Support Groups for Parents of Children with Autism Spectrum Disorders: Predictors and

Effects of Involvement

by

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Abstract

Support groups are an effective source of support in a number of populations (e.g., Beaudoin & Tao, 2007; Preyde & Ardal, 2003; Singer, et al., 1999). Parents of children with autism spectrum disorders (ASD) are a particularly stressed group who can benefit from support (Blacher & McIntyre, 2006). These studies investigated: 1) predictors of participation in support groups for parents of children with ASD and 2) the effects of participation in an online support group for these parents.

One hundred seventy-eight parents completed a series of online questionnaires measuring their beliefs about support groups and ASD, coping style, social support, mood, parenting stress, and their child's autistic symptoms and daily functioning. Parents who were currently using parent support groups (PSGs) reported using more adaptive coping strategies than both parents who had never used PSGs and parents who had used PSGs in the past. Parents who had used PSGs in the past reported that they did not find the groups as beneficial as parents who were currently using them, and parents who had never participated in PSGs reported several issues with accessibility that made it difficult to participate in PSGs.

A smaller group of parents ($n = 36$), who had participated in the first study, participated in an online support group designed for this study. An additional group of parents ($n = 25$), who had also completed the first study, served as a no-treatment control group. The parents in these two groups completed a subset of the questionnaires used in the first study following the 4-month support group, so that changes in mood, anxiety, parenting stress, and positive perceptions could be documented over time. No significant

differences between the groups and across time were found. However, parents who participated in the group reported being satisfied with the support they received and finding the group helpful.

Overall, the results of these studies suggest that interventions for parents of children with ASD need to be individualized and focused on the needs of the parents. Further research is required to investigate the efficacy of online support groups for parents of children with ASD.

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Chapter 1: General Introduction

All parents experience stressors related to parenting and parents differ in their abilities and opportunities to adapt to these challenges (Deater-Deckard, 2004). Parents of children with disabilities are faced with even more stressors than parents of typically developing children and they experience more parenting stress (Floyd & Gallagher, 1997; Hastings, 2002). In particular, research shows that parents of children with autism spectrum disorders (ASD) experience more parenting stress and mental health problems than parents of children with other disabilities (e.g., Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005). There are many reasons for the increased parenting stress in this population, and it is likely that the nature of the child's symptoms and the difficulty in obtaining timely, effective interventions play a role (see Mandell & Salzer, 2007 for an overview). Research on parents of children with disabilities and serious health problems shows that participation in support groups can provide a sense of belonging and is associated with reduced stress (Kerr & McIntosh, 2000; Preyde & Ardal, 2003; Singer, et al., 1999). Support groups are a relatively cost-effective and easily-implemented intervention in order to support the needs of these families (Smith, Gabard, Dale, & Drucker, 1994). Despite this fact, very little research has examined the benefits of support groups for parents of children with ASD or the variables that distinguish parents who choose to participate in support groups from those who do not.

Stress, Coping, and Well-Being

The term stress is a complex construct with several meanings dependent on context. There are three general definitions of stress described within the literature

(Monat, Lazarus, & Reevy, 2007): 1) as a stimulus that elicits a response (i.e., a stressor or strain), 2) as a physiological response to a stimulus, and 3) as the interactive process between an external stimulus, an individual's reaction to it and the intervening factors (e.g., perceptions, previous experiences, pre-existing stressors). According to the latter definition, which will be used for the current study, an individual experiences stress when he perceives that he is not capable of coping with the stressors that have been presented. Coping is another complicated concept that is often discussed within the context of stress and generally refers to the process of managing demands that are associated with stress (Monat et al., 2007). Research has found that experiencing stress is associated with poor physical and psychological health, and specifically increases in symptoms of depression (Jones & Bright, 2007). In the literature and in the current study, a distinction is made between reported symptoms of depression and experiencing a Mood Disorder or Depression, given that endorsing some symptoms of depression on a screening checklist is not indicative of a disorder.

In contrast to stress, is the construct of well-being. In general, well-being refers to experiencing good physical and psychological health, or the ability to cope with stressors (Cohen & Wills, 1985). Efforts to define well-being theoretically and empirically have included the following constructs: self-acceptance, environmental mastery, positive relations, purpose in life, personal growth, and autonomy (Ryff & Keyes, 1995). Within the literature on parents, the term well-being has been used to refer to a lack of problems with mood, anxiety, or stress, and more recently the definition has come to include positive perceptions of the effect of the child. In the literature and the current study, these perceptions of the positive effects of the child on the parent are referred to as "positive

perceptions", and include personal growth or a sense of purpose, which are conceptualized as strategies that help a family cope or adapt to their situation (Hastings & Taunt, 2002). Research has found that parents report experiencing positive perceptions at the same time as they experience stress and negative perceptions (Hastings & Taunt, 2002), suggesting that experiencing high parenting stress, does not preclude one from reporting positive perceptions of one's child. Positive perceptions and negative perceptions (i.e., stress, symptoms of depression) have become common measures of outcome in the research literature examining the adaptation of parents of children with disabilities (Blacher & Baker, 2007; Hassall & Rose, 2005) and are often used as measures of the overall construct of well-being. For the purposes of the current study, the term well-being will refer to psychological health, which includes symptoms of depression and anxiety, stress, and positive perceptions.

Parenting Stress

Theories of parenting stress have generally used the definition of stress that refers to the interactive process between the stressor and one's reactions and perceptions of it. One of the predominant theories of parenting stress refers to the interaction of three components: stressors related to the parent, stressors related to the child's behaviour, and stressors related to the relationship between the parent and the child (Abidin, 1990; 1992; 1995). Elevations in all three areas are related to high overall parenting stress and problems with parenting and child development. The theory is ultimately bi-directional with parents' well-being and parenting style affecting the child and the child's behaviour affecting the parent (Deater-Deckard, 2004). For example, a parent who is not coping well with stress may react with angry yelling when the child does not complete their

chores, which can elicit yelling and outbursts from the child. This outburst from the child can serve as evidence, from the parent's perspective, that the child and parent's relationship is strained.

A complementary theory of parenting stress, the Daily Hassles Theory (Crnic & Low, 2002 as cited in Deater-Deckard, 2004), incorporates aspects of other theories of stress, and suggests that the experience of stressors related to parenting is normal or typical; however, parenting stress can become problematic if parents are unable to adapt and to learn to cope with the everyday stressors of child rearing. Although daily hassles are not major stressors, their build-up can lead to the experience of distress and eventually the onset of psychological disorder in some parents. One variable that researchers have identified as particularly important in distinguishing between daily hassles as annoyances and daily hassles as stressors is the parents' perceptions (Deater-Deckard, 2004). If the parent attributes a child's misbehaviour to the child's personality, the parent is more likely to tolerate the annoyance than if the parent perceives the misbehaviour as a sign of his or her own incompetence as a parent or an indicator of the weak relationship between the parent and child. In the latter case the parent's perceptions and lack of adaptation are more likely to lead to parenting stress (Deater-Deckard, 2004). In circumstances where a child engages in frequent problem behaviour (e.g., children with behaviour disorders or developmental disabilities) the parent may experience chronic stress, which requires different methods of adjustment or coping than the experience of a specific stressful event (Pearlin, Lieberman, Menagan, & Mullin, 1981).

Stress in Parents of Children with Intellectual Disabilities

Parents of children with intellectual disabilities experience higher levels of parenting stress than parents of children without disabilities (Minnes, 1998). As such, models of parenting stress and coping have been developed and researched with this population, and they generally focus on examining family adaptation as opposed to family pathology (Hassall & Rose, 2005). For example, the Double ABCX model (McCubbin & Patterson, 1983) examines the role of (A) the stressor (i.e., child's problem behaviour), (B) the family's resources for coping with the stressor, and (C) the family's perceptions of the stressor and how they interact to determine (X) how the family adapts to the stressor. The "double" aspect of the model refers to the fact that families of children with disabilities are re-exposed to stressors frequently and often experience a pile-up of stressors (or chronic stress), which leads to an ongoing interaction between the three factors over time. The Double ABCX model was developed to represent the interactive process of parenting a child with a disability that includes both the initial onset of the stressor (i.e., child's diagnosis) and dealing with ongoing stressors.

One of the main explanations for the difference in parenting stress between parents of children with intellectual disabilities and parents of children without disabilities is the presence of behaviour problems (Hastings, 2002). Children with intellectual disabilities tend to present with more difficult behaviour than children without intellectual disabilities (Hastings, 2002). In addition, some children with disabilities, particularly those with ASD, lack interest in social relationships, which makes it more difficult for parents to develop a positive relationship with their child. These differences contribute to increased parenting stress and poorer well-being for

parents of children with disabilities, in comparison to parents of children without disabilities (Floyd & Gallagher, 1997; Hauser-Cram et al., 2001). Research shows that parents of children with ASD report more parenting stress and mental health problems than parents of children with other disabilities (Blacher & McIntyre, 2006; Eisenhower et al., 2005; Sharpley, Bitsika, & Ephrimidis, 1997). The reasons for this difference are not completely understood, but they may be related to some of the common behaviours associated with ASD such as lack of social interest, self-stimulatory behaviour, and self-injurious behaviour, which can all be very difficult for parents to cope with. Regardless, the research evidence suggests that parents of children with ASD are a particularly distressed group that may require support to cope with the stressors associated with their child's disability.

Autism Spectrum Disorders

The term "Autism Spectrum Disorder" (ASD) has been adopted in the research and clinical literature to refer to a group of neurodevelopmental disorders also called the Pervasive Developmental Disorders (PDD), which include Autistic Disorder (i.e., Autism), Asperger's Syndrome, and PDD-Not Otherwise Specified (PDD-NOS). These disorders are characterized by varying degrees of deficit in two broad domains: social communication and restrictive interests/ repetitive behaviours (American Psychiatric Association, 2000). The term ASD was proposed by Wing (1992) following the decision to use the term PDD in the Diagnostic and Statistical Manual of Mental Disorders 3rd Edition-Revised (DSM-III-R, American Psychiatric Association, 1987) and International Classification of Diseases10[th] Edition (ICD-10, World Health Organization, 1992). Since this time, a shift in the clinical perspective of these disorders has involved categorizing

the severity of symptoms as falling on a continuum or spectrum, with Asperger's Syndrome representing the higher functioning end, Autistic Disorder on the lower functioning end, and PDD-NOS falling in the middle. In fact, the proposed revision to the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-V), which outlines the criteria for psychological and psychiatric diagnoses in North America, has adopted the term ASD to refer to all of these disorders and includes the following broad diagnostic criteria: 1) deficits in social communication and interactions, 2) restrictive, repetitive patterns of behaviour, interests, and activities, and 3) symptoms must be present in early childhood (American Psychiatric Association, 2010). Consistent with the literature, this study uses the term ASD to refer to this group of disorders.

Typically, children are diagnosed with ASD in the preschool years, although higher functioning children are often not diagnosed until the primary grades (Ouellette-Kuntz et al., 2009). The prevalence of ASD has risen in North America over the last decade, and a recent study in the United States estimated the rate of ASD at 110 per 10,000 children between the ages of 3-18 years (Kogan et al., 2009). Many of these children with ASD receive specialized, intensive interventions, some of which are designed specifically for young children; however, in some jurisdictions, including Ontario, there are very long (i.e., 2-3 years) wait-lists for services and services may last only a year or two. Parents often face frustrations in advocating for life-long services for their children with ASD.

Intellectual Disability

Intellectual Disability, also called Developmental Disability or Mental Retardation, refers to significant limitations in both general intellectual functioning and

adaptive functioning with an onset prior to the age of 18 years (American Psychiatric Association, 2000). Adaptive functioning or adaptive behaviour refers to an individual's daily living skills, typically including communication, social, and self-care skills. Although not part of the diagnostic criteria, when compared to their typically developing peers, individuals with intellectual disability present with more behaviour problems (Baker, McIntyre, Blacher, Crnic, Edelbrock, & Low, 2003), which may also be referred to as maladaptive behaviour. Typically, children are diagnosed with intellectual disability in the preschool and early childhood years. The prevalence of diagnosed intellectual disability is about 1-2% in the general population worldwide; however, different estimates are often obtained depending on the source (i.e., government agencies or research studies; Australian Institute of Health and Welfare, 2004).

Although intellectual disabilities are also sometimes referred to as developmental disabilities, the term developmental disability has been used clinically to refer to a broader group of individuals who have delayed development in some areas, but do not necessarily meet criteria for an intellectual disability. The term developmental disability may include individuals with physical or mobility problems, deficits in speech/language abilities, or ASDs among other presenting problems. Intellectual disability often co-occurs with ASD; there are discrepancies in the reported rates of comorbidity, but it is estimated that about 50-70% of individuals with ASD also have an intellectual disability (Matson & Shoemaker, 2009). Although not all people with ASD meet the diagnostic criteria for intellectual disability, people with ASD are often included in studies of people with intellectual or developmental disabilities. This overlap and the co-morbidity of ASD and intellectual disability means that the research literature related to parents of children

with intellectual disability is likely to shed some light on the experiences of parents of children with ASD, although in some areas, differences exist between the two groups.

Support Groups

Healthcare professionals can help people cope with stress in many ways. Support groups have become a commonly used intervention for a number of client populations, with the cost-effectiveness and low-resource demand being identified as strengths of the approach. Support groups overlap with many of the aspects of self-help groups and sometimes the terms are used interchangeably (Smith et al., 1994). Self-help groups, such as Alcoholics Anonymous, often focus on developing a system of mutual support that serves to promote individual change. Self-help groups are typically considered therapeutic with a focus on changing participants' behaviour and maintaining these changes in behaviour (e.g., reducing problem eating, smoking cessation). In comparison, support groups often focus on developing relationships between participants, while also providing the opportunity to share information and resources; the goal of support groups is typically not therapeutic change. Within the context of the current study, support groups refer to groups in which the participants are encouraged to engage in supportive relationships with each other, with or without the moderation of a helping professional (e.g., psychologist, social worker, counsellor). The goal of these groups is generally to introduce other members as positive role models, share information about resources and coping, and provide a shared understanding and sense of belonging.

Research that has investigated the effects of support groups on the psychological well-being of participants has found that participation in these groups is associated with decreased negative mood and stress (Beaudoin & Tao, 2007; Kerr & McIntosh, 2000;

Preyde & Ardal, 2003; Stevens & Duttlinger, 1998). In addition, changes in perceptions and attitudes are associated with participation in support groups, such that participants report being able to cope better with the same stressors (Silverman-Dresner, 1990; Singer et al., 1999; Soloman, Pistrang, & Barker, 2001). It is commonly reported, clinically and in the research literature, that the sense of belonging and sense of community that participants feel once connected with the group is hugely important (e.g., Singer et al., 1999). Despite the benefits of participating in support groups, research shows that very few people participate in the groups that are available to them (Bitsika & Sharpley, 1999; Fontana, Fleischman, McCarton, Meltzer, & Ruff, 1988; Plass & Koch, 2001; Smith et al., 1994). Little research has been done to investigate why people participate or do not participate in support groups (for an exception see Grande, Myers, & Sutton, 2006), although the reasons are likely to be important for understanding how best to support these individuals.

Parent Support Groups

In general, parent support groups (PSGs) focus on providing mutual support through parent-led or counseling professional-facilitated groups. Research shows that parents prefer when PSGs focus on support, such as meeting other parents and sharing feelings, rather than information sharing (Smith et al., 1994). It has been suggested that parents of children with disabilities are uniquely qualified to support each other (Kerr & McIntosh, 2000), and in fact, parents of children with ASD report that their most common source of information and support is other parents (MacIntosh, Myers, & Goin-Kochel, 2005). Parents of children with disabilities who belong to mutual support groups report that the main benefits of PSG participation are a sense of belonging, sense of

advocacy, and change in perceptions of their child with a disability (Solomon et al., 2001). Because these PSGs focus on mutual support, there is often not a defined curriculum or goal, beyond providing support, and the focus of each session tends to be the topic presented by participants at the session or determined at the previous session.

Support Groups for Parents of Children with ASD

Previous research on support groups for parents of children with disabilities shows that participation in PSGs is associated with less stress, less negative mood (Kerr & McIntosh, 2000; Preyde & Ardal, 2003), and more positive perceptions (Singer et al., 1999). In a study examining the needs reported by parents of children with intellectual disabilities, Douma, Dekker, and Koot (2006) found that parents reported a need for social and informational support, which is a common goal of PSGs. This information suggests that PSGs are an intervention that is worth evaluating in the population of parents of children with ASD; however, to date there is little published research with this population.

To date, one quantitative study investigated predictors of support group use for parents of children with ASD (Mandell & Salzer, 2007). This study was limited in the types of predictors that were investigated, which were family demographic variables and child symptoms (See Chapter 2 for more information). Studies with other populations show that characteristics of the potential participant (e.g., beliefs, coping style, social support, and mood; Grande et al., 2006) and aspects of the group (e.g., accessibility; Smith et al., 1994) are important predictors of support group use. One of the aims of this project was to investigate the role of many of these variables in differentiating between parents who are participating in PSGs and those who are not.

