

Stress and Coping in Mothers of Children with Autism Spectrum  
Disorders

Karim Mekki

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**Dedication**

With immense love to my son Hamza, for being the wonderful child he is, for teaching me about autism, and for allowing me to join him on his journey through life.

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**Abstract**

Heightened levels of stress are observed in mothers of children with autism spectrum disorders (ASD), yet little is known about the relationship between stress and coping in mothers of children recently diagnosed with an ASD. The objectives of this study were to determine the levels of maternal stress, identify coping strategies used by mothers, examine the relationship between stress and coping, and ascertain whether coping mediated the relationship between ASD symptom severity and subsequent maternal stress. Data on 128 mothers of children who had received a diagnosis of ASD in the last four months were examined. Results indicated that mothers presented with elevated levels of stress. With regards to coping, escape-avoidance and confrontive coping were positively correlated with stress, while seeking social support was negatively correlated with stress. Confrontive coping did not mediate the relationship between ASD symptom severity and maternal stress. Results confirm previous findings, while underscoring the importance of helping mothers understand the relationship between the coping strategies they adopt and the subsequent stress they experience.

## Chapter 1: Introduction

The prevalence of autism spectrum disorders (ASD) in Canada is now estimated to be approximately 1 in 125 people, and approximately .8% of children have ASD (Lazoff, Zhong, Piperni, & Fombonne, 2010). This rate of incidence means a significant number of parents face the challenge of raising a child with an ASD. Receiving a diagnosis for ASD for one's child is often a traumatic experience, which can be even more difficult to bear due to the lack of support (Keenan, Dillengerger, Doherty, Byrne, & Gallagher, 2010). The result is a high prevalence of stress among parents of children with ASD (Sénéchal & des Rivières-Pigeon, 2009). Indeed, research indicates these parents endure higher levels of stress when compared to parents of typically developing children (Dabrowska & Pisula, 2010); parents of children with physical handicaps, such as cystic fibrosis (Bouma & Schweitzer, 1990); and parents of children with other developmental disabilities, such as Down syndrome (Dabrowska & Pisula, 2010). Currently, research supports the claim that parents of children with ASD endure the highest levels of stress when compared to both the general population and parents of children with other disabilities (Weiss, 2002). Stress in this population can lead to marital problems, financial problems, and a loss social support (Sénéchal & des Rivières-Pigeon, 2009). In addition, parental stress can increase behavioural problems among children with an ASD (Lecavalier, Leone, & Wiltz, 2006) and undermine the potential benefits of intervention (Osborne, McHugh, Saunders, & Reed, 2008).

According to the soon-to-be published Diagnostic and Statistical Manual of Mental Disorders (DSM-5), ASD is a single category disorder characterized by impairments in social communication and other relevant cognitive and motor behaviours.

This new approach asserts that ASD symptoms represent a continuum from mild to severe. As a result, separate diagnoses previously included within ASD will no longer be used (American Psychiatric Association, 2012).

In light of the complex web of stressors that result from caring for a child with ASD (Randall & Parker, 1999), a substantial number of studies have been conducted to understand the sources and implications of stress in parents of children with ASD. Some researchers have explored the severity of ASD symptoms as a potential mediator of stress in parents (Lyons, Leon, Roecker Phelps, & Dunleavy, 2010; Lecavalier et al., 2006; Konstantareas & Papageorgio, 2006). Other studies focused on problem behaviours in children with ASD and found these to be significant predictors of stress in this population of parents (Blacher & McIntyre, 2006; Floyd & Gallagher, 1997; Hastings, 2002). All of these approaches have included many variables, such as stressors, coping strategies, differences between mothers and fathers experiences of stress, age of the child, and the presence of siblings. This underscores both the complexity of parental stress in this population, and the need for further research.

## Chapter 2: Relevant Literature

### Stress

**Heightened levels of stress.** Lazarus and Folkman (1984) define stress as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p. 19). Due to the significant rate of ASD diagnoses, researchers are increasingly looking at stress in parents of children with ASD, particularly mothers. Thus far, research continues to show that high levels of stress are associated with raising a child with an ASD. For example, Duarte, Bordin, Yazigi, and Mooney (2005) looked at additional determinants of maternal stress in mothers of children with ASD. Thirty-one mothers of children diagnosed with ASD (children’s average age 6.8 years) were compared with 31 mothers of children without behaviour problems. Mothers from both groups had the same overall demographic profile. Although maternal stress was the outcome of interest, other factors such as personality characteristics and demographic variables were considered as potential contributors to maternal stress. With regards to demographic variables, older mothers and mothers of younger children increased the likelihood of presenting higher rates of parenting stress. In terms of personality factors, expressing low affection and having low interest in people contributed to stress in mothers of children with autism.

In addition to having higher levels of stress than parents of typically developing children, research indicates parents of children with ASD have higher levels of stress than parents of children with other neurodevelopmental disabilities. Eisenhower, Baker, and Blacher (2005) investigated the effects specific syndromes of intellectual disability have on maternal well-being. Their sample included 215 children classified in five groups:

typically developing ( $n = 136$ ), undifferentiated developmental delay ( $n = 43$ ), Down syndrome ( $n = 12$ ), ASD ( $n = 14$ ) and cerebral palsy ( $n = 10$ ). Children were assessed at ages three, four, and five on motor and cognitive development, and behaviour problems. Maternal well-being was assessed at the same time-points. As a child's behaviour problems have the potential of causing stress, and that behaviour problems vary by disorder, the authors hypothesized that the impact a child would have on their mother's well-being would vary as a function of the child's disorder/syndrome. Results indicated that mothers of children with ASD reported more stress than mothers in other groups at child ages 3 and 4. Only when this child was 5, did mothers of children with Cerebral Palsy exhibit higher levels of stress than mothers of children with ASD. However, when controlling for child behaviour and cognitive level, disorder/syndrome specificity contributed to maternal stress, and ASD in particular, at child ages three, four, and five.

More recently, Dabrowska and Pisula (2010) also compared parents of children with ASD, Down syndrome, and typically developing children on levels of stress. As the authors had expected, parents of children with ASD scored highest on levels of stress. An interesting finding was that the most significant difference was found in the *life span* scale of the QRS, indicating that parents of children with ASD are more stressed about the long-term care of their children than parents of children with Down syndrome and parents of typically developing children. However, the accuracy of maternal stress levels assessed in this study is questionable. The QRS consists of a list of statements which parents declare either "true" or "false." Responses are then added to give a total stress score. For example, parents are asked if their child is "able to take part in games and sports." Simply stating whether one's child is able or unable to partake in an activity or

accomplish any given task is not necessarily evidence of parental stress. An accurate measure of stress needs to assess the parent's reaction to the stressor.

A number of researchers have speculated as to why parents of children with ASD experience higher levels of stress when compared to parents of children with other neurodevelopment disabilities. Pisula (1998) posited that physical limitations might be the only source of stress for parents of children with cerebral palsy. Likewise, children with Down syndrome do not have as many behavioural problems as children with ASD. Collectively, in addition to underlining the high level of stress associated with raising a child with an ASD, these studies suggest that particular characteristics of ASD may be the cause of parental stress.

**Causes of stress.** According to Hastings (2003), with respect to stress in parents of children with ASD, the most frequently studied variables are the child's behaviour problems and the magnitude of the child's disability. Previous research on these variables has generally supported the notion that both child behaviour particular to ASD and severity of the child's disability predict parental stress (Bromley, Hare, Davison, & Emerson, 2004; Hastings 2003; Hastings & Johnson, 2001; Kasari & Sigman, 1997; Konstantareas & Papageorgiou, 2006; Lecavalier et al., 2006).

However, despite findings that show links between symptom severity and parental stress, there is some evidence that certain factors may be more stressful than others. Konstantareas and Papageoriou (2006) looked at the effects of child temperament, symptom severity, and level of functioning on maternal stress in a sample of 43 Greek mothers and their children (aged 2 years and 3 months to 26 years and 1 month). Konstantareas and Papageorgiou hypothesized that when having a child with an ASD,

temperament, which looks at the “goodness of fit” between the child’s behavioural dispositions and his/her caregivers’ reactions, would be a stronger predictor of parental stress than symptom severity. Results indicated temperament accounted for maternal stress. Specifically, a positive relationship was found between the child’s activity level and maternal stress. Conversely, flexibility/rigidity (i.e., a child’s adherence to routine and resistance to change) was found to be inversely related to total stress. Lastly, lower quality in a child’s mood was related to greater maternal stress.

