD, as well as acquire better education and understanding of how to utilize ASD-specific assessment tools (Dosreis et al., 2006).

Screening Tools

Another challenge that medical practitioners encounter when diagnosing ASD is using inappropriate assessment tools (Steiner et al., 2012). Pinto-Martin and colleagues (2008) discussed some of the flaws regarding the screening tools, such as general developmental surveillance, that are used by pediatricians in order to detect ASD in children. As these authors discussed, pediatricians in the United States are recommended to integrate general developmental surveillance into every child’s visit, especially among children as young as 18 months old who are at risk for ASD. Such developmental screening tools are rated to be high in terms of sensitivity, but have very low specificity (Pinto-Martin et al., 2008). That is, utilizing general developmental surveillance can put practitioners at higher risk of misdiagnosis, especially in cases where children with suspected diagnoses of ASD show delays in language and cognitive development. In such cases, these children are often misdiagnosed with intellectual disabilities or specific language disorder (SLD; Pinto-Martin et al., 2008).

Medical practitioners have raised their concerns about how demanding the ASD screening tools are with regards to knowledge, time and administration (Carbone et al., 2010; Nah, Young, Brewer, & Berlinger, 2014). They found that most parents raised their concerns regarding physicians' lack of contribution and expertise to ASD treatment planning; and some parents mentioned physicians' busy schedules, which prevent them from spending extra time to address some of the issues with ASD. Nonetheless, only a few physicians considered themselves as the primary providers of extensive ASD care. Most pediatricians mentioned that they were not willing to prolong their office visits to accommodate children with ASD and their families. In addition, according to the physicians, lack of time, resources, and expertise in behavioural management are the leading obstacles to helping individuals with ASD in health care settings (Carbone et al., 2010).

Overall, researchers have found that most physicians do not receive thorough education and training in medical school regarding the etiology, IQ profiles, prognosis, and treatment of ASD (Crais et al., 2014; Rhoades et al., 2007). These studies shed light on the fact that there are many health care providers including family physicians and pediatricians, in the U.S, Ireland, New Zealand, and Australia, who are either reluctant to make the diagnosis of ASD, or they lack knowledge with regards to symptoms and characteristics of ASD and how they need to approach ASD, especially among children. Nonetheless, there is lack of research on the knowledge of medical practitioners in Canada regarding the diagnosis and treatment of children with ASD.

Purpose

This study aimed to understand the perceived levels of knowledge and competency among Ontario physicians with regards to the diagnosis and treatment of ASD, as well as the experiences (i.e., challenges and facilitators) of physicians in providing care for this population.

The goal of this study was also to further understand the level of training and education that Ontario medical practitioners have received regarding the characteristics of ASD, and their overall experiences when diagnosing and treating individuals with ASD. In order to reach this goal, this study employed a mixed-methods approach to explore the level of knowledge, and competency of medical practitioners regarding the diagnosis and treatment of ASD, as well as their overall experiences when dealing with individuals with ASD.

Rationale

Research shows that for the past two decades, the prevalence rate of ASD has increased significantly (i.e., 1 in 68 children; CDC, 2014). Children with ASD who receive a diagnosis before the age of four years have been shown to benefit more from the treatment programs (e.g., significant improvement in IQ as well as their adaptive functioning; Wright, Poulin, & Dubois, 2012) than those who receive diagnosis after the age of four (Boyd et al., 2010; Finke Drager, & Ash, 2010; Nah et al., 2014). Nonetheless, parents of children with ASD have raised their concerns regarding delays in the diagnosis of their children. Many parents have reported that their children showed signs of ASD as early as six months of age, but they did not receive diagnosis until the age of 3 or 4 years (Rhoades et al., 2007).

Another issue that is commonly discussed in the literature is the difficulties that individuals with ASD encounter in receiving proper care and treatment in healthcare systems (e.g., Glazzard & Ovrall, 2012; Kogan et al., 2008). Nonetheless, the question that remains unanswered in the literature is whether medical practitioners in Ontario, Canada, are prepared to identify and treat individuals with ASD. Although there are studies investigating the knowledge and attitudes of medical practitioners about the diagnosis and treatment of ASD in the U.S, New Zealand, U.K, Australia, and Ireland, there is a paucity of research on these matters in Ontario, Canada.

Therefore, this study examined the perceived levels of knowledge and competency of physicians regarding the diagnosis and treatment of ASD in Ontario. This study also investigated the factors that help or impede physicians' knowledge and competency in providing care for individuals with ASD. It is important to gather information regarding medical practitioners' knowledge of ASD in Ontario in order to better understand their perceived competence in dealing with this population and where they need further professional development. It is also crucial to look at medical practitioners' perceived levels of knowledge and comfort regarding ASD in order to better understand the factors influencing the level of health care service that individuals with ASD receive in Ontario.

Research Questions

1. *What are Ontario physicians' perceived levels of knowledge and competency regarding the diagnosis and treatment of ASD?*
2. *What are the barriers and facilitators that Ontario physicians encounter when diagnosing and treating individuals with ASD?*

Methodology: Mixed Methods

As part of a larger study addressing medical practitioners' knowledge regarding various disabilities, this thesis looked at Ontario physicians' perceived levels of knowledge and competency as well as their overall experiences when diagnosing and treating individuals with ASD. This study employed a two-phase, mixed-method approach. During the first phase, in which quantitative methods were employed, participants filled out an online questionnaire regarding their knowledge, attitudes, and competence about ASD, as well as other developmental disabilities in general. The second phase incorporated individual semi-structured interviews. The purpose of phase II was to qualitatively comprehend the knowledge and comfort level of medical

practitioners regarding the diagnosis and treatment of ASD.

Participants

A total of 27 medical practitioners including family physicians, pediatricians, developmental pediatricians, psychiatrists and an emergency doctor, participated in this study. Participants were recruited from four different regions of Ontario including Northern Ontario, Ottawa region, Niagara Falls, and Toronto (see Table 1). The participants were recruited through snowball sampling whereby participants referred other participants to take part in the study. Participants were also recruited in-person at various conferences such as Child Development Update conference, the Health and Wellbeing Conference, and the College of Physicians and Surgeons of Ontario (CPSO) website. Participants who were recruited at the conferences had the opportunity to fill out the online questionnaire on an iPad, and those who were recruited through snowball sampling, and the CPSO website received an email, containing information about the study and the link to the online survey. At the end of the questionnaire, participants were invited to participate in the semi-structured interview.

Table 1. Participant Demographic Characteristics

Demographic Characteristics	
Characteristics of physicians (n)	27
Average age (SD)	43 (9.65)
Age range	28-62
Specialty (n, %)	
Family physician	12 (44.4%)
Paediatrician	7(25.9%)
Psychiatrist	2(7.4%)
Other:	
Developmental Paediatrician	5
Emergency Physician	1
Gender (n, %)	
Male	4(14.8%)
Female	23(85.2%)
Year(s) of practice (n, %)	
1	
3-5	3(11.1%)
6-10	6(22.2%)
11-15	5(18.5%)
16-20	6(22.2%)
20+	1(3.7%)
Community of practice (n)	6(22.2%)
Rural	3
Urban	21
Sub-urban	4
Northern	4
Southern	1
Other	1

Phase I: The Healthcare Professional Questionnaire: Participants filled out the Healthcare Professional Questionnaire, which was adapted from the Healthcare Student Questionnaire (Isaacs, Minnes, Burbidge, Loh, & Versnel, 2012; Minnes, Isaacs, Burbidge, Loh, & Versnel, 2012). The Healthcare Professional Questionnaire was used in this study because it measures different aspects of medical practitioners' qualifications, knowledge, training, and attitudes regarding the diagnosis and treatment of individuals with different developmental disabilities, including ASD. The inclusion of a range of developmental disabilities (e.g., Down syndrome,

ASD, and fragile X syndrome) in this questionnaire allowed the researcher to gather thorough information and understanding with regards to physicians' general knowledge and attitudes regarding developmental disabilities in comparison to ASD. This measure was comprised of 14 questions, and some responses were rated on a 4-point Likert scale (i.e., ranging from "Very Limited" to "Extensive"), on a nominal scale (i.e., "Yes" or "No"); and for some open-ended questions, the participants were required to state their answers. For example, participants were asked : " How would you rate your current level of knowledge regarding the assessment/diagnosis of individuals with the following: Autism Spectrum disorders, Down syndrome, and Fetal alcohol spectrum disorder", " How would you rate your current level of knowledge regarding the treatment of individuals with the following:". Participants answered these questions on a scale from "very limited" to "extensive" (see Appendix B for full questionnaire). The survey only took the participants between 5-10 minutes to complete.

Phase 2: Semi-Structured Interview: In the second phase, the participants participated in a semi-structured interview, whose purpose was to investigate physicians' understandings regarding the characteristics of individuals with ASD; how they perceive their experiences working with individuals with ASD; and what their knowledge and attitudes are with regards to their encounters with individuals with ASD. The interview consisted of 14 questions, with prompting questions as needed. All questions were open-ended, such as "can you tell me about your previous medical education", "how you been exposed to ASD during your medical practice?", "what disabilities would you feel comfortable taking care of?", and "how have these previous experiences influenced your perceived self-efficacy (ability) to care for individuals with ASD or developmental disabilities?" (see Appendix C for full interview guide). Interviews lasted approximately 30-50 minutes in duration.

Ethical Considerations

The study was approved by the Research Ethics Boards at Laurentian University, Ontario, Canada, which is in accordance with the Canadian Tri-Council Recommendations for Research with Human Participants. All participants received consent forms prior to participation in the study. Throughout the research, all participants had the freedom to withdraw at any point during the study without receiving penalty. Participants' names and personal information were kept anonymous and confidential (i.e., pseudonyms were used to protect participant confidentiality). In addition, the interview transcripts were retained in a locked filing cabinet to ensure the safety of the information.

Conclusion and Overview of Subsequent Chapters

As this thesis was completed in a manuscript style, the analysis was split into two separate manuscripts. The first manuscript, using a mixed-methods design, focused on Ontario physicians' perceived levels of knowledge and competency regarding the diagnosis and treatment of ASD. Both the questionnaire and the semi-structured interview had several questions about the perceived knowledge and competency with regards to the diagnosis of ASD and other developmental and physical disabilities. The second manuscript, using a mixed-methods design, focused on the barriers and facilitators that Ontario physicians experience when providing care for individuals with ASD. Both the questionnaire and the semi-structured interview had several questions regarding physicians' perspectives about their education and training about ASD, their work or volunteer experience working with this population, and whether they have worked as part of an interdisciplinary team or not. Finally, the first manuscript will be submitted to the Journal of Autism Spectrum Disorders, and the second one will be submitted to the Journal of Autism and Developmental Disorders.

**“In Medical School, You Get Far More Training on Medical Stuff than Developmental
Stuff”: Perspectives on ASD from Ontario Physicians**

Golnaz Ghaderi

Laurentian University

Abstract

Background: Despite the high prevalence rate of ASD (i.e., 1 in 68 children), these individuals often do not receive a diagnosis until the age of 4-5 years. Parents of children with ASD have raised concerns regarding the delay in diagnosis of ASD, and physicians' lack of knowledge about diagnosis and treatment of ASD. Many health care providers feel incompetent providing care for this population. Therefore, this study aimed to investigate the knowledge and competency of Ontario physicians regarding the diagnosis and treatment of ASD.

Method: A total of 27 physicians practicing in Ontario were recruited. This study employed a mixed methods approach. During the first phase, participants filled out a questionnaire regarding their knowledge and attitudes about ASD. The second phase incorporated a semi-structured interview, in which participants were asked to answer questions with regard to their knowledge about the diagnosis and treatment of ASD. The participants were also asked about their experiences of working with this population.

Results: The findings of this study revealed that even though participants rated their perceived knowledge regarding the diagnosis and treatment of ASD higher in comparison to other developmental disabilities, they do not feel comfortable in providing such services to this population. Additionally, several participants stated that diagnosing and treating the developmental needs of individuals with ASD is not within their scope of practice. As a result, they often refer individuals with ASD to other healthcare professionals.

Discussion/Conclusions: The results of this study provide a better understanding of medical practitioners' knowledge with regards to the diagnosis and treatment of ASD. Findings also have implications for raising awareness in health care systems regarding the steps that need to be taken in order to enhance the diagnosis and treatment of ASD.

“In Medical School, You Get Far More Training on Medical Stuff than Developmental Stuff”: Perspectives on ASD from Ontario Physicians

Autism Spectrum Disorders (ASD) are neurodevelopmental disorders that are characterized by impairments in two major developmental domains: social-communication and behavioural skills (American Psychological Association, 2013; McPartland, Reichow, & Volkmar, 2012). Researchers examining the prevalence rate of ASD have demonstrated that the number of individuals who are diagnosed with ASD has significantly increased over the past two decades (Autism Speaks, 2015; Baron-Cohen et al., 2009; Kanner, 1943; Rice et al., 2010; Skuse, 2012; Tsai & Ghaziuddin, 2014). The most recent study investigating the prevalence rate of ASD reported that 1 in 68 children are diagnosed with ASD (CDC, 2014). Medical professionals play an important role in managing care, including both diagnosis and treatment for individuals with ASD. Because of the increase in the prevalence of ASD, there is a necessity for health care professionals to be educated about ASD, particularly in regards to ASD diagnosis and disability management.

Despite the high prevalence rate of ASD, as well as the increase in awareness regarding the identification of ASD (Tsai & Ghaziuddin, 2014), children often do not receive a diagnosis until later in life (i.e., five or six years of age; McMorris, Cox, Hudson, Liu, & Bebko, 2013). It is crucial for individuals with ASD to receive an early diagnosis in order to receive appropriate medical, social, and behavioural care (Anagnostou et al., 2014; Harris & Handleman, 2000). In addition to receiving early supports, research shows that early diagnosis leads to better treatment outcomes for children with ASD. Many researchers have found that children with ASD who receive an early diagnosis and appropriate treatment show significant improvement in their language, cognitive, social, and behavioural development (Boyd et al, 2010; Finke, Drager, &

Ash, 2010; Nah, Young, Brewer, & Berlinger, 2014). For instance, Early Intensive Behavioural Intervention (EIBI), which is considered best practice for ASD, is more effective at increasing the cognitive functioning of these children when treatment begins before the age of four years (Harris & Handleman, 2007). Current studies have reported that many children do not receive an early diagnosis due to numerous referrals to various healthcare professionals (e.g., specialists, speech therapist), and in most cases (i.e., 70%), educators and parents identify ASD symptoms before physicians provide a diagnosis (Keenan et al., 2010).

Medical Practitioners' Perspectives

Medical practitioners (e.g., family physicians and paediatricians) are the primary health care professionals who receive parents' concerns regarding their children's development. Research has shown that parents of children with ASD are less satisfied with the healthcare services they receive from physicians in comparison to the families of children with other developmental or physical disabilities such as Down syndrome or cystic fibrosis (Liptak et al., 2006). Liptak and colleagues (2006) found that families of children with developmental disabilities are overall dissatisfied with their primary care medical practitioners' level of knowledge and qualifications in terms of health care management of their children. Therefore, these parents must often become self-reliant with regard to learning and gathering information about the diagnosis and treatment of their children (Liptak et al., 2006). As Self and colleagues (2015) discussed, routine screening of children with a suspected diagnosis of ASD will increase the likelihood of receiving early diagnosis and treatment. For instance, paediatricians in Canada are required by the Canadian Paediatric Society (2015) to use behavioural and developmental screening tools, such as the Ages and Stages Questionnaire (ASQ), the Child Developmental Inventory (CDI), and the Nipissing District Developmental Screen, at every well-child visit.

Although physicians are required to follow specific guidelines as part of their routine developmental screening, there are many children with a suspected diagnosis of ASD who do not receive the diagnosis until five or six years of age as a result of factors that are discussed further in the following sections (McMorris et al., 2013).

Because of the symptomology and diagnostic process of ASD, physicians are required to have knowledge and training with regards to the symptoms, assessment tools, and developmental trajectories of individuals with ASD (Steiner, Goldsmith, Snow, & Chawarska, 2012).

Nevertheless, one of the challenges that physicians experience when attempting to screen for ASD in the paediatric population is the symptom presentation of this disorder (McMorris et al., 2013). Children who exhibit less severe language, social, and behavioural problems are at a disadvantage in terms of receiving an early diagnosis in comparison to those who show severe speech and language, as well as explicit behavioural impairments (McMorris et al., 2013; Self et al., 2015). Additionally, Rhoades and colleagues (2007) found that healthcare professionals, including paediatricians and family physicians, are often reluctant to diagnose children with ASD because they hope that their early symptoms will change as they age. More importantly, many physicians do not feel competent to assess and diagnose ASD because they do not feel they receive sufficient education and training in medical school with regards to the assessment, diagnosis, and treatment of ASD (Carbone, Behl, Azor, & Murphy, 2010; Daniels et al., 2014; Harrington, Rosen, Garnecho, & Patrick, 2006; Rhoades et al., 2007).

Although there is an extensive body of literature based in the U.S, New Zealand, U.K, Australia, and Ireland regarding the knowledge and competency of physicians regarding the diagnosis and treatment of ASD (Havercamp et al., 2016; Woodard, Havercamp, Zwygart, & Perkins, 2012), little is known about these matters in Canada, specifically in Ontario. To that

end, employing a mixed methods design, the present study examined the perceived levels of knowledge and competency of Ontario physicians regarding the diagnosis and treatment of ASD.

Methods

Participants in this study completed a set of quantitative questionnaires and a subset participated in a semi-structured interview. All participants in this study will be referred to by pseudonyms to protect their identities. Ethical approval for this study was obtained from the Laurentian University Ethics Board. All participants provided informed consent at both phases of the study. Participants were assured that they had the freedom to withdraw from the study at any time.

Participants

Participants in this study included physicians who work in the province of Ontario who might encounter children with developmental disabilities, specifically, ASD (e.g., family physicians, paediatricians, and developmental paediatricians). The participants were accessed through snowball sampling, social media (e.g., Facebook), as well as conferences in health- and developmental-related areas.

A total of 27 physicians participated in this study. The average age was 43 years ($SD=9.66$, range= 28-62), and the majority of participants were female (85%). Physicians in this study had been in practice from one to over 20 years, but most participants have been practicing for an average of 4 years at the time of data collection ($SD= 1.89$, range= 1-20+ years). In addition, most participants ($n=21$) reported practicing in urban communities, with the remaining physicians working in rural, Northern, and sub-urban communities. Five participants took part in the interview component of this study. Further information outlining participant demographics can be found in Table 1 below.

Table 1. Participant Demographic Characteristics

Demographic Characteristics	
Characteristics of physicians (n)	27
Average age (SD)	43 (9.65)
Age range	28-62
Specialty (n, %)	
Family physician	12 (44.4%)
Paediatrician	7 (25.9%)
Psychiatrist	2 (7.4%)
Other:	
Developmental Paediatrician	5
Emergency Physician	1
Gender (n, %)	
Male	4 (14.8%)
Female	23 (85.2%)
Year(s) of practice (n, %)	
1	
3-5	3 (11.1%)
6-10	6 (22.2%)
11-15	5 (18.5%)
16-20	6 (22.2%)
20+	1 (3.7%)
Community of practice (n)	6 (22.2%)
Rural	3
Urban	21
Sub-urban	4
Northern	4
Southern	1
Other	1

Materials

Phase I: In this phase, participants completed the Healthcare Professional Questionnaire, which was adapted from the Healthcare Student Questionnaire (Isaacs, Minnes, Burbidge, Loh, & Versnel, 2012; Minnes, Isaacs, Burbidge, Loh, & Versnel, 2012). The questionnaire was set up via REDCap, which is an online survey website hosted at Laurentian University. Participants also had the option of filling out a paper copy of the questionnaire. The initial section of the Healthcare Professional Questionnaire was designed to capture participants' demographic

information such as age, gender, areas of speciality, years of practice, as well as the types of communities, in which they practice (i.e., rural, urban, etc).

