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Stress, Coping, and Quality of Life Among Parental Caregivers of Children with Autism Spectrum Disorder

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STRESS, COPING, AND QUALITY OF LIFE AMONG PARENTAL CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

by

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ABSTRACT

Purpose: Parental caregivers of children with Autism Spectrum Disorder (ASD) are exposed to stressors associated with the daily care of raising a child with a developmental disability, which may negatively impact parental quality of life (QOL). The specific aim of this study was to examine the relationships between demographic factors, stress, and coping among parental caregivers of children with ASD to determine whether predictors of QOL exist.

Methodology: This study was descriptive, and an electronic survey was distributed to Florida parents of children, age 3-21 years old, diagnosed with ASD. The survey measured parent-reported demographic factors, severity of the diagnosis of ASD in the child, parental stress, coping, and QOL. Data were analyzed using multiple regression.

Findings: Study findings suggest that, in parental caregivers of children with ASD in Florida (*N* = 152) daily stressors, coping self-efficacy, and household income were predictors for physical QOL; daily stressors and coping self-efficacy were predictors of psychological QOL, and coping-self efficacy, household income, and severity of the diagnosis of the child were predictors for environmental QOL.

Conclusion: Coping self-efficacy and improved income can positively improve QOL, while severity of the diagnosis of ASD and daily stressors can negatively impact QOL. Clinically, nurses with a better understanding of the parental stress and coping in parents of children with ASD can better recommend tailored resources to improve QOL. Policies to support financial help for families may also improve QOL. Future research should focus on interventions to improve coping-self efficacy.

Keywords: Stress, Coping, Autism Spectrum Disorder, Caregiver

This research is dedicated to my husband Chris, my partner in caregiving and in life, and to my mom and dad, who taught me to do what makes me happy and to always put family first. It is also dedicated to Jared, the smartest person I know and the best autism sibling in the world, and to Justin, the sweetest, most amazing, smart, and loving son, who also has autism.

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CHAPTER ONE: INTRODUCTION

Parental caregivers of individuals with Autism Spectrum Disorder (ASD) have increased levels of stress related to the daily care of raising a child with a developmental disability (Autism Society of America [ASA], 2018). Because ASD has no cure and is a lifelong disorder, the care that parents of individuals with ASD provide may be indefinite (ASA, 2018). This long-term obligation of caregiving can lead to chronic stress, which can negatively impact parental caregivers' health and quality of life (QOL) (Hsaio, 2016).

QOL is defined by the World Health Organization (WHO) using the variables of physical health, psychosocial health, social health and environmental health (WHO, 1997). In addition to the daily stressors and the cumulative effect of chronic stress, other factors may contribute to the QOL of parental caregivers of ASD. The needs of a newly diagnosed toddler, a school aged child, an adolescent, and an adult with ASD can also vary greatly. Likewise, stressors faced by parental caregivers throughout an individual with ASD's different developmental stages may vary greatly and parents' coping mechanisms may vary (Lan, Goh, Eei, & Sund, 2015). Additionally, the variability of the spectrum of autism means that severity of the diagnosis and of associated behaviors can differ between children with ASD. While it is known that stressors and coping can be influential in determining parental QOL, it is unclear what, if any, predictors of QOL exist in parental caregivers of children with ASD.

Problem Statement

The number of children diagnosed with ASD continues to rise (CDC, 2018), and along with this increase, the number of parental caregivers is rising. Parental caregivers of individuals with ASD have stress related to the daily care of their children with ASD. The Pearlin Caregiver Stress Process model suggests that there are relationships between stressors, coping, and health-related quality of life in caregivers, of which parents of children with ASD are a part (Pearlin, Mullan, Semple & Skaff, 1990). However, the available literature to support these relationships is limited. It is necessary for researchers and clinicians to have an awareness of predictors of stress in parental caregivers of children with ASD, so that recommendations for interventions and resources to promote QOL in this population may be made.

Specific Aim

The specific aim of this study is to identify the relationships among demographic factors, severity of the diagnosis of ASD, stress, and coping in parental caregivers of children with ASD in order to identify a subset of predictors of QOL in parents of children with ASD.

Objectives

This research study has five objectives that focus on predictors of QOL in parental caregivers of children with ASD:

1.To determine whether the following demographic factors: Age of the parent; gender of the parent; education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; and gender of the child, with ASD predict physical health, psychosocial health, social health or environmental health in parental caregivers of children with ASD.

2. To determine whether severity of ASD predicts physical health, psychosocial health, social health or environmental health in parental caregivers of children with ASD.

3. To determine whether parental stress predicts physical health, psychosocial health, social health, or environmental health in parental caregivers of children with ASD.

4. To determine whether coping self-efficacy predicts physical health, psychosocial health, social health, or environmental health in parental caregivers of children with ASD.

5. To identify a subset of two or more variables (demographic factors, stress, coping self-efficacy, and severity of diagnosis) that predict the greatest variance in physical health, psychosocial health, social health or environmental health among parental caregivers of children with ASD.

Research Questions

There were four research questions in this study. Questions were aligned with the objectives of the study and focused on determining what, if any, correlations were present between dependent and independent variables and also whether or not predictors of QOL can be determined in parental caregivers of children with ASD.

Research Question One. What, if any, relationships are present among the dependent variables: Physical QOL, psychosocial QOL, social QOL; and environmental QOL in parental caregivers of children with ASD?

Research Question Two. What, if any, relationships are present among the independent variables: Age of the parent; gender of the parent; biological sex of the child, education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; and coping self-efficacy?

Research Question Three. What, if any, relationships are present among independent and dependent variables: Age of the parent; gender of the parent; education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; coping self-efficacy, physical health, psychosocial health, social health; and environmental health in parental caregivers of children with ASD?

Research Question Four. Do any of the independent variables: Age of the parent; gender of the parent; education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; and coping self-efficacy, either alone or in a subset, predict the following dependent variables: Physical health, psychosocial health, social health; and environmental health in parental caregivers of children with ASD?

Relevance of Study

There is a potential for lower QOL for parents of children with ASD because of the initial diagnosis and additional stressors and burdens faced daily (Family Care Alliance [FCA], 2018). Additional stressors may include daily care, coordinating medical care and therapies, behavioral problems of the child, missed time from work, and financial strain. Because there is no cure for ASD, parents often bear the burden of lifelong care of their child with ASD. This build-up of stressors over time can have a negative impact on parental QOL. This long-term exposure to stress may cause caregivers to have a greater risk for stress related health concerns including depression, cardiovascular disorders, and chronic illnesses (FCA, 2018). Additionally, because of the time required to care for a child with ASD, caregivers have little time to focus on health promotion activities to keep themselves healthy, which may lead to a decrease in QOL. Studies to analyze QOL in parents of children with ASD are necessary to improve QOL in parents, which may prevent chronic illnesses and depression (FCA, 2018).

Clinicians with a better understanding of predictors of QOL in this population can offer tailored resources to parents of children with ASD to improve parental QOL. Because the prevalence of ASD among children has now increased to one in 59 (CDC, 2018), the number of parents caring for children with ASD is also increased. This rapidly increasing population of parents of children with ASD is at risk for decreased QOL; however, predictive factors of QOL in this population are not known. Nurses with a better understanding and awareness of the factors that affect QOL of parental caregivers of children with ASD may be able to recommend tailored resources to optimize QOL in this population.

Brief Summary of the Study

This study was approved by the University of Central Florida Institutional Review Board and determined to be exempt from human research. The study was descriptive and cross-sectional. Participants were parental caregivers of children, age 3-21, with ASD. Participants for this study were recruited from the Autism Society of Greater Orlando and multiple Center for Autism and Related Disorders (CARD) organizations supporting individuals and families living with autism in Florida. An electronic survey was distributed via an anonymous link. The survey evaluated demographic factors of both the parent and the child with ASD, the severity of the diagnosis of ASD in the child, and parental stress, coping, and QOL. Data were analyzed using multiple regression to identify predictors of QOL as defined by the World Health Organization (WHO) using self-perceived outcome measures in parents of children with ASD: Physical health, psychosocial health, and environmental health.

Organization of the Study

This dissertation follows a traditional dissertation format and is presented in five chapters. Chapter One describes the problem to be addressed, the purpose of the study, specific aims and research objectives. Chapter Two includes a description of the theoretical framework used in this study, the background and significance of the study, and a review of the literature. Chapter Two also includes identification of gaps within the literature. Chapter Three includes a description of the research design and methodology. Chapter Four includes a presentation of the results of the study. Chapter Five includes a summary of the study and a discussion of the findings, limitations and implications for policy, research, and clinical practice.

Summary of Chapter One

This first chapter included an introduction of the research, specific aims, research objectives, and relevance of the study to the community and to nursing. A description of the overall organization of the study was also presented. The next chapter will include a discussion of the conceptual framework used to guide the study, the background and significance, and a review of the existing literature on parental caregivers of children with ASD related to stress, coping, and QOL.

CHAPTER TWO: BACKGROUND AND SIGNIFICANCE

This chapter includes a discussion of the Pearlin Caregiver Stress Process model as a framework for this study. The background and significance of ASD, including prevalence and economic impact, are also discussed. Additionally, a review of the literature is presented, including gaps within the existing literature.

Conceptual Framework

The Pearlin Caregiver Stress Process model (1990) (Figure 1) is well suited, as a conceptual framework, to discuss stress, coping, and QOL in parental caregivers of children with ASD, and was, therefore, an appropriate framework to guide this study. While the Caregiver Stress Process model (1990) was originally proposed to define caregiver burden in individuals caring for a family member with dementia, the principle concepts within the framework also apply to caregivers of children with ASD. Pearlin et al. (1990) defined four concepts within the caregiver stress process model: Background and context, stressors, mediators, and outcomes.

The model describes the stressors faced by the caregiver as a relational process, where the four concepts are related to each other. The primary stressor is the care recipient and the recipient's disability (Pearlin et al., 1990). Additional stressors, or life events, can further impact the caregiver's stress. Additional stressors can include small things like assisting the care recipient with daily care, or larger obstacles like a death in the family or a financial hardship. Mediators can also affect the outcome of the health of a caregiver. Mediators can be social support, either formal or informal, or the mechanisms used by the caregiver to cope with stressors. This process alters the caregiver's self-concept and, dependent on mediators, can have a positive or negative outcome. The outcomes in the Pearlin model are depression, anxiety, irascibility, cognitive disturbance, physical health, and yielding of role (Pearlin et al., 1990).

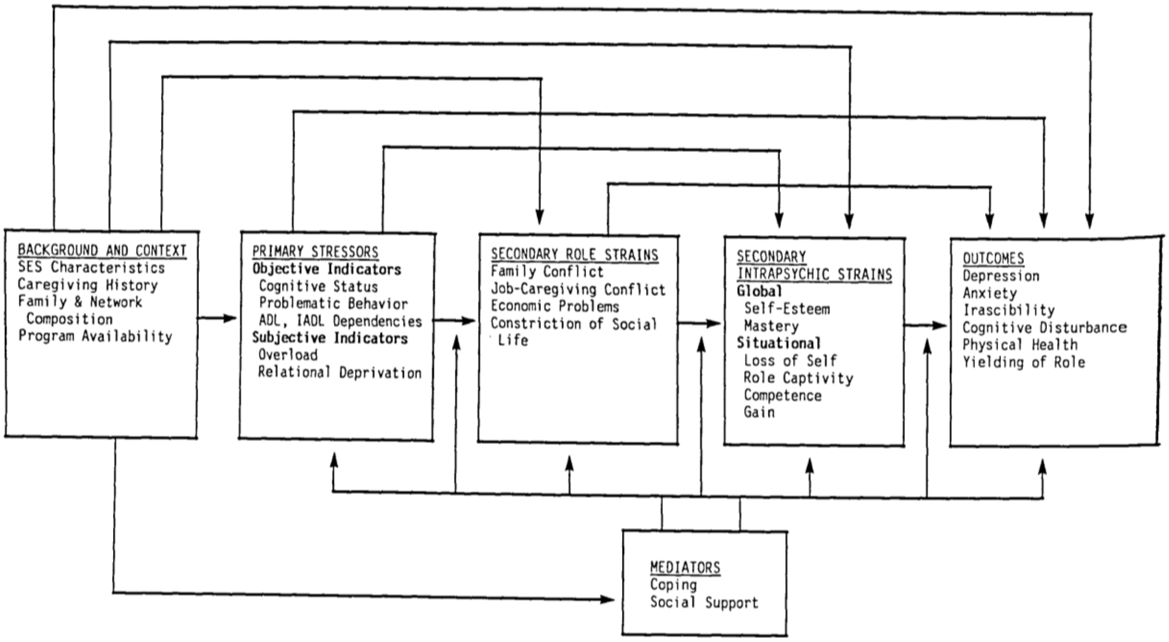


Figure 1. A conceptual model of Alzheimer's caregivers' stress. The stress process is made up of four domains: the background and context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress.

Figure 1 : Pearlin's Alzheimer's Caregiver Stress Process Model (1990)

Concepts and Interrelationships Applied to Parental Caregivers of Children with ASD

Parental caregivers of children with Autism Spectrum Disorder (ASD) are exposed to stressors associated with the daily care of raising a child with a developmental disability. These stressors can negatively affect parental quality of life (QOL). The components of the Pearlin framework, background and context, stressors, strains, mediators, and outcomes, can be easily adapted to represent experiences faced by parental caregivers of children with ASD.

Background and context. Background and context within the Pearlin framework are demographic factors (Pearlin et al., 1990). Specific to parental caregivers of children with ASD, these would include parental age, gender, relationship to care recipient, household income, level of education, and number of children (Benjak, 2011; Favero-Nunes & dos Santos, 2010).

