PREDICTIVE FACTORS THAT INFLUENCE TREATMENT CHOICE

FOR AUTISM SPECTRUM DISORDERS

by

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Abstract

A limited number of studies have investigated the role of individual child and family

characteristics in treatment decisions for autism spectrum disorders (ASD). The current study

utilized secondary data to evaluate associations between child characteristics, family

characteristics, and treatment choice for children with ASD. Through an online questionnaire,

parents ($n = 901$) reported features of their child's diagnosis, resources, and treatments used. A

series of logistic regression analyses examined relations between child and family characteristics,

and five treatment categories. It was expected that child age, diagnostic features, comorbid

disorders, family services, and socioeconomic status would predict treatment choice. Findings

demonstrated that child age, comorbid disorders, and socioeconomic status had associations with

specific treatment use. Results suggest that parents are not considering attributes of the

diagnosis when selecting treatments. Future research examining specific child characteristics is

needed to discriminate among what treatment(s) work for individual ASD children and their

families.

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This thesis is dedicated to the parents of children with autism spectrum disorders—without you there would not be a way. With you, the possibilities are endless.

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Predictive Factors that Influence Treatment Choice for Autism Spectrum Disorders

There has been much debate over the etiology, course, and treatment for Autism

Spectrum Disorders (ASD). The characteristics associated with ASD can affect all aspects of

functioning, including: communication, social interaction, and behaviour. Symptoms can range

from relatively mild to severely impairing depending on spectrum diagnosis, and are commonly

displayed through comorbid disorders or stereotyped behaviours, such as irregular sleeping

patterns, self-injurious and self-stimulating behaviours. As prevalence rates increase and

diagnosis onsets earlier, a wide variety of behavioural, educational, pharmaceutical, vitamin, and

diet therapies have been used by parents in search of a treatment for their child with ASD

(Bowker, D'Angelo, Hicks & Wells, 2010; Goin-Kochel et al., 2007; Green at al., 2006; Levy &

Hyman, 2002). The uncertainty in prognosis is problematic for parents when deciding on a

treatment approach since therapies are often shaped toward a perceived cause of the disorder

(Matson, 1988). Moreover, empirically conducted studies of the efficacy of various treatments

for ASD are limited, providing parents with little evidence on which to base their treatment

decisions (Kasari, 2002).

There are few studies that investigate which factors influence parents in their decisions

regarding choice of treatment for their children with ASD. Ideally, treatment efficacy would be

a leading factor (Coplan et al., 2003). However, treatments that are empirically supported

demonstrate considerable variability in outcome. Numerous studies examining treatment

efficacy on children with ASD report moderate to dramatic improvements; while others see no

improvement at all (Goin-Kochel et al., 2007; Lovaas, 1987; Schreibman, 2000; Smith, Buch, &

Gamby, 2000a). The variability in treatment efficacy indicates that many factors affect treatment

outcome and that there is no "one treatment fits all" approach (Heflin & Simpson, 1998;

Schreibman, 2000). There is a great need for research examining which treatments and/or combination of treatments are effective for children based on their individual characteristics (Campbell et al., 1996; Bryson et al., 2008; Itzchak & Zachor, 2011; Schreibman, 2000; Sherer & Schreibman, 2005).

Rather than determining which treatment is most effective, research should address "a priori" which treatment(s) will be most beneficial for individual children and their families (Schreibman, 2000; Sherer & Schreibman, 2005). It has been acknowledged that perceived treatment needs of children and families differ significantly based on culture, development, and environmental factors (WHO, 1991, p. 65). Contextual factors often shape thoughts and behaviours, and play an important role in how parents interpret ASD symptoms (Pachter & Harwood, 1996). Consequently, the interpretation and beliefs of symptoms have an impact on the types of treatments used (Mandell & Novak, 2005).

Metz, Mulick, & Butter (2005) suggest that parents' choice of treatment is influenced by: the severity of the disorder, poor prognosis, and emphasis on the need for early intervention. These factors often encourage parents to find a treatment that will have a quick and significant impact. Moreover, the lack of knowledge related to the diagnosis and conflicting information from professionals play an important role in parents' treatment decisions. In a recent study, Green (2007) used an online survey to examine how parents found out about treatments and which sources of information most influenced their decision to try a treatment. Results indicated that parents generally learned about treatments from one of these three sources: (a) the Internet, (b) professionals, or (c) other parents. In addition, it was found that the ease of implementation, perceived effectiveness, and time commitment, contributed to the use of non-evidence based treatments (Green, 2007). Thus, it is apparent that the availability of resources is also a

contributing factor in the treatment selection process.

The purpose of the current thesis was to examine what factors might influence choice of treatment for autism. More specifically, the current study explored the extent to which child characteristics, family characteristics and services influence parental choice of treatment for children with ASD. First, an overview will be provided on the characteristics of autism spectrum disorders, addressing the variables of symptom severity based on spectrum diagnosis, restricted and repetitive behaviours (i.e., self-injurious and self-stimulatory behaviours), and comorbid disorders. Most children with ASD display stereotyped behaviours (e.g., hand flapping) and are often diagnosed with a secondary or comorbid disorder (Howlin, 1998). It is unclear whether parents are selecting appropriate approaches to treat the diagnosis or if the treatments are being selected based on the symptoms of comorbid behaviours associated with ASD. Thus, it is important to examine the types of treatments parents are choosing and the factors that can influence their treatment decisions. Next, prior research on the influence of family and community resources in treatment decisions will be discussed and further developed. Lastly, research objectives and hypotheses for the current study will be introduced.

Child Characteristics

Autism is a pervasive developmental disorder that has lifelong effects on the individual and their family (Dyches et al., 2004; Smith, 1999; Tidmarsh & Volkmar, 2003). First described as "infantile autism" by Kanner in 1943, autism was believed to be a disorder of social deficits, impaired communication, and behavioural oddities, with little impact on other areas of development, such as intellect and motor functioning (Volkmar & Klin, 2005; Wing, 1996). Today, the diagnosis of autism is often characterized by a continuum of severe delays in social and communication skills, usually accompanied by restricted and repetitive behaviours and

interests (American Psychiatric Association, 2000). The greatest risk factor for ASD is being male, since boys are four times more likely than girls to develop the disorder. Moreover, the disorder is evenly distributed across all educational and socioeconomic levels (Fombonne, 2005; Sattler, 2002). Recent epidemiological studies suggest that prevalence rates for all spectrum disorders range from 36 to 60 per 10 000 (Fombonne, 2005).

Although levels of functioning differ for individuals on the spectrum, most children diagnosed with ASD have a comorbid developmental disability and/or psychiatric disorder (Gillberg & Billstedt, 2000; Howlin, 1998). For instance, individuals with low-functioning ASD often have severe cognitive impairments, tend to be non-verbal, and usually display stereotyped behaviours, such as self-injury (Howlin, 1998). Thus, the long-term prognosis for individuals with autism is generally poor with nearly 80% of adults remaining significantly dependent on family and support services (Howlin, Goode, Hutton, & Rutter, 2004). Since the onset of ASD can be diagnosed as early as the age of two, an understanding of the symptoms, diagnosis, and developmental trajectory is important for parents and professionals when making treatment decisions (Itzchak & Zachor, 2011).

Diagnosis. The term "autism spectrum" refers to a classification of five pervasive developmental disorders that include the most common form of autism, more specifically known as Autistic disorder (American Psychiatric Association, 2000). Altogether, the autism spectrum consists of Autistic disorder, Asperger syndrome, Rett syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS). Rett syndrome and Childhood Disintegrative Disorder include the progressive deterioration of motor skills, may have unrelated causes, and occur at lower incidences than the other three categories (Matson & LoVullo, 2008; Volkmar & Rutter, 1995). Therefore, they will not be included in the

present study. The remaining categories of Autistic disorder, Asperger syndrome, and PDD-NOS are of particular interest to the study and will be referred to as the Autism Spectrum Disorders (ASD).

Research suggests there are few substantive differences between Autistic disorder and Asperger syndrome, yet there continues to be debate over the extent to which these categories differ (Lord & Rutter, 1994). Autistic disorder (AD) or "classic" autism is the most severe form of spectrum disorder with deficits in cognitive functioning and non-verbal communication in half of all autistic preschool children (Smith, 1999). Approximately, 70-80% of these individuals meet the diagnostic criteria for mental retardation (Fombonne, 2003; Wodrich, 1997). The diagnosis of AD is based on severe and profound impairments in social development, communication, and language, which become established before the age of three (Rogers, 2009). Children diagnosed with AD often pay less attention to social stimuli than typical developing children. They may avoid eye contact, smile or show emotion less, and be unresponsive to their own name or instructions (Volkmar, Chawarska, & Klin, 2005). Furthermore, autistic children may demonstrate difficulties in imaginative and symbolic play, joint attention, and sensitivities to common sounds and textures (Landa, 2007; Tager-Flusberg & Caronna, 2007).

Children with AD may also display restricted and repetitive behaviours such as self-stimulatory behaviours (e.g., hand flapping, body rocking), compulsive behaviours (e.g., arranging objects in a line), ritualistic behaviours (e.g., having the table set the exact same way every day), and self-injurious behaviours (e.g., head banging, skin picking). While restricted and repetitive behaviours are not specific to Autistic disorder, it appears to be the only spectrum disorder to be at the greatest risk for occurrence of these severe behaviours (Bodfish et al., 2000).

During the time Kanner systematically described the condition of "infantile autism", a similar account was written by Austrian pediatrician, Hans Asperger. Asperger coined the term "Asperger syndrome" (AS) to describe a group of children who demonstrated impairments in social-emotional and physical development, yet appeared competent in their linguistic and cognitive skills (Frith, 1991; English Translation). Similar to other ASDs, Asperger syndrome can be characterized by a pattern of symptoms that include impairment in social interaction and restricted and repetitive behaviours; and is considered to be most similar to Autistic disorder in symptoms and probable causes. However, a distinguishing factor of AS is that a significant delay in cognitive or language development is not present in the first three years of life (American Psychiatric Association, 2000). Therefore, individuals with AS tend to be diagnosed later in childhood and are considered to be "high functioning" or on the less severe end of the spectrum.

Children who display many but not all of the symptoms required for a diagnosis of Autistic disorder or Asperger syndrome, are diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) or atypical autism. PDD-NOS is often described as a milder form of autism in which key features of the other spectrum disorders may not be present and symptoms exhibited are less severe (Tidmarsh & Volkmar, 2003).

Restricted and repetitive behaviours. Although most children with ASD have social impairments and some form of communication deficit, there is variability in the presence of restricted and repetitive behaviours (RRBs). This inconsistency in RRB symptoms has researchers and clinicians wondering whether these types of behaviours are fundamental to an ASD diagnosis. Despite the inconsistencies, recent studies on large samples of children with ASD have demonstrated that the majority of individuals do display several RRBs from childhood

to adolescence (Bishop, Richler, & Lord, 2006). In fact, longitudinal studies suggest that an

ASD diagnosis is more stable when RRBs are exhibited (Lord et al., 2006). The debate over

diagnostic criteria has implications for policy makers, clinicians, and parents when selecting

appropriate treatments based on symptomology. Therefore, the following paragraphs will

elaborate on two forms of RRBs that increase the severity of an ASD diagnosis.

     Self-injurious behaviour. Prior to selecting a treatment approach, it is important

to obtain accurate information on the individual characteristics of the child. Problem behaviours

can be caused by a combination of multiple factors for different children (Howlin, 1998). For

many children diagnosed with ASD, these problem behaviours are often categorized into a group

of restricted and repetitive behaviours (RRBs). As mentioned previously, RRBs comprise one of

the domains of behaviour required for a diagnosis of autism according to the Diagnostic and

Statistical Manual of Mental Disorders-IV-TR (American Psychiatric Association, 2000). Two

severe characteristics of the RRBs are of particular interest to the present study: self-injurious

behaviours and self-stimulatory behaviours. Self-injurious behaviours (SIBs) are a challenging,

yet common characteristic of children with ASD. In a study of 102 individuals diagnosed with

Autistic disorder, 49% displayed SIBs (Ballaban-Gil, Rapin, Tuchman, & Shinnar, 1996). The

DSM-IV-TR describes self-injurious behaviours in terms of stereotyped movements (American

Psychiatric Association, 2000). A stereotyped movement is often voluntary, repetitive, and non-

functional. Such movements can be subdivided into two groups: "non self-infliction" and "self-

infliction". The latter group is categorized by behaviours that are self-injurious including: hair

pulling, swallowing air (aerophasia), head hitting, skin abrasions, arm biting, scratching, and eye

pressing or gouging (Day et al., 1998; Harding et al., 2005).