The research that has examined outcomes of support groups for parents of children with ASD is limited to qualitative and exploratory methods (Bitsika & Sharpley, 1999; Bitsika & Sharpley, 2000; Carter, 2009; further discussion in Chapter 3). Bitsika and Sharpley (1999) have found that parents who participated in a PSG reported experiencing less distress and more positive self-concept over the course of the group, and parents who participated reported that the support was valuable. However, these parents of children with ASD also reported that they required more specific stress management strategies, rather than the general support they received from participating in the PSG. In another study, with 11 participants, Bitsika and Sharpley (2000) focused on teaching parents specific biofeedback-based strategies for managing their stress, including progressive muscle relaxation, deep abdominal breathing, and guided imagery, and they found no difference in parent-reported stress or mood symptoms from pre- to post-group. However, again the parents reported enjoying the group and finding it helpful because they learned stress management strategies and were able to connect with other parents. Finally, in a qualitative study of the effects of online support for parents of children with ASD (including PSGs and other types of support), Carter (2009) concluded that this type of support has many potential benefits, such as increasing advocacy, providing a sense of connectedness or social support, and empowerment. All of these studies recommended further research examining outcomes for parents of children with ASD participating in support groups.

Summary and Objectives

Parents of children with ASD report experiencing poorer psychological well-being, than parents of children with other disabilities and without disabilities (Blacher &

McIntyre, 2006; Eisenhower et al., 2005; Sharpley et al., 1997). The prevalence of ASD is approximately 1% of children (Kogan et al., 2009), thus many families are affected by this disorder. Support groups are an effective method of providing support in other populations, including parents of children with disabilities (e.g., Beaudoin & Tao, 2007; Kerr & McIntosh, 2000; Preyde & Ardal, 2003; Stevens & Duttlinger, 1998), and the limited research with parents of children with ASD suggests that PSGs may be a helpful intervention (Bitsika & Sharpley, 1999; Bitsika & Sharpley, 2000; Carter, 2009). However, there have been difficulties in recruiting and retaining participants in studies of PSG use (Bitsika & Sharpley, 1999), and only one study has investigated predictors of PSG use among parents of children with ASD (Mandell & Salzer, 2007). The current project focused on two main objectives: 1) to evaluate the differences between parents of children with ASD who use PSGs and those who do not use PSGs and 2) to examine changes in psychological well-being (including parenting stress, symptoms of depression and anxiety, and positive perceptions) in parents of children with ASD who participated in an online parent support group. These results were expected to be helpful in guiding future research and clinical recommendations for working with families of children with ASD.

Chapter 2: Who Participates in Support Groups for Parents of Children with

Autism Spectrum Disorders? The Role of Beliefs and Coping Style

Parents of children with intellectual disabilities (ID) face unique challenges

related to their child's behaviour, planning for the future, and financial stresses (among

other issues). Parenting a child with an ID is associated with higher levels of parenting

stress than parenting typically developing children or children with other disabilities or

illnesses (Floyd & Gallagher, 1997; Hastings, 2002). In particular, parents of children

with autism spectrum disorders (ASD) report experiencing more stress and mental health

problems than parents of children with other IDs (e.g., Blacher & McIntyre, 2006;

Eisenhower, Baker, & Blacher, 2005). Research on parents of children with disabilities

has shown that participating in support groups is associated with less stress, less negative

mood (Kerr & McIntosh, 2000; Preyde & Ardal, 2003) and more positive perceptions

(Singer et al., 1999) in participating parents compared to parents who do not participate

in support groups. Social and informational support, both of which can be provided by

parent support groups (PSGs), are some of the needs most commonly reported by parents

of youth with ID (Douma, Dekker, & Koot, 2006). Support groups are a relatively cost-

effective and easily-implemented intervention in order to support the needs of these

families (Smith, Gabard, Dale, & Drucker, 1994). Despite the high support needs of

parents of children with ASD, very little research has focused on differences between

parents who participate in PSGs and those who do not, or on how best to support more

parents using PSGs. The research on parents of children with other disabilities sheds light

on the support needs of parents of children with ASD, including those who are not currently involved in support groups.

Information collected from parents of children with disabilities other than ASD can be informative when identifying differences between those parents who participate in support groups and those who do not. A survey of parents of children with physical disabilities and chronic illnesses found that about half of the parents in the sample had participated in a PSG at some point since their child's diagnosis (Smith et al., 1994). When examining what factors influenced participation, Smith and colleagues found that having participated in the past was not necessarily associated with a desire to participate in the future. Most parents were looking for emotional support and resources, but not necessarily information, which is contrary to the psycho-educational approach of many interventions designed for parents. They also found that accessibility issues, such as transportation and child care, were likely to influence PSG use. Additionally, the characteristics of the group leader were important, with parents preferring counseling professionals (e.g., social worker, psychologist) and parents to other health professionals (e.g., nurse, physician). This finding seems to relate to parents' preference for emotional rather than informational support.

Mandell and Salzer (2007) appear to have published the only quantitative study of predictors of support group use for parents of children with ASD. This study examined family demographics (i.e., age and gender of child, ethnicity, household income, parent education, marital status, and geographic location), health systems interactions (i.e., clinician referral to group and child inpatient stay in hospital) and child's clinical characteristics (i.e., specific ASD diagnosis; co-morbid diagnoses of mental retardation,

hearing impairment, seizures, self-injurious behaviour, sleep problems, aggression, and severe language deficits) as predictors of PSG use. The authors found that about two-thirds of the sample had participated in a PSG (defined as "support advocacy group for parents") at some time, and parents who were involved in support groups had higher household incomes and educational attainments, were more likely to be in two-parent families, and were less likely to be African-American than parents who were not involved. The authors reported that this finding is consistent with the literature on support group use in other populations, which generally finds that participants tend to be in higher income brackets, more educated, married, living in suburban areas, and white (e.g., Katz et al., 2002). Mandell and Salzer also found that PSG participants were more likely to have older children and children with self-injurious behaviour, sleep problems, and severe language deficits. The authors suggested that these parents may be experiencing more distress related to their child's symptoms and thus seek out the support of others with similar experiences. Finally, they found that PSG participants were more likely to have been referred by their diagnosing clinician than non-participants; however, only about 25% of PSG participants reported being referred, whereas the remaining participants found the groups on their own.

Although these studies (Mandell & Salzer, 2007; Smith et al., 2004) provide some basic information about factors that may influence participation in PSGs, neither study investigated characteristics of the parents (e.g., coping style, beliefs, mood and social support). Personal factors distinguish support group users and non-users in other populations and these variables may also be relevant to parents of children with ASD.

The current study will investigate the influence of parents' coping style, beliefs, social support, and mood on PSG participation.

The Self-Regulatory Model

The Self-Regulatory Model (SRM; Leventhal, et al., 1997; Leventhal, Brissette, & Leventhal, 2003) was used as a theoretical framework for examining predictors of involvement in support groups in this study (Figure 1). The SRM asserts that beliefs about illness, coping strategies used in dealing with illness, and social input received from significant others (i.e., family, friends, professionals) contribute to decisions about seeking treatment or help. This is a widely used model for evaluating treatment use and adherence to treatment for individuals with a variety of medical illnesses (e.g., Bradley, Calvert, Pitts, & Redman, 2001; Hobro, Weinman, & Hankins, 2004; Whitmarsh, Koutantji, & Sidell, 2003) and researchers have recently proposed that it is a useful model for understanding treatment use for people with mental health problems (Lobban, Barrowclough, & Jones, 2003).

Figure 1. Self-Regulatory Mode: Theoretical Framework for Study 1.
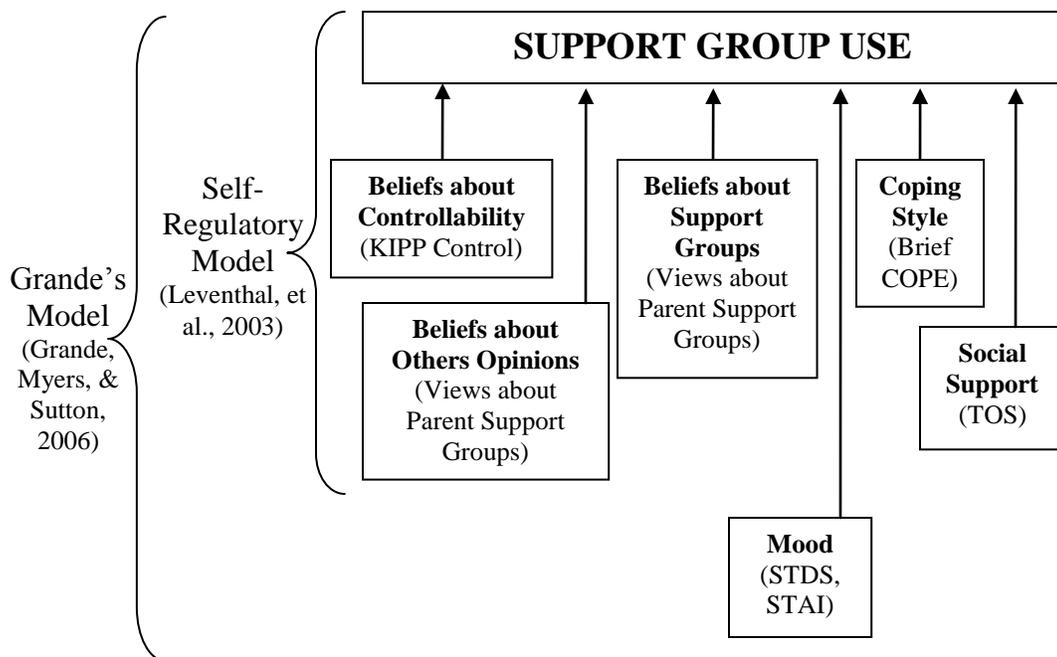
One study that was influential in the development of hypotheses for the current project used the SRM as a theoretical framework to examine factors distinguishing cancer patients who participate in support groups from those who do not (Grande, Myers, & Sutton, 2006). The authors also measured symptoms of anxiety and depression, hypothesizing that anxiety specifically may lead to seeking more support. Consistent with the SRM, the authors hypothesized that participants in the support group would be more likely to perceive their illness as controllable and would use more "adaptive" forms of coping (i.e., problem-focused, support seeking, and reframing). The authors proposed that current level of social support could affect whether one sought support from a group and hypothesized that people would be more likely to participate in a support group if they believed it would be beneficial and if they believed significant others supported their involvement. The results of the study supported these hypotheses with participants in support groups differing significantly from non-participants on several variables. Support group participants had more positive beliefs about the benefits of support group participation, felt more support from others to participate in support groups, and perceived fewer difficulties associated with joining support groups. They also used more adaptive coping strategies, perceived a greater level of personal control of their illness, experienced more anxiety symptoms, and reported receiving less support from a "special person" than non-participants. In addition to this study, other researchers (Cook, Heller, & Pickett-Schenk, 1999; Fontana et al., 1988; Koroloff & Friesen, 1991; Mandell & Salzer, 2007; Mickelson, 1997) have supported the use of some of these variables in differentiating between people who do and do not use support groups.

Beliefs. The SRM purports that beliefs about the controllability of the illness and the effectiveness of the interventions will affect whether the individual uses the intervention (Leventhal et al., 1997; 2003). Research suggests that parents who participate in support groups may have different beliefs about support groups or about their child's disability (or illness) from parents who do not participate in support groups (Fontana et al., 1988; Mandell & Salzer, 2007). Parents who believe that it is important for them to not only help their child, but also to help themselves, were more likely to participate in support groups for parents of infants in intensive care (Fontana et al., 1988). As well, in a study examining differences in parents of children with ASD who do and do not participate in support groups, Mandell and Salzer found that in addition to differences in several demographic variables, participants in support groups were more likely to be referred to the group by a clinician rather than parents who had not participated in a PSG. This finding suggests that the clinician may have provided information about the available service that the parent otherwise would not have known about, or perhaps the parents interpreted their referral as an important recommendation they should follow. However, Mandell and Salzer did not investigate parents' beliefs about PSGs or their perceptions of their healthcare providers' beliefs about them. Grande and colleagues (2006) also found that support group participants differed from non-participants in their beliefs about the usefulness and difficulties associated with attending support groups. The current study will examine beliefs about controllability of ASD and beliefs about PSGs as predictors of participation in PSGs.

Coping style. As discussed above, Grande and colleagues (2006) found that participants in support groups for cancer patients were more likely to use adaptive coping

strategies, including active coping (i.e., doing something to deal with the stressor), planning, reframing, acceptance, emotional support seeking, and instrumental support seeking than patients who were not involved in a support group. Although seeking support is referred to as a coping strategy in some measures of coping (e.g., Brief COPE, Carver, 1997; F-COPES, Olson, McCubbin, Barnes, Larsen, Muxen, & Wilson, 1982), few researchers have investigated coping style as a predictor of support group use. Because coping style is one of the predictors of intervention use in the SRM, use of adaptive coping strategies (i.e., reframing, active coping, planning, acceptance, emotional support, and instrumental support) will be used in this study to differentiate support group participants from non-participants.

Social support. Another hypothesized predictor of intervention use from the SRM is social support (Leventhal, 1997; 2003). Social support includes the "psychological and material resources" that one receives from partners, family members, and close friends, and increases in social support are associated with better health and well-being (Cohen & Wills, 1985, p. 310). The measurement of social support is based on the participant's perspective of the availability of social support. In general, support group participants tend to report having fewer social supports than those who do not participate in support groups (Cook et al., 1999; Fontana et al., 1988; Koroloff & Friesen, 1991; Mickelson, 1997). In studies of support group use for parents of infants in the neonatal intensive care unit (Fontana et al., 1988), caregivers of adults with mental illness (Cook et al., 1999), parents of children with emotional disorders (Koroloff & Friesen, 1991), and parents of children with developmental disabilities (Mickelson, 1997), participants in support groups reported more unmet needs or fewer social supports than

non-participants. These findings suggest that parents may be seeking social support from support groups when they are unable to find it from professionals, family members, and friends. The current study will investigate the role of perceived availability of instrumental, emotional, and informational support in differentiating between parents who use PSGs and those who do not.

Mood. Although mood is not one of the predictors included in the SRM (Leventhal, 1997; 2003), Grande and colleagues (2006) found that mood is an important predictor of support group use. As a result, it was included in the model for the current study. Other research suggests that people who are experiencing more psychological distress may be more likely to seek help from support groups (Cook et al., 1999; Mickelson, 1997). A study examining predictors of support seeking in parents of children with developmental disabilities found that parents who reported more depressive symptoms sought more support (Mickelson, 1997). Another study found that participants in a support group for caregivers of adults with mental illness also reported more symptoms of depression than caregivers who were not participating (Cook et al., 1999). In the current study, state depression and state anxiety will be used to differentiate between PSG participants and non-participants.

Limitations of previous research

Previous research on predictors of support group use for parents of children with ASD is sparse. As well, research on support group use for parents of children with disabilities is largely atheoretical (Mandell & Salzer, 2007; Smith et al., 1994). These studies focused on distinguishing parents based on demographic information and their experiences with support groups, including perceived barriers to participation (Mandell &

Salzer, 2007; Smith et al., 1994). Previous research on this topic was exploratory and used surveys that were developed for the studies, rather than established measures. As well the representativeness of the sample in the Smith et al. study is questionable given there were only 45 participants. The current study builds on the available literature on PSG use among parents of children with ASD by employing a theoretical model to address the research questions and by using standardized measures to examine parent characteristics that are hypothesized to be predictors of PSG use.

Summary

In summary, the aim of this study was to explore the contributions of factors in the SRM framework as predictors of participation of parents of children with ASD in support groups. Differences in the following variables were analyzed: beliefs about support groups, beliefs about significant others' opinions about support groups, mood, coping style, and social support. I predicted that parents who participated in support groups would believe that there are more benefits and fewer difficulties to participating in support groups, report more mood symptoms, use more adaptive coping strategies, and have fewer sources of social support than parents who were not participating in support groups.

<div align="center">

Method

</div>

Participants

One hundred forty-nine parents were included in this study. The vast majority of the participants were mothers ($n =$142), and there was 1 grandmother and 6 fathers. The participants' mean age was 41 years ($SD = 7.11$ years), though participants ranged in age from 24 to 65 years. The majority of the parents who participated were in a relationship

(84 %) with most being married ($n = 116$) and some living in common-law ($n = 10$), whereas few were single ($n = 8$), separated ($n = 3$), or divorced ($n = 12$). They were a highly educated group, with most participants having attended college or university (95%, $n = 140$). Thirty-two participants (22%) had a college diploma (two year or associates degree), 35 participants (24%) had a university degree, and 39 participants (26%) had a graduate or professional degree[1]. The participants' partners were also highly educated, with most having attended post-secondary training (87%, $n = 118$). Of the participants' partners who attended post-secondary training, 34 (25%) had a college diploma, 30 (22%) had a university degree, and 27 (20%) had a graduate or professional degree.[2] The parents' reported annual household incomes ranged from $10,000 to $3.5 million, with the median income being $75,000. The majority of the parents lived in Canada (56%) or the United States (40%) with 82% of the Canadians being from Ontario.

Procedure

I recruited participants through multiple sources including posting on websites and online forums, mailing through research labs and agencies in several Ontario cities, flyers in agency waiting rooms, and ads in newsletters. Parents were invited to complete a series of questionnaires in a secure online survey program. If participants did not complete all of the questionnaires at once they were asked via email to return and complete the remaining questionnaires. It took about 1 hour to complete the questionnaires, and participants received an invitation to participate in an online parent support group (see Chapter 3) after they had completed this study.

Measures

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[1] Note: One participant did not indicate their level of education.
[2] Note: Two participants did not indicate their partner's level of education and 11 indicated that this question was not applicable.

The following measures were included in the online questionnaires:

Demographics. Information was collected about the child's date of birth, diagnosis, and sex; the family constellation; household income; the parents' employment and education; and service use.

Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003). The SCQ uses parent report on 40 yes-no items to measure social and communication skills in children who may have ASD. The Current Form, which was used for this study, collects information about the child's functioning over the 3 month period prior to completing the questionnaire, and it can be used to track changes in behaviour over time. The SCQ has good sensitivity, ranging from .71 to .90, and specificity, ranging from .71 to .86 (Chandler, et al., 2007; Corsello, et al., 2007). However, with children under the age of 8 years, better sensitivity has been found when lowering the cut-off score from 15 to 11 or 12 (Corsello, et al., 2007). This finding was considered when interpreting the results for this study, and a cut-off score of 15 was used for children 8 years and older, whereas a cut-off score of 11 was used for children under 8 years. For this study, the SCQ was primarily used to screen participants for inclusion.

Scales of Independent Behavior-Revised Short Form (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996). The SIB-R assesses adaptive and maladaptive (or problem) behaviour. Parents rate the child's ability on 40 skills on a 4-point scale ranging from 0 (*never or rarely*) to 3 (*does very well-always or almost always-without being asked*) in order to obtain adaptive behaviour and age equivalent scores. Parents are also asked to indicate whether the child engages in eight domains of problem behaviour and to rate both the frequency and severity of the behaviour. This information is used to

calculate general, internalized, asocial, and externalized maladaptive behaviour scores. Maladaptive behaviour scores ranging from 10 to -10 are considered within the "normal range", scores from -11 to -20 are "marginally serious", -21 to -30 are "moderately serious", -31 to -40 are "serious", and scores lower than -41 are "very serious". The SIB-R was standardized on a normative population, including a sample of individuals with intellectual disabilities and is reported to have good to excellent internal consistency, high test-retest reliability, and good inter-rater reliability (Bruininks, et al., 1996). The SIB-R was primarily used to provide descriptive information about this sample.

Family Stress and Coping Interview (FSCI; Nachshen, Woodford, & Minnes, 2003). The FSCI is a measure of perceived stress and coping developed for use with caregivers of individuals with developmental disabilities, including ASD. For this study, only the questions measuring perceived stress were used. Parents are asked to rate the stressfulness of 23 issues (e.g., "The diagnosis of your child as having a disability" and "Deciding on the best level of integration for your child") on a 4-point scale from 0 (*Not Stressful*) to 3 (*Extremely Stressful*). The individual items can be summed to create a total score, with higher scores indicating higher levels of perceived stress. The results of research to date with the FSCI demonstrate high internal consistency ($\alpha = .89$), high test-retest reliability ($r = .80$), and face validity (Nachshen et al., 2003). In the current study internal consistency was good ($\alpha = .90$), and the FSCI was primarily used to provide descriptive information about the participants.

Predictors of support group use. The following measures were used to collect information about potential predictors of participants' use of support groups.

State Trait Anxiety Inventory (STAI; Spielberger, 1983). The STAI measures both current (state) and general (trait) anxiety using two 10-item scales. Participants are asked to rate how much each item, describes how they feel on a scale from 1 (*not at all/almost never*) to 4 (*very much so/almost always*) for the state and trait subscales respectively. After the relevant items are reversed scored, two total scores (state and trait) are provided, with higher scores reflecting more symptoms of anxiety. Inter-item reliability for both the trait subscale (ranging from $\alpha = .72$ to $\alpha = .96$) and state subscale (ranging from $\alpha = .65$ to $\alpha = .96$) has been quite good in previous research (Barnes, Harp, & Jung, 2002), as well as in the current study ($\alpha = .86$ and $\alpha = .90$, respectively).

State-Trait Depression Scales (STDS; Spielberger, Ritterband, Reheiser, & Brunner, 2003). The STDS is a measure of both current (state) and general (trait) symptoms of depression designed for non-clinical samples. It includes 20 items, 10 from each scale: state and trait. Similar to the STAI, participants rate how much a given characteristic describes them currently or in general on a scale from 1 (*not at all/almost never*) to 4 (*very much so/almost always*) for the state and trait scales respectively. After the relevant items are reversed scored, two total scores (state and trait) are provided, with higher scores reflecting more symptoms of depression. High internal consistency for both scales was reported in previous research (ranging from $\alpha = .91$ to $\alpha = .96$; Spielberger et al., 2003) and the current study (ranging from $\alpha = .92$ to $\alpha = .94$).

Kansas Inventory of Parental Perceptions (KIPP; Behr, Murphy, & Summers, 1992). The KIPP measures parent perceptions in several domains. For the current study, the Mastery/Control domain scores were used to measure parents' beliefs about the control they and professionals have over their child's disability. Participants are asked to

rate each item in terms of how much control they have over it from 1 (*none*) to 4 (*a lot*), with high scores on the scale indicating more control. Each subscale of the KIPP has adequate to good internal consistency (mean Cronbach's α ranging from .66 to .87; Behr et al., 1992), and in the current study the internal consistency for the Mastery/Control domains was also good ($\alpha = .85$ and $\alpha = .91$).

Types of Support questionnaire (TOS; McColl & Skinner, 1995). The TOS is a measure of social support that was adapted from the Interpersonal Support Evaluation List (ISEL; Cohen & Hoberman, 1983). The TOS includes 25 questions within three categories of support: instrumental (e.g., "If I needed a quick emergency loan of $100, there is someone I could get it from."), informational (e.g., "When I need suggestions for how to deal with a personal problem, there is someone I can turn to."), and emotional (e.g., "There are people who invite me to do things with them."). Participants are asked to indicate their perception of the availability of each type of support on a scale from 0 (*never true*) to 3 (*always true*); they are also given a "not applicable" option. In addition, there are three questions assessing satisfaction with each domain of support. Although the TOS has been used in other studies investigating perceived support, the psychometric properties have not previously been reported. In the current study, the subscales had good internal consistency (ranging from $\alpha = .85$ to $\alpha = .94$). Total scores for each of the three domains were used to measure the perceived availability of social support for the parents in this study with higher scores indicating more perceived support.

Brief COPE (Carver, 1997). The Brief COPE is a shortened version of the original COPE (Carver, Scheier, & Weintraub, 1989), which measures respondents' use of 14 types of coping strategies, including Active Coping, Planning, Positive Reframing,

Acceptance, Humour, Religion, Using Emotional Support, Using Instrumental Support, Self-Distraction, Denial, Venting, Substance Use, Behavioural Disengagement, and Self-Blame. The Brief COPE includes 28 items in which the participant is asked to rate the extent to which they have been using that strategy on a scale from 1 (*I haven't been doing this at all*) to 4 (*I've been doing this a lot*). Although there are just two items to measure each type of coping, the items chosen had the highest reliability scores in the original COPE, and reliability scores range from acceptable ($\alpha = 0.50$) to good ($\alpha = 0.90$). For the current study, the following coping strategies were combined to form an Adaptive Coping score on which a higher score indicates more adaptive coping: Positive Reframing, Active Coping, Planning, Acceptance, Using Emotional Support, and Using Instrumental Support. This is the same combination of scores as was used by Grande and colleagues (2006) when examining differences between those who participated in support groups for cancer survivors and those who did not participate. In the current study, this combination of subscales had acceptable reliability ($\alpha = .71$).

Views about Parent Support Groups questionnaire. This scale was adapted from the Views about Cancer Support Groups questionnaire (Grande et al., 2006) in order to measure parents' views about both PSGs and others' opinions about support group use. Additionally, the scale measures difficulties that parents associate with participating in support groups. The following themes were addressed with this measure and subscale scores were calculated:

Beliefs about the outcomes of support group participation. Participants were asked to rate how much they agreed or disagreed with each of eight statements on a 7-point scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). For example,

"Participating in a parent support group gives me positive role models for coping with ASD". For parents who have not participated in support groups, the items are altered slightly to be phrased as hypothetical (e.g., "Joining a parent support group would give me positive role models for coping with ASD."). The ratings on these eight statements were averaged to provide an "Attitudes toward Parent Support Groups Mean Score" on which higher scores indicated more positive beliefs about support groups. The reliability of this subscale in the current study was excellent ($\alpha = .92$).

Other people's views of participation in support groups. Parents were asked two questions about the perceived views of "most people who are important to me" and "my doctors and service providers". They were asked to rate on a scale from 1 (*definitely should not*) to 7 (*definitely should*) how much the other person believes they should participate in a support group. The mean score on these items was calculated and called "Others' Opinions of Parent Support Groups Mean Score" with higher scores representing more positive perceived opinions about participating in support groups. The reliability of this subscale in the current study was good ($\alpha = .80$).

Difficulties associated with joining a support group. Participants were asked to rate how much they agreed on a scale from 1 (*strongly disagree*) to 7 (*strongly agree*) with four items related to difficulties with joining a support group (e.g., "It was difficult for me to join a parent support group because of the meeting time"). The mean of these four items was labeled "Difficulties with Parent Support Groups Mean Score" and higher scores indicated more difficulties. The reliability of this subscale in the current study was acceptable ($\alpha = .76$).

Data Analyses

Two hundred seventy-four parents of children with ASD were recruited and completed at least one part of the survey. Approximately two-thirds ($n = 178$) of these parents completed all of the online questionnaires; those who did not complete all of the questionnaires were excluded from these analyses. Twenty-nine participants were excluded from the analyses because their child did not meet the cut-off for ASD on the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003), leaving 149 parents included in this sample.

Parents were divided into three groups based on their support group use: never used support groups ($n = 36$), past support group use ($n = 37$), and current support group use ($n = 76$). This was done, rather than comparing support group users to non-users, because there were many participants who reported having used support groups at some time in the past, and it was thought that this division of groups may provide more meaningful clinical information. One-way analysis of variance (ANOVA) was conducted to compare these three groups of participants on the following variables: social support (instrumental, emotional, and informational), use of adaptive coping strategies, state symptoms of depression, state symptoms of anxiety, beliefs about personal and professional control of ASD, attitudes about PSGs, beliefs about difficulties with PSGs, and others' opinions of PSGs. Given the sample size ($N = 149$), this study had the power to detect a medium effect size ($\eta^2 = .06$) 78% of the time ($\alpha = .05$) and a large effect size ($\eta^2 = .14$) 99% of the time ($\alpha = .05$) (Faul, Erdfelder, Lang, & Buchner, 2007).

In order to examine factors that predicted participation in PSGs the three groups were collapsed into two groups; parents who were currently participating in a PSG ($n =$

76) or those who were not ($n = 67$). A logistic regression examining the following predictors was calculated: adaptive coping, instrumental support, informational support, emotional support, symptoms of anxiety, symptoms of depression, beliefs about control of ASD, attitudes and beliefs about PSGs, and difficulties associated with participating in PSGs.

Results

Descriptives

The majority (75%, $n = 113$) of parents had participated in a "parent support group" at some time, whereas 19% ($n = 29$) reported that they were currently participating in an in-person support group and 31% ($n = 47$) reported that they were currently participating in a PSG online.[3] The parents reported experiencing mild to moderate stress ($M = 37.54$, $SD = 13.86$), employing several adaptive coping strategies ($M = 35.67$, $SD = 5.64$) and experiencing few symptoms of anxiety ($M = 22.76$, $SD = 6.97$) and depression ($M = 20.58$, $SD = 6.74$). The parents reported that they "sometimes" or "usually" received instrumental ($M = 1.68$, $SD = 0.75$) and informational ($M = 1.69$, $SD = 0.76$) support and that they "usually" received emotional support ($M = 2.33$, $SD = 0.91$). They reported being neither satisfied nor dissatisfied with the instrumental ($M = 5.88$, $SD = 2.46$), informational ($M = 6.33$, $SD = 2.28$), and emotional ($M = 5.80$, $SD = 2.67$) support they received.

The parents reported having children (122 boys and 27 girls) with a variety of diagnoses. Although the majority of the children had Autism or Autistic Disorder ($n = 77$), there were a number of children with PDD-NOS ($n = 22$), Asperger's Syndrome (n

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[3] Note: The data from 6 participants are missing for these questions.

=35), and ASD ($n = 43$).[4] The children ranged in age from 2 to 23 years with a mean age of 9 years old ($SD = 4.62$ years). The children were a diverse group in terms of functioning level, with their adaptive behaviour scores ranging from an age equivalent of 9 months to 21 years with a mean of 4 years 7 months (SIB-R Adaptive Behaviour Total Score: $M = 68.45$, $SD = 18.64$), which is considerably lower than the mean chronological age. Parents reported that their children had relatively few behaviour problems (General Maladaptive Index: $M = -18.87$, $SD = 12.36$, Marginally Serious Range).

Differences between PSG Participants and Non-Participants

The groups (i.e., never used PSGs, past PSG use, and current PSG use) differed significantly in their beliefs and attitudes about support groups and their use of adaptive coping strategies; there were no significant differences in availability of social support, symptoms of anxiety or depression, or beliefs about control of ASD (see Table 1). Parents in the three groups did not differ based on child characteristics (i.e., age, maladaptive behaviour, adaptive behaviour or symptoms of ASD).

Post hoc comparisons using Tukey HSD tests were used to examine the differences between groups that had significant ANOVA results. Parents who had participated in PSGs in the past reported significantly lower mean scores ($p < .05$) on the Attitudes toward PSGs domain, indicating less positive views of the benefits of PSGs, than parents who had never participated in support groups and parents who were currently participating in support groups. Parents who had never participated and those who were currently participating in support groups did not differ in their attitudes toward PSGs.

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[4] Note: These categories were not mutually exclusive; some parents indicated that their child had both Autism and Autism Spectrum Disorder, likely because the child was given different diagnoses by different professionals.

Table 1

Mean Scores on all Variables for Parents who Never Participated, Participated in the Past, or Currently Participated in Support Groups

Variable	Participation In PSG	*M*	*SD*	*F*	*p*	η^{2*}
Instrumental Support Total Score	Never[a]	12.34	4.63	0.33	.77	
	Past	11.81	5.46			
	Current	11.46	5.51			
Informational Support Total Score	Never[a]	9.66	4.54	0.57	.57	
	Past	9.59	4.88			
	Current	10.43	4.54			
Emotional Support Total Score	Never[a]	21.31	8.86	2.46	.09	.03
	Past	21.95	9.66			
	Current	10.43	4.54			
Attitudes about PSGs Mean Score	Never	5.30[b]	1.22	8.26	<.001	.10
	Past	4.65[c]	1.35			
	Current	5.61[b]	1.05			
Others' Opinions of PSGs Mean Score	Never	4.96[bc]	1.40	6.43	<.001	.08
	Past	4.49[b]	1.57			
	Current	5.48[c]	1.33			
Difficulties with PSGs Mean Score	Never	4.32[b]	1.32	5.06	.01	.06
	Past	4.00[bc]	1.44			
	Current	3.44[c]	1.48			

Professional Controllability	Never	21.56	5.79	0.43	.65	
	Past	22.68	5.35			
	Current	22.41	5.38			
Personal Controllability	Never	19.78	2.71	1.30	.28	.02
	Past	19.43	3.63			
	Current	20.39	3.06			
State Anxiety Symptoms	Never[a]	23.94	7.74	0.82	.44	
	Past	22.95	6.37			
	Current	22.13	6.90			
State Depression Symptoms	Never[a]	20.71	7.51	0.99	.38	
	Past	21.81	6.96			
	Current	19.92	6.25			
Adaptive Coping	Never	32.72[b]	5.32	11.19	<.001	.13
	Past	34.54[b]	6.14			
	Current	37.62[c]	5.01			

Note. Sample sizes were: Never ($n = 36$), Past ($n = 37$), and Current ($n = 76$).
[a] data from one participant is missing for the Never group on these variables.
[b] and [c] indicate where the groups are statistically significantly different from each other according to post-hoc Tukey HSD tests ($p < .05$).
* $\eta^2 = .01$ denotes small effect size, $\eta^2 = .06$ denotes medium effect size, and $\eta^2 = .14$ denotes large effect size. Effect size was not calculated when $F < 1$.

Parents who were currently participating in PSGs reported significantly higher scores on the Others' Opinions about PSGs domain than parents who had participated in PSGs in the past, indicating the belief that people who were important to them thought

that they should be participating in support groups. There were no differences between those who had never participated and either of the other two groups.

Parents who had never participated in PSGs reported significantly more difficulties with joining PSGs than parents who were currently participating in PSGs, whereas parents who had participated in the past did not differ significantly from either of the other two groups.

Finally, parents who were currently participating in PSGs reported using significantly more adaptive coping strategies (i.e., Positive Reframing, Active Coping, Planning, Acceptance, Using Emotional Support, and Using Instrumental Support) than both parents who had previously participated in PSGs and parents who had never participated in PSGs. Parents who participated in support groups in the past and parents who had never participated in support groups did not differ significantly on this domain.

Predictors of Current Support Group Use

There was no multicollinearity ($r > .80$) between the predictor variables (Table 2). However, the three domains for the Types of Support questionnaire were strongly correlated, as were state anxiety symptoms and state depression symptoms. Combined scores were calculated (Total Social Support and Total Mood) and tested as predictors in the logistic regression model; however, the results did not differ from the model with each individual predictor, therefore the latter model is presented here.