Davis and Carter (2008) investigated associations between parental stress and child characteristics as well as the nature of the stress in a sample of 54 toddlers (average age 26.9 months) with ASD and their parents. In addition to assessing anxiety and depression in parents, the researchers also used the Parenting Stress Index (PSI; Abidin, 1995) to assess stress related to parenting a child with an ASD. Child functioning was assessed on several dimensions, including social and communicative functioning, repetitive behaviours and interests, gross and fine motor skills, and emotional problems (externalizing, internalizing, dysregulation, and competence). Results indicated that 39% of the mothers who completed the PSI scored in the clinically significant range, indicating very high levels of stress that were likely affecting their daily functioning. According to the scores on the various subscales, it appears that mothers are mostly stressed by the parent-child relationship. In addition, 50% of mothers who completed the survey had scores in the clinically significant range on the *Parent-Child Dysfunctional Interaction* domain. Conversely, only about a quarter of mothers reported clinically significant scores on the *Difficult Child* domain and the *Parent Distress* domain, respectively.

According to Davis and Carter (2008), the most consistent predictor of stress for mothers was child behaviour. Mothers who reported that their children had low levels of social relatedness also presented higher levels of overall stress. In particular, mothers were stressed by issues related to their children's regulatory problems (e.g., sleeping, eating, and emotion regulation) as well as externalizing behaviours. Interestingly, cognitive and verbal functioning were not found by the researchers to be predictive of maternal stress. It should be noted, however, that the researchers' failure to find a relationship between cognitive and verbal functioning and maternal stress might be due to young age of the sample. Studies looking at preschool-age children or even older are likely to find mothers of these children stressed as a result of their children's cognitive and verbal impairment at an age where such absence of such skills is more evident.

These results echo findings from previous research by Hastings (2003), the first study to focus on the effect of child behaviours on parental stress. Hastings found that mothers' stress was primarily associated with the child's behaviour problems, and not other symptoms, such as level of functioning. This fact is consistent with more general research on children with disabilities that found links between behaviour problems and parental stress (e.g., Baker, Blacher, Crnic, & Edelbrock, 2002).

Defining ASD severity is not an easy matter. Researchers attempting to assess symptom severity typically employ standardized rating instruments that are either completed by clinicians or parents. Such instruments typically measure a child's verbal skills, social responsiveness, and, inevitably, behaviours. Consequently, research indicating that symptom severity affects maternal stress provides only a limited picture.

This fact is due in part to the fact that some measures of ASD severity focus more on behaviours than others.

In an attempt to address this issue, Lecavalier et al. (2006) used a separate measure of behaviour with their sample of 293 children and adolescents (aged 3–18) with ASD. The Nisonger Child Behavior Rating Form (NCBRF; Aman, Tassé, Rojahn, & Hammer, 1996; Tassé, Aman, Hammer, & Rojahn, 1996) was designed to evaluate behaviour problems and social competence in children and adolescents with developmental disabilities. In order to assess a child's symptom severity, the authors looked at the child's level of functionality by using the Scales of Independent Behavior–Revised (SIB–R; Bruininks, Woodcock, & Weatherman, 1996). In addition, the authors had teachers of the children involved in the study complete the same two measures. Stress was assessed with the PSI. According to Lecavalier and colleagues, their research design would enable them to disentangle the effects of behaviour problems and symptom severity on maternal stress. A second objective was to assess the stability of the results over 12 months. Preliminary results revealed positive correlations between all eight subscales of the NCBRF and stress, with the strongest correlations found with the *compliant/calm* and *conduct problem* subscales. Conversely, in terms of symptom severity (measured here as level of functionality), the only statistically significant correlation found was with the *social and communication* domain. Collectively, the results suggest that a child who lacks prosocial behaviours and demonstrates conduct problems is more stressful for parents than a child without these issues.

The teachers' participation in the study offers important insight. Although, teachers and parents did not completely agree on the types of behaviour problems

exhibited by the children, negative behaviour was strongly associated with stress for both parents and teachers. Moreover, the stress scores demonstrated stability over 12 months, as did the behaviour, with the exception of a slight increase in scores on the *adaptive/social* sub-scale of the NCBRF. Further hierarchical multiple regressions revealed that although stress scores were stable over a 12-month period, behaviour problems exacerbated stress over this period. Nonetheless, the most important contribution made by this study is that it disentangled child behaviour problems and other child characteristics, revealing that certain externalized behaviours are most strongly associated with stress. One drawback of this study is that it employed a wide range of child age. Focus on a particular age group, or a comparison between different age groups would help elucidate the relationship between maternal stress and child behaviours particular to certain age groups.

In sum, these studies indicate that a child's high activity, lower quality in child mood, a poor parent-child relationship, impaired social relatedness and communication, regulatory problems, and conduct problems pose as significant stressors to parents. Conversely, compliance and prosocial behaviours are associated with lower levels of maternal stress.

### **Coping**

In light of the importance of both the stressors and the reaction of parents of children with ASD to these stressors, a number of studies have focused on identifying coping strategies used by parents of children with ASD. However, given the variety of instruments used to measure coping by researchers, as well as the multiplicity of coping

strategies reported by parents, the comparison of findings has been limited (Mancil, Boyd, & Bedesem, 2009).

Hastings and his colleagues (2005) are one of the first researchers to explore the structure of coping strategies used by parents of children with ASD. Adopting a broadly based coping instrument, the authors used factor analysis to establish the underlying structure of coping. The 28-item brief COPE inventory (Carver, Scheier, & Weintraub, 1989) consists of coping statements, which parents rate using a 4-point Likert scale that ranges from “I haven’t been doing this at all” to “I’ve been doing this a lot.”

Factor analytic results indicated that four coping dimensions pertinent to mothers of children with an ASD could be identified: *active avoidance*, *problem-focused*, *positive reframing*, and *religious coping*. Hastings et al.’s study also looked at the effect of coping strategies on maternal stress. Only *active-avoidance* coping was found to significantly affect maternal stress. In other words, mothers who used this coping strategy presented greater levels of stress. Nonetheless, the results confirm findings of an earlier study by Abbeduto et al. (2004) who only considered *problem-focused* coping versus *emotion-focused* (which is equivalent to *active-avoidance*) coping. They found *problem-focused coping* to be associated with lower levels of stress. One problem that emerges from this research is that the instrument used to assess coping only yields four possible coping strategies. Yet, the complexity of coping and the variety of strategies enumerated in different studies suggests that people cope in a number of ways. As such, an appropriate instrument should contain more than 28 items in order to allow for a greater number of coping strategies.

The majority of research looking at coping has been cross-sectional in nature, often asking parents to rate their stress levels and coping strategies at a single point in time. A single retrospective measure may not fully capture the dynamics of stress and coping in this population of mothers, particularly if they engage in emotional coping, whereby they are more likely to only recall negative events. Therefore, Pottie and Ingram (2008) asked their participants to complete their surveys twice weekly over a 12-week period. The authors' main objective was to examine the moderating effects of parental coping responses on the daily stress-mood relationship. Therefore, they did not look at direct effects of coping on stress.

Nonetheless, the authors found statistical support for a stress-moderating model in three of the stress-daily mood relationship: *emotional regulation*, *worrying coping*, and *social support* coping. That is, stressed mothers who used more emotional-regulation coping (i.e., they controlled/expressed their distress in a manner that is constructive for the situation) reported more daily positive mood. Mothers who were stressed and who used more worrying coping (i.e., they constantly and frequently thought about the negative aspect of their stressful situation) reported more negative daily mood. And finally, on days where mothers faced stressful events, and subsequently coped by seeking social support, the outcome was greater negative daily mood.

At first glance, this last finding seems to conflict with previous research highlighting the positive effects of seeking support on parental stress (Billings, Folkman, Acree, & Moskowitz, 2000; Gunthert, Cohen, & Armeli, 2002). However, as Pottie and Ingram (2008) explain, past studies have only looked at direct effects, thereby ignoring the possible interaction between stress and coping. It is thus plausible that mothers who

are stressed cope by seeking out social support, but either do not receive it, or receive negative responses. Alternatively, it is possible that seeking social support does not address the situation as effectively as problem-solving. In light of this seemingly conflicting result, a deeper investigation is warranted, in order to understand why seeking social support was related to negative outcomes in this particular study.

