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# Family Quality of Life for Parents of Children with Autism: The Role of Social Support and Unsupportive Social Interactions

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**Family Quality of Life for Parents of Children with Autism: The Role of Social  
Support and Unsupportive Social Interactions**

by

Jenna B. Jones

A Dissertation  
Submitted to the Faculty of Graduate Studies  
through the Department of Psychology  
in Partial Fulfillment of the Requirements for  
the Degree of Doctor of Philosophy at the  
University of Windsor

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Family Quality of Life for Parents of Children with Autism: The Role of Social Support and  
Unsupportive Social Interactions

by

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### **Declaration of Originality**

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### **Abstract**

Family quality of life refers to the extent to which families are satisfied with different domains in their lives. The concept of family quality of life was originally developed by a group of international researchers as a way to evaluate how having a family member with a disability, such as autism, affects the entire family unit. Parents of children with autism report higher levels of stress than other parents. McCubbin and Patterson developed the double ABCX model, which describes how families adapt to stress. In the double ABCX model, the stressor (aA factor), social support (bB factor), parental appraisals (cC factor), and coping skills (BC factor) interact to determine family adaptation (xX factor). The purpose of the present study was to evaluate the utility of the double ABCX model in predicting family quality of life for parents of children with autism. The variables were operationalized as child challenging behaviour (aA factor), child disability severity (aA factor), unsupportive social interactions (aA factor), social support (bB factor), parental sense of competence (cC factor), acceptance (cC factor), coping (BC factor), and family quality of life (xX factor). Another purpose of this study was to determine the extent to which unsupportive social interactions and online social support may also affect parents of children with autism. Unsupportive social interactions refer to responses from others that are perceived as being unhelpful, and may be detrimental to the well-being of parents of children with autism. Seeking social support online or using technology may also influence family quality of life, but little is known from past research. A sample of 194 parents (103 mothers and 91 fathers) of children with autism aged 4 to 11 years completed an online survey, and 24 participants (12 mothers and 12 fathers) completed follow-up phone interviews. The double ABCX model was found to be a good fit for understanding what contributes to family quality of life for both mothers and fathers of children with autism. Higher adequacy of social support and

greater use of the reframing coping style were the most closely related to higher family quality of life for fathers. For mothers, greater adequacy of social support, higher psychological acceptance, and greater use of the reframing and acquiring social support coping styles and less use of passive coping styles were the most closely related to higher family quality of life.

Unsupportive social interactions were not significantly related to family quality of life within the double ABCX model, but they were associated with lower ratings of family quality of life on their own, particularly for parents with poorer coping. Online social support was not significantly related to family quality of life. However, parents who reported using technology daily to access social support also reported more unsupportive social interactions, and more child challenging behaviour than parents who used technology less frequently. Thematic analysis was conducted with the parents' interview responses and several themes were identified related to both within-family and external influences on family quality of life. Some themes were identified that were not captured in the survey component, including the importance of connecting with other parents of children with autism, and access to appropriate childcare. These results suggest that the double ABCX model is useful for understanding how the stresses associated with raising children with autism affect parents' family quality of life. Consistent with this model, the resources employed and parent responses to the stressors are key for family quality of life. The findings of this study are hopeful, in that most parents of children with autism in this study reported good family quality of life, especially the parents who had relatively more supports and resources. Applied implications of the results are presented in the context of the double ABCX model.

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## Introduction

### Overview

Raising children with autism is an experience that can greatly affect parents and their family quality of life. The double ABCX model is one of several models that have been proposed to help understand how families adapt to stress (McCubbin & Patterson, 1983). In this model, the extent to which the stressor (aA factor) affects family adaptation (xX factor) depends on the interaction between family resources (bB factor), family appraisal (cC factor), and coping (BC factor). The purpose of this study was to evaluate how the double ABCX model can explain family quality of life in a sample of parents of children with autism. The roles of online social support and of unsupportive social interactions in family quality of life were also considered. Approximately equal numbers of both mothers and fathers of children with autism were included in this study because fathers tend to be under-represented in autism research.

Autism Spectrum Disorder (referred to as autism in this document) is a neurodevelopmental disorder characterized by social communication deficits and restricted, repetitive patterns of behaviour (APA, 2013). Parents of children with autism consistently report more stress and responsibilities than parents of typically developing children (Eisenhower, Baker, & Blacher, 2005; Gardiner & Iarocci, 2012; Padden & James, 2017).

The double ABCX model (McCubbin & Patterson, 1983) is based on a theory which explains how families adapt to stressful situations. When a change occurs in a family, it introduces stress and demands that the family needs to adjust to. In this model, the stressor (aA factor), social support (bB), family appraisal (cC factor) and coping (BC

factor) interact to determine family adaptation (xX factor). If a family is not able to balance the demands with their resources, then they are said to be in a crisis. If equilibrium is achieved, then the family is said to be in a state of “bonadaptation” (McCubbin & Patterson, 1983).

Family quality of life was used as the outcome or xX factor in the present study. This concept was originally developed to understand how families are affected by having members with disabilities (Park et al., 2003). It includes the quality of life of the entire family unit, in addition to the individual with a disability. Family quality of life has been shown to be affected by many variables, including child characteristics such as challenging behaviour, family characteristics such as parent coping styles, and environmental characteristics such as social support (McStay, Trembath, & Dissanayake, 2015). The stressor, or aA factor, includes characteristics of children with autism and their additional needs that affect parents’ adaptation to stress (McCubbin & Patterson, 1983). Parenting a child with autism is associated with higher levels of parental stress (Eisenhower, Baker, & Blacher, 2005; Gardiner & Iarocci, 2012; Padden & James, 2017). Research suggests that child challenging behaviour is more closely related to parental outcomes when compared to child disability severity (Blacher & McIntyre, 2006).

Unsupportive social interactions refer to behaviours from others that are perceived as being negative or unhelpful, and are distinct from social support (Rook, 1984). In a previous qualitative study, several parents of children with autism spontaneously described experiences that could be understood as unsupportive social interactions (Jones & Gragg, 2016). For example, some of these parents described feeling misunderstood by others due to a lack of understanding about autism. Pottie et al. (2009) conducted the only



known study that considered unsupportive social interactions specifically for parents of children with autism. These authors focused on parents' daily experiences of feeling blamed by others for their children's behaviour. Their results showed that parents of children with autism who reported experiencing more unsupportive social interactions also reported higher negative affect and lower positive affect (Pottie et al., 2009). The present study evaluated how unsupportive social interactions affect parents of children with autism and whether unsupportive social interactions fit into the double ABCX model as an additional stressor (aA factor) that these families may face.

Family resources (bB factor) refer to social supports, which include both emotional and practical support (McCubbin & Patterson, 1983). Higher levels of social support are associated with better outcomes for parents of children with autism (Ekas, Lickenbrock, & Whitman, 2010). Recently, many parents have been using technology to access social support (Duggan et al., 2015). Past research is unclear regarding the potential benefits of *online* social support in particular. Studies have tended to focus on comparing in-person and online social support with each other, rather than exploring how online social support as an entity affects parents' well-being or family quality of life. Previous research generally suggests that in-person social support is superior to online social support. There is little research on the benefits of online social support in itself (Doty & Dworkin, 2014). A further aim of the present study was to explore the benefits and limitations of online social support for parents of children with autism and how online social support use relates to their family quality of life.

Family appraisal (cC factor) refers to the ways that parents perceive the situation (McCubbin & Patterson, 1983). This can include parental sense of competence, or

parents' confidence in their abilities to be good parents to their children, and their satisfaction with their roles as parents (Bandura, 1977). Higher parental sense of competence is associated with better outcomes for parents of children with autism (Pozo, Sarria, & Brioso, 2014). Psychological acceptance is another concept that was included as a cC factor in the double ABCX model in the present study. Acceptance refers to parents' willingness to experience negative emotions in relation to parenting children with autism (Bond et al., 2011).

Coping styles (BC factor) are considered to be an interaction between mobilizing social support and modifying appraisals (McCubbin & Patterson, 1983). Problem-focused coping styles and positive reframing are associated with better outcomes, whereas avoidant coping styles are associated with worse outcomes for parents of children with autism (Benson, 2014). The present study evaluated how different coping styles affected family quality of life within the double ABCX model for both mothers and fathers of children with autism.

Fathers have typically been underrepresented in research about parents of children with autism (Braunstein, 2013). Therefore, fathers were included in this research study because there is evidence that fathers and mothers of children with autism show different patterns of stress and adaptation (Vasilopoulou & Nisbet, 2016).

This study used a mixed methods approach to evaluate how the factors within the double ABCX model are related to family quality of life for parents of children with autism. An online survey allowed for quantitative analyses using multiple regression analyses. Thematic Analysis of semi-structured interviews allowed for greater exploration of parents' experiences with unsupportive social interactions and online social support in

particular, which have received less attention in past research. This study also used a Participatory Action Research approach in which a mother of children with autism served as a Parent Advisor to provide meaningful input throughout the entire research process.

In the following section, relevant theories and research findings related to the double ABCX model (McCubbin & Patterson, 1983) are presented. First, theories about family adaptation are presented that could help explain how parents adjust to the stresses associated with raising children with autism. The remaining literature review is presented within the context of the double ABCX model. First, research related to family quality of life is presented (xX factor). Then research findings about potential stressors (aA factor), including child challenging behaviour, child disability severity, and unsupportive social interactions, are reviewed. Next, social support and online social support are reviewed as family resources (bB factor). Research about family appraisal (cC factor) is reviewed which focused on parental sense of competence and psychological acceptance. Then research related to coping (BC factor) is reviewed. The literature review concludes with empirical findings of studies that used the double ABCX model as a whole, and a discussion of the limitations of previous research. Finally, study questions and hypotheses are presented.

## **Literature Review**

### **Autism Spectrum Disorder and Family Stress**

Autism Spectrum Disorder is a developmental disability that is characterized by deficits in social communication and the presence of repetitive behaviours or interests. A recent study reported that the prevalence rate of autism in 5- to 17-year-olds in Canada is 1 in 66, with males being four times more likely to have an autism diagnosis than females

(Public Health Agency of Canada, 2018). It is also common for individuals with autism to have a comorbid intellectual disability (APA, 2013).

Coping with the symptoms of autism, as well as associated factors such as the children's intellectual abilities, challenging behaviour, adaptive functioning deficits, and need for long-term care, can place stress on parents (Harper, Dyches, Harper, Roper, & South, 2013; Karst & Van Hecke, 2012). For example, in a recent study of 543 parents of children with autism (average age 10 years), 41% of the sample reported moderate stress, and 44% reported severe stress (Sim et al., 2018). Raising children with autism involves many practical demands, such as financial pressures, providing accommodations for children, accessing treatment, and less opportunity for parents to work outside the home (Karst & Van Hecke, 2012). Consequently, parents of children with autism report higher levels of stress, more mental health problems, poorer physical health, higher rates of divorce, and lower marital satisfaction when compared to parents of children with other developmental disabilities such as Down Syndrome or parents of children without disabilities (Benson, 2006; Gardiner & Iarocci, 2012; Harper et al., 2013; Hartley et al., 2010; Karst & Van Hecke, 2012; Padden & James, 2017; Smith, Buch, & Gamby, 2000; Vasilopoulou & Nisbet, 2016). As such, there has been a trend towards more research focusing on how the stresses associated with raising children with autism affect families (Cridland, Jones, Magee, & Caputi, 2014). As reviewed further below, several theories have been developed to describe which factors can best explain how families adapt to stressful situations, which can be applied to families of children with autism.

### **Theories of Family Adaptation**

Over the past several decades, researchers have made efforts to understand and explain how families adapt to stress. The present study relied on the double ABCX model (McCubbin & Patterson, 1983) due to its utility, empirical support, ability to be tested empirically, and applicability to clinical work. The double ABCX model was influenced by family systems theory, and models such as the roller coaster model (Koos (1946, as cited in McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980), the ABCX model (Hill, 1949), the contextual model of family stress (Boss, 1987; 2002), and the family adjustment and adaptation response model (FAAR; Patterson, 1988; 2002). Each of these theories and their development will be briefly explained below to provide additional context for the development of the double ABCX model.

Many of the models listed above have been strongly influenced by family systems theory, which emphasizes processes within the various systems related to the family (Lavee, 1997). This theoretical approach views families as interactive, reactive, and each having a unique social composition (Cridland et al., 2014). Family systems approaches consider factors such as interactions between members within a family, boundaries and permeability in family roles, ambiguous loss, and resilience (Cridland et al., 2014). Family systems theory encourages research and clinical approaches that consider the family as a whole, rather than focusing solely on one individual or the family as a closed unit. This theory emphasizes how family members interact with one another and with other systems outside the family. Family systems theory was not evaluated directly in the present study, but contributed to the development of the double ABCX model. Family systems theory was a foundation of the following models because they included

components of it such as considering family-level factors and processes, and how these relate to the adaptation of the family unit as a whole.

One of the earliest models of family stress was the roller coaster model which was first presented by Koos (1946, as cited by McCubbin et al., 1980). This model was built upon by others including Hill (1949) and Boss (1987). According to this model, when presented with a stressor, the family's overall functioning may decline in a period of disorganization if their existing resources and coping strategies are insufficient. This phenomenon is like going down the hill of a roller coaster. The period of recovery refers to when a family recovers from the stressor and the functioning improves, like going up a hill of a roller coaster. The final result is a new level of reorganization which could be lower, equivalent to, or higher than the original level of functioning (Boss, 1987). This model infers that some families may in fact become stronger following a crisis rather than weaker. This model was expanded by other researchers to develop a more comprehensive understanding of family adaptation to stress (Malia, 2006). As explained in more detail below, later theorists specified the factors which are thought to influence how families adapt to stress (e.g., family resources and perceptions).

Hill (1949) built upon the roller coaster model to create one of the seminal models of family stress: the ABCX model. Like the roller coaster model, the stressful event and its related challenges result in periods of disorganization, recovery, and a resulting level of family organization. This model states that a stressor (A) interacts with a family's resources (B) and their perception of the event (C) to produce the crisis (X). This model was based on a longitudinal study of families whose fathers were missing in war (Hill,

1949). The ABCX model has formed the basis for the double ABCX model and several other models.

Burr (1973, as cited in McCubbin et al., 1980) reworked the conceptualization of the ABCX model to include family vulnerability and regenerative power. Families' vulnerability to stress (new addition to the model) and their existing resources (B factor from the ABCX model) are important in determining the extent to which a crisis is experienced by families. How families define the crisis (C factor: family appraisal in the ABCX model) is thought to play an important role in this process. Burr (1973, as cited in McCubbin et al., 1980) also added regenerative power to the double ABCX model, which refers to the resilience of families and their ability to recuperate from the crisis evoked by the stressor.

Boss (1987, 2002) presented the contextual model of family stress. This model also includes the A, B, C, and X factors that were included in the ABCX model (Malia, 2006). The main difference in this model is that the X factor includes both stress and crisis. Stress represents first order change, which refers to how existing family resources can meet the demands of a stressor to maintain equilibrium. Crisis represents second order change, which is when the family's pre-stressor resources are not adequate for responding to the stressor (Malia, 2006). Crisis is seen as being acute, whereas stress is more chronic. Like the roller coaster model, families experiencing a crisis can have a resulting level of family reorganization that is lower, the same as, or higher than the pre-stressor level of family functioning.

Patterson (1988, 2002) proposed the family adjustment and adaptation response model (FAAR). This model describes systems at the individual level, family level, and

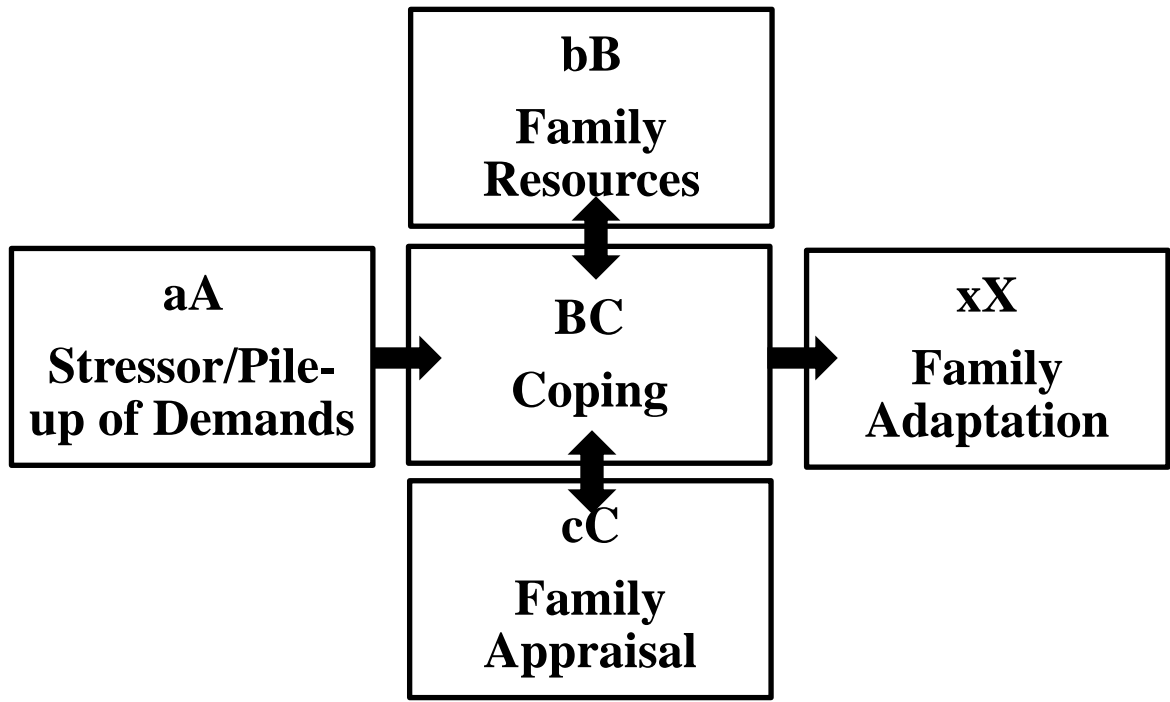
community level (Patterson, 1988). The family experiences cycles of adjustment, crisis, and adaptation following stressors. The model emphasizes family-level factors including the resources and coping styles that are employed to balance the demands of a stressor and achieve equilibrium. A family's capabilities and meanings interact to balance the demands resulting in family adjustment or adaptation (Patterson, 2002). In this model, family demands include normative stressors, unusual stressors, ongoing strains, and daily hassles. The FAAR model relates to the double ABCX model because both explain how family resources are used to determine the extent to which stress is experienced by the family.

The models just reviewed all share many similarities in their views of family adjustment to stress. Most of these models see adjustment to stress as an ongoing process and acknowledge that family functioning could be lower or higher following the experience of a stressor. Family resources are thought to determine how well families adjust to stress in these models. The ways that family resources are conceptualized vary between these models. The double ABCX model is another model that shares some of these characteristics and has strong support in the research literature.

### **The Double ABCX Model**

One of the most widely used adaptations of Hill's (1949) ABCX model is the double ABCX model (McCubbin & Patterson, 1983; see Figure 1). This model is commonly used because the variables are amenable to being operationalized and tested statistically. As in the ABCX model, the double ABCX model focuses on factors thought to influence family adaptation to a stressful event. Bonadaptation refers to when the family has adjusted to the stressor in a positive manner, whereas maladaptation refers to





*Figure 1.* The double ABCX model of family adaptation. Used with permission from McStay, Trembath, and Dissanayake (2015).

negative outcomes following a stressor (Hill & Rose, 2010). These positive and negative outcomes function in a positive feedback loop.

Although the original ABCX model (Hill, 1949) considered only factors preceding the stressful event (the capital letters), the double ABCX model expanded this theory to include factors that occur after the stressful event (the lowercase letters) such as stress proliferation and seeking additional social supports (McCubbin & Patterson, 1983). In the double ABCX model, the relation between a stressor (aA factor) and family adaptation (xX) is influenced by family resources (bB), perceptions of the situation (cC), and coping styles (BC factor).

The outcome in the double ABCX model is family adaptation (xX factor). It refers to the ways that families have adapted to the stressful event. Family adaptation can be measured in a variety of ways, and typically has been conceptualized as negative outcomes such as parent stress. Some examples include maternal depression and marital adjustment (Bristol, 1987), parental stress (Saloviita, Italinna, & Leinonen, 2003; Shahrier, Islam, & Debroy, 2016), and parental distress (Manning Wainwright, & Bennett, 2011; Paynter, Riley, Beamish, Davies, & Milford, 2013). More recently, family adaptation has been conceptualized in a more positive manner in studies of family quality of life (e.g., Pozo et al., 2014). Family resources (bB factor) typically refer to the parents' social support, while appraisals (cC factor) refer to the meaning that parents give to the stressors (Saloviita et al., 2003). Coping strategies (BC factor) are viewed as an interaction between family resources and perceptions of the situation. Parents may employ several types of coping strategies to deal with the stressors such as modifying appraisals or seeking social support (Pozo et al., 2014).

**Strengths and Criticisms of the Double ABCX Model.** The double ABCX model has many strengths, which has led to its widespread acceptance and use in research about the experiences of families of children with developmental disabilities (Lavee, 1997; Pickard & Ingersoll, 2017). Whereas models such as the roller coaster model provide a simple way to understand family adaptation to stress, they are more difficult to use in research contexts. These models are broad, and the factors thought to influence family adaptation are not well-conceptualized or operationally defined. The double ABCX model lends itself well to statistical analyses and provides researchers with a template for factors to include as study variables.

One of the seminal studies evaluating the double ABCX model used structural equation modeling in a sample of army families who relocated to a foreign country (Lavee, McCubbin, & Patterson, 1985). Lavee et al. (1985) operationalized the stressor (aA factor) as relocation strains and family events, family resources (bB factor) as family system resources and social support, family appraisal (cC factor) as coherence, and family adaptation (xX factor) as well-being, satisfaction, and family distress. The findings of this study provided initial support for the double ABCX model. They coined the term “pile-up” of stressors, which refers to the ongoing and cumulative stressors resulting from the initial stressor (Lavee et al., 1985). The concept of “pile-up” of stressors was supported empirically, as both pre-existing and new stressors were related to family adaptation. Social support was found to play an indirect role in predicting family adaptation to stress and the authors, therefore, concluded that it plays a buffering role against stress (Lavee et al., 1985). Although this study focused on the experiences of military families, the results are likely applicable to parents of children with autism who also experience substantial

stress. The nature of the stressors experienced by military families and parents of children with autism may differ, but the factors included in the double ABCX model are universal. Interestingly, a study by Seltzer et al. (2010) found that mothers of children with autism show patterns of stress hormones that are similar to combat soldiers.

Another advantage of the double ABCX model is the flexibility within the model in the operationalization of the specific variables to be included for each factor (Lavee, 1997). This flexibility allows the model to be applicable to different stressful situations and populations, including parents of children with autism. Although the model was originally created to explain stress in response to a crisis, it can also be used to understand positive outcomes such as family quality of life and allows that positive outcomes may result from stressful situations (Hill & Rose, 2010). The double ABCX model is also applicable to ongoing stressors, such as those associated with raising children with autism.

Some researchers have taken a more linear approach in which child characteristics represent the stressor, which affect other family members' well-being. However, the double ABCX model considers within-family variables as additional important factors in determining family outcomes (Garcia-Lopez, Sarria, & Pozo, 2016). The double ABCX model is comprehensive and includes several variables that work together to determine adaptation to stress rather than considering each factor in isolation, which allows it to better explain family outcomes (Pickard & Ingersoll, 2017).

Although the double ABCX model has been useful, it has some limitations. The flexibility in how variables can be operationalized is both a strength and a drawback of the model (Lavee, 1997). Some researchers have criticized a lack of clarity and

consistency in defining the factors in the model (Rose & Hill, 2010; Smith, 1984). As a result, there is excessive variability in how each factor has been conceptualized across studies, which makes it difficult to draw conclusions about the model. The definitions of crises or stressors have also varied substantially, as they could refer to traumatic events, normative family transitions, or chronic stressors (Rose & Hill, 2010).

Another criticism is that the statistical analyses that have been used in studies of the double ABCX model often focus on main effects and have given less attention to potential mediation and moderation effects (Blacher, 2001). The double ABCX model has also been criticized for not giving enough consideration to subsystems within the family such as parents' relationships with one another (Garcia-Lopez et al., 2016; Lavee, 1997). Although some research has addressed this limitation by using multilevel modeling designs (e.g., Garcia-Lopez et al., 2016), this is not the norm in this area of research. The double ABCX model is typically used for quantitative studies, and mixed methods or qualitative approaches are less commonly used.

Perry (2004) developed “a model of stress in families of children with developmental disabilities” (p. 5) that is similar to the double ABCX model. Her criticisms of the double ABCX model were that the xX factor is often considered to be an acute crisis or the way that a family adapts to a crisis, which may not necessarily be applicable to chronic stressors, such as raising children with autism (Perry, 2004). The double ABCX model gives little consideration to family-level variables as predictors and makes little distinction between sources and types of supports (Perry, 2004).

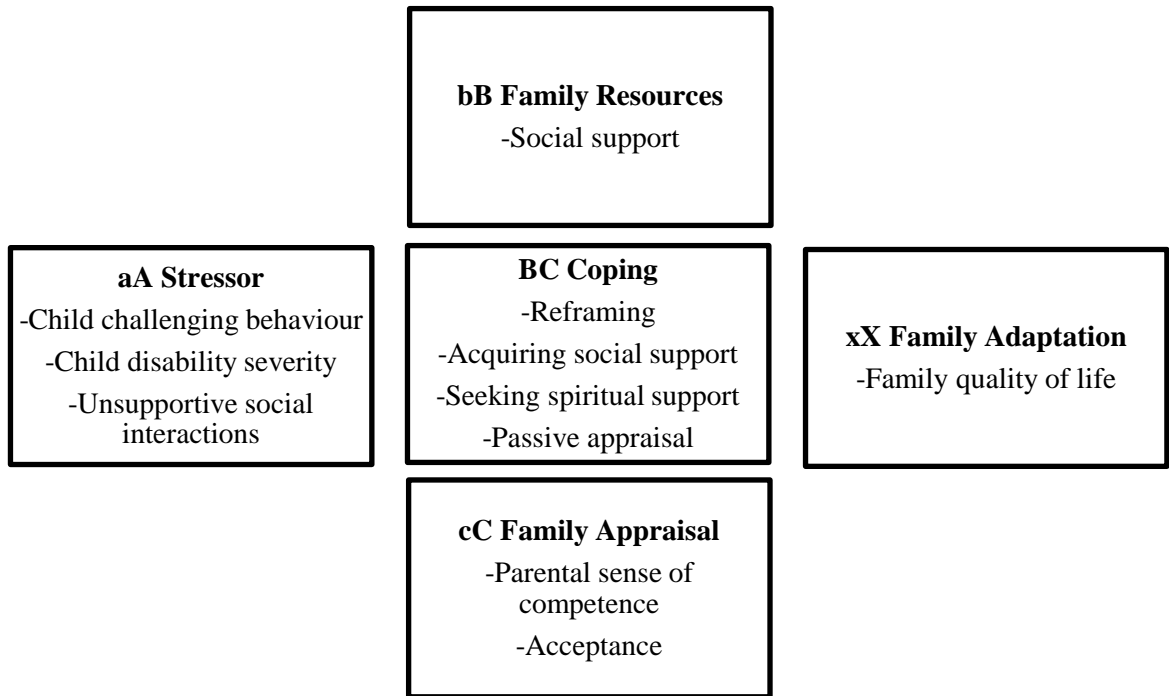
Despite the criticisms noted above, the double ABCX model was used to examine the ways in which raising children with autism affects parents in the present study.

Although it shares many similarities to the other models that have been reviewed (e.g., the ABCX model and the roller coaster model), the double ABCX model was chosen in large part due to its existing empirical support. The strengths of the model, including its applicability, comprehensiveness, and widespread acceptance in the field outweigh the weaknesses highlighted above. The double ABCX model has been shown to be applicable to the experiences of parents of children with autism in previous studies (McStay et al., 2015). The model also allows for consideration of family strengths and positive adaptation following a stressor. Therefore, it is appropriate to use family quality of life as the outcome measure within the double ABCX model (e.g., Pozo et al., 2014).

The following section outlines research related to each of the individual factors, and the double ABCX model as a whole. Figure 2 includes the variables that were used in the present study for each of the factors represented in the double ABCX model. Some of the limitations of the double ABCX model noted above were addressed in the present study, which explored some mediation and moderation effects, and included specific measures of the sources, valence, and satisfaction with different types of social supports.

**Family adaptation (xX factor).** Family adaptation (xX factor) is the outcome in the double ABCX model, and represents the extent to which a family is disrupted by the stressor. If the demands associated with the stressor exceed the family's resources, then the result is a crisis (McCubbin & Patterson, 1983). Family stress can result from an imbalance between an individual family member's needs and the family unit's ability to meet these needs.

Family adaptation has been conceptualized in many ways by researchers. Traditionally, it has referred to parental distress and mental health outcomes (e.g., Bristol,



*Figure 2.* Factors in the double ABCX model (McCubbin & Patterson, 1983) that were included in the present study.

1987; Saloviita et al., 2003; Pakenham et al., 2005). In the research literature, parental stress has been the most widely used way of measuring family adaptation (e.g., Saloviita et al., 2013). Parent mental health, such as depression and anxiety, has also been commonly used to examine parent outcomes (e.g., Paynter et al., 2013).

Some researchers have considered the well-being of the entire family as an outcome, such as research examining family quality of life (e.g., Pozo et al., 2014). In the present study, parent report of family quality of life was used to measure family adaptation (xX factor). This concept, which is explained in more detail below, was chosen because it takes a positive approach and considers how the entire family unit is affected by stressors such as raising children with autism. Although measures of stress are typically used to measure family adaptation (xX factor) within the double ABCX model, family quality of life also fits within this framework because the double ABCX model considers the positive aspects of family adaptation to stressors.

Other researchers have used family quality of life as the xX factor in recent studies evaluating the double ABCX model in samples of parents of children with autism. For example, McStay, Trembath, & Dissanayake (2014) studied 98 mother-father pairs of children with autism aged three to 16 years. There was partial support for the double ABCX model in predicting family quality of life. Lower child externalizing behaviour and greater family sense of cohesion were associated with higher family quality of life for both mothers and fathers. Higher coping was also a predictor of better family quality of life for mothers. Similarly, Pozo et al. (2014) evaluated the double ABCX model in a sample of 59 mother-father pairs of children with autism aged four to 38 years. In their study, more behaviour problems, lower parental sense of competence, greater autism



severity, and less social support were associated with lower family quality of life for both mothers and fathers. Greater use of active avoidance coping was also associated with higher family quality of life ratings for fathers. Family quality of life was chosen as the outcome variable in these studies because it is a measure of overall family functioning rather than individual parent well-being, and because it takes a positive approach.

*Family quality of life.* The concept of family quality of life was developed specifically for families raising children with disabilities. Family quality of life is defined as the extent to which families' needs are met, they enjoy their lives, and they have opportunities to pursue what is important to them (Park et al., 2003). Key stakeholders such as individuals with developmental disabilities and their family members were involved in the conceptualization of family quality of life, unlike concepts such as family adaptation and parent mental health (Gardiner & Iarocci, 2015). Family quality of life was originally based on research considering the individual quality of life of persons with disabilities and was expanded to include the dimensions of parenting and family relationships (Rillotta et al., 2012).

Family quality of life is a concept used to consider the ways that parents are affected by raising children with disabilities. Family quality of life has been consistently defined and is based on a strong theoretical model (Zuna, Turnbull, & Summers, 2009). The quality of life of each family member, including the member with a disability, influences one another. Therefore, it is crucial to consider these together. Family quality of life research investigates the degree to which families are willing and able to act as caregivers for children with developmental disabilities and how this affects the quality of life of all family members (Samuel, Rillotta, & Brown, 2012).

It is important to consider the quality of life of the entire family unit, rather than just the quality of life of the individual with a developmental disability for many reasons. One main reason is that, in the past few decades, governments, organizations, and families have been moving towards a model of care for individuals with developmental disabilities that is based in the home rather than in institutions (Brown, Anand, Fung, Isaacs, & Baum, 2003). Although positive in many ways, this shift also involves additional responsibilities, stresses, and supports needed by families caring for sons or daughters with disabilities. Families now represent the immediate environment of many children and adults with developmental disabilities throughout the lifespan (Samuel et al., 2012). Families are a constant influence on children's lives, and are the most involved in their children's care, even more so than professionals (Wang & Brown, 2009).

Although family quality of life considers the well-being of all family members, including parents and siblings, the present study focused on family quality of life from the perspective of parents. Past research supports that parents are strongly influenced by the stresses associated with raising children with autism (e.g., McStay et al., 2015). Because parents are leaders of families, they can represent and report on their families' overall functioning. Therefore, most research evaluating family-level outcomes such as family quality of life rely on parent report (Cridland et al., 2014).

*Family quality of life theory.* The conceptualization of family quality of life is the result of a program of research by several groups, one out of the Beach Center on Disability at the University of Kansas (Summers et al., 2005) and another international group based in Canada, Australia, and Israel (Brown et al., 2003). These groups have focused on defining family quality of life and developing appropriate measures for family

quality of life, with the input of stakeholders such as families and individuals with developmental disabilities themselves (Samuel et al., 2012). The concept of family quality of life grew out of family systems theory, which recognizes that individual family members influence one another, and that families are goal-directed, self-correcting, dynamic, interconnected systems that influence and are influenced by the environment (Summers et al., 2005). Family quality of life theory recognizes families as the building blocks of society, and that families with good quality of life are an asset to society, and thus it is advantageous to support families to improve their family quality of life (Brown & Brown, 2003; Samuel et al., 2012).

Earlier research efforts focused on conceptualizing family quality of life and developing empirical measures. It has also been recommended that family quality of life be used as an outcome measure to monitor the effectiveness of interventions (Kober & Eggleton, 2009). Zuna et al. (2009) then presented a unified theory of family quality of life, which entails four major explanatory concepts. Systemic concepts include systems, policies, and programs. Performance concepts include services, supports, and practices. Individual member concepts include demographics, individual characteristics, and beliefs. Family unit concepts include family dynamics and characteristics such as demographic variables (e.g., size of family and family income). In this model, systemic concepts and performance concepts directly affect individual member and family unit concepts, which directly influence family quality of life. The family's resulting strengths and needs re-enter the model, thus making it a continuous feedback loop (Zuna et al., 2009; see Figure 3).

Despite the presentation of the unified theory by Zuna et al. (2009), no studies

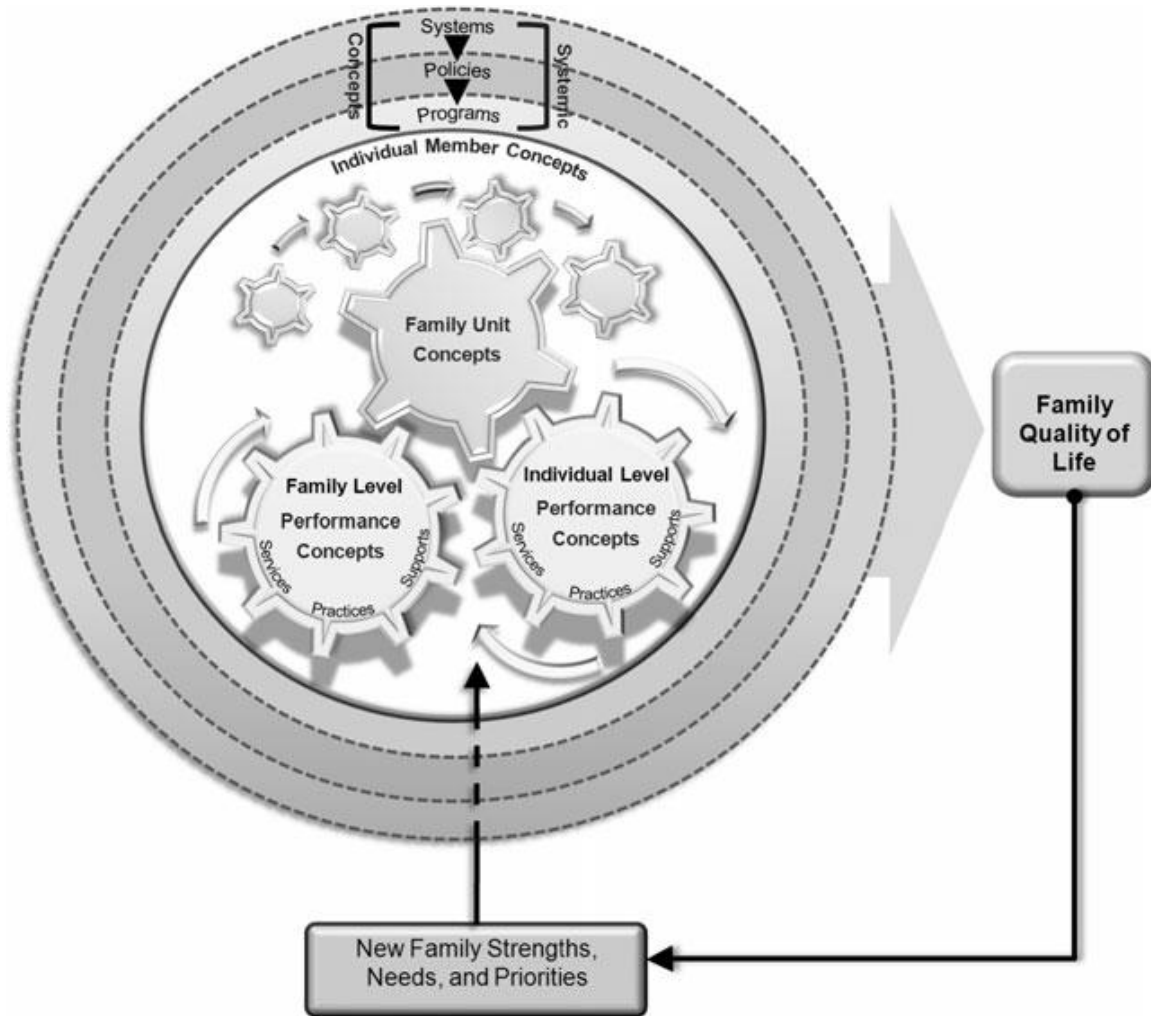


Figure 3. Unified theory of family quality of life. Reproduced from Zuna et al. (2009) with permission from the publisher.

were found that explicitly tested this model as a whole. Research has focused more on measuring family quality of life (Summers et al., 2005) or evaluating the importance of individual components of the theory (e.g., the effects of Pivotal Response Training interventions on family quality of life; Buckley, Ente, & Ruef, 2014).

The present study used the double ABCX model (McCubbin & Patterson, 1983) as the basis for the present study as an overarching framework to guide analyses. The double ABCX model was chosen to better understand which factors relate to family adaptation for parents raising children with autism. Specifically, the double ABCX model includes family-level and parent-level characteristics as explanatory variables, rather than broader policies and practices. Parent- and family-level factors are better suited for interventions by a psychologist. Family quality of life was chosen as the outcome variable within the double ABCX model because it takes a positive approach to understanding family adaptation, family stress, needs, and priorities. There is less empirical evidence supporting family quality of life theory, which is broader and less specific in comparison to the double ABCX model. Therefore, the Zuna et al. (2009) family quality of life theory was not directly evaluated in this study, but was reviewed to provide a more thorough understanding of the concept of family quality of life. Family quality of life theory explains other variables such as the impact of policies that could be related to family quality of life that were beyond the scope of the present study.

There is some overlap between the double ABCX model and family quality of life theory, as both emphasize the importance of supports, individual characteristics, and beliefs. More specifically, family quality of life theory's individual level concepts and family unit concepts are very similar to the stressor (aA factor), family appraisal (cC

factor), and coping (BC factor) in the double ABCX model. There are some differences between these two theories as well, as family quality of life theory focuses more on policies and broader systems, which are not typically included in the double ABCX model. The double ABCX model includes family resources (bB factor) which could include services as described in the family quality of life theory, but has typically referred to informal social supports.

Family quality of life theory emphasizes systems, policies, and practices which are broad and therefore difficult to operationalize (Zuna et al., 2009). These policies can vary greatly between provinces and countries, which makes it challenging to understand, measure, and compare. Family quality of life theory is broad and complex, which makes it daunting to consider all the variables that are included within one study. The double ABCX model emphasizes family-level and individual-level variables, which are more amenable to change through psychological intervention (McCubbin & Patterson, 1983). Therefore, there are more clinical applications for psychologists and other professionals working with this population that can be drawn from the double ABCX model. The present study sought to build upon the existing literature supporting the utility of the double ABCX model as a way to explain family quality of life for parents of children with autism. In the present study, the double ABCX model was used as a framework to guide statistical analyses and interpretation of the findings.

*Research on family quality of life.* Family quality of life has been used in clinically-based research to assess families' needs for supports and services, guide service delivery, and evaluate family outcomes (Hu, Wang, & Fei, 2012). In measuring family quality of life, researchers value using a multidimensional, multi-method approach (i.e.,

subjective and objective measures), multivariate research designs, and using a systems perspective. Family quality of life researchers should promote increasing the involvement of individuals with disabilities and their families in the design and implementation of quality of life research (Samuel et al., 2012). Qualitative research methods are one way to meet this goal by ensuring that participants' voices are heard. Kober and Eggleton (2009) proposed that family quality of life be used as an outcome measure to evaluate the effectiveness of programs and service providers.