Table 2

Pearson Two-Tailed Correlations between Predictor Variables for Logistic Regression

	Inst	Info	Emo	Att	OO	Diff	Prof	Pers	Anx	Dep	Cope
Inst	1.00	.60**	.64**	.14	.10	-.27**	.23*	.16	-.26*[a]	-.33**[a]	.11
Info	-	1.00	.79**	.18*	.19*	-.26**	.31**	.26**	-.32**[a]	-.43**[a]	.29**
Emo	-	-	1.00	.32**	.17*	-.34**	.32**	.22*	-.44**[a]	-.54**[a]	.46**
Att	-	-	-	1.00	.53**[b]	-.30**[b]	.16*[b]	-.02[b]	-.15	-.21*	.27*[b]
OO	-	-	-	-	1.00	-.21*[b]	.19*[b]	.09[b]	.04	.01	.23*[b]
Diff	-	-	-	-	-	1.00	-.04[b]	-.13[b]	.23*	.27**	-.26**[b]
Prof	-	-	-	-	-	-	1.00	-.03[b]	-.10	-.16	.28**[b]
Pers	-	-	-	-	-	-	-	1.00	-.05	-.13	.16*[b]
Anx	-	-	-	-	-	-	-	-	1.00	.79**	-.16*
Depr	-	-	-	-	-	-	-	-	-	1.00	-.33**
Cope	-	-	-	-	-	-	-	-	-	-	1.00

Note: *n* = 148 except [a] *n* = 147, [b] *n* =149

* *p* < .05, ** *p* < .001

Inst = Instrumental Support Total Score; Info = Informational Support Total Score; Emo = Emotional Support Total Score; Att = Attitudes about PSGs Mean Score; OO = Others' Opinions of PSGs Mean Score; Diff = Difficulties with PSGs Mean Score; Prof = Professional Controllability; Pers = Personal Controllability; Anx = State Anxiety Symptoms Total; Depr = State Depression Symptoms Total; Cope = Adaptive Coping

The overall model examining predictors of participation in PSGs was significant, χ^2 (11, *N* = 143) = 35.81, *p* < .001 and able to correctly classify 73% of the participants, which is an improvement from the correct classification rate of 53% in the null model.

The only significant predictor in the model was Adaptive Coping; for every unit increase on the 48-point scale measuring use of adaptive coping methods the odds of participating in a PSG increased by 12% (Table 3).

Table 3

Summary of Logistic Regression Analyses for Variables Predicting Current Participation in PSG

Predictor	*B*	*SE B*	Wald's χ^2	Odds Ratio
Instrumental Support Total Score	-0.10	0.05	3.33	0.91
Informational Support Total Score	-0.04	0.08	0.28	0.96
Emotional Support Total Score	0.04	0.04	0.90	1.04
Attitudes about PSGs Mean Score	0.23	0.20	1.41	1.26
Others' Opinions of PSGs Mean Score	0.28	0.16	3.00	1.32
Difficulties with PSGs Mean Score	-0.22	0.14	2.30	0.80
Professional Controllability	-0.44	0.04	1.25	0.96
Personal Controllability	0.07	0.06	1.05	1.07
State Anxiety Symptoms Total	-0.06	0.05	1.43	0.95
State Depression Symptoms Total	0.05	0.05	1.07	1.05
Adaptive Coping	0.11*	0.04	6.48	1.12
Constant	-5.25	2.44	4.61	0.01

* $p < .05$

Discussion

The aim of this study was to examine differences between parents who were and were not participating in parent support groups in several variables, including social support, symptoms of anxiety and depression, beliefs about support groups, beliefs about ASD, and coping style. Participants were divided into three groups based on their participation in PSGs: Never, Past, and Current participators. These three groups differed in their beliefs about support groups and in their use of adaptive coping strategies, although they did not differ in their social support, beliefs about controllability of ASD, and symptoms of anxiety or depression. In addition, these variables were examined as predictors of current PSG use. The hypotheses that parents who participated in support groups would believe that there are more benefits and fewer difficulties to participating in support groups and would use more adaptive coping strategies were supported, and adaptive coping was a particularly meaningful predictor of PSG participation. On the other hand, the hypotheses that parents who participated in PSGs would report more mood symptoms and have fewer sources of social support than parents who were not participating in support groups were not supported.

Beliefs about PSGs

Overall, parents who were participating in support groups reported stronger beliefs in the benefits associated with support groups, greater support from important others to participate in PSGs, and fewer difficulties with participating than parents who were not currently participating. Parents who had participated in support groups in the past, but who were not currently participating, believed there were fewer benefits of participating in support groups than either current participants or those who had never

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participated in support groups. This finding suggests that parents who had participated in support groups in the past were not satisfied with their experiences or did not see the benefits that parents who were currently participating in PSGs experienced. Additionally, the past participants reported less support from important others in choosing to participate in PSGs than current participants, whereas the parents who had never participated in a PSG did not differ from either group in their beliefs about the opinions of important others. These results suggest that the reason some parents who had never participated in PSGs were not participating in PSGs was not because of a perceived lack of benefits to participation, but instead more likely due to another reason. In particular, difficulties with attending support groups, such as the location, meeting time, and lack of child care, seemed to be the main reasons participants in the current study initially did not get involved in PSGs. Parents who reported having never participated in support groups only differed from the other two groups of parents in their beliefs about the difficulties associated with participating in PSGs. Taken together, the results of this examination of attitudes toward support groups indicate that there were two distinct groups of parents who were not currently participating in support groups: 1) those who, despite believing PSGs to be beneficial, had never tried them, because of difficulties associated with attendance and 2) those who had tried PSGs in the past and found them not to be beneficial.

The results of the current study add a new understanding to a topic that has received limited research interest. Smith and colleagues (1994), in their study of support group use among parents of children with chronic illness, found that, similar to the present study, having participated in a PSG in the past was not necessarily associated

with current participation. They also reported that some of the main reasons parents

seemed not to be participating in support groups were related to the difficulties associated

with attendance, namely transportation and lack of child care. These authors also

described the widespread issue of low enrollment, and poor attendance in PSGs, and they

suggested that some PSGs may not be meeting the needs of the parents to whom they are

targeted because of the focus on information sharing and teaching rather than on

emotional support. It is quite likely that this issue was being reflected in the second group

of parents identified in this study who had tried PSGs in the past and had not found them

beneficial.

The findings of the present study are also similar to those of Grande and

colleagues (2006), who examined differences between cancer patients who were and

were not participating in support groups. These authors found that among other variables,

attitudes towards support groups and others' opinions about them were more positive in

the patients who were participating in support groups compared to those who were not

participating. Similarly, support group participants reported fewer difficulties with

participation than non-participants.

Adaptive Coping

In addition to differing in their beliefs about PSGs, parents who were participating

in support groups in the current study differed from both parents who had participated in

the past and those who had never participated in their use of adaptive coping strategies,

and using adaptive coping strategies was the only significant predictor of current PSG

use. Specifically, parents who were currently using PSGs reported using more adaptive

coping strategies, including seeking emotional and instrumental support, active coping,

and planning, than parents in both of the other groups. The association between coping

style and support group use has not been investigated in other parent groups, but has been

examined in cancer patients (Grande et al., 2006; McGovern, Heyman, & Resnick, 2002).

Grande and colleagues and McGovern and colleagues both found that support group

participants used more adaptive coping strategies than the control group. This finding is

not surprising given that participating in a PSG would be considered a form of active

coping that involves seeking support. However, this finding does offer some interesting

implications for the theoretical understanding of the issue of support group involvement.

Theoretical Implications

This study used the SRM as a theoretical model for investigating differences

between parents of children with ASD who use PSGs and those who do not. The SRM

purports that one's beliefs about the illness or disorder, beliefs about the intervention,

coping style, and social support are important predictors of service use (Leventhal et al.,

1997; Leventhal et al., 2003). In addition, mood symptoms were added to the SRM when

it was used in a study of support group use among cancer survivors (Grande et al., 2006),

and mood symptoms were also considered in the current study. The results provide

support for some aspects of the model as relevant for differentiating between parents of

children with ASD who are currently using support groups, have used support groups in

the past, and have never used support groups; however, the full model did not hold for

this population.

According to these results, several characteristics of the parents, including the

self-reported distress or symptoms of anxiety and depression and the social support that

they receive, did not differentiate support group users from non-users. This may be

because the participants, as a group, had few symptoms of anxiety and depression, were not experiencing significant stress, and were receiving some social support. The parents' beliefs about the controllability of ASD also did not differentiate between groups, which may speak to the fact that in general parents feel that they and the professionals they work with have a moderate amount of control of their child's ASD symptoms and behaviour. The only individual variables that were relevant in predicting support group use among these parents was their coping style and their beliefs about PSGs. These findings suggest that participation in PSGs for this group was not about need, nor about beliefs about the importance of supporting themselves, but more about their chosen method of coping with stress, the ease with which they could participate in PSGs, and their past experience with PSGs. As such, the SRM may not be the most appropriate theoretical model for examining involvement in support groups for parents of children with ASD, rather, a model that includes previous experience with PSGs, beliefs about PSGs, and coping style may be more useful. Considering the findings from previous research on PSG use in parents of children with ASD (Mandell & Salzer, 2007), future research on predictors of PSG use should include both characteristics of the parents and characteristics of the child, such as age, diagnosis, and functioning level, as predictors. Investigating the role of characteristics of the child in differentiating PSG users from non-users was not a goal of the current study; however, analyses found that child age, adaptive behaviour, maladaptive behaviour and symptoms of ASD did not significantly differ between the groups of parents in this study.

Coping style has been hypothesized as an important individual predictor of success in psychological interventions (Baker & Neimeyer, 2003) and has been linked to

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social support use (e.g., Fondacaro & Moos, 1987). Adaptive coping styles have also been associated with support seeking and support group involvement (Grande et al., 2006; McGovern et al., 2002). In this study, we cannot be certain that coping style is the reason some parents participated in support groups; it is possible that parents changed their coping style as a result of participating in a support group. Regardless of the direction of this relationship, it is clear that there is a relationship between use of adaptive coping strategies and participating in support groups, and the link between these variables deserves further investigation in order to replicate these findings and to determine whether participation in PSGs can lead to positive changes in coping style.

Previous research examining the use of support shows that in general, the perceived usefulness of support is of great importance when predicting its effectiveness in reducing stress and improving well-being (Vaux, 1988). It is not surprising that when participants perceive support as not useful, they tend to withdraw from participation. Similar to what Smith and colleagues (1994) have suggested, it seems that the support groups that are being offered to parents may not be meeting the needs of all parents. Some do not find PSGs beneficial and others face difficulties related to attendance. Future research on both predictors of support group use and the effectiveness of support groups should consider the beliefs and needs of the participants in these groups, as well as the types and foci of groups that are being offered. The findings of the current study suggest that support for parents of children with ASD, as with support for their children, should be focused on individual needs in order to optimize the effects. This finding leads to some direct recommendations for clinical interventions with these families.

Clinical Implications

This study is the first to investigate the role of parent characteristics in examining differences in PSG use among parents of children with ASD, and as such, the conclusions drawn from these results should be considered preliminary until further research replicates these findings. However, several suggestions for supporting parents of children with ASD can be offered. Predominantly, the results support the assertion that these parents comprise a diverse group with a variety of support needs, not unlike their children. In addition, parents' previous experience with supports may offer suggestions as to how (or how not) to provide support. Based on the findings of this study, it would appear that parents who are more likely to be well supported by traditional in-person PSGs will 1) tend to cope by seeking emotional and instrumental support and by planning and doing something about their problem, 2) believe that support groups will be beneficial, and 3) believe that they will not have difficulties attending PSGs. However, those parents who have not tried a support group and believe them to be beneficial may be well supported by alternatives to traditional groups such as online support groups, which will alleviate many of the difficulties associated with attending in-person group meetings. Finally, there is a subgroup of parents, including those who have tried support groups and not found them beneficial and those who do not seek support as a form of coping, who would be better supported by other methods. For example, these parents could be quite satisfied with respite care, which would provide them with the opportunity to spend some time away from their child in order to re-energize or relax. These parents might also prefer a parent-to-parent support model or a parent-led group, which would be more focused on bonding with other parents. It will be important to determine through

discussion with the parent what she feels would be the best support match for her. If a

parent has expressed an interest in participating in a support group, it will be important to

determine her goals for the support group.

Limitations and Directions for Future Research

The generalizability of the results of this study is limited by the method of

recruiting the parents who participated. Although the parents were recruited through a

variety of means, including flyers in clinics and mailings through other research projects,

and were from across North America, it is expected that the majority of the parents were

recruited through online postings on listservs and websites for families of people with

ASD. As such, it is likely that the parents who were recruited were a selected group who

were more likely to be involved in some kind of supportive relationship with other

parents. However, the representativeness of the sample is unclear as there was diversity

in the experiences of the participants with respect to support group use. Information about

where parents learned about the study was not collected; therefore we cannot be sure

from where the majority were recruited. In the future, researchers using online studies

would benefit from collecting information about where the participants learned about the

study. Future research on support groups for parents of children with ASD that uses a

similar approach to recruitment as the current study will likely replicate these findings,

whereas it is unclear whether others who use different recruitment strategies, such as

recruiting parents directly from clinics, will find the same results.

In addition, because the questionnaires were administered in an online format,

only parents with access to the internet were able to participate in the study. It is not clear

how many parents were excluded from participation based on this method of data

collection. Given that the majority of the recruitment was done online, it is expected that very few of those who had heard about the study were unable to participate due to a lack of internet access. Given the range of income levels, it does not seem likely that the format of the questionnaires affected the overall representativeness of the sample. Furthermore, it is now estimated that at least 75% of North Americans have access to the internet (Miniwatts Marketing Group, 2010).

Specific information about the types of support groups that participants were using, the format, curriculum, leaders, and other participants was not collected in this study. Rather, participants were only asked to indicate whether they had participated in an in-person or online support group and whether they were currently participating in a group. It is likely that different parents had very different experiences with the support groups because of the heterogeneity of the PSGs available to them. More detailed information about the characteristics of the groups could help improve the understanding of how parents of children with ASD can be supported. Research on this topic would be improved by the addition of a series of questions through which parents describe more relevant details of the intervention in which they participated.

Previous research (Grande et al., 2006; McGovern et al., 2002) has shown that support group participants reported using more adaptive coping strategies than non-participants. Although it was presumed that participants and non-participants chose different methods of coping, it is possible that support group participants identified using more adaptive strategies *because* they were participating in a support group. It cannot be determined from these data whether these parents chose to participate in PSGs because of their coping style or whether they developed more adaptive coping styles because of

participating in the PSG. It is possible that parents who do not participate in support groups may learn more adaptive coping strategies if they were to enroll in support groups. Future studies should consider following parents prospectively and measuring changes in their coping style and other measures of well-being to determine whether participating in support groups can help parents learn to cope better or if coping style is in fact a predictor of support group use.

Conclusions

This study provides new information about a topic that has received relatively little research interest to date. This study evaluated the applicability of the SRM for identifying variables that differentiated between parents of children with ASD who were currently participating in PSGs, who had participated in PSGs in the past, and who had never participated in PSGs. These three groups of parents differed on some, but not all, of the variables examined in the SRM. Some parents, who had never participated in PSGs, reported that accessibility issues, such as the time, location, and lack of child care made it difficult to participate. Other parents, who had participated in PSGs in the past, did not find the groups to be as beneficial as parents who were currently participating in support groups. Those parents who participated in PSGs reported using more adaptive coping strategies than parents who were not currently participating in PSGs. These findings suggest that a one-size-fits-all approach to supporting parents of children with ASD will not be most effective, but rather focusing on the individual needs of the parent, as they identify them, could lead to better support for parents of children with ASD and more efficient use of community resources. Given that parents if children with ASD experience more distress than other parents, further research on support for these parents is

warranted in order to learn more about the benefits of PSGs and the applicability of

unique and innovative models of support, such as online groups.

Chapter 3: Logging On: Evaluating an Online Support Group for Parents of Children with Autism Spectrum Disorders

Parenting a child with an intellectual disability can be a stressful experience. Research shows that in this population the presence of more behaviour problems in the children is related to increased stress among parents (Baker et al., 2003). Children with autism spectrum disorders (ASD) tend to experience more behaviour problems than children with other intellectual disabilities, and thus, research shows that parents of children with ASD experience more stress than other parents (Blacher & McIntyre, 2006; Dabrowska & Pisula, 2010; Eisenhower, Baker, & Blacher, 2005; Lecavalier, Leone, & Wiltz, 2006). Many of these behaviour problems, such as self-injury and repetitive behaviours, are especially frustrating and upsetting for parents and are associated with daily stress (Bitsika & Sharpley, 2004). Furthermore, parents of children with ASD report more symptoms of anxiety and depression compared to parents of children with other disabilities (Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007) and parents of typically developing children, with the negative effects being especially strong for those parents who do not have support from family members who understand their child's disability (Sharpley, Bitsika, & Ephrimidis, 1997).

Despite the large amount of research indicating that parenting a child with ASD is extremely stressful, little research has examined methods of alleviating parenting stress for these families. Parent support groups (PSGs) are one way to help parents of children with ASD cope with their stress, meet other parents, and develop a sense of belonging. Support groups for parents are a relatively cost-effective and easily-implemented

intervention for supporting the needs of these families (Smith, Gabard, Dale, & Drucker, 1994). Few studies have reported rates of support group use in parents of children with ASD or other disabilities; however, 42% of a sample of parents of children with chronic illness reported using PSGs (Smith et al., 1994). Previous research has found that two-thirds of parents of children with ASD report having used PSGs at some point (Mandell & Saltzer, 2007), and in another study, I found that 75% of parents of children with ASD reported using a PSG at some time (see Chapter 2). It is important to note that there is a natural response bias in these studies, such that parents who do not use PSGs are unlikely to participate in studies of PSGs; therefore, it is difficult to know the true rate of PSG use. Clinically, parents report accessing support groups for free on the internet, by invitation from other parents or from agency staff who are aware of community groups, and as part of the services offered while their child is on a wait-list for government-funded intervention. Given the apparent popularity of PSGs for parents of children with ASD, surprisingly little research has evaluated these interventions.