Stressors and strains. The initial stressor, the diagnosis of the child with ASD, can be stressful to the caregiver (Ooi, Ong, Jacob & Khan, 2016). Severity of the diagnosis can also contribute to stress, where children with a more severe diagnosis of ASD can have aberrant behaviors such as sleep disturbances, aggression, decreased social interaction, and elopement (Ooi et al., 2016; Hsiao, 2016; Pozo, Sarria & Brioso, 2014). These behaviors can contribute to the overall stress, coping, and ultimately QOL of parental caregivers. Additional stressors include the financial burden of caring for a child with ASD, coordination of medical care including appointments and therapies, and the potential for comorbidities like epilepsy and cognitive disabilities (Altiere & von Kluge, 2009). These stressors can compound over years and can impact the QOL of parental caregivers of children with ASD (Setzer et al., 2010).

Strains can also contribute to the overall burden felt by a parental caregiver of a child with ASD. Strains can include inter-family relationships, stress from work, whether an inability to work outside of the home or stress at a job, or financial difficulties, which may or may not be related to caring for the child with ASD. Also, the lack of social interaction outside of the home can cause strain on a parental caregiver. In adapting the Pearlin et al. model to the population of parental caregivers of children with ASD, these strains can be seen in demographic data like household income and hours worked outside of the home (1990). These strains can also be seen in the social QOL domain.

Mediators. Coping is the mechanism or set of mechanisms used by caregivers to deal with the stressors related to caring for the child with ASD. Coping can be either positive or negative. Examples of positive coping include engaging in health promotion activities like a healthy diet and regular exercise. Another positive coping mechanism is to seek help in the way of medical treatment for physical or psychosocial issues and to seek social support. Negative coping mechanisms include denial of the severity of the diagnosis, avoidance of caring for the child with ASD, and addictive behaviors (Cappe, Wolff, Bobet & Adrien, 2011). Both positive and negative coping mechanisms can impact parental caregiver QOL.

Outcomes. The outcomes of this framework, when adapted to the population of caregivers of children with ASD, can be explained using the domains of parental caregiver QOL. These include QOL in the physical, psychosocial, social, and environmental domains.

Because there is no known cure for ASD, parental caregivers of children with ASD often provide care throughout the lifespan of the child (FCA, 2018). The stressors faced by parental caregivers and the coping mechanisms used may change. The Pearlin model (Pearlin et al., 1990) accounts for changes in stress and coping over time, making this model an appropriate framework for this study.

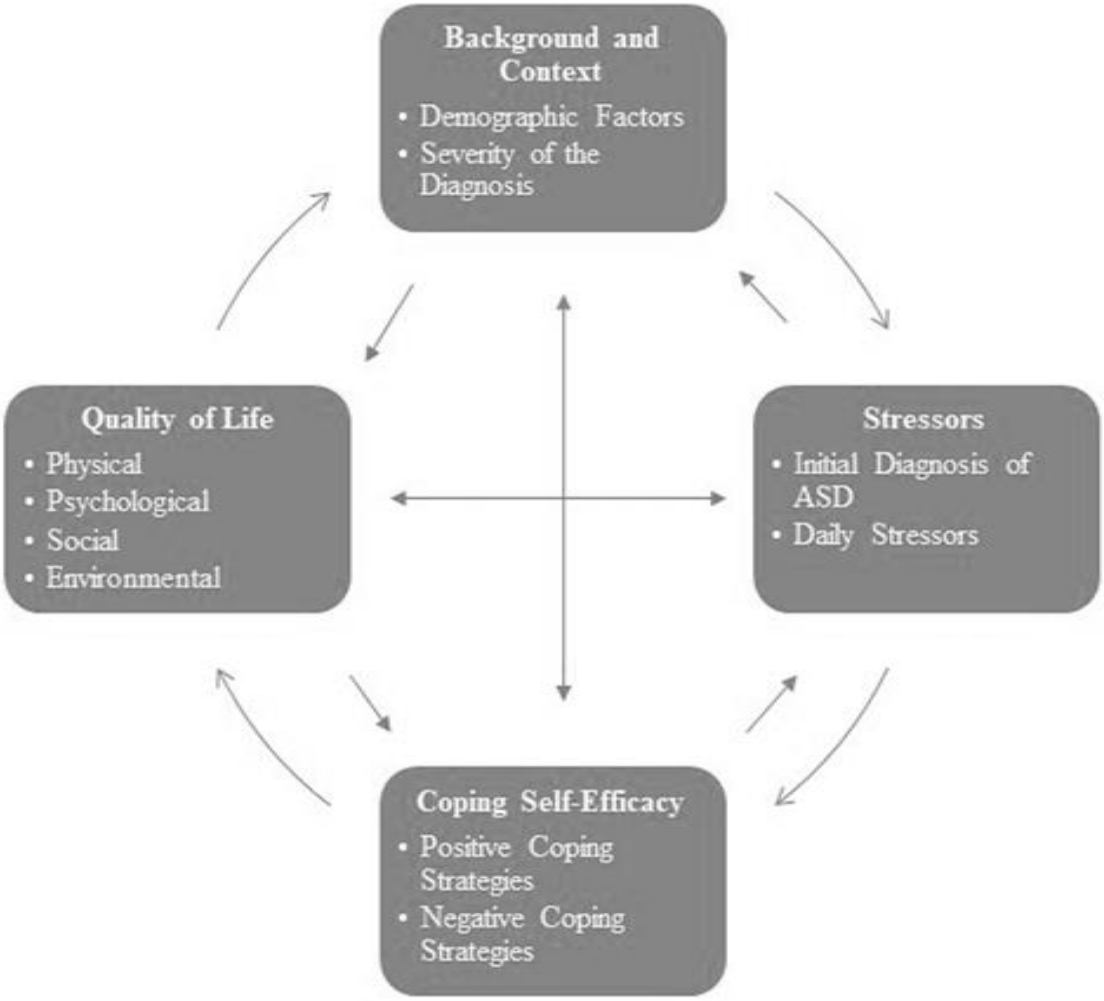


Figure 2: ASD Parental Caregiver Stress Process Model as Adapted from Pearlin's Alzheimer's Caregiver Stress Process Model

Background and Significance

Autism spectrum disorder. ASD is a broad term used to describe a set of developmental disabilities (National Institute of Mental Health [NIMH], 2019). The American Psychiatric Association (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-V) lists three diagnoses under the ASD umbrella: Autism, Asperger's syndrome, and pervasive developmental disorder-not otherwise specified (PDD-NOS) (American Psychiatric Association

[APA], 2013). The term “spectrum” is used to describe the variability of the diagnosis of autism, where symptoms and severity of diagnosis can range from mild to severe (APA, 2013). Symptoms of ASD can include communication problems, social impairment, behavioral problems, sleep disturbances, and repetitive behaviors (APA, 2013; NIMH, 2019; CDC, 2018). Children with ASD may also have additional diagnoses of mental or behavioral disorders, or other comorbidities and medical needs, which may add to the overall severity of symptoms (APA, 2013).

Prevalence of ASD. The Centers for Disease Control and Prevention (CDC) estimate that one in 59 children are diagnosed with ASD (CDC, 2018). The prevalence of ASD has increased significantly from previous studies in 2000, where one in 200 children were diagnosed (Mortality and Morbidity Weekly Report [MMWR], 2012). A recent 2016 National Survey of Children’s Health, conducted by the United States Census Bureau, indicated that the national prevalence of ASD may be even higher and that one in 40 children in the U.S. has a diagnosis of ASD (Kogan et al., 2018). This increased prevalence of children with ASD means that there is also an increase in the number of parents who care for children with ASD.

Economic impact. The economic impact of ASD is immense. The average lifetime cost of care for one child with ASD is over $3 million (Ganz, 2007). Costs include medical care, therapy costs, in-home nursing and respite services, missed time from work, and costs related to special needs education. In 2011, the yearly total cost of care for all children with ASD was estimated to be between $11 billion and $61 billion dollars (CDC, 2018). The average yearly cost for medical services alone was $4,000-6,000 per child higher for children with ASD versus children without ASD (CDC, 2018). Additionally, the average yearly cost paid by Medicaid for a child with ASD was six times greater than the yearly Medicaid cost for a child without ASD

(CDC, 2018). Costs related to care of a child with ASD can also impact the family. Some parents are unable to work outside the home because of high out-of-pocket costs for specialized childcare equipped to handle the behaviors of the child with ASD, where average childcare facilities would not be adequate (Ganz, 2007).

Changing age of the child with ASD. While the diagnosis of ASD often occurs at the age of 18 months to 2 years (CDC, 2018), parents may not fully comprehend the ramifications of the diagnosis trajectory, where the needs of the child with ASD change as the child ages (Bonis & Sawin, 2016). The stressors faced by the parents may vary, dependent on the age of the child and severity of the diagnosis of ASD (Bonis & Sawin, 2016). Also, parents of adolescents and adults with ASD have been shown to have chronic stress, as evidenced by low cortisol levels comparable to the cortisol levels of combat soldiers and individuals with post-traumatic stress disorder, supporting the idea that stressors faced by parents of children with ASD have a cumulative effect (Setzer et al., 2010).

Examples of stressors faced as the child ages can be seen throughout the phases of a child's development. For example, if a toddler is diagnosed with ASD, parents must cope with the new diagnosis, therapies, behaviors, and toilet training (Altiere & von Kluge, 2009). Parents of school-aged children with ASD have stressors related to school placement, specialized education plans, and difficulties with the decreased social interactions of ASD in a time where children without ASD are learning to interact with friends (Cale, Car, Blakely-Smith & Owen-DeSchryver, 2009). Parents of adolescents with ASD have the additional stressors of puberty where hormonal changes are made more difficult when coupled with the decreased ability for self-care, limited communication to express changes felt, and limited cognition to understand those changes (Fong, Wilgosh & Sobsey, 1993). Parents of young adults with ASD have the additional stressors of transitioning out of the school system, securing supported work and supported living for those young adults (Debrowska & Pistula, 2010).

Impact of stress over time. There are many challenges for parents of children with ASD. The burden of care begins with the stressor of receiving the initial diagnosis. After diagnosis, additional stressors include daily care, coordinating medical care and therapies, behavioral problems of the child, missed time from work, and financial strain (FCA, 2018). These stressors can be physically and emotionally draining. Because there is no cure for this disorder, parents often bear the burden of lifelong care of their child with ASD. This accumulation of stress over time can have a negative impact on parental QOL. Also, caregivers have greater risk for depression, cardiovascular disorders, and chronic illnesses (FCA, 2018). Additionally, because of the time required to care for a child with ASD, caregivers have little time to focus on health promotion activities to keep themselves healthy. These missed activities include routine medical appointments, screening tests, exercise and healthy meal planning, (FCA, 2018).

Quality of life. The World Health Organization (WHO) has identified six domains of health related QOL: Physical health, psychological health, level of independence, social relationships, environment, and spirituality (WHO, 1997). There is a potential for lower QOL in all domains for parents of children with ASD because of the additional stressors and burdens faced daily (FCA, 2018). Additionally, the increased incidence and prevalence of individuals with ASD means the number of parents experiencing high levels of stress and burden is also increased.

Review of the Literature

A comprehensive, systematic, electronic literature review was performed to identify relevant articles. The following databases were searched: CINAHL, the Cochrane Database of Systematic Reviews, MEDLINE, and PsycINFO. The following search terms were used: "autistic disorder" or autis*or ASD, and caregiver* or "care giver*" or parent* or mother* or father* or maternal or paternal, and HRQL or "quality of life" or "health-related quality of life." An initial search yielded 729 articles.

Inclusion and exclusion criteria. Inclusion and exclusion criteria were then applied to refine the search. Inclusion criteria were any peer-reviewed, academic journal articles, written in English and studying health-related quality of life (HRQOL) in parents of individuals with Autism Spectrum Disorder (ASD). Exclusion criteria were any study addressing children as the population or any disorder that was not solely ASD. This yielded 268 articles. Subject terms were added to further refine the search. The subject terms were "ASD," "QOL," parent, caregiver, caregiver burden, health, and parenting. This yielded 74 articles.

Sample. Seventy-four articles were retrieved for title review. Fifty-six articles did not meet search criteria for the following reasons: Eleven articles addressed disabilities other than ASD, 10 articles focused on therapies or treatments for ASD, 25 articles focused on the individual with ASD, four were editorials or book reviews, five focused on psychometric properties of instruments, and in one study, authors discussed perceptions of ASD faced by people without ASD. Eighteen articles were retrieved for abstract review. Of those 18 articles, three did not focus on quality of life and two did not solely address ASD. These articles were discarded. Ten articles were found to be included in either a systematic review or a meta-synthesis and were not considered as single studies; however, the systematic review and meta-synthesis were included in the review. Six articles were kept for review. An additional seven articles were retrieved from reference lists. A total of 13 articles were kept for analysis to determine the effect of caregiver burden on health-related quality of life in parents of individuals with ASD.

Results of the review. The emergent themes in this literature review were QOL outcomes and risk and protective factors of QOL. For the purpose of organizing themes, the QOL findings are discussed as related to the WHO QOL domains: Physical health, psychological health, level of independence, social relationships, environment, and spirituality (WHO, 1997). While most articles in this review addressed at least one domain of QOL, there were no articles that addressed all six components. The only domain not addressed in any article in this review was level of independence. The domain of level of independence addresses whether an individual is independently mobile, has the ability to complete activities of daily living, has dependence on medications, and the capacity to physically work outside of the home. The exclusion may be because this domain, as related to QOL, is specific to WHO criteria and because the two studies in this review (Favero-Nunes & dos Santos, 2010; Siah & Tan, 2015) using WHO instruments to measure QOL used the WHOQOL-BREF instrument. The WHOQOL-BREF instrument includes items from 4 domains: Physical, psychological, social, and environmental, but omits the level of independence and spirituality domains. Risk factors were variables that were shown to decrease QOL and protective factors were variables that were shown to improve QOL.