Research about family quality of life in families with a member with a developmental disability has generally found that ratings of family quality of life are fairly high and that family members typically report that they are satisfied overall with their family life (Bertelli et al., 2011; Brown et al., 2003; Rillotta et al., 2012). Families tend to highly rate the importance of family quality of life and its associated domains (Cagran, Schmidt, & Brown, 2011). However, these studies are often conducted in developed countries and the participants often have higher family incomes than the national averages. Therefore, these samples are not representative of the general population, which limits generalizability. In addition, families with children with developmental disabilities report lower family quality of life than do families with only typically developing children (Brown et al., 2003; Brown, MacAdam-Crisp et al., 2006; Gardiner & Iarocci, 2012).

Characteristics of children with disabilities, such as disability severity and challenging behaviour, have been associated with outcomes such as family quality of life and parental stress (discussed in greater detail in the Stressor (aA Factor) section of the Introduction). Higher child adaptive behaviour has been found to be related to higher

family quality of life for parents of children and adolescents with autism aged six to 18 years (Gardiner & Iarocci, 2015). In addition, older child age was associated with higher family quality of life for parents of children with autism aged six to 18 years (Gardiner & Iarocci, 2015) and four to 38 years (Pozo et al., 2014). This finding could be because older children usually require less care from their parents and because the parents have had more time to adjust to the demands associated with caring for their children (age two to 12 years) and to develop positive coping skills (Dardas & Ahmad, 2014). It could also be because older children tend to exhibit less challenging behaviour (Pozo et al., 2014).

Family-level characteristics and resources may also be related to family quality of life. A large body of research has found that more social support is beneficial for parents of adolescent and adult children with autism (e.g., Smith, Greenberg, & Seltzer, 2012; see bB factor: Family resources section for more details). Families with higher incomes consistently report higher family quality of life, likely because they have more resources to cope with their children's disabilities, especially when there are barriers to accessing publicly funded organizational supports (Bayat, 2005; Dardas & Ahmad, 2014; Davis & Gavidia-Payne, 2009; Gardiner & Iarocci, 2015; Hu et al., 2012; Wang et al., 2004). Other family characteristics that influence family quality of life include living conditions such as housing and transportation (Hu et al., 2012), parental depression (Bayat, 2005), and how family members understand and perceive their children's disabilities (Bayat, 2005). Higher family quality of life has been associated with greater availability of services such as government financial support for parents of children with autism aged three to 21 years (Eskow, Pineles, & Summers, 2011) and participation in a parent training program for a mother of a six-year-old boy with autism (Buckley et al., 2014).



Research has examined which factors are most strongly associated with family quality of life. A review by Vasilopoulou and Nisbet (2016) suggested that stress, coping style, and parental self-efficacy have the greatest influence on individual quality of life for parents of children with autism up to 18 years old. Their review focused on the quality of life of one family member rather than the family as a whole. Their findings are likely applicable to the body of research on family quality of life because the concepts of individual quality of life and family quality of life overlap. Brown et al. (2006) identified that family relations, leisure and enjoyment of life, career, and health contributed the most to family quality of life in parents of children with Down Syndrome or autism age three to 13 years. Davis and Gavidia-Payne (2009) identified that professional support, intensity of child challenging behaviour, and support from extended family members were the most strongly related to family quality of life in parents of three- to five-year-old children with developmental disabilities, including autism.

There is some evidence that the most influential factors on family quality of life may vary between mothers and fathers of children with autism. A systematic review of research about parents of children with autism aged 18 years and under found that mothers of children with autism typically rate their individual quality of life lower than fathers of children with autism (Vasilopoulou & Nisbet, 2016). Similarly, Dardas and Ahmad (2014) found that child challenging behaviour was a significant predictor of individual quality of life for mothers, but not for fathers of children with autism aged two to 12 years. Higher household income and more siblings were also related to higher family quality of life for mothers but not for fathers in this study. A potential explanation for these findings is that mothers are more often the primary caregivers and are, therefore,

more strongly affected by their children's behaviour (Dardas & Ahmad, 2014). Although these studies focused on the individual quality of life of parents of children with autism, these factors likely also impact family quality of life because the concepts overlap.

Family quality of life is considered to be an expansion of individual quality of life and includes many of the same concepts (Isaacs et al., 2007; Zuna et al., 2009). Accordingly, factors that influence individual quality of life of one family member are likely to influence the quality of life of other family members, and therefore the family as a whole.

McStay, Trembath, and Dissanayake (2014) found different patterns of family quality of life for mothers and fathers of children with autism aged three to 16 years. In this study, mothers reported higher stress levels and lower family quality of life than fathers. In addition, less child externalizing behaviour and greater parental ability to see stressors as a challenge were the most closely related to higher family quality of life for mothers, whereas for fathers, better coping skills were the most closely related to higher family quality of life (McStay, Trembath, & Dissanayake, 2014).

Pozo et al. (2014) found that parental sense of competence had an indirect relation to family quality of life through active avoidance coping for fathers, but not mothers, of children with autism aged four to 38 years. In addition, higher autism symptom severity was associated with lower family quality of life for mothers, but higher family quality of life for fathers (Pozo et al., 2014). The authors suggested that greater autism symptom severity was likely related to more caregiving demands for mothers, but that it could be related to different expectations of the child and better attachment for fathers of children with autism (Pozo et al., 2014).

To summarize, research has been conducted by family quality of life researchers

about the factors that can best predict family quality of life for parents of children with developmental disabilities such as autism. This has included child characteristics such as challenging behaviour and age (e.g., Gardiner & Iarocci, 2015), family-level characteristics such as social support and family income (e.g., Smith et al., 2012), availability of professional or financial supports (e.g., Eskow et al., 2011), and parent-level variables such as coping style and parental self-efficacy (Vasilopoulou & Nisbet, 2016). Differences between family quality of life for mothers and fathers of children with autism have also been found (Vasilopoulou & Nisbet, 2016). Many of the factors that have been supported as predictors of family quality of life map well onto the double ABCX model, which provides a theoretical framework from which to conceptualize these findings. The following sections describe each of the factors included in the double ABCX model in more detail and review relevant literature.

**Stressor (aA factor).** Several factors have been evaluated as contributors to the stress experienced by parents of children with autism and how they relate to outcomes such as family quality of life. In the double ABCX model, the stressor (Aa factor) refers to the precipitating factor or stressful event that a family experiences. McCubbin and Patterson (1983) define the stressor as a life event that introduces a change to the family system. Hardships refer to additional demands that result from the stressor. Stress represents the balance between the demands of the stressor and a family's resources in response. If a family does not have adequate resources to address the stressor, distress is the result (McCubbin & Patterson, 1983). The stressor could be a specific event, such as a family member who has experienced a stroke (Hesamzadeh, Dalvandi, Maddah, Khoshknab, & Ahmadi, 2015), or a more chronic stressful situation, such as raising a

child with a disability (e.g., Pozo et al., 2014). The stressor is often conceptualized as the child's disability, or other family difficulties such as divorce, death or incarceration of a family member (Saloviita et al., 2003). The lowercase 'a' refers to the accumulation or "pile-up" of other stressors associated with the stressor (McCubbin & Patterson, 1983). In the case of raising a child with a disability, additional stressors may include financial strains, limits on family opportunity, time constraints (Bristol, 1987), and unsupportive social interactions.

Qualitative studies have added richness and depth to the quantitative results reviewed above in exploring how raising children with autism affects parents. Stewart, Knight, McGillivray, Forbes, and Austin (2017) completed focus groups with 12 mothers of children with autism aged 6 to 18 years. These authors structured their findings around the DSM-5 criteria for Post-Traumatic Stress Disorder (PTSD). Many parents reported traumatic symptoms related to receiving their children's autism diagnoses and in response to their children's severe aggressive behaviour (Stewart et al., 2017).

A qualitative study by Myers, Mackintosh, and Goin-Kochel (2009) asked parents of children with autism to describe how raising children with autism affected their families' lives. Their responses led to five clusters of both positive and negative themes, which included stress, child behaviour and demands of care, impact on parent well-being/work/marriage, impact on family as a whole, and social isolation.

Ludlow, Skelly, and Rohleder (2012) interviewed 20 parents of children with autism and used Thematic Analysis to identify six themes: difficulties changing routine, dealing with challenging behaviours, judgment from others, lack of support, impact on the family, coping, and the importance of appropriate support.

Nicholas et al. (2016) interviewed 85 mothers of children with Autism Spectrum Disorder (ASD). The themes these authors identified included: journey of navigating through ASD: seeking services, living and breathing ASD: a new form of motherhood, exhaustion, relational strain, and isolation, living with uncertainty, an emergent ASD-informed maternal identity, redefining success, and lessons from mothering a child with ASD.

Safe, Joosten, and Molineux (2012) used Interpretative Phenomenological Analysis in their study of seven Australian mothers of children with autism. They identified four themes: a paradox of emotions, the frustration of finding the right support, mother as therapist, and “something’s got to give” (p. 297). These mothers explained how they needed to adjust their expectations for their children’s futures while simultaneously wishing they could have a “normal” life (Safe et al., 2012). They also highlighted the difficulties with managing multiple roles and how this impacts their own health and well-being (Safe et al., 2012). These studies provide insight for researchers into reasons why raising children with autism is particularly stressful from a parent perspective.

Some qualitative studies have focused on more specific groups within the population of parents of children with autism. Hall, Fruh, Zlomke, and Swingle (2017) conducted focus groups of Black or Hispanic parents of children with autism. The themes they identified included: coping strategies, family teamwork, spiritual support, culture, resources, stress, and future. These families explained that autism is a taboo topic among African American groups and that spiritual support is an important aspect of their family lives (Hall et al., 2017).

Martins, Walker, and Fouche (2013) interviewed fathers of children with autism

and explored ways that fathering a child with autism is particularly stressful, and how the fathers cope. Some fathers described using problem-focused coping strategies such as providing reinforcement to improve challenging behaviour and learning more about autism. Fathers in this study also used positive reframing, such as seeing their roles as fathers in a more positive light and viewing raising a child with autism as an opportunity for self-development (Martins et al., 2013). Some fathers in this study also used avoidant coping strategies such as minimizing the challenges their children face or focusing on the present rather than the future. Social isolation was identified by many of these fathers as an additional source of stress resulting from raising a child with autism (Martins et al., 2013). Further qualitative research would be beneficial to further explore the experiences of parents of children with autism in their own words to expand on these important findings.

Children with autism require more attention, time, and financial resources than typically developing children, which contributes to parents' stress, isolation, and sibling relationships (Myers et al., 2009). A quantitative study by Sim et al. (2018) found that parents of children with autism who had fewer opportunities to socialize (often due to caregiving demands and lack of appropriate childcare) were 10 times more likely to report severe family stress than parents with more social opportunities. The financial costs and lost income, as well as negative impact on co-parenting relationships and lack of access to parent mental health resources also were associated with higher ratings of family stress for parents of children with autism in this study (Sim et al., 2018).

The present study included school-aged children with autism aged four to 11 years. The minimum age of four years was chosen because most children with autism are

diagnosed reliably by that age. The median age of autism diagnosis was four years, 4 months in a recent American study (Baio et al., 2018). Children younger than four years were not included in this study, because more than half of the children with autism in this age group have not yet received a diagnosis of autism. Therefore, this would restrict the sample that could be drawn from. Further, children with autism who are diagnosed younger typically have more severe symptoms of autism, are from families with more financial resources, and have parents who were more concerned about their development (Daniels & Mandell, 2014). Including younger children with autism in the study would introduce additional bias into the sample and would be less representative of the population of children with autism. The maximum age of 11 years was chosen because this is the age that marks the transition into puberty (May, Pang, O'Connell, & Williams, 2017). Children begin entering the pre-teenage years by age 12 which introduces additional challenges that are beyond the scope of this study.

Autism is a spectrum, so there is wide variability in children's adaptive skills and functioning, which can contribute to additional stress for parents. Because many children with autism have comorbid intellectual disabilities (APA, 2013), attainment of developmental milestones may be delayed. Adaptive skill delays imply that parents need to provide greater support for their children, which results in more strain and responsibility for parents.

Children of these ages also need to make transitions between preschool and kindergarten, and from one grade to another. Transitions are especially challenging for children with autism because of their difficulty with change, and deficits in social skills and communication (Forest, Horner, Lewis-Palmer, & Todd, 2004). This can cause

additional stress for parents who need to provide additional supports for their children during these times. Parents often need to advocate for their children to ensure that they receive appropriate services in school and to co-ordinate the services for their needs, which can be an additional source of stress (White, McMorris, Weiss, & Lunskey, 2012).

School-age children with autism may also have difficulty with navigating social relationships due to impairments in social communication skills. Children with autism generally have fewer friends, poorer quality friendships, and less reciprocity in friendships, and are more likely to be bullied compared to typically developing children (Maino, Normand, Salvas, Moullec, & Aime, 2016; Petrina et al., 2013). Parents can experience stress from helping their children manage relationships with other children (Weiss, Cappadocia, Tint, & Pepler, 2015). More notably, child challenging behaviour and child disability severity greatly affect parents, and were selected as measures of the stressor in this study (see sections below for more details). The other factors described were beyond the scope of the present study and therefore were not included in analyses (e.g., child adaptive behaviour, school transitions, child social functioning). They were reviewed to provide the reader with additional context about how raising children with autism can be stressful for parents. There is less research support for these factors as they relate to family quality of life. For example, child challenging behaviour has been found to be a stronger predictor of parental stress and family quality of life for parents of children with autism compared to disability severity and child age (McStay & Dissanayake, 2014; Gardiner & Iarocci, 2015). School transitions and social functioning are also difficult to measure. Clinical tools used to measure adaptive behaviour are often copyrighted, which introduces a barrier for using them in online research studies. Finally,



although there are many factors which can contribute to stress and reduced family quality of life for parents of children with autism, the focus of this study was on parent-related predictors and therefore, only the child-related predictors that had the strongest research support were included (namely, child challenging behaviour and child disability severity). Considerations were made about how to best balance including variables of interest without making the length of the survey too long, which could reduce meaningful participation from parents of children with autism who experience competing demands.

The double ABCX model assumes that the presence of a stressor does not invariably lead to negative outcomes, rather the outcome is determined by the interactions between family resources (bB factor), coping strategies (BC factor), and perceptions of the situation (cC factor; Xu, 2007). Extensive research has studied how raising children with developmental disabilities affects parents and found that parents of children with autism are particularly stressed compared to parents of children with other developmental disabilities and parents of children who are typically developing (Benson, 2006; Gardiner & Iarocci, 2012; Harper et al., 2013; Hartley et al., 2010; Karst & Van Hecke, 2012; Padden & James, 2017; Smith, Buch, & Gamby, 2000; Vasilopoulou & Nisbet, 2016).

Within the double ABCX model, the stressor has been operationalized in ways such as child challenging behaviour, autism symptom severity, adaptive functioning, and the “pile-up” of stressors (McStay, Dissanayake, Scheeren, Koot, & Begee, 2014). Research has focused on stress proliferation, comparing parents of children with and without developmental disabilities, or with different types of developmental disabilities, disability severity, and child challenging behaviour (e.g., Padden & James, 2017; Paynter et al., 2013; Shahrier et al., 2016). The present study focused on child challenging

behaviour and child autism symptom severity, which are each discussed below. These variables were chosen for this study because they had the strongest empirical support relating them to parent outcomes such as family quality of life.

***Child challenging behaviour.*** There is consensus in the research literature that more child challenging behaviour is associated with poorer outcomes for parents raising children with disabilities (Baker et al., 2005; Hastings, 2003; Sikora et al., 2013). Many children with developmental disabilities have higher rates of challenging behaviour than children who are typically developing (Blacher & McIntyre, 2006; Eisenhower et al., 2005). Child challenging behaviour is distinct from autism symptom severity and generally includes externalizing behaviour (e.g., defiance and aggression), internalizing symptoms (e.g., anxiety), and attentional difficulties (McStay et al., 2015). These challenging behaviours may place more stress on parents, which can result in parental mental health problems (Baker et al., 2005).

Many studies have found a significant association between child challenging behaviour and outcomes such as greater parental stress for parents of preschool children with developmental delays (Baker et al., 2005), and parents of children aged six to 16 years with Intellectual Disabilities (Hassall, Rose, & McDonald, 2005). A recent review of studies across the lifespan (including parents of sons and daughters who were infants up to age 59 years with Intellectual Disabilities) provided additional support for the relation between child behavioural difficulties and parental stress (Biswas, Moghaddam, & Tickle, 2015). Research also supports the positive relation between child challenging behaviour and parental stress for parents of children with autism aged two-and-a-half to six years (Paynter et al., 2013), two to 21 years (Hall & Graff, 2012), and six to 18 years

(McStay, Dissanayake, et al., 2014). Studies have found that child challenging behaviour is associated with poorer family quality of life for parents of children aged three to five years old with developmental disabilities (Davis & Gavidia-Payne, 2009), parents of children with autism aged three to 16 years (McStay, Trembath, & Dissanayake, 2014) and parents of children with autism aged four to 38 years (Pozo et al., 2014). Parents of children with autism in qualitative studies have also explained how child challenging behaviour such as aggression and tantrums can be disruptive to their family life (Ludlow et al., 2012).

Researchers have found that child challenging behaviour is more strongly related than child disability severity to parent outcomes such as parental stress and well-being (e.g., Baker et al., 2002; Benson, 2010; 2005; Blacher & McIntyre, 2006; McStay, Dissanayake, et al., 2014; Vasilopoulou & Nisbet, 2016). For example, McStay, Dissanayake, et al. (2014) found that after perceived child challenging behaviour and quality of life were accounted for, child age, verbal ability, and autism symptom severity were not associated with parenting stress in mothers of children with autism aged six to 18 years. Similarly, Gardiner and Iarocci (2015) found that child challenging behaviour was associated with family quality of life even after autism symptom severity, family income, child gender, and child age were taken into consideration in their study of caregivers of children with autism aged six to 18 years. These findings imply that child challenging behaviour is more strongly related to parents' well-being than autism symptom severity.

***Child disability severity.*** Researchers have explored the role of both intellectual functioning and autism symptom severity exhibited by children in relation to parental

well-being and family quality of life. A recent American study found that 31% of 8-year-old children diagnosed with autism had a comorbid Intellectual Disability, and 25% had Borderline Intellectual Functioning (Baio et al., 2018). Autism symptom severity is distinct from child challenging behaviour and refers to the extent to which a child displays the core symptoms of autism (i.e., deficits in social communication and the presence of restricted patterns of behaviour, APA, 2013).

There are conflicting findings as to the role that child disability severity plays in affecting parental stress and mental health. Many studies have found that raising children with more severe developmental disabilities is related to poorer outcomes for parents. More specifically, raising children with lower intellectual functioning was associated with lower family quality of life and higher levels of depression in parents of children, adolescents, and young adults with Intellectual Disabilities (Hu et al., 2012), or preschoolers with various developmental disabilities (Eisenhower et al., 2005) and children up to eight years old with various special needs (Wang et al., 2004). Parents of children with autism aged five to eight years with higher IQ scores reported less stress (Pastor-Cerezuela, Fernandez-Andres, Tarraga-Minguez, & Navarro-Pena, 2016). However, other studies have found that child disability severity did not predict outcomes such as parenting stress and family quality of life in parents of children aged three to five years with a developmental delay (Davis & Gavidia-Payne, 2009) or in a sample of parents of children with autism aged six to 18 years (Gardiner & Iarocci, 2015). The inclusion of other related factors such as adaptive functioning and professional supports in the latter studies may have contributed to the lack of relation between child disability severity and parental outcomes, however more research is needed to help clarify these

discrepant findings.

The research is also unclear in relation to autism symptom severity. Whereas some studies have found that raising children with more severe autism symptoms was associated with lower family quality of life and well-being or greater stress in parents (Benson, 2006; Gardiner & Iarocci, 2012; Pastor-Cerezuela et al., 2016), other studies found that child autism symptom severity was not related to parent outcomes (Bayat, 2005; McStay, Dissanayake, et al., 2014; McStay, Trembath, & Dissanayake, 2014). Pruitt, Willis, Timmons, and Ekas (2016) found that children aged three to 13 years with more deficits in social motivation had mothers with higher daily positive affect. On the other hand, Konstantareas and Papageorgiou (2006) found that mothers of children and youth with autism aged two to 26 years who were nonverbal reported greater stress. This discrepancy in findings is likely influenced by differences in defining and measuring child disability severity. For example, some researchers have used only one parent-report item to measure child disability severity, whereas others have used standardized clinical measures. Standardized clinical tools are probably more accurate measures of the child's disability. Measures that are completed by clinicians may also be more accurate because they may be more objective and have more experience working with children of various abilities from which to compare. Other factors such as child challenging behaviour may be more important in determining outcomes for parents of children with autism (Dissanayake, 2014; Gardiner & Iarocci, 2015).

***Unsupportive social interactions.*** In addition to child characteristics, unsupportive social interactions are another potential stressor that parents of children with autism may face. Unsupportive social interactions refer to negative or unhelpful responses received

from others in response to a stressor (Ingram, Betz, et al., 2001). The double ABCX model and social support research have typically focused on positive responses elicited from others in the face of negative events (i.e., social support: bB factor) and have not included the negative aspects of social interactions. Many researchers have restricted their studies to beneficial social contact and therefore the negative effects of social relationships on well-being have not yet been widely researched (e.g., Rook, 1984; Weiss et al., 2013). Individuals facing a stressful life event often receive responses from others that are negative or unintentionally upsetting. For example, in a recent study (Jones & Gragg, 2016), six of 11 parents of children with autism who were interviewed spontaneously remarked that they had experienced some sort of negative response in relation to raising their children with autism when asked about how their family and friends influenced their family quality of life. Many parents in this study expressed the sentiment that some people “just don’t get it” (Jones & Gragg, 2016). For example, one mother described a situation where friends judged her for using a harness with her son with autism for safety reasons while camping. Another parent described how their extended family was upset that they did not bring their child with autism to a family event because it was too overwhelming (Jones & Gragg, 2016). These experiences appeared to be quite common for parents of children with autism and to have an impact on their family quality of life. However, the negative aspects of social interactions for parents of children with autism have not been adequately explored by researchers. The concept of unsupportive social interactions appeared to best capture these experiences that were described by the parents who were interviewed.

Ingram, Betz. et al. (2001) coined the term “unsupportive social interactions” to

refer to responses that individuals receive from others that are perceived as negative or unsupportive. Unsupportive social interactions are stressor-specific, which means that they are thought to occur in response to a particular stressor that an individual experiences, such as breast cancer or HIV-related losses (Ingram et al., 2001). The concept of unsupportive social interactions includes responses that are overtly negative, such as blaming an individual for their problem, but also includes responses that are unintentionally negative or unhelpful, such as forced optimism. It takes into account that unsupportive social interactions and supportive responses could come from the same people, rather than assuming that everyone in a person's social network is unidimensionally supportive or unsupportive. Ingram et al. (2001) explain that "even if well-intentioned individuals are available to provide support, they may respond in a manner that is unsupportive or distressing" (p. 288).

Unsupportive social interactions are also conceptualized as *behaviours* rather than attitudes, and thus are distinct from concepts such as stigma (Ingram, Betz, et al., 2001). An example of unsupportive social interactions would be if a person gave unsolicited advice to someone, whereas stigma would be if a person had a negative attitude towards someone.

In a study of college students experiencing various stressors, Ingram, Betz, et al. (2001) used factor analysis to identify four types of unsupportive social interactions that may follow a stressful life event: distancing, bumbling, minimizing, and blaming. Distancing refers to when people avoid or disengage themselves from the affected person. Bumbling refers to behaviours that are perceived as being awkward, unwelcome, or intrusive by the affected person. Minimizing is when people do not take the affected

person's concerns seriously, and force optimism. Blaming means assuming that it is the affected person's fault for being in the stressful situation and may include critical comments. Family and friends may make unsupportive responses because they are unsure how to respond, they do not understand the situation, or because of stigma and their own negative feelings (Ingram, Betz, et al., 2001).

Ingram, Betz, et al. (2001) conceptualized unsupportive social interactions as being responses to a specific stressor, rather than negative interactions in general. Unsupportive social interactions have been studied in populations of people who have experienced a variety of stressful life events, such as bereavement, cancer, and AIDS (Ingram et al., 2001). Initial research identified that unsupportive social interactions are distinct from negative interactions in general. Research by Ingram et al. (2001) found that unsupportive social interactions were associated with the recipients' psychological distress, depressive symptoms, and physical symptoms, even after present grief had been taken into account in a sample of individuals experiencing multiple AIDS-related losses.

Unsupportive social interactions could fit into the double ABCX model as a stressor (aA factor). This is the first known study to include unsupportive social interactions in the double ABCX model and so its fit within the model has not been agreed upon. Within the context of the double ABCX model, the stressor (aA factor) is not limited to a one-time event, but also includes the "pile-up" of demands associated with the original stressor (the lowercase a). Unsuptive social interactions could be an additional stressor in response to the child's autism diagnosis or associated features such as challenging behaviour and comorbid developmental delays. For example, challenging behaviour demonstrated by a child with autism such as aggression towards others could



lead to increased unsupportive social interactions such as judgmental comments about parenting strategies, or more distancing in relationships due to practical constraints. These experiences could represent additional stressors (aA factor) that could in turn lead to reduced family quality of life.

As summarized below, a few studies have examined negative social interactions experienced specifically by parents of children with autism. Some parents of children with autism who participated in qualitative studies shared experiences that could be conceptualized as unsupportive social interactions (e.g., Jones & Gragg, 2016; Ludlow et al., 2012; Nicholas et al., 2016; Safe et al., 2012). Parents of children with autism in several studies explained how strangers reacted negatively when their children were having tantrums in public. Parents in these situations often felt judged about their parenting skills due to a lack of understanding from others (Nicholas et al., 2016; Safe et al., 2012). Parents of children with autism interviewed by Ludlow et al. (2012) also explained ways that they perceived a lack of support, such as difficulty finding appropriate childcare and lack of understanding about autism from extended family members. African American parents of children with autism in focus groups explained that they were uncertain about the level of understanding and acceptance of extended family members and spiritual community members (Hall et al., 2017).

A qualitative study by Neely-Barnes, Hall, Roberts, and Graff (2011) explored parents' experiences of blame using focus groups. These parents reported feeling like "bad parents". The invisible nature of autism makes it so that people in public assume that children having tantrums are undisciplined (Neely-Barnes et al., 2011). Sometimes extended family members offered unwanted advice about parenting due to a

misunderstanding of the nature of autism. Some parents reported directly confronting the people who made judgmental comments, whereas others chose to ignore it (Neely-Barnes et al., 2011). Although these experiences were not labelled as unsupportive social interactions by these researchers, their results appear to fit well with the concept.

Blogs written by parents of children with disabilities have also described experiences of unsupportive social interactions, such as feeling judged for parenting decisions made based on their children's disabilities. For example, Seidman (2017), a mother of a son with autism, explains how she often feels judged in public about her parenting. She feels that strangers assume that her son is "spoiled" or that she is coddling him because of things like how she responds to her son's "meltdowns".

There is minimal quantitative research that has examined the negative aspects of social interactions for parents of children with autism. Smith et al. (2012) asked mothers of adults and adolescents with autism to identify up to 10 people in their social network and to respond whether each person gave positive or negative support (e.g., made excessive demands on the mother). In this study, higher levels of negative support were associated with higher levels of depressive symptoms and negative affect, and lower levels of positive affect. There was strong evidence for negative support in determining lower well-being outcomes, but less evidence for the role of positive support. Although Smith et al. (2012) did not study unsupportive social interactions directly, their findings about negative support are consistent with other studies.

There is one study that has been conducted that evaluated unsupportive social interactions specifically for parents of children with autism. Pottie et al. (2009) asked parents of children with autism aged four to 12 years to rate their mood, social support,

and unsupportive social interactions on a daily basis. They found that higher levels of daily unsupportive social interactions were related to higher levels of daily negative mood and lower levels of daily positive mood. More research is needed to describe how parents of children with autism experience unsupportive social interactions and how this may impact their family quality of life. Qualitative methods are well-suited as a first step towards this goal.

Earlier research has been conducted that has examined the effects of negative social responses more generally before the term unsupportive social interactions was developed. Negative social responses have been conceptualized in many ways, such as social negativity (Brooks & Dunkel Schetter, 2011), problematic social ties (Rook, 1984), and negative social exchange (Ingram, Betz, et al., 2001). The negative aspects of social interactions are important because there is evidence that they are associated with negative outcomes in terms of both physical and mental health (Brooks & Dunkel Schetter, 2011; Mindes et al., 2003). The concept of unsupportive social interactions was used in the present study because in past research, parents of children with autism spontaneously identified it as being relevant to their experiences (Jones & Gragg, 2016). This concept captures the milder and well-intentioned responses commonly found to be unhelpful and potentially distressing for parents of children with autism.

Although unsupportive social interactions share some similarities with social support, research suggests that the positive and negative aspects of social relationships are distinct from each other. Earlier researchers suggest that general negative social responses do not represent a *lack* of social support, and these two concepts are not inversely related (Rook, 1984). Just as being given poison is different from being denied medicine,

unsupportive social interactions and social support are not opposites on the same continuum, but are independent from one another (Mindes et al., 2003). For example, someone could have a high level of social support, but also receive many unsupportive social interactions. It is possible to receive both supportive and unsupportive responses from the same person. For example, a family member could be helpful in providing childcare, but could also give unwanted or unhelpful advice to the parents.

Research has consistently found that the positive and negative aspects of relationships are separate factors (Brooks & Dunkel Schetter, 2011). Unsupportive social interactions were not significantly correlated with trait negative affectivity in a sample of college students, which means that unsupportive social interactions are not simply a result of a tendency to perceive events in a negative manner (Ingram, Betz, et al., 2001).

Unsupportive social interactions may have more potent effects than positive social support in determining psychological outcomes. Generally, negative events are more salient than positive events, and may decrease well-being more than positive events increase well-being (Rook, 1984; 1990). The majority of the studies cited in a literature review by Lincoln (2000) found that negative social interactions (“those actions by a member in one’s social network that cause distress”, Lincoln, 2000, p. 233) had a greater effect than positive social interactions on psychological well-being. Similarly, Rook (1984) found that negative social interactions had a stronger effect on well-being than positive social interactions among older women who were widowed. In a study of mothers of adolescents and adults with autism, Smith et al. (2012) found that “negative support” (defined as responses that were critical or blaming, making excessive demands, or making them feel uncomfortable) was a stronger predictor of maternal mental health

symptoms than positive support. These findings emphasize that negative social interactions need to be included when studying the well-being of parents of children with autism, rather than focusing solely on positive social interactions.

High levels of unsupportive social interactions have been associated with negative outcomes in a variety of populations. In a longitudinal study of women struggling with infertility, Mindes et al. (2003) found that higher levels of unsupportive social interactions were associated with increased depressive symptoms, psychological distress, and lower self-esteem six to 12 months later. Figueiredo et al. (2004) studied women with breast cancer, and found that unsupportive social interactions were related to weaker social functioning and role limitations even after demographic variables, cancer-related variables, and social support were considered. They also found that unsupportive social interactions negatively affected the quality of life of women with breast cancer. Ingram et al. (2001) studied people who have experienced the deaths of multiple people with AIDS and found that the Bumbling (awkward responses) and Distancing (reduced interpersonal contact) subscales of their Unsupportive Social Interactions Inventory were significantly associated with depression to a greater extent than present grief.

Coping styles have been found to mediate the relation between unsupportive social interactions and psychological outcomes. Mindes et al. (2003) found that avoidance coping mediated the relation between unsupportive social interactions and depressive symptoms, psychological distress, and self-esteem among women with infertility. Similarly, Ingram et al. (2001) found that the relation between distancing, unsupportive social interactions, and depression was partially mediated by avoidance coping in their study of people experiencing AIDS-related losses. These findings fit within the context of

the double ABCX model which suggests that responses to stressors including family resources, family appraisal, and coping affect family adaptation.

Although the double ABCX model includes social support as a predictor of family adaptation, it has not included negative social interactions such as unsupportive social interactions. Based on the research reviewed above, unsupportive social interactions may be more strongly associated with outcomes such as family quality of life than positive social support for people faced with stressful life events. In the current study, the relation between unsupportive social interactions and social support and how these related to family quality of life was evaluated. The present study also examined whether unsupportive social interactions could add to the double ABCX model as an additional stressor (aA factor) that parents may face that may affect family quality of life for parents of children with autism. Unsuptive social interactions have not been studied within the context of the double ABCX model and therefore their place within the model has not been agreed upon. Unsuptive social interactions were considered within the double ABCX model because there is some preliminary evidence suggesting that the concept is relevant to parents of children with autism. Some research suggests that unsupportive social interactions may have more potent effects than positive social support, so it was important to consider both variables together as they relate to family quality of life. Further, there is a well-developed measure of unsupportive social interactions.

**Family resources (bB factor).** The double ABCX model hypothesizes that adaptation is affected by the family resources (bB factor) that can be drawn upon in times of stress. Resources can exist at the individual level, family level, or community level (McCubbin & Patterson, 1983). These resources represent a family's ability to manage

the demands associated with the stressor to minimize the disruption in their family lives and prevent a crisis (McCubbin & Patterson, 1983). The inclusion of both the uppercase “B” and the lowercase “b” in the double ABCX model refers to the concept that some parents may access resources and supports in response to the stressor in addition to their existing resources (McStay et al., 2015). The bB factor has typically been conceptualized as family hardiness, the family environment, and the amount of social support that family members can access (McStay et al., 2015). The present study focused on how social support was related to family quality of life to further explore the strong relation found in the literature. Parents in a previous qualitative study (Jones & Gragg, 2016) also emphasized the importance of support from others.

Social support refers to social interactions of a positive nature between individuals. It can include instrumental and emotional support. Instrumental support refers to tangible help such as helping with household tasks or providing childcare. Emotional support is less tangible, such as having someone to talk to or rely on when feeling stressed (Cohen & Willis, 1985). Parents of children with autism report that they receive more emotional than instrumental support from family and friends (Brown et al., 2003; Rillotta et al., 2012). Some models also include informational support, which is when people provide information or make referrals (Trepte, Dienlin, & Reinecke, 2015). Informational support is more common in online interactions than in-person interactions because there is a broader audience online (Trepte et al., 2015). Emotional and instrumental support were more common in in-person interactions (Trepte et al., 2015). In a study of social network site users, online social support was not related to life satisfaction, whereas greater use of in-person social support was related to higher life

satisfaction (Trepte et al., 2015).

Cohen and Willis (1985) put forth the buffering hypothesis in relation to social support. According to this model, social support helps to buffer or protect people from the deleterious effects of stressful events. Social support acts as a buffer by providing the individual with more resources to handle the stressor or by modifying the way in which the stressor is perceived (Cohen & Willis, 1985). These authors also proposed a main effects model in which higher levels of social support are beneficial, regardless of whether a person is experiencing high levels of stress or not. In their review, there was evidence in the literature for both the buffering hypothesis and the main effects model. This finding implies that social support is beneficial for people whether they are experiencing high levels of stress or not.

Another important distinction is between the availability and perceived adequacy of social support. Availability refers to the amount of support that an individual or family can access, whereas perceived adequacy of social support refers to the individual's satisfaction with the amount and quality of social support that they are receiving (Neuling & Winefield, 1988). Research suggests that the perceived adequacy of social support is more salient than the availability of social support in determining outcomes such as mental health (Neuling & Winefield, 1988).

The source of the support is another important consideration. Many people have different reactions or expectations for support from family and friends than from professionals (Neuling & Winefield, 1988). Most social support research focuses on informal supports, such as that given by family and friends. Less research has been conducted on the role of social support given by professionals. Research has found that



the source of support was more important than the type of support (Lee & Goldstein, 2016; Neuling & Winefield, 1988; Winefield, Winefield, & Tiggemann, 1992). More specifically, women with breast cancer expected more informational support from medical professionals than from family and friends (Neuling & Winefield, 1988). Family members provided the most empathic support. Satisfaction with the adequacy of social support from family and friends was related to less anxiety and depression in the early stages of the illness (Neuling & Winefield, 1988). In another study of young adults facing various stressors, support from family and close friends was more closely related to well-being than support from peers or people in authority positions such as job supervisors (Winefield et al., 1992). In a more recent study of young adults, social support from friends and romantic partners was more strongly related to lower stress and loneliness than social support from family members (Lee & Goldstein, 2016).

Research points to the benefits of social support for parents of children with disabilities. Higher ratings of social support from romantic partners, family members, and friends have been associated with lower levels of depression, negative affect, and parenting stress, and higher levels of life satisfaction, family quality of life, daily parental mood, positive affect, family functioning, and psychological well-being in parents of children with autism or other developmental disabilities of various ages (Ekas et al., 2010; Hassall et al., 2005; Manning et al., 2011; Pozo et al., 2014). Instrumental support and emotional support, but not support services, were associated with higher daily ratings of positive mood and lower daily ratings of negative mood in a sample of parents of children with autism aged four to 12 years (Pottie et al., 2009). Emotional support was found to be the most closely related to family quality of life in a sample of mothers of school-age

children with Intellectual Disabilities and autism (Meral, Cavkaytar, Turnbull, & Wang, 2013). In a longitudinal study conducted over 18 months, parents of children with autism aged 11 to 50 years who listed more members in their social network also had higher ratings of well-being (Smith et al., 2012). Social support was related to improvements in well-being even after child challenging behaviour was taken into account. However, studies of parents of children with disabilities have found that many parents perceive their social support as inadequate, especially from extended family and friends (Bertelli et al., 2011; Brown et al., 2003; Rillotta et al., 2012; Werner, Edwards, & Baum, 2009; Werner, Edwards, Baum, et al., 2009).

***Online social support.*** Online communication is increasingly popular as a way to access social support. For example, a recent study found that 75% of American parents of typically developing children reported using social media, and 80% of mothers and 65% of fathers reported receiving social support through social media (Duggan, Lenhart, Lampe, & Ellison, 2015). Many parents use technology to communicate with family, friends, or even strangers to seek social support. This may include online support groups, social media, online discussion forums, or sharing a personal blog (Doty & Dworkin, 2014; Jordan, 2010). Many parents seek online social support and report this method as being helpful (Jeans, 2013).

Using the internet as a way to access social support has some benefits for its users. Social media allows people both to deepen connections with people who are close to them, and to make new connections with people with whom they have weaker ties such as strangers (Schrock, 2016). It provides people with opportunities to receive supportive responses from people who may not be relationally close to them (Rozzell et al., 2014).

People generally have access to more people through the internet than in real life and are not limited by geographical location, which may facilitate better access to informational support (Trepte et al., 2015) and help maintain previously established relationships (Schrock, 2016). Online social support is also available 24 hours a day, seven days a week, which allows for greater access to support for parents who might find it difficult to leave the house to access in-person supports due to their children's challenging behaviours or sensory aversions (Doty & Dworkin, 2014). A sense of belonging is another function of social media use for parents (Schrock, 2016).

Online communities typically afford their users more anonymity, which may allow parents to ask questions or share experiences that they might find embarrassing with people they know (Doty & Dworkin, 2014). However, anonymity online may also have negative consequences, such as increasing the likelihood that someone might say something offensive (Christopherson, 2007).

Some research has been done in the general population evaluating the role of online social support. For example, Haslam, Tee, and Baker (2017) found that greater frequency of social media use was associated with greater online social support for parents of typically developing children. Further, supportive interactions through social networking websites was associated with positive affect in a study of adults in the general population (Oh, Ozkaya, & LaRose, 2014). However, in this study, the quality of the online interactions was found to be influential, while the frequency of use and the size of the online social network was not influential. Schrock (2016) studied parents of young children who were typically developing and found that greater frequency of Facebook use was associated with building stronger personal connections and making new connections

with others.

However, there are also drawbacks to accessing social support online. Because it is easy to share information online, misinformation can also be easily shared, which could be potentially harmful. Online interactions also lack the personal contact inherent to face-to-face interactions (Doty & Dworkin, 2014). It is generally deemed inappropriate to disclose excessive personal details online, which results in less intimacy in online relationships than in-person relationships. This atmosphere may make it harder for people to seek emotional support online (Trepte et al., 2015). It is also more difficult for people to give and receive practical support online (Liu & Yu, 2013). Although online friends might share information, make referrals, or even send money online, they are less likely to provide services such as childcare or help with household duties unless they share physical proximity (Doty & Dworkin, 2014; Trepte et al., 2015). Instrumental social support is important for parents of children with disabilities such as autism (Vanegas & Abdelrahim, 2016). Trolling is a recent phenomenon in which people intentionally make negative comments or are disruptive online (Bharati, Lee, & Syed, 2017; Buckels, Trapnell, & Paulhus, 2014). Internet trolls can contribute to making the online atmosphere negative and hostile.

Despite the benefits that come with using the internet to access social support, it may be less beneficial than in-person social support. Most of the previous research to date has focused on directly comparing online and in-person social support. For example, Grant and Dill-Shackleford (2015) found that adults in sobriety recovery programs preferred face-to-face over online support groups. Face-to-face groups had better attendance and better success rates than online support groups. In a study comparing

online and in-person social support in a longitudinal study of German adults, Trepte et al. (2015) found that online social networking sites were superior for receiving informational support, whereas in-person contexts were superior for receiving emotional and instrumental support. These authors also found that social support received through social networking websites was not significantly related to life satisfaction, whereas social support received in person was significantly related to life satisfaction. Online relationships tend to be weaker than in-person interpersonal relationships (Giota & Kleftras, 2014). Although research comparing in-person and online social support has its merits, this approach is overly dichotomous and assumes that the two concepts are distinct. These approaches do not consider how in-person and online social support methods could overlap. There is evidence that online social support has an indirect effect on well-being and is mediated by general social support (Liu & Yu, 2013). This finding implies that online social support is an extension, rather than a replacement, of in-person social support.

