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Family Cohesion and Perceived Stress as Predictors of Quality of Life in Maternal Caregivers of Children with Autism Spectrum Disorder

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Philadelphia College of Osteopathic Medicine

School of Professional and Applied Psychology

FAMILY COHESION AND PERCEIVED STRESS AS PREDICTORS OF QUALITY
OF
LIFE IN MATERNAL CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM
DISORDER

By Emily Henry M.S, M.S, BCBA

Submitted in Partial Fulfillment of the Requirements for the Degree of

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DEPARTMENT OF PSYCHOLOGY

Dissertation Approval This is to certify that the thesis presented to us by Emily Henry on the 2nd day of May, 2019, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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Abstract

The present study investigated factors that predict maternal caregivers' quality of life in 115 mothers (25 - 55 years old) who had a child aged 5 to 12 years old with Autism Spectrum Disorder (ASD). Caregivers' perceived stress and family cohesion were assessed to determine each factor's predictive ability in predicting four domains of quality of life: physical health, psychological health, relationships, and environment. Results indicate that perceived stress significantly predicted all four quality-of-life domains. When adding in family cohesion, modest increases in predictive strength were observed for two domains of caregiver quality of life (i.e., psychological health and relationships). These results demonstrate that family variables have some modest impact on certain domains of quality of life and support further investigation and understanding of these and other related family variables.

Keywords: autism spectrum disorder, family cohesion, perceived stress, quality of life

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Chapter 1: Introduction

Autism spectrum disorder (ASD) impacts many individuals and families throughout the world, affecting approximately 1 in 59 individuals (Centers for Disease Control and Prevention [CDC], 2018). While individuals with ASD often exhibit many strengths, several functional impairments accompany this disorder. Treatment of these impairments in children has taken an evidenced-based and strength-based approach, with caregivers providing most of the care and treatment outside of service hours. The treatment for children with ASD is often quite taxing on family functioning, relates to perceived familial stress, and negatively impacts family relationships. Researchers argue that examining these outcomes from a systemic viewpoint through such models as the stress process model, which incorporates multiple levels of stress and types of supports to predict mental-health-related outcomes, is useful (Schwichtenberg & Poehlmann, 2007). The current treatments are focused on the individual with the diagnosis and on treatment of symptomatology typically observed in individuals with ASD; however, treatment for the family system or for those providing care to the individual is lacking (Cooper, Heron, & Heward, 2007).

Caregivers of individuals with ASD experience many unique caregiver burdens that tend to negatively affect caregivers' quality of life and, subsequently, the care that they provide (Lecavalier, Leone, & Wiltz, 2006). Several factors are thought to contribute to the quality of life of these caregivers (Johnson, Frenn, Feetham, & Simpson, 2011). For example, a notable factor is a caregiver's perceived stress, particularly that of maternal caregivers (e.g., Hastings, 2003). Perceived stress positively correlates not only

with the child's maladaptive behaviors, but also with the overall mental health of all the family members living with the child (e.g., Hastings, 2003). Stressors, both internal and external, impact parental quality of life, subsequently impacting the care provided to the child (Perry, 2004). However, perceived stress as a predictor explains on average only 15 to 22% of the variance in the outcome of parental quality of life across a variety of childhood mental-health disabilities (e.g., Johnson et al., 2011; Lee et al., 2009). While the contribution of perceived stress to a caregiver's quality of life is significant, one must investigate other factors that may contribute to the additional 78 to 85% of the variance explaining caregiver quality of life (e.g., Johnson et al., 2011; Lee et al., 2009).

Studies using a family systems approach to understanding caregiver quality of life have revealed that the functioning and cohesion among family members impact the mental- and physical-health outcomes of the entire family (Higgins, Bailey, & Pearce, 2005). This approach has been particularly useful in understanding and analyzing family functioning, as it explores the whole system rather than the individual as a subsystem (Altiere, 2006). However, family variables have not been extensively studied regarding the ASD population (Cridland, Jones, Magee, & Caputi, 2014). Much of the research has emphasized the challenges the individual with ASD faces, with less focus on the rest of the family unit (e.g., Boyd, 2002). While ASD presents many challenges to the diagnosed individual, caregivers and family members are also impacted because they must often accommodate the individual with ASD, yet research focused on this area is lacking (Myers, Mackintosh, & Goin-Kochel, 2009).

The purpose of this study was to investigate factors that predict the quality of life in maternal caregivers of children with ASD with a focus on family cohesion. The study

investigated whether a mother's level of perceived stress and family cohesion predict maternal quality of life. Although mothers play a vital role in supporting the child with ASD, few studies have examined how these factors together predict maternal quality of life, but rather studies have investigated the impact of perceived stress alone or such factors as marital distress (e.g., Rivers & Stoneman, 2003). This current study helps clarify the relationship between perceived stress, family cohesion, and maternal quality of life.

Literature Review

Family is a vital component to consider in the treatment of ASD-related symptomatology, as this treatment relies strongly on family members' use of interventions and support for the child. The caregivers of individuals with ASD experience many unique caregiver burdens that tend to negatively affect caregivers' quality of life and, subsequently, the care that they provide (Lecavalier et al., 2006). Understanding ASD, its impact on the family, and specific variables that predict better quality of life in caregivers lays a foundation for the present study.

Defining Autism Spectrum Disorder

ASD is characterized by developmental delays that can present in the first few months of life but are often more readily observed by 2 to 3 years of age, when speech, social skills, motor skills, and other developmental skills would normally start to develop (Rapin & Tuchman, 2008). Children diagnosed with ASD typically demonstrate deficits with social interactions, impaired social communication, and restricted behaviors (American Psychiatric Association, 2013). Also, contrary to common stereotypes, while many individuals with ASD have cognitive limitations, cognitive abilities of some

individuals with ASD are within normal limits, or possibly even advanced (Rapin & Tuchman, 2008).

Deficits associated with ASD include factors related to social interactions, communication, ritualistic behavior, play and imaginative behavior, dietary habits, mood, sleep, and intellectual ability (Fein & Dunn, 2007). Some individuals with ASD suffer psychomotor difficulties, including a lack of body eccentricity and difficulty walking, climbing, and running, as well as issues with fine-motor skills, such as handwriting or cutting with scissors (Noterdaeme, Mildenberger, Minow, & Amorosa, 2002). Cognitive deficits, learning delays, and comorbid psychiatric disorders, such as anxiety or depression, are also common with this population, further complicating treatment for these individuals (Simonoff et al., 2008). However, one should understand that not every individual's disorder presents in a similar fashion or at the same level of severity as another person's disorder with the same diagnosis; therefore, case conceptualization and treatment should be individualized (Riby & Hancock, 2008).

Prevalence

ASD is considered a developmental disorder that affects approximately 1 in 59 individuals in the United States and affects persons of various races, genders, and socioeconomic classes (Autism and Developmental Disabilities Monitoring, 2014). Gender disparity exists in that male individuals are 4 times more likely to have ASD as their female counterparts (Whiteley, Todd, Carr, & Shattock, 2010). Within the United States, prevalence of ASD varies, from the lowest number in Florida to the highest in Missouri and Arizona (42 per 10,000 and 121 per 10,000, respectively; Duchan & Patel, 2012). Recent estimates are more than double previous estimates. The

increased prevalence of this diagnosis over the past 10 years can be attributed to several factors, one of which is a better conceptual understanding of the disorder, thereby making the disorder more easily identifiable and diagnosable (Rapin & Tuchman, 2008).

Cultural differences have been examined among individuals with ASD (CDC, 2013). While research suggests that ASD occurs equally across cultures and ethnicities, it is 30% more likely diagnosed in Caucasians, with other races more likely receiving alternative diagnoses (CDC, 2013). Recent research suggests this racial disparity results mainly from underreporting of symptoms by non-Caucasian parents, whether for cultural reasons or from a misunderstanding of the symptomatology (Donohue, Childs, Richards, & Robins, 2017). Considering culture on a global scale, global prevalence estimates of ASD are less than 50% of the lowest estimates in the United States (Berg, 2017). These prevalence differences may be attributed to acceptance and understanding of the diagnosis across cultures, as well as differences in child-rearing and behavioral expectations in the home (CDC, 2013).

Cause

Although the causes of ASD remain unclear, it appears to be affected by components in brain abnormalities that are genetically determined (Fein & Dunn, 2007). Other genetic links that have been indicative of ASD in some individuals have also been explored through twin studies (Szatmari, 2003). Twin studies investigating the role of genetics in ASD have determined that the concordance rate is much greater in identical twins than in fraternal twins, further suggesting genetic components may be responsible for the development of ASD (Szatmari, 2003). While genetics clearly plays a

major etiological role, the genes that impact this disorder are still unclear (Szatmari, 2003).

Additionally, prenatal environmental factors have been pinpointed as possible etiological factors (Szatmari, 2003). Prenatal factors that have been shown to potentially affect the development of this disorder are the mother's use of anticonvulsant medication during pregnancy and thalidomide-induced embryopathy (Szatmari, 2003). Thalidomide is a drug used to treat cancers, but when taken by a pregnant woman, it can cause developmental deficits in the fetus, ultimately leading to developmental concerns in the child (Flohe et al., 1981).

Additional theories regarding the cause of ASD have been investigated. Paternal and maternal age have been shown to be indicative of potentially higher risks (Wu et al., 2017). According to a recent study, a 10-year difference in age raised the risk of ASD 21 % when considering paternal age and 18 % for maternal age (Wu et al., 2017). Several conflicting theories on the causes of ASD, spanning from prenatal immune dysfunction, which can result from such issues as maternal infections, to explanations related to paternal age, still appear in the literature (Meltzer & Van de Water, 2017). The only clear link scientists have agreed upon is genetics as a contributing factor to the development of ASD (Szatmari, 2003).

Treatment

With the substantial functional impairments that accompany ASD, most caregivers search to understand and find a solution or treatment for the symptomatology. Therapeutic treatment has been shown to positively impact the adaptive functioning of individuals with ASD (e.g., Patel, Preedy, & Martin, 2014; Vismara & Rogers,

2010). While ASD is considered a lifelong condition, improvement in symptomatology is possible when evidenced-based services, such as behavioral therapy, are involved (Patel et al., 2014).

Despite the availability of such evidenced-based services several treatments have surfaced with the hope of “curing” ASD (Metz, Mulick, & Butter, 2005). Some of these treatments include gluten- and casein-free diets, avoiding administration of vaccinations, and use of chiropractic and acupuncture therapies (e.g., Knight, 2017; Metz et al., 2005). While these treatments are often implemented, research is still ongoing and currently has not found adequate evidence to suggest these treatments are effective. A focus by parents on the use of fad treatments is often accompanied by a decrease in the optimization of appropriate and evidenced-based treatments for ASD, further delaying progress (Matson, Adams, Williams & Rieske, 2013). Currently, no medication is prescribed to specifically treat or cure ASD, but ASD can often be comorbid with other psychiatric diagnoses, such as attention deficit hyperactivity disorder, which can be treated with medication (Leyfer et al., 2006). Researchers are continuing to better understand the best treatment approaches, but as of now, treatment predominantly lies in psychological therapeutic interventions, such as behavioral therapy (Vismara & Rogers, 2010).

Few evidenced-based treatments are currently being employed for ASD (Green et al., 2006). Behavioral therapy, in the form of applied behavioral analysis, is currently the most widely employed treatment modality (e.g., Denne, Hastings & Hughes, 2017; Vismara & Rogers, 2010). This treatment approach has been empirically supported, and research continues to be conducted on this approach with a variety of populations (Bailey & Burch, 2017). Behavioral therapy is used with varying degrees of intensity, from a

basic wraparound program involving therapeutic support to a full applied behavioral analysis program instituted by a licensed, board-certified behavioral analyst (Bolte, 2014). Often, and depending on the severity of symptoms, these services are intensive, time consuming, and long term, requiring a considerable investment of time and energy from the caregivers (Bolte, 2014). Caregivers experience additional stress, fatigue, and other negative outcomes when having to engage in intensive support services while accommodating schedules for themselves and other family members (Bolte, 2014).

