THESIS

FAMILY QUALITY OF LIFE AND COPING IN FAMILIES OF CHILDREN WITH AN ASD

Submitted by

Ashlyn King

Department of Human Development and Family Studies

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Master's Committee:

Advisor: Susan Hepburn

Shelly Lane
Zeynep Biringen

ABSTRACT

FAMILY QUALITY OF LIFE AND COPING IN FAMILIES OF CHILDREN WITH AN ASD

Given the prevalence of Autism Spectrum Disorder (ASD) diagnoses, this study sought to explore the impact of an ASD on Family Quality of Life (FQOL). While stress in families who have children with an ASD has been well-documented, the factors that impact FQOL have not been researched as heavily. This study explored associations between ASD symptom severity, coping strategies, and FQOL. For this study, I utilized data from a sample of 36 parent-child dyads in which the child had received a diagnosis of an ASD. Caregivers reported on ASD symptom severity, family quality of life, and coping strategies they employed, among other measures as part of a baseline battery. This study found a significant negative association between ASD symptom severity and FQOL but did not find a significant correlation between the use of coping strategies (specifically passive appraisal, reframing, and acquiring social support) and FQOL. The results indicate that ASD symptom severity is related to lower family quality of life and indicates the need for intervention and support for families.

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CHAPTER 1 – INTRODUCTION TO FAMILY IMPACTS OF ASD

Since 1970, the rates of Autism Spectrum Disorder (ASD) diagnoses have drastically increased in the United States. In 2000, 1 in 150 children were diagnosed with an ASD. Currently, 1 in 54 American children are suspected of having an ASD, surveillance record review methods (Baio et al., 2018). ASD impacts individuals of all ethnicities and genders, although males are four times more likely to be diagnosed with an ASD than females (Schaafsma & Plaff, 2014). While the etiology of ASD is currently unknown, recent studies have found several genetic and environmental factors that contribute to the disorder (Shaafsma & Plaff, 2014).

ASD is a complex developmental disability resulting in "deficits in social-emotional reciprocity…and nonverbal communication used in social interaction..." as well as "restricted, repetitive patterns of behavior" (American Psychiatric Association, 2013, p. 50). Part of the restricted behaviors include a need for routine and sameness, and unexpected changes in routine can trigger behavioral problems or meltdowns. ASD may be present with or without intellectual disability, and 31% of individuals identified with an ASD also have a diagnosis of intellectual disability (Baio et al., 2018). The DSM-V diagnosis of ASD includes specifiers that provide information about the severity of the disorder as well as other conditions, such as language impairment, intellectual disability, and "known medical or genetic condition or environmental factors" (American Psychiatric Association, 2013, p. 53). Symptoms can range from mild to severe, and each individual with an ASD is unique, which makes diagnosing the disorder and evaluating efficacious treatments difficult (Kanne et al., 2013). Individuals with an ASD are also prone to sensory processing difficulties (i.e. an over- or under-sensitivity to sensory stimuli such as touch, taste, smell, or sound), gastrointestinal difficulties, and other comorbid disorders of physical or psychiatric nature (Bluth et al., 2013). Individuals with an ASD may exhibit problem behaviors, including self-harm, as a result of misunderstanding, overstimulation, poor emotional regulation, or struggles with communication (Shaafsma & Plaff, 2014). Although ASD shares some characteristics with other developmental and intellectual disabilities, the complexity and unpredictability of behaviors make the family impact of an ASD especially high.

Impacts of Parenting a Child with an ASD

The unique combination of behavioral, intellectual, and social deficits of ASD result in many stressors that impact a family's wellbeing (Karst & Van Hecke, 2012). This section will focus on the common sources of stress for parents and families, the outcomes associated with this stress, and other factors that influence the interplay of ASD symptoms and family outcomes.

Sources of Stress

Having a child with an ASD requires many financial, relational and emotional resources over time. The high amount of stress experienced by caregivers is thought to come from a variety of demands on the family, and a lack of resources to meet those demands (Krakovich et al., 2016; McStay, Trembath & Dissanayake, 2014). Financially, interventions for ASD can be expensive, and parents have less opportunity for job advancement due to time constraints (Karst & Van Hecke, 2012; Krakovich et al., 2016). Parenting a child with an ASD can be time-consuming, and other relationships, work responsibilities, and even the needs of other children may be less of a priority (Ludlow, Skelly & Rohleder, 2011). Emotionally, the daily challenges of caring for children with an ASD can be exhausting, as some children may act out with tantrums and behavioral challenges when routines are violated (Hall & Graff, 2011). When children have rigid routines, it is also difficult for parents to be spontaneous and attend to the needs of other family members (Ludlow, Skelly & Rohleder, 2011).

Lack of Social Reciprocity

One of the core symptoms of ASD is a “deficit in social-emotional reciprocity” (American Psychiatric Association, 2013, p. 50). Individuals with an ASD struggle to interact in social situations, and in general have behaviors that are seen as “socially unacceptable” by many cultures (Hall & Graff, 2012, p. 199). These behaviors can range from a lack of eye contact and poor social awareness to severe emotion regulation difficulties. Many times, children who lack social awareness are excluded from relationships with peers, which may cause parents emotional distress (Ludlow, Skelly & Rohleder, 2011). Parents may also feel judged by other parents for their child’s behavior or lack of social skills, which increases feelings of isolation (Ludlow, Skelly & Rohleder, 2011).

Emotional Impact

Additionally, the lack of social reciprocity impacts parents emotionally. Some parents express a sense of failure as a parent due to their child’s lack of reciprocity (Ludlow, Skelly & Rohleder, 2011). This sense of failure, as well as their child’s challenging behaviors, may cause parents to have lower parenting self-efficacy, which is the belief that they can parent their children effectively (Karst & Van Hecke, 2012). Self-efficacy appears to mediate stress for mothers in some studies (Hastings & Brown, 2002). Parents with lower parenting self-efficacy struggle with greater guilt about their parenting style, which can further erode family functioning (Karst & Van Hecke, 2012).

Parents in several studies discussed the grief of having a child with an ASD (Fernańdez-Alćantara et al., 2016; Ludlow, Skelly & Rohleder, 2011; O’Brien, 2007). Because their child is different from the “ideal child,” parents expressed feeling a sense of ambiguous loss (Fernańdez-Alćantara et al., 2016, p. 313; O’Brien, 2007). This grief may add to the pile-up of stressors that families face (Fernańdez-Alćantara et al., 2016; Ludlow, Skelly & Rohleder, 2011; O’Brien, 2007).

Behavioral Difficulties

Another source of stress that emerges in the literature is the severity of child behavior problems reported by parents. In more severe cases, individuals with an ASD can have many maladaptive behaviors, such as self-harm, violence, and destructive repetitive behaviors (Hall & Graff, 2012). These behaviors can cause considerable distress for the family, making parents fear for their child’s safety and often leading to fear concerning the need for more intensive intervention, which can be time-consuming, expensive, and disruptive to the family’s way of life (Hall & Graff, 2012; Mount & Dillon, 2014). From early childhood, some parents reported feeling “permanently in a state of crisis” (Mount & Dillon, 2014, pp. 70) because of the unexpected challenges that arise daily. For some children with an ASD, behavior challenges increase as they enter their teens, increasing stress on the parents and the need for interventions (Mount & Dillon, 2014). In multiple studies, child behavior problems predicted parent stress (Estes, Olson, Sullivan, Greenson, Winter, Dawson, & Munson, 2013; Ingersoll & Hambrick, 2011; Ludlow, Skelly, & Rohleder, 2012; Hall & Graff, 2012; Mount & Dillon, 2014) and more behavioral problems were associated with poorer parental mental health (Ingersoll & Hambrick, 2011; Ludlow, Skelly, & Rohleder, 2012; Hall & Graff, 2012; Mount & Dillon, 2014).