     Despite the problem behaviours associated with SIB, it has not received considerable

attention throughout the ASD literature. Treatment for ASD has largely focused on behaviour

modification and interventions for general outcome variables such as communication, adaptive

behaviour, and cognitive functioning (Matson & Smith, 2007).

Self-stimulatory behaviour. Stereotyped behaviours that do not produce a

consequence and are categorized as "non-self infliction" are referred to as self-stimulatory

behaviours (SSBs; Lovaas, 1987). Self-stimulatory behaviours are characterized by conduct that

produces visual stimulation (e.g., twirling objects, staring at lights or rotating fans and hand

flapping), vestibular stimulation (e.g., rhythmic body rocking, head nodding, and body spinning),

tactile stimulation (e.g., stroking, poking, or rubbing oneself or objects), or auditory stimulation

(e.g., feedback when an object is tapped on a table, repeating a pattern of music notes, echoing a

series of words; Lovaas, 1987). Behaviours may also reflect some degree of interaction with the

environment, varying from body-rocking to arranging objects in a precise order or repeatedly

constructing and reassembling puzzles. While SSBs are more intricate than simple motor

movements, they are similar to other stereotypies in that such behaviours are independent from

external reinforcement and create a patterned stimulus response.

Although these behaviours are frequently seen in individuals with severe developmental

delays, SSBs have been recognized as a characteristic in children with ASD. Lovaas, Litrownik,

& Mann (1971) found that children with Autistic disorder, who were conditioned to approach a

dispenser at the sound of a tone for a reinforcement of candy, had slower response times when

involved in self-stimulatory behaviours. However, such behaviours are not isolated to

individuals with developmental disabilities. SSBs are a common occurrence in the typical

population and can be often observed in individuals experiencing stress or loss (Lovaas, 1987).

Comorbid disorders. Comorbidity, or the occurrence of two or more disorders, is an

emerging topic in the ASD literature. Rarely discussed in terms as ASD, as compared to other developmental disorders, comorbid conditions remain poorly understood (Matson & Nebel-Schwalm, 2007). Comorbidity in ASD is often addressed in terms of intellectual disability (ID). With the exception of Asperger syndrome, ID co-occurs frequently in ASD diagnoses and often increases the severity of restricted and repetitive behaviours (Wing & Gould, 1979). Debate exists over whether ID and RRBs should be viewed as core features of an ASD diagnosis or a co-occurring disorder (AACAP, 1999). Furthermore, intellectual disabilities complicate assessment of comorbid disorders in ASD by limiting the understanding and expression of some complex psychiatric disorders, such as depression (Witwer & Lecavalier, 2010). Since these conditions commonly co-occur in ASD, this thesis will continue to categorize ID and RRBs as ASD symptoms, while focusing on emotional and challenging behaviours that are separate from an ASD diagnosis in the discussion of comorbidity. The following addresses a variety of comorbid conditions often displayed in ASD children and is not intended to be an exhaustive list.

Sleep disorders. Whereas restricted and repetitive behaviours are often present for the diagnosis of ASD, sleep disturbance is a condition that accompanies symptoms (Matson & LoVullo, 2008). Numerous research studies demonstrate that sleep disturbances are more prevalent in children with ASD than the general population, with rates of occurrence ranging from 40% to 80% (Richdale, 1999; Schreck & Mulick, 2000; Souders et al., 2009; Wiggs & Stores, 2001). Evidence suggests that sleep disturbances in children with autism are the result of medication use and/or extreme sensitivity to environmental changes, including noise, light, colour, texture, and movement (Richdale, 1999). Flavia et al. (2010) revealed that 86% of children with ASD reported to have at least one sleep problem that was related to a multitude of factors. Therefore, sleep disturbances in children with ASD may be a comorbid condition that is

the result of an interaction of medical, biological, psychosocial, and environmental factors

(Flavia, Flavia, Ivanenko, & Johnson, 2010).

It is believed that addressing hypersensitivity in children with ASD can improve sleep

quality. Therefore, behavioural therapies are a widely accepted treatment for children with ASD

who exhibit sleep disturbances (Oyane & Bjorvatn, 2005; Richdale, 1999; Schreck, Mulick, &

Smith, 2004). Behavioural interventions aim to foster the needs of the child so that the sleeping

environment has an optimal control of noise, light, temperature, and texture. Techniques can

include graduated extinction and scheduled nocturnal awakening to encourage the development

of self-appeasing skills and behavioural limits (Kuhn & Floress, 2008).

To date, there are no evidence-based pharmacological options for the treatment of

sleeping disorders in children with ASD. Thus, parents should consider a wide variety of factors

before selecting a sleep promoting medication for their child with ASD, including: the child's

characteristics, medical history, the pharmacological features of the drug, and other medical

comorbidities (Flavia, Flavia, Ivanenko, & Johnson, 2010).

Neurological and movement disorders. Physical deficits of motor movements

are often the result of a genetic or neurological abnormality. Hence, the co-occurrence of such

conditions in ASD diagnoses is often linked to a neurological impairment. Baron-Cohen et al.

(1999) found that 8% of youth with ASD were are also diagnosed with comorbid Tourette

syndrome. A study conducted in Sweden, demonstrated that 20% of children diagnosed with AS

also had Tourette syndrome, while 80% displayed "tics" (Ehlers & Gillberg, 1993). It is

important to differentiate restricted and repetitive behaviours from comorbid tics. Self-

stimulatory behaviours are stereotyped movements similar to tics; however, SSBs are slower and

continuous movements that do not involve the involuntary sensation, urges, and suppressive rebound that occur in tics (Canitano & Vivanti, 2007; Hollander, Kolevzon, & Coyle, 2011).

Children with ASD are also more likely to develop epilepsy and seizures than typically developing children. Approximately, one in four children with ASD will experience seizures caused by deficits in brain activity (Hollander, Kolevzon, & Coyle, 2011). Thus, treatments for seizures and Tourette syndrome are usually based on pharmacological interventions, whereas treatments for restricted and repetitive behaviours involve behavioural interventions (Canitano & Vivanti, 2007).

Affective disorders. Affective disorders, such as major depressive disorder, bipolar mood disorder, obsessive-compulsive disorder (OCD), general anxiety disorder, and phobias, are commonly reported in children with ASD. Feelings of anxiety and depression are often linked to loneliness and isolation that arise from social impairments (Wing, 1996). Affective disorders can negatively impact the long-term prognosis of ASD, by altering mood and increasing symptoms of withdrawal, aggression, and non-compliance. Furthermore, behaviours generated by anxiety, as seen in OCD and phobias, can be alienating and irrational, leading to severe emotional and financial distress. As a result, such comorbid conditions create additional stress for the family of the ASD child (Gold, 1993).

Given that affective disorders produce anxiety and increase social withdrawal, the expression of symptoms is often complex and difficult to understand. For example, fears and phobias are generally selective to children on the autism spectrum. Matson and Love (1990) examined the intensity of fears and phobias in AD children and chronologically matched typically developing (TD) children. The fears and phobias most common to the AD children

differed significantly from TD children in that AD children were more likely to have medical, animal, and situation phobias (Evans et al., 2005; Matson & Love, 1990).

At large, ASD individuals with affective disorders seek and receive treatment less often than ASD individuals with severe behavioural disturbances, such as aggression or self-injurious behaviours (Hellings, 2000). While affective disorders are frequently treated with pharmacological interventions, such as mood stabilizers and antidepressants, implications for treatment depend on the accurate identification of affective disorders accompanying an ASD diagnosis (Matson & Nebel-Schwal, 2007).

Eating disorders. Research suggests that children on the spectrum may be prone to eating disorders, including anorexia nervosa and gastrointestinal problems. In a longitudinal study on anorexia nervosa, 18% of adolescents had been diagnosed with an ASD (4% AD, 6% AS, and 8% PDD-NOS) prior to onset of the eating disorder (Wentz, Gillberg, & Rastam, 1998). Furthermore, children with ASD often develop permeable intestinal tracts or "leaky gut syndrome". Subsequently, many professionals recommend that ASD individuals with food sensitivities go on wheat, soy, and dairy free diets.

In addition to food sensitivities and refusal, children on the spectrum commonly demonstrate: pica (i.e., eating anything within reach, such as paper and dirt), hoarding, overeating, and compulsive arranging of food (Gillberg & Billstedt, 2000). The reason why some ASD children develop certain sensitivities and behavioural oddities toward food remains unclear; thus, many parents of ASD children with eating disorders will opt to try alternative diets and therapies (Levy & Hyman, 2005).

Attention-deficit and disruptive behaviour disorders. Comorbid psychopathology in ASD includes various attention and behavioural problems. Among the most

commonly co-occurring are Attention Deficit/Hyperactivity Disorder (ADHD) and disruptive behaviours. Although, the DSM-IV states that ASD and ADHD should not be diagnosed as co-occurring, the high incidence of ADHD symptoms (i.e., attention difficulties, incompliance, and hyperactivity) associated with ASD is not ignored by practitioners. In a preliminary study of psychiatric disorders in thirty-five patients diagnosed with Asperger syndrome, two-thirds of the patients had a co-occurring psychiatric disorder; the majority of children displayed symptoms of ADHD, while adolescents and adults were more likely to be diagnosed with depression (Ghaziuddin & Greden, 1998; Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). In Lee & Ousley (2006), 65% of individuals diagnosed with ASD also met the criteria for ADHD.

The overlap and co-occurrence of ADHD symptoms in ASD diagnosis varies in degree of disruptive behaviours. Among the severely impaired, ASD children also display associated deficits known as "DAMP" (Deficits in Attention, Motor control, and Perception; Gillberg, 2003). While there is much debate over the overlap of attention-deficit and disruptive behaviours in ASD children, ADHD characteristics are often emphasized in treatment goals for an ASD diagnosis (Strayhorn et al., 1998). Common approaches for treating features of ADHD and disruptive behaviours in ASD focus on pharmacological interventions (Reiersen & Todd, 2008).

Family Characteristics

As demonstrated above, the characteristics of ASD encompass a wide array of symptoms and clinical disorders. Consequently, selecting the appropriate treatment and services for a child with ASD is often a stressful process for many families. Most parents select treatment approaches in hope that their child can be cured, rather than trying to meet the specific needs of the child (Schopler, 2001). Thus, families will utilize a number of services in order to find a

beneficial treatment for their child.

Family services. Autism is often addressed as a low occurrence outside of the education system. However, many families are beginning to seek out community-based services as a means of care and treatment for their child with ASD (Thomas, Morrissey, & McLaurin, 2007). Most often, treatment approaches families seek can be carried out through a variety of community services. Hence, many services are well-suited for a number of treatments (Thomas, Morrissey, & McLaurin, 2007). In a survey of 383 families with ASD children, Thomas et al. (2007) found that families reported using a wide array of services, with an average of four different types of services outside of the education system. Common services included health services (e.g., hospital-based), speech and language therapy, respite care (i.e., babysitter service), social skills therapy, and behaviour intervention. This finding supports an earlier study by Kohler (2000) who found that children received a mean of four different services provided by more than seven different professionals (e.g., early intervention agencies, primary care clinics, tertiary care-centers, community mental health centers, financial agencies).

Family resources. While it is evident that a number of resources are available to families of ASD children, study limitations make it difficult to survey families who may not have access to resources due to characteristics of the family, including: socioeconomic status, lack of information, lack of accessibility, geographical location, and cultural and language barriers (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Thomas, Morrissey, & McLaurin, 2007). Turnbull & Turnbull (2001) describe these characteristics as family resources or "the abilities, resources, and capacities of the family to meet the needs of each individual family member and also of the family as a whole" (Hecimovic & Gregory, p. 120). Although currently understudied in the literature, family resources are imperative factors in treatment decisions that need to be

fully explored.