Functional Impairments and Family Functioning

While one should recognize the strengths and advantages related to ASD, several functional impairments are also related to this disorder (O'Brien & Daggett, 2006). Exploring both impacts is imperative in understanding the challenges experienced by these families on a regular basis. The functional impairments typically associated with this disorder include behavioral concerns, social-skill deficits, and psychiatric/cognitive deficits.

Common behavioral concerns. For many individuals with ASD, behavioral problems, such as tantrums, noncompliance, and elopement, often present many difficulties for these individuals and those around them (e.g., Matson & Nebel-Schwalm, 2007). These behavioral concerns are not necessarily universal among individuals with this disorder. Some of these behavioral concerns fall under the social-skill domain; however, other behavioral concerns can more appropriately be considered compliance-related behaviors (Johnson & Rodriguez, 2013). Some examples of compliance-related behavioral concerns include tantrums, aggression, elopement, and difficulty transitioning

and completing tasks, especially those that are nonpreferred (Johnson & Rodriguez, 2013). Additional behaviors that are often observed in individuals with this disorder include rigid and fixated movements, as well as fixed topics of interests or obsessions (Matson & Nebel-Schwalm, 2007). These behavioral concerns can also include stereotypy, dietary refusals, and, at times, attention deficits (Matson & Nebel-Schwalm, 2007).

The severity of behavioral symptomatology can impact the functioning and cohesion within the family (Lyons, Leon, Phelps, & Dunleavy, 2010). For example, behavioral difficulties make finding a babysitter willing and adequate to handle extreme behaviors much more difficult (Boyd, 2002). Marital relations can be particularly impacted by the inability to find a babysitter or respite care, then impacting family cohesion as the couple is unable to have time for self-care or time for one another (Harper, Dyches, Harper, Roper, & South, 2013). Parents also often disagree on the best ways to parent their children, and their involvement in services often differs substantially (McBride & Mills, 1993). Also, behavioral difficulties impact the family because families often need to accommodate their plans to avoid public behavioral outbursts (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). These accommodations could include modifying family holiday plans, vacation plans, and weekly morning routines, possibly impacting both family cohesion and overall quality of life. Accommodations made for the child, at times, can create tension and jealousy among siblings and may damage the potential for a sibling bond (Feiges & Weiss, 2004). Lee, Harrington, Louie, & Newschaffer's (2008) quality-of-life research further extended the list of restrictions

these families face, such as reduced attendance at religious services, missed school, and lack of group activities.

Social concerns. Another set of concerns is social-skill deficits, such as limited eye contact, inappropriate vocalizations or expressions, difficulty sharing and participating with peers, and understanding common social cues (Osterling & Dawson, 1994). Social exclusion and social isolation are important to consider, as both have their own implications for the functioning of these individuals (Chevallier, Kohls, Troiani, Brodtkin, & Schultz, 2012). Social exclusion refers to a perceived deficit in belongingness with others (Stillman et al., 2009). Social isolation refers to a self-chosen complete or nearly complete isolation from contact with other people (Hawton et al., 2011). While many individuals with ASD isolate and prefer to be alone, some individuals are neglected and ignored by peers because of their differences, even when they want to be included.

The deficits in social skills that often accompany ASD usually impact peer and family interactions (White, Keonig, & Scahill, 2007). For example, peers may find an individual with ASD to be different from themselves, difficult to get along with, and difficult to relate to (Bauminger, Shulman, & Agam, 2003). Family interactions are often impacted by social-skill deficits as well. Bonding with caregivers may be affected by the child's unresponsiveness to his or her name, limited eye contact, or demonstration of low orientation toward others (Osterling & Dawson, 1994). In addition to these factors, individuals with ASD sometimes do not have much interest in peer or family interactions, and their preferred activities often result in their being socially isolated (White et al., 2007).

Several family factors are impacted by the social-skill deficits in a child with ASD (e.g., Moyson & Roeyers, 2011). For example, bonding difficulties are identified as a potential stressor of having a child with ASD, as these children can have difficulties engaging affectionately and appropriately with family members. This factor may specifically impact familial relations and family cohesion (Norton & Drew, 1994). Also, social-skill deficits of children with ASD can impact family dynamics, particularly when siblings are not interested in interacting with the child who has ASD, or they struggle to relate to the child (Moyson & Roeyers, 2011). Further, considering supports, many families become isolated when they have children with ASD because they have a difficult time having their children engage in play dates, spend time with family friends, attend family holidays and gatherings, or engage in activities with others (Bernheimer & Keogh, 1995). These social-skill difficulties can create further complications and stressors for the family working with the child and could impact caregiver outcomes, such as caregiver's quality of life (Moyson & Roeyers, 2011).

Psychiatric and cognitive challenges. In addition to behavioral difficulties and social-skill deficits, individuals with ASD often suffer from comorbid psychiatric difficulties, learning impairments, and other cognitive challenges that can further complicate treatment (Wood et al., 2009). For example, a greater rate of anxiety and mood disorders has been shown to occur in children with ASD when compared to a normative sample from the same community (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). Additionally, learning, attention, processing speed, and graphomotor abilities differ between children with ASD and typically developing children in that children with ASD often experience deficits in several of these areas (Mayes & Calhoun,

2007). These deficits often perpetuate academic difficulties, such as delayed reading and writing skills, in the ASD population (Mayes & Calhoun, 2007).

As discussed, practical complications often arise in families with children who have a developmental disability, such as ASD (Lecavalier et al., 2006). With the complexity of ASD and the added challenges children with ASD often experience, additional time and energy are needed to care for these individuals (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). These families experience more challenges related to financial stress, psychological stress, restricted social activities, and decreased family functioning (Lecavalier et al., 2006). Children with ASD also tend to have several other comorbid medical disorders, such as gastrointestinal, sleep, and seizure disorders, that require additional caregiving responsibilities (Bauman, 2010). With the additional care required, caregivers themselves often experience several mental, physical, and social difficulties that could impact their quality of life and, in turn, could compromise their ability to appropriately care for the child, leading to a bidirectional negative effect (Schulz & Sherwood, 2008).

Caregiver Quality of Life

Quality of life is a difficult construct to define, as it is considered multidimensional and multileveled; however, the World Health Organization has defined quality of life as “an individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” (Skevington, Lotfy, & O’Connell, 2004, pp. 1). A reliable method to assess for an individual’s quality of life is through the World Health Organization’s Quality of Life Scale (WHOQOL Group, 1998). Several domains of

quality of life are composed of several related facets, but those of interest in the present study include physical health, psychological health, relationships, and the environment. Caregiver burden, which is often shown to significantly impact caregiver quality of life, is defined as “the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired family members,” thus essentially encompassing factors that directly impact quality of life (George & Gwyther, 1986; p. 253).

Impact on maternal caregivers. While caring for a child with ASD has several advantages, such as increased understanding and empathy for others, practical support, and parental empowerment, challenges also exist (Calzada, Pistrang, & Mandy, 2012). Research conducted with caregivers demonstrates that caregivers of those with a mental- or physical-health issue often experience stress, depression, worry, decreased well-being, loneliness, and decreased physical health, such as sleep difficulties (e.g., Hastings, 2003; Pinquart & Sorensen, 2003; Slaunwhite, Ronis, Sun, & Peters, 2017; Totsika, Hastings, & Vagenas, 2017). Additionally, caregivers often experience negative changes in their social, personal, and work lives (Pinquart & Sorensen, 2003). These outcomes result from a lack of time, resources, money, and energy to interact not only in their social lives with friends, but also in their intimate relationships (Pinquart & Sorensen, 2003).

Caregiver burdens can vastly impact a caregiver’s quality of life. For example, parents who have a child with a disability have been shown to have a compromised quality of life specifically because of mental-health difficulties resulting from caregiving (Khanna et al., 2011). These mental-health complications are often exacerbated by the increased perceptions of stress that often correlate with increased behavioral difficulties

(Khanna et al., 2011). Quality of life is also thought to be negatively impacted in caregivers of a child with ASD because these caregivers often report feeling unsupported by family and outside services, and they tend to lack effective coping strategies to deal with the stressors that accompany caregiving (Lin, Orsmond, Coster, & Cohn, 2011). Specifically, in regard to ASD-related symptomatology, a study conducted by Allik, Larsson, and Smedje (2006) identified that maternal caregivers' health-related quality of life was negatively related to their children's behavioral difficulties. Thus, when children engaged in higher rates of problematic behavior, the maternal caregivers' health-related quality of life was negatively impacted (Allik et al., 2006). This quality of life outcome was supported and expanded upon to include overall quality of life in a 2007 study comparing caregivers of children with ASD to caregivers of children who have other disorders (Lee et al., 2007).

While several caregiver burdens affect mothers and fathers equally, mothers of children with ASD are shown to have higher rates than fathers of anxiety and depression related to the rates of problem behavior exhibited by the child (Hastings & Brown, 2002). Similar results have not been found with fathers (Hastings & Brown, 2002). These trends with maternal anxiety and depression outcomes have been demonstrated in several studies emphasizing the importance of focusing on maternal quality of life (Johnson et al., 2011). Additionally, several factors that affect quality of life, such as perceived stress, are perceived more negatively and rated as more detrimental by maternal caregivers than by paternal caregivers, supporting a need to specifically investigate maternal caregivers' quality of life (Johnson et al., 2011). Consideration of gender norms also influences the focus on maternal caregivers, as the research shows mothers tend to

handle behavioral and academic concerns of their children more often than fathers (McBride & Mills, 1993).

Quality of care. The overall functioning of the family, but particularly that of the maternal caregiver, impacts the care provided to the child (Hastings & Brown, 2002). The mother more often experiences negative outcomes affecting her quality of life, and these factors are typically referred to as caregiver burden (Chappell & Reid, 2002). The quality of the care provided by the caregivers is often negatively impacted by the extensive burdens experienced by most caregivers (e.g., Fleming et al., 2006). For example, findings from a study that investigated perceptions of caregivers and patients demonstrated that the mental and physical health of the caregiver significantly correlated with the patient's health and perception of the quality of the care (Fleming et al., 2006). More importantly, a caregiver who is experiencing a poor quality of life may interact with a child in a maladaptive way, possibly further delaying progress of the child (Siller & Sigman, 2002). Research investigating parental/caregiver interactions with children who have ASD indicated that a caregiver's interactions with the child, such as social interactions, attention, and communication, tend to impact the child's behaviors (Siller & Sigman, 2002). Additionally, the way a caregiver handles stress and cares for his or her own health have been shown to associate directly with the child's stress and overall well-being (e.g., Fleming et al., 2006). Without social, financial, and other additional supports, caregiver burden may negatively affect parents' quality of life and therefore could negatively affect their children (Siller & Sigman, 2002).

