An Assessment of Autism Knowledge in the Medical Field

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Abstract

Once thought to be rare, pervasive developmental disorders (PDDs) are now recognized as the most common neurological disorders affecting children and one of the most common developmental disabilities (DD) in Canada (Autism Society of Canada, 2006). Recent reports indicate that PDDs currently affect 1 in 150 children (Centre for Disease Control and Prevention, 2007). The purpose of this research was to provide an understanding of medical resident and practicing physicians' basic knowledge regarding PDDs.

With a population of children with PDDs who present with varying symptoms, the ability for medical professionals to provide general information, diagnosis, appropriate referrals, and medical care can be quite complex. A basic knowledge of the disorder is only a first step in providing adequate medical care to individuals with autism and their families.

An updated version of Stone's (1987) Autism survey was administered to medical residents at four medical schools in Canada and currently practicing physicians at three medical schools and one community health network. As well, a group of professionals specializing in the field of PDDs, participating in research and clinical practice, were surveyed as an 'expert' group to act as a control measure. Expert responses were consistent with current research in the field.

General findings indicated few differences in overall knowledge between residents and physicians, with misconceptions evident in areas such as the nature of the disorder, qualitative characteristics of autism, and effective interventions. Results were also examined by specialty and, while pediatricians demonstrated additional accurate
knowledge regarding the nature of the disorder and select qualitative impairments, both residents and practicing physicians demonstrated misconceptions about PDDs. This preliminary study replicated the findings of Stone (1987) and Heidgerken (2005) concerning several misconceptions of PDDs held by residents and practicing physicians. Future research should focus on additional replications with validated measures as well as the gathering of qualitative information, in order to inform the medical profession of the need for education in PDDs at training and professional levels.
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Introduction

Given the increased prevalence of pervasive development disorders (PDDs) (American Psychiatric Association [APA], 2000), that has recently been reported as 1 in 150 (Centers for Disease Control and Prevention, 2007), the needs and challenges of children, particularly in the area of medical care, are steadily growing. Providing medical care is important for children with various PDDs who, similar to typically developing children, encounter everyday health concerns. The ability of medical personnel to provide care can often be difficult and complex when an adequate knowledge of the disorder, and the special needs and challenges that accompany it are not present in their repertoire. For a physician who does not recognize early characteristics of the disorder, a referral for a diagnosis, and subsequent intervention, may be delayed. Research concerning the assessment of medical personnel’s knowledge of autism is exceedingly sparse, but preliminary findings thus far suggest that medical students have limited knowledge regarding various areas of autism, specifically concerning treatment (Shah, 2001). When medical school curriculum was examined, Hutchinson (2005) showed that students reported a significant lack of information throughout their training and perceived their own levels of knowledge as inadequate as to what is necessary to provide quality care to patients. As well, primary health care providers, including pediatricians and family physicians, were found to have significant limitations in knowledge regarding prognosis, course and treatment (Heidgerken, Grefken, Modi, & Frakey, 2005).

Similar to previous studies, the present research will assess the knowledge of PDDs held by medical residents in pediatrics and family medicine, as well as practicing physicians in Canada. A strong foundation of knowledge is necessary for these
practitioners to provide necessary screening, referrals, knowledge to parents, and quality health care to young children and their families. The following literature provides an overview of basic knowledge concerning PDDs, and, likely, information that medical residents and professionals should know in providing adequate medical care.

*Pervasive Developmental Disorders*

Once thought to be rare, PDDs are now recognized as the most common neurological disorder affecting children and one of the most common developmental disabilities in Canada (Autism Society of Canada, 2006). PDDs are now considered to be more prevalent in the pediatric population than cancer, diabetes, spina bifida, and Down syndrome (Filipek et al., 1999). They are pervasive in nature, and while present at birth, symptoms may not become noticeable before 24 months of age (Heidgerken et al., 2005). PDDs are known to include qualitative impairments in social interaction, communication, and/or restrictive or repetitive activities and interests. Specifically, qualitative impairments in social interaction may include the following: direct eye-to-eye gaze; failure to develop peer relationships appropriate to developmental level; a lack of spontaneity in seeking to share enjoyment, interests or achievements with other people; and a lack of social or emotional reciprocity (APA, 2000).

Qualitative impairments in communication may include the following: a delay in, or lack of spoken language without a means of alternative communication; in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others; stereotyped and repetitive use of language; and lack of make-believe play or social imitative play appropriate to developmental level (APA, 2000). Finally, restricted, repetitive and stereotyped patterns of behaviour, interests and activities
may include the following: preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus; inflexible adherence to specific nonfunctional routines or rituals; stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting); and persistent preoccupation with parts of objects (APA, 2000). Although we define, assess and treat behavioral characteristics of PDDs, they are not considered a behavioral, emotional, conduct disorder, or a mental illness (Shriver, Allen, & Matthews, 1999).

**Spectrum Disorders**

Presently in the DSM-IV-TR (APA, 2000), there are five recognized PDDs: Autistic disorder, Rett's disorder, Childhood disintegrative disorder, Asperger's syndrome and Pervasive developmental disorder-not otherwise specified (PDD-NOS). Individuals diagnosed with these spectrum disorders show heterogeneity in symptom presentation, regarding the areas of socialization, communication and/or behavioural variability (APA, 2000). For example, given the DSM-IV-TR (APA, 2000) diagnosis of PDD-NOS, an individual needs to satisfy criteria in one of three core domains; one child diagnosed with PDD-NOS may show limited language deficits, whereas another child may present with repetitive behaviour patterns.

For medical practitioners, a differential diagnosis is often necessary to understand the core deficit areas of a particular child, and how this may influence the care being provided. Thus, knowledge of the various characteristics and impairments displayed by young children with a PDD is extremely important in order to appropriately interact with and effectively provide the necessary medical care for the child. Note that the general term PDD is often used interchangeably with Autism and Autism Spectrum Disorder...
(ASD). For the purpose of this paper, the three terms (i.e., PDD, Autism and ASD) will be used interchangeably when referring to the spectrum disorders.

History

Autism was first described in 1943 by psychiatrist Leo Kanner who referred to it as an “inborn disturbance of affective contact” (Fein, Robins, Liss, & Waterhouse, 2001). He initially applied this term to a group of boys who were socially withdrawn and preoccupied with routine, manifesting poor or no verbal communication (Zafeiriou, Ververi, & Vargiami, 2007). Further, these children were often classified under the term schizophrenic (Filipek et al., 1999). Beginning in the 1950’s, and persisting through the 1960’s and 70’s, the psychodynamic view prevailed, with the belief that the symptoms of autism were a response to a deep emotional disturbance or ‘cold’ mothering and led to blaming the parent for the child’s challenges. Moreover, research on causes and treatment at this time continued to focus on parental attitudes and emotional reactions to their children. Early epidemiological surveys suggested a correlation between social class, specifically high SES, and Caucasian ethnicities in autism. However, current rates across social classes present similar frequencies, suggesting previous findings were likely to reflect biases and availability in accessing services at the time (Fombonne, 2005).

Beginning with the publication of Rimland’s (1964) book, Infantile Autism: The Syndrome and Its Implication for a Neural Theory of Behavior, the focus of research in the mid to late 1970s shifted to describing the cognitive and behavioral details of the syndrome, including efforts to develop effective behavioral interventions. Throughout the 1980s and 1990s, biological research became the prime focus of autism research.
Currently there is a nearly unanimous view that autism and related syndromes are disorders of brain development, with a strong genetic basis (Fein et al., 2001).

**PDD as a Neurodevelopmental Disorder**

While knowledge is still unclear regarding the specific etiologies of PDDs, it is widely recognized that PDD is a neurodevelopmental disability, resulting from organic and genetic factors. Currently, multiple areas in the brain have been implicated as responsible for the disorder (Szatmari et al., 2007). Specifically, data show that the symptoms of PDDs are not made up of a single core deficit, but rather a variety of deficits that come together in varying degrees in different individuals (Gupta & State, 2007). Several reported and consistently replicated findings have appeared from Magnetic Imaging Resonance (MRI) studies; they include increased head circumference, and brain mass, reductions in the area of the corpus callosum and the neocerebellar vermis of the cerebellum as well as reduced Purkinje cells (Szatmari et al., 2007).

Concerning the genetics of PDDs, the number of contributing chromosomes or genetic regions has been estimated to be in the neighborhood of 15, but it is likely that this may be an underestimation (Gupta & State, 2007). Research to date indicates the involvement of various areas of chromosomes 1, 2, 5, 6, 7, 10, 11, 12 and 17 (Katzov, 2007; Szatmari, 2003). In addition to mapping out specific genes and chromosomes, findings have supported increased risk for recurrence in siblings. Specifically, the overall risk to siblings of children with autistic disorder is estimated at 3 to 6%, and the risk to siblings of children born after the proband with autism may be as high as 9% (Nicolson, & Szatmari, 2003). However, in terms of all PDDs as a group, recent studies have reported reoccurrence rates ranging from 20 to 30% in genetically at-risk siblings (e.g.,
Further supporting a genetic basis, research indicates 60-70% concurrence rates in monozygotic twins (e.g., Nicolson, & Szatmari, 2003; Wolf, 2004; Zwaigenbaum et al., 2005) and up to 92% of twins presenting with social deficits and stereotypies (Filipek, 2003; Nicolson, & Szatmari, 2003). However, without genetic concordance rates of 100%, environmental factors such as prenatal factors including viral infections in utero cannot be ruled out as a contributing factor to the development of a PDD.

Prevalence Rates

Historically, autism was estimated as 0.5 per 1,000 in the 1960s and 1970s and approximately 1 per 1,000 in the 1980s (Newschaffer et al., 2007). Recently, Rutter (2006) identified a prevalence of 1 in 166, and a rate of 1 in 150 was announced by health officials (Centers for Disease Control and Prevention, 2007). Specifically, prevalence rates of Autistic disorder, Asperger’s Syndrome and PDD-NOS, the more common of the spectrum disorders, are 1.3 in 1,000, 0.26 in 1,000 and at least 2.08 in 1,000, respectively (Fombonne, 2003). However, Fombonne (2005) examined nine recent epidemiological surveys that yielded even higher rates. According to Fombonne, these studies now provide the best estimate of all PDDs combined which is approximately 6 per 1,000 or 1 in 166.

It is widely debated as to whether the overall prevalence rate of autism has increased or if past prevalence rates have been under recognized. For instance, a widening of the definition in recent decades to include all spectrum disorders (e.g., Asperger’s disorder, Pervasive developmental disorder-not otherwise specified) which
include less severe or variable symptoms may play a role (Connor, 2003). Also, it is suggested that increased rates of diagnoses reflect changes in diagnostic criteria, improved diagnostic tools, as well as heightened public awareness and medical coverage (Fombonne, 2005; Tidmarsh, & Volkmar, 2003).

Despite argued trends of increased prevalence, the mean male to female ratio of 4.3:1 has been maintained (Fombonne, 2005). Overall, current prevalence rates contribute to a growing need to understand knowledge of PDD and, if limited, how training curricula may need to be adapted.

Comorbidity

Comorbidity is defined as the co-occurrence of two or more discrete disorders in the same individual. Most notably, intellectual disabilities (ID) have commonly been associated with PDDs. ID is defined as an IQ of 70 or below and impairments in at least two areas of adaptive functioning (e.g., self-help skills, communication) (APA, 2000). In a recent epidemiological survey, 37 studies have shown that approximately 70% of children with autism also have an ID, with 29.3% scoring in the mild to moderate range of ID, and 38.5% scoring in the moderate to profound range (Fombonne, 2005).

In addition to a comorbidity of autism and ID, there is a reported high comorbidity of autism with seizure disorders and/or epilepsy (Fombonne, 2005). Estimates of the prevalence of seizures and PDD range from one-quarter to one-third of the population, which is far in excess of the prevalence of seizures in the general population. Other common comorbid disorders include: attention deficit hyperactivity disorder (ADHD), anxiety, depression, Tourette’s syndrome, sleep disorders, feeding
disorders as well as several biomedical conditions such as fragile X syndrome, tuberous sclerosis, and phenylketonuria (PKU) (Fein et al., 2001).

Assessment and Diagnosis

By definition, the onset of a PDD is before three years of age. However, recent research has demonstrated that symptoms of autism are now measurable by 18 months of age and that these symptoms are stable from toddler age onward (Lord, Rutter, & Le Couteur, 1994). Further, recent studies have revealed that signs of abnormality and symptoms of autism can be present in the first year of life (Landa et al., 2007; Zwaigenbaum et al., 2005). However, making a diagnosis is challenging in infants and toddlers, reflecting both the rapid pace of developmental change as well as issues related to clinical presentation of symptoms that may be difficult to differentiate at this point of development (Newschaffer et al., 2007).

Early screening and identification are crucial for improving outcomes of children with PDDs. It has been recommended that routine developmental surveillance and screening be performed for all children to identify those who are potentially at-risk for any type of delayed or atypical development and specifically for those children who are genetically at risk (Filipek et al., 2002). However, according to the American Academy of Pediatrics (2002), it was reported that despite this practice guideline, many primary care providers (including pediatricians and family practitioners) are unfamiliar with the recommendations and do not use standardized techniques to screen for developmental problems.