Broader Autism Phenotype (BAP)

Another factor present in the research that may impact parental stress is the presence of the Broader Autism Phenotype (BAP). While the current study does not measure this factor, it is a factor that could impact the family's coping and stress. The BAP includes certain personality characteristics that seem phenotypically related to an ASD, such as lack of social awareness and reciprocity, difficulties with executive functioning, and rigidity (Rubenstein & Chawla, 2018). Multiple studies have found support for the concept of the BAP that may be present in immediate and extended relatives of individuals with an ASD (Sasson et al., 2013; Rubenstein & Chawla, 2018; Ingersoll & Hambrick, 2011). Ingersoll and Hambrick (2011) hypothesize that family stress may also be caused by the interaction between the BAP characteristics and child ASD characteristics, and not just the child's diagnosis of an ASD. If parents have fewer interpersonal relationships they may not receive social support, which is an important mediator of parental stress in this population (Ingersoll & Hambrick, 2011; Karst & Van Hecke, 2012). Finally, having BAP characteristics increases vulnerability to maladaptive coping and mental illness (Ingersoll & Hambrick, 2011; Rubenstein & Chawla, 2018).

Family Outcomes

Research suggests that parents who have children with an ASD experience both acute and chronic stress throughout their lifetimes, which leads to greater vulnerability for mental health and physical health problems (Bluth et al., 2013; Brown, MacAdam–Crisp, Wang, & Iarocci, 2006; Gray, 2006; Karst & Van Hecke, 2012; McStay, Trembath, & Dissanayake, 2014; Vasilopoulou & Nisbet, 2016). Parents of children with an ASD tend to report higher stress than parents of children with other disorders or developmental disabilities, behavior problems and chronic illnesses (Estes et al., 2009; Ingersoll & Hambrick, 2011; Karst & Van Hecke, 2012; McStay, Trembath, & Dissanayake, 2014; Wainer, Hepburn, & Griffith, 2016). These high levels of stress can result in higher rates of anxiety and depression for parents of a child with an ASD. Some studies found that between 28% and 42% of mothers of children with an ASD had clinical levels of depression and that up to 30% of parents experience moderate to severe levels of anxiety (Karst & Van Hecke, 2012). Additionally, some studies have found that divorce rates are higher in couples who have children with an ASD than in the general population (Freedman et al., 2012; Hartley et al., 2010; Karst & Van Heck, 2012). One study found 23.5% of marriages or partnerships dissolved in the ASD sample, compared to 13.8% in the control group of couples who did not have a child with an ASD (Hartley et al., 2010). However, a literature review article of 59 articles found that divorce rates for this population are inconclusive (Saini et al., 2015).

While it seems important to alleviate the stress of parents to reduce suffering, it is also vitally important to understand the impact of parental stress on the family system. Stress not only impacts parents; its ripples extend to children with an ASD, their siblings, and extended family members (Karst & Van Hecke, 2012; McStay, Trembath, & Dissanayake, 2014; Vasilopoulou & Nisbet, 2015). Because an ASD is a lifelong disorder, it seems important to focus on ways to increase positive adaptation in families. While many studies focus on interventions that would decrease ASD symptoms in the child with an ASD, the wellbeing of the entire family is sometimes ignored (Karst & Van Hecke, 2012; McStay, Trembath, & Dissanayake, 2014; Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2016). One way to measure the wellbeing of families who have children with an ASD is by looking at Family Quality of Life (FQOL).

CHAPTER 2 – FAMILY QUALITY OF LIFE (FQOL)

Zuna et al. (2010) defines Family Quality of Life (FQOL) as “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact” (p. 242). Considering the challenges that many families who have children with disabilities experience, FQOL is a useful construct for understanding the health of the entire family system and what supports they may need to adapt positively. Stemming from well-established measures of individual quality of life, the concept of FQOL attempts to capture the overall well-being of families across several domains (Brown et al., 2006; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). FQOL is a construct with many dimensions and involves the subjective perceptions of individual family members as well as the family as a whole unit (Zuna et al., 2010). FQOL is also based on a systemic understanding of the family, meaning that the family is viewed as a dynamic system that is influenced bidirectionally by individual family members, environment, culture, and other factors, including public policy. Quality of life may look different for each family, based on their culture and the needs of the individuals in the family (Zuna et al., 2010). However, the concept of FQOL can be applied to families regardless of differences, because it is based on a subjective “sense of wellbeing” and the family’s satisfaction for how individual and family needs are met (Zuna et al., 2010, p. 242).

Most FQOL scales focus on measures of physical well-being, emotional well-being, social support, and family interaction dynamics. Several studies have used FQOL as an outcome to measure the effectiveness of interventions for children and families (Karst & Van Hecke, 2012; McStay et al., 2010; Pozo et al., 2013; Wainer, Hepburn, & Griffith, 2017; Zuna et al., 2010). In studies seeking to understand the needs of families who have children with an ASD, FQOL measures have been used to compare families of children with an ASD to families with typically developing children or children with other forms of developmental disability.

In multiple studies stress has been negatively associated with FQOL (Davis & Gavidia-Payne, 2009; Hsaio, 2018; Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2015). Compared to families with typically developing children, families who have children with an ASD have lower overall quality of life, with the lowest subdomain being physical health (Gardiner & Iarocci, 2014; Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2015). More child behavior problems, less social support, and lack of leisure time and respite care also contribute to lower FQOL (Davis & Gavidia-Payne, 2009; Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2015). Compared with families who had children with Down Syndrome, families with children with an ASD had lower FQOL, many scoring below the 50% satisfaction range on the overall quality of life (Brown et al., 2006). Discussing FQOL in the context of ASD is important because of the high stress that families who have children with an ASD experience, which has been associated with lower FQOL (Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2015; Zuna et al., 2010).

Table 1

Descriptions of Family Quality of Life Domains (according to FQOL Scale by Hoffman et al., 2006)

Domain/Subscale	Description
Family Interaction	The family's ability to support each other, enjoy time with each other, and handle difficulties together (Hoffman et al., 2006).
Parenting	The family's ability to help children learn and grow, including the adults ability to teach children and be involved in their lives (Hoffman et al., 2006).
Emotional Well-Being	The family's sense of emotional support and ability to manage stress (Hoffman et al., 2006).
Physical/Material Well-Being	The family's access to medical and dental care, transportation, and resources. This domain also includes sense of safety in environment (Hoffman et al., 2006).
Disability-Related Support	The family's perception that the individual with special needs has the support they need to succeed at school, home, work, and relationships (Hoffman et al., 2006).

Physical Dimensions of FQOL

In several studies, the FQOL domain most consistently affected by ASD was physical health (Gardiner & Iarocci, 2014; Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2015). Parents who reported more physical fatigue and stress had lower FQOL scores (Gardiner & Iarocci, 2014; Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2015). Although some parents cited rewards that come with caring for a child with an ASD, such as personal growth and increased spirituality, the physical strain of caregiving resulted in lower quality of life (Vasilopoulou & Nisbet, 2015). In these studies, physical strain often came from caring for a child's daily needs and challenging behaviors.

Financial Dimensions of FQOL

Financial wellbeing is another important dimension that affects FQOL, and families who have children with an ASD reported lower quality of life in this dimension (Davis & Gavidia-Payne, 2009; McStay, Trembath, & Dissanayake, 2014; Vasilopoulou & Nisbet, 2016). Vasilopoulou and Nisbet (2016) posit this could be due to the way ASD affects the financial health of a family because of the extensive, and expensive, interventions that may be needed, as well as the medical needs of the child and work missed because of caregiving. Compared to families raising typically developing children, families who have children with an ASD spent over three thousand dollars more annually on healthcare, and over eight thousand on school related costs (Lavelle et al., 2014). Families who have a child with an ASD are also more likely to only have one income (Karst & Van Hecke, 2012; Vasilopoulou & Nisbet, 2016). Families who had higher income had higher FQOL in some studies (Vasilopoulou & Nisbet, 2016), and parental employment was associated with higher FQOL (McStay, Trembath, & Dissanayake, 2014). This may be because families with more income have more access to services and interventions and more opportunities to seek out support because they have financial margin (Vasilopoulou & Nisbet, 2016). However, some families discussed fewer opportunities for career advancement because of the time they need for caregiving, and the need they feel to set aside personal goals to care for their child (Davis & Gavidia-Payne, 2009).