Notwithstanding the wide variety of instruments used in assessing coping in parents of children with ASD, a number of strategies are commonly identified across instruments. Both general studies on coping (e.g. Folkman & Lazarus, 1980) and studies on coping in parents of children with ASD have looked at emotion-focused coping, which involves responding to stress with self-oriented emotional reactions (e.g. 'Become very upset') (Dabrowky & Pisula, 2010). Overall, the research has continued to support the finding that both active/escape-avoidance coping (i.e., avoiding stressful situations, Hastings et al., 2005) and emotion-focused coping are associated with higher levels of parental stress.

For example, Lyons et al. (2010) looked at coping styles as moderators of the impact of child symptom severity on stress in parents of children with ASD. Based on the findings that show symptom severity predicts stress in parents of children with ASD (e.g., Lecavalier et al., 2006; Konstantareas & Papageoriou, 2006), Lyons et al. hypothesized that certain coping strategies would moderate the impact of core ASD symptoms on parental stress. Using a sample of 77 primary caregivers of children with ASD, the authors measured severity of ASD symptoms, stress, and coping style using the CARS-P (Schopler, Reichler, DeVellis, & Dally, 1980), the QRS-F (Friedrich, Greenberg, Crnic, 1983), and the CISS (Endler & Parker 1990), respectively. The CISS consists of 48 items

that comprise three scales: *emotion-oriented* (focusing on reducing the emotional tension caused by the stressor, e.g., crying, becoming upset), *task-oriented* (working at solving the problem), and *avoidance* (either via social diversion, e.g., going out with a friend; or via distraction, e.g., getting a snack or turning on the television).

Preliminary results revealed the severity of autism symptoms was consistently found to be the strongest predictor of stress. In terms of coping strategies, task-oriented coping was associated with less physical incapacity. As predicted, emotion-oriented coping exacerbated the impact of ASD severity on parental stress. Distraction coping moderated the impact of ASD symptom severity on parental stress.

Similarly, Dabrowsky and Pisula (2010) looked at various coping strategies and their effects on parenting stress in parents of children with ASD. They also used the CISS to assess coping. Their results indicated emotion-oriented coping predicted stress in their sample of parents. However, interestingly, their results also indicated that parents of children with ASD coped by way of social diversion significantly less than mothers in comparison groups (i.e., parents of typically developing children and parents of children with Down syndrome). This finding is particularly interesting because it suggests this population of mothers may view the task of raising a child with ASD as a barrier to engaging in social activities (Dabrowska & Pisula). This would corroborate findings discussed earlier that indicated parents of children with ASD are often socially isolated.

In contrast, problem/task-focused coping, which can be defined as making efforts aimed at solving the problem through cognitive restructuring (e.g., parents strive to understand the situation) or attempts to alter the situation and solve the problem (Dabrowsky & Pisula, 2010), has been found to predict lower levels of anger (Lyons et

al., 2010), better adjustment (Twy, Connolly, & Novak, 2007), better well-being (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008), and most relevant to our discussion, lower levels of stress in parents of children with ASD (Lustig, 2002). Some studies have identified additional coping strategies and found these to be linked to parental stress. For example, Luther, Canham, and Cureton (2005) found positive reframing (i.e. how one perceives stressful events and their situation) predicted lower levels of stress in parents of children with ASD. Similarly, positive religious coping, such as attending church, accepting the child's disability as a gift from God, and reframing the situation as an opportunity to attain a higher level of spirituality, was found by Tarakeshwar and Pargament (2001) to be associated with decreased stress levels in parents of children with ASD. Table 1 presents a summary of coping strategies and their effect on maternal stress levels.

Table 1

*Summary of Coping Strategies and their Effect on Maternal Stress Levels*

Study	Coping Strategy	Effect on Stress
Hastings et al. (2005)	Active-avoidance	Increase
Abbudeto et al. (2004)	Problem-focused	Increase
Pottie & Ingram (2008)	Emotional regulation	Decrease
	Worrying	Increase
	Seeking social support	Increase
Lyons et al. (2010)	Emotion oriented	Increase
Dabroska & Pisula (2010)	Emotion oriented	Increase
	Problem/task-focused	Decrease

Lustig (2002)	Problem/task-focused	Decrease
Luther, Canham, & Cureton (2005)	Positive reframing	Decrease
Tarakeshwar & Pargament (2001)	Positive religious coping	Decrease

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Despite the variety of coping measures used, it appears that coping strategies involving self-oriented emotional reactions lead to greater stress levels, while strategies aimed at focusing on the task/problem and thinking positively about the situation decrease maternal stress levels. The disparity in the results may be due to the different measures used and the imparity with which they define a same coping strategy.

The majority of studies in the area of coping have been cross-sectional, assessing stress and coping by way of parental self-reports, with only one study to date examining coping in parents of ASD children over time. In a unique longitudinal study, Gray (2006) compared the coping strategies used by parents of children with ASD over a period of eight to ten years. Results indicated a dramatic decrease in using treatment services as a way of coping. Coping by seeking support from family members also decreased, though not as much. According to Gray, eight and ten years later, religious faith and emotion-focused strategies were the favoured coping strategies by parents of children with ASD. The most striking difference, however, was that the follow-up study showed that the total number of strategies used by parents of children with ASD significantly decreased over time. This finding is particularly important, considering the fact that other researchers claim that using a variety of coping strategies is more beneficial to parents of children with ASD (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). In addition to identifying changes in coping habits across time, Gray's study showed that most parents experienced

lower levels of stress, partly because many children improve as they become more orderly in their habits, but also because parents adapt to a routinized family life. Although this study is unique, it falls short of explaining the relationship between stressors and coping over time. It is therefore unknown whether parents are less stressed because they have learned to effectively cope, or whether the stressors themselves have changed.

Thus far, literature in this area continues to show that, whether parents, clinicians, or teachers rate them, children with ASD present a wide variety of symptoms. More importantly, regardless of the differences in the measures used to assess the severity of a child's ASD, symptom severity continues to be a significant cause for maternal stress, causing mothers to employ a number of coping strategies. Moreover, studies have mainly focused on the moderating effect coping may have on the relationship between ASD symptom severity and maternal stress. Although research on stress in mothers of children with ASD has included samples of children from a wide variety of ages, little is known about the effect of coping strategies on stress in mothers whose preschoolers have recently received a diagnosis of ASD. Consequently, the sample used in this study consisted of mothers whose children had received a diagnosis of ASD in the last four months. The purpose of this research was to examine the effect of child symptom severity on maternal stress, and subsequently determine if this relationship is mediated by coping strategies.

### Chapter 3: Theoretical Framework

Lazarus' transactional model of the stress process (Lazarus & Folkman, 1984) is a useful general model of the stress experience and provides an appropriate theoretical perspective for studying stress and coping in parents of children with ASD. The transactional model originated in the 1960s, when a group of researchers headed by Lazarus attempted to understand and describe stress and coping (Beresford, 1994).

According to Lazarus' model, "the stress process includes (a) an external, causal event or agent; (b) a cognitive *appraisal* of this event or agent to determine whether it is noxious or not; (c) coping *mechanisms* to reduce the noxiousness of this event or agent; and (d) consequential effects on the mind and body, or the stress *reaction*" (Deater-Deckard, 1998, p. 316). In the present study, (a) the external, causal event or agent consists of the child's diagnosis of ASD, and is therefore not addressed by a research question since all of the children in our sample have an ASD. In addition, (b) cognitive *appraisal* of the event or agent was not included as a study variable.

Beresford (1994) notes that since the mid 1980s, the model has been widely adopted and recognized as the most inclusive theory of stress, adjustment, and coping (Coyne & Smith, 1991; Slavin, Rainer, McCreary & Gowda, 1991).