According to Filipek et al. (2002), a diagnosis should be made based on developmental history, clinical observation, DSM-IV-TR (APA, 2000) criteria, and
should include diagnostic instruments with at least moderate sensitivity and good specificity for autism. It is recommended that one component of an assessment is a thorough interview with parents to review the child’s early developmental history and an understanding of parental concerns regarding their child. As well, direct observation of and interaction with the child should take place. The Autism Diagnostic Interview-Revised (ADI-R) (Lord, Rutter, & LeCouteur 1994; Rutter, LeCouteur, & Lord, 2003) and the performance-based Autism Diagnostic Observation Schedule (ADOS) (Lord, Risi, Lambrecht, Cook, Leventhal, & DiLavore, 2000) are considered to be the ‘gold standard’ instruments in diagnosing autism spectrum disorder (Filipek et al., 2002).

Given the heterogeneity of children diagnosed with a PDD, identification and diagnosis can become complicated (Heidgerken et al., 2005). However, as the knowledge base regarding the etiology, prognosis, and treatment of autism expands, diagnostic criteria will likely be even further refined. While research has provided evidence that an increased awareness of the disorder, in addition to the improvement of diagnostic sensitivity, has led to providing a reliable diagnosis by 18 months of age, this has only become apparent in recent years (Newschaffer et al., 2007). Thus, it is likely that with future research in early identification and refinement of assessment tools, the ability of clinicians to diagnose at progressively early ages will occur. Advantages of early identification include a focus on educational planning and treatment, support for families, reduction of stress and delivery of appropriate medical care to the child (Filipek et al., 1999).

_Treatment_
The increased prevalence rate in children diagnosed with a PDD and the establishment of empirically based treatments has led to a continued demand for services and treatments. The general consensus among researchers in the field suggests that the most effective approach for addressing the core symptoms of PDD includes a curriculum of early intensive behavioural interventions (EIBI) based on principles and procedures of applied behaviour analysis, across multiple settings (e.g., home and school) (Levy et al., 2003).

Applied Behaviour Analysis (ABA) employs methods based on scientific principles of behaviour to enhance skill development in communication and social interaction, as well as reduce inappropriate behaviours. Behavior analytic treatment for autism focuses on teaching small, structured units of behavior systematically (Green, 1994). There is an abundance of scientific evidence that early intensive behavioural intervention based on the principles of ABA can produce comprehensive and lasting improvements in key skill areas for most people with autism, regardless of age. To date, no other treatment for autism offers comparable evidence of effectiveness (Newschaffer et al., 2007).

In 1987, a groundbreaking study by Lovaas described successful outcomes for 47% of participants (n=19), who were all less than 46 months old, who began an intensive treatment program at 40 hours a week in the home setting. These children were followed up at 11.5 years of age and results indicated that gains (i.e., IQ and regular educational placement) were maintained (McEachin, Smith, & Lovaas, 1993). However, the Lovaas (1987) study had methodological limitations including no random assignment. Since this study, there have been several partial replications (e.g., Cohen, Amerine-
Dickens, & Smith, 2006, Graff, Green, & Libby, 1998; Howard, Dickens & Smith, 2006; Smith, 1999), with two randomized control trials (RCT’s) (i.e., Smith, Groen, & Wynn, 2000, Sallows & Graupner, 2005) conducted to date. Concerning the RCT’s, they have shown very positive outcomes with increases in IQ and adaptive functioning, as well as reduced aberrant behaviours and social problems. The RCT’s studies have attempted to alleviate some of the methodological limitations of Lovaas (1987) by randomly assigning participants to the groups. While most recent research on early intensive behavioral intervention supports gains in intellectual functioning, adaptive functioning, as well as communication and social interaction, delays are still evident in many children (Kabot, Masi, & Segal, 2003; Sallows & Graupner, 2005; Smith, Eikeseth, Klevstrand, & Lovaas, 1997).

Research continues to redefine appropriate and effective early intervention practices. The optimal age to begin early intensive behavioral intervention is before the age of five and, thus far, the best outcomes have been reported for children who start in the early childhood years (Howard et al., 2005). In general, it is suggested that EIBI should be provided at the earliest stage possible and must be intensive in nature; a minimum of 30 to 40 hours per week (Howard et al., 2005). The instruction should be systematic with individualized goals and objectives. Finally, an emphasis should be placed on programming for generalization to a variety of settings. Studies have also shown that parent training and support may be an advantageous component to the program (Kabot, et al, 2003).

While no medication is available to effectively treat the socio-communicative symptoms of autism, medication is commonly prescribed for behavioural issues
including: repetitive/restricted behaviors, short attention span, impulsivity/ hyperactivity, sleep problems, anxiety, agitation, aggression, and disruptive or self-injurious behaviors. Surveys have estimated that psychotropic medication use in children with autism is as high as 47% (Newschaffer et al., 2007). While further research is needed, Risperidone (Risperdal) trials have been conducted with children with autism, including double-blind randomized control trials, and have shown promising outcomes in treating behavioural symptoms (e.g., aggression, self-injurious behaviour) in multiple studies across various locations (e.g., McDougle et al., 1998; Sheat et al., 2004; Williams et al., 2006).

Although EIBI, based on ABA, and medication (i.e., Risperidal) have shown to be empirically validated treatments for PDDs, there is a lack of agreement among researchers and professionals in the field concerning the recommended treatment approaches for children with PDDs. In combination with the fact that many children with autism have poor access to effective treatment (e.g., long waiting times, age restrictions, and financial limitations) it is not surprising that families turn to complimentary and alternative medicine (CAM) strategies.

Complimentary and alternative medicine strategies. CAM treatments have been defined as “a broad domain of healing resources that encompass all health system modalities and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system” and as “strategies that have not met the standards of clinical effectiveness, either through randomized controlled clinical trials or through the consensus of the biomedical community” (Levy et al., 2004, p. 418). Some examples of these alternative treatments include: nutritional supplements; special diets (e.g., yeast free-diets; gluten-free/casein-free diet, specific carbohydrate diet); avoidance
of allergenic foods; treatment of intestinal bacterial/yeast overgrowth; and detoxification of heavy metals [e.g., mercury]). Further, clinical research and randomized controlled trials have found no clear evidence of Secretin’s (a gastrointestinal hormone) effectiveness in the reduction of symptoms of autism (Levy, & Hyman, 2005). In particular, Sturmey (2005) reviewed 15 double-blind trials of Secretin use with children with autism, and concluded it had no significant effects. More importantly, Secretin use has been linked to harmful side effects, including death.

Further, sensory integration (SI) therapy has been thought to be effective for improving the sensory processing capabilities of the brain. SI is based on the premise that many young children with autism have sensory and motor difficulties. Ayers (1972) developed SI therapy in order to provide controlled sensory experiences for the child. According to principles of SI, it is through such experiences that “the nervous system is thought to be able to better modulate, organize, and integrate information from the environment, which in turn provides a foundation for further adaptive responses and higher order learning” (Baranek, 2002, p. 406). While SI therapy has been around for more than 25 years, it has been the subject of little rigorous research and currently, is not empirically supported (Green, 1994). Overall, alternative therapies and treatments need to be approached with caution.

Despite recent advances and increased awareness, the body of research on early behavioral intervention is still relatively small, but very promising. There is strong evidence that behavioral intervention is more favorable for young children with autism than no intervention and more effective than typical early education services and assorted other therapies (Green, 1994). Recent studies have consistently shown that EIBI (25 to 40
hours per week) provided greater gains in cognition, language and adaptive skills than the same number of hours of eclectic treatments. As well, a combination of EIBI and eclectic treatments revealed no greater gains than EIBI treatments alone (Howard et al., 2005; Smith et al., 2006; Eikeseth, Smith, Jahr, & Eldvik, 2002). Results suggested that some children may make larger gains with EIBI, and that specific aspects of behavioural treatment (not just intensity) may account for favorable outcomes.

The above research continues to support the need for practitioners to be knowledgeable in the area of symptoms, diagnosis, and treatment, in order to provide support and quality healthcare to families and children with autism. Providing an understanding of basic knowledge levels held by primary medical providers, including pediatricians and family physicians, will provide insight into curriculum areas that may be lacking, and may help to identify pre-requisite skills that are required to provide appropriate and empathetic care.

Stone’s Autism Survey (1987) and Measures of Autism Knowledge

While the emphasis on providing competent care to young children with PDDs starts with an adequate knowledge base, few studies have attempted to directly assess knowledge and beliefs regarding PDDs with validated assessment tools.

One validated tool, the Stone Autism Survey (see Appendix B) was originally developed in 1987, and was designed to assess knowledge and beliefs regarding various aspects of autistic disorder. The original measure is comprised of two sections. Part I assesses 21 beliefs regarding social/emotional, cognitive, and treatment/prognosis of autism. These survey items, grouped into three categories, include eight items regarding social emotional features, six items specific to cognitive features and seven items specific
to general descriptive features. The statements in this survey were based on common misconceptions regarding autism derived from research and practice. Questions include statements such as “autism is an emotional disorder” and “autism can occur in mild as well as extreme forms”. The responder is instructed to rate each item on a six-point scale, ranging from 1 (fully agree) to 6 (fully disagree).

Part II of the Stone Autism Survey (1987) assesses responders’ knowledge regarding specific DSM-III-R (APA, 1987) diagnostic criteria for assessing autism. This section is comprised of two questions in which 18 descriptors of behaviour, cognition, and symptoms are listed. In the first question, participants are instructed to mark those items which are ‘necessary’ for diagnosis. In the second question, participants are instructed to mark from an identical list those items which are ‘helpful, but not necessary’ for diagnosis.

Modified survey. The recently modified version (see Appendix E) of Stone’s (1987) original survey was developed by Dr. Naomi Sweizy and the Christian Sarkine Autism Treatment Centre (2005) to account for current research and knowledge surrounding autism and related disorders. The original survey was based on DSM-III-R (APA, 1987) criteria, whereas the modified version of the survey accommodated the updated DSM-IV-TR criteria (APA, 2000). The modified survey also accounted for up-to-date language use, to reflect recent research and advocacy, such as the use of person-first language. Swiezy’s (2005) updated measure assesses 20 beliefs regarding social/emotional, cognitive and treatment/prognosis of autism. Similar to the originally survey, the responder is instructed to rate each item on a 6-point scale, ranging from 1 (fully agree) to 6 (fully disagree). While preliminary findings indicate appropriate levels
of reliability and validity, further assessment is currently underway (N. Swiezy, Personal Communication, January 2008). The purpose of the current study is to use the modified version of Stone’s Autism Survey (1987) to assess residents’ and primary health care providers’ knowledge and understanding of the symptoms, diagnosis and treatment of autism.

*Access to a Diagnosis*

In general, it is suggested that satisfaction reflects the difference between the quality of care expected relative to what is actually received (Goin-Kochel, McKintosh, & Myers, 2006). Concerning a diagnosis of PDD, there is little doubt that quality of care will have a significant impact on a family unit. Further, research indicates that the way in which diagnostic information is conveyed may have a long-term influence on parental attitudes, levels of family stress and overall satisfaction with health care provided. Although there have been indications of improvements in diagnosis and intervention over the past decade, parental accounts of experiences continue to indicate considerable dissatisfaction (Howlin, & Moorf, 1997). One parent said the following, “It was a lack of knowledge on the physician’s part leading to a later diagnosis for my child. Even after I expressed my concerns, I had to fight for referrals to specialists and still did not receive them. I had to go in on my own and essentially look past the regular physician towards other alternatives” (Harrington, Patrick, Edwards, & Brand, 2006, p. 459).

One of the largest barriers that parents report is the complex pathway to a diagnostic assessment. Parents and children are likely to encounter multiple healthcare professionals before a diagnosis is made. This lengthens and further complicates the process, often leading to diagnostic confusion (Heidgerken et al., 2005). Parents report
visiting, on average, between four and five clinicians en route to a potential PDD diagnosis. As well, a child’s age has been found to be negatively associated with parental satisfaction with the diagnostic process (Goin-Kochel, McKintosh, & Myers, 2006). These barriers have led to conclusions that upwards of 72% of parents indicate that they were either not at all or only somewhat confident in their primary care physician’s ability to recognize autism (Harrington, et al., 2006). Previous research findings using the Autism Survey (Stone, 1987) have also indicated that health care workers in various disciplines (e.g., pediatrics, speech language pathology) were found to differ significantly on knowledge of diagnostic criteria for PDDs when compared to responses of experts consistent with the DSM-III-R criteria (Stone, 1987). The delays and problems that parents experience in obtaining a formal diagnosis of autism for their child is often only the first confrontation of many when accessing appropriate support, education and information necessary for their child (Renter & Roeyers, 2006).