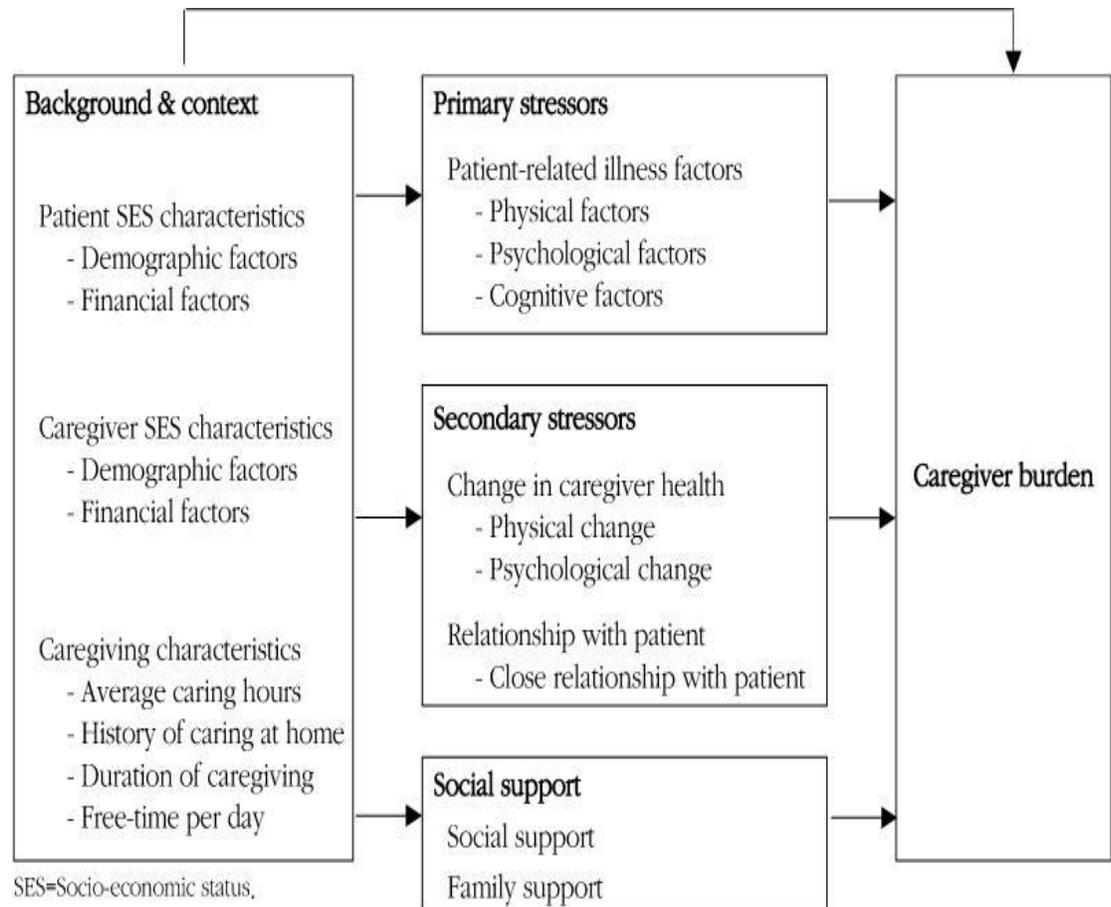
Transactional process of care. Quality of life is an important construct to evaluate when considering caregivers because quality of life in caregivers relates not only to the quality of care they provide, but also to the quality of life for the diagnosed child (Talley & Crews, 2007). The individuals caring for children with ASD often experience several stressors and burdens that can negatively impact their quality of life (Perry, 2004). The relationship between the caregiver's quality of life and the child demonstrates a bidirectional pattern of reciprocating influence (Hastings, 2003). Behavioral issues and complications exhibited by the child negatively impact the quality of life of the caregiver, and then the caregiver provides less-than-adequate care, therefore impacting the quality of life of the child (Schulz & Martire, 2004). Inadequate care can result in increased symptomatology in the child, further exacerbating the complications experienced by the caregiver (Schulz & Martire, 2004).

Stress Process Model and Caregivers

The stress process model helps to inform the understanding of the impact of certain variables, such as perceived stress and family cohesion, on caregiver quality of life (e.g., Pearlin, Menaghan, Lieberman, & Mullan, 1981). The stress process model (see Figure 1) provides a framework for understanding the complexities of stress and the factors influencing a caregiver's quality of life (Pearlin, 1999). This model includes several assumptions and focal points (Pearlin, 1999). For example, this model assumes that factors related to stress are interrelated (Pearlin, 1999). Second, the stress process model assumes that this process applies to the average person and is not strictly applicable to rare and extreme situations (Pearlin, 1999). Lastly, the focus of the model demonstrates that while different disciplines explain stress in unique ways, the

commonality among the disciplines is the interest in adaptive resources and individual outcomes (Pearlin, 1999). Further, this model is not intended to be a linear explanation of the stress process but rather a guide to understanding how life events and outcomes can be interpreted and perceived by an individual (Pearlin, 1999).

Stress as a concept is often the outcome following discrete life events or relatively continuous problems (Pearlin et al., 1981). Stress occurs when an individual is in a state of disequilibrium, and a new explanation of stress suggests that events are not the indicator of stress but rather the life strains that result from the events serve as the indicator (Pearlin et al., 1981). Several mediators exist between events and negative outcomes, such as stressors, familial support, or coping strategies, that can negate the negative outcomes (Pearlin et al., 1981). The following stress process model considers the complexity of stress and accounts for mediating and contextual factors.



The stress process model has been used to better understand how caring for someone can impact the outcomes of the caregiver (Pearlin, Mullan, Semple, & Skaff, 1990). This model elucidates caregiver burdens, background variables, chronic life stressors, current life events, coping abilities, and social supports to understand the process of stress and its impacts on caregivers' quality of life (Pearlin et al., 1981). The effect these variables have on the individual is said to change in severity over time, dependent upon the primary and secondary stressors currently affecting the individual (Raina et al., 2004). Overall, the model examines caregiver outcomes by first detailing background variables that could affect how the caregiver handles stress, such as different socioeconomic factors related to both the caregiver and the individual for whom he or she is providing care. These factors then affect primary and secondary stressors (e.g., patient-

related factors, health of the caregiver) the individual experiences, as well as impact the overall social support the person experiences. For example, this model explains that a caregiver's family and friends do not necessarily equate to support, but rather the level of cohesion and quality of the relationships are more indicative of access to support (Pearlin et al., 1981). When examining these factors together, caregiver burden can then be accurately explained and predicted.

The original application of this model examined the impact that such factors as life strains, self-concept, and social supports can have on an individual who is experiencing a major life event, such as a job loss (Pearlin et al., 1981). Since then, this model has been evaluated in a variety of different populations and settings, such as nursing homes for patients with Alzheimer's disease, within residential homes with caregivers caring for individuals with dementia, with parental caregivers of children with disabilities, and with spousal caregivers who care for someone in hospice care (e.g., Languette, Savage, Rosenburg, & Caserta, 2016; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Raina et al., 2004; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001)

Of interest is the application of this model to parental caregivers of a child with a disability (Cramm & Nieboer, 2011). The most recent application of the model with the ASD population included structured interviews exploring subjective caregiver burden, depression, and supports of 70 maternal caregivers (Singh, Ghosh, & Nandi, 2017). In this qualitative study, higher levels of caregiver burden significantly predicted increased levels of negative outcomes, such as higher levels of depression, among the caregivers (Singh et al., 2017).

In relationship to maternal caregivers of a child with ASD, the stress process model provides a framework for understanding how primary stressors, such as severity of symptomatology experienced by the child with ASD, and secondary stressors, such as the bonding with the child, can impact caregiver outcomes. With these stressors, a lack of perceived social or familial support further exacerbates the poor caregiver outcomes. These stressors and support are all further impacted by such background factors as finances; therapeutic services and appointments; demographic variables, such as level of education; and hours of care. The model can help to explain how family functioning (e.g., family cohesion) and social supports may be just as impactful on caregiver outcomes as stressors (Pearlin et al., 1981).

Caregivers and Perceived Stress

Maternal caregivers' perceived stress significantly predicts caregivers' quality of life (e.g., Pinquart & Sorensen, 2003). Perceived stress is defined as "a condition subjectively experienced by an individual who identifies an imbalance between demands addressed to him/her and the resources available to encounter these demands" (Kausar, 2010, pp. 1). More specifically, caregivers' perceived stress is defined as a caregiver's response to a variety of fundamentally intolerable situations: discrete life events, possibly converging with chronic life strains and exacerbated by certain self-concepts and values that manifest in a variety of ways affecting the individual (Amirkhanyan & Wolf, 2003). With stress being a multidimensional construct that is ever changing, and individually unique, perceived stress more accurately captures the actual perception and experience of the individual (Cohen, Kamarck, & Mermelstein, 1983). However, while stress alone is often ever changing, many caregivers experience life strains that are often more stagnant

(Pearlin, 1981). Additionally, with stress often being interpreted through an individual's own cognitive appraisal of a situation, objective stress does not always capture the full picture (Cohen et al., 1983).

Caregiver quality of life has also been shown to be impacted by increased perceived stress levels (e.g., Pinqart & Sorensen, 2003). A meta-analysis examining caregivers versus noncaregivers identified that particular stressors impacting caregivers were also shown to impact caregiver quality of life, but similar results were not shown for noncaregivers (Pinqart & Sorensen, 2003). Some of the stressors identified included behavioral problems of the individual being cared for, increased need for child supervision, social isolation of the caregiver, and lack of gratitude expressed by the individual receiving care (Pinqart & Sorensen, 2003). While this study was exploring caregivers in general, each of these factors is relevant in the ASD population.

Additionally, research has reliably demonstrated that perceived stress is a predictor of caregiver's quality of life for caregivers who have a child with ASD (e.g., Lee et al., 2009; Johnson et al., 2011). Anywhere from 15 to 22% of the variance of caregivers' quality of life with this population is explained by perceived stress (e.g., Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson., 1999; Johnson et al., 2011; Lee et al., 2009). With the ASD population, the ambiguity of the diagnosis, as well as the severity and duration of symptomatology, often presents a large stressor for caregivers. Self-reports indicate that these caregivers experience more perceived stress and adjustment problems than caregivers of a child with Down syndrome or of a neurotypical child (Sanders & Morgan, 1997). Although deficient adaptive skills are shown to be stressful for caregivers of youth with ASD, behavioral problems have a

much greater impact on the caregiver's perceived stress (Lecavalier et al., 2006). In a study of parents and teachers of 293 children with ASD, both groups agreed that behavioral problems strongly impacted their perceived stress (Lecavalier et al., 2006). However, adaptive skills did not demonstrate the same association in that caregivers were more able and willing to put more energy into daily life skills, such as learning to cook, brush teeth, and get dressed, when compared to behavioral challenges, such as tantrums, noncompliance, or rigidity (Lecavalier et al., 2006). Other research also demonstrated that maternal caregivers report experiencing more stress when behavioral difficulties are more severe as these behaviors often cause embarrassment in public situations and increased time and attention to care for the child (Estes et al., 2009).

Returning to this idea of a transactional process and looking at this problem through a systemic lens, several of the behavioral and cognitive difficulties that are often present in ASD create substantial stress in caregivers, and this perception of stress has been shown repeatedly to negatively impact the caregiver's quality of life (e.g., Pinquart & Sorensen, 2003). This transactional process is particularly relevant because parental perceived stress in caregivers of a child with ASD and the child's behavioral problems continue to exacerbate one another in a cycle of reciprocating influence. For example, parental perceived stress increases following increased behavioral problems, and, in turn, the child perceives the increased emotional reactions from his or her parents and will likely engage in more problematic behavior in response (Lecavalier et al., 2006).