Average annual household income. A common misperception surrounding

ASD is that children on the spectrum are more prevalent in wealthier families. Indeed, upper-

income families have more access to services, support groups, conferences, and public events;

whereas, lower-income families may be misrepresented in the ASD population because of a lack

of funds, accessibility, and/or social support (Mackintosh, Myers, & Goin-Kochel, 2006). In a

study examining types of services and support used by parents of children with ASD,

Mackintosh, Myers, & Goin-Kochel (2006), found that lower-income families were at a

disadvantage compared to middle- and upper-income families. With barriers in accessibility to

community and professional services, low-income families are less likely to obtain information

about ASD and treatments from other parents and professionals. As a result, factors that

influence treatment decisions for low-income families warrant further investigation.

Parental occupation. Research in the field has proposed that parents of children

with ASD may display mild symptoms of the diagnosis suggested through their reported

occupation (Baron-Cohen & Hammer, 1977; Baron-Cohen et al., 2001). Baron-Cohen et al.

(1997) found that fathers of children on the spectrum were more likely to be practicing a

technical skill (e.g., engineering) than fathers of children in the control group. A criticism of the

study was that a potential socioeconomic status bias existed since parents working in

professional occupations were more likely to participate in the selection process of the study

(Windham, Fessel, & Grether, 2009).

While it is evident that socioeconomic status plays a role in the diagnosis and prognosis

of ASD, limited studies have investigated the relationship between socioeconomic status and

treatment decisions.

Treatment Approaches

There are several predominant intervention approaches to the care and treatment of autism (Bryson et al., 2003; Campbell et al., 1996). Parent report, through internet survey, has provided researchers with greater insight into treatment usage, efficacy of treatments, and parental perceptions. Yet, few studies examine how parents make decisions regarding treatments to implement for their child with ASD.

Green et al. (2006) conducted an internet survey on a sample of 552 parents of children with autism to ascertain the variety of treatments in actual use. The study found that 108 different programs, procedures, and approaches were in use or had been tried in the past by parents (Green et al., 2006). Subsequent studies share similar findings, with parents reporting an average current use of between four and seven different treatments. The greater the severity of symptoms, the more treatments are likely to be in use (Goin-Kochel et al., 2007; Green et al., 2006). Moreover, Goin-Kochel et al. (2007) found that treatment use differed by age, where younger children use more behavioural, educational, and alternative treatments compared to older children, who tend to use more prescribed medications and drug therapies. Similarly, Bowker et al. (2010) sampled 970 parents of ASD children and found that treatment use varies depending on age and diagnosis. Most families tried a combination of treatment approaches, regardless of empirical support, and discontinued treatments when they did not perceive improvement in their child's functioning. Overall, the most common types of treatments reported to be currently in use were: standard therapies, including speech and music therapy, followed by other skill-based treatments, such as social stories and fast-forward, and ABA treatments (Bowker, D'Angelo, Hicks & Wells, 2010).

Behavioural treatments. Behavioural interventions are currently at the forefront of

literature as empirically validated treatments for autism (Schreibman, 2000). These types of treatments, also known as applied behaviour analysis (ABA), encompass a science that uses applications to help improve and develop socially acceptable behaviours in children with ASD. An observed behavioural problem provides little information about the cause of the behaviour. Therefore, the goal of applied behaviour analysis is to explore the underlying cause of the behaviour and find replacement behaviours (Sturmey, 1996). Intensive behavioural treatments (IBI) are applied behaviour approaches delivered in high dosages (e.g., 40 hours per week) and in structured settings. Lovaas (1996) found that 42% of children with autism between the ages of 2 to 4 who were treated with home-based IBI "maintained normal functioning at follow-up." Such behavioural programs have demonstrated success in reducing severe symptoms of the disorder and by increasing skills in language, cognition, and social development. However, despite these empirically validated gains, behavioural interventions have encountered many problems with generalizability. Criticisms have surrounded the recruitment of subjects, the research design and experimental setting, and the definition of normality (Schopler, Short, & Mesbov, 1989; Schreibman, 1997). IBI often involves intensive training for at least two years. Many families cannot commit to or afford to the demands of the therapy (Howlin, 1998). Moreover, because behaviour is influenced by many factors for different children at different times, it is not likely that a specific function can be identified as the underlying problem (Emerson & Bromley, 1995).

Educational treatments. Research on autism intervention has long recognized that the delivery of structured educational programming is important to successful treatment outcomes (Rutter & Bartak, 1973; Schopler et al., 1971). Currently, a variety of educational interventions exist in the school system, covering a broad area of issues, such as: structured teaching,

behavioural programming, communication and social skills training, academic instruction, and the development of life long skills (Koegel et al., 1999; Schopler et al., 1995; Schreibman, 2000; Strain et al., 2001). There is evidence to suggest that the most effective educational programs are early interventions, usually beginning around the ages of 2 to 4 years (Rogers, 1996). Bryson, Rogers, & Fombonne (2003) recommended that evidence-based early interventions are used in the public school system to ensure that developmental gains are maintained and acquired throughout a child's school career. Moreover, educational strategies should be suited towards the specific pattern of developmental skills, focusing on the weaknesses and strengths displayed by the child with ASD. Emphasizing the development of existing skills is a more constructive treatment approach than trying to "cure" fundamental deficits (Howlin, 1998). The effective use of educational programming is particularly important during periods of transition (i.e., kindergarten to grade one, elementary school to high school; Bryson, Rogers, & Fombonne, 2003).

Pharmacological treatments. Even though behavioural and educational interventions are reported as the most preferred treatment types for children with ASD, medications are often used to relieve severe symptoms associated with behavioural problems, such as self-injurious behaviours, irregular sleeping patterns, aggression, obsessive compulsive behaviours, and anxiety (Howlin, 1998; Konstantareas, Homatidis, & Cesaroni, 1995). Recent studies show that approximately 50% of individuals with autism take some form of medication (Aman et al., 1995; Aman et al., 2003). Through a review of the literature, Konstantareas et al. (1995) proposed a number of factors that influence the choice to medicate, including: symptom severity, family support and availability of resources, information provided by professionals, testimonial of other parents, and the stress level experienced by the family caring for the child with ASD.

Although medication is usually prescribed for comorbid behavioural or physical problems that are a result of the disorder (e.g., sleeping disorders, epilepsy), it is often not clear for what purpose the treatment is being used. For example when anticonvulsant medications are reported to be in use, it is not known if this is to treat a comorbid condition of seizures, or if it is solely for the treatment of autistic symptoms, a practice which is currently controversial (Tharp, 2003). Furthermore, pharmacological drugs should be supported with other treatments, as they are not a cure for autism, nor are they always effective for individual children (Heflin & Simpson, 1998). Campbell (1996) suggests that not all pharmacological treatments have been appropriately evaluated. It is difficult to predict the efficacy and side effects of a specific treatment on an individual child.

Physiological treatments. The aim of physiological intervention programs is to target a believed cause of ASD, a neurological dysfunction. These types of treatments emphasize changing the individual's neurological functioning by altering how the brain receives and processes information (Heflin & Simpson, 1998). Forms of physiological interventions include sensory and auditory integration. Occupational and/or physical therapy are often recommended to be incorporated into early intervention and education plans to assist children who have deficits with fine and gross motor and adaptive skills (Jensen & Spannagel, 2011). In a sample of 970 parents, approximately 35% reported using some form of physiological treatments (Bowker, D'Angelo, Hicks, & Wells, 2010). Moreover, physiological treatments were reported as one of the top five types of therapies selected by parents for treating their young children with ASD. Despite the evaluation of physiological interventions, many researchers and clinicians remain skeptical about the efficacy of such treatments (Heflin & Simpson, 1998).

Alternative treatments. Alternative therapies and complementary and alternative

medicines (CAM) are an increasingly common treatment approach selected by parents (Bowker, D'Angelo, Hicks & Wells, 2010; Hanson et al., 2007; Harrington et al., 2006). Studies have shown variability regarding the efficacy of alternative interventions. While some are addressed as "safe and effective" for treating specific symptoms, others are widely used despite the lack of empirical support (e.g., diets and supplements; Jensen & Spannagel, 2011). Hanson et al. (2007) provide reasons to explain why so many parents are choosing CAM to treat their child with autism. Among many, the reasons are summarized as follows: conventional treatments, although addressing specific symptoms, may not demonstrate the improvement parents are expecting in their child's functioning; lack of accessibility and affordability of evidence-based approaches; trying all possible treatments and treatment combinations; more support and information provided by CAM professionals; and families may prefer less invasive and more "natural" remedies.

In a review of complementary and alternative therapies for ASD, Levy & Hyman (2005) postulate that choice of treatment is based on the perceived underlying cause of the disorder. Parents may believe that by treating the root cause of the disorder, symptoms can be reversed and their children will return to a typical rate of development. These authors cite the use of Secretin as an example of how parents, and even professionals, are vastly influenced by testimonials and observations. Secretin is a gastrointestinal hormone that stimulates the secretion of bile from the liver, as well as acts as a stress regulatory hormone that impacts GABA levels (Kern at al., 2004; Yung et al., 2001). Secretin was an unstudied treatment that gained widespread popularity and use through anecdotal reports before scientific investigation failed to find any evidence of efficacy for treating ASD (Levy & Hyman, 2005; Sandler, 2005). Thus, the

publication of both significant and non-significant findings can help guide parents in making better treatment choices (Levy & Hyman, 2005).

The Current Study

As described above, there are a variety of treatment options to choose from for children with ASD. Some treatments are supported by evidence-based research, while others gain popularity through media, testimonials, and observation. Many families adopt various treatment approaches and often use multiple combinations of treatments at one time (Bowker, D'Angelo, Hicks & Wells, 2010). However, prior to selecting a treatment approach, parents should consider a number of individual factors that can affect treatment outcome for their child, such as the ASD diagnosis, the severity of symptoms, and comorbid conditions (Bryson et al., 2008; Schreibman, 2000; Sherer & Schreibman, 2005). Furthermore, the types of services available to families, parental occupation, income, and geographical location, can also influence treatment decisions and adherence (Mandell & Novak, 2005). Studies examining reasons why parents choose certain treatments over others have concluded through parent self-report that lack of funds, availability, and treatment efficacy help parents make the decision to start or discontinue treatments (Bowker, D'Angelo, Hicks & Wells, 2010; Green, 2007). There has been agreement throughout the literature that individual characteristics influence treatment outcome, with a no "one treatment fits all" approach (Heflin & Simpson, 1998; Schreibman, 2000). Yet, limited studies have investigated the role of individual child and family characteristics in treatment decisions. It is not known to what extent child characteristics might combine with family characteristics to increase the chance of selecting one treatment type over another. Thus, it is important to examine the types of treatments parents are choosing for their children with ASD, and the individual characteristics that can influence their treatment decisions.

Overview of the present study. The purpose of the current study was to examine what factors influence parental choice of treatment for children with ASD by examining associations among variables through a series of hierarchical logistic regressions. The objectives of the study were:

1. To test associations between child characteristics (i.e., age, gender, diagnosis, presence of restricted and repetitive behaviours, and presence of comorbid disorders); family characteristics (i.e., services and socioeconomic status); and five outcome variables: behavioural treatments, educational treatments, pharmacological treatments, physiological treatments, and alternative treatments.

2. To evaluate how child and family characteristics interrelate in their associations with treatment choice.

Hypotheses. Regarding child characteristics, the following hypotheses were tested:

H1: As suggested by Goin-Kochel et al. (2007), child age would have associations with treatment use. Children in early childhood would be more likely to use behavioural, educational, and alternative treatments than adolescents, and less likely to use pharmacological treatments.

H2: Due to the more advanced cognitive and language skills associated with Asperger syndrome (Howlin, 1998; American Psychiatric Association, 2000), it was predicted that children diagnosed with Asperger syndrome would be more likely to have associations with educational and physiological treatments; and less likely to have associations with behavioural treatments compared to children diagnosed with Autistic disorder or PDD-NOS.

H3: Based on previous work by Canitano & Vivanti (2007) and Matson & Smith (2007), it was predicted that the presence of restricted and repetitive behaviours (i.e., self-stimulatory and self-injurious behaviours), would be more positively associated with behavioural treatments than

neurological and movement disorders.

H4: The presence of comorbid sleep disorders, affective disorders, and attention-deficit disorders, would be more strongly associated with behavioural and pharmacological treatments and less likely to be associated with alternative treatments as compared to comorbid eating disorders.