Social/Interpersonal Dimensions of FQOL

Across multiple studies, social support was a key factor for FQOL (Pozo, Sarriá, and Brioso, 2014; Twoy, Connoly & Novak, 2007; Vasilopoulou &Nisbet, 2014; Zeng et al., 2020). Pozo, Sarriá, and Brioso (2014) called social support protective for families of children with an ASD. Social support can come from a variety of sources including family, friends, support groups, online communities, and professional services (Zeng et al., 2020). Unfortunately, because of social stigma that is sometimes attached to ASD, a child's difficult behavior, and lack of support, families may tend to isolate from others and not receive the support they need (Karst & Van Hecke, 2012).

Sex Differences in FQOL

There also seem to be sex differences in quality of life for mothers and fathers. In several studies, mothers reported lower overall quality of life than fathers, especially in the physical dimensions of FQOL measures (McStay, Trembath, & Dissanayake, 2014; Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2016). This may be because mothers tend to be the primary caregivers. Mothers also had lower quality of life when the child had more severe disabilities, while fathers showed higher quality of life when the child was more severely affected by an ASD (McStay, Trembath, & Dissanayake, 2014; Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2016). This may be because mothers are more likely to be full-time caregivers if their child has a more severe ASD, requiring them to care for daily physical needs, such as eating and toileting, and behaviors that may be difficult, such as self-harm or aggression (Vasilopoulou & Nisbet, 2016). On the other hand, fathers had higher quality of life when their child had a more severe ASD, which may be because of the expectations that the father has about their child's behavior and future ability (Pozo, Sarriá, & Brioso, 2014). When children had more severe disabilities fathers were able to accept their limitations and let go of expectations that they held for a typically developing child. Finally, several studies found differences in sex, the use of specific coping strategies, and FQOL (McStay, Trembath, & Dissanayake, 2014; Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2016). Fathers tended to use more active avoidance coping strategies, and this was related to lower FQOL when compared with mothers in some samples. In contrast, mothers tended to use reframing and problem-focused coping, and this was related to higher FQOL (McStay, Trembath, & Dissanayake, 2014).

CHAPTER 3 – COPING

Given the overwhelming stress that parents of children with an ASD may experience, and the impact on family quality of life, research has also focused on how families handle stress through the use of specific coping strategies. A seminal work by Lazarus and Folkman (1984) defines coping as the cognitive, behavioral, and emotional attempts to manage a changing, distressing environment. Although there are many kinds of coping strategies that people utilize in stressful situations, Lyons and colleagues (2010) detailed several of the coping styles that parents of children with an ASD use. These included task-oriented coping (i.e. problem solving, reframing, and finding practical ways to reduce stress), emotion-oriented coping (i.e. rumination and negative mood), avoidance-oriented coping (i.e. avoiding the situation and withdrawing from support) and distraction (i.e. distracting from distress by engaging with other activities) (see *Table 1*). Some parents reported that acceptance of their child's diagnosis was an important aspect of coping, as well as finding humor even in the difficulty (Mount & Dillon, 2014). Additionally, family style of coping may change over time (Gray, 2006). As time passes, families tend to rely less on professional support and more on family, emotion-focused coping, and spiritual support (Gray, 2006). Although several studies have found significant associations between coping styles and specific mental health outcomes, a review of coping literature found that results were inconsistent across the literature (Lai & Oei, 2014). This may be due to the wide spectrum of symptoms and impairment seen in ASD, as different families may have different needs based on their child's presentation of an ASD (Lyons et al., 2010).

Table 2

Descriptions of Coping Styles

Coping Style	Description
Avoidance and distraction (passive appraisal)	Coping with difficult situations or emotions through passive behaviors or avoidance (i.e. watching television, isolation from family) (Twoy, Novak, & Connoly, 2010; Lyons et al., 2010).
Task-oriented	Attempting to solve the problem by minimizing or reconceptualization (Lyons et al., 2010)
Social and interpersonal	Recruiting help and respite from families, friends, and community (Lai & Oei, 2014; Lyons et al., 2010).
Reframing	Redefining the situation from a different perspective (Twoy, Novak, & Connoly, 2010).
Emotion-oriented	Seeking to alleviate emotional distress through venting, rumination, and dwelling on the negative (Lyons et al., 2010).
Seeking spiritual support	Utilizing spiritual community and resources such as faith in a higher power (Twoy, Novak, & Connoly, 2010).

Coping Strategies

Avoidance and Distraction

Avoidance-oriented coping, or passive appraisal, involves ignoring or avoiding situations and emotions. Consistently, this coping strategy is seen as maladaptive and related to higher feelings of stress (Lai & Oei, 2014; Pottie & Ingram, 2008). Avoidance-oriented coping is related to increased depression and family problems (Lyons et al., 2010). In contrast, intentional distraction was associated with decreased stress (Lyons et al., 2010). Intentional distraction, such as engaging in a pleasurable activity when feeling stressed, was an adaptive coping strategy. However, this association was seen with families who have children with more severe ASD and not as strongly associated with less severe ASD (Lyons et al., 2010). Some parents also engaged more passive appraisals, choosing to avoid or distract themselves from the situation to decrease stress (Twoy, Novak & Connoly, 2006). While passive appraisal is temporarily effective, some studies found hat this coping strategy is related to worse mental health over time (Lai & Oei, 2014).

Task-Oriented Coping

Task-oriented coping involves problem-solving and taking action to decrease stress. In a study by Lyons et al. (2010), task-oriented coping was related to better outcomes, while emotion-oriented coping was more likely to lead to psychopathology. When parents engaged in task-oriented coping, they tried to problem solve and see the problem from a new perspective. This was seen as a more beneficial perspective; however, the benefits of task-oriented coping may depend on the child’s level of impairment. According to Lyons et al. (2010), having a task-oriented approach may increase pessimism and disillusionment if the child has greater impairment. In a literature review by Lai & Oei (2014), task-oriented coping was identified as an adaptive coping strategy.

Social and Interpersonal Coping

Along with other effective coping strategies, social support is a key factor for parents of children with an ASD. Multiple sources confirm that social support is essential for family wellbeing (Karst & Van Hecke, 2012; Ludlow & Roehler, 2012; Twoy, Novak & Connoly, 2006). Having support from others offers social connection, respite, and intervention for parents who can feel overwhelmed by the daily stresses of caring for a child with an ASD (Mount & Dillon, 2014). Social support can be found in several forms including family support, friendships, formal support groups, outside therapeutic assistance, and community support (Shepherd et al., 2018). Because of the challenging behaviors that accompany an ASD, many families have found that it is difficult to receive enough social support (Brown et al., 2006). Family members may be less likely to offer to babysit, and professional respite care may be expensive or unavailable. Finding support from empathetic professionals may also be key. Davis and Gavidia-Payne (2009) found that support from professionals who gave adequate information and were respectful of the family was related to increased FQOL for families who had children with an ASD.

Reframing

Reframing is the process of looking at the same situation from a more positive perspective to decrease stress (Twoy, Novak & Connoly, 2007). Some families utilize reframing by viewing challenges as opportunities for growth, or setbacks as set-ups for future momentum. Reframing is a cognitive strategy (Lustig, 2004) that involves active reinterpretation. Twoy, Novak, and Connoly (2007) found that families of children with an ASD employed reframing in similar rates to the norm group (29.65% to 30.25%). Reframing is associated with more positive outcomes for parents of children with ASD (Twoy, Connoly & Novak, 2007).