Perceived stress and mental health. A caregiver's perceived stress, particularly for maternal caregivers, correlates not only with the child's behavior, but also with the mental health of all the family members who are coping with the differences and changes

needed for the child who has the disability (e.g., Hastings, 2003). If other children are receiving less attention or are having difficulty coping with the differences in their sibling, maternal caregivers may experience increased perceived stress worrying about their other children (e.g., Hastings, 2003). Also, caregivers of children with ASD have been shown to experience higher levels of aggravation and perceived stress than parents who have a neurotypically developing child. This report of heightened stress was even greater for families that currently have special services, such as behavioral therapy services, provided in the home for the child, because of the added time and effort required to engage in these services (Schieve et al., 2007). Further, services are more intensive and time consuming for high levels of maladaptive behavior, creating additional stress for the caregivers (Bolte, 2014). Additionally, Pinquart and Sorensen (2003) demonstrated that caregivers in general on average perceive more stress, experience more depressive symptomatology, and have lower levels of subjective well-being, self-efficacy, and physical health when compared to non-caregivers. Further, correlations have been demonstrated between social-skill deficits and a caregiver's perceived stress level, showing that caregivers who have a higher perceived stress level also tend to have a child with more severe social-skill deficits (Schieve et al., 2007). Perceived stress was also shown to increase immediately following an ASD diagnosis, and the perception of stress increased more with increases in the severity of symptoms, lack of parental coping strategies, decreased social support, and increases in other life demands (Stuart & McGrew, 2009).

Perceived stress and physical health. In conjunction with the psychological components of the perceived stress these caregivers experience, the damages that the stress causes to the physical body and overall health of these individuals is often significant (Miodrag & Hodapp, 2010). Miodrag and Hodapp (2010) conducted a meta-analysis of several past studies that examined parental perceptions of stress and linked this stress to physical-health implications. The research revealed a positive relationship between perceived stress and physical-health complications within the cardiovascular, immune, and gastrointestinal systems (Miodrag & Hodapp, 2010).

Perceived stress and support. Additionally, when caring for a child with a disability, several unique stressors are related to support, such as finding services, receiving informal supports from family and friends, providing time and energy to learn how best to help the child, and altering daily activities in the home to accommodate the child (e.g., Weiss, 2002). Often, when caregivers are trying to support their children and provide them with the resources to help them flourish, they tend to neglect their own needs and experience feelings of stress as a result (Acton, 2002). A descriptive research study conducted with families who had a child with a disability indicated that maternal caregivers felt their social lives, working lives, and family relationships were negatively impacted (Sen & Yurtsever, 2007). Further, many families have reported feelings of hopelessness and an overall lack of help or support from the greater governmental system, mental-health insurance, school staff, and extended family members, further contributing to the level of perceived stress experienced (e.g., Sen & Yurtsever, 2007).

While perceived stress has been demonstrated to impact caregivers' quality of life, the stress process model explains that perceived stress is not the sole factor

responsible for outcome variables (Pearlin et al., 1981). Therefore, in addition to investigating perceived stress, other factors that may also be responsible for impacting maternal caregivers' quality of life should be investigated. One factor of interest is family cohesion and the impact family cohesion have on quality-of-life outcomes among maternal caregivers.

Caregivers and Family Cohesion

As quality of life is a complex construct impacted by many different factors, one should consider more than stress-related outcomes when determining the quality of life of the caregiver, particularly the maternal caregiver (Dardas & Ahmad, 2014). Additionally, research has reliably demonstrated that the environment is integral in the development of the child and that a well-functioning family system can decrease the overall perceived stress experienced by family members (Altiere, 2006). A major factor to consider is support, and one aspect of support relates to family functioning and cohesion. Family cohesion is the shared affection, support, helpfulness, and caring among family members (Barber & Buehler, 1996). A strong level of family cohesion is thought to correlate with more positive parental outcomes (McStay, Trembath, & Dissanayake, 2014). Past studies have suggested that living with a person who has a disability, whether medical- or mental-health related, may present challenges within the family dynamic and overall family functioning (Cridland et al., 2014). Poor cohesion within the family system can create additional stressors for caregivers, decrease their supports, and impact their quality of life, in turn tending to impact the care the child is receiving (Ekas et al., 2016).

Family cohesion has been investigated as potentially impacting caregivers' quality of life with several populations (e.g., Hocking et al., 2011). For example, this relationship has been investigated with patients with lung cancer and their caregivers (Simonoff, Wilson-Genderson, & Baker, 2010). Simonoff et al. (2010) demonstrated that ratings of unhealthy family cohesion among patients and caregivers correlated with higher levels of depression among the caregivers. This relationship was noted to impact caregivers' quality of life (Simonoff et al., 2010). Similarly, Crespo, Carona, Silva, Canavarro, & Dattilio (2011) investigated the relationship between caregiver burden, family environment, and quality of life with caregivers of children with asthma. The researchers developed structural equation models of caregivers' perceptions of family cohesion based on a sample of 97 families (Crespo et al., 2011). The models demonstrated that caregivers' perceptions of family cohesion were correlated with both the caregiver's and child's quality of life (Crespo et al., 2011). Additionally, perceptions of family cohesion mediated the relationships between caregiver burden and quality of life, demonstrating that caregiver burden does not necessarily equate to quality of life, but it does relate when considering mediating factors, such as perceptions of family cohesion (Crespo et al., 2011). The model indicated that when levels of burden were higher, parental perceptions of family cohesion were more negative, in turn decreasing the quality of life of both the child and the caregiver (Crespo et al., 2011). Furthermore, Hocking et al. (2011), surveyed children with brain tumors and their caregivers to develop a model to understand survival and determined that healthy levels of cohesion not only increased coping, resources, and support but also promoted a better quality of life. The positive relationship between family cohesion and quality of life has been

demonstrated with medical patients and children with severe physical-health complications across numerous studies (e.g., Crespo et al., 2011).

Family cohesion more recently emerged as a factor impacting the quality of life in caregivers of children with ASD (e.g., Myers et al., 2009). The added difficulties that accompany caring for a child with ASD often negatively impact family cohesion, which is the support, care, and affection for one another within the family (e.g., Meadan, Halle, & Ebata, 2010). Additionally, parenting difficulties often increase, particularly with increased behavioral challenges (Myers et al., 2009). The time spent caring for these additional concerns often negatively impacts marital relationships, thereby decreasing the support and bonding within the family (Myers et al., 2009). With the social-skill deficits and increased attention needed in children with ASD, sibling relationships are often negatively impacted as well (Myers et al., 2009). Understanding these relations through a systemic view suggests that family cohesion may be an important factor that helps to predict caregivers' quality of life and the care children receive.

Only a few studies within the last 2 decades have examined the impact of family cohesion on the quality of life of caregivers of youth diagnosed with ASD, with mixed results. For example, Higgins et al. (2005) found that families with a child with ASD experienced considerable stress and decreased marital satisfaction, decreased family cohesion, and decreased family adaptability. These findings support further investigation of these variables as potential factors involved in the quality of life of both the caregivers and the children (Higgins et al., 2005). Another study, conducted by Gau et al. (2012), demonstrated relevant findings regarding the impact of family cohesion on caregivers' quality of life in the ASD population but also specifically identifies a mother's

maladjustment to having a child with ASD. Gau et al. (2012) surveyed 151 Taiwanese families with a child with ASD and 113 who had a neurotypical child. The findings suggested that mothers are more impacted than fathers psychologically and in their perceptions of the family functioning (Gau et al., 2012). The findings also demonstrated that families with a child with ASD suffer more psychopathology-related issues and have less dyadic consensus (Gau et al., 2012). In another study, family cohesion was assessed as a moderator of the relationship between maternal characteristics and adjustment for both Hispanic and Caucasian families (Ekas et al., 2016). Benefit finding, optimism, and support were shown to increase maternal adjustment and family cohesion (Ekas et al., 2016). These findings indicate that numerous factors impact maternal outcomes and illustrate why exploring more than stress is helpful (Ekas et al., 2016). Also, in those families with a child who has ASD, severe behavioral symptomatology of the child was related to heightened family conflict, demonstrating the impact the child's behavior has on the family and also the impact the family environment has on the child (Kelly, Garnett, Attwood, & Peterson, 2008). One additional study investigated the impact of cohesion and adaptability levels on coping styles and found that families with stronger levels of cohesion and adaptability were significantly more likely to use positive coping strategies (Altiere & Von Kluge, 2009). These studies provide preliminary support for family cohesion as an impactful factor affecting the quality of life of maternal caregivers who have a child with ASD.

However, a few studies describe some differences among the research and provide some general considerations to the topic of stress and family factors within other specific populations. For example, Rodrigue, Morgan, and Geffken's (1990) study

revealed that mothers of a child with ASD report more family cohesion than that reported by mothers of typically developing children and by families with a child with Down syndrome. Twenty families were included in each group and were recruited from middle- to upper-class families. The results demonstrated that families with a child with ASD have higher levels of cohesion than families with typically developing children, but the researchers made several cautionary statements. While the cohesion was shown to be higher, a finding that is rather contradictory to most other research, the cohesion levels were high to a fault. These families often experienced enmeshment, resulting in poorer adaptation. Enmeshed families are often overly restrictive and involved to the point where it may disrupt the growth and independence of the diagnosed child (Altieri, 2006). Additionally, the researchers noted that the children in the ASD group were young and had a seemingly neurotypical physical presentation. The researchers suggested that the families might be hopeful the impairments were only temporary (Rodrigue et al., 1990). Additionally, Kelly et al. (2008) investigated the impact of family conflict, cohesion, and peer support on ASD symptomatology in 322 families through structural equation modeling. The results demonstrated that family cohesion did not predict anxiety, depression, or increased symptomatology in the children; however, impacts on the caregivers were not evaluated. Related research showed that perceptions of family interactions (e.g., conversations, participation with one another) were reported consistently across families regardless of having a child with ASD; however, this study did not specifically explore cohesion (Koegel, Schreibman, O'Neill, & Burke., 1983).

Support and helpfulness. Research has indicated that additional stress often develops from lack of support, whether formal or informal, as well as from additional background contexts, such as socioeconomic characteristics and symptomatology of the individual being cared for (Pearlin et al., 1981). Supports are defined as “perceived or actual instrumental and/or expressive provisions supplied by the community, social networks, and family” (Zimet, Dahlem, Zimet, & Farley, 1988, pp. 31). A major source of informal support comes from family members and cohesion within the family unit (Olson, Sprenkle, & Russell, 1979). Raising a child with ASD often involves additional time and resources, particularly challenging with a lack of support (Ludlow, Skelly, & Rohleder, 2012). Additionally, the increased time spent trying to care for the child with ASD can lead to increased jealousy among siblings, less time to care for other children, and marital issues (e.g., Rivers & Stoneman, 2003; Ward, Tanner, Mandelco, Dyches, & Freeborn, 2016).

Bonding and affection. Research demonstrates that high levels of family cohesion increase family functioning, bonding, and teamwork (Gau et al., 2012). Children with ASD often struggle to appropriately engage with others socially, even with family members, impacting the bond within the family unit (Hudson et al., 2017). Family cohesion is often decreased because the bond between the caregiver and child is weak (Hudson et al., 2017). Research has investigated the impact of impaired family cohesion on quality of life in families with a child with a disability, but few studies have explored the effect of family cohesion on maternal quality of life specifically (e.g., McStay, Trembath, & Dissanayake, 2014). Furthermore, the studies that have

investigated familial quality of life are minimal and recommend further investigations of this construct (e.g., McStay et al., 2014).

The research on familial quality of life has demonstrated common perceptions parents have and the impact of these factors on parental quality of life. For example, in the study by Myers et al. (2009), 493 parents were questioned through a qualitative analysis regarding the impact on their lives of having a child with ASD. Most of the responses were negative in nature, indicating that parents reported mostly negative reactions to having a child with ASD, but a few had only positive reactions. Findings from this study indicated several negative outcomes for these caregivers, such as perceived stress, isolation, marital issues, and decreased parental well-being. Therefore, while perceived stress was a common emergent theme, familial relations were also greatly affected because parents tended to devote a great deal of energy to helping the child with ASD. Thus, the siblings of these children often received less attention, and the parents spent less alone time with their spouses, often leading to marital strain and further impacting family cohesion. The most common negative theme was perceived stress, with greater than 70% of the caregivers' responses including themes related to perceived stress. The positive themes that emerged essentially encapsulated only positivity in the face of adversity (Myers et al., 2009).