Some individuals may seek social support online because they do not perceive adequate social support from other sources. In addition, some people living in isolated locations may seek social support online because they do not have access to a network of in-person social supports. For example, people with hearing loss were more active participators in an online self-help group if they had a lack of in-person social support (Cummings, Sproull, & Kiesler, 2002). Similarly, Chung (2013) found that users of health-related online support groups who preferred online support groups over face-to-face interactions tended to be more dissatisfied with support received offline. This preference is potentially problematic if the users “replace” their in-person network with

their online network. Online support groups may not be a viable alternative to in-person supports, as an overreliance on online supports could lead to further isolation from face-to-face contacts (Chung, 2013).

However, in-person and online social support are interconnected in many ways. Social media can serve a bonding purpose in which it allows people to further develop relationships and communicate with people they know in real life (Schrock, 2016). For example, family and friends rather than strangers represented the majority of Facebook “friends” in a study of parents in the general population (Duggan et al., 2015). Social media can also serve a bridging purpose in which broad social ties can be formed with people who are less relationally close (Schrock, 2016). Some parents might forge in-person friendships with people that they have initially met online. Best practice recommendations for online social support suggest incorporating existing networks of support into online modalities and recognizing the interdependence between the two (Weiss et al., 2013). Taking this approach can produce better outcomes. For example, there were more benefits to people with hearing loss whose real-world friends and family also participated in online support groups (Cummings et al., 2002).

Parents of children with autism are in a relatively unique situation, so they might not have pre-existing connections with other parents who have similar experiences, and feel isolated (Kerr & McIntosh, 2000). The internet allows this group of parents to connect with one another. They may then feel like they are not alone, and may feel comforted by knowing that other parents are in similar situations. Indeed, online social support has been found to reduce isolation among parents of children who are typically developing (Doty & Dworkin, 2014). In their analysis of social support through Twitter

and blogs, Saha and Agarwal (2016) reported a high sense of community and solidarity within the community of parents of children with autism. Key functions of this type of technology use are connecting with other parents for information about raising children with autism, coping, and raising autism awareness and acceptance.

The internet also plays a role in allowing parents to access information about autism. However, the consistency, quality, and accessibility of information that is presented online for parents of children with autism varies (Hall, Culler, & Frank-Webb, 2016). A recent study evaluated the quality of responses given to an online question and answer forum about early signs of autism. Parents tended to prefer answers that included support and anecdotes, whereas clinicians tended to prefer answers that suggested actions or seeking additional resources (Ben-Sasson, Pelleg, & Yom-Tov, 2016). Another study found that many parents of children with autism preferred local sources of informational support such as organizations, other parents, or professionals who they were familiar with and that they tended to get information online using local forums, e-mail listservs, and national organization websites such as Autism Speaks (Gibson, Kaplan, & Vardell, 2017). The parents in this study also reported feeling that the amount of information available to them was inadequate. However, national organization websites can also contain information that is not scientifically-supported (Hall et al., 2016).

Few published articles have evaluated the role of online social support for parents of children with autism (Hall et al., 2016). A qualitative study found that many mothers of children with autism aged two to 17 years used the internet to access informational support and emotional support (Reinke & Solheim, 2014). In this study, participants reported that they appreciated the sense of community online and the opportunity to share

their stories and have their experiences be affirmed by others in similar situations.

Another qualitative study of the experiences of parents of children with autism who participated in online support groups found positive effects such as finding information about autism, accessing professionals, receiving social support, reducing isolation, and creating collective action (Carter, 2009). Some negative effects associated with online support groups included concerns about confidentiality, etiquette, and accessibility (Carter, 2009).

Clifford and Minnes (2013a) studied the use of support groups for parents of children with autism. They found no differences between parents who reported currently participating in parent support groups online compared to in-person support groups on ratings of anxiety, depression, social support, coping, or attitudes towards parent support groups. Online support groups were recommended for parents who had difficulty accessing in-person support groups based on tangible barriers such as transportation and childcare. Clifford and Minnes (2013b) next studied 20 mothers of children with autism aged two to 22 years who participated in an online support group. No differences were found in parenting stress, anxiety, depression, or positive perceptions over time or in comparison to a control group. However, participants in this study reported a high level of satisfaction with the online support group and felt that connecting with other parents and getting information about resources were the most helpful functions of the group (Clifford & Minnes, 2013b). Therefore, online support groups may be useful for parents of children with autism.

A quantitative study of mothers of children with autism found that among those who use online social networks, higher levels of perceived online support was associated



with lower levels of stress and depression. However, there were no significant differences between mothers who used online social networks and those who did not (Davis, 2013). In another study, higher perceived social support and more participation in online support groups was related to lower stress for mothers of children with autism (Garbe, 2008). These mothers also reported higher satisfaction with social support from in-person contexts than from online contexts.

Together, these findings suggest that there are many potential benefits and drawbacks to accessing social support online, particularly for parents of children with autism. However, the paucity of research in this relatively new area prevents a consensus from being drawn. More research is needed to determine the functions of technology for seeking social support, how it is related to in-person social support, and how it is related to outcomes such as family quality of life for parents of children with autism, which were some of the goals of this study. There were no adequate measures of online social support available, so an existing measure of social support was modified, and a new measure of frequency of technology use to access social support was created for this study. The present study focused on understanding how to best measure online social support, and determining whether it was related to family quality of life on its own. Online social support was examined outside of the double ABCX model because the other goals listed above were of primary importance.

It is unclear from past research how online social support is used by parents of children with autism, and why they choose to use technology in these ways. Qualitative approaches would be useful to gather more information about the experiences of parents of children with autism and their use of online social support. This study used interview

questions to better understand the perspective of parents of children with autism about online social support use.

**Family appraisal (cC factor).** In the double ABCX model, the cC factor refers to family appraisal, or the ways in which family members perceive stressful situations. The family appraisal is a subjective judgment by the family about the stressor (McCubbin & Patterson, 1983). The lowercase c refers to the ways in which the meaning of the stressor that a family makes can change over time. Family appraisal is considered one of the most powerful determinants of a family's adaptation to a stressor, although it is difficult to measure due to its subjective nature (Boss, 1987). Family appraisal has been conceptualized in many ways, including seeing the situation as a challenge versus a threat, cognitive reframing, parental sense of coherence, parental sense of competence, and psychological acceptance (McStay et al., 2015). The present study focused on parental sense of competence and psychological acceptance which are each reviewed below. Parental sense of competence was chosen as a variable of interest due to its strong support within the literature as being related to parent outcomes such as higher family quality of life (e.g., Pozo et al., 2013). Psychological acceptance is a concept which has not yet been studied within the double ABCX model. It considers parents' ability to tolerate the difficult emotions associated with raising children with autism. It was included because it considers the parents' perceptions of the situation from an emotional perspective, which would not be captured by measures of parental sense of competence. As explained in the section below, there is empirical support that greater psychological acceptance has been associated with better mental health for parents of children with autism (Jones, Hastings, Totsika, Keane, & Rhule, 2014; Weiss, Cappadocia, MacMullin,

Viecili, & Lunsky, 2012).

***Parental sense of competence.*** Researchers using the double ABCX model commonly conceptualize the cC factor as parental sense of competence. This variable, also called parenting self-esteem or parental self-efficacy, refers to parents' beliefs that they are competent and able to be effective parents for their children (Bandura, 1977; Jones & Prinz, 2005). Parental sense of competence includes two dimensions: parenting efficacy and parenting satisfaction. Parenting efficacy refers to how competent and comfortable parents feel in their roles as parents. Parenting satisfaction is an affective dimension which refers to how satisfied, motivated, and content they are in their roles as parents (Johnston & Mash, 1989). Parental sense of competence is relatively stable across time, as Benson (2014) found that levels of parenting efficacy remained stable for mothers of children with autism over a seven-year period.

There is evidence that higher parental sense of competence is associated with better outcomes for parents. Higher parental sense of competence has been associated with positive outcomes such as higher family quality of life, lower fatigue, and reduced parenting stress (Giallo, Wood, Jellett, & Porter, 2013; Hassall et al., 2005; Minnes, Perry, & Weiss, 2015; Pozo et al., 2014). Parenting efficacy is also closely related to the use of positive parenting strategies such as warmth and involvement, which in turn result in better outcomes for children (Jones & Prinz, 2005). Some studies have used parental sense of competence as a target of parent-based interventions for children with autism (e.g., Keen, Couzens, Muspratt, & Rodger, 2010).

Studies have found that parents of children with autism typically report lower parental sense of competence than parents of children with other disabilities, or no

disabilities (McStay et al., 2015). Mothers of children with autism or ADHD had lower parental self-efficacy than parents of typically developing children (Rosenblum-Fishman, 2013). However, this difference was better accounted for by child challenging behaviour, which means that child challenging behaviour is the likely cause of lower parental self-efficacy rather than the specific diagnosis. In another study, lower levels of parenting efficacy were prevalent in single mothers with elevated levels of stress and depression who were raising children with and without developmental disabilities (Small, 2010).

There are differences between ratings of parental sense of competency towards children with and without disabilities even within families where parents have children both with disabilities and without disabilities. Mothers reported more stress, lower parenting competence, and more depression in relation to their children with autism compared to their typically developing children (Meirsschaut, Roeyers, & Warreyn, 2010). Parents of children with autism may have lower parental efficacy because their children display challenging behaviour and may not be able to communicate their needs, or because it is less clear how best to parent children with autism than typically developing children (Karst & Van Hecke, 2012).

Research supports the association of higher parental sense of competence with better outcomes specifically among parents of children with autism. Mothers of children with autism aged two to five years who had high levels of fatigue also had lower ratings of parenting satisfaction and efficacy (Giallo et al., 2013). Kuhn and Carter (2006) found that parenting self-efficacy was associated with better well-being, higher agency, and fewer feelings of guilt in their study of mothers of children with autism aged two to 10 years. May, Fletcher, Dempsey, and Newman (2015) suggested that the relation between

autism-specific parenting self-efficacy and parenting stress was mediated by ratings of co-parenting quality by both fathers and mothers of children with autism up to age 13 years.

Parental sense of competence has also been investigated as a potential mediating variable that acts as a protective factor against stress. Perceived parental efficacy mediated the relation between stressors and family hardiness in mothers of children and adults with autism aged four to 41 years (Weiss et al., 2013). Parental sense of competence also mediated the relation between child challenging behaviour and maternal anxiety and depression in mothers of children with autism (average age 12 years; Hastings & Brown, 2002). However, in the same study, parental sense of competence was found to be a moderator, but not a mediator, of the same relation among fathers. Based on the results of the studies reviewed above, higher parental sense of competence is associated with positive outcomes for parents of children with autism and could fit into the double ABCX model as family appraisal (cC factor).

***Acceptance.*** Parental psychological acceptance may be another important factor to consider when studying the perceptions of the situation (cC factor). Psychological acceptance is a concept drawn from the Acceptance and Commitment Therapy literature (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). Acceptance refers to accepting a situation without trying to change it and a willingness to experience the negative thoughts and emotions associated with the situation to reach an over-arching goal (Bond et al., 2011). Acceptance has also been conceptualized as psychological flexibility or a lack of experiential avoidance. In the general population, lower ratings of psychological acceptance have been associated with higher ratings of psychological distress, anxiety, and depression (Hayes et al., 2006). It has been proposed that the concept of acceptance

may help to explain differences in well-being for parents who have children with developmental disabilities (Blackledge & Hayes, 2006). It may be especially important to consider parents' acceptance in relation to their children's autism diagnosis because their children's disabilities are likely to persist (Lloyd & Hastings, 2008).

Some research has considered the role of psychological acceptance in relation to well-being for parents of children with intellectual disabilities. Lloyd and Hastings (2008) found that mothers of children with Intellectual Disabilities who had higher levels of acceptance had lower anxiety, depression, and stress. This relation was found when measured simultaneously and when measured 18 months apart. In another study, acceptance partially mediated the relation between child challenging behaviour and parental anxiety, depression, and stress in fathers of children with intellectual disabilities (MacDonald, Hastings, & Fitzsimons, 2010). In addition, greater acceptance was associated with more self-perceptions of positive growth for the parents raising children with intellectual disabilities.

Other studies have focused on psychological acceptance in parents raising children with autism. Weiss et al. (2012) found that greater psychological acceptance was associated with fewer mental health problems in parents of children with autism aged six to 21 years. They also found that acceptance mediated the relation between child challenging behaviour and parent mental health, as did another group of researchers (Jones et al., 2014). These findings suggest that it is important to consider the way that the parents perceive the situation or the degree to which they accept their children's disabilities because acceptance can determine how parents adapt to the stress associated with raising children with autism. Although acceptance has not previously been studied

within the context of the double ABCX model, it may fit as a cC factor: family appraisal. Acceptance captures parents' perceptions of the situation from a more emotional perspective. Parents who are lower in psychological acceptance may perceive raising a child with autism as being devastating and painful. They could view themselves as having limited abilities to tolerate these difficult emotions. Acceptance could fit as a cC factor: family appraisal because it considers how parents understand their own feelings and worries about their situation.

**Coping (BC factor).** Coping refers to the ways that people respond, both cognitively and behaviourally, to stressful situations (Benson, 2014). In the double ABCX model, coping (BC factor) refers to the ways in which families integrate family resources (bB factor) and perceptions of the situation (cC factor) to adapt to stressful situations (McStay et al., 2015). According to the double ABCX model, some effective coping strategies include seeking out additional supports or cognitive reframing to see the stressful event in a more positive light (McCubbin et al., 1981).

Coping strategies have often been conceptualized as either problem-focused coping, which uses strategies that work to change the situation, or emotion-focused coping, which uses strategies that work to attenuate emotional reactions to the situation (Benson, 2014). Problem-focused coping has generally been found to be associated with better outcomes for parent mental health (Benson, 2014). A factor analysis by Benson (2010) identified four coping strategies used by parents of children with autism. These include engagement (problem-focused coping), disengagement (withdrawing from the stressor), distraction (thinking about things other than the stressor), and cognitive reframing (thinking of the stressor more positively, acceptance, and religious coping;

Benson, 2010). Some studies include the cognitive reframing coping style as a cC factor: family appraisal (e.g., Manning et al., 2011). This further reflects the variability in operationalization of the factors in the double ABCX model. The BC factor: coping is considered to be a combination of both the bB factor: family resources and cC factor: family appraisal, and therefore there is overlap between these factors.

In comparing parents of children with autism to parents of typically developing children, Samadi, McConkey, and Kelly (2013) found that parents of children aged three to 17 years with autism tended to rely more on emotion-focused coping strategies, such as withdrawal, rather than problem-focused coping strategies, which are usually associated with more positive outcomes. It could be that parents use emotion-focused coping strategies because they have little control over whether their children have diagnoses of autism. Problem-focused coping strategies may be perceived as less effective by parents of children with autism because autism is considered to be a life-long disability. Parents of children with autism may also experience more stress and therefore rely more on emotion-focused coping strategies to reduce this stress. Parents of children with autism may also use problem-focused coping strategies less often because it is sometimes unclear how to best approach a problem that their children may be facing. Parents of children with autism may rely more on emotion-focused coping strategies such as withdrawal due to their emotional distress, which may have further negative effects on their own well-being (Samadi et al., 2013). Parents of children with autism can benefit from psychoeducational interventions which can teach them to use healthier problem-focused coping strategies more often (Samadi et al., 2013).

Research has shown that the coping strategies that parents use have different



effects on their well-being. Distraction and disengagement coping styles are generally associated with poorer outcomes. These types of coping were related to higher levels of depression, anger, and stress proliferation, and lower well-being and parenting efficacy in a study of mothers of children with autism (Benson, 2010). Further, the use of active avoidance coping was associated with more stress and mental health problems for both mothers and fathers of children with autism (Hastings et al., 2005).

In general, problem-focused coping and positive reframing are associated with the best outcomes for parents of children with disabilities (McStay et al., 2015; Minnes et al., 2015). Mothers of children with autism who used these coping strategies had less stress and higher parenting efficacy and well-being over a seven-year period (Benson, 2014). Cognitive reframing was associated with better well-being and reduced the negative effects of child challenging behaviour for mothers of children with autism (Benson, 2010; 2014). Similarly, parents of children with autism who used positive reframing had lower levels of depression (Hastings et al., 2005), less parental distress, and higher levels of family functioning (Manning et al., 2011). Problem-focused coping was associated with higher ratings of family quality of life by mothers of children with autism (Pozo et al., 2014). The use of positive coping strategies has been associated with more positive outcomes even on a biological level. Ruiz-Robledillo, De Andres-Garcia, Perez-Blasco, Gonzalez-Bono, and Moya-Albiol (2014) found that caregivers of people with autism who used resilient coping strategies had lower levels of stress, as measured by cortisol levels.

The relation between religious coping and family outcomes is less clear, and has been associated with both positive and negative outcomes for parents of children with

disabilities (Kamei, 2015). Some studies have found that coping through spiritual support has been related to lower parental distress among parents of children with autism (Manning et al., 2011). Conversely, Hastings et al. (2005) found that religious coping was not beneficial for parents of school-age children with autism. In addition, Paynter et al. (2013) found that parents who used religious or denial coping had higher levels of depression. However, these negative associations could be due to the inclusion of items related to denial of stressors in some measures of religious coping. It could also be related to different geographical and cultural contexts in which this research was conducted. More specifically, the study by Manning et al. (2011) included a racially diverse sample from throughout the United States, whereas the participants from other studies were from the United Kingdom (Hastings et al., 2005) and Australia (Paynter et al., 2013). In addition, Black and Hispanic parents in the United States who participated in a qualitative study highlighted the importance of spiritual support (Hall et al., 2017), whereas this theme was less prevalent in other qualitative studies that included predominantly white samples (e.g., Ludlow et al., 2012).

Some research has compared coping styles and outcomes between mothers and fathers of children with autism (McStay et al., 2015). Martins et al. (2013) conducted interviews with fathers of children with autism. Their participants reported using both problem-focused and avoidant coping methods. Mothers of children with autism were more likely than fathers to use positive and problem-focused coping strategies (Hastings et al., 2005; Pozo et al., 2014). In a study of couples, Pozo et al. (2014) found that for fathers of children with autism, active avoidance strategies (e.g., distraction, disengagement, denial) were related to higher family quality of life, whereas for mothers

of children with autism, positive coping strategies (e.g., problem-focused coping) were related to higher family quality of life. These findings highlight the need to include fathers in research and to take parental gender into account when evaluating coping styles.

**Research evaluating the double ABCX model.** Several studies have evaluated the double ABCX model as a whole for families of children with developmental disabilities and autism. These studies have used different measures for each of the factors, but have generally found support for this model in predicting family adaptation (McStay et al., 2015).

Two studies have studied family quality of life for parents of children with autism using the double ABCX model. In the first study, Pozo et al. (2014) studied couples raising children with autism aged four to 38 years. They included measures of child behaviour problems and disability severity (aA factor), social support (bB factor), sense of coherence (cC factor), positive and problem-focused coping (BC factor), and active avoidance coping (BC factor) to predict family quality of life (xX factor) and psychological well-being of the parents (xX factor). They found that child challenging behaviour was negatively related to parents' sense of coherence, which was positively related to family quality of life and parental well-being. Sense of coherence refers to the feeling of having the resources available to meet the demands of the environment, whereas parental sense of competence (which was used in the present study) relates specifically to confidence in parenting skills (Pozo et al., 2014). Social support was also positively related to family quality of life. Mothers of children with more severe autism had lower ratings of family quality of life, but the opposite pattern was found in fathers.

The authors suggest that mothers often have more responsibility for caregiving for children, and so a child with a more severe disability would invoke greater caregiving demands. For fathers, more severe autism diagnoses could help them to adjust their expectations for their children, which may serve to enhance their family quality of life (Poza et al., 2014). Avoidant coping strategies were associated with higher family quality of life for fathers, whereas for mothers, positive and problem-focused coping strategies were associated with higher family quality of life (Poza et al., 2014).

In the second study, McStay, Trembath, and Dissanayake (2014) found that factors in the double ABCX model were closely related to family quality of life for both mothers and fathers of children with autism aged three to 16 years. This study operationalized the stressor (aA factor) as child behaviour problems, child autism severity, child adaptive functioning, and life stress; resources (bB factor) as family hardiness, family environment, marital support, and social support; family appraisal (cC factor) as family sense of coherence; coping (BC factor) as coping strategies; and family adaptation (xX factor) as parental stress and family quality of life. They found that lower child challenging behaviour, and higher family sense of coherence and coping were important predictors of lower stress and higher family quality of life for both mothers and fathers. For mothers, perceptions of stressors as challenges was also associated with less stress and higher family quality of life (McStay, Trembath, & Dissanayake, 2014). This difference could indicate that family appraisal (cC factor) is particularly important for mothers. Mothers typically have more caregiving demands than fathers and may be more strongly affected by the emotional burdens of caring for children with autism. Therefore, the way that mothers understand the stressor may have a stronger impact for them than for

fathers (McStay et al., 2014).

Other researchers have used the double ABCX model to predict outcomes aside from family quality of life for parents of children with autism. Bristol (1987) conducted the first study evaluating the double ABCX model for study of parents of children with autism aged two to 10 years. In this study, it was found that the severity of the child's disability was not closely related to family adaptation once stress proliferation, family resources, beliefs, and coping styles were included (Bristol, 1987). Pakenham, Samios, and Sofronoff (2005) evaluated the double ABCX model in mothers of children aged 10 to 12 years with Asperger syndrome and found that each of the components tested (social support, child behaviour, "pile-up" of demands, stress appraisals, and coping styles) were related to maternal adjustment. They also found that mothers who were older and those with higher annual incomes had better adjustment.

Manning et al. (2011) evaluated the double ABCX model in families of school-age children with autism and found that the model was closely related to family functioning and parental distress. They operationalized the stressor (aA factor) as autism symptom severity, problem behaviour severity, and "pile-up" of demands; family resources (bB factor) as informal and formal support; coping (BC factor) as coping strategies; family appraisal (cC factor) as reframing; and family adaptation (xX factor) as family functioning. Child challenging behaviour and cognitive reframing were the most strongly related to family functioning and parental distress in this study.

Paynter et al. (2013) evaluated the double ABCX model in families of children with autism aged two-and-a-half to six years who were participating in early intervention services. They studied the effects of symptom severity (aA factor), "pile-up" of demands

(aA factor), self-esteem (bB factor), social support (bB factor), appraisal of stressor (cC factor), and coping strategies (BC factor) on parenting stress (xX factor), psychological distress (xX factor), marital satisfaction (xX factor), and family outcome (xX factor).

These authors found that “pile-up” of demands (pre-existing and additional stressors), less social support, and greater use of active-avoidant coping strategies were the most strongly related to psychological distress in parents.

Noblejas, Maseda, Perez, and Pozo (2016) found support for the double ABCX model in their sample of parents of sons and daughters with autism aged nine to 38 years. They considered how severity of the stressors (aA factor), “pile-up” of demands (aA factor), support (bB factor), coping (BC factor), and appraisal of the situation (cC factor) could predict family satisfaction (xX factor) and depression (xX factor) in mothers and fathers. In this study, family appraisal (cC factor) was most strongly related to outcomes, which they suggested indicates that the parental perception of the situation is more important than child characteristics in predicting family adaptation.

Pozo and Sarria (2014) studied couples raising children with autism aged four to 38 years and found that a path analysis gave partial support to the double ABCX model. They included measures of child behaviour problems (aA factor) and disability severity (aA factor), social support (bB factor), sense of coherence (cC factor), and coping (BC factor) to predict parental stress (xX factor). In this study, child disability severity and challenging behaviour were related to parental stress, and parental sense of coherence mediated this relation. Positive and problem-focused coping styles were not related to stress, and less social support was only related to higher stress for mothers. This could indicate that social support is particularly important for mothers to bolster their emotional

needs and to support the demands of caregiving.

Krakovich, McGrew, Yu, and Ruble (2016) found support for the ABCX model in predicting child domain stress and parent domain stress in a sample of parents of children with autism aged three to nine years. They evaluated how demands (child and family characteristics) and resources (internal and external resources of the parent) could predict adaptation (parental stress). Another study detailing the experiences of fathers of young children with autism using qualitative interviews supported the double ABCX model as well (Paynter, Davies, & Beamish, 2017).

The double ABCX model has also been used to predict family adaptation in parents of children with developmental disabilities. For example, Shin and Crittenden (2003) found support for the ABCX model among American and Korean mothers with children aged four to 14 years with Intellectual Disabilities. This study included measures of maladaptive child behaviour (aA factor), social support (bB factor), and maternal attitudes towards children with disabilities (cC factor) as predictors of stress (xX factor). In another study, Saloviita et al. (2003) found that family demands (aA factor), family adaptive resources (bB factor), and family definition and meaning (cC factor) were strongly associated with parental stress among mothers and fathers of children with intellectual disabilities age one to 10 years. These authors found that characteristics of the child were not strongly related to parental stress, whereas family resources and family definition of the situation were more strongly related to stress in this study. Shahrier, et al. (2016) found support for the double ABCX model in predicting stress for parents of children with Intellectual Disabilities. They included measures of the nature of the stressor (aA factor), perception of support (bB factor), and accepting challenge (cC

factor) to predict perceived stress and social adaptation (xX factors).

The overall findings of these studies suggest that the double ABCX model is useful in predicting outcomes such as family quality of life in parents of children with developmental disabilities such as autism. However, little research has been done evaluating the model using positive approaches to family adaptation such as including family quality of life as the outcome measure. There is also variability in the operationalization of the predictors within the model and in the results of these studies. For example, the stressor has been operationalized as child autism severity, child challenging behaviour, or as the “pile-up” of demands. There is variability in how social support and coping are measured, but they are generally conceptualized in similar ways across studies. Family appraisal (cC factor) varies in its conceptualization, as some researchers operationalize it as sense of coherence, whereas others include reframing or parent beliefs. The xX factor also includes substantial variability, with some studies focusing on negative outcomes such as stress, and others focusing on positive outcomes like family quality of life or parent well-being. There is support for each of the factors included in the double ABCX model across the studies that were reviewed above. The evidence is mixed for which variables are related to the outcomes in the double ABCX model across studies due to differences in operationalization. Some studies have also shown differences between mothers and fathers in predictors within the double ABCX model, which also varies across studies (e.g., McStay et al., 2014; Pozo et al., 2014; Pozo & Sarria, 2014). Therefore, in the present study, the double ABCX model was evaluated separately for mothers and for fathers of children with autism. More research needs to be done to evaluate which factors are most closely related to family adaptation within the



double ABCX model and how these patterns may vary between mothers and fathers of children with autism.

### **Limitations of Previous Research**

Although many well-conducted studies of family quality of life for parents of children with autism have been reviewed, there are some limitations to this literature. There has not been enough diversity and representativeness in the samples of parents of children with autism who have participated in research.

Disproportionately more mothers than fathers have participated in most research evaluating outcomes for parents of children with autism (Braunstein, Peniston, Perelman, & Cassano, 2013; McStay et al., 2015; Paynter et al., 2017). It is important to include both mothers and fathers of children with autism in research because research suggests that levels of parental stress and patterns of predictors of family quality of life vary between mothers and fathers (Dardas & Ahmad, 2014). Previous studies that have had equal representation of mothers and fathers of children with autism included only couples (e.g., Pozo et al., 2014). This sampling method is problematic because fathers from married couples are not representative of the entire population of parents of children with autism. Married fathers may have unique experiences that are different than single fathers (Karst & Van Hecke, 2012). The present study partially addressed this gap by recruiting approximately equivalent samples of mothers and fathers of children with autism without the requirement that they be couples. Qualitative methods are another way to explore how family structure affects the experiences of parents of children with autism.

Online social support is a relatively new area of research, and there is much more work to be done. In addition, there are few studies that have examined unsupportive

social interactions for parents of children with autism, yet they appear to be a common experience based on qualitative studies (e.g., Jones & Gragg, 2016; Neely-Barnes et al., 2011). Neither online social support nor unsupportive social interactions have been studied in relation to family quality of life. Further, most studies that have used the double ABCX model have not included variables such as unsupportive social interactions and psychological acceptance which may greatly affect family quality of life for parents of children with autism. The literature about unsupportive social interactions suggests that they are distinct from social support and may be a more important predictor of outcomes.

In addition, little research has examined the role of psychological acceptance of the autism diagnosis in relation to family quality of life. The few studies that have measured acceptance in parents of children with autism have shown that higher ratings of acceptance are associated with better mental health (Jones et al., 2014; Weiss et al., 2012). Acceptance could help explain how parents are responding to their children's autism diagnoses emotionally. This is particularly important because parents cannot change whether their children have autism, but they do have some control over their reactions to the situation.

To date, no studies were found in the literature search for this study that have researched all the variables used in this study together (namely, factors included in the double ABCX model, family quality of life, online social support, and unsupportive social interactions). Although two studies have used the double ABCX model to predict family quality of life in parents of children with autism (McStay, Trembath, & Dissanayake, 2014; Pozo et al., 2014), these studies both relied on samples of couples from the same family, and did not include online social support, unsupportive social interactions, or

psychological acceptance. The present study sought to address these limitations by including variables of interest, namely child challenging behaviour, child disability severity, unsupportive social interactions, social support, online social support, parental sense of competence, acceptance, coping, and family quality of life. This study also addressed some of the limitations in sampling present in previous studies by recruiting approximately equivalent samples of mothers and fathers of children with autism without requiring that parents be recruited together as couples. A mixed methods approach was used to gather additional information about parents' experiences in areas with less research support such as online social support and unsupportive social interactions.

### **The Current Study**

**Overview of theoretical framework.** There are several theories and models which have been reviewed that influenced the development of the present study. The double ABCX model (McCubbin & Patterson, 1983) was used to direct the focus of this study and the variables that were included in the quantitative analyses. The double ABCX model explains how families adapt to stress. In this model, the stressor (aA factor), family resources (bB factor), family appraisal (cC factor) and coping (BC factor) interact to determine family adaptation (xX factor; McCubbin & Patterson, 1983). The resulting family adaptation can be worse, or better, compared to the level of family functioning prior to the stressor. Family adaptation to stress is considered to be an ongoing process in the double ABCX model. The lowercase and uppercase letters reflect the pre-existing resources and the additional resources that are sought after the stressor (McCubbin & Patterson, 1983).

Family quality of life was chosen as the outcome measure for the present study. It

can be understood as the xX factor (family adaptation) within the double ABCX model (McCubbin & Patterson, 1983). Zuna et al. (2009) presented a comprehensive theory explaining what factors are thought to influence family quality of life. Family quality of life theory was not tested explicitly in the present study because it is quite broad. The double ABCX model focuses on child- and family-level variables which could be more easily addressed by psychological interventions. There are some similarities between family quality of life theory (Zuna et al., 2009) and the double ABCX model (McCubbin & Patterson, 1983), as both include family-level and individual-level variables that affect how families adapt to the stress associated with raising children with disabilities. Family quality of life theory also considers the role of broader policies, which was beyond the scope of the present study.

The buffering hypothesis (Cohen & Willis, 1985) explains that social support works as a buffer to protect individuals against the negative effects of stressors. The buffering hypothesis fits within the double ABCX model because both depict social support as a moderator of stress on individual or family outcomes.

The concept of unsupportive social interactions (Ingram, Betz, et al., 2001) was also included in the present study. Unsupportive social interactions may fit into the double ABCX model as an additional stressor that parents face as a result of having children with autism in their families. Unsupportive social interactions are seen as being distinct from social support and may have negative effects on individual well-being (Ingram et al., 2001; Ingram, Betz, et al., 2001). Online social support could also be related to family quality of life for parents of children with autism as an additional family resource.

**Purpose.** The purpose of the current study was to determine the extent to which factors included in the double ABCX model, namely child disability severity (aA factor), child challenging behaviour (aA factor), social support (bB factor), parental sense of competence (cC factor), psychological acceptance (cC factor), and coping skills (BC factor), could predict family quality of life (xX factor) for parents of school-age children with autism. Children with autism aged four to 11 years were included because most children with autism are diagnosed by age four years, and age 11 marks the transition into puberty for many children. Research suggests that higher family quality of life is associated with child characteristics such as lower challenging behaviour, parent characteristics such as better coping skills, and environmental characteristics such as higher social support. It is important to recognize how raising children with autism affects parents and to better understand the factors that enhance or detract from family quality of life. Determining the most influential factors for family quality of life allows for interventions to be better designed to help families with children with autism.

Parents of children with autism who participated in a recent study (Jones & Gragg, 2016) spontaneously mentioned unsupportive social interactions as frequent experiences. Experiencing judgment from others was also commonly reported by parents of children with autism who participated in other qualitative studies (e.g., Ludlow et al., 2012; Neely-Barnes et al., 2011; Nicholas et al., 2016; Safe et al., 2012). Other research suggests that unsupportive social interactions for people in stressful situations are distinct from social support and can influence outcomes in addition to social support (Ingram et al., 2001; Ingram, Betz, et al., 2001). One purpose of the present study was to evaluate how unsupportive social interactions may be experienced by parents of children with autism,

whether they are distinct from social support, and how they may affect family quality of life in concert with the variables included in the double ABCX model. Unsupportive social interactions were initially examined outside of the double ABCX model. The purpose of this evaluation was to determine how unsupportive social interactions were related to general social support and family quality of life. Unsupportive social interactions are a newer concept, particularly within the sample of parents of children with autism. The theory underpinning unsupportive social interactions suggests that they are distinct conceptually from social support (Ingram, Betz, et al., 2001). This analysis was conducted in order to confirm that unsupportive social interactions are indeed distinct from a more general measure of social support. This was an important step to consider before including unsupportive social interactions in the double ABCX model.

In the present study, unsupportive social interactions were added to the double ABCX model to determine whether their inclusion as a stressor (aA factor) would add incremental value in predicting family quality of life among parents of children with autism. Past research suggests that the negative aspects of social interactions can have more potent effects than positive social interactions (Brooks & Dunkel Schetter, 2011). This means that unsupportive social interactions may be able to explain variation in family quality of life in addition to the other factors in the double ABCX model such as general social support, and that it is important to consider them together. Although unsupportive social interactions had not been studied within the double ABCX model before, there was past research in other samples suggesting that it may play an important role in individual well-being outcomes (Ingram et al., 2001; Pottie et al., 2009). Further, the Unsupportive Social Interactions Inventory (Ingram, Betz, et al., 2001) has been

validated by previous researchers, suggesting that it was an appropriate measurement tool to use. It is important to understand the effects that social relationships have on parents of children with autism and to consider that unsupportive interactions may negatively affect their well-being. The relative importance of social support and unsupportive social interactions could inform interventions and advice for parents.

Although it is becoming increasingly popular for parents of children with autism to seek social support online, the little research that has been conducted thus far is inconclusive regarding whether seeking online social support is beneficial or not and how it relates to in-person social support. One goal of this study was to determine how to best measure online social support because existing measures were not adequate for the purposes of this study. One measure of social support was modified to include “online communities”, and another measure of frequency of technology use was created for this study. Parent interviews were also used to explore the ways that parents use technology to access social support, and their experiences in doing so.

One purpose of the present study was to determine whether online social support was related to family quality of life for parents of children with autism. Most of the past research has focused on comparing in-person and online support groups (e.g., Clifford & Minnes, 2013a). Therefore, this study evaluated online social support outside of the double ABCX model as a necessary first step in the literature.

Research about parents of children with autism has typically not included proportionate numbers of fathers. Research suggests that different factors are associated with family quality of life for fathers and mothers of children with autism (e.g., Pozo et al., 2014). As a result, the present study included a sizable sample of fathers who were not

required to be couples with the mothers in the sample. Data were analyzed separately for mothers and fathers of children with autism for the analysis of the double ABCX model, based on evidence in the literature suggesting different patterns based on parent gender (e.g., Pozo et al., 2014). Data from mothers and fathers were analyzed together for the remaining analyses in order to maximize statistical power.

**Participatory action research.** The present study included a participatory action research component. In this model, people from the population being studied are involved in the research to provide insights, foster inclusion in the research process, and ensure that the purpose and methodology of the study are relevant to the target population (Walmsley & Mannan, 2009). Cridland, Jones, Caputi, and Magee (2015) discussed the importance of involving participants who are parents of children with autism in the research process. Similarly, family quality of life researchers recommend including family members of individuals with disabilities in research (Samuel et al., 2012). A representative from the autism community provided input and consultation throughout the research process for the present study.

Jessica Szucki, a mother of three children with autism and an advocate in the autism community, is the parent advisor for the present study. She was involved throughout the duration of this study in the study design, recruitment, data analysis, and interpretation of results. She has given permission to include information about her in this document.

**Qualitative research.** The present study used a mixed methods approach that incorporated thematic analysis (Braun & Clarke, 2006) in addition to the quantitative analyses. Several researchers in the field have emphasized the importance of including a



qualitative component to research. For example, Cridland et al., (2014) suggest that qualitative approaches to research are less restrictive and can give greater insight into the complexities that are present within a family. Further, little research has been published about topics included in this study such as unsupportive social interactions and online social support, which makes qualitative research methods a useful avenue for obtaining information.

Thematic analysis has been presented by Braun and Clarke (2006, 2013, 2014a, 2014b) who have written extensively about its use. Thematic analysis is situated within a non-positivist paradigm where information is thought to be subjective with different meanings depending on the context (Braun & Clarke, 2014b). Qualitative research often takes a more inductive approach to generate theories rather than seeking information that is consistent with an existing theory, although it is flexible in its use. Using a mixed methods approach to research provides greater balance in the research and the qualitative portion in particular provides richer information about the experiences of the participants.

Thematic analysis is a method of qualitative data analysis that was designed to be flexible in fitting with different theoretical approaches and data collection methods (Braun & Clarke, 2013). It can be used in both inductive (bottom-up) or deductive (top-down) manners, or in combination. Other strengths of this method include that it does not prescribe sample sizes, is relatively straightforward, and is accessible to consumers of research. In particular, thematic analysis lends itself well to participatory action research approaches which involve representatives from the population being studied in the research process (Braun & Clarke, 2013). The present study used an inductive approach for the thematic analysis in which the themes were derived from the content of the parent

interview responses (Braun & Clarke, 2014b). This approach was chosen because of the lack of research about unsupportive social interactions and online social support for parents of children with autism.

### **Hypotheses and Research Questions**

Based on the review of literature the following hypotheses and research questions were proposed:

**Hypothesis 1.** Unsupportive social interactions will predict family quality of life above and beyond general social support for both mothers and fathers of children with autism.

**Hypothesis 2a.** The double ABCX model overall (i.e., aA factor: child disability severity and child challenging behaviour, bB factor: social support, cC factor: parental sense of competence and acceptance, and BC factor: coping skills) will predict family quality of life for *mothers* of children with autism.

**Hypothesis 2b.** Unsupportive social interactions will predict family quality of life in addition to the factors included in the double ABCX model for *mothers* of children with autism.

**Hypothesis 3a.** The double ABCX model overall (i.e., aA factor: child disability severity and child challenging behaviour, bB factor: social support, cC factor: parental sense of competence and acceptance, and BC factor: coping skills) will predict family quality of life for *fathers* of children with autism.

**Hypothesis 3b.** Unsupportive social interactions will predict family quality of life in addition to the factors included in the double ABCX model for *fathers* of children with autism.

**Hypothesis 4.** It is expected that greater frequency of use of online social support, greater availability of online social support, and greater perceived adequacy of online social support will predict higher family quality of life for both mothers and fathers of children with autism.

**Research Questions.** The focus of the qualitative component of this study was to gather additional information about parents' experiences raising children with autism and its impact on family quality of life. The following research questions guided the interviews:

- How does family structure impact the experiences of parents of children with autism?
- How does raising a child with autism affect family quality of life from a parent's perspective?
- What types of supports are helpful for parents and how do they impact family quality of life?
- What types of experiences have parents had with unsupportive social interactions and how do these experiences affect parents?
- How do parents use online social support, what are their reasons for doing so (or not doing so), and how do these activities affect their family quality of life?

## Method

### Participants

The participants were parents of children with autism aged four to 11 years. A final sample of 194 participants' responses were included in statistical analyses ( $n = 103$  mothers and  $n = 91$  fathers). Some of these participants were couples ( $n = 11$  mothers and  $n = 11$  fathers). A subsample of 24 parents completed follow-up phone interviews ( $n = 12$  mothers and  $n = 12$  fathers).

A power analysis was conducted to determine the number of participants that would be needed using G\*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007). Before collecting data, it was originally planned to do a hierarchical multiple regression with 10 predictors for hypotheses 2a, 2b, 3a and 3b. To detect a medium effect size ( $f^2 = .15$ ) with a power of .80 for a hierarchical multiple regression with 10 predictors, 89 participants would be needed. As such, 90 to 110 mothers and 90 to 110 fathers of parents of children with autism were sought as research participants. However, Hypotheses 2b and 3b were analyzed using a multiple regression analysis with 11 predictor variables because potential covariates were removed, and subscales of the coping scale were used instead of the total score. To detect a medium effect size ( $f^2 = .15$ ) with a power of .80 for a multiple regression analysis with 11 predictors, 123 participants would be needed. Therefore, this study may not have had sufficient power to detect significant effects, which is a limitation of the study.