More optimistically, while a considerable amount of literature regarding parental satisfaction indicates significant barriers faced before obtaining diagnostic assessment, research has suggested a continuing trend in clinicians’ abilities for timely recognition of PDDs. Also, contrary to the findings of Stone (1987), the results of Heidgerken et al. (2005), with a similar sample and method, indicate that health care specialists (e.g., psychiatrists, speech and language pathologists and clinical psychologists) and primary health care providers (e.g., family practitioners, pediatricians, and neurologists) reflected accurate representation of the DSM-IV-TR (APA, 2000) criteria. Although these results are promising, the majority of research, thus far, indicates the need for continued improvement in several areas including recognition of symptoms and diagnosis.
Access to Intervention

Satisfaction of parents of children with a PDD has also been linked to the amount of knowledge and support that medical professionals are able to provide following debriefing of a diagnosis (Renter & Roeyers, 2006). Professional support plays a vital role in, among other things, providing information and effective problem solving strategies to help alleviate the stress associated with a diagnosis of PDD. Previous research has found that the evaluation of services for children with a PDD and their families demonstrates shortcomings in the areas of accessing specialty care, and more importantly, practitioners’ knowledge concerning interventions for PDDs (Renter & Roeyers, 2006).

Specialty care. Children with PDDs and special health care needs may experience additional barriers to needed services (Shah, 2001). Recent reports have emphasized the requirement for more comprehensive and coordinated special services, particularly during the early childhood period. It is likely that these children with dual diagnoses will require a higher level of care (Mandell, Cao, Ittenbach, & Pinto-Martin, 2006). For example, PDD is often associated with comorbid medical problems, such as seizures and sleep disorders, which are likely to require the support of specialized health care providers, such as neurologists. Further, children with PDDs may need a referral to psychiatrists, psychologists, and speech language pathologists, in relation to behavioural and developmental concerns (Heidgerken et al., 2005).

However, more than one-third of parents of children with a PDD have reported problems when accessing needed specialty care for their children. It is reported that the availability of physicians with the skills and experience necessary to serve children with
comorbid medical problems is lacking (Krauss et al., 2003). Moreover, families rated physicians’ knowledge concerning specialty care and the qualifications to manage developmental disabilities as less than satisfactory (Liptak et al., 2006). Thus, the need for a network of providers with the necessary knowledge and special competencies required to serve children with complex health conditions is becoming increasingly apparent.

_Lack of knowledge._ Another determinant of parental satisfaction includes the quality of information provided by professionals. The National Autism Plan for Children (NASA, 2003) states that the response of many professionals regarding parents’ first concerns was often an inappropriate reassurance, giving the impression that parents were being ‘over anxious’ about their child. Furthermore, several authors have emphasized the importance of communication of knowledge concerning the features of PDD in establishing and maintaining good practice (Heidgerken et al., 2005; Renter & Roeyers, 2006; Shah, 2001). As well, parents often rely upon the knowledge and experience of physicians to explain the long-term outcomes of PDD, and a lack of knowledge from healthcare providers prevents parents from obtaining accurate and relevant information.

In a similar vein, front line professionals working with children with autism (e.g., regular and special education teachers, social workers and health care providers) were also shown to have significant misconceptions across social/emotional, cognitive and general descriptive features of PDD. Significant differential belief patterns existed between the various groups of professionals considered to work most directly with children with autism and knowledge of PDD held by ‘experts’ in the field (Heidgerken et al., 2005; Mavropoulou & Padeliadu, 2000; Preece, & Jordon, 2006; Stone, 1987; Stone...
& Rosebaum, 1988). The trend of differential responding and misconceptions regarding knowledge about PDDs was also supported in a study assessing knowledge in medical students (Shah, 2001). As previously mentioned, knowledge regarding diagnosis has improved over time; however, preliminary results assessing cross-disciplinary knowledge levels indicate a common trend of restricted and varying knowledge. Professionals with limited experiences are not likely to understand the range of outcomes for persons with a PDD (Ruble & Dalrymple, 1996).

Overall, impressions and comments of parents indicate the continued need for early diagnosis and increased awareness of developmental problems in young children among healthcare professionals, particularly among physicians involved in primary care. Professionals in clinical settings need to be aware of parents’ concerns and the necessity of addressing these concerns when communicating with families (Ivey, 2004). In order to accomplish this, one step may be to identify where the gaps in knowledge lie.

**General Medical Needs and Care**

Very little has been published on health care needs of children with PDDs (Liptak et al., 2006). Given the apparent increase in prevalence rates, it is now likely that primary care providers, including family physicians and pediatricians, will encounter multiple children with PDDs (Daley, & Sigman, 2002; Heidgerken et al., 2005; Shah, 2001). In the last decade, the number of children with a PDD being served increased more than 1000% (Mandell, Cao, Ittenbach, & Pinto-Martin, 2006). With prevalence rates now ranging as high as 1 in 150 (Centers for Disease Control and Prevention, 2007), it would be expected that an average pediatric practice, with up to 5000 patients, will now include approximately 30 such children (Harrington, Patrick, Edwards, & Brand, 2006). Thus,
according to recent rates, PDDs are no longer considered a rare disorder, and accordingly, a greater number of primary care providers will provide medical care for children with a PDD.

When serving children with PDDs, professionals need to consider that often these children have various challenges that impact upon the expression of symptoms (Goldson, 2002). For example, when a child feels pain, he/she may not verbally express the symptoms, but instead may exhibit a behavioural problem in attempt to communicate the difficulty. Further, common ailments may not be diagnosed because a child does not visually or physically express the symptoms (e.g., pain) in the same manner as typical children. For example, a child may have a medical condition (e.g., iron deficiency) but shows no visible signs of it. In these cases, additional medical tests may need to be performed. In summary, in addition to providing care for comorbid conditions, diagnosis and treatment of common ailments may not be as clear cut as with a typical child population. Therefore, knowledge of the challenges of PDD may be helpful in providing a differential diagnosis regarding health care issues.

*Personal Reflections of Medical Students: What are their Thoughts?*

A recent study examined the degree to which curriculum related to PDDs were present in medical education and in turn, students’ perceived competence of PDD knowledge upon completion of their undergraduate medical education. Hutchinson (2005) discussed the notion that medical school is an ideal setting to teach students about PDDs and early detection practices (further information on education and training is discussed in the following section, *Medical Curriculum and Continuing Education*).
The anticipated long-term outcome is the ability to adequately prepare medical students for their future practices so that they have a positive impact on the health of children, including those with PDDs and their families. However, student reports indicated vague, if any, recollections of knowledge of PDD in the curricula and, consequently, students expressed that the first two years of the program did not adequately prepare students for treating patients with PDD during clerkship (the time of direct patient contact during last two years of undergraduate medical education). While students did not report a learning gap for general child development (e.g., knowledge of developmental milestones), it was expressed that there was a significant learning gap in knowledge regarding PDDs. Overall, all medical students expressed that the content or teaching on PDDs was unsatisfactory.

Given the limited emphasis on PDDs within the curriculum, one participant questioned whether students would understand that PDD knowledge is important for practice when they have limited clinical knowledge and minimal patient contact. When patient contact did occur, students reported that it was overwhelming because of the complexity of PDDs and became exceedingly frustrating because they did not have the skills to conduct patient interviews. Also, one instructor discussed that he chose patients for clerks based on complexity of the case.

[During clerkship], I didn’t send my student in to meet the parents, the social worker and the worker from the home with the patient with autism because essentially they would be lost on their own. [Students at this level] see patients on their own...[Autism Spectrum Disorder] ASD is either too hard to teach or it is too hard for students to learn. Few clinical instructors have the time to teach students about ASD and so students report minimal or unsuccessful learning experiences with ASD patients (Hutchinson, 2005, p. 104).
Not surprisingly, students also expressed the concern that they received clinical guidance from residents (a physician who recently completed medical school, and is specializing in a given area, e.g., family medicine or pediatrics) who often lacked experience with PDDs as well. This lack of exposure and clinical leadership creates doubt about students’ knowledge of PDDs and capacity to help children based on the medical education they receive. Despite this, almost 50% of medical students chose general practice and pediatric residency programs; two of the most common practices where it would be likely to encounter children with a PDD. Not surprisingly, one student expressed a great concern, “I’m frightened because I’m just graduating and I don’t know anything yet and I’m going to be a family doctor and I’m going to be the first in line for all of this stuff” (Hutchinson, 2005, p. 64).

While general conclusions cannot be drawn from the results of one qualitative study, it suggests that medical students report that they do not have enough exposure to adequately recognize early symptoms of PDDs or to interact appropriately with these patients. Without this knowledge, these physicians are also highly unlikely to possess the skills necessary to provide general medical care to this group of children. Thus, they greatly lack the understanding of the complexity of PDDs, which may have an impact on future clinical application.

Overall, data on student reports (Hutchinson, 2005) and the testing of knowledge by Stone (1987) and Heidgerken et al. (2005) are congruent. Together, these results speak to a limited knowledge set concerning PDDs, but also an awareness of the deficiency and its perceived impact. The current study will focus on assessing knowledge of PDDs, and will also ask respondents to rate their perceived knowledge of this topic.
Medical Curriculum and Continuing Education

As previously discussed, the ideal opportunity for education and training pertaining to PDDs and developmental disabilities should start with early medical training (Hutchinson, 2005). Currently, within medical education, there is a notion of core curricula for necessary practice, and choices of specialty studies to develop particular interest areas. However, as Piachaud (2002) points out, the struggle of what is core and what can and should be left to student choice, has been, and remains, complex. The ‘patient of tomorrow’ for new doctors is no longer what it was 10 years ago. This is precisely where patients with PDDs fit in; the prevalence and awareness of the needs of individuals with developmental disabilities and PDDs is growing, and may now require a place in core curricula of medical education.

Research Questions and General Hypotheses

Thus far, limited research has focused on assessing knowledge of assessment, intervention, and healthcare needs of children with a PDD (Heidgerken et al., 2005). While studies have examined the knowledge levels of healthcare workers (e.g., Stone, 1987) and medical students (e.g., Shah, 2001), only one study to date has focused on a population of primary health care providers (Heidgerken et al., 2005). Further, no study has conducted a cross-disciplinary comparison of healthcare students and practicing professionals. Overall, this research is the first of its kind in Canada to examine the basic knowledge held by medical residents and practicing physicians.

More specifically, based on the questions provided in the updated version of the Stone Autism Survey (1987), and using a group of experts in the field of PDD as a control measure, what basic knowledge of PDDs do residents and practicing physicians
have? Further, are there significant differences in the basic knowledge held by family physicians and pediatricians?

It was hypothesized that the combination of education and experience with PDDs, or medical practice in general, held by currently practicing physicians would lead to an increased accuracy of basic knowledge of PDDs compared to residents who lack the same levels of education and practical experience with autism. Second, given increased years of training and a child-centered focus, it was expected that pediatricians could demonstrate greater knowledge when compared to family physicians.
Method

Participants

Ninety-three participants including family physicians, pediatricians, and medical residents from five Canadian Medical Schools (four in Ontario and one in Alberta) and one Ontario Health Network (of practicing physicians) participated in the study. Specifically, this included 59 medical residents (students) and 34 currently practicing physicians. Furthermore, a control group consisting of eight individuals who rated themselves as experts in PDD (and met specific criteria, see below) were included, for a total of 101 participants divided into three groups. Below, the characteristics of the resident, physician, and control groups are described.

Residents. Individuals in this group were completing a two-year family medicine residency or a four-year pediatric residency program in Canada. Thirty-three (56%) participants were completing a residency in family medicine and 26 (44%) participants in pediatrics. Twenty-nine participating medical residents were in their first year of residency (49%), with 21 (36%) in their second year, six (10%) in their third year, and three (5%) in their fourth year. Note that a family medicine residency is two years in length, while a pediatrics residency is four, therefore contributing to the disproportionate number of residents in their first or second year of residency programs. As well, many senior year residents were completing residency positions outside of their local area, and therefore, were difficult to access. See Figure 1 for a graph of residents’ year in program.

Practicing physicians. At the time of the study, these individuals were current physicians practicing in the area of family medicine or pediatrics. They included practitioners in a community health setting or staff physicians in a medical school and/or affiliated teaching hospital in Ontario. A total of 34 practicing physicians were surveyed,
Figure 1

Residents’ Year in Program

![Bar graph showing the number of participants in Family Medicine and Pediatrics across different years of the program.](image-url)
including 21 family physicians (62%), and 13 pediatricians (28%). Each physician was asked how many years of experience he/she had in his/her current specialty. Two physicians chose not to respond to the question, 17 physicians (53%) replied that they had more than 15 years of experience in their respective field, while only 2 physicians (6%) indicated they had less than 5 years of experience.

Control group. Similar to Stone (1987), the ‘experts’ were recruited by the researcher, members of the research team, and local practitioners in the field. All ‘experts’ identified themselves as either psychologists, professors or both, with a primary involvement in clinical practice, research and/or teaching responsibilities pertaining to individuals with PDD. Also, they perceived their knowledge of PDD as excellent or extensive. While ten individuals were originally surveyed, two expressed a perceived knowledge of only moderate, and were subsequently excluded from the final sample and analysis based on the perception that they did not fit the criteria as an expert. This left a final sample of eight ‘experts’.

Sample Size

The determination of sample size for this study was based on a table of powers published in Cohen and Cohen (1977). Samples were chosen based on a standard power level of .80, a minimum significance level of p < .05, and a moderate effect size between .4 and .5. This effect size was derived from a similar study by Heidgerken et al. (2005) that had representative procedures and significant results. Cohen and Cohen’s power tables (1977) suggest a sample size between 28 and 46 participants per group, at our chosen level of significance of p < .05.

Ethical Approval
Ethics approval for this study was obtained from the Brock University Research Ethics Board (REB) (See Appendix A). Necessary modifications were submitted on two occasions to allow for electronic participation and to expand recruitment to include participants from a community health setting.

