

THE KNOWLEDGE OF PHYSICIANS REGARDING AUTISM SPECTRUM DISORDER
(ASD) ACROSS ONTARIO: A MIXED METHODS STUDY

by

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Abstract

The current study is a manuscript-based thesis, divided into 2 journal articles. The first article examines the facilitators and barriers to recruiting physicians for psychological research and is a reflexive article written from the author's personal perspective. Physicians have been a hard population to recruit for research purposes over the years and the article provides insight into recruitment methods from a unique perspective. The second article investigates the knowledge of Ontario physicians regarding autism spectrum disorder (ASD), employing a mixed methods approach. ASD is a complex disorder and is rising in prevalence. Physicians are said to be one of the first to come into contact with an individual with ASD and need to be able to recognize or identify signs and symptoms of the disorder. Previous research highlights that physicians may not feel competent in diagnosing and treating ASD because of their lack of knowledge and training. Physicians completed questionnaires and participated in semi-structured interviews. Analysis of quantitative data included t-tests and ANOVA's, while thematic analysis was employed to analyze the interview transcripts. Areas where knowledge or information regarding ASD was lacking is discussed. Additionally, recommendations for improving medical education regarding ASD and physicians' knowledge, as well as clinical and research implications are discussed.

Keywords:

Autism Spectrum Disorder, diagnosis, physicians' knowledge, physician recruitment, graduate students research, issues in methodology

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Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that is pervasive and chronic throughout the life of the individual living with ASD. ASD interferes with a person's capacity to communicate and relate to others across multiple contexts and causes clinically significant deficits in function (American Psychiatric Association [APA], 2013; Elsabbagh et al., 2012). The way in which ASD manifests symptomology is through impairments in social communication, repetitive behaviours and restricted interests (Anagnostou et al., 2014; Liew et al., 2015). The Centers for Disease Control and Prevention show the prevalence of this spectral disorder are rising, about 1 in 59 individuals now live with ASD (Baio et al., 2018). This estimation has grown from 1 in 150 children in 2000 and is described as one of the fastest growing disabilities in children (Hartley-McAndrew et al., 2014). Despite high prevalence rates, there are still misconceptions surrounding its diagnosis and identification. Physicians are at the front line when it comes to identifying and diagnosing ASD (Crais et al., 2014). The current study investigates the knowledge that physicians have regarding ASD.

1.1 History of ASD

Autism was defined by Leo Kanner in 1943 as an inherent incapacity to create normal, biologically determined, emotional contact with others (Chaste & Leboyer, 2012). There has been an evolution of the (definition) and diagnostic criteria over the years in attempt to accurately define ASD, in addition to negating some of the historical misconceptions and confusion surrounding the disorder, such as prevalence rate discrepancies regarding racial and socio-economic status (SES). These areas of confusion came to be viewed as an aspect of referral bias (Volkmar, 2015). It is now recognized that discrepancies in diagnosis pertaining to SES and

race are likely reflective of under-diagnosis in underprivileged populations, bias or lack of education surrounding ASD (Mandell et al., 2009). The view of the nature and definition of the disorder has also greatly changed over the years. An example that illustrates the change is that ASD was viewed as an early form of childhood schizophrenia up until 1979 (Wolff, 2004).

Paul Eugen Bleuler created the word autism from the Greek word *autos*, meaning “self” in 1912 within the American Journal of Insanity. Bleuler defined autism as separating oneself from external reality (Stotz-Ingenlath, 2000). His view was inaccurate as it was congruent with childhood schizophrenia, which influenced the course of early history associated with ASD. The view was strongly held until studies in the U. K. in the 1970’s made it clear that, in line with Kanner’s distinction, ASD was an exclusive disorder that differed from childhood schizophrenia in terms of onset, clinical presentations, and associated familial history (Volkmar, 2015). As a result of the conceptual change regarding ASD, attempts were made to develop more appropriate approaches to diagnosis, and subsequently the diagnosis shifted from being recognized as childhood schizophrenia in DSM’s I and II, to a specific childhood onset recognized as a Pervasive Developmental Disorder in the DSM-IV (PDD; Powers, 2010).

1.2 The DSM

Infantile autism was first included in the DSM III in 1980 and the diagnostic criteria has undergone numerous revisions thus far (Smith et al., 2015). Confusion and misconception have been prevalent since the inception of the DSM III criteria for ASD. For example, Stone (1987) developed a test to assess professionals’ knowledge of ASD, and the criteria in the DSM III. He found that health care professionals differed significantly from experts in accurately classifying

criteria for diagnosis, in addition to identifying misconceptions regarding social/emotional, cognitive, and general descriptive features of ASD.

The subsequent discussion is based on the DSM 5 and discusses the changes from the DSM-IV-TR to the current DSM 5. The DSM 5 was published in 2013 and five key differences were implemented regarding diagnostic criteria. First, the subcategories such as Autistic Disorder, Asperger's syndrome, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Rett's Disorder and Childhood Disintegrative Disorder, were combined into one dimensional category of ASD, and Rett's Disorder was removed. Second, in the DSM-IV-TR only one criterion of the restrictive and repetitive behaviours was needed for diagnosis, but the updated version requires at least two restrictive and repetitive behaviours (RRB). Third, stereotyped and repetitive use of language was categorized in the updated DSM as a symptom present in the restricted and repetitive behaviours domain, rather than in the communication domain. Fourth, hypo or hyperactivity to sensory stimuli was added as a criterion in the RRB domain (Jashar et al., 2016). Finally, the core features were reduced from a triad to a dyad. For example, the core features in the DSM-IV-TR are characterized as impairments in social interactions, communication deficits and restrictive/repetitive behaviours and interest.

The DSM 5 characterizes two core features; impaired social interactions/communication and restrictive behaviour (Matson et al., 2012). The three disorders (Autistic disorder, Asperger syndrome, and PDD) are condensed into ASD, which oversimplifies identifying core symptomology, increasing difficulty of what behaviours may constitute an ASD, and subsequently leading to possible confusion for physicians as to what is on the spectrum (Lobar, 2015). This change implies that ASDs are not discrete disorders within an umbrella, instead a

spectrum of similar disorders with different presentations. This is shown in the levels which define the differing support needed. Level one individuals require support, level two individuals require substantial support, and individuals rate level three require very substantial support. With the change from categorical diagnoses to a spectrum, health care professionals are expected to view ASD as a continuum of mild to more severe symptoms (APA, 2013).

1.3 Characteristics

ASD is a complex neurodevelopmental disorder characterized by significant impairments in three areas of development: social, communication, and behaviour. Due to the heterogeneity of the disorder, there are large variations in the clinical manifestations of ASD. Spectral differences of ASD may include: levels of language, social and cognitive impairment, developmental ages, aberrant behaviour, as well as restrictive and repetitive behaviours. With the advent of the DSM 5, the core symptoms are represented as a dyad, which consists of impairments in social interaction and communication, as well as the presence of restricted and repetitive behaviours (APA, 2013; Farmer et al., 2013). Social and communication characteristics as well as common behavioural tendencies are subsequently discussed further.

1.3.1 Social and Communication Aspects

It is critical to understand typical developmental stages when making a diagnosis for autism. This is critical knowledge for physicians to be aware of because what may be normal at one age, may be problematic at another. For example, in children who are developing normally, pre-intentional communication soon becomes intentional and by the second year most infants are able intentional communicators, whereas autistic children may not gain the skill of intentional

communication. Understanding intentional communication is being able to make inferences about another person's purpose or aim through interpreting their body language or other forms of communication they may use. A deliberate communicative act requires a gesture, vocalization, or verbalization that is directed toward the adult and that serves a communicative function (Maljaars et al., 2011). For example, getting the mother's attention by saying "mommy." This intentional communication can be akin to theory of mind (Frye & Moore, 2014). Theory of mind is the ability to infer the mental states of others (Ozonoff & Miller, 1995). It has been shown that individuals with autism have deficits in the theory of mind and this leads to impairments in social communication (Happé, 1993).

Infants who are developing typically are, by nature, socially inclined. Gazing at faces, turning toward voices, grasping fingers, eye contact, and reciprocal smiling is prevalent in infancy. Deficiencies in some of these areas as well as oral motor coordination and muscle tone can be indicative of autistic features as early as six months of age (Bryson et al., 2008; Dawson et al., 2000). Moreover, at six months old, infants with ASD demonstrate a qualitative pattern of attention, lacking social attention such as not engaging in social interactions (Bryson et al., 2008). The qualitative pattern demonstrated by infants lacking early social attention and reciprocation fits within the spectrum, as they are congruent with the social aspects or deficits found in ASD (Maestro et al., 2002). Many infants who have or develop the characteristics of ASD are showing some indications of social deficits early, such as not responding to their names (Dawson et al., 2004), lack of curiosity for people (Grelotti et al., 2002), late babbling (Bryson et al., 2008), and social smiling (Maestro et al., 2002). As the child progresses to the toddler stage, many children with ASD have trouble interacting in social games, do not imitate the actions of others, and prefer to play alone. They may fail to seek comfort or respond to parents' displays of

anger and affection in atypical ways. The lack in these social qualities beginning with eye gazing from two to six months of age can cascade down and perpetuate deficits in social and communication skills, due to the lack of social reciprocation. Therefore, they may receive fewer social experiences in subsequent interactions (Rollins et al., 2015).

Social deficiencies are a substantial challenge that affect children with ASD. Studies of elementary school-aged children with ASD have concentrated on the discrepancies of children with ASD in comparing outcomes to children without ASD (Locke et al., 2016). Some examples of these outcomes include: detachment and seclusion in the schoolyard or at recess, decreased likelihood of communal friendships (Bauminger et al., 2010), less probability to obtain quality relationships (Calder et al., 2012), and less likelihood of acceptance as compared to their typically developing peers (Locke et al., 2013). These negative outcomes can often perpetuate social deficiencies as they may not be involved in as much social engagement as their peers, which may begin with eye gazing as a social interaction with their parents (Rollins et al., 2015).

Some overall social symptomology is inclusive of, but not limited to, restricted or no eye contact, reluctance to being held or touched, proximal deficiencies, responding to social interactions, but not initiating them, neglect to share observations or experiences with others, difficulty understanding jokes, figures of speech or sarcasm, and difficulty reading facial expressions and body language (Autism Speaks, 2016). Speech ability in children with ASD can influence social interactions especially if speech is absent or incoherent. Individuals with ASD occasionally do not develop verbal communication ability and some respond to a narrow variation of topics. Some may be so unresponsive to context that it is somewhat nonsensical in usual conversation (Belmonte et al., 2004).

1.3.2 Behaviours

Atypical behaviours related to ASD are imperative for physicians to be aware of so they can properly diagnose or identify ASD. The DSM-5 characterizes the behavioural aspects of ASD as restricted, repetitive patterns of behaviour, interests, or activities. Some of these behaviours are inclusive of, but not limited to; stereotyped or repetitive, motor movements, use of objects, or speech. Examples of these behaviours can be lining up toys like cars, echolalia (repeating a phrase back in the same tone), and phrases that are of specific interest to the individual (APA, 2013). Furthermore, the DSM-5 delineates behavioural symptomology as: insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal and nonverbal behaviour.

Behavioural symptoms of ASD are sometimes characterized as secondary symptoms. Some of these serious behavioural disturbances include self-injurious behaviour, aggression, and tantrums in response to routine environmental demands (McCracken et al., 2002). These behaviours could be the result of an inability or difficulty in regulating emotions. The propensity to “lose control” may be predominantly marked in unfamiliar or unexperienced, overwhelming or frustrating situations. Frustration can also result in self-injurious behaviours such as head banging, hair pulling or self-biting (Autism Speaks, 2012). The children with ASD at highest risk of aggression displayed the following characteristics: more repetitive behaviours, especially self-injurious or ritualistic behaviours, and extreme resistance to change (Autism Speaks, 2012). Brutally intense self-aggression is present in as many as 14.6%, and this practice may lead to hospitalization, institutionalization, and removal from less restrictive school settings, and a worse prognosis (Brentani et al., 2013).

1.4 Etiology/Risk factors

If physicians have knowledge regarding some of the potential causes and risk factors discussed subsequently, this may lead to a more competent identification of ASD as many aspects of ASD remain poorly understood. Some of this misunderstanding is a result of multiple unclear etiologies (Autism Speaks, 2015). Major advances have been made in terms of highlighting the genetic, biological, environmental, and developmental origins of the condition (Elsabbagh et al., 2012). Furthermore, it is suggested that the cause may be better understood as a multidirectional interaction between genetics and the environment, activation of the immune system and epigenetic dysregulation in the fetal brain (Nardone & Elliott, 2016). To explain it further, genetics may lay a foundation or disposition and environmental triggers are needed to activate, articulating the interaction between genetics and the environment. Some genes that have been identified as playing a potential role in the make up of ASD are: NLGN3, NLGN4, SHANK2 and SHANK3 (Liu et al., 2013). Genetic variations are now included in ASD testing, but genetic variation only occurs in less than 25 percent of individuals with ASD (Chen et al., 2013), highlighting the fact that it is a multifaceted disorder.

One chromosome that has been identified as associated with ASD presence is the 16th chromosome. The 16p11.2 deletion syndrome is a condition caused by a deletion of a small piece of chromosome 16. In this syndrome the small piece deleted is near the middle of the chromosome at a location labelled p11.2. People with 16p11.2 deletion syndrome typically have developmental delay and intellectual disability. Most individuals with this syndrome also show autistic like symptoms and are usually on the spectrum (Hanson et al., 2010). Some of these symptoms include impaired communication and socialization skills, as well as delayed

development of speech and language. Expressive language skills, which are vocabulary and speech production, are more commonly affected than receptive language, which is the ability to comprehend speech. Some people with this syndrome have recurrent seizures or epilepsy as well, which is common with individuals with ASD. A meta-analysis completed by Amiet et al. (2008) substantiates the commonality of co-occurring epilepsy or seizures between this syndrome and ASD by showing that individuals with ASD and intellectual disability have a higher rate of comorbidity with epilepsy. Furthermore, the more severe the intellectual disability, the higher the comorbidity rate between ASD and epilepsy (Amiet et al., 2008). Therefore, the deletion syndrome and ASD share many common clinical presentations.

Some prenatal environmental factors contributing to the etiology of autism have been explored. Prenatal environmental factors include maternal gestational diabetes, maternal bleeding during pregnancy, and maternal medication (Chaste & Leboyer, 2012). There are many prenatal factors that may contribute to autistic features, but there is not enough evidence to declare one factor as the cause of ASD (Gardener et al., 2009). Furthermore, prenatal exposure to certain toxins or chemicals such as thalidomide (used to treat certain cancers and of a complication of leprosy), terbutaline (used to stop premature labor), and valproic acid (used to control seizures) have been correlated with an increased risk of ASD (Autism Speaks, 2016). Proximity of the mother, during certain gestation periods, to pesticides such as organochlorine pesticide, or chlorinated hydrocarbon, has also been linked to the etiology of autism (Roberts et al., 2007). Studies have also discovered that children who are exposed to heavy metals such as lead and mercury during critical early developmental period, show ASD-like characteristics (Winneke, 2011). Although there is still much research needed to encapsulate all risk factors and what causes ASD, some factors are clear.

Heritability is one factor that influences the risk of ASD. Researchers suggest that the overall heritability of ASD is estimated at 90% (Lichtenstein et al., 2010). Additionally, researchers conducting twin studies demonstrate at least some of the increase is due to genetic variation rather than environmental influences. For example, monozygotic twins have a greater likelihood of autistic traits than dizygotic twins (Lichtenstein et al., 2010). Researchers have articulated rates among monozygotic twins having autistic traits to be 65% to 95% versus 3% to 8% among dizygotic twins (Boyd et al., 2010; Volker & Lopata, 2008). Of note, researchers have also found that the comorbidity rate of other disorders occurred more frequently within monozygotic twins and these included attention deficit hyperactivity disorder (ADHD), developmental coordination disorder, and tic disorder (Lichtenstein et al., 2010).