Maternal caregivers and cohesion. Past research investigating perceptions of family dynamics has shown that family cohesion was perceived by the mothers to be weaker in families with a child with ASD. For example, in a study with 151 families with a child with ASD and 113 families with typically developing children, investigators assessed psychopathology, family functioning, and marital distress through caregiver

report (Gau et al., 2012). The study results revealed that mothers who had a child with ASD perceived less family cohesion when compared to parents who had typically developing children. Maternal perception of family cohesion was positively correlated with the perceived quality of life of these mothers. These factors were not shown to be as problematic when rated by fathers, further emphasizing the importance of the investigation into the mothers' interpretations in this study. Fathers who were caregivers of a child with ASD were shown to be impacted by being a caregiver, but the outcomes were not significant when compared to norm groups (Gau et al., 2012). Additionally, Rodrigue et al. (1990) noted that mothers with a child with ASD were more likely than fathers to experience a lack of resources and increased loneliness and responsibility.

Conclusion

Several previous studies have explored perceived stress as a main predictive factor in maternal caregivers' quality of life. However, few studies have specifically explored family cohesion and its impact on maternal quality of life within the ASD population. Given the bidirectional relationship between caregiver outcomes, care provided, and symptomatology of the child with ASD, caregivers' quality of life in families with a child with ASD must be examined (Schulz & Martire, 2004). While quality of life is a complex construct, certain variables have been identified as predictors of quality of life (e.g., Orsmond, Seltzer, Greenberg, & Krauss, 2006). Identifying specifically the factors and the degree to which quality of life is impacted can lead to more directed research in the future. The present study explored family cohesion and perceived stress as primary factors and addressed several of the limitations of past studies. The limitations addressed in the present study include small sample sizes, lack of

diversity in samples, and geographic relevance. The current study extends on these previous studies, accounts for limitations and considerations, and is the only study to investigate through quantitative measures perceived stress and family cohesion as predictors for quality of life of mothers who have a child with ASD.

Chapter 2:

Hypotheses

1. After controlling for income, hours of respite care, and severity of the child's diagnosis, perceived stress and family cohesion will significantly predict *physical-health*-related quality of life in a sample of mothers who have a child with autism spectrum disorder (ASD).
2. After controlling for income, hours of respite care, and severity of the child's diagnosis, perceived stress and family cohesion will significantly predict *psychological-health*-related quality of life in a sample of mothers who have a child with autism spectrum disorder (ASD).
3. After controlling for income, hours of respite care, and severity of the child's diagnosis, perceived stress and family cohesion will significantly predict quality of life regarding *social relationships* in a sample of mothers who have a child with autism spectrum disorder (ASD).
4. After controlling for income, hours of respite care, and severity of the child's diagnosis, perceived stress and family cohesion will significantly predict quality of life related to one's *environment* in a sample of mothers who have a child with autism spectrum disorder (ASD).

Chapter 3: Method

Overview

The main objective was to investigate whether after controlling for household income, hours of respite care, and severity of the child's diagnosis, family cohesion and perceived stress would significantly predict quality of life in a sample of mothers who had a child with Autism Spectrum Disorder (ASD). This objective was examined across four domains of quality of life: physical health, psychological health, relationships, and environment.

Participants

Power analyses indicated that to obtain power of 0.8 and a .15 medium effect size, 91 participants were needed for five predictor variables at a .05 probability level (Cohen, 1992). The investigator recruited participants via social media (i.e., Facebook) and other online outlets, such as Instagram and AutismSpeaks. These places either did not have their own formal Internal Review Board (IRB) committee or were willing to submit this study through their IRB process. The study attempted to garner a culturally diverse sample by contacting participants from various parts of the country through social media. Additionally, the investigator contacted AutismSpeaks to inquire about advertising this study.

In total, 115 maternal caregivers of children diagnosed with ASD participated in this study. Of the 115 completed surveys, 103 were completed by individuals who identified as Caucasian (89.6%), four as African American (3.5%), one as American Indian or Alaskan Native (0.9%), two as Middle Eastern (1.7%), three as Other (2.6%), and two chose not to answer (1.7%). These participants ranged in age from 25 to 55 years

old. Of these participants, 26 identified as single (22.6%), 78 as married (67.8%), seven as divorced (6.1%), and four as separated (3.5%).

Some diversity of educational status was represented in this sample, with two participants reporting less than a high-school education (1.7%), 40 having completed high school or obtained their GED (34.8%), 19 with an associate's degree (16.5%), 33 with a bachelor's degree (28.7%), 15 with a master's degree (13.0%), five with a doctorate degree (4.3%), and one with a professional degree (0.9%). Regarding annual household income, 17 reported less than \$20,000 (14.8%), 19 reported \$20,000 to \$34,999 (16.5%), 22 reported \$35,000 to \$49,999 (19.1%), 33 reported \$50,000 to \$74,999 (28.7%), six reported \$75,000 to \$99,999 (5.2%), and 18 reported over \$100,000 (15.7%).

Additional relevant factors assessed in this study related to the other children in the home. The participants reported demographic information related to mental and physical health of their other children. Eighty participants (69.6%) reported their other children did not have any medical conditions requiring ongoing care, 24 (20.9%) had one child requiring ongoing medical care, six (5.2%) had two children needing medical care, three (2.6%) had three children requiring ongoing medical care, and two (1.7%) had four or more children requiring ongoing medical care. In regard to mental-health concerns, 77 participants (67%) reported they did not have any other children with a mental-health diagnosis, 28 (24.3%) had one other child with a mental-health diagnosis, three (2.6%) had two other children with a mental-health diagnosis, six (5.2%) had three other children with a mental-health diagnosis, and one (0.9%) had four or more other children with a mental-health diagnosis. Further, participants were asked specifically about their other

children, and whether they too had an ASD diagnosis. Of the 115 participants, 73 (63.5%) did not have other children with this diagnosis, 25 (21.7%) had one other child with the diagnosis, 12 (10.4%) had two other children with the diagnosis, and five (4.3%) had three other children with the diagnosis. Participants were also asked the age at which the target child was diagnosed, the number of hours of services the child receives, and the number of hours of respite care provided. Regarding age of diagnosis, 30 (26.1%) children were diagnosed at age 2 years, 29 (25.2%) at age 3 years, 20 (17.4%) at age 4 years, 14 (12.2%) at age 5 years, seven (6.1%) at age 6 years, four (3.5%) at age 7 years, five (4.3%) at age 8 years, five (4.3%) at age 9 years, and one (0.9%) at age 12 years. Of these participants, the hours of services provided weekly ranged significantly (0 hours to 60 hours), but the majority (57 participants) reported receiving 3 or fewer hours every week. Respite care services also had a substantial range from 0 to 33 hours per week, with only 17 participants reporting that they received any respite care at all. The low rates of reported respite care in part is likely because of lack of knowledge regarding resources and extensive waiting lists.

Another significant participant factor is the family setup. Of the 115 participants, 66 (57.4%) reported having a nuclear family. An additional seven participants (6.1%) reported living in a cohabitating family. Further, four (3.5%) participants reported living in an extended family, six (5.2%) in a reconstituted family, 29 (25.2%) in a single-parent family, and three (2.6%) in a different/other family setup.

Inclusion

Participants from this study were biological mothers of children diagnosed with ASD. The children of the participants were between the ages of 5 and 12 years old and lived in the United States.

Exclusion

Individuals excluded from participation in this study were those caregivers who were not the biological parent of the child, but who were still caring for the child. Further, caregivers of children who had a primary diagnosis other than ASD were excluded from participation in this study.

Design

This study used a correlational design. The independent variables were perceived stress as well as family cohesion, after controlling for the severity of the diagnosis, income, and hours of respite care. The dependent variables under investigation were the four domains of quality of life of the maternal caregivers: physical health, psychological health, social relationships, and environment. Multiple regression analyses were conducted to assess for whether these different factors reliably predict quality of life among maternal caregivers of a child with ASD, based on the scores of the factors included in the study. Multiple regression analyses are often used in the psychology field, as they help to test hypotheses to determine whether predictive effects exist and, if so, the strength of these effects and to compare these effects among the different groups within the design (Stolzenberg, 2004). These analyses are used to predict the value of a specific dependent variable contingent on the values of the other variables of interest, namely the independent variables (Stolzenberg, 2004).

Measures

Demographic Information

A demographic questionnaire with supplemental questions was included in the online questionnaire completed by the participants. This measure included questions regarding age of parent and child, income, gender, race, number of children in the home, length of time receiving services for the child, hours of respite care, age of child at the time of diagnosis, and marital status. See Appendix A.

Columbia Impairment Scale (CIS)

The Columbia Impairment Scale (CIS) is a 13-item scale designed to measure impairment. The scale assesses four domains of functioning: interpersonal relations, broad psychopathological domains, functioning in job or schoolwork, and use of leisure time. Each question ranges from 0 (*not a problem*) to 4 (*a very big problem*). In previous studies, the internal validity was shown to range from 0.762 to 0.826, and the reliability was also shown to be strong (Zanon, Tomassoni, Gargano, & Granai, 2016). See Appendix E.

World Health Organization Quality of Life Brief Scale (WHOQOL-BREF)

The World Health Organization Quality of Life Brief Scale (WHOQOL-BREF) was developed by a group led by Dr. J. Orley in 1996. This questionnaire was used to assess maternal quality of life. This scale is an abbreviated version of the WHOQOL. It includes 26 questions, which are assessed on a 5-point Likert scale that ranges from *never* to *very often*. The WHO identified 25 facets of quality of life via a cross-cultural assessment composed of 100 questions (Skevington et al., 2004). The WHOQOL-BREF was developed to assess for quality of life in populations in which time is restricted,

burden should be minimized, and the specific facet interpretation is not as crucial to the outcomes of the assessment (Skevington et al., 2004). This scale assesses the facets previously noted across four domains based on their relevance to one another (Skevington et al., 2004). The four domains are physical health, psychological health, social relationships, and environment. The physical-health domain investigates such aspects as activities of daily living, energy and fatigue, mobility, pain and discomfort, sleep and rest, work capacity, and dependence on medical substances and aids. The psychological domain includes body image and appearance; negative and positive feelings; self-esteem; spirituality/religion/personal beliefs; and thinking, learning, memory, and concentration. The social relationships domain is made up of personal relationships, social support, and sexual activity. Lastly, the environment domain consists of questions related to financial resources, freedom, physical safety, security, health and social care, acceptability and quality, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment (e.g., pollution, noise, traffic, climate), and transportation. In previous studies, the internal consistency of this measure ranged from 0.64 (Domain 2) to 0.80 (Domain 1). The test-retest reliability ranged from 0.49 to 0.88. Validity was examined through numerous methods. Concurrent validity was explored by taking self-reports on subjective health. These scores correlated to Domains 1 through 4 at .65, .44, .32, and .45, respectively. Discriminant validity was shown to be very high and to have a strong ability to distinguish between healthy and unhealthy participants. This measure has demonstrated the ability to accurately predict quality of

life, as well as a history and reliability when applied to caregiver populations (Hasanah, Naing, & Rahman, 2003). See Appendix B.