The second portion of the questionnaire aimed to investigate participants' perceived levels of knowledge with regards to the diagnosis and treatment of several developmental and physical disabilities such as ASD, Fragile X syndrome and Down syndrome. Other developmental and physical disabilities were included in the questionnaire because this study is part of a larger project investigating knowledge and experiences of developmental disabilities in general; however, for the purpose of this study, participants' perceived levels of knowledge and competency regarding the diagnosis and treatment of ASD, specifically, are investigated. This measure included 19 questions, consisting of 4-point Likert scale as well as open-ended questions. For example, the participants were asked to rate their knowledge with regards to the diagnosis and treatment of ASD on a scale from "*very limited*" to "*extensive*".

The questionnaire was also designed to explore levels of education and training with regards to dealing with individuals with developmental disabilities throughout undergraduate degrees, medical school, as well as professional training (e.g., paediatric residency), on a 3-point Likert scale (i.e., "*not helpful*" to "*very helpful*").

Phase II: At the end of the survey, the participants were invited to participate in a semi-structured interview. A total of five participants participated in the interview, and all the interviews took place over the phone. The interview guide consisted of approximately 14 questions, which were intended to explore the participants' perceived competency when dealing with individuals with ASD. Sample questions included "What do you know about ASD? In what context did you receive this education or training?", and "What disabilities would you feel comfortable taking care of?".

Analysis

To analyze the questionnaire responses, data were coded in Statistical Package for the Social Sciences (SPSS; v22). Basic descriptive analysis (e.g., frequency tables, means, and standard deviations), repeated measures analysis of variance (ANOVA), paired-samples *t*-test, Chi-Square and correlational analyses were computed using SPSS. Descriptive analyses were employed to determine the demographic characteristics of the participants, as well as the frequency of their answers with regards to questions such as “*Have you had experience working in the field of developmental disabilities*” and “*How competent do you feel collaborating with different healthcare providers, educators, and other professionals?*”. Repeated measures ANOVA was also used to investigate the differences among the participants’ perceived levels of knowledge with regards to ASD in comparison to other developmental disabilities. Next, in order to further explore such differences, paired-sample *t*-tests were conducted. Finally, using correlational analyses, the relationships among different variables such as the participants’ years of practice and their competency in meeting the needs of individuals with developmental disabilities were examined.

Semi-structured interviews were analysed using a deductive approach to thematic analysis (Braun & Clarke, 2006). All interviews were digitally recorded and transcribed verbatim. Transcripts were read and reread in order for the researcher to become familiar with the data. Following repeated readings, the researcher gathered detailed notes, and comments were made in the margins of the transcript with regards to the thoughts and statements that were discussed by participants, as well as patterns that occurred in the data. Next, the initial codes were generated based on recurring patterns, and the data were collapsed into labels. Then the codes were combined to create themes that accurately represented the data. The themes were

defined based on the aspects of the data that were being captured as well as their meaningfulness in the present study.

Results

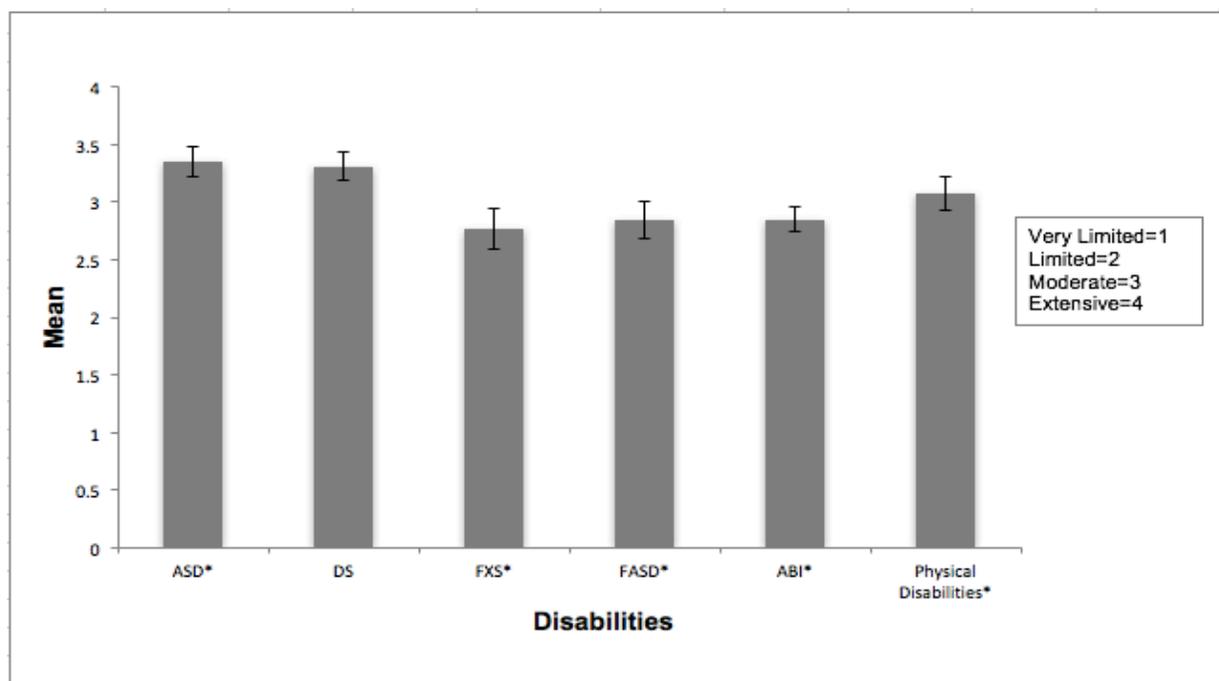
The following section examines the perceived levels of knowledge and competency of participants when providing diagnosis and treatment for individuals with ASD. These subsections are based on the main themes identified in the analysis of the interviews and are supported by the questionnaire responses in an integrated approach. Creswell and Tashakkori (2007) suggest that a “good” empirical mixed methods article have two distinct “strands” of research findings (i.e., qualitative and quantitative) and that the two components are integrated while presenting analysis and interpretation of the results. Therefore, this article presents mixed methods findings; qualitative themes are described and demonstrated in participants’ own words, in addition to quantitative themes, which are supported with participant responses on individual questionnaire items, as described below.

“I know a little about it”: *Perceived Knowledge Regarding the Diagnosis of ASD*

The results of the questionnaire revealed that most participants rated perceived knowledge regarding the diagnosis of ASD higher in comparison to other developmental disabilities. However, interviews showed a lack of perceived knowledge in diagnosing patients with ASD.

Participants were asked to rate their perceived knowledge regarding the diagnosis of ASD and other developmental and physical disabilities. Using repeated measures ANOVA, a significant difference was found in perceived levels of knowledge regarding the diagnosis ($F_{(6, 156)} = 6.139, p < 0.001, \eta^2 = .191$) of various developmental and physical disabilities. The results of the paired samples *t*-tests showed that there were statistically significant differences between

perceived levels of knowledge regarding the diagnosis of ASD in comparison to Fragile X syndrome [FXS; $t_{(26)} = 5.199, p = .001, M_{(ASD)}(3.33) > M_{(FXS)}(2.70)$], fetal alcohol spectrum disorder [FASD; $t_{(26)} = 4.64, p = .001, M_{(ASD)}(3.33) > M_{(FASD)}(2.81)$], acquired brain injury [ABI; $t_{(26)} = 3.84, p = .001, M_{(ASD)}(3.33) > M_{(ABI)}(2.81)$], as well as hearing and/or visual difficulty [$t_{(26)} = 3.358, p < .05, M_{(ASD)}(3.33) > M_{(Hearing\ and/or\ Visual)}(2.70)$]. However, the results of the paired samples t -tests indicated that there were no significant differences between the participants' perceived levels of knowledge regarding the diagnosis of ASD in comparison to Down syndrome ($t_{(25)} = .273, p = .787$). There was also no significant difference between the participants' perceived levels of knowledge regarding the diagnosis of ASD compared to physical disabilities ($t_{(26)} = 1.986, p = .058$). In addition, looking at the mean differences in terms of perceived knowledge regarding the diagnosis of ASD and other disabilities, it was found that participants rated their knowledge regarding the diagnosis of ASD higher in comparison to other developmental and physical disabilities. In other words, they rated their knowledge as moderate to extensive when diagnosing ASD. See Figure 1 below for a summary of the results.



Note: * $p < 0.05$; *Bars represent standard errors

* Significant means differences between participants' perceived level of knowledge regarding the diagnosis of ASD in comparison to other DDs or physical disabilities

Figure 1. Perceived levels of knowledge regarding the diagnosis of developmental and physical disabilities.

During the interviews, most participants elaborated on their extensive knowledge about the symptomology and medical needs of individuals with ASD, but also discussed their lack of knowledge regarding the diagnostic procedures. For example, when Nina, a family physician, was asked about her knowledge regarding the diagnosis of ASD, she stated:

I know a little about it. I don't actually do official diagnosis for ASD. The way we have always said is that as family doctors, what is important is that we should know what normal milestones and normal developmental trajectories are and when a child is deviating from the normal, we need to do earlier recognition and then link those children to people who can make the diagnosis whether they are psychologists, paediatricians, speech therapists.

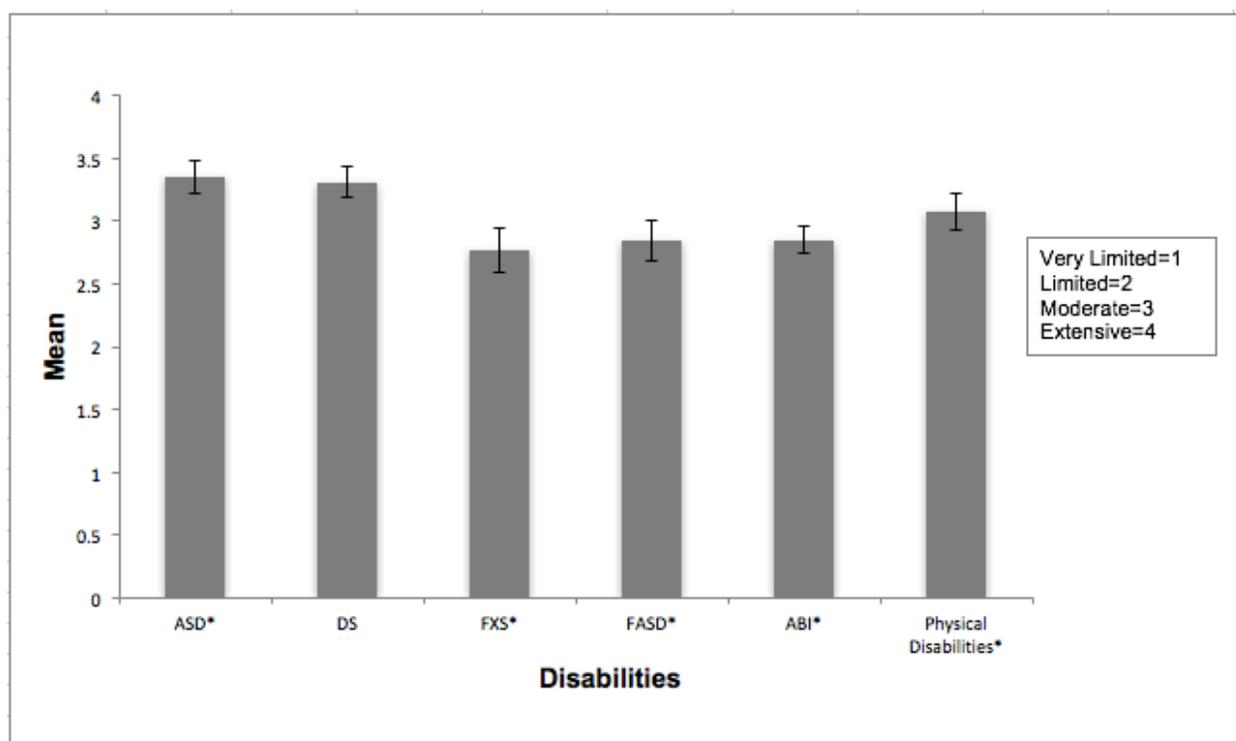
As this quote demonstrates, despite participants' high ratings of their perceived knowledge regarding the diagnosis of ASD on the questionnaires, in the interviews some participants also reported a lack of familiarity with diagnostic procedures and results revealed that they may not feel well-equipped to diagnose ASD.

“I don't actually do it and I have never actually seen it”: *Perceived Knowledge Regarding the Treatment of ASD*

When asked about their perceived knowledge regarding the treatment of ASD, participants discussed a lack of familiarity with intervention for this population. Nevertheless, they rated their perceived knowledge regarding the treatment of ASD higher in comparison to other developmental disabilities.

Repeated measures ANOVA was also used to investigate the mean differences among the participants' perceived levels of knowledge with regards to the treatment of different developmental and physical disabilities. A significant difference was found in participants' perceived levels of knowledge regarding the treatment ($F_{(6, 150)} = 4.449, p < 0.001, \eta^2 = .151$) of various developmental and physical disabilities. The results of the paired samples t -tests demonstrated that there were statistically significant differences between the participants' perceived levels of knowledge regarding the treatment of ASD in comparison to treatment for Fragile X syndrome [FXS; $t_{(25)} = 5.302, p = .001, M_{(ASD)}(3.15) > M_{(FXS)}(2.50)$], fetal alcohol spectrum disorder [FASD; $t_{(25)} = 3.638, p = .001, M_{(ASD)}(3.15) > M_{(FASD)}(2.69)$], acquired brain injury [ABI; $t_{(25)} = 2.368, p = .025, M_{(ASD)}(3.15) > M_{(ABI)}(2.81)$], physical disabilities ($t_{(25)} = 2.13, p = .043, M_{(ASD)}(3.15) > M_{(Physical\ disability)}(2.85)$) as well as hearing and/or visual difficulty [$t_{(25)} = 2.56, p = .017, M_{(ASD)}(3.15) > M_{(Hearing\ and/or\ Visual)}(2.81)$]. However, the results of the paired samples t -tests indicated that there were no significant differences between the participants' perceived

levels of knowledge regarding the treatment of ASD ($t_{(25)} = .273, p = .787$) in comparison to Down syndrome. In other words, similar to the previous findings regarding the *diagnosis* of ASD, these results revealed that the participants also perceive their knowledge regarding the *treatment* of ASD higher in comparison to other developmental and physical disabilities. They reported moderate to extensive level of knowledge regarding the treatment of ASD. See Figure 2 below for a summary of the results.



Note: * $p < 0.05$; Bars represent standard errors

* Significant mean differences were found between participants' perceived level of knowledge regarding the treatment of ASD in comparison to other DDs or physical disabilities.

Figure 2. Perceived levels of knowledge regarding the treatment of DDs and physical disabilities.

Although participants rated their knowledge regarding the treatment of ASD higher compared to other developmental and physical disabilities on the questionnaires, in the interviews participants discussed a lack of experience and general knowledge regarding the

treatment options for this population. For example, Jasmine, a family physician, stated “What I hear from lectures and I know there is IBI, and it is intensive and they are 20 hours and 40 hours, and there is a psychologist. I know about it sort of generally so that I can kind of explain it a little bit, but I don’t actually do it and I have never actually seen it”. Interview results again reveal a discrepancy between participants’ perceived knowledge regarding the treatment of ASD and their perceived expertise in treating this population. The participants may therefore have a general theoretical knowledge regarding ASD treatment, but they discussed that the treatment of ASD is not within their scope of practice.

“I am a family doctor, and I treat people as a family doctor”: *Physicians’ Perceived Competency Regarding the Diagnosis and Treatment of ASD*

When asked about their comfort level regarding the diagnosis and treatment of ASD, participants felt competent providing medical care for individuals with ASD, but they stated that treating the developmental needs of such patients is not within their scope of practice. They also reported uncertainty in terms of who to refer to when they have questions about ASD. The findings also revealed that exposure to patients with ASD helped the participants to feel more comfortable in providing care for this population.

Using descriptive analysis (i.e., a frequency distribution), the competency level of participants in meeting the needs of individuals with ASD was examined. The results showed that most participants (61%) indicated that they feel moderately competent in meeting the needs of individuals with ASD. Contrary to these findings, the interview analysis revealed that participants experience a lack of perceived competency in meeting the developmental needs of individuals with ASD or other developmental disabilities. For instance, when Jasmine, a family

physician, was asked about her comfort level with regards to ASD and developmental disabilities, she stated:

If I knew that they had [an] intellectual disability, I would change my approach to individualize it to meet their needs; so, if they are sick and they are coming with an ear infection, or stomach-ache, skin rash, that's the context in which I would do. I don't do one-on-one therapy with ASD; I am a family doctor, and I treat people as a family doctor.

Therefore, these results demonstrate that even though medical practitioners feel competent meeting the medical needs of individuals with ASD (i.e., treating health-related problems), they do not feel comfortable treating their developmental needs (e.g., poor social skills, delay in language skills, and behavioural problems).

Descriptive analysis (i.e., a frequency distribution) was also used to investigate to whom participants would likely go to when they have questions regarding developmental disabilities and ASD. The results showed that 14.8% ($n=4$) of the participants go to psychologists, 37% ($n=10$) go to special needs consultant, 3.7% ($n=1$) go to speech and language pathologists, 3.7% ($n=1$) go to social workers, and 37% ($n=10$) indicated "others", which included pediatricians, developmental pediatricians, knowledgeable colleagues, inter-professional team, and childcare workers. The disparity in participants' answers illustrates that participants are often unsure of where to refer patients when they have questions about individuals with developmental disabilities or ASD.

Chi-square analysis was conducted to determine whether or not the participants' number of years in practice was related to how they rated their perceived competence in meeting the needs of individuals with ASD. No significant relationship was found between years of practice and perceived level of competence in meeting the needs of these individuals [$\chi^2(15) = 11.505$,

$p=.716$]. Although analysis of the questionnaire responses did not reveal any statistically significant results, in the interviews, participants who have been practicing for a longer period of time (i.e., more than five years) described a greater sense of competency dealing with individuals with ASD, both in terms of the identification and treatment. For example, Nina, a family physician, explained, “every patient we encounter we learn. One of the critical things is to have exposure as medical students and residents”. Monica, a psychiatrist, also acknowledged the impact of having experience working with the ASD population when making a diagnosis or treating these individuals: “I have to say that it was after graduating, and there were experiences that got me ready to say that ‘I wanna do this’ and work with people with developmental disabilities.” These quotes shed light on the importance of exposure to persons with disabilities. Participants who have encountered more individuals with ASD, through their clinical practice, discussed a greater sense of comfort level working with this population compared to those who have less clinical experience in this area.

Discussion

This study aimed to address the paucity of research regarding Ontario physicians’ perceived levels of knowledge and competency regarding the diagnosis and treatment of ASD. Contrary to previous findings (e.g., Crais et al., 2014; Steiner et al., 2012) in the U.S and U.K, the results of this study indicated that Ontario medical practitioners have a higher level of perceived knowledge regarding the diagnosis and treatment of ASD in comparison to other developmental and physical disabilities. Nevertheless, the results of the interviews revealed a discrepancy between participants’ perceived knowledge and their reported competency in regard to such matters. In other words, participants in this study expressed their lack of familiarity and comfort in regards to ASD-specific diagnostic tools and procedure. The interview results also

revealed that participants lack knowledge regarding the types of treatment for individuals with ASD. Perhaps the wealth of literature around ASD and its diagnosis and treatment has significantly contributed to medical practitioners' perceived knowledge and competence providing care for this population.

According to Steiner and colleagues (2012), because the diagnosis of ASD is an intricate process, medical practitioners are required to have knowledge and training about the assessment tools as well as the developmental trajectories of individuals with ASD. Nonetheless, research shows that physicians are often hesitant to provide care for individuals with ASD due to their lack of competence and comfort level in meeting the needs of these individuals (Carbone et al., 2010; Daniels et al., 2014; Rhoades et al., 2007). In line with such findings, the results of this study also revealed that most participants (61%) felt moderately competent in meeting the developmental needs of individuals with ASD. However, they expressed higher comfort levels treating the medical needs of individuals with ASD (i.e., ear infection, skin rash, etc) rather than their developmental needs, as such treatments are not felt to be within their scope of practice. Therefore, due to their lack of knowledge and comfort in dealing with the ASD population, they tended to refer individuals with ASD to other healthcare professionals such as psychologists and speech pathologists. These findings provide further explanations for delay in the diagnosis of ASD (McMorris et al., 2013), as waiting for referral to another medical professional takes time.