QOL outcomes. The psychological domain of QOL includes body image, positive and negative feelings, and self-esteem (WHO, 1997). This domain of QOL was reported as the outcome most negatively impacted in parental caregivers of children with ASD and more studies reported lower QOL in this domain than in any other domain (Favero-Nunes & dos Santos, 2010; Hsiao, 2016; Johnson, Frenn, Feetham & Simpson, 2011; Ooi et al., 2016; Pozo et al., 2014; Siah & Tan, 2015; Walsh, Mulder & Tudor, 2012; Van Tongerloo, van Wiingaarden, van der Gaag & Lagro-Janssen, 2015; Vasilopoulou & Nisbet, 2016. While most studies addressed negative feelings, stress, and burden, two studies addressed positive feelings (Hall, 2012; Ooi et al., 2016). Hall (2012) reported that increased social support in parents of children with ASD led to improved coping mechanisms (r = .451; p = .001). Ooi et al. (2016) described the emergent theme in several studies included in the meta-synthesis, where parents found happiness in caring for their child with ASD, which strengthened their feelings of caring and compassion.

Physical QOL. The domain of physical QOL includes energy, fatigue, pain, discomfort, sleep and rest (WHO, 1997). Physical health was found to be negatively impacted in parental caregivers of children with ASD (Benjak, 2011; Hoefman…Tilford, 2014; Johnson et al., 2011; Ooi et al., 2016; Van Tongerloo et al., 2015 & Vasilopoulo & Nisbet, 2016). Siah and Tan (2015) studied correlations between QOL and Sense of Coherence (SOC) (Antonovsky, 1987) and found that higher levels of SOC were associated with higher levels of physical health. Only one article (Favero-Nunes & dos Santos, 2010) ranked physical health higher than any other QOL domain. This study had a small sample size of 20 mothers in Brazil who did not work outside of the home. The authors discussed that the mothers' views of their roles as full-time caregivers may have influenced the physical health ranking results (Favero-Nunes & dos Santos, 2010). No studies in this review examined present illnesses, chronic illnesses or comorbidities, which may have provided more clarity on the physical health of the participants.

Social QOL. The social domain of QOL includes personal relationships, social support, and sexual activity (WHO, 1997). Social quality of life was found to be decreased in parental caregivers of children with ASD (Benjak, 2011, Hsiao, 2016, and Ooi et al., 2016. This poor parental social QOL can be attributed to increased caregiver demands with little to no time to develop and maintain social relationships (Benjak, 2011, Hsiao, 2016, and Ooi et al., 2016. Hall (2012), discussed that increased community support was found to promote increased coping in parents of children with ASD. No articles reported data on sexual health.

Environmental QOL. The environmental domain of QOL includes finances, freedom, safety and security, accessibility of health care, quality of health care, the home environment, recreation and leisure, transportation, and opportunities to learn new skills and get new information (WHO, 1997). The environmental QOL domain was negatively impacted in parental caregivers of children with ASD (Benjak, 2011; Favero-Nunes & dos Santos, 2010; Hoefman et al., 2014; Ooi et al., 2016, Van Tongerloo et al., 2015). Parents of children with ASD had lower environmental QOL in the specific areas of personal safety, future security, and financial problems (Benjak, 2011; Hoefman et al., 2014). Additionally, Favero-Nunes and dos Santos (2010) and Siah and Tan (2015) found overall lower perceived environmental QOL. In a qualitative study, Van Tongerloo et al. (2015) discussed emergent themes related to healthcare quality, where parents felt that healthcare professionals did not listen to concerns about their children's behaviors prior to and after their ASD diagnoses. Pozo et al. found a negative correlation between family income and behavior problems of the ASD child (2014). This correlation may be attributed to better healthcare or the ability to afford expensive behavior therapies in high income families, leading to lower severity of behavior problems in the child. In the systematic review, Vasilopoulo and Nisbet (2016) reported that parents working outside of the home had improved environmental QOL while Favero-Nunes and dos Santos (2010) reported that parents with higher education levels had improved environmental QOL. These improved environmental QOL correlations may also be attributed to higher family incomes and the ability to afford better therapies and healthcare.

Spiritual QOL. The spirituality domain includes religion, spirituality, and personal beliefs (WHO, 1997). Only one article (Ooi et al., 2016) in this review reported on spirituality and religion, however, this article was a meta-synthesis of 50 qualitative studies. One of the emergent themes of the synthesis was that parents' hopes and beliefs included the belief in a higher power who gave the ASD child to them or entrusted the child's care to them. The qualitative synthesis discussed that parents used spirituality as a positive coping mechanism to improve QOL (Ooi et al., 2016).

Risk and protective factors. Predictors of QOL were factors showing either risk or protective factors. Risk factors showed a potential to lower parental QOL and protective factors showed a potential to improve QOL.

Risk factors. Risk factors in this review were aberrant behaviors of the child with ASD and also parental perceived threat or loss. Aberrant behaviors of the child include irritability, being uncooperative, or hyperactivity. These behaviors were the strongest predictor and were found to decrease parental QOL (Cappe et al., 2011; Hsaio, 2016; Ooi et al., 2016; Pozo et al., 2014; Walsh et al., 2013; Van Tongerloo et al., 2015; Vasilopoulou and Nisbet, 2016). Multiple studies reported on behaviors of children with ASD that were severe enough to disrupt parents' lives (Cachia, Anderson & Moore, 2016; Cappe et al., 2011). While severity of the diagnosis of ASD was not measured in any of the studies, it can be implied that children with increased aberrant behaviors have an increased severity of diagnosis.

Parental perceived threat or loss describes parents' feelings that ASD threatens the functioning of the family or that the diagnosis of ASD causes loss of participation in family and social functions or loss of future plans for the child with ASD (Cappe et al., 2011; Ooi et al., 2016; Walsh et al., 2013. Cappe et al. (2011) found perceived threat or loss to be the greatest predictor for lower parental QOL (Beta = .41; $B = 1.75$; $t = 4.40$; $p = .000$). Other predictors of lower parental QOL included the inability of the child to communicate, particularly to communicate pain, the need for the parent to be vigilant at all times, and maladaptive emotion-based coping (Ooi et al., 2016; Walsh et al., 2013).

Protective factors. Several protective factors were found in this review. Children with higher functioning ASD, where the child had improved communication of wants and needs, or improved cognition or independence with skills of daily living were found to have an improved effect on parental quality of life (Baghdali, Pry, Michelon & Rattaz, 2014). Another protective factor was increased family income and higher level of parent education (Favero-Nunes & dos Santos, 2010). Increased social support was also found to have a protective effect on parental coping mechanisms (Hall, 2012).

Discussion. There were some limitations and measurement concerns in this review of the literature. Most studies were descriptive and used cross-sectional or convenience sampling, which were lower levels of evidence and weakened the overall results of this review. Some studies also used purposive or convenience sampling, or had small sample sizes, which also weakened the overall results of this review. Another limitation was that many of the articles used differing definitions of children and the age ranges varied. Some studies considered children from 0-12 years old, some 3-18 years old, and some did not limit the age of the child. These gaps in age may be due to the various countries and locations included in the review; however, it is important to note that parents caring for a toddler with ASD may have a different perception of QOL than parents who have cared for an older child with ASD for multiple years. Another limitation was that some studies used tools not originally designed to measure QOL in caregivers. For example, the Par-DD-QOL scale was designed for ear, nose, and throat patients (Baghdadli et al., 2014), and the Cancer Locus of Control Scale was designed for cancer patients (Cappe et al., 2011). Instruments specific to caregiving, QOL, and ASD, would result in more precise data for this population.

Gaps in knowledge. ***Studies Comparing Age of the Child with ASD.*** This review revealed several gaps in the state of the science regarding the QOL of parents of children with ASD. One gap was that no studies compared differences in parental QOL based upon the age of the child with ASD. Additional studies would be helpful to examine the effects of build-up of stressors, and differences in parents caring for toddlers, school-aged children, adolescents, and young adults. Additionally, these studies may give insight to whether early interventions, like behavior therapy, for children with ASD, can improve parental QOL over the course of several years.

Stress and Coping. There were no studies examining if or how stressors differed dependent upon the age of the child with ASD. Studies to examine these differences would be beneficial to understanding the needs of parental caregivers and whether these needs change with the age of the child with ASD. This knowledge could aid clinicians in recommending appropriate resources. For example, it may be more appropriate to offer behavior therapy and resources on toilet training to caregivers with a toddler with ASD and it may be more beneficial to the parents of a 19-year-old with ASD to offer resources on transitioning to adult care.

There was also a clear gap in this review where coping was addressed only minimally in the existing literature. While most articles addressed the initial stressor of the diagnosis of ASD and the additional stressors of caring for a child with ASD, there are unanswered questions about whether positive and negative coping mechanisms significantly affect parental QOL. Additionally, there is no discussion of whether parental caregivers learn improved coping skills over time and how this impacts parental QOL. Additional studies to examine positive and negative coping strategies, differences in coping between mothers and fathers, the capability to improve upon coping skills over time, and the impact of these factors on parental QOL would be beneficial to clinicians developing targeted interventions for parents.

Fathers and Siblings of Children with ASD. Another major gap was that there were a limited number of studies including fathers of children with ASD. In the existing literature, the number of fathers participating in research is minimal to none. This lower number of fathers as participants may be because mothers are traditionally caregivers of children. Additionally, there were no studies to measure the QOL of siblings of children with ASD. Studies focusing on fathers and on siblings might be helpful to determine relationships between stress and coping, particularly when looking at family functioning. This information could be used to determine whether family interventions are appropriate.

Level of Independence. Parental QOL in the domain of level of independence was not addressed in any of the articles in this review. It is unknown whether this domain is affected in parents of children with ASD. Studies including measures of parental level of independence might shed light on parents' ability to work outside of the home and on parents' dependence on medications. Parents experiencing signs and symptoms of depression or substance abuse due to the increased stress of caring for a child with a disability may have decreased QOL in this domain. This information could be a useful measure when determining interventions promote health in parents of children with ASD.

Other Developmental and Intellectual Disabilities. While this review analyzed the QOL of parents of children with ASD, studies with parents of children with other developmental or intellectual disabilities may provide useful data for comparison. Comparing parents of children with other developmental and intellectual disabilities would be helpful to determine whether the impact on QOL seen in this review is specific to ASD, or whether these findings can be applied to children diagnosed with other developmental or intellectual disabilities.

Longitudinal studies. Another gap uncovered in this review was that there are no longitudinal studies on QOL in parents of children with ASD. Longitudinal studies would be helpful to examine the effects of build- up of stressors in parents of children with ASD, and to identify differences in parents caring for younger children with a new diagnosis of ASD versus older adolescents. Additionally, longitudinal studies could give insight to whether early interventions for children with ASD, like behavior therapy, can improve parental QOL over the course of several years.

Chapter Two Summary

This chapter presented the Pearlin Caregiver Stress Process model as a framework for this study and discussed the interrelationships between components of the model, as related to parental caregivers of ASD: Background and context, the initial stressor, additional stressors, mediators, and outcomes (Pearlin et al., 1990). The background and significance of ASD, including prevalence and economic impact, were discussed as significant rationales to justify this study. Additionally, a review of the existing literature related to parental caregivers of children with ASD, stress, coping, and QOL, was presented. This review also included a discussion of the gaps within the existing literature on parental caregivers of children with ASD, including studies comparing the age of the child with ASD, stress and coping, studies including fathers or siblings, studies examining level of independence of the parental caregiver, studies focusing on children with other developmental or intellectual disabilities, and longitudinal studies. The following chapter will outline the research design and methodology of the study.

CHAPTER THREE: RESEARCH DESIGN AND METHODOLOGY

Chapter Three will outline the research design and methodology of this study, including a discussion of the process of receiving approval from the University of Central Florida (UCF) Institutional Review Board (IRB), protection of human subjects, justification for the research design and methodology, and the methods used to conduct the study.

IRB Approval and Protection of Human Subjects

Prior to any data collection, a research proposal was submitted to the UCF IRB to describe the intent, purpose, and method, of the study. No vulnerable populations were included in this study. No identifiable data were collected. All data were stored on a password protected laptop. No deception was used in this study and no illegal or sensitive information was included in the survey. Participants were not compensated for participation. The only risk related to this study was the potential for stress related to answering survey questions. The indirect benefit to completing the study was that there will be a better understanding of QOL in parental caregivers of children with ASD. A request was made to consider this study exempt from human research as the study involved no more than minimal risk to participants. The UCF IRB determined the research to be exempt from human research and approval was obtained to proceed with the study (Appendix B).

Research design

The research design was descriptive and non-experimental with a cross-sectional approach.

Justification for Research Design and Methodology

The Pearlin Caregiver Stress Process model has been used within the caregiver literature to provide a framework for relationships between stress, coping, and QOL in caregivers of individuals with Alzheimer's disease and cancer (Pearlin et al., 1990). However, this model has only been used as a conceptual framework for parental caregivers of children with ASD in one study (Schwichtenberg & Poehlmann, 2007). While the literature suggests that relationships between stress, coping, and QOL exist in parental caregivers of children with ASD, further studies are needed to identify and describe relationships between these variables in this population. Because these relationships have not yet been established, the most appropriate research design is a correlational design. Wood and Brink (2012) give underlying assumptions necessary to select a correlational design. For this proposed design, all assumptions were met, making this the most appropriate design choice: (1) Study variables have not been shown to covary in previous studies of similar populations; (2) A conceptual framework can be proposed to support the possibility of relationships between the variables; (3) There is no tested theory on which to predict the possible relationships between the variables; (4) The variables exist in the population and are amenable to the study; (5) The sample is representative of the population; and (6) There is no manipulation of variables; they are studied as they exist naturally (Wood & Brink, 2012). For these reasons, a correlational design was the best fit for this study.