In this study, parents were defined as biological, adoptive, foster, or step-parents, or custodial grandparents of children with autism. Extra efforts in recruitment were made to seek out participants who were fathers. Participants were required to be a primary

caregiver for the child. The target child was required to be aged four to 11 years and have Autism Spectrum Disorder. This age range was chosen to recruit parents of children old enough that many are diagnosed with autism (four years), and before entering into adolescence (12 years). This age range is also consistent with the age limits for the screening measure for autism that was used (Scott Baron-Cohen, Bolton, & Brayne, 2002). In order to verify that the target children met criteria for autism, the parents completed the Childhood Autism Spectrum Test (CAST; Scott et al., 2002; see Measures section for more detail). Only participants who indicated that their children's scores were in the clinical range could complete the remainder of the survey.

Two parents from the same family could participate since data for mothers and fathers were analyzed separately for most, but not all, analyses. There were 11 couples (11 mothers and 11 fathers) who were each from the same family. These 11 mothers were omitted from analyses where responses from both mothers and fathers were analyzed together (Hypotheses 1 and 4, and exploratory analyses). No self-identified same-sex couples participated in this study. Demographic information such as the child's birth year and month and the family's location were used to determine whether more than one parent from the same family or of the same child had participated in this study. An additional question that asked, "to your knowledge, has your partner completed this study?" was also used to help identify parents from the same family. Mothers from couples ( $n = 11$ ) were excluded in some analyses to avoid violating the assumption of independence of observations and because there were more mothers than fathers in the sample. See the Results section for more details.

**Demographic Information.** A unique survey link was sent to 280 parents of

children with autism who e-mailed the primary researcher to indicate interest in participating (not including participants suspected of being fraudulent; see Procedure for more details). Of those participants, a total of 243 responses were received for the present study. This means that 37 parents did not begin the study, despite being sent two reminder e-mails.

Some participants completed only part of the survey but did not finish, despite being sent two reminder e-mails. Participants were required to complete at least 80% of the survey questions to receive the incentive (a five-dollar e-gift card to Amazon or Starbucks). A total of 21 participants fell into this category and their responses were not included in analyses.

Participants were required to complete a screening measure of their children's symptoms of autism (CAST; more information below) to continue to the remainder of the survey questions. A total of 26 participants' children had scores on this measure that were below the cut-off (15 points). Scores for ineligible participants' children ranged from seven to 14 with an average score of 11.96. These participants were not permitted to complete the remainder of the survey and therefore were not included in any analyses and did not receive the incentive.

A total of 196 parents of children with autism completed all questionnaires in the study. Two participants that were influential outliers were removed (see Results for more details), resulting in a final sample of 194 parents (103 mothers and 91 fathers). Most parents were married (78%), had completed post-secondary education (71%), were employed full-time (60%), and had an annual household income of \$75,000 or more (46%). For participants who were not from Canada, household income values were

converted to Canadian dollars based on currency exchange rates. Most of the partners of participants were employed full-time (57%). Parent age ranged from 23 to 67 years (mean = 38.38). See Table 1 and Table 2 for more detailed demographic information.

Recruitment was completed primarily in Canada, although parents from any country could participate. Therefore, most of the participants were Canadian (72%). Other countries represented included the United States (18%), United Kingdom (2%) or others (4%). Most parents were White (80%) and most of the target children were also White (77%).

Participants reported having one to 11 children in their family (mean = 2.21). Note that although having 11 children is unusual, there were no other indicators suggesting that this participant provided inaccurate responses. Most parents reported having one child with autism ( $n = 164$ ; 85%), while the remaining parents had two or more children with autism ( $n = 30$ ; 15%). Parents who had more than one child between the ages of four and 11 years with autism in their family were instructed to “think about the child that has the greatest effect on your family’s well- being” while responding (referred to as the target child in this document).

There were 168 male children and 26 female children identified as the target children in this study. This ratio (6.46:1) includes a higher proportion of males compared to recent estimates of a 4.5:1 gender ratio of male to female children with autism (Christensen et al., 2016). Inclusion criteria specified that the target child had to be age four to 11 years, which resulted in an average age of 6.81 years ( $SD = 2.33$ ). It was unclear which child was the target child for six parents who had two children with autism in the age range because they did not respond to a follow-up e-mail was sent to these

Table 1

*Demographic Information for Participants in the Overall Sample (n=194)*

	<i>n</i>	%
Parent Gender		
Female	103	52
Male	93	48
Education Level		
Completed college diploma or undergraduate degree	95	49
Completed post-graduate degree	43	22
Some college	41	21
High school or less	14	7
No response	1	1
Employment Status		
Full-time	116	60
Unemployed	48	25
Part-time	18	9
Student	6	3
Retired	4	2
No response	2	1
Partner Employment Status		
Full-time	111	57
Unemployed	32	17
Not applicable	28	14
Part-time	13	7
Retired	6	3
Student	4	2
Household Income <sup>a</sup>		
\$75,000 and over	89	46
\$50,000-\$74,999	44	23
\$25,000-\$49,999	32	17
Under \$25,000	14	7
Prefer not to answer	15	8

<sup>a</sup>In Canadian dollars



	<i>n</i>	%
Relationship to Target Child		
Birth parent	187	95
Custodial grandparent	3	2
Adoptive parent	2	1
Foster parent	1	1
Step parent	1	1
Race/Ethnicity		
White	156	78
Mixed Race	11	6
South Asian	6	3
Latin American	4	2
Other	4	2
Black	4	2
Arab/West Asian	3	2
South East Asian	2	1
Aboriginal	1	1
Chinese	1	1
Filipino	1	1
Korean	1	1

Table 2

*Marital Status for Mothers and Fathers in the Overall Sample*

	Mothers		Fathers	
	<i>n</i>	%	<i>n</i>	%
Married and living with partner	73	73	77	82
Unmarried and living with partner	14	14	4	4
Separated or divorced	7	7	6	7
Single	5	5	6	7
Widowed	1	1	0	0

parents after the study was completed.

Parents reported living with the target children for 20% to 100% of the time (mean = 95%). Most parents were the birth parent of a child with autism (87%). Most participants (90%) reported that the target child had a diagnosis of Autism or Autistic Disorder. Other diagnoses reported by parents included Pervasive Developmental Disorder Not Otherwise Specified (3%) and Asperger's Disorder (8%). A breakdown of the demographic variables for the participants who completed the follow-up phone interview is available in Table 3. For this subsample, the average parent age was 40.72 years and the average child age was 6.52 years.

The participants in the present study are not representative of the general population, which limits the generalizability of these findings. More specifically, 22% of the participants in this study reported having a post-graduate degree, whereas 7.5% of the Canadian population has a university degree above a Bachelor's degree (Statistics Canada, 2015). Similarly, 6% of the participants were from single-parent families, compared to 16.3% of Canadian families (Statistics Canada, 2015). The participants in this sample were mostly White/Caucasian (78%), which is consistent with the proportion of visible minorities in Canada (19.1%, Statistics Canada, 2016). Parents in this study reported a high family income (46% reported \$75,000 or more per year). This is actually lower than the median income of two-parent Canadian families with children of \$91,000, but higher than single-parent Canadian families whose median yearly income was \$43,400 (Statistics Canada, 2016).

Table 3

*Demographic Information for Interview Participants (n = 24)*

	<i>n</i>	%
Education Level		
Completed college diploma or undergraduate degree	15	62
Completed post-graduate degree	5	21
Some college	4	17
Employment Status		
Full-time	17	71
Unemployed	4	17
Part-time	2	8
Student	1	4
Partner Employment Status		
Full-time	12	50
Unemployed	4	17
Not applicable	4	17
Part-time	3	12
Retired	1	4
Household Income <sup>a</sup>		
\$75,000 and over	16	66
\$50,000-\$74,999	3	13
\$25,000-\$49,999	2	8
Prefer not to answer	3	13
Relationship to Target Child		
Birth parent	22	92
Custodial grandparent	1	4
Adoptive parent	1	4
Race/Ethnicity		
White	21	88
Latin American	1	4
Other	1	4
Black	1	4
Marital Status		
Married and living with partner	21	87
Separated or divorced	3	13

<sup>a</sup> In Canadian dollars

## Measures

**Screening questionnaire.** Participants first answered two screening questions to confirm their eligibility (see Appendix B). The participants were asked whether they are parents (including biological, adoptive, foster, step-parents, and custodial grandparents) of children with autism and whether their children were between age four to 11 years.

**Confirmation of child's diagnosis.** Participants completed the Childhood Autism Spectrum Test (CAST; Scott et al., 2002) to confirm that their child met diagnostic criteria for autism. Parents who had more than one child with autism between the age of four to 11 years were instructed to complete the CAST while thinking about the child that has the greatest effect on their family life. The CAST, previously called the Childhood Asperger Syndrome Test, has 37 items that are answered in a yes or no format. It has been validated for children aged four to 11 years, which is why this age range was selected as one of the eligibility criteria for this study. The items on the CAST were developed based on behavioural descriptions of autism from the DSM-IV, the ICD-10, and related questionnaires. Of the 37 items, six items related to the child's general development are included that are not scored. The remaining 31 items relevant to autism are each given a score of one (with some items being reverse-scored), resulting in a maximum possible score of 31. The test publisher's website indicates that written permission is not needed to use the measure if it is for research purposes and the source is acknowledged (Autism Research Centre, 2015).

Scott et al. (2002) determined that the ideal cut-off score for the CAST is 15 for autism or related social-communication difficulties. In the original study (Scott et al., 2002), 82% of children scoring at or above the cut-off on the CAST met criteria for

autism or a related social communication deficit using the Autism Diagnostic Observation Schedule-Generic (Lord, Rutter, Di Lavore, & Risi, 1999) or the Autism Diagnostic Interview-Revised (Lord, Rutter, & Le Couteur, 1994). Scott et al. (2002) found that the CAST had a specificity of 0.99. These numbers are comparable to the psychometric properties of the Social Communication Questionnaire, another commonly used questionnaire about symptoms of autism (Kazak-Berument, Rutter, Lord, Pickles, & Bailey, 1999).

Further research has provided additional support for the reliability and validity of the CAST. Williams et al. (2006) examined the test-retest reliability of the CAST over two to three weeks. They found a correlation of 0.83 between the scores at the two time points and that 97% of the children had scores that remained on the same side of the cut-off point of 15. Allison et al. (2007) examined the test-retest reliability of the CAST in a sample of children with high scores (i.e., 12 or higher) over a period of approximately two months. They found moderate test-retest reliability as the correlation between the scores at the two time points was 0.67, and 74% of children remained on the same side of the cut-off point of 15. Although the authors of the CAST recommend against using the measure as a screening test in general populations, it is appropriate for screening participants for research studies (Allison et al., 2007). Indeed, it has been used to confirm children's diagnoses of autism in other related research studies (e.g., Pakenham et al., 2005).

Williams et al. (2005) found that the cut-off score of 15 resulted in 100% sensitivity and 97% specificity and that test-retest reliability was adequate. In this study, the positive predictive value was low (0.50) due to a low prevalence rate of autism in

general samples (Williams et al., 2005). This finding means that there could be a high proportion of false negatives. Although this may be problematic for screening in community samples, it ensures that parents of children with autism who wish to participate in the present study would likely meet this inclusion criterion to complete the study based on scores on the CAST. However, in the present study, 26 participants (14%) who presumably have children with autism had scores below the cut-off and were therefore not permitted to participate in the study. This indicates that there may be a subset of children with autism who are being missed based on this questionnaire. However, other factors may have contributed to the high false negative rate observed in the present study such as parent denial, misdiagnosis, and fraudsters attempting to complete the study.

**Demographic questionnaire.** A series of 17 questions pertaining to the demographic information of the family was created for this study (see Appendix C). Items are related to the family structure, parent's demographics, child's demographics, and child's diagnosis. The race/ethnicity categories were based on those used by Statistics Canada (2015).

**Family quality of life (Xx factor).** The Beach Center Family Quality of Life Scale (FQOLS; Hoffman et al., 2006) was used as the outcome variable in this study. It was designed to measure satisfaction with different areas of family quality of life for family members of individuals with disabilities. It includes 25 items that are rated on a scale from 1 (*Very Dissatisfied*) to 5 (*Very Satisfied*). These items form the basis for five subscale domains, including Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability-Related Support. Each of these subscales

has four to six items. This FQOLS has no age restrictions, although the researchers focused on families with children up to age 21 when developing the measure. Permission to use the FQOLS was given by the authors (see Appendix D for all author permissions).

The FQOLS is a quantitative measure that was developed in three phases: qualitative studies to develop a pool of items (Poston et al., 2003), initial psychometric evaluation (Park et al., 2003), and further psychometric evaluation with confirmatory factor analysis (Hoffman et al., 2006). Evaluation of the psychometric properties of the FQOLS indicated that the Cronbach's alpha for the FQOLS subscales was .88 (Hoffman et al., 2006). Test-retest reliability three months later showed significant correlations. Confirmatory factor analysis of the subscales resulted in a model that had excellent fit (Hoffman et al., 2006). The FQOLS shows convergent validity with similar measures such as the Family APGAR (Smilkstein, Ashworth, & Montano, 1982), the Family Resource Scale (Dunst & Leet, 1985), and the Family Quality of Life Scale-2006 (Perry & Isaacs, 2015). In the present study, the alpha value for the total scale was .94. For the subscales, the alpha values were .87 for Family Interaction, .83 for Parenting, .83 for Emotional Well-Being, .77 for Physical/Material Well-Being, and .73 for Disability-Related Support.

**Stressors (Aa factors).** The stressors were operationalized in this study as child challenging behaviour, child disability severity, and unsupportive social interactions. The measures used for each of these variables are described below.

***Child challenging behaviour.*** In this study, child challenging behaviour was measured using the Autism Spectrum Disorder-Behavior Problems for Children (ASD-BPC; Matson, Gonzalez, & Rivet, 2008). This measure has 18 items to which parents or



other informants give ratings of 0 (*not different; no impairment*), 1 (*somewhat different; mild impairment*) or 2 (*very different; severe impairment*). The items each represent challenging behaviours that may be seen in individuals with autism, such as aggression, self-injurious behaviour, and stereotyped behaviour. The items were developed based on diagnostic guidelines for autism, a review of research literature, and the authors' clinical experiences. The original sample contained children aged two to 16 years who had autism or other psychological disorders.

Evidence for the reliability of this measure has been demonstrated by Matson et al. (2008). The original scale had 20 items, but two items were removed because they had poor psychometric properties. After these items were removed, the authors found that the mean percent agreement for inter-rater reliability was 92%, and test-retest reliability was also 92%. The internal consistency of the scale was excellent, with an alpha value of .90. An alpha value of .85 was found in the present study. A factor analysis revealed a two-factor solution, with externalizing and internalizing factors (Matson et al., 2008). Mahan and Matson (2011) compared the responses of parents of children with autism on the ASD-BPC to the Behavioral Assessment System for Children, Second Edition (BASC-2; Reynolds & Kamphaus, 2004). These authors found that the ASD-BPC showed good convergent and discriminant validity with the BASC-2. The authors of the ASD-BPC indicate that the measure may be used for research purposes without seeking written permission (Matson et al., 2008).

***Child disability severity.*** To measure the child's disability severity, a set of five questions were designed for the present study (Child Disability Severity Measure; Jones, 2016; see Appendix E). Although many previous studies have relied on a single

demographic question pertaining to the child's overall level of functioning (e.g., Hu et al., 2012), five questions were created to improve the reliability of participant responses. These questions pertain to the parents' perceptions of the severity their children's autism symptoms, language level, and intellectual level. Each question is rated on a four-point Likert scale, with options that vary by question. These options typically range from 0 (*At age level*) to 3 (*Severely impaired*). The CAST was not used as a measure of child disability severity because it was designed to be used as a screening measure (Scott et al., 2002). However, the CAST total score was found to be significantly correlated with the Child Disability Severity Measure total score ( $r = .47, p < .001$ ), which indicates that parents who reported a higher frequency of autism symptoms also reported greater severity of their children's disability. This finding supports the concurrent validity of the Child Disability Severity Measure used in this study. An alpha value of .85 was found in the present study.

***Unsupportive social interactions.*** The Unsupportive Social Interactions Inventory (USII; Ingram, Betz, et al., 2001) was used to measure unsupportive social interactions. The USII has 24 items that are rated on a scale from 0 (*none*) to 4 (*a lot*). Each item reflects an unhelpful behaviour that an individual might experience from others in response to a stressful situation (e.g., breast cancer). Items were modified (with permission, see Appendix D) to refer to "your child's autism" rather than "your illness". In addition to the total score, a factor analysis resulted in four subscales, which are Distancing, Bumbling, Minimizing, and Blaming (Ingram, Betz, et al., 2001). Distancing refers to behaviours in which others withdraw or avoid the person. Bumbling refers to responses that are awkward or to uninvited behaviour from others. Minimizing refers to

forced optimism and downplaying the seriousness of the stressful situation. Blaming refers to when others criticize the individual and find fault with them (Ingram, Betz, et al., 2001).

Reliability for the scale is adequate, with alpha values of .86 for the total score, .78 for Distancing, .73 for Bumbling, .76 for Minimizing, and .85 for Blaming (Ingram, Betz, et al., 2001). In the present study, the alpha value for the total score was .94, with subscale alpha values of .85 for Distancing, .77 for Bumbling, .84 for Minimizing, and .79 for Blaming. Ingram, Betz, et al. (2001) found that the USII was distinct from social support, negative affectivity, and social desirability. The USII also predicted symptoms of psychological distress.

**Family Resources (Bb factor).** The Multidimensional Support Scale (MDSS; Winefield et al., 1992) was used to measure general social support and online social support. It has 16 items that are each rated twice, resulting in a total of 32 responses. Respondents rate the *availability* of support for each item on a scale from 1 (*Never*) to 4 (*Usually or Always*), as well as the *perceived adequacy* for each item on a scale from 1 (*More often*) to 3 (*It was just right*). The items on the MDSS are divided into three categories for support from family and friends, peers, and professionals. The same five items are repeated for each category, and the first category (family and friends) includes an additional item (“How often did they really make you feel loved?”). The six subscales for the MDSS correspond with the availability and perceived adequacy of support for each of the three categories. In this study, two composite measures were created. The Social Support Availability Composite was created by summing the availability from family and friends subscale, and the availability from professionals subscale. Similarly,

the Social Support Adequacy Composite was created by summing the adequacy from family and friends subscale, and the adequacy from professionals subscale.

To measure online social support, in the present study, the second category of the MDSS, which typically refers to support from peers, was modified (with permission) to refer to the participants' online communities. Participants answered a screening question "Do you use the internet (e.g., social media, e-mails, personal blogs, online groups, etc.) to communicate with friends, family, or others about parenting your child with autism?" Participants who answered "yes" to this question continued to answer this section. Participants who answered "no" to this question skipped this section. The examples given about practical support in item 3 in this section were modified to say, "like sending you links or suggesting referrals" instead of saying "like doing things for you or lending you money".

The MDSS was originally developed to measure social support among women with breast cancer (Neuling & Winefield, 1988). However, the authors suggested that the measure may be useful for other populations and designed it to be flexible in format. The subscales used from the MDSS account for a significant amount of variance in psychological well-being, which supports its validity (Winefield et al., 1992). The reliability of the subscales is good, ranging from .81 to .90 (Winefield et al., 1992). In the present study, alpha values were .84 for the Social Support Availability Composite and .87 for the Social Support Adequacy Composite, which indicates excellent reliability of the measure. For supports from family and friends, alpha values were .83 for availability of supports and .82 for adequacy of supports. For supports from online communities, alpha values were .86 for availability of supports and for .85 adequacy of supports. For

supports from professionals, alpha values were .92 for availability of supports and .90 for adequacy of supports.

***Online social support.*** To determine the sources of online social support, a measure was developed for the present study in consultation with the Research Supervisor and parent advisor. The Menu of Online Support Types (MOST; Jones, 2016; see Appendix F) includes 20 items that refer to methods that parents of children with autism may use to access social support using the internet or other forms of technology (e.g., cell phones). Participants were asked “how often do you use each of the following to get information or support for raising your child with autism (e.g., chatting with a friend, getting advice, looking up tips)?” Each item was then rated on a four-point scale with scores ranging from 0 to 3 (*Never, Every Month, Every Week, or Every Day*). Higher scores on this measure indicate greater use of online social support seeking. Internal consistency for this measure in the present study was good, with an alpha value of .86.

This measure was scored by summing the scores for the entire measure. In addition, parents were categorized into daily technology users or less frequent technology users based on their responses. Parents who endorsed using at least one form of technology daily were categorized as daily technology users and all other parents were categorized as less frequent technology users.

**Family Appraisal (Cc factor).** Family appraisal was operationalized in this study as parental sense of competence and psychological acceptance. The measures used for each of these variables are described below.

***Parental sense of competence.*** The Parenting Sense of Competence Scale (PSOC; Gibaud-Wallston & Wandersman, 1978; Johnston & Mash, 1989) was used to measure

parental sense of competence in this study. The original scale developed by Gibaud-Wallston and Wandersman (1978) had 17 items. Johnston and Mash (1989) have continued work with the measure and use a 16-item version of the measure. One item was removed because it had a low loading on the factor structure. The items on the PSOC are rated on a Likert scale from 1 (*Strongly disagree*) to 6 (*Strongly agree*). The PSOC is scored to generate a total score, as well as Satisfaction and Efficacy subscales. Some items are reverse-scored, so that higher scores indicate higher parental sense of competence. When the PSOC is given to parents, the title “Being a Parent Scale” is used instead of “Parenting Sense of Competence Scale” to hide the construct being measured.

The two subscales in the PSOC have been confirmed by factor analyses by Johnston and Mash (1989) and by Ohan et al. (2000). The PSOC has good reliability, with alpha values of .79 for the total score, .75 for the Satisfaction subscale, and .76 for the Efficacy subscale. In the present study, alpha values of .83 for the total score, .79 for the Satisfaction subscale and .82 for the Efficacy subscale were found. The validity of the PSOC is demonstrated by its significant correlations with other measures of family functioning, such as child rearing practices and child behaviour (Ohan et al., 2000).

***Acceptance.*** In the present study, psychological acceptance was measured using a modified version of the Acceptance and Action Questionnaire, second edition (AAQ-II; Bond et al., 2011). The AAQ-II has seven items that are rated on a Likert scale from 1 (*Never True*) to 7 (*Always True*). This measure is scored by summing the scores. For ease of interpretation, total scores were then inverted so that higher scores indicate greater acceptance. Evidence for the reliability of the AAQ-II suggests that it is a unidimensional measure that has an alpha coefficient of .84 and test-retest reliability of .81 over a three-

month period and .79 over a 12-month period (Bond et al., 2011). Further work suggests that the AAQ-II has good reliability ( $\alpha = .85$ ) and that it predicts mental health outcomes (Fledderus, Oude Voshaar, ten Klooster, & Bohlmeijer, 2012).

The AAQ-II has been modified in previous work to measure acceptance related to parenting a child with an Intellectual Disability or autism (e.g., MacDonald et al., 2010). In these studies, two items were removed, and the wording was changed. The Cronbach's alpha coefficient of the version used by MacDonald et al. (2010) was .80, representing good reliability. The present study used the AAQ-II-A, a 7-item version of the AAQ-II that was modified by Drouillard (2015) to relate to parenting a child with autism. In the present study, internal consistency was excellent, with an alpha value of .93.

**Coping (BC factor).** The Family Crisis Oriented Personal Scales (F-COPES; McCubbin et al., 1981) was used to measure the parents' coping styles. The F-COPES has 30 items that are rated on a scale from 1 (*Strongly disagree*) to 5 (*Strongly agree*). The scores on this measure provide an overall score and five subscale scores. The five subscales are Acquiring Social Support (nine items, e.g., "sharing concerns with close friends"), Reframing (eight items, e.g., "accepting stressful events as a fact of life"), Seeking Spiritual Support (four items, e.g., "having faith in God"), Mobilizing Family to Acquire and Accept Help (five items, e.g., seeking information and advice from the family doctor"), and Passive Appraisal (four reverse-scored items, e.g., "believing if we wait long enough, the problem will go away). These subscales were developed based on a factor analysis.

The reliability for the total F-COPES score is .87, with subscale reliabilities ranging from .62 to .84. The test-retest reliability after four to five weeks is .81 for the

total score, with subscale test-retest reliabilities ranging from .61 to .95 (McCubbin et al., 1981). In the present study, internal consistency varied. Alpha values were .84 for the total scale, .86 for Acquiring Social Support, .76 for Reframing, .90 for Seeking Spiritual Support, and .61 for Passive Appraisal. The alpha value was low for the Mobilizing Family to Acquire and Accept Help subscale (.49). Since the items in this scale represent different sources of support (i.e., peers, community agencies, family doctor, and counselors), it could be that inter-item correlations were low because some families rely on certain sources of support more than others. This subscale was not included in further analyses. Permission to use this measure was given by the authors (see Appendix D).

### **Procedure**

**Parent Advisor.** In keeping with a participatory action research model, a parent advisor was involved in the research process and gave permission to include information about her in this document. Jessica Szucki is the mother of 3 young boys who are diagnosed with autism. She is an advocate for the autism community in many ways. Jessica has a Facebook blog where she shares what her family's daily life is like called "A is for Awesome... and Autism" (n.d.). She is the administrator for a local Facebook support group called Autism Awareness and Support Windsor-Essex (n.d.). Jessica also does fundraising for autism. She manages "iPads for Autism" (n.d.) in which money is raised to buy iPads for children with autism. She has designed and sold t-shirts to promote autism awareness and raise funds for a local organization. She organized a human puzzle piece event for autism awareness with over 400 people in attendance for five years in a row (so far). Jessica is interested in research because she has a desire to understand what her boys are dealing with in their daily lives and wants to help other families dealing with



autism to understand it as well. She wants to learn as much as she can on the subject and to use that knowledge to her benefit and the benefit of others.

Jessica assisted with the present study in a number of ways. She created a logo, using her oldest son's handprint, for the t-shirts she sold, which was used with permission in the recruitment poster for the present study (see Appendix G). Jessica also provided input about the relevance of measures such as the USII and reviewed the wording of qualitative interview questions created for the study. She assisted in recruitment for the study through her online blog and connections with other parents of children with autism. She was part of the team that completed the thematic analysis for this study. Finally, she consulted in interpretation of quantitative results and implications of the present study from a parent's perspective. She may also play a role in disseminating the results of the present study to a parent audience. She is an invaluable member of the research team.

**Recruitment.** Parents of children with autism were recruited using a multi-method approach, including online, by phone, and in person. The study was open to participants over a span of four months. Participants who completed the study were asked to indicate how they found out about the study. The most common response was Facebook (43%). Of note is that many participants, especially fathers, indicated that they heard about the study from a spouse. A breakdown of the recruitment sources that were reported by participants is included in Table 4.

A snowball recruitment method was used in which participants were asked to share information about the study with other parents of children with autism that might be interested in participating (including their own partners or their children's other parents). The parent advisor also assisted with recruiting by sharing the study flyer with other

Table 4

*Recruitment Methods Reported by Participants*

	<i>n</i>	%
Facebook	83	43
E-mail	39	20
Word of mouth	36	19
Website	15	8
Phone call	5	3
Physical Poster	3	2
In person	2	1
Other	11	4

parents of children with autism and bloggers that she knew.

Most recruitment was conducted online by contacting organizations or groups who have contact with parents of children with autism. Organizations were asked to assist with recruitment by sharing the study flyer or a brief description by e-mailing, sharing on their social media sites, posting on a website, telling people about the study, or putting up posters in their offices.

In research involving parents of children with autism, more mothers than fathers often participate. Because this study sought approximately equivalent samples of mothers and fathers, after the minimum number of mothers was recruited, the study flyer and description were modified to include fathers only (see Appendix G for recruitment flyers). Organizations were re-contacted to assist in recruiting additional fathers.

In total, 255 organizations were e-mailed, such as chapters of Autism Ontario. Of that number, 118 organizations responded (46%) and agreed to assist in recruitment, whereas 13 organizations denied the request. Conversely, 124 organizations (49%) did not respond, even after receiving up to two reminder e-mails (although it is possible that they assisted in recruitment without notifying the researcher).

Recruitment also took place using social media (Facebook in particular). The Autism Research Group at the University of Windsor has its own Facebook page which posted the flyers (<https://www.facebook.com/AutismResearchGroupUWin>). Organizations were encouraged to “share” the flyer or to post the flyer on their own page in the recruitment e-mails. In addition, the administrators of Facebook pages for other organizations for children with autism or Facebook blogs by parents of children with autism (e.g., Ink4Autism) were contacted and asked to share the flyer for the study. A

total of 66 private messages were sent to Facebook pages asking them to share the post. The original Facebook posts by the Autism Research Group Facebook page that included the study flyers were shared by other Facebook pages or individuals who “follow” these Facebook pages 189 times. This resulted in a total post reach of 13,224, which means that the study flyers were seen 13,224 times (this could include the same person seeing the post more than once). Some people who saw the post may not have been eligible to complete the study.

There are many Facebook groups designed for parents of children with autism to discuss and gain support (e.g., Autism Awareness and Support - Windsor Essex Area). Private messages were sent to the administrators of 92 Facebook groups asking them to share the study information on their group page. However, very few administrators saw the message due to Facebook’s message filtering, and others did not reply to the message, or replied but did not agree to post the study.

Some parents (4% of the sample) were recruited in-person or by phone through The Summit Centre for Preschool Children with Autism (<http://www.summitcentre.org/>). Because the Research Advisor for this study is also the Clinical Director at the Summit Centre, she was not involved with recruitment in any way and did not know which parents chose to participate or not participate in the study. Standard scripts, approved by the University of Windsor’s Research Ethics Board, were used to discuss the study with potential participants in-person or by phone. Parents who were recruited from the Summit Centre for Preschool Children with Autism were asked to provide an e-mail address and later sent a unique link to the survey, which gave them another opportunity to later decide if they would like to participate or not without feeling pressure to do so.

**Fraudulent Responses.** Unfortunately, it is becoming more common for people to attempt to complete online surveys fraudulently to receive multiple incentives (Teitcher et al., 2015). Numerous strategies were put in place in the present study to prevent these people from completing the survey (e.g., having a unique link generated for each participant who e-mailed the researcher). The researcher received a number of e-mails that were immediately identified as suspicious due to being highly similar in nature and being received within minutes of each other. These e-mails were likely sent using an automated computer program. Suspicious e-mails were responded to with screening questions regarding eligibility requirements. The questions asked the person's first name, how they heard about the study, and why they are eligible to participate (i.e., if they are a mother or father of a child with autism, and the child's age). If these screening questions were not answered satisfactorily, these individuals were denied access to the survey.

However, it is much more difficult to identify individuals who mimic real participants and complete the study multiple times. An article by Teitcher et al. (2015) describes ways to identify and prevent "human fraudsters" from participating in online surveys. In the present study, it appeared that a few individuals completed the survey multiple times using different e-mail addresses to accrue multiple e-gift card incentives. It was discovered mid-way through data collection that 111 completed responses were likely completed by fraudsters. These responses were removed from the data set.

Fraudsters were identified based on several factors, some of which were based on suggestions from Teitcher et al. (2015). These included characteristics of the initial e-mail that was sent to the researcher indicating interest in the study (e.g., a vague request such as "send the link"), matching IP addresses, consecutive incentive redemptions,

unwillingness to participate in a follow-up interview, and inconsistency of responses (e.g., birth year and child age). In addition, five validity questions were included throughout the survey in different formats. Some validity questions instructed participants to select a certain response option (e.g., “If you are paying attention, select ‘Always’ for this question”). Other questions asked the same information in more than one way (e.g., child’s age and child’s birth year). Another question was added that asked if the child engaged in reckless driving, which should be answered negatively since the children in the study were too young to drive. Individuals were deemed to be fraudsters based on several factors in combination with the researcher’s best judgment, not on one characteristic alone.

After it was discovered that human fraudsters had been participating in the study, more methods were put into place to identify and deter additional fraudsters from participating. All potential participants who e-mailed the researcher were then required to answer screening questions by e-mail before being sent a unique link to the survey (e.g., eligibility characteristics and how they heard about the study). Additional questions were added to the survey to ensure validity and reliability of responses (e.g., the participants’ current city). The University of Windsor’s Research Ethics Board was contacted frequently and was helpful throughout the process.

**Quantitative Component: Survey.** In the study advertisement (see Appendix G), interested parents were directed to contact the author by e-mail to receive a unique link to access the survey online using Fluid Surveys. This method was put in place to help ensure that each participant only completed the survey once and to reduce the number of fraudulent responses. Parents who were recruited in person or by phone were asked to

provide an e-mail address and were sent a unique link later. As mentioned earlier, several fraudulent responses were received (see Fraudulent Responses section for more details). After this was discovered, all interested participants were required to answer screening questions by e-mail before being sent a unique link.

After the parent received the link for the survey, a consent process was completed online (see Appendix H). Participants' e-mail addresses were associated with their responses during data collection so that parents who were selected for follow-up phone interviews could be contacted. This process also helped with identification and removal of fraudulent responses. Any identifying information was removed from the dataset prior to statistical analyses in order to ensure anonymity of the participants. The consent information included stipulations that a participant would not receive the incentive if they did not meet the eligibility requirements, if they completed the survey in an exceptionally brief period of time (e.g., under five minutes), or if more than 20% of the responses were left blank. The median completion time for participants who were included in analyses to complete the survey was 33 minutes, 24 seconds.

To begin, parents completed a series of screening questions (see Appendix B) online using Fluid Surveys, including whether they were a parent of a child with autism, if the child's age was between four and 11 years, and the questions from the CAST. Parents who had more than one child with autism were directed to answer the questions while thinking about their child who was between four and 11 years old. If they had more than one child with autism in this age range, then they were directed to answer the questions while thinking about the child that has the greatest effect on their family's well-being. If the parent did not meet inclusion criteria (i.e., had a score below the clinical cut-

off for the CAST, or did not meet other criteria), then they were directed to a page where they were thanked and given an explanation that they were not eligible to complete the survey and would not receive the incentive.

Parents who met the eligibility criteria were directed to complete the remainder of the survey online through Fluid Surveys. First, parents completed the demographic questionnaire. Then the remainder of the questionnaires were presented in a counter-balanced order. After completing the online survey, participants were asked if they would like to participate in an optional interview by phone or Skype. Most participants agreed to complete the interview (54%). Then all participants were asked to include their e-mail address so they could receive the incentive of a five-dollar e-gift card from Amazon.ca or Starbucks by e-mail. In total, 83% of the participants indicated that they wanted an incentive, whereas 17% denied the incentive. E-gift card incentives were sent to participants through the company's website by e-mail. All participants were sent a follow-up e-mail thanking them for participating and asking them to share the study information with other parents who may wish to participate.

**Qualitative Component: Phone Interview.** A subsample of 24 parents of children with autism derived from the survey sample participated in follow-up phone interviews. Of the 105 participants who indicated interest in completing a follow-up interview, 31 were selected based on their responses (e.g., ratings of family quality of life, technology use, unsupportive social interactions) and demographic factors (e.g., gender, marital status, number of children with autism) to ensure a sampling of diverse experiences. More specifically, an even sample of mothers and fathers was included for the interviews. Parents from diverse family structures were also selected (e.g., a custodial



grandparent, adoptive parent, and single parents). Some parents who had lower household incomes or who were unemployed were also selected to participate. Parents who reported both higher and lower use of online social support were also selected in order to solicit varied experiences and opinions about online social support use.

The remaining 74 participants who were willing to complete the interview were not contacted further as the consent form explained that not all interested participants would be selected for the interview. Participants who were selected for the interview were contacted by e-mail to arrange a time to complete the interview. A total of 24 interviews were completed with participants by phone (all participants preferred phone over Skype). Seven participants who were contacted about the interview did not respond to arrange a time to complete the interview. The interviews ranged in length from 11 minutes, 21 seconds to 41 minutes, 41 seconds. The average interview length was 25 minutes, 21 seconds ( $SD = 7$  minutes, 28 seconds).

The author conducted all the phone interviews. First, information from the consent form was reviewed with the participants (see Appendix H). Then, parents responded to the Semi-Structured Interview Questions prepared for this project. There were five main areas with follow-up questions based on the parents' responses (see Appendix I for the more detailed interview script). The questions were:

- To start, can you please tell me a bit about your family? How does being [married, a single parent, a foster parent, a custodial grandparent] affect your family quality of life?
- How does having a child with autism affect your family quality of life?
- How has support from others affected your family quality of life? What

kinds of things do people do that are helpful to your family and make you feel really supported?

- Can you tell me about any experiences that you have had where someone made you feel particularly unsupported as a parent of a child with autism?
- What kinds of activities do you do online related to your child with autism? What kinds of activities do you do online related to your own well-being?

Parents were also given an opportunity to share additional information that was not asked about specifically.

At the end of the interview, participants were given the opportunity to withdraw, and then were offered an additional five-dollar electronic gift card (21 of the 24 interview participants accepted the incentive). The interviews were audio recorded, and later transcribed by a trained research assistant.

The purpose of the interview was to gather additional information to support, explain, and add richness to the findings from the quantitative responses. Parents were asked more in-depth questions about the variables being studied (e.g., family quality of life, online social support, unsupportive social interactions). The interview was especially helpful in gathering information about the types of activities that parents engage in for online social support and their reasons for choosing to seek or not seek social support online.

***Thematic Analysis.*** The thematic analysis approach to qualitative data analysis was used, as it has been recommended for applied research that is accessible to consumers (Braun & Clarke, 2014b). Thematic analysis involves generating themes to capture the

information provided by the participants. In this study, the six steps to thematic analysis were followed, as described below (Braun & Clarke, 2006; 2012).

The first step was “familiarizing yourself with the data” (Braun & Clarke, 2012, p. 60). The author listened to the recorded interviews to familiarize herself with the content, check the accuracy of the transcriptions by the research assistant, and ensure that identifying information was not included.

The second step was generating initial codes. This was done by distilling the interview transcripts into shorter segments to make the data more manageable. Summaries of the participants’ main points were each made into codes, instead of including the full quotes. For example, a parent’s five-sentence story about an incident at a grocery store would be represented as a one sentence summary code. The codes were closely related to the participants’ language because whenever possible, specific words that participants used were retained. Data-derived codes were used in which codes were created for all the interview information in the transcripts (Braun & Clarke, 2013). The author coded the entire data set using Microsoft Excel.

The third step was to identify themes by collating the codes. The codes were printed as hard copies and cut into slips of paper (Braun & Clarke, 2006). Each slip of paper had the code, participant identification number, and the question number for the response. A small group of five people then arranged the slips of paper into potential themes based on conceptual similarity. The group consisted of the author, dissertation supervisor, parent advisor, research assistant, and a clinical psychology Master’s student. The thematic analysis approach is flexible, as it can be done individually or by a group (e.g., Clarke and Braun, 2013). A small group was selected in order to capitalize on the

experience and different perspectives of the group members (biases and experience are explained in more detail below). Discussion between group members also allowed for additional insights into implications of the parents' interview responses.

The printed codes were divided among the group members, who read and arranged them into potential themes, on tables. Tentative theme names were developed and used to label the potential themes and facilitate further sorting. Group members discussed any uncertainties and also re-arranged codes into different themes, combined themes, and divided themes. This process was repeated individually for each of the five interview questions (see Appendix I).

The fourth step was to review the themes and to ensure that the codes fit the themes (Braun & Clarke 2006; 2012). This was done at the initial meeting by reading over the codes that were included in each potential theme. Some codes were moved to different themes, some themes were combined or separated, and some themes were re-named. Once the group was satisfied with the potential themes, all printed codes for each theme were taped onto larger pieces of paper labelled with the theme names. The author later input the theme name for each code into the Excel spreadsheet. The author then reviewed the codes for each theme to ensure that they represented each theme and made changes as necessary.

To make the themes more manageable, they were then sorted into overarching themes (Braun & Clarke, 2006) across interview questions by the author, dissertation supervisor and parent advisor in another meeting. This was done to reduce the amount of overlap between initial themes. Overarching themes were created by combining the responses for questions two, three, and four. Overarching themes were also identified for

question five (online social support). The themes for question one, which referred to family structure, were determined to be concise without the need for overarching themes.

The overarching themes were arranged into a thematic map (Braun & Clarke, 2006) by the author (see Figure 4 in the Results section). Feedback from the dissertation supervisor and parent advisor was incorporated to make modifications to the thematic map.

The fifth step was to define and name the themes, which was done by the research team simultaneously with the third and fourth steps. Some minor modifications were made to the theme names upon later review by the author, research supervisor, and parent advisor.

The final step was to produce the report by writing up the results and selecting quotes from the original interviews, which was done by the author with feedback from the dissertation supervisor and parent advisor and is presented in the Results section of this dissertation (Braun & Clarke, 2006).

Braun and Clarke (2013) emphasize relying on the qualitative information that is provided by participants rather than focusing on numbers because it implies that higher frequency is equated with greater importance of a theme (Braun & Clarke, 2013). However, numbers can be useful as a supplement to the qualitative information that was gathered (Braun & Clarke, 2013). Therefore, frequencies of themes are presented in the Results section to supplement the theme names and quotes that are presented.

***Biases and Experience.*** Qualitative research takes a constructivist approach in which data analysis is understood to be highly influenced by its context and is not thought of as being neutral (Braun & Clarke, 2013). Each person has unique experiences and

biases that must be considered while conducting qualitative research. The researchers' subjectivity is seen as an asset in the research process. The results of a thematic analysis are subjective and reflective of the experiences that were brought by each member of the research team (Braun & Clarke, 2013). Instead of trying to eliminate this subjectivity, it was acknowledged, and embraced. As such, approaches common to quantitative data analysis like calculating inter-rater reliability are not required and are seen as being problematic in qualitative approaches to research (Braun & Clarke, 2013; 2014).