With regard to family characteristics, the following hypotheses were tested:

H5: Families use a variety of services for different treatment approaches based on availability and accessibility (Thomas, Morrissey, & McLaurin, 2007). It was hypothesized that families with access to community and financial services would be more likely to have associations with behavioural and alternative treatments and less likely to use pharmacological treatments. In contrast, families with access to health services would be more likely to use pharmacological treatments.

H6: As suggested by previous studies (Bowker, D'Angelo, Hicks, & Wells, 2010; Levy & Hyman, 2005), accessibility to treatments and services influence parental treatment decisions. Therefore, based on occupation and income, it was predicted that families with high socioeconomic status would be more likely to use behavioural treatments compared to families with low socioeconomic status, who would be more likely to adopt educational treatment approaches.

Lastly, with regard to the interrelation of child and family characteristics, the following hypotheses were tested:

H7: It was predicted that child and family characteristics would each contribute uniquely to the prediction of parental treatment choice. However, given the paucity of previous studies on the influence of child and family characteristics on treatment decisions, exploratory analyses were

completed to examine possible main effects and moderated relationships between these factors. In particular, the moderating role of socioeconomic status in the relationship between child characteristics and treatment choice was examined.

Method

Survey Development

The present study used secondary data collected from an extensive online questionnaire, designed to explore a variety of issues surrounding the course and treatment of autism. Parents of children with ASD were asked to respond to a series of questions regarding general information on demographics, family history, diagnosis, child characteristics, and treatment. At the time that the survey was developed, no other similar research had been published. As a result, the survey covered a broad range of issues, with a total of 72 multiple choice and open-ended questions, to afford the opportunity for responses that may not have been anticipated by the researchers (see Appendix A). Treatment data collected from this survey have been analyzed in a separate research study revealing that treatment type, combination of treatments, and discontinuation of treatments, differed between groups based on age and the severity of ASD characteristics (Bowker, D'Angelo, Hicks, & Wells, 2010).

Participants

An online survey was posted on Canadian and American autism-related websites and autism-related distribution email lists for three months. Participation was voluntary, with a total of 1,034 parents of ASD children completing the online questionnaire. Parents were asked to report the most current diagnosis of their child with ASD. Of the 1,034 respondents, 901 reported a current ASD diagnosis. For purposes of this thesis, only participants with an ASD diagnosis were included in the analysis. As indicated in Table 1, of the 901 participants, 54.3 %

(n = 489) were diagnosed with Autistic disorder, 29.6% (n = 267) with PDD-NOS, and 16.1% (n = 145) with Asperger syndrome. The sample included 749 (83.1%) males and 152 (16.9%) females, which represents a ratio of 4.9:1. The majority of respondents were North American (n = 826; 91.7%) with 77.5% from the United States and 14.2% from Canada. The remaining submissions were from other countries including areas of Europe, Australia and others (n = 62; 6.9%). The mean age was 8.34 (SD = 4.44). The average age of diagnosis for each diagnostic category was 4 years for Autism (M = 4.15; SD = 2.79) and PDD-NOS (M = 4.46; SD = 3.09), and 5 years for Asperger syndrome (M = 5.38; SD =3.46).

Procedure

Of particular interest to the present study, parents were asked to provide information on the current diagnosis of their child, features of the diagnosis, and any comorbid conditions that accompanied the diagnosis. Items included: "Does your child display any sleep disorders?" and "How old was your child when he/she was diagnosed?" In addition, parents were asked to choose from a list of services that were accessible in their community, including: community services, financial assistance, and hospital-based services. Moreover, parents responded to demographics on income, occupation, age, cultural background, and geographic location, to describe their family characteristics. Finally, parents were asked to list in their own words, the current treatment(s) given to their child with ASD.

Results

Data Preparation

To conduct the analyses, categorical variables were dichotomized or dummy coded. A dummy variable is used to represent group membership of a variable. This method of coding involves assigning "1" to members of a group and "0" to everyone else. In order to examine

Table 1

Child Characteristics

		n	%
Gender	Male	749	83.1
	Female	152	16.9
Age	Early childhood (2-5 yrs.)	250	27.7
	Middle childhood (6-10 yrs.)	373	41.4
	Late childhood (11 + yrs.)	276	30.6
Diagnosis	Autistic disorder	487	54.3
	Asperger syndrome	145	16.1
	PDD-NOS	267	29.6
Presence of RRBs	Self-injurious behaviours	300	33.3
	Self-stimulating behaviours	686	76.1
Comorbid disorders	Sleep	515	57.2
	Neurological and movement	166	18.4
	Affective/Attention-deficit	69	7.7
	Eating	151	16.7

associations between variables, a reference group was chosen for each categorical variable to compare differences in variable levels. Categorical variables with more than two levels were assigned more than one dummy variable to represent membership in each of the groups examined. As a general rule, the number of dummy variables required is equal to m-1, where m denotes the number of categories of a variable (Jaccard, 2001).

Treatments. Treatment responses provided by parents were coded into categories for analyses. The treatments were first coded into 14 categories using Green et al. (2006) and Heflin & Simpson (1998) as a guide (Table 2). For the purpose of logistic regression analyses, treatments were then coded into a total of five outcomes: (a) Behavioural (e.g., Applied Behavioural Analysis, Discrete Trial Training, Pivotal Response Training, Picture Exchange Communication System); (b) Educational (e.g., special education, TEACHH, specialized preschool, early intervention programs); (c) Pharmacological (e.g., Haldol, Risperdal, Zoloft, Secretin, Luvox, Tegretal, Paxil); (d) Physiological (e.g., Auditory Integration Training, sensory integration, occupational therapy, physical therapy, neuro-feedback); and (e) Alternative (e.g., Gluten free diets, Craniosacral manipulation, aromatherapy, dolphin therapy, hippo therapy, detoxification, mega-vitamin therapy, Magnesium). All treatment outcomes were dichotomized to fit a logistic regression model, where 1= *Yes*, treatment used, and 0 = *No*, treatment not used.

Socioeconomic status. Socioeconomic variables, including average annual household income and parental occupation, were coded and weighted on a five-point scale for both mothers and fathers. Income levels were based on intervals of $20,000 that allowed for differences in international currencies. Occupational level was classified using the 2006 National Occupational

Table 2

Categories of Treatments for ASD

Category	Examples of Treatment
Standard therapies	Speech Therapy, Music Therapy, Osteopathy
Other skills-based	Fast-forward, Lindamood bell, social stories, visual schedules
Applied Behaviour Analysis (ABA)	Discrete Trial Teaching, Applied Verbal Behaviour, Pivotal Response Training, Picture Exchange Communication System
Medications	Haldol, Risperdal, Zoloft, Secretin, Luvox, Tegretal, Paxil
Physiological	Auditory Integration Training, sensory integration, occupational therapy, physical therapy, neuro-feedback
Vitamin supplement	DMG, mega-vitamin therapy, Magnesium
Alternative diets	Gluten free, casein free, Feingold diet, yeast free diet
Alternative therapies & medicines	Craniosacral manipulation, weighted vests, aromatherapy, dolphin therapy, hippo therapy
Relationship-based treatments	Holding therapy, gentle teaching, son rise, floor-time, play therapy, counselling
Combined programs	TEACCH, Giant Steps, Eden
Detoxification	Chelation, Clathration, reduced L-glutathione
Medical procedure	Vagal nerve stimulation
Special education	Specialized preschool or school services
Other	Non-specific responses such as "early intervention"

Classification (NOC) Matrix and then further coded into five broad categories based on

occupation type and skill level (HRSDC, Government of Canada, 2007). The mean

score across socioeconomic variables was then categorized into five levels of socioeconomic

status, with "1" indicating the highest status and "5" being the lowest. For the interpretation of

findings, levels were valued as classes, with 1 representing the *upper class*, 2 (*the mid-upper*

class), 3 (*the middle class*), 4 (*the low-middle class*), and 5 (*the lower class*).

Pre-analysis Issues

The goal of the present study was to predict parental choice of treatment by examining

associations among the discrete variables of child characteristics, family characteristics, and

treatment using hierarchical logistic regression. Prior to analyses, all variables were examined

for data entry error, missing values, and goodness-of-fit. Modeling assumptions, as well as

specific logistic assumptions were evaluated.

Missing values. Missing value analysis (MVA) results revealed that approximately 25%

of values were missing from the total data set. The majority of values were missing from the

dichotomous predictors, comorbid disorders, and the five treatment outcomes. All other

variables had none or less than 5% of values missing. This problem was addressed by running

Expectation Maximization (EM) correlations matrix. Little's MCAR test was significant, $p =$

.001 and the pattern of missing values indicated that the data were missing at random (MAR).

Values for the missing data were dealt with through multiple imputations (MI). Multiple

imputation uses patterns in the observed data to create multiple predicted models that are then

used to impute data for the missing values (Tabachnick & Fidell, 2007). Parameter estimates of

the imputed data sets were pooled for a combined result to be used for analysis.

Lack of perfect separation and outliers. The adequacy of expected frequency and

power of the sample was assessed using a goodness-of-fit test that compared the observed and

expected frequencies of all pairs of categorical variables. Comorbid attention-deficit and

affective behaviours had too few cases per cell, and therefore, were collapsed into one group

based on their similar symptoms. A reassessment indicated conditions of goodness-of-fit were

satisfied; all expected frequencies were greater than one and less than 20% of the frequencies

had fewer than five cases. The assumption of lack of complete separation was examined through

parameter estimates and standard errors, with an adequate ratio of cases to variables. No

violations of linearity in the logit were observed since continuous predictor variables were not

used in the present model. Next, outliers and influential cases were evaluated through residuals.

All standardized residuals fell within range (-3.0 to 3.0 standard deviations). Cook's distance,

DFBeta, and leverage values showed no evidence of influential cases.

     Multicollinearity. The last step involved screening data for multicollinearity (the

presence of two or more variables highly correlated). Tolerance values below 0.50 were found

for diagnosis1 (Autistic disorder vs. Asperger syndrome) and diagnosis2 (PDD-NOS vs.

Asperger syndrome). To address this issue, the variables were reassigned dummy codes using

the largest category of diagnosis, Autistic disorder, as the reference group. Multicollinearity was

then reassessed through examination of tolerance values, convergence, and the standard error of

parameters. Violations of multicollinearity were no longer evident.

Descriptive Data

     Respondents were asked to provide information on the features of their child's ASD

diagnosis. Of the 901 total responses, 33.3 % reported their child displayed self-injurious

behaviours and 76.1% displayed self-stimulating behaviours. The majority of respondents

indicated that their child had a comorbid sleep disorder (57.2%), with only 7.7% ($n = 69$) of

children diagnosed with comorbid attention-deficit and affective disorders (see Table 1).

Respondents were also asked to indicate what treatments were in current use for their child with ASD. Of the 901 respondents, 75% ($n = 676$) reported that they have tried some type of treatment. Approximately, 30% ($n = 278$) of the sample were currently using one treatment, while 70% reported a current use of at least two or more multiple treatment combinations. Overall, the most common treatments used were behavioural (80.8%), physiological (47.8%), and alternative treatments (30.0%), followed by pharmacological (20.2%), and educational (19.3%) treatments as illustrated in Table 3.

Table 3

Frequency of Treatment Use

Treatment Use	n	$\%$
Behavioural	728	80.8
Educational	174	19.3
Pharmacological	182	20.2
Physiological	431	47.8
Alternative	270	30.0
Multiple Use	629	69.8

Demographic information, including parental age, cultural background, geographical location, and family income, was collected to further describe family characteristics of the sample. The mean age for mothers was 38.75 ($SD = 7.27$), which was slightly younger than that of fathers ($M = 40.99$; $SD = 7.92$). The majority of respondents identified as Caucasian (74.6%; $n = 581$), with 16.7% indicating a mixed cultural background, 2.7% Asian Pacific Islander, 2.6%

Hispanic, 1.9% Middle Eastern, and 1.5% African American. Approximately 30% of the sample

had an average annual household income greater than $80,000, with a mean income falling in the

range of $60,000- $80,000. The majority of parents were employed in skilled labour positions

(e.g., doctors, teachers, engineers, accountants), 52.3% for mothers, and 64.3% for fathers, with

39.8% of mothers indicating their occupation status as homemakers, students, or retired and

29.0% of fathers reported working in unskilled labour positions (e.g., trades, warehouse

assembly lines, agriculture). Most families reported the use of community services (51.3%);

however, many received financial (36.6%) and hospital-based (12.1%) support as well (see Table

4).