Perceived Stress Scale (PSS)

The Perceived Stress Scale (PSS), developed by Cohen et al. (1983), assesses the subjective score of perceived stress experienced by maternal caregivers. This measure consists of 10 questions, rated on a 5-point Likert scale ranging from 0 (*never*) to 4 (*very often*). Coefficient alpha reliability has been shown to range from .84 to .86, and the test-retest reliability has ranged from .55 to .85. This measure was used because of its continued and successful application in studies assessing perceived-stress scores, as well as its high degree of reliability (Cohen et al., 1983). See Appendix C.

Family Environment Scale (FES)

The third measure was the Family Environment Scale (FES), which was developed by Moos and Moos in 1994. This scale is a 90-item, self-report measure that assesses the family environment through responses to true (1) and false (0) questions (Moos & Moos, 1994). This measure includes 10 subscales; however, only the cohesion subscale, which includes nine items shown to demonstrate the level of cohesion within a family, was evaluated (Moos & Moos, 1994). This subscale is included in the family relationship domain of the scale and examines the degree of commitment and support provided by family members to one another (Moos & Moos, 1994). Internal consistency estimates range from .61 to .78, with the cohesion subscale scoring the highest at .78 (Moos & Moos, 1994). Test-retest reliabilities ranged from .68 to .86, again with the cohesion subscale scoring .86. Additionally, this measure has demonstrated reliability in an item to scale correlation for family cohesion at .58 (Sholevar, 2008). The convergent

validity of this measure has been shown to be high, although at times difficult to assess with the lack of measures focused on similar constructs. Validity has been demonstrated to be high by the significant relationships between parent and child administrations (Moos & Moos, 1981). This measure was used because of its ability to test for an individual's perception of the cohesion within his or her family, as well as the reliability and validity demonstrated in other research using this scale (Sholevar, 2008). See Appendix D.

Procedure

The investigator obtained IRB approval from the Philadelphia College of Osteopathic Medicine. Following the IRB approval, the four surveys and demographic questions were uploaded to SurveyMonkey.

The investigator recruited participants through social media by posting a request for participation on such platforms as Facebook, online groups, and healthcare agencies. The link for the survey containing the study questionnaires was included in the request for participation on social media. The investigator requested that anyone who met the requirements or knew anyone who did to either complete the survey or pass on the information to someone they knew. Those who agreed to participate completed a survey including demographic questions, the CIS, the PSS, the FES, and the WHOQOL-BREF, which required approximately 15 to 20 minutes to complete in total. The researcher emphasized that participants had the right to stop participation at any time. Further, the investigator explained that all who participated could be included in a drawing to be one of 10 individuals to win a \$10 gift card to Giant Food Stores. With 115 completed surveys, participants had approximately a 1 in 11 chance of winning a gift card. After

completing the survey, participants who were interested in being entered into the raffle were provided instructions for entering the drawing. This method ensured that names were not linked to the surveys.

Following accumulation of the surveys, the investigator analyzed and interpreted the results using SPSS and then drew names from the pool of participants entered for the drawing to determine the winners of the compensation prize. The winners were notified by e-mail. The data collected were also kept confidential and anonymous throughout the study.

Chapter 4: Results

Statistical Analysis

Stepwise linear multiple regression analyses were conducted using SPSS 22.0 to assess whether after controlling for income, hours of respite care, and severity of diagnosis, perceived stress (PSS) and family cohesion (FES) predicted quality of life (WHOQOL-BREF). The stepwise method of regression was employed to partial out the effects of perceived stress, which have been shown to predict quality of life of caregivers reliably and consistently in past research (e.g., Rivers & Stoneman, 2003). A regression analysis was completed for each of the four factors that make up quality of life as described by the World Health Organization (WHO): (a) physical health, (b) psychological health, (c) social relationships, and (d) environment. Sample means, minimums, and maximums are included (See Table 1).

Prior to the use of regression models, certain assumptions must be met and evaluated. First, all predictor variables must be quantitative or categorical. Each of the independent variables in this analysis are quantitative. Normality of the outcome variables must also be determined. Normality was determined by conducting the Shapiro-Wilk test of normality, which verified normality for Regression 2 only (i.e., psychological domain of quality of life). In a sample this size, further evaluation of Q-Q plots is recommended to determine if the Shapiro-Wilk test was too sensitive to minor shifts in data. When evaluating the Q-Q plots, each outcome measure was normally distributed.

*Table 1**Descriptive Statistics for Predictor and Outcome Variables (N = 115)*

	Minimum	Maximum	Mean	Standard Deviation
Behavior severity (CIS)	10	52	34.066	7.62
Respite care (hours)	0	33	1.04 ^a	4.16 ^a
Income ^b	1	6	3.4	1.58
Family cohesion (FES)	10	16	12.73	1.50
Perceived stress (PSS)	14	40	26.14	6.08
Physical health (WHOQOL)	7	32	23.62	4.98
Psychological health (WHOQOL)	6	27	17.53	4.62
Social relationships (WHOQOL)	3	15	8.82	3.29
Environment (WHOQOL)	15	39	26.40	5.41

^a Only 17 participants reported receiving respite care. These hours ranged from 1-33 hours per week. Most of the participants did not receive respite care likely because of lack of knowledge regarding resources. ^b Income options were coded in the survey. Options ranged from 1.00 (less than \$20,000) to 6.00 (greater than \$100,000).

Further, the outcome variable must also be quantitative, continuous, and unbounded, and a linear relationship between the outcome variable and the independent variables must be demonstrated. The linearity was assessed through analyzing scatter plots and P-P plots. Regressions 2, 3, and 4 each demonstrated a strong linear

relationship. Regression 1 demonstrated that the general trend was linear but with a few outliers. Therefore, this regression was interpreted with this caveat in mind (Field, 2013).

Additionally, the predictor variables cannot be correlated with one another, as this correlation would cause multicollinearity whereby the independent variables are too highly correlated and variance cannot be differentiated (Field, 2013). Correlation matrices were completed, and values less than .80 indicated that multicollinearity was not present between the independent variables. See Table 2 for the correlation matrix.

Table 2

Correlation Matrix

	Physical health QOL	Psychological health QOL	Relationship QOL	Environment QOL	Behavior Severity	Hours of respite	Income	PSS	Cohesion
Physical QOL	1.000	.668	.477	.616	-.038	-.037	.320	-.574	-.214
Psychological QOL		1.000	.639	.663	.042	-.005	.281	-.743	-.347
Relationship QOL			1.000	.671	.095	.017	.429	-.602	-.486
Environment QOL				1.000	.008	.033	.625	-.576	-.371
Behavior severity					1.000	-.103	.046	-.066	-.085
Hours of respite						1.000	-.056	.036	-.029
Income							1.000	-.274	-.279
Perceived stress								1.000	.294
Cohesion									1.000

The boldfaced numerical values signify values of significant correlations.

In Table 2, income related to environmental quality of life. This relationship is logical in that if one has lower income, one is less likely to upgrade one's home/environment. Additionally, a family supporting a child with additional needs will likely have to use any extra income for resources that child might need. Income was related to other domains of quality of life but not as highly correlated as it was with environmental quality of life.

Perceived stress also highly negatively correlated with psychological health quality of life and relationship quality of life. Individuals who reported that their relationships with others were poor or their psychological health was low tended to have increased levels of perceived stress. Individuals with limited supports and increased mental-health symptomatology experience stress as a byproduct of life stressors and lack of support.

Regression analyses must also meet the assumption that the predictors have some variation in value and do not have a variance of zero. To assess for homogeneity of variance, plots of standardized predicted values against standardized residuals were reviewed and indicated no violations in the assumption of homogeneity of variance. As no clear pattern appeared, the homoscedasticity of the sample can be assumed, meeting this final assumption. However, examination of case-wise diagnostics showed three cases with standardized residuals with absolute values greater than 2.5, one in the regression analysis predicting physical-health quality of life and two in the regression analysis predicting psychological-health quality of life (approximately 0.008% and 0.017% of the sample, respectively). According to Field (2013), having less than 1% of cases with standardized residuals with absolute values greater than 2.58 is best. Having more than

1% of cases with standardized residuals with absolute values greater than 2.58, such as in the regression analysis predicting psychological-health quality of life, suggests potential error. Field (2013) also suggested that 99.9% of cases should have absolute values that fall between -3.29 and 3.29. Each of the previous three cases fell within this given range, and therefore, interpreting both regressions were considered acceptable with the understanding that some caution was needed with the regression predicting psychological-health quality of life.

Hypothesis 1

To determine whether perceived stress and family cohesion could predict quality of life for Domain 1 (i.e., physical health), a hierarchical regression analysis was conducted to examine perceived stress and family cohesion as predictor variables and quality of life as the outcome variable. The base model including the covariates of behavioral symptomatology, hours of respite care, and income was found to be statistically significant, $R^2 = .102$, $F(2, 110) = 6.268$, $p < .05$. The second model including the covariates of behavioral symptomatology, hours of respite care, and income, and the inclusion of perceived stress as the predictor variable was found to be statistically significant, $R^2 = .402$, $F(1, 109) = 54.598$, $p < .001$, with 36.2% of the variance accounted for in the outcome variable. With the addition of family cohesion scores in the third step, the model was not statistically significant, $R^2 = .404$, $F(1, 108) = .413$, $p > .05$. No additional variance was accounted for after adding family cohesion to the model. See Table 3.

Table 3

Physical Health Quality of Life Regression

Model	R	R square	Adjusted R square	F change	Sig. F change
1 (Controls)	.320	.102	.086	6.268	.003
2 (Controls and PSS)	.634	.402	.385	54.598	.000
3 (Controls, PSS, FES)	.636	.404	.382	.413	.522

PSS stands for the Perceived Stress Scale scores. FES stands for the scores from the Family Environment Scale.

Hypothesis 2

To determine whether perceived stress and family cohesion could predict quality of life for Domain 2 (i.e., psychological health), a hierarchical regression analysis was conducted to examine perceived stress and family cohesion as predictor variables and quality of life as the outcome variable. The base model including the covariates of behavioral symptomatology, hours of respite care, and income was found to be statistically significant, $R^2 = .080$, $F(2, 112) = 2.368$, $p < .05$. The second model including the covariates of behavioral symptomatology, hours of respite care, and income and the inclusion of perceived stress as the predictor variable was found to be statistically significant, $R^2 = .571$, $F(1, 111) = 126.864$, $p < .001$, with 57.1% of the variance accounted for in the outcome variable. With the addition of family cohesion scores in the third step, the model was statistically significant, $R^2 = .586$, $F(1, 110) = 4.145$, $p < .05$,

accounting for 58.6% of the variance, providing a 1.5 % increase from the prior step of the model. See Table 4.

Table 4

Psychological Health Quality of Life Regression

Model	R	R square	Adjusted R square	F change	Sig. F change
1 (Controls)	.282	.080	.063	4.845	.010
2 (Controls and PSS)	.755	.571	.559	126.864	.000
3 (Controls, PSS, FES)	.766	.586	.571	4.145	.044

PSS stands for the Perceived Stress Scale scores. FES stands for the scores from the Family Environment Scale.

Hypothesis 3

To discover whether perceived stress and family cohesion could predict quality of life for Domain 3 (i.e., relationships), a hierarchical regression analysis was conducted examining perceived stress and family cohesion as predictor variables and quality of life as the outcome variable. The base model including the covariates of behavioral symptomatology, hours of respite care, and income was found to be statistically significant, $R^2 = .184$, $F(2, 112) = 12.650$, $p < .001$. The second model including the covariates of behavioral symptomatology, hours of respite care, and income and the inclusion of perceived stress as the predictor variable was found to be statistically significant, $R^2 = .443$, $F(1, 111) = 51.611$, $p < .001$, with 44.3% of the variance

accounted for in the outcome variable. With the addition of family cohesion scores in the third step, the model was statistically significant, $R^2 = .522$, $F(1, 110) = 18.209$, $p < .001$, accounting for 52.2% of the variance, providing a 7.9% increase in the variance accounted for from the prior step of the model. See Table 5.