The Stress Buffering Model

The Stress Buffering Model (SBM; Cohen & Wills, 1985) purports that support moderates (or buffers) the effect of stressors on well-being (Cohen & Wills, 1985). Specifically, in the presence of support, it is thought that stressors have less impact on psychological well-being (i.e., stress, mood, and positive perceptions). The SBM was used as a framework for this study (Figure 2) due to its simplicity compared to other models of stress in describing the relationship between stressors, well-being, and support in a clinically relevant way. Previous research with this model has found mixed results; however, it appears that the model is valid under certain conditions (Vaux, 1988). For

example, it is important that the specific stressors measured have an effect on the specific

measure of well-being and that the support is deemed helpful. The SBM was used to

investigate the role of online support group involvement in (a) decreasing stress and

negative mood and (b) increasing positive perceptions in parents of children with ASD.

Figure 2. Stress Buffering Model: Theoretical Framework for Study 2.
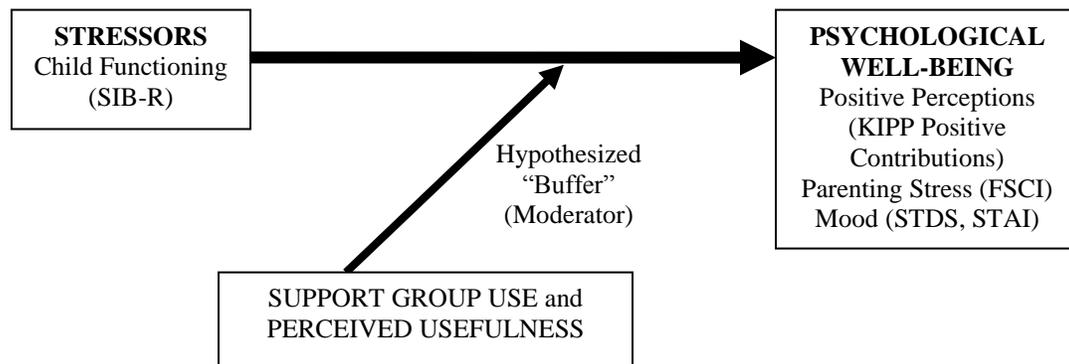
Support Groups and Perceived Stress and Mood

Several studies have investigated the effects of support groups on the well-being

of participants, and in general, findings indicate that support groups tend to have positive

effects (e.g., Beaudoin & Tao, 2007; Preyde & Ardal, 2003; Stevens & Duttlinger, 1998).

Because many studies have investigated the effects of support groups on both perceived

stress and mood, an overview of the findings related to these two variables will be

combined. Participants report decreases in perceived stress and symptoms of depression

and (current) anxiety following involvement in support groups for cancer patients

(Beaudoin & Tao, 2007). In another study, mothers of pre-term infants who participated

in support groups reported less stress and negative mood than those who did not

participate in the support group (Preyde & Ardal, 2003). A study examining stress and

psychological well-being in women with breast cancer found that women who had been long-standing members of a support group reported the least stress, anxiety, and depression when compared to new members and non-members, with the latter reporting the most stress and negative mood (Stevens & Duttlinger, 1998). In a qualitative study, parents of children with physical disabilities reported that contact with other parents of children with similar disabilities provided emotional, social, and practical support that could not be derived from professionals or family and friends. This contact with other parents also seemed to have a "powerful stress buffering influence" (Kerr & McIntosh, 2000, p. 309).

Support Groups and Positive Perceptions

Some research also suggests that involvement in support groups can affect the attitudes and perceptions of participants (Silverman-Dresner, 1990; Singer et al., 1999; Soloman, Pistrang, & Barker, 2001). Following involvement in a support group for women with breast cancer, Silverman-Dresner (1990) found that although women who participated reported more life difficulties, they reported less distress than women who had not participated in the group. This finding suggests that the participants' perceptions of their problems had changed as a function of the group. Similarly, research with parents of children with developmental disabilities found statistically significant positive changes in parents' reported perceptions of their child with a disability following PSG involvement that were not observed in the wait-list control group (Singer et al., 1999). When asked about their experiences in support groups, parents of children with disabilities reported an increased sense of control in the world, an increased sense of belonging or being part of a community, and positive changes in their relationship with

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and perception of their child (Soloman et al., 2001).

Effects of Support Groups for Parents of Children with ASD

The research that has focused on outcomes of support groups for parents of children with ASD is exploratory and qualitative (Bitsika & Sharpley, 1999; Bitsika & Sharpley, 2000; Carter, 2009). Bitsika and Sharpley (1999) completed a small ($n = 14$) exploratory study of outcomes associated with participation in an informational counseling group for parents of children with ASD. These participants chose to attend one of three in-person support groups held every second week for 75 minute sessions. At the end of each session, parents chose the theme for the upcoming session, and the focus of the sessions was generally in providing support, rather than discussing specific strategies for dealing with personal stress. Following each session, the participants completed a brief questionnaire that was developed by the authors for the study, which examined participants' comfort and connection with group members, perceptions of themselves, self-efficacy, and well-being. The exploratory analyses indicated trends towards an increase in positive self-concept and a decrease in distress over time. Both group cohesion and self-efficacy increased gradually until about the half way point of the intervention and then decreased gradually; the authors were unsure of the explanation for this finding, especially in light of the reports that participants valued the opportunity to connect with other parents. When asked to rate their experience with the group at follow-up, the parents indicated that they very much enjoyed participating, they found the group very valuable, and they would recommend that other parents participate. Compared to these ratings, parents had lower, but still positive ratings of the helpfulness of the group in dealing with a series of problems. When asked about the major benefits of

participating in the group, almost all of the parents indicated that receiving support and understanding from the other group members was the best outcome; whereas one parent stated that the major benefit for her was providing assistance to other group members. Overall, the authors concluded that the group was of value and was helpful to the participants, but the methodological limitations of the study, such as small sample size and the use of unstandardized measures that the participants found difficult to answer, may have reduced the effects seen on standardized measures of well-being. The authors recommended that further research be conducted to examine the benefits of support groups for parents of children with ASD.

In a second study, Bitsika and Sharpley (2000) evaluated the effects of a parent support program with a psycho-educational focus on learning stress management techniques that included time in each session to discuss parents' current concerns. The groups were scheduled for eight weekly 75-minute sessions, and parents completed questionnaires after each session and pre- and post-group. There were no significant changes in stress, anxiety, or depression symptoms following participation in this group. The lack of reported change may have occurred because the pre-group assessment showed that neither the mean anxiety nor mean depression scores of participants fell outside of the normal range prior to participation in the group. Parents reported that they enjoyed the sessions and found them helpful. This study was also limited by a small sample size ($n = 11$), and therefore the authors reported that it lacked sufficient power to detect differences in the outcome measures, although they were able to detect a significant increase in group cohesion from pre- to post-group. The authors concluded that the parents were especially satisfied with the focus on learning strategies for coping

with stress, and the parents emphasized the value of learning with other parents with whom they could relate. Bitsika and Sharpley also suggested that assisting parents in learning to cope with their stresses could improve their ability to learn strategies for managing their child's behaviour problems. However, this suggestion is in contrast with the recommendations of other researchers (Smith et al., 1994; Solomon et al., 2001) who have found that parents prefer groups that focus on emotional support and developing a sense of belonging, rather than sharing information.

Carter's (2009) qualitative study of parents' experiences with online support appears to be the only study that examined outcomes of online support groups for parents of children with ASD. Parents were asked about the positive and negative experiences they had when using "the Internet for self-help group support and advocacy" (p. 47). Twenty-two parents were interviewed about their experiences with using the internet. These parents had not necessarily participated in a formal online support group; they needed only to have used the internet for support (e.g., accessing information or resources, participating in a listserv), and/or advocacy. The main themes that emerged in the parents' responses about the positive aspects of using the internet for support included receiving access to information and services, connecting with others, and increasing advocacy. At the same time, the disadvantages of accessing support through the internet were that it provided inaccurate, confusing, or overly negative information and sacrificed time with family for advocacy that was not always effective. The author concluded that online support groups for parents of children with ASD have many potential benefits, but efforts should be made in order to ensure that parents receive accurate and useful information. She recommended that further research was required to evaluate the

outcomes of online PSGs specifically.

Limitations of Previous Research

Previous research on support groups for parents of children with ASD is sparse and predominantly exploratory (Bitsika & Sharpley, 1999; Carter, 2009). Those studies that have examined pre- to post-group changes (Bitsika & Sharpley, 1999; 2000) are limited by small sample sizes (ranging from $n = 11$ to $n = 14$) and the use of unstandardized measures. In addition, there has been no published quantitative research examining the effects of online PSGs for this population despite the growing trend for parents to connect in this way. Those studies that have examined the broader group of parents of children with special needs are qualitative (e.g., Kerr & McIntosh, 2000) and largely atheoretical (e.g., Singer et al., 1999; Solomon et al., 2001), focusing on a few general variables (e.g., helpfulness, group climate, empowerment) expected to change as a result of support group use. By establishing a theory base to measure the effects of PSGs systematically, research can assess the role of PSGs in supporting parents of children with ASD in order to provide the most appropriate and effective support.

In developing the format for the support groups in this study, the findings from previous research on parents' preferences for support groups were taken into consideration. Smith and colleagues (1994) surveyed parents of children with special needs about their experiences with PSGs. Parents reported a preference for the support aspect of the group as opposed to information sharing and teaching from professionals; they enjoyed being able to meet other parents and share feelings. As well, parents reported that child care and transportation were both barriers to using support groups. Taking these findings into consideration, this study examined an online parent support

group that was designed as a discussion group for parents focusing on sharing experiences and developing relationships with facilitation from a counseling professional. The online component was expected to reduce some barriers to participation; for example, parents were able to participate from their home and after their child had gone to bed. The topics of discussion for these group sessions were based on parent suggestions, so as to mirror both the approach taken by many community PSGs and previous research on in-person PSGs for parents of children with ASD (Bitsika & Sharpley, 1999). Finally, this group design was chosen with a view to providing a model for agencies wishing to implement similar groups to support families of children with ASD.

Summary

This study aimed to determine whether involvement in an online parent support group affects parent reported perceived stress, symptoms of anxiety, symptoms of depression, and positive perceptions of their child. Consistent with the effects of support group involvement in previous research, it was hypothesized that parents involved in the online support groups would report less perceived stress, fewer symptoms of state anxiety and depression, and more positive perceptions of their child than the control group following participation in the group, and that the two groups (control and treatment) would not differ in these measures of well-being before participation in the group. In addition, the Stress Buffering Model was used as a framework to assess whether support group use for parents who perceive the support group to be useful moderated (or "buffered") the effect of child functioning on parent psychological well-being. It was hypothesized that for parents who perceived the support group to be useful, involvement

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in the support group would moderate the effect of child functioning on psychological well-being. Specifically, it was expected that when comparing parents who have children with a similar amount of behaviour problems, parents who participated in a PSG they perceived to be useful would report less stress, anxiety, and depression, and more positive perceptions than parents who do not participate in the PSG. Finally, this study provides new documentation about how to develop and implement an online support group for parents of children with ASD. Recommendations for future implementation of the protocol employed in this study may be useful to clinicians working with these families. Findings from this study on outcomes associated with involvement in an online PSG provide information for future research and the development of supports for families.

Method

Participants

Parents of children with ASD were recruited from the larger sample of participants ($n = 178$) who completed a study examining predictors of involvement in PSGs (Chapter 2). Parents were required to have access to a computer with an internet connection in order to participate. Those parents who indicated an interest in participating in a new online parent support group were invited to participate ($n = 119$). Thirty-six of these parents registered for the online support groups, 30 attended at least one of the sessions, and 20 completed all of the post-group measures. Parents who did not participate in the online support group ($n = 144$) were invited to participate in the control group and 25 of them completed all of the post-group measures.

Measures

Demographic information, including the child's gender and date of birth, the

parent's gender and date of birth, household income, and parental education and employment, was collected as part of the pre-group questionnaires. The following measures were included in the pre- and post-group online questionnaires:

Parent well-being. The following measures were used to assess parent well-being.

Family Stress and Coping Interview (FSCI; Nachshen, Woodford, & Minnes, 2003). The FSCI measures perceived stress and coping in caregivers of individuals with intellectual disabilities, including ASD. For this study, only the questions measuring perceived stress were used. Parents rate the stressfulness of 23 issues (e.g., "The diagnosis of your child as having a disability" and "Deciding on the best level of integration for your child") on a 4-point scale from 0 (*Not Stressful*) to 3 (*Extremely Stressful*). Total scores are calculated by summing individual scores and higher scores indicate higher levels of perceived stress. Previous research with the FSCI found high internal consistency ($\alpha = .89$), high test-retest reliability ($r = .80$), and face validity (Nachshen et al., 2003). In the current study there was also good internal consistency ($\alpha = .87$) and high test-retest reliability ($\alpha = .77$).

State Trait Anxiety Inventory (STAI; Spielberger, 1983). The STAI measures both current (state) and general (trait) anxiety using two scales with 20 items each. Participants rate how much each item describes them, currently or in general, on a scale from 1 (*not at all/almost never*) to 4 (*very much so/almost always*) for both the state and trait subscales, respectively. The scale provides total scores for both state and trait anxiety and higher scores reflect more symptoms of anxiety. In previous research, inter-item reliability for both the trait subscale (ranging from $\alpha = .72$ to $\alpha = .96$) and state

subscale (ranging from α = .65 to α = .96) was quite good (Barnes, Harp, & Jung, 2002).

Reliability was also good in the current study for both the trait (α = .79) and state (α = .91) scales.

State-Trait Depression Scales (STDS; Spielberger, Ritterband, Reheiser, & Brunner, 2003). The STDS measures current (state) and general (trait) symptoms of depression using 40 items, 20 from each scale (state and trait). Participants rate how much a given characteristic describes them, currently or in general, on a scale from 1 (*not at all/almost never*) to 4 (*very much so/almost always*) for the state and trait scales, respectively. Relevant items are reverse scored, and two total scores (state and trait) are calculated with higher scores reflecting more symptoms of depression. Previous research (Spielberger et al., 2003; ranging from α =.91 to α =.96) and the current study (α = .92 to α = .94) have found high internal consistency for both scales.

Kansas Inventory of Parental Perceptions (KIPP; Behr, Murphy, & Summers, 1992). The KIPP measures parents' perceptions of the contributions their child has made to their family (Positive Contributions), how their child compares to others around them (Social Comparisons), the causes of their child's disability (Causal Attributions), and the control they have over their child's disability (Mastery/Control). For the current study, the Positive Contributions domain was used to measure positive perceptions of the child with ASD. The other domains were not included. Parents are asked to rate each item in terms of how much they agree or disagree on a scale from 1 (*strongly disagree*) to 4 (*strongly agree*). The resulting score indicates how positively the parent perceives the effect of their child on their life, with higher scores indicating more positive perceptions. Each subscale on the KIPP had adequate to good internal consistency in the

standardization sample (mean Cronbach's α ranging from .66 to .87; Behr et al., 1992).

In the current study, internal consistency of the subscales ranged from acceptable (α =

.60) to excellent (α = .92). The subscale scores have not been found to be stable over

time, and rather they tend to reflect the current cognitions of the individual.

Child Functioning. The following measures were used to asses various

characteristics of the participants' children, including adaptive functioning, maladaptive

behaviours, and symptoms of ASD.

Scales of Independent Behavior-Revised Short Form (SIB-R SF; Bruininks,

Woodcock, Weatherman, & Hill, 1996). The SIB-R measures adaptive and maladaptive

behaviour by parent ratings of the child's ability on 40 different skills. Parents rate the

child's ability to complete each task on a 4-point scale ranging from 0 (*never or rarely*) to

3 (*does very well-always or almost always-without being asked*). Adaptive behaviour and

age equivalent scores are obtained, on which higher scores indicate more abilities or

adaptive behaviour. Parents are also asked to report whether the child engages in any of 8

different types of problem behaviour, and rate the frequency and severity of the

behaviour. General, internalized, asocial, and externalized maladaptive behaviour scores

can be calculated with lower maladaptive behaviour scores being more problematic.

Scores ranging from 10 to -10 fall within the "normal range", scores from -11 to -20 are

"marginally serious", -21 to -30 are "moderately serious", -31 to -40 are "serious", and

scores lower than -41 are "very serious". The SIB-R was standardized on a population

that included a sample of individuals with intellectual disabilities, and is reported to have

good to excellent internal consistency, high test-retest reliability, and good inter-rater

reliability (Bruininks et al., 1996).

Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003). The

SCQ is a parent-report measure used for screening children who may have ASD. Parents

are asked to answer 40 yes-no questions regarding the child's social and communication

skills. The Current Form, which was used for this study, asks about the child's

functioning over the last 3 months. The SCQ has good sensitivity, ranging from .71 to

.90, and specificity, ranging from .71 to .86 (Chandler et al., 2007; Corsello et al., 2007).

For this study, the SCQ was primarily used for screening participants for inclusion.

Consistent with the literature (Corsello et al., 2007), a cut-off score of 15 was used for

children 8 years and older, whereas a cut-off score of 11 was used for children under 8

years.

Post-session and post-group evaluations of the parent support group.

Participants in the online support group were asked to complete brief post-session

surveys after each of the support group meetings. They rated their satisfaction with the

support they received and with the topic discussed during the session on a 5-point scale

from 1 (*Very Dissatisfied*) to 5 (*Very Satisfied*). The participants also reported the most

and least helpful aspects of the session and provided suggestions for future topics.

In addition, parents who participated in the support group were asked questions

about the group in their post-treatment questionnaires. Specifically, parents were asked to

indicate how many of the sessions they had attended, their reason(s) for missing sessions,

and whether they thought it was important to change something about the group in order

to improve attendance. Parents also used a 10-point scale ranging from 1 (*Very

Dissatisfied*) to 10 (*Very Satisfied*) to rate their overall satisfaction with the support

received during the group, and they reported qualitatively the most and least useful

aspects of the group.