Emotion – Oriented Coping

Emotion-oriented coping includes negative thinking, venting, and rumination (Lyons et al., 2010). In this coping strategy, parents may fantasize to distract from negative emotions or be hyper-focused on their feelings of guilt, self-criticism, or frustration. Some studies found that parents of children with an ASD and other disabilities used more emotion-oriented coping than parents with typically developing children (Lai et al., 2015; Lai & Oei, 2014; McStay, Trembath, & Dissanayake, 2014). Parents may use this coping strategy to alleviate stress, but it is a maladaptive coping strategy that is associated with poorer mental health (Lyons et al., 2010; Pottie & Ingram, 2008).

Seeking Spiritual Support

In the coping literature, seeking spiritual support is defined as gaining support from spiritual leaders, having faith in God, and finding meaning within their spiritual framework of understanding the world (Twoy, Connoly & Novak, 2007; Bingham, Correa, & Huber, 2012). Parents utilized spiritual support through their own individual spiritual practices, such as prayer, as well as asking for support from their church or spiritual community. For some mothers, finding meaning in their child's diagnosis meant believing that "God has a purpose…he is in control" (Bingham, Correa, & Huber, 2012, pp. 381).

Coping in Cultural Context

When examining coping, it is important to note that context and culture play an essential role in determining effective coping for families of children who have an ASD. The use of various coping strategies is determined by a variety of factors, including family demographics, culture, parent gender, child characteristics, and psychological characteristics of the parents (Lai & Oei, 2014). For example, coping strategies vary for families of Asian versus Western cultures. For families in Asian cultures, where collectivism is more valued, active coping is more frequently used (Twoy, Connoly & Novak, 2006). Asian families, guided by values of interdependence, employ strategies to adjust the family expectations and accommodate the differences of having a child with an ASD. In contrast, families in Western cultures engage in more passive appraisal or avoidance, due to a value of individualism (Lai & Oei, 2014). Similar to families in Asian cultures, Latino families also tend to be more collectivistic and rely on family support (Blanche et al., 2015). However, there tends to be a lack of awareness about an ASD among the Latino community, as well as less access to quality health care, leading to late diagnoses, delayed intervention, and stigma/social isolation for mothers (Zuckerman, 2014). Although research concerning coping skills in Latino families with an ASD is scarce, Blanche et al. (2015) found that families who had children with an ASD coped with their child's difficult behavior by having a "wait and see" attitude and by trusting in God.

CHAPTER 4 – THE CURRENT STUDY

The current study examined family quality of life and coping styles in families of children who have been diagnosed with an ASD and are seeking early intervention. This study adds to the literature by addressing family quality of life in families who have children with an ASD, a topic that is not commonly examined (Karst & Van Hecke, 2012; Vasilopoulou & Nisbet, 2016; Pozo, Sarriá, & Brioso, 2014; McStay, Trembath, & Dissanayake, 2014). Many studies identify the impact of stress on parents of children with an ASD and the coping strategies that families employ; however, there are also few studies that examine the impact of specific coping strategies on family quality of life (Vasilopoulou & Nisbet, 2016). When viewing families as an interconnected system of individuals, it seems important to address the family as a whole to improve family quality of life and resilience (Bowen, 1966). Additionally, many studies have found inconsistencies in the association between coping strategies and family outcomes such as family quality of life, and several studies have discussed the need to further family-focused and positive research about family quality of life, coping strategies, and resilience in this population (Karst & Van Hecke, 2012; Lai & Oei, 2014; Pozo, Sarriá, & Brioso, 2014; Vasilopoulou & Nisbet, 2016). The current study hopes to address these gaps in the research.

Hypotheses

There are three hypotheses in the present study. (1) Higher ASD symptom severity, measured by higher scores on the Autism Impact Measure (AIM), will be associated with lower FQOL. If this is supported, it may indicate that ASD severity impacts family quality of life, indicating the need for more support for families who have children more severely affected by ASD symptoms. If this hypothesis is unsupported, it could mean that ASD symptom severity is not strongly associated with FQOL but that other factors in the family are more important targets for intervention.

(2) The coping strategies of reframing and acquiring social support will be positively correlated to family quality of life (FQOL). If these correlations are found to be statistically significant, it may suggest that coping style impacts family quality of life for families who have children with an ASD and that interventions should focus on building these coping strategies. If this hypothesis is not supported, it may be that other factors are more significantly impactful to family quality of life.

(3) The coping strategy of passive appraisal will be negatively correlated with FQOL. If the results of this correlation are not significant, this may mean that passive appraisal is not a coping style that negatively impacts family quality of life. Finally, if some or all of these hypotheses are not supported, it may be that there are confounding variables in the sample, or that the sample did not have adequate power to detect significance.

CHAPTER 5 – METHODS

The Study

Data for the current study were collected during an earlier project completed at a regional child development clinic at a specialty hospital (Children's Hospital of Denver, Colorado). The study focused on using the Early Start Denver Model, a parent-mediated intervention for children recently diagnosed with an ASD. The Early Start Denver Model is a brief intervention for children under the age of three and has been empirically validated (Rogers et al., 2019). The intervention has been particularly effective in social-emotional domains of development. In a single-blind, randomized study, significant differences were found in the ESDM group compared to the community treatment-as-usual group, with the ESDM group displaying significant gains in language development, less autism severity, and gains in development (Rogers et al., 2019). The data for this study were collected during the first visit, previous to any participation in the intervention. Participation was voluntary in this study and did not impact a family's access to intervention. Families paid for the clinical intervention through Medicaid, private insurance, or private pay.

Participants

In the study, 36 parent-child dyads participated in a 12-week intervention utilizing the Early Start Denver Model (ESDM; Rogers, Vivanti, & Rocha, 2017). The children who participated were between 21 and 66 months of age ($M = 36.69$, $SD = 9.53$). Participants were mainly mothers (86.5%) of children with ASD, recruited from a waitlist for intervention services at the hospital. For this study, participants were eligible if they had one or more children diagnosed with an ASD between 12 and 60 months of age and spoke English. Of the families who had more than one child with an ASD, none consented to research.

Child Characteristics

Thirty-six (36) children participated in the study (see *Table 2)*. The age of the children ranged from 21 and 66 months of age and the mean age was 36.94 months (*M* = 36.69, *SD* = 9.53). All children had obtained a diagnosis of an ASD through a clinical service. A majority of the children had siblings (94%) and two had a twin sibling. A majority of the children received some kind of outside services during the week (the definition of outside services included school, behavioral therapy, and activities with other children). Of the participants, 37.3% received less than 5 hours of outside services per week, 3.9% received between 6 and 10 hours of services per week, 23.5% had 11-20 hours of services per week, and 5.9 % received over 20 hours per week. 15 of the caregivers reported that their children had other medical diagnoses, including ADHD, global delay, delayed milestones, apraxia, sensory processing disorder, sleep disturbance, and lack of coordination. Half (*n* = 18) of the caregivers reported that the participating child had other medical conditions. Some of these conditions included chronic lung disease, cerebral cardiovascular disease, gastroesophageal reflux disease (GERD), pica, immune deficiencies, and asthma.