Of particular interest to the current study, was the distribution of service availability by

geographical location. Further research indicated that geographical locations differed with

respect to government funded services. For example, in Canada most provinces offered

government funded services for children of all ages with ASD. Provinces such as Quebec and

P.E.I., and the three territories, did not provide services. If services were offered, they had been

recently implemented and were only available to young children. Similarly, most states in

Australia provided government funded services. Unfortunately, information pertaining to the

United States and Europe were difficult to obtain. Thus, conclusions based on government

funding of services could not be made.

Nevertheless, descriptive analyses on the information provided by parents indicated that

service availability differed depending on geographical location.[1] The availability of financial

services was greater in Europe, X^2 (4, N = 856) = 39.21, $p < .001$, while community services

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[1] For purposes of the current study, geographical location refers to large regions (i.e., Canada, United States, Europe, Australia, New Zealand, and others).

were more available in Canada, X^2 (4, N = 856) = 66. 67, p < .001, when compared to the United States, Australia/New Zealand, and other.

Table 4

Family Characteristics

		n	$\%$
Maternal Age	20-29 years	67	8.3
	30-39 years	382	47.5
	40-49 years	305	37.9
	50-59 years	44	5.5
	60 + years	6	0.7
Paternal Age	20-29 years	41	5.1
	30-39 years	318	39.6
	40-49 years	344	42.8
	50-59 years	84	10.4
	60 + years	17	2.1
Family Services	Community	445	51.3
	Financial	317	36.6
	Hospital-based	128	12.1

Family Characteristics (Continued)

		n	%
Average income	> $80,000	252	30.3
	$60,000-$80,000	168	20.2
	$40,000-$60,000	175	21.0
	$20,000-$40,000	168	20.2
	< $20,000	70	8.4
Maternal occupation	Skilled labour	404	52.3
	Self-employed	2	0.3
	Unskilled labour	44	5.7
	Student/Homemaker/Retired	308	39.8
	Disabled/Unemployed	15	1.9
Paternal occupation	Skilled labour	497	64.3
	Self-employed	14	1.8
	Unskilled labour	224	29.0
	Student/Homemaker/Retired	13	1.7
	Disabled/Unemployed	25	3.2

Family Characteristics (Continued)

		n	%
Geographic location	Canada	128	14.4
	United States	698	78.6
	Europe	33	3.7
	Australia/New Zealand	16	1.8
	Other	13	1.5
Cultural background	Caucasian	581	74.6
	Asian Pacific Islander	21	2.7
	Hispanic	20	2.6
	Middle Eastern	15	1.9
	African American	12	1.5
	Mixed	130	16.7
Socioeconomic status	Class 1	182	20.2
	Class 2	351	39.0
	Class 3	279	31.0
	Class 4	71	7.9
	Class 5	13	1.4

Hierarchical Logistic Regression

The goal of the present study was to predict parental choice of treatment by examining

associations among the variables of child characteristics, family characteristics, and treatment

use. A limitation of linear regression is that it cannot deal with dichotomous and categorical

dependent variables. To overcome this problem, statistical techniques such as logistic regression

and discriminant factor analysis have been developed. A logistic regression was employed in the

following study for various reasons: (a) logistic regression is like multiple linear regression but

the dependent variable is dichotomous and the independent variables are continuous or

categorical; (b) this technique predicts group membership; (c) logistic regression requires fewer

assumptions than discriminant analysis; and (d) it is more statistically robust than discriminant

analysis (Fields, 2005; Hosmer & Lemeshow, 1989; Tabachnick & Fidell, 2007).

Similar to linear regression, logistic regression provides a regression coefficient 'b',

which measures the partial contribution of each predictor to variations in the outcome variables.

$$P(Y) = \frac{1}{1 + e - (b_0 + b_1X_1 + b_2X_2 + \ldots + b_nX_n + \square_i)}$$

The goal of the analysis is to correctly predict the category of outcome (1 = *Yes*,

treatment is used; 0 = *No*, treatment is not used) for individual cases using the most parsimonious

model. However, unlike multiple linear regression, the assumption of linearity is violated in

logistic regression because the dependent variable is dichotomous (Berry, 1993). Thus, the

outcome of logistic regression is not a prediction of a Y value, but the probability of belonging to

a condition of Y. This theory, known as binomial probability, states that there are only two

values of Y to predict: 1 or 0. Logistic regression uses the maximum likelihood method to form

a best fitting equation and to maximize the probability of correctly predicting the outcome

category given the regression coefficients. To normalize the distribution, and therefore, meet the assumption of linearity, data are transformed using a logarithmic transformation (Berry & Feldman, 1985). A logarithmic transformation expresses the form of the relationship in a linear equation, despite the non-linearity of the actual relationship. Therefore, a logistic regression uses logarithmic terms to form a multiple linear regression equation in order to meet the assumption of linearity (Fields, 2005).

To conduct the analyses, a series of hierarchical logistic regressions were performed through IBM SPSS 19.0 to assess prediction of membership for each of the five treatment outcomes- behavioural, educational, pharmacological, physiological, alternative; first, based on child characteristics (age, diagnosis, restricted and repetitive behaviours, and comorbid disorders), and then to analyze the full model after the addition of family characteristics (family services and socioeconomic status), while controlling for multiple treatment use.[2] Results for the logistic regression analyses are presented in Tables 5-9. Tables for the hierarchical logistic regressions include b coefficients (B), standard error $(SE\ B)$, odds ratio (exponential B) and 95% confidence intervals. The odds ratio or exponential B represents the proportionate change in odds. A value greater than 1 indicates a positive relationship between the predictor and the outcome, whereas a value less than 1 indicates a negative relationship (Tabachnick & Fidell, 2007).

Predicting treatment choice.

Behavioural treatment use. A hierarchical logistic regression was conducted to predict the influence of child and family characteristics on behavioural treatment use, while controlling for multiple treatment combinations. There was a good model fit of child

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[2] The variable "Other treatments" was entered in the model to control for the use of multiple treatments and meet the assumption of independence.

characteristics alone based on a non-significant Hosmer and Lemeshow statistic, X^2 (8, N = 862)

= 9.65, p = .29.[3] Entering the variables socioeconomic status and family services as predictors in

the second block did not improve the predictive ability of the model above and beyond the

predictors of child characteristics, X^2 (6, N = 862) = 1.98, p = .92. Nagelkerke's R^2 indicated

that 20.6% of variance in behavioural treatments was accounted for by the model.[4] Specifically,

age and comorbid disorders predicted the odds of behavioural treatment use. Children in middle

childhood were more likely to have positive associations with behavioural treatments than

children in later childhood, p = .01 (Table 5). According to the odds ratio, when controlling for

all other predictors, children in middle childhood were approximately two times more likely to

use behavioural treatments compared to older children. Moreover, children with attention-

deficit/affective disorders were more likely to have negative associations in predicting

behavioural treatment use than children with eating disorders, such that as the percentage of

attention-deficit/affective disorders increased the odds of using behavioural treatments became

smaller. Correct classification rates were 18.2% for behavioural treatments not being used and

98.0% for behavioural treatments used, with an overall correct classification rate of 83.3%.

    Educational treatment use. Results of the hierarchical logistic regression with

child characteristics alone indicated a good model fit, X^2 (8, N = 862) = 5.08, p = .75; however,

no variables were significant. After entering family characteristics in the next block of the

model, and controlling for multiple treatment use, the model improved but not significantly, X^2

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[3] Hosmer and Lemeshow is a decile-of-risk statistic that evaluates goodness-of-fit by ordering subjects into 10 groups according to estimated probability. The groups are then compared based on observed and predicted frequencies. A non-significant value indicates a good model fit.

[4] Nagelkerke's R^2 is a pseudo R^2 measure for logistic regression most commonly reported.

Table 5

Hierarchal Logistic Regression of Predictors of Behavioural Treatments, Controlling for Multiple Treatment Use

Variables	B	SE B	Wald	OR (e^B)	95% CI
Block 1					
Age (Late childhood)					
Early childhood	.42	.26	2.62	1.52	.92, 2.52
Middle childhood	.60**	.23	6.58	1.82	1.15, 2.88
Diagnosis (Autistic disorder)					
Asperger syndrome	-.25	.28	.77	.78	.45, 1.36
PDD-NOS	-.10	.221	.22	.90	.58, 1.40
Self-injurious behaviours	-.08	.21	.13	.93	.61, 1.41
Self-stimulating behaviours	.33	.22	2.25	1.40	.90, 2.157
Comorbid disorders (Eating disorders)					
Sleep	.25	.24	1.06	1.28	.80, 2.06
Neurological/Movement	-.44	.28	2.47	.65	.38, 1.11
Attention-deficit/Affective	-.79*	.37	4.71	.45	.22, .93

Variables	B	SE B	Wald	OR (e^B)	95% CI
Block 2					
Family Services (Hospital-based)					
Community	-.18	.21	.73	.84	.56, 1.26
Financial	.04	.22	.03	1.04	.68, 1.60
Socioeconomic status (Class 1)					
Class 2	-.07	.27	.06	.94	.55, 1.58
Class 3	-.13	.27	.24	.88	.52, 1.49
Class 4	.097	.43	.05	1.10	.48, 2.54
Class 5	.87	1.12	.61	2.39	.27, 21.27

Note: Controls are multiple treatments (omitted from the table); reference categories are in parentheses; SE = standard error; OR = odds ratio; e^B = exponentiated B; CI = confidence interval; Class 1= high socioeconomic status. $N = 862$. *$p < .05$, **$p < .01$

Table 6

Hierarchal Logistic Regression of Predictors of Educational Treatment, Controlling for Multiple Treatment Use

Variables	B	SE B	Wald	OR (e^B)	95% CI
Block 1					
Age (Late childhood)					
Early childhood	.25	.24	1.05	1.28	.80, 2.07
Middle childhood	.06	.22	.07	1.06	.68, 1.64
Diagnosis (Autistic disorder)					
Asperger syndrome	.21	.27	.58	1.23	.72, 2.09
PDD-NOS	.28	.20	1.96	1.32	.89, 1.96
Self-injurious behaviours	.03	.19	.03	1.03	.71, 1.51
Self-stimulating behaviours	.03	.22	.01	1.03	.87, 1.56
Comorbid disorders (Eating disorders)					
Sleep	-0.91	.22	.18	.913	.599, 1.39
Neurological/Movement	.22	.25	.77	1.25	.76, 2.04
Attention-deficit/Affective	-.58	.45	1.67	.56	.23, .1.35

Variables	B	SE B	Wald	OR (e^B)	95% CI
Block 2					
Family Services (Hospital-based)					
Community	.16	.19	.63	1.17	.80, 1.71
Financial	-.05	.20	.05	.96	.65, 1.42
Socioeconomic status (Class 1)					
Class 2	.34	.26	1.74	1.41	.85, 2.35
Class 3	.64**	.27	5.77	1.90	1.13, 3.20
Class 4	.28	.41	.46	1.32	.59, 2.93
Class 5	1.21	.67	3.26	3.35	.901, 12.44

Note: Controls are multiple treatments (omitted from the table); reference categories are in parentheses; SE = standard error; OR = odds ratio; e^B = exponentiated B; CI = confidence interval; Class 1= high socioeconomic status. N = 862. **$p < .01$

(6, N = 862) = 8.19, p = .23. Nagelkerke's R^2 indicated that only a small amount of variance, 8.1%, in educational treatments was accounted for by the model. While child characteristics remained non-significant for the full model, socioeconomic status, in particular, the difference between families in Class 3 compared to families in Class 1 increased the odds of educational treatment use (p < .05). Families in Class 3 were twice as likely to have positive associations with educational treatments as families in Class 1 (Table 6). The entire model correctly classified an overall rate of 80.6%.