Procedure

      Participants were initially recruited to participate in a larger study on support

group use among parents of children with ASD through multiple sources including

postings on websites and online forums, mailings through research labs and agencies in

several Ontario cities, flyers in agency waiting rooms, and ads in newsletters. Parents

were invited to complete a series of questionnaires in a secure online survey program. If

participants did not complete all of the questionnaires at once they received a reminder

via email to return and complete the remaining questionnaires. It took about 1 hour to

complete the questionnaires, which served as the pre-group time point in this study. At

the end of the 8-session support group, participants completed a post-group survey, which

consisted of a selection of the measures they had completed during the pre-group survey

(see above) and took about 30 minutes to complete online. Parents who did not

participate in the online support group and who had completed the pre-group survey were

invited to be part of the control group for this study and were also asked to complete the

post-group survey.

      Online parent support group. Participants who indicated an interest in

participating in the online PSG were invited to participate and were asked to select from

several possible meeting times for the PSG. Meeting times were chosen based on the

preference of the parents with 5 to 10 parents registered in each of the groups, although

on average 3 parents attended each session. Four of the five groups were held from 9:00

pm until 10:00 pm on weekday evenings, whereas the fifth was held from noon until 1:00

pm on a weekday. Parents also chose the frequency of meetings, with 4 of the 5 groups

being held bi-weekly and one held weekly. Most groups ran for 8 sessions, except for one that ran for 7 sessions because of a statutory holiday on the day of one of the sessions.

Each parent was assigned an account with a pseudo-name and a private password to be used during the real-time online chat sessions. The facilitator also invited the parents to post comments and questions on an online discussion board that could be checked at their convenience. Following each session, the parents completed a short survey regarding their experience during that session and provided recommendations regarding changes to the format and structure for future sessions. The participants also recommended topics for future group sessions. The facilitator looked for common themes in the recommendations from the participants and chose topics that could apply to parents at various stages in parenting a child with ASD. The topics included: treatment issues, the impact of ASD on families, managing behaviour problems, coping with stress, advocacy, dealing with schools and the community, useful resources, and transitions. The topics for each group varied based on the interests of the members; however, most of these topics were covered in each group. In general the group sessions focused on providing mutual support and a sense of belonging among the participants, with specific topics structuring the discussion.

Facilitator. The facilitator was a Master's level clinician (doctoral student in clinical psychology) who was experienced in working with families of children with ASD and in facilitating psychoeducational groups. In addition to assigning the topics for discussion, the facilitator's roles during each session included coordinating the beginning of the session (e.g., inviting each participant to join the group chat and ensuring their technology was functioning so that they could participate); observing the session;

occasionally providing information or clarification; redirecting the conversation when the

discussion moved away from the topic; introducing subtopics to keep the discussion

flowing; drawing participants' attention to a question or comment that had not been

addressed; and reminding the participants when it was time to wrap up the session. The

facilitator sent emails to the participants reminding them of the upcoming meetings 3

days prior to the session, the morning of the session, and, for those who had not logged

in, 5 minutes after the session began. She also sent emails after each session reminding

the parents to complete the post-session survey and to share any resources that were

discussed during the group.

Data Analyses

Changes in the well-being of the parents in the treatment and control groups were

evaluated using a multivariate mixed model analysis of variance (MANOVA).

Specifically, differences in parenting stress, state anxiety, state depression, and positive

perceptions were examined between groups (treatment and control) and over time (pre-

and post-treatment). A series of multiple regressions was planned to evaluate the

relationship between PSG use, child functioning and parent psychological well-being, in

accordance with Baron and Kenny's (1986) guidelines for assessing moderators. The

multiple regressions included; 1) child functioning as a predictor and psychological well-

being as the outcome variable, 2) support group use as the predictor and psychological

well-being as the outcome variable, and 3) child functioning and support group use as

predictors and psychological well-being as the outcome variable.

Previous studies examining the outcome of participation in PSGs have been

limited by insufficient power due to small sample sizes (ranging from $N = 10$ to $N = 14$;

Bitsika & Sharpley, 1999; 2000; Fontana, Fleishman, McCarton, Meltzer, & Ruff, 1988; Troester, 2000). For the purposes of the current study, I had proposed to recruit 60 participants in order to have the power to detect a medium effect size ($\eta^2 = .06$) in the overall result of a MANOVA 80% of the time ($\alpha = .05$). However, I was only able to recruit 45 participants, therefore I had the power to detect a medium effect size ($\eta^2 = .06$) in the overall result of a MANOVA 71% of the time ($\alpha = .05$) or a significant interaction (i.e., moderator) 24% of the time (Faul, Erdfelder, Lang, & Buchner, 2007). This study had the power to detect a Pearson correlation with a medium effect size ($r = .36$) 80% of the time (Faul, Erdfelder, Buchner, & Lang, 2009).

Results

Descriptives

Support group participants. All of the parents who participated in the online PSG were mothers and their mean age was 43 years ($SD = 5.61$ years), though these participants ranged in age from 33 to 53 years. The majority of these parents were in a relationship (80 %) with most being married ($n = 15$) and one living in common-law ($n = 1$), whereas few were single ($n = 3$) or divorced ($n = 1$). Most of the parents who participated in the online PSG had attended college or university (90%, $n = 18$); 20% had a college diploma ($n = 4$), 30% had a university degree ($n = 6$), and another 30% had a professional or graduate degree ($n = 6$). The parents' reported annual household incomes ranged from $19,000 to $600,000, with the median income being $83,000. Fourteen of the parents lived in Canada (70%) and the remaining 6 lived in the United States (30%). Prior to participating in the online PSG, the parents reported experiencing mild to moderate parenting stress ($M = 38.50$, $SD = 14.49$), and few symptoms of state anxiety

(M = 20.80, SD = 8.65) or depression (M = 19.65, SD = 7.65). They also reported that in some aspects of their life their child with ASD had made positive contributions and in other aspects they had not, thus their mean score on the measure of positive perceptions was between "agree" and "disagree" (M = 137.80, SD = 22.98). None of the variables measuring well-being showed significant skewness or kurtosis.

The children (17 boys and 3 girls) of the parents who participated in the online PSG ranged in age from 2 to 22 years with a mean age of 9 years (SD = 4.83 years), and they had a variety of diagnoses. The parents reported that half of the children (n =10) had a diagnosis of Autistic Disorder or Autism, 30 % had PDD-NOS (n = 6) and 20% had Asperger's Syndrome (n = 4). One of the children had a co-morbid diagnosis of intellectual disability. The children also varied in their functioning level and their mean adaptive behaviour score had an age equivalent of about 3 years, 10 months (M = 65.25, SD = 20.19), and ranged from 9 months to 14 years, 6 months, which is significantly lower than their mean chronological age. Overall, these parents reported that their children had some behaviour problems with the mean general maladaptive behaviour score falling within the Moderately Serious range (M = -21.05, SD = 16.64).

Control group. The majority of the parents who participated in the control group were mothers (n = 23); however, there were also 2 fathers in this group. These parents ranged in age from 26 to 65 years with a mean age of 43 years (SD = 8.42 years). Most of the parents were married (n = 20, 80%), two were in common-law relationships (n = 2), two were single (n = 2), and one was divorced (n = 1). This was also a highly educated group with 96% having completed some college or university (n = 24). Sixteen percent (n = 4) had a college diploma, 20 % had an undergraduate degree (n = 5), and 36 % had a

professional or graduate degree ($n = 9$). The parents in the control group reported that their household incomes ranged from $17,000 to $200,000 with a mean income of $89,541 ($SD = $48,538$). Most of the parents ($n = 19$) lived in Canada, and the others were in the United States of America ($n = 6$). The parents in the control group reported experiencing mild to moderate parenting stress ($M = 37.00$, $SD = 11.27$), and few symptoms of state anxiety ($M = 21.45$, $SD = 6.02$) or depression ($M = 20.38$, $SD = 8.34$). In some aspects of their life, their child with ASD had made positive contributions and in other aspects they had not, thus their mean score on the scale measuring positive perceptions was between "agree" and "disagree" ($M = 129.12$, $SD = 26.82$). None of the variables measuring well-being showed significant skewness or kurtosis.

The parents in the control group had children (24 boys and 1 girl) ranging in age from 3 to 17 years with a mean age of 10 years old ($SD = 4.14$ years). They reported that their children had a variety of diagnoses within the autism spectrum, with the majority having a diagnosis of Autistic Disorder or Autism ($n = 13$), 40% with Autism Spectrum Disorder ($n = 10$), 24 % with Asperger's Syndrome ($n = 6$), and one with PDD-NOS ($n = 1$)[5]. Two of the children also had co-morbid intellectual disabilities. These children were reported to have a range of adaptive behaviour with the mean score at the age equivalent of 5 years, 2 months ($M = 71.08$, $SD = 16.09$) and ranging from 1 year, 6 months to 11 years, 8 months, which is considerably lower than the mean chronological age for this group. In addition, these children were described as having few behaviour problems ($M = -16.64$, $SD = 12.28$).

The parents who participated in the online PSG did not differ significantly from

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[5] Note: These categories were not mutually exclusive; some parents indicated that their child had both Autism and Autism Spectrum Disorder, likely because the child was given different diagnoses by different professionals.

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the parents who participated in the control group on any of the demographic variables, nor did either group of parents differ significantly from the parents who were invited, but did not participate in this study (Table 4).

Table 4

Demographics for Participants in the Treatment and Control Groups, and Parents who did not Participate

Demographic Variable	Treatment (*n* = 20) Mean (*SD*)	Control (*n* = 25) Mean (*SD*)	Non-Participant (*n* = 107) Mean (*SD*)	*F*
Household Income	$113,444 ($133,466)	$89,541 ($48,538)	$121,419 ($348,661)	0.11
Parent Age (years)	42.70 (5.61)	42.82 (8.42)	41.08 (7.08)	0.89
Child Age (years)	9.32 (4.83)	9.81 (4.14)	9.10 (4.67)	0.26
Child Adaptive Behaviour	65.25 (20.19)	71.08 (16.09)	68.80 (18.68)	0.56
Child Maladaptive Behaviour	-21.05 (16.64)	-16.64 (12.28)	-18.35 (11.20)	0.73
Child ASD Symptoms	22.40 (5.00)	20.00 (8.11)	19.80 (4.88)	1.88

Group Attendance

As outlined above, 119 parents were invited to participate in the PSG; 30% (*n* =

36) of the invited parents registered for a group, and 25% ($n = 30$) of the invited parents attended at least one session. Sixty-four percent ($n = 23$) of the parents who initially registered attended 3 or more of the support group sessions, whereas 25% attended 6 or more sessions ($n = 9$), and only 1 parent attended all of the sessions in her group. Despite numerous reminders, only 56% ($n = 20$) of the parents who initially registered for the groups completed the post-group survey. The most common reasons that parents who had participated in at least one session reported for not attending the meetings were scheduling conflicts ($n = 10$), problems with computer or internet access ($n = 6$), illness ($n = 4$), forgetting to login ($n = 4$), and being too busy ($n = 3$). One parent indicated that the group was not useful to her and that she did not receive enough support from the group, so she chose to stop attending. None of the other parents chose these latter two options as the reasons they did not attend the sessions. When asked specifically, 75% ($n = 15$) of the parents who had participated in at least one session said they would not recommend changing anything about the group in order to increase attendance.

Effects of Online Parent Support Group

Changes in the well-being of the parents (i.e., parenting stress, anxiety, depression, and positive perceptions) were examined between the treatment and control groups and over time (pre- and post-treatment). Neither the main effects of group, nor the main effects of time, nor the group by time interaction were significant, and the observed power for these analyses was low (i.e., .31, .21, and .09, respectively). As discussed above, the participants had relatively high well-being scores (Table 5).

Table 5

Well-being Scores for Parents in the Treatment and Control Groups Pre- and Post-Parent Support Group

Variable	Treatment ($n = 20$)		Control ($n = 25$)		
	Pre-PSG Mean (*SD*)	Post-PSG Mean (*SD*)	Pre-PSG Mean (*SD*)	Post-PSG Mean (*SD*)	Interaction *F*
Parenting Stress	38.50 (14.49)	37.10 (12.67)	37.00 (11.28)	33.52 (10.53)	0.42
Positive Perceptions	139.84 (29.67)	138.74 (15.81)	129.58 (27.29)	133.25 (17.24)	0.83
Anxiety Symptoms	20.80 (8.64)	21.75 (7.36)	21.46 (6.02)	21.63 (7.81)	0.21
Depression Symptoms	19.65 (7.65)	19.20 (6.13)	20.38 (8.34)	20.04 (6.80)	0.01

Perceived usefulness of support group participation was hypothesized to be a predictor of parental well-being and a moderator of the relationship between child problem behaviours and parental well-being. Overall the parents rated the group as useful ($M = 7.35$, $SD = 2.21$); however, there was not a significant relationship between perceived usefulness of the PSG and parenting stress ($r = .36$, $p = .12$), state anxiety ($r = .25$, $p = .30$), state depression ($r = .14$, $p = .57$), or positive perceptions ($r = .01$, $p = .99$) among the support group users post-group. Child maladaptive behaviour (SIB-R General Maladaptive Index, $M = -21.30$, $SD = 14.02$, Moderately Serious Range) was

significantly correlated with parenting stress ($r = .64$, $p < .01$), state anxiety ($r = .76$, $p < .001$), and state depression ($r = .74$, $p < .001$), but not with positive perceptions ($r = .21$, $p = .37$). Child adaptive behaviour was significantly correlated with positive perceptions ($r = .49$, $p < .05$), but not with the other measures of well-being, and child age was not correlated with any of the variables measuring well-being. Due to the small sample size and the lack of significant correlations between the variables (Table 6), the proposed multiple regressions to investigate moderation were not calculated.

Table 6

Pearson Correlations between Child Characteristics and Parent Well-Being in Online Support Group Users

Parent Well-Being	Child Characteristics			
	Maladaptive Behaviour	Adaptive Behaviour	Autism Symptoms	Child Age
Parenting Stress	-.64**	-.18	.38	-.25
Positive Perceptions	.21	.49*	-.40	.13
State Anxiety Symptoms	-.76**	-.05	.38	-.36
State Depression Symptoms	-.74**	-.24	.34	-.29

*$p < .05$, ** $p < .01$

Satisfaction with the Online Parent Support Group

Parents who participated in the PSG were asked to rate their satisfaction with the support they received during each session and with the topics of discussion for each

session on a 5-point scale. Overall, parents reported being "Satisfied" with both the

support received (*M* = 4.10, *SD* = 0.93) and the topics discussed (*M* = 4.12, *SD* = 0.90) in

the sessions. This was the general finding for each of the sessions (see Figure 3).

Following the completion of the group, when asked to rate the usefulness of the support

group overall on a 10-point scale, parents reported that the group was useful (*M* = 7.35,

SD = 2.21), and they reported receiving a moderate amount of support from the group (*M*

= 6.85, *SD* = 2.30).

Figure 3. Bar graph of satisfaction with support received and topics discussed during

PSG sessions
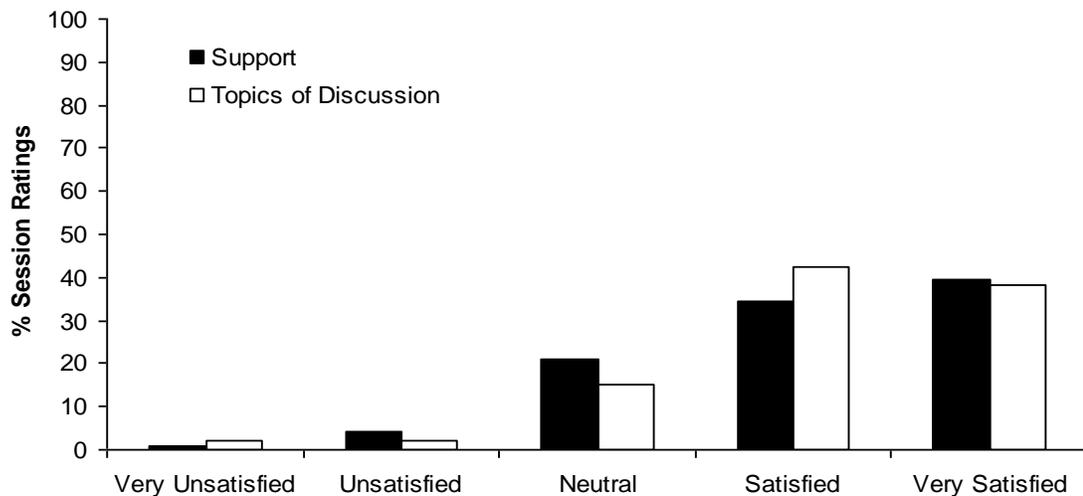
When asked to report qualitatively about the most and least useful aspects of the

group, while the participants tended to have similar beliefs about the most useful aspects

of participating in the PSG; there was more variability in their reports of the least useful

aspects. Many parents reported that the most useful aspect of the group was the

opportunity to connect with other parents (*n* = 8) and to gain information about resources

(*n* = 5). In addition, a few of the participants (*n* =3) reported that the facilitation provided

was the most useful aspect of the group, and one parent reported that helping with a research project was useful. In terms of the least useful aspects of the group, some parents reported issues with the online format, such as the delay in receiving responses ($n = 2$) or participants typing at the same time ($n = 1$). Other parents reported that the differences in experiences of the parents, such as age of child ($n = 1$) or geographic location ($n = 2$) made the group less useful. A couple of parents were concerned with attendance ($n = 2$), one found that other parents' complaints were not useful, a couple ($n = 2$) reported that some of the topics were difficult to chat about, and one reported that she wanted more resources from the facilitator.