*Recruitment*

The administration staff or directors of English speaking medical schools, in the aforementioned specialties, were contacted for permission to access both students and faculty (residents and practicing physicians) for participation in the current study.

As well, physicians were recruited through a current practitioner in the medical field, who requested participation from practicing physicians in a community health setting, and distributed in-person copies of the survey to these individuals. Recruitment of the control group (‘experts’) was described in the participant section.

French-speaking medical schools were excluded from this research due to the primary researcher and research team lacking bilingual language abilities. These language abilities would be essential for initiating contact with the schools, as well as the requirement of translating questionnaires.

*Materials*

To assess knowledge of PDDs, a modified version of the Stone Autism Survey (1987) was used (see Appendix E). This survey, originally designed by Stone in 1987, has been recently updated by Dr. Naomi Sweizy and the Christian Sarkine Autism Treatment Centre (2005) to account for current research and knowledge surrounding autism and related disorders. This measure provides 20 statements regarding knowledge in the area of social/emotional, cognitive and treatment/prognosis of autism. Four
additional questions were added to account for areas of knowledge that the research team felt was pertinent to the population being assessed (see bolded questions in Appendix E). These questions were inserted throughout the survey following questions of similar knowledge areas (e.g., a question corresponding to treatment was placed following another question regarding treatment) rather than at the end of the survey, so as to not isolate added questions. Each respondent was instructed to rate each item on a 6-point scale, ranging from 1 (fully agree) to 6 (fully disagree).

Reliability. The updated version of the Stone Autism Survey (1987) by Swiezy (2005) is currently undergoing further validation, and while results are not yet complete, preliminary analyses are proving positive.

However, the original version of the Stone Autism survey (1987) has shown stability over time, with Cronbach’s alpha revealed a total score alpha coefficient of .72. The total score was internally consistent (Campbell et al., 1996).

Validity. Groups were originally generated for the analyses of the relationships between occupation and knowledge of autism. As expected, individuals with high experience have significantly greater knowledge of autism that those with low experience (Campbell et al., 1996). The overall survey was found to measure a single variable, with total score equaling knowledge and beliefs about autism as opposed to multiple latent variables (cognitive features, social-emotional features, general descriptive features). Overall, Campbell et al.’s study supports the reliability and validity of Stone’s Autism Survey (1987).

Modifications to updated survey. As stated previously, four additional questions were developed by our research team to be included in the survey (see bolded questions
in Appendix E). Questions in the areas of treatment, medication and comorbidity were added to reflect current research in the field. Moreover, the questions were designed to be general in nature and indicative of foundational knowledge necessary for any professional providing health care to children with PDDs.

Furthermore, demographic questions (see Appendix E) were added to the end of the survey to collect additional information concerning participant characteristics. Information included: current specialty (i.e., family medicine, pediatrics, expert); current practicing level (i.e., resident, physician, expert); current year of residency (for residents); years of experience in the field (for practicing physicians and ‘experts’); and for all participants, years of experience with autism; approximate number of patients seen; percentage of patient population with autism; and perceived knowledge of autism. Note that the expert group received a copy of the survey with demographic questions specific to their group. See the end of Appendix E for a copy of both demographic questions for medical professionals and experts.

Procedure

The modified version of the Stone Autism Survey (1987) by Swiezy (2005) was administered to the aforementioned groups. The survey, along with a letter of invitation providing details about the study (see Appendix C) and informed consent forms (see Appendix D) were distributed by the principal investigator to groups of residents, practicing physicians, and the ‘expert’ group. The survey took approximately 5 to 10 minutes to complete.

Survey administration took place in three methods. One method included an e-mail version of the survey being sent to the director of each participating medical school.
The survey was distributed by the director to participating residents and physicians. A separate e-mail account was set up through the Spartan server of the Brock University network for the sole purpose of sending and receiving study related materials (e.g., contact e-mails, follow up e-mails, and surveys). E-mail versions of the survey and letters of invitation were distributed to the participants and returned directly to the aforementioned e-mail account. For e-mail surveys, completion and the subsequent return of the survey were considered consent to participate. Completion of the computer administered survey was unsupervised. Due to a high number of requests for research access, and feedback from students to directors stating that their on-campus academic days were filled, two medical schools chose this dissemination strategy. All participants from the ‘expert’ group also completed e-mail versions of the survey, and returned completed copies to the aforementioned research account.

A second data collection method included the researcher and members of the research team visiting two medical schools to collect data in person. Upon approval from the director of each department, the researcher was invited to resident academic days and staff physician departmental meetings. Locations included respective departments within the school, as well as conference rooms within the affiliated teaching hospitals. In some instances, the primary researcher was invited to administer surveys before a departmental meeting, or prior to a guest speaker. On one occasion, a member of the research team was invited to give a short presentation on recent research in the field of PDDs. In this case, questionnaires were completed prior to the presentation, to avoid the possibility of newly acquired knowledge influencing the results.
A final collection strategy included a current physician in the medical field distributing in-person copies of the survey to physicians in a community health network setting. Surveys were administered and collected by the physician, and returned to the primary investigator. As surveys were received from each medical site, data entry and analysis were completed using SPSS 15.0 for windows (See Results section for more detail).

Research Design

A cross-sectional survey design was used to understand knowledge differentials among groups (i.e., residents, physicians, experts). Results were further examined by specialty (i.e., family physicians, pediatricians). A cross-sectional design collects data at one point in time, accommodating for the limited time frame of the research project (Peat, 2004). A survey format allowed for timely data collection, which was reported to be particularly important given the occupational demands of medical residents and practicing physicians.

Plan for Analysis

First, responses to demographic questions regarding years of experience with autism, number of patients seen and perceived knowledge of autism are presented for groups of residents, physicians and ‘experts’, respectively. Also, responses are presented by specialty (i.e., family medicine and pediatrics) combining the resident and physician groups.

Next, similar to the study conducted by Heidgerken et al. (2005), Multivariate Analysis of Variance (MANOVA) was used. Analyses were run with each group (i.e., residents, professionals, and ‘experts’) as the independent variable and each of the 24
statements regarding knowledge concerning PDDs as the dependent variables. To further explore significant findings, follow-up Tukey post hoc tests were conducted. Specifically, comparisons were made between residents and practicing professionals, irrespective of specialty. Second, results were analyzed by area of expertise (i.e., family medicine and pediatrics) combining residents and practicing professionals within each specialty. Further, results from the each were compared against the results of the ‘expert’ group.
Results

Demographic Responses

Residents. Residents (n=58) were asked to indicate how many years of experience they had with individuals with autism. Thirty-one residents (52.5%) expressed that they had no experience, and seventeen residents (29%) indicated that they had less than two years of experience. Three residents (5%) specified that they had more than five years of experience. When categorized by specialty, pediatric residents reported more years of experience with patients with autism than family medicine residents. In fact, sixty-six percent of family medicine residents indicated having no years of experience with patients with autism in comparison to only 28% of pediatric residents. See Table 1 for a summary of years of experience for residents.

Table 1

<table>
<thead>
<tr>
<th>Residents’ Years of Experience with Autism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years of experience with autism</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>Current Specialty</td>
</tr>
<tr>
<td>Pediatrics</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

Residents were also asked to approximate how many patients with autism they had served during their medical career. Across specialties, eleven residents (19%) indicated they did not have any experience with patients with autism. Only 2 residents (3%) expressed that they had seen 15 to 20 patients with autism. No resident reported that they had seen more than 20 patients with autism. Fewer pediatric residents expressed having seen no patients with autism (12% of pediatric residents versus 25% of family medicine residents) or only one to two patients (15% of pediatric residents versus 53% of
family medicine residents). As well, thirty-six percent of pediatric residents (and no family medicine residents) indicated that they had seen more than 10 patients with autism. See Figure 2 for a summary of the number of patients with autism reportedly seen by residents.

Finally, residents were asked to rank their perceived knowledge of autism on a 5-point scale. Thirty-one residents (53%) indicated a minimal perceived knowledge of autism, and the remaining 28 residents (47%) indicated a moderate knowledge level. Comparing specialties, family medicine residents (61%) were more likely to rank their knowledge level as minimal and pediatric residents (58%) were more likely to indicate their knowledge as moderate. While no residents expressed a perceived knowledge of none, no residents expressed their knowledge level as excellent or extensive.

Physicians. Similar to residents, practicing physicians (n=34) were also asked to indicate their years of experience with autism. Seventeen physicians (50%) indicated they had more than five years of experience with autism, while eight physicians (24%) indicated that they had no experience with autism. When examined by specialty, sixty-two percent of pediatricians indicated they had more than 5 years of experience with autism, while thirty-three percent of family physicians expressed that they had no years of experience with autism. See Figure 3 for a summary of physicians’ years of experience with autism.

Physicians were also asked to report approximately how many patients with autism they had seen in their years of practice. The majority of family physicians (91%) had seen less than ten patients with autism, whereas the majority of pediatricians (69%) had seen
Figure 2

*Number of Patients with Autism seen by Residents*

![Bar chart showing the number of patients seen by residents in categories of no patients, 1-2 patients, 3 to 5 patients, 5 to 10 patients, 10 to 15 patients, and 15 to 20 patients. The chart includes data for Family Medicine and Pediatrics.]
Figure 3

Physicians’ Years of Experience with Autism

[Bar chart showing the number of participants in different years of experience categories: None, Less than 2 years, 2 to 5 years, More than 5 years for Family Medicine and Pediatrics.]
more than ten patients with autism. Figure 4 outlines the number of patients with autism seen by physicians.

Similarly, each physician was asked to rank their perceived knowledge of autism on a 5-point scale. Sixteen physicians (47%) ranked their perceived knowledge as minimal, while another sixteen physicians (47%) ranking their knowledge as moderate. The remaining two physicians (6%) ranked their knowledge as excellent, and both of these physicians were pediatricians. While 15 family physicians (71%) expressed a perceived knowledge of minimal, only one pediatrician (3%) indicated the same.

‘Experts’. Each ‘expert’ was asked to indicate how many years of experience they had with autism. Two experts (25%) indicted they had 5 to 10 years of experience with autism, while the remaining six ‘experts’ (75%) indicated they had more than 15 years of experience. Further, each ‘expert’ was asked to approximate the number of patients with autism they had worked with. All eight experts identified working with more than 50 patients with autism during their years in the field.

Finally, the ‘experts’ were asked to rank their perceived knowledge of autism on the same 5-point scale as the other participants. Five of the ‘experts’ (62.5%) perceived their knowledge of autism as ‘excellent’ with the remaining 3 ‘experts’ (37.5%) ranking their knowledge as ‘extensive.’

Autism Survey

Data screening. Data screening was done prior to analyses being conducted, and, as expected, significant skewness and kurtosis were observed for a selection of questions, indicating a strong level of agreement among responses, particularly pertaining to
Number of Patients with Autism Seen by Physicians

![Bar graph showing the number of patients with autism seen by physicians across different numbers of patients seen. The graph compares Family Medicine and Pediatrics.]
‘expert’ responses. Variables were transformed using square root, logarithmic and/or inverse functions. Data were examined using both transformed and non-transformed raw data. Results were consistent; therefore, for ease of interpretation, only results using non-transformed data are reported in text (see Appendix F for report of skewness and kurtosis pre and post transformation).

Further, Levene’s test was utilized to test for homogeneity of variances, used to determine if groups have equal variances (See Appendix G for results). Some statistical analyses, including Multivariate Analysis of Variance tests (MANOVA), assume that variances are equal across groups. As expected, some questions failed the assumption of homogeneity of variance, as variance, particularly in the ‘expert’ group, was expected to differ from the resident and physician (as well as pediatric and family medicine) groups. Thus, for individual questions violating homogeneity of variance, follow-up non-parametric Jonkheere-Terpstra tests and individual Kruskall-Wallis tests were used to confirm significant group differences found by MANOVA and Tukey post hoc tests, respectively (see Appendix H for results). Non-parametric tests are designed for group analyses with unequal variances, and the particular test (i.e., Jonkheere-Terpstra) was chosen as most appropriate as it is recommended for data falling into ordered groups, that are not randomly assigned (Norusis, 2006).

Knowledge by Groups

Results of the MANOVA indicated a significant Wilk’s Lambda of .143 (F (48,120) = 4.106, p < .001). Significant main effects were found for twelve of the twenty-four statements, with an alpha level of .051. Further, two trends were observed with p >
.051 and ≤ .1. Significant findings of the MANOVA and *post hoc* analyses are listed in Table 2.

**Significant Main Effects and Post hoc Results**

Eight of the eleven main effects were found for the statements “autism is an emotional disorder,” “children with autism do not show attachment, even to parents/caregivers,” “research indicates that Sensory Integration Therapy is an effective treatment for autism and its symptoms,” “autism occurs more commonly among higher socioeconomic and educational levels,” “children with autism are at a greater risk for developing seizures than typically developing children,” “autism is more frequently diagnosed in males than females,” “research indicates that Applied Behaviour Analysis is an effective treatment for autism and its symptoms” and “autism tends to run in families.” *Post hoc* analyses supported significant group differences between experts and residents, as well as experts and physicians, with lower mean scores reported by experts. No other significant effects were observed.