Research shows that children often do not receive an early diagnosis of ASD as a result of several referrals to different health care professionals such as psychologists and speech therapists (Keenan et al., 2010). In line with such findings (e.g., Keenan et al., 2010), the results of the interview revealed that participants were more inclined to refer individuals to other health care professionals for the diagnosis and treatment. Furthermore, a significant variation was found

in participants' responses in terms of who they would refer to if they have questions regarding developmental disabilities and ASD. Many participants indicated that they would refer to professionals such as special needs consultants, child care workers, and knowledgeable colleagues. The confluence of the findings from the present study highlights the need for medical practitioners to receive more education and training with regard to ASD throughout medical education, especially in undergraduate medical school. Further to the need for more education and training, participants discussed a lack of direction provided throughout their medical education in terms of who to refer to when they have questions or need help when providing care for individuals with developmental disabilities and ASD.

Despite a lack of research investigating factors that influence medical practitioners' perceived competence in providing care for individuals with ASD, the results of this study showed that participants who have been practicing for a longer period of time (i.e., more than five years) described a higher level of comfort with regards to identification and treatment of individuals with ASD. In other words, it is more likely for physicians with more years of experience to encounter individuals with ASD than those with fewer years in practice, as exposure provides more opportunities to a wider range of patients including ASD. Therefore, those who have had the opportunity to provide care for the ASD population are more inclined to perceive their sense of competency higher in comparison to participants who have been practicing for less number of years and have less clinical experience with these individuals.

Limitations

Although this study addressed the gap in the literature with regards to Ontario medical practitioners' knowledge, experiences, and competency in working with individuals with ASD, a number of limitations are present. This study presents the perceived levels of knowledge and

competency of medical practitioners in limited geographic areas in Ontario, and therefore may not be generalizable to other communities in this province. Additionally, due to the nature of their profession, physicians are considered the busiest professionals and therefore often unable to participate in research (Cunningham et al., 2015; Flanigan & McFarlane, 2008). As a result, a more than 50 participants were contacted to participate in the study, but only 27 participants filled out the questionnaires and five participated in the interviews. Consequently, the perceived knowledge and experiences of current participants with regard to working with individuals with ASD may not be generalizable to other physicians practicing in Ontario.

Finally, in order to facilitate medical practitioners' participation in this study, a significant number of participants were recruited at conferences. These conferences were in the areas of physical and developmental disabilities, where participants were exposed to education and training about developmental disabilities. Therefore, due to the educational setting, the possibility exists that these participants may have had biased perceptions of their own knowledge and competence. Participants recruited at the conferences may have higher levels of interest in acquiring knowledge and training with regards to developmental disabilities, as well as ASD. In addition, due to the educational nature of the conferences, some participants may have experienced a heightened perception of their knowledge about the diagnosis and treatment of ASD, therefore, they may have rated their perceived knowledge higher in comparison to other developmental disabilities.

Conclusion and Implications

This study investigated Ontario physicians' perceived levels of knowledge and competency about the diagnosis and treatment of ASD. Contrary to previous research showing that medical practitioners lack knowledge and competence with regards to the diagnosis and

treatment of ASD, the results of this study revealed that Ontario physicians in this sample report a high level of perceived knowledge and competence in this area. The findings also illustrated a discrepancy between the participants' perceived knowledge and their reported comfort level when diagnosing and treating individuals with ASD. In other words, even though participants perceive their knowledge regarding the diagnosis and treatment of ASD as higher compared to other developmental and physical disabilities, their perceived competence was lower when dealing with this population.

Because of this lack of comfort in diagnosing and treating individuals with ASD, participants reported making several referrals to other healthcare professionals, perhaps because of lower perceived comfort. Medical practitioners in this study believed that the diagnosis and treatment of ASD is the responsibility of practitioners whose scope of practice is more focused and specialized in the field of developmental disabilities (e.g., developmental paediatricians or developmental psychiatrists). They also discussed a lack of clarity and direction in terms of who to refer patients to when they have a question about developmental disabilities or ASD.

In conclusion, the results of this study provide a better understanding of Ontario physicians' perceived levels of knowledge and confidence with regards to the diagnosis and treatment of ASD. The findings of this study have implications for raising awareness in health care systems regarding the steps that need to be taken to enhance the diagnosis and treatment of ASD. Given the importance of a physician's role in providing care for individuals with ASD, it is important for medical schools and policy makers to put forward medical curriculum that better prepares future medical professionals about the diagnosis and treatment of ASD. Finally, the results of this study highlight a positive change regarding the overall perceived knowledge of medical practitioners about the diagnosis and treatment of ASD in comparison to previous

research. Although there are many participants who did not report feeling comfortable diagnosing and treating individuals with ASD, there has been a significant increase in their awareness regarding ASD, as well as the needs of these individuals (i.e., etiology, symptomology, behavioural, social and emotional characteristics).

References

- Anagnostou, E., Zwaigenbaum, L., Szatmari, P., Fombonne, E., Fernandez, B. A., Woodbury-Smith, M., . . . Scherer, S. W. (2014). Autism spectrum disorder: Advances in evidence-based practice. *Canadian Medical Association Journal, 186*(7), 509-519.
- Autism Speaks. (2015). *Autism prevalence*. Retrieved January 14, 2015, from <http://www.autismspeaks.org/what-autism/prevalence>.
- Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S., & Drew. A. (2000). A screening instrument for autism at 18 months of age: A 6 year follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*, 694–702.
- Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *British Journal of Psychiatry, 194*, 500–509.
- Boyd, B. A., Odom, S. L., Humphreys, B. P., & Sam, A. M. (2010). Infants and toddlers with autism spectrum disorder: Early identification and early intervention. *Journal of Early Intervention, 32*(2), 75-98.
- Brookman-Fraze, L., Baker- Ericzén, M., Stadnick, N., & Taylor, R. (2012). Parent perspective on Community mental health services for children with autism spectrum disorders. *Journal of Child and Family Studies, 21*(4), 533-544.
- Carbone, P. S., Behl, D. D., Azor, V., & Murphy, N. A. (2010). The medical home for children with Autism Spectrum Disorders: Parent and pediatrician perspectives. *Journal of Autism and Developmental Disorders, 40*(3), 317-324.
- Crais, E. R., Mccomish, C. S., Humphreys, B. P., Watson, L. R., Baranek, G. T., Reznick, J. S., . . . Earls, M. (2014). Pediatric healthcare professionals' views on autism spectrum disorder

- screening at 12-18 months. *Journal of Autism and Developmental Disorders*, 44(9), 2311-28.
- Creswell, J. & Tashakkori, A. (2007). Developing publishable mixed methods manuscripts. *Journal of Mixed Methods Research*, 1(2), 107-111.
- Cunningham, C. T., Quan, H., Hemmelgarn, B., Noseworthy, T., Beck, C. A., Dixon, E., . . . Jetté, N. (2015). Exploring physicians specialist response rates to web-based surveys. *BMC Medical Research Methodology*, 15(32), 1-8.
- Daniels, A. M., Halladay, A. K., Shih, A., Elder, L. M., & Dawson, G. (2014). Approaches to enhancing the early detection of autism spectrum disorders: A systematic review of the literature. *Journal of the American Academy of Child & Adolescent Psychiatry*, 53(2), 141-152.
- Dosreis, S., Weiner, C. L., Johnson, L., & Newschaffer, C. J. (2006). Autism spectrum disorder screening and management practices among general pediatric providers. *Journal of Developmental and Behavioral Pediatrics*, 27, S88-S94.
- Finke, E. H., Drager, K. D. R., & Ash, S. (2010). Paediatricians' perspectives on identification and diagnosis of Autism Spectrum Disorders. *Journal of Early Childhood Research*, 8(3), 254-268.
- Flanigan, T., & McFarlane, E. S. (2008, May). *Conducting Survey Research Among Physicians and Other Medical Professionals: A Review of Current Literature*. Presented at AAPOR 2008, New Orleans, LA.
- Guthrie, W., Swineford, L. B., Nottke, C., & Wetherby, A. M. (2013). Early diagnosis of autism spectrum disorder: Stability and change in clinical diagnosis and symptom presentation. *Journal of Child Psychology and Psychiatry*, 54(5), 582-590.

- Harrington, J. W., Rosen, L., Garnecho, A., & Patrick, P. A. (2006). Parental perceptions and use of complementary and alternative medicine practices for children with autistic spectrum disorders in private practice. *Journal of Developmental and Behavioral Pediatrics, 27*, S156-S161.
- Harris, S., & Handleman, J. (2000). Age and IQ at intake as predictors of placement for young children with autism: A four- to six-year follow-up. *Journal of Autism and Developmental Disorders, 30*, 137–142.
- Havercamp, S. M., Ratliff-Schaub, K., Macho, P. N., Johnson, C. N., Bush, K. L., & Souders, H. T. (2016). Preparing tomorrow's doctors to care for patients with autism spectrum disorder. *Intellectual and Developmental Disabilities, 54*(3), 202-216.
- Isaacs, B., Minnes, P., Burbidge, J., Loh, A., & Versnel, J. (2012). *Comparison of medical, nursing and allied healthcare students' training in developmental disabilities*. Poster presented at the Ontario Association on Developmental Disabilities Research Special Interest Group Meeting, Kingston, Ontario, April 2012.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*, 217–250.
- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 23*(4), 390-397.
- Liptak, G. S., Orlando, M., Yingling, J. T., Theurer-Kaufman, K. L., Malay, D. P., Tompkins, L. A., & Flynn, J. R. (2006). Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of Pediatric Health Care, 20*(4), 245-252.
- Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of

- diagnosis among children with autism spectrum disorders. *Pediatrics*, 116, 1480-1485.
- Matson, J., Mahan, S., Fodstad, J. C., Hess, J. A., & Neal, D. (2010). Motor skills abilities in toddlers with autistic disorder, pervasive developmental disorder-not otherwise specified, and atypical development. *Research in Autism Spectrum Disorders*, 4(1), 444- 449.
- McMorris, C. A., Cox, E., Hudson, M., Liu, X., & Bebko, J. M. (2013). The diagnostic process of children with autism spectrum disorder: Implications for early identification and intervention. *Journal on Developmental Disabilities*, 19(2), 42-49.
- McPartland, J. C., Reichow, B., & Volkmar, F. R. (2012). Sensitivity and specificity of proposed DSM-5 diagnostic criteria for Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(4), 368-383.
- Minnes, P., Isaacs, B., Burbidge, J., Loh, A., & Versnel, J. (2012). *Predictors of healthcare students perceived competence working with individuals with developmental disabilities*. Poster presented at the Ontario Association on Developmental Disabilities Research Special Interest Group Meeting, Kingston, Ontario, April 2012.
- Nah, Y., Young, R. L., Brewer, N., & Berlinger, G. (2014). Autism detection in early childhood (ADEC): Reliability and validity data for a level 2 screening tool for autistic disorder. *Psychological Assessment*, 26(1), 215-226.
- Rhoades, R. A., Scarpe, A., & Salley, B. (2007). The importance of physician knowledge of autism spectrum disorder: results of a parent survey. *BMC Pediatrics*, 7(37), 1-10.
- Rice, C., Nicholas, J., Baio, J., Pettygrove, S., Lee, L. C., Braun, K. V. N., Doernberg, N. Yeargin-Allsopp, M. (2010). Changes in autism spectrum disorder prevalence in 4 areas of the United States. *Disability and Health Journal*, 3 (3), 186-201.
- Self, T. L., Parham, D. F., & Rajagopalan, J. (2015). Autism spectrum disorder early screening

- practices: A survey of physicians. *Communication Disorders Quarterly*, 36(4), 195-207.
- Skuse, D. H. (2012). DSM-5's conceptualization of Autistic Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(4), 344-346.
- Steiner, A. M., Goldsmith, T. R., Snow, A. V., & Chawarska, K. (2012). Practitioner's guide to assessment of Autism Spectrum Disorders in infants and toddlers. *Journal of Autism and Developmental Disorders*, 42, 1183-1196.
- Tsai, L. Y. & Ghaziuddin, M. (2014). DSM-5 ASD moves forward into the past. *Journal of Autism and Developmental Disorders*, 44(2), 321-330.
- Wallis, K. E. & Smith, S. M. (2008). Developmental screening in pediatric primary care: The role of nurses. *Journal for Specialists in Pediatric Nursing*, 13(2), 130-4.
- Wiggins, L. D., Baio, J., & Rice, C. (2006). Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Journal of Developmental and Behavioral Pediatrics*, 27, S79-S87.
- Wilson, B. N., Neil, K., Kamps, P. H., & Babcock, S. (2013). Awareness and knowledge of developmental co-ordination disorder among physicians, teachers and parents. *Child: Care, Health and Development*, 39(2), 296-300.
- Woodard, L. J., Haverkamp, S. M., Zwygart, K. K., & Perkins, E. A. (2012). An innovative clerkship module focused on patients with disabilities. *Academic Medicine*, 87, 537-542.

**Autism Spectrum Disorder Knowledge, Training and Experience:
Ontario Physicians' Perspectives about What Helps and What Does Not**

Golnaz Ghaderi

Laurentian University

Abstract

Background: Research shows that many physicians feel incompetent in both the diagnosis and treatment of ASD, and experience barriers such as lack of time and expertise in providing ASD care, especially with diagnosis. On the other hand, factors such as collaboration with other healthcare professionals and parental involvement in the diagnostic process have been identified as facilitators in diagnosing children with ASD. This study aimed to identify Ontario physicians' overall experience in providing diagnosis and treatment for individuals with ASD.

Method: A total of 27 physicians practicing in Ontario were recruited to participate in a two-phase, mixed methods study. During the first phase, participants filled out a questionnaire regarding their knowledge, competency and experiences when providing care for ASD individuals. The second phase incorporated a semi-structured interview, where five participants answered questions about their experiences when providing care for individuals with ASD.

Results: The results of this study showed that physicians expressed their needs for further education and training regarding the diagnosis and treatment of ASD. Even though physicians reported lack of comfort and expertise in diagnosing individuals with ASD, they stated that working in an interdisciplinary team aids them with this process. The findings also revealed that previous work or volunteer experiences with individuals with ASD as well as working in a multidisciplinary team and collaborating with parents of children with ASD enhance physicians' experiences when providing care for this population.

Conclusions: Findings have implications for raising awareness in health care and educational systems regarding the steps that need to be taken in order to enhance physicians' experiences when providing care for individuals with ASD and their families.

**Autism Spectrum Disorder Knowledge, Training and Experience:
Ontario Physicians' Perspectives about What Helps and What Does Not**

Despite the high prevalence rate of Autism Spectrum Disorder (ASD), 1 in 68 children (CDC, 2016), many medical practitioners experience barriers (e.g., lack of education and training) in providing care for this population, especially in areas such as diagnosis and treatment (Daniels, Halladay, Shih, Elder, & Dawson, 2014; Fenikilé, Ellerbeck, Filippi, & Daley, 2015). In addition to challenges, researchers have also identified several facilitators (e.g., working in a multidisciplinary team) that enhance the diagnostic and treatment processes for both physicians as well as individuals with ASD (Major, Peacock, Ruben, Thomas, & Weitzman, 2013). Given the importance of physicians' roles in providing care for the ASD population, it is necessary to investigate their experiences, both positive and negative, in order to enhance healthcare management for individuals with ASD.

ASD is a pervasive neurodevelopmental disorder that is characterized by deficits in two developmental areas including social-communication as well as behavioural skills (American Psychological Association, 2013). Although caregivers often identify early symptoms of ASD (i.e., delay in language and social skills development) as early as 18 months of age, research shows that many children with ASD do not receive a diagnosis until the age of four or five (McMorris, Cox, Hudson, Liu, & Bebko, 2013; Warren, Stone, & Humber, 2009). Additionally, the literature shows that parents of children with ASD have raised concerns regarding the delay in the diagnosis as well as the lack of direction and support they receive from healthcare professionals throughout this process (Brookman-Fraze, Baker-Ericzén, Stadnick, & Taylor, 2012; Glazaard & Overall, 2012). Even though the diagnosis of ASD often employs a multidisciplinary approach (i.e., collaboration among healthcare professionals as well as families

of individuals with ASD), many parents feel left out, as their views are not sufficiently included in the process. These parents must often become self-reliant and gain knowledge regarding the diagnosis of their children on their own (Brookman-Frazee et al., 2012; Keenan et al., 2010; Glazzard & Overall, 2012). Besides the lack of direction in terms of the diagnostic process, research also shows that parents have raised concerns in terms of receiving the diagnosis for their children after the fourth visit with a medical professional (Siklos & Kerns, 2007).

Challenges in Providing Care

Because physicians are the first healthcare professionals who interact with children suspected of having ASD, they play an important role in the early identification of ASD symptoms in the pediatric population (Self, Parham, & Rajagopalan, 2015). A growing body of research has revealed some of the barriers that medical practitioners experience when making a diagnosis of ASD. For instance, a study investigating physicians' experiences in terms of knowledge and preparedness in identification and diagnosis of ASD showed that medical practitioners expressed their need for further education and training regarding this matter (Fenikilé et al., 2015). Research shows that many physicians in the U.S. have described the ASD diagnostic tools as time-consuming as well as demanding in terms of knowledge and expertise (Carbone, Behl, Azor, & Murphy, 2010; Fenikilé et al., 2015; Nah, Young, Brewer, & Berlinger, 2014). In line with such findings, Finke and colleagues (2010) investigated general paediatricians' experiences with regard to the diagnosis of ASD, using a qualitative interview methodology. Paediatricians reported a lack of ASD-specific training during medical school. Some paediatricians stated that developmental paediatricians receive more training about ASD, while other participants expressed their lack of comfort with the diagnostic process, and discussed referring individuals with a suspected diagnosis of ASD to more specialized

professionals (i.e., developmental paediatricians, psychologists; Finke et al., 2010). Research also shows that paediatricians in different regions of the U.S report screening children for developmental delays, but only 8% screen for ASD (Dosreis, Weiner, Johnson, & Newschaffer, 2006). In the same study, most paediatricians referred children to other clinical specialists, and 20% used a wait-and-watch strategy for children younger than two years of age (Dosreis et al., 2006). As a result of such challenges, the diagnostic process of ASD is often prolonged (i.e., approximately two years), which in turn leads to a delay in diagnosis and in accessing treatment services.

Facilitators

In addition to the barriers faced by physicians, recent studies have identified factors that enhance medical practitioners' experiences when providing care for individuals with ASD. For instance, Ritzema, Sladeczek, Ghosh, Karagiannakis, and Manay-Quian (2014) recommended collaboration among physicians and psychologists in order to facilitate the delivery of health care services for individuals with developmental disabilities including ASD. Through partnerships with other healthcare professionals, researchers have identified significant benefits for physicians (e.g., consulting with other healthcare professionals), children (e.g., receiving early diagnosis and treatment), and families of individuals with developmental disabilities (e.g., less frustration in terms of obtaining medical support for their children). Such collaborations ultimately promote optimal service delivery for individuals with ASD and other developmental disabilities (Ritzema et al., 2014; Zwaigenbaum et al., 2016).

Researchers in the United States, Australia and United Kingdom have identified working experience with individuals with ASD and other developmental disabilities as imperative in improving medical practitioners' knowledge, skills, comfort levels and attitudes when providing

care for this population (Havercamp et al., 2016; Woodard, Havercamp, Zwygart, & Perkins, 2012). According to Havercamp and colleagues (2016), medical training that provides opportunities for medical students to gain hands-on experience working with individuals with ASD and developmental disabilities has been shown to be effective in enhancing practitioners' knowledge, competencies and attitudes. In other words, medical students who directly worked with patients with developmental disabilities indicated improvements in their knowledge, communication skills, self-efficacy, and attitudes when providing care for this population (Havercamp et al., 2016).

Despite a wealth of research based in the U.S, U.K and Australia investigating the experiences of medical practitioners when providing care for the ASD population, there is little known about these matters in Canada, specifically in Ontario. Overall, research illustrates that there are obstacles (i.e., delay in diagnosis, medical practitioners' lack of knowledge and comfort level in providing care for individuals with ASD) and facilitators (i.e., collaboration with other healthcare professionals) that impact physicians' experiences when dealing with individuals with ASD. Nevertheless, there is a need to explore Ontario medical practitioners' experiences when providing diagnosis and treatment for individuals with ASD. Employing a mixed methods design, the present study examined the overall experiences of Ontario physicians when providing care for the ASD population.