Because it was not feasible to survey every parental caregiver with ASD, the determination was made to use a cross-sectional approach and to survey parental caregivers of children with ASD living in Florida. Geographically, it was not feasible to travel throughout the state to conduct the study. For this reason, it was decided to use an electronic survey.

Participants and Consent

Sample. The sample included parental caregivers of children, age 3-21, with ASD living in Florida. This age range was selected to capture a range of participants, from the time of diagnosis to the time of transition to adult services. Participants for this study were recruited from eight organizations supporting individuals and families living with autism in Florida. Participants must have been able to read and answer questions in English and have access to a computer to complete the electronic survey. Using G Power 3.1 ® software, an alpha = 0.05, and power = 0.80, the estimated sample size needed was N = 139.

Consent. Participants' completion and submission of the online survey served as an acceptance of informed consent.

Operationalizing Concepts

The Pearlin Caregiver Stress Process model defined four concepts within the caregiver stress process model: Background and context, stressors, mediators, and outcomes (Pearlin et al., 1990). In this study, the background and context were measured by demographic factors. Stressors faced by parents was measured by using the Autism Parenting Stress Index (APSI). Because severity of the ASD diagnosis may also contribute to parental stress, this was measured by using parental report of a provider's diagnosis of severity of the child's diagnosis. Mediators are the mechanism that parents use to deal with these stressors and was measured by using the Coping Self-Efficacy Scale (CSES). The outcomes for this study are QOL as measured by the WHOQOL-BREF using the following variables: Physical health, psychosocial health, social health, and environmental health (WHO, 1997).

Predictor Measures

Demographic questionnaire. A demographic questionnaire was included to assess characteristics of both the parental caregiver and the child with ASD. No names, dates of birth, or any other identifying data were collected. The demographic questionnaire included the following: Parental relationship to the child with ASD; biological sex of the child with ASD; age of the parental caregiver; age of the child with ASD; number of children with ASD; total number of children; number of hours per week worked outside of the home; marital status; highest level of education; and household annual income.

Severity of diagnosis. The severity of the child's diagnosis of ASD was measured through parental report via a single question: Which of the following best describes the clinician's description of your child's level of ASD?

Autism Parenting Stress Index (APSI). The Autism Parenting Stress Index (APSI) scale has 13 items and uses a five point, Likert-type scale. The scale assesses stressors specific to the parental caregiver of a child with ASD, including sleep, toileting, communication, and concerns about the future. The scale also has one total score that reports the parental level of stress, with a higher number indicating a higher level of stress. The total score has shown an acceptable internal consistency and good test-retest reliability for parents of children with ASD, as well as parents of children with other developmental disabilities (Silva & Shalock, 2012). The Cronbach's alpha was 0.827. The specific variable to be used to measure stressors was the overall stress index score (Silva & Schalock, 2012).

Coping Self-Efficacy Scale (CSES). The Coping Self-Efficacy Scale (CSES) measures coping self-efficacy and has 26 items. The scale assesses an individual's ability to cope with stressors. The scale has one total score that reports overall CSES. The total score has previously demonstrated internal consistency, test-retest reliability, and concurrent validity. Cronbach's alpha was 0.91 (Chesney, Neilands, Chambers, Taylor & Folkman, 2006). Within the literature addressing parental caregivers of children with ASD, Vasilopoulou and Nisbet (2016) discuss that a clear gap in research in this population is that coping self-efficacy has not yet been studied and that studies to address coping self-efficacy could help to clarify parental caregivers' self-perceptions of coping.

Outcome Measures

World Health Organization Quality of Life BREF Scale (WHOQOL-BREF). This scale has 26 items and uses a five point, Likert-type scale. This is an abbreviated version of the WHOQOL-100 scale. Two questions assess general quality of life and the remaining 24 questions assess QOL in 4 domains: Physical, psychological, social, and environmental health. This instrument has been widely developed and used. Reliability of the 4 measured domains falls in the acceptable to good range, as measured using Cronbach's alpha: Physical health = 0.79; psychological health = 0.78; social relationships = 0.76; environment = 0.87 (Fu et al., 2013). This instrument has also shown good content validity, criterion-related validity, and construct validity (Fu et al., 2013; Trompenaars, Masthoff, Van Heck, Hodiamont & De Vries, 2005). Specific variables used to measure health outcomes are the overall QOL assessment and 4 domains of the WHOQOL-BRIEF instrument. These 4 variables were: Physical health, psychosocial health, social health, and environmental health.

Data Collection

No personal identifying date, including name, address, date of birth, or other identifying information, were collected on the electronic survey. Data are stored on a password protected laptop. All data were collected using Qualtrics® software. Autism support organizations throughout the state of Florida were asked to distribute a link to the electronic survey to their organization members. The organizations were contacted via email and included the Autism Society of Greater Orlando (ASGO) and the seven Center for Autism and Related Disabilities (CARD): University of Florida CARD in Jacksonville, Florida; Florida State University CARD in Tallahassee, Florida; University of Florida CARD in Gainesville, Florida; University of Central Florida CARD in Orlando, Florida; University of South Florida CARD in Tampa, Florida; Florida Atlantic University in Boca Raton, Florida; and University of Miami CARD in Miami, Florida. Because survey responses were anonymous, it was not possible to determine whether all organizations participated in distributing the survey link. Organizations were asked to distribute the electronic link within their organization and emailed reminders were sent weekly for 30 days. The survey remained open for 30 days.

Chapter Three Summary

Chapter Three included a discussion of the methods of the study. Population and sampling method were discussed. Concepts related to Pearlin Caregiver Stress Process model (Pearlin et al., 1990) and specific to the population of parental caregivers of children with ASD were operationalized for this study. The instruments used within the study were explained. Finally, the process of data collection for this study was explained. The following chapter will include results of this study.

CHAPTER FOUR: RESULTS

The purpose of this study was to determine whether demographic factors, severity of the diagnosis of ASD of the child, coping self-efficacy of the parental caregiver, and stressors faced by the caregiver were predictors of overall quality of life, satisfaction with health, or quality of life in the physical, psychological, social, and environmental domains in parental caregivers of children with ASD. A descriptive, cross-sectional survey was conducted. Participants in the study were parents of children with ASD, age 3 to 21 years old, and English-speaking. Participants were recruited from seven Centers for Autism and Related Disorders (CARD) agencies throughout Florida and from the Autism Society of Greater Orlando (ASGO).

Participants were sent links to access the survey electronically via Qualtrics® software. No personal identifying information was collected. Prior to accessing the survey, participants viewed an explanation of the study. Participants were informed that they could leave the survey at any time or leave questions unanswered. Participants were also informed that answering the questions within the survey may cause stress and they were given a link to the Family Caregiver Alliance page to locate local resources, should they need them (FCA, 2018). Participants were then able to access the survey and electronic consent. Instruments used in this survey were: A demographic survey to assess the parental relationship of the participant to the child with ASD, the biological sex of the child with ASD, parental age, age of the child with ASD, total number of children with ASD, total number of children, total number of hours worked outside of the home, marital status, highest level of education of the parental caregiver, and household income; parent reported level of severity of the diagnosis of ASD of the child; the World Health Organization Quality of Life-BREF (WHOQOL-BREF)(WHO, 1997); the Coping Self-Efficacy Scale (CSE-S)(Chesney et al., 2006); and the Autism Parenting Stress Index (APSI) (Silva &

Shalock, 2012). The data were analyzed using the IBM® Statistical Package for Social Sciences (SPSS®), student version 25.0 for Windows®. The descriptive statistics and data analysis and findings are presented in this chapter.

Psychometric Properties of the Instruments

To evaluate the internal consistency of the instruments used in this study, Cronbach's alpha coefficients were calculated for the APSI, C-SE, and the WHOQOL-BREF in all four domains. The ASPI had an alpha coefficient of .816 in this study, which was consistent with a previous study to determine psychometric properties ($\alpha = .827$, $N = 274$) (Silva & Shalock, 2012). Authors of the C-SE scale (Chesney et al., 2006) reported psychometric properties of multiple studies and reported alpha coefficients between .80-.91($N = 348$), where results of this study were slightly higher at .966 ($N = 117$). The WHOQOL-BREF alpha coefficients in previous psychometric analyses (Skevington, Lotfy & O'Connell, 2004) were reported by domains: Physical QOL ($\alpha = .829$; $N = 11{,}830$); psychological QOL ($\alpha = .81$; $N = 11{,}830$); social QOL ($\alpha = .68$, $N = 11{,}830$); and environmental QOL ($\alpha = .80$; $N = 11{,}830$). Alpha coefficients for the WHOQOL-BREF in this study were consistent with these findings in all domains: Physical QOL ($\alpha = .829$; $N = 151$); psychological QOL ($\alpha = .795$; $N = 152$); social QOL ($\alpha = .613$; $N = 152$); environmental QOL ($\alpha = .819$; $N = 151$).

Table 1: Cronbach's alpha Reliability of Instruments: A Comparison of Previous and Current Studies

Study	*Autism Parenting Stress Index*	*Coping Self-Efficacy Scale*	*WHOQOL-BREF Physical*	*WHOQOL-BREF Psychological*	*WHOQOL-BREF Social*	*WHOQOL-BREF Environmental*
Silva & Shalock, 2012	.827 (N = 274)	N/A	N/A	N/A	N/A	N/A
Chesney et al., 2006	N/A	.80-.91 (N = 348)	N/A	N/A	N/A	N/A
Skevington et al., 2004	N/A	N/A	.82 (N = 11,830)	.81 (N = 11,830)	.68 (N = 11,830)	.80 (N = 11,830)
Current Study	.816 (N = 138)	.966 (N = 130)	.829 (N = 151)	.795 (N = 152)	.613 (N = 152)	.819 (N = 151)

Data Management

Survey results were exported from Qualtrics® software to an IBM®SPSS® compatible file. All surveys were coded with a numeric value and numeric values were assigned randomly after ranking surveys in order of completeness. Surveys were analyzed to determine eligibility criteria, likely errors, and missing variables. All data are stored on a password protected laptop. Data will be retained for five years from the date of survey distribution, October 15, 2018. After five years, data will be destroyed using Microsoft®Eraser® or similar software.

Eligibility. Twenty respondents did not consent to the survey or consented but answered no survey questions and these were removed from the data set (*n* = 20). Twelve respondents did not meet the criterion for age of the child with ASD and were removed from the data set (*n* = 12).

Missing Variables and Errors. All missing variables were coded as 999 in the data set and were excluded from the reported descriptive statistics and statistical analyses. All data were then checked for inconsistencies and those inconsistencies were corrected and recoded. Any data that were determined to be a likely error were coded as 888 in the data set and were excluded from the reported descriptive statistics and statistical analyses.

Additionally, the WHOQOL instrument scoring guidelines recommend that when using the WHOQOL-BREF, any completed survey where less than 20% of data in the Physical, Psychological, or Environmental domains, is missing should be excluded from analysis (WHO, 1996). The guidelines recommend that the respondents' mean score in any domain be calculated and used in surveys where less than 20 % of questions were missing. Similarly, the C-SE instrument also recommended that any survey where less than 20% of the data for the instrument was missing, that should also be excluded from analysis and that respondents' mean scores for the instrument should be calculated and used in surveys where less than 20% of questions were missing (Chesney et al., 2006). While there were no such formal guidelines to scoring the APSI, to maintain consistency in this study, the same procedure was followed. Finally, any survey where any instrument was not completed was omitted from the regression model and analyses.

Where respondents listed multiple ages for the child/children with ASD, the highest age was used in the data set. The determination to use the highest age was made considering that the parent would have experienced being a parental caregiver of a child with autism for the highest number of years. This occurred in two instances, where one parent listed 9, 8, and 6 and another parent listed 6 and 8. One respondent answered that the age of the child was 161, and after careful review of that survey, this was determined to be an error and corrected as 16 years old. Three respondents answered that the age of the parent was 6, 7, and 8. These three answers were coded as an error using the key 888 in the data set. One respondent answered that the number of children with ASD was 13. This was not consistent with the age of the parental caregiver or the respondents answer to age of the child with ASD. This was considered to be an error and coded using the key 888 in the data set.

Three parents reported work hours as a range of 30-40 hours per week (*n* = 2) or 20-30 hours per week (*n* = 1). In these three instances, mean averages of 35 and 25, respectively, were recoded to replace the ranges reported. One parent reported the biological sex of the child, where 1 = male and 2 = female, as 9. This was determined to be an error and recoded as 888.

Independent and Dependent Variables. Independent variables were: Age of the parental caregiver; gender of the parental caregiver; education level of the parental caregiver; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; and coping self-efficacy. Dependent variables were quality of life outcomes in four domains: Physical health; psychological health; social health; and environmental health in parental caregivers of children with ASD.

Demographics

Continuous variables. Continuous variables were the age of the parental caregiver, age of the child with ASD, number of children with ASD, total number of children, and total number of hours worked outside the home. All continuous variables were analyzed for normal distribution by evaluating histograms and by comparing skewness and kurtosis.

The mean age of the parental caregiver in years was 41.88 (SD 10.12, *N* = 151). The ages of parental caregivers ranged from 25-64 years old. The ages of the parental caregiver were normally distributed (skewness = .28; kurtosis -.26).

The mean age, in years, of the child with ASD was 10.51 (SD 5.36; *N* = 149; see Table 4). The age of the child with ASD ranged from 3-21 years old. Ages of the child with ASD were normally distributed (skewness = .31; kurtosis = -1.12).

The mean number of children with ASD was 1.23. Number of children with ASD ranged from 1-4. The number of children with ASD was positively skewed with positive kurtosis Because the data were skewed, it was decided to transform the data to a categorical variable with two categories: 1) one child with ASD; and 2) more than one child with ASD. The percentage of parents with one child with ASD was 81% (*n* = 121). The percentage of parents with more than one child with ASD was 19% (*n* = 29). This transformed variable was considered to be dichotomous and categorical in all other analyses for this study.