Pharmacological treatment use. Results indicated a good model fit on the basis of child characteristics alone, X^2 (8, N = 862) = 9.65, p = .29. Controlling for multiple treatment use, the first block demonstrated negative associations for early childhood vs. late childhood (p <.05), middle childhood vs. late childhood (p < .01), and positive associations for sleep disorders vs. eating disorders (p < .01) and neurological and movement disorders vs. eating disorders (p < .05). Entering family characteristics in the second block did not improve the predictive ability of the model, X^2 (6, N = 862) = 5.93, p = .43. Nagelkerke's R^2 indicted that a small amount of variance, 6.6%, in pharmacological treatments was accounted for by the entire model. Furthermore, the variable neurological and movement disorder vs. eating disorders was no longer significant (Table 7). However, early childhood and middle childhood vs. late childhood remained significant, in that the odds of using pharmacological treatments decreased for children in early childhood (p < .01) and middle childhood (p < .01) compared to children in late childhood. Sleep disorders vs. eating disorders also remained significant (p < .01), demonstrating that children who displayed sleep disorders were two times more likely to use pharmacological treatments than children who had eating disorders. Overall correct

Table 7

Hierarchal Logistic Regression of Predictors of Pharmacological Treatment, Controlling for Multiple Treatment Use

Variables	B	SE B	Wald	OR (e^B)	95% CI
Block 1					
Age (Late childhood)					
Early childhood	-.62**	.24	6.59	.54	.34, .86
Middle childhood	-.62**	.21	8.51	.54	.36, .82
Diagnosis (Autistic disorder)					
Asperger syndrome	.12	.25	.21	1.12	.69, 1.84
PDD-NOS	-.22	.21	1.12	.80	.53, 1.21
Self-injurious behaviours	.15	.19	.03	1.16	.80, 1.69
Self-stimulating behaviours	-.16	.21	.56	.86	.57, 1.29
Comorbid disorders (Eating disorders)					
Sleep	.73**	.24	9.55	2.08	1.31, 3.30
Neurological/Movement	.51	.27	3.61	1.67	.98, 2.85
Attention-deficit/Affective	-.55	.39	1.97	.1.73	.80, 3.72

Variables	B	SE B	Wald	OR (e^B)	95% CI
Block 2					
Family Services (Hospital-based)					
Community	.274	.19	2.08	1.32	.91, 1.91
Financial	-.08	.20	.16	.92	.63, 1.36
Socioeconomic status (Class 1)					
Class 2	-.10	.23	.22	.90	.57, 1.41
Class 3	-.38	.25	2.30	.69	.42, 1.12
Class 4	.03	.37	.01	1.03	.50, 2.11
Class 5	-.71	.82	.74	.49	.10, 2.45

Note: Controls are multiple treatments (omitted from the table); reference categories are in parentheses; SE = standard error; OR = odds ratio; e^B = exponentiated B; CI = confidence interval; Class 1= high socioeconomic status. N = 862. **$p < .01$

classification rate was 80.2% for the full model, with no improvement in classification after the

addition of family characteristics.

     Physiological treatment use. There was a good model fit of child characteristics

alone based on a non-significant Hosmer and Lemeshow statistic, X^2 (8, N = 862) = 2.71, p =

.95. The addition of socioeconomic status and family services as predictors in the second block

did not improve the predictive ability of the model above and beyond that of child

characteristics, X^2 (6, N = 862) = 1.98, p = .92 (Table 8). However, this model accounted for a

large amount of variance in physiological treatments with a Nagelkerke's R^2 of 45.2%. Although

family characteristics did not demonstrate significance in the model, sleep disorders vs. eating

disorders showed negative associations with physiological treatments ($p < .05$). The odds of

using physiological treatments decreased as the percentage of sleep disorders compared to eating

disorders increased. Correct classification rates were 56.4% for physiological treatments not

being used and 96.2% for physiological treatments used, with an overall correct classification

rate of 75.6%.

     Alternative treatment use. Results indicated a good model fit of child

characteristics alone, X^2 (8, N = 862) = 3.25, p = .92. The addition of family characteristics in

the second block had a non-significant reduction according to the likelihood ratio test, X^2 (6, N =

862) = 8.52, p = .20, although, the accuracy of classification improved from the first block. The

entire model correctly classified 96.0% of participants not using alternative treatments and

13.7% as using alternative treatments, with an overall correct classification rate of 71.6%.

Nagelkerke's R^2 indicated that 17.5% of variance in alternative treatments was accounted for by

the model. In particular, attention-deficit/affective disorders vs. eating disorders demonstrated

positive associations with alternative treatments, such that children with attention-deficit and

Table 8

Hierarchal Logistic Regression of Predictors of Physiological Treatment, Controlling for Multiple Treatment Use

Variables	B	SE B	Wald	OR (e^B)	95% CI
Block 1					
Age (Late childhood)					
Early childhood	-.05	.23	.05	.95	.60, 1.50
Middle childhood	.22	.21	1.03	1.24	.82, 1.88
Diagnosis (Autistic disorder)					
Asperger syndrome	-.18	.25	.49	.84	.51, 1.38
PDD-NOS	-.18	.20	.84	1.20	.81, 1.77
Self-injurious behaviours	-.05	.19	.08	.95	.66, 1.36
Self-stimulating behaviours	-.02	.21	.01	.99	.65, 1.48
Comorbid disorders (Eating disorders)					
Sleep	-.48*	.21	5.16	.62	.41, .94
Neurological/Movement	-.28	.25	1.26	.75	.46, 1.24
Attention-deficit/Affective	-.43	.38	1.25	.65	.31, 1.38

Variables	B	SE B	Wald	OR (e^B)	95% CI
Block 2					
Family Services (Hospital-based)					
Community	-.14	.19	.54	.87	.61, 1.25
Financial	.23	.19	1.48	1.26	.63, 1.36
Socioeconomic status (Class 1)					
Class 2	.29	.23	1.56	1.33	.85, 2.08
Class 3	.23	.24	.90	1.26	.78, 2.02
Class 4	-.32	.35	.80	.73	.37, 1.45
Class 5	.21	.71	.08	1.23	.30, 4.99

Note: Controls are multiple treatments (omitted from the table); reference categories are in parentheses; SE = standard error; OR = odds ratio; e^B = exponentiated B; CI = confidence interval; Class 1= high socioeconomic status. N = 862. **$p < .01$

Table 9

Hierarchal Logistic Regression of Predictors of Alternative Treatment, Controlling for Multiple Treatment Use

Variables	B	SE B	Wald	OR (e^B)	95% CI
Block 1					
Age (Late childhood)					
Early childhood	.11	.22	.26	1.12	.73, 1.71
Middle childhood	-.30	.20	2.28	.74	.50, 1.10
Diagnosis (Autistic disorder)					
Asperger syndrome	-.28	.25	1.34	.75	.47, 1.22
PDD-NOS	-.12	.18	.45	.88	.62, 1.27
Self-injurious behaviours	-.03	.18	.02	.98	.69, 1.37
Self-stimulating behaviours	-.07	.19	.12	.94	.64, 1.37
Comorbid disorders (Eating disorders)					
Sleep	-.16	.20	.67	.85	.58, 1.25
Neurological/Movement	.03	.23	.02	1.03	.65, 1.62
Attention-deficit/Affective	.73*	.33	4.77	2.07	1.08, 3.97

Variables	B	SE B	Wald	OR (e^B)	95% CI
Block 2					
Family Services (Hospital-based)					
Community	-.14	.17	.63	.87	.62, 1.22
Financial	-.11	.18	.35	.90	.63, 1.28
Socioeconomic status (Class 1)					
Class 2	-.36	.21	2.93	.70	.46, 1.05
Class 3	-.52*	.23	5.20	.60	.38, .93
Class 4	.04	.33	.01	1.04	.55, 1.97
Class 5	-.19	.68	.08	.83	.22, 3.14

Note: Controls are multiple treatments (omitted from the table); reference categories are in parentheses; *SE* = standard error; *OR* = odds ratio; e^B = exponentiated B; *CI* = confidence interval; Class 1= high socioeconomic status. *N* = 862. *p < .05, **p < .01

affective disorders were two times more likely to use alternative treatments than children with

eating disorders (Table 9). Moreover, families with a socioeconomic status of Class 3 were less

likely to use alternative treatments than families from Class 1.

Exploratory analyses. Interaction terms were entered into Block 3 of the model to

explore possible moderating effects between socioeconomic status and child characteristics.

Interaction terms were computed for age, diagnosis, comorbid disorders, and restricted and

repetitive behaviours, and entered separately into the model for each of the five treatment

outcomes. No significant moderating effects were found.

Summary

These results highlight that child characteristics, including age and comorbid disorders,

were significant predictors of treatment use. Findings indicate that younger children were more

likely to use behavioural treatments and less likely to use pharmacological treatments than older

children. Children diagnosed with a comorbid sleeping disorder were more likely to use

pharmacological treatments and less likely to use physiological treatments when compared to

children with eating disorders. Children with comorbid attention-deficit/affective disorder used

alternative treatments more often and behavioural treatments less often than did children with

eating disorders. With regard to family characteristics, middle class families were likely to use

educational treatments more often and alternative treatments less often when compared to upper

class families.

Discussion

Overview of Results

The purpose of this study was to use secondary data to examine associations between

child characteristics, family characteristics, and parental treatment choice for children diagnosed

with autism spectrum disorders. Hypothesis one predicted that children in early childhood would be more likely to use behavioural, educational, and alternative treatments and less likely to use pharmacological treatments compared to older children. There was partial support for this prediction, with findings indicating that children in middle childhood were more likely to have positive associations with behavioural treatments, while children in early and middle childhood were more likely to have negative associations with pharmacological treatments when compared to older children. However, no associations were found between child age and educational and alternative treatments.

Hypothesis two suggested that children diagnosed with Asperger syndrome would be more likely to have associations with educational and physiological treatments, and less likely to have associations with behavioural treatments compared to children diagnosed with autistic disorder or PDD-NOS. Hypothesis three predicted that the presence of restricted and repetitive behaviours (i.e., self-injurious and self-stimulating behaviours) would be more positively associated with behavioural treatments than comorbid neurological and movement disorders. There were no significant findings to support these predictions.

Hypothesis four was partially supported in that children with sleep disorders had positive associations with pharmacological treatments compared to children with eating disorders. Sleep disorders also had negative associations with physiological treatments. In addition, it was found that children with attention-deficit/affective disorders were more likely to have positive associations with alternative treatments and negative associations with behavioural treatments compared to children with eating disorders; contrary to the prediction that sleep disorders, and attention-deficit/affective disorders compared to eating disorders would have positive associations with behavioural treatments and negative associations with alternative treatments.

Hypothesis five, which predicted that that families with community and financial services would be more likely to use behavioural and alternative treatments and less likely to use pharmacological treatments compared to families with access to hospital-based services, was not supported by this study. Hypothesis six suggested that families with high socioeconomic status would be more likely to use behavioural treatments compared to families with low socioeconomic status, who would be more likely to use educational treatments. This prediction was partially supported in that middle class families (Class 3) were more likely to use educational treatments and less likely to use alternative treatments than upper class families (Class 1).

In the pages that follow, hypotheses will be discussed further in comparison to previous findings in the literature. Emphasis will be on the variables of child age, comorbid disorders, and socioeconomic status as these variables were found to be predictors of treatment use in this study. Discussion on the implications of the current study, strengths and limitations, and directions for future research will follow.

Interpretation of Results

Child characteristics. The results of the current study indicated that child age could be used to predict parental treatment choice. This finding is consistent with previous literature by Goin-Kochel et al. (2007) and Green et al. (2006). Goin-Kochel et al. (2007) found that young children were more exposed to behavioural, educational, and alternative treatments than older children. Older children used more pharmacological treatments than did children in early and middle childhood. Green et al. (2006) found that parents of younger children with a severe ASD diagnosis reported using more treatments and combinations of treatments than parents of older children with a less severe ASD diagnosis. Similarly, Bowker et al. (2010) found that treatment

use was dependent on age and diagnosis.

As demonstrated in this study, younger children were more likely to use behavioural treatments and less likely to use pharmacological treatments compared to older children. However, no associations were found between child's age and educational and alternative treatments. These results suggest that parents of children with ASD opt to try behavioural treatments during middle childhood (i.e., 6-10 years old), when a child is still young but old enough to manage intensive behavioural training. Moreover, parents might try a combination of educational and alternative treatments during early childhood, when an ASD diagnosis is new, and perhaps uncertain to families. As a child grows older, and an ASD diagnosis becomes more stable, parents will try behavioural treatments in order to help "normalize" important aspects of their child's developmental functioning, such as social skills, communication, and adaptive behaviour. It seems likely that that parents resort to pharmacological treatments when they perceive little improvement in their child's functioning. Furthermore, as a child grows older, the rate of pharmacological treatment use most likely increases because many children with ASD develop novel and challenging behaviours during puberty that cannot be managed with child-based behavioural interventions (Goin-Kochel, 2007).