1.5 Prevalence Rates

It is clear that prevalence rates have increased over time, but these increases are variable based on regions and ethnic background (Elsabbagh et al., 2012). In an American study completed by Dickerson and associates (2016), the prevalence rates decrease compared to the average due to a number of factors such as belonging to a racial minority, living in a rural community, and being below the poverty line. This is not to say that ASD is less prevalent in these populations, but rather it is less identified. Regardless of these factors, the prevalence rate is still increasing on average and is described as one of the fastest growing disabilities in children (Hartley-McAndrew et al., 2014). There are a number of potential factors associated with influencing the increase in prevalence, including: expansion of the diagnostic criteria, diagnostic switching from other developmental disabilities to PDD, service availability, and awareness of autistic spectrum disorders in both the lay and professional public (Elsabbagh et al., 2012). As

mentioned previously, the Centers for Disease Control and Prevention CDC (2018) estimated that currently ASD affects 1 in 59 children, and boys are four times more likely to have a diagnosis of ASD than girls.

1.6 Assessment, Screening and Diagnosis

Pathophysiology of ASD is not yet clearly established, therefore clinicians and researchers observe patterns of behaviour within an individual and across time to make a diagnosis (Lord & Risi, 1998). There are standardized behavioural checklists and assessment tools, which have been validated to assist in the diagnosis of ASD. Some of these screening, assessment, or diagnostic tools include the Modified Checklist for Autism in Toddlers (M-CHAT), the Autism Diagnostic Observation Schedule (ADOS), the Childhood Autism Rating Scale (CARS), and the Diagnostic and Statistical Manual 5 (DSM-5).

The American Academy of Paediatrics (AAP) collected data from a survey and revealed that 23% of pediatricians employed a developmental standardized screening tool when assessing for ASD (Sharon, 2015). Barriers to using the standardized screening tools were noted and a common theme was apparent. Pediatricians cited lack of familiarity with the screening tools as a major reason for not using them regularly (Dosreis et al., 2006). Due to the lack of familiarity or knowledge of these tools, some children may not receive a diagnosis as early as they would if these tools were regularly used. Therefore, it is important for physicians to familiarize themselves with some standardized diagnostic tools such as the ones discussed subsequently. Current studies demonstrate screening tools such as the Modified Checklist for Autism in Toddlers (M-CHAT) identify toddlers with ASD earlier and more consistently than pediatrician clinical judgement. Additionally, screening tools increase the pediatrician's capability to refer

toddlers at risk for ASD (Robins, 2008). It is therefore recommended by the AAP that universal ASD screening occurs at well-child visits at 18 and 24 months. Furthermore, they recommend that standardized developmental tools be used at nine, 18, 24, and 30 month visits regardless of whether a concern has been raised in order to screen early for potential developmental disabilities (Johnson & Myers, 2007).

1.6.1 M-CHAT-R

The M-CHAT-R is a valid screening tool to assess for risk of ASD in toddlers between 16 and 30 months (Robins et al., 2009). The M-CHAT-R was designed to maximize sensitivity, which means it detects as many cases of ASD as possible. The M-CHAT-R has a reliability rating of .79 as measured by Cronbach's alpha. There may be a high false positive rate, and therefore health care professionals should be cognizant of this fact (Robins et al., 2009). Not all children who are scored in the at-risk level will warrant a diagnosis of ASD. In an attempt to mitigate this issue, follow-up questions were developed, and an amended version came out titled the M-CHAT-R/F. However, even with the follow-up version, a significant number of individuals who score at risk level on the M-CHAT-R/F may not be diagnosed with ASD. It is important to bear in mind that these children may be at high risk for other developmental disorders or delays so further evaluation is still needed. The M-CHAT-R can be scored in less than two minutes, making it quite an efficient tool. A parent completes the M-CHAT-R questionnaire, then the instrument is scored according to the instructions (Robins et al., 2009).

1.6.2 Autism Diagnostic Observation Schedule (ADOS)

The ADOS – 2 is described as a standardized diagnostic measure designed for both clinical and research use. The ADOS – 2 is a revised version of the ADOS which is a semi-structured assessment of communication, social interaction, and play (or imaginative use of materials) to identify individuals with ASD's. The ADOS is considered the gold standard in terms of a diagnostic measurement but it was limited in use for younger children (Luyster et al., 2009), therefore, the advent of the toddler module was created, intended for children under the age of 30 months. The measure provides raw scores from the two domains of Social Affect (SA) and Restricted and Repetitive Behaviours (RRB) (Hus et al., 2014). There is a standardized set of materials and activities as well as a series of coded behaviours targeting symptoms of an autism spectrum disorder. The ADOS – 2 is divided into five different modules that were established to address the developmental changes in autism spectrum disorders over time. The administration of the modules is based on age and language level and it ranges from a toddler module up to a module established for older adolescents and adults. Clinical training for the ADOS – 2 typically takes two days and an additional day for the toddler module. Research training for the measurement takes an additional two and a half days of hands on practice in administration and scoring.

1.6.3 CARS

One of the most prevalent rating scales used around the world is The Childhood Autism Rating Scale (CARS; Dawkins et al., 2016). The CARS evaluates clinical behaviours and has undergone revision to stay consistent with new ASD criteria and it is now known as the CARS2-Standard Version (CARS2-ST), which includes updated field trial data. This assessment tool

continues to be used with children under the age of 6 and additionally, individuals of any age with underdeveloped verbal skills and IQ scores less than 80. The CARS2-High Functioning Version (CARS2-HF) was added to evaluate individuals who have overall IQ scores of 80 or higher, individuals who have verbal fluency, and who are 6 years old or older (Dawkins et al., 2016). Studies have been completed measuring the congruence between the updated version of the DSM and the assessment tool. Mayes et al. (2014) found 84 % congruence between the CARS and DSM-5 in a sample of individuals between the ages of 1 and 18.

1.7 Treatment

After the assessment and relevant screening tools are conducted and employed, treatment referrals or recommendations are the next appropriate step for health care professionals (CDC, 2016). There are programs that are designed to facilitate the improvement of behavioural, social, communication, and cognitive domains. Some of the intervention strategies that are employed by health care professionals are: motor and sensory interventions, assistive and adaptive technology, medications, behavioural interventions (e.g., EIBI) and psychotherapy (e.g., CBT). ASD is heterogeneous in nature and therefore treatment interventions must be tailored to the individual and the symptoms they display.

Given the multidimensional etiological make up that includes genetic variation as well as environmental factors, therapeutic interventions should also reflect such diversity. However, due to the lack of consistency and understanding surrounding ASD, this diversity may not be adequately established yet. For example, there is no “cure” or specific treatment for ASD (Leyfer et al., 2006), and biological intervention or pharmacological treatment is limited to reducing secondary symptoms (Eikeseth, 2009). While Risperidone may be used to treat aggression, self-

injury, and temper tantrums, this pharmacological treatment does not mitigate the core deficits of the ASD, namely, the deficits in social interaction, communication, and stereotyped behaviours (Eikeseth, 2009).

When taking a biological perspective, younger brains are more plastic in nature. Children are more susceptible to pick up verbal and behavioural skills, which demonstrates a more appropriate window of opportunity to intervene (Dawson, 2008; Pickles et al., 2014). Additionally, at an early age, environmental factors may contribute, such as greater opportunities or experiences for social interaction. The brain undergoes continuous and rapid development throughout childhood (Thompson, 2001), therefore the brain will be negatively affected when crucial social experiences do not occur (Greenough et al., 1987). Children who interact socially are approached more often by other children to engage in play, leading to more social experiences (Lang et al., 2014). If the child does not engage in play or social interaction because of a lack of interest due to ASD tendencies, they will miss these experiences that influence brain development. Therefore, it is crucial to identify ASD at an early age in order to facilitate engaging in social interaction and to perpetuate social experience (Dawson, 2008). Furthermore, children who learn to verbally ask for items may in turn receive more social interaction. For example, a child may ask for a drink and the adult may reciprocate the social engagement by asking the child what kind of drink, increasing social involvement (Raulston et al., 2013). It has been stated that it is an influence of both biology and environmental factors that are the causes for successful early intervention, somewhat reflecting the multidimensional nature of ASD (Webb et al., 2014). The most common intervention strategy is discussed subsequently, which is Early Intensive Behavioural Intervention (EIBI).

1.7.1 Early Intensive Behavioural Intervention (EIBI).

Evidence shows that EIBI is a well-established intervention for ASD, and it is suggested that no other treatment intervention for ASD warrants this distinction (Eldevik et al., 2009; Rogers & Vismara, 2008). Research continues to shed a positive light on the effects of this treatment, with the first empirical results established by Lovaas (1987). The results demonstrate that 47% of children receiving EIBI had an IQ greater than 85 and were able to be placed in a general education classroom post treatment. McEachin et al. (1993) followed up six years later and found that the improvements were maintained. The essential elements of EIBI programs and what they should include are discussed subsequently. Intervention should be comprehensive and additionally be tailored for the individual, addressing all skill domains. Behavioural techniques are used to build new appropriate behaviours and should reduce maladaptive behaviours. These techniques include: prompting, differential reinforcement, discrete-trial instruction, incidental teaching, activity-embedded trials, task analysis, and others. Age appropriate behaviours and normal developmental progression are considered when selecting the intervention goals and short-term objectives (Eldevik et al., 2009).

Initially, intervention is one on one and takes place at the home with a slow progression towards small or large groups when needed and to other environments. EIBI is directed by one or more individuals with advanced training in the domain of applied behavioural analysis and with young children with ASD, in addition, parents serve as therapist for their children when the child is not in therapy. The program is intensive in nature and can be up to 40 hours per week, in addition it is delivered year-round for approximately two years. Furthermore, children typically begin intervention in preschool years at the ages of three to four (Eldevik et al., 2009). Riechow

(2012) reviewed five meta-analyses, which included 26 studies evaluating the effectiveness of EIBI. Surveys were completed by parents and service providers and they indicated that EIBI is one of the most prevalent and requested treatment approaches for young children with ASDs (Reichow, 2012). After investigation, Reichow (2012) identified that four out of the five analyses have significant results in terms of the individual's improvements. He therefore concluded that EIBI could be considered an evidence-based practice for children with ASD.

Engaging in treatment can paint a positive picture because of the progress that can take place. What is crucial for therapy to be effective is a recognition or diagnosis of ASD by health care professionals, especially at an early age. Knowledge of ASD directly affects early and accurate diagnosis and results of previous studies demonstrate that knowledge needs to be improved in order to reduce the age of diagnosis for individuals with ASD.

1.8 Previous Studies of Health Care Professionals Knowledge of ASD

Knowledge of ASD in medical professionals is instrumental in decreasing the average age of diagnosis for individuals with ASD, which subsequently improves their prognosis. There have been studies completed in other countries assessing health care professionals' knowledge surrounding ASD (Hartley-McAndrew et al., 2014; Igwe et al., 2011; Imran et al., 2011). Igwe and associates (2011) concluded that education about ASD is needed to increase health care professionals' knowledge and can be delivered through continuing medical instruction and highlighting childhood ASD in their training curriculum. Continual instruction and training will improve early identification and diagnosis of childhood ASD, in addition to allowing children with ASD to participate in early interventions that are known to improve prognosis. Researchers have described a need for continual education when knowledge and self-efficacy are not

adequate for the diagnosis and treatment of ASD. There are also geographic differences pertaining to knowledge and competency for diagnosing and treating ASD, articulating the relevance of Ontario specific research to inform where additional education or training pertaining to ASD may be needed.

Hartley-McAndrew and associates (2014) concluded that the majority of health care professionals are well informed regarding the prevalence of ASD, but many had gaps in knowledge when it came to the specific diagnostic criteria according to the new DSM-5. For example, the DSM-5 requires deficits in non-verbal communication and difficulty in developing and maintaining relationships for diagnosis, and only 53% and 46% of professionals felt these two features were necessary, respectively.

Researchers in the United States have illustrated the need for additional education and training for physicians (Finke et al., 2010; Hartley-McAndrew et al., 2014). Hartley-McAndrew et al. (2014) assessed physicians, nurses, nurse practitioners, therapists, and educators because they all come into contact with children from an early age. Health care professionals are in a particularly important position to inform, diagnose, provide support, and intervention to the children they come into contact with; however, the majority of participants felt that it would be beneficial to receive further training on the diagnosis and identification of ASD. The health care professionals further identified the need for more education pertaining to the interaction with individuals with ASD and the tools that aid in diagnosis. This study was completed in the U.S. and the researchers recognized and articulated that DSM updates lead to confusion and misconceptions of the current diagnosis needs.

Furthermore, Finke and associates (2010) found in the United States that pediatricians indicated a lack of training, in addition to indicating that experience or education regarding ASD gained from their residency and medical school was disproportionate to other training. The disproportion was explicitly stated by one doctor who said, “Generally, in pediatric residency, there was no specific training on autism . . . it’s usually covered under rotations in pediatric neurology or developmental pediatrics” (p. 258). This statement does raise concerns because of the complexity of ASD, and the importance of diagnosis when signs first appear. If this information and knowledge is not taught, health care professionals will not be aware of the importance of early diagnosis. As a result, the average age of diagnosis will not decrease.

Imran and colleagues (2011) revealed that in Pakistan there is hesitance to diagnosis ASD at an early age. The researchers concluded that this may be due to lack of understanding or knowledge of surrounding presentation, reluctance of labeling a child at an early age, in addition to viewing symptoms as a result of potential comorbid disorders such as cognitive delay. The researchers also concluded that for earlier and more accurate diagnosis, negative opinions and beliefs of health care professionals regarding various aspects of ASD should be changed regarding ASD. Education and training could facilitate changing negative beliefs and improve understanding of the benefits in early diagnosis, and the knowledge to accurately identify ASD at an earlier age.

Rhoades et al. (2007) found significant differences between health professionals’ knowledge of ASD, with developmental pediatricians articulating the highest level of knowledge, characterized by diagnosing at the youngest age and offering information to parents regarding ASD and services available. This study found that most professionals provided

caregivers with further information about ASD, especially developmental pediatricians, but many did not. Furthermore, only about 15-34% gave advice on educational or medical programs, and even fewer (6%) made referrals to ASD specialists. The lack of information and direction given to caregivers may reflect a lack of training and knowledge of ASD. In the study, it was recommended that all physicians should be provided with additional training surrounding ASD. Moreover, the lack of referral to services identified may be due to lack of knowledge pertaining to services available. Because of the lack of information given to parents by medical professionals, parents had to turn to outside sources to learn more about ASD.

Furthermore, Rhoades and associates (2007) discussed how increased training would address the other concern raised, namely the average age of diagnoses. Further training would lead to a decrease in the age at which ASD is screened for and diagnosed. It was found in one study that as low as 10% of pediatricians regularly screen for ASD (Dosreis et al., 2006). The lack of screening reflects a lack of knowledge and training surrounding ASD and may act as a barrier to obtaining an earlier diagnosis of ASD.

The studies previously discussed demonstrate that there are differences in geographic areas pertaining to knowledge and attitudes towards ASD. For example, in Pakistan there is still negative attitudes towards ASD delaying diagnosis. Another example of differences of knowledge in geographic regions is, researchers demonstrated that in America there is a lack of knowledge specifically pertaining to the need for deficits in non-verbal communication and difficulty in developing and maintaining relationships for a diagnosis. However, a consistent issue emerges in the previous studies, which is there is a recognition for an increase in knowledge and training for medical professionals. There may be no direct cure for ASD as of

yet, but early identification and intensive behavioural and intervention (EIBI) can make a substantial impact in a child's IQ, verbal, and adaptive functioning (Dawson et al., 2010; Reichow, 2012; Wallace & Rogers, 2010; Warren et al., 2011) and can significantly decrease cost of care over the life time of the individual (Jacobson & Mulick, 2000; Rollins et al., 2015; Stahmer et al., 2011).

With the development of intervention methods, along with early diagnosis, the treatment of ASD is now plausible. What is necessary for the best outcome is detecting and diagnosing ASD and screening infants at risk before the disorder has fully been established (Dawson, 2008). For the best possible treatment of ASD, it is crucial for health care professionals to possess the necessary and knowledge, understanding, and self-efficacy to identify and diagnose ASD at an early age by recognizing the signs. Studies have evaluated the knowledge and efficacy of health care professionals in other countries and found misconceptions and lack of knowledge (Hartley-McAndrew et al., 2014; Igwe et al., 2011; Imran et al., 2011). Moreover, there is a recognition that further training and education would be beneficial by the health care professionals themselves.

1.9 Purpose and Research Questions

The current study's objectives are to understand physicians' levels of knowledge regarding ASD in Ontario.

1. What do Ontario health care practitioners know about ASD diagnosis?
2. What are the factors/facilitators that contribute to increased knowledge?