In this project, the researchers' experience with families of children with autism allow them to better understand the context of the information that was presented in the interviews and to better appreciate the meaning intended by the participants. As mentioned above, the small group who completed the thematic analysis included the author, dissertation supervisor, parent advisor, research assistant, and a psychology graduate student. A brief summary of the background of each of the researchers is included below.

The author is a PhD candidate in Child Clinical Psychology. She has completed clinical practica with preschoolers with autism and their families as well as other clinical experiences. She is very familiar with the research literature on the experiences of parents of children with autism and designed the methodology for this study. The author created the interview questions and personally interviewed each of the 24 participants. She has assisted other psychology graduate students in conducting Thematic Analyses and also in her own research (Jones & Gragg, 2016). The other psychology graduate student was a Master's student at the time and had similar experiences.

The dissertation supervisor is a faculty member in the Department of Psychology at the University of Windsor, and Clinical Director at the Summit Centre for Preschool Children with Autism. She has over 30 years experience working with children with autism and their families. This includes facilitating support groups for parents of children with autism for over 25 years. Further, she has been involved in autism research and has supervised several students who have used Braun and Clarke's (2006) thematic analysis in their projects as well. She was not involved in recruitment for this study in order to reduce the potential for conflict of interest.

The parent advisor has three young boys who are diagnosed with autism, which gives her a personal perspective about parenting children with autism. She is heavily involved in the autism community and has many connections, both in-person and online, with other parents of children with autism. Her lived experience provides a unique perspective to the thematic analysis as she contributed to a deeper understanding of the experiences of the interview participants.

The Research Assistant was an undergraduate psychology student who had limited experience with children with autism and their families and with thematic analysis. She listened to and transcribed all of the interviews, which gave her greater familiarity with the context, and the interpersonal context of the participants' interview responses.

## Results

### Preliminary Analyses for Quantitative Results

For the quantitative portion of the main study, the data set was examined and any out of range responses were deleted (e.g., two participants wrote their child's age instead of their own age). Subscales and total scale scores were calculated for each measure based on the scoring instructions and items were reverse-coded where necessary. The Acceptance and Action Questionnaire was also reverse-scored so that higher scores indicate greater acceptance.

**Missing Data.** As explained in the Participants section, data from parents who did not complete the entire survey ( $n = 21$ ) or who did not meet screening criteria ( $n = 26$ ) were omitted from analyses. Of the responses from the remaining sample, up to 7.1% of data were missing for each subscale. No patterns of missing data were present based on Little's Missing Completely at Random (MCAR) test,  $\chi^2(758) = 286.25, p = 1.000$ . Missing data were imputed using multiple imputation at the subscale level. This analysis generated five predicted values for each missing value, which were averaged and then input into the data set. This method of estimation ensures that the sample size is maximized.

For the Multidimensional Support Scale (MDSS), participants were asked a screening question pertaining to whether they engaged in online social support. Participants who indicated that they were not involved in online social support ( $n = 52$ ) did not complete the subscale related to social support from online communities. Therefore, the adequacy of online social support and availability of online social support subscales were not computed for these participants. Data from participants who do not



participate in online social support were not included in the analyses for Hypothesis 4, which investigated the role of online social support.

**Outliers.** The data set was examined for outliers using visual inspection of the histograms and boxplots for each scale. Standardized residuals (z scores) were examined for each scale, with a cut-off value of  $\pm 3.29$  (Field, 2013). The following outliers were identified: one participant for the Menu of Online Support Types (MOST), two participants for the Autism Spectrum Disorders- Behavior Problems Checklist (ASD-BPC), one participant for the Family Quality of Life Scale (FQOLS), and one participant for the Family Crisis Oriented Personal Scales (F-COPES). For these values, the Winsorizing procedure was implemented in which outlier values were replaced with a score that is 3 standard deviations away from the mean. This process reduces the impact of outliers while maximizing the sample size (Field, 2013).

Cook's distance was also examined to identify any influential multivariate outliers. No cases were identified that would affect the statistical model as a whole using a cut-off of 1.0. Standardized residuals were also examined to detect outliers on the dependent variable (scores on the FQOLS) and no cases had values that were greater than the cut-off of 3.3.

Leverage values were also examined to identify any remaining outliers. Two cases had leverage values that exceeded the cut-off of three times the average leverage distance of .063. Data from these two participants were removed from further analyses, resulting in a total N of 194. These cases were removed because they could potentially be influential observations. For example, one of the participants that was removed reported scores that were at the maximum of the measure for the Family Quality of Life Scale and

for the Multidimensional Support Scale online community subscale. No other unusual patterns of responses were noted for participants who were outliers.

**Assumptions.** Assumptions were tested for a multiple regression analysis, which included adequate sample size, normality, linearity, homoscedasticity of errors, absence of multicollinearity and singularity, independence of observations, and absence of outliers (Tabachnick & Fidell, 2013). As mentioned above, outliers were identified and addressed.

The first assumption refers to having an adequate sample size. The multiple regression analyses conducted for this study included eleven predictor variables or fewer. Using the guideline of 10 to 15 cases per predictor, 110 to 165 participants would be needed (Field, 2013). A total of 103 mothers and 91 fathers completed the study, which indicated that the sample size was low. As explained in the Procedure section, the post hoc power analysis indicated that the power is low, which makes it more difficult to detect an effect.

The next assumption tested was that the dependent variable (FQOLS) was normally distributed. A visual inspection of the histograms indicated that normality was adequate. The Kolmogorov-Smirnov value was not significant for the FQOLS ( $D(196) = 0.06, p = .200$ ), indicating that the observed distribution was not significantly different from a normal distribution. In addition, the skewness and kurtosis values were examined. Although there was a slight skew in the FQOLS and other independent variables, no data transformations were implemented to maintain interpretability of the findings. Therefore, the assumption of normality was met.

In order to test the assumptions of linearity and homoscedasticity of errors, the scatterplot of the residuals between predictor variables and errors of predictions was

examined. Based on visual inspection, this assumption appears to be met.

Multicollinearity was assessed by examining bivariate correlations between the variables being used in the models. No correlations were identified as being excessively high (i.e., above .80; Field, 2013). Therefore, no composite measures were created. The variance inflation factor (VIF) was also examined, and all values were lower than 3, which is far below the typical cut-off value of 10 (Field, 2013). Therefore, this assumption was met.

Because more than one parent of the same child was permitted to participate in the study, there was a potential for non-independence of observations. Data were analyzed separately for mothers and fathers for Hypotheses 2a, 2b, 3a, and 3b in order to explore potential differences based on parent gender. This practice also ensures independence of observations. There were 22 participants (11 mothers and 11 fathers) who were identified as having a partner who also completed the study. Including more than one parent of the same child with autism in the same analysis would violate the assumption of independence of observations because there would be two reports about the same child.

Data for both mothers and fathers were analyzed together in Hypotheses 1, and 4. In order to ensure independence of observations for these analyses, the 11 responses from the mothers whose partners also participated in this study were excluded. The decision to remove mothers' responses rather than fathers from couples was made because more mothers than fathers participated (103 mothers vs. 91 fathers), so removing these mothers' responses resulted in approximately equivalent sample sizes (92 mothers vs. 91 fathers).

**Preliminary Analyses.** See Table 5 for the statistical analyses, variables, and

Table 5

*Variables, Measures, and Analyses for Each Hypothesis*

Hypothesis	Variables	Measures	Analysis
1. Unsupportive social interactions will predict family quality of life above and beyond general social support in both mothers and fathers of children with autism.	<p><b>Predictors:</b></p> <ul style="list-style-type: none"> <li>-Social support</li> <li>-Unsupportive social interactions</li> </ul> <p><b>Outcome:</b></p> <ul style="list-style-type: none"> <li>-Family quality of life</li> </ul>	<ul style="list-style-type: none"> <li>-MDSS- Social Support Adequacy Composite and Social Support Availability Composite</li> <li>-USII</li> <li>-FQOLS</li> </ul>	Bivariate correlation, hierarchical multiple regression
2a. The double ABCX model overall will predict FQOL for mothers of children with autism.	<p><b>Predictors:</b></p> <ul style="list-style-type: none"> <li>-Child challenging behaviour (aA factor)</li> <li>-Child disability severity (aA factor)</li> <li>-Social support (bB factor)</li> <li>-Parental sense of competence (cC factor)</li> <li>-Acceptance (cC factor)</li> <li>-Coping skills (BC factor)</li> </ul> <p><b>Outcome:</b></p> <ul style="list-style-type: none"> <li>-Family quality of life (xX factor)</li> </ul>	<ul style="list-style-type: none"> <li>-ASD-BPC</li> <li>-Child Disability Severity Measure</li> <li>-MDSS- Social Support Adequacy Composite and Social Support Availability Composite</li> <li>-PSOC</li> <li>-AAQ-II-A</li> <li>-F-COPES (4 subscales)</li> <li>-FQOLS</li> </ul>	Multiple Regression Analysis

*Note.* FQOL = Family quality of life; AAQ-II-A = Acceptance and Action Questionnaire- Autism; ASD-BPC = Autism Spectrum Disorder- Behavior Problems for Children; CAST = Childhood Autism Spectrum Test; F-COPES = Family Crisis Oriented Personal Scales; FQOL = Family Quality of Life; FQOLS = Family Quality of Life Scale; MDSS = Multidimensional Social Support Scale: AC = Family, Friends, and Professionals, B = Online Communities; PSOC = Parental Sense of Competence Scale; PSS = Parental Stress Scale; USII = Unsupportive Social Interactions Inventory.

Hypothesis	Variables	Measures	Analysis
2b. Unsupportive social interactions will predict family quality of life in addition to the factors included in the double ABCX model for mothers of children with autism.	Unsupportive social interactions (aA factor)	-USII	Multiple Regression Analysis
3a. The double ABCX model overall will predict in FQOL for fathers of children with autism.	<p><b>Predictors:</b></p> <ul style="list-style-type: none"> <li>-Child challenging behaviour (aA factor)</li> <li>-Child disability severity (aA factor)</li> <li>-Social support (bB factor)</li> <li>-Parental sense of competence (cC factor)</li> <li>-Acceptance (cC factor)</li> <li>-Coping skills (BC factor)</li> </ul> <p><b>Outcome:</b></p> <ul style="list-style-type: none"> <li>-Family quality of life (xX factor)</li> </ul>	<ul style="list-style-type: none"> <li>-ASD-BPC</li> <li>-Child Disability Severity Measure</li> <li>-MDSS- Social Support Adequacy Composite and Social Support Availability Composite</li> <li>-PSOC</li> <li>-AAQ-II-A</li> <li>-F-COPES (4 subscales)</li> <li>-FQOLS</li> </ul>	Multiple Regression Analysis
3b. Unsupportive social interactions will predict family quality of life in addition to the factors included in the double ABCX model for fathers of children with autism.	Unsupportive social interactions (aA factor)	-USII	Multiple Regression Analysis

*Note.* FQOL = Family quality of life; AAQ-II-A = Acceptance and Action Questionnaire- Autism; ASD-BPC = Autism Spectrum Disorder- Behavior Problems for Children; CAST = Childhood Autism Spectrum Test; F-COPES = Family Crisis Oriented Personal Scales; FQOL = Family Quality of Life; FQOLS = Family Quality of Life Scale; MDSS = Multidimensional Social Support Scale: AC = Family, Friends, and Professionals, B = Online Communities; PSOC = Parental Sense of Competence Scale; PSS = Parental Stress Scale; USII = Unsupportive Social Interactions Inventory.

Hypothesis	Variables	Measures	Analysis
4. Greater frequency of use of online social support, greater availability of online social support, and greater perceived adequacy of online social support will predict higher family quality of life for both mothers and fathers of children with autism.	<p><b>Predictors:</b></p> <ul style="list-style-type: none"> <li>-Availability of online social support</li> <li>-Adequacy of online social support</li> <li>-Frequency of use of online social support</li> </ul> <p><b>Outcome:</b></p> <ul style="list-style-type: none"> <li>-Family quality of life</li> </ul>	<ul style="list-style-type: none"> <li>-MDSS- availability of online social support subscale and adequacy of online social support subscale</li> <li>-MOST</li> <li>-FQOLS</li> </ul>	Multiple Regression Analysis

*Note.* FQOL = Family quality of life; AAQ-II-A = Acceptance and Action Questionnaire- Autism; ASD-BPC = Autism Spectrum Disorder- Behavior Problems for Children; CAST = Childhood Autism Spectrum Test; F-COPES = Family Crisis Oriented Personal Scales; FQOL = Family Quality of Life; FQOLS = Family Quality of Life Scale; MDSS = Multidimensional Social Support Scale: AC = Family, Friends, and Professionals, B = Online Communities; PSOC = Parental Sense of Competence Scale; PSS = Parental Stress Scale; USII = Unsupportive Social Interactions Inventory.

measures for each hypothesis. Table 6 shows the number of mothers and fathers whose responses were included in the analyses for each hypothesis. Preliminary analyses examined the range, means, and standard deviations for each measure (see Table 7), as well as the bivariate correlations (see Table 8). The mean score for the FQOLS in the present study ( $M = 93$ ) was similar to scores found in other studies that used this measure in parents of children with autism (e.g.,  $M = 91$ ; Gardiner & Iarocci, 2015).

A preliminary analysis was done to determine whether the subscales of the coping measure should be included in analyses rather than the overall coping score. Differences between mothers and fathers were examined for the four subscales of the Family Crisis Oriented Personal Scales (F-COPES; McCubbin et al., 1981) using a multivariate t-test. The Mobilizing Family to Acquire and Accept Help subscale was not included in analyses due to low reliability. The only subscale that showed a significant difference was Seeking Spiritual Support, in which mothers had significantly higher ratings than fathers,  $t(192) = 2.08, p = .039$ . See Table 9 for full results. Therefore, the four subscales of the F-COPES were included in the multiple regression analyses in Hypotheses 2a and 3a.

### **Hypothesis 1**

Hypothesis 1 that unsupportive social interactions would be predict family quality of life above and beyond general social support for both mothers and fathers of children with autism was partially supported.

Data for hypothesis 1 were analyzed together for mothers and fathers, with mothers from couples removed ( $n = 11$ ), resulting in an  $N$  of 183 for this analysis. The Social Support Adequacy Composite and Social Support Availability Composite variables were created by summing the subscales that included social support from family and

Table 6

*Number of Participants, Mothers, and Fathers Whose Data Were Included in Each**Analysis*

Analysis	Total N	Number of Mothers	Number of Fathers	Mothers from Couples Included?
Overall Sample	194	103	91	Yes
Hypothesis 1	183	92	91	No
Hypotheses 2a and 2b	103	103	0	Yes
Hypotheses 3a and 3b	91	0	91	No
Hypothesis 4 <sup>a</sup>	131	64	67	No
Thematic Analysis	24	12	12	Yes

<sup>a</sup> *Note:* 52 participants were not included in this analysis who answered “no” to a screening question about their use of online social support.



Table 7

*Descriptive Results for Variables Included in the Survey Portion of the Study*

	Potential Range	Observed Range	Mean	SD
Child challenging behaviour	0 - 36	0 - 29.27	11.08	5.92
Child disability severity	0 - 15	1 - 15	8.14	3.54
Unsupportive social interactions	0 - 96	1 - 93	33.05	20.06
Social Support Availability Composite <sup>a</sup>	2 - 8	2.33 - 8	5.24	1.23
Social Support Adequacy Composite <sup>a</sup>	2 - 6	2 - 6	4.11	1.25
Availability of online social support	1 - 4	1 - 4	2.49	0.72
Adequacy of online social support	1 - 3	1 - 3	2.31	0.81
Frequency of technology use	0 - 60	0 - 40	12.81	8.39
Acceptance	7 - 49	7 - 49	19.45	10.38
Parental sense of competence	17 - 102	24 - 92	62.96	12.87
Overall coping	30 - 150	51.03 - 136	92.96	13.87
Acquiring social support	9 - 45	9 - 43	24.37	7.64
Reframing	8 - 40	15 - 40	31.17	4.50
Seeking spiritual support	4 - 20	4 - 20	8.43	4.82
Mobilizing family to acquire and accept help <sup>b</sup>	4 - 25	4 - 20	14.12	3.04
Passive appraisal	4 - 20	5 - 20	14.85	3.17
Family quality of life	25 - 125	42 - 125	93.42	17.00

Note: Numbers in the Observed Range column may not be whole numbers due to the use of the Winsorizing procedure to reduce the impact of outliers.

<sup>a</sup> From family, friends, and professionals

<sup>b</sup> This subscale was not included in statistical analyses due to low reliability

Table 8  
*Correlations between Variables Included in Main Analyses and Demographic Variables*

	1	2	3	4	5	6	7	8	9
1. Social Support Availability Composite <sup>a</sup>	-								
2. Social Support Adequacy Composite <sup>a</sup>	.67***	-							
3. Availability of online social support	.17*	.00	-						
4. Adequacy of online social support	0.14	.29***	.48***	-					
5. Frequency of technology use	-.09	-.19**	.25**	.01	-				
6. Child challenging behaviour	-0.14	-.20**	.09	-.20*	.22**	-			
7. Acceptance <sup>b</sup>	.37***	.43***	.04	.26**	-.19*	-.41***	-		
8. Unsupportive social interactions	-.36***	-.42***	.19*	-.10	.36***	.35***	-.49***	-	
9. Overall coping	.35***	.25***	.07	.07	.15*	-.13	.38***	-.18*	-
10. Child disability severity	-.05	-.22**	.01	-.01	.04	.34***	.21**	.05	.02
11. Parental sense of competence	.35***	.35***	.10	.20*	.05	-.30***	.62***	-.37***	.42***
12. Family quality of life	.46***	.54***	.02	.13	-.01	-.26***	.57***	-.38***	.58***
13. Parent gender <sup>c</sup>	-.01	.12	-.02	.15	-.06	.07	-.03	-.09	-.09
14. Parent age	-.03	-.03	-.02	-.01	-.10	-.04	.01	-.17*	.01
15. Household income	.12	.03	.01	-.12	-.03	.02	.03	-.03	-.12
16. Single parent status <sup>d</sup>	.00	.02	.10	.07	-.03	.02	-.06	.00	-.11
17. Parent education	.08	.07	-.15	-.09	.04	-.14	-.02	-.02	-.03
18. Number of children	.01	-.03	.12	.01	-.07	-.04	.05	.05	.09
19. Number of children with autism	-.05	-.09	-.00	.00	.14	.02	-.01	.09	-.02
20. Child age	.02	-.02	.11	.04	-.01	-.02	.07	-.07	.03

<sup>a</sup> From family, friends, and professionals

<sup>b</sup> Reverse-scored so higher scores indicate greater acceptance.

<sup>c</sup> 0 = female, 1 = male.

<sup>d</sup> 1 = single parent, 2 = not a single parent.

\*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$ .

	10	11	12	13	14	15	16	17	18	19
10. Child disability severity	-									
11. Parental sense of competence	-0.11	-								
12. Family quality of life	-0.12	.50***	-							
13. Parent gender <sup>c</sup>	.00	-.04	.06	-						
14. Parent age	.03	.07	-.03	.11	-					
15. Household income	.02	.07	.08	-.06	.25***	-				
16. Single parent status <sup>d</sup>	.04	.02	.10	.00	.03	.30***	-			
17. Parent education	-.10	.00	-.01	-.13	.11	.24**	-.03	-		
18. Number of children	.01	.03	.03	.08	.00	.09	-.11	-.10	-	
19. Number of children with autism	.10	.00	-.09	.06	-.02	-.28***	-.27***	-.17*	.36***	-
20. Child age	-.06	.12	-.05	-.12	.38***	.09	-.14	.06	.03	.16*

<sup>c</sup> 0 = female, 1 = male.

<sup>d</sup> 1 = single parent, 2 = not a single parent.

\*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$ .

Table 9

*Comparison of Mothers and Fathers of Children with Autism on Coping Subtypes*

Analysis	Mothers Mean (SD)	Fathers Mean (SD)	F	<i>p</i>
Acquiring Social Support	24.46 (7.70)	24.27 (7.60)	.03	.857
Reframing	30.94 (4.73)	31.42 (4.26)	.56	.455
Seeking Spiritual Support	9.11 (4.89)	7.69 (4.66)	4.31	.039
Passive Appraisal	15.23 (2.97)	14.43 (3.33)	3.11	.079

friends, and professionals for both the adequacy and availability subscales, respectively. This was done to create measures of overall social support. The bivariate correlations were significant between the amount of unsupportive social interactions and the Social Support Adequacy Composite ( $r = -.42, p < .001$ ) and the Social Support Availability Composite ( $r = -.36, p < .001$ ).

However, it was not clear from the findings whether unsupportive social interactions and social support are separate constructs that are highly related to one another or whether they are opposite ends of the same continuum. Therefore, a hierarchical multiple regression predicting family quality of life was conducted. The Social Support Availability Composite and Social Support Adequacy Composite variables were included as predictors in the first step, and unsupportive social interactions were included in the second step to predict family quality of life.

The Social Support Availability Composite and Social Support Adequacy Composite variables were included in the first step of the hierarchical multiple regression analysis based on the well-established relation found in previous research. Unsupportive social interactions were included in the second step in order to determine whether they could account for additional variance in family quality of life beyond the effects of social support. Unsupportive social interactions accounted for a significant amount of variance in family quality of life after the adequacy and availability of social support were taken into account ( $\Delta R^2 = .02, p = .023$ ; see Table 10). These findings suggest that some distinction can be made between unsupportive social interactions and social support because unsupportive social interactions contribute unique variance in family quality of life. It was not clear from these results whether unsupportive social interactions and social

Table 10

*Hierarchical Multiple Regression Predicting Family Quality of Life from Social Support and Unsupportive Social Interactions (Hypothesis 1)*

	R <sup>2</sup>	ΔR <sup>2</sup>	Standardized Coefficients (β)	Squared Semi-Partial Correlations
Step 1	.31	.31***		
Social Support Adequacy Composite <sup>a</sup>			.43	.10
Social Support Availability Composite <sup>a</sup>			.17	.02
Step 2	.33	.02*		
Unsupportive social interactions			-.17	.02

<sup>a</sup> From family and friends and professionals.

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

support are two separate constructs that are correlated with one another, or whether they represent two different constructs. Due to the lack of clarity about the meaning of the results, Hypothesis 1 was considered to be partially supported.

### **Hypotheses 2a and 2b**

It was expected in Hypothesis 2a that the double ABCX model overall (i.e., aA factor: child disability severity and child challenging behaviour, bB factor: social support, cC factor: parental sense of competence and acceptance, and BC factor: coping skills) would predict family quality of life for *mothers* of children with autism.

It was also expected in Hypothesis 2b that unsupportive social interactions (aA factor) would predict family quality of life in addition to the factors included in the double ABCX model for *mothers* of children with autism. To test these hypotheses, a multiple regression analysis was conducted using family quality of life as the outcome (see Table 11). Hypothesis 2a was supported, but hypothesis 2b was not supported.

It was originally planned to do a hierarchical multiple regression with demographic factors that could be potential covariates entered in the first step, and predictors from the double ABCX model included in the second step. The potential covariates included family income, parent marital status, and target child age. However, family income and target child age were not significantly related to family quality of life (as shown in Table 8) and were therefore removed from this and further analyses. The regression was conducted with marital status as a covariate, but marital status was not a significant predictor of family quality of life. Therefore, the final analysis was conducted without marital status as a covariate in order to maximize statistical power.

Table 11

*Multiple Regression Predicting Family Quality of Life for Mothers (Hypotheses 2a and 2b)*

	Standardized Coefficients ( $\beta$ )	<i>p</i>	Squared Semi- Partial Correlations
<b>Coping- acquiring social support</b>	<b>.36</b>	<b>&lt; .001</b>	<b>.08</b>
<b>Coping- reframing</b>	<b>.32</b>	<b>&lt; .001</b>	<b>.07</b>
<b>Coping- passive appraisal <sup>a</sup></b>	<b>.22</b>	<b>.007</b>	<b>.03</b>
<b>Social Support Adequacy Composite <sup>b</sup></b>	<b>.27</b>	<b>.010</b>	<b>.03</b>
<b>Acceptance</b>	<b>.19</b>	<b>.037</b>	<b>.02</b>
Parental sense of competence	-.11	.229	.01
Child disability severity	-.09	.242	.01
Coping- seeking spiritual support	.06	.422	.00
Child challenging behaviour	-.06	.423	.00
Unsupportive social interactions	-.07	.427	.00
Social Support Availability Composite <sup>a</sup>	-.01	.943	.00

<sup>a</sup> Reverse-scored so higher scores indicate less use of passive appraisal coping strategies.

<sup>b</sup> From family and friends and professionals.



The 11 predictors that were included in the regression were child disability severity, child challenging behaviour, Social Support Availability Composite, Social Support Adequacy Composite, parental sense of competence, acceptance, coping-acquiring social support, coping-reframing, coping-passive appraisal, coping-seeking spiritual support, and unsupportive social interactions.

To address Hypotheses 2a and 2b, a multiple regression analysis was conducted for the sample of mothers of children with autism ( $n = 103$ ). The overall model was statistically significant,  $R^2 = .65$ ,  $F(11, 89) = 15.16$ ,  $p < .001$  (see Table 11). The predictors that were statistically significant within the model included adequacy of social support, and the passive appraisal, reframing, and acquiring social support coping subscales, and acceptance. Although the overall model was significant, unsupportive social interactions were not a significant predictor within the model ( $p = .512$ ). These findings indicate that Hypothesis 2a was supported and that Hypothesis 2b was not supported.

### **Hypotheses 3a and 3b**

It was expected in Hypothesis 3a that the double ABCX model overall (i.e., aA factor: child disability severity and child challenging behaviour, bB factor: social support, cC factor: parental sense of competence and acceptance, and BC factor: coping skills) would predict family quality of life for *fathers* of children with autism. Hypothesis 3a was supported. It was also expected in Hypothesis 3b that unsupportive social interactions (aA factor) would predict family quality of life in addition to the factors included in the double ABCX model for *fathers* of children with autism. Hypothesis 3b was not supported. To test these hypotheses, a multiple regression analysis was conducted using

family quality of life as the outcome variable (see Table 12). The eleven predictors that were included in the regression were child disability severity, child challenging behaviour, Social Support Availability Composite, Social Support Adequacy Composite, parental sense of competence, acceptance, coping skills, and unsupportive social interactions. As in Hypothesis 2a, demographic variables were not included as covariates because they did not correlate with family quality of life. Similar to Hypothesis 2a, the regression was run with marital status as a covariate, but this variable was not a significant predictor of family quality of life. Therefore, the final analysis was conducted without marital status as a covariate.

To address Hypothesis 3a, a multiple regression analysis was conducted for the sample of fathers of children with autism ( $n = 91$ ). The overall model was statistically significant,  $R^2 = .63$ ,  $F(11, 81) = 12.26$ ,  $p < .001$  for fathers (see Table 12). The predictors that were statistically significant within the model included the Social Support Adequacy Composite, and the reframing subscale of the coping measure. Unsupportive social interactions were not a significant predictor within the model ( $p = .207$ ). These findings indicate that Hypothesis 3a was supported and that Hypothesis 3b was not supported.

**Exploratory Analysis.** The pattern of results for mothers and fathers was compared statistically (see Table 13). This was an exploratory analysis and therefore type I error is likely to be inflated. There is variability in the few studies that have compared mothers and fathers for predictors of family quality of life using the double ABCX model. Therefore, all of the variables within the double ABCX model in this study were included in this analysis. To test for differences in predictors of family quality of life between mothers and fathers, interaction terms between each centered predictor variable and

Table 12

*Multiple Regression Predicting Family Quality of Life for Fathers (Hypotheses 3a and 3b)*

	Standardized Coefficients ( $\beta$ )	<i>p</i>	Squared Semi- Partial Correlations
<b>Social Support Adequacy Composite <sup>a</sup></b>	<b>.36</b>	<b>&lt; .001</b>	<b>.07</b>
<b>Coping- reframing</b>	<b>.34</b>	<b>.001</b>	<b>.06</b>
Acceptance	.16	.150	.01
Unsupportive social interactions	-.12	.207	.01
Parental sense of competence	.13	.252	.01
Coping- seeking spiritual support	.10	.265	.01
Coping- acquiring social support	.09	.324	.00
Social Support Availability Composite <sup>a</sup>	-.08	-.427	.00
Child challenging behaviour	.07	.429	.00
Child disability severity	.02	.787	.00
Coping- passive appraisal <sup>b</sup>	.02	.833	.00

<sup>a</sup> From family and friends and professionals.

<sup>b</sup> Reverse-scored so higher scores indicate less use of passive appraisal coping strategies.

Table 13

*Differences in Predictors of Family Quality of Life for Mothers and Fathers of Children with Autism*

	Standardized Coefficients ( $\beta$ )	<i>p</i>	Squared Semi-Partial Correlations
<b>Main Effects</b>			
Parent gender	.03	.667	.00
Parental sense of competence	-.10	.325	.00
<b>Social Support Availability Composite<sup>a</sup></b>	<b>.29</b>	<b>.001</b>	<b>.04</b>
<b>Social Support Adequacy Composite<sup>a</sup></b>	<b>.29</b>	<b>.001</b>	<b>.04</b>
<b>Acceptance</b>	<b>-.40</b>	<b>&lt;.001</b>	<b>.04</b>
<b>Coping</b>	<b>.46</b>	<b>&lt;.001</b>	<b>.10</b>
Child disability severity	-.09	.348	.00
Child challenging behaviour	-.04	.646	.00
Unsupportive social interactions	-.11	.216	.00
<b>Interaction Terms<sup>b</sup></b>			
<b>Parental sense of competence</b>	<b>.26</b>	<b>.017</b>	<b>.02</b>
<b>Social Support Availability Composite<sup>a</sup></b>	<b>-.21</b>	<b>.017</b>	<b>.02</b>
<b>Social Support Adequacy Composite<sup>a</sup></b>	<b>.18</b>	<b>.020</b>	<b>.02</b>
Acceptance	.17	.137	.01
Coping	-.12	.192	.01
Child disability severity	.12	.206	.00
Child challenging behaviour	.09	.340	.00
Unsupportive social interactions	.04	.695	.01

<sup>a</sup> From family and friends and professionals.

<sup>b</sup> Interaction terms between variable and parent gender

parent gender were created. These variables were then entered into a regression along with the predictor variables and parent gender to predict family quality of life. This analysis could also be accomplished using a hierarchical multiple regression and examining the change in  $R^2$ , but interpreting the squared semi-partial correlations using this method provides the same information.

Based on this analysis, the interactions between parent gender and the Social Support Availability Composite ( $p = .017$ ), Social Support Adequacy Composite ( $p = .020$ ), and parental sense of competence ( $p = .017$ ) were statistically significant. These findings indicate that there is a statistically significant difference in how these factors predict family quality of life between mothers and fathers in this sample. More specifically, parental sense of competence and the adequacy of social support were more strongly related to family quality of life for fathers than for mothers. Availability of social support was more strongly related to family quality of life for mothers than for fathers.

#### **Hypothesis 4**

Hypothesis 4 that greater frequency of use of online social support, greater availability of online social support, and greater perceived adequacy of online social support would predict higher family quality of life for both mothers and fathers of children with autism was not supported. See Table 7 for descriptive information. A multiple regression analysis was conducted to predict family quality of life from the availability of online social support, adequacy of online social support and frequency of technology use.

This analysis was conducted using a sample of 131 participants ( $n = 64$  mothers and  $n = 67$  fathers). Responses from both mothers and fathers were included in these

analyses with responses from mothers from couples removed. The 52 participants who answered “no” to the screening question that asked whether they used the internet for support were not included because they did not complete the online community subscale of the Multidimensional Support Scale. The overall model of the multiple regression analysis was not statistically significant,  $R^2 = .03$ ,  $F(3, 127) = 1.32$ ,  $p = .272$  (see Table 14). This finding indicates that Hypothesis 4 was not supported.

**Exploratory Analysis.** It was further explored whether online social support would be related to family quality of life within the double ABCX model using a multiple regression analysis. This analysis was exploratory and therefore type I error is likely to be inflated. The variables tested included child challenging behaviour, child disability severity, and unsupportive social interactions (aA factor), Social Support Adequacy Composite and Social Support Availability Composite (bB factor), parental sense of competence (cC factor), coping subscales (BC factor), and the adequacy of online social support, availability of online social support, and frequency of use of online social support (bB factor) to predict family quality of life (xX factor). The overall model was significant,  $R^2 = .63$ ,  $F(14, 127) = 15.27$ ,  $p = < .001$ . However, none of the three measures of online social support were significant within the model (see Table 15). This finding is consistent with the results of Hypothesis 4 which suggests that online social support is not related to family quality of life.

### **Thematic Analysis of Responses to Phone Interview**

A total of 24 parents (12 mothers, 12 fathers) participated in a follow-up semi-structured interview by phone. As described in the Method section, the interview

Table 14

*Multiple Regression Predicting Family Quality of Life from Online Social Support**(Hypothesis 4)*

	Standardized Coefficients		Squared Semi-Partial Correlations
	$\beta$	$p$	
<b>Adequacy of online social support<sup>a</sup></b>	<b>.20</b>	<b>.049</b>	<b>.03</b>
Availability of online social support <sup>a</sup>	-.11	.314	.01
Frequency of technology use <sup>b</sup>	.02	.818	.00

<sup>a</sup> Based on the Multidimensional Support Scale (MDSS)<sup>b</sup> Based on the Menu of Online Support Types (MOST)

Table 15

*Multiple Regression Predicting Family Quality of Life Using the Double ABCX Model**Including Online Social Support*

	Standardized Coefficients ( $\beta$ )	<i>p</i>	Squared Semi- Partial Correlations
<b>Coping- reframing</b>	<b>.31</b>	<b>&lt; .001</b>	<b>.06</b>
<b>Social Support Adequacy Composite <sup>b</sup></b>	<b>.29</b>	<b>.001</b>	<b>.04</b>
<b>Coping- acquiring social support</b>	<b>.22</b>	<b>.002</b>	<b>.03</b>
<b>Acceptance</b>	<b>.24</b>	<b>.003</b>	<b>.03</b>
Coping- passive appraisal <sup>a</sup>	.13	.074	.01
Unsupportive social interactions	-.13	.083	.00
Coping- seeking spiritual support	.10	.109	.00
Frequency of use of online social support	.10	.122	.00
Adequacy of online social support	-.08	.271	.00
Parental sense of competence	-.04	.581	.00
Availability of online social support	.03	.642	.00
Child challenging behaviour	-.03	.688	.00
Social Support Availability Composite <sup>b</sup>	-.03	.706	.00
Child disability severity	-.02	.803	.00

<sup>a</sup> Reverse-scored so higher scores indicate less use of passive appraisal coping strategies.

<sup>b</sup> From family and friends and professionals.



responses were analyzed using the thematic analysis method as described by Braun & Clarke (2006; 2014b).

A total of 624 codes were generated from all of the interview transcripts. These codes were first collated into themes separately for each of the five main questions that were presented. The five questions were about the participants' families, how raising children with autism affects their families, how supports affect family quality of life, experiences of unsupportive social interactions, and online social support use (see Method or Appendix I for wording of questions). Next, overarching themes were identified that combined parents' responses to questions two, three and four, which had to do with how raising a child with autism affects family quality of life, supports, and unsupportive social interactions. Overarching themes were also identified for the fifth question, which asked parents about online social support. The themes identified for the first question about family structure were succinct and therefore overarching themes were not identified for this question. A list of all themes and overarching themes is in Table 16. The number of fathers and mothers who endorsed each overarching theme is shown in Table 17.

As noted by Braun and Clarke (2006), the number of times that a theme is endorsed does not necessarily imply that a theme is more important. Braun and Clarke (2013) discourage the use of numbers in thematic analysis because it implies that numbers are more important than words, themes, and narratives. Using numbers in qualitative research is in contrast with the constructivist approach used in most qualitative research. They state that "Whether something is insightful or important for elucidating our research questions is not necessarily determined by whether large numbers of people said it." (Braun & Clarke, 2013, p. 261). Numbers are included here as a way to illustrate potential

Table 16

*Overarching Themes, Themes, and Subthemes from Thematic Analysis of Phone Interview Responses*

Overarching Theme	Themes	Subthemes
<b>Question 1: Family Structure</b>		
	<ul style="list-style-type: none"> <li>· Divorced</li> <li>· Having a partner is more important than being legally married</li> <li>· Teamwork in marriage</li> </ul>	<ul style="list-style-type: none"> <li>· Couldn't do it alone</li> </ul>
<b>Questions 2, 3, &amp; 4: Impact of raising children with autism on family quality of life</b>		
Child challenging behaviour	<ul style="list-style-type: none"> <li>· Sensory</li> <li>· Toilet training</li> <li>· Communication</li> <li>· Autism is not misbehaviour</li> </ul>	
Unsupportive social interactions	<ul style="list-style-type: none"> <li>· Negative relationships with others</li> <li>· Lack of autism awareness</li> </ul>	<ul style="list-style-type: none"> <li>· Family</li> <li>· Judging</li> <li>· Dismissive</li> <li>· Unhelpful comments</li> <li>· Public</li> </ul>
Stress/Isolation	<ul style="list-style-type: none"> <li>· Can't go out</li> <li>· Stress</li> <li>· Isolation</li> <li>· Busy</li> </ul>	
Same/Different	<ul style="list-style-type: none"> <li>· Change our way of doing things</li> </ul>	
Siblings	<ul style="list-style-type: none"> <li>· Positive and negative effects</li> <li>· More understanding</li> </ul>	
Personal Growth	<ul style="list-style-type: none"> <li>· Perspective</li> <li>· Patience</li> <li>· Professional development</li> <li>· Appreciate the small things</li> <li>· Child's Qualities</li> </ul>	

Overarching Theme	Themes	Subthemes
Professionals	<ul style="list-style-type: none"> <li>· Positive</li> <li>· Negative</li> </ul>	<ul style="list-style-type: none"> <li>· Activities</li> <li>· Positive relationships with professionals</li> <li>· Applied Behaviour Analysis</li> <li>· School/inclusion</li> <li>· Government waitlists</li> <li>· School</li> <li>· Not helpful/not trained</li> <li>· Services not co-ordinated</li> </ul>
Financial Effects/Work		
Location	<ul style="list-style-type: none"> <li>· Distance from family</li> </ul>	
Supportive Peers	<ul style="list-style-type: none"> <li>· Listening</li> <li>· Instrumental support</li> <li>· Support groups</li> <li>· Friends</li> <li>· Other parents of children with autism</li> </ul>	
Family Support	<ul style="list-style-type: none"> <li>· Positive family relations</li> </ul>	<ul style="list-style-type: none"> <li>· Grandparents</li> </ul>
Childcare	<ul style="list-style-type: none"> <li>· Grandparents</li> </ul>	
Reactions to Unsupportive Social Interactions	<ul style="list-style-type: none"> <li>· It doesn't bother me</li> <li>· I don't say anything</li> </ul>	
<b>Question 5: Online Social Support</b>		
Don't Post Online		
Disadvantages	<ul style="list-style-type: none"> <li>· Negative experiences</li> <li>· Comparison</li> <li>· Bad information</li> <li>· Prefer in-person</li> </ul>	

Overarching Theme	Themes	Subthemes
Advantages	<ul style="list-style-type: none"> <li>· General</li> <li>· Convenient</li> <li>· Anonymous</li> </ul>	
Functions	<ul style="list-style-type: none"> <li>· Blogs/stories</li> <li>· Information gathering</li> </ul>	<ul style="list-style-type: none"> <li>· Strategies</li> <li>· Services</li> </ul>
Support	<ul style="list-style-type: none"> <li>· Facebook- personal page</li> </ul>	<ul style="list-style-type: none"> <li>· Milestones</li> <li>· Positive response</li> </ul>
Connecting with Other Parents of Children with Autism	<ul style="list-style-type: none"> <li>· Facebook groups</li> </ul>	

Table 17

*Overarching Themes Endorsed by Mothers and Fathers*

	Mothers n (%)	Fathers n (%)
<b>Question 1- Family Structure</b>		
Teamwork in Marriage	7 (58)	7 (58)
Divorced	3 (25)	3 (25)
Having a Partner is More Important Than Being Legally Married	1 (8)	3 (25)
<b>Questions 2, 3, &amp; 4- Impact of Raising Children with Autism</b>		
Supportive Peers	12 (100)	10 (83)
Unsupportive Social Interactions	12 (100)	10 (83)
Stress/Isolation	11 (92)	11 (92)
Professionals	11 (92)	10 (83)
Same/Different	8 (67)	8 (67)
Personal Growth	<b>8 (67)</b>	<b>4 (33)</b>
Reactions to Unsupportive Social Interactions	7 (58)	5 (42)
Child Challenging Behaviour	6 (50)	7 (58)
Financial Effects/Work	6 (50)	6 (50)
Childcare	<b>5 (42)</b>	<b>8 (67)</b>
Siblings	4 (33)	3 (25)
Location	4 (33)	2 (17)
Family Support	<b>3 (25)</b>	<b>7 (58)</b>
<b>Question 5- Online Social Support</b>		
Functions	<b>12 (100)</b>	<b>7 (58)</b>
Disadvantages	9 (75)	10 (83)
Don't Post Online	<b>9 (75)</b>	<b>5 (42)</b>
Advantages	<b>8 (67)</b>	<b>2 (17)</b>
Support	5 (42)	6 (50)
Connecting with Other Parents of Children with Autism	4 (33)	6 (50)

*Note:* n = 12 mothers and n = 12 fathers. Bolded responses suggest potential differences between mothers and fathers.

differences between responses from mothers and fathers and to provide additional information about the themes that were identified. The numbers that are included should be interpreted with caution. Although some differences were noted in the interview responses from mothers and fathers in this study, they should be interpreted cautiously because the sample size was small for both mothers ( $n = 12$ ) and fathers ( $n = 12$ ) who were interviewed. As Braun and Clarke (2013) explain, we cannot assume that participants who did not endorse a certain theme did not share that perspective. It is possible that other participants may have the same views, but did not specifically state them due to the open-ended and interactive nature of the interview process.