Table 5

Social Relationship Quality of Life Regression

Model	R	R square	Adjusted R square	F change	Sig. F change
1 (Controls)	.429	.184	.170	12.650	.000
2 (Controls and PSS)	.666	.443	.428	51.611	.000
3 (Controls, PSS, FES)	.723	.522	.505	18.209	.000

PSS stands for the Perceived Stress Scale scores. FES stands for the scores from the Family Environment Scale.

Hypothesis 4

To determine whether perceived stress and family cohesion could predict quality of life for Domain 4 (i.e., environment), a hierarchical regression analysis was conducted examining perceived stress and family cohesion as predictor variables and quality of life as the outcome variable. The base model including the covariates of behavioral symptomatology, hours of respite care, and income was found to be statistically significant, $R^2 = .395$, $F(2, 112) = 36.613$, $p < .001$. The second model including the covariates of behavioral symptomatology, hours of respite care, and income and the

inclusion of perceived stress as the predictor variable was found to be statistically significant, $R^2 = .591$, $F(1, 111) = 52.969$, $p < .001$, with 59.1% of the variance accounted for in the outcome variable. With the addition of family cohesion scores in the third step, the model was not statistically significant, $R^2 = .604$, $F(1, 110) = 3.625$, $p > .05$, accounting for no additional variance. See Table 6.

Table 6

Environmental Quality of Life Regression

Model	R	R square	Adjusted R square	F change	Sig. F change
1 (Controls)	.629	.395	.385	36.613	.000
2 (Controls and PSS)	.769	.591	.580	52.969	.000
3 (Controls, PSS, FES)	.777	.604	.589	3.625	.060

PSS stands for the Perceived Stress Scale scores. FES stands for the scores from the Family Environment Scale.

Chapter 5: Discussion

Major Findings

It was hypothesized that family cohesion and perceived stress would significantly predict quality of life (i.e., physical health, psychological health, relationships, and environment) in a sample of mothers who had a child with Autism Spectrum Disorder (ASD) after controlling for income, hours of respite care, and severity of the child's diagnosis. The participants in this study ranged in age from 25 to 55 years old and were of various ethnic, educational, and socioeconomic classifications.

The outcomes of this study were in line with two of the hypotheses. The findings indicate that perceived stress was a significant predictor of physical health, psychological health, social relationships, and environment as related to quality-of-life perceptions. Family cohesion had a weaker relationship with quality of life. The results confirmed that family cohesion has a modest predictive value for maternal caregivers' psychological health and relationship quality of life. These findings suggest that mothers of children with autism perceive increased stress and less bonding, support, and affection among family members. These perceptions were shown to impact these mothers' perceptions of certain aspects of their quality of life.

Considerations/ Implications

These findings demonstrated a strong and robust relationship between stress and quality of life and are in line with findings from past studies (e.g., Lee et al., 2009). Focusing specifically on the relationship between stress and quality of life in caregivers of children with disabilities, past research has yielded similar results. For example, in a comparison study exploring factors that predict physical- and mental-health quality of life

in caregivers of children with special needs versus those without, stress was one of the main variables accounting for negative perceptions of quality of life in the caregivers of children with special needs (Lee et al., 2009). This relationship was further supported in a study examining quality of life in families with children with pervasive development disorder (PDD), high-functioning autism, intellectual disabilities, or cerebral palsy (Mugno, Ruta, D'Arrigo, & Mazzone, 2007). This study demonstrated that stress was reported highest among the PDD and autism spectrum (AS) groups as a result of both environmental and genetic stressors and that quality of life was perceived more negatively by these caregivers (Mugno et al., 2007). The robust relationship between caregiver stress and quality of life is even apparent in the medical field with such issues as cancer, asthma, and traumatic brain injuries (e.g., Bellin et al., 2013). A study exploring stress and quality of life in caregivers of children with asthma demonstrated that poor quality of life was associated with illness stress, as well as with life stress (Bellin et al., 2013). In each of these studies, stress was related to the functioning of the caregiver and negatively influenced several other aspects of the caregiving relationship and quality of care the recipient received (e.g., Lee et al., 2009).

When interpreting individual domains of quality of life, as presented in this study, prior research has found similar and robust findings linking perceived stress to quality-of-life perceptions. Considering physical-health quality of life as it relates to perceived stress, studies have continued to demonstrate the effects of stress on quality of life of caregivers (Dardas & Ahmad, 2014). In Dardas et al.'s (2014) study, they noted that the prolonged effects of caring for a child with ASD is shown to have both long- and short-term effects on the caregiver's physical-health quality-of-life perceptions (Dardas &

Ahmad, 2014). Psychological-health quality of life has also consistently demonstrated a relationship to perceived stress as demonstrated in studies exploring the subjective stress and quality of life of caregivers caring for children with obsessive-compulsive disorder (Grover & Dutt, 2011). This cross-sectional analysis of 50 families demonstrated the significant relationship between subjective burden and psychological-health quality of life (Grover & Dutt, 2011).

Social-relationship quality of life has also been shown to relate to perceived stress in past studies, as shown in a study examining caregivers of children with intellectual disabilities (Lin et al., 2009). The study conducted multiple regression analyses to determine the role stress, health, and income played on caregivers' quality of life (Lin et al., 2009). The results indicated that stress was impactful across all domains, similar to the present study's findings, but further suggested that stress from lack of support was perhaps most impactful (Lin et al., 2009).

Lastly, the relationship between environmental quality of life and perceived stress has been demonstrated in a study comparing caregivers of children with ASD or intellectual disabilities disorder (IDD) and caregivers without children with an ASD or intellectual disabilities (Malhotra, Khan & Bhatia, 2012). Parents in the IDD/ASD group demonstrated lower quality of life in all areas compared to the control group (Malhotra et al., 2012). With respect to the environmental domain, Malhotra et al. (2012) addressed the possible implications of the impact of perceived stress on the environmental quality of life of these caregivers. Environmental aspects, such as level of supervision needed, service dissatisfaction, concerns for living arrangements, and financial strains, were all

environmental variables likely to impact caregivers' stress levels and thus impact their environmental quality of life (Malhotra et al., 2012).

The novel aspect of the current study was the focus on family cohesion and its predictive value in determining quality of life in these caregivers. While the findings were modest, perceptions of family cohesion did explain some aspects of quality of life in these caregivers, specifically their psychological health and social relationships as they pertain to quality of life. Family cohesion and its modest associations to social relationships and psychological quality of life are consistent with other studies specifically related to support and bonding. For example, a study exploring 66 caregivers' quality of life as it related to their network, support, and spousal support demonstrated that those caregivers with increased support demonstrated improved quality of life and more effective coping strategies for life burdens (Amendola, Oliveira, & Alvarenga, 2011). The results in the current study in conjunction with those of past studies suggest that while caregivers tend to experience high levels of stress that can impact perceptions of caregivers' quality of life, other social factors may contribute as well. When individuals feel supported and bonded with others, they tend to be able to handle stress more effectively and more positively view their psychological health and relational quality of life, despite having significant life strains that may be unique to a family caring for a child with special needs.

In the current study, perceived stress and family cohesion together demonstrated some predictive value. Relationship quality of life demonstrated the largest change when adding in family variables to the individual's perception of his or her stress. Social relationships were probed by assessing perceptions of such factors as personal

relationships, social support, and leisure time. Considering the time commitment, restrictions, and lack of understanding by friends and family, these caregivers are often experiencing isolation and marital distress (e.g., Harper et al., 2013). These caregivers often have increased stress and little support both informally and formally, in turn impacting their perceptions of their relationship quality of life. Woodgate, Ateah, & Secco (2008) suggested such recommendations as increased education for friends and family regarding ASD to help increase the support these caregivers receive from friends and family.

In the current study, perceived stress and family cohesion demonstrated a modest predictive value as related to psychological-health quality of life as well. Psychological-health quality of life was defined as perceptions related to body image and appearance; negative and positive feelings; self-esteem; spirituality/religion/personal beliefs; and thinking, learning, memory, and concentration. Research on caregiving, in general, has found that caregivers' quality of life suffers as a result of the care recipients' behavioral, cognitive, and functional impairments; the duration of care needed, the caregivers' age and sex (with female individuals being more affected); and the relationship between the caregivers and recipients (Schultz & Sherwood, 2008). With ASD's association with several impairments, the care being long term if not lifelong, and the primary caregiver being the mother, the findings align with past caregiver research regarding the impacts of stress. When considering family cohesion as an added variable to the equation, research has focused on mental illness in general or with specified populations, such as schizophrenia (Saunders, 2003). Families living with a member with a mental-health-related issue tend to be forced to adjust and adapt, often resulting in emotional and

psychological distress, especially in families lacking coping and problem-solving skills and social support (Saunders, 2003). Therefore, these adaptations align with the outcomes presented in the current study. Caregivers of children with ASD are often forced to adjust and adapt, and with the increased stress and perceived lack of support and family togetherness, psychological health is often impacted.

Family cohesion and perceived stress together predicted two domains of maternal caregiver quality of life (i.e., psychological and social relationships) but not physical-health or environmental quality of life. Physical-health quality of life was composed of such facets as activities of daily living, energy and fatigue, mobility, pain and discomfort, sleep and rest, work capacity, and dependence on medical substances and aids. The findings of the current study support that perceived stress predicts overall quality of life, including physical-health quality of life, but family cohesion did not add to the predictive utility of the model. Cohesion has not been previously assessed specifically with this population regarding quality of life, but when considered with health-related disorders, such as diabetes, family cohesion has been found to be impactful in a few studies (Trief, Grant, Elbert, & Weinstock, 1998). In a study of adults with diabetes, improved family cohesion led to more successful psychosocial adaptation in the caregivers and, in turn, improved health-related quality of life for the patient (Trief et al., 1998). However, one can infer that because ASD is a mental-health-related disorder and not a physical disorder physical-health quality of life was not reported negatively, as the child's diagnosis does not impact the caregiver's physical health (Trief et al., 1998). Certainly, the stress of raising a child with additional needs may impact physical health, a finding supported in

the current study, but the support, bonding, and affection the individual perceives may not show a direct relationship with physical-health quality of life.

Environmental quality of life was also not predicted by family cohesion. This domain concerned such facets of quality of life as financial resources, freedom, physical safety, security, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment (e.g., pollution, noise, traffic, climate), and transportation. Past research has shown the environmental quality-of-life domain to be of least importance to caregivers of children with ASD (Tung et al., 2014). Tung et al. (2014) assessed 82 caregivers of children with autism using the WHOQOL Scale and the Perceived Stress Index(PSI)-Short Form. Each domain of quality of life was predicted by stress, but the results showed that environmental quality of life was of least importance and had the least significant relationship to stress compared to the other domains. Tung and colleagues (2014) presumed that caregivers are so consumed by other aspects of caring for their children that the living areas in their daily lives often go unnoticed unless a dramatic change in the environment occurs. This lack of perceived importance may certainly impact the perception of environmental quality of life if the caregiver finds the environment inconsequential, despite family variables. Considering the impairments that accompany ASD and the stress and lack of support the caregiver has, dismissal of the environmental factors is not surprising. These caregivers exert most of their energy helping their children, and thus cleaning, upkeep, and other environmental stressors are often overlooked (Vasilopoulou & Nisbet, 2016).