1.9.1 Rationale

ASD has an early onset, with signs showing as early as 6 months of age (Rhoades et al., 2007; Rollins et al., 2015); however, concerns have been raised by researchers pertaining to the age at which children get a diagnosis. Although more than 80% of children with ASD show clear behavioural signs by two years of age and a diagnosis can be made reliably this early, the average age at diagnosis is about four years (Anagnostou et al. 2014; Daniels & Mandell, 2013). The delay in diagnosis can delay treatment at a critical developmental period as the early the treatment is implemented, the better the outcome (Daniels & Mandell, 2013).

Concerns have been raised by researchers pertaining to lack of information about services available for ASD (Rhoades et al., 2007), differences in diagnostic age of individuals with ASD (Jo et al., 2015), and knowledge of medical professionals specific to geographical regions (Mandell et al., 2005; Ouellette-Kuntz et al., 2009; Rosenberg et al., 2011). Furthermore, studies hypothesize that discrepancies or differences in ASD diagnoses, particularly age of diagnosis, may result from inconsistencies in the amount of knowledge of typical developmental milestones across groups (Harrison et al., 2016). Moreover, a qualitative study found that parents felt that physicians did not intervene early enough or react early enough to parental concerns pertaining to development (Carbone et al., 2010). Additionally, Carbone et al. (2010) found that parents identified that care for children with ASD after the diagnosis was not as well-rounded, harmonized, and family-centered than desired. The researchers identified that pediatricians recognize their lack of knowledge and desire to improve services, but due to insufficient time, training, and resources, their understanding of ASD still needs improvement. Furthermore, areas that would likely see the most benefit are rural and northern communities as rural communities

have been identified as having higher ages of diagnosis, potentially due to medical professional knowledge (Daniels & Mandell, 2013; Mandell et al., 2005).

It has been stated that physicians or health care professionals are on the front line when it comes to identifying a possible case of ASD as they likely are first to come into contact with the child (Crais et al., 2014). Health care professionals play a vital role in identifying ASD. They need to recognize signs as early as possible has been clearly documented (Bethell et al., 2011; Johnson et al., 2007; Miller et al., 2011). In a study completed by Self et al. (2015), it was found that there was a high rate (~80%) of health professionals using screening tools, but only 27% of pediatricians and 3% of family physicians screened in accordance with American Academy of Pediatrics (AAP) guidelines. These guidelines were implemented in order to assist in the identification of concerns from birth to three years of age and specify screening at 18 to 24 months of age with an ASD specific screening tool (Self et al., 2015). As stated previously, researchers have demonstrated that tools such as the Modified Checklist for Autism in Toddlers (M-CHAT) identify toddlers with ASD earlier and more consistently than pediatrician's clinical judgement (Robins, 2008). Health care professionals who indicated that they did not screen, identified barriers such as: insufficient training, confidence, and knowledge of available resources (Self et al., 2015; Sharon, 2015).

This literature establishes the need for studying medical practitioners' roles in the diagnosis and treatment of ASD. There is a paucity of research examining the knowledge of health care practitioners in Ontario. Furthermore, there is a need for more research investigating factors that contribute to increased knowledge across health care disciplines.

1.11 Overview of document

This thesis is organized into 2 journal articles, which are formatted according to the journal to which they will be submitted. The first article (Chapter two) explored recruitment methods for physicians, as the target sample size for the overall study was not able to be obtained. Chapter two explores the difficulties and challenges that were faced from attempting to recruit such a difficult population (i.e., physicians). The document explores the techniques utilized during the study and addresses the facilitators and barriers for potential methods of recruitment. The article is written in the context of a psychological graduate student recruiting participants from a medical field (i.e. physicians), and explores some inherent difficulties for this research, such as perceived scope of practice of physicians.

Additionally, the second chapter is a reflective piece of a graduate student completing graduate level research. Challenges and difficulties for research manifest in any graduate student's journey. The chapter also acts as a validation for graduate students who do face adversity during their research. Moreover, chapter two illustrates the process of reframing perceived failure from the perspective of a graduate student in order to continually progress throughout the journey.

Chapter three investigates the research questions presented above, specifically what Ontario physicians know regarding ASD. Physicians are an integral part in the journey of ASD and are usually the first to come into contact with an individual with ASD (Crais et al., 2014). The study employed a mixed methods approach, utilizing questionnaires and a semi-structured interview. Results are discussed quantitatively and qualitatively regarding physicians' knowledge

surrounding ASD. Additionally, implications, recommendations, and future research are explored.

Chapter 2

2 « Facilitators and Barriers to Recruiting Physicians for Psychological Research: The Personal Experience of a Graduate Student»

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Author note:

Please consider this article for publication in the International Journal of Qualitative Methods.

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Conflict of Interest:

None

Abstract

This article is a reflective piece on a master's student's journey, and my navigation through a perceived methodological failure. The article explores the challenges recruiting physicians as participants for psychological research, particularly when a graduate student. The interdisciplinary nature of this project bridged into the health field as the focus was on physicians' knowledge surrounding autism spectrum disorder (ASD). There are unique difficulties with recruiting from a physician population. Facilitators and barriers regarding the techniques and methods utilized are described and recommendations are made. Implications regarding conceptualizing research failures for graduate students are discussed, as well as implications for supervisors and the research population.

Facilitators and Barriers to Recruiting Physicians for Psychological Research:

The Personal Experience of a Graduate Student

I am a Master of Arts student studying Applied Psychology at Laurentian University. I began my professional and research journey studying Autism Spectrum Disorder (ASD) through personal experiences and a fascination with the disorder. I was fortunate enough to have had the opportunity to work as an intensive behavioural intervention (IBI) instructor therapist before my graduate work. Through this experience, I worked closely with children with ASD and developed a fondness for these individuals. The ambiguous and complex nature of ASD captured my interest, and I decided to pursue graduate studies in this field. I began graduate school with the intent to help advance the field to better support individuals with ASD and their families.

For my Master's research, I wanted to study the geographic differences in physicians' knowledge pertaining to ASD, with an emphasis on the differences between physicians' knowledge in northern and southern Ontario, as well as differences between rural and urban settings. Physicians are considered to be at the front line when it comes to care for individuals with ASD (Crais et al., 2014), and therefore it was essential to work closely with physicians for my proposed graduate research.

Despite my best efforts, I was unfortunately unable to reach these goals and complete the study I intended to conduct for a number of reasons, including methodological and strategic issues. Researchers have drawn attention to the importance of reflecting on, and publishing about, their research failures (Ellis et al., 2014). Reflecting on research failures is important as it is an active learning experience. Furthermore, failures in research can offer valuable knowledge

and insight for future research directions (Gregory, 2019). However, this opportunity is missed in many research disciplines, as the emphasis is overwhelmingly on publishing statistically significant results. Given that researchers, particularly students, often do not publish on these downfalls, this paper describes some of the challenges I faced during the completion of my Master's thesis data collection. Specifically, the focus of the following paper is on giving insight into the facilitators and barriers of recruiting physicians from my personal perspective as a graduate student.

The identification and reflection on these facilitators and barriers in the recruitment of physicians is also taken from a somewhat unique perspective – psychological research. The perspective in the context of psychological research, as opposed to specifically medical or pharmacological research, provides information regarding specific challenges that may be faced in this context. Unique strategies and techniques may be more suitable to recruit physicians for psychological research as physicians may be hesitant to address mental health in their practice because of a perceived lack of resources, confidence, and weaknesses in their own competency (Loeb et al., 2012). While most studies specifically examine barriers to physician recruitment in the context of physician-to-physician recruitment in primary care research (e.g., Asch et al., 2000; Johnston et al., 2010), to the researcher's knowledge, there is no literature analyzing these barriers from the perspective of a graduate psychological researcher. Subsequently, I reflect on the process and outcomes of “failing” in the aspect of graduate research and reflect on the personal effects of failure during my graduate research and my process to conceptually reframe this failure.

Physicians as Participants in Psychological Research

Difficulty recruiting and retaining physicians for medical and pharmacological research has been previously discussed in the literature (Asch et al., 2000; Borgiel et al., 1989; Goodyear-Smith, 2009; Hoddinott et al., 2007; Johnston et al., 2010; Levinson et al., 1998; Loeb et al., 2012; Rahman et al., 2011; Thorpe et al., 2009) and is still a persistent problem (Noel & Huang, 2019; Ziegenfuss et al., 2014). In fact, researchers have shown that most clinical research does not obtain the intended recruitment targets (Rahman et al., 2011), and response rates are continually declining (Keating et al., 2008; Taylor & Scott, 2019; Turnbull et al., 2015). Some of the challenges or reasons physicians decline to participate in various research studies include: time constraints, the population being heavily studied, and research outside their scope of practice, or more specifically, an area in which they feel they are not performing well in or are not very knowledgeable.

Presently, there is a paucity of research concerning physician recruitment for qualitative research, specifically pertaining to the facilitators and barriers that influence response rates and best practices in recruitment for (graduate) psychological research. In the context of my proposed Master's thesis research, this challenge is particularly relevant as the prevalence of ASD continues to rise, with estimated prevalence rates increasing from 1 in 68 in 2014 to 1 in 59 in 2018 (CDC, 2014; CDC, 2018). Furthermore, there are a number of physical problems associated with ASD, such as gastrointestinal problems, epilepsy, and feeding and eating issues that require the care of a physician (Geier et al., 2012). As physicians are often the first line of care for both medical concerns and mental illnesses (Loeb et al., 2012), their perspectives on caring for individuals with ASD are important to improving overall outcomes.

My Proposed Study

The current study was designed to identify and assess physicians' levels of knowledge and self-efficacy pertaining to ASD and how they feel about their ability to identify, diagnose, and help treat ASD. My study was originally guided by three specific research questions:

1. What do Ontario physicians know about ASD diagnosis?
 - a. Are there significant differences in physicians' levels of knowledge and self-efficacy regarding diagnosis in northern Ontario compared to southern Ontario?
 - b. Are there differences in physicians' knowledge and self-efficacy regarding diagnosis and treatment between rural and urban communities?
2. What are the factors/facilitators that contribute to increased knowledge among physicians?
3. What are the factors/facilitators that contribute to increased self-efficacy among physicians?

Questionnaires and Semi-Structured Interviews

A mixed methods approach was employed, consisting of an initial survey, which included two questionnaires: The Health Care Professional Questionnaire, adapted from the Health Care Student Questionnaire (Isaacs, Minnes, Burbidge, Loh, & Versnel, 2012; Minnes, Isaacs, Burbidge, Loh, & Versnel, 2012), and the Knowledge about Childhood Autism among Health Workers Questionnaire (KCAHW; Bakare, Ebigbo, Agomoh, & Menkiti, 2008). Both questionnaires were accessed through a REDCap (Research Electronic Data Capture) link hosted at Laurentian University. REDCap is a secure, web-based software platform designed to support data capture for research studies (Harris et al., 2009).

The semi-structured interview consisted of 15 open-ended questions, which allowed physicians to discuss how they became physicians (e.g., their journey) and their knowledge regarding ASD in general as well as their comfort level regarding assessment, diagnosis, and treatment of ASD. Additionally, the interview guide was designed to understand physicians' perceived competencies and knowledge regarding ASD. All interviews were transcribed and analyzed using thematic analysis (Braun & Clarke, 2013). Initially, the content was read and re-read in order to code and generate the themes. The analysis of the interviews was conducted to enrich the quantitative results obtained from the phase I surveys. Unfortunately, very few physicians that filled out the survey agreed to participate in the semi-structured interview (3 out of 17, ~18%).

Initially, it was established that I would need a sample size of 80 Ontario physicians to statistically compare the differences geographically and cross-disciplinarily to answer my primary research questions. Personally, I was more interested in studying the statistical findings that the questionnaire portion of the study would provide, because I wanted to see if there were specific knowledge differences between regions in Ontario, given regional differences in the average age of diagnosis for ASD across the province (Ouellette-Kuntz et al., 2009). However, given the lack of questionnaire responses, a major shift in study focus occurred subsequent to the methodological challenges. The focus shifted from the quantitative analysis to a more qualitative focus as a lot of information can be gleaned from the semi-structured interviews conducted for this study.

Study Challenges

Administrative difficulties obtaining ethics, committee member departure, and methodological issues (namely participant recruitment), led to the desired sample size not being obtained. The perceived failures in physician recruitment (e.g., challenges/difficulties) resulted in substantial amendments to my proposed study design and essentially significantly delayed my graduation, causing a lot of stress across multiple contexts (e.g., financial, career, and personal sense of inadequacy). Table 1 outlines the methods or techniques I employed to recruit physicians.

Why Physicians Did Not Participate

There are a plethora of reasons why physicians may choose not to participate in research including: lack of peer to peer recruitment, physician time constraints, competing research and participation in previous research, outside of their scope, fear of evaluation, lack of recognition/rewards/incentives, and a lack of perceived relevance to the population. These barriers to participation specifically pertain to my study and are subsequently discussed in detail. Table 1 below describes the specific methods I employed during the current study.

Table 1 Methods Employed

Method/Technique Employed	Strategies Utilized
Peer-to-Peer Recruitment.	<ul style="list-style-type: none"> -Recruited a “peer” – an individual working closely with physicians -“Peer” belonged to a community organization capable of referring a large number of physicians -Consulted with a professional in the field -My recruitment script was disseminated in large gatherings (e.g. conferences) of physicians -Met with other professionals in the research field who agreed to disseminate the recruitment script on my behalf
Conference Attendance	<ul style="list-style-type: none"> -I personally attended multiple conferences (3; two relating to children and one related to advanced life care) -Contacted directors and conference organizers to get table space for my recruitment script to be handed out -Arranged to have an announcement of my study to all physicians in attendance
Phone calling	<ul style="list-style-type: none"> -Physicians with no fax number listed on College of Physicians and Surgeons of Ontario (CPSO) -Some gatekeepers (e.g., administrative staff and administrative assistants) were gracious enough to provide an email address for the physician

Faxing	<ul style="list-style-type: none"> -Fax numbers for physicians in Ontario are listed on the CPSO website -Systematically faxed physicians based on alphabetical order and region of the province -Used a regular fax machine as well as free online fax services (e.g., gotfreefax.com, faxzero.com, myfax.com).
Social media	<ul style="list-style-type: none"> -I advertised on my own social media accounts -Friends shared the recruitment script -Contacted other health care teams via Facebook to disseminate my recruitment script
Advertisement in medical magazines/newsletters	<ul style="list-style-type: none"> -Took out paid advertising in a medical journal
Snowball sampling	<ul style="list-style-type: none"> - Participating physicians were asked if they could refer colleagues that may be interested in participating in the research - Physician peers with whom I had previously networked with passed out my recruitment script to peers at medical conferences -Recruitment script was sent to multiple colleagues working for physicians and medical students who had access to physicians -Friends with family members as registered physicians referred me to those individuals -Contacted medical organizations (administration) and they agreed to disseminate my recruitment script to physicians on their specific list servers

Lack of Peer to Peer Recruitment

One of the most prevalent barriers faced in this study, and a barrier that is corroborated by previous literature, was the lack of peer-to-peer recruitment (Asch, 2000; Carey et al., 1996; Ellis et al., 2007). All data collection and recruitment were completed by me, a Master's student in the field of psychological studies. Additionally, there was no affiliation with a medical organization for the current study. Close connections with local medical organizations have been identified as being a facilitator in physician recruitment (Carey et al., 1996).

Physician Time Constraints

Physicians have many responsibilities that are even increasing in some areas (Konrad et al., 2010) that represents another significant barrier to physician recruitment (Rahman et al., 2011). My personal experience recruiting physicians for this study also confirms the barrier of time constraints, as I was told over the phone by administrative assistants that the physicians would not have time for my study. Additionally, I was given the reason of insufficient time in face to face interactions with physicians in various capacities (e.g., at the office, at conferences).

Competing Research and Participation in Previous Research

Competing research has also been cited as being a significant barrier to recruiting physicians for research (Cave, Ahmadi, & Makarowski, 2009). If previous research on the topic at hand has been conducted recently, it can act as a barrier to physician recruitment (Asch, 2000). My study had similarities to other studies being conducted at a similar time (e.g., Ghaderi & Watson, 2018; 2019). My peers working at, and affiliated with, a medical organization were also told directly by physicians that they had participated in a similar study and would not be willing

to participate in another one. If the topic has been exhausted from the physician's perspective and experience, they will be overly hesitant to allocate their time to the new study.