### Chapter 4: Research Questions

1. What levels of stress do mothers of children who have received a diagnosis of ASD within the last four months report?

*We expect high maternal stress scores on the PSI, although we have no basis for predicting a specific profile.*

2. What coping mechanisms do these mothers use?

*We suspect mothers will use strategies that involve escape and avoidance.*

3. What is the relationship between coping strategies and stress in mothers of children with ASD?

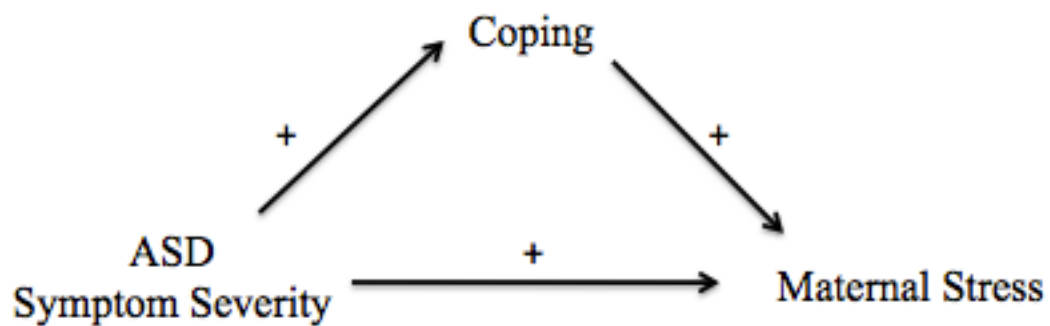
Table 2

*Hypotheses on the Impact of Coping Strategies on Stress in Mothers of Children with ASD*

Coping Strategies (WAYS, Folkman & Lazarus, 1988)	Predicted Correlation with Stress
Confrontive coping	+
Distancing	+
Self-controlling	+
Seeking social support	–
Accepting responsibility	–
Escape-avoidance	+
Planful problem-solving	–
Positive reappraisal	–

4. Is the relationship between ASD severity and subsequent parental stress mediated by coping?

*We tentatively predict that coping mediates ASD severity and parental stress, so that the severity of ASD affects the type of coping mothers use, and coping then impacts their level of stress. There is likely a direct and indirect link between ASD severity and parental stress, as indicated in Figure 1.1. In other words, in the mediated relationship, symptom severity leads to a variety of coping strategies, and these strategies (given their effectiveness) will likely increase or decrease stress.*



*Figure 1. Direct and Mediated Effect of ASD Symptoms on Parenting Stress.*

## **Chapter 5: Methodology**

### **Research Design**

The epistemology underlying the present study is postpositivism. Postpositivists believe that causes most likely determine outcomes or effects, and, as a result, they focus on problems in which ideas are reduced into small, discreet variables. In turn, these variables make up the research questions and hypotheses (Creswell, 2009). In this endeavour to examine and comprehend the relationship between cause and effect, we adopted approaches to measure and observe the variables included in the hypotheses and research questions. This study used a cross-sectional survey as a strategy of inquiry for the collection and analysis of data. It is an appropriate design to collect data from a large sample of parents of children with ASD, in order to make inferences about the population.

Quantitative methods were used to conduct this research. They allow the researcher to collect and analyze the data while permitting for the generalization of the findings beyond the study sample. This approach is particularly important in ASD-related research where the affected population is not concentrated in one particular area, and therefore, conducting research on the entire population is not possible. In addition, a majority of studies on stress in parents of children with ASD are quantitative in nature. Therefore, using a quantitative methodology in this study allows for the comparison of findings. The design included a deductive use of the Transactional Model of the stress process. Accordingly, the aim of this study was to examine the relationship among the variables involved in the research questions.

### **Participants**

Participants in this study consist of mothers of children with ASD who are involved in an ongoing Canadian study entitled *Pathways in ASD*. A total of 423 mothers and fathers are currently involved in the Pathways study. A great deal of the literature pertaining to stress in parents of children with ASD focuses on mothers because in the majority of cases, they are the primary caretakers of children, particularly in the early years (Benson, Karlof, & Siperstein, 2008). This was the case in the Pathways study, as the overwhelming majority of participants who completed the study questionnaires were mothers. Consequently, as a control measure, we decided to focus solely on mothers, and responses from fathers were not included. It is important to note that as the Pathways study is ongoing, participants have joined at various time-points. After only selecting mothers who were involved in the study at Time 1, and removing fathers and missing data, we were left with a sample of 128 mothers. All of the participants are the biological mothers of the children involved in the study.

### **Procedure**

Data were obtained from Pathways in Autism Spectrum Disorders, a national research. The larger study aims at following children with ASD and their parents from the point of diagnosis at 2 to 5 years of age through 11 years of age. Children and their families from five regional referral centres across Canada were invited to participate in the study. Inclusion criteria were: (a) a recent (i.e., within 4 months) clinical diagnosis of ASD; and (b) chronological age between 24 and 60 months at the time of diagnosis. Measures to assess the child's social competence, communication skills, behaviour and ability to adapt and function independently were administered. In addition, data collected on the family's background, and family outcomes, such as levels of stress, were assessed.

For the purpose of this study, only data from Time 1 (baseline) were used, and only the measures listed below were included in the data analyses. Other measures in the Pathways study were not used in this thesis research project and are not included here.

### **Measures**

**Stress.** Parental stress was assessed through the Parenting Stress-Index Short Form (PSI-SF, Abidin, 1995). The PSI-SF is a 36-item derivative of the original PSI, and has been used with samples of parents of children with ASD (Zaidman-Zait et al., 2010). The PSI-SF is a self-administered survey completed by parents who indicate to which extent they agree with a statement using a five-point Likert scale. The PSI-SF consists of three subscales each containing 12 items. Scores on the first subscale, *Parental Distress*, indicate the level of distress resulting from personal factors such as conflict with a partner or depression, as well as life-restrictions caused by the demands of child rearing. The second subscale, *Parent-Child Dysfunctional Interaction* indicates parents discontent with interaction with their children and the extent to which they find their children intolerable. Finally, the last subscale, *Difficult Child* assesses parental perceptions of their children's self-regulatory capabilities.

A number of studies support a two-factor model of stress (Haskett, Ahern, Ward, & Allaire, 2006; Whiteside-Mansell et al., 2007; McKelvey et al., 2009). The first factor consists all of the items in the *Parental Distress* subscale, also called *Personal Distress (PD)*. The second factor consists of items from both the *Parent-Child Dysfunctional Interaction* and the *Difficult Child* subscales, collectively called *Childrearing Stress (CS)*.

Haskett, Ahern, Ward, & Allaire (2006) assessed the validity of the PSI-SF and found the *PD* scale was significantly related to measures of psychological distress,  $r =$

.54, as measured by the SCL-90-R (Derogatis, 1983). In addition, scores on the *CS* scale were significantly associated to two measures of parenting behaviour: the CTS,  $r = .23$ , and the observed Sensitive Parenting index,  $r = -.22$ . Similarly, the *CS* scale was statistically significantly related to two measures of child behaviours: the observed Positive Child Behaviour scores,  $r = -.25$  and parent reports on the ECBI (assesses parents perception of their child's behaviours),  $r = .61$ . Test-retest stability was established by examining and comparing scores on the first assessment, and a subsequent assessment one year later. Correlations between these two assessments were  $r = .61$  for the PD scale;  $r = .75$  for the *CS* scale; and  $r = .75$  for the Total scale.

**Coping.** The Ways of Coping Questionnaire (WCQ; Folkman & Lazarus, 1988) was used to assess coping. This 66-item instrument is comprised of the eight subscales: *confrontive coping* (exerting effort to take control of a situation in an aggressive manner), *distancing* (attempting to cognitively detach oneself from a distressful situation by diminishing its significance), *self-controlling* (actively trying to regulate one's feelings and actions), *seeking social support* (exerting effort to obtain various types of supports), *accepting responsibility* (recognizing one's role in the problem, and seeking to resolve it), *escape-avoidance* (behaviours and thoughts, such as wishful thinking, to avoid the problem), *planful problem-solving* (active efforts to solve and contain the situation), and *positive reappraisal* (striving to give a positive meaning for a situation). Participants complete this self-administered questionnaire by recalling a recent stressful event and then indicating how frequently they have used the coping strategies described to them from 0 (does not apply) to 3 (used a great deal). According to Folkman and Lazarus

(1988), reliability coefficients for these subscales ranged from .68 to .79 (Pisula & Kossakowska, 2010).

**ASD symptom severity.** In order to control for the severity of ASD in children, the Social Responsiveness Scale (SRS; Constantino & Gruber, 2005) was used. This 65-item self-administered questionnaire assesses a child's reciprocal social interactions, a central impairment of ASD. Parents complete the questionnaire by scoring each item from 1 (not true) to 4 (almost always true). As described by Constantino, Davis, Todd, Schindler, and Gross (2003, p. 429-430), the scale contains five subscales: *social awareness* (e.g., "Knows when he/she is too close to someone or invading someone's space"), *social information processing* (e.g., "Concentrates too much on parts of things rather than 'seeing the whole picture' (for example, if asked to describe what happened in a story, child may talk only about the kind of clothes the characters were wearing)"), *capacity for reciprocal social responses* (e.g., "When under stress, child seems to go on 'auto-pilot' (for example, shows rigid or inflexible patterns of behavior)"), *social anxiety/avoidance* (e.g., "Does not join group activities unless told to do so"), and *characteristic autistic preoccupations/traits* (e.g., "Has repetitive, odd behaviors, such as hand flapping or rocking").