With this caution, the frequency of endorsement of the themes that were identified from the thematic analysis were generally consistent between the mothers and fathers who were interviewed in this study. A few differences were noted between mothers and fathers in the frequency with which themes were endorsed (i.e., a difference of three or more participants mentioning the theme). Mothers more frequently described instances of *Personal Growth* than fathers. The importance of *Childcare* and *Family Support* were spontaneously described more frequently by fathers than mothers. In terms of online social support, mothers more frequently stated that they *Don't Post Online* and more frequently described *Functions* and *Advantages* of online social support than fathers. It is difficult to say whether these results represent true differences between mothers' and fathers' experiences raising children with autism due to the caveats mentioned above and due to the small sample size of parents who were interviewed which are likely not representative of the population.

**Family Structure.** For question one, about family structure, the themes were

*Divorced, Having a Partner is More Important than Being Legally Married, and Teamwork in Marriage*, with a sub-theme of *Couldn't Do It Alone*. Although most parents in the overall sample and the interview sample were married, single parents and a custodial grandparent were selected for the interview to ensure diversity of experiences. None of the 18 parents who were unmarried and living with a partner were chosen to participate in the interviews, which was an oversight.

***Divorced.*** Divorced parents who participated in interviews (n = 3) explained that they needed to give 100% of their attention to their children and some noted that autism contributed to conflict that led to their separation. Some of the parents also indicated that being divorced was positive because it reduced the amount of conflict in their homes. One parent's response illustrated the theme *Divorced*:

In some ways, [being divorced has] added more stress. But in other ways it has lessened it. So, it was more of a workload for me, but I guess the friction it caused between us has lessened the stuff that I have daily.

***Having a Partner is More Important than Being Legally Married.*** On the other hand, married parents (n = 21) often noted that having a partner was beneficial, rather than the institution of marriage itself. A quote that illustrates the theme of *Having a Partner is More Important than Being Legally Married* is: "I don't know if marriage in and of itself helps that but the fact that having a supportive partner is definitely a big positive." Other married parents noted that they did not think that their family quality of life would be different if they still had a partner but were not legally married.

***Teamwork in Marriage.*** Married parents described *Teamwork in Marriage* as being relevant to their family lives. Having a partner was described as being helpful

because both parents can work together as a team to share responsibilities. As one father stated:

I think [being married] makes it much easier. You know, as far as taking care of [our son with autism] goes, he requires 24/7 supervision at this point... being married helps definitely because me and my wife can share those responsibilities.

A sub-theme in this area was *Couldn't Do It Alone* which reflected married parents' speculations about the difficulties in raising children with autism without a partner. One married father commented, "I genuinely couldn't imagine [being a single parent]. I don't know, me personally, if I would have been strong enough to look after... a child on my own."

**Impact of Raising Children with Autism.** Questions two, three, and four referred to how raising children with autism affects parents' family quality of life and the influence of both supportive and unsupportive responses from others (see Appendix I for exact wording of questions). The thematic map (Braun & Clarke, 2006) of the overarching themes for these questions is in Figure 4.

Overarching themes were organized into two broad categories that included the within-family effects on family quality of life and the external influences on family quality of life. The within-family effects on family quality of life reflected negative effects, positive effects, and mixed effects.

***Child Challenging Behaviour.*** One overarching theme with a negative effect on family quality of life was *Child Challenging Behaviour*. Within this overarching theme, one theme that parents described was challenges related to *Communication* with their children. One mother explained, "he doesn't talk yet, so he's not verbal... so I think that



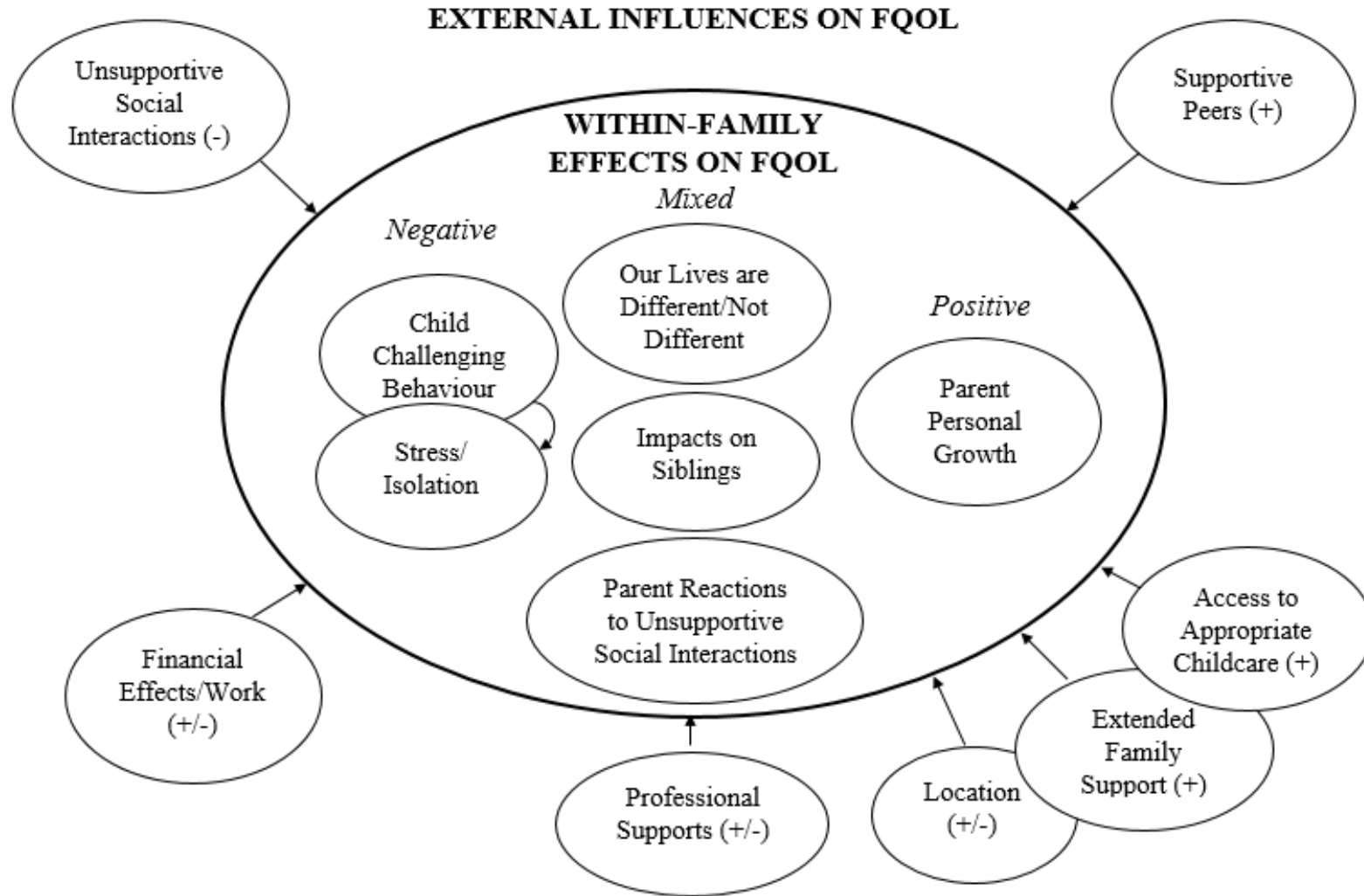


Figure 4. Thematic map of overarching themes related to how parenting a child with autism affects Family Quality of Life (FQOL).

that makes it more difficult, him not being able to explain what he wants differently.”

Child communication deficits also affect parents emotionally. For example, one mother said:

My child is nonverbal, and he is four and a half and it seems like he likes me... but I am not sure if he loves me. I mean, in five years I have never been called ‘mom’. He shows some affection, but it’s something that I am the primary caregiver and he just enjoys my company, or he really likes me, sometimes I am not sure, and that’s challenging, that’s tough to deal with.

*Toilet Training* was another sub-theme related to child challenging behaviour.

Many children with autism have comorbid intellectual disabilities, including weaknesses in adaptive functioning (APA, 2013). Therefore, some children are delayed in acquiring skills such as toilet training. Frustrations and challenges associated with toilet training were expressed by parents, illustrated by one mother who said:

At the age of four and a half, [my son with autism] is not toilet trained yet. So, when we go out in public places we have to kind of be conscious that we need to be near a bathroom, and then that in itself poses a challenge, because he’s a little bit sensitive when it comes to using bathrooms with automatic dryers, that alarms him. So, if we go to somewhere like Tim Horton’s where they have automatic dryers, it’s just a no go, he just won’t go. So, we kind of have to make sure that we’re never too far away from home, if he does have to go home.

Sensory seeking behaviour or aversions were added to the diagnostic criteria for Autism Spectrum Disorder in the latest revision to the Diagnostic and Statistical Manual (DSM-5; American Psychological Association, 2013). Child challenging behaviours

related to *Sensory* issues were identified by parents. Some examples were aversions to water, difficulties getting haircuts, and “stimming” on furniture. One parent explained:

One of the brands of milkshake that we use changed their label in the last couple of months and [my son with autism] stopped drinking it because the label changed from a white teddy bear to like a tan teddy bear. Same content, even when we took it and poured it into a cup, wouldn't have it. What we have to do is go into the recycling and fish out an old bottle and we've been using that for the past two months now.

Parents also described how they often feel that people do not understand that their children's behaviour is related to autism and not just attributable to bad parenting (*Autism is Not Misbehaviour*). For example, as one mother stated:

They don't understand the reason behind the behaviours is a medical reason, not because [my daughter with autism is] just misbehaving, it's more than that, so that's really frustrating when you've already explained the situation to people, but they are very insensitive towards her.

***Stress/Isolation.*** A second overlapping overarching theme that falls under negative effects on family quality of life was *Stress/Isolation*. Within this overarching theme, the themes were *Stress*, *Isolation*, *Can't Go Out*, and *Busy*. Parents explained different ways that raising children with autism introduces additional stress in their lives, such as becoming exhausted more easily, and feeling like they do not get a break. A quote that highlights the theme of *Stress* is:

It definitely adds stress, you know. It's really difficult, it makes raising a child more difficult and it's the main reason why I didn't have another... Just the time

and energy that it requires to raise a child with special needs is probably, it's just very demanding and exhausting. Yeah, I feel like you never get a break.

Parents also explained how worrying about their children's futures was an additional source of stress. This can be illustrated by one mother who said,

It's been a rough road, but it will continue that way, and I don't really know what the future holds. Maybe when she's an adult, I'm still going to have some responsibility. I hope not, but I'm hoping for the best.

More than half of the parents who were interviewed spontaneously identified challenges related to going out with a child with autism (*Can't Go Out*). For example, one mother explained:

It limits us in some of the things that we can do. Our son is a bolter, so, he likes to take off, so we kind of have to plan where we're going, or I might not take all three of [the children] by myself if I'm going to certain parks, because I cannot control all three of them if he goes in the opposite direction.

The additional stress and limitations related to going out can also lead parents to feel more isolated (*Isolation*). One mother said:

You lose a lot of friends when your kid gets diagnosed... People kind of pull away once you have a child with a diagnosis. And you know, at first, they're like 'oh yeah, it's okay, everything will be good' and then you'll notice they'll stop calling you and they'll find other friends.

Parents also explained ways that raising children with autism has made their families *Busy*. For example, one father explained that "there's always planning, which is actually not stressful, I don't mind the planning, but you probably have ten, twelve

meetings a year that you wouldn't have otherwise, right? So, it's time commitments."

Similarly, one mother said:

I basically was working all day, then I had to come home and be here for so many hours while he had his [Applied Behaviour Analysis therapy]. So, you know, it's kind of like there wasn't too much of a life outside of all of that.

***Our Lives are Different/Not Different.*** Three overarching themes were identified that represented mixed positive and negative effects that raising a child with autism has on families. The first overarching theme is *Our Lives are Different/Not Different*.

Although one parent explained that autism has made their lives "not negative, just a different way of raising a child," another parent reflected, "I don't know what it is like to raise a neurotypical child, so it's hard to compare."

***Impact on Siblings.*** Second, parents also explained ways that raising children with autism has an *Impact on Siblings* in the home who do not have autism. Parents identified concerns such as using different parenting styles, conflicts between siblings, and effects on sibling relationships. For example, one father said:

I have to kind of approach things in a different way with [my son with autism] than I was with [my daughter without autism]. That's sometimes a challenge because we don't discipline them in the same way and that sometimes creates conflict of course.

However, parents also reflected ways that their typically developing children have become more understanding and accepting of others' differences as a result of having a sibling with autism. One mother said that her daughter who does not have autism is "a bit more sensitive and tolerant to other kids and teachers at school have noticed that about

her. That she's much more open to other kids."

***Parent Reactions to Unsupportive Social Interactions.*** The third mixed overarching theme was *Parent Reactions to Unsupportive Social Interactions*. Parents said that they try not to let negative experiences affect them in a negative way, illustrated by one father who said, "No, they don't bother me. I look at it as an opportunity to educate [people who are unsupportive]." Some parents described how they usually do not say anything to people who are unsupportive to them. For example, when asked about how he responds to unsupportive social interactions, one father said:

I realize you can't say things to people, right? Without starting an argument, it's really unnecessary, plus if you want to set a good example for your children. So, you also don't want to put your kid in the spotlight like that, or put them in a negative light, so really, we ignore it, because that's the best thing to do.

Unsupportive social interactions do seem to have negative influences on parents. One mother described how challenging it was to receive unsupportive social interactions when her son was first diagnosed with autism. She said:

At the beginning it was really difficult. It would make us, my husband and I, feel pretty terrible about ourselves for sure. And that no matter what you're doing it just might feel like it's an uphill battle all the time, but it's not like that really anymore... At the beginning it was hard, like I would feel really, really bad about things people would say or even if they don't say anything, the looks that you would get.

***Parent Personal Growth.*** *Parent Personal Growth* was an overarching theme that represented positive within-family effects on family quality of life. Parents explained how

raising children with autism has made them “less judgmental, more understanding and empathic,” “patient and more calm,” and “more appreciative and we don’t take things for granted.” Parents also reflected positive qualities of their children and said that they enjoy doing things together. Being involved in the autism community also led a few parents to careers related to the field. One mother explained:

Because of his autism it kind of gave me a career direction, and also my sister. My sister started doing ABA therapy with children, so she currently does ABA with four children. And in our province, you hire your own ABA therapists and even though it’s a subsidized program, you still need a bookkeeper to do your payroll and stuff like that. It’s not done through the government, or the hospitals, or whatever. So, I do bookkeeping for them. So, because of his autism it’s kind of veered us in a different direction, in our own personal life, business life.

The second broad category of overarching themes represented the External Influences on family quality of life. Again, some themes were negative, some were positive, and some had mixed effects.

***Unsupportive Social Interactions.*** *Unsupportive Social Interactions* was one overarching theme that was predominantly negative. Parents described experiences when people were *Dismissive*, and seemed to downplay the challenges that their families face. This was illustrated by one father who said:

The problem is that friends haven’t really moved along at the same pace as we have. A lot of our friends don’t have kids and when they do see [our son with autism] he’s behaved well enough to them to assume we’re over-exaggerating when we talk about downs and when we talk of sensory overloads.

Parents also described experiences when they felt like others were *Judging* them.

For example, one father explained:

If our son is having a bit of a crisis for whatever reason, or not listening, or running away or things like that, the autism obviously doesn't really have massive, it's not something you can just say, 'oh look' and say he's autistic, it doesn't really have any physical characteristics, like a broken limb, or a missing limb or something like that, or blindness. So, the negative thing would potentially be the judgment on others, that you know, we're being too, we're being overprotective, or we're not using the right strategies for our child, or things like that.

Parents described experiences that reflect a *Lack of Autism Awareness* in others.

One mother explained:

People don't understand actually what [autism] means, right? So, a lot of people, their experience with somebody with autism is they think about the movie Rain Man, and they think that that's what all autistic people are like.

Sometimes people are well-intentioned, but their lack of understanding about autism leads to unsupportive responses. For example, one father said:

With people in public, if I've had enough with someone then I'll tell them she has autism, she doesn't communicate. Especially if someone else, even if it's in a positive way, if someone is trying to talk to the kids, they won't talk to them, I'll tell them that she's non-verbal.

Parents gave examples of *Unhelpful Comments* from others such as, "you have a lot of work on your hands," "he will grow out of it," "it could be worse, he could have



cancer,” “parents don’t watch their children enough,” and the use of the word “retarded.” One mother described how a relative frequently asks questions about her child’s progress, which feels unsupportive. She said:

[My relative asks] ‘Has he improved? Is he toilet trained? Is he eating more?’ kind of like he wants to see that progression steadily and with [my child with autism] it’s really slow.

***Financial Effects/Work.*** *Financial Effects/Work* was another overarching theme that was identified. Parents explained how many services are expensive if paid for out of pocket to avoid long waitlists. Participants who had higher incomes described how they are thankful that they could afford private services. For example, one father explained:

I think when he was put on the waiting list for [Intensive Behavioural Intervention] therapy, I paid for two years of private therapy which I think was about \$85,000 that I paid for those two years. So, there is a financial cost.

A couple of parents described how their work schedules were flexible to accommodate their children’s needs.

***Professional Supports.*** Many parents described the influence of *Professional Supports* on their family quality of life. Both positive and negative aspects were identified. Parents were generally pleased with the availability of supports from professionals, inclusion in schools, communication with professionals, Applied Behaviour Analysis (ABA) interventions, and activities designed specifically for children with autism. For example, one father explained:

Having different people and different, all the different therapies, like the ABA [Applied Behaviour Analysis] and the speech [language therapy] and the OT

[occupational therapy], being able to tackle the same problems from different angles or having different people tackling the same problems. And being able to help [my daughters with autism] generalize on their skills.

However, parents also identified several negative experiences with professionals, such as schools that did not provide appropriate supports, professionals that were not trained in working with children with autism, and long waitlists for access to services. Parents also identified concerns about co-ordination of services. Parents described the confusion from so many different services and difficulties in navigating the system. For example, one mother said:

We were just finding there was a waitlist for everything. He was on a waitlist for like three years for occupational therapy and was never getting any assistance, no therapy offered. The [educational assistants] and stuff that worked with him were untrained in understanding how to help him with autism and how to simplify things and you know break things down for him. I think they tried their best, they just weren't qualified or had the necessary skills to help him succeed. They did have an ART team, which is an Autism Resource Team that is through the [school] board and they came in and provided a great binder with all sorts of information and tools and recommendations for the school to do, but I find that type of support lacking, because you're throwing this type of stuff onto people who aren't really trained to do that activity and then the school didn't follow through with a lot of the recommendations, so it was very frustrating.

***Extended Family Support.*** A more positive overarching theme was *Extended Family Support*. Parents explained how their family members are supportive, have a

special relationship with their children with autism, and are available to talk. The children's grandparents were identified as being an important source of family support.

When talking about his child's grandparents, one father said:

I think that there's a very special relationship between grandparents and children. And I think that's a relationship that our son really treasures quite a bit. There's a relationship he has with us, with his sister, and then there's a separate one with his grandparents and he's very connected to them. So, on a superficial level it helps keep, it just helps us by taking over for a little bit... the biggest thing is just an extra pair of hands to help take care, implement the strategies that we're looking for, and also it helps with that emotional connection.

*Access to Appropriate Childcare.* An overlapping overarching theme was *Access to Appropriate Childcare*. Parents explained challenges in finding appropriate childcare, and how helpful it was to have someone watch their children, so the parents can go out or run errands. This overarching theme and the *Extended Family Support* overarching theme overlapped, because family members such as grandparents often provided childcare. The *Childcare* overarching theme also overlaps with the *Stress/Isolation* overarching theme because not having access to appropriate childcare prevents parents from going out and contributes to greater isolation. For example, one father said:

We have trouble getting support people in. In terms of like babysitters, because it is more challenging, so we can't just bring in some teenagers because we will break them. And we don't know a lot of people who have the capacity to look after them. Their grandparents aren't able to and so we don't have those supports.

*Location.* A third overlapping overarching theme was *Location*. Within this

theme, parents described how the location in which they live affected their families, both positively and negatively. Some parents explained that they have neighbours or community members who are familiar with their children and are very supportive. Other parents explained how they have considered moving to a different location to be eligible for different publicly funded supports for their children with autism. Some parents described how they live far away from extended family members who therefore can not provide as much support. For example, one father explained:

[My wife's] parents live 12 hours away, my parents live a couple hours away, but again they're not, they're not really able to help with the kids and they're busy with their own stuff. And we're quite new to [our current city], we had a reasonably good support system when we moved to [a different city] five years ago now and I've had a lot of trouble getting established in that social theme.

*Supportive Peers.* Last, *Supportive Peers* was another overarching theme, which included parents' friends and other parents of children with autism. Parents explained how their friends support them by doing things such as asking how they are doing, spending time doing fun things together, listening, and assisting with household tasks. For example, one custodial grandmother said, "Well, one of my friends will, she'll do my ironing, she loves to iron. So, she'll do my ironing, you know, something like that, or run and get some groceries or those kinds of things."

Participants also noted that *Support Groups* and connecting with *Other Parents of Children with Autism* are important sources of support. Many parents noted that it is helpful to interact with other parents because hearing their stories can provide hope and they can share resources. Parents described how other parents of children with autism

were the only ones who could truly understand their experiences. As one mother said:

Sometimes when you put something out there you'll get a fair bit of support. I do find that with autism moms a lot. It's like a club, we understand each other. We understand what's going on, whereas if somebody doesn't have an autistic child [sic], they really don't understand things.

**Online Social Support.** For Question 5, which asked parents about their use of online social support, four overarching themes were identified, including *Don't Post Online, Functions, Disadvantages, and Advantages* of online social support.

***Don't Post Online.*** Some parents described that they *Don't Post Online* or they restrict what they post online for several different reasons. Some of the reasons included lack of time, personal preference, and concerns about privacy. Some fathers also said that their wives use online social support, so they do not feel the need to do so. When asked about why she chose not to post about her daughter with autism online, one mother explained:

...Because I wouldn't want to share that with just anyone. So, I just go to my friends for that. Like my better friends, not just acquaintances or family. You know, not that I don't want my family to know, but I'm not close to some of my family, so I might have them on my Facebook because they're my family, but not necessarily because I want them to know about my daughter and what difficulties she's having or I'm having.

***Functions.*** Parents who did use online social support identified several *Functions* or ways that they use technology to access social support. One function was *Blogs/Stories* in which parents read narratives about others with similar experiences. For example, one

father explained that he enjoys reading blogs online by saying:

In some ways it can be something positive, it can be inspiring to read, so when someone has a difficult experience and has an outcome that is positive, it gives you encouragement to say that you're not alone... you get to see, what we didn't have 20 years ago, what we do have now, the ability to read people's experiences and it's out there if you want to.

*Information Gathering* about services, strategies, and general researching was also identified as a major function of technology. One father said, "A lot of research, reading articles, reading books, looking for information about how people deal with the challenges with autistic kids." Another mother explained that she finds a local center's online presence to be helpful. She said:

There's so many people who advertise on it, so I get a real broad base sense of what's going on, so I like that, to know there's options and that's been very positive, just the resources part and it's allowed me to try a lot of different things with Special Olympics, going to the [name] community centre, sometimes they have things, they'll have adapted play.

Parents described how the internet is a source of *Support*. Parents who post on their personal social media sites (e.g., Facebook) often receive positive responses from others, particularly when their children reach milestones. Social media was also identified as a tool to help spread autism awareness and acceptance. For example, one mother said:

I post stuff like 'yay [child's name] didn't have a meltdown when we cut his hair today,' you know and then people who know him are like 'way to go, way to go.'

And yeah, really proud of him. I have people that I've never met in my life and they follow us, and they just love seeing his progress.

Similarly, one father said:

And the odd time he'll say 'dada', but I have a video of that that I posted, and we had mad support for that, just small things like that that we like to post. It might seem small for a neurotypical child to say 'dada', but for a five-year-old saying it for the first time, it's a huge step... with Facebook it's all the likes and comments and you know my mom will phone me and say, 'oh my God, I can't believe I saw that.' That kind of support, and positivity.

Different methods of online communication (e.g., Facebook groups, texting) were also identified as being important for *Connecting with Other Parents of Children with Autism*. Several parents explained how other parents of children with autism are the most understanding of their situations and are helpful for providing suggestions. One parent stated, "It's good to feel like you are part of a community of people who are going through the exact same thing."

***Disadvantages.*** Parents described several *Disadvantages* related to online social support seeking. Some parents described *Negative Experiences* that they encountered online. For example, one father said:

It kind of irritates me when people, like somebody said, somebody was offering advice and they said, 'hey I don't know if you want my advice, but I can offer it to you.' And I was like, well if it doesn't really relate to autism, then no offense but, you know, keep it to yourself kind of thing.

Another disadvantage of online support is *Comparison*. Parents explained that with social media, it can be emotionally difficult when other children meet milestones that their children have not reached yet. For example, one mother explained:

That makes me feel bad sometimes, for example my son is not completely potty trained yet and then if I see something from someone whose kid is younger and they say ‘oh he did this and did that,’ I’m a jealous person, so that kind of makes me feel bad...when I see stuff like that, that to me kind of compares things in my head... it’s almost like people just kind of like put it in your face and they’re like ‘oh yeah, Johnny’s so great.’ And so that would be a negative thing I would say.

Concerns were raised about the credibility of online information, so many of the parents who were interviewed prefer obtaining information from professionals in person (*Bad Information*). For example, one father explained:

It’s a lot of information to take in and you have to take some of it with a grain of salt and really realize what’s actually fact-based and what’s opinion-based.

Because a lot of stuff that’s opinion-based is very skewed one way or the other.

Several parents described that they *Prefer In-Person* interactions over online interactions because they are more personal and because information from professionals that they know is more trustworthy. One father explained the reasons why he does not seek social support online by saying:

I just prefer meeting people, and speaking to them in person. We have enough of that, enough going on that it’s accessible to us and that’s just my preference... I feel like it’s easier to communicate. And again, when you post things online



they're there permanently and sometimes it's misconstrued or something like that... I'd rather keep private with those kinds of things.

*Advantages.* On a more positive note, parents identified several *Advantages* of using online social support, such as having time to reflect while writing, not being interrupted, and the opportunity to access other people with similar experiences. An advantage of online social support was that it is *Convenient* because it can be accessed from home quickly. One father illustrated this by saying:

It's certainly easier to get support online rather than in person when you have an autistic child [sic] who isn't necessarily comfortable with going out. Or when it's not particularly easy to find cover... whereas online, when the kids go to bed you can spend an hour or two before bed time you can go through reading and interacting, and the support. It's very much, the online, it's something you can do within the comfort of your own home and it's a little bit easier and a little bit more manageable.

Another advantage of online support that was identified by parents is that it can be more *Anonymous* than in-person interactions, so parents may feel less judged. For example, one mother said, "I feel like the online stuff is more anonymous, right, so just maybe things that you don't want to talk to about people that you know because you don't want them to judge you."

### **Exploratory Analyses**

Exploratory analyses were conducted in order to further investigate the relations between variables of interest in this study. More information was sought about unsupportive social interactions and online social support specifically due to the limited

previous research in this population. Many of the ideas for these analyses were drawn from responses from the interview participants (see section about Thematic Analysis of Responses to Interview Questions for details about qualitative findings). Best practices for mixed methods approaches to research involve integrating findings from both quantitative and qualitative methodologies (Johnson & Onwuegbuzie, 2004). The following results are exploratory and therefore type I error is likely to be inflated.

**Moderation of Unsupportive Social Interactions, Overall Coping, and Family Quality of Life.** An exploratory analysis was conducted to determine whether the relation between unsupportive social interactions and family quality of life was moderated by overall coping. More unsupportive social interactions were associated with lower family quality of life ratings. However, unsupportive social interactions were not a significant predictor of family quality of life once the other factors in the double ABCX model were included in the analysis (Hypothesis 2b and 3b). Some of the interview participants described experiencing unsupportive social interactions, but not being bothered by them. Therefore, it was suspected that parents' coping skills would influence the extent to which unsupportive social interactions impacted their family quality of life ratings.

The findings of this multiple regression analysis indicated that both unsupportive social interactions ( $p < .001$ ) and overall coping ( $p < .001$ ) were significant predictors of family quality of life. Further, a significant interaction between unsupportive social interactions and coping was found ( $p = .037$ ; see Table 18), indicating a moderation effect. These findings indicated that the relation between unsupportive social interactions and family quality of life changed depending on the parents' coping. Based on a visual inspection of the graph of the simple slopes (see Figure 5), it appeared that there was little

Table 18

*Moderation of Unsupportive Social Interactions and Coping in Predicting Family Quality of Life*

	Standardized Coefficients		Squared Semi-Partial Correlations
	$\beta$	$p$	
Unsupportive social interactions	-.26	< .001	.07
Coping	.53	< .001	.27
Unsupportive social interactions x Coping interaction	.12	.037	.01

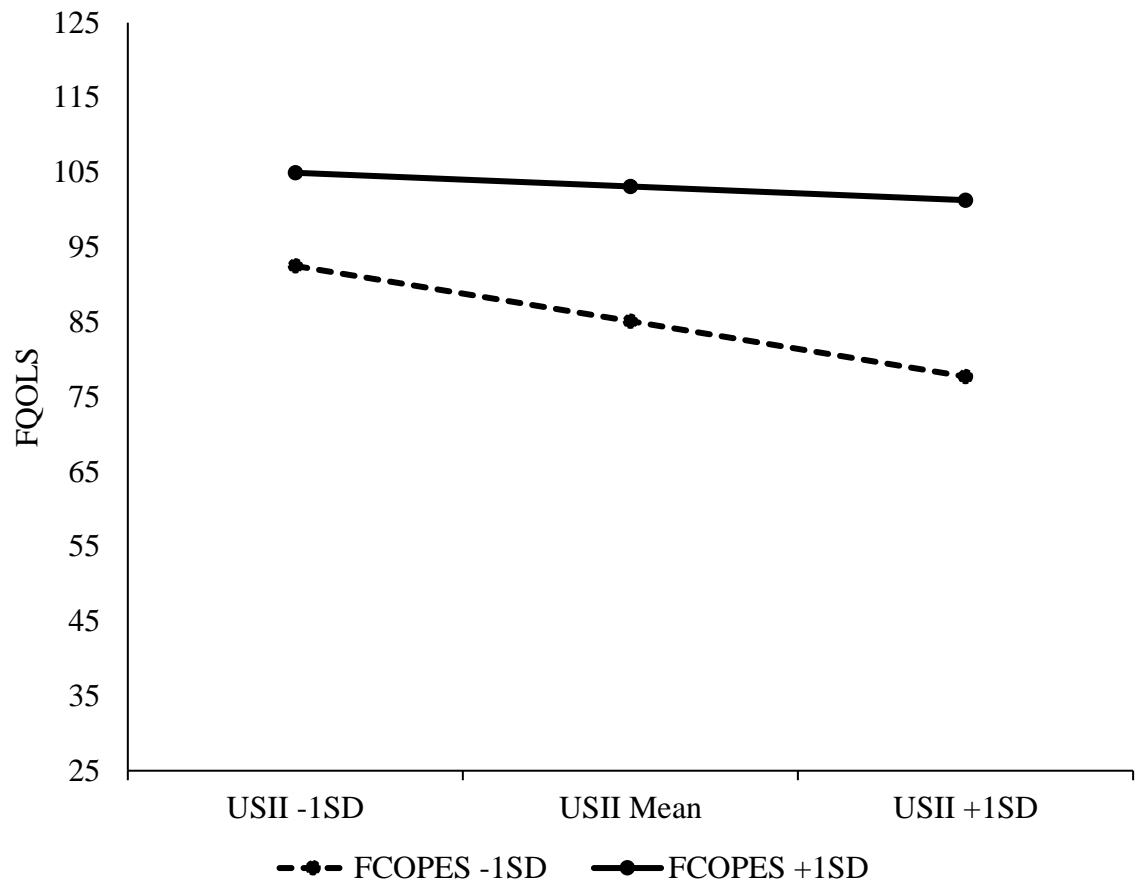


Figure 5. Moderation between Unsupportive Social Interactions (USII) and Overall Coping (F-COPES) in predicting Family Quality of life (FQOLS).

change in family quality of life based on the level of unsupportive social interactions for parents who reported higher levels of overall coping. However, for parents with relatively lower levels of overall coping, more unsupportive social interactions were associated with lower family quality of life.

It should be noted that many of the parents in this study reported relatively high levels of overall coping using the F-COPES (McCubbin et al., 1983). The mean overall score was 92.96 in this study, with a potential range of 30 to 150. Parents in the present study who had relatively lower levels of coping (one standard deviation below the mean for this sample) reported an average rating of 2.63 on a five-point Likert scale from 1 (*Strongly disagree*) to 5 (*Strongly agree*) using the F-COPES. These scores are similar to scores observed in other samples. McCubbin et al. (1983) reported a mean of 93.12 for male adults and 95.64 for female adults in their normative sample drawn from families with adolescents in residential treatment facilities. The parents of children with autism aged three to 16 years in the study by McStay et al. (2014) had an average rating of 97.82.

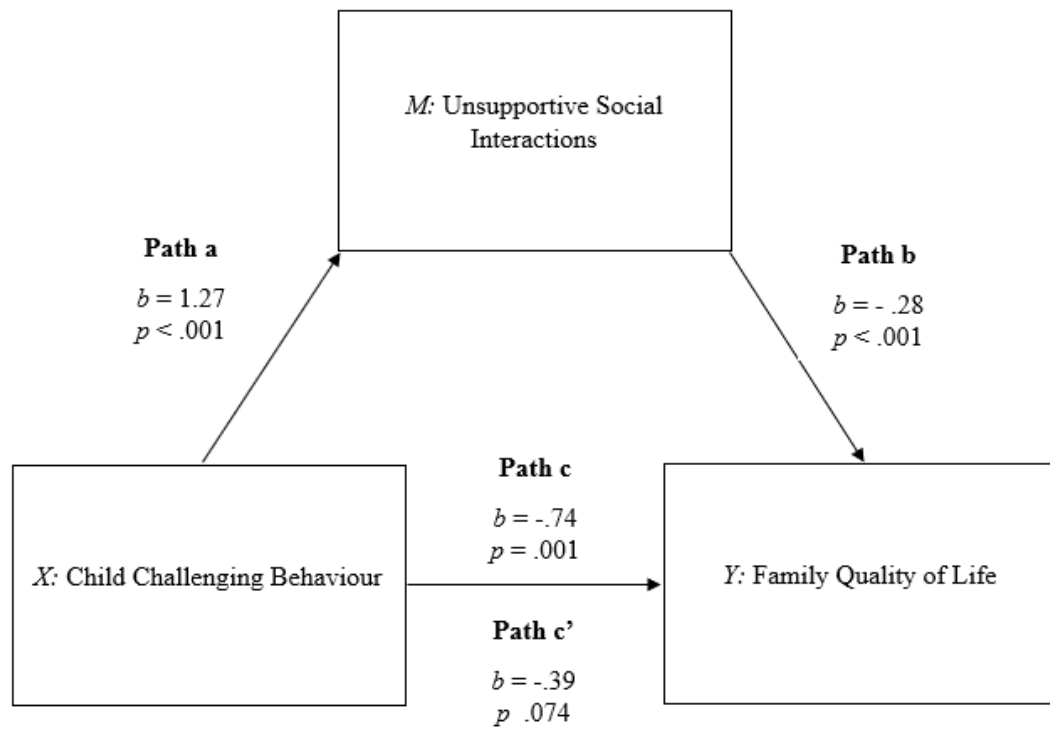
**Mediation of Unsupportive Social Interactions, Child Challenging Behaviour, and Family Quality of Life.** Another exploratory analysis was conducted to determine whether unsupportive social interactions had a mediating effect on the relation between child challenging behaviour and family quality of life. It was suspected that child challenging behaviour could lead to increased unsupportive social interactions, which would in turn lead to lower family quality of life. This idea was drawn from participant interview responses, previous qualitative research, parent blogs, and personal clinical experience. Parents often reported that when their children with autism demonstrate challenging behaviour in public, strangers make rude comments or make them feel

judged. Greater child challenging behaviour could potentially elicit unsupportive social interactions from others, which could negatively impact parents' family quality of life.

The process mediation macro for Statistical Package in Social Sciences (SPSS) was used (Hayes, 2013). Bootstrapping was used because it does not assume normality or need a large sample size (Preacher & Hayes, 2008). Unsupportive social interactions significantly mediated the relation between child challenging behaviour and family quality of life,  $b = -0.36$ , 95% CI [-0.61, -0.19] (see Figure 6). This indicated that more child challenging behaviour was associated with more unsupportive social interactions, which in turn resulted in lower family quality of life.

**Frequency of Technology Use.** The characteristics of online social support use by parents of children with autism was further explored due to the paucity of previous research. Some parents reported more frequent use of technology to access social support whereas other parents used technology less often for this purpose. In order to explore potential reasons why certain parents rely on technology to access social support more than others, differences between these groups were evaluated.

Of the entire sample of 194 parents, 93 parents (48%) reported using some method of technology for support at least daily. Two groups were created based on whether parents used technology for support daily or less frequently (i.e., every week, every month, or never). A multivariate t-test was used to compare daily technology users to less frequent technology users on the variables that were measured in the present study (see Table 19). Responses from mothers from couples were not included in these analyses. Overall, there were differences between daily and less frequent technology users on the variables in question  $F(11, 163) = 2.17$ ,  $p = .018$ . It was found that daily technology users



*Figure 6.* Model showing unsupportive social interactions mediated the relation between child challenging behaviour and family quality of life.

Table 19

*Comparison of Daily and Non-Daily Technology Users*

	Daily Users Mean (SD)	Non-Daily Users Mean (SD)	<i>F</i>	<i>p</i>
<b>Unsupportive social interactions</b>	<b>38.85 (20.37)</b>	<b>27.76 (18.95)</b>	<b>12.54</b>	<b>.001</b>
<b>Child challenging behaviour</b>	<b>12.02 (6.35)</b>	<b>9.98 (5.32)</b>	<b>7.64</b>	<b>.006</b>
Acceptance	35.08 (11.26)	38.22 (9.29)	3.54	.062
Social Support Adequacy	3.99 (1.29)	4.30 (1.18)	3.36	.069
Composite <sup>a</sup>				
Child disability severity	8.43 (3.48)	7.68 (3.56)	2.20	.140
Overall Coping	94.80 (13.59)	92.15 (14.27)	1.72	.191
Parent age	37.99 (6.16)	39.35 (7.18)	1.48	.226
Social Support Availability	5.15 (1.22)	5.41 (1.22)	1.33	.251
Composite <sup>a</sup>				
Family quality of life	92.93 (19.15)	94.40 (15.42)	0.29	.594
Child age	6.93 (2.40)	6.81 (2.27)	0.18	.669
Parental sense of competence	63.00 (13.26)	63.51 (12.49)	0.06	.805

<sup>a</sup> from family, friends, and professionals.



reported significantly higher levels of child challenging behaviour ( $p = .006$ ), and more unsupportive social interactions ( $p = .001$ ) in comparison to parents who used technology less frequently.

Chi square analyses were conducted to determine whether there was a different pattern of results for daily technology users compared to non-daily technology users in child gender, parent gender, marital status, family income, or parent education level. No significant associations were found at the  $p < .05$  level (see Table 20 for chi square results, and Table 21 through Table 25 for contingency tables).

### **Summary of Results**

**Summary of Quantitative Results.** Hypothesis 1 was partially supported. A hierarchical multiple regression indicated that unsupportive social interactions accounted for unique variance in family quality of life above and beyond social support (see Table 26 for summary of results). Therefore, unsupportive social interactions and social support were found to be distinct concepts.

Hypothesis 2a was supported, as a multiple regression analysis using the variables included in the double ABCX model accounted for 66% of the variance in family quality of life for *mothers*. The variables that were significant within this model included the adequacy of social support, acceptance, and the passive appraisal, reframing, and acquiring social support subscales of the coping measure. Hypothesis 2b was not supported because unsupportive social interactions were not a significant predictor within this model.