Table 3

Child Characteristics

Demographic Characteristic	*n*	%	*M*	*SD*
Gender of Child				
Male	24	66.6%		
Female	12	33.4%		
Chronological Age	36		38.67	9.19
Seizure history				
Yes	3	8.1%		
No	33	91.9%		
Significant medical concerns				
Yes	17	48.6%		
No	19	51.4%		
Premature birth				
Yes	9	26%		
No	27	74%		
Vineland Adaptive Behavior	25		85.76	53.59
Mullen Scales of Early Learning			60.87	11.83
ADOS				
Met Criteria for an ASD	34			
At Risk for an ASD	2			

Caregiver Characteristics

In this sample, mothers were the primary caregivers and participants in the study (91.4%) (see *Table 3*). Approximately 83% of the caregivers were married or living with a partner, and the mean age of the mothers was 34.41 years old. It is important to note that mother were the primary participants in this study and that the data collected on FQOL is from the mother's perspective. A majority of the caregivers (94%) also had other children, and 66.4% of the caregivers identified as white.

Table 4

Caregiver Characteristics

Demographic Characteristic	*n*	%	*M*	*SD*
Household income [a]				
<$50,000	15	42.9		
$50,000-75,000	9	25.7		
$75,000-$100,000	6	14.3		
>$100,000	6	17.1		
Education [a]				
Some High School	4	11.4		
High School Graduate	6	17.1		
1-3 years College (includes business schools)	9	25.7		
College Graduate	10	28.6		
Some graduate training or terminal masters	5	14.3		
Professional degree (lawyer, Ph.D., MD)	1	2.9		
Age				
Mother	36	-	34.41	5.90
Father	36	-	37.94	8.93
Role of Primary Caregiver				
Mother	33	86.5		
Father	3	8.1		
Primary Caregiver Employed Outside of Home?				
Yes	16	45.9		
No	20	54.1		
Secondary Caregiver Currently Employed Outside of Home?				
Yes	32	88.6		
No	4	11.4		
Parents married?				
Yes	26	73%		
No	10	27%		
Never married	3	33.3%		
Living together	4	44.4%		
Divorced	2	11.1%		
Unknown	1	11.1%		
Race				
Black or African American	3	8.3%		
Caucasian	24	66.7%		
Asian	2	5.6%		
Biracial	5	13.9%		
Not Known	1	2.8%		

Ethnicity		
Hispanic/Latino	9	25%
Not Hispanic/Latino	25	69.4%
Not Known	2	5.6%

CHAPTER 6 – MEASURES

Qualifying Battery

Mullen Scales of Early Learning (MSEL; Mullen, 1995). The MSEL is a standardized developmental measure for children from birth to 68 months and is used to provide information on a child's development across 5 domains (Mullen, 1995). The MSEL measures development in Gross Motor, Visual Reception, Fine Motor, Expressive Language, and Receptive Language domains and provides a standardized Early Learning Composite Score. The MSEL is used to evaluate development for children with a variety of neurodevelopmental disorders, and reliability for cognitive and gross motor scales is high (.82-.85 and .96) (Burns, King & Spencer, 2013)

Vineland Adaptive Behavior Scales 3 (VABS; Sparrow, Cicchetti, Saulnier, 2015). The Vineland Adaptive Behavior Scales is a standardized measure utilizing semi-structured interviews to measure adaptive functioning in children. The VABS evaluates adaptive functioning in four domains: communication, socialization, daily living skills, and motor skills (de Bildt et al., 2005). Sparrow et al. (1984) found that test-retest reliability and internal consistency was adequate. The VABS was also consistent across samples with a variety of developmental disabilities (De Bildt et al., 2005).

Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, Risi, Gotham & Bishop, 2012). The ADOS is considered the "gold standard" for an ASD diagnosis (McCrimmon, 2014, p. 88). The assessment is administered by a professional and has items intended to measure core symptoms of an ASD, specifically social affect (SA) and restrictive, repetitive behaviors (RRB). The four modules are based on verbal ability. Different from other developmental assessments, the ADOS is administered through interaction with the assessor and coded based on observation. Modules 1-3 involve activities to measure social reciprocity and joint attention, while Modules 3-4 contain more interview questions that measure the participants' understanding of social relationships and emotions. Internal consistency was high for SA items and moderate for RRB items and test-retest reliability was .68-.92 (McCrimmon, 2014). Interrater reliability was 92-98% for Modules 1-3, and Module 4 was not tested (McCrimmon, 2014). The ADOS was used as a qualifier for this study.

Outcome Battery

Autism Impact Measure (AIM; Kanne, Mazurek, Sikora, Bellando, Branum-Martin, Handen, Katz, Freedman, Powell & Warren, 2014). ASD symptom severity will be measured using data from the Autism Impact Measure (AIM). The Autism Impact Measure (AIM) (Kanne, Mazurek, Sikora, Bellando, Branum-Martin, Handen, Katz, Freedman, Powell & Warren, 2014) measures core Autism symptoms and tracks the change of symptoms over time to measure the effectiveness of interventions. The AIM is a 25-item parent-report scale, and items are divided into frequency and impact factors. Parents rated impact on a five-point scale, with 0 representing "not at all" to 5 representing "severely" for specific behaviors. According to Kanne and colleagues (2014), the frequency factor denoted good test-retest reliability (.65 to .84) as did the impact factor (.53 to .78). The test-retest reliability was measured for each subscale f the measure. The AIM has demonstrated convergent validity to other measures of disability impact (Kanne et al., 2014). This study utilized a version of AIM with four subdomains: restricted/ritualized behavior, communication/language, social-emotional reciprocity, and odd/atypical behavior. Since its development, several studies have used the AIM as an effective measure of ASD symptom severity and impact (Shepherd, Landon, Taylor, & Goedeke, 2018; Jacobson, et al., 2016). In this study, the first AIM was included for baseline.

Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin, Olsen, and Larsen, 1981). This measure has 30 items that capture constructs related to family coping such as meaning-making, resources, and stressor pile up. Items include statements such as "[our family] accepts stress as a part of life" and "[our family] shares difficulty with relatives" using a 5-point scale from "never" to "always." The F-COPES has been used to measuring family coping for diverse families experiencing a range of crises and stressors, such as child chronic illness, cancer, homelessness, mental illness and an ASD (Nabors, Cunningham, Lang, Wood, Southwick & Stough, 2018; Pereira, Pedras, Ferreira, & Machado, 2019). Test-retest reliability for the measure ranged from .61 to .95 for the subscales, and the overall reliability was .86 (Barnett, Hall & Bramlett, 1990). Content and construct validity were supported for the F-COPES measure (Barnett, Hall & Bramlett, 1990).

Beach Center Family Quality of Life Scale (FQOL) (Hoffman et al., 2006). The primary dependent variable for this study was the Family Quality of Life (FQOL), assessed using the Beach Center Family Quality of Life scale (Hoffman et al., 2006). Family Quality of Life is the degree to which families perceive their overall wellbeing and life satisfaction. This is a 25-item, self-report measure which includes questions for five domains of wellbeing. Participants rate each item on a five-point Likert scale. The scale has two different categories of questions, "Importance" and "Satisfaction", with 1 indicating that the item is not important to the family/the family is very dissatisfied and 5 indicating that the item is very important/the family is very satisfied. For the Emotional Well-Being domain, items include phrases such as "my family has the support we need to relieve stress" ("Satisfaction" category), and "my family members have time to pursue their own interests" ("Importance" category). The Beach Center Family Quality of Life scale has demonstrated acceptable test-retest reliability (.41 to .82 based on the subscale)

(Hoffman et al., 2006). There are also significant correlations for convergent validity, with $r(87) = .68$, $p < .001$ for the Family Interaction subscale, and $r(58) = .60$, $p < .001$ for the Physical wellbeing subscale when compared to two measures that most closely relate with family quality of life (Hoffman et al., 2006). Higher scores on the FQOL measure indicate greater family quality of life, and lower scores indicate poorer family quality of life.