Three other main effects were found for the statements “most parents/caregivers of children with autism report their first concerns were related to the child’s social behaviour,” “autism can be diagnosed as early as 18 months,” and “the need for routine and sameness is one of the earliest features of autism.” Follow up *post hoc* analyses revealed group differences between experts and residents, with higher mean scores reported by experts. No other significant group differences were observed.
Table 2

*MANOVA and Post hoc Results by Group*

<table>
<thead>
<tr>
<th>Question</th>
<th>Residents</th>
<th>Physicians</th>
<th>‘Experts’</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Emotional disorder</td>
<td>4.33&lt;sub&gt;a&lt;/sub&gt;</td>
<td>4.78&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.75&lt;sub&gt;b&lt;/sub&gt;</td>
<td>3.731</td>
<td>.028</td>
</tr>
<tr>
<td>2. Early intervention</td>
<td>1.69&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.26&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.50&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.228</td>
<td>.114</td>
</tr>
<tr>
<td>3. Anxiety disorders</td>
<td>2.45&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.22&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.13&lt;sub&gt;a&lt;/sub&gt;</td>
<td>.629</td>
<td>.536</td>
</tr>
<tr>
<td>4. Seizures</td>
<td>3.75&lt;sub&gt;a&lt;/sub&gt;</td>
<td>3.52&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.25&lt;sub&gt;b&lt;/sub&gt;</td>
<td>3.529</td>
<td>.034</td>
</tr>
<tr>
<td>5. Poor eye contact</td>
<td>2.78&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.98&lt;sub&gt;a&lt;/sub&gt;</td>
<td>4.13&lt;sub&gt;b&lt;/sub&gt;</td>
<td>2.782</td>
<td>.068</td>
</tr>
<tr>
<td>6. Visual/verbal</td>
<td>2.39&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.37&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.75&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.352</td>
<td>.264</td>
</tr>
<tr>
<td>7. Social relatedness</td>
<td>2.22&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.16&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.00&lt;sub&gt;a&lt;/sub&gt;</td>
<td>.260</td>
<td>.772</td>
</tr>
<tr>
<td>8. Males/females</td>
<td>2.39&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.19&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.00&lt;sub&gt;b&lt;/sub&gt;</td>
<td>5.783</td>
<td>.004</td>
</tr>
<tr>
<td>9. Attachment</td>
<td>3.61&lt;sub&gt;a&lt;/sub&gt;</td>
<td>3.70&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.38&lt;sub&gt;b&lt;/sub&gt;</td>
<td>6.626</td>
<td>.002</td>
</tr>
<tr>
<td>10. Sensory integration therapy</td>
<td>2.59&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.59&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.38&lt;sub&gt;b&lt;/sub&gt;</td>
<td>36.079</td>
<td>.000</td>
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<tr>
<td>11. Applied behavior analysis</td>
<td>2.92&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.63&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.50&lt;sub&gt;b&lt;/sub&gt;</td>
<td>7.732</td>
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<td>12. Deliberately uncooperative</td>
<td>5.51&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.26&lt;sub&gt;a&lt;/sub&gt;</td>
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<td>1.238</td>
<td>.295</td>
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<tr>
<td>Question</td>
<td>Residents</td>
<td>Physicians</td>
<td>‘Experts’</td>
<td>F</td>
<td>p</td>
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<td>-----</td>
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<tr>
<td>13. Social behaviour</td>
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<td>2.70&lt;sub&gt;a,b&lt;/sub&gt;</td>
<td>3.50&lt;sub&gt;b&lt;/sub&gt;</td>
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<td>.047</td>
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<td>14. Run in families</td>
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<td>2.74&lt;sub&gt;a,b&lt;/sub&gt;</td>
<td>3.00&lt;sub&gt;b&lt;/sub&gt;</td>
<td>3.218</td>
<td>.045</td>
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<td>15. Treatment/cure</td>
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<td>5.37&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.75&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.297</td>
<td>.279</td>
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<tr>
<td>16. Live independently</td>
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<td>2.85&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.88&lt;sub&gt;a&lt;/sub&gt;</td>
<td>.134</td>
<td>.875</td>
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<tr>
<td>17. One approach</td>
<td>5.63&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.52&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.13&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.238</td>
<td>.295</td>
</tr>
<tr>
<td>18. Respiridol</td>
<td>4.67&lt;sub&gt;a,b&lt;/sub&gt;</td>
<td>4.15&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.13&lt;sub&gt;b&lt;/sub&gt;</td>
<td>3.083</td>
<td>.051</td>
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<td>19. Special education</td>
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<td>1.44&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.88&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.480</td>
<td>.234</td>
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<tr>
<td>20. Higher socioeconomic</td>
<td>3.45&lt;sub&gt;a&lt;/sub&gt;</td>
<td>4.04&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.50&lt;sub&gt;b&lt;/sub&gt;</td>
<td>10.340</td>
<td>.000</td>
</tr>
<tr>
<td>21. 18 months</td>
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<td>2.15&lt;sub&gt;a,b&lt;/sub&gt;</td>
<td>1.88&lt;sub&gt;b&lt;/sub&gt;</td>
<td>4.541</td>
<td>.013</td>
</tr>
<tr>
<td>22. Outgrow the disorder</td>
<td>5.45&lt;sub&gt;a&lt;/sub&gt;</td>
<td>4.96&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.00&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.772</td>
<td>.068</td>
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<tr>
<td>23. Do not show affection</td>
<td>4.31&lt;sub&gt;a&lt;/sub&gt;</td>
<td>4.88&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.13&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.422</td>
<td>.247</td>
</tr>
<tr>
<td>24. Routine and sameness</td>
<td>2.16&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.59&lt;sub&gt;a,b&lt;/sub&gt;</td>
<td>3.25&lt;sub&gt;b&lt;/sub&gt;</td>
<td>6.088</td>
<td>.003</td>
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</table>

*Note: matching pairs of subscripts indicate no group differences, while different subscripts indicate significant post hoc group differences.
A final significant main effect was observed for the statement, “Respiridol is effective in treating the socio-communicative challenges faced by children with autism.” Post hoc analysis revealed a significant group difference between experts and physicians, with higher mean scores reported by experts. No other significant group differences were observed.

*Trends.* Trends ($p > .051$ and $\leq .10$) were observed with an additional two statements including, “all children with autism display poor eye contact” and “with the proper treatment, most children diagnosed with autism will eventually outgrow the disorder.” For the statement concerning eye contact, post hoc analyses revealed significant group differences between experts and residents, as well as experts and physicians, with higher mean scores reported by experts. No other significant group differences were observed.

*Knowledge by Specialty*

When analyzing the results by specialty (i.e., family medicine and pediatrics), results of the MANOVA indicated a significant Wilk’s Lambda of .178 ($F (48,120) = 3.423, p < .001$). Significant main effects were found for eleven of the twenty-four statements, with an alpha level of .051. Further, one trend ($p > .051$ and $\leq .10$) approached significance. Significant findings and *post hoc* analyses are reported in Table 3.
### Table 3

**MANOVA and Post hoc Results by Specialty**

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean Response</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Family Physicians</td>
<td>Pediatrics</td>
<td>'Experts'</td>
</tr>
<tr>
<td>1. Emotional disorder</td>
<td>4.32&lt;sub&gt;a&lt;/sub&gt;</td>
<td>4.71&lt;sub&gt;a,b&lt;/sub&gt;</td>
<td>5.75&lt;sub&gt;b&lt;/sub&gt;</td>
</tr>
<tr>
<td>2. Early intervention</td>
<td>1.59&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.47&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.50&lt;sub&gt;a&lt;/sub&gt;</td>
</tr>
<tr>
<td>3. Anxiety disorders</td>
<td>2.34&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.41&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.13&lt;sub&gt;a&lt;/sub&gt;</td>
</tr>
<tr>
<td>4. Seizures</td>
<td>3.75&lt;sub&gt;a&lt;/sub&gt;</td>
<td>3.56&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.25&lt;sub&gt;b&lt;/sub&gt;</td>
</tr>
<tr>
<td>5. Poor eye contact</td>
<td>2.84&lt;sub&gt;a&lt;/sub&gt;</td>
<td>3.00&lt;sub&gt;a,b&lt;/sub&gt;</td>
<td>4.13&lt;sub&gt;b&lt;/sub&gt;</td>
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<tr>
<td>6. Visual/verbal</td>
<td>2.45&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.29&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.75&lt;sub&gt;a&lt;/sub&gt;</td>
</tr>
<tr>
<td>7. Social relatedness</td>
<td>2.18&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.18&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.00&lt;sub&gt;a&lt;/sub&gt;</td>
</tr>
<tr>
<td>8. Males/females</td>
<td>2.48&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.12&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.00&lt;sub&gt;b&lt;/sub&gt;</td>
</tr>
<tr>
<td>9. Attachment</td>
<td>3.77&lt;sub&gt;a&lt;/sub&gt;</td>
<td>3.47&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.38&lt;sub&gt;b&lt;/sub&gt;</td>
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<tr>
<td>10. Sensory integration therapy</td>
<td>2.66&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.50&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.38&lt;sub&gt;b&lt;/sub&gt;</td>
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<tr>
<td>11. Applied behavior analysis</td>
<td>2.89&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.74&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.50&lt;sub&gt;b&lt;/sub&gt;</td>
</tr>
<tr>
<td>12. Deliberately uncooperative</td>
<td>5.50&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.32&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.88&lt;sub&gt;a&lt;/sub&gt;</td>
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<td>Question</td>
<td>Mean Response</td>
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<td></td>
<td>Family Physicians</td>
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<td>Pediatrics</td>
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<td></td>
<td>'Experts'</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Social behaviour</td>
<td>2.23&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.88&lt;sub&gt;a,b&lt;/sub&gt;</td>
<td>3.50&lt;sub&gt;b&lt;/sub&gt;</td>
</tr>
<tr>
<td>14. Run in families</td>
<td>3.45&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.82&lt;sub&gt;a&lt;/sub&gt;</td>
<td>3.00&lt;sub&gt;b&lt;/sub&gt;</td>
</tr>
<tr>
<td>15. Treatment/cure</td>
<td>5.52&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.56&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.75&lt;sub&gt;a&lt;/sub&gt;</td>
</tr>
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<td>16. Live independently</td>
<td>2.93&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.97&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.88&lt;sub&gt;a&lt;/sub&gt;</td>
</tr>
<tr>
<td>17. One approach</td>
<td>5.61&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.56&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.13&lt;sub&gt;a&lt;/sub&gt;</td>
</tr>
<tr>
<td>18. Respiridol</td>
<td>4.48&lt;sub&gt;a&lt;/sub&gt;</td>
<td>4.50&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.13&lt;sub&gt;b&lt;/sub&gt;</td>
</tr>
<tr>
<td>19. Special education</td>
<td>1.61&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.71&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.88&lt;sub&gt;a&lt;/sub&gt;</td>
</tr>
<tr>
<td>20. Higher SES</td>
<td>3.44&lt;sub&gt;a&lt;/sub&gt;</td>
<td>3.82&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.50&lt;sub&gt;b&lt;/sub&gt;</td>
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<td>21. 18 months</td>
<td>2.73&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.44&lt;sub&gt;a&lt;/sub&gt;</td>
<td>1.88&lt;sub&gt;b&lt;/sub&gt;</td>
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<td>22. Outgrow the disorder</td>
<td>5.27&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.29&lt;sub&gt;a&lt;/sub&gt;</td>
<td>5.00&lt;sub&gt;a&lt;/sub&gt;</td>
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<td>23. Do not show affection</td>
<td>4.61&lt;sub&gt;a,b&lt;/sub&gt;</td>
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<td>5.13&lt;sub&gt;b&lt;/sub&gt;</td>
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<td>24. Routine and sameness</td>
<td>2.36&lt;sub&gt;a&lt;/sub&gt;</td>
<td>2.24&lt;sub&gt;a&lt;/sub&gt;</td>
<td>3.25&lt;sub&gt;b&lt;/sub&gt;</td>
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*Note: matching pairs of subscripts indicate no group differences, while different subscripts indicate significant post hoc group differences*
**Significant Main Effects and Post hoc Results**

Eight of eleven main effects for analyses by specialty were found for the statements, “children with autism are at a greater risk for developing seizures than typically developing children,” “autism is more frequently diagnosed in males than females,” “children with autism do not show attachment, even to parents/caregivers,” “research indicates that sensory integration therapy is an effective treatment for autism and its symptoms,” “research indicates that Applied Behaviour Analysis is an effective treatment for autism and its symptoms,” “autism tends to run in families,” “autism occurs more commonly among higher socioeconomic and educational levels” and “the need for routine and sameness is one of the earliest features of autism.” Follow up *post hoc* analyses reveal significant group differences between experts and family physicians, as well as experts and pediatricians, with lower mean scores reported by experts. No other significant group differences were observed.

Two of eleven main effects were found for the statement, “autism is an emotional disorder” and “most parents/caregivers of children with autism report their first concerns were related to the child’s social behaviour.” *Post hoc* analyses revealed significant group differences between ‘experts’ and family physicians, with higher mean scores reported by experts. No other significant group differences were found.

A final main effect emerged for the statement, “children with autism do not show affection.” Follow-up analysis indicated no significant group differences.