In a study by Constantino and Todd (2000), the three-month test-retest reliability for a sample of 1,900 children was found to be .88. More recently, Constantino et al. (2003) reported a 27-month test-retest reliability of .83 with a sample of 15 children. In this same study, they assessed the validity of the SRS by comparing its scores with scores on the Autism Diagnostic Interview–Revised (ADI–R; Lord, Rutter, & Le Couteur, 1994). The ADI–R is a well-established instrument that has been consistently regarded as

the gold standard for diagnosing ASD (Constantino, Davis, Todd, Schindler, & Gross, 2003). The ADI-R assesses three domains: (a) qualitative impairments in reciprocal social behavior (b) delays in language development, and (c) restricted range of interest and/or stereotypic behaviors. The authors found strong correlations between scores on the SRS and each domain of the ADI-R, with coefficients ranging from 0.65–.77.

**Demographics.** Participants in the Pathways to ASD study were also asked to complete two questionnaires about their demographic background. The Family Background Information Questionnaire (FBIQ) is comprised of 21 questions and is completed by the person who knows the child best. For the purpose of this study, only five questions were retained from the FBIQ and possible answers were grouped as follows: marital status (married or common law vs. single, legally separated, divorced, or widowed), level of education (secondary, postsecondary, or graduate), employment status (full time, part time, or unemployed), household income (eight categories ranging from less than \$5,000 to more than \$80,000), ethnic or cultural heritage. In addition, many of the participants also completed the Children in Family Questionnaire (CFQ). This short survey collected descriptive information on both the children involved in the study, as well as their siblings.

## Results

### Description Statistics

Table 3 shows the results from the demographic questionnaire (FBIQ). Demographic information provided by the mothers indicates that nearly 90% were either married or living in a common-law relationship. More than half of mothers had completed university and approximately 16% had attained a graduate's degree. Approximately half of mothers were employed either part-time or full-time. In terms of income, 43% of mothers' household income was above the Canadian average for economic families of two persons or more of \$80,000 (Statistics Canada). Finally, a little more than three-quarters of mothers identified themselves as Caucasian. Table 4 provides demographic information on the children with ASD involved in the study as well as their siblings.

Table 3

#### *Demographic Variables Obtained from the FBIQ*

Demographic	Percentage of mothers in the sample
Marital Status	
Married/Common Law	89.8
Single	10.2
Education	
Secondary	29.9
Postsecondary	42.5
Graduate	16.5
Employment Status	
Employed	52.3
Unemployed	47.7
Estimated household income	
Less than \$80,000	56.8
More than \$80,000	43.2
Ethnic or cultural heritage	
White/Caucasian	77.3
Non-Caucasian	22.7

Table 4

*Demographic Variables Obtained from the CFQ*

Demographic	Characteristics
Average age of child in study	3 years and 4 months
Sex of the child in the study	Male: 84%
Average age of children in study	3 years and 4 months
Other developmental issues	Yes: 15
Are any siblings living with the child in the study?	Yes: 88
Are any of the siblings diagnosed with ASD?	Yes: 5
Do any of the siblings have any other developmental issues?	Yes: 16

**Stress.** Raw stress scores were converted to percentiles in order to interpret maternal stress levels, relative to a normative sample. The normative sample on which the PSI was standardized consists of 1,056 American adults (534 mothers, 522 fathers) who had children with ages ranging from younger than 1 year old to 12 years of age. Results contained in Table 5 indicated the sample mean for total stress was 89.3, which corresponds to the 70<sup>th</sup> percentile. The *Difficult Child* domain was most stressful for mothers (mean = 34.4) and corresponded to the 78<sup>th</sup> percentile. The remaining two domains were almost equally stressful for mothers: Scores on the *Parental Distress domain* (mean = 29.4) and the *Parent-Child Dysfunctional Interaction* (mean = 25.6) corresponded to the 67<sup>th</sup> and 64<sup>th</sup> percentile, respectively.

Table 5

*Descriptive Statistics for the PSI, WAYS, and SRS*

Measure	Mean (SD)	Number of Items (Scale Points)	Scale Alpha
Autism symptom severity – SRS			
1. Total Score	75.0 (13.1)	65 (4)	.94
Coping – WAYS			
1. Confrontive	5.2 (3.5)	6 (4)	.62
2. Distancing	4.3 (3.3)	6 (4)	.64
3. Self-Controlling	7.4 (4.3)	7 (4)	.65

4. Seeking Social Support	7.5 (4.8)	6 (4)	.80
5. Accepting Responsibility	2.8 (2.6)	4 (6)	.60
6. Escape-Avoidance	4.6 (4.0)	8 (4)	.71
7. Planful Problem Solving	7.7 (4.2)	6 (4)	.75
8. Positive Reappraisal	6.0 (5.0)	7 (4)	.81
Maternal Stress – PSI			
1. Parental Distress	29.4 (9.8)	12 (5)	.90
2. Parent-Child Dysfunctional Interaction	25.9 (7.2)	12 (5)	.80
3. Difficult Child	34.4 (9.0)	12 (5)	.86
4. Total Score	89.39 (21.0)	36 (5)	.92

**Coping.** Responses to items on the WAYS are summed within each type of coping to give a score for each of the eight coping subscales. Results from the measure are presented in Table 5 in rank order from “most used” to “least used” coping style. These results show that the most frequently used coping strategies were *planful problem-solving* (7.7), *seeking social support* (7.4), and *self-controlling* (7.4). *Coping by accepting responsibility* was used the least frequently (2.8). Overall, mothers’ mean scores on the WAYS subscales were comparable to the norm sample of middle- and upper-middle-class white married couples with which the scale was developed. These parents had at least one child at home, though these children did not necessarily have an ASD (Folkman & Lazarus, 1988). However, results with our sample suggest high variability within each subscale, as standard deviations were high compared to the norm sample.

**ASD symptom severity.** Although the SRS contains various subscales, we were only concerned with obtaining a total score in order to conduct our analyses. The mean total score for our sample was 75. Scores between 60 and 75 indicate mild to moderate symptom severity, while scores equal or greater than 76 indicate severe ASD symptom severity (Constantino & Gruber, 2005). Table 5 summarizes the results on the various measures.

### Regression Analysis

**Stress and Coping.** As mentioned earlier, there appears to be a relationship between coping strategies and maternal stress, with some strategies increasing stress, while others appear to decrease stress levels experienced by mothers of children with ASD. In order to examine the relationship between coping styles and stress in this sample of mothers of children with ASD, a regression analysis was conducted with the eight WAYS subscales (the independent variables) and the total score on the PSI (the dependent variable). As illustrated in Table 6, only three subscales were significantly related with total scores on the PSI, *escape avoidance*, *confrontive coping*, and *seeking social support*. *Escape avoidance* and *confrontive coping* were associated with increased stress scores, while *seeking social support* was linked to decreasing stress scores. The regression analysis yielded a multiple R of .50. This means that the different coping strategies accounted for approximately 25% of variance in maternal stress scores.

Table 6

*Summary of Regression Results with Coping Subscales as the Independent Variable and Total stress as the Dependant Variable*

WAYS subscales	Unstandardized Coefficients		Standardized Coefficients
	B	Standard Error	Beta
Confrontive Coping	1.61	.65	.26*
Distancing	.16	.67	.02
Self-Controlling	-.29	.60	-.05
Seeking Social Support	-.98	.46	-.22*
Accepting Responsibility	.63	.85	.08

Escape Avoidance	1.82	.52	.34**
Planful Problem Solving	.12	.53	.02
Positive Reappraisal	-.35	.48	-.09

\*  $p < .05$ , \*\*  $p < .001$

### Mediational Analysis

Recognizing that higher symptoms of ASD in children are associated with higher maternal stress levels, we wanted to find out if coping strategies affect this relationship. Therefore, a mediational analysis was conducted using analytic procedures outlined by Baron and Kenny (1986). Researchers are often interested in assessing whether and to what extent a variable affects another, for example, the effect of ASD symptom severity (predictor) on maternal stress (criterion). However, as noted by Preacher and Hayes (2004), knowing the extent to which a third variable (mediator) accounts for the relationship between the first two variables provides a more practical and accurate understanding of the relationship between variables. In the context of the current study, we were interested in determining if the relationship between ASD symptom severity and maternal stress is mediated by the type of coping strategies that mothers use in their daily lives.