Methods

Participants in this study were accessed through snowball sampling, social media (e.g., Facebook), as well as conferences in health- and developmental-related areas. The Laurentian University Ethics Board approved this study, and informed consent was obtained from all participants at both phases of the study (i.e., quantitative and qualitative). Participants were

assured that they had the freedom to withdraw from the study at any time. All participants will be referred to by pseudonyms to protect their identities.

Participants

Participants in this study included physicians who would encounter individuals with ASD (e.g., family physicians, paediatricians, developmental paediatricians, etc), and who practice in the province of Ontario. Twenty seven participants completed a set of quantitative questionnaires and five participated in a semi-structured interview. The age of participants ranged from 28 to 62, with a mean age of 43, and the majority were female (85%). Most medical practitioners in this study had been practicing for an average of 4 years ($SD= 1.89$, range= 1-20+ years) at the time of data collection. In addition, 21 participants reported practicing in urban communities, and the remaining worked in rural, Northern, and sub-urban communities. Further information outlining participant demographics can be found in Table 1 below.

Materials

Phase I: In this phase, participants completed the Healthcare Professional Questionnaire, which was adapted from the Healthcare Student Questionnaire (Isaacs, Minnes, Burbidge, Loh, & Versnel, 2012; Minnes, Isaacs, Burbidge, Loh, & Versnel, 2012). The questionnaire was set up via REDCap, which is an online survey website hosted at Laurentian University. Participants also had the option of filling out a paper copy of the questionnaire. The initial section of the Healthcare Professional Questionnaire was designed to capture participants' demographic information such as age, gender, areas of speciality, years of practice, as well as the communities that they have practiced in (i.e., rural and urban).

Table 1. Participant Demographic Characteristics

Demographic Characteristics	
Characteristics of physicians (n)	27
Average age (SD)	43 (9.65)
Age range	28-62
Specialty (n, %)	
Family physician	12 (44.4%)
Paediatrician	7 (25.9%)
Psychiatrist	2 (7.4%)
Other:	
Developmental Paediatrician	5
Emergency Physician	1
Gender (n, %)	
Male	4 (14.8%)
Female	23 (85.2%)
Year(s) of practice (n, %)	
1	
3-5	3 (11.1%)
6-10	6 (22.2%)
11-15	5 (18.5%)
16-20	6 (22.2%)
20+	1 (3.7%)
Community of practice (n)	6 (22.2%)
Rural	3
Urban	21
Sub-urban	4
Northern	4
Southern	1
Other	1

In addition to the demographic information, the questionnaire included questions investigating participants' perceived levels of knowledge with regards to the diagnosis and treatment of several developmental and physical disabilities such as ASD, Fragile X syndrome and acquired brain injury on a 4-point Likert scale from "very limited" to "extremely". The questionnaire was also designed to explore levels of education and training that participants have received in regards to providing care (i.e., diagnosis and treatment) to individuals with developmental disabilities, throughout their undergraduate degrees, medical school, as well as

professional training (e.g., paediatric residency). For example, participants were asked to rate their opinion about the usefulness of general undergraduate medical training in increasing their knowledge about developmental disabilities on a 3-point Likert scale (i.e., “*not helpful*” to “*very helpful*”). In addition, they were asked to report their work or volunteer experiences with individuals with ASD and other developmental disabilities on a 4-point Likert scale (i.e., “*very limited*” to “*extensive*”).

Phase II: At the end of the survey, the participants were invited to partake in a semi-structured interview. All the interviews took place over the phone. The semi-structured interview consisted of approximately 14 questions, which were intended to explore the participants’ perceived levels of competency as well as their experiences when dealing with individuals with ASD. Sample interview questions included “What previous experience(s) do you have with people with intellectual or developmental disabilities? ASD?”, “How have these previous experiences influenced your perceived self-efficacy (ability) to care for individuals with intellectual or developmental disabilities? ASD?”, and “What disabilities would you feel comfortable taking care of?”.

Analysis

To analyze the questionnaire responses, data were coded in SPSS (v22). Basic descriptive analysis (e.g., frequency, mean, and standard deviation), Chi-Square, Independent-samples *t*-test, and correlational analyses were computed using SPSS. Descriptive analyses were employed to outline the demographic characteristics of the participants, as well as the frequency of their answers with regards to questions such as “*How competent do you feel collaborating with different healthcare providers, educators, and other professionals?*”. Using Chi-square, the relationships among different variables such as the participants’ years of practice and their

competency in meeting the needs of individuals with developmental disabilities were examined. Next, Independent-samples *t*-tests were used to investigate the differences between participants' perceived knowledge regarding the diagnosis and treatment of ASD and whether they had enough access to resources regarding developmental disabilities including ASD. Finally, correlational analyses were employed in order to investigate whether there was a relationship between participants' involvement in professional and postgraduate training and their perceived knowledge regarding the diagnosis of ASD.

In order to capture participants' experiences, this paper employed an integrated approach where the interview results that coincided with findings from the quantitative analyses were analyzed and presented here. Participants' responses to open-ended interview questions, such as "*Have you been exposed to ASD during your medical practice*", were examined and analyzed using a deductive thematic analysis (Braun & Clarke, 2006). All interviews were digitally recorded and transcribed verbatim. Transcripts were read and reread in order for the researchers to become familiar with the data. Following repeated readings, the researchers gathered detailed notes, and comments were made in the margins of the transcript with regards to the thoughts and statements that were discussed by participants, as well as patterns that occurred in the data. Next, the initial codes were generated based on recurring patterns, and the data were collapsed into labels. Then the codes were combined to create themes that accurately represented the data. The themes were defined based on the aspects of the data that were being captured as well as their meaningfulness in the present study. For the purpose of this paper, the data that were gathered during the interview were integrated with the results of the quantitative analyses.

Results

The following section examines what aspects of education and training do not improve participants' competency in diagnosing and treating ASD, and what aspects of their training and experiences are perceived as helpful. These sub-sections are based on the main themes identified in the analysis of the interviews and are supported by the questionnaire responses in an integrated approach.

“There was no particular focus on ASD”: *Barriers in Providing Care for ASD Individuals*

Participants stated that factors such as limited focus on ASD in medical school and professional trainings or workshops, as well as difficulties accessing resources or information about providing services to individuals with ASD, hinder their ability to provide care to individuals with ASD. The results of the questionnaire also revealed that most participants identified insufficient education and training throughout undergraduate medical education and unhelpfulness of resources available to them as barriers impeding their preparedness to meet the needs of patients with ASD.

Participants were asked to rate the usefulness of their general undergraduate training and professional or postgraduate training in increasing their knowledge about developmental disabilities including ASD on a 3-point Likert scale. Thirty-three percent of the participants rated their undergraduate training as “*not helpful*”, 37% rated it as “*moderately helpful*”, and 3.7% rated it as “*very helpful*” (see figure 1). In addition, 53% of the participants rated their professional or postgraduate training as “*moderately helpful*”, and 42% rated it as “*very helpful*” (see figure 2).

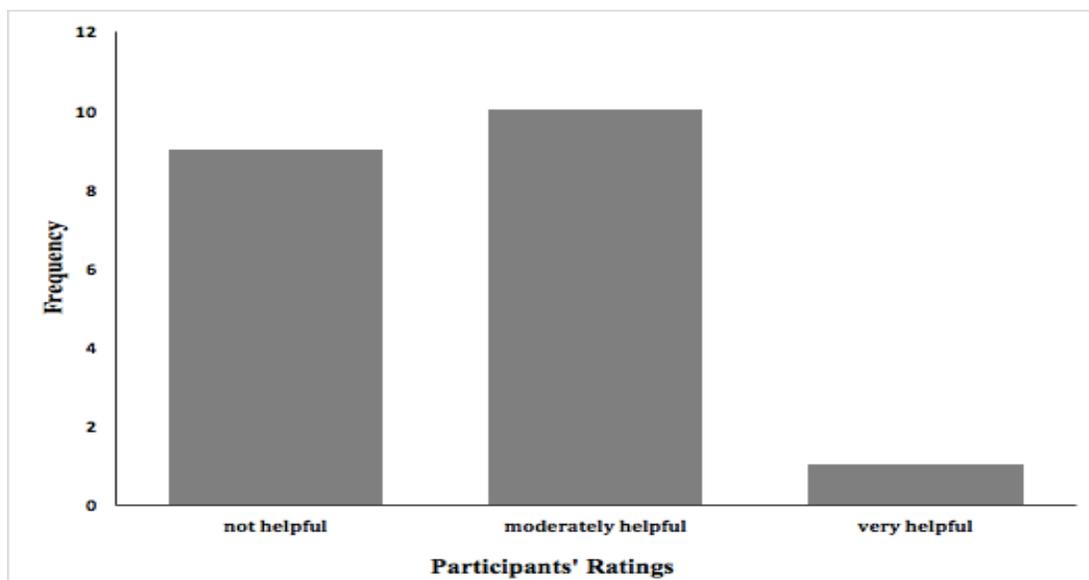


Figure 1. Participants' Ratings on Usefulness of Undergraduate Training in Increasing their Knowledge Regarding Developmental Disabilities*

*20 of 27 participants answered this question

These results show that most participants did not feel that they received sufficient knowledge and training with regards to the diagnosis and treatment of ASD during their undergraduate medical education. Additionally, less than half the participants found their professional training on ASD as very helpful in providing them with knowledge and training regarding such matters. Similar to these findings, all participants who participated in the interview raised concerns with regard to the lack of education on ASD and developmental disabilities during their undergraduate and post-graduate medical education. For example, when asked about his medical education and training on ASD, Jason, a family physician, responded that “There was no particular focus on ASD.” Monica, a psychiatrist, also stated “I imagine there would have been a lecture, but I can’t remember; there would have been a ... paediatric lecture”. Other participants with paediatric or developmental psychiatry specialties claimed they obtained most of their education about the diagnosis and treatment of ASD during their professional

medical training, as opposed to their undergraduate training. For instance, Monica, a developmental psychiatrist, stated “after psychiatry, I did an extended fellowship in child and adolescent psychiatry. It’s been 20 years, I have been working in developmental disabilities with both children and adults”. Based on these results, it appears that physicians who pursue professional or postgraduate medical education are more likely to gain knowledge and training regarding ASD in comparison to other physicians. Overall, all participants expressed the need for more extensive education about ASD throughout their medical education.

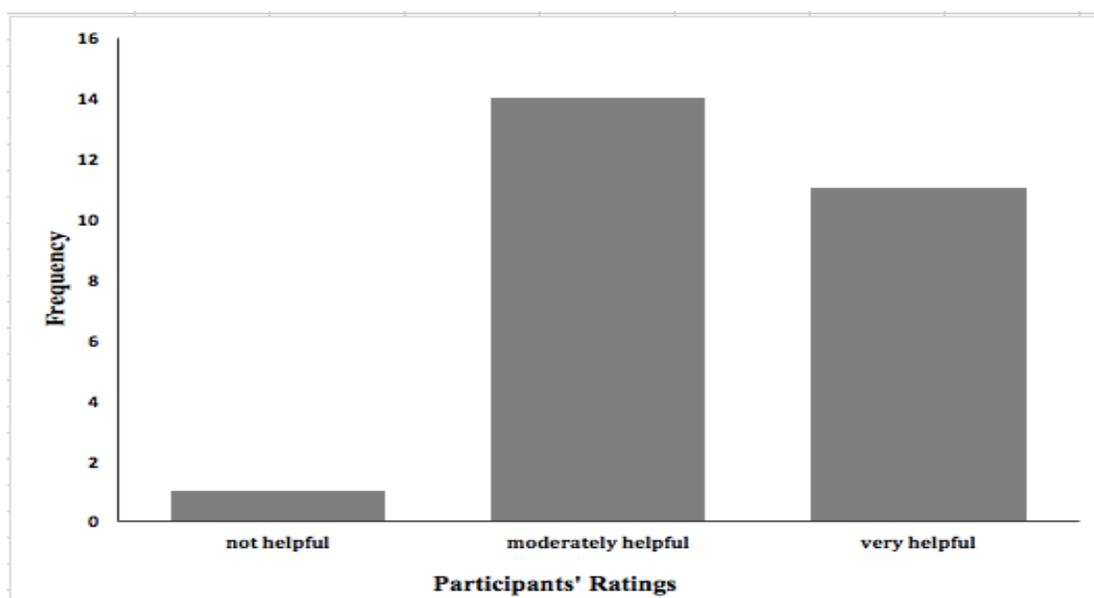


Figure 2. Participants’ Ratings on Usefulness of Professional/Postgraduate Training in Increasing their Knowledge Regarding Developmental Disabilities

Although participants reported high rates of participation in professional trainings and workshops on ASD (85.2%), they did not report these trainings as being helpful in improving their knowledge about the diagnosis or treatment of autism. This lack of relationship between training and increased knowledge is demonstrated by Sharon, a developmental paediatrician, who when asked about the helpfulness of training sessions, stated “with conferences, yes and no, because sometimes they are very generalized; so, they discuss general things and not very

specific like, OK, we have a kid with ASD, and this is what we should do”. Therefore, it is likely that the educational content of the professional opportunities and workshops may not be judged as helpful in enhancing physicians’ knowledge about ASD.

Participants were also asked whether they had enough access to information or resources to meet the needs of individuals with developmental disabilities on a nominal scale (i.e., “yes” or “no”). The results revealed that 70 percent of the participants ($n=19$) felt they had enough access to such resources, and 30 percent ($n=8$) stated otherwise. Even though most participants have had enough access to resources to meet the needs of individuals with ASD, no significant difference was found in terms of perceived knowledge regarding the diagnosis of ASD ($t_{25}=1.035$, $p=.310$). In other words, the results of the Independent samples t -test showed that the perceived knowledge of participants who had enough access to resources did not significantly differ from those who did not have such access [$M_{\text{access}}(3.42) > M_{\text{no access}}(3.13)$]. These results are perhaps better explained by participants’ motivations or interests in learning about developmental disabilities or ASD, or the content of such resources in enhancing their knowledge regarding such disabilities.

“I definitely see a lot of ASD in my practice”: *Facilitators in Providing Care for Individuals with ASD*

When asked about factors that enhance their experience and perceived competency when providing care for individuals with ASD, participants reported that clinical exposure and working with this population as well as working as part of an interdisciplinary team facilitated their experiences and improved their perceived comfort level. When looking at the questionnaire results, years of experience, work or volunteer experiences with individuals with ASD, and

collaboration with other healthcare professionals enhanced their overall experiences when dealing with the ASD population.

Chi square analyses were conducted to determine whether or not the participants' years in practice were associated with how they rated their perceived levels of knowledge regarding the diagnosis and treatment of ASD. No significant relationships were found between years of practice and perceived levels of knowledge with regards to the diagnosis ($\chi^2(10)=9.927, p=.447$) and treatment ($\chi^2(10)=5.510, p=.855$) of ASD. However, results of the chi square analyses showed that there was a positive significant relationship between participants' perceived knowledge regarding the diagnosis ($\chi^2(6)=20.08, p<.05$) and treatment ($\chi^2(6)=19.185, p<.05$) of ASD and their work or volunteer experiences with these individuals. Additionally, a significant relationship was found between participants' work or volunteer experiences with individuals with ASD and their perceived competence in meeting the needs of these individuals ($\chi^2(9)=28.375, p<.001$). These results demonstrate the importance of clinical experience as well as experiential opportunities working with individuals with ASD. That is, those who had either work or volunteer experiences with this population perceived themselves as more knowledgeable in the diagnosis and treatment of ASD.

In line with these quantitative results, the interview analysis showed that participants who have worked with individuals with ASD reported higher knowledge regarding the diagnosis and treatment of autism. For example, Sharon, a developmental paediatrician, stated "I definitely see a lot of ASD in my practice. Prior to residency, not much exposure in medical school, but I definitely see a lot more in my private practice, a lot more diagnosis of ASD". Additionally, Nina, a family physician, also stated "I think the more experience people have, especially in the training, and understanding of what's going, the easier it becomes, because we learn from our

patients; every patient we encounter, we learn. So, one of the critical things to have is exposure as medical students and residents”. These findings reveal that despite the desire for more education and training throughout their medical education, work experiences with this population enhanced their perceived knowledge about the diagnosis and treatment of ASD. Questionnaire and interview findings thus highlight the importance of hands on experience with the ASD population to enhance physicians’ perceived knowledge about the diagnosis and treatment of ASD.

The literature has demonstrated that collaboration among healthcare professionals is one of the leading factors in enhancing the healthcare system for both physicians and individuals with ASD (Swiezy, Stuart, & Korzekwa, 2008). Descriptive analysis was performed in order to investigate the frequency of participants who have had experience working as part of an inter-professional team. The results showed that 89% of the participants ($n=24$) have worked as part of a professional interdisciplinary team. Chi-square analysis revealed no significant association between the perceived knowledge regarding the diagnosis of ASD [$X^2 (9, N = 27) = 2.70, p = .259$] and having the experience working as part of a professional team. In other words, previous experience working as part of an inter-professional team was not significantly related to participants’ ratings of their perceived knowledge regarding the diagnosis of ASD. Additionally, chi-square analysis was performed in order to investigate the relationship between participants’ perceived levels of competence in collaborating with other healthcare professionals and their perceived levels of competency in meeting the needs of individuals with developmental disabilities. Contrary to the previous findings (i.e., no significant relationship between having experience working as part a professional team and perceived knowledge regarding the diagnosis of ASD), the results showed that there was a significant relationship between participants’ levels

of competence collaborating with other healthcare providers and their perceived levels of competence meeting the needs of individuals with developmental disabilities including ASD, [$\chi^2(2, N = 25) = 31.01, p = .001$].

In line with questionnaire results pointing to the role of collaboration in improving perceived competence, analysis of the interview transcripts also revealed that participants working in an interdisciplinary team reported higher levels of comfort and competence in providing care for individuals with ASD. For example, when Monica, a psychiatrist, was asked about her experience working with individuals with developmental disabilities and ASD, she stated

I love it. It's extremely appealing and rewarding, and part of it is when you have the ability to work as an interdisciplinary team, and I think if you are trying to do it on your own as a healthcare provider, it is rather daunting and very very time consuming. I think, part of the joy is when you feel confident, they know you are gonna to do your best to understand them and help them to have a better quality of life, they feel better and is best done in team settings.

These results illustrate that even though having experience working as part of an interdisciplinary team is not associated with participants' perceived knowledge regarding the diagnosis of ASD, such experiences are positively associated with their perceived competence in meeting the needs of these individuals. Therefore, working as part an interdisciplinary team may not have increased participants' perceived knowledge regarding diagnosis of ASD, but it was identified as enhancing their experiences and perceived competence when providing care (i.e., making a diagnosis) for individuals with ASD.

Discussion

Despite the high prevalence rate of ASD (i.e., 1 in 68 children; CDC, 2014), many children do not receive a diagnosis until later in life (i.e., four or five years of age; Keenan et al., 2010). Research also shows that families of individuals with ASD have expressed concerns with regard to the diagnostic process (Watson, Coons, Hayes, 2013; Wiggins et al., 2006). As a result of such concerns, the present study was conducted to explore the barriers and facilitators physicians experience when providing care for individuals with ASD. Previous studies have shown that lack of education and training regarding ASD throughout medical education is a significant barrier medical practitioners experience when dealing with this population (Carbone et al., 2010; Fenikilé et al., 2015; Nah et al., 2014). In support of these findings, the results of this study also revealed that most participants rated the usefulness of undergraduate medical education as moderate in increasing their knowledge regarding developmental disabilities and ASD. Furthermore, a handful of participants expressed their needs for further education and training regarding ASD in medical school. Most participants stated that they may have received only one lecture regarding ASD during their undergraduate medical education. Due to a perceived lack of ASD training throughout their medical education, participants felt the need to educate themselves by attending conferences, workshops, and training on their own time, which can be time-consuming. While some participants reported such workshops and trainings helpful in providing them with knowledge and skills about dealing with individuals with ASD, other participants found such trainings to be too general and therefore unhelpful.