*Trends.* A trend was found for “all children with autism display poor eye contact” (F(2,83)= 2.720, *p* = .072), with family physicians endorsing this statement more often than ‘experts’.
Discussion

The present study was conducted to replicate and extend previous research exploring medical students’ and professionals’ basic knowledge regarding autism (e.g., Heidgerken et al., 2005; Shah, 2001; Stone, 1987; Stone & Rosenbaum, 1988). Specifically, this study examined residents’ and practicing physicians’ (specializing in family medicine and pediatrics) basic knowledge in comparison to an expert group. First, knowledge differentials between groups of residents, physicians, and experts are explored. Immediately following, there is a discussion of significant findings related to specialty (with both residents and practicing physicians subdivided into their respective specialties of family medicine and pediatrics). Results will be compared and contrasted to those reported in past studies.

Residents, Practicing Physicians and Experts

Some misconceptions concerning the nature of PDDs held by residents and physicians. Similar to past studies (e.g., Stone, 1987; Heidgerken et al., 2005), results of the present study indicate that, compared to experts in the field of PDD, residents and practicing physicians exhibit some belief patterns inconsistent with current research in the field of autism. In the present study, similar to Heidgerken et al., both residents and physicians more strongly consider autism an emotional disorder, and believe that there is a higher prevalence rate of autism in upper SES groups.

First, when considering autism as an emotional disorder, this misconception may not be surprising when considering emotional problems (e.g., emotional withdrawal, outbursts and difficulty interpreting emotional cues) that are often apparent in individuals with autism (Volkmar et al., 1997). However, although individuals with PDD may exhibit these types of challenges, PDD is not considered an emotional disorder. In fact, discussing autism as an
emotional disorder may mislead one to view autism as linked to type of parenting. Historically, autism was thought to be a result of poor parenting, and, in particular, having a ‘cold’ and distant mother. Specifically, in the 1950’s and 60’s, parents’ emotional reactions were thought to be the cause of symptoms of autism (Fein et al., 1999). At present, it is widely recognized that PDD is a neurodevelopmental disability, resulting from organic and genetic factors. Currently, multiple areas in the brain have been implicated as responsible for the disorder (Szatmari et al., 2007).

Next, both residents and practicing physicians more strongly endorsed a higher prevalence rate of autism in the upper SES categories. While historically this belief was presented and supported by professionals, recent epidemiological research supports the finding that the occurrence of autism is consistent across socioeconomic groups (Volkmar et al., 1997). Physicians’ support of these two statements may have the potential of leading parents to misinterpret the disorder, and further, to possibly engage in self-blame. As well, if physicians hold the belief that autism occurs in certain (i.e., high) SES groups, this may lead to patient selectivity. Careful screening of all children should be conducted based on emerging and prominent characteristics of autism. Also, children who are genetically at-risk for the disorder should be carefully monitored (Szatmari, 2003).

Inconsistencies regarding some general facts about PDDs. Similar to results reported in past studies (e.g., Stone, 1987; Heidgerken et al., 2005), questions concerning general facts about autism (e.g., a belief that children with autism will outgrow the disorder) were shown to be inaccurately endorsed by health care professionals. In the current study, a number of residents and physicians showed inaccuracies concerning some general facts about autism. For instance, some individuals did not endorse the statement that autism is more frequently diagnosed in males than females, and indicated that children with autism will outgrow the disorder. It is important
that resident and physicians are equipped with accurate knowledge on general facts of the disorder, as parents often pose questions.

Further, a physician may need to provide early support to a parent regarding questions pertaining to his/her child’s prognosis. While many children with autism grow up to lead a life as an independent adult, the belief that children will ‘outgrow’ the disorder may be misleading to parents. Rather, autism is a lifelong disorder, and while significant gains are often made through the implementation of (E)IBI, the concept of ‘outgrowing the disorder’ is not supported by research (Howard et al., 2005). Thus, it is important that physicians are aware of realistic prognoses for all severities of spectrum disorders, and that proper information, referrals and resources are provided to families.

Misconceptions concerning assessment characteristics. Results revealed numerous misconceptions concerning core characteristics of PDDs, replicating findings from Stone (1987) and Heidgerken (2003). While survey questions administered in various studies were not identical, similar questions regarding qualitative characteristics such as attachment and social interaction yielded parallel results. First, many residents did not believe that problems with social behaviour and the need for routine and sameness are some of earliest signs of autism. Further, both residents and physicians held misconceptions concerning the belief that autism tends to run in families and that it can be diagnosed as early as 18 months. Moreover, both residents and physicians were significantly more likely (in comparison to experts) to maintain the notions that children with autism do not show attachment, even to parents and caregivers, and that all children with autism display poor eye contact.

With regard to statements concerning routine and sameness, as well as social behaviour, it may be that currently practicing physicians exhibited more accurate knowledge given
increased encounters with these concerns (with greater number of years of experience and patient contact). While years of experience and more patient contact may not have contributed to differential knowledge regarding other statements (e.g., the belief that autism runs in families), it is likely that physicians have repeatedly encountered parents expressing concerns regarding social behaviour, and children’s need for routine and sameness.

Concerns regarding social behaviour and routine and sameness are two of the earliest features of autism (Fein et al., 2001). Thus, overlooking either of these characteristics may lead a physician to inappropriately reassure a parent that typical development is occurring, and, further, may result in a delay in diagnosis, contributing to a later start for intervention. Also, a lack of support for the belief that autism tends to run in families may lead to a delay in diagnosis of a subsequent sibling of a child with autism, who should be considered at-risk and carefully screened in the infant and toddler years. Current research supports the finding that autism can be formally diagnosed as early as 18 months of age, with noticeable symptoms before this time (Zwaigenbaum et al., 2005). This is a promising finding considering the ‘window of opportunity’ for EIBI, with the best results being achieved when children receive intervention starting at or before 2 years of age. However, if physicians are not aware of the age of diagnosis, they may encourage parents to ‘wait until at least two years of age’, a typical previous age marker, to have them screened. Overall, an accurate knowledge of qualitative impairments and assessment characteristics specific to autism is necessary in order to prevent a delay in diagnosis, and subsequent intervention.

Finally, while challenges with attachment to caregivers as well as specific behaviors like direct eye contact commonly exist in children with autism (Naber et al., 2007), they do not occur in every child and intervention can often have a positive impact on these behaviors. Moreover,
despite deficiencies in these areas, many children with autism build and maintain supportive relationships with parents, caregivers and peers (Bruinsma, Koegel & Koegel, 2007). Similar to previous discussions, these generalizations have the potential to have an impact on delivery of accurate information to parents, correct and timely diagnosis, as well as subsequent intervention.

 Misunderstandings concerning effective intervention strategies. While previous studies administering the Autism Survey (Stone, 1987) had little focus on questions pertaining to intervention strategies, the current study attempted to increase this focus and account for up-to-date research by adding three questions concerning intervention to the version of the survey administered in this study. While previous research in this area is limited, findings of the current study were congruent with Shah (2001), who identified a lack of medical students correctly identifying behavioural therapy as the treatment most likely to be effective for children with autism. In the present study, physicians and residents more strongly believe that sensory integration therapy is an effective treatment for autism and its symptoms, and, on the other hand, were less likely to endorse the statement that research indicates that applied behaviour analysis is an effective treatment for autism and its symptoms. Further, residents and physicians were significantly less likely to support the finding that children with autism are at a greater risk for developing seizures than typically developing children. Finally, physicians alone were more likely to support the idea that Respiridol is effective in treating the socio-communicative challenges faced by children with autism.

 A misunderstanding of effective interventions has implications regarding referral to safe and appropriate interventions, as well as potential to provide necessary and adequate medical care. While SI therapy has been around for more than 25 years, it has been the subject of little
rigorous research, and most importantly, is not empirically supported as an intervention strategy for PDDs (Jacobson, Foxx, & Mulick, 2005).

The endorsement of a non-empirically based treatment is of alarming concern, as this speaks to the possibility that physicians may be supporting, and further endorsing the use of other complimentary and alternative, non-empirically supported treatments. Even further, while the recommendation of non-empirically supported treatments has the potential to inhibit the use of empirically supported treatments such as (E)IBI, harmful side effects, including death, have been shown with some drug therapies, such as the use of Secretin therapy (Sturmey, 2005).

Furthermore, while some residents and physicians are endorsing the use of (at least one) non-empirical intervention, the support for the use of applied behaviour analysis, often synonymous with the term (E)IBI, was not consistent across these groups. Responses to the statement regarding ABA had the least number of completed responses, with a select number of physicians indicating with a question mark or written statement that they did not know what ABA was. This is alarming considering EIBI based upon the principles and procedures of applied behaviour analysis is the ‘gold standard’ treatment of choice for young children with autism, and, in Ontario, is the mandated treatment for this disorder (Ministry of Children and Youth Services, 2004). The use of ABA, most favorable when started as early as 2 years of age and intensive in nature (up to 40 hours per week) is nearly universally acknowledged to provide an opportunity to make meaningful and lasting improvements for children with autism. To date, no other treatment for autism offers comparable evidence of effectiveness (Newschaffer et al., 2007).

Moreover, while Respiridol has recently been approved by the FDA to treat behavioural concerns such as aggression, attention and hyperactivity (e.g., McDougal et al, 1998; Williams et
al., 2006; Shea et al., 2004), there is no empirical support for the use of Respiridol to treat the socio-communicative challenges faced by children with autism. Rather, EIBI is the treatment of choice to improve both language and social skills in these children. Interestingly, only physicians indicated a misconception that Respiridol helps treat the socio-communicative domains of autism. A concern arises as to whether physicians are prescribing a medication to children to treat social-communicative symptoms, or rather that this medication is being prescribed to help treat behavioural challenges faced by these children. Regarding the latter, with the help of Respiridol in reducing behavioural concerns, this could subsequently result in improvement of social and communication challenges.

Finally, it is of utmost importance that physicians are aware of common comorbid conditions associated with autism and related disorders. An associated medical condition such as epilepsy or seizure disorders occurs in as many as one quarter to one third of children with autism (Fombonne, 2005). Therefore, physicians need to be able to offer advice, guidance and reassurance to parents who face the possibility of comorbid medical concerns for their child.

Overall, residents and physicians need to be equipped with the knowledge of empirically supported treatments for autism, in order to make good recommendations and field questions from concerned parents. These primary care physicians are the most likely to be approached by parents with questions about the latest and most popular treatment options, often alternative, in the media and need to be equipped with the knowledge necessary to provide safe and favorable treatment options. At the very least, if physicians feel that they are not up-to-date on effective interventions, they should make referrals to professionals who can provide this information.

Following the analysis of autism knowledge by group (i.e., residents, practicing physicians, and experts), to expand previous research (e.g., Shah, 2001; Heidgerken, 2003),
results were also analyzed by specialty (i.e., family medicine, pediatrics, experts). While past research has assessed the knowledge of health care professionals, this is the first study to compare the knowledge of family physicians to the knowledge of pediatricians.

*Family Physicians, Pediatricians and Experts*

Given that significant group differences existed on the same statements as when analyzed by group, the focus of the following section is on discussing differential responding by specialties of family physicians and pediatricians (with each specialty including both residents and practicing physicians) while also compared to the expert control group.

*What pediatricians know.* Findings indicate that selective pediatricians’ responses were consistent with the responses of experts, but differed from those of family physicians. For example, pediatricians dismissed the ideas that autism is an emotional disorder, as well as the belief that *all* children with autism display poor eye contact, and correctly supported the idea that most parents report their first concerns were related to their child’s social behaviours.

These findings may be a result of the fact that pediatricians have a longer residency focused solely on a pediatric population, and reported more years of direct experience with autism as well as a larger patient population of individuals with autism. As a result, this specialized group may be more likely to learn the classification criteria of infant and childhood disorders from the DSM-IV-TR (APA, 2000), and well as general characteristics such as the nature of the disorder. Further, through more years of experience and patient contact, pediatricians likely encountered a great number of reports from parents of a concern of children’s social behaviour, and observed some children who met the criteria for PDD who did not display poor eye contact.
Pediatricians' inaccuracies. While pediatricians showed consistency with experts in a few areas that differed from family physicians, a majority of responses indicated that both pediatricians and family physicians differed from the responses provided by experts. For example, similar to results obtained when analyzing responses by groups (i.e., residents, practicing physicians, and experts), both family physicians and pediatricians harbored the inaccurate beliefs that autism occurs more commonly in high SES groups, children with autism do not show attachment to parents, and sensory integration therapy is an effective treatment for autism.

While pediatricians believe more strongly that autism is not an emotional disorder, misconceptions concerning the above mentioned statements are still apparent. This may indicate that while pediatricians may be aware of the DSM-IV-TR (APA, 2000) classification of autism, and therefore dismiss the interpretation of autism as an emotional disorder and display knowledge of some basic characteristics of autism, they may not have been exposed to knowledge of other basic information focusing on etiology, assessment, diagnosis, and treatment. As supported by Hutchinson (2005), this information may be absent in the curriculum, and a lack experiences with a variety of patients with autism during clerkship and clinical practice may contribute.