The mean total number of children, including children with ASD and children without ASD, was 2.31 (SD 0.979; N = 149). Total number of children ranged from 1-6. The total number of children was normally distributed (skewness = .368; -1.600).

Table 2: Continuous Variables

Continuous Variables	*Frequency (n)*	*Mean (SD)*	*Min*	*Max*	*Skewness*	*Kurtosis*
Age of the parental caregiver	151	41.26 (7.99)	25	64	.27	-.26
Age of the child with ASD	149	10.51 (5.36)	3	21	.31	-1.12
Total number of children	149	2.31 (.97)	1	6	.79	.80
Total number of hours worked outside the home	147	17.73 (18.32)	0	56	.36	-1.60

Table 3: Number of Children with ASD

Variable	*Frequency (n)*	*Mean (SD)*	*Min*	*Max*	*Skewness*	*Kurtosis*
Number of children with ASD	150	1.19 (.40)	1	2	1.56	.47

Because household income was measured in even and sequential increments of $25,000, these data were considered to be continuous. Ranges for household income were between less than $25,000 and more than $150,000. Most participants reported that their income was less than $25,000 (*n* = 21; 13.8%), $25,000-49,999 (*n* = 34, 22.4%), or $50,000-74,999 (*n* = 31; 20.4%). Other participants reported that their household income was $75,000-99,000 (*n* = 19, 12.5%), $100,000-124,999 (*n* = 16; 10.5%), $125,000-149,999 (*n* = 16; 10.5%), or more than $150,000 (*n* = 10; 6.6%). These data were slightly negatively distributed, where most of the participants' household income was less than $74,999 (*n* = 86; 56.6%).

Table 4: Household Income

Household Income	*Frequency*	*Percent*
less than 25,000	21	13.8
25,000-49,999	34	22.4
50,000-74,999	31	20.4
75,000-99,999	19	12.5
100,000-124,999	16	10.5
125,00-149,999	16	10.5
more than150,000	10	6.6
999 (missing)	5	3.3
888 (error)	0	0
Total	152	100%

Categorical variables. Categorical variables were the parental relationship to the child with ASD, biological sex of the child with ASD, marital status, level of education, and severity of the diagnosis of ASD. The variables level of education, and severity of the diagnosis of ASD were also considered to be ordinal. Data for all categorical variables were reported as frequencies and distribution were analyzed using histograms and scatter plots.

In analyzing the parental relationship to the child, 96.1% of survey participants were mothers (*n* = 146) and 3.9% were fathers (*n* = 6) (*N* = 152;). These data were unevenly distributed, where more mothers completed surveys than fathers. Because of the uneven distribution, this variable was reported as a descriptive statistic, but was excluded from the regression model and analyses.

Table 5: Parental Relationship to the Child with ASD

Parental Relationship	*Frequency*	*Percent*
Mother	146	96.1
Father	6	3.9
999 (missing)	0	0
888 (error)	0	0
Total	152	100 %

For the variable biological sex of the child, respondents reported that 77% of their children with ASD were male (*n* = 77), while 22.4% were female (*n* = 34) (*N* = 151). These data were unevenly distributed, where more children with ASD were male versus female, which is consistent with data reported by the CDC, where boys are four times more likely to have a diagnosis of ASD (CDC, 2018). Because of the uneven distribution, this variable was reported as a descriptive statistic, but was excluded from the regression model and analyses.

Table 6: Biological Sex of the Child with ASD

Biological Sex	*Frequency*	*Percent*
Male	117	77
Female	34	22.4
888 (error)	1	0.7
999 (missing)	0	0
Total	152	100 %

In analyzing the results of the variable marital status, most participants reported being married or in a domestic partnership (*n* = 116, 76.3%). Ten percent of participants reported being divorced (*n* = 15; 9.9%). Eight percent of participants reported their status as single, never married (*n* = 12; 7.9). Few participants reported that they were either separated (n = 7; 4.6%) or widowed (*n* = 2; 1.3%). These data were also unevenly distributed, with most participants being married. Because of the uneven distribution, this variable was transformed to a dichotomous categorical variable with two groups: Married or domestic partnership or other. Marital status was considered to be a dichotomous categorical variable for the remainder of the study.

Table 7: Marital Status

Current Marital Status	*Frequency*	*Percent*
Married or domestic partnership	116	76.3
Widowed	2	1.3
Divorced	15	9.9
Separated	7	4.6
Single, Never Married	12	7.9
999 (missing)	0	0
888 (error)	0	0
Total	152	100

Most participants reported that their highest level of education was a bachelor’s degree (*n* = 41; 27%), associate degree (*n* = 33; 21.7%) or master’s degree (*n* = 28; 18.4%).

Some participants reported that their highest level of education was a high school diploma or GED (*n* = 26; 17.7%) or career/technical training (*n* = 18; 11.8%). Few participants reported that their highest level of education was a professional degree (MD, DDS, DMV) (*n* = 3; 2%) or doctoral degree (*n* = 2; 1.3%). Only one participant reported that their highest level of education was some high school (*n* = 1; 0.7%). The highest level of education of parental caregivers was evenly distributed.

Table 8: Highest Level of Education of the Parental Caregiver

Highest Level of Education	*Frequency*	*Percent*
Some High School (HS) or HS diploma or GED	27	17.8
Career or Technical	18	11.8
Associate degree	33	21.7
Bachelor's degree	41	27.0
Master's degree or higher	33	21.7
999 (missing)	0	0
888 (error)	0	0
Total	152	100%

Participants were asked to answer how a healthcare provider described the severity of the diagnosis of ASD for their child. They reported that health care providers described their child's severity of the diagnosis of ASD as moderate (*n* = 39.5%), mild (*n* = 58; 38.2%), or severe (*n* = 34%) (see Table 14). The severity of the diagnosis of ASD was evenly distributed.

Table 9: Severity of the Diagnosis of ASD

Severity of Diagnosis	*Frequency*	*Percent*
Mild	58	38.2
Moderate	60	39.5
Severe	34	22.4
999 (missing)	0	0
888 (error)	0	0
Total	152	100%

Stressors

The Autism Parenting Stress Index (APSI) was used to measure self-perceived stressors faced by parental caregivers of children with ASD. The instrument has 13 items measured on a

Likert-type scale of 1 through 5, with 5 being the most stress (*N* = 138). After adjusting for missing variables, the mean total score was 35.92 (SD = 8.36, see Table 15). The data were normally distributed (skewness = .55; kurtosis = -.21).

Table 10: Autism Parenting Stress Index (APSI) Results

Stressors	*Frequency*	*Mean (SD)*	*Min*	*Max*	*Skewness*	*Kurtosis*
Social development	139	3.44 (.99)	1	5	-.03	-.86
Ability to communicate	139	2.96 (.99)	1	5	-.09	-.53
Tantrums/meltdowns	139	3.05 (1.16)	1	5	.09	-.88
Self-injurious behavior	138	1.97 (1.15)	1	5	.98	.00
Aggressive behavior (toward siblings)	139	2.71 (1.36)	1	5	.27	-1.15
Difficulty making transitions (from one activity to another)	139	2.80 (1.01)	1	5	.24	-.70
Sleep problems of the child	139	2.53 (1.31)	1	5	.33	-1.11
Diet (picky eater, sensory issues)	139	2.94 (1.27)	1	5	-.01	-1.11
Bowel problems	139	1.95 (1.18)	1	5	1.09	.23
Potty training	139	1.92 (1.35)	1	5	1.16	-.14
Not feeling close to your child	139	2.09 (1.13)	1	5	.77	-.37
Concern for the future of your child being accepted by others	139	3.83 (.91)	2	5	-.47	-.51
Concern for the future of your child living independently	139	3.73 (1.10)	1	5	-.63	-.37
Adjusted Total	139	35.92 (8.36)	20	57	.55	-.21

Coping Self-Efficacy

The Coping Self-Efficacy (C-SE) scale was used to measure parental caregivers' self-perceived strategies to cope with stressors. The instrument has 26 items measured on an 11-point Likert-type scale ranging from 0 (cannot do at all) to 10 (able to do all the time) (*N* = 130). After adjusting for missing variables, the mean total score was 133.95 (SD = 47.20, see Table 16). The data were normally distributed (skewness = .09; kurtosis = -.20).

Table 11: Coping Self-Efficacy (C-SE) Results

C-SE Strategies	*Frequency*	*Mean (SD)*	*Min*	*Max*	*Skewness*	*Kurtosis*
Keep from getting down in the dumps	140	5.39 (2.09)	0	10	-.02	-.07
Talk positively to yourself	139	5.48 (2.36)	0	10	-.01	-.67
Sort out what can be changed, and what cannot be changed	140	6.22 (2.30)	0	10	-.28	-.76
Get emotional support from friends and family	137	4.78 (2.93)	0	10	.23	-1.01
Find solutions to your most difficult problems	138	5.19 (2.44)	0	10	-.04	-.76
Break an upsetting problem down into smaller parts	140	5.69 (2.34)	1	10	-.06	-.91
Leave options open when things get stressful	138	5.35 (2.29)	0	10	-.03	-.44
Make a plan of action and follow it when confronted with a problem	140	5.69 (2.36)	0	10	-.34	-.45
Develop new hobbies or recreations	133	3.46 (2.60)	0	10	.80	-.10
Take your mind off unpleasant thoughts, stop unpleasant thoughts	136	4.96 (2.56)	0	10	.07	-.98
Look for something good in a negative situation	138	6.12 (2.36)	0	10	-.34	-.56
Keep from feeling sad	136	4.97 (2.30)	0	10	-.02	-.73
See things from the other person's point of view during a heated argument.	139	5.87 (2.34)	0	10	-.32	-.41
Try other solutions to your problems if your first solutions don't work	139	6.12 (2.30)	0	10	-.43	-.46
Stop yourself from being upset by unpleasant thoughts	138	5.00 (2.50)	0	10	-.05	-1.01
Make new friends	134	3.68 (2.89)	0	10	.70	-.57
Get friends to help you with the things you need	135	3.59 (2.72)	0	10	.59	-.64
Do something positive for yourself when you are feeling discouraged	137	4.50 (2.69)	0	10	.30	-.78
Make unpleasant thoughts go away	139	4.73 (2.45)	0	9	.03	-1.07
Think about one part of the problem at a time	138	5.20 (2.33)	0	10	-0.79	-0.87
Keep yourself from feeling lonely	135	5.12 (2.78)	0	10	.077	-1.14
Pray or meditate	137	5.66 (3.40)	0	10	-.20	-1.34
Get emotional support from community organizations or resources	129	3.32 (2.72)	0	10	.77	-.18
Stand your ground and fight for what you want	138	6.51 (2.63)	1	10	-.29	-1.04
Resist the impulse to act hastily when under pressure	1300	5.25 (2.77)	0	10	-.07	-1.06
Adjusted Total Score		133.95 (47.20)	14	257	.09	-.20

Quality of Life

The World Health Organization (WHO) Quality of Life (QOL) BREF survey measures QOL in four domains: Physical, psychological, social and environmental health (WHO, 1997). The instrument has a total of 26 questions scored on a 5-point Likert-type scale. The first two questions are not included in the four domains of QOL and are scored separately. All but three questions are ranked positively, where a higher score signifies improved QOL; however, two questions in the physical domain and one question in the psychological domain are ranked negatively in the instrument and needed to be reverse scored prior to analysis. All scoring was done in accordance with the WHOQOL-BREF scoring guidelines. These guidelines state that mean scores should be calculated for each domain and when scoring the physical, social, and environmental domains, any survey with missing data less than 20% of the total survey should use the mean domain score in place of the missing data and surveys with more than 20% missing data should not be included in further analyses. In the social domain, where only three questions are included, for surveys missing one question, the mean score for the social domain can be substituted for the missing data and surveys missing more than one question should not be included in further analyses. All surveys had less than 20% of questions missing; therefore, all surveys were retained. Some surveys had missing data in the physical, social, and environmental domains and mean scores for each domain were calculated and substituted for the missing data. In the social domain, one question, "How satisfied are you with your sex life?" was unintentionally omitted from the distributed electronic survey. This was handled as missing data for the social domain and the mean score for that domain was substituted for each survey. Continuing with the scoring guidelines, mean scores were calculated for each item in the domain and then multiplied by four, to arrive at a transformed score of between 4-20, to be consistent with scoring of the WHOQOL-100 Long Version survey (WHO, 1997).

The first two questions stand alone, should be reported as individual questions and should not be included in the analysis of the four domains of QOL (WHO, 1997). The first two questions were scored on a 1-5 Likert-type scale with 5 being the highest. Question 1 measured self-perceived overall QOL of the parental caregiver and the mean score was 3.45 (SD = .964; *N* = 151). The data were normally distributed (skewness = -.47; kurtosis = -.28) (see Table 17). Question 2 measured self-perceived satisfaction with health of the parental caregiver. The mean score was 2.9 (SD = .99; N= 152). The data were normally distributed (skewness = .02; kurtosis = -1.02).

Table 12: Overall Quality of Life (QOL) and Satisfaction with Health

QOL measures	*Frequency*	*Mean (SD)*	*Min*	*Max*	*Skewness*	*Kurtosis*
How would you rate your QOL?	151	3.45 (.96)	1	5	-.47	-.28
How satisfied are you with your health?	152	2.89 (.99)	1	5	.02	-1.02

Physical Quality of Life (QOL). Two questions were reverse scored: The question evaluating physical pain and the question evaluating dependence on medical aids. Mean scores for each survey for the physical QOL domain were calculated and substituted for missing data. Mean scores for each question in the physical QOL ranged from 2.57 (SD1.03) to 3.99 (SD 1.14) on a scale of 1-5. Raw scores were transformed using the WHOQOL-BREF scoring guidelines, where mean scores were calculated for all questions in the domain and multiplied by 4 to arrive at a transformed total score (WHO, 1997). The transformed total score for the physical QOL domain was 12.93 on a scale of 4-20 (SD 3.04; skewness = -.29; kurtosis = -.33; N = 152).