The current study was one of the first to examine the relationship between comorbidity and treatment use in children with autism spectrum disorders. Comorbidity, as a predictor of treatment use, was partially supported in this study. More specifically, consistent with the literature, children with reported comorbid sleep disorders demonstrated positive associations with pharmacological treatments compared to children with reported comorbid eating disorders. Flavia, Flavia , Ivanenko, & Johnson (2010) acknowledge the use of pharmacological treatments for children with sleep disorders, despite the lack of availability of evidence-based options. Thus,

many parents are trying pharmacological treatments for their children with ASD who exhibit sleep disorders, regardless of empirical support. Since the severity of sleep disturbances can vary from night terrors to insomnia, it is possible that fatigued parents become persuaded to find a "quick fix". Although, no significant findings were demonstrated for restricted and repetitive behaviours in the present study, it has been suggested that comorbid sleep disorders precipitate key features of RRBs (Matson & LoVullo, 2008). Perhaps, parents are inadvertently treating symptoms of RRBs with pharmacological interventions, and not necessarily addressing the problem of sleep disturbance.

Sleep disorders were also found to be negatively associated with physiological treatments compared to eating disorders. Some physiological techniques, such as sensory integration, help to relax sensory sensitivity, which is a common feature of an ASD diagnosis. Previous research suggests that sensory sensitivity can result in eating problems when a child refuses to eat certain foods because of taste, texture, or smell (Gillberg & Billstedt, 2000). Therefore, it is expected that more parents will try physiological interventions for eating disorders compared to sleep disorders.

Prior research indicates that children with ASD, who exhibit comorbid attention-deficit/affective disorders, are more likely to use pharmacological and behavioural interventions to deal with the complex symptoms that accompany altered mood and irregular behaviour patterns (Gold, 1993; Reiersen & Todd, 2008). Contrary to the literature, the current study demonstrated that these comorbid disorders did not have positive associations with behavioural and pharmacological treatments, nor did they have negative associations with alternative treatments. In fact, children with reported comorbid attention-deficit /affective disorders had positive associations with alternative treatments and negative associations with behavioural

treatments. The reasons for this are not clear. It has been proposed that parents of children with comorbid eating disorders tend to use more alternative treatments such as diets, therapies, and procedures, many of which are not empirically supported. It is believed that since the origins of most eating disorders remain unknown many parents will turn to alternative methods (Levy & Hyman, 2005). However, despite these findings, it is possible that children on the spectrum with reported comorbid attention-deficit/affective behaviours display an array of challenging symptoms that are not easily treated with behavioural and pharmacological interventions. For example, an ASD child with a comorbid diagnosis of ADHD will likely not receive the same benefits from an intensive behavioural intervention as a child who does not have severe attention problems. It is also likely that families exhaust all evidence-based options and turn to alternative therapies when severe symptoms persist.

There is a limited understanding of the impact of comorbidity on children with ASD and the recommended approach to treatment. Thus, these findings highlight the importance of considering comorbid disorders when discussing treatments for autism spectrum disorders.

Family characteristics. With regard to family characteristics, the literature suggests that upper class families have more access to ASD treatments and services than do lower class families (Mackintosh, Myers, & Goin-Kochel, 2006). Similarly, the current study found that socioeconomic status (based on parental occupation and average household income), was associated with treatment use. It was found that middle class families were more likely to use educational treatments and less likely to use alternative treatments compared to upper class families. Educational treatments, most often offered through school programs such as special education, are accessible for all families with children in the education system. Therefore, it is not surprising that middle class families used more educational treatments than upper class

families. Upper class families tend to have more access to services, support groups, conferences, and professionals, thereby receiving information on new treatments and experimenting with alternative methods. While the use of services was not associated with treatment choice in the present study, it is clear that the affordability of treatments is a key factor in determining treatment choice.

The finding that family services were not associated with treatment use suggests that while most families do have access to services, it has yet to be determined whether those services assist in treatment selection. It may be that families are optimizing the use of services available, but are being exposed to multiple treatment options.

Treatment Implications

This study contributes to the literature by providing a preliminary examination of the associations between ASD characteristics, in particular comorbidity, family characteristics, and treatment use. While it is recognized that there is no "one treatment fits all" approach to treating autism spectrum disorders, few studies have investigated the role of ASD characteristics in treatment decisions (Heflin & Simpson, 1998; Schreibman, 2000). Results of the current study demonstrated that treatment choice does not seem to be influenced by features of an ASD diagnosis, such as diagnostic category and restricted and repetitive behaviours. Furthermore, there does not appear to be an agreed upon approach to the treatment of ASD symptoms. The fact that behavioural interventions are the most empirically supported treatment does not inform the way parents seek treatments. Consistent with previous research, it is evident that the majority of parents are trying a combination of treatments (Bowker, D'Angelo, Hicks, & Wells, 2010; Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006). Combining treatments may be an efficient and essential way of treating such complex symptoms, especially when a

child presents comorbid conditions. Yet little is known about the safety and efficacy of combining multiple treatment approaches. Often, it is not known if a treatment is being used for an ASD diagnosis or for specific features of the diagnosis, such as a comorbid disorder. In the case of comorbid disorders, when pharmacological and alternative methods are pursued, it cannot be certain whether children are displaying symptoms of an ASD diagnosis, comorbid disorder, or the side effects of a treatment or treatment interaction. The non-systematic use of multiple treatments adds to the complexities of the disorders, often leading parents to exhaust all possible treatment options. In addition, combinations of treatments further complicate the assessment of efficacy of individual treatment outcomes.

Most children with ASD exhibit some form of comorbid disorder. Findings from the current study suggest that parents are not considering features of the diagnosis when selecting treatments for ASD. It seems as though the goal of ASD treatment for many families is to "fix" the ASD diagnosis, rather than treat the specific symptoms. As mentioned previously, it is not known whether treatments are targeting symptoms of the ASD diagnosis or symptoms of the comorbid condition, as many of these symptoms tend to overlap. Therefore, the issue of separate diagnosis becomes relevant in discussion of comorbid disorders. Debate exists over whether certain comorbid disorders should be viewed as core features of an ASD diagnosis or classified as a separate disorder (AACAP, 1999). For example, the DSM-IV states that ASD and ADHD should not be diagnosed as co-occurring because of overlapping features. It becomes difficult for parents, and even professionals, to determine whether a symptom such as "hyperactivity" is the result of the ASD or the ADHD. Accordingly, the issue of comorbidity in autism spectrum disorders needs to be studied in further detail.

It is obvious that parents of children with ASD face a complex path of dealing with

symptoms, treatment options, and unanswered questions. Choice of treatment is influenced by a

multitude of factors, many of which do not recognize the individual needs of the child.

Essentially, choice of treatment is not a choice, but an attempt for parents to make sense of an

ambiguous childhood disorder. Through parental report, it is clear that parents are aware of the

symptoms their child displays, yet they are not necessarily selecting treatments based on their

child's characteristics. Conceivably, many parents become overwhelmed by the extensive

choice of treatment options. Furthermore, parents may feel self-blame for their child's condition,

seeking out all possible treatment options as a coping strategy. It is important for parents to

understand that the persistence of symptoms is a failure of the treatment approach, and not the

fault of the family or child.

Evidently, there is a great need for professional support among parents of children with

ASD. Parents and physicians must work together to understand the individual needs of the child

and create a treatment plan that is attuned with the child's own abilities. Rather than setting

short-term goals, placing greater demands on the child, treatments should be strategized to work

with the child's individual developmental pace. Moreover, parents need to become better

educated in the prognosis of the disorder and direction of treatment.

Strengths and Limitations

The main objective of the present study was to examine secondary data on child

characteristics, family characteristics, and treatment use for children diagnosed with autism

spectrum disorders. The survey questions were designed to give parents the opportunity to

provide information in their own words rather than responding to a series of checklists. One of

the limitations to this approach was that the categorization of child characteristics and treatments

used often required further research to investigate which characteristics and/or treatments the

parent was describing. Parents varied in terms of the sophistication with which they described their child's behaviours and symptoms. Some parents used the actual medical term to describe their child's comorbid condition (e.g., Hirschsprung's disease), while others defined the symptoms in words (e.g., "constipated due to eating disorder").

It is believed that parents may have under-reported treatment use, including special education and specific skill-based strategies, such as visual schedules (Bowker, D'Angelo, Hicks, & Wells, 2010). This gives insight into how most parents view treatment; seeing 'treatment' as something distinct from educational programming or the use of a specific behavioural strategy. Moreover, it is believed that parental reports of child characteristics, including comorbid disorders, may have been 'over-reported' in that parents indicated a secondary condition whether or not the child received a medical diagnosis, validating that condition as a legitimate medical condition. Unlike a physician's report, parental reports provide a detailed overview of an individual child's most prevalent characteristics based on the perspective of parents, regardless of clinical diagnosis. This strength of parental reports contributes to the understanding of an ASD diagnosis by describing observed characteristics of a child in natural settings.

The use of open-ended responses also limited the degree to which answers could be categorized. For the purposes of analyses, specific categories were collapsed into broad categories, not taking into account the degree of a comorbid disorder (e.g., severity of a sleeping disorder) or the exact function of a treatment. Future research should concentrate on specific comorbid conditions and /or treatments.

One of the advantages, however, of open-ended questions was that answers were unscripted, allowing for responses that may have not been anticipated, such as an extensive list of treatments and child characteristics. In addition, participants were not recruited for this study,

such that responses were provided by parents who voluntarily completed the survey on autism-related websites, out of interest. As a result, a large international sample was collected, providing researchers with a preliminary investigation of cross-cultural differences in ASD. Exploratory analyses demonstrated that service availability differs depending on geographical location, with financial services being more available in Europe, and community services more often used in Canada, when compared to the United States and Australia/New Zealand. While these results should be interpreted with caution because of unequal group sizes (the majority of participants were from the United States), it is an interesting result nonetheless that deserves further attention.

This study was also the first to examine the influence of child and family characteristics on treatment choice for autism spectrum disorders. Information was collected not only on characteristics of the child's diagnosis, but on characteristics of their family environment that may have had an influence on the availability and affordability of treatment options. The use of a large and rich data set is difficult to obtain in this specific area of research on special populations.

Future Directions

Treatment choices for children with autism spectrum disorders are determined by a number of factors. The individual characteristics of a child, such as features of the diagnosis and comorbidities, play a role in treatment choice. However, the extent to which these characteristics influence treatment choice is still unknown. This study demonstrated that while certain characteristics tend to be associated with specific treatment types, it is difficult to determine whether treatments are being used to target these problematic features or to "remedy" the diagnosis as a whole. The lack of knowledge surrounding an ASD diagnosis and the large

complexities associated with its features make an understanding of prognosis disconcerting. Further research examining the individual characteristics of children with ASD is needed in order to discriminate among what treatment(s) work for a specific child.

The findings from this study highlight the importance of considering comorbid disorders when selecting treatments for autism spectrum disorders. Evidently, there is a limited understanding of the impact of comorbidity on children with ASD. Often, symptoms of a comorbid disorder become lost in the complexities of the diagnosis. There is a great need for further research on the issue of comorbidity in ASD, specifically addressing the problem of overlapping features and separate diagnosis. Research in this area will assist parents and professionals in recognizing the symptoms a child is exhibiting and targeting the symptoms with appropriate treatment strategies.

To further understand the influence of child characteristics on treatment use and outcome, it is important to collect data on symptoms from both parents and professionals. Although, parental reports have proven to be beneficial in describing a child's symptoms and behaviours, it is possible that parents "over-report" or "under-report" certain features. Therefore, in addition to parental reports, future studies should collect clinical reports, which document the child's specific conditions as diagnosed by a professional.