Overall Knowledge and Hypotheses Support

Surprisingly, contrary to hypotheses that currently practicing physicians would have greater knowledge concerning autism than residents, few significant differences between residents and practicing physicians were found. While other studies have examined knowledge held by medical students and health care providers in separate studies, currently, no study has
compared the knowledge of medical students or residents to the knowledge of practicing physicians.

While it may be expected that experience and knowledge would increase with a greater number of years in practice, many professionals may not be able to keep their skills and knowledge up-to-date. This is particularly likely with a disorder where research is constantly producing new findings. This lack of up-to-date knowledge may be a result of a lack of available resources and/or time. Autism was only first described in the mid 1940's, and not conceptualized as a diagnosis separate from mental retardation and schizophrenia until the 1960's. Asperger's syndrome did not receive its own classification until 1981 and in 1994 it was added to the fourth edition of APA (Fein et al., 2001; Fombonne, 2005). Ongoing changes, therefore, reflect a necessity for continuing education. It is essential that professionals keep updated and aware of treatment trends, existing and emerging research, as well as misconceptions in popular culture.

Further, if currently practicing physicians' knowledge of the disorder is lacking, it is likely that an emphasis on autism in the medical curriculum is also absent, with a scarcity of well trained physicians to teach these areas. As mentioned previously, Hutchinson (2005) reported that current medical students indicated vague, if any, recollections of knowledge of PDD in curricula. Residents expressed that the first two years of knowledge from the classroom did not adequately prepare them to treat patients with PDDs during their clerkship. An overall significant learning gap in knowledge regarding PDDs was emphasized. Importantly, Hutchinson reported that not one participant felt the content or teaching on PDDs was satisfactory.

While preparation at this level for students is general, and a specialty has not yet been chosen, nearly 50% of medical students chose family medicine and pediatric residency
programs; these are two of the most common practices where it would be likely to encounter a child with a PDD (Hutchinson, 2005). One resident expressed that when patient contact did occur, it became overwhelming as a result of the complexity of PDDs, and exceedingly frustrating because he did not have the necessary skills to assess these patients.

Overall, residents and physicians held some misconceptions and demonstrated some inaccurate knowledge concerning general facts about autism, as well as knowledge specific to assessment and intervention. These results, paired with a majority of responses indicating a minimal to moderate perceived knowledge by both residents and physicians support findings from Hutchinson. Based on the results of this study that support Hutchinson’s findings that medical students feel ill prepared in supporting and providing care to children with PDD, further research should incorporate a needs-based assessment of the learning gaps and information residents and physicians feel is necessary to provide competent and quality care when interacting with these young patients and their families. While it is unrealistic that physicians become ‘experts’ in the field of PDDs, it is necessary that physicians have a sound knowledge of the basic characteristics and symptoms of autism, particularly those related to medical concerns, in order to provide advice and reassurance to families. At the very least, the presence of strong referral networks is necessary if primary health care providers are not comfortable with screening, diagnosis, and service provision, and need to refer these children to the necessary specialists in a timely manner.

Finally, it was hypothesized that pediatricians would have a greater overall knowledge concerning autism than family physicians, based on years of residency and likelihood of experience with the population. Past research has assessed the knowledge of health care professionals, combining groups of family physicians and pediatricians under the umbrella of
primary providers, and comparing them to groups of specialists (e.g., neurologists, psychologists, etc.), rather than comparing them to each other. This study is the first to compare the knowledge of family physicians to the knowledge of pediatricians. Overall, the present study revealed that, despite greater years of residency and experience held by pediatricians, there was little difference between the responses of family physicians and pediatricians. Potential answers for these findings again point to a lack of focus on autism and related disorders within the medical curriculum. While it is expected that both family physicians and pediatricians will encounter children with autism in practice, it is likely that pediatricians will encounter an even great number of these patients, and a greater number of concerns from parents based on their particular specialized focus on a pediatric population. This speaks to a continued necessity of pediatricians, in particular, to be adequately equipped with the knowledge necessary to recognize characteristics, provide referrals, support parents and provide competent medical care.

Limitations

Several limitations are present with the design of the current study and should be considered when interpreting the obtained results. First, the original survey developed by Stone (1987) was considered valid and reliable, however, the updated version of the survey developed by Dr. Naomi Sweizy and the Christian Sarkine Autism Treatment Centre (2005) that was used in this study, was still undergoing validation. However, preliminary findings indicate acceptable psychometric properties (N. Sweizy, Personal Communication, January 2008). Additionally, four questions were added to the current measure to reflect up-to-date research in the field, with a preliminary full scale reliability alpha of .604. While this is recognized to be low, a lenient cutoff of .6 is considered acceptable for preliminary measures (Miller & Neil, 2002). As well, a small sample size and a heterogeneous population are recognized as possible contributors.
Second, in our analyses, a standard alpha level of .051 was used. Although the majority of our results were significant at an alpha level of \( p < .05 \), two results were significant at the level of .051. It is likely that with a larger sample size, these results would have reached the more conventional significance level.

As well, in the design of the survey, initial administration was targeted for in-person data collection. However, when the survey was re-designed for e-mail administration, answers to demographic questions were provided on a scale. In the process of designing these scales, answers to questions regarding years of experience and number of patients seen were not mutually exclusive, and overlap between groups resulted (e.g., 2-5 years, 5-10 years, etc). This limitation may have the potential to contribute to some inaccuracies in the interpretation of these results.

Moreover, the potential for some misinterpretation based on terminology and wordings of survey questions is possible. For example, the question relating to the use of Respiridol for treating the socio-communicative domains of autism may have been misleading to a physician who believed that it could help behavior problems which would then, in turn, lead to improving social and communicative characteristics. Further, the statement about Applied Behaviour Analysis as a treatment for autism may also have misled some physicians who are more familiar with the term intensive behaviour intervention, and as a result, these physicians may have replied inappropriately or not at all. Perhaps in future studies, experts in PDD can be recruited to increase the clarity of statements and incorporate lingo that in popular in the media.

Furthermore, although many efforts were made to increase sample size, including expanding recruitment by requesting that e-mail versions of the survey to be re-distributed, and using multiple avenues (e.g., e-mails, phone calls, and recommendations from members of the
research team and ‘expert’ group of appropriate contacts for medical school directors and community physicians) of obtaining access to medical schools and health networks, the overall number of participants was relatively low. However, significant results were still achieved, supporting many of the same findings of past research (e.g., Stone, 1987; Shah, 2001, & Heidgerken, 2005).

Finally, the response rate of participants was very low (an exact figure is unknown due to the director of the medical schools distributing the e-mail versions of the surveys directly for confidentiality reasons), but was approximated at 10-20%. Thus, it is likely that only residents and physicians with a particular interest in autism may have responded, particularly to the e-mail version of the survey. Further, no measures were implemented with the e-mail version of the survey to ensure each participant was completing the survey independently, and without the assistance of other people or resources. As well, due to the survey being voluntary, it is likely that non-respondents without a vested interest in autism and pervasive developmental disorders may have chosen not to respond. As a result, this factor may be reflected in the results. For example, residents and physicians who chose not to respond may be less confident in their knowledge of autism. However, this may be balanced somewhat by the majority of resident data being collected in-person on-site, where no residents opted out of completing the survey.

Implications and Future Directions

Overall, results of the current study were congruent with data on student reports (Hutchinson, 2005) and the assessment of knowledge by Stone (1987), Shah (2001) and Heidgerken et al (2005). Together, these results speak to a limited knowledge set concerning PDDs, but also an awareness by healthcare professionals of the deficiency of knowledge and its perceived impact.
These findings also have major implications and potential promise to contribute to future research concerning the learning and teaching of PDD curricula through medical school training and continuing education. Future research needs to focus on additional replications with validated measures, consistent and objective administration, as well as larger sample sizes. In the meantime, preliminary findings indicate that courses in introductory knowledge and providing services to special populations would be an asset, particularly for those specialties (i.e., family medicine and pediatrics) most likely to encounter these children. While it is unrealistic to expect programs to devote an entire course to autism, it may be reasonable to suggest that all programs address autism in some focused manner, perhaps through invitation of guest speakers who specialize in the field. Feedback from undergraduate medical students (Hutchinson, 2005) expressed that they felt autism had no ‘home’ in the medical curriculum, but rather, was briefly mentioned in various areas of the curriculum.

These findings also support the increased importance of collaborating across the disciplines associated with PDDs to establish a support system for health care professionals and the children and families they serve. This too speaks to the increased need for professionals in the field of autism and developmental disorders to ensure that they disseminate their knowledge in a manner accessible to the medical field.

The current study has continued to contribute to a small, yet growing understanding of autism knowledge in the healthcare field. Further research is needed to provide a greater understanding of where knowledge gaps concerning autism lie. In addition to conducting quantitative studies, it is important to elicit qualitative information concerning the needs of students and professionals. While the number of children diagnosed with autism continues to grow, it becomes exceedingly important that physicians have a foundation of knowledge
necessary to recognize characteristics of the disorder for diagnosis and referral, and have the ability to provide quality care to these children.
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Appendix A

Ethics Approval

DATE: November 15, 2007
FROM: Michelle McGinn, Chair
Research Ethics Board (REB)
TO: Tricia Vause, Child and Youth Studies
Lindsay CAMPBELL
FILE: 07-068 CAMPBELL
TITLE: A Survey of Autism Knowledge in the Health Care Field

The Brock University Research Ethics Board has reviewed the above research proposal.

DECISION: Accepted as clarified; however, please remove the phrases “if applicable” and “where applicable” from the consent form. These are part of a generic template.

This project has received ethics clearance for the period of November 15, 2007 to July 31, 2008 subject to full REB ratification at the Research Ethics Board’s next scheduled meeting. The clearance period may be extended upon request. The study may now proceed.

Please note that the Research Ethics Board (REB) requires that you adhere to the protocol as last reviewed and cleared by the REB. During the course of research no deviations from, or changes to, the protocol, recruitment, or consent form may be initiated without prior written clearance from the REB. The Board must provide clearance for any modifications before they can be implemented. If you wish to modify your research project, please refer to http://www.brocku.ca/researchservices/forms to complete the appropriate form Revision or Modification to an Ongoing Application.

Adverse or unexpected events must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants and the continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocols.

The Tri-Council Policy Statement requires that ongoing research be monitored. A Final Report is required for all projects upon completion of the project. Researchers with projects lasting more than one year are required to submit a Continuing Review Report annually. The Office of Research Services will contact you when this form Continuing Review/Final Report is required.

Please quote your REB file number on all future correspondence.

MM/bb
Office of Research Ethics, MC D250A
Brock University
Office of Research Services
500 Glenridge Avenue
St. Catharines, Ontario, Canada L2S 3A1
phone: (905)688-5550, ext. 3035 fax: (905)688-0748
email: reb@brocku.ca
http://www.brocku.ca/researchservices/ethics/humanethics/
Appendix B

** For Reference Only- Not used in current study**
See Appendix E for current measure

**Autism Survey**
©Stone, 1984

### Part I

**Directions:** For each of the following statements, choose the number that best reflects how much you AGREE with the statement. Write the appropriate number on the line following each statement. Use the following scale:

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
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<tbody>
<tr>
<td>Fully Agree</td>
<td>Mostly Agree</td>
<td>Somewhat Agree</td>
<td>Somewhat Disagree</td>
<td>Mostly Disagree</td>
<td>Fully Disagree</td>
</tr>
</tbody>
</table>

1. Autism is an emotional disorder. 

2. Autism exists only in childhood.

3. Even with the early intervention, the prognosis for independent community functioning of autistic individuals is poor.

4. Autistic children are “untestable”.

5. Autism can occur in mild as well as extreme forms.

6. Autistic children are more intelligent than scores from appropriate test indicate.

7. It is difficult to distinguish between autism and childhood schizophrenia.

8. Autism is a communication disorder.

9. Autistic children do not show social attachments, even to parents.

10. Autistic children usually grow up to be schizophrenic adults.

11. Most autistic children are also mentally retarded.

12. Most autistic children do not talk.
<table>
<thead>
<tr>
<th></th>
<th>Fully Agree</th>
<th>Mostly Agree</th>
<th>Somewhat Agree</th>
<th>Somewhat Disagree</th>
<th>Mostly Disagree</th>
<th>Fully Disagree</th>
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<tbody>
<tr>
<td>13.</td>
<td>Autistic children are deliberately negativistic and noncompliant.</td>
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<td>14.</td>
<td>It is important that autistic children receive Special Education services at school.</td>
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<td>15.</td>
<td>Autism occurs more commonly among higher socioeconomic and educational levels.</td>
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<td>16.</td>
<td>Autism is a developmental disorder.</td>
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<td>17.</td>
<td>Autistic children’s withdrawal is mostly due to cold, rejecting parents.</td>
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<td>18.</td>
<td>Most autistic children have special talents or abilities.</td>
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<td>19.</td>
<td>Emotional factors play a major role in the etiology of autism.</td>
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<td>20.</td>
<td>With proper treatment, most autistic children eventually “outgrow” autism.</td>
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<td>21.</td>
<td>I feel comfortable diagnosing or identifying a child as autistic.</td>
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<td>22.</td>
<td>Autistic children do not show affectionate behavior.</td>
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**Part II**

**Directions:** For the following questions, check all items that apply:

23. Which of the following behaviors or characteristics **must be present** for a diagnosis of autism:

   - [ ] Language delays
   - [ ] Hallucinations
   - [ ] Sudden, unexplained mood changes
   - [ ] Lack of eye contact
   - [ ] Mutism
   - [ ] Need for sameness; resistance to change in routine
   - [ ] Peculiar speech characteristics
   - [ ] Inappropriate laughing or giggling
24. Which of the following behaviors or characteristics are helpful (though not necessary) in making a diagnosis of autism:

- Attention deficits
- Unusual sensory responses
- Lack of social responsiveness
- Thought disorder
- Rigid or stereotyped play activities
- Aggressive behavior
- Onset of symptoms before thirty (30) months
- Unusual mannerisms such as finger flicking
- Hyperactivity
- Allergies

References:


For more information, please contact:

**Wendy Stone, Ph.D.**

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*Director, TRIAD*

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fax 615.322.8236

www.TRIADatVanderbilt.com
Appendix C

Letter of Invitation

Title of Study: A Survey of Autism Knowledge in the Health Care Field

Principal Investigator: Lindsay Campbell, MA Candidate, Department of Child and Youth Studies, Brock University
Faculty Supervisor: Dr. Tricia Vause, Associate Professor, Department of Child and Youth, Brock University

I, Lindsay Campbell, MA Candidate, from the Department of Child and Youth, Brock University, invite you to participate in a research project entitled A Survey of Autism Knowledge in the Health Care Field.