Table 13: Physical Quality of Life (QOL)

Physical QOL Items	*Frequency*	*Mean (SD)*	*Min*	*Max*	*Skewness*	*Kurtosis*
Physical pain	152	3.64 (1.177)	1	5	-.671	-.364
Dependence on medical aids	152	3.80 (1.135)	1	5	-.938	.311
Mobility	152	3.99 (.983)	1	5	-.821	-.084
ADL's	152	3.07 (1.071)	1	5	-.263	-.853
Capacity to work	151	2.96 (1.142)	1	5	-.248	-1.034
Sleep (of the parental caregiver)	152	2.57 (1.027)	1	5	.099	-1.017
Energy	152	2.61 (1.037)	1	5	.130	-.528

Psychological Quality of Life. One question was reverse scored: How often do you have negative feelings such as blue mood, despair, anxiety, depression? Mean scores for each survey for the psychological QOL domain were calculated and substituted for missing data. Mean scores for each question in the psychological QOL ranged from 2.72 (SD 1.07) to 3.50 (SD 1.05) on a scale of 1-5. Raw scores were transformed using the WHOQOL-BREF scoring guidelines, where mean scores were calculated for all questions in the domain and multiplied by 4 to arrive at a transformed total score (WHO, 1997). The transformed total score for the psychological QOL domain was 11.93 on a scale of 4-20 (SD 2.71; skewness = -.06; kurtosis = -.19; N = 152).

Table 14: Psychological Quality of Life (QOL)

Psychological QOL Items	*Frequency*	*Mean (SD)*	*Min*	*Max*	*Skewness*	*Kurtosis*
Enjoyment of life	152	3.24 (.87)	1	5	.00	-.37
Ability to concentrate	152	2.77 (.80)	1	5	.13	-.47
Finding meaning in life	152	3.50 (1.05)	1	5	-.35	-.50
Accepting body appearance	152	2.72 (1.07)	1	5	.13	-.75
Frequency of negative feelings (blue, anxiety, depression)	152	2.68 (1.01)	1	5	-.05	-.61
Satisfaction with self	152	2.98 (1.00)	1	5	.05	-.61

Social Quality of Life (QOL). No questions in this domain were reverse scored. Mean scores for each survey for the social QOL domain were calculated and substituted for missing data. Mean scores for each question in the social QOL ranged from 2.73 (SD 1.139) to 3.04 (SD 1.179) on a scale of 1-5. Raw scores were transformed using the WHOQOL-BREF scoring guidelines, where mean scores were calculated for all questions in the domain and multiplied by 4 to arrive at a transformed total score (WHO, 1997). The transformed total score for the social QOL domain was 11.54 on a scale of 4-20 (SD 3.936; skewness = .121; kurtosis = -.452; N = 152).

Table 15: Social Quality of Life (QOL)

Social QOL Items	*Frequency*	*Mean (SD)*	*Min*	*Max*	*Skewness*	*Kurtosis*
Satisfaction with support from friends	152	2.73 (1.13)	1	5	.28	-.60
Satisfaction with personal relationships	152	3.04 (1.17)	1	5	-.10	-.89
Adjusted Total	152	11.54 (3.940	4	20	.12	.45

Environmental Quality of Life (QOL). Mean scores for each survey for the environmental QOL domain were calculated and substituted for missing data. Mean scores for each question in the environmental QOL ranged from 2.23 (SD 1.040) to 3.99 (SD 1.003) on a scale of 1-5. Raw scores were transformed using the WHOQOL-BREF scoring guidelines, where mean scores were calculated for all questions in the domain and multiplied by 4 to arrive at a transformed total score (WHO, 1997). The transformed total score for the environmental QOL domain was 13.33 on a scale of 4-20 (SD 2.862; skewness = -.161; kurtosis = -.015; N = 152).

Table 16: Environmental Quality of Life (QOL)

Environmental QOL Items	*Frequency*	*Min*	*Max*	*Mean (SD)*	*Skewness*	*Kurtosis*
Safety in daily life	152			3.77 (.888)	-.509	-.085
Healthy physical environment	152			3.64 (.794)	-.222	-.321
Enough money to meet needs	152			2.82 (1.373)	.105	-1.229
Opportunity for leisure activities	151			2.23 (1.040)	.832	.324
Conditions of living space	152			3.55 (1.167)	-.610	-.471
Access to health services	152			3.16 (1.263)	-.335	-.992
Satisfaction with transport	152			3.99 (1.003)	-1.130	1.095
Availability of information	152			3.50 (1.023)	-414	-.357

Additional statistical tests were performed to determine the normal distribution of each of the four QOL domains. The Shapiro Wilk test was used to assess normality. Results are reported in Table 18. For the Physical, Psychological and Environmental domains, p values were greater than 0.05% and the assumption of normality was supported for those variables. For the Social domain, the Shapiro Wilk test was not statistically significant (.965; p = .00). This failure to meet the assumption of normality may be related to the low alpha coefficient scores in both previous studies (α = .68; N = 11,380) (Skevington et al., 2004) and in this study (α = .613; N = 152), where there were only three questions evaluating Social QOL and questions may not effectively measure this outcome. Additionally, one question of the three was unintentionally omitted from this survey, which may have also affected normality. Due to the failure of this domain outcome to meet the assumptions of normality, only frequencies, adjusted scores, and relationships between the other domains were reported. The social domain of QOL was not included in regression analyses.

Table 17: WHOQOL-BREF Adjusted Scores

Domain	*Frequency*	*Mean (SD)*	*Min*	*Max*	*Skewness*	*Kurtosis*	*Shapiro-Wilk*	*Sig.*
Physical	152	12.93 (3.036)	5.71	19.43	-.293	-.331	.984	.08
Psychological	152	11.93 (2.708)	4.87	18.00	-.057	-.189	.988	.24
Social	152	11.54 (3.936)	4.00	20.00	.121	-.452	.965	.00
Environmental	152	13.33 (2.862)	5.50	20.00	-.161	-.015	.991	.449

Research Questions

Research Question One. What, if any, relationships are present among the dependent variables: Physical QOL, psychosocial QOL, social QOL; and environmental QOL in parental caregivers of children with ASD?

A correlation matrix was used to determine whether any relationships exist between dependent variables. Relationships were reported as Pearson's correlation coefficient, *r.* A *p* = 0.05, two-tailed, was used to determine statistical significance. Each of the four domains of QOL were positively correlated with the other three domains, showing that if there is an increase in any one domain of QOL, the other three domains will also increase. Physical QOL was correlated with psychological QOL (*r* = .614, *p* = .000, *N* = 152), social QOL (*r* = .459, *p* = .000, *N* = 152), and environmental QOL (*r* = .555, *p* = .000, *N* = 152). Psychological QOL was correlated with physical QOL (*r* = .614*,* *p* = .000, *N* = 152), social QOL (*r* = .650, *p* = .000, *N* = 152, environmental QOL (*r* = .580, *p* = .000, *N* = 152). Social QOL was correlated with physical QOL (*r* = .459, *p* = .000, *N* = 152), psychological QOL (*r* = .650, *p* = .000, *N* = 152), and environmental QOL (*r* = .580, *p* = .000, *N* = 152). Environmental QOL was correlated with physical QOL (*r* = .555, *p* = .000, *N* = 152), psychological QOL (*r* = .580, *p* = .000, *N* = 152), and social QOL (*r* = 539, *p* .000, *N* = 152). Histograms were used to determine normal distribution, linearity, to assess for outliers, and to determine homoscedasticity. No assumptions of normality were violated; therefore, no further non-parametric analysis was needed.

Table 18: Correlations Between Dependent Variables

Dependent Variables	*Physical*	*Psychological*	*Social*	*Environmental*
Physical (N = 152)				
Pearson Correlation	1	.614**	.459**	.555**
Significance (2-tailed)		Sig = .000	Sig = .000	Sig = .000
Psychological (N = 152)				
Pearson Correlation	.614**	1	.650**	.580**
Significance (2-tailed)	Sig = .000		Sig = .000	Sig = .000
Social (N = 152)				
Pearson Correlation	.459**	.650**	1	.539**
Significance (2-tailed)	Sig = .000	Sig = .000		Sig = .000
Environmental (N = 152)				
Pearson Correlation	.555**	.580**	.539**	1
Significance (2-tailed)	Sig = .000	Sig = .000	Sig = .000	

**Correlation was significant at p = .0001 (two-tailed)

Research Question Two. What, if any, relationships are present among the independent variables: Age of the parent; gender of the parent; biological sex of the child, education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; and coping self-efficacy?

A correlation matrix was used to determine whether any relationships exist between continuous independent variables. Relationships were reported as Pearson's correlation coefficient, r. A $p = 0.05$, two-tailed, was used to determine statistical significance. The age of the child with ASD was positively correlated with age of the parent ($r = .714$, $p = .000$, $N = 152$). Number of hours per week was negatively correlated with total number of children ($r = -.192$ $p = .021$, $N = 152$). Household income was positively correlated with age of the parent ($r = .252$, $p = .002$, $N = 152$). Household income was also negatively correlated with number of hours worked outside the home (*r* = -.418, *p* = .000, *N* = 152). Coping Self-Efficacy was positively correlated with the age of the child (*r* = .215, *p* = 0.15, *N* = 152). Stressors were negatively correlated with the age of the parent (*r* = -.206, *p* = .015, *N* = 138), the number of hours worked outside of the home (*r* = -.19, *p* = .027, *N* = 138), house income (*r* = -.236, *p* = .006, *N* = 138) and coping self-efficacy (*r* = -.381, *p* = .000, *N* = 130). Histograms were used to determine normal distribution, linearity, to assess for outliers, and to determine homoscedasticity. No assumptions of normality were violated; therefore, no further non-parametric analyses were needed.

Table 19: Correlations between Continuous Independent Variables

	Age of parent	*Age of child*	*Total number of children*	*Hours worked outside the home*	*Household Income*	*C-SE*	*Stress*
Age (parent)	1						
Pearson correlation							
Significance							
Age (child)		1					
Pearson correlation	.714**						
Significance	.000						
Total #of children	--	--	1				
Pearson correlation							
Significance							
Hours worked/week	--	--	-.192*	1			
Pearson correlation			.021				
Significance							
Household Income							
Pearson correlation	.252*			-.418**			
Significance	.002			.000			
C-SE	--		--	--	--	1	
Pearson correlation		.215*					
Significance		.015					
Total Stress		--	--				1
Pearson correlation	-.206*			-.191*	-.236**	-.381**	
Significance	.015			.027	.006	.000	

**Correlation is significant at the .01 level (2-tailed)
*Correlation is significant at the .05 level (2-tailed)

Chi square tests of independence were used to examine relationships between all categorical dichotomous variables: Parental relationship to the child with ASD; biological sex of the child; marital status; and number of children with ASD. Pearson Chi-Square values were analyzed for each pair of categorical dichotomous variables. No relationships were statistically significant.

One-way ANOVA tests were used to examine relationships between all continuous and the categorical variables level of education and severity of the diagnosis of ASD. There were no significant relationships between age of the parent, age of the child with ASD, total number of children, and coping self-efficacy and the categorical variables of level of education and severity of the diagnosis of ASD.

Table 20: Significant Relationships Between Continuous and Categorical Variables

Continuous variable	*Categorical variables*	*Sum of squares*	*df*	*Mean Square*	*F*	*Sig.*
Hours worked outside the home	Level of education	90.73	26	3.490	1.802	.018
Household income	Level of education	79.51	6	13.25	7.51	.000
	Severity of diagnosis	10.43	6	1.74	3.33	.004
Stressors	Severity of diagnosis	35.53	35	1.02	2.27	.001

Additional post-hoc tests were done to further analyze the relationships between variables using Tukey alpha and a statistical significance at $p = .05$. There was statistical significance between household income and level of education, suggesting that for every increase in level of education, there was a related increase in household income, (Mean differences -.69 to -1.29; $p =$ 0.10-.000). No other post-hoc Tukey values were statistically significant.

Research Question Three. What, if any, relationships are present among independent and dependent variables: Age of the parent; gender of the parent; education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; coping self-efficacy, physical health, psychosocial health, social health; and environmental health in parental caregivers of children with ASD?

A correlation matrix was used to determine whether any relationships exist between continuous independent and dependent variables. Relationships were reported as Pearson's correlation coefficient, *r*. A $p = 0.05$ value was used to determine statistical significance. The outcome variable, social health, was excluded from this analysis due to normality values that were not statistically significant, as previously discussed.

Physical QOL was positively correlated with number of hours worked outside the home (*r* = .202, *p* = .014, *N* = 152), household income (*r* = .211, *p* = .010, *N* = 152), and coping self-efficacy (*r* = .449, *p* = .000, *N* = 130). Physical QOL was also negatively correlated with stressors (*r* = -.495, *p* = .000, *N* = 138).

Psychological QOL was positively correlated with coping self-efficacy (*r* = .640, *p* = .000, N = 152). Psychological QOL was also negatively correlated with stressors (*r* = -.502, *p* = .000, *N* = 138).

Environmental QOL was positively correlated with household income (*r* = .482, *p* = .000, *N* = 152), and coping self-efficacy (*r* = .539, *p* = .000, *N* = 130). Environmental QOL was also negatively correlated with stressors (*r* = -436, *p* = .000, *N* = 138).