Discussion

This study faced many of the same challenges that other studies of PSGs have encountered (Bitsika & Sharpley, 1999; 2000; Fontana et al., 1988; Troester, 2000) and unfortunately it was not possible to answer the main research questions concerning the effects of participating in an online support group for parents of children with ASD. Previous studies had sample sizes ranging from 10 to 14 participants in the PSG (Bitsika & Sharpley, 1999; 2000; Fontana et al., 1988; Troester, 2000), and used exploratory data analyses (e.g., regression line of best fit) and under-powered (.43) multivariate analysis of variance (MANOVA) to analyze differences across time (Bitsika & Sharpley, 1999; 2000). The current study had a sample size of 45 and the power to detect a medium effect ($r = .36$) 80% of the time, therefore, it would appear that the effect size for the relationship between perceived usefulness of the PSG and parental well-being was below this level. The power to detect moderator effects is generally very low, because the test is in the interaction term. This study only had the power to detect a medium effect ($\eta^2 = .06$)

of the interaction between time and treatment group on well-being 24% of the time, and no such effect was detected. It is possible that because the parents had relatively few symptoms of anxiety and depression, and little parenting stress, as in a previous study (Bitsika & Sharpley, 2000), there was little room for change in their well-being scores.

This study did provide some descriptive information that will be useful for replicating this online PSG, and it provided information about parents' reports of their experiences while participating in this group. Similar to the research on in-person PSGs (Bitsika & Sharpley, 1999; 2000), the parents who participated in the online support group reported being satisfied with the support they received and the topics discussed during each session of the support group. In general, the parents reported that the group was useful and that they received some support from it. They especially enjoyed the opportunity to connect with other parents and share information about resources. It will be important, however, to replicate this study with a larger sample before firm conclusions can be made.

Theoretical Implications

Consistent with previous research (Bitsika & Sharpley, 2004; Blacher & McIntyre, 2006; Dabrowska & Pisula, 2010; Eisenhower et al., 2005; Hamlyn-Wright et al., 2007; Lecavalier et al., 2006; Sharpley et al., 1997), parents reported that their children displayed behaviour problems and the severity of behaviour problems was correlated with parental well-being. Unfortunately, I was not able to assess the merits of the Stress Buffering Model in understanding the impact of an online support group for parents of children with ASD. Although this study did meet the criteria outlined by Vaux (1988) - the stressor (child functioning) was related to the outcome (perceived stress) and

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the buffer (support group use) was deemed useful by participants - there was not enough power to assess the moderation. Further research examining this model as it applies to this population is warranted as this study was largely inconclusive, and the model has been successfully applied in other populations and has promise to be relevant for parents of children with disabilities who experience considerable stress in their lives.

Clinical Implications

The development of this online support group for parents of children with ASD is a first step in developing accessible, cost-effective, and efficient means of supporting parents of children with ASD. To this author's knowledge, no other online support programs for this population have been developed and researched in a systematic way (i.e., with pre- and post-group data collection, and post-session data collection). The online nature of the group offers the potential to reach parents who may not participate in traditional support groups because of geographic location, lack of child care, or inconvenience. Further development of online support groups should continue in order to find ways to support as many parents as possible.

For parents of children with disabilities, connecting with other parents is seen as an excellent way to enhance well-being (Kerr & McIntosh, 2000; Soloman et al., 2001). Although Bitsika and Sharpley (1999) also failed to find many statistically significant changes over time, their parents reported that the in-person PSG was helpful, especially because of the opportunity to connect with other parents. The same was true in the current study, despite the fact that these parents had never met face-to-face. For most parents, having even one other parent to chat with was helpful, and they did not need a large group in order to feel supported or heard. This sentiment was captured in the

qualitative responses of the participants, many of whom reported that the support, understanding, and validation received from other parents were the most useful aspects of participating in the group. Furthermore, many participants valued the experience as it made them feel as though they were not alone. The second most commonly reported benefit of the group in the current study was access to information about resources and services, which is also an important reason to connect parents with each other.

Clearly, further research is needed to determine the true effectiveness of this online support group for parents of children with ASD. However, based on the experience of the author in this study, the following recommendations are made to clinicians who are interested in implementing this type of group: 1) ensure that the facilitator is experienced and comfortable working with families of children with ASD and is able to think quickly to intervene effectively during group sessions; 2) clearly outline the format and expectations of the group at the beginning of the group to ensure that parents understand that it is a mutual parent support group, rather than a facilitator-led psychoeducational group; 3) find ways to encourage regular attendance in order to obtain the most benefit for the parents involved; 4) if numbers permit, consider dividing parents into groups based on the age of the children and/or geographic location; 5) encourage parents to take a role in deciding the focus and direction of the group, including the frequency of meeting times and the topics of discussion; and 6) encourage the development of relationships among the parents.

Limitations and Directions for Future Research

It is difficult to know whether the lack of differences over time and between groups was due to relatively high well-being scores among the participants prior to

participation in the group or one of the following possible limitations: small sample size, an ineffective intervention, the variables chosen to measure change over time, the measurement tools chosen, or some other problem. Future research with this population should focus on ruling out these potential problems when examining the effectiveness of support groups for parents of children with ASD.

Sample size. Recruitment and participant retention were major concerns in this study and in other studies of PSG use (Bitsika & Sharpley, 1999; Fontana et al., 1988; Smith et al., 1994). The majority of parents who indicated an interest in participating in this online parent support group did not, in the end, register for a group. Of those who registered, many did not attend even half of the sessions. Other researchers report similar issues with attendance in their studies of support groups in this population (Bitsika & Sharpley, 1999) and in parents of children with other disabilities (Smith et al., 1994) and special needs (Fontana et al., 1988). For example, Troester (2000) invited 200 parents of children in special education to participate in PSGs at the school, 20 parents registered for the groups, and only 12 of these parents attended a group. Eight more parents were registered with the groups, for a total of 20, with only 10 completing the post-group survey. Troester did not complete any quantitative data analyses. In another study, parents of infants in neonatal intensive care unit (NICU) were invited to participate in a PSG ($n = 53$) or a control group ($n = 41$), and 60% ($n = 32$) and 88% ($n = 36$) agreed to participate, respectively (Fontana et al., 1988). However, of those who agreed to participate in the PSG, only 12 (38%) attended at least one session, and the authors were not able to calculate changes over time. Interestingly, most of the parents who completed the post-group survey (75%) in the current study indicated that the low attendance was

not something they would change or consider a problem. Researchers who examine

support groups for parents of children with ASD in the future should expect a very low

proportion of interested parents to actually register and attend the support group, and

thus, efforts should be made to recruit many more parents than are required for sufficient

power in the study. Unfortunately, the issue of poor attendance is also a common problem

for in-person parent support groups (Smith et al., 1994). Further research should examine

whether the online format of the group is able to improve attendance rates by directly

comparing online and in-person support groups. Further, the role of individual

differences and preferences of parents could be important in optimizing attendance and is

worthy of investigation.

Group. This support group had not been implemented before being evaluated in

this study; however, parts of its design were based on previously researched groups

(Bitsika & Sharpley, 1999) and on groups currently available in the clinical community.

Any number of variables related to the group design could have affected whether or not

significant changes were found post-group. For example, perhaps a greater number of

group sessions overall would have yielded more changes in parents' well-being, or

perhaps longer sessions or more frequent sessions would have had a different effect.

Parents liked the topics of discussion, but it is possible that other topics might have led to

more change in well-being. Bitsika and Sharpley (1999; 2000) found that parents seemed

to prefer more strategy-focused groups that had the goal of teaching parents to cope with

stress rather than groups like those conducted in the current study that had a less direct

focus, only connecting parents and allowing them to discuss topics of interest, although

this preference is not supported by all researchers (Smith et al., 1994; Solomon et al.,

2001). Program evaluation of support groups that are implemented clinically could help to determine which of these variables may be the most important contributors to change in well-being for parents of children with ASD.

Given that expectations for the group and parent needs may have an affect both on outcomes and attendance, it may be particularly useful to ask parents about their expectations and needs. If sample size warrants, it may be helpful to group parents based on their expectations for the group (e.g., share resources, find others like me) in order to best meet the needs of these parents. Monitoring whether expectations are met across the sessions may make it possible to make changes to the group in order to retain more participants and provide the most appropriate support to these participants. Because of the small number of parents who registered for the online support groups, all parents who were available for a given time were included in that session. Some parents indicated that being in groups with others with similar experiences to themselves would have been more useful, especially with respect to parents of older children who were under-represented in this study. In the future, efforts should be made to offer separate groups to parents of older and younger children and to separate groups by geographic location.

Measures. It is important to consider the outcome measures used when examining explanations for the lack of change over time in this study. Although the measures chosen have sound psychometric properties, it is possible that the constructs measured would not change over relatively short term involvement in an intervention. It is also be possible that only responses to certain items might change over the course of treatment and the subsequent changes in the total score on the measure may not be large enough to yield a noticeable difference given the sample size.

Another possible limitation related to measures is that different variables could change for different parents at different times, which may mean that examining group effects may not demonstrate real changes over time, although individual changes may have occurred. Further investigation of these possible issues is warranted; choosing theoretically important items for examination rather than total scores may provide more sensitive measures of outcome. For example, the parents in this study reported qualitatively that the group was useful in providing connection with other parents, making parents feel less alone, and increasing knowledge of resources. Thus, if parents were specifically asked about these experiences and if changes in their reports were measured over time, group participation could be found to enhance a parent's well-being when measured in this way. In an unpublished study of the effects of a support group for parents of children with Asperger's Syndrome (AS; Viecili, Weiss, & Lunsky, 2010), the researchers found that parents reported increases in their empowerment to access services in the community, greater acceptance of their child and their feelings toward their child, and more positive feelings towards having a child with AS. These findings suggest that empowerment, acceptance, and beliefs and feelings about the child are important outcome measures for future studies of parent support groups.

Conclusions

This is a unique study, the first known to this author to investigate changes in parental well-being following involvement in an online support group for parents of children with ASD. Unfortunately, I was not able to detect any changes in parental well-being; however, the parents who participated in this online PSG reported being satisfied

with the group and with the support they received. This study provides suggestions for both clinical work and research in the new and innovative area of online support.

Chapter 4: General Discussion

This project aimed to add to the sparse literature on parent support groups (PSGs) for parents of children with ASD by 1) investigating differences between parents who use PSGs and those who do not and 2) measuring outcomes for parents of children with ASD who participated in an online PSG. Taken together, the results of these studies suggest that parents of children with ASD may benefit from individualized supports that are tailored to their needs, coping style, and lifestyle. For those parents who do not cope by seeking support, support groups may not be the best way to intervene; however, for other parents, such groups can be beneficial. Further research is required to investigate outcomes associated with participation in online PSGs, although this type of support may be ideal for parents who find traditional, in-person support groups to be inaccessible. These studies provide new information regarding the use of PSGs among parents of children with ASD. Specifically, the study of the outcomes associated with an online PSG provides a starting place for the development of guidelines related to the use of the internet in providing support to parents.

Theoretical Implications

These studies focused on evaluating the application of two distinct models: the Self-Regulatory Model (SRM) and the Stress Buffering Model for understanding 1) differences between parents of children with ASD who have or have not participated in PSGs and 2) the impact of an online support group for parents of children with ASD. There was some evidence to support aspects of the SRM fitting with this population. Specifically, how parents approach a stressor (i.e., coping style), their experiences with PSGs, and the availability of PSGs that fit within their lifestyle were important in

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differentiating between those who do and do not participate in PSGs. These findings suggest that in future research examining the participation of parents in support groups, parents' distress, mood, beliefs about controllability of their child's difficulties, and level of social support may not be relevant for distinguishing between participants and non-participants, although further research examining the role of both parent and child characteristics may provide additional information. As there was not enough power in this study to assess the fit of the Stress Buffering Model it was essentially untested in this study, thus; further research is needed to test its usefulness.

Clinical Implications

The results of these studies indicate that, for at least some parents of children with ASD, parent support groups can be a useful source of support. Few studies have examined either predictors or effects of support group use in parents of children with ASD, hence, it can be difficult to draw conclusions about how to best support these parents. The current studies provide both some preliminary information about how parents of children with ASD may be supported using PSGs and a model for implementing and evaluating an online PSG. Further research is required to provide support for these recommendations, but until this research is available, these guidelines can be considered.

This research found that, much like their children, parents of children with ASD are a heterogeneous group with diverse support needs. Determining how best to support individual parents can be done through discussions with each parent that include the following topics: 1) experiences with PSGs, 2) beliefs about PSGs, 3) coping style, 4) potential barriers to participating in in-person PSGs, and 5) perceived support needs. The

following factors have been identified as indicators that the parent will be best supported by traditional in-person support groups: 1) previous positive experience with support groups, 2) coping by seeking instrumental and emotional support, and 3) perceiving few difficulties with the logistics of attending in-person groups (i.e., scheduling, travel, and childcare). On the other hand, parents may be best supported by alternatives to in-person support groups, such as online support groups, if they indicate 1) they have not tried a support group because of difficulties with physically attending and 2) they believe support groups to be beneficial. Finally, parents who would likely be better supported by services other than PSGs, such as respite, may report 1) having tried PSGs and not found them beneficial and 2) coping in ways other than seeking instrumental or emotional support.

The finding that past negative experience with PSGs affected future enrollment or interest in PSGs is important to consider when developing and implementing these types of groups. It will be important to identify early in the intervention which parents may be better suited to another type of intervention and to refer them to that intervention in order to reduce the likelihood of frustration or unmet needs and a subsequent avoidance of this (or any other) type of support in the future. When parents express an interest in participating in PSGs, it is prudent to help the parent identify their goals for the group and find a group that is well matched to these goals. Making the goals and focus of PSGs clear from the outset (i.e., prior to registration) will also be helpful for all (potential) participants.

Directions for Further Research

In these studies and in the literature (Bitsika & Sharpley, 1999; Smith et al., 1994), two of the major difficulties in supporting parents through participation in support groups are recruitment and retention. One possible way to increase the amount of data collected from parents and to improve participant attendance is to complete the research in clinical settings. Although parents report a number of reasons for not attending the sessions, scheduling conflicts and being too busy were common explanations reported in this study that are often reported clinically. In their study of support groups for parents of infants who were in neonatal intensive care, Fontana and colleagues (1988) suggested that focusing intervention first on the child and later on the parent may yield better recruitment and retention. Anecdotally, parents in the present study reported that it was much easier to commit to attending appointments that were intended for the direct benefit of their child, than to commit to attending appointments for themselves, such as supportive counseling or PSGs. A recent study (Viecili et al., 2010) examining a group for parents of children with Asperger's Syndrome capitalized on this trend by requiring that parents wait for their children, who were participating in a therapeutic group, in a room together with a facilitator. The authors reported that they believed it was important not to refer to the group as a "support group"; rather it was presented as a social group for parents waiting for their children. Furthermore, the fact that parents were required to wait for their child while their child attended a therapeutic group rendered attendance mandatory, while allowing parents to feel as though they were attending in order to support their child. Given the high retention rate in that study (93%), it is recommended that future research investigate the effectiveness of offering parent groups concurrently

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with groups for children with an expectation that parents must stay in the clinic while their child attends the group. In addition, scientifically investigating the effect of removing the title "Parent Support Group" from the name of groups is warranted.

Given that the current studies are among the few that have examined the use of PSGs in parents of children with ASD, further research is certainly required in this area in order to broaden knowledge related to how best to support these parents. There are many agencies currently offering support groups for parents of children with ASD. For example, in Ontario most Autism Ontario chapters and Autism Intervention Programs offer PSGs, although there are not published statistics on the number of programs available. If these agencies were encouraged to evaluate their programs, the information collected would provide an excellent base for understanding the potential benefits of participation in PSGs. Combining the information collected from multiple agencies or programs would increase the power for measuring the effects of the groups; however, it would be important to ensure that this combining of information does not serve to "wash out" true differences or effects by grouping the data according to relevant participant and support group variables. Research comparing different approaches to support, such as didactic, psychoeducational, mutual support, and parent-to-parent support may help to further identify indicators that are associated with a match between support provided and individual support needs and might provide evidence for one type of support as more effective. Projects that focus on learning from parents how they would like to be supported would likely identify excellent alternatives to PSGs. Finally, continued efforts to incorporate technology in the development of support for parents would likely be well received by participants.

Summary and Conclusions

These studies provide new information related to the relatively under-researched topic of support for parents of children with ASD. Overall, the results suggest that parents of children with ASD can be well supported by both traditional in-person support groups and online PSGs, particularly if they believe these supports will be beneficial, do not perceive difficulties with attendance, and use more active, support-seeking coping strategies. However, there appears to be a subset of parents who would be better supported by alternatives to parent support groups. Further research is required to determine the types of support that would best meet the needs of these parents. In addition, through the course of this project, an online PSG was developed and implemented. Further research is required to evaluate the effectiveness of such groups, although the results at this point are promising. With further research on the use of PSGs for parents of children with ASD more effective systems of support can be developed for these parents who report experiencing more stress and poorer psychological well-being than other parents.

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Appendix A: Letter of Information and Consent Form for Study 1

You are invited to participate in a study on…..

Support Groups for Parents of Children with Autism Spectrum Disorders:

Predictors and Benefits of Involvement

PART 1
Letter of Information and Consent Form

What is this study about? We want to learn about the experiences of parents of children with autism spectrum disorders. We are especially interested in your experiences with parent support groups, and would like to learn how best to support all families of children with autism spectrum disorders.