On the other hand, approximately half of the participants (i.e., 53%) rated the usefulness of postgraduate and professional training as very helpful in increasing their knowledge regarding such disabilities. Those who obtained their degrees in more specialized programs regarding

children and adolescents (e.g., paediatricians and developmental paediatricians) received more training and education with regard to individuals with developmental disabilities and ASD, but, participants in other areas of medical practice, such as family physicians, felt they did not receive sufficient training with regard to this population, unless they participated in specialized workshops on developmental disabilities due to their personal interests. Overall, the results of this study are in line with previous findings with regards to medical practitioners' concerns about challenges they experience in terms of the time they must spend in order to educate themselves on the diagnosis and treatment of ASD (Carbone et al., 2010; Nah et al., 2014).

According to Havercamp and colleagues (2016), in order to improve the quality of care for individuals with ASD, there is a need for healthcare providers to receive ASD-specific training. Despite the high rates of medical practitioners' participation (i.e., 85%) in professional training sessions on ASD (e.g., workshops and conferences), the results of the current study showed no significant correlation between the participants' perceived knowledge regarding the diagnosis and treatment of ASD and their professional training. This lack of relationship was explained through the interview analysis, which revealed that participants often do not find the educational content helpful in increasing their knowledge regarding ASD in approaching the needs of this population. Specifically, professional trainings and workshops may focus on the general topic of developmental disabilities rather than being specific to ASD and its diagnostic and treatment approach. In line with previous research (e.g., Havercamp et al., 2016; Major et al., 2013), the findings of this study shed light on physicians' needs for more specific training, through which they learn about ASD, its symptomology, identification, diagnosis, and treatment, rather than education or workshops focused on the general topic of developmental disabilities. Therefore, it is imperative to implement ASD-specific training in medical curricula and

residency programs in order to provide physicians with clinical exposure to the ASD population.

Previous literature has shown that one of the factors impeding the diagnostic process of ASD is medical practitioners' lack of interest in utilizing ASD-specific diagnostic tools due to the demands these tools make in terms of knowledge, time, and reimbursement (Carbone et al., 2010; Fenikilé et al., 2015; Nah et al., 2014). Similar to these findings, the results of this study also revealed that even though most participants (i.e., 70%) stated they have had enough access to information and resources to meet the needs of individuals with developmental disabilities, their perceived knowledge was not significantly different compared to those who did not have access to such resources. Perhaps these findings are better explained by participants' levels of interest and comfort in using such resources to enhance their knowledge and skills in providing care for individuals with ASD.

The results of this study also identified a few facilitators reported by participants related to their training and experiences when providing care for this population. As discussed by Haverkamp and colleagues (2016), clinical experience working with individuals with ASD improved medical students' attitudes, knowledge and skills in providing care for this population. Similar to such findings, participants in this study also identified in-vivo and clinical experience working with individuals with ASD as tremendously helpful in enhancing their knowledge and comfort level in meeting the needs of this population. Additionally, the interview analysis revealed that, regardless of participants' areas of specialty, those who have had greater exposure to individuals with ASD discussed a higher level of comfort dealing with this population. Research shows, receiving education and training with regards to ASD has proven to be imperative in physicians' preparedness and comfort level providing care (i.e., diagnosis and treatment) for individuals with ASD (Finke et al., 2010). Therefore, implementing clinical

placements and residency programs that are focused on ASD will provide physicians with opportunities to enhance their competency in meeting the needs of patients with ASD.

Finally, collaboration among healthcare professionals (e.g., physicians, psychologists, etc.) has demonstrated to enhance the ASD diagnostic process as well as medical practitioners' experiences when providing care for individuals with autism and developmental disabilities (Ritzema et al., 2014). In line with these findings, the results of this study revealed a significant association between perceived competence in meeting the needs of individuals with ASD and experience working as part of an inter-professional team. In other words, participants reported higher comfort levels and perceived competence providing care for individuals with ASD when they work with other healthcare professionals. Therefore, promoting and improving communication and collaboration between medical practitioners and other health care professionals such as psychologists as well as speech and language pathologists is a critical step towards enhancing the primary care for individuals with ASD and their families.

Limitations

Even though this study addressed the gap in the literature with regards to Ontario medical practitioners' experiences when providing care for individuals with ASD, a number of limitations are present. This study investigated the experiences of medical practitioners in limited geographic areas in Ontario, and therefore results may not be generalized to other communities in this province. Furthermore, given the nature of the medical profession, physicians are often considered the busiest professionals (Cunningham et al., 2015; Flanigan & McFarlane, 2008). Thus, a vast number of invitations (i.e., via emails, phone calls, etc) were sent out to participants to participate in the study, but only 27 participants filled out the questionnaires and five participated in the interviews. Consequently, the current participants may have different

experiences working with individuals with ASD than practitioners practicing in other regions of Ontario due to their interest in terms of obtaining education and training in this area.

Finally, in order to facilitate medical practitioners' participation in this study, a significant number of participants were recruited at conferences. These conferences were in the areas of physical and developmental disabilities, where participants were exposed to education and training about developmental disabilities. Therefore, due to the educational setting, the possibility exists that these participants may have had biased perceptions of their own knowledge and competency. Participants recruited at the conferences may have higher levels of interest in acquiring knowledge and training with regards to developmental disabilities, as well as ASD. In addition, due to the educational nature of the conferences, some participants may have experienced a heightened perception of their knowledge about the diagnosis and treatment of ASD, and therefore, may have rated their perceived knowledge higher in comparison to other developmental disabilities.

Conclusion and Implications

This study investigated the barriers and facilitators that Ontario physicians experience when providing care to individuals with ASD. The findings illustrate a number of challenges that physicians often encounter when dealing with individuals with ASD. Most participants expressed their needs for further ASD-specific education and training throughout their undergraduate medical education. Despite this desire for more educational opportunities, results did not show a significant relationship between the participants' professional participation in workshops and their perceived competency in diagnosing and treating ASD. In other words, perhaps, professional trainings and workshops that are focused on the general topic of developmental disabilities are not effective in educating and training medical practitioners in meeting the needs

of individuals with ASD. Therefore, physicians would benefit from professional development opportunities that are focused specifically on ASD and would provide them with knowledge and hands-on experience with regard to providing care for the ASD population.

The current study supports the findings of existing research that regardless of participants' years of practice, those who have had clinical and experiential experience working with individuals with ASD reported higher levels of comfort and competence in meeting the needs of this population. Furthermore, the findings of this study revealed that collaboration among physicians and other healthcare professionals have been found to play a significant role in their knowledge and comfort level when dealing with this population.

In conclusion, the findings of this study point to the importance of increasing discussion of ASD in medical school curricula and professional development. In addition to providing more ASD education and training throughout medical education, it is imperative for medical students and practitioners to gain experiential and in-person experiences working with individuals with ASD throughout their medical education and residency programs. Finally, even though lack of education and training are identified as some of the significant barriers medical practitioners experience when dealing with this population, other facilitators such as collaboration with other healthcare professionals can be promoted in order to enhance the experiences and perceived competence of physicians, ultimately improving the care for patients with ASD and their families.

References

- Arunyanart, W., Fenick, A., Ukritchon, S., Imjaijitt, W., Northrup, V., & Weitzman, C. (2012). Developmental and autism screening: A survey across six states. *Infants & Young Children, 25*(3), 175-187.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. doi:10.1191/1478088706qp063oa
- Brookman-Frazee, L., Baker- Ericzén, M., Stadnick, N., & Taylor, R. (2012). Parent perspective on Community Mental Health services for Children with Autism Spectrum Disorders. *Journal of Child and Family Studies, 21*(4), 533-544.
- Bruder, M. B., Kerins, G., Mazzarella, C., Sims, J., & Stein, N. (2012). Brief report: The medical care of adults with autism spectrum disorders: Identifying the needs. *Journal of Autism and Developmental Disorders, 42*(11), 2498-2504.
- Carbone, P. S., Behl, D. D., Azor, V., & Murphy, N. A. (2010). The medical home for children with Autism Spectrum Disorders: Parent and pediatricians perspectives. *Journal of Autism and Developmental Disorders, 40*(3), 317-324.
- Cox, D. J. (2012). From interdisciplinary to integrated care of the child with autism: The essential role for a code of ethics. *Journal of Autism and Developmental Disorders, 42*(12), 2729-2738.
- Centers for Disease Control and Prevention. (2016). *Autism Spectrum Disorder (ASD)* [Data and Statistics]. Retrieved from <http://www.cdc.gov/ncbddd/autism/data.html>.
- Cunningham, C. T., Quan, H., Hemmelgarn, B., Noseworthy, T., Beck, C. A., Dixon, E., . . . Jetté, N. (2015). Exploring physicians specialist response rates to web-based surveys. *BMC Medical Research Methodology, 15*(32), 1-8.

- Daniels, A. M., Halladay, A. K., Shih, A., Elder, L. M., & Dawson, G. (2014). Approaches to enhancing the early detection of autism spectrum disorders: A systematic review of the literature. *Journal of the American Academy of Child & Adolescent Psychiatry, 53*(2), 141-152.
- Davidovitch, M., Levit-Binnun, N., Golan, D., & Manning-Courtney, P. (2015). Late diagnosis of autism spectrum disorder after initial negative assessment by a multidisciplinary team. *Journal of Developmental and Behavioral Pediatrics, 36*(4), 227-234.
- Dietz, C., Swinkels, S., van Daalen, E., van Engeland, H., & Buitelaar, J. K. (2006). Screening for autistic spectrum disorder in children aged 14-15 months. II: Population screening with the early screening of autistic traits questionnaire (ESAT). design and general findings. *Journal of Autism and Developmental Disorders, 36*(6), 713-722.
- Dosreis, S., Weiner, C. L., Johnson, L., & Newschaffer, C. J. (2006). Autism spectrum disorder screening and management practices among general pediatric providers. *Journal of Developmental and Behavioral Pediatrics, 27*, S88-S94.
- Falkmer, T., Anderson, K., Falkmer, M., & Horlin, C. (2013). Diagnostic procedures in autism spectrum disorders: A systematic literature review. *European Child & Adolescent Psychiatry, 22*(6), 329-40.
- Finke, E. H., Drager, K. D. R., & Ash, S. (2010). Pediatricians' perspectives on identification and diagnosis of Autism Spectrum Disorders. *Journal of Early Childhood Research, 8*(3), 254-268.
- Fenikilé, T. S., Ellerbeck, K., Filippi, M. K., & Daley, C. M. (2015). Barriers to autism screening in family medicine practice: A qualitative study. *Primary Health Care Research and Development, 16*(4), 356-366.

- Flanigan, T., & McFarlane, E. S. (2008, May). *Conducting Survey Research Among Physicians and Other Medical Professionals: A Review of Current Literature*. Presented at AAPOR 2008, New Orleans, LA.
- Glazzard, J. & Overall, K. (2012). Living with autistic spectrum disorder: Parental experiences of raising a child with autistic spectrum disorder (ASD). *Support for Learning, 27*(1), 37-45.
- Grodberg, D., Siper, P., Jamison, J., Buxbaum, J. D., & Kolevzon, A. (2016). A simplified diagnostic observational assessment of autism spectrum disorder in early childhood. *Autism Research, 9*(4), 443-449.
- Harrington, J. W., Rosen, L., Garnecho, A., & Patrick, P. A. (2006). Parental perceptions and use of complementary and alternative medicine practices for children with autistic spectrum disorders in private practice. *Journal of Developmental and Behavioral Pediatrics, 27*, S156-S161.
- Havercamp, S. M., Ratliff-Schaub, K., Macho, P. N., Johnson, C. N., Bush, K. L., & Souders, H. T. (2016). Preparing tomorrow's doctors to care for patients with autism spectrum disorder. *Intellectual and Developmental Disabilities, 54*(3), 202-216,230,232.
- Heidgerken, A. D., Geffken, G., Modi, A., & Frakey, L. (2005). A survey of autism knowledge in a health care setting. *Journal of Autism and Developmental Disorders, 35*(3), 323-30.
- Isaacs, B., Minnes, P., Burbidge, J., Loh, A., & Versnel, J. (2012). *Comparison of medical, nursing and allied healthcare students' training in developmental disabilities*. Poster presented at the Ontario Association on Developmental Disabilities Research Special Interest Group Meeting, Kingston, Ontario, April 2012.

- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 23*(4), 390-397.
- Liptak, G. S., Orlando, M., Yingling, J. T., Theurer-Kaufman, K., Malay, D. P., Tompkins, L. A., & Flynn, J. R. (2006). Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of Pediatric Health Care, 20*(4), 245-252.
- Major, N. E., Peacock, G., Ruben, W., Thomas, J., & Weitzman, C. C. (2013). Autism training in pediatric residency: Evaluation of a case-based curriculum. *Journal of Autism and Developmental Disorders, 43*(5), 1171-7.
- McMorris, C. A., Cox, E., Hudson, M., Liu, X., & Bebko, J. M. (2013). The diagnostic process of children with autism spectrum disorder: Implications for early identification and intervention. *Journal on Developmental Disabilities, 19*(2), 42-49.
- Minnes, P., Isaacs, B., Burbidge, J., Loh, A., & Versnel, J. (2012). *Predictors of healthcare students perceived competence working with individuals with developmental disabilities*. Poster presented at the Ontario Association on Developmental Disabilities Research Special Interest Group Meeting, Kingston, Ontario, April 2012.
- Nah, Y., Young, R. L., Brewer, N., & Berlinger, G. (2014). Autism detection in early childhood (ADEC): Reliability and validity data for a level 2 screening tool for autistic disorder. *Psychological Assessment, 26*(1), 215-226.
- Ritzema, A. M., Sladeczek, I. E., Ghosh, S., Karagiannakis, A., & Manay-Quian, N. (2014). Improving outcomes for children with developmental disabilities through enhanced

communication and collaboration between school psychologists and physicians.

Canadian Journal of School Psychology, 29(4), 317-337.

Self, T. L., Coufal, K., & Parham, D. F. (2010). Allied healthcare providers' role in screening for autism spectrum disorder. *Journal of Allied Health, 39(3), 165-174.*

Self, T. L., Parham, D. F., & Rajagopalan, J. (2015). Autism spectrum disorder early screening practices: A survey of physicians. *Communication Disorders Quarterly, 36(4), 195-207.*

Sices, L., Feundtner, C., McLaughlin, J., Drotar, D., & Williams, M. (2003). How do primary care physicians identify young children with developmental delays? A national survey. *Journal of Developmental and Behavioral Pediatrics, 24(6), 409-417.*

Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities, 28(1), 9-22.*

Thomas, R. E., Spragins, W., Mazloum, G., Cronkhite, M., & Maru, G. (2016). Rates of detection of developmental problems at the 18-month well-baby visit by family physicians' using four evidence-based screening tools compared to usual care: A randomized controlled trial. *Child: Care, Health and Development, 42(3), 382-393.*

Warren, Z., Stone, W., & Humberd, Q. (2009). A training model for the diagnosis of autism in community pediatric practice. *Journal of Developmental and Behavioral Pediatrics, 30(5), 442-446.*

Watson, S.L., Coons, K. D., & Hayes, S. A. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. Part I: A comparison of parenting stress. *Journal of Intellectual and Developmental Disability, 38(2), 95-104.*

- Wiggins, L. D., Baio, J., & Rice, C. (2006). Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Journal of Developmental and Behavioral Pediatrics, 27*, S79-S87.
- Woodard, L. J., Havercamp, S. M., Zwygart, K. K., & Perkins, E. A. (2012). An innovative clerkship module focused on patients with disabilities. *Academic Medicine, 87*, 537–542.
- Zerbo, O., Massolo, M. L., Qian, Y., & Croen, L. A. (2015). A study of physician knowledge and experience with autism in adults in a large integrated healthcare system. *Journal of Autism and Developmental Disorders, 45*(12), 4002-4014.
- Zwaigenbaum, L., Nicholas, D. B., Muskat, B., Kilmer, C., Newton, A. S., Craig, W. R., . . . Sharon, R. (2016). Perspectives of health care providers regarding emergency department care of children and youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(5), 1725-1736.

Chapter 4: Conclusion

The purpose of this manuscript-based thesis was to contribute to the existing literature addressing the overall experiences of physicians when providing care (i.e., both diagnosis and treatment) to individuals with ASD. Two separate articles were included in the present thesis, the first that explored the perceived knowledge and competency of Ontario physicians regarding the diagnosis and treatment of ASD. The second study explored the barriers and facilitators that Ontario physicians experience when providing care to individuals with ASD. In this final chapter, the results of both studies are summarized, and the author will also discuss the considerations and recommendations for future research, knowledge translation, as well as the clinical implications.

Summary of Findings

The first article titled “In medical school, you get far more training on medical stuff than developmental stuff”: Perspectives on ASD from Ontario physicians” employed a mixed methods design to examine Ontario medical practitioners’ perceived levels of knowledge and comfort regarding the diagnosis and treatment of ASD in comparison to other developmental disabilities. Even though many children show early signs of ASD as early as 18 months of age, they often do not receive a diagnosis until the ages of five or six years (McMorris et al., 2013). Additionally, parents have raised their concerns regarding the lack of direction they receive from health care professionals with regards to receiving diagnosis, treatment, as well as medical and social support (Liptak et al., 2006). Physicians play a vital role in early identification, diagnosis and treatment of ASD, yet little is known about the perceived levels of knowledge and competency of Ontario physicians with regards to the diagnosis and treatment of ASD. In this study, 27 medical practitioners practicing in Ontario completed the Healthcare Professional

Questionnaire, adapted from the Healthcare Student Questionnaire (Isaacs et al., 2012; Minnes et al., 2012). Data were analyzed using descriptive statistics, paired-samples T-tests, repeated measures ANOVA, and chi-square analysis. Five participants also participated in a semi structured interview, in which questions focused on exploring physicians' perceived knowledge and comfort level in diagnosis and treatment of ASD.

The findings from this study revealed that participants reported higher perceived knowledge regarding the diagnosis of ASD in comparison to other developmental and physical disabilities, but they stated that they may not feel well-equipped to diagnose ASD. In other words, the results of interview analysis revealed that the participants feel they lack clinical experience in utilizing ASD-specific diagnostic tools; and in terms of treatment, they tend to treat the medical needs (e.g., ear infection) of individuals with ASD rather than treating their developmental needs (e.g., impairment in social skills development). Consistent with the existing literature investigating medical practitioners' preparedness in terms of knowledge and competency in providing diagnosis and treatment for ASD individuals (i.e., Carbone et al., 2010; Crais et al., 2014; Steiner et al., 2012), the results of this study showed that medical practitioners desire more training and education in medical school regarding such matters.

Furthermore, the results showed that participants who have been in practice more than five years discussed higher comfort levels providing care for the ASD population in comparison to those with less years in practice. In line with previous research investigating factors leading to the delay in diagnosis of ASD (e.g., Keenan et al., 2010), the findings of this study showed that participants often refer individuals with ASD to other healthcare professionals such as psychologists due to their perceived lack of competence or comfort in meeting the needs of these individuals. The participants also stated that providing diagnosis and treatment for individuals

with ASD is not within their scope of practice, and they believe their responsibility as physicians is to treat the medical needs (e.g., ear infection) of such patients.

Previous studies have revealed a lack of ASD-specific education and training throughout medical school as one of the barriers medical practitioners experience when providing care for the ASD population (Daniels et al., 2014; Fenikilé et al., 2015). Further to such challenges, research also shows that working in collaboration with other healthcare professionals enhances physicians' experiences when providing care for individuals with ASD (Major et al., 2013; Swiezy, Stuart, & Korzekwa, 2008). Therefore, gaining a better understanding of physicians' experiences when providing health services to the ASD population inspired the second article, titled "Autism spectrum disorder knowledge, training and experience: Ontario physicians' perspectives about what helps and what does not". This article also employed a mixed methods design, in which 27 medical practitioners completed the Healthcare Professional Questionnaire, and five participated in the same semi-structured interview. The questionnaires were analyzed using descriptive statistics, paired-samples T-tests, repeated measures ANOVA, and chi-square analysis.