Prior to conducting the mediational analysis, correlations were calculated between the possible mediators, the predictor variable, and criterion variable. Variables were only considered for possible mediation (and subsequent analyses) when combinations in which all three variables are linked by statistically significant zero-order correlations. Thus, we first calculated all of the bivariate correlations between subscales of the PSI, WAYS, and SRS (see table Table 7).

Table 7

*Bivariate Correlations between Stress (PSI), Coping (WAYS), and ASD Symptom Severity (SRS)*

Measure	PSI				WAYS						
	1	1	2	3	4	5	6	7	8	9	
PSI	1										
	1	.33**									
	2	.11	.32**								
	3	.15	.52**	.57**							
	4	-.05	.38**	.36**	.41**						
WAYS	5	.23**	.43**	.42**	.48**	.28**					
	6	.40**	.48**	.32**	.38**	.33**	.43**				
	7	.07	.46**	.28**	.55**	.42**	.30**				
	8	.04	.43**	.44**	.48**	.57**	.45**	.31**	.46**		
	9	.21*	.71**	.65**	.79**	.71**	.64**	.60**	.67**	.77**	
SRS	1	.44**	.19*	.04	.08	-.04	.02	.10	.15	-.00	.09

PSI 1 = Total Score

WAYS 1 = Confrontive Coping

WAYS 2 = Distancing

WAYS 3 = Self-Controlling

WAYS 4 = Seeking Social Support

WAYS 5 = Accepting Responsibility

WAYS 6 = Escape Avoidance

WAYS 7 = Planful Problem Solving

WAYS 8 = Positive Reappraisal

WAYS 9 = Total Score

SRS 1 = Total Score

Table 7 was examined in order to locate pairs of statistically significant bivariate correlations between a) ASD symptom severity (SRS total — predictor) and the eight coping styles (WAYS subscales — possible mediators) and b) the eight coping styles and parental stress (PSI total — criterion). Of all the possible combinations, only one met the criteria for further analysis: *confrontive coping*. *Confrontive coping* correlated significantly with both total scores on the SRS and the PSI. We therefore proceeded with the mediational analysis.

At step 1, it is determined whether or not the initial variable (X) is significantly correlated with the outcome (Y). This is done through regression analysis, entering the

outcome variable  $Y$  as the criterion variable and the initial variable  $X$  as a predictor. This path is labeled  $c$  and is called the *total effect* (see Figure 2). Following this step, we entered maternal stress as the criterion variable and ASD symptom severity as a predictor.

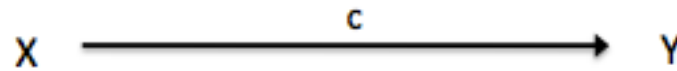


Figure 2. Path  $c$ , Total Effect Model.

At step two, it is then determined if the initial variable  $X$  is correlated with the mediator  $M$ . A second regression analysis, entering the  $M$  as the criterion variable and  $X$  as the predictor, is conducted. This step represents path  $a$  (see Figure 3). Consequently, we entered coping as the criterion variable and ASD symptom severity as a predictor in the linear regression equation.

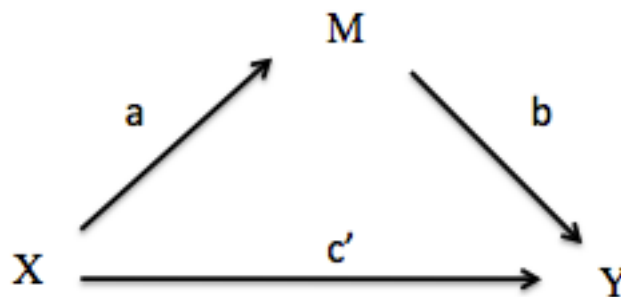


Figure 3. Mediated Model.

The analysis at step three establishes whether or not the mediator  $M$  is significantly correlated with the outcome  $Y$ , while controlling for the effect of  $X$  on  $Y$ . A multiple regression is thus conducted, entering  $Y$  as the criterion variable and  $X$  and  $M$  as predictors. This is path  $b$  (see Figure 3). (Note: path  $c'$  consists of the direct path ( $X$ - $Y$ ) when there is also a significant indirect path ( $X$ - $M$ - $Y$ ) through the mediator variable.) In

our multiple regression, we entered maternal stress as the outcome and both ASD symptom severity and coping as predictors.

At step 4, the analysis determines whether or not the mediated path (X-M-Y) accounts for a statistically significant proportion of variance, in which case path  $c'$ , which represents the effect of X on Y through M should be significantly reduced (i.e., partial mediation) or zero (i.e., complete mediation). In order to verify this, the unstandardized coefficients ( $\beta$  and the standard error of  $\beta$ ) from both the linear regression and the multiple regression is used to compute the z-value and the p-value from the Sobel's test in order to determine if the mediation is significant. Our results indicated the mediated path was not significant in the case of *confrontive coping*, Sobel test statistic = 1.75,  $p = .08$ . Table 8 illustrates the results of the regressions.

Table 8

*Regression Analyses for the Direct and Mediated Path*

Model	R <sup>2</sup>	Predictor	B (SE)	$\beta$
Direct Path	.193	SRS	0.709 (0.133)	0.440***
Mediated Path	.272	Confrontive Coping (WAYS)	10.880 (2.995)	0.291***
		SRS	0.623 (0.129)	0.387***

Note: Outcome PSI Total, \*\*\*  $p < .001$

### Discussion and Conclusion

The main aims of this research were to: (1) assess maternal stress related to raising a child with an ASD, (2) identify the coping strategies used by these mothers, (3) assess the relationship between these coping strategies and their levels of stress, and (4) determine if coping mediates the relationship between a child's ASD symptom severity and maternal stress.

#### Stress

The PSI (PSI-SF, Abidin, 1995) was used to assess maternal stress. The total average stress score for our sample fell at the 70<sup>th</sup> percentile. Although not in the clinical range (i.e., above the 90<sup>th</sup> percentile), the stress level on the whole among participating mothers is still above average. Thus, our hypothesis that mothers of children with ASD would present high levels of stress appears to be confirmed by this finding.

The PSI measures stress in several different domains related to parenting, and mothers in this sample scored highest on the *Difficult Child* domain with raw scores corresponding to the 78<sup>th</sup> percentile. This suggests that their children's behavioural characteristics were most stressful for them. According to Abidin (1995), high scores by parents of children two years of age or older indicate child-behavioural adjustment and behavioural symptoms. In other words, mothers in our sample struggle to adapt to the constellation of behavioural symptoms their children present, and the result is that mothers experience the most stress in the face of these particular issues. These results are consistent with the relatively few studies that have considered behavioural problems when looking at stress in parents of children with ASD (e.g., Hastings, 2003; Lecavalier et al., 2006).

Scores on the *Parental Distress* domain and the *Parent-Child Dysfunctional Interaction* were also above the norm average, at the 67<sup>th</sup> and 64<sup>th</sup> percentiles, respectively. Based on the content of the items in the *Parental Distress* subscale, the results suggest that mothers who scored high on *Parental Distress* may question their own parenting competence, may feel their child's condition restricts their opportunities, or may feel they lack support. For example, some of the items included in this subscale are: "I often have the feeling that I cannot handle things very well," and "since having this child, I have been unable to do new and different things," and "I feel alone and without friends." The *Parent-Child Dysfunctional Interaction* looks at a parent's negative perception of the parent-child relationship. High scores indicate that the parent-child relationship is at-risk or non-existent.

While the average score on the *Parent Child Dysfunctional Interaction* scale indicates that parents derive stress from the relational issues that accompany ASD, it tends to generate relatively less stress than the other domains. On the one hand, it is very likely that mothers in our sample are stressed about their relationship with their newly-diagnosed child because it does not meet their expectations of the warmth of the relationship and motherhood in general, which explains stress in this domain. On the other hand, the fact that stress in this domain is lower than stress in other domains may be in part due to the young age of the children involved in the study. It is plausible that many of the developmental delays that constitute symptoms of ASD are not yet as apparent in these young children as they are in older children, and thus, parents suspect only a temporary delay and maintain hope for improvement. As a result, the mother-child

relationship is not affected. Alternatively, it may be that externalized behaviours are simply stronger stressors than communication problems.