CHAPTER 7 – PROCEDURES

As part of the broader research study from which data for the current study was drawn, participants completed four assessment sessions and were compensated for their time ($25 per measure per timepoint). Each assessment session included parent questionnaires and participation in parent-child interaction observed by clinicians. Data for the current study were collected during the first assessment, before participation in the intervention, during which the participants completed a battery of measures. Some of the measures, such as the ADOS and Mullen Scales of Early Learning, were completed in person with a psychologist or advanced trainee in clinical psychology, while the parent-report questionnaires were completed in person or online using REDCap. All relevant data from the data set were entered into SPSS for analysis by the researchers of the original study. During the process of cleaning the data, it was found that some participants had not answered all the items in the online questionnaires.

CHAPTER 8 – RESULTS

FQOL and AIM

The first hypothesis for this study is that higher ASD symptom severity, measured by higher scores on the Autism Impact Measure (AIM), will be associated with lower FQOL scores.

Descriptive Statistics

The average AIM score for this sample was 227.11 (*SD* = 68.23). The AIM scores ranged from 137 - 514 (see *Table* 4 for descriptive statistics). This is slightly higher than the mean total AIM scores of 220.8 found in a study of 4,400 children with an ASD by Houghton et al. (2019). In our sample, Repetitive and Restrictive behaviors had the highest mean score (*M*= 41.9) of the subscales and Peer Interaction had the lowest mean score (*M*=22.2). For the AIM variable, 8 values were missing from 8 different items across the measure, and one participant did not complete 13 out of 41 items. The average score of the item was used for missing items. The mean overall FQOL score was 3.07 (*SD* = .655). For this measure, higher scores reflect higher satisfaction with quality of life. There has not been a national study to establish norms for the Beach Center Family Quality of Life Scale (Eskow, Pineles, & Summers, 2011). However, studies have found overall FQOL means range from 3.6 – 3.91 in a sample with ASD (Eskow, Pineles, & Summers, 2011), greater than 4 for families who have children who are deaf (Jackson et al., 2010), and greater than 4 in a study evaluating early childhood service programs (Summers et al., 2007). In this study, the data were compared to results found in Summers et al. (2007), which was completed with 180 participants with comparable demographics to the current study. In the FQOL data, one participant in the sample did not complete the measure in total and was removed from the analysis. When running descriptive statistics for the variables, it was discovered that the FQOL data were skewed (-1.519, *SE* = .398) and kurtotic (3.055, *SE* = .778). Therefore, a Spearman correlation was used to test the hypotheses.

Correlational Analysis

ASD symptom severity, as measured by the AIM, was significantly and negatively associated with FQOL, (r_s=-.343; p = .04). This supports the first hypothesis that more severe ASD symptoms are negatively associated with FQOL.

FQOL, Reframing, and Acquiring Social Support

Secondly, it was hypothesized that higher scores on the Reframing and Social Support subscales of the F-COPES measure would be positively associated with FQOL.

Descriptive Statistics

The mean statistic for the F-COPES variable was 104.58, with the Reframing subscale having the highest average score (M=32.6) (see *Table* 4 for descriptive statistics). The mean score for a study of 2740 participants was 93.34 (McCubbins et al., 1996). For this sample, the mean FQOL score was 3.07, with a range of 0.8 – 3.96.

In the F-COPES data, there were a total of 16 missing data points across 14 different items. For each item where a participant's score was missing, the average score of the item from all participants was used as a placeholder. Subscales and total scores were calculated for each participant, per McCubbin, Olson, and Larsen (1981).

Correlational Analysis

Total Scores on the FQOL were not significantly associated with F-COPES scores in the Reframing (r_s = .305, p =.075) or the Acquiring Social Support domains (r_s = .250, p =.147).

FQOL and Passive Appraisal

Finally, the third hypothesis was that the use of Passive Appraisal, demonstrated by F-COPES scores, would be associated with lower FQOL.

Descriptive Statistics

The mean statistic for the Passive Appraisal subscale in this sample was 15.89 (*SD* = 3.19). This is relatively higher than the mean score of 8.33 found in a study of 2740 participants (McCubbins et al., 1996).

Correlational Analysis

The use of Passive Appraisal was not significantly correlated to FQOL (r_s = -.153, *p* =.381). The third hypothesis was not supported, suggesting that family quality of life is not significantly impacted by the use of passive appraisal as a coping strategy.

Table 5

Descriptive Statistics for Study Variables Compared with Norms

	Current Study		*Reference Norms*	
Variable	*M*	*SD*	*M*	*SD*
FCOPES Total Score (McCubbins et al., 1996)	104.58	13.45	93.34	13.64
Reframing	32.61	4.83	30.24	4.85
Acquiring Social Support	26.22	6.54	27.19	6.44
Passive Appraisal	15.89	3.19	8.55	3.01
Seeking Spiritual Support	11.11	5.68	16.07	3.05
Mobilizing	15.31	3.85	11.97	3.37
AIM Total Score (Houghton et al., 2019)	227.11	68.24	220.8	*not provided in article*
Repetitive and Restrictive Behavior	41.95	13.83	41.3	*not provided in article*
Communication	36.44	9.03	30.7.	*not provided in article*
Odd/atypical Behavior	32.12	9.85	34.8.	*not provided in article*
Social Reciprocity	26.76	5.74	27.1.	*not provided in article*
FQOL (Summers et al., 2007)	3.07	.655	3.99	0.64
Family Interaction	3.38	.482.	4.06	0.76
Parenting	3.04	.705	4.07	0.71
Emotional Wellbeing	2.32	.991	3.43	1.00
Physical Wellbeing	3.28	.703	4.21	0.73
Disability-Related Supports	3.63	2.32	4.13	0.73

CHAPTER 9 — DISCUSSION

Families who have children with an ASD are impacted by the disorder in many multidimensional ways. The stress that these families experience is well documented and impacts the coping strategies, relational outcomes, and overall family quality of life (Vasilopolou & Nisbet, 2014). Many studies have found that the chronic and acute stress these families experience can lead to several negative outcomes, for parents, siblings, and the family as a whole (Bluth et al., 2014; Brown, MacAdam–Crisp, Wang, & Iarocci, 2006; Karst & Van Hecke, 2012; Lyons et al, 2006; McStay, Trembath, & Dissanayake, 2014; Teague, Newman, Tonge, & Gray, 2018; Twoy, Connoly, & Novak, 2007; Vasilopolou & Nisbet, 2014). For example, parents of children with an ASD report higher levels of mental illness (Brown, MacAdam–Crisp, Wang, & Iarocci, 2006; Karst & Van Hecke, 2012), less physical wellbeing, less financial wellbeing, and less overall satisfaction with their lives (McStay, Trembath, & Dissanayake, 2014; Vasilopolou & Nisbet, 2014). Relationships in the family can also suffer due to the stress families experience. Relationship satisfaction is lower for couples who have a child with an ASD, compared to couples who have children with other disabilities (Bluth et al., 2014). It is hypothesized that the stress of having a child with an ASD stems from multiple sources, one of which is the severity of the child's behavior problems and the number of an ASD symptoms (Pozo et al., 2014). In some studies, more child behavior problems were negatively associated with mother quality of life and less adaptive coping strategies (McStay, Trembath, & Dissanayake, 2014). While there are a plethora of studies focused on the stress that families who have children with an ASD experience, there are not many that have focused on family quality of life and specific coping strategies that increase well-being (Vasilopoulou & Nisbet, 2014; Lai & Oei, 2014). As the rates of an ASD diagnosis have continued to rise and awareness about the disorder increases, it seems important to address the impact of an ASD on the entire family system and to provide practical guidance for clinicians working with this population. The current study sought to bridge the gap in the literature by exploring the important variables of family quality of life and coping.