The results of this study illustrated several obstacles that impede as well as factors that enhance medical practitioners' experiences and competency when providing care for individuals with ASD. Participants in this study identified limited education and training on ASD throughout their undergraduate medical education as one of the challenges they experience when providing care for individuals with ASD. Participants who had obtained more specialized training (e.g., pediatricians) reported higher level of comfort when providing care for ASD individuals in comparison to those with less specialized training. Additionally, participants who had attended professional trainings and workshops found the educational content somewhat helpful in

increasing their knowledge regarding the needs of individuals with ASD. More specifically, they found the overall educational content of professional trainings and workshops as general in terms of being more focused on developmental disabilities rather than ASD, and they expressed their needs for more specialized training opportunities regarding ASD. Perhaps, as discussed by Swiezy and colleagues (2008), current trainings and workshops focus on theoretical information regarding ASD rather than providing physicians with clinical skills that they can apply in their practice when providing care for this population.

The findings of this study also revealed several factors that enhance medical practitioners' experiences when providing diagnosis and treatment for the ASD population. Participants indicated that clinical exposure or hands-on experience with individuals with ASD is significantly helpful in increasing their knowledge and comfort level in meeting the needs of this population. Furthermore, in line with previous research investigating the importance of collaboration among healthcare professionals (e.g., Ritzema et al., 2014), the results of this study revealed that participants who work as part of an inter-professional team reported a higher sense of competency in providing care for individuals with ASD.

Considerations and Recommendations for Future Research

Despite the attempt to achieve good quality in both studies, there were several considerations to be made, including: issues surrounding recruitment, limited geographic area, and sample size. Furthermore, suggestions for future research are made to address the limitations of the current studies and to expand on the results of this thesis.

Physicians were recruited for both studies primarily at conferences because they are considered the busiest professionals (Cunningham et al., 2015; Flanigan & McFarlane, 2008), which created an additional difficulty to recruit this population. Recruitment via email met with

limited success. In other words, physicians did not reply to the recruitment invitations. Nevertheless, medical practitioners who attend conferences in the areas of developmental and physical disabilities may have higher interest with regard to learning about such matters. In addition, participants at these conferences were exposed to education and training about developmental disabilities, which may have created a bias in perception of their own knowledge and competence. In other words, some physicians may have rated their perceived knowledge and comfort level regarding the diagnosis and treatment of ASD higher in comparison to other participants in this study.

Secondly, the majority of participants in this study practice in limited geographic areas in Ontario (i.e., Northern Ontario, Ottawa region, Niagara Falls, and Toronto); therefore, the results may not be generalized to physicians in other areas in this province. Furthermore, more than 50 participants were contacted to participate in the study, but only 27 participants filled out the questionnaires and five participated in the interview. Given the limited number of participants partaking in the interview (i.e., $n=5$), their perceived knowledge and competency working with individuals with ASD may not represent the experiences of physicians in other regions of Ontario.

Lastly, the Healthcare Professional Questionnaire was adapted from the Healthcare Student Questionnaire, which was developed to capture the knowledge and training of healthcare students with regard to developmental disabilities. Therefore, there were several questions in the Healthcare Professional Questionnaire (e.g., *“how competent do you feel in meeting the needs of individuals with developmental disabilities?”*) that were focused on developmental disabilities in general, and created a difficulty in teasing out physicians’ responses regarding ASD. Despite such a limitation, the results of the interviews provided a more specific perspective in terms of

physicians' perceived knowledge and competency with regard to diagnosing and treating individuals with ASD.

Future research should explore and identify, using in-depth qualitative interviews, areas of need for Ontario physicians to better characterize elements that should be included in medical curricula and residency training. Given the research illustrating the effectiveness of clinical exposure with individuals with ASD (Havercamp et al., 2016; Swiezy et al., 2008), it is important to investigate the educational and training methods that are employed in Canadian medical education systems in terms of teaching and preparing medical students to provide care for this population. For instance, implementing multi-modal teaching strategies that include a combination of didactic teaching, small group discussions, and case studies, would provide medical students with knowledge and perspective regarding the specific needs of individuals with ASD. Medical students may also benefit from lectures delivered by individuals with ASD speaking about their lived experiences when accessing resources. It is also imperative for medical schools to implement curricula, where medical students learn how to identify and assess ASD through educational sessions paired with standardized patient encounters.

Pediatricians in Canada are required by the Canadian Paediatric Society (2015) to utilize behavioural and developmental screening tools at every well-child visit. Therefore, future research should examine the specifics of assessment procedures that medical practitioners, including family physicians and pediatricians follow when diagnosing individuals with ASD in their practice. Furthermore, it is important to investigate the differences between physicians who practice in different regions (e.g., northern, rural, urban, southern, etc.) in the province in terms of knowledge and experience in providing diagnosis and care for individuals with ASD.

Knowledge Translation

An important aspect of academic research is knowledge translation. The most widely used definition of knowledge translation was put forward by the Canadian Institutes for Health Research (2015): “a dynamic and iterative process that includes synthesis, disseminations, exchange and ethically-sound application of knowledge to improve the health of Canadians, [and] provide more effective health services...” (¶.4). The findings of this thesis largely pertain to available services in Ontario, and the results will be shared with all knowledge users through publications, presentations, and reports, as discussed specifically below.

For the purpose of this thesis, the knowledge users consist of other disability researchers, Ontario medical practitioners and medical schools, policy makers and stake holders, the College of Physicians and Surgeons in Ontario, as well as educators and families of individuals with ASD. The present research will be published in peer reviewed academic journals (i.e., *Research in Autism Spectrum Disorder* and *Journal of Autism and Developmental Disorders*) to add to the growing body of developmental disability and health care literature. However, one of the barriers to knowledge translation is the accessibility of information, and not all knowledge users will have the knowledge of, or means to, access academic journals (Martin, Shooshtari, Temple, & Yu, 2010). Therefore, in order to overcome such barriers, it would be of an importance to provide physicians, both working in hospitals and private practices, with pamphlets or brochures which include information regarding the ASD diagnostic tools and procedures, treatment and intervention options, the ASD symptomology, as well as a list of regulated health care professionals specialized in the area of ASD.

To promote information access for individuals outside of the academic community, a brief report containing the results of each study will be sent to all of the aforementioned

knowledge users such as medical schools, the College of Physicians and Surgeon of Ontario, and educators. The results of each study will also be presented to physicians and students at the Northern Ontario School of Medicine in order to highlight the need for appropriate education and training. Additionally, presentations have already been made at several conferences that cater to both researchers and professionals who work within the field of developmental disabilities. The dissemination of disability research is important not only for policy making, but for informing professionals of the issues most relevant to medical practitioners, so that formal supports can be tailored to their needs when providing care for individuals with ASD.

Clinical Implications

Understanding the experiences of physicians when providing care to individuals with ASD is essential in developing, improving, and implementing appropriate and effective medical education and training as well as the healthcare system for individuals with ASD. Given the importance of receiving early diagnosis for children with ASD (Anagnostou et al., 2014; Boyd et al., 2010; Finke, Drager, & Ash, 2010), implementing appropriate and ASD-focused educational curricula and training for medical students and practitioners is crucial in enhancing their perceived knowledge and competence. By listening to medical practitioners' educational needs and a desire for more training, appropriate modifications in medical educational systems can hopefully be made to enhance physicians' perceptions of their own competency in providing care for individuals with ASD and their families.

Emphasizing the importance of clinical exposure to individuals with ASD is also essential. According to Sweizy and colleagues (2008), integrating educational strategies such as hands-on experiences with individuals with ASD, as well as promoting hospital-based professional training programs in medical schools are effective models that facilitate and

improve the knowledge and competency of medical practitioners. In line with previous research, the physicians in this study also expressed their educational needs for ASD-specific training and education in medical school. Therefore, medical schools should provide future physicians with clinical and residency opportunities that would help them acquire and develop skills through coaching, practice and feedback (Sweizy et al., 2008). Furthermore, employing teaching strategies facilitated by ASD specialists or consultants in medical schools can provide students with comprehensive and cohesive learning opportunities. It is also of significance to provide medical practitioners with training opportunities in which they receive information regarding ASD diagnostic tools. Such professional development can be implemented through workshops, webinars, or collaboration with health professionals who have specialized training with regard to ASD diagnosis as well as adults with ASD who can share their lived experiences with the healthcare system.

There is also a need to promote collaboration among health care professionals, including physicians, psychologists and speech and language pathologists, when providing care for individuals with ASD (Ritzema, Sladeczek, Ghosh, Karagiannakis, & Manay-Quian, 2014). The Canadian healthcare systems should implement policies and guidelines that promote collaboration among healthcare professionals in order to facilitate the diagnostic and treatment processes for individuals with ASD. Research also shows that families of individuals with ASD have raised their concerns with regards to receiving proper medical and social services for their children with ASD (Brookman-Frazee et al., 2012; Glazaard & Overall, 2012). Therefore, educating physicians is crucial for the successful diagnostic process as well as early childhood interventions, which can in turn enhance the experiences of both physicians in providing care for the ASD population and alleviate the stress the families of individuals with ASD experience

when receiving diagnosis and treatment for their children. To achieve this goal, it is crucial for the healthcare systems to equip physicians with a medical tool kit including appropriate ASD services provided in community by healthcare professionals such as psychologists. Such tool kits will inform physicians regarding professionals whom they can either collaborate with or refer individuals with ASD to them to receive appropriate services in a timely manner. This tool kit should also include information regarding the guidelines for identification, diagnosis, core ASD symptoms and treatment options in order to better provide service to this population.

Conclusion

This thesis has expanded on a larger project pertaining to the overall knowledge and experiences of healthcare professionals with regards to developmental disabilities. Research shows that medical practitioners, including pediatricians and family physicians, are often reluctant to make a diagnosis of ASD due to insufficient education and training they receive in medical school (Rhoades et al., 2007). Rhoades and colleagues (2007) also found that physicians have expressed their discomfort when providing care for individuals with ASD, and expressed their needs for further education and training regarding such matters (Fenikilé et al., 2015). In addition to such challenges, researchers have concluded that collaboration among physicians and other healthcare professionals such as psychologists and speech and language pathologists enhances medical practitioners' experiences when dealing with the ASD population (Ritzema et al., 2014).

In line with the previous research, the findings of this thesis revealed that even though participants perceived their knowledge regarding the diagnosis and treatment of ASD higher compared to other developmental disabilities, they did not feel prepared enough to provide a diagnosis or treat the developmental needs of individuals with ASD. Ontario physicians also

expressed their needs for more ASD specific education and training in order to increase their comfort level when providing care for this population. Lastly, the findings revealed that participants who worked as part of an interdisciplinary team with other healthcare professionals felt more comfortable and competent in meeting the needs of individuals with ASD and their families.

Understanding physicians' needs regarding medical training is an essential component to improve healthcare systems (e.g., medical professionals, medical schools, and policy makers) that deliver medical and social services for individuals with ASD and their families. Physicians are the first healthcare professionals who interact with children with ASD and therefore require an ongoing education, training and supports to continue providing appropriate care for this population. In order to better equip physicians with knowledge and training regarding ASD, it is imperative for the educational system to implement programs and trainings that are facilitated by ASD specialists and adults with ASD who would share their personal experiences when dealing with the healthcare systems. Additionally, providing medical students and physicians with opportunities such as medical curricula and residency trainings on ASD, as well as workshops that are focused on ASD diagnostic tools and procedures, treatment options, and the overall needs of this population would be tremendous in enhancing medical practitioners' competency in providing care for this population.

References

- Abrahams, B. S. & Geschwind, D. H. (2008). Advances in autism genetics: On the threshold of a new neurobiology. *Nature Reviews.Genetics*, 9(5), 341-55.
- Akbar, M., Loomis, R., & Paul, R. (2013). The interplay of language on executive functions in children with ASD. *Research in Autism Spectrum Disorders*, 7(3), 494-501.
- Allison, C., Baron-Cohen, S., Wheelwright, S., Charman, T., Richler, J., Pasco, G., & Brayne. C. (2008). The Q-CHAT (Quantitative Checklist for Autism in Toddlers): A normally distributed quantitative measure of autistic traits at 18-24 months of age: Preliminary report. *Journal of Autism and Developmental Disorders*, 38, 1414-1425.
- American Association on Intellectual and Developmental Disabilities. (2013). *Frequently Asked Questions on Intellectual Disability*. Retrieved November 05, 2014, from <http://aaid.org/intellectual-disability/definition/faqs-on-intellectual-disability#.VFrLFufqnu0>.
- Anagnostou, E., Zwaigenbaum, L., Szatmari, P., Fombonne, E., Fernandez, B. A., Woodbury-Smith, M., . . . Scherer, S. W. (2014). Autism spectrum disorder: Advances in evidence-based practice. *Canadian Medical Association Journal*, 186(7), 509-519.
- Aronson. M., Hagberg. B., & Gillberg. C. (1997). Attention deficits and autistic spectrum problems in children exposed to alcohol during gestation: a follow-up study. *Developmental Medicine & Child Neurology*, 39, 583–87.
- Autism Speaks. (2015). *Autism prevalence*. Retrieved January 14, 2015, from <http://www.autismspeaks.org/what-autism/prevalence>.
- Autism Speaks. (2015). *How is autism diagnosed?* Retrieved January 19, 2015, from <http://www.autismspeaks.org/what-autism/diagnosis>.

- Avramidis, E., Bayliss, P., & Burden, R. (2000). A survey into mainstream teachers' attitudes towards the inclusion of children with special educational needs in the ordinary school in one local education authority. *Educational Psychology, 20*, 191–211.
- Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S., & Drew, A. (2000). A screening instrument for autism at 18 months of age: A 6 year follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*, 694–702.
- Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research, 49*, 575 – 590.
- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*, 217 – 230.
- Baker-Ericzén, M. J., Brookman-Fraze, 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*(4), 194-204.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215.
- Bandura, A. (1989). Regulation of cognitive processes through perceived self-efficacy. *Developmental Psychology, 25*(5), 729-735.
- Bandura, A., Adams, N. E., & Beyer, J. (1977). Cognitive processes mediating behavioral change. *Journal of Personality and Social Psychology, 35*(3), 125-139.
- Barned, N. E., Knapp, N. F., & Neuharth-Pritchett, S. (2011). Knowledge and attitudes of early childhood preservice teachers regarding the inclusion of children with autism spectrum

- disorder. *Journal of Early Childhood Teacher Education*, 32, 302-321.
- Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *British Journal of Psychiatry*, 194, 500–509.
- Barton, M. L., Dumont-Mathieu, T., & Fein, D. (2012). Screening young children for autism spectrum disorders in primary practice. *Journal of Autism and Developmental Disorders*, 42(6), 1165–1174.
- Bauminger, N., Solomon, M., & Rogers, S. J. (2010). Externalizing and internalizing behaviors in ASD. *Autism Research*, 3(3), 101-112.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), 702-714.
- Ben Itzchak, E. & Zachor, D. A. (2011). Who benefits from early intervention in autism spectrum disorders? *Research in Autism Spectrum Disorders*, 5(1), 345-350.
- Benson, P. R. & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders*, 39(2), 350-62.
- Blijd-Hoogewys, E., Bezemer, M. L., & van Geert, P. L. C. (2014). Executive functioning in children with ASD: An analysis of the BRIEF. *Journal of Autism and Developmental Disorders*, 44(12), 3089-3100.
- Blumberg, S. J., Bramlett, M. D., Kogan, M. D., Schieve, L. A., Jessica, R., Jones, J. R ... Lu, M. C. (2013). Changes in prevalence of parent-reported Autism Spectrum Disorder in school-aged U.S. children: 2007 to 2011–2012. *National Health Statistics Reports*, 65, 1–7.

- Bölte, S. (2014). Is autism curable? *Developmental Medicine & Child Neurology*, 56(10), 927-931.
- Boyd, B. A., Odom, S. L., Humphreys, B. P., & Sam, A. M. (2010). Infants and toddlers with autism spectrum disorder: Early identification and early intervention. *Journal of Early Intervention*, 32(2), 75-98.
- Braiden, H., Bothwell, J., & Duffy, J. (2010). Parents' experience of the diagnostic process for autistic spectrum disorders. *Child Care in Practice*, 16(4), 377-389.
- Brookman-Fraee, L., Baker- Ericzén, M., Stadnick, N., & Taylor, R. (2012). Parent perspective on Community mental health services for children with autism spectrum disorders. *Journal of Child and Family Studies*, 21(4), 533-544.
- Bryson, S. E., Zwaigenbaum, L., Brian, J., Roberts, W., Szatmari, P., Rombough, V., & McDermott, C. (2007). A prospective case series of high-risk infants who developed autism. *Journal of Autism and Developmental Disorders*, 37(1), 12-24.
- Carbone, P. S., Behl, D. D., Azor, V., & Murphy, N. A. (2010). The medical home for children with Autism Spectrum Disorders: Parent and pediatrician perspectives. *Journal of Autism and Developmental Disorders*, 40(3), 317-324.
- Carrington, S. J., Kent, R. G., Maljaars, J., Le Couteur, A., Gould, J., Wing, L., . . . Leekam, S. R. (2014). DSM-5 autism spectrum disorder: In search of essential behaviours for diagnosis. *Research in Autism Spectrum Disorders*, 8(6), 701-715.
- Carpenter, L. A., Soorya, L., & Halpern, D. (2009). Asperger's syndrome and high-functioning autism. *Pediatric Annals*, 38(1), 30-5.
- Charman, T. & Baird, G. (2002). Practitioner review: Diagnosis of autism spectrum disorder in 2-and 3-year-old children. *Journal of Child Psychology and Psychiatry*, 43(3), 289-305.