Table 21: Significant Correlations Between Independent and Dependent Variables

QOL Domains	*Physical*	*Psychological*	*Environmental*
Age of the parent			
Pearson Correlation			
Significance			
Age of the child with ASD			
Pearson Correlation			
Significance			
Total # of children			
Pearson Correlation			
Significance			
Hours worked outside the home			
Pearson Correlation	.202*		
Significance	.014		
Household income			
Pearson Correlation	.211*		.482**
Significance	.010		.000
C-SE			
Pearson Correlation	.449**	.640**	.539**
Significance	.000	.000	.000
Stress			
Pearson Correlation	-.495**	-.502**	-.436**
Significance	.000	.000	.000

**Correlation is significant at the .01 level (2-tailed)
*Correlation is significant at the .05 level (2-tailed)

Additional two-sample t-tests were performed on the categorical dichotomous independent variables, parental relationship to the child, biological sex of the child with ASD, marital status, and number of children with ASD, with the dependent outcomes, physical, psychological, and environmental QOL. The requirement to perform a two-sample t-test is equality of variances, as measured by a statistically significant *Levene'*s test at value $p = .05$.

In examining parental relationship to the child and biological sex of the child and QOL outcomes in the physical, psychological, and environmental domains, equality of variances was met in all domains, however, t-tests were not statistically significant in any domain. Additionally, number of children with ASD in the physical and psychological domains met equality of variances, but t-tests were not statistically significant.

In examining marital status with the physical, psychological, and environmental domains, equality of variances was met, and t-tests were statistically significant. Similarly, equality of variances was met between number of children with ASD and the environmental QOL domain and the t-test was statistically significant.

Table 22: Statistically Significant Relationships Between Categorical Dichotomous and Continuous Variables

Categorical dichotomous variable	*QOL Domain*	*F*	*Sig*	*t*	*df*	*Sig (2-tailed*	*95% CI Lower*	*95% CI Upper*
Marital status	Physical	.09	.76	2.61	150	.01	.36	2.60
	Psychological	.02	.89	2.48	150	.01	.26	2.26
	Environmental	.53	.47	4.73	150	.00	1.4	3.43
# of children with ASD	Environmental	1.06	.31	2.21	148	.028	.14	2.44

A one-way ANOVA was performed to examine relationships between the categorical variable of level of education and the QOL domains of physical, psychological, and environmental QOL. No tests were statistically significant. Additionally, a one-way ANOVA was performed to examine relationships between the categorical variable of severity of the diagnosis of ASD and the QOL domains of physical, psychological, and environmental QOL. Results were statistically significant in all three domains.

Table 23: Statistically Significant Relationships Between Severity of ASD and QOL Domains

Categorical variable	*QOL domains*	*Sum of squares*	*df*	*Mean Square*	*F*	*Sig.*
Severity of the diagnosis of ASD	Physical	88.58	2	44.29	5.07	.007
	Psychological	81.54	2	40.77	5.92	.003
	Environmental	159.29	2	79.65	11.01	.000

Research Question Four. Do any of the independent variables: Age of the parent; gender of the parent; education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; and coping self-efficacy, either alone or in a subset, predict the following dependent variables: Physical health, psychosocial health, social health; and environmental health in parental caregivers of children with ASD?

Relationships uncovered in Questions 1-3 were further analyzed to identify predictors of the dependent variables: The outcomes of QOL in the physical, psychological, and environmental domains. The social domain was omitted from further analysis, as previously discussed. The goal of this research question was to identify whether any independent variables, either alone or in a subset, would predict the dependent variables. Because the three dependent outcomes were continuous variables measured at the interval level, and because all three outcomes were normally distributed, an Ordinary Least Squares (OLS) regression model was selected as the most appropriate statistical analysis. A p value less than 0.05 was considered statistically significant. Only variables with a statistically significant Pearson correlation coefficient corresponding to that domain, a statistically significant t-test, or a statistically significant ANOVA were added to the models. The Durbin-Watson test was used to examine autocorrelation for all models, where a value of 1.50-2.50 was considered to be normal (Walker & Madden, 2020). All models were between 1.50 and 2.50, showing no autocorrelation. Additionally, multicollinearity between variables was assessed by analyzing variance inflation factors (VIF), where a normal value of VIF was less than 5.0. All models were between 1.000-2.000, showing no multicollinearity. Histograms were analyzed, and all data were normally distributed.

Physical QOL. In the physical QOL domain the following independent variables showed a statistically significant correlation and were added to the regression model: Hours worked outside of the home, marital status, severity of the diagnosis of ASD of the child, coping self-efficacy, and stressors. A stepwise ordinary least squares regression was run in SPSS®. Three models were uncovered in this regression and all were statistically significant ($p = .000$). Model 1 included the independent variable of stressors (Adjusted $R^2 = .266$). Model 2 included the independent variables of coping self-efficacy and stressors (Adjusted $R^2 = .326$). Model 3 included the independent variables of coping self-efficacy, stressors, and household income and was found to be the best fit for the model (Adjusted $R^2 = .347$). A subset of the variables coping self-efficacy, stressors faced by parents, and household income was determined to predict 34.7% of QOL in the physical domain.

In model 1, the predicted value of physical QOL was 19.465 when controlling for stressors ($b = 19.465$). For every one unit increase in stressors, there was a .176 decrease in physical QOL ($b = -.176$). For every one unit increase in stressors, there is a .522 unit decrease in physical QOL ($\beta = -.522$). The R-square change for model 1 was .273.

In model 2, the predicted value of physical QOL was 15.914 when controlling for stressors and coping self-efficacy ($b = 15.914$). For every one unit increase in stressors, there was a .140 decrease in physical QOL ($b = -.140$). For every one unit increase in stressors, there is a .417 unit decrease in physical QOL ($\beta = -.417$). Also, for every one unit increase in coping self-efficacy, there is a .276 unit increase in physical QOL ($\beta = .276$). The R-square change for model 2 was .065.

In model 3, the predicted value of physical QOL was 14.563 when controlling for stressors, self-efficacy, and household income ($b = 14.563$). For every one unit increase in stressors, there was a .128 decrease in physical QOL (*b* = -.128). For every one unit increase in stressors, there was a .382 unit decrease in physical QOL (β = -.382). For every one unit increase in coping self-efficacy, there was a .279 unit increase in physical QOL (β = .279). Also, for every one unit increase in household income, there was a .164 unit increase in physical QOL (β = .164). The R-square change for model 3 was .026.

Further exploration of the final model was performed to evaluate the bivariate relationship between the physical QOL domain outcome and the independent variables of coping self-efficacy, stressors, and household income. Stressors had a negative relationship with physical QOL (*t*= -4.651; *p* = .001), showing that the more stressors faced by parents of children with ASD, the lower physical QOL. Coping self-efficacy and household income had positive relationships with physical QOL (*t* = 3.458; *p* = .033 and *t* = 2.152; *p* = .033, respectively), showing that parents with better coping skills and a higher household income were shown to have higher physical QOL. Additionally, the strength of these relationships was explored by evaluating the unstandardized effects of the independent variables: Stressors (*b* = -.128), coping self-efficacy (*b* = .017), and household income (*b* = .259).

This multiple regression analysis was used to identify predictor variables for physical QOL in parental caregivers of children with ASD. The results of the regression indicated that three predictors explained 36.3% of the variance of physical QOL (R^2 = 36.3, *F* = 4.656, *p* = .033). It was found that stressors significantly predicted physical QOL (*B* = -.382, *p* = .001). Coping self-efficacy (*B* = .279, *p* = .033) and household income (*B* = .164, *p* = .033) were also predictors of physical QOL. The VIF for each variable was analyzed and all factors were found to be less than 1.5, confirming that there was no multicollinearity between variables. The OLS regression model assumptions were met, as evidenced by the random distribution of residuals when analyzed using a scatterplot of residuals against predicted values.

Table 24: Model Summary: Predictors of Physical QOL

Model	*R*	*R Square*	*Adjusted R Square*	*Std. Error of the Estimate*	*R2 Change*	*F Change*	*F Change Sig.*
Model 1	.522	.273	.266	2.455	.273	43.852	.000
Model 2	.581	.338	.326	2.353	.065	11.364	.001
Model 3	.603	.363	.347	32.37	.026	4.656	.033

Model 1: Stressors
Model 2: Stressors; Coping Self-Efficacy
Model 3: Stressors; Coping Self-Efficacy; Household Income

Table 25: Regression ANOVA: Predictors of Physical QOL

		Sum of Squares	*df*	*Mean Square*	*F*	*Sig*
Model 1	Regression	264.386	1	264.386	43.852	.000
	Residual	705.404	117	6.029		
	Total	969.790	118			
Model 2	Regression	327.326	2	163.663	29.550	.000
	Residual	642.464	116	5.538		
	Total	969.790	118			
Model 3	Regression	352.326	3	117.442	21.873	.000
	Residual	617.464	115	5.369		
	Total	969.790	118			

Model 1: Stressors
Model 2: Stressors; Coping Self-Efficacy
Model 3: Stressors; Coping Self-Efficacy; Household Income

Table 26: Influence of Stressors and Coping Self-efficacy on Physical QOL

Model 1	*Variable*	*Unstandardized B*	*S.E.*	*Standardized Beta*	*t*	*Sig*	*CI Lower*	*CI Upper*	*Tolerance*	*VIF*
	(constant)	19.465	.973	--	20.004	.000	17.537	21.392	--	--
	Stressors	-.176	.027	-.522	-6.622	.000	-.228	-.123	1.00	1.00
Model 2	(constant)	15.914	1.407	--	11.313	.000	13.128	18.700	--	--
	Stressors	-.140	.028	-.417	-5.097	.000	-.195	-.086	.854	1.171
	Coping Self-Efficacy	0.17	.005	.276	3.371	.001	.007	.027	.854	1.171
Model 3	(constant)	14.563	1.520	--	9.580	.000	11.552	17.574	--	--
	Stressors	-.128	.028	-.382	-4.651	.001	-.183	-.074	.821	1.218
	Coping Self-Efficacy	.017	.005	.279	3.458	.033	.027	.854	.854	1.171
	Household Income	.259	.120	.164	2.152	.033	.021	.496	.957	1.045

Model 1: Stressors
Model 2: Stressors; Coping Self-Efficacy
Model 3: Stressors; Coping Self-Efficacy; Household Income

Psychological QOL. In the psychological QOL domain the following independent variables showed a statistically significant correlation and were added to the regression model: Marital status, severity of the diagnosis of ASD of the child, coping self-efficacy, and stressors. None of these variables were dichotomous. A stepwise ordinary least squares regression was run in SPSS®. Two models were uncovered in this regression and both were statistically significant (p = .000 (F)). Model 1 included the independent variable of coping self-efficacy (Adjusted R^2 = .415). Model 2 included the independent variables of coping self-efficacy and stressors (Adjusted R^2 = .481). A subset of the variables coping self-efficacy and stressors faced by parents, was determined to predict 48.1% of QOL in the psychological domain.

In model 1, the predicted value of psychological QOL was 7.347 when controlling for coping self-efficacy (b = 7.347*)*. For every one unit increase in coping self-efficacy, there was a .036 increase in psychological QOL (*b* = .036). For every one unit increase in coping self-efficacy, there is a .647 unit increase in psychological QOL (β = .647). The R-square change for model 1 was .419.

In model 2, the predicted value of psychological QOL was 11.280 when controlling for coping self-efficacy and stressors (*b* = 11.280*)*. For every one unit increase in coping self-efficacy, there was a .030 increase in psychological QOL (*b* = .030). For every one unit increase in coping self-efficacy, there is a .539 deviation increase in psychological QOL (β = .539). For every one unit increase in stressors, there was a .088 decrease in psychological QOL (*b* = -.088). Also, for every one unit increase in stressors, there is a .286 unit decrease in psychological QOL (β = -.286). The R-square change for model 2 was .070.

Further exploration of the final model was performed to evaluate the bivariate relationship between the psychological QOL domain outcome and the independent variables of coping self-efficacy and stressors. Coping self-efficacy was found to have a positive relationship with psychological QOL (*t*= 7.790; *p* = .000), showing that parents with better coping skills were found to have higher psychological QOL. Stressors were found to have a negative relationship with psychological QOL, where parents faced with increased stressors had a decrease in psychological QOL (*t* = -4.140, *p* = .000).

This multiple regression analysis was used to identify predictor variables for psychological QOL in parental caregivers of children with ASD. The results of the regression indicated that two predictors explained 48.1% of the variance of psychological QOL (R^2 = .481; *F* = 17.137, *p* = .000). It was found that coping self-efficacy significantly predicted psychological QOL (*B* = .539, *p* = .000). Stressors were also a predictor for psychological QOL (*B* = -.286, *p* = .000). The VIF for each variable was analyzed and all factors were found to be less than 1.5, confirming that there was no multicollinearity between variables. The OLS regression model assumptions were met, as evidenced by the random distribution of residuals when analyzed using a scatterplot of residuals against predicted values.