FQOL and ASD Symptom Severity

The current study hypothesized that higher ASD symptom severity would be associated with lower FQOL. The FQOL scores in this study were slightly lower than in a comparable study, with a mean total of 3.07 compared to 3.99 (Summers et al., 2007). In accordance with other studies (Pozo et al., 2014; Vasilopolou & Nisbet, 2016; McStay, Trembath, & Dissanayake, 2014), I found that ASD symptom severity, measured by scores on the Autism Impact Measure (AIM), was significantly correlated with FQOL. In this analysis, ASD symptom severity was negatively correlated to FQOL, meaning that more severe ASD symptoms was related to lower FQOL. ASD symptom severity may be associated with lower FQOL due to several reasons.

ASD symptoms and behaviors were rated by the child's primary caregiver according to frequency (*during the past two weeks, how often has your child…)* and impact (*how much did this interfere with your child's everyday functioning?)*. The subscales of ASD symptoms measured by the AIM, such as repetitive behaviors, social reciprocity, and communication, may impact wellbeing due to the interference they cause in daily life. When a child with an ASD shows fascination with certain objects, has routines and rituals that they must follow, or avoids certain sensory experiences, this may interfere with the family's ability to complete daily living tasks without conflict (Gardiner & Iarocci, 2015). For example, the stress of getting children ready for school may be exponentially multiplied if a child is not able to get dressed due to fascination with a toy, or a meltdown due to disliking the feel of a shirt collar. Similarly, Gardiner and Iarocci (2015) found that impairments in daily adaptive skills in children with an ASD led to lower FQOL for mothers.

Other ASD symptoms measured by the AIM include peer interaction, communication, and social reciprocity. These subareas may impact FQOL because of the distress that parents and siblings may feel if they are not able to communicate effectively with the individual who has an ASD, as well as distress about social stigma (Karst & Van Hecke; Ludlow, Skelly & Rohleder, 2011). Social reciprocity is an important part of human thriving in relationships, and the lack of social reciprocity may be distressing for parents and siblings. Additionally, children who have an ASD may become frustrated with communication as well, which could lead to conflict, stress, and negative behaviors in both the child and parents. When comparing the AIM subscales to FQOL in this study, it was found that only the Communication subscale had a significant relationship to FQOL when separated from the measure as a whole, indicating that communication may be an important factor in FQOL.

Due to their child's social impairments, it may be difficult for parents to maintain social support. This is another explanation for the impact of ASD symptom severity on FQOL. Parents of children with an ASD may struggle to receive social support because they are not able to be as involved in social events. It also may be difficult for parents to find respite caregivers that they can rely on, due to the child's needs. Lack of social support has been related to depression and lower FQOL in other studies and could be a factor in the results of low FQOL in this study (Pozo, Sarriá, and Brioso, 2014). Interestingly, the highest mean subscale score in this sample was Disability Related Supports (*M*=3.63, *SD* = 2.32). The higher mean score for Disability Related Supports could be due to the fact that these families had young children (under the age of 4) and were already receiving diagnoses, services, and support. The age of a child with an ASD could also impact the experience of the family and parents, and the needs of families with older children appear to be different than the needs of those with younger children with an ASD (Vasilopoulou & Nisbet, 2015).

In this sample the lowest subscale mean for FQOL was Emotional Wellbeing (*see Table 5)*. Emotional wellbeing was indicated by statements on the Beach Family Quality of Life survey such as "*my family has the support we need to relieve stress"* and "*my family members have time to pursue their own interests."* Because families of children with an ASD experience high levels of chronic and acute stress, and stress is related to a variety of physical and emotional problems, it is understandable that this subscale would receive the lowest mean score in this population (Karst & Van Hecke, 2012). Parents who have children with an ASD may have increased anxiety about their child's behaviors that are related to an ASD and less time to focus on stress-relieving activities.

FQOL and Coping

Additionally, the author hypothesized that certain coping styles would be significantly associated with FQOL. Specifically, it was hypothesized that coping strategies of reframing and acquiring social support would be positively correlated to FQOL, and that passive appraisal would be negatively associated with FQOL. This study did not find support for the other hypotheses. This could be due to several factors. First, coping styles have been inconsistently associated with FQOL (Lyons et al., 2010). Some studies found that active coping, such as reframing and acquiring social support, was related to greater FQOL and less stress, while others found that there was not a significant association (Vasilopoulou & Nisbet, 2015). Gray (2006) found that coping styles changed over time for families of children with an ASD, moving from problem-solving coping to more emotional coping and less reliance on service providers. This may be because of the diversity of family experiences, family structure, and the impact of culture on coping.

CHAPTER 10 – IMPLICATIONS AND FUTURE DIRECTIONS

Because this study implicates that ASD symptom severity impacts FQOL, it seems important that clinicians and professionals focus on supporting family wellbeing. This could be done in a variety of ways. Because FQOL is composed of several domains of wellbeing, there may be multiple ways to increase wellbeing. For example, emotional wellbeing may be increased by respite care, which also impacts satisfaction concerning disability related supports. Emotional wellbeing may also increase with psychotherapy, support groups for families of children with an ASD, and an increased focus on relational health for couples.

Future Directions

While more research is needed concerning the specific impacts of ASD on FQOL, one thing is clear in this study and others: a diagnosis of ASD does affect the entire family system. This study added to the literature by finding a significant association between ASD symptom severity and FQOL. However, there are still many questions that need to be answered in order to support families who have children with an ASD. While the research shows that FQOL is important and is impacted by several factors, it is not known what specific interventions increase FQOL in families who face many challenges. The mechanisms through which an ASD symptom severity impacts FQOL are also unknown. Future studies should focus on this question in order to provide practical help for families.

Although this study did not find significant associations between coping style and FQOL, this is an association that could be explored further. If coping style increases or lessens FQOL, families could learn to lean on more effective coping strategies in order to increase FQOL. This is a practical way that clinicians could impact family functioning. While many of the family’s circumstances may not change (i.e. the child’s diagnosis or behavior problems, the availability of social support, etc.), the family’s perceptions and reactions could improve the experience of their circumstances. This aligns with other studies and family adaptation models, such as the ABC-X model of stress for families who have children with an ASD (McStay, Trembath, & Dissanayake, 2014; Pozo et al., 2014).

Future studies could also explore the different needs of parents based on gender. McStay et al. (2014) hypothesized that fathers and mothers may experience different needs, different ways of coping, and be impacted by different aspects of an ASD. In some studies, fathers were more impacted by an ASD severity, and mothers by emotion regulation difficulties (McStay, Trembath, & Dissanayake, 2014). Mothers used more problem focused coping, fathers used more active avoidance and less social support. This could be due to cultural expectations of the role of fathers versus the role of mothers in a child’s life, which could impact family functioning and FQOL.

CHAPTER 11 – LIMITATIONS

There are several limitations to the current study. First, this study sought to explore family quality of life. However, the majority of the parents who participated were mothers. Therefore, I only received perspectives from one member of the family, and this single perspective may not capture the view of the entire family. Secondly, this study utilizes a relatively small sample size ($N = 36$) that is more homogeneous than the average population. Also, this study utilized only one measure for each of the independent and dependent variables. It may be beneficial to include more measures of an ASD severity, impact, coping styles, and family quality of life. Using more sophisticated analyses may also be helpful, as this study only used correlations. Due to the small sample size and the study design, this study was not able to identify any mechanisms through which an ASD severity impacts FQOL. Future studies would benefit from looking further into this association.

This study also utilized a clinical sample of parents who were actively seeking services for their children. This could have impacted their experience of FQOL, as well as the way they answered the FCOPES questionnaire. Finally, there is a possibility of confounding variables such as culture, socioeconomic status, and parental mental health that could also impact family quality of life. This study was composed largely of white, middle class parents, and most of the caregivers were married or in committed relationships.

Finally, a majority of the caregivers who participated in the study were mothers. Although mothers tend to be the primary caregivers in this population of families, the experience of fathers is also important and impacts FQOL. This study did not have data from the fathers or the siblings of children with an ASD. The perspectives of other family members may provide other insight in FQOL as well as insight into interventions that could be especially helpful for the entire family system.