- Chlebowski, C., Green, J. A., Barton, M. L., & Fein, D. (2010). Using the Childhood Autism Rating Scale to diagnose autism spectrum disorders. *Journal of Autism and Developmental Disorders, 40*(7), 787-799.
- Constantino, J. N., Todorov, A., Hilton, C., Law, P., Zhang, Y., Molloy, E., . . . Geschwind, D. (2013). Autism recurrence in half siblings: Strong support for genetic mechanisms of transmission in ASD. *Molecular Psychiatry, 18*(2), 137-138.
- Crais, E. R., Mccomish, C. S., Humphreys, B. P., Watson, L. R., Baranek, G. T., Reznick, J. S., . . . Earls, M. (2014). Pediatric healthcare professionals' views on autism spectrum disorder screening at 12-18 months. *Journal of Autism and Developmental Disorders, 44*(9), 2311-28.
- Croonenberghs, J., Wauters, A., Devreese, K., Verkerk, R., Scharpe, S, ... Maes, M. (2002). Increased serum albumin, gamma globulin, immunoglobulin IgG, and IgG2 and IgG4 in autism. *Psychology Medicine, 32*, 1457–63.
- Cunningham, C. T., Quan, H., Hemmelgarn, B., Noseworthy, T., Beck, C. A., Dixon, E., . . . Jetté, N. (2015). Exploring physicians specialist response rates to web-based surveys. *BMC Medical Research Methodology, 15*(32), 1-8.
- Dahle, K. B. (2003). Services to include young children with autism in the general classroom. *Early Childhood Special Education, 31*, 65–70.
- Damiano, C. R., Mazefsky, C. A., White, S. W., & Dichter, G. S. (2014). Future directions for research in Autism Spectrum Disorders. *Journal of Clinical Child & Adolescent Psychology, 43*(5), 828- 843.
- Daniel, K.S. (2011). *Identifying the gaps towards an inclusive educational system within Quebec: Collectively examining the perceptions of different groups of educators*

- (Doctoral dissertation). McGill University, Montreal, Quebec.
- Daniel, K. & Cornish, K. (2006). *The McGill Inclusive Education Questionnaire*. Unpublished manuscript. Montreal: McGill University.
- Daniels, A. M., Halladay, A. K., Shih, A., Elder, L. M., & Dawson, G. (2014). Approaches to enhancing the early detection of autism spectrum disorders: A systematic review of the literature. *Journal of the American Academy of Child & Adolescent Psychiatry, 53*(2), 141-152.
- Devlin, B., & Scherer, S. W. (2012). Genetic architecture in autism spectrum disorder. *Current Opinions in Genetics & Development, 22*(3), 229-237.
- Dietz, C., Swinkels, S., Emma, v. D., Herman, v. E., & Buitelaar, J. K. (2006). Screening for autistic spectrum disorder in children aged 14-15 months. II: Population screening with the early screening of autistic traits questionnaire (ESAT). Design and general findings. *Journal of Autism and Developmental Disorders, 36*(6), 713-22.
- Dosreis, S., Weiner, C. L., Johnson, L., & Newschaffer, C. J. (2006). Autism spectrum disorder screening and management practices among general pediatric providers. *Journal of Developmental and Behavioral Pediatrics, 27*, S88-S94.
- Eldar, E., Talmor, R., & Wolf-Zukerman, T. (2010). Success and difficulties in the individual inclusion of children with Autism Spectrum Disorder (ASD) in the eyes of their coordinators. *International Journal of Inclusive Education, 14*(1), 97-114.
- Eldevik, S., Hastings, R. P., Hughes, 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*(3), 439-50.
- Elo, S. & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced*

- Nursing*, 62(1), 107-115.
- Falkmer, T., Anderson, K., Falkmer, M., & Horlin, C. (2013). Diagnostic procedures in autism spectrum disorders: A systematic literature review. *European Child & Adolescent Psychiatry*, 22(6), 329-40.
- Faso, D. J., Neal-Beevers, A., & Carlson, C. L. (2013). Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 7(2), 288-297.
- Fava, L., Strauss, K., Valeri, G., D'Elia, L., Arima, S., & Vicari, S. (2011). The effectiveness of a cross-setting complementary staff-and parent-mediated early intensive behavioural intervention for young children with ASD. *Research in Autism Spectrum Disorders*, 5, 1479-1492.
- Fein, D., Stevens, M., Dunn, M., Waterhouse, L., Allen, D., Rapin, I., & Feinstein, C. (1999). Subtypes of Pervasive Developmental Disorder: Clinical characteristics. *Child Neuropsychology*, 5(1), 1-23.
- Fenikilé, T. S., Ellerbeck, K., Filippi, M. K., & Daley, C. M. (2015). Barriers to autism screening in family medicine practice: A qualitative study. *Primary Health Care Research and Development*, 16(4), 356-366.
- Finke, E. H., Drager, K. D. R., & Ash, S. (2010). Paediatricians' perspectives on identification and diagnosis of Autism Spectrum Disorders. *Journal of Early Childhood Research*, 8(3), 254-268.
- Firth, I. & Dryer, R. (2013). The predictors of distress in parents of children with autism spectrum disorder. *Journal of Intellectual and Developmental Disability*, 38(2), 163-171.
- Fisher, D., Frey, N., & Thousand, J. (2003). What do special educators need to know and be

- prepared to do for inclusive schooling to work? *Teacher Education and Special Education*, 26, 42–50.
- Flanigan, T., & McFarlane, E. S. (2008, May). *Conducting Survey Research Among Physicians and Other Medical Professionals: A Review of Current Literature*. Presented at AAPOR 2008, New Orleans, LA.
- Fleury, A., Kushki, A., Tanel, N., Anagnostou, E., & Chau, T. (2013). Statistical persistence and timing characteristics of repetitive circle drawing in children with ASD. *Developmental Neurorehabilitation*, 16(4), 245-254.
- Frazier, T. W., Youngstrom, E. A., Speer, L., Embacher, R., Law, P., Constantino, J., ... Eng, C. (2012). Validation of proposed DSM-5 criteria for autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51, 28–40 e23.
- Frances, A. (2013). *Two fatal technical flaws in the DSM-5 definition of autism*. http://www.huffingtonpost.com/allen-frances/two-fatal-technical-flaws_b_3337009.html?view=screen
- Freeman, B. J., Vronin, P., & Candela, P. (2002). Asperger Syndrome or Autistic Disorder? The Diagnostic dilemma. *Focus on Autism and Other Developmental Disabilities*, 17(3), 145-151.
- Gibbs, V., Aldridge, F., Chandler, F., Witzlsperger, E., & Smith, K. (2012). Brief report: An exploratory study comparing diagnostic outcome for Autism Spectrum Disorders under DSM-IV-TR with the Proposed DSM-5 Revision. *Journal of Autism and Developmental Disorders*, 42(8), 1750-1756.
- Gill, M.J. & Harris, S.L. (1991). Hardiness and social support as predictors of psychological discomfort in mothers of children with autism. *Journal of Autism and Developmental*

Disorders, 21, 407–416.

- Glazzard, J. & Overall, K. (2012). Living with autistic spectrum disorder: Parental experiences of raising a child with autistic spectrum disorder (ASD). *Support for Learning, 27*(1), 37-45.
- Goines, P. E. & Ashwood, P. (2013). Cytokine dysregulation in autism spectrum disorders (ASD): Possible role of the environment. *Neurotoxicology and Teratology, 36*, 67-81.
- Gulati, S. & Wasir, V. (2005). Prevention of Developmental Disabilities. *Indian Journal of Pediatrics, 72*(11), 975-978.
- Guthrie, W., Swineford, L. B., Nottke, C., & Wetherby, A. M. (2013). Early diagnosis of autism spectrum disorder: Stability and change in clinical diagnosis and symptom presentation. *Journal of Child Psychology and Psychiatry, 54*(5), 582-590.
- Harris, S., & Handleman, J. (2000). Age and IQ at intake as predictors of placement for young children with autism: A four- to six-year follow-up. *Journal of Autism and Developmental Disorders, 30*, 137–142.
- Hastings, R. P., Kovshoff, H., Ward, N. J., Francesca, d. E., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders, 35*(5), 635-44.
- Havercamp, S. M., Ratliff-Schaub, K., Macho, P. N., Johnson, C. N., Bush, K. L., & Souders, H. T. (2016). Preparing tomorrow's doctors to care for patients with autism spectrum disorder. *Intellectual and Developmental Disabilities, 54*(3), 202-216.
- Hodge, D., Hoffman, C. D., & Sweeney, D. P. (2011). Increased psychopathology in parents of children with autism: Genetic liability or burden of caregiving? *Journal of Developmental and Physical Disabilities, 23*(3), 227-239.

- Howlin P. & Moore A. (1997) Diagnosis in autism: a survey of over 1200 patients in the UK. *Autism 1*, 135–162.
- Hsai, Y., Wong, A. Y. S., Murphy, D. G. M., Simonoff, E., Buitelaar, J. K., & Wong, I. C. K. (2014). Psychopharmacological prescriptions for people with autism spectrum disorder (ASD): a multinational study. *Psychopharmacology*, *231*, 999-1009.
- Heurta, M., Bishop, S.L., Duncan, A., Hus, V., & Lord, C. (2012). Application of DSM-5 criteria for autism spectrum disorder to three samples of children with DSM-IV diagnoses of pervasive developmental disorders. *American Journal of Psychiatry*, *169*, 1056–1064.
- Isaacs, B., Minnes, P., Burbidge, J., Loh, A., & Versnel, J. (2012). *Comparison of medical, nursing and allied healthcare students' training in developmental disabilities*. Poster presented at the Ontario Association on Developmental Disabilities Research Special Interest Group Meeting, Kingston, Ontario, April 2012.
- Jang, J., Dixon, D. R., Tarbox, J., & Granpeesheh, D. (2011). Symptom severity and challenging behavior in children with ASD. *Research in Autism Spectrum Disorders*, *5*(3), 1028-1032.
- Kanne, S. M. & Mazurek, M. O. (2011). Aggression in children and adolescents with ASD: Prevalence and risk factors. *Journal of Autism and Developmental Disorders*, *41*(7), 926-37.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, *2*, 217–250.
- Kasari, C., Locke, J., Gulsrud, A., & Rotheram-Fuller, E. (2011). Social networks and friendships at school: Comparing children with and without ASD. *Journal of Autism and Developmental Disorders*, *41*(5), 533-44.
- 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(4), 337-343.
- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities*, 23(4), 390-397.
- Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim, E. C., ... Grinker, R. R. (2011). Prevalence of autism spectrum disorders in a total population sample. *American Journal of Psychiatry*, 168, 904–912.
- Kleinman, J., Robins, D. L., Ventola, P. E., Pandey, J., Boorstein, H. C., Esser, E. L., ... Fein, D. (2008). The Modified Checklist for Autism in Toddlers: A follow-up study investigating the early detection of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38, 827–839.
- Koegel, L., Matos-Freden, R., Lang, R., & Koegel, R. (2012). Interventions for children with autism spectrum disorders in inclusive school settings. *Cognitive and Behavioral Practice*, 19(3), 401-412.
- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & Van Dyke, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States. *Journal of the American Academy of Pediatrics*, 122(6), 1148–1159.
- Kolevzon, A., Mathewson, K. A., & Hollander, E. (2006). Selective serotonin reuptake inhibitors in autism: A review of efficacy and tolerability. *Journal of Clinical Psychiatry*, 67(3), 407-414.
- Kuusikko-Gauffin, S., Pollock-wurman, R., Mattila, M., Jussila, K., Ebeling, H., Pauls, D., &

- Moilanen, I. (2013). Social anxiety in parents of high-functioning children with autism and asperger syndrome. *Journal of Autism and Developmental Disorders*, 43(3), 521-9.
- Lai, M. C., Lombardo, M. V., & Baron-Cohen, S. (2014). Autism. *Lancet*, 383(9920), 896-910.
- Lang, R., Regeher, A., Lauderdale, S., Ashbaugh, K., & Haring, A. (2010). Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: A systematic review. *Developmental Neurorehabilitation*, 13(1), 53-63.
- Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50, 172-183.
- Le Couteur, A., Haden, G., Hammal, D., & McConachie, H. (2008). Diagnosing autism spectrum disorders in pre-school children using two standardised assessment instruments: The ADI-R and the ADOS. *Journal of Autism and Developmental Disorders*, 38(2), 362-72.
- Lee, G. K. (2009). Parents of children with high functioning autism: how well do they cope and adjust? *Journal of Developmental and Physical Disabilities*, 21, 93–114.
- Libbey, J. E., Sweeten, T. L., McMahon, W. M., & Fujinami, R. S. (2005). Autistic disorder and viral infections. *Journal of NeuroVirology*, 11, 1–10.
- Lindsay, S., Proulx, M., Scott, H., & Thomson, N. (2014). Exploring teachers' strategies for including children with autism spectrum disorder in mainstream classrooms. *International Journal of Inclusive Education*, 18(2), 101-122.
- Lindsay, S., Proulx, M., Thomson, N., & Scott, H. (2013). Educators' challenges of including children with Autism Spectrum Disorder in mainstream classrooms. *International Journal of Disability, Development and Education*, 60(4), 347-362.

- Liptak, G. S., Orlando, M., Yingling, J. T., Theurer-Kaufman, K. L., Malay, D. P., Tompkins, L. A., & Flynn, J. R. (2006). Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of Pediatric Health Care, 20*(4), 245-252.
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Jr., Leventhal, B. L., DiLavore, P. C., . . . Rutter, M. (2000). The Autism Diagnostic Observation Schedule—Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders, 30*(3), 205-223.
- Luc, L. (2013). Thoughts on the DSM-5. *Autism, 17*(5), 507-509.
- Maenner, M. J., Rice, C. E., Arneson, C. L., Cunniff, C., Schieve, L. A., Carpenter, L. A., . . . Durkin, M. S. (2014). Potential impact of DSM-5 criteria on Autism Spectrum Disorder prevalence estimates. *JAMA Psychiatry, 71*(3), 292-300.
- Major, N. E., Peacock, G., Ruben, W., Thomas, J., & Weitzman, C. C. (2013). Autism training in paediatric residency: Evaluation of a case-based curriculum. *Journal of Autism and Developmental Disorders, 43*(5), 1171-1177.
- Marshall, K. L. & Deane, F. P. (2004). General practitioners' detection and management of patients with a dual diagnosis: Implications for education and training. *Drug and Alcohol Review, 23*, 455-462.
- Martin, T., Shooshtari, S., Temple, B., & Yu, C. T. (2010). Facilitating and impeding factors for knowledge translation in developmental disabilities: Outcomes of community-based workshops method participants and setting. *Journal on Developmental Disabilities, 16*(3), 41-47.
- Mattila, M.L., Kielinen, M., Linna, S.L., Jussila, K., Ebeling, H., Bloigu, R., . . . Moilanen, I.

- (2011). Autism spectrum disorders according to DSM-IV-TR and comparison with DSM-5 draft criteria: An epidemiological study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 50, 583–592.
- Matson, J. L., González, M., & Wilkins, J. (2009). Validity study of the autism spectrum disorders-diagnostic for children (ASD-DC). *Research in Autism Spectrum Disorders*, 3(1), 196-206.
- Matson, J. L. & Konst, M. J. (2015). Why pharmacotherapy is overused among persons with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 9, 34-37.
- Matson, J. L., Kozlowski, A. M., Hattier, M. A., Horovitz, M., & Sipes, M. (2012). DSM-IV vs DSM-5 diagnostic criteria for toddlers with autism. *Developmental Neurorehabilitation*, 15, 185–190.
- Mayes, S. D., Black, A., & Tierney, C. D. (2013). DSM-5 under-identifies PDDNOS: Diagnostic agreement between the DSM-5, DSM-IV, and Checklist for Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, 7, 298–306.
- Mazefsky, C. A., McPartland, J. C., Gastgeb, H. Z., & Minshew, N. J. (2013). Brief report: Comparability of DSM-IV and DSM-5 ASD research samples. *Journal of Autism and Developmental Disorders*, 43(5), 1236-1242.
- McConkey, R., MacLeod, S., & Cassidy, A. (2011). The keyhole® rainbow resource kit: Meeting the needs of parents of newly diagnosed preschoolers with ASD. *Early Child Development and Care*, 181(3), 321-334.
- McGillivray, J. A. & Evert, H. T. (2014). Group cognitive behavioural therapy program shows potential in reducing symptoms of depression and stress among young people with ASD.

Journal of Autism and Developmental Disorders, 44(8), 2041-2051.

McMorris, C. A., Cox, E., Hudson, M., Liu, X., & Bebko, J. M. (2013). The diagnostic process of children with autism spectrum disorder: Implications for early identification and intervention. *Journal on Developmental Disabilities*, 19(2), 42-49.

McLeod, B. D., Wood, J. J., & Klebanoff, S. (2015). Advances in evidence-based intervention and assessment practices for youth with an Autism Spectrum Disorder. *Behavior Therapy*, 46, 1-6.

McPartland, J. C., Reichow, B., & Volkmar, F. R. (2012). Sensitivity and specificity of proposed DSM-5 diagnostic criteria for Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(4), 368-383.

Merriam, S. B. (2002). *Qualitative research in practice: Examples for discussion and analysis*. San Francisco, California: John Wiley & Sons, Inc.

Miller, J. S., Gabrielsen, T., Villalobos, M., Alleman, R., Wahmhoff, N., Carbone, P. S., & Segura, B. (2011). The each child study: Systematic screening for autism spectrum disorders in a pediatric setting. *Pediatrics*, 127(5), 866-871.

Minnes, P., Isaacs, B., Burbidge, J., Loh, A., & Versnel, J. (2012). *Predictors of healthcare students perceived competence working with individuals with developmental disabilities*. Poster presented at the Ontario Association on Developmental Disabilities Research Special Interest Group Meeting, Kingston, Ontario, April 2012.

Molloy, C. A., Morrow, A. L., Meizen-Derr, J., Schleifer, K., Dienger, K., Manning-Courtney, P., ... Wills-Karp, M. (2006). Elevated cytokine levels in children with autism spectrum disorder. *Journal of Neuroimmunology*, 172 (1-2), 198-205.

- Molloy, C. A., Murray, D. S., Akers, R., Mitchell, T., & Manning-Courtney, P. (2011). Use of the autism diagnostic observation schedule (ADOS) in a clinical setting. *Autism, 15*(2), 143-162.
- Morgan, L., Wetherby, A. M., & Barber, A. (2008). Repetitive and stereotyped movements in children with autism spectrum disorders late in the second year of life. *Journal of Child Psychology and Psychiatry, 49*, 826-837.
- Murray, M. L., Hsia, Y., Glaser, K., Simonoff, E., Murphy, D. G. M., Asherson, P. J . . . Wong, I. C. K. (2014). Pharmacological treatments prescribed to people with autism spectrum disorder (ASD) in primary health care. *Psychopharmacology, 231*(1), 1011-1021.
- Nah, Y., Young, R. L., Brewer, N., & Berlinger, G. (2014). Autism detection in early childhood (ADEC): Reliability and validity data for a level 2 screening tool for autistic disorder. *Psychological Assessment, 26*(1), 215-226.
- Neal, D., Matson, J. L., & Hattier, M. A. (2014). Validity of the autism spectrum disorder observation for children (ASD-OC). *Journal of Mental Health Research in Intellectual Disabilities, 7*(1), 14-33.
- Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E . . . Windham, G. C. (2007). The epidemiology of autism spectrum disorder. *Annual Review of Public Health, 28*, 235-258.
- Opacic, D. A. (2003). The relationship between self-efficacy and student physician assistant clinical performance. *Journal of Allied Health, 32*(3), 158-66.
- Ouellette-Kuntz, H., Coo, H., Lam, M., Breitenbach, M. M., Hennessey, P. E., Jackman, P. D., . . . Chung, A. M. (2014). The changing prevalence of autism in three regions of

- canada. *Journal of Autism and Developmental Disorders*, 44(1), 120-136.
- Ozonoff, S., Iosif, A., Baguio, F., Cook, I. C., Hill, M. M., Hutman, T., . . . Young, G. S. (2010). A prospective study of the emergence of early behavioral signs of autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 49(3), 256-266.
- Ozonoff, S., Macari, S., Young, G. S., Goldring, S., Thompson, R., & Rogers, S. J. (2008). Atypical object exploration at 12 months of age is associated with autism in a prospective sample. *Autism: The International Journal of Research and Practice*, 12, 457-472.
- Patel, D. R., Greydanus, D. E., Calles, J. L., & Pratt, H. D. (2010). Developmental disabilities across the lifespan. *Disease-a-Month*, 56(6), 305-397.
- Patterson, J. M. (1988). Families experiencing stress: I. the family adjustment and adaptation response model: II. applying the FAAR model to health-related issues for intervention and research. *Family Systems Medicine*, 6(2), 202-237.
- Perry, A., Cummings, A., Geier, J. D., Freeman, N. L., Hughes, S., LaRose, L . . . Williams, J. (2008). Effectiveness of Intensive Behavioral Intervention in a large, community-based program. *Research in Autism Spectrum Disorders*, 2, 621-642.
- Pinto-Martin, J., Young, L. M., Mandell, D. S., Poghosyan, L., Giarelli, E., & Levy, S. E. (2008). Screening strategies for autism spectrum disorders in pediatric primary care. *Journal of Developmental and Behavioral Pediatrics*, 29(5), 345-350.
- Piven, J. & Palmer, P. (1999). Psychiatric disorder and the broad autism phenotype: evidence from a family study of multiple-incidence autism families. *The American Journal of Psychiatry*, 156, 557-563.

- Pouw, L. B. C., Rieffe, C., Oosterveld, P., Huskens, B., & Stockmann, L. (2013).
Reactive/proactive aggression and affective/cognitive empathy in children with ASD.
Research in Developmental Disabilities, 34(4), 1256-1266.
- Probst, P. & Leppert, T. (2008). Brief report: Outcomes of a teacher training program for autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(9), 1791-6.
- Research Autism. (2015). *Behavioural and developmental interventions and Autism*. Retrieved April 13, 2015, from <http://www.researchautism.net/behavioural-and-developmental-interventions>.
- Research Autism. (2014). *Types of Autism interventions, treatments and therapies*. Retrieved April 13, 2015, from <http://www.researchautism.net/autism-interventions/types>.
- Reichow. B., Barton. E. E., Boyd. B. A., & Hume. K. (2012). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews, 10*, 1-60.
- Reichow. B. & Wolery. M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA Young Autism Project model. *Journal of Autism and Developmental Disorders, 39*(1), 23–41.
- Rhoades, R. A., Scarpe, A., & Salley, B. (2007). The importance of physician knowledge of autism spectrum disorder: results of a parent survey. *BMC Pediatrics, 7*(37), 1-10.
- Rice, C., Nicholas, J., Baio, J., Pettygrove, S., Lee, L. C., Braun, K. V. N., Doernberg, N
Yeargin-Allsopp, M. (2010). Changes in autism spectrum disorder prevalence in 4 areas of the United States. *Disability and Health Journal, 3* (3), 186-201.