### **Coping**

The Ways of Coping Questionnaire (WAYS) was used to assess coping. The WAYS has the advantage of going beyond the original and somewhat limited classification of “problem focused” vs. “emotion-focused” items (Folkman & Lazarus, 1980). Instead, the WAYS considers a number of coping strategies that may lie between the two aforementioned types of coping. As explained by Folkman and Lazarus (1988) certain strategies may constitute both problem-focused and emotion-focused approaches to coping. In order to capture the richness and complexity of human coping processes, the WAYS considers eight different types of coping strategies. Results of this study indicate that mothers in this sample engaged in a wide range of coping strategies. This finding is consistent with longitudinal research conducted by Gray (2006), who demonstrated that parents of newly diagnosed children employ a wide range of coping strategies. Gray also found that the total number of strategies used by parents of children with ASD significantly decreased over time. Thus, it is plausible that in the struggle to adapt to the challenges that come with raising a young child with ASD, mothers in our sample engage in a wide variety of coping strategies in order to discover optimum strategies.

Our hypothesis that mothers of children with ASD would favour escape-avoidance as a coping strategy was not supported by our results. Nonetheless, mothers did use three coping strategies more than others: *planful problem solving* (7.7), *seeking social support* (7.4), and *self-controlling* (7.4). Planful problem solving consists of both an analytical approach and a problem-focused effort to solving a problem. This strategy

would appear to be more appealing to parents in situations over which they have more control, or in which they feel more confident, perhaps due to past experiences in which they successfully handled a similar problem. For example, one of the subscale items states: “Drew on my past experiences, I was in a similar position before.” It would therefore make sense that, despite their child’s diagnosis, mothers favour planful problem-solving because stressful encounters are fewer and consequently more manageable. This is in part due to the fact that the children in the sample are still very young, and the types of challenges that would significantly tax a mother’s coping skills have yet to emerge. A study by Davis and Carter (2008) on stress in parents of toddlers with ASD revealed that cognitive and verbal functioning, and more importantly atypical behaviours were not related to parental stress. According to the authors, these deficits usually appear after the toddler years.

Seeking social support may also be useful for mothers, particularly after recently receiving a diagnosis of ASD for their child. A lack of understanding of the disorder likely causes mothers to search for answers to their questions (informational support), request help with managing their child (tangible support), or simply seek comfort from close ones (emotional support). *Self-controlling* refers to efforts to control one’s actions and feelings. Items in this scale depict efforts to be rational, remain calm, and think things over. At first glance, such an approach to coping may seem somewhat challenging for this population of mothers. However, as mentioned earlier, at this stage of their children’s development, mothers may still feel a sense of control that allows them to regulate their actions and feelings.

Noteworthy is that scores on these three subscales were somewhat similar to scores by the norm sample. Moreover, it is interesting to note that these three coping strategies are also the most commonly used strategies by parents in the norm group described earlier. This result may suggest that these strategies are intuitive to parents, or that they prove to be the most useful, regardless of their particular situations. Likewise, Accepting responsibility, which refers to coping by acknowledging one's role in the problem, combined with an intention to fix things, was the least used strategy by both our sample and the norm group.

### **Stress and Coping**

In addition to assessing levels of stress in mothers of children with ASD and identifying the coping strategies they use, we examined the relationship between stress and coping. Folkman and Lazarus (1988) argue that the quality of a coping strategy may only be determined by assessing its adaptativeness in the context of a specific situation. For example, the authors argue that while denial is often maladaptive, in some circumstances, such as immediately following trauma, it can be adaptive. Still, as discussed earlier, specific research focusing on stress and coping in mothers of children with ASD has shown some coping strategies are more adaptive than others, which formed the basis of our hypotheses. For example, Hastings (2005) argued that because coping is context-dependent, the nature of the stress and the interaction with the environment would likely affect the development of coping strategies.

Results of the present study indicated that approximately 25% of variance in maternal stress scores was accounted for by the coping strategies assessed by the WAYS, which underscores the significant role certain coping strategies may play in either

diminishing or exacerbating stress. This means, however, that 75% of maternal stress is accounted for by variables other than coping strategies. Such variables may be the age of the child, the age of the mothers, the number of children in the household, and level of education amongst a number of other demographic variables.

Three of the eight coping strategies on the WAYS were significantly correlated with total stress and in the hypothesized directions. First, *confrontive coping* was positively correlated with stress, indicating that the more mothers employed this coping strategy, the more they were stressed. *Confrontive coping* describes aggressive efforts to change a situation and involves hostility and risk-taking. Although this particular domain is unique to the WAYS, it is similar to a domain found in the Daily Coping Inventory *blaming or directing one's anger* (Stone & Neale, 1984) in the sense that they both denote a certain level of hostility and aggression. Pottie and Ingram (2008) found this form of coping to be negatively related to stress.

Second, *seeking social support* was negatively correlated with maternal stress. That is, the more mothers sought out informational, tangible, or emotional support, the less they were stressed. The effect of both seeking and receiving social support on stress is well documented in the literature. In general, social support has been found to reduce stress in parents of children with ASD (Siklos & Kerns, 2006; Weiss, 2002). Dunn et al. (2001) found that social support resulted in less negative outcomes for parents, such as stress, depression, social isolation, and marital problems. For many parents of children with ASD, social support constitutes the most important source of support available to them (Siklos & Kerns, 2006). In their study, Mandell and Selzer (2007) found that the contact and exchange that results from parents attending parental support groups played a

significant role in reducing social isolation, thereby decreasing stress and increasing opportunities to access information about other services. In addition, such events give mothers the opportunity to spend some time alone and away from home.

Lastly, *escape-avoidance* was positively correlated with maternal stress. Therefore, the more mothers engaged in wishful thinking and behaviours in an attempt to avoid or escape problems, the higher their levels of stress. Escape avoidance is a coping strategy that is commonly used by parents of children with ASD. For example, Hastings et al. (2005) examined coping strategies in 135 mothers and fathers of children with ASD. In their analyses, they explored the relationship between coping strategies, on the one hand, and stress and mental health, on the other. Results indicated a strong positive correlation between active-avoidance coping and stress, anxiety, and depression. Moreover, Hastings et al. argued that active avoidance was similar to the *emotion-oriented* domain included in the Coping Inventory for Stressful Situations (CISS; Endler & Parker 1990), because it describes efforts to focus one's activities on reducing one's emotions, often by way of denial. Dabrowsky and Pisula (2010) used the CISS to look at the effect of coping strategies on parenting stress in parents of children with ASD. Their results indicated emotion-oriented coping predicted stress in their sample of parents.

Our findings suggest that confronting a stressful situation in an aggressive manner results in higher levels of stress for mothers in our sample. Children with ASD are often characterized by neuropsychological impairments in emotional and social processing, meaning they are often unable to comprehend and recognize facial expressions and basic emotions (Adolphs, Sears, & Piven, 2001). In addition, approximately 25% of children with ASD never develop functional language, while the remaining 75% develop language

later than typically developing children and often exhibit impairments in different areas of language (Klinger, Dawson, & Renner, 2002). It is not surprising then, that children with ASD differ from typically developing children in their behavioural responses to speech (Kuhl, Coffey-Corina, Padden, & Dawson, 2005). Based on our knowledge of these core symptoms, aggressive verbalization and gestures that are typical of aggressive/confrontive behaviour may bring little if no change to a stressful situation involving a child with an ASD who is unable to process his or her mother's speech and actions. As a result, the child's unresponsiveness to likely causes added stress for mothers engaging in confrontive coping.

Similarly, escaping or avoiding a stressful situation seems to only increase maternal stress, possibly because this coping strategy solely focuses on self-directed emotions, such as wishful thinking, fantasizing, and denial, as indicated by virtually all the items of the *escape-avoidance* subscale. Mothers using escape-avoidance coping inevitably endure high levels of stress, since none of these strategies are aimed at bringing about change to the stressful situation. Moreover, according to Dun et al. (2001), escape-avoidance coping leads to increased isolation, which, in turn, leads to a decrease in social support. As our results indicated, seeking social support is linked to lower levels of maternal stress.