The purpose of this research project is to provide an understanding of autism knowledge held by residents and professionals in the health care field. Overall, we would like to understand how knowledge translates into clinical practice for professionals most likely to encounter young children with autism.

The present research may provide preliminary avenues to make suggestions as to potential gaps in education regarding autism. These gaps could be addressed and further implemented within curriculums. Ideally, this will be later translated into clinical practice and ultimately lead to increased satisfaction of services received and improve the overall quality of care provided to young children with autism.

The survey will take approximately 5 minutes to complete.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

If you have any questions, please feel free to contact me.

Thank you

Lindsay Campbell
MA Candidate
905-688-5550 ext. 5546
lindsay.campbell@brocku.ca

Dr. Tricia Vause
Associate Professor
905-688-5550 ext. 3559
tvause@brocku.ca

This study has been reviewed and received ethics clearance through Brock University’s Research Ethics Board (07-068)
Appendix D

Informed Consent

Date: February 2008
Project Title: A Survey of Autism Knowledge in the Health Care Field

Principal Investigator:
Lindsay Campbell, MA Candidate
Department of Child and Youth Studies
Brock University
905-688-5550 ext. 5546
lindsay.campbell@brocku.ca

Faculty Supervisor:
Dr. Tricia Vause, Associate Professor
Department of Child and Youth Studies
Brock University
(905) 688-5550 Ext. 3559
tvause@brocku.ca

INVITATION
You are invited to participate in a study that involves research. The purpose of this study is to understand what healthcare professionals know about autism. We hope that this study can contribute to improved educational and clinical experiences for you and future practitioners.

WHAT’S INVOLVED
As a participant, you will be asked to complete a short survey about autism. Participation will take approximately 5-10 minutes of your time.

POTENTIAL BENEFITS AND RISKS
There are no known or anticipated risks associated with participation in this study.

CONFIDENTIALITY

Confidential survey/questionnaire
All information you provide is considered confidential; your name will not be included or, in any other way, associated with the data collected in the study. Furthermore, because our interest is in the average responses of the entire group of participants, you will not be identified individually in any way in written reports of this research.

Data collected during this study will be stored in locked filing cabinets, in the laboratory of the principal investigator. Data will be kept for a maximum of one year, while data entry and analysis take place, after which time all data will be destroyed in a safe manner. Access to this data will be restricted to the principal investigator, faculty supervisor and members of the research team.
VOLUNTARY PARTICIPATION
Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS
Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available upon completion of analysis, from the principal investigator.

CONTACT INFORMATION AND ETHICS CLEARANCE
If you have any questions about this study or require further information, please contact the Principal Investigator or the Faculty Supervisor using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (07-068). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM
I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: ____________________________
Signature: _________________________
Date: ____________________________
Appendix E

AUTISM SURVEY
(ADAPTED FROM STONE, 1984 AND SWIEZY, 2006)

Directions: Please answer the following questions on this survey as best you can. Do not spend too much time on any one question. For each of the following statements, circle the number that best reflects how much you AGREE with each statement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Fully Agree</th>
<th>Mostly Agree</th>
<th>Somewhat Agree</th>
<th>Somewhat Disagree</th>
<th>Mostly Disagree</th>
<th>Fully Disagree</th>
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<tbody>
<tr>
<td>1. Autism is an emotional disorder</td>
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<td>2. Early intervention can lead to significant gains in children’s socio-communicative skills</td>
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<td>3. Children with autism are at a greater risk for developing anxiety disorders than typically developing children</td>
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<td>4. Children with autism are at a greater risk for developing seizures than typically developing children</td>
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<td>5. All children with autism display poor eye contact</td>
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<td>6. Children with autism typically perform better when tasks are presented visually than when tasks are presented verbally</td>
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<td>7. Problems with social relatedness that are present in autism are different from social problems seen in other psychiatric conditions</td>
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<td>8. Autism is more frequently diagnosed in males than females</td>
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<td>9. Children with autism do not show attachment, even to parents/caregivers</td>
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<td>10. Research indicates that sensory integration therapy is an effective treatment for autism and its symptoms</td>
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<td>11. Research indicates that Applied Behaviour Analysis is an effective treatment for autism and its symptoms</td>
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<td>12. Children with autism are deliberately uncooperative</td>
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<td>13. Most parents/caregivers of children with autism report their first concerns were related to the child’s social behaviour</td>
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<td>14. Autism tends to run in families</td>
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<td>15. We now have treatment that can cure autism.</td>
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<tr>
<td>16.</td>
<td>Children with autism can grow up to live independently.</td>
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<td>5</td>
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<td>17.</td>
<td>There is one approach/program that works for all children with autism.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18.</td>
<td>Respiridol is effective in treating the socio-communicative challenges faced by children with autism.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19.</td>
<td>It is important that all children diagnosed with autism receive some form of special education services at school</td>
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<td>20.</td>
<td>Autism occurs more commonly among higher socioeconomic and educational levels</td>
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<td>21.</td>
<td>Autism can be diagnosed as early as 18 months</td>
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<td>4</td>
<td>5</td>
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<tr>
<td>22.</td>
<td>With the proper treatment, most children diagnosed with autism will eventually outgrow the disorder</td>
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<td>4</td>
<td>5</td>
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<tr>
<td>23.</td>
<td>Children with autism do not show affection</td>
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<td>3</td>
<td>4</td>
<td>5</td>
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<td>24.</td>
<td>The need for routine and sameness is one of the earliest features of autism</td>
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Please Provide the Following Information:

**Current Specialty**
- Family Medicine
- Pediatrics
- Dentistry

**Current Practicing Level**
- Student/Resident
- Physician
- Dentist

**Students- Year of residency**
- 1
- 2
- 3
- 4

**Professionals- Years of experience in field**
- <5
- 5-10
- 10-15
- 15+

**How many years of experience have you had with autism?**
- None
- < 2 years
- 2- 5 years
- 5 + years

**Approximately how many patients with autism have you served?**
- 0
- 1-2
- 3-5
- 5-10
- 10-15
- 15-20
- 20+
What percentage of your patient population falls on the autism spectrum?

- [ ] <1%
- [ ] 1%
- [ ] 2-3%
- [ ] 4-5%
- [ ] 10%
- [ ] >10%

Please identify your current perceived knowledge of autism

- [ ] None
- [ ] Minimal
- [ ] Moderate
- [ ] Excellent
- [ ] Extensive

OR (Demographic Questions for Experts)

Please Provide the Following Information:

Current Position: Please choose

- [ ] If other:

Primary involvement with autism: Please choose

- [ ] If other:

How many years of experience have you had with autism?

- [ ] < 5 years
- [ ] 5-10 years
- [ ] 10-15 years
- [ ] > 15 years

Approximately how many patients with autism have you served?

- [ ] >10
- [ ] 10-20
- [ ] 20-30
- [ ] 30-40
- [ ] 40-50
- [ ] 50+

Please identify your current perceived knowledge of autism

- [ ] None
- [ ] Minimal
- [ ] Moderate
- [ ] Excellent
- [ ] Extensive

For questions, please contact
Lindsay Campbell, M.A.
Candidate, Brock University at
lindsay.campbell@brocku.ca
## Appendix F

### Skewness and Kurtosis Pre and Post Transformation

<table>
<thead>
<tr>
<th>Question</th>
<th>Pre-Transformation</th>
<th>Post-Transformation</th>
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<td>Kurtosis</td>
<td>Skewness</td>
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<td>3. Anxiety disorders</td>
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<td>2.256</td>
<td>.256</td>
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<td>4. Seizures</td>
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<td>1.090</td>
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<td>5. Poor eye contact</td>
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<td>-.509</td>
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<td>7. Social relatedness</td>
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<td>-.034</td>
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<td>8. Males/females</td>
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<td>9. Attachment</td>
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<td>10. Sensory integration therapy</td>
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<td>1.160</td>
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<td>11. Applied behavior analysis</td>
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<td>.007</td>
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<td>12. Deliberately uncooperative</td>
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<td>8.360</td>
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<tr>
<td>13. Social behaviour</td>
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<td>14. Run in families</td>
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<td>Pre-Transformation</td>
<td>Post-Transformation</td>
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<td></td>
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<td>Kurtosis</td>
<td>Skewness</td>
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<tr>
<td>15. Treatment/cure</td>
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<td>2.038</td>
<td>-1.607</td>
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<td>16. Live independently</td>
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<td>-.351</td>
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<td>17. One approach</td>
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<td>24. Routine and sameness</td>
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### Appendix G

**Levene’s Test**

Levene’s test for MANOVA by Group

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<td>.846</td>
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<td>.567</td>
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Levene’s test for MANOVA by Specialty

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<td>.624</td>
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<td>.671</td>
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<td>.634</td>
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<tr>
<td>Poor eye contact</td>
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<td>2</td>
<td>83</td>
<td>.719</td>
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<td>Visual presentation</td>
<td>.356</td>
<td>2</td>
<td>83</td>
<td>.702</td>
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<tr>
<td>Social relatedness</td>
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<td>.898</td>
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<td>More frequent in males</td>
<td>6.421</td>
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<td>83</td>
<td>.003</td>
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<td>83</td>
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<td>.097</td>
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Appendix H

Non-Parametric Results

By Group

Non-parametric Jonkheere-Terpstra tests were completed for questions where Levene’s test indicated a violation of homogeneity of variance (see Appendix H), due to extremely low variance in the ‘expert’ groups, indicating a strong level of agreement among expert responses. For the five questions of interest (“Autism is an emotional disorder”, Autism is more frequently diagnosed in males than females”, “Children with autism do not show attachment, even to parents/caregivers” “Autism occurs more commonly among higher socioeconomic and educational levels” and “Autism can be diagnosed as early as 18 months), the Jonkheere-Terpstra and Mann-Whitney non-parametric tests confirmed significant main effects and group differences.

Non-Parametric Jonkheere-Terpstra test for confirmation of Sig. with different Variance

<table>
<thead>
<tr>
<th></th>
<th>Emotional disorder</th>
<th>More frequent in males</th>
<th>Attachment</th>
<th>SES</th>
<th>18 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chi-Square</td>
<td>10.259</td>
<td>13.061</td>
<td>13.520</td>
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<td>2</td>
<td>2</td>
<td>2</td>
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<tr>
<td>p</td>
<td>.008</td>
<td>.024</td>
<td>.039</td>
<td>.000</td>
<td>.005</td>
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Non-Parametric Mann-Whitney for Significant group differences (Residents & Experts)

<table>
<thead>
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<th>Emotional disorder</th>
<th>More frequent in males</th>
<th>Attachment</th>
<th>SES</th>
<th>18 months</th>
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<tbody>
<tr>
<td>Mann-Whitney U</td>
<td>148.000</td>
<td>85.000</td>
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<td>73.500</td>
<td>181.000</td>
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Non-Parametric Mann-Whitney for Significant group differences (Physicians & Experts)

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<tr>
<td>Mann-Whitney U</td>
<td>113.000</td>
<td>35.000</td>
<td>72.500</td>
<td>49.500</td>
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<tr>
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<td>.000</td>
<td>.005</td>
<td>.001</td>
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By Specialty

Non-parametric Jonkheere-Terpstra tests were completed for questions where Levene’s test indicated a violation of homogeneity of variance, due to extremely low variance on particularly questions, specifically in the ‘expert’ groups, indicating a strong level of agreement among responses. For the three questions of interest (“Autism is an emotional disorder”, Autism is more frequently diagnosed in males than females” and “Most parents/caregivers of children with autism report their first concerns were related to the child’s social behaviour), Jonkheere-Terpstra and Mann-Whitney non-parametric tests confirmed significant main effects and group differences.

Non-Parametric Jonkheere-Terpstra

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<th>Social behaviour</th>
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<td>5.996</td>
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<td>df</td>
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Non-Parametric Mann-Whitney for Significant group differences (Family Medicine & Experts)

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Non-Parametric Mann-Whitney for Significant group differences (Pediatrics & Experts)

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