Outside Scope

While in the field recruiting for this study, it was discovered that physicians declined participation if they felt the research was outside of their scope of practice. Research of this nature (i.e., psychological research) poses a somewhat unique difficulty as physicians may perceive psychological research to be outside of their scope in some cases. To give further support for the fact that physician recruitment in psychological studies is crucial, researchers have shown that many individuals with a psychological issue will consult with a physician prior to a mental health expert (Steel et al., 2006). If physicians feel that they are not able to provide the support for a particular group, or feel that they are not competent in the specific area, they may be less inclined to participate in research (Asch et al., 2000).

Fear of Evaluation

Fear of evaluation has also been cited as being a potential barrier to recruiting physicians for research (Asch et al., 2000). Fear of evaluation may be an even bigger factor or influence in not participating in psychological research as physicians may see research in this area as an evaluation of their skills in diagnosing and treating individuals with ASD. In psychological research, the physician may not feel as competent in the domain or concept being researched, and therefore may be more hesitant to participate in the study. If time allows, informing participants that there is no evaluation aspect to the research study may be important to include in the informed consent. However, even if physicians are told that they are not being evaluated, they still might feel that they are being assessed or judged by the researcher, or they may have

fears about what may happen to them as physicians if they reveal that they are not knowledgeable about a topic, such as ASD. Additionally, physicians may fear that they may disclose practices that may not be ideal even if the study is not evaluation focused. Disclosure of malpractice is a specific barrier to the physician population, as their approaches are criticized heavily if they employ questionable practices (Cave et al., 2009). Furthermore, physicians may not be confident in their knowledge and practices regarding ASD (Unigwe et al., 2017).

To further substantiate the issues regarding topics outside of the physician's medical scope, this is a quote from one of the physicians that agreed to participate in this study:

If I wasn't exposed to them [individuals with ASD] I would probably not be too willing to add them to my list because some of my colleagues find them very overwhelming. So, I understand where they're coming from but, me having exposure for a long time, I don't really have a problem with working with those children.

When declining the invitation to participate, I was told by some physicians that they do not “do that kind of thing” (i.e., participate in research regarding ASD), or that they do not have any individuals with ASD in their practice.

Lack of Recognition/Rewards/Incentives

Lack of recognition or rewards was also described as a potential barrier in the literature; however, this barrier should be assessed carefully. Deciding on an appropriate or adequate amount of compensation to stimulate higher response rates poses a substantial challenge (Turnbull et al., 2015). Before undergoing research, it is important to carefully evaluate if an incentive should be used. I decided not to provide any monetary incentives as it has been cited

that they do not seem to be either a facilitator or a barrier (e.g., Asch, 2000; Draper et al., 2009); however, competing research also states that, in some cases, incentives, and specifically monetary incentives, have been cited as contributing to higher response rates (VanGeest et al., 2007).

Relevance to the Population

In a classic study completed by Sudman (1985), results revealed that the participant must perceive the study to have relevance professionally, the questionnaire should be focused on a single topic, and the results of the study have to reach beyond the investigator's interests and career advancement (Klabunde et al., 2013). The last variable may be a particularly difficult barrier for psychological research at the graduate level. Specifically, much of the research conducted by graduate students can be perceived as being for their interest or career advancement, especially in the context of a thesis, as opposed to professionals who engage in research.

Recommendations to Overcome Barriers: Facilitators for Recruiting a Physician Population

Participant recruitment is potentially the most difficult aspect of the research process in general (Blanton et al., 2006). The issue of physician recruitment has plagued research in the context of substance and quality, and has been a major problem in health research for a long time (Borgiel, 1989; Levinson et al., 1998; Rahman et al., 2011; Taylor & Scott, 2019); and in multiple geographical areas (Chan et al., 2018; Goodyear-Smith et al., 2009; Hoddinott et al., 2007).

One of the most common facilitators to physician recruitment and retention is peer-to-peer recruitment. As part of graduate or psychological based research, it may be important to include a physician as part of the research team to assist with recruitment. It may also be good practice for psychological research involving physicians to recruit a physician or “peer” to the research team. To help facilitate recruitment of a physician or a peer to the research team, it may be appropriate to at least offer authorship as lack of recognition has been cited as a barrier (Cave et al., 2009). If physicians know each other prior to physician-to-physician recruitment, this strategy contributes to higher participation rates because there may be an established level of comfort in the relationship. The familiarity aspect also contributes to a networking perspective and continued contact with the participant. Ongoing contact has also been shown to increase physician response rates.

At the conferences I attended, I was able to get physicians to mention my study and that I was recruiting participants (and pass out my recruitment script). The strategy of physician-to-physician recruitment may be the biggest factor for successful physician recruitment, as researchers have illustrated that physician to physician, or perceived peer-to-peer, recruitment produces much higher and successful participation rates (Asch, 2000), as well as related affiliation to organizations (Chan et al., 2018). Attending these conferences also allowed for another facilitator, specifically recruiting outside of the conventional vocational setting, or outside of work hours.

Medical conferences have an inherent underlying understanding that the event is for educational purposes (Mishra, 2016). Additionally, it was identified that besides the educational function, physicians appreciate medical conferences because they have time to interact with peers. The level of comfort for interaction was apparent at the medical conferences I attended, as

I was able to interact with groups of physicians that seemed to be more willing to hear about my study than if it was in a vocational setting (i.e., clinic). Physicians freely engaged in conversations with me, and I was able to take advantage of this informal approach. There was much more enthusiasm about research in general in this context compared to other settings where I recruited in (e.g., hospitals, family health teams, clinics). Furthermore, attending a medical conference is an opportunity to learn and contribute to new relevant ideas and research, and develop consensus for improving health care delivery and patient results. Therefore, recruiting physicians at medical conferences allowed for a unique setting where physicians seemed to be more likely to participate.

Additionally, close connections with local medical organizations have been identified as being a facilitator in physician recruitment (Carey et al., 1996; Chan et al., 2018). Having an affiliation with other physicians or medical associations can be related to peer-to-peer recruitment, as fellow medical professionals likely have knowledge of, or may even be connected through local medical organizations. For graduate research, it may be beneficial to associate with a relevant local or national medical organization.

A medical organization in this context can be quite broad. For example, hospitals, community care networks, educational medical organizations, and provincial or state associations (e.g., the Ontario Medical Association [OMA]; the College of Physicians and Surgeons of Ontario [CPSO]) can be allies concerning physician recruitment. Being associated with other medical organizations may also help articulate the broader importance of the study and give more weight to the study from the perception of the physician. In addition, affiliation with a medical organization may also contribute to more successful snowball sampling. The medical affiliation procured, whether it be a physician or medical association, will likely have

colleagues or contacts that will be able to be referred. My affiliations with various medical associations, such as Ontario Medical Review [OMR], Dufferin Family Health Team, and Family Health Teams of Ontario aided in my physician recruitment.

As previously mentioned, a potential barrier that may hold more weight for a graduate researcher is the perception by the physician that the intentions for the study go beyond the scope of the researcher's interests and career advancement (Klabunde et al., 2013). Mitigating the perception that the research being conducting is for purposes other than career advancement can be challenging. One potential recommendation for overcoming this barrier includes the necessity of the researcher to clearly articulate or delineate the impact the research will have beyond personal interest and career advancement. Particularly with graduate student research, it may be important to describe how the research may benefit others in society, or society as a whole. I found establishing the benefits of the research to be helpful in appealing to physicians' moral and ethical obligation to advance medical research. Additionally, if it is beneficial to the physician, or their patients, clearly show the relevance in the recruitment script or in the recruitment pitch.

I did attempt to establish the relevance of the research to the physician population. I tried to articulate, when I was able, that this research was intended to identify what areas of knowledge are prevalent, and which are lacking, for physicians in Ontario pertaining to ASD. The research was intended to identify how education and knowledge can be transferred more effectively in order for physicians to help care for individuals with ASD.

Additionally, in the context of scope, all of the participants who agreed to participate in the semi-structured interview were paediatricians, and all were working with individuals with ASD. Moreover, all physicians that participated in the semi-structured interview indicated that

they either had a family member with ASD or had experiences with individuals with ASD growing up. The physicians that participated conveyed genuine interest in this field and described feelings of competency working with individuals with ASD. All three physicians that participated in the semi-structured interview had between 10- and 15-years' experience, and therefore likely felt more comfortable participating given the length of their careers in the field. If appropriate, specifically recruiting physicians that perceive the research at hand to be within their scope, may act as a facilitator.

Furthermore, as competing research was cited as a barrier (Cave et al., 2009), it is important to draft recruitment scripts in a unique way, highlighting how the research will specifically contribute to new knowledge/information, or how the research differs from previous research in the field. My research was similar to other research out of the same university. As previously mentioned, physicians articulated that they were not willing to participate in studies that seemed to be the same. Unfortunately, it can be very hard to illustrate the differences and the importance of these differences between the studies in a one-page recruitment script. A recommendation to effectively mitigate this barrier is to consider consulting with physicians during a pilot study. The physician may lend suggestions on how to clearly describe the importance of the study and how it differs from similar research, in a way that speaks to the specific population of physicians.

Some physicians may have a rational or irrational fear that they will accidentally disclose practices that are not ideal (Cave et al., 2009). Minimizing this perception can reduce the fear of evaluation barrier. Minimizing the perception of fear can be achieved by drafting a disclaimer articulating that this is not the intention of the research. Furthermore, it is recommended that the

disclaimer or informed consent be piloted by receiving feedback from the specific participant pool (e.g., physicians).

Physicians may be more hesitant to participate in research that they perceive as being outside of their scope of practice. A suggestion to alleviate this barrier is motivational messaging (Chan et al., 2018). More specifically, highlight the research findings' potential impact, make the physician cognizant of their possible contribution to address the problem, and articulate the importance of research participation. This approach may lead to grabbing the attention and support of the physician, and can be embedded into the recruitment script. For example, this is a brief message I included in my recruitment script: *“The information we gather will be used to identify areas within health care curricula that may need additional attention. It will also be used to improve the confidence, perceived competence, and knowledge of future physicians regarding developmental disabilities and ASD.”*

Moreover, my paid advertisement in a medical journal included a motivational messaging example, *“Research participation opportunity for physicians! Why? Identify areas where physicians are seeking more professional development about Autism Spectrum Disorder (ASD) and better support individuals with ASD and their families.”* Messages like this may also provide more transparency in the research, simultaneously reducing fear of evaluation. Taking out a paid advertisement in this study was a facilitator which may have also addressed the barrier of reaching physicians outside of their demanding schedule.

Physician recruitment for medical research is crucial for the field to advance. Before undertaking research involving physicians, it is helpful to consult information about the facilitators and barriers that contribute to higher response rates. Additionally, a guide to

physician recruitment may be a worthwhile task to draft in terms of delineating the fundamentals in research with this population, as it is so vital in continuing to better health care for society.

Overall Recommendations and Reflection: Personal Reflections on How These Challenges Impacted Me

The barriers I faced in recruiting participants for my thesis contributed to a variety of negative feelings and had significant personal/mental, and academic impacts. The subsequent final discussion addresses these domains and their effect on my life because of the previously described challenges and failures in my research.

Personal/Mental

I took the issues with physician recruitment as a personal failure. Because my personal identity includes my research and work, the perceived failure in my research had consequences for me mentally. The way I had mentally framed this challenge was at a detriment to my work in the end. Because of the difficulties in recruitment, my thesis was significantly delayed, and I had constant stress and feelings of inadequacy. As graduate students conducting research that is near and dear to us, a huge toll can occur when challenges happen. At times, it seemed overwhelming to me with all the variables at play. During this time, time management was integral; however, because of the perceived failures and how I internalized these challenges, it was difficult for me to reorient myself back to completing my thesis.

For me personally, I conceptually framed my challenges in a drastic, and in an ultimately unproductive and negative, way. Because my research was so important to me, and because it is so integrated in who I am, the recruitment challenges had more consequences than they should

have had on me personally. Reflexivity is important as a graduate student when challenges occur in order to overcome these obstacles or barriers. Addressing these failures and reflecting on them allowed for me to understand why these failures occurred, and what strategies and steps were needed to take to overcome them.

Academically

My academic timelines were also impaired because of the difficulties in physician recruitment. I had a personal expectation for my timelines, which again added to the stress as more and more time passed without me graduating. It was important for me to come to the realization that everyone's academic journey is different. I realized in reflecting on my experiences that it is important not to compare my timeline to any external source, but rather structure the academic timeline personally. This tentative timeline should be flexible as amendments may need to be implemented. Realizing that the challenges may not have to be perceived as failures, and reframing the narrative, helped me to move forward and eventually overcome these obstacles.

Framing and Conceptualizing Failure

It is important for graduate students to reflect on the perceived challenges and failures of the research process, and to accurately consider them from a personal (productive) perspective. Reflection and reframing allow a medium to express emotions, feelings, and need for changes in a productive way. This reflection on perceived challenges and failures may facilitate learning and personal growth, not in a traditional or conventional manner, but in a nuanced personal way. For example, problems that occurred during my thesis as discussed previously caused frustration and created an additional barrier. I overcame these barriers when reflecting and when realizing the

need to amend my initial intentions and expectations, which allowed me to keep progressing through the journey of my Master's degree.

Looking back at my frame of mind during the extended recruitment process, I see how this delay negatively affected me personally, as well as professionally. My recruitment process was significantly prolonged because I had an initial target in mind in terms of my sample size. I was too rigid in terms of amending aspects such as target sample size, and general changes to my thesis. This rigidity negatively impacted my frame of mind and delayed my thesis. It is important to reflect and reframe during research process; if I had taken the opportunity to reflect and reframe at the time, these processes may have contributed to a faster completion of my thesis

Challenges or perceived failures are experienced by most, if not all, graduate students and researchers. The reflection process can also be used to reframe maladaptive perceptions or outlooks to adaptive ones. For example, this paper was produced after I had accepted challenges and failures and attempted to reframe and amend my goals and journey completing my Master's.

As I am reflecting back on the journey that is the Master's experience, no matter how many times I was told it will not go as planned, and to not get married to my ideas or intentions, it was hard to imagine the changes that would paint the picture of my personal journey. I would recommend heeding these words of advice and keeping an open, flexible frame of mind when completing graduate research. I am sure that there are challenges or failures that occur with every student; I am sure that both occurred in my personal experience. These challenges or failures in research do not have to be perceived as negative, but can be analyzed through a different lens to motivate, cultivate, and integrate a fruitful learning experience for you, me, the scientific community, and the public. I could not see nor appreciate the benefits that manifest when

reflection and reframing occur during the research process. Looking at the situation differently seemed to me to be an inherent failure; however, this thought process ultimately led to a delay in research and maladaptive behaviour (e.g., not physically sitting down and finishing the writing process). Had reflection and reframing happened earlier, it would have mitigated some of the barriers I faced in my research. I think that students should keep in mind that changes may be necessary, and to 'roll with the punches' instead of getting caught up in a perceived personal failure.

Implications for Supervisors

Reflection should occur through multiple lenses throughout the graduate journey. Another lens in which reflection should occur if challenges or failures arise is through the eyes of the supervisor. Supervisors are in place to give alternative or reframed options to facilitate in overcoming challenges or failures. I will conclude with some considerations for supervisors when challenges arise in your student's research.

It would be helpful to collaboratively create and establish an agreed upon time frame for different aspects of the research process. Additionally, consider breaking up the process in unique and pertinent ways for the specific study. For example, with the current study, a timeline for the recruitment phase would have been beneficial. Provide the student with suggestions on moving forward after the established time frame has expired. Additionally, brainstorm (i.e., being proactive) predictable challenges or barriers that may arise, prior to the research. Having multiple amendment ideas should a predicted barrier arise can help the process along and may mitigate the magnitude of effect that it could have on your student. For example, with the current study, the recruitment challenges could have been foreseen, and perhaps an alternative plan

could have been established if delays exceeded a certain amount of time. Additionally, certain measures could have been put in place to overcome this conceivable barrier. Furthermore, checking in on your student at appropriate times may help reorient your graduate student and help to get the research back on track. It is hard to predict what may happen but you as a supervisor can be a source for support to help navigate through challenging times in research.

Conclusion

Failures and challenges are inevitable in research, and in a Master's journey. This article brings to light the importance for reflexivity, not just to overcome these challenges or failures, but to help conceptualize and frame the reasons in a productive, proactive manner to alleviate some of the negative consequences that a Master's student may face (i.e., personal/mental and academic). Moreover, being reflexive will help a student to make amendments to their research and come to terms with the changes needed should they be necessary. Additionally, physicians are an important component to research; in this paper, I have helped to frame and assess methods and techniques used for physician recruitment from the perspective of a graduate student in psychological research.