Social support has been correlated with improved coping in parents of children with ASD (Hastings & Brown, 2002) and lower levels maternal stress (Crnic & Low, 2002; Siklos & Kerns, 2006; Turnbull, Summers, & Brotherson, 1986). The results of our study confirmed these findings. As elaborated on by previous research, the comfort, help, and advice received by mothers of children with ASD through social support decreased

the stress they endure. Interestingly, Siklos and Kerns (2006) argued that one of the core benefits of social support is the opportunity for mothers to have some leisure time in order to participate in recreational activities. As mentioned earlier, a lack of personal time and opportunities to engage in desired activities was a leading cause of stress for mothers of children with ASD, perhaps because they feel trapped by their situation.

### **Coping as a Mediator Between ASD Symptom Severity and Stress**

The final objective was to examine if coping mediated the relationship between the severity of ASD symptoms presented by children and maternal stress. Our hypothesis regarding this matter was a general one. We hypothesized maladaptive coping would mediate the relationship between ASD symptoms and maternal stress. In order to determine if mediation existed, each of the coping strategies was examined individually for possible mediation. This analysis was done by conducting correlations between the possible mediator, the predictor variable, and the criterion variable. If a significant correlation existed, the next step was to conduct a linear regression in which the criterion is entered as the dependant variable and the predictor is entered as the independent variable. Then, a second linear regression was conducted by entering the mediator as the dependent variable and the predictor is entered as the independent variable. Finally, a multiple regression was performed entering the criterion as the dependent variable and the mediator in question and the predictor as independent variables.

Preliminary analyses indicated only *confrontive coping* was significantly correlated with both ASD symptoms and maternal stress. However, further analyses revealed that *confrontive coping* did not mediate the relationship between ASD symptoms and maternal stress. Therefore, the relationship between ASD symptom

severity and maternal stress is not explained by *confrontive coping*. Failure to find statistically significant mediation may be explained by the number of our participants. Perhaps with a greater number of participants, we could have increased statistical power and found an effect.

### **Contributions and Implications for Practice**

The present study used the data obtained by the largest ongoing study on families of Canadian children with ASD. Consequently, the sample used in this study is quite substantial. Our results add to the findings that continue to show that mothers of children with ASD endure higher levels of stress. The effects of stress on both mental and physical health have been well documented. This study highlights the importance of raising awareness about stress in mothers of children with ASD, particularly with the aim of informing mothers that certain coping strategies may be beneficial or detrimental to their mental health. With coping accounting for approximately one-quarter of maternal stress, professionals working with families of children with ASD should explain to parents the relationship between the way they cope with stressful situations involving their children and the levels of stress they experience. In particular, parents need to be made aware that dealing with a stressful situation either in a confrontive manner or by escaping and avoiding the situation will likely increase their stress. These discussions with mothers should take into consideration their context and their particular needs.

Highlighting the importance of avoiding confrontive coping and escape-avoidance coping is also beneficial, not only in terms of maternal stress, but also in terms of improvement for the child with an ASD. This is because parental stress has been found to undermine the effects of intervention programs aimed at helping children with ASD

improve, as shown in a study by Osborne, McHugh, Saunders, and Reed, 2008. These researchers looked at the effect of parental stress in a sample of 65 children with ASD and their families. The study focused on the gains made by children enrolled in an early teaching intervention for children with ASD, and whether these gains were affected by levels of stress reported by parents both at baseline and 10 months after the intervention was implemented. Results indicated that children in the program produced fewer gains, particularly in educational and adaptive behavioural functioning, when parents reported high levels of parental stress. As noted by Osborne et al., this study is unique in that it is not simply correlational, but rather time-lagged, meaning that levels of stress measured at baseline cannot be said to have been caused by child gains, since these are measured afterwards.

Moreover, since seeking social support is related to lower levels of maternal stress, practitioners and therapists should help mothers locate formal supports in their community as well as encourage them to seek out informal supports. Formal supports may include respite programs that allow them to get some time off, professional counseling, and parent groups. Informal types of supports include support from one's spouse, other family members, and friends. These people who form the immediate circle around the mother and can be strategic sources of support by either helping out with tasks, babysitting, offering emotional support, and offering companionship at times when the mother feels alone and trapped.

Lazarus' (1984) transactional model of stress proved to be correct in our study for three of eight coping strategies. Mothers were faced with (a) an external causal event (a stressful situation involving their child with an ASD), (c) they used certain coping

strategies, and (d) a stress reaction was observed. In addition, our findings that 25% of the variance in maternal stress was accounted for by the coping strategies that mothers use further supported Lazarus' theory.

### **Limitations and Future Directions**

In terms of our results, four out of eight coping subscales had internal consistency reliabilities below normally acceptable levels (i.e.,  $>.70$ ). Consequently, the reliability of the WAYS with respects to these coping strategies is questionable. Also related to coping, it is important to note that research has indicated that mothers and fathers differ in the types of coping strategies they favour. According to Hastings (2005), this may be due to inherent characteristics, or the fact that mothers and fathers interpret their child's disability differently. Nonetheless, this underscores the importance of understanding that mothers may be predisposed to favouring certain coping strategies over others. Consequently, this fact should be considered when interpreting the results of our study.

One limitation to this study is the fact that measures of parental stress, coping strategies, and child symptom severity consisted of self-report measures. Although self-report measures are widely used in studies of children with ASD and their families, research indicates that certain parental characteristics may compromise the accuracy of the information parents report about themselves and their children. For example, Bennett et al. (2012) found that mothers who reported higher levels of stress also rated their children as demonstrating a greater number of ASD behaviours. Thus, it is possible that depression, stress, or other parental characteristics influenced mothers' responses in our study.

Another limitation to the study is the use of total ASD symptom severity as a predictor. While overall symptom severity is clearly a predictor of maternal stress, determining which symptoms create greater stress would be more informative. For example, Davis and Carter (2008) investigated associations between parental stress and child characteristics, as well as the nature of the stress. Child functioning was measured for social and communicative functioning, repetitive behaviours and interests, gross and fine motor skills, and emotional problems (externalizing, internalizing, dysregulation, and competence). Results indicated that both child regulatory problems (e.g., sleeping, eating, and emotion regulation) and externalizing behaviours were significantly correlated with stress for both mothers and fathers. Interestingly, cognitive and verbal functioning were not found by Davis and Carter to be predictive of parental stress.

As was mentioned earlier, the Pathways in ASD team have and continue to administer a number of measures that look at ASD symptom severity and child functioning and have used these in their own analyses. Determining which area of a child's functioning causes the most stress can help both mothers and therapists focus their interventional strategies on particular areas when working with the child. Therefore, researchers may want to consider utilizing more of Pathways' measures of child symptom severity in order to assess the child's capabilities in a number of areas, and then look at their individual effects on maternal stress. Another possibility would be to use a broader measure that looks at multiple areas of a child's functioning, such as verbal skills, social skills, behaviours etc. This same approach could be used when entering coping into the mediation equation. For example, perhaps certain coping strategies are more useful when

dealing with stressful situations involving non-verbal children as opposed to children with high levels of inappropriate behaviours.

Our study is also limited by the fact that we looked at stress shortly after mothers had received a diagnosis of ASD for their child (i.e., within the preceding 4 months). Perhaps comparing maternal stress at multiple times would inform us of whether stress increases or decreases as the child ages. In the same vein, looking at coping strategies at multiple time points would reveal whether coping strategies change over time in function of increasing or decreasing stress levels. In a unique longitudinal study, Gray (2006) compared the coping strategies used by parents of children with ASD over a period of eight to ten years. Results indicated changes in the types of coping strategies used. One of these changes was a decrease in the use of social support, a coping strategy that was found to be used significantly by mothers in our sample.

This study adds to the growing body of research indicating mothers of children with ASD endure high levels of stress. It also confirms previous findings that child behaviours represent the greatest stressor for mothers. In addition, although to a lesser extent than child behaviours, our study suggests that mothers in our sample question their parenting skills and may have a negative perception of their relationship with their children, as suggested by the results on the *Parental Distress* and *Parent-Child Dysfunctional Interaction* scales of the PSI.

Similarly, like previous research, we found that mothers employ a wide range of coping strategies. Nonetheless, careful planning to solve the problem at hand, seeking out social support, and controlling one's emotion emerged as the most commonly used strategies. However, only seeking social was related to maternal stress, whereby mothers

who sought social support experienced lower levels of stress. The use of other strategies, however, such as escape-avoidance and confrontive coping is linked to higher levels of stress.

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