- Ritzema, A. M., Sladeczek, I. E., Ghosh, S., Karagiannakis, A., & Manay-Quian, N. (2014). Improving outcomes for children with developmental disabilities through enhanced communication and collaboration between school psychologists and physicians. *Canadian Journal of School Psychology, 29*(4), 317-337.
- Rivard, M., Terroux, A., & Mercier, C. (2014). Effectiveness of early behavioral intervention in public and mainstream settings: The case of preschool-age children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 8*, 1031-1043.
- Robins, D. I. (2008). Screening for autism spectrum disorders in primary care settings. *Autism, 12*, 537-556.
- Robinson, S., Goddard, L., Dritschel, B., Wisley, M., & Howlin, P. (2009). Executive functions in children with autism spectrum disorders. *Brain and Cognition, 71*(3), 362-368.
- Ronald, A., Happe, F., Bolton, P., Butcher, L. M., Price, T. S., Wheelwright, S. . . . Plomin, R. (2006). Genetic heterogeneity between the three components of the autism spectrum: A twin study. *Journal of the American Academy of Child & Adolescent Psychiatry, 45*(6), 691-699.
- Russell, A. J., Jassi, A., Fullana, M. A., Mack, H., Johnston, K., Heyman, I. . . . Mataix-Cols, D. (2013). Cognitive behavior therapy for comorbid obsessive-compulsive disorder in high-functioning autism spectrum disorders: A randomized controlled trial. *Depression and Anxiety, 30*(8), 697-708.
- Safran, J. S. & Safran, S. P. (2001). School-based consultation for Asperger syndrome. *Journal of Educational and Psychological Consultation, 12*, 385-395.
- Schacter, D. L., Gilbert, D. T., Wegner, D. M., Nock, M. K., & Johnsrude, I. (2014). *Psychology*.

New York: Worth.

- Segall, M. J. & Campbell, J. M. (2012). Factors relating to education professionals' classroom practices for the inclusion of students with autism spectrum disorders. *Research in Autism Disorders, 6*, 1156-1167.
- Selevan, S. G., Rice, D. C., Hogan, K. A., Euling, S. Y., Pfahles-Hutchens, A., & Bethel, J. (2003). Blood lead concentration and delayed puberty in girls. *The New England Journal of Medicine, 348*, 1527-1536.
- Self, T. L., Coufal, K., & Parham, D. F. (2010). Allied healthcare providers' role in screening for autism spectrum disorders. *Journal of Allied Health, 39*(3), 165-74.
- Self, T. L., Parham, D. F., & Rajagopalan, J. (2015). Autism spectrum disorder early screening practices: A survey of physicians. *Communication Disorders Quarterly, 36*(4), 195-207.
- Shea, S., Turgay, A., Carroll, A., Schulz, M., Orlik, H., Smith, I., & Dunbar, F. (2004). Risperidone in the treatment of disruptive behavioural symptoms in children with autistic and other pervasive developmental disorders. *Pediatrics, 114*(5), e634-e641.
- Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities, 28*(1), 9-22.
- Simpson, R. L., de Boer-Ott, S. R., & Smith-Myles, B. (2003). Inclusion of learners with autism spectrum disorders in general education settings. *Topics in Language Disorders, 23*(2), 116-133.
- Siperstein R, & Volkmar F. (2004). Parental reporting of regression in children with pervasive

- developmental disorders. *Journal of Autism and Developmental Disorders*. 34(6), 731-734.
- Skuse, D. H. (2012). DSM-5's conceptualization of Autistic Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(4), 344-346.
- Smith, J. A., & Eatough, V. (2007). Interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp. 35–50). Thousand Oaks, CA: Sage.
- Spain, D., Sin, J., Chalder, T., Murphy, D., & Happé, F. (2015). Cognitive behaviour therapy for adults with autism spectrum disorders and psychiatric co-morbidity: A review. *Research in Autism Spectrum Disorders*, 9, 151-162.
- Spears, R., Tollefson, N., & Simpson, R. (2001). Usefulness of different types of assessment data in diagnosing and planning for a student with high-functioning autism. *Behavioral Disorders*, 26(3), 227–242.
- Statistics Canada. (2013). *Disability in Canada: Initial findings from the Canadian Survey on Disability*. Retrieved October 01, 2014, from <http://www.statcan.gc.ca/pub/89-654-x/89-654-x2013002-eng.htm>.
- Steiner, A. M., Goldsmith, T. R., Snow, A. V., & Chawarska, K. (2012). Practitioner's guide to assessment of Autism Spectrum Disorders in infants and toddlers. *Journal of Autism and Developmental Disorders*, 42, 1183-1196.
- Strunk, J. (2009). School nurses' knowledge of autism spectrum disorders. *The Journal of School Nursing*, 25(6), 445-52.
- Stuart, S. K., Flis, L. D., & Rinaldi, C. (2006). Connecting with families: Parents speak up about

- preschool services for their children with autism spectrum disorders. *Teaching Exceptional Children*, 39(1), 46-51.
- Sukhodolsky, D. G., Bloch, M. H., Panza, K. E., & Reichow, B. (2013). Cognitive-behavioral therapy for anxiety in children with high-functioning autism: A meta-analysis. *Pediatrics*, 132(5), e1341-e1350.
- Sutherland, G., Couch, M. A., & Lacono, T. (2002). Health issues for adults with developmental disability. *Research in Developmental Disability*, 23(6), 422-445.
- Swiezy, N., Stuart, M., & Korzekwa, P. (2008). Bridging for success in autism: Training and collaboration across medical, educational, and community systems. *Child and Adolescent Psychiatric Clinics of North America*, 17(4), 907-922.
- Sze, K. M. & Wood, J. J. (2008). Enhancing CBT for the treatment of autism spectrum disorders and concurrent anxiety. *Behavioural and Cognitive Psychotherapy*, 36(4), 403-409.
- Taheri, A. & Perry, A. (2012). Exploring the proposed DSM-5 criteria in a clinical sample. *Journal of Autism and Developmental Disorders*, 42, 1810–1817.
- Taylor, J. L., Lindsay, W. R., & Willner, P. (2008). CBT for for people with intellectual disabilities: Emerging evidence, cognitive ability and IQ effects. *Behavioural and Cognitive Psychotherapy*, 36(6), 723-733.
- Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 34-42.
- Thanh, N. X., Jonsson, E., Salmon, A., & Sebastianski, M. (2014). Incidence and prevalence of

- Fetal Alcohol Spectrum Disorder by sex and age group in Alberta, Canada. *Journal of Population Therapeutics and Clinical Pharmacology*, 21(3), 395-404.
- Thompson, M. N., & Dahling, J. J. (2012). Perceived social status and learning experiences in social cognitive career theory. *Journal of Vocational Behavior*, 80(2), 351-361.
- Tsai, L. Y. & Ghaziuddin, M. (2014). DSM-5 ASD moves forward into the past. *Journal of Autism and Developmental Disorders*, 44(2), 321-330.
- Turner, L. M. & Stone, W. L. (2007). Variability in outcome for children with an ASD diagnosis at age 2. *Journal of Child Psychology and Psychiatry*, 48(8), 793-802.
- van Tongerloo, Michelle A. M. M., van Wijngaarden, Patricia J. M., van, d. G., & Lagro-Janssen, A. (2015). Raising a child with an autism spectrum disorder: 'If this were a partner relationship, I would have quit ages ago'. *Family Practice*, 32(1), 88-93.
- Ventola, P., Kleinman, J., Pandey, J., Barton, M., Allen, S., Green, J., ... Fein, D. (2006). Agreement among four diagnostic instruments for autism spectrum disorders in toddlers. *Journal of Autism and Developmental Disorders*, 36, 839-847.
- Villa, R., Thousand, J., Meyers, H., & Nevin, A. (1996). Teacher and administrator perceptions of heterogeneous education. *Exceptional Children*, 63, 29-45.
- Volker, M. A. & Lopata, C. (2008). Autism: A review of biological bases, assessment, and intervention. *School Psychology Quarterly*, 23(2), 258-270.
- Wallis, K. E. & Smith, S. M. (2008). Developmental screening in pediatric primary care: The role of nurses. *Journal for Specialists in Pediatric Nursing*, 13(2), 130-4.
- Walsh, C. E., Mulder, E., & Tudor, M. E. (2013). Predictors of parent stress in a sample of

- children with ASD: Pain, problem behavior, and parental coping. *Research in Autism Spectrum Disorders*, 7(2), 256-264.
- Watson, S.L., Coons, K. D., & Hayes, S. A. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. Part I: A comparison of parenting stress. *Journal of Intellectual and Developmental Disability*, 38(2), 95-104.
- Watson, S. L., Hayes, S. A., Coons, K. D., & Radford-Paz, E. (2013). Autism spectrum disorder and fetal alcohol disorder. Part II: A qualitative comparison of parenting stress. *Journal of Intellectual and Developmental Disability*, 38(2), 105-113.
- Weiss, M.J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6, 115–130.
- White, S. W., Scahill, L., Klin, A., Koenig, K., & Volkmar, F. R. (2007). Educational placements and service use patterns of individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 37, 1403–1412.
- Wiggins, L. D., Baio, J., & Rice, C. (2006). Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Journal of Developmental and Behavioral Pediatrics*, 27, S79-S87.
- Will, D., Barnfather, J., & Lesley, M. (2013). Self-perceived Autism competency of primary care nurse practitioners. *The Journal for Nurse Practitioners*, 9(6), 350-355.
- Winneke, G. (2011). Developmental aspects of environmental neurotoxicology: lessons from lead and polychlorinated biphenyls. *Journal of Neurological Science*, 308 (1-2), 9-15.
- Wood, J. J., Ehrenreich-May, J., Alessandri, M., Fujii, C., Renno, P., Laugeson, E ... Storch, E.

- A. (2015). Cognitive Behavioral Therapy for early adolescents with autism spectrum disorders and clinical anxiety: A randomized controlled trial. *Behavior Therapy, 46*, 7-19.
- Wood, J. J., Fujii, C., Renno, P., & Dyke, M. V. (2014). Impact of cognitive behavioral therapy on observed autism symptom severity during school recess: A preliminary randomized, controlled trial. *Journal of Autism and Developmental Disorders, 44*, 2264-2276.
- Worley, J. A. & Matson, J. L. (2012). Comparing symptoms of autism spectrum disorders using the current DSM-IV-TR diagnostic criteria and the proposed DSM-5 diagnostic criteria. *Research in Autism Spectrum Disorders, 6*, 965–970.
- Wright, K. & Poulin-Dubois. (2012). Modified Checklist for Autism in Toddlers (M-CHAT) screening at 18 months of age predicts concurrent understanding of desires, word learning and expressive vocabulary. *Research in Autism Spectrum Disorders, 6*, 184-192.
- Yirmiya, N., & Shaked, M. (2005). Psychiatric disorders in parents of children with autism: a meta-analysis. *Journal of Child Psychology and Psychiatry, 46*, 69–83.
- Young, E. L., & Rodi, M. L. (2013). Redefining autism spectrum disorder using DSM-5: The implications of the proposed DSM-5 criteria for autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(4), 758-765.
- Zaidman-Zait, A., Mirenda, P., Zumbo, B. D., Wellington, S., Dua, V., & Kalynchuk, K. (2014). "An item response theory analysis of the parenting stress index-short form with parents of children with autism spectrum disorders": Correction. *Journal of Child Psychology and Psychiatry, 55*(1), 96.
- Zimmerman, A.W., Jyonouchi, H., Comi, A. M., Connors, S. L., Milstien, S., & Heyes, M. P. (2005). Cerebrospinal fluid and serum markers of inflammation in autism. *Pediatric*

Neurology, 33,195–201.

Appendix A

Laurentian University Research Ethics Board Approval



APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS
Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New <input checked="" type="checkbox"/> / Modifications to project / Time extension	
Name of Principal Investigator and school/department	Golnaz Ghaderi, MA PSYCH, supervisor, Shelley Watson/ Psychology
Title of Project	The Perceived Level of Knowledge and Self-Efficacy Regarding the Diagnosis and Treatment of Children with ASD: Perspectives from Medical Professionals
REB file number	2015-06-11
Date of original approval of project	June 26, 2015
Date of approval of project modifications or extension (if applicable)	
Final/Interim report due on: <i>(You may request an extension)</i>	June, 2016
Conditions placed on project	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PHD, Chair, Laurentian University Research Ethics Board

APPENDIX B

Health Care Questionnaire

As a health care professional in practice, you are invited to participate in this study. We will ask you to answer questions about your knowledge and experiences regarding individuals with developmental disabilities in general, as well as individuals with autism spectrum disorder. In addition, we will ask you about your experiences and beliefs about individuals with ASD. You do not have to answer all questions if you do not want to. You can also discontinue your participation at any time without penalty. The questionnaire will take approximately 15 minutes to complete.

Would you also be interested in participating in a semi-structured interview about your experiences as a medical practitioner in relation to developmental disabilities and autism spectrum disorder? If yes, please indicate below and provide your contact information.

No Yes

Name: _____

E-mail Address: _____

Phone Number: _____

We would like to begin by asking a few questions about you.

1. What is your gender?

- Male**
- Female**
- Transgender**
- Prefer not to answer**

2. What is your age? _____ years

3. What is the area of your specialty?

- Family physician**

- Pediatrician
- Psychiatrist
- Other: (please specify) _____

4. How many years you have been practicing as a medical practitioner?

- 1 2 3-5 6-10 11-15 16-20 Other: _____

5. What is your marital status?

- Single
- Married
- Living with a partner
- Divorced
- Separated
- Widowed

6. What type of community do you practice in? Check all that apply.

For the purposes of this question, an urban community would include Sudbury, Timmins, and Sault Ste. Marie; a rural community would include Kapuskasing and Elliot Lake; a remote community would include Sioux Lookout, Moose Factory, and Attawapiskat. A Northern community would include any location north of Parry Sound.

- rural urban sub-urban remote Northern Southern
- First Nations community other (please specify): _____

7. Do you have a family member or close friend with a developmental disability?

Yes No

If yes, what developmental disability?

8. Which degrees and/or qualifications have you already completed?	<i>Degree/Qualification</i>	<i>Educational Institution, City</i>	<i>Year of Completion</i>

We would like to ask you some questions regarding your knowledge about developmental disabilities.

9. How would you rate your current level of knowledge regarding the <u>assessment/diagnosis</u> of individuals with the following:	<i>Very limited</i>	<i>Limited</i>	<i>Moderate</i>	<i>Extensive</i>
Autism spectrum disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Down syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fragile X syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fetal alcohol spectrum disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acquired brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical disabilities (e.g., cerebral palsy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing and/or visual difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other disability (please specify): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. How would you rate your current level of knowledge regarding the <u>treatment</u> of individuals with the following:	<i>Very limited</i>	<i>Limited</i>	<i>Moderate</i>	<i>Extensive</i>
Autism spectrum disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Down syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fragile X syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fetal alcohol spectrum disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acquired brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical disabilities (e.g., cerebral palsy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing and/or visual difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other disability (please specify): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. Have you participated in any <u>training sessions</u> or <u>workshops</u> on any of the following topics:	<i>General undergraduate training</i> (e.g., BA, BSc, etc.)	<i>Professional /graduate training</i> (e.g., MD, BScN, MSc, MSW, PhD, etc.)	<i>Other training</i> (please specify)
Assessment/diagnosis of individuals with developmental disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Treatment of individuals with developmental disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Autism spectrum disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Down syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Fragile X syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Fetal alcohol spectrum disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Acquired brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Physical disabilities (e.g., cerebral palsy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Hearing and/or visual difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____

Other disability (please specify): <hr/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
--	--------------------------	--------------------------	--------------------------------

12. Overall, how helpful did you find the following for increasing your knowledge about developmental disabilities?	<i>Not helpful</i>	<i>Moderately helpful</i>	<i>Very helpful</i>
General undergraduate training (e.g., BA, BSc, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Professional/postgraduate training (e.g., MD, BScN, MSc, MSW, PhD, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify): <hr/> <hr/> <hr/> <hr/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13a. Do you have experience (work or volunteer) with individuals with the following disabilities? (choose all that apply)	<i>Very limited</i>	<i>Limited</i>	<i>Moderate</i>	<i>Extensive</i>
Autism spectrum disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Down syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fragile X syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fetal alcohol spectrum disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acquired brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical disabilities (e.g., cerebral palsy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing and/or visual difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other disability (please specify):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<p>13b. Do you feel that you had enough access to information or resources to meet the needs of individuals with disabilities?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>				
<p>13c. If not, what resources would be most helpful?</p> <p><input type="checkbox"/> Web-based material</p> <p><input type="checkbox"/> Written material (books, journal articles, etc.)</p> <p><input type="checkbox"/> Information obtained from workshops/training seminars</p> <p><input type="checkbox"/> Webinars</p> <p><input type="checkbox"/> Information obtained from colleagues</p> <p><input type="checkbox"/> Other (please specify) _____</p>				
<p>14. In what areas would you like more training or education about different developmental disabilities? Check all that apply.</p> <p><input type="checkbox"/> Social Skills</p> <p><input type="checkbox"/> Language Skills</p> <p><input type="checkbox"/> Fine/Gross Motor Skills</p> <p><input type="checkbox"/> Memory</p> <p><input type="checkbox"/> Sensory</p> <p><input type="checkbox"/> Other (please specify) _____</p>				
<p>15. If you had questions regarding an individual with a developmental disability, to whom</p>				

would you most likely go for help?				
<input type="checkbox"/> Child Care Workers <input type="checkbox"/> Psychologists <input type="checkbox"/> Special Needs Consultants <input type="checkbox"/> Speech and Language Pathologists <input type="checkbox"/> Social Workers <input type="checkbox"/> Other (please specify): _____				
	<i>Not very competent</i>	<i>Mildly competent</i>	<i>Moderately competent</i>	<i>Very competent</i>
16. How competent do you feel <u>collaborating</u> with different healthcare providers, educators, and other professionals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Not very competent (could meet few needs)</i>	<i>Mildly competent (could meet some needs)</i>	<i>Moderately competent (could meet most needs)</i>	<i>Very competent (could meet all needs expertly)</i>
17. How competent do you feel in <u>meeting the needs</u> of	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

individuals with developmental disabilities?				
18a. Have you had experience working as part of an inter-professional team?				
<input type="checkbox"/> No <input type="checkbox"/> Yes				
18b. If yes, was this experience in the field of developmental disabilities?				
<input type="checkbox"/> Yes				
<input type="checkbox"/> No (please specify), it was in the field of _____				
19a. Do you belong to any organizations or groups supporting individuals with developmental disabilities?				
<input type="checkbox"/> No <input type="checkbox"/> Yes				
19b. If yes, what organizations? (please specify):				

Appendix C

Semi-Structured Interview Guide for Medical Practitioners

1. Can you tell me about your previous medical education? Can you tell me about any ongoing health care education? (e.g., CME conferences, journal reading, self-learning modules)
2. What made you want to become a medical practitioner?
3. What made you want to work in Ontario/Northern Ontario?
4. Have you ever heard of Autism Spectrum Disorder (ASD)? What do you know about ASD?
In what context did you receive this education or training? Prompt: Did you learn about ASD in relation to developmental disabilities?
5. Have you been exposed to ASD during your medical practice? How?
6. Where do you obtain your information about ASD? How do these sources impact your perception of ASD?
7. What do you know about the DSM-5 or ICD with regards to diagnosis of ASD?
8. What do you know about best practices for treatment/ management of ASD?
9. How do you feel about working with people with intellectual or developmental disabilities? ASD?
10. What previous experience(s), if any, do you have with people with intellectual or developmental disabilities? ASD?
11. How have these previous experiences influenced your perceived self-efficacy (ability) to care for individuals with intellectual or developmental disabilities? ASD?
12. What disabilities would you feel comfortable taking care of? What disabilities would you not feel comfortable taking care of? Why or Why not?
13. How do you think your discipline is set up to take care of individuals with intellectual disabilities or developmental disabilities? ASD?
14. If you were helping to design a curriculum on the diagnosis and treatment of ASD, what would you include?