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Chapter 3

3 « Ontario Physicians' Knowledge Regarding Autism Spectrum Disorder: A mixed methods study»

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Conflict of Interest:

None

« Abstract »

Employing a mixed methods approach, this study examined the knowledge and information Ontario physicians have concerning Autism Spectrum Disorder (ASD). Physicians are at the front line when it comes to identifying ASD. A total of 46 Ontario physicians filled out the questionnaire component and seven participated in a semi-structured interview. Findings revealed that physicians are lacking in information regarding some early signs, added diagnostic criteria, and the prevalence rate of ASD. Additionally, exposure was found to be a facilitator to knowledge acquisition regarding ASD. The physicians recommended a method to disseminate and increase knowledge and awareness. Implications of the findings include what areas of knowledge and information need to be increased, and how knowledge and competency can be increased, to better care for this population.

Ontario Physicians' Knowledge Regarding Autism Spectrum Disorder:

A Mixed Methods Study

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that interferes with an individual's ability to communicate and relate to others. Additionally, social deficits can be observed across multiple contexts and cause clinically significant deficits in social and adaptive function (American Psychiatric Association [APA], 2013; Elsabbagh et al., 2012). Symptoms of ASD include impairments in social communication, repetitive behaviours, and restricted interests. (Anagnostou et al., 2014; Liew et al., 2015). Recent findings demonstrate that the prevalence of this disorder is rising, with approximately 1 in 59 individuals now living with ASD (Centers for Disease Control and Prevention [CDC]; 2018). In this study, what factors are associated with an increased competency and perceived ability in caring for these individuals by physicians are identified, as well as what areas of knowledge need to be increased.

Physicians' Knowledge and Role Regarding ASD

Health care professionals are on the front line when it comes to identifying a possible case of ASD, as they likely are the first people to come into contact with the child (Crais et al., 2014). Physicians play a vital role in identifying ASD and the need to recognize signs and symptoms as early as possible has been clearly documented (Bethell et al., 2011; Johnson & Myers, 2007; Miller et al., 2011). It is crucial for physicians to possess the necessary knowledge in order to diagnose or identify ASD at an early age by recognizing the early signs and symptoms, such as social smiling (Maestro et al., 2002). When individuals with ASD are identified, diagnosed, and treated within a certain period (i.e., the critical period), the prognosis greatly increases (Clark et al., 2018; Dawson, 2008). An early diagnosis is said to be critical in

providing the best outcome (Elder et al., 2017), and delays in diagnosis can significantly hamper prognosis (Rhoades et al., 2007). To further articulate the importance of physicians' need for knowledge in caring for this population, individuals with ASD often have comorbid medical issues, which leads to an increase in the visits to a physician's office (Bauman, 2010).

Health care professionals themselves are concerned that they are not equipped with adequate knowledge and confidence for the overall care of these individuals (Bultas, 2012). Furthermore, researchers hypothesize that discrepancies or differences in ASD diagnoses, particularly age of diagnosis, may result from inconsistencies in the amount of knowledge of typical developmental milestones across groups (Harrison et al., 2016).

One source of potential confusion is the change in diagnostic criteria in the Diagnostic and Statistical Manual 5 (DSM-5; Lobar, 2015). Misconception and confusion have been identified regarding ASD since its appearance in the DSM-III in 1980 (Stone, 1987). Five key differences were implemented for ASD in the DSM-5, but most relevant to the purpose of this article is the addition of hypo- or hyper-activity to sensory stimuli as a criterion (Jashar et al., 2016), as these are the newest criteria inclusions.

Paediatricians have recognized their lack of knowledge and their desire to improve services in the area of ASD (Carbone et al., 2010). Moreover, health care professionals in general indicate that further training and education would be beneficial (Hartley-McAndrew et al., 2014; Igwe et al., 2011; Imran et al., 2011). However, because of insufficient time, training, and resources, their understanding of ASD still needs improvement (Carbone et al., 2010). There have been several studies completed in other countries assessing health care professionals' knowledge surrounding ASD (e.g., Hartley-McAndrew et al., 2014; Igwe et al., 2011; Imran et

al., 2011); however, research and literature pertaining to this topic has been scarce in Ontario, Canada. The subsequent research questions guided the current study: (1) *What do Ontario health care practitioners know about ASD diagnosis?* and (2) *What are the factors or facilitators that contribute to increased knowledge, comfort, and perceived competency when addressing the needs of individuals with ASD?*

Methods

Two phases of data collection were integrated in this study. The first set of data was gathered between 2015 and 2017 and was gathered using the same methods as the second data set. The second set was gathered between 2018 and 2019. Additionally, this study employed a two-phase, mixed-methods approach, including an online survey and a semi-structured interview.

Procedure

Physicians were recruited using a variety of methods including: email, telephone, fax, snowball sampling, medical conferences, creative paid advertisement, and social media. In order to increase the sample size, the data were supplemented by a previous phase of data collection (see Ghaderi & Watson, 2018 & 2019). The data sets contained the same measures except the second data set included an objective measure discussed subsequently. The semi-structured interview was guided by the same supervisor, Dr. Shelley Watson, for consistency during data collection. Additionally, the same data collection platform was used (RedCap). Difficulties occurred during the recruitment and data collection phases of this study; the challenges associated with this particular study are beyond the scope of this paper and are discussed elsewhere (see Davin, manuscript in preparation).

In the first phase of the study, physicians filled out an online survey administered via REDCap (Research Electronic Data Capture), a secure data capture tool hosted at Laurentian University (Harris et al., 2009) and took approximately 10-20 minutes. The survey included questionnaires regarding the physician's knowledge, awareness, and perceived competence related to ASD, as well as other developmental disabilities. Participants were then asked if they would be willing to participate in the second phase, completing a semi-structured interview which took approximately 20-45 minutes. The semi-structured interview allowed for examination and understanding of participants' overall knowledge regarding ASD and allowed for the exploration of physicians' personal and educational journeys in gaining knowledge pertaining to ASD.

No incentive was provided for completing either section of the current study. Data were analysed using Statistical Package for the Social Sciences (SPSS) version 24; specifically, *t*-tests and one-way Analysis of Variance (ANOVA) tests were conducted. Additionally, percentages were calculated for certain items.

The semi-structured interview transcripts were analysed using a deductive approach to thematic analysis (Braun & Clarke, 2013). This approach allowed for a flexible framework to analyse the interview transcripts. Familiarization of the data took place in the initial step. The data were transcribed, read, and re-read. Subsequently, generation of initial codes in a systematic fashion took place. Themes were categorized and condensed if there were similarities. The themes were then again reviewed after they were finalized by the primary researcher, and themes were confirmed with the co-authors. Themes were defined and assigned names, then the themes and quantitative data were integrated to help explain and enrich the overall findings.

Phase 1:

The Healthcare Professional Questionnaire. In this study, physicians filled out the Healthcare Professional Questionnaire, which has been adapted from the Healthcare Student Questionnaire (e.g., Isaacs et al., 2012; Minnes et al., 2012). Data were collected from 2015-2017 from a sample of physicians across Ontario ($n = 29$). A second sample of physicians also filled out the survey in 2018-2019 ($n = 17$), leading to a total sample of 46 participants.

The Healthcare Professional Questionnaire was used in this study because it measures different aspects of medical practitioners' qualifications, knowledge, training, demographics, and attitudes regarding the diagnosis and treatment of individuals with different developmental disabilities including ASD. The questionnaire consists of 14 questions, and responses are rated on Likert scale ranging from "Very Limited" to "Extensive."

The Knowledge about Childhood Autism among Health Workers Questionnaire (KCAHW). Medical professionals from the second sample were asked to fill out the KCAHW questionnaire, which assesses knowledge pertaining to ASD. A total of 16 physicians filled out the KCAHW. Because the sample size was significantly lower for this measure, results discussed were analysed utilizing an item by item approach and the subsequent discussion regarding items on this survey will be illustrated in percentages.

The KCAHW questionnaire has established reliability and is a good resource for assessing knowledge of health care professionals about childhood ASD (Bakare, Ebigbo, Agomoh, & Menkiti, 2008). The KCAHW questionnaire has 19 items that are divided into four domains. The KCAHW was amended to fit the new DSM-5 criteria (e.g., Hypo- and Hyper-

reactivity to sensory information was added). A prevalence rate question was also added to gauge how common physicians estimate ASD to be.

Phase 2:

Semi-Structured Interview. Interviews were completed in two phases. The 2015-2017 interviews were analysed and consisted of a sample of four. Three physicians agreed to participate in the 2018-2019 round of data collection. The subsequent results and discussion sections integrate both sets of interview data from these physicians and apply sequential chronological pseudonyms (P.1 – P.7). The interview consisted of 15 open-ended questions, with prompting questions as needed.

Participants

Participants involved in the current study were Ontario practicing physicians, including family physicians, paediatricians, psychiatrists, and others (e.g., orthopaedic physicians, emergency medicine physicians, and one physician that identified as a student). A total of 46 physicians filled out the surveys on REDCap, where written consent was provided. Seven physicians agreed to participate in a semi-structured interview, where verbal consent was provided. The participants' demographic information is displayed in Table 1, including both samples of participants. The demographic characteristics of race/ethnicity and socioeconomic status were not obtained. While exploring the two data sets, there was no significant variation between the populations. Additionally, the Levene's statistic was not violated, indicating the equality of variances between the groups.

Table 2 Demographic information of participants in both phases of data collection

Characteristics	Previous Data (2015-2017)		Current Data (2017-2019)	
	<i>(n = 29)</i>		<i>(n = 17)</i>	
Type of Physician (%)				
Family Physician	12	(41.4)	13	(76.5)
Paediatrician	11	(37.9)	2	(11.8)
Psychiatrist	2	(6.9)	1	(5.9)
Other	4	(13.8)	1	(5.9)
Gender (%)				
Male	7	(24.1)	5	(29.4)
Female	22	(75.9)	11	(64.7)
Prefer not to answer	0	(0)	1	(5.9)
Years of Experience (%)				
0-5	10	(34.5)	6	(35.3)
6-10	5	(17.2)	3	(17.6)
11-15	6	(20.7)	3	(17.6)
16-20	1	(3.4)	1	(5.9)
21+	7	(24.1)	4	(23.5)
Age M (SD)	44.03 (9.93)		42 (10.92)	

Ethical Consideration

Ethics approval was obtained from the Laurentian University Ethics Board, Ontario, Canada, which is in line with the Canadian Tri-Council Recommendations for Research with Human Participants.

Results

The quantitative results from the two questionnaires are presented first. Subsequently, the qualitative results from the interview data are presented.

Quantitative Results

Independent sample *t*-tests were performed to analyse differences between the two samples (the two different phases of data collection), regarding their perceived knowledge and ability to assess and treat ASD. The results of the *t*-tests are displayed in table 2. If the denominator for any of the survey analysis items in the results section differs, it is indicated in this section. The two samples differed in their perceived levels of knowledge regarding ASD with the initial sample having higher levels of knowledge regarding ASD. For example, for the question: “Do you feel that you have enough access to information or resources to meet the needs of individuals with disabilities?”, 53% of participants in the second sample indicated “No” while only 32% of participants in the first sample indicated “No”.

Table 3 Knowledge differences between responding 2015-2017 physicians and 2018-2019 physicians

Knowledge Area	<i>t</i>	<i>p</i>	<i>n</i>	Sample 1		Sample 2	
				<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Assessment	2.33	0.024	43	3.25	.70	2.71	.85
Treatment	1.57	0.124	41	3.00	.83	2.56	.96

Quantitative results showed that the most recently added criterion to the DSM-5 (i.e., hypo-reactivity to sensory information) revealed the lowest levels of knowledge (44% correct; 50% incorrect; 6% I Don’t Know). Hypo-reactivity to sensory information is a clinical presentation or criteria of ASD that appears to be under-detected based on these results. In

contrast, 100% of participants correctly identified hyper-reactivity to sensory information as being a diagnostic criterion of ASD.

Some of the earliest detectable signs or symptoms of ASD such as social smiling (50% correct) and staring into open space (56% correct) were less likely to be identified as signs or symptoms of ASD by physicians in this study. This is a sharp contrast to well established symptomology, such as stereotyped and repetitive movement or behaviours (100% correct) and love for regimented routine activities (100% correct).

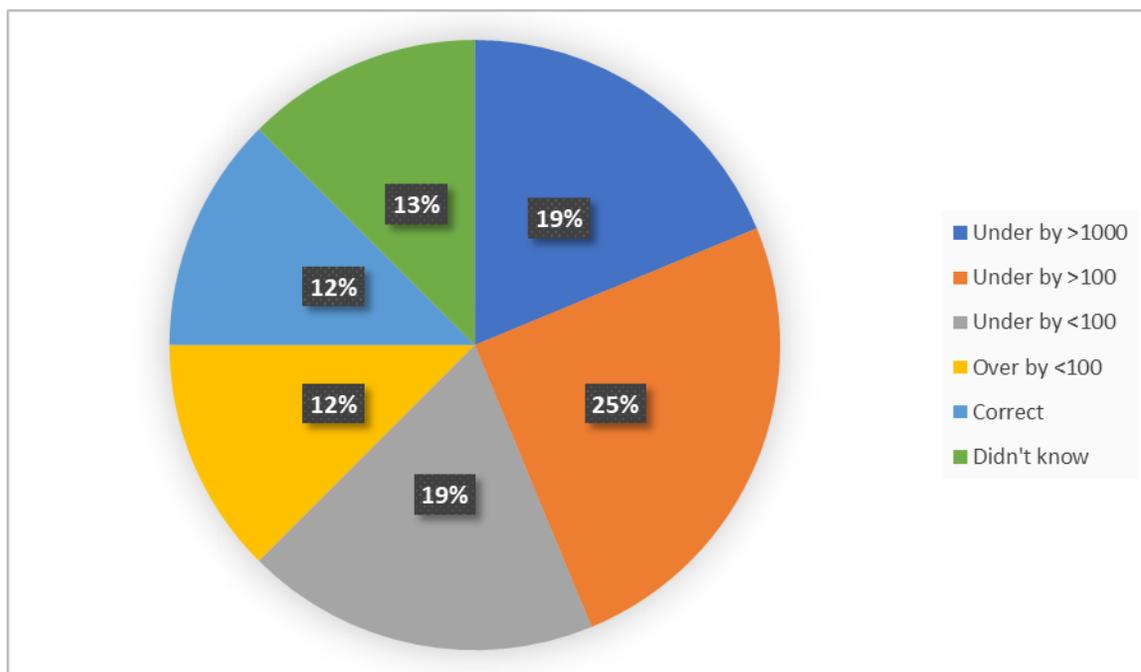
The two data sets were then combined. Each type of physician corresponded as the two data sets were collected in the same way. In essence, the physicians involved fell in the same vocational categories (Family Physician, Paediatrician, Psychiatrist, and Other). A one-way ANOVA was conducted to compare differences in physicians' perceived levels of knowledge across disciplines for assessment of ASD. The test of Least Significant Difference (LSD) indicated that paediatricians ($M = 3.62$, $SD = .51$) reported significantly higher levels of knowledge than family physicians ($M = 2.88$, $SD = .80$), and the "other" physician category ($M = 2.33$, $SD = .52$), $F = (3, 42) = 5.835$, $p = .002$. Additionally, results showed that psychiatrists ($M = 3.33$, $SD = .58$) felt that they had significantly more knowledge regarding ASD assessment than the "other" physicians ($M = 2.33$, $SD = .52$).

A one-way ANOVA was also conducted to compare the differences across disciplines for levels of knowledge regarding ASD treatment. The post hoc test of LSD indicated that paediatricians ($M = 3.50$, $SD = .52$) again felt they had significantly more knowledge than family physicians ($M = 2.61$, $SD = .89$), and the "other" physician category ($M = 2.1667$, $SD = .75277$), $F = (3, 40) = 5.509$, $p = .003$. The result was significant even after the correction was made for

the post hoc test. Additionally, the results revealed that psychiatrists ($M = 3.33$, $SD = .58$) felt that they had significantly more knowledge regarding ASD treatment than the “other” physicians ($M = 2.1667$, $SD = .75$).

Figure 1 displays the results of the prevalence estimation by physicians. The estimations ranged from overestimating the prevalence of ASD at 1 in 20, to underestimating the prevalence of ASD at 1 in 10000. ASD was greatly underestimated by physicians with an average estimate of 1 in 1109.