Why should I participate? You can help us develop a better understanding of the experiences of parents of children with autism spectrum disorders. After getting information from many parents we hope to understand the types of support that parents of children with autism spectrum disorders need. If you are interested you may become involved in Study 2 where you can become a member of a new online parent support group.

Who would we like to participate? We would like parents of children who have been diagnosed with autism spectrum disorders to participate. Parents with children with autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), Aspergers disorder, or autism spectrum disorder are invited to participate.

How long will it take? It should take you about 1 hour to answer all of the questions online. You do not need to complete all of the questions at once. You can save what you have done and come back later.

What will I be asked to do? You will be asked to complete an online questionnaire. There are questions about how you usually think, feel and act, how you interact with your child, and how you see your child and your child's disability. There are also some questions about your child's social and communication skills, and your experiences and preferences related to support groups.

What will happen to my information? The information we gather is private. We will keep all of the information confidential. No one will see your answers except members of the research team. The information about your identity (i.e., name, address, birth date) will be stored in a separate electronic file from your answers to the other questions. All of this information will require a password to be accessed.

None of the information you give us about you or your child will be shared with any other individual or group. (Note: we are under the same legal requirements as other

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professionals to report evidence of potential abuse.) However, we may send you information about other studies you may be interested in, if you are not interested in receiving this information please check the appropriate box below.

After gathering all of the information we will be writing a report to give to parents and other people involved in the study. Your name will not be in any of the information and no one will know your answers to our questions.

How can I become part of this study? If you would like to be a part of this study, please click the check box beside "Yes, I agree to participate" and complete the questionnaires that you are directed to.

What if I change my mind? If you decide you are no longer interested in participating in this study you can quit at any time without penalty. You are not required to participate in this study, your participation is completely voluntary.

People you can contact for more information:
Tess Clifford, Project Leader, 4tc29@queensu.ca, (613) 533-3059
Dr. Patricia Minnes, Project Supervisor, patricia.minnes@queensu.ca , (613) 533-2885
Dr. Albert Clark, Queen's University Health Sciences Research Ethics Board Chair, (613) 533-6081

I have read and understand this consent form and agree to participate in the research described.
My participation in this study is voluntary.
I understand that I may refuse to participate or withdraw at any time without any penalties of any kind.
I understand that my information will be kept confidential.
I understand that I can contact the people listed above if I have any questions.

⦾ Yes, I agree to participate.

⦾ No, I would not like to participate.

⦾ I would like to receive information about other studies I may be interested in.

⦾ Please do not send me information about other studies.

Appendix B: Letter of Information and Consent Form for Study 2

You are invited to participate in a study on …..

Support Groups for Parents of Children with Autism Spectrum Disorders:
Predictors and Benefits of Involvement: PART 2
Letter of Information and Consent Form

Thank you for participating in PART 1. Our records indicate that you are interested in becoming involved in a new online support group. We are starting a new online support group for parents of children with autism spectrum disorders and would like to invite you to participate.

What is this study about? We want to learn about the effects of involvement in an online support group for parents of children with autism spectrum disorders.

Why should I participate? You can help us develop a better understanding of the benefits of support groups for parents of children with autism spectrum disorders and their children. You will be able to chat with other parents of children with autism spectrum disorders from around the world. You can share ideas, experiences, stories and other information with other parents, while also learning from them. You may make connections with other parents, develop new friendships and gain information.

Who would we like to participate? We would like parents of children who have been diagnosed with autism spectrum disorders to participate. Parents with children with autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), Aspergers disorder, or autism spectrum disorder are invited to participate.

How will the support group work? You will be randomly assigned to become involved in the online support group immediately or in 4 months. If you are not able to wait 4 months to begin the support groups we will provide you with information about other support groups that you can get involved in.

You will be asked to attend a one-hour online meeting every two weeks for the next four months. We will attempt to schedule a time that works for everyone, but we recognize that you may not be able to participate in every meeting. We hope that you can attend as often as possible.

What will I be asked to do? After 4 months you will be asked to complete the online questionnaires you completed in Study 1 again. There are questions about how you usually think, feel and act, how you interact with your child, and how you see your child and your child's disability. There are also some questions about your child's day-to-day skills, and your experiences and preferences related to support groups.

What will happen to my information? The information we gather is private. We will keep all of the information confidential. No one will see your answers except members of

the research team. The information about your identity (i.e., name, address, birth date) will be stored in a separate electronic file from your answers to the other questions. All of this information will require a password to be accessed.

When the support group begins you will be asked to provide a username and password, and only people with this information will be able to sign into the chatroom. The project leader will be present for all support group meetings, but will act as a moderator and speak only when necessary (e.g., to provide a topic of discussion). Transcripts of the online support groups may be used to gather information about the topics that are discussed in these types of groups. The transcripts will be stored securely in password protected electronic files, only accessible to the research team.

None of the information you give us about you or your child will be shared with any other individual or group. (Note: we are under the same legal requirements as other professionals to report evidence of potential abuse.) However, we may send you information about other studies you may be interested in, if you are not interested in receiving this information please check the appropriate box below.

After gathering all of the information we will be writing a report to give to parents and other people involved in the study. Your name will not be in any of the information and no one will know your answers to our questions.

How can I become part of this study? If you would like to be a part of this study, please click the check box beside "Yes, I agree to participate". We will contact you to let you know whether you are beginning the support group immediately or in 4 months, and to determine the times you are available to participate.

What if I change my mind? If you decide you are no longer interested in participating in this study you can quit at any time without penalty. You are not required to participate in this study, your participation is completely voluntary.

People you can contact for more information:
Tess Clifford, Project Leader, 4tc29@queensu.ca, (613) 533-3059
Dr. Patricia Minnes, Project Supervisor, patricia.minnes@queensu.ca , (613) 533-2885
Dr. Albert Clark, Queen's University Health Sciences Research Ethics Board Chair, (613) 533-6081

I have read and understand this consent form and agree to participate in the research described.
My participation in this study is voluntary.
I understand that I may refuse to participate or withdraw at any time without any penalties of any kind.
I understand that my information will be kept confidential.
I understand that I can contact the people listed above if I have any questions.

○ Yes, I agree to participate in the online parent support group.

○ No, I would not like to participate in the online parent support group.

○ I would like to receive information about other studies I may be interested in.

○ Please do not send me information about other studies.

Appendix C: Family Stress and Coping Interview

Family Stress and Coping Interview (FSCI)
(© Nachshen, Woodford, & Minnes, 2003)

Interviewer Instructions: Read the italicized statement below and then each "stressor"statement as listed and mark the stress ratings given by the parent or guardian. Where blanks appear, use the name of the child.

Instruction for Interviewee:

*For the next questions, you will need the scale that we sent you, Number 3-Stress, I am going to list some issues that you may or may not have encountered in your experiences as a parent of a child with special needs. You may have dealt with some of these issues in the past, and some may be coming up in the future. I'm going to ask you to rate a series of issues in terms of how stressful they are to you on a scale of 0 to 3. It is important that you tell me how stressful these issues **are now, at this time in your life**. Please use the scale to help you decide on a rating. You can choose not to answer specific questions if it makes you uncomfortable. Also, if you find the issues too upsetting, or if you feel that you cannot complete the interview and wish to stop, we will do so, and can set up an appointment to continue at another time.*

Not Stressful	Mildly Stressful	Moderately Stressful	Extremely Stressful
0	1	2	3

1. The diagnosis of _____ as having a developmental disability/delay……… ☐

2. Explaining to others about _____'s developmental disability/delay……… ☐

3. Your feelings about the cause of _____'s developmental disability/delay….. ☐

4. Dealing with friends/family/people in the neighbourhood on a day-to-day basis. ☐

5. Dealing with doctors and other allied health professionals…………………… ☐

6. Dealing with legal professionals…………………………………………… ☐

7. Dealing with _____'s teachers and the educational/preschool system… ☐

8. Creating and/or finding opportunities for _____ to make friends and participate in activities…………………………………………………………… ☐

9. Deciding on the best level of integration for _____............................. ☐

10. Making the decision concerning accommodation in the home or in the community…………………………………………………………………… ☐

11. Meeting the needs of your (other) children………………………………….. ☐

12. Meeting your own personal needs………………………………………….. ☐

13. Meeting the needs of your spouse/partner…………………………………. ☐

14. Maintaining satisfying friendships……………………………………….. ☐

15. Dealing with _____'s sexuality…………………………………. ☐

16. Work placements or employment for _____.................................. ☐

17. Long-term planning for accommodation for _____.................. ☐

18. Planning for wills, trusts, and guardianships…………………………………. ☐

19. Planning for emotional and social support for _____.................. ☐

20. Transportation………………………………………………………………. ☐

21. Day to day assistance with care of _____.................................. ☐

22. Time apart from _____.. ☐

23. Dealing with financial and insurance issues…………………………………. ☐

Appendix D: Types of Support Questionnaire

Types of Support
(adapted from Interpersonal Support Evaluation List, Cohen, et al., 1985; revised by McColl & Skinner, 1991)

For each statement below, please indicate if it is always true about you, usually true, sometimes true of never true about you. Try to decide **quickly** which answer is most correct about you. Please remember that this is not a test and there are no right or wrong answers.

Always True (3)	Usually True (2)	Sometimes (1)	Never True (0)	Not Applicable (9)

Instrumental Support

1. If I had to go out of town for a few weeks, I know I could find someone to look after my home/plants/pet etc.

2. If I needed a quick emergency loan of $100, there is someone I could get it from.

3. If I were sick, there is someone who would help me with my daily chores.

4. If I had to mail an important letter at the post office by 5:00 and couldn't make it, there is someone who could do it for me.

5. There is someone who would help with minor home modifications or repairs.

6. There is someone who would help with personal care it I needed it (e.g., bathing, dressing, toileting).

7. There is someone who helps with outdoor chores and heavy work when I need it.

Informational Support

8. There is someone who can give me good financial advice.

9. When I need suggestions for how to deal with a personal problem, there is someone I can turn to.

10. There is someone who can give me objective feedback about how I'm handling things.

11. There is someone I could turn to for advice about my work.

12. There is someone who I feel comfortable going to for advice about sexual problems.

13. There is someone I can ask for information or advice related to my child's disability.

Emotional Support

14. There are people who invite me to do things with them.

15. I know people who enjoy the same things that I do.

16. If I wanted to go out of town for the day, I could find someone to go with me.

17. People I know accept me as I am.

18. There is at least one person who really understands me.

19. There is someone who takes pride in my accomplishments.

20. I receive moral support and encouragement from a friend or family member.

21. There is someone with whom I can share my most private worries and fears.

22. There is someone who can sheer me up when I feel down.

23. How satisfied are you with the advice and information that you receive from others?

Very satisfied   Not satisfied at all
        10   9   8   7   6   5   4   3   2   1

24. How satisfied are you with the practical help you receive from people?

Very satisfied   Not satisfied at all
        10   9   8   7   6   5   4   3   2   1

25. How satisfied are you with the emotional support you receive from people?

Very satisfied   Not satisfied at all
        10   9   8   7   6   5   4   3   2   1

Appendix E: Views about Parent Support Groups Questionnaire

VIEWS ABOUT PARENT SUPPORT GROUPS
Participants in Support Groups Version

The following questions are about your views of parent support groups. If you are no longer actively participating in a group, please try to answer the questions below according to your thoughts and feelings when you did participate. Please circle the number that best represents your response to each statement (e.g. if you disagree a little, you would circle 3; if you neither agree or disagree, you would circle 4).

(1) Participating in a parent support group gives me useful information and advice about ASD

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(2) Participating in a parent support group gives me useful information about resources or help for my child with ASD and our family

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(3) Participating in a parent support group gives me positive role models for coping with ASD

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(4) Participating in a parent support group makes me depressed

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(5) Participating in a parent support group means I receive special understanding from people who have been through the same experience as me

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(6) Participating in a parent support group means I get burdened with other people's problems

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(7) Participating in a parent support group gives me a place of positive, mutual support outside the home

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(8) Participating in a parent support group helps me meet new people and make new friends

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(9) Most people who are important to me think that

      I definitely should not   1   2   3   4   5   6   7   I definitely should

participate in a parent support group

(10) My doctors and service providers think that

      I definitely should not   1   2   3   4   5   6   7   I definitely should

participate in a parent support group

(11) It was difficult for me to join a parent support group because of my worries or distress

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(12) It was difficult for me to join a parent support group because of the meeting time

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(13) It was difficult for me to join a parent support group because of the location

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(14) It was difficult for me to join a parent support group because of child care responsibilities

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(15) It is important to seek support not only for my child with ASD, but also for myself

      Strongly disagree   1   2   3   4   5   6   7   strongly agree

(16) What type of parent support group are you participating in? (check all that apply)
      ASD specific
      Developmental Disabilities specific

General parenting group
Other_____

(17) Are you interested in participating in a new online parent support group?
Yes, go to next question
No, I have no need for such a group
No, I am already attending another group
No, I do not have time to participate
No, I do not have access to a computer
No, it would be difficult for me to interact with other parents
No, other_____

(18) How often would you be interested in attending an online parent support group?
Once a week
Twice a month
Once a month

(19) How long would you like each group meeting to last?
_____

(20) Would you like to be able to contact other group members outside of the group meeting time (via email or private chat)?
Yes
No

(21) Would you prefer to be in a group with members from the same geographic region as you?
Yes
No

(22) Have you participated in a parent support group in the past?
Yes, in person
Yes, online
No

(23) Why are you no longer participating in the group?
The group was not helpful
No longer needed the support
Inconvenient location
Inconvenient time
Other _____

VIEWS ABOUT PARENT SUPPORT GROUPS

Non-participants Version

The following questions are about your views of parent support groups. Please try to answer the questions below according to your thoughts and feelings when you did participate. Please circle the number that best represents your response to each statement (e.g. if you disagree a little, you would circle 3; if you neither agree or disagree, you would circle 4).

(1) Joining a parent support group would give me useful information and advice about ASD

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(2) Joining a parent support group would give me useful information about resources or help for my child with ASD and our family

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(3) Joining a parent support group would give me positive role models for coping with ASD

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(4) Joining a parent support group would make me depressed

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(5) Joining a parent support group would mean I receive special understanding from people who have been through the same experience as me

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(6) Joining a parent support group would mean I would get burdened with other people's problems

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(7) Joining a parent support group would give me a place of positive, mutual support outside the home

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(8) Joining a parent support group would help me meet new people and make new friends

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(9) Most people who are important to me think that

I definitely should not   1   2   3   4   5   6   7   I definitely should

participate in a parent support group

(10) My doctors and service providers think that

I definitely should not   1   2   3   4   5   6   7   I definitely should

participate in a parent support group

(11) It would be difficult for me to join a parent support group because of my worries or distress

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(12) It would be difficult for me to join a parent support group because of the meeting time

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(13) It would be difficult for me to join a parent support group because of the location

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(14) It would be difficult for me to join a parent support group because of child care responsibilities

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(15) It is important to seek support not only for my child with ASD, but also for myself

Strongly disagree   1   2   3   4   5   6   7   strongly agree

(16) Are you interested in participating in a new online support group for parents of children with ASD?
Yes, go to next question
No, I have no need for such a group
No, I am already attending another group
No, I do not have time to participate

No, I do not have access to a computer
No, it would be difficult for me to interact with other parents
No, other_____

(17) How often would you be interested in attending an online parent support group?
Once a week
Twice a month
Once a month

(18) How long would you like each group meeting to last?
_____

(19) Would you like to be able to contact other group members outside of the group meeting time (via email or private chat)?
Yes
No

(20) Would you prefer to be in a group with members from the same geographic region as you?
Yes
No

(21) Have you participated in a parent support group in the past?
Yes, in person
Yes, online
No

(22) Why are you no longer participating in the group?
The group was not helpful
No longer needed the support
Inconvenient location
Inconvenient time
Other _____

Appendix F: Post-Session Evaluation

1. How satisfied were you with the support you received during this session?

Very unsatisfied   Unsatisfied   Neutral   Satisfied   Very Satisfied

2. How satisfied were you with the topics of discussion during this session?
Very unsatisfied   Unsatisfied   Neutral   Satisfied   Very Satisfied

3. What was most helpful about this session?

4. What was least helpful about this session?

5. Is there anything else you would like to share?

6. What topics would you like to cover in future sessions?

Appendix G: Post-Group Evaluation

1. How many online support group sessions did you attend?
0,1,2,3,4,5,6,7,8, I don't know

2. When you did not attend the online support group sessions, what was the reason? (check all that apply)

☐ I attended all the online support group sessions

☐ Not enough time

☐ Illness

☐ Scheduling conflict

☐ I did not receive support from the group

☐ I did not find the group useful

☐ I forgot to login

☐ I was too busy

☐ I was feeling stressed

☐ Problems with my computer/internet access

☐ Problems with the technology

☐ Session was at an inconvenient time

☐ Session was too long

☐ Session was too short

☐ Group met too often

☐ Group did not meet often enough

☐ Other (please specify)

3. Would you recommend changing the way the group worked in order to increase attendance?

☐ No

☐ Yes (please specify changes you recommend)

4. Overall, how useful did you find this online parent support group?

Not at all									Very much
1	2	3	4	5	6	7	8	9	10

5. Overall, how much support did you receive from this online parent support group?

Not at all   Very much

1   2   3   4   5   6   7   8   9   10

6. Do you have any other thoughts or recommendations to improve the online parent support group?

7. What was most useful about this support group?

8. What was least useful about this support group?

9. How many participants would be ideal in a group like this?