The present study demonstrated that socioeconomic status influences the types of treatments parents are using for their children with ASD, over and above that of child characteristics. Hence, the affordability of treatments influences the selection process. This finding requires further examination as this was a preliminary step in understanding the role of socioeconomic status in treating children with ASD. Since it is acknowledged that many factors influence treatment choice, demographics such as socioeconomic status, cultural background,

and geographical location need to be addressed in greater detail when considering research with an ASD population. Although the current study found significant results when comparing the use of treatment across socioeconomic class levels, the majority of respondents were categorized in the middle to upper class levels. Research needs to expand to lower income families who may not have the opportunities to participate in autism research, in order to collect a more representative sample and a grasp a greater understanding of ASD children and their families.

An interesting aspect of this study was the abundant amount of information collected from parents describing their environment and resources. A large international sample allowed researchers to make preliminary comparisons based on geographical location. While the majority of participants were identified as Caucasian situated in the United States, it would be interesting to develop future research on ASD treatments in a cross-cultural context. Little is known about ASD within a cultural context. The ways in which cultures manage developmental disorders are intriguing and suggest that ASDs are not universally understood. For example, autism was not legally recognized as a developmental disorder in India until 1999 (Daley, 2002). Furthermore, Korean families of developmentally disabled children, often suffer from shame, guilt, and depression, believing that the disability is a punishment for a wrong-doing committed in their past (Kim-Kypnow, 2001). Parents' interpretation of symptoms may influence their choice of treatment or their decision to engage in treatment at all (Mandell & Novak, 2005).

In addition, studies on developmental disabilities have demonstrated that in cross-cultural contexts, views of "normal" functioning often differ from the criteria of normalcy on which intervention and treatment decisions are based in Western culture (Wilder et al., 2004). For example, in Asian culture, lack of eye contact, non-verbal gestures, indirect interaction and communication are socialized behaviours and may be misinterpreted as an ASD (Wilder et al.,

2004). Despite these problematic interpretations, research tends to focus on immigrant groups and the prevalence of autistic symptoms within a given culture. A limited understanding of cultural differences may further alienate immigrant families and can cause low treatment adherence if interventions are inconsistent with a family's cultural beliefs. Future research needs to overcome the cultural barriers and broaden the scope of autism research in order to address the individual needs of children with autism spectrum disorders.

The use of services, while not significant in the current study, warrants further attention and proper investigation. The difficulty in researching government funded services suggests that these programs are not readily available to families. Moreover, the fact that most services are not funded for older children with ASD may explain why parents opt to try more pharmacological treatments for their older children.

Conclusion

The current study examined the influence of child and family characteristics on parental treatment choice for children diagnosed with autism spectrum disorders. Findings indicated that parents are using multiple treatment combinations to target features of the diagnosis. In addition, age of the child and comorbid disorders have more associations with specific treatment use than any other feature of the diagnosis. Socio-demographic factors, such as socioeconomic status, also appear to contribute to the treatment selection process. The individual needs of the child, parents' interpretation of symptoms, and the affordability and availability of services and treatments, have been shown to play a significant role in treatment use and outcome, and therefore, warrant further investigation.

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Appendix A

Survey

By completing this survey it is assumed that you have given your consent for the researchers to use the information as required. The survey is completely anonymous and under no circumstances will you be identified by name or have your personal information shared. The information collected will only be used for research purposes. Please omit any questions which make you feel uncomfortable and/or you would rather not answer.

When this survey refers to "your child" or "your son/daughter" we are referring to the child diagnosed with an autism spectrum disorder (ASD), unless otherwise specified. Should you have two or more children with an ASD it would be greatly appreciated if you could fill out one survey for each child. Thank you very much for your participation. For each question please **circle** the response(s) that best apply.

General Information

1. What is the sex of your child?

    male   female

2. What is his/her birth date (year/month/day)? _____

3. How many children do you have (including the child(ren) with ASD)?

    1   2   3   4   5   +5

4.If you have more than one child, please answer the following:

	SEX	DATE OF BIRTH
Sibling #1	M OR F	
Sibling #2	M OR F	

Sibling #3	M OR F	
Sibling #4	M OR F	

5. What is the father's birth date (year/month/day)? _____

6. What is the mother's birth date (year/month/day)? _____

7. Where do you currently reside?

  (please indicate City and Province/State only) _____

8. What services are available for you to access?

  a) community services

  b) financial assistance

  c) hospital-based services

  d) occupational therapy

  e) speech therapy

  f) physical therapy

  g) special education

  h) other (please specify) _____

Diagnosis

9. How old was your child when he/she was diagnosed? _____

10. What diagnosis did your child receive?

  a) PDD-NOS

  b) Autistic disorder

  c) Asperger's disorder

d) Other (please specify)_____

11. What instruments were used to diagnose your son/daughter? _____

_____

12. If the diagnosis was based (at least in part) on clinical observation, how long was your child observed for (round to the closest full hour)?

    a) 5 or less hours

    b) 6-10hrs

    c) 11-15hrs

    d) 16-20hrs

    e) 21 or more hours

13. Has your child's diagnosis changed since the original diagnosis?

    yes   no (if no, skip to question 15)

14. If yes, what is their current diagnosis?

    a) PDD-NOS

    b) Autistic disorder

    c) Asperger's disorder

    d) Other (please specify) _____

Family History

15. Are there any other cases of ASDs in your family?

    yes   no (if no, skip to question 17)

16. If yes, what is the relation of that person to your son/daughter?

a) mother

b) father

c) sibling

d) grandmother

e) grandfather

f) first cousin

g) second cousin

h) aunt

i) uncle

j) other (please specify) _____

17. Are there any cases of other mental disorders in your family (either immediate or extended)?

yes   no (if no, skip to question 18)

18. If yes, please indicate the disorder, along with the affected individual's relationship to your

child (including which side of the family he/she is on) in the following chart:

Relationship to child	Mother's (Mo) or Father's (Fa) side of the family (circle Mo or Fa)	Disorder(s)
	Mo OR Fa	
	Mo OR Fa	
	Mo OR Fa	
	Mo OR Fa	
	Mo OR Fa	

19. What is the mother's occupation? _____

20. What is the father's occupation? _____

21. What is the household's average annual income?

    a) less than $20,000

    b) 20,000 to 40,000

c) 40,000 to 60,000

    d) 60,000 to 80,000

    e) above 80,000

22. What cultural background does your family come from? (e.g. Italian, Asian, Irish etc.)

_____

Medical History

23. Were there any complications during the pregnancy or delivery of your child? (e.g. breech

birth, excessive bleeding)   yes   no (if no, skip to question 24).

24. If yes, what were the complications? _____

25. At what week of gestation was your child born? _____

26. Does your child display any self-injurious behaviours?

        yes   no (if no, skip to question 31)

27. If yes, what are they? _____

28. When do they occur? (please select as many that apply)

    a) when frustrated

    b) unprovoked

    c) when excited

    d) when under stimulated

    c) randomly

    e) other (please specify)_____

29. How many times per day do the behaviour(s) occur?

    a) less than 1

    b) 1-5

    c) 6-10

    d) 11-15

    e) 16-20

    f) over 20

30. How severe are these behaviours (state, for example, if they leave bruises, marks, is

hospitalization required, have they caused permanent physical damage, etc.)? _____

_____

31. Does your child engage in any self-stimulatory behaviour?

        yes   no (if no, skip to question 35)

32. If yes, what are the behaviours that your child engages in? For each behaviour please also

indicate which sensory mechanism is being stimulated. In other words, is it a verbal, visual, oral,

tactile (feel), gross motor, movement/motion, or olfactory (smell) stimulatory behaviour?

_____

_____

33. When do the behaviour(s) occur? (please select as many that apply)

    a) when frustrated

    b) unprovoked

    c) when excited

    d) when under stimulated

    c) randomly

    d) other (please specify)_____

34. How many times per day do the behaviour(s) occur?

    a) less than 1

    b) 1-5

    c) 6-10

    d) 11-15

    e) 16-20

    f) over 20

35. What form of communication does your child use?

    a) verbal

    b) sign

    c) picture exchange

    d) other (please specify) _____

36. Does your daughter/son have any allergies or sensitivities?

    yes   no (if no, skip to question 38)

37. If so, what are they? _____

_____

38. Does your daughter/son have any other medical conditions or problems?

    yes   no (if no, skip to question 40)

39. If yes, what are they? _____

40. Does your child display any sleep disorders?

       yes   no (if no, skip to question 42)

41. If yes, what kinds of sleep problems does your child display (please circle all that apply)?

    a) apnea

    b) awakenings

    c) night terrors

    d) irregular sleeping times

    e) other (please specify) _____

42. Has you daughter/son ever stayed overnight at a hospital?

       yes   no (if no, skip to question 45)

43. If yes, how many times? 1   2   3   4   5   6   +7

44. For what reason(s) was the hospital stay necessary? _____

45. Has your child ever been taken to an emergency room?

       yes   no (if no, skip to question 48)

46. If so, how many times?   1   2   3   4   5   6   +7

47. For what reason(s) did your child go to the emergency room? _____

48. Has your child ever undergone a neurological exam? (for example, MRI, CAT etc.)

        yes   no (if no skip to question 50)

49. If yes, at what age was the test taken, and what were the results?_____

_____

50. Has your child ever undergone an IQ assessment/intelligence test?

        yes   no (if no skip to question 50)

51. If so at what age, and what were the results? _____

_____

52. In your opinion, what is the most salient feature of the disorder in your son/daughter? In other words, what is the single most ASD characteristic that your child typifies (circle the one that best applies)?

    a) self-stimulatory behaviours

    b) self-injurious behaviours

    c) echolalia

    d) fixations

    e) rigidity/inflexibility

    f) lack of social connectedness

    g) other (please specify) _____

Treatment

53. Has your child ever undergone any type of treatment for ASD?

yes   no (if no, skip to the end of the survey)

54. Please complete the following chart indicating what treatment(s) is your child

currently involved in and when it started?

Treatment	Date started (month/year)

55. If using behaviour modification, how many hours per week does the child undergo?

a) under 15

b) 15-20

c) 21-25

d) 26-30

e) 31-35

f) 36-40

g) over 40

56. Have you witnessed any behavioural or physical changes in your child that you attribute to

the behaviour modification?

yes   no (if no, skip to question 58)

57. If yes, what areas of functioning have been improved? _____

_____

58. Is your son/daughter currently on any medication?

yes   no (if no, skip to question 62)

59. If yes, what is it, and what is the dosage? _____

_____

60. Have you witnessed any behavioural, functional, or physical changes in your child that you

attribute to the medication?

yes   no (if no, skip to question 62)

61. What were these changes? _____

_____

62. Is your son/daughter currently on any special diets?

yes   no (if no, skip to question 66)

63. If yes, what kind of diet is your child on? _____

_____

64. Have you witnessed any behavioural or physical changes in your child that you attribute to

the diet?   yes   no (if no, skip to question 66)

65. What were these changes? _____

_____

66. How often does the child "cheat" on their diet?

a) never

b) 1-10 times a year

c) 1-10 times a month

d) 1-10 times a week

e) more than once a day

67. Have you tried any other treatments in the past?

yes   no (if no, skip to question 69)

68. If yes, please complete the following chart indicating what the treatments were, the length of

time they were used, and why were they discontinued?

Treatment	Date begun (month/year)	Date ended (month/year)	Reason for discontinuing treatment

69. In your opinion, what area of the child's functioning has been most improved by the

treatments used, both past and present?

a) cognitive

b) behavioural

c) attentional

d) linguistic

e) physical

f) social connectedness

g) other (please specify) _____

70. In your opinion, what area of your child's functioning has been <u>least improved</u> through the treatments you have used, both past and present?

    a) cognitive

    b) behavioural

    c) attentional

    d) linguistic

    e) physical

    f) social connectedness

    g) other (please specify) _____

71. What advice would you give to a parent whose child has recently been diagnosed with an autism spectrum disorder?

72. Do you have any other comments that you would like to add?

Thank you for your participation in this study. It is hoped that this research will add to the body of autism literature a complete and accurate representation of the autistic population. In doing so we hope to stimulate further research in the area and at the same time gain a better idea of the disorder itself. As soon as the results have been collected, we will release them to your organization, or if you would like a copy please contact us.

If you have any other comments, questions, or concerns please feel free to contact:

Kerry Wells at: 613-520-2600 or

Thank you again for you time and participation.