Figure 1 Physician Prevalence Estimation



Qualitative Results

During their interviews, physicians discussed potential facilitators to increasing comfort levels, competency, and knowledge in caring for individuals with ASD. Using a deductive approach to thematic analysis (Braun & Clarke, 2013), two themes were generated. The first was

labeled as “Exposure as a facilitator”, in which prior exposure to individuals with ASD led to increased levels of comfort in caring for these individuals, and an increase in knowledge surrounding the disorder. The second theme was labeled as “The Need for, and Awareness of, ‘Road Maps’”, in which physicians recognized the need for having a clear road map of how to navigate the journey of ASD.

Exposure as a Facilitator

Physicians discussed how exposure to individuals with ASD is a source, or facilitator, of knowledge acquisition and feelings of comfort when caring for individuals with ASD.

Additionally, the participants indicated that had prior exposure to individuals with ASD not taken place, they would be less willing to take these patients on in their respective practices.

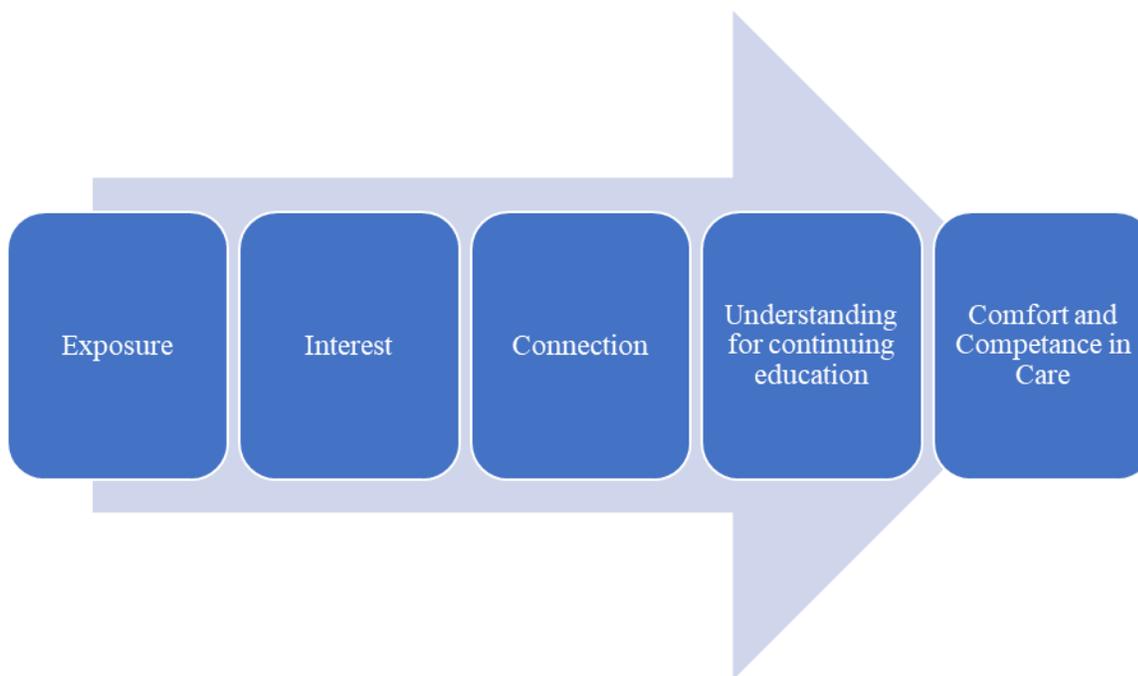
Exposure to individuals with ASD also lead to feelings of competency, as illustrated by two quotes from physicians who had experience with ASD outside their medical training: P. 3 stated that “I was exposed to it and I was comfortable...I feel comfortable and competent” and P. 2 felt that “If I wasn’t exposed to them I would probably not be too willing to add them to my list”.

Most physicians that agreed to participate in the semi-structured interview articulated that exposure to individuals with ASD was beneficial in increasing their knowledge, feelings of comfort, and competency when caring for individuals with ASD.

Interviews revealed that exposure to ASD extended beyond the scope of medical education and training. For example, exposure to parents who have a child with ASD was cited as a facilitator to obtaining knowledge, with P.6 saying that “I learn all the time from parents”. Specifically, physicians described their individual interest and self-exploration, guiding their exposure that leads to increased knowledge, comfort levels, and competency regarding ASD.

The progression from exposure to competence and feelings of comfort in caring for individuals with ASD is displayed in figure 2.

Figure 2 Knowledge and Comfort Facilitation Progression



Exposure can manifest in a variety of ways, including personal exposure via a family member with an ASD, exposure to individuals in the community, or previous volunteer experiences throughout their lives. Without these personal connections, physicians may find these patients to be overwhelming, as stated by P.2: “If I wasn’t exposed to them I would probably not be too willing to add them to my list because some of my colleagues find them very overwhelming.” Having no exposure contributes to limited understanding, and thus, limited perceived ability or competency to address their needs. Understanding the need for continuing education was articulated by P.6, “the more I see them, the more I learn and the more I find out what’s new out there...” This quote illustrates the need for continued exposure and education as there is always more to know and understand.

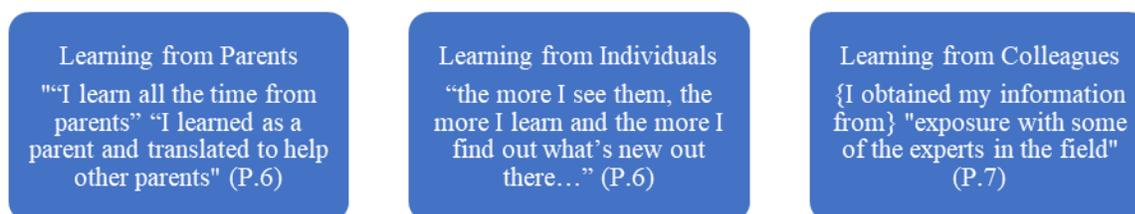
Another physician explained the link between exposure, interest, connection, and the need for knowledge and recognition of ASD as a family physician:

As a family doctor, we have to know a little bit about everything; and then, there are some people like myself who have an extra area of interest in children and developmental delay, partly because of my own son; partly because I have always wanted to work with children... if ASD walks in the door, I need to be able to recognize it. (P.7)

This quote helps to illustrate the link between exposure, interest, connection, continuing education and competence in caring for these individuals as there is a recognition for the need to identify ASD when it “walks in the door.” Interest is facilitated by exposure in this context and the connection is inherent.

Exposure in this context is not just exposure to individuals with ASD. Effective exposure that leads to learning or knowledge can be conceptualized in three domains, including learning from parents, learning from individuals, and learning from colleagues (see figure 3).

Figure 3 The Three Domains for Exposure



Therefore, the results suggest that integrating education and information gathered from all of these sources can lead to enhanced knowledge, competency, and comfort in caring for individuals with ASD.

An inadvertent piece of evidence that corroborates these findings is the fact that all physicians who agreed or volunteered to complete the semi-structured interview in the second sample ($n = 3$) had exposure to individuals with ASD, prior to, and outside of medical training. Furthermore, two physicians that agreed to complete the interview had family members affected by the condition, and a third had exposure growing up to individuals with ASD. Additionally, of these three physicians, two felt that they had extensive knowledge with regards to assessing and treating individuals with ASD, while one felt they had moderate knowledge in assessing and treating individuals with ASD.

The Need for, and Awareness of, “Road Maps”

It was clear that physicians knew that something needed to be produced to assist families and individuals with ASD in navigating the complex journey that is ASD. There was an awareness of how the complexity of the disorder can lead to confusion for all parties involved. For example, P.3. illustrated the inherent complexity of the journey and confusion involved: “It’s confusing for us, let alone the families to know how to navigate the system.” This quote helps to articulate a need for having a clear-cut “road map” to navigate caring for an individual with ASD. The term “road map” was mentioned across several interviews and terms akin to road map were also mentioned, such as “passport.” The physicians did not think that a “road map” for the journey of ASD had been clearly made, and expressed that having a clear-cut road map may help alleviate some of the challenges for the families involved in the system.

A recommendation of how this sequence could flow, or what a road map could look like, was expressed by several physicians. For example, one physician noted that it could be “something that is very pictorial, that if you suspect, go to this person first” (P.3). This is a

recommendation that may be essential in the future, as discussed by another participating physician: “when children are suspected to have Autism, your parents run around a lot and may fall victim to people who have programs and promised them that ‘oh, if you go to this program your child would be better’ and I think there should be a guideline” (P.2). Another example that illustrates the need for a clearer picture of the road or journey after the diagnosis was expressed by P. 6, “OK, you can diagnose but what is the next step?” The physicians in the study articulate a need for something to help facilitate the journey for the individual with ASD and their family will embark on after a diagnosis of ASD is made.

Discussion

Overall, the results of this study demonstrate a need for more awareness of resources, as the majority of the second sample indicated they did not have enough access to resources (53%), which was higher than the first sample (32%). To further this conclusion, the first sample had significantly higher self reported knowledge regarding ASD assessment ($M = 3.25, SD = .70$) than the second sample ($M = 2.71, SD = .85$). Additionally, the first sample reported higher levels of knowledge regarding treatment indicating a decrease in perceived knowledge about ASD. These findings suggest a need for an increase or enhancement of effective and continuing education regarding ASD for physicians who may provide care to individuals with ASD in their practices. Findings of studies running concurrent to the present study, but in various geographic locations support the results that physicians perceive a lack of resources and have knowledge limitations (Mazurek et al., 2020; Morris et al., 2019; Rizzolo et al., 2019).

Furthermore, physicians often report a lack of education surrounding ASD and developmental disabilities in general (Altay, 2019; Ghaderi & Watson, 2019;). This finding is

confirmed by other researchers who have indicated a need for additional education (Zerbo et al., 2015). Because medical education does not provide enough (perceived) knowledge, and perceived knowledge seems to be decreasing, perhaps a focus needs to begin, or be established throughout the educational process. The findings suggest that some information regarding the early signs of ASD as well as the new diagnostic criteria is important to increase physicians' knowledge, as these two areas were found to be some of the most lacking pieces of information.

It was also found that exposure leads to higher levels of comfort, competence, and increased knowledge regarding caring for individuals with ASD. Furthermore, analysis of the semi-structured interviews revealed that having road maps or a pictorial illustration of information regarding ASD would be a helpful resource.

Results indicate that parents should have access to an informed paediatrician. Paediatricians and psychiatrists in this study both reported that they felt as though they had more knowledge surrounding care for individuals with ASD compared to family physicians and other physicians, indicating a proper referral source. These findings are consistent with previous studies (Eseigbe et al., 2015). Results confirm CPS recommendations as paediatricians reported higher levels of knowledge than physicians as they recommend paediatricians diagnose ASD.

Proper Referral

A takeaway from the results is that if a family physician suspects ASD, they should refer to a paediatrician or pursue getting the diagnostic process started. Additionally, parents should have access to a paediatrician because it was found that paediatricians felt as though they had better knowledge surrounding the assessment of ASD. Additionally, as family physicians tend to refer to other experts in the field, having the proper knowledge of who to refer to is essential.

The only population where paediatricians did not have significantly greater perceived knowledge was psychiatrists. These professionals likely had a focus on ASD in their education and are likely more equipped to assist in the ASD journey, and psychiatrists are likely more informed regarding the updates to ASD compared to family physicians. This speculation is confirmed in the literature, as it was found that paediatricians and psychiatrists had significantly higher levels of knowledge than family physicians, as measured by the KCAHW (Eseigbe et al., 2015).

Knowledge of Prevalence Rates and Early Signs of ASD

The Canadian Paediatric Society (CPS; 2019) indicates that there is need for awareness of the increased prevalence rates. The estimate the prevalence of ASD in Canada is 1 in 66 (Zwaigenbaum et al., 2019). The CDC (2018) estimates the prevalence rate to be 1 in 59 in the United States (Baio et al., 2018). However, prevalence rates were grossly underestimated in the current study, with the average estimation of 1 in 1109.

Prevalence rates are a vital piece of information because physicians may not identify ASD if the physician is not aware of how common ASD is. To substantiate this statement, knowledge of prevalence rates was identified by physicians as being important during the semi-structured interview. Additionally, individuals with ASD often have comorbid medical issues associated with ASD and therefore are more likely to engage more often with physicians. If physicians are not aware of these facts, they may be less likely to screen for ASD or appreciate parents' and patients' concerns pertaining to ASD. As previously discussed, a way to efficiently and effectively disseminate this information is through a road map for physicians.

The CPS Early Years Task Force (2011) also stated that physicians should be aware of the early signs of ASD, including maintaining their skills to be able to identify or diagnose ASD.

They also stated that a reliable diagnosis can be made by the age of two, but signs and symptoms can be recognized as early as six months (Rhoades et al., 2007; Rollins et al., 2015). The results of this study showed that some of the areas that were lacking in terms of knowledge were the early signs and symptoms. However, as previously mentioned, the prognosis of ASD is positively influenced with early detection and access to early treatment (Clark et al, 2018; Dawson, 2008; Elder et al., 2017). If signs are flagged or identified, even if the physician does not feel comfortable or competent in making a diagnosis, a referral can take place. Physicians in this study articulated that even after a diagnosis, it can be a lengthy process and take a lot of time before the individual engages in treatment. Therefore, early detection and diagnosis is even more imperative. Increasing physicians' knowledge and information surrounding the early signs of ASD may result in a uniform decrease in the average age of diagnosis (Rhoades et al., 2007).

Enhancing the Educational Process for Physicians

Given that exposure was identified as a facilitator, it may be beneficial for medical school curricula to introduce individuals with ASD during field visits or as in class case studies. According to previous researchers, as well as the results of the current study, exposure seems to make the physician more comfortable in caring for these individuals, as well as feeling more knowledgeable about assessment and treatment (Ghaderi, & Watson, 2018). Exposure continues to enhance knowledge, feelings of comfort, and competency among physicians based on the qualitative results of this study. Additionally, in one study, exposure to individuals with a disability such as ASD in medical school, led to higher comfort levels and an increase in knowledge and skills of medical students (Warfield et al., 2015). Health care providers have also reported that experiences with children with ASD had been more valuable than any training they received (Morris et al., 2019).

Exposure to ASD, as well as other developmental disabilities, should be mandatory in the medical education process as the benefits are apparent. This exposure may be more paramount for paediatrics training because they will come into contact with ASD at an earlier date, during the well baby checkups (Zwaigenbaum et al., 2019). Exposure could involve experiential learning or clinical rotations including patients with ASD and other developmental disabilities, guest speakers in lectures, and case studies (e.g., scenario-based learning; standardized patients with ASD). Case studies were identified by physicians in the current study as being an effective exposure opportunity that leads to more knowledge and competency. In addition to having a session with an individual or individuals with ASD, the inclusion of parents and caregivers with lived experience would be beneficial as well. The Canadian Paediatric Society's (2019) position statement indicates that parents should be listened to. Additionally, results show from the current study suggest that physicians can, and do, learn from parents. Therefore, parents should also be involved with the medical education process. Exposure and interaction with parents during the medical education process could be valuable to understanding complex disorders such as ASD.

Parents involved in medical education is not a foreign concept, as researchers have shown favourable outcomes when parents are involved in the process (Kube et al., 2013). Because ASD is a heterogeneous disorder, it would be very helpful to include parents on these cases. Parents are experts on the individual case before them and have insight into their child's unique behavioural and social presentations. Additionally, the individuals with ASD can provide significant insight into their functioning and maladaptive behaviours, which could lead to improved knowledge.

Because physicians discussed how medical education does not provide enough information regarding ASD, and perceived knowledge of ASD seems to be decreasing, perhaps a focus needs to begin or be established throughout the educational process. Altay (2019) reached a similar conclusion, affirming that educational programs focused on ASD awareness should be provided for family physicians who are likely to come into contact with cases.

Understanding the Areas where Knowledge is Lacking

The current findings indicate that some of the new updates to the diagnostic criteria for ASD, as identified in the DSM-5, are the least understood by physicians. For example, identifying hypo-reactivity to sensory information was the item that was least identified as being a sign or symptom of ASD. Hypo-reactivity to sensory information can be impactful on the individual's life as it is characterized as apparent indifference to pain/temperature (APA, 2013). The individual's lack of reaction could lead to harm of the child if the awareness of hypo-reactivity to sensory information is not present (e.g., a child could touch a hot stove and not react in a typical fashion, such as by moving their hand away or showing discomfort). Furthermore, the lack of understanding that hypo-reactivity to sensory information is a component of ASD, could be an issue in meeting the diagnostic criteria.