Similarly, Hypothesis 3a was supported, as a multiple regression analysis using the variables included in the double ABCX model accounted for 63% of the variance in

Table 20

*Chi Square Analyses Comparing Daily and Non-Daily Technology Users on Categorical**Variables*

	Chi Square	df	<i>p</i>
Parent gender	2.37	1	.123
Child gender	2.14	1	.144
Parent education level	5.20	3	.158
Household income	6.46	4	.167
Marital status	1.61	4	.658

Table 21

*Contingency Table for Chi Square Analysis Comparing Daily and Non-Daily Technology*

*Users on Child Gender*

	Daily Technology Users	Non-Daily Technology Users	Total
Male child			
Observed	70	88	158
Expected	73.39	84.61	
$\chi^2$	0.16	0.14	
Female child			
Observed	15	10	25
Expected	11.61	13.39	
$\chi^2$	0.99	0.86	
Total	85	98	183

Table 22

*Contingency Table for Chi Square Analysis Comparing Daily and Non-Daily Technology*

*Users on Parent Gender*

	Daily Technology Users	Non-Daily Technology Users	Total
Fathers			
Observed	38	55	93
Expected	43.20	49.80	
$\chi^2$	0.63	0.54	
Mothers			
Observed	47	43	90
Expected	41.80	48.20	
$\chi^2$	0.65	0.56	
Total	85	98	183

Table 23

*Contingency Table for Chi Square Analysis Comparing Daily and Non-Daily Technology Users on Marital Status*

	Daily Technology Users	Non-Daily Technology Users	Total
Single			
Observed	6	6	12
Expected	5.57	6.43	
$\chi^2$	0.03	0.03	
Married and Living with Partner			
Observed	62	78	140
Expected	65.03	74.97	
$\chi^2$	0.14	0.12	
Unmarried and Living with Partner			
Observed	9	9	18
Expected	8.36	9.64	
$\chi^2$	0.05	0.04	
Separated or Divorced			
Observed	8	5	13
Expected	6.04	6.96	
$\chi^2$	0.64	0.55	
Total	85	98	183

*Note:* One widowed participant was included in the single category

Table 24

*Contingency Table for Chi Square Analysis Comparing Daily and Non-Daily Technology**Users on Household Income*

	Daily Technology Users	Non-Daily Technology Users	Total
Under \$25,000			
Observed	7	7	14
Expected	6.50	7.50	
$\chi^2$	0.04	0.03	
\$25,000 - \$49,999			
Observed	14	16	30
Expected	13.93	16.07	
$\chi^2$	0.00	0.00	
\$50,000 - \$74,999			
Observed	26	16	42
Expected	19.51	22.49	
$\chi^2$	2.16	1.87	
\$75,000 and over			
Observed	32	52	84
Expected	39.02	44.98	
$\chi^2$	1.26	1.09	
Prefer not to answer			
Observed	6	7	13
Expected	6.04	6.96	
$\chi^2$	0.00	0.00	
Total	85	98	183

*Note:* Income was reported in Canadian dollars and converted where necessary

Table 25

*Contingency Table for Chi Square Analysis Comparing Daily and Non-Daily Technology*

*Users on Parent Education Level*

	Daily Technology Users	Non-Daily Technology Users	Total
High school or less			
Observed	8	6	14
Expected	6.54	7.46	
$\chi^2$	0.33	0.29	
Some college			
Observed	21	18	39
Expected	18.21	20.79	
$\chi^2$	0.43	0.37	
Completed college diploma or undergraduate degree			
Observed	33	54	87
Expected	40.63	46.37	
$\chi^2$	1.43	1.26	
Completed post- graduate degree			
Observed	23	19	42
Expected	19.62	22.38	
$\chi^2$	0.58	0.51	
Total	85	98	183

family quality of life for *fathers*. The variables that were significant within this model included the adequacy of social support, and the reframing subscale of the coping measure. Hypothesis 3b was not supported because unsupportive social interactions were not a significant predictor within this model.

Hypothesis 4 was not supported, as a multiple regression analysis was not significant when the frequency of use of different types of online social support, and the availability and adequacy of social support from online communities were used to predict family quality of life.

Exploratory analyses were also conducted that were developed based on the results of the Thematic Analysis, consistent with a mixed methods approach to research. A significant interaction between unsupportive social interactions and overall coping was found. For parents with high levels of overall coping, unsupportive social interactions had little effect on family quality of life. However, for parents with relatively lower levels of overall coping, more unsupportive social interactions were associated with lower family quality of life. Unsupportive social interactions significantly mediated the relation between child challenging behaviour and family quality of life. More child challenging behaviour was associated with more unsupportive social interactions, which was associated with lower family quality of life. Finally, parents who used technology daily to access support reported significantly higher levels of child challenging behaviour, and more unsupportive social interactions in comparison to parents who used technology less frequently.

**Summary of Thematic Analysis.** Based on the parents' telephone interview responses (n = 12 mothers, 12 fathers), several themes, sub-themes, and overarching



themes (shown in Italics) were identified by the research team. Table 16 includes a list of overarching themes, themes, and sub-themes.

The first interview question referred to the influence of differing family structures on parents of children with autism. The parents who were *Divorced* explained some of the challenges associated with raising children with autism alone and how it could result in less conflict after the divorce. Parents who were married explained that *Having a Partner is More Important Than Being Legally Married*. Having a partner to help raise their children was of more benefit than the legal status of marriage. *Teamwork in Marriage* was highlighted by married parents, many of whom reflected that they *Couldn't Do It Alone* if they did not have a spouse.

The second, third, and fourth interview questions pertained to the effects of raising children with autism, supports, and unsupportive social interactions. Some negative effects were identified by parents, including *Child Challenging Behaviour*. Similarly, *Unsupportive Social Interactions* were identified, including more distant and judgmental relations with others, a lack of autism awareness, and unhelpful comments. *Stress/Isolation* was another negative effect identified by parents as a result of raising children with autism.

Some mixed effects associated with raising children with autism were identified. Parents reflected about ways that their lives are *The Same or Different* as a result of having children with autism as parts of their families. Parents explained both positive and negative effects on *Siblings* who do not have autism.

Several positive effects of raising children with autism were identified by parents. Parents reflected about their own *Personal Growth*, and many parents also described positive *Child Qualities* in reference to their children with autism.

Influences on family quality of life that were external to the family were identified. Support from *Professionals* was described in both positive ways (e.g., inclusion in schools) and negative ways (e.g., lack of appropriately trained professionals). Parents described ways that *Financial Effects/Work* and *Location* affected their families. The importance of *Supportive Peers*, particularly other parents of children with autism was identified. *Family Support* played an important role in the family quality of life of the participants. *Childcare* was identified as being very helpful for families, and often provided by extended family members such as grandparents. Parents also described their *Reactions to Unsupportive Social Interactions*, such as not saying anything.

The fifth interview question pertained to parents' experiences using online social support. Some parents who were interviewed explained that they *Don't Post Online* for various reasons, such as personal preferences, lack of time, and preferring in-person interactions. Parents identified both *Disadvantages* of online social support (e.g., bad information) and *Advantages* (e.g., convenience). *Functions* of online social support were also identified, including *Support*, *Information Gathering*, *Connecting with Other Parents of Children with Autism*, and *Blogs/Stories*.

Table 26

*Summary of Quantitative Results by Hypothesis*

Hypothesis	Findings	Supported?
<b>1.</b> Unsupportive social interactions (USI) will predict family quality of life above and beyond general social support in both mothers and fathers of children with autism.	There was a significant correlation between USI and social support. A hierarchical regression found that USI predicted unique variance in family quality of life above and beyond the effects of social support.	Partially
<b>2a.</b> The double ABCX model overall (i.e., aA factor: child disability severity and child challenging behaviour, bB factor: social support, cC factor: parental sense of competence and acceptance, and BC factor: coping skills) will predict family quality of life for <i>mothers</i> of children with autism.	The double ABCX model significantly predicted family quality of life for mothers. The predictors that were statistically significant within the model included adequacy of social support, acceptance, and the passive appraisal, reframing, and acquiring social support coping subscales.	Yes
<b>2b.</b> Unsupportive social interactions will predict family quality of life in addition to the factors included in the double ABCX model for <i>mothers</i> of children with autism.	Unsupportive social interactions were not a significant predictor within the double ABCX model.	No
<b>3a.</b> The double ABCX model overall (i.e., aA factor: child disability severity and child challenging behaviour, bB factor: social support, cC factor: parental sense of competence and acceptance, and BC factor: coping skills) will predict family quality of life for <i>fathers</i> of children with autism.	The double ABCX model significantly predicted family quality of life for fathers. The predictors that were statistically significant within the model included adequacy of social support, and the reframing subscale of the coping measure.	Yes

Hypothesis	Findings	Supported?
<b>3b.</b> Unsupportive social interactions will predict family quality of life in addition to the factors included in the double ABCX model for <i>fathers</i> of children with autism.	Unsupportive social interactions were not a significant predictor within the double ABCX model.	No
<b>4.</b> It is expected that greater frequency of use of online social support, greater availability of online social support, and greater perceived adequacy of online social support will predict higher family quality of life for both mothers and fathers of children with autism.	The overall model was not significant and online social support was not associated with family quality of life.	No

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### **Exploratory Analyses**

The relation between unsupportive social interactions and family quality of life was moderated by coping.

Unsupportive social interactions mediated the relation between child challenging behaviour and family quality of life.

Daily users of technology to access social support had more child challenging behaviour, and more unsupportive social interactions than parents who used technology less frequently.

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## **Discussion**

The purpose of this study was to evaluate how the factors in the double ABCX model could explain family quality of life in a sample of parents of children with autism aged four to 11 years. The impact of unsupportive social interactions and of online social support were also explored in relation to family quality of life. Both quantitative analyses of parents' online survey responses and thematic analysis of phone interviews were used in this study.

The development of the purpose for this study was based on the double ABCX model (McCubbin & Patterson, 1983), results from a previous qualitative study (Jones & Gragg, 2016), and the currently available literature on family quality of life, unsupportive social interactions, and online social support. The results of the present study are mostly supportive of the double ABCX model, and generally consistent with previous research findings, as discussed in more detail below.

### **Double ABCX Model**

One of the main findings of the present study was that the double ABCX model can explain family quality of life for parents of children with autism. The double ABCX model explains the ways that stressors (aA factor), family resources (bB factor), perceptions of the situation (cC factor), and coping styles (BC factor) influence family adaptation (xX factor; McCubbin & Patterson, 1983). In the present study, the stressors were child challenging behaviour, child disability severity, and unsupportive social interactions, and family adaptation was conceptualized as family quality of life. Family resources were conceptualized as the adequacy and availability of social support, and family appraisal was conceptualized as parental sense of competence and acceptance.

The results of the present study were mostly consistent with the double ABCX model, as the variables specified by the double ABCX model were related in the predicted directions to family quality of life in this sample of parents of children with autism. These findings are consistent with the body of research demonstrating the utility of the double ABCX model for parents of children with developmental disabilities (e.g., Saloviita et al., 2003; Shahrier et al., 2016; Shin & Crittenden, 2003) and parents of children with autism (e.g., Manning et al., 2011; Pakenham et al., 2005; Paynter et al., 2013). However, parental sense of competence (family appraisal: cC factor) was not related to family quality of life when the other factors in the model were also considered. This finding indicates that there are some limitations in the utility of the double ABCX model for this sample.

In the present study, although child challenging behaviour was related to family quality of life on its own, it was not related to family quality of life once the other factors in the double ABCX model were considered. This finding is discrepant from McStay, Trembath, and Dissanayake (2014) who found that lower child challenging behaviour was associated with higher family quality of life in their analysis of the double ABCX model. In their study, child challenging behaviour was measured using a parent-report measure often used in clinical settings that measures child internalizing and externalizing behaviours (e.g., anxiety, conduct problems), whereas in the present study a measure of specific challenging behaviours often seen in children with autism was used. The measure used by McStay, Trembath, and Dissanayake (2014) could reflect underlying psychopathology and more widespread difficulties. The challenging behaviours measured by McStay, Trembath, and Dissanayake (2014) could be more extreme than the specific

behaviours included in the present study, therefore, they may have had a strong effect on parent outcomes.

In addition, unsupportive social interactions were not related to family quality of life within the double ABCX model. Therefore, the results of this study do not support its inclusion in the double ABCX model as a stressor (aA factor). It is likely that the other factors included in the model, such as family resources and coping, are more important for determining parent outcomes. Some parents who were interviewed were not always bothered by their experiences of unsupportive social interactions, and some chose to use those experiences as an opportunity to educate others. These findings are positive because it implies that stressors such as child challenging behaviour do not invariably lead to negative outcomes such as poorer family quality of life.

Child disability severity was not associated with family quality of life on its own or within the double ABCX model in the present study. This is discrepant from the findings of Pozo et al. (2014), which could be explained by differences in measurement of autism severity. In the study by Pozo et al. (2014), autism severity was rated by clinicians using a validated tool, whereas a more general parent-report measure of child disability severity was created for the present study. The measure used in the present study had not been previously validated and may therefore be a less accurate measurement tool than the one used by Pozo et al. (2014). Also, clinicians may rate autism severity differently than parents. The findings of the present study are consistent with previous research that has found that other factors such as parental coping and social support are more closely related to parent outcomes in comparison to the child's disability severity (e.g., Baker et al., 2005). This finding is positive for parents because intervention improves child

challenging behaviour more readily than autism symptom severity.

Social support was found to influence family quality of life in this study. The perceived adequacy of social support was more closely related to family quality of life than the availability of social support. This finding is consistent with previous research which suggests that satisfaction with support, rather than the amount of social support is important for adaptation to stress (Neuling & Winefield, 1988). It is well established in the literature that social support plays an influential role in alleviating stress and enhancing well-being for parents of children with autism (e.g., Ekas et al., 2010; Manning et al., 2011; Pottie et al., 2009). Parents' interview responses also highlighted the importance of diverse types of supports for their family quality of life. As one father stated:

I don't think we'd be as happy and stable and on top of things if we didn't have the supports that we got. So, we've done speech therapy, occupational therapy, and the school program that I mentioned. My younger daughter is doing ABA therapy five hours a week right now. And all that sort of adds up, respite care, having that coverage as well, all of it adds up to making it easier for us to cope with everything.

The findings of the current study are also consistent with the buffering hypothesis, which suggests that social support helps to reduce the negative effects of stress (Cohen & Willis, 1985).

Family appraisal is an important factor for determining parent outcomes in the double ABCX model and in this study was operationalized as parental sense of competence and psychological acceptance. In the present study, parental sense of



competence was associated with family quality of life on its own, but not when the other factors in the double ABCX model were included. This finding is in contrast with the other studies which found that parental sense of competence is related to better outcomes such as higher family quality of life for parents of children with autism (McStay et al., 2015; Kuhn & Carter, 2006; Weiss et al., 2013). It is also discrepant from the theory underpinning the double ABCX model (McCubbin & Patterson, 1983) which suggests that family appraisal plays a key role in determining how a family adapts to stressors. It could be that the inclusion of other factors within the double ABCX model such as social supports and coping were more strongly related to family quality of life than parental sense of competence. Differences in specific measures may have also contributed to this discrepancy in findings. For example, Pozo et al. (2014) operationalized the cC factor: family appraisal as parental sense of coherence, whereas the present study used parental sense of competence. Sense of coherence is a more general concept that refers to an individual's feeling that life is meaningful and manageable (Pozo et al., 2014), whereas parental sense of competence is related specifically to a parent's confidence in their parenting skills.

Psychological acceptance was found to be related to family quality of life alone for the entire sample, and within the double ABCX model for mothers, but not fathers in the present study. Mothers who were more willing to accept their children's diagnoses and endure the negative emotions associated with the stress of raising children with autism reported higher family quality of life. This finding is consistent with past research which suggests that acceptance is related to mental health for parents of children with autism (Jones et al., 2014; Weiss et al., 2012). Acceptance has not been previously

studied within the context of the double ABCX model for parents of children with autism. The results of the present study do not fully support its inclusion as a cC factor (family appraisal) in this model, as was expected. Again, other factors in the double ABCX model such as social support and coping were likely more closely related to family quality of life than was psychological acceptance. The reframing subscale of the coping measure was a significant predictor of family quality of life within the double ABCX model, and may be accounting for differences in the parents' perceptions of the situation rather than parental sense of competence.

Overall coping was also strongly related to family quality of life in the present study. This result was as expected given the large body of research linking coping strategies to positive outcomes for parents of children with autism (e.g., Benson, 2014; Manning et al., 2011; Ruiz-Robledillo et al., 2014). Further, coping has been found to be a significant predictor of family quality of life for parents of children with autism in other studies using the double ABCX model (McStay, Trembath, & Dissanayake., 2014; Pozo et al., 2014). These findings provide additional support for the importance of positive coping strategies for parents to help reduce the effect of stressors and enhance their family quality of life. Parents who were interviewed also reported some growth in their use of positive coping strategies as the years passed and they became more experienced with raising children who were diagnosed with autism.

Within the double ABCX model, the adequacy of social support and reframing coping styles were associated with higher family quality of life ratings for both mothers and for fathers. The association between reframing coping strategies and family quality of life found in this study is consistent with previous literature that has found positive coping

styles to be beneficial for parents of children with autism (Benson, 2010; 2014; Hastings et al., 2005; Manning et al., 2011) and other disabilities (McStay et al., 2015; Minnes et al., 2015).

Mothers and fathers of children with autism in this sample reported some differences in coping strategies. More specifically, acquiring social support and less use of passive appraisal coping strategies were related to higher family quality of life for mothers, but not fathers, in this study. Differences between mothers and fathers of children with autism in their use of coping strategies have been found in previous research (e.g. Pozo et al., 2014). These findings suggest that different coping strategies may be beneficial for mothers compared to fathers of children with autism. More specifically, seeking social support was more important for mothers. Passive appraisal coping strategies were more detrimental to family quality of life for mothers than fathers in this study. This could be because mothers have more caregiving demands and are more emotionally affected by raising children with autism than fathers. Some fathers who were interviewed reported that they felt like their wives had more caregiving responsibilities and needed more emotional support. These results further underscore the need to include both mothers and fathers in research and to take parent gender into account.

Parents' interview responses in this study resulted in several themes that related to the within-family influences on raising children with autism as well as the external influences on the family (see Figure 4). Some of the themes map on to the factors in the double ABCX model, such as the influence of child challenging behaviour and the importance of social support from family, friends, professionals, and other parents of children with autism. Themes related to parents' coping strategies and perceptions of the

situation were not identified, possibly because the interview questions focused mostly on supports rather than individual coping strategies.

### **Family Quality of Life**

Family quality of life was chosen as the outcome variable within the double ABCX model in this study in order to take a positive approach to family adaptation for parents of children with autism. The parents in this sample reported a generally high level of satisfaction with their family quality of life. Parents' interview responses focused on their perceptions of factors that influenced their family quality of life.

The parents' interview responses highlighted several overarching themes relevant to family quality of life. Although some negative effects of raising children with autism were noted, such as feeling stressed, isolation, and coping with child challenging behaviour, the parents also identified positive changes in themselves and their families. Some positive changes were being more open-minded and accepting, and appreciating the little things in life. Supports from peers, extended family members, and professionals were seen as positively affecting their families. Practical considerations such as finances, employment, childcare, and location also played a role in family quality of life, as did unsupportive social interactions.

Some of the parents' interview responses from this study support the family quality of life theory posited by Zuna et al. (2009; themes from this study identified in italics). Parents identified the importance of *Professionals* and *Family Support*, which related to the performance concepts of supports, services, and practices in family quality of life theory (Zuna et al., 2009). Similarly, themes were identified that map onto individual-level concepts such as *Child Challenging Behaviour* and family unit concepts

such as *Parent Reactions to Unsupportive Responses* that influence parents' family quality of life.

Many of the themes identified in this study are similar to those identified in other qualitative studies including parents of children with autism (Ludlow et al., 2012; Myers et al., 2009; Nicholas et al., 2016). Stress and isolation are often identified by parents in these qualitative studies, which appears to be a common experience reported in quantitative studies as well (e.g., Biswas et al., 2015). Child challenging behaviour and financial/work-related strains were also identified as themes in many of these studies. Parents in these studies explained how their other children were affected in both negative and positive ways by having a sibling with autism (Myers et al., 2009).

### **Unsupportive Social Interactions**

The concept of unsupportive social interactions is relatively new in the literature and little research has explored this phenomenon as it relates to the experiences of parents of children with autism. One study by Pottie et al. (2009) found that unsupportive social interactions were associated with parent daily stress and mood ratings. Ingram, Betz, et al. (2001), who first described the concept and its subtypes in people experiencing AIDS-related losses, explained that unsupportive social interactions are distinct from social support and do not simply reflect a lack of social support. Although more social support was related to less unsupportive social interactions in this study, unsupportive social interactions contributed to lower family quality of life above and beyond the effects of social support. Therefore, unsupportive social interactions may be distinct from social support, but more research is needed to confirm this.

Unsupportive social interactions appear to be commonly experienced by parents

of children with autism. In the survey portion of the study, there was variability in the amount of unsupportive responses that parents reported. However, many parents who were interviewed indicated that they experience unsupportive responses on a regular basis. This could be because they were asked directly to give examples in the interview. Parents who were interviewed could easily understand and relate with the concept of unsupportive social interactions. It is possible that unsupportive social interactions are frequently experienced by parents, but do not necessarily have a negative impact on family quality of life for all.

In parents' interview responses, *Dismissive* and *Judging* were identified as themes, which map onto the minimizing and blaming subtypes of unsupportive social interactions identified by Ingram, Betz, et al. (2001). Parents who were interviewed gave several examples of unhelpful comments from others, some of which reflected forced optimism, saying things that were not welcome, and implying that the child's behaviour was caused by poor parenting rather than autism. For example, one parent said:

I mentioned to [a co-worker] that my son had autism and then of course she wanted me to describe it, and she said, 'oh no, he doesn't have autism, I know somebody that has autism, he's not like that at all.'

These subtypes, in addition to the bumbling subtype (saying or doing things that are awkward or unwelcome), are clearly distinct from a lack of social support because they include behaviours that are directed towards an individual or family by someone else. On the other hand, a lack of social support means that a family does not have the positive resources that they feel they need from others.

Another important distinction is that supportive responses and unsupportive social

interactions can be from the same person. For example, some interview participants spoke about how they have great support from extended family members for things like childcare, but that these family members also make comments that are judgmental or unwelcome. This distinction further indicates that supportive and unsupportive responses should both be considered by researchers and professionals because people may not be unilaterally supportive.

Some parents who were interviewed also explained how they felt like others withdrew from them as a result of their children's diagnoses of autism. This is an example of the distancing subtype of unsupportive social interactions. One father explained that, "we find people avoid us a little bit because the children are hard to control and difficult and very attention demanding." Although this subtype shares some similarities with a lack of social support, it is distinct because it is seen as a withdrawal of support that previously existed rather than limited supports from the outset. Therefore, the concept of unsupportive social interactions was found to be relevant to the experiences of parents of children with autism and may be useful for future studies.

In this study, more unsupportive social interactions on their own were associated with lower family quality of life ratings. However, unsupportive social interactions did not significantly contribute to family quality of life when the factors in the double ABCX model were included. It was expected that unsupportive social interactions would fit into the model as a stressor (aA factor), which was not fully supported. The other stressors (aA factors) that were included in the present study (child disability severity and child challenging behaviour) were also not related to family quality of life when the other factors in the double ABCX model were included. It is likely that the family resources

(bB factor), family appraisal (cC factor), and coping (BC factor) were more strongly related to family quality of life (xX factor) than the stressors (aA factor). Future research could take a more nuanced perspective by examining how the four subtypes of unsupportive social interactions are related to parent outcomes such as family quality of life. It is possible that certain subtypes affect parents differently from one another. For example, awkward responses (bumbling) may be less insulting compared to experiences of being judged. Examining the sources of unsupportive social interactions would also be helpful because they may be perceived of more negatively when received from closer friends and family members compared to strangers in public.

This interpretation of the results is further supported by the finding that the effect of unsupportive social interactions on family quality of life was moderated by coping. Parents with relatively higher levels of coping were the least affected by unsupportive social interactions. Some parents who were interviewed also stated that although they experience unsupportive social interactions, these experiences had little influence on their family quality of life because they have resources to cope with them. For example, one parent said, “I don’t think there’s really a change in our quality of life per se.... It didn’t make me feel very good, but we shrugged it off...we didn’t let it get to us.” These findings further underscore the importance of positive coping strategies for parents of children with autism because these strategies can help to buffer against the negative effects of stressors such as unsupportive social interactions.

The relation between child challenging behaviour and family quality of life was significantly mediated by unsupportive social interactions. Parents whose children had more challenging behaviour reported more unsupportive social interactions, which was



related to lower family quality of life. For example, children who demonstrate challenging behaviours such as tantrums in public often elicit negative reactions from others. As one parent said:

You know like when you're out in public, and maybe you're standing in line to check out or something like that and your kids are acting up, my daughter, the crying and the whining and her not being able to communicate with me. You know, you'll hear some comments... like someone will tell you 'you should be doing this.'

Experiences of unsupportive social interactions may be common for parents of children with autism partly because autism is an invisible disability. It is not apparent from simply looking at children whether or not they have autism. People expect parents to control their children's behaviour in public, and children's disruptive behaviour is often seen as a lack of parenting skills in the parent (Ryan, 2010). The combination of the invisible nature of autism with disruptive child behaviour contributes to judgment felt by parents when in public with their children (Ryan, 2010). This experience is consistent with reports from parents of children with autism who have participated in other qualitative studies (Ludlow et al., 2012; Nicholas et al., 2016; Safe et al., 2012).

The findings of this study also suggest that it may be important to consider the *source* of unsupportive social interactions, which was not measured in the survey component of the present study. Some parents who were interviewed described being unaffected by unsupportive responses from strangers in public. Some parents described feeling more upset when unsupportive responses came from family members or friends

who they expected to be more supportive. For example, when talking about his child's grandparents, one father said:

There's a very limited personal support where, you know, I would kind of expect that someone would want to come and see their grandson on a more regular basis or try and make a greater effort... in terms of the individuals that are closest to us, that's where our biggest challenges are, in terms of feeling supported.

Dismissive responses and unmet expectations for support may affect parents of children with autism. Future research could evaluate whether this phenomenon would fit within the concept of unsupportive social interactions and how it affects parents of children with autism. Comparing parents' expectations and the amount of social support and unsupportive social interactions across different sources (e.g., family, professionals, and strangers) may be one way to research this further.

### **Online Social Support**

This study explored the role of online social support in relation to family quality of life for parents of children with autism. The availability and perceived adequacy of online social support, and the frequency of technology-related social support were not associated with family quality of life in the present study. Online social support does not appear to fit within the double ABCX model. There is robust evidence that general social support is related to positive outcomes for parents of children with autism, but the role of online social support is unclear (Doty & Dworkin, 2014; Vanegas & Abdelrahim, 2016). Although some studies have found that online social support was associated with lower stress for mothers of children with autism (Garbe, 2008), others have found mixed results. For example, Davis (2013) found that online support was associated with lower stress and

depression in mothers of children with autism who used online support, but that there were no differences between users and non-users of online support in ratings of parenting stress or depression.

Parents' interview responses provided insight into their uses of online social support, and its associated advantages and disadvantages. Parents in this study reported using technology to gather information and to connect with others. They described how online social support is beneficial because it is convenient, relatively more anonymous, and some parents find it easier to connect with others online. It is important for some parents to share their children's progress, connect with family members who live far away, and to communicate with other parents who have similar experiences. One parent said, "It's just so easy to connect with people, like you post it and almost instantly you get support."

Some disadvantages of using technology to access support were comparison of children with autism with typically developing children, being uncertain of the credibility of information, and being exposed to negative comments. Many parents indicated a general preference for in-person support. As one parent stated:

I find that the emotional component, the need for connection, the need to feel like you're being heard to me isn't satisfying through social media. Because that's more what I need, is someone to just talk to and emotionally exchange views and things like that.

These responses emphasize the limitations of online social support and the need for in-person social support.

Parents in this study who reported daily use of technology to access information

and support also reported more unsupportive social interactions, and more child challenging behaviour than did less frequent technology users. Thus, more frequent use of technology-mediated social support may be related to more negative outcomes for parents.

However, the directionality of these findings is uncertain. It is unclear whether parents with more unsupportive social interactions, and more child challenging behaviour use technology more often to seek social support or information, or whether the more frequent use of technology contributes to these difficulties, or if there is merit to both of these explanations. It is likely that greater online support seeking occurs in response to difficulties experienced by parents. For example, one study found that parents of children with disabilities including autism who used online support groups had less support from other sources (Mickelson, 1997, as cited in Davis, 2013). Past research also suggests that obtaining information is a common function of technology use for parents of children with autism or other developmental disabilities (Garbe, 2008; Parette et al., 2010).

Parents whose children demonstrate more challenging behaviour may also turn to technology for support or for information. Some parents in this study described using technology to research parenting strategies to address challenging behaviour. On the other hand, parents who use technology more frequently may be devoting less attention to their children, which could lead to more challenging behaviour. A recent study by McDaniel and Radesky (2017) found that greater parental technology use can cause “technoference,” which refers to disruptions in parent-child interactions. In their study of parents of typically developing children, technoference was associated with greater child internalizing and externalizing behaviour. Parents may be less responsive to their

children's attempts to get their parents' attention when the parents are paying attention to a cellphone or other device, which could contribute to escalation of child challenging behaviour. One father who was interviewed explained how his own technology use affects his children. He said:

One thing that I noticed that I do is that I will sometimes go online to escape reality I suppose, I think we all do that to a degree, we all sometimes kind of, if life is getting stressful, I find a quiet corner and just sort of, some people will binge their ideas online or vent their frustrations and other people go there to kind of distract through a different means. That's sometimes, that I try and work on, I shouldn't have my phone on me when the kids are running around in circles acting crazy, because I know that I'll just find, use that as a filter to try and block them out. That's not a fantastic way of being a parent and sort of not be there.

Further research is needed to determine the directionality of the relation between child challenging behaviour and parental technology use and whether technofence may apply to parents of children with autism. Nevertheless, the American Academy of Pediatrics recommends that parents limit the amount of time that young children spend using technology and that parents act as role models for their children (Licata & Baker, 2017). Therefore, parents of children with autism should be encouraged to limit their own use of technology while spending time with their children.

Parents of children with autism in this study who used technology more frequently also reported more experiences of unsupportive social interactions. It is again unclear whether there is a causal relation, and if so, the directionality. One possibility is that parents who receive unsupportive social interactions in person may use technology to

access support for these experiences.

Technology use could also be contributing to greater incidence of unsupportive social interactions because it is likely that some unsupportive social interactions are experienced by parents online, as mentioned by some parents who were interviewed. Parents who use technology more frequently may be at risk for exposing themselves to “trolls” or negative comments that are posted online. Online trolling is a phenomenon in which people on the internet act disruptively, such as commenting about controversial issues, starting arguments, or intentionally upsetting others (Bharati et al., 2017; Buckels et al., 2014). Autism is a topic that has garnered significant attention in the media, and has related controversial topics such as the role of vaccines in causing autism (Smith, Ellenburg, Bell, & Rubin, 2008). Therefore, parents of children with autism who spend more time online are more likely to encounter trolls than those who are online less frequently.

The distinction between seeking emotional support and information gathering functions of technology use was not clearly made in the measures used in the present study, as was done in some previous research (Reinke & Solheim, 2014). Considering the intended functions of technology use may be useful for understanding how it affects parental well-being. For example, parents who have children with more challenging behaviour might be more likely to seek informational support online, whereas parents having difficulty coping with stressors may be more likely to seek emotional support online. Although online social support was not associated with family quality of life for parents of children with autism in this study, it is being used frequently by this population and it may serve other purposes.

### **Applied Implications**

The results of this study have a number of practical implications to inform interventions and clinical practice for professionals who work with children with autism and their families.

**The Double ABCX Model as an Intervention Framework.** Although the double ABCX model has been used mostly in research contexts, Pickard and Ingersoll (2017) described its utility in guiding intervention efforts for parents of children with autism. Instead of focusing solely on providing interventions for individual children with autism, a family-focused approach should be taken.

In the model by Pickard and Ingersoll (2017), direct interventions to reduce autism symptom severity and challenging behaviours in children with autism target the stressor (aA factor). Interventions including Applied Behaviour Analysis and Pivotal Response Therapy could improve the child's behaviour, and in turn improve the parent's family quality of life (e.g., Buckley et al., 2014; Wong et al., 2015). Video modeling techniques may also be useful; for example, Boudreau and D'Entremont (2010) demonstrated its utility in teaching pretend play to 4-year-olds with autism. Providing parent-mediated interventions to target child characteristics can also improve parenting self-efficacy and parenting stress (cC factor; Keen et al., 2010).

In order to enhance social support (bB factor), Pickard and Ingersoll (2017) recommend in-person and online support groups, and respite care. Mindfulness-based stress reduction groups were also recommended to foster improved coping skills (BC factor) for parents of children with autism (Pickard & Ingersoll, 2017). These findings are supportive of interventions to target the factors included in the double ABCX model

as described above.

**Coping and Acceptance for Parents.** Based on the findings of this study and the theoretical underpinnings of the double ABCX model, parents' coping skills, perceptions of the situation, and supports are important determinants of family adaptation (McCubbin & Patterson, 1983). Although stressors such as child disability severity, child challenging behaviour, and unsupportive social interactions may negatively affect parents, most parents in the present study were highly satisfied with their family quality of life. Many parents who were interviewed reported positive outcomes such as personal growth and positive qualities of their children that they appreciated. This is a positive message because parents cannot control whether their children have autism or not, but parents do have some control over how they react to the associated stressors.

Greater use of positive coping strategies such as reframing and acquiring social support were key factors for enhanced family quality of life for parents in this study. Use of coping strategies may differ between mothers and fathers. Seeking out additional supports may be more important for mothers' emotional well-being. Passive approaches such as waiting for the problem to solve itself may be especially harmful for mothers, who tend to have more caregiving responsibilities than fathers and report being more stressed (Dardas & Ahmad, 2014). A few fathers who were interviewed described that they felt like their wives had more active roles in caring for their children and therefore had a greater need for social support than they did themselves. Some fathers did not feel the need to seek online support because their wives were involved with it instead.

Parents' coping strategies should continue to be a target of intervention. Interventions such as a parent coping skills training program have been found to reduce



feelings of hopelessness and increase the use of social support for mothers of adolescents with autism (Erguner-Tekinalp & Akkok, 2004). Parents could be encouraged to use adaptive coping strategies such as viewing the situation in a positive light, actively seeking supports from others, reframing, and avoiding passive coping.

Parents who appear to be struggling more with their children's diagnoses may benefit from psychotherapy to enhance their mental health. For example, parents of children with autism who did not have access to their own individual treatment were seven times more likely to report severe family stress (Sim et al., 2018). Several different approaches to interventions to address mental health for parents of children with autism have been used in clinical practice and evaluated in research (Da Paz & Wallander, 2017). These approaches include Cognitive Behaviour Therapy, mindfulness-based approaches, relaxation therapy, biofeedback, Acceptance and Commitment Therapy, support groups, and psychoeducation interventions (e.g., Da Paz & Wallander, 2017; Hastings & Beck, 2004; Keen et al., 2010; Samadi et al., 2013). Most of these interventions resulted in improvements in stress, depression, life satisfaction, and parental sense of competence relative to control groups (Da Paz & Wallander, 2017).

Although the evidence that acceptance is related to family quality of life in parents of children with autism is mixed in this study, other researchers have support for including acceptance as a target of intervention. This concept is especially relevant for parents of children with autism because a child's diagnosis of autism is likely to persist across the lifespan (Woolfenden, Sarkozy, Ridley, & Williams, 2012). Interventions for parents of children with autism based on Acceptance and Commitment Therapy have been found to be beneficial in improving mental health and stress (e.g., Blackledge &

Hayes, 2006; Kowalkowski, 2012). It is currently an evidence-based practice for disorders such as depression and anxiety (Society of Clinical Psychology, 2016). Further clinical practice and intervention research is indicated to determine whether Acceptance and Commitment Therapy could become a widely accepted evidence-based treatment to support the well-being of parents of children with autism.

Professional services are important for the well-being of children with autism and their parents. However, parents' interview responses in this study highlighted some challenges associated with professional services. Zablotzky et al. (2015) found that 81% to 98% of children with autism were currently receiving at least one professional service, yet there was a high proportion of unmet needs reported by parents in their study.

Practical considerations should be made when designing interventions for families with children with autism, such as being busy with other appointments, difficulty finding appropriate childcare, and co-ordination of services. Some parents may become overwhelmed by too many interventions due to time and financial demands (Estes et al., 2014).

**Social Supports.** As with coping and acceptance, social support has been identified as a key factor that determines outcomes for parents raising children with autism both in past research and in the present study. The perceived adequacy of social support was more important than the availability of social support in the present study. Therefore, the amount of support needed will vary from parent to parent. Parents can be encouraged to seek out social supports and organizations can create opportunities for peer support.

**Childcare.** The importance of childcare was another theme that was identified in

the thematic analysis that was not thoroughly evaluated in the quantitative component of this study. Parents in the present study, and in past research, have described concerns about the competence of potential caregivers for managing their children's exceptional needs and behaviour (Sim et al., 2018). A lack of appropriate childcare could contribute to parental isolation because parents may not be able to engage in social events or have difficulty leaving the house without their children. For many parents who were interviewed, the children's grandparents took on roles as childcare providers. In some families, grandparents were not able to provide childcare due to their own limitations or to geographical distance. Families in these situations would benefit even more from professional respite supports.

Research has identified the importance of high quality childcare for children with developmental disabilities. For example, Houser, McCarthy, Lawer, and Mandell (2014) found that the availability and quality of childcare was a barrier for work-life balance for parents of children with autism. Some parents of children with autism miss time at work or stop working outside the home in order to care for their children (Brennan & Brannan, 2005; Houser et al., 2014; Vanegas & Abdelrahim, 2016). This can lead to financial burdens such as lost income, as well as social isolation of the parents (Sim et al., 2018). The challenges associated with leaving the house with children with autism and the resulting isolation has also been expressed by parent blogs (e.g., Gwynne, 2016). These findings further emphasize the necessity of affordable, quality childcare for families with children with autism.

***Other parents of children with autism.*** The importance of connecting with other parents of children with autism was also identified as a theme from the parent interviews

in this study. Parents who were interviewed described limitations of emotional support from friends, family, and professionals who do not have the same lived experiences. As one parent stated:

[Raising a child with autism] adds stress that only another parent that has a child with special needs would understand... So, it's like an invisible weight that you're carrying around. And if the person doesn't know you, then they don't really understand it, unless you're explaining it. And even when you do explain it, they don't understand it unless they are also living it.

Other research has indicated that the opportunity to meet other parents of children with autism is an important function of support groups (Clifford & Minnes, 2013b; Papageorgiou & Kalvya, 2010). Parents in qualitative studies have also expressed the helpfulness of meeting with other parents of children with autism (Paynter et al., 2017; Safe et al., 2012). For example, mothers of children with autism in a qualitative study by Nicholas et al. (2016) explained that you need to “live it to understand it” (p. 921).

It is important for professionals to recognize their limitations in understanding parents' experiences. Professional agencies can play a role in helping parents of children with autism to connect with one another. This could happen through opportunities such as parent support groups or social events.

Some parents described how, when their children were first diagnosed with autism, it was challenging to navigate the system for accessing supports. Perhaps parents of children with autism who are familiar with the process could act as mentors to parents whose children are newly diagnosed with autism. Professional agencies may play a role in making these arrangements, such as the “Parent to Parent Pilot Program” being offered by

the Geneva Centre for Autism (2017) or Parent to Parent USA (2018). Parent Advisors can foster improved communication between parents and professionals because they are more approachable.

***Online social support.*** Benefits and functions of online social support were identified by interview participants in this study, such as connecting with people including other parents of children with autism, receiving social support, finding information about services, and researching strategies to manage child challenging behaviour. However, parents who were interviewed and other researchers have raised concerns about the quality of information available online about autism (Ben-Sasson et al., 2016; Gibson et al., 2017; Hall et al., 2016). Online resources that are helpful and are based on empirically supported approaches such as Applied Behaviour Analysis are important. Professional agencies and researchers can play a role in curating information for parents or in educating them about strategies to find credible sources. For example, the Parent Advisor for this study explained how a professional told her key words to search online such as “peer-reviewed” or “evidence-based” to find legitimate sources of information. Professional agencies should also continue to use technology to their advantage to distribute information about services for families (e.g., the Summit Centre for Preschool Children with Autism, 2017)

Online social support is less beneficial than in-person social support to parents of children with autism. Online social support is not an effective replacement for in-person social support. However, online supports may be necessary for parents who are more isolated or who have smaller in-person social networks. It is also likely that there is some overlap between in-person and technology-related social support. Many people might be

in contact with people from their in-person networks using technology (Duggan et al., 2015). Some parents in this study said that they do find using technology for support to be helpful and so there may be some merits to its use aside from improving family quality of life. Further research could evaluate how different subtypes of online social support (e.g., gathering information about services, strengthening existing in-person connections) may benefit parents of children with autism.

Parents who used technology daily to access information and social support also reported experiencing more unsupportive social interactions. Although it is possible that parents seek online social support and information in response to unsupportive social interactions that occurred in-person, it is also possible that they could be receiving unsupportive responses from online communities or via other technology. The quantitative portion of this study did not consider the sources of unsupportive social interactions, but some parents' interview responses referred to negative experiences online. For example, one mother said, "sometimes the feeds go negative... something controversial is posted and then everybody kind of gets negative on top of each other, like, so it's not really directed at me, but, you know, it still makes you feel not positive."

Parents also described how using social media led them to compare their children with friends' children who do not have autism. Seeing other children reach milestones that their own children have not yet reached highlighted to parents the ways that their children are delayed. One mother explained, "you see other people's kids doing things and then it kind of makes you happy, but then it makes you sad because your kid's not doing it."