The exploration of family variables stems from literature suggesting caregiver burden/stressors and diminished quality of life relate to lack of support, affection, and bonding within the family (Myers et al., 2009). Logically then in this study, family variables were hypothesized to be potentially more significantly impactful in this specific population. This consideration stems from the understanding that caregivers who have children with a disability, such as ASD, have added burdens and stressors but tend to lack adequate supports and resources to assist them with the added challenges (Thomas et al., 2007). A major source of many people's support comes from their family. Without that support and cohesion among family members, many individuals experience negative mental- and physical-health outcomes, possibly impacting their perceptions of their quality of life (Higgins et al., 2005). A qualitative study conducted by Woodgate et al. (2008) indicated that caregivers of children with autism tend to feel as though they are "in a world of their own." This qualitative study noted mothers tended to serve as the primary caregivers, and three themes emerged within these caregivers: vigilant parenting, sustaining the self and family, and fighting all the way (Woodgate et al., 2008). Each of these themes suggests a battle these caregivers are facing every day, and much of the qualitative data demonstrated a perception of a lack of informal and formal support (Woodgate et al., 2008). Woodgate et al. (2008) suggested several recommendations, such as fostering the relationship between healthcare providers and caregivers, providing advocacy information to families, and increased education for friends and family, to assist with this lack of perceived support.

The stress process model conceptualizes the relationship between stress and mental-health outcomes, such as quality of life. Stress occurs when an individual is in a state of disequilibrium (Pearlin et al., 1981). The stress process model demonstrates that stress does not simply equal quality-of-life outcomes (Pearlin et al., 1981). Rather, several mediators, such as stressors, familial support, or coping strategies, have an impact on the relationship between events and negative outcomes that can negate the negative outcomes or perpetuate the outcomes (Pearlin et al., 1981). In this conceptualization, Pearlin suggested that events are not the indicator of stress, but rather the life strains that result from the event are the indicator of stress (Pearlin et al., 1981). Essentially, having a child with autism does not solely intensify one's stress level and subsequent mental-health outcomes, but rather the life strains that are coupled with raising and caring for a child with ASD are daily stressors that seldom diminish in intensity. These strains might include daily tantrums from the child, food refusal that makes every mealtime difficult, or excessive rigidity that makes everyday life more difficult to navigate. Studies exploring similar variables but for caregivers of children with PDD suggest that stress management interventions be used with these caregivers (Cappe, Wolff, Bobet, & Adrien, 2011). Specifically, a five-axis intervention model based on cognitive-behavioral therapy for stress management was recommended (Cappe et al., 2011).

An additional implication relates to the discussion of respite care. This factor did not demonstrate a significant impact, as only 17 participants of the 115 used respite care. The 17 participants who had respite care varied in the amount, with some receiving only 1 hour per week. As mentioned, a major lack of support for these families comes from professionals in the field (Woodgate et al., 2008). Information on resources is not

adequately dispersed, and enough time with the families in medical appointments is lacking (Woodgate et al., 2008). Families often never hear about respite care as an option (Harper et al., 2013). This notion is supported by a study investigating services and stress in families who have a child with autism (Harper et al., 2013). The study reported that most families are unaware of the services offered and includes a quotation from a mother who described social services as “secret services” (Harper et al., 2013). When families are aware, a perceived lack of inadequacy of the services being provided is often expressed (Sajjadi, Vameghi, Ghazinour & KhodaeiArdakani, 2013). This perception has been shown to impact the caregiver’s quality of life and life satisfaction (Sajjadi et al., 2013).

Cultural considerations are also relevant to consider. The topic of family cohesion, while specifically defined in literature, differs across cultures (Georgas, 2003). Some cultures have an expectation that the family members showed significant physical affection toward one another while other more Western cultures tend to exhibit more physical distance and less physical affection with family members (Georgas, 2003). With this study’s relatively homogeneous sample, cultural differences related to family cohesion may not have been highlighted.

While the focus of this study was on the caregivers, negative mental-health-related outcomes may impact the child as well, when considering reciprocating influence (Hastings, 2003). Caregivers of individuals with ASD experience many unique caregiver burdens that tend to negatively affect caregivers’ quality of life and, subsequently, the care that they provide (Lecavalier et al., 2006). A transactional effect is thought to occur whereby the child’s behavioral, emotional, and medical concerns relate to poor mental-

health outcomes for the caregivers (Schulz & Sherwood, 2008). The negative outcomes impact the quality of care that the caregivers can provide, in turn further exacerbating the child's symptomatology (Schulz & Sherwood, 2008).

Limitations

Several limitations are present in this study. An obvious limitation is that the study relies solely on the participants' self-reports, which can be subject to self-report bias. Self-report bias could affect the honesty and accuracy of responses. A research study conducted related to this topic and the use or lack of social desirability scales demonstrated that only 0.2% of studies that used self-report also included a social desirability scale to detect for bias (Van de Mortel, 2008). Interestingly, of those that did use this scale, half of the studies identified that the results of their study were impacted by self-report bias (Van de Mortel, 2008). Owing to the already extensive length of the present study, an additional scale was not reasonable, but this factor should be considered when interpreting the results.

The sample may not represent a significant range of all caregivers of children with autism. Parents who are highly stressed may be less likely to engage in such a study, as they may feel they do not have time to complete the study. This potential limitation could be the result of multiple life strains (e.g., financial, familial, work-related, caregiving responsibilities.). Parents who have a child with increased behavioral needs may also be less likely to participate because of added demands. In addition to stress precluding individuals from potentially participating, financial limitations also serve as a barrier to participation, as some individuals may not own a computer or have access to

the Internet to participate in the study. Maternal caregivers in the current study, however, reported moderate to severe perceived stress.

In addition, homogeneity of the sample's demographics should be considered a limitation. While the study planned to enlist individuals of diverse ages, backgrounds, and incomes, the participants who completed the study had minimal demographic differences. The sample consisted mostly of middle-aged, Caucasian mothers of average socioeconomic status.

An additional limitation includes the lack of control of other variables that may have an impact on the outcome variables of this study. The number of children in the home, the variety of comorbid disorders, the strain of having multiple children with disabilities, and several other participant differences were not controlled for in this study. Future studies could extend on this study to include some of these factors.

Threats to external validity should also be considered as potential limitations in this study. Past research has focused on other countries, and therefore, this present study recruited participants only from the United States. This limitation could affect the generalizability of the findings, as comparing the results directly to those of past studies will be difficult because significant cultural and geographical differences have an impact on quality of life. Similarly, applying these results to caregivers of those with mental- or physical-health conditions different from ASD would be difficult.

Future Directions

The concept of perceived stress as it relates to quality of life has been demonstrated time and time again. Numerous studies have been conducted over the years in various ways and with different populations. At this point, additional studies may not

be the logical next step. Perceived stress can presumably be considered a major factor impacting a caregiver's quality of life, and thus, future steps should consider interventions to mitigate this relationship and lessen overall perceived stress. One approach would be to include increasing support and resources and knowledge of such for these families, as discussed by Harper et al. (2013).

Based on the results of this study specifically related to the novel findings demonstrating some predictive ability with the family cohesion factor, a qualitative analysis should be completed to support these findings, as these methods may garner additional informative results. This type of research not only allows for a more in-depth exploration of the variables, but also allows for a critical review of feelings, perceptions, insights, and understandings these caregivers may have about their lives in relation to their children (Rahman, 2016). Replication of this study with more controls, such as accounting for caregivers who have multiple children with disabilities or have their own mental- or physical-health conditions, would also be recommended to ensure reliability of the research findings.

Preassessments and more in-depth intake procedures with families may highlight familial issues and quality-of-life deficits. When these deficits are presented, focus on family interventions may be more applicable. Thus, in these situations, service providers should extend their models of care to include the entire family or encourage other family members to engage in their own treatment. While the use of such treatments as cognitive-behavioral therapy has not been studied with these specific caregivers, past research has demonstrated that use of individualized therapy is effective at curbing depressive symptomatology and other mental-health-related outcomes in caregivers (Gallagher-

Thompson & Steffen, 1994). A major determinant of the most appropriate treatment was related to length of care provided by the caregiver. Cognitive-behavioral therapy was most effective for long-term caregiving, which is applicable to the population within the present study, as parental responsibilities are considered a long-term caregiving role (Gallagher-Thompson & Steffen, 1994).

Support groups should also be made more available to maternal caregivers to discuss and relate to other caregivers experiencing similar struggles. One study examined the relationships between the lack of available support groups and increased stress levels (Boyd, 2002). This study demonstrated that caregivers who received support informally, such as from support group members, were better able to relate to their children emotionally than caregivers without support, and their levels of depression and anxiety were reduced (Boyd, 2002). Access to this resource may have a profound effect on not just the caregiver but the child as well.

Lastly, other family variables would be important to investigate, as ASD symptomatology has been shown to impact the entire familial system, and cohesion is only one subset of family dynamics that may influence the outcome for caregivers. The modest predictive ability may in part show that family dynamics are impactful, but the most critical family variables were not investigated. Other family variables that may have some impact are family interaction, social support, and family structure (e.g., Armstrong, Birnie-Lefcovitch, & Ungar, 2005).

Conclusions

The data show that family cohesion has some predictive ability when examining certain quality-of-life outcomes for maternal caregivers of children diagnosed with ASD.

Quality-of-life outcomes for these caregivers may improve if steps are taken to enhance the bonding, affection, and support within the family, as well as to incorporate stress management techniques. With stress having such a substantial impact on these caregivers, interventions aimed at reducing stress (e.g., relaxation training, stress management, coping skills) appear especially important.

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Appendix A

Demographic Questionnaire

You have completed a number of questions about yourself and your child diagnosed with Autism Spectrum Disorder. Please answer the following questions about this child and their family.

1. How old is this child? _____ years old.
2. At what age was your child diagnosed with autism? _____
3. What type of medical professional diagnosed your child?
Licensed Clinical Psychologist
School Psychologist
Other _____
4. How many hours of services (e.g., behavior therapy, speech therapy, etc.) does your child receive each week? _____
5. How many hours of respite care does your child receive each week? _____
6. How would you describe your family set up?
 - A Nuclear Family (A basic family group consisting of a married couple of the opposite gender and dependent children, living away from other relatives)
 - A Cohabiting Family (A family group which consists of two people living together, who may be raising children together)
 - An Extended Family (A family group consisting of more than two generations of the same family line, living together within the same household, or very close to one another)
 - A Reconstituted Family (A family in which two adults marry or cohabit with children from previous relationships)
 - A Single Parent Family (A family that consists of a single parent, not living with a partner or spouse, who has the day-to-day responsibility of raising children)
 - A Same Sex Family (A family which consists of two parents of the same sex - either a gay or lesbian couple raising children together)
 - Other (please specify) _____
7. How many of your other children have received a diagnosis of Autism Spectrum Disorder?

0

1

2

3

4 or more

8. How many of your other children have a mental health diagnosis?

0

1

2

3

4 or more

9. How many of your other children have a medical issue that requires significant ongoing care?

0

1

2

3

4 or more

10. What is your current age? _____ years old

11. Are you of Hispanic, Latino, or Spanish origin?

Yes___

No ___

12. How would you describe yourself?

African American

Caucasian

Hispanic or Latino/a

American Indian or Alaska Native

Asian

Native Hawaiian or other Pacific Islander

Middle Eastern
Other
Prefer not to answer

13. What is your total household income including all earners in your household?

Less than \$20,000
\$20,000-\$34,999
\$35,000-\$49,999
\$50,000-\$74,999
\$75,000-\$99,999
Over \$100,000
Prefer not to answer

14. What is your marital status?

Single
Married or in a domestic partnership
Widowed
Divorced
Separated
Prefer not to answer
Other: _____

15. What was the highest level of education you have completed?

Less than High School
High School Diploma or equivalent (e.g., GED)
Associate's Degree
Bachelor's Degree
Master's Degree
Professional Degree
Doctorate Degree