Additionally, hypo-reactivity may be less identifiable by a physician. Because the new edition of the DSM requires two restrictive and repetitive behaviours to meet diagnostic criteria, physicians not aware that this criterion may negate a diagnosis. Additionally, the three domains were collapsed into two domains in the current version of the DSM, and the individual needs to meet criteria in both domains (APA, 2013). Therefore, there are implications for physicians not aware of these changes. Physicians should have up to date knowledge of the diagnostic criteria,

as well as how signs and symptoms present or manifest in order to improve care and reduce the time it takes to diagnose.

Furthermore, it is imperative for physicians to have knowledge surrounding some of the early signs and prevalence rates of ASD in order to lower the average age of diagnosis. This study shows that physicians may lack awareness regarding some of the early signs that may manifest (e.g., social smiling; 50% correct), as well as the epidemiology of ASD (e.g., average rating of 1 in 1109). However, early recognition of the signs and symptoms of ASD is paramount given that the earlier the individual with ASD enters treatment, the better the prognosis (Clark et al., 2018; Dawson, 2008). Physicians' abilities to recognize the signs of ASD early is vital for the best care for this population (Self et al., 2015). If signs are identified, the assessment and treatments processes can begin, or a referral can be made.

If ASD is not something the physician knows to be as common as it is, this lack of recognition may delay identification or referral for the individual to be diagnosed. There is an understanding by physicians that there is a lengthy process to access support and treatment even after ASD has been identified or diagnosed. Physicians want to help the individuals to the best of their ability, so knowledge, education, and access to resources should be provided.

Road Maps

The theme of a road map (a visual guide to help navigate the journey of ASD) to better help care for individuals with ASD by increasing knowledge and awareness was established. To create this map, interdisciplinary collaboration should take place. From behavioural analysts to the physicians on the front line, there should be a collaboration of individuals and literature to produce a concise and standardized map to help all parties involved navigate the complexity of

ASD. The road map could help to create a closer relationship between the families and physicians by establishing a foundation of caring and facilitating personal interest. This sort of road map may lead to increased feelings of comfort and a sense of competency as described by participants in this study.

A variety of information could be disseminated quickly and efficiently with regards to educational tools, resources, and evidence-based information, which could help establish higher levels of knowledge. The information could be easily digestible in an easy to navigate pamphlet that physicians could have, as well as a version tailored for the individuals and the families involved. It is said that parents are the gatekeepers to early intervention, and they appreciate clear, direct, concrete written and verbal feedback (Jashar et al., 2019). A road map could help to provide this crucial information, and it could take a variety of forms such as a booklet or pamphlet for example. Separate road maps could be drafted for physicians, individuals, and families/parents.

As recommended by a physician, road maps could be pictorial, which may result in a more efficient dissemination of vast amounts of knowledge and information pertaining to ASD. For example, road maps for parents specifically could be drafted and kept at certain physicians' offices. The road map could illustrate and disseminate a variety of information including developmental stages, what to look for with ASD or developmental disabilities in general, where to go for help or resources, and effective treatments (e.g., Applied Behavior Analysis) versus aversive treatments (e.g., Gluten-free/Casein-free diet). Additionally, a tailored version for the individuals with ASD could also be drafted, which could include personal accounts from other individuals, as well as information to help them better understand their disorder.

Study Strengths and Considerations

The intended target sample size of the study ($n = 80$) was not able to be reached, and the majority of physicians were from urban settings, leaving significant discrepancy in practice locations and patterns among the different groups. The limited sample size also made comparing differences across disciplines less meaningful. A future study with more participants could tease out specific differences across professions, such as any differences between developmental paediatricians from the paediatrician population or between family physicians and other specialties.

To help mitigate the limitations of the small sample size, data from a previous round of data collection were included in order to bolster the overall sample size. A comparison of the two sets of data was also implemented to see if there was a change over time. The comparison revealed some key differences that were able to be explored. Because of the limitations in the recruitment phase (described in Davin, manuscript in preparation), data were limited, and analysis and direction had to be amended. As a result, there were limitations in the analysis, including that the KCAHW objective questionnaire could not be properly evaluated. Analysis was made on an item by item basis, which did result in some concrete findings that are integrated with the qualitative data.

Future Research and Recommendation

This study was initially designed to analyse geographic differences in physicians' knowledge and competency regarding ASD. There are geographic and regional differences regarding the average age of diagnosis for individuals with ASD in Ontario (Ouellette-Kuntz et al., 2009), and perhaps it is due to geographic differences in physicians' knowledge. Other

differences may come to light regarding additional factors influencing physician knowledge and the overall average age of diagnosis. It is recommended that future research look at geographic differences in order to investigate what variables contribute to the discrepancies in the average age of diagnosis for individuals with ASD. Some potential areas of difference may include the supports and services available region by region. A collaboration project between experts in the field and physicians would help to shed light on some of these unanswered questions, and could produce a concise, visually appealing, and easily digestible, centralized information database for all parties (e.g., physicians, individuals, and parents). This resource could also be customized, region by region.

Davin (manuscript in preparation) describes methods and techniques for recruiting physicians and eliciting a higher response rates from this specific population. Establishing method such as conference attendance, creative advertising, and snowball sampling prior to recruitment may result in higher response rates. Additionally, collaboration with an agency or a peer to physicians (i.e., a physician) will likely lead to higher response rates as well.

Future studies akin to the current one can bring awareness to the fact that physicians need more resources and information (i.e., knowledge) regarding ASD and other developmental disabilities, as well as bring awareness to the resources and information that is available (e.g., updated diagnostic criteria; early signs). The Canadian Paediatric Society (2019) published a list of recommendations for physicians that is helpful in guiding physicians. The recommendations are valuable in helping care for this population and they should be consulted by physicians (Brian et al., 2019; Ip et al., 2019; Zwaigenbaum et al., 2019).

Conclusion

Being a physician is a highly demanding job, as they care for their many patients with diverse needs, but physicians are integral to the early identification and diagnosis of ASD. It is important that physicians are equipped with the best resources and knowledge in order to help them care for, and support, individuals with ASD and their families. Additionally, physicians offered recommendations on how to enhance knowledge to individuals involved in the journey of ASD. Findings of this study will hopefully lead to increased efficiency and effectiveness in identifying and diagnosing individuals with ASD in order to allow them to engage in treatment as early as possible.

It is obvious that physicians have many demands, and that they care for their patients. These demands extend to many knowledge and experiential requirements during school and training. However, given that the prevalence of ASD continues to increase, awareness and knowledge should be instilled at the educational and foundational levels (e.g., during medical education). It seems almost inevitable that an individual with ASD will walk into a physician's office, or the cross any physicians' path, at some point in their lives or career. Therefore, it is imperative that physicians are equipped with adequate, evidence-based knowledge, and are comfortable and competent in the field of ASD. Continuing education in such an evolving disorder seems to lead to higher levels of comfort, confidence, and competency in caring for individuals with ASD (Major, 2015).

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Chapter 4

« Conclusion »

The current study explored a variety of areas including methods to recruiting physicians, physicians' knowledge surrounding ASD, and differences across disciplines of licenced physicians in Ontario. In the proposed study, the intention was to geographically analyze differences in physicians' knowledge of ASD in Ontario given the geographic differences previously found in the age of diagnosis of ASD in Ontario (Ouellette-Kuntz et al., 2009). It was hypothesized that one potential variable that could contribute to this variability is physicians' knowledge pertaining to diagnosis and identification of ASD. Unfortunately, the target sample size was not reached, and amendments were made, which are subsequently discussed.

Additionally, differences in the average age of diagnosis contribute to the prognosis if individuals engage in treatment before a certain age (i.e., critical period, about 2-4 years of age; Clark et al., 2018; Dawson, 2008). Studies have demonstrated that physicians may be hesitant to make a diagnosis at a young age (Imran et al., 2011). Moreover, physicians indicate that training, experience, and education in medical school may be lacking (Finke et al., 2010). This lack of training, education, and experience may result in later diagnosis for individuals with ASD. Previous researchers mentioned in the introduction chapter, recommended that physicians receive specialized training about ASDs to reduce the average age of diagnosis (Rhoades et al., 2007).

The purpose of the amended study was to research physicians' knowledge, level of comfort, and perceived competency regarding ASD in general. Areas of focus included aspects such as treatment, assessment, detection of signs and symptoms, and knowledge of prevalence

rates as these are important factors that contribute to the care of individuals with ASD. As lack of education, training, and experience have been identified as being potential barriers to better care for this population (Finke et al., 2010), the subsequent discussion integrates the findings of the current study and in the context of improving these areas (training, experience, and education). The current thesis included two separate articles. The first article contributes to the literature surrounding physician recruitment for psychological research from the perspective of a graduate student. The first article explored techniques regarding the recruitment of physicians and was a personal reflection on the challenges within graduate research. In this paper, I addressed failures in my proposed research, techniques to recruitment, overall recommendations for graduate students, and recommendations for researchers utilizing physicians as their population of study.

In the second article, I employed a mixed-methods approach to discovering differences in physicians' knowledge regarding ASD in general, including what facilitated knowledge transfer and acquisition. In this final discussion chapter, the article findings are summarized and critically analyzed. Additionally, recommendations are made for research and for clinical practice. The implications of this research are then presented.

4.1 Guiding Research Questions

The initial research questions that were presented in chapter 1 included:

- What do Ontario health care practitioners know about ASD diagnosis?;
- Are there significant differences in practitioners' levels knowledge and self-efficacy of diagnosis in northern Ontario compared to southern Ontario?;
- Are there differences in diagnosis and treatment between Rural and Urban communities?;
- What are the factors/facilitators that contribute to increased knowledge?; and

- What are the factors/facilitators that contribute to increased self-efficacy?

The amended research questions, as described in the second article, then became: What do Ontario physicians know about ASD? and What are the factors or facilitators that contribute to increased knowledge, comfort, and perceived competency when addressing the needs of individuals with ASD?

A supplemental data set was added to bolster the sample size because the initial sample size was too small for analysis. The two separate phases of data collection were conducted by two separate primary researchers; Golnaz Ghaderi completed the first phase and Nathaniel Davin completed the second phase of data collection. The first phase took place from 2015 to 2017 and had a sample size of $n = 29$ for the questionnaire component, and of $n = 4$ for the semi-structured interview component. The second phase of data collection took place from 2018 to 2019 and had a sample size of $n = 17$ for the questionnaire component and $n = 3$ for the semi-structured interview component. The questions for the questionnaire and semi-structured interview were the same. Additionally, both questionnaires were hosted on REDCap (Research Electronic Data Capture), a secure data capture tool hosted at Laurentian University (Harris et al., 2009). The secondary data set had the same measure (i.e., the Health Care Professional Questionnaire) and same semi-structured interview guide. The semi-structured interview was initially guided by the same supervisor, Dr. Shelley Watson, to ensure similarities in conducting the interview. The major differences between the two data sets were that the secondary data set did not include the Knowledge about Childhood Autism among Health Workers Questionnaire (KCAHW; Bakare et al., 2008), and the time interval between the data collection. The KCAHW is an objective questionnaire aimed at understanding health professionals' knowledge of ASD.

4.2 Summary of Findings for Quantitative Analysis

One of the major findings included physicians' estimations of the prevalence rates of ASD. Overall, the epidemiology of ASD was greatly underestimated by physicians with an average estimate of 1 in 1109. According to the CDC (2018), the current prevalence rate is 1 in 59 (Baio et al., 2018). Additionally, the newest diagnostic criteria, hypo-reactivity to sensory information, which was introduced in the DSM-5, was the least identified as being a criterion of ASD. Only 44% of physicians correctly identified hypo-reactivity to sensory information as a criterion of ASD. This finding could illustrate a need for more awareness and knowledge regarding updates in DSM-5 criteria. Physicians likely do not focus on the DSM-5, and specifically ASD in their continuing medical education.

Hyper-reactivity to sensory information was also added to the diagnostic criteria in the DSM-5; however, physicians did recognize this as a sign of ASD (100% correct). It is possible that physicians are not up to date with the revised diagnostic criteria for ASD. Furthermore, some of the earlier signs or identifiers of ASD, such as social smiling (50% correct) and staring into open space (56% correct), were under identified as being signs or symptoms of ASD. Overlooking these signs as potential identifiers for ASD may delay diagnosis. The delays in diagnosis can also delay treatment engagement. Early diagnosis is considered best practice and a better prognosis is associated with early diagnosis as individuals with ASD are able to engage in treatment earlier (Clark et al., 2018; Dawson, 2008). Furthermore, a delay in diagnosis is also associated with a higher financial cost to the family (Horlin et al., 2014).

Statistical analyses (e.g., ANOVA) were performed on the levels of perceived knowledge across disciplines (i.e., paediatricians, family physicians, psychiatrists, and other). Results

revealed that paediatricians had significantly more perceived knowledge regarding the assessment and treatment of ASD compared to family physicians and those physicians in the other category (e.g., orthopaedic physicians, emergency medicine physicians, and one physician that identified as a student), but not significantly more than psychiatrists. Additionally, it was found that psychiatrists had significantly more perceived knowledge regarding ASD assessment and treatment than the other physician category. Although the current study has a limited sample size, superior knowledge of psychiatrists regarding ASD has been demonstrated elsewhere (Eseigbe et al., 2015). This finding speaks to the enhanced education that paediatricians and psychiatrists may receive regarding ASD; however, other researchers have found that if appropriate training is given to general practitioners, the resources are still lacking to properly diagnose (Unigwe et al., 2017). Therefore, a paediatrician should receive the referral if ASD is detected. A psychiatrist could be a source for information or an expert that physicians could consult if needed. The results indicate that health care providers, particularly family physicians, need more education and training.

Independent sample *t*-tests were performed on the two sets of data (2015-2017 and 2018-2019). The first sample of physicians ($n = 29$) felt that they had significantly higher knowledge regarding the assessment of ASD compared to the second sample of physicians ($n = 17$; $M = 3.25 > M = 2.71$). The difference in perceived knowledge may be because of the increasing prevalence rate (Fombonne, 2018), and the perceived lack of resources that physicians identified in this study. Physicians should be more knowledgeable pertaining to resources available for ASD including community resources (Carbone et al., 2010). No statistically significant difference was found regarding the treatment of ASD; however, the first sample felt they had

more knowledge, on average, compared to the second sample regarding treatment ($M = 3.00 > M = 2.56$).

To the question “*Do you feel that you have enough access to information or resources to meet the needs of individuals with disabilities?*”, only 32% of participants in the first sample indicated “No” while the majority of the second sample indicated that they did not feel that they had access to enough information or resources to meet the needs of individuals with ASD (53%). The increase in prevalence rates of ASD may highlight the lack of awareness for resources as more and more individuals with ASD come into contact with physicians. Additionally, physicians often feel that the education and training they receive in medical school may be inadequate (Major, 2015). The perceived lack of resources may also be because of Ontario budget cuts surrounding ASD and public health in general that have drawn considerable attention within the past year (The Canadian Press, 2019). The cutting of funding and the decrease of resources is unfortunately counter to literature that indicates a need for more awareness and resources regarding ASD in all health care, including physicians (Morris et al., 2019).

4.3 Summary of Findings for Qualitative Analysis

A total of seven transcripts for the semi-structured interviews conducted with physicians were analyzed. Four transcripts came from the 2015-2017 data collection phase, and three transcripts were analyzed from the current 2018-2019 data collection phase.

The physicians from both phases highlighted potential facilitators to improving their comfort, competency, and knowledge in caring for individuals with ASD. Two main themes were generated. The first was labelled “Exposure as a facilitator”, where prior exposure to individuals with ASD was identified as leading to higher levels of comfort in caring for these

individuals, and an increase in knowledge regarding the disorder. Additionally, it was found that physicians learn about ASD from a variety of sources including parents, individuals with ASD, and colleagues. The finding of “Exposure as a facilitator” and the sources for that exposure (i.e., parents, individuals with ASD, and colleagues) provide implications for physician knowledge acquisition, as well as increasing physicians’ comfort levels in caring for individuals with ASD. Exposure could begin in medical school, where parents and individuals with ASD could be part of the learning process. There is literature that illustrates positive outcomes when parents are involved in the medical training process (e.g., Kube et al., 2013). The Canadian Paediatric Society (CPS) recommends physicians listen to parents regarding ASD, as it is integral to a family-centred approach, which is essential in the ASD diagnostic process (Brian et al., 2019). Additionally, medical training that includes real life cases of ASD has been endorsed by the American Academy of Pediatrics (AAP; Major, 2015).