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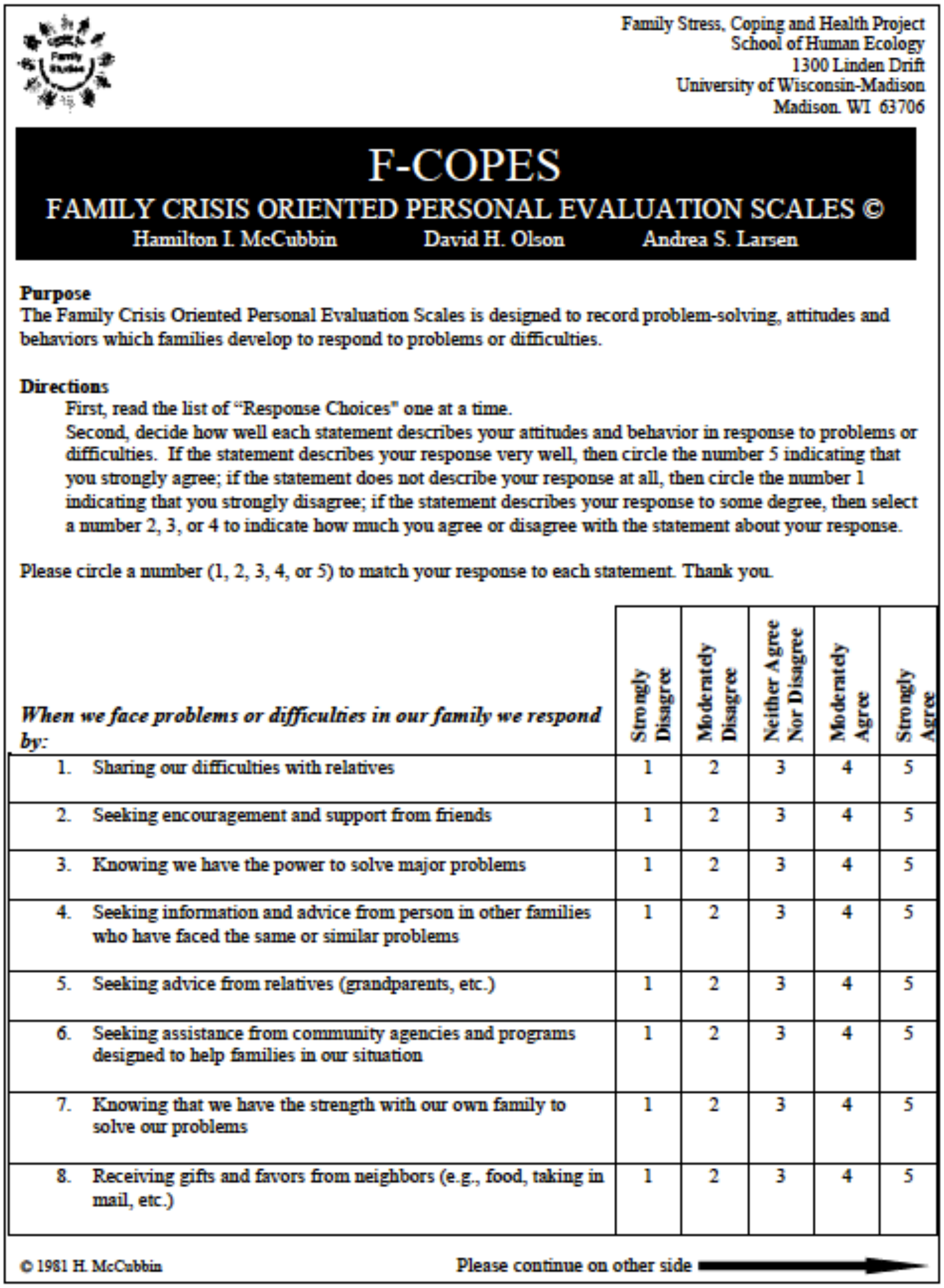
APPENDIX: MEASURES



Family Stress, Coping and Health Project
School of Human Ecology
1300 Linden Drift
University of Wisconsin-Madison
Madison. WI 63706

F-COPES

FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES ©

Hamilton I. McCubbin David H. Olson Andrea S. Larsen

Purpose
The Family Crisis Oriented Personal Evaluation Scales is designed to record problem-solving, attitudes and behaviors which families develop to respond to problems or difficulties.

Directions
First, read the list of "Response Choices" one at a time.
Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you strongly agree; if the statement does not describe your response at all, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

Please circle a number (1, 2, 3, 4, or 5) to match your response to each statement. Thank you.

When we face problems or difficulties in our family we respond by:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friends	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from person in other families who have faced the same or similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6. Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7. Knowing that we have the strength with our own family to solve our problems	1	2	3	4	5
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	1	2	3	4	5

Please continue on other side ➡

When we face problems or difficulties in our family we respond by:	Strongly Disagree	Moderately Disagree	Neither Agree Nor	Moderately Agree	Strongly Agree
9. Seeking information and advice from the family doctor	1	2	3	4	5
10. Asking neighbors for favors and assistance	1	2	3	4	5
11. Facing the problems "head-on" and trying to get solution right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5
14. Attending church services	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-together, dinners, etc.)	1	2	3	4	5
21. Seeking professional counseling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in church activities	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27. Seeking advice from a minister	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5
29. Sharing problems with neighbors	1	2	3	4	5
30. Having faith in God	1	2	3	4	5

FAMILY QUALITY OF LIFE (cont.)

How satisfied am I that...	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
1. My family enjoys spending time together.	☐	☐	☐	☐	☐
2. My family members help the children learn to be independent.	☐	☐	☐	☐	☐
3. My family has the support we need to relieve stress.	☐	☐	☐	☐	☐
4. My family members have friends or others who provide support.	☐	☐	☐	☐	☐
5. My family members help the children with schoolwork and activities.	☐	☐	☐	☐	☐
6. My family members have transportation to get to the places they need to be.	☐	☐	☐	☐	☐
7. My family members talk openly with each other.	☐	☐	☐	☐	☐
8. My family members teach the children how to get along with others.	☐	☐	☐	☐	☐
9. My family members have some time to pursue our own interests.	☐	☐	☐	☐	☐
10. Our family solves problems together.	☐	☐	☐	☐	☐
11. My family members support each other to accomplish goals.	☐	☐	☐	☐	☐
12. My family members show that they love and care for each other.	☐	☐	☐	☐	☐
13. My family has outside help available to us to take care of special needs of all family members.	☐	☐	☐	☐	☐
14. Adults in our family teach the children to make good decisions.	☐	☐	☐	☐	☐

FAMILY QUALITY OF LIFE (cont.)

How satisfied am I that…	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
15. My family gets medical care when needed.	☐	☐	☐	☐	☐
16. My family has a way to take care of our expenses.	☐	☐	☐	☐	☐
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	☐	☐	☐	☐	☐
18. My family is able to handle life's ups and downs.	☐	☐	☐	☐	☐
19. Adults in my family have time to take care of the individual needs of every child.	☐	☐	☐	☐	☐
20. My family gets dental care when needed.	☐	☐	☐	☐	☐
21. My family feels safe at home, work, school, and in our neighborhood.	☐	☐	☐	☐	☐
22. My family member with a disability has support to accomplish goals at school or at workplace.	☐	☐	☐	☐	☐
23. My family member with a disability has support to accomplish goals at home.	☐	☐	☐	☐	☐
24. My family member with a disability has support to make friends.	☐	☐	☐	☐	☐
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	☐	☐	☐	☐	☐

Thank you! You have finished completing this survey. Please make sure you erase any extra marks and have answered all the questions.