Research in the general population has made links between greater social media

use and lower self-esteem and lower self-evaluation. One potential explanation is because people make upward social comparisons by comparing their own state to others who appear to be doing better than them (Vogel, Rose, Roberts, & Eckles, 2014). However, comparison is likely to happen both online and in-person when parents have friends or family members with children that are similar ages to their children.

The results of this study suggest that frequent use of technology may be associated with negative effects for parents of children with autism, particularly if they have weaker coping skills. Some information found online about autism may not be in line with best practices (Ben-Sasson et al., 2016; Hall et al., 2016). Parental technology use may also contribute to child challenging behaviour through “technofence” (McDaniel, & Radesky, 2017). Therefore, professionals should be cautious about promoting the use of online social support for parents of children with autism.

Parents should be made aware of the potential harm from using technology to access social support. Being prepared for negative responses could make parents more resilient when they occur. For example, when one father was asked about negative experiences online, he said, “it’s there if you want to find it, but if you don’t want to go there then you can pretty much stay away from it.” This type of awareness could allow parents to avoid negative experiences online if they are likely to be negatively influenced by them.

***Professional supports.*** Parents in this study indicated that supportive professionals and access to appropriate interventions were important to them. It is clear that timely services that are accessible to parents regardless of income are helpful to children with autism and their families. Applied Behaviour Analysis was identified by

parents who were interviewed as being particularly helpful to their children. These results are consistent with previous research which has noted improvements in family quality of life when parents are engaged with professional supports such as financial support (Eskow et al., 2011), Pivotal Response Treatment (Buckley et al., 2014), and early intervention programs (Wang et al., 2006).

Child challenging behaviour was significantly related to family quality of life in this study and is an important target of intervention. Child challenging behaviour can contribute to greater parental stress, isolation, unsupportive social interactions and lower family quality of life (Ludlow et al., 2012; McStay, Trembath, & Dissanayake, 2014; Ryan, 2010). Goals such as reducing reactivity to sensory stimuli, improving child communication skills, and assisting with developmental tasks such as toilet training can help to improve parents' family quality of life and reduce barriers for accessing social supports.

Parents in the present study often perceived professionals to be unsupportive. During the interviews, parents described how some agencies or individuals were not understanding of their children's needs or their family situations. For example, one parent explained how she told a professional that she was happy that her son with autism wearing his glasses 80 percent of the time, which was an improvement. She went on to explain, "the doctor looks at me and says, 'well he should be wearing them 100 percent of the time'. And I said, 'well you do know that he has autism, right?' And he said, 'oh, that's just an excuse.'"

Parents also identified how some professionals appeared to have a lack of training in how to best work with children with autism and their families, particularly in school



settings. These professionals were perceived as being well-intentioned, but uninformed. All professionals who may have contact with children with autism, including medical professionals and educators, would benefit from education about autism. Considering the rising prevalence of autism in school-aged children, information about teaching students with autism should be included in the curriculum for educational professionals. Continued education workshops or other training opportunities may also be useful for professionals who are already working in the field. This is already being done in many places and there are numerous resources available such as books written for educators, webinars designed for professionals, and college level programs (e.g., the Autism & Behaviour Science program at St. Clair College).

Parents' interview responses also noted that the number of different services was confusing and often uncoordinated. One parent said, "I don't really use any of the other services because I find that there's so many of them out there, they just confuse the living daylights out of me...I find it's just too many, there's not enough coordination." It may be ideal to have all autism services centralized through one organization in a given city, however this may not be realistic. Instead, organizations should continue to communicate with one another to minimize the gaps and overlaps between services and clarify to parents what services are being offered by whom and how to access services. For example, it is helpful to have databases of autism-related services that are accessible to parents (e.g., Autism Junction through Autism Canada, 2017).

Other parents explained that it was difficult for them to find out what services were available when their children were first diagnosed. Clinicians who diagnose autism should connect parents with appropriate services and explain how to access them. For

example, professionals could develop a list of community organizations to distribute to parents after their children are given a diagnosis and follow up after they have had time to adjust to the diagnosis (e.g., M. Gragg, personal communication, July 13, 2017).

**Unsupportive Social Interactions.** In this study, unsupportive social interactions were relatively common, and had negative effects on family quality of life particularly for parents with weaker coping skills. Preparing parents for receiving unsupportive social interactions may help them generate coping strategies. Some parents' interview responses described how they choose to respond to unsupportive social interactions in a positive way to educate others. For example, one father related how he said, "this is what autism looks like" to a stranger who made a rude comment in public. He went on to explain:

If an experience like that happens, I've done it before, I just mention that our son has autism and it's something that, you know, he doesn't necessarily act the way others do, and that's generally been, there's always sort of regret on their part, just saying 'Aw, I'm sorry, I didn't realize that.' ... It makes them a little bit more aware that not all kids are exactly the same.

Other parents could be encouraged to take this perspective of using unsupportive social interactions as opportunities to spread autism awareness instead of taking them to heart as personal insults.

Numerous campaigns have worked towards increasing awareness and early identification of autism such as "Learn the signs. Act early." (Daniel, Prue, Taylor, Thomas, & Scales, 2009). This approach may be helpful to reduce the prevalence of unsupportive social interactions toward parents of children with autism. Many people may respond negatively simply because they do not have a good understanding of the

challenges associated with autism and wrongly assume that a child's misbehaviour is attributable to willful disobedience rather than autism-related deficits in self-regulation. Psychoeducation for extended family members about autism could be helpful. For example, Smith, Greenberg, and Mailick (2013) described multi-family group psychoeducation as an approach to intervention for families of individuals with autism who are transitioning to adulthood. Another example is "A Grandparent's Guide to Autism" which is available for free online (Autism Speaks, 2011).

At this point, it appears that many people are aware of what autism is. For example, a general population survey by Dillenburger, Jordan, McKerr, Devine, and Keenan (2013) found that 80% of those surveyed were aware of autism. However, knowledge of autism is not sufficient for reducing the prevalence of unsupportive social interactions by others. It may be time to move beyond autism awareness to a point of understanding, acceptance, and inclusion.

**Positive Outcomes for Parents.** Another practical implication from this study is for positive outcomes for parents of children with autism to be more widely disseminated. Many studies have focused on the negative effects that parents face due to raising children with autism such as stress and isolation (e.g., Padden & James, 2017). However, many other researchers have begun using a strengths-based approach to focus on positive outcomes for parents of children with autism such as well-being or family quality of life (Tint & Weiss, 2016).

Many parents of children with autism are quite resilient. Participants in this and other studies have reported a high level of satisfaction with their family quality of life (e.g., Bertelli et al., 2011; Brown et al., 2003; Rillotta et al., 2012). Parents who were

interviewed also reported that raising children with autism affected their families in positive ways, such as increased patience and understanding, appreciating the little things, not taking things for granted, and being more “open-minded, accepting, and flexible”. Parents spoke highly of their children with autism and their many positive traits, for example, one mother said, “[my son is] just awesome. He’s smart and he’s funny.”

### **Strengths of the Present Study**

The present study had several strengths. One strength is the large sample size relative to other studies of parents of children with autism, particularly for fathers (Paynter et al., 2016). It is also important to note that the majority of these fathers (80 of 91) were not recruited as couples, as has often been done in other studies (e.g., Pozo et al., 2014). Fathers of children with autism are typically under-represented in research and are more difficult to recruit than are mothers of children with autism (Braunstein et al., 2013). Concerted efforts to target recruitment of fathers of children with autism such as targeted posters and restricting eligibility criteria helped to ensure approximately equivalent sample sizes of fathers and mothers in this study.

The use of parent interviews in this study provided valuable information and gave a voice to parents of children with autism. Using a mixed methods approach gave further insight, depth, and richness to the results. In this study, information from the parent interviews was used to direct exploratory analyses, which may not have been done otherwise. Parents’ interview responses also helped with the interpretation of quantitative analyses and provided additional evidence to corroborate these findings. For example, reframing was a stronger predictor of family quality of life compared to stressors such as unsupportive social interactions. Some parents who were interviewed explained how

unsupportive social interactions did not bother them and they viewed them in a positive manner, such as an opportunity to educate others. The qualitative interviews were an important component of this study because the results revealed important aspects that were not addressed in the quantitative portion of the study, such as the importance of childcare and connecting with other parents of children with autism. This allowed for parent voices to be considered rather than just focusing on the researcher perspective. Qualitative methods also allowed for some exploration to be done of factors with insufficient information to study using quantitative methods. More specifically, in this study, the effects of family structure on family quality of life were considered in the qualitative portion of the study, but comparisons of parents based on marital status were not possible because the majority of participants in this sample were married.

The Parent Advisor for this study participated in the entire research process and assisted with several tasks. Her consultation helped to ensure that the study would be helpful, relevant, and accessible to other parents of children with autism. Her involvement with the thematic analysis and interpretation of results helped to enhance the applicability of the study's findings. She also helped to generate some of the applied implications of the results of this study.

Finally, although fraudsters attempted to participate in the study, several detection methods were employed to ensure that the participants who were included in the final analyses were likely to be genuine parents of children with autism. Validity check questions that were included throughout also ensured that parents who participated were paying attention and answering the questions accurately.

### **Limitations of the Present Study**

The limitations of the present study are summarized below.

**Sampling.** The recruitment methods for this study resulted in a sample that is likely not representative of the general population of parents of children with autism. Most recruitment took place online through autism-related organizations. Thus, the parents who saw the study advertisement were connected with services and had internet access. Those who chose to participate likely had more interest and belief in research, more time, and perhaps more supports. Parents of children with autism who are overwhelmed, have lower socioeconomic status, lower education, time constraints, or are from diverse populations may be less likely to participate in research (West et al., 2016; Wright, 2016). The sample obtained was biased in that it was predominantly parents who were Caucasian/white and had higher family income and education level relative to the general Canadian population. This study did not emphasize the role that culture may have played in the experiences of parents from diverse backgrounds, which is a limitation common in this body of literature (Hall et al., 2017). Parents of children with autism from different cultural backgrounds may have different experiences with family quality of life and the double ABCX model. For example, although seeking spiritual support was not a significant predictor of family quality of life in this study, parents of children with autism who were Black and Hispanic explained the importance of spiritual support in a qualitative study by Hall et al. (2017). People from some cultural groups may also be less accepting of children with disabilities such as autism, which can pose a barrier to accessing social support for families in those groups (Hall et al., 2017). In addition, families who have lower incomes may have fewer resources overall, which can make it difficult to access additional supports for their children.

Similarly, a much smaller percentage of single parents participated in this study compared to the Canadian population. Single parents of children with autism remain under-represented in the literature (West et al., 2016). Single parents may have more responsibilities and fewer resources for caring for their children with autism and therefore may have less time and interest in participating in research. In the future, more extensive recruitment efforts should be made to recruit more single parents. A similar approach to the one that was taken for recruiting fathers in the present study may be useful. The eligibility criteria and study advertisements could be modified to include only single parents and disseminated widely or within targeted groups.

In this study, there was a higher proportion of boys than girls who were the target child with autism. Although autism is more common in boys than in girls, there was a higher proportion of boys in the current study when compared to recent prevalence estimates. It is possible that parents of daughters with autism may have been less likely to meet screening criteria because autism can present differently for girls and be more difficult to identify using standardized measures (Christensen et al., 2016). For example, girls may present with fewer repetitive behaviours than boys, and have stronger imaginative play skills (Beggiato et al., 2016). Therefore, girls with autism are less likely to be diagnosed with autism, and are less likely to meet the screening criteria for the present study which used a standardized measure of autism symptoms. Some girls with autism may have been previously diagnosed with Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) from the previous edition of the Diagnostic and Statistical Manual (DSM-IV-TR, APA, 2000). Some parents of children with this diagnosis may not have realized that PDD-NOS is considered to be equivalent to Autism

Spectrum Disorder in the DSM-5 (APA, 2013) and opted not to participate in this study.

**Fraudsters.** Unfortunately, this study was the target of human fraudsters who completed the online survey. Although efforts were made to detect potential fraudsters and remove them from the final sample, it is possible that some fraudsters were not detected. This could influence the validity of the results. However, careful attention was paid to each participant's responses to help determine whether the participants whose data were analyzed were likely to be genuine parents of children with autism. Even when data collection is completed in-person or diagnostic reports are obtained, it is not always possible to know for certain that all participants meet the eligibility criteria. In-person data collection methods would have limited the potential sample size of this study due to the niche population being researched, whereas online data collection allows participants from broader geographical regions to participate. Online data collection also reduced practical barriers for parents of children with autism such as finding appropriate childcare.

**Limitations of Measures.** Some measures that were used in the present study had limitations. In particular, the Menu of Online Support Types (MOST; Jones, 2016; see Appendix F) and the child disability severity measure (Jones, 2016; see Appendix E) were created for this study and therefore have not been validated elsewhere. However, these measures did correlate in the expected direction with other variables included in this study, which provides some support for convergent validity. More specifically, the MOST was positively correlated with the online community subscale of the Multidimensional Stress Scale, and the child disability severity measure was positively correlated with child challenging behaviour. The MOST could be modified in future studies to include subscales for different functions of technology use, such as information gathering and



social support. It would also be interesting to measure whether or not parents use technology to contact people who they also know in-person. Another limitation is that the Unsupportive Social Interactions Inventory (USII; Ingram, Betz, et al., 2001) did not take into account the source of unsupportive social interactions because it is a relatively new concept, which could be an interesting avenue for future research. Unsupportive social interactions may be viewed as more hurtful when coming from a close friend or family member in comparison to strangers.

Interview participants also identified that they had difficulty answering some items from the Child Autism Spectrum Test (CAST, Baron-Cohen, 2002). More specifically, some of the items refer to verbal behaviours such as conversational skills which parents with non-verbal children had difficulty answering. Including response options for parents of non-verbal children to select, or to providing clarification about which answers to select in that situation would be beneficial.

In the present study, 26 individuals received scores below the clinical cut-off on the Childhood Autism Spectrum Test (CAST; Scott et al., 2002), a screening measure of autism symptoms. Although some of these individuals may have been fraudsters, five of the individuals were recruited in person or by phone through a local agency and were considered likely to be genuine parents whose children were diagnosed with autism. Some of the other ineligible individuals may have also been genuine parents of children with autism. These parents may have under-reported their children's symptoms or their children could have made gains due to early intervention. Not including individuals who reported subclinical scores for their children may have introduced some bias into sampling in the present study because parents of children with milder symptoms were not

allowed to complete the study. This could have impacted the results because it restricts the range of child disability severity that was represented. More specifically, children with higher functioning autism may place fewer additional demands on their parents compared to children with more severe forms of autism, therefore having a lesser impact on family quality of life (Pastor-Cerezuela et al., 2016). It is also possible that parents of children with higher functioning autism may experience more dismissive responses because others may not fully understand how autism affects their children or families.

Conversely, many fraudsters reported CAST scores that were above the clinical cut-off and completed the online survey. Of the 31 CAST items that are scored, 16 items are reverse-scored and are dispersed throughout the survey. Thus, by chance alone, random responding would result in a score of around 15, the clinical cut-off. However, this issue is not unique to the CAST measure as random responding can lead to scores above clinical cut-offs in other measures (e.g., the Social Communication Questionnaire, Kazak-Berument et al., 1999).

If the CAST cut-off was lowered to 14, six additional parents could have participated and if the cut-off was lowered to 13, seven more additional parents could have participated (13 parents total). Because many participants who may have been parents of children with autism did not meet the screening criteria, it is possible that the CAST measure is not sensitive enough, particularly for children who may be higher functioning or who have already received early intervention (Wong et al., 2015).

Lowering the clinical cut-off or using alternate methods such as asking parents to provide a diagnostic report for confirming eligibility criteria in future research may be warranted. In addition, it is problematic that completing the survey randomly could result in a score

above the cut-off, which makes this measure less helpful for deterring fraudsters from completing an online study. Measures that include more reverse-scored items could help to reduce this phenomenon.

The survey component included measures of social supports, and child challenging behaviour. However, the survey in the present study did not include questions on components of the family quality of life theory included by Zuna et al. (2009), such as policies and social services. Researchers interested in these broader concepts could evaluate these components of the family quality of life theory (Zuna et al., 2009).

**Limitations of Analyses.** Some limitations of the analyses should be considered as well. This study was not experimental, and therefore any observed relationships were correlational, and it is not possible to determine the directionality of an effect. For example, it is not clear whether parents use technology more frequently for support in response to child challenging behaviour or whether their technology use contributes to child challenging behaviour. Exploratory analyses were conducted which introduced the potential for inflated statistical error. There was a large number of predictors included in the multiple regression analysis relative to the sample, which means that there may not have been sufficient power to detect the effects that were present. However, this study had many statistically significant results despite being potentially under-powered.

Finally, biases inherent to interpreting qualitative data based on the researchers' own experiences likely influenced how the qualitative themes were identified and interpreted. Knowledge of the study's aims and previous research literature could have led to interpretations of the interviews in a manner that is consistent with the hypotheses. Personal and clinical experience working with parents of children with autism may have

also affected how parents' interview responses were understood and analyzed by members of the research team. Although Braun and Clarke (2013) considered the subjectivity of the researchers to be an advantage, others have cautioned that researchers' biases may undermine the value and validity of thematic analysis (Javadi & Zarea, 2016). These issues are not unique to this study but need to be considered when interpreting these results.

### **Implications for Future Research**

Future research can build upon the findings from this study in several ways. The present study used a convenience sample of parents of children with autism, which is likely not representative of the population. Many studies in the autism literature have a disproportionate number of participants who are White relative to other ethnic groups (West et al., 2016) and with higher socioeconomic status (e.g., Gardiner & Iarocci, 2015). This gap in the literature was not addressed in the current study and therefore efforts should be made to ensure a more diverse sample and to include under-represented groups in future research (e.g., families with lower socioeconomic status, single parents, ethnic minorities). Community-based approaches to recruitment and data collection, such as those used by autism genetics researcher Daniel Geschwind are one way to recruit more representative samples (Wright, 2017).

The high rate of human fraudsters encountered in this study was another methodological concern. Researchers using online recruitment and data collection methods need to be aware of this phenomenon to put preventative and reactive measures in place (see Teitcher et al., 2015).

The double ABCX model (McCubbin et al. 1983), was generally supported in this

study as a useful theory for understanding how parents adapt to the challenges associated with raising children with autism. The factors in this model can continue to be operationalized in different ways. For example, psychological acceptance was related to family quality of life for mothers in this study as representing family appraisal (cC factor). It is important to continue to consider positive outcomes for parents and to focus on resilience and strength, rather than negative outcomes alone. Parents have reported many positive experiences raising children with autism, so a more balanced approach is needed (Kayfitz et al., 2010; Potter, 2016). Future research evaluating the double ABCX model could use more advanced statistical methods such as path analysis and mediation analyses to determine specific pathways and how the factors may interact with one another (e.g., Weiss, MacMullin, & Lunsky, 2015). These methods will allow for a more sophisticated understanding of the relations between the factors included in the double ABCX model. In addition, only the total family quality of life score was considered in the analyses for this study. More work could be done to evaluate how the different subscales of family quality of life may be affected by the variables in the double ABCX model. For example, the emotional well-being subscale of family quality of life may be more closely related to variables such as parental coping and social support in comparison to other subscales such as physical/material well-being.

Considering the relation between unsupportive social interactions and family quality of life for parents of children with autism was a novel contribution from this study and represents a fruitful area for future research. Receiving unsupportive social interactions is a relatively common experience for parents of children with autism, which can negatively affect their well-being. As unsupportive social interactions are a relatively

new concept, more research is needed considering their role in relation to parents of children with autism, and effective ways for parents to cope with unsupportive social interactions. The source of unsupportive social interactions is important to consider in future research. Rude comments from strangers may be less hurtful to parents than feeling distant from family members. In addition, unsupportive social interactions are experienced by parents online (“trolling”). Future research could determine the nature of these interactions and how they affect parents, especially those who spend more time online.

More research is needed to explore the uses and effects of online social support for parents of children with autism. Researchers could examine why parents seek online social support, how they are accessing it, and most importantly how it affects their well-being or family quality of life. The current findings suggest that seeking social support online may not be helpful for parents of children with autism but may be associated with negative outcomes.

Further efforts need to be made to determine how best to define and measure online social support use. The Menu of Online Support Types (MOST; Jones, 2016; see Appendix F) is a measure that was created for this study, and could be used in other studies. Subscales of this measure could be designed about the types of technology used (e.g., social media vs. video calls) and the purposes for which each method is used. It is also not clear from this measure with whom the participants were interacting. People could use technology to connect with family members or friends that they know in person, or to meet other parents of children with autism who may be strangers. Technology serves both social and informational purposes for parents of children with

autism, which should be further explored. Technology is evolving rapidly, and it is important for researchers to keep up with these advances and to modify measures as needed.

Mixed methods approaches that include a qualitative component in addition to quantitative analyses are useful in determining directions for future research from the participants' perspectives. The parents' interview responses in a previous study (Jones & Gragg, 2016) spontaneously described experiences consistent with the concept of unsupportive social interactions which was a major focus of the main study. Further, in the present study, several themes were identified that had not been addressed in the quantitative portion of the study. For example, many parents emphasized the importance of connecting with other parents of children with autism, which could be studied further. Measures of social support, such as the Multidimensional Support Scale (MDSS; Winefield et al., 1992) could easily be adapted to measure the adequacy and availability of social support from other parents of children with developmental disabilities such as autism. For example, Nicholas et al. (2012) used the MDSS to measure peer support of fathers of children with brain tumors who participated in an online support group. Access to appropriate childcare was another theme that was identified by parents in their interview responses. The relation between quality childcare and family quality of life for parents of children with autism should be explored in future research. Some of the other suggestions for future research, such as better understanding the experiences of parents who are minorities, from diverse family structures, and considering the subtypes of unsupportive social interactions could be further explored using qualitative approaches.

Including a parent advisor in the research process helped to enhance the validity

and applicability of this study. Researchers need to remain aware of current trends and needs of parents of children with autism. Collaborating with a parent advisor and involvement in the autism community can help reach this goal and ensure that research questions and methodology are relevant to the population being studied.

### **Conclusion**

Although parenting a child with autism can be a challenge in many ways, many parents report having a satisfying family quality of life. The ways that parents respond to the challenges associated with raising children with autism such as accessing social supports, thinking about the situation more positively, and employing helpful coping strategies greatly affect their well-being. Researchers and clinicians should continue to emphasize the many positive outcomes and growth that come from raising children with autism. As one father said, “He is the most loving kid on the planet...it’s brought definite light to our life for sure.” Raising children with autism brings many challenges for parents, who will continue to require social supports and family-based interventions. Further research is needed to better understand parents’ experiences from a positive perspective to help them have highly satisfying family quality of life.



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### **Appendix A: List of Acronyms**

AAQ-II-A = Acceptance and Action Questionnaire- Autism  
ASD-BPC = Autism Spectrum Disorder- Behavior Problems for Children  
CAST = Childhood Autism Spectrum Test  
F-COPES = Family Crisis Oriented Personal Scales  
FQOL = Family Quality of Life  
FQOLS = Family Quality of Life Scale  
MDSS = Multidimensional Social Support Scale  
MOST = Menu of Online Support Types  
PSOC = Parental Sense of Competence Scale  
PSS = Parental Stress Scale  
USII = Unsupportive Social Interactions Inventory



## **Appendix B: Screening Questionnaire**

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Are you the parent of a child with autism? (Note: this could include biological parent, foster parent, adoptive parent, step-parent, or custodial grandparent)

- Yes
- No

Is your child with autism age 4 to 11 years?

- Yes
- No

**Appendix C: Demographic Questionnaire**

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**1. Your Gender:** \_\_\_\_\_**2. Your Age:** \_\_\_\_\_**3. Your Marital Status:**

- Single
- Married and living with partner
- Unmarried and living with partner
- Partner and not living together
- Separated or divorced
- Widowed
- Other \_\_\_\_\_

**4. Your Household Income:**

- Under \$25,000
- \$25,000 - \$49,999
- \$50,000 - \$74,999
- \$75,000 and over
- Prefer not to answer

**5. Your Education:**

- High school or less
- Some college
- Completed college diploma or undergraduate degree
- Completed post-graduate degree

**6. Your Employment Status:**

- Full-Time
- Part-Time
- Unemployed
- Retired
- Student

**7. Your Partner's Employment Status:**

- Not Applicable
- Full-Time
- Part-Time
- Unemployed
- Retired
- Student

8. Number of children in your immediate family: \_\_\_\_\_

9. Number of children in your immediate family with autism: \_\_\_\_\_

10. Age of your child(ren) with autism: \_\_\_\_\_

11. Birth year of your oldest child with autism: \_\_\_\_\_

12. Birth month of your oldest child with autism: \_\_\_\_\_

13. Gender of your child(ren) with autism:

- Male
- Female
- Other

14. What specific diagnosis was your child(ren) given?

- Autism or Autistic Disorder
- Pervasive Developmental Disorder Not Otherwise Specified
- Asperger's Disorder
- Other: \_\_\_\_\_

15. How old was your child(ren) with autism when first diagnosed? \_\_\_\_\_

16. Your relationship to your child with autism:

- Birth parent
- Step parent
- Adoptive parent
- Foster parent
- Custodial grandparent
- Other: \_\_\_\_\_

17. Your race/ethnicity:

- Aboriginal (Inuit, Métis, North American Indian)
- Arab/West Asian (e.g., Armenian, Egyptian, Iranian, Lebanese, Moroccan)
- Black (e.g., African, Haitian, Jamaican, Somali)
- Chinese
- Filipino
- Japanese
- Korean
- Latin American
- South Asian
- South East Asian
- White (Caucasian)
- Other: \_\_\_\_\_
- Mixed race

**18. Your child's race/ethnicity:**

- Aboriginal (Inuit, Métis, North American Indian)
- Arab/West Asian (e.g., Armenian, Egyptian, Iranian, Lebanese, Moroccan)
- Black (e.g., African, Haitian, Jamaican, Somali)
- Chinese
- Filipino
- Japanese
- Korean
- Latin American
- South Asian
- South East Asian
- White (Caucasian)
- Other: \_\_\_\_\_
- Mixed race

**19. What percentage of the time do you live with your child with autism?**

- 0%
- 10%
- 20%
- 30%
- 40%
- 50%
- 60%
- 70%
- 80%
- 90%
- 100%

**20. Your country:** \_\_\_\_\_**21. To your knowledge, has your partner completed this study?**

- Yes
- No

**22. How did you hear about this study?**

- Facebook (please specify): \_\_\_\_\_
- Word of mouth
- E-mail
- Physical poster
- In-person event
- Website (please specify): \_\_\_\_\_
- Other (please specify): \_\_\_\_\_

**Appendix D: Permissions to Use Measures**

Measure	Authors	Permission
Screening Questionnaire, Demographic Questionnaire, Child Disability Severity Measure, Menu of Online Support Types (MOST)	Jones, 2018	Created for this study
Childhood Autism Spectrum Test (CAST)	Scott, Baron-Cohen, Bolton, & Brayne, 2002	PsycTests indicates that it may be used and reproduced for research purposes
Family Quality of Life Scale (FQOLS)	Hoffman et al., 2006	E-mail from Dr. Summers July 31, 2014 with permission to use if referenced appropriately
Autism Spectrum Disorder-Behavior Problems Checklist	Matson, Gonzalez, & Rivet, 2008	PsycTests indicates that it may be used and reproduced for research purposes
Multidimensional Support Scale (MDSS)	Winefield et al., 1992	E-mail from Dr. Winefield July 30, 2015 with permission to use and modify to include online social support
Parental Sense of Competence Scale (PSOC)	Johnston & Mash, 1989	E-mail from Dr. Johnston July 30, 2015 with permission to use measure, which is in public domain
Acceptance and Action Questionnaire- Autism (AAQ-II-A)	Bond et al., 2011	Website indicates that additional permission is not needed if for research purposes
Family Crisis Oriented Personal Evaluation Scales (F-COPES)	McCubbin et al., 1991	E-mail from Dr. McCubbin July 31, 2015 with permission to use measure once purchased
Unsupportive Social Interactions Inventory (USII)	Ingram et al., 2001	E-mail from Dr. Ingram August 4, 2015 with permission to use and modify wording as “related to parenting your child with autism”

**Appendix E: Child Disability Severity Measure**

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How severe are your child's symptoms of autism?

- None
- Mild
- Moderate
- Severe

At what level are your child's social communication abilities (e.g., social interest, social skills)?

- At age level
- Mildly impaired
- Moderately impaired
- Severely impaired

At what level is your child's language functioning?

- At age level
- Mildly impaired
- Moderately impaired
- Severely impaired

At what level is your child's restricted and repetitive behaviour (e.g., stimming, rigidity)

- None
- Mild
- Moderate
- Severe

At what level is your child's cognitive or intellectual functioning?

- At age level
  - Mildly impaired
  - Moderately impaired
  - Severely impaired
- .

**Appendix F: Menu of Online Support Types (MOST)**

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How often do you use each of the following to get information or support for raising your child with autism (e.g., chatting with a friend, getting advice, looking up tips)?

	Never	Every Month	Every Week	Every Day
E-mail Lists/Listservs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-mailing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Facebook				
a. Groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Liking or following pages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Messenger/private messages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Personal posts (e.g., sharing pictures or status updates)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Instagram	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LinkedIn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online Blogs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online Community/Discussion Board	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Phone calls	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pinterest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Snapchat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Texting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tumblr	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Twitter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Video calls (e.g., Skype, Facetime)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Visiting other websites/google	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
YouTube	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix G: Recruitment Flyers

# Parents of children age 4-11 with Autism

**Share your opinions about family  
quality of life in an online survey**



You will receive a \$5 e-gift card to Amazon for participating.

Contact Jenna Jones, [jonesjb@uwindsor.ca](mailto:jonesjb@uwindsor.ca) for the study link or more information

Supervisor: Dr. Marcia Gragg, [mgragg@uwindsor.ca](mailto:mgragg@uwindsor.ca)

This study has been reviewed and received clearance from the Research Ethics Board at University of Windsor.



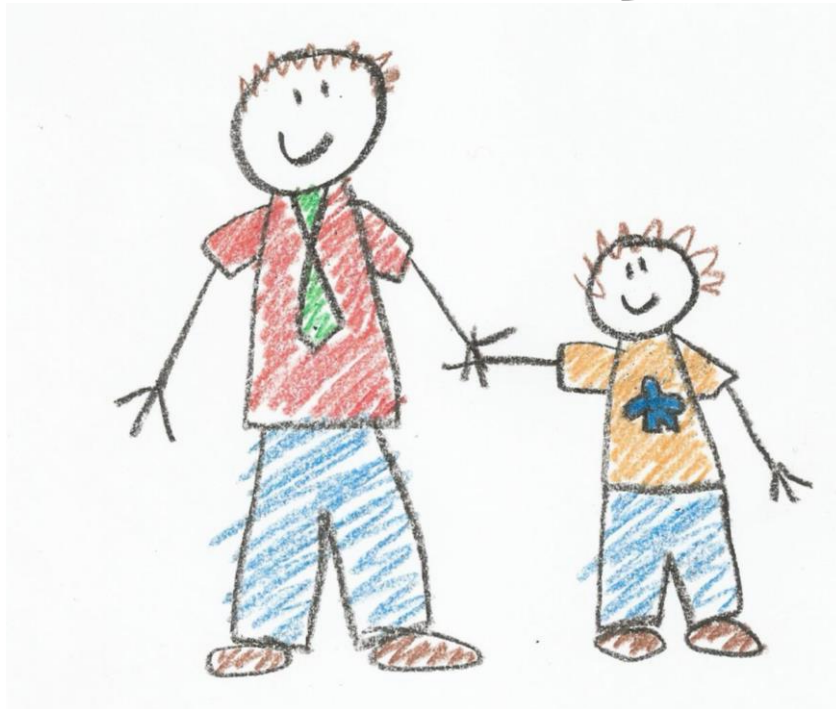
University  
of Windsor



Fathers Only Study Advertisement

# Fathers of children age 4-11 with Autism

## Share your opinions about family quality of life in an online survey



You will be offered a \$5 e-gift card to Amazon or Starbucks for participating.

Contact Jenna Jones, [jonesjb@uwindsor.ca](mailto:jonesjb@uwindsor.ca) for the study link or more information

Supervisor: Dr. Marcia Gragg, [mgragg@uwindsor.ca](mailto:mgragg@uwindsor.ca)

This study has been reviewed and received clearance from the Research Ethics Board at University of Windsor.



University  
of Windsor

## Appendix H: Consent Information



### CONSENT TO PARTICIPATE IN RESEARCH

**Title of Study:** Predictors of Family Quality of Life among Parents of Children with Autism

You are asked to participate in a research study conducted by and Jenna Jones, M.A. and Dr. Marcia Gragg, Ph.D. from the Department of Psychology at the University of Windsor. Results will form the basis of a doctoral dissertation.

If you have any questions or concerns about this research please feel free to contact Dr. Gragg at (e-mail and phone number), or Jenna Jones at (e-mail).

#### PURPOSE OF THE STUDY

To understand more about how

- family quality of life is affected by raising a child with autism, and
- factors such as social support and stress affect family quality of life.

#### ELIGIBILITY

To participate in this study, you must be a parent (biological, adoptive, foster, custodial grandparent or step-parent) of a child with autism aged 4 to 11 years. In order to confirm that your child meets criteria for autism, you will complete a survey about your child's behaviour. If your responses are below the cut-off, then you will not be eligible to complete the rest of the survey, or to receive the incentive.

#### PROCEDURES

If you volunteer to participate in this study, you will be asked to:

- Complete an online survey with questionnaires about your family, your child with autism, and yourself (30-45 minutes). The interview will be digitally audio recorded and then transcribed by trained Research Assistants
- If you would like, participate in an optional phone or Skype interview. This will take approximately 20-30 minutes, at a later date/time that would be mutually agreed upon.

- 20-30 participants will be selected by the primary researcher from those who have indicated interest in participating in the phone or Skype interview. Due to the limited number of participants needed for the interview, not all that indicate interest may be selected.

### **POTENTIAL RISKS AND DISCOMFORTS**

Some people might feel uncomfortable answering questions about their child and their family with a researcher. We do not expect any other risks from participating in this study. If you participate and feel uncomfortable, please contact Dr. Marcia Gragg (Clinical Director of the Summit Centre for Preschool Children with Autism and Psychologist).

### **POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY**

Some parents are happy that their experiences can be used to help other families through research. Family quality of life has not been studied in autism very much yet, so it is important to learn more about what kinds of things affect it.

### **PAYMENT FOR PARTICIPATION**

As a thank you, parents who participate will receive a \$5 e-gift card from Amazon.ca or Starbucks. It will be e-mailed to you within one week of completing the survey. Participants who do not complete at least 80% of the survey, or complete it in an extremely short amount of time (i.e., less than 5 minutes) will not receive the e-gift card. Please note that the e-gift card is provided in Canadian dollars, but may be redeemed in the United States.

Participants who complete the optional phone or Skype interview will be offered an additional \$5 e-gift card from Amazon.ca or Starbucks.

### **CONFIDENTIALITY**

We will keep your responses for this study confidential. Your completed questionnaires will be associated with your identifying information in order for you to receive the \$5 gift card for your participation and to allow us to select and contact you for a telephone or Skype interview. The data will only be available to the Researcher and trained Research Assistants who have signed Confidentiality Agreements.

### **PARTICIPATION AND WITHDRAWAL**

You may choose to be in this study or not. Your decision will not affect your child's current or future services at any organization. If you volunteer to be in this study, you may withdraw at any time before submitting your online survey. Once you have started the survey, if you no longer wish to participate, you may simply exit the browser. However, once you submit your survey, you will no longer be able to withdraw your information. Note that you will not be given the \$5 gift card unless you complete at least

80% of the questions on the survey. You may also not answer any of the questions by choosing 'prefer not to answer' and still remain a participant in the study.

If you agree to participate in a Skype/telephone interview you may change your mind at any time. If you are contacted for the phone or Skype interview and no longer wish to do so, you may simply tell the researcher, and your contact information will be destroyed after the completion of this study. At any point during the phone or Skype interview and once all responses have been given, you may still request to withdraw your participation. After the interview is completed, you will be asked once more if you are willing to allow your responses to be used as part of this research study or if you would like to withdraw your participation. After this point, you will no longer be able to withdraw your participation. You will not receive the \$5 gift card if you choose to withdraw from the phone or Skype interview.

The investigator may remove you from the study if needed.

### **FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS**

After the study is done, a summary of the results will be posted on the website: <http://www.uwindsor.ca/autism> .

You may also contact the primary investigator, Jenna Jones, or the research supervisor, Dr. Marcia Gragg, using the contact information provided on this letter.

### **SUBSEQUENT USE OF DATA**

These data may be used in subsequent studies, in publications and in presentations. Do you agree to be contacted by members of the Autism Research Group at the University of Windsor to ask if you would be interested in participating in future studies?

Yes

If yes, please enter your e-mail address: \_\_\_\_\_

No

### **RIGHTS OF RESEARCH PARTICIPANTS**

You may withdraw your consent at any time. You may stop participating without penalty. This research received ethics clearance through the University of Windsor Research Ethics Board. If you have questions regarding your rights as a research participant, contact:

Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: [ethics@uwindsor.ca](mailto:ethics@uwindsor.ca)

### **RESEARCH PARTICIPANT CONSENT**

*Check the box below if you agree.*

I understand the information provided for the study **Family Quality of Life for Parents of**

**Children with Autism** as described. My questions have been answered to my satisfaction, and I agree to participate in this study. Please print this page for your records if you would like a copy.

### Appendix I: Semi-Structured Interview Questions

Hi, may I speak to [NAME]? Hi [NAME], it's Jenna calling to do the interview for my research study about autism and family quality of life. It will take about 20 to 30 minutes. Is this still a good time for you?

[if yes, continue with interview]

[if no, ask when a better time would be to re-schedule the interview]

Are you in a location that is private enough for you to talk about your experiences?

[if yes, continue with interview]

[if no, ask the participant if there is another place that they could easily go to to complete the interview, or if they would like to reschedule]

Thank you for your interest in the interview portion of my study. The purpose of the interview is to gather more information using parents' own voices about how raising a child with autism has affected your family quality of life.

First, I am going to review some of the information that was in the consent form that I e-mailed you. At the end of the interview, I will offer you a five-dollar e-gift card for either Starbucks or Amazon. You don't have to answer any question that you are not comfortable answering. If you want to withdraw from this portion of the study, let me know and we will end the interview. In this case, you would not receive the incentive. The interviews will be audio recorded and then transcribed by trained Research Assistants. When they transcribe the interviews, they will remove any identifying information such as names of people or places. We will gather themes and then we may use some illustrative quotes in publications in the future. Do you have any questions? Do you agree to continue with the interview and for me to audio record it? OK, then I will turn on the audio recorder now.

[turn on recording device]

Today we will be talking about family quality of life, which is the extent to which your family is satisfied with different areas of your life together including emotional well-being, parenting, family interaction, physical/material well-being and disability-related support. I will ask you five main questions that have to do with your family, having a child with autism, and different types of supports, both positive and negative, including online interactions and how these relate to your family quality of life.

#### **Family**

To start, can you please tell me a bit about your family? How does being [married, a single parent, a foster parent, a custodial grandparent] affect your family quality of life?

#### **Autism**

- How does having a child with autism affect your family quality of life?
- [depending on if they include positive or negative responses, query:]
  - o What kinds of challenges have occurred from having a child with autism in your family?
  - o How has having a child with autism affected your family in positive ways?

### **Supports**

Now we are going to talk about different types of supports and how they affect your family quality of life. Supports could be formal or informal, and could be from family, friends, professionals, or other parents of children with autism.

- How has support from others affected your family quality of life?
- What kinds of things do people do that are helpful to your family and make you feel really supported?

### **Unsupportive Social Interactions**

Can you tell me about any experiences that you have had where someone made you feel particularly unsupported as a parent of a child with autism?

- How did this experience affect your family quality of life?
- How did you react to this experience?
- How do you cope with these experiences?

### **Online Supports**

What kinds of activities do you do online related to your child with autism? What kinds of activities do you do online related to your own well-being?

- Who do you typically interact with online during these activities?
- Why (or why not) do you do these activities online?
- How do your online interactions with others affect your family quality of life?
- How is online support different from the support that you get in person?
- Was there a particularly negative experience you have had online?
- Was there a particularly positive experience you have had online?

That is all of the questions that I have. Is there anything else you want to share?

Thank you for participating in my study, I really appreciate it. Before we end, I just wanted to give you one last chance to withdraw from the study and have your data removed. Is it OK for us to use your interview responses in this study, or would you like to withdraw?

[if they would like to withdraw] OK no problem. This means that you will not be eligible to receive the incentive. We will delete your audio recording and will not use your interview responses in this study. Thank you again for participating. Have a great day. Bye!

[If they agree to using their responses]

Would you like a five-dollar e-gift card to Amazon or Starbucks?

[if yes] OK, can I send the code to the same e-mail that you used for us to set up this interview? Which one would you like?

[if no] Thank you very much.

Thank you again for participating. Have a great day! Bye.

[turn off recording device]



**Vita Auctoris**

NAME: Jenna B. Jones (nee Williams)

PLACE OF BIRTH: Kitchener, ON

YEAR OF BIRTH: 1990

EDUCATION: Great Lakes Christian High School, Beamsville ON, 2008  
Brock University, B.A., St. Catharines, ON, 2012  
University of Windsor, M.A., Windsor, ON, 2014