The second theme that was generated and labelled, “The Need for, and Awareness of, Road Maps,” recognized the need for physicians to have a clear road map of how to navigate the complex journey of ASD. A sub-theme was generated in which physicians described that having a “road map” for parents may also be beneficial for increasing general knowledge regarding ASD. Physicians identified that navigation of the “system” is confusing to the parents and even to the physicians themselves. According to the CPS, physicians should familiarize themselves with programs and services in their communities and be capable of discussing specifics with parents (Brian et al., 2019). A pictorial road map drafted for each community is an efficient way of disseminating this information.

There have been attempts at creating some sort of map for the parents and family, even in Ontario, as the Ottawa Autism Roadmap is congruent with suggestions physicians have when

drafting one (very pictorial and having information regarding resources; Autism Advocacy Ottawa, 2014). However, this example is somewhat confusing and seemingly too busy. Additionally, the map was developed solely by parents. There are publications from The Center for Autism Research (2016), Autism Speaks (n.d), and the community of parents in Ottawa (2014). Availability of such resources should be made aware to physicians. Physicians may not be aware of recourses available to them and to the families based on the results of this study. Moreover, resources such as the ones mentioned previously should be available in clinics. Additionally, knowledge and information should be disseminated to physicians in Ontario regarding quick resources to help support parents, families, and individuals regarding the “road,” “Journey,” “Pathway,” and this strategy seems to convey a lot of information efficiently.

4.4 Implications for Research

Physicians are an integral part of medical and psychological research. There is a move toward a more interdisciplinary approach to the medical model and research involving physicians in topics such as ASD and other developmental disabilities may increase. The first paper in this study described various methods and techniques in order to help bolster physician recruitment in psychological research, as well as contributing information regarding physician recruitment for graduate research. Future research should continue to delineate the best methods for physician recruitment in psychological research.

Additionally, the results of the first paper highlight the importance of reflexivity for research failures, especially for students. The paper acts as a validation for some of the inherent struggles graduate student researchers face, and suggestions for overcoming these perceived failures. Additionally, implications include the personal acceptance of amendments or changes to

research. Hopefully, this paper will help students who face research challenges to continue progressing and making appropriate changes when needed. The paper also encourages students to reflect on, and pursue publication of, perceived research failures. Furthermore, it encourages editors and journals to publish research failures or negative results as valuable lessons can be learned and insight gained regarding future research directions (Gregory, 2019).

Future research is also needed in order to identify what pertinent information may need to be included in a road map for parents, individuals with ASD, and health care professionals. There are publications from The Center for Autism Research, Autism Speaks, Canadian Autism Spectrum Disorders Alliance, and the community of parents in Ottawa to offer templates for what to be included and what specific regional road maps could look like (Autism Advocacy Ottawa, 2014; Autism Speaks, n.d; Center for Autism Research, 2016; Canadian Autism Spectrum Disorders Alliance, 2016). However, future research is needed regarding what specific programs and services are available in individual communities, and information regarding access to the services or programs.

There are implications regarding the finding that physicians identified the navigation of the “system” as confusing to parents and even to themselves. If physicians find it confusing, information about services may not be translated adequately to the parents. Research could be conducted regarding the formulation of a road map, not just for the families and individuals with ASD, but also for physicians. Pertinent information as decided by governing bodies, such as the CPS and the AAP, could be included in the road map for physicians. Additionally, focus groups with knowledgeable experts in the field could be conducted in order to identify what specific information could be included in a concise pictorial or graphic pamphlet that every physician’s

office could have. Based on the results of this study, information could include developmental milestones, up to date diagnostic criteria, and early identifiable signs of ASD.

Research is also needed in the area of why the more recent sample of physicians felt as though they had less access to information and resources than the previous round of physicians. Potential reasons for these differences could include more knowledge and awareness of the complexity and heterogeneous nature of ASD (APA, 2013), funding cuts and changes in the province (The Canadian Press, 2019), or the realization that their medical education and training may have been insufficient with regards to ASD (Warfield et al., 2015). Warfield and associates (2015) discuss how there are few medical schools that offer effective case-based training on ASD. Future research in this area can help illustrate how equipped physicians feel in caring for individuals with ASD, and what resources could be put in place to increase their knowledge, comfort level, and competency in providing care for this population.

4.5 Implications for Clinical Practice

As the ASD prevalence rates grow, physicians may be realizing they do not have enough access to resources. Research have found that even with adequate training, physicians may not have the resources to diagnose or provide care for individuals with ASD (Unigwe et al. 2017). Additionally, physicians may feel as though they lack the knowledge and ability to meet the needs of individuals with ASD. The researchers of this study found a sharp contrast in physicians' access to information and resources regarding ASD from the 2014-2015 sample to the 2017-2018 sample. The authors of other recent studies have identified a lack of knowledge and adequate education and training to sufficiently care for these individuals (e.g., Altay, 2019; Atun-Einy & Ben-Sasson, 2018; Major, 2015; Rizzolo et al., 2019). Lack of resources was

identified as being a common theme in a recent meta-analysis (Morris et al., 2019). Based on the results of the current study, this theme is supported, and lack of resources is an issue that needs to be addressed in clinical practice. Additionally, training and education needs to be enhanced to provide physicians with the best ability to care for this population.

Given that this lack of training and knowledge has been well established in the introduction and throughout this document (Fenikilé et al., 2015; Finke et al., 2010; Imran et al., 2011; Morris et al., 2019; Rhoades et al., 2007;), it is now time to review factors or facilitators that lead to efficient knowledge transfer and acquisition, such as the findings of this study. Consistent with the findings of the current study, many studies noted similar limited knowledge and/or skills, and limited awareness or access to (Morris et al., 2019). In fact, findings of the current study indicate that access to resources and knowledge limitations may be increasing. This trend may continue if funding is not allocated and education is not enhanced. Due to the rising prevalence rates of ASD, and physicians' prevalence under estimation of 1 in 1109, more awareness regarding the lack of resource may come to light as the epidemiology is better understood by physicians.

A facilitator to knowledge transfer for physicians was exposure to individuals with ASD, parents of children with ASD, and to experts and colleagues in the field. Physicians identified exposure to be a facilitator to knowledge and competency. Physicians have also indicated that they value interactive experiences (or exposure) with individuals with ASD more than their formal training in some cases (Morris et al., 2019). Implementing a collaborative approach where physicians get exposure to individuals with ASD, parents of children with ASD, and established experts in the field seems like an efficient method to enhance training and education. The importance of the family and individual involved in the diagnostic process has been highlighted

in literature (Jashar et al., 2019), and perhaps there is importance for the individual and the family to be involved in the education process.

Exposure could be implemented at the educational level. This could take place by having guest lectures (with both the parents and individuals with ASD), case studies with real life cases, and site training in collaboration with experts in the field (e.g., clinic visits).

Significant attention has been paid to the effectiveness of treatment programs, namely IBI and ABA (De Rivera, 2008). It is widely accepted that the time at which an individual with ASD engages in treatment influences the treatment effectiveness and the individual's overall prognosis. Research has been conducted evaluating the overall cost for the family if individuals engage in treatment, and the implications of the time in which the individual engages in treatment (Piccininni et al., 2017). The authors of this study found that the societal cost is contingent on the variable of the age in which the individual engages in treatment. The cost is not only associated with intervention, but also the high costs over the lifetime, particularly for social support and education (Piccininni et al., 2017).

In order for individuals to engage in treatment programs, a diagnosis must first be made in most cases. It is time to focus more resources and funding, particularly in Ontario, to equip the health professionals responsible for diagnosing this complex neurological disorder, to be able to efficiently diagnose as early as possible. The diagnostic scope in terms of which professionals are responsible for diagnosing should be clearly delineated, such as the CPS's statement (2019) recommending paediatricians or a specialized team should diagnose. However, the fact of the matter is that physicians and health care providers should be equipped with adequate, up to date knowledge and resources to at least be able to flag or identify ASD (Zwaigenbaum et al., 2019).

Up to date knowledge will provide physicians with the ability to make a referral to the professionals or specialized teams responsible for making the diagnosis. Additionally, the implication of the finding that indicated paediatricians' feelings of superior knowledge regarding ASD assessment is that parents of newborns should have access to a paediatrician who has knowledge, experience, and exposure to ASD.

A clear-cut road map for individuals with ASD, for the families, and for physicians may facilitate better care for individuals with ASD. The road map will facilitate better care as information regarding community services and programs should be included. Additionally, pertinent information as identified by other professionals in the field on ASD could be included in the road maps (Atun-Einy & Ben-Sasson, 2018; Bhat et al., 2011; Dillenburger, et al., 2016; Filipek et al., 2000; Volkmar et al., 1999). These health professionals include psychologists, speech-language pathologists, occupational therapists, and physical therapists. There are articles now written to bring awareness to physicians regarding tools such as tools available at autism speaks (Bellando et al., 2016). This study also brings awareness and makes recommendations for tools, and more awareness for resources.

4.6 Study Limitations and Considerations

The intended target sample size of $n = 80$ was not reached. Therefore, one of the initial questions for this study could not be answered regarding the geographic differences in levels of knowledge pertaining to ASD. Additionally, the majority of physicians ($n = 37$) were from urban settings. Therefore, regional differences in physicians' knowledge of ASD could not be analyzed. Because of limitations during participant recruitment, data were limited, and analysis

and research questions had to be amended. As a result, there were additional limitations in the analysis.

The KCAHW objective questionnaire could not be evaluated properly. Because of the sample size, objective statements pertaining to levels of knowledge were unable to be assessed or made. Additionally, the intended scoring of the KCAHW could not be completed. In order to help mitigate these limitations, previous data collected were added to bolster the sample size. Differences in the samples were analyzed and noted; however, the KCAHW was not included in the first sample. There has been some inherent sample bias for the fact that physicians that felt more knowledgeable about this topic were more likely to participate. All physicians that participated in the semi-structured interview in the second sample ($n = 3$) indicated they had previous experience with individuals with ASD prior to medical training and had interest in ASD beyond the medical scope. Therefore, it is possible that other perspectives regarding physicians' knowledge, comfort, and competency were not captured in the present study. Results should be interpreted with caution.

4.7 Conclusion

This thesis is part of an ongoing project focused on overall knowledge and experience of health care professionals pertaining to developmental disabilities in general (e.g., Coons, 2017; Ghaderi & Watson, 2018; Ghaderi & Watson, 2019). Additionally, the overall study intends to shed light on the current paradigm of a cooperative interdisciplinary education and practice within the health care field as it pertains to developmental disabilities. The goal of this thesis was not necessarily to push for physicians to diagnose, but rather for physicians to have the knowledge and information to be able to efficiently recognize the symptoms of ASD in order to

be able to refer for a diagnosis. The information gleaned from this thesis will draw awareness to this issue.

Previous literature has shown that medical professionals can be hesitant to make a diagnosis of ASD because of insufficient education and training they have received (Rhoades et al., 2007). Physicians and health care professionals alike have indicated a need for increased education and training in helping care for this population (Fenikilé et al., 2015). Additionally, training and knowledge have been found to be inadequate in caring for individuals with ASD (Altay, 2019). Furthermore, a collaborative interdisciplinary effort has been expressed as a potential resource to physicians that may feel hesitant or uncomfortable in diagnosing ASD (Ritzema et al., 2014).

Overall, and in line with previous research, the current study found that physicians feel that resources are lacking, and that their knowledge and ability to diagnose ASD is insufficient. It was found that exposure to individuals with ASD, both in a professional setting and in a personal setting, led to feelings of comfort, competency, and increased knowledge regarding ASD. Furthermore, findings include what physicians indicate may be helpful to help mitigate this lack of knowledge. Physicians mentioned resources like “road maps” to be able to navigate the system for themselves, parents, and the individuals with ASD. These road maps could include community-based resources for parents and individuals, which parents have indicated they want (Jashar et al., 2019). Moreover, the findings of this study suggest that some of the early signs or symptoms of ASD are areas where knowledge needs to be increased.

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List of Appendices

Appendix A Health Care Questionnaire

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

1. What is your gender? Male; Female; Prefer not to answer; Other: (please specify) Other:

2. What is your age? _____

3. What is the area of your specialty (e.g. Family, Physician, Paediatrician, Psychiatrist, Developmental Paediatrician)? _____

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

5. What is your marital status? Single; Married; Living with a partner; Divorced; Separated; Widowed; Other: (please specify) other: _____

6. Where do you currently practice (Geographic Location; i.e. town/city)? (If there's more than 1 location list in order of most time spent practicing) _____

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 or workshops</u> on any of the following topics:	<i>General undergraduate training (e.g., BA, BSc, etc.)</i>	<i>Professional /graduate training (e.g., MD, BScN, MSc, MSW, PhD, etc.)</i>	<i>Other training (please specify)</i>
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): _____	<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,	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PhD, etc.)				
Other (please specify): _____ _____ _____ _____	<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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(e.g., cerebral palsy)				
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>				

Fine/Gross Motor Skills

Memory

Sensory

Other (please specify) _____

15. If you had questions regarding an individual with a developmental disability, to whom would you most likely go for help?

Child Care Workers

Psychologists

Special Needs Consultants

Speech and Language Pathologists

Social Workers

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</i>	<i>Mildly competent</i>	<i>Moderately competent</i>	<i>Very competent</i>

	<i>(could meet few needs)</i>	<i>(could meet some needs)</i>	<i>(could meet most needs)</i>	<i>(could meet all needs expertly)</i>
17. How competent do you feel in <u>meeting the needs</u> of individuals with developmental disabilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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 B 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 factors (e.g. training, programs, education, exposure) have helped increase your knowledge or self-efficacy with regards to diagnosis and treatment of developmental disabilities in general and ASD specifically?
13. What disabilities would you feel comfortable taking care of? What disabilities would you not feel comfortable taking care of? Why or Why not?
14. How do you think your discipline is set up to take care of individuals with intellectual disabilities or developmental disabilities? ASD?
15. If you were helping to design a curriculum on the diagnosis and treatment of ASD, what would you include?

*Appendix C Knowledge about Childhood Autism among Health Workers
(KCAHW) Questionnaire*

Please do not consult formal text books to answer these questions.

Thank you for your co-operation.

The following behaviours best describe a child with childhood autism:

1. Marked impairment in use of multiple non-verbal behaviours such as eye to eye contact, facial expression, body postures and gestures during social interaction?

(A) Don't Know, (B) Yes, (C) No

2. Failure to develop peer relationship appropriate for developmental age?

(A) Don't Know, (B) Yes, (C) No

3. Lack of spontaneous will to share enjoyment, interest or activities with other people? (A) Don't Know, (B) Yes (C) No

4. Lack of social or emotional reciprocity? (A) Don't Know (B) Yes, (C) No

5. Staring into open space and not focusing on anything specific? (A)Don't Know, (B) Yes, (C) No

6. The child can appear as if deaf or dumb? (A) Don't Know (B) Yes, (C) No

7. Loss of interest in the environment and surroundings?

(A) Don't Know, (B) Yes, (C) No

8. Social smile is usually absent in a child with Autism?

(A)Don't Know, (B) Yes (C) No

9. Delay or total lack of development of spoken language?

(A) Don't Know (B) Yes (C) No

10. Stereotyped and repetitive movement (e.g. Hand or finger flapping or twisting)?
(A) Don't Know (B) Yes, (C) No
11. May be associated with abnormal eating habit?
(A) Don't Know, (B) Yes, (C) No
12. Persistent preoccupation with parts of objects?
(A) Don't Know (B) Yes, (C) No
13. Love for regimented routine activities? (A) Don't Know (B) Yes, (C) No
14. Hyper-reactivity to sensory input? (A) Don't Know (B) Yes, (C) No
15. Hypo-reactivity to sensory input? (A) Don't Know (B) Yes, (C) No
16. Autism is Childhood Schizophrenia? (A) Don't Know (B) Yes (C) No
17. Autism is an auto-immune condition? (A) Don't Know (B) Yes (C) No
18. Autism is a neuro-developmental disorder? (A) Don't Know (B) Yes (C) No
19. Autism could be associated with Mental Retardation? (A) Don't Know (B) Yes (C) No
20. Autism could be associated with Epilepsy? (A) Don't Know (B) Yes (C) No
21. Onset of Autism is usually in, (A) Neonatal age, (B) Infancy, (C) Childhood
22. Approximately what is the prevalence rate of ASD to your knowledge 1 in _____