Table 27: Model Summary: Predictors of Psychological QOL

Model	*R*	*R Square*	*Adjusted R Square*	*Std. Error of the Estimate*	*R2 Change*	*F Change*	*F Change Sig.*
Model 1	.647	.419	.415	1.97647	.419	90.933	.000
Model 2	.699	.489	.481	1.86089	.070	17.137	.000

Model 1: Predictors: Coping Self-Efficacy
Model 2: Predictors: Coping Self-Efficacy, Stressors

Table 28: Regression ANOVA: Predictors of Psychological QOL

		Sum of Squares	*df*	*Mean Square*	*F*	*Sig*
Model 1	Regression	355.222	1	355.222	90.933	.000
	Residual	492.209	126	3.906	--	--
	Total	847.209	127	--	--	--
Model 2	Regression	414.567	2	207.283	59.858	.000
	Residual	432.864	125	3.463	--	--
	Total	847.431	127	--	--	--

Model 1: Predictors: Coping Self-Efficacy
Model 2: Predictors: Coping Self-Efficacy, Stressors

Table 29: Influence of Coping Self-efficacy and Stressors on Psychological QOL

	Variable	*Unstandardized B*	*S.E.*	*Standardized Beta*	*t*	*Sig*	*CI Lower*	*CI Upper*	*Tolerance*	*VIF*
Model 1	(constant)	7.347	.532	--	13.820	.000	6.295	8.399	--	--
	Coping Self-Efficacy	.036	.004	.647	9.536	.000	.028	.043	1.000	1.000
Model 2	(constant)	11.280	1.074	--	10.505	.000	9.155	13.405	--	--
	Coping Self-Efficacy	.030	.004	.539	7.790	.000	.022	.037	.855	1.169
	Stressors	-.088	.021	-.286	-4.140	.000	-.129	-.046	.855	1.169

Model 1: Predictors: Coping Self-Efficacy
Model 2: Predictors: Coping Self-Efficacy, Stressors

Environmental QOL. In the environmental QOL domain the following independent variables showed a statistically significant correlation and were added to the regression model: Number of children with ASD, marital status, household income, severity of the diagnosis of ASD of the child, coping self-efficacy, and stressors. A stepwise ordinary least squares regression was run in SPSS®. The re-coded variable of number of children with ASD was dichotomous; however, this variable was excluded from the regression models. No other variables were dichotomous. Three models were uncovered in this regression and both were statistically significant ($p = .000$ (F)). Model 1 included the independent variable of coping self-efficacy (Adjusted $R^2 = .284$). Model 2 included the independent variables of coping self-efficacy and household income (Adjusted $R^2 =.477$). Model 3 included the independent variables of coping self-efficacy, household income, and severity of the diagnosis of ASD (Adjusted $R^2 =503$). A subset of the variables coping self-efficacy and stressors faced by parents, was determined to predict 50.3% of QOL in the environmental domain.

In model 1, the predicted value of environmental QOL was 8.885 when controlling for coping self-efficacy ($b = 8.885$). For every one unit increase in coping self-efficacy, there was a .033 increase in environmental QOL ($b = .033$). For every one unit increase in coping self-efficacy, there is a .538 unit increase in environmental QOL ($\beta = .538$). The R-square change for model 1 was .290.

In model 2, the predicted value of environmental QOL was 6.747 when controlling for coping self-efficacy and household income ($b = 6.747$). For every one unit increase in coping self-efficacy, there was a .031 increase in environmental QOL ($b = .031$). For every one unit increase in coping self-efficacy, there was a .538 unit increase in environmental QOL ($\beta = .538$). For every one unit increase in household income, there was a .702 increase in environmental

QOL (*b* = .702). Also, for every one unit increase in household income, there is a .430 unit decrease in environmental QOL (*β* = .430). The R-square change for model 2 was .196.

In model 3, the predicted value of environmental QOL was 8.394 when controlling for coping self-efficacy, household income, and severity of the diagnosis of ASD (*b* =8.394). For every one unit increase in coping self-efficacy, there was a .028 increase in environmental QOL (*b* = .028). For every one unit increase in coping self-efficacy, there was a .456 unit increase in environmental QOL (*β* = .456). For every one unit increase in household income, there was a .679 increase in environmental QOL (*b* = .679). Also, for every one unit increase in household income, there is a .430 unit decrease in environmental QOL (*β* = .430). For every one unit increase in severity of the diagnosis of ASD, there was a .665 decrease in environmental QOL (*b* = -.665). Also, for every one unit increase in severity of the diagnosis of ASD, there was a .177 decrease in environmental QOL (*β* = -.177). The R-square change for model 3 was .029.

Further exploration of the final model was performed to evaluate the bivariate relationship between the environmental QOL domain outcome and the independent variables of coping self-efficacy, household income, and severity of the diagnosis of ASD. Coping self-efficacy was found to have a positive relationship with environmental QOL (*t*= 6.888; *p* = .000), showing that parents with better coping skills were found to have higher environmental QOL. Household income was found to have a positive relationship with environmental QOL, where parents faced with an increased annual household income have an increase in environmental QOL (*t* = 6.663, *p* = .000). Severity of the diagnosis of ASD was found to have a negative relationship with ASD, where parents of children with a diagnosis of ASD that was more severe had a decrease in environmental QOL (*t* = -2.674, *p* = .009).

This multiple regression analysis was used to identify predictor variables for environmental QOL in parental caregivers of children with ASD. The results of the regression indicated that coping self-efficacy, household income, and severity of the diagnosis of ASD in the child were predictors of parental caregiver environmental QOL. The results of the regression indicated that these three predictors explained 51.5% of environmental QOL (R^2= .515, F = 7.151, p = .000). It was found that coping self-efficacy significantly predicted environmental QOL (B - .456, p = .000). Household income (B = .430, p = .000) and severity of the diagnosis of ASD (B = -.177, p = .000) were also found to be predictors of environmental QOL. The VIF for each variable was analyzed and all factors were found to be less than 1.5, confirming that there was no multicollinearity between variables. The OLS regression model assumptions were met, as evidenced by the random distribution of residuals when analyzed using a scatterplot of residuals against predicted values.

Table 30: Model Summary: Predictors of Environmental QOL

Model	*R*	*R Square*	*Adjusted R Square*	*Std. Error of the Estimate*	*R2 Change*	*F Change*	*F Change Sig.*
Model 1	.538	.290	.284	2.42837	.290	48.923	.000
Model 2	.697	.486	.477	2.07430	.195	45.462	.000
Model 3	.718	.515	.503	2.02268	.029	7.151	.000

Model 1: Coping Self-efficacy
Model 2: Coping Self-efficacy, Household Income
Model 3: Coping Self-efficacy, Household Income, Severity of ASD

Table 31: Regression ANOVA: Predictors of Environmental QOL

		Sum of Squares	*df*	*Mean Square*	*F*	*Sig*
Model 1	Regression	288.498	1	288.498	48.923	.000
	Residual	707.635	120	5.897	--	
	Total	996.133	121	--	--	
Model 2	Regression	484.108	2	242.054	56.256	.000
	Residual	512.025	119	4.303	--	
	Total	996.133	121	--	--	
Model 3	Regression	513.366	3	171.122	41.826	.000
	Residual	482.767	118	4.091	--	
	Total	996.133	121	--	--	

Model 1: Coping Self-efficacy
Model 2: Coping Self-efficacy, Household Income
Model 3: Coping Self-efficacy, Household Income, Severity of ASD

Table 32: Influence of Stressors, Coping Self-efficacy, and Household Income on Environmental QOL

Model 1	*Variable*	*Unstandardized B*	*S.E.*	*Standardized Beta*	*t*	*Sig*	*CI Lower*	*CI Upper*	*Tolerance*	*VIF*
	(constant)	8.885	.674	--	13.185	.000	7.551	10.219	--	--
	Stressors	.033	.005	.538	6.995	.000	.024	.043	1.000	1.000
Model 2	(constant)	6.747	.657	--	10.268	.000	5.446	8.049	--	--
	Coping Self-Efficacy	.031	.004	.498	7.539	.000	.023	.039	.992	1.008
	Household Income	.702	.104	.445	6.743	.000	.496	.908	.992	1.008
Model 3	(constant)	8.394	.889	--	9.446	.000	6.634	10.154	--	--
	Coping Self-Efficacy	.028	.004	.456	6.888	.000	.020	.036	.937	1.067
	Household Income	.679	.102	.430	6.663	.000	.477	.880	.985	1.016
	Severity of ASD	-.665	.249	-.177	-2.674	.009	-1.158	-.173	.935	1.070

Model 1: Coping Self-efficacy
Model 2: Coping Self-efficacy, Household Income
Model 3: Coping Self-efficacy, Household Income, Severity of ASD

Post-hoc Statistical Power

Analysis of number of predictors, R^2, probability, and sample size were performed, post-hoc, to determine statistical power or the multiple regression analyses using the Free Statistics Calculator (Free Statistics Calculator, 2019). Post-hoc calculations for physical QOL with 3 predictors, and observed $R^2 = .363$, $p = .05$, and $N = 128$ yielded an observed statistical power of 1.0 ($r = 1.0$; $f^2 = .570$). Post-hoc calculations for psychological QOL with 2 predictors, an observed $R^2 = .489$, $p = .05$, and $N = 128$ yielded an observed statistical power of 1.0 ($r = 1.0$; $f^2 = .957$). Post-hoc calculations for environmental QOL with 3 predictors, an observed $R^2 = .515$, $p = .05$, and $N = 128$ yielded an observed statistical power of 1.0 ($r = 1.0$; $f^2 = 1.061$).

Chapter Four Summary

This chapter included a presentation of the statistical analyses and data in this study. Data were presented in written and table format. Findings showed that among parental caregivers of children with ASD in Florida, daily stressors, coping self-efficacy, and household income were predictors for physical QOL; daily stressors and coping self-efficacy were predictors of psychological QOL, and coping-self efficacy, household income, and severity of the diagnosis of the child were predictors for environmental. Additionally, relationships among independent and dependent variables were discussed. The following chapter will further discuss these findings and expand on relationships uncovered in this study.

CHAPTER FIVE: DISCUSSION

The purpose of this study was to determine whether demographic factors, severity of the diagnosis of ASD, coping self-efficacy, or stressors faced by parental caregivers of children with ASD could predict quality of life in the physical, psychological, social, and environmental domains. The Pearlin Caregiver Stress Process model served as a conceptual framework for the study (Pearlin et al., 1990. This chapter will present a discussion of the relationships between variables in the study and predictors that were uncovered.

Discussion of the Conceptual Model

The components of the Pearlin Caregiver Stress Process model (Pearlin et al., 1990), background and context, initial stressors and strain, coping, and outcomes were all represented by use of the variables in this study. The background and context of the study were represented by data collected from the demographic questionnaire. The initial stressors and strain were represented by participant confirmation of the diagnosis of ASD by consenting to the study, the APSI questionnaire (Silva & Shalock, 2012) to evaluate the daily stressors faced by parental caregivers of children with ASD, and also parent reported severity of the diagnosis of ASD. Coping was represented by data collected from the coping-self efficacy scale (Chesney et al., 2006. QOL was represented by data collected from the WHOQOL-BREF in the domains of physical, psychological, social, and environmental QOL (WHO, 1997).

Research questions in this study are also directly related to the components of the Pearlin Caregiver Stress Process model (Pearlin et al., 1990). Research Question One examined relationships between the four QOL outcomes. Research Question Two examined relationships between the background and context, stressors, and coping. Research Question Three examined relationships between all variables in the study. Research Question Four examined predictors of

QOL in the study. The findings from all four research questions, taken together, can be used to support the adapted caregiver stress process model for parents of children with ASD.

Discussion of Findings

Relationships Among Dependent Variables. Research Question One focused on relationships between the dependent variables. There were positive correlations between the four outcome domains of the WHOQOL-BREF: Physical, psychological, social, and environmental (WHO, 1997). When QOL in any one domain is positively affected, all remaining domains are also positively affected. Likewise, when QOL in any one domain is negatively affected, all remaining domains are also negatively affected.

Relationships Among Independent Variables. Research Question Two focused on relationships between the independent variables. The age of the parental caregiver was positively correlated with the age of the child, which was to be expected, given that when parents age, children are also aging. As parents age, their income is also improved, most likely due to the increased amount of work experience that comes with working a greater number of years in a career.

The number of hours worked per week was negatively correlated with total number of children, where the more children a parental caregiver had, the less hours worked outside the home. Given that most participants in this study were mothers, this finding may be attributed traditional gender roles where primary caregivers are female (Vasilopoulou & Nisbet, 2016). Additionally, female caregivers may be less likely to work with an increased number of children, especially coupled with the increased duties of caring for a child with ASD (Bourke-Taylor, Howie & Law, 2011). Household income was also negatively correlated with number of hours worked outside the home. This might, again, be attributed to female primary caregivers staying home to care for children, particularly if the caregiver is part of a married couple where only one parent works, or where the family cannot afford to hire childcare. The most significant reason cited by maternal caregivers for not working outside of the home is the inability to find childcare that is skilled (Bourke-Taylor et al., 2011).

Coping self-efficacy was positively correlated with the age of the child. This suggests that as the child ages, parental caregivers learn more effective ways to cope with the day to day stressors of raising a child with ASD. This finding, in part, addresses a gap in the literature where coping is minimally addressed in parental caregivers of children with ASD. Future research could focus on identifying specific coping strategies learned over time. While few studies within the literature focus on coping in parental caregivers of children with ASD, Cappe et al., (2011) studied coping as a means to mediate stress in an effort to recommend effective interventions. Cappe et al. (2011), found that strategy-based coping, such as seeking resources or active problem solving, were associated with better well-being in parents of children with ASD. Alternatively, Cappe et al., (2011) found that emotion-based coping strategies, such as ‘denial, fantasy, withdrawal, and self-blame’ were linked to poorer well-being in parents of children with ASD. Additionally, Hall (2012) studied family coping and found that an increase in the availability of community resources to support families of children with ASD was associated with an increase in family coping. Future studies are also necessary to determine whether the availability of similar community resources is effective at increasing the individual coping of parental caregivers of children with ASD.

Stressors were negatively correlated with the age of the parent, the number of hours worked outside of the home, household income, and coping self-efficacy. This suggests that older parents may have learned to better manage the day to day stressors of raising a child with

ASD. Caregivers with a higher income may be better able to hire resources like child behavioral therapists or specialized childcare workers for respite (Vasilopoulou & Nisbet, 2016; Bourke-Taylor et al., 2012). Working outside of the home may also provide parents a type of respite from caregiving, or something else to focus on outside of the day to day stressors and may also provide an avenue for additional social support through relationships with colleagues (Vasilopoulou & Nisbet, 2016).

Relationships Among Dependent and Independent Variables. Research Question Three focused on relationships between the dependent and independent variables within the study. As social QOL was excluded from statistical analysis, it will not be discussed here.

Physical QOL was positively correlated with number of hours worked outside the home, household income, and coping self-efficacy. Like the relationships discussed with stressors, parental caregivers who can work outside of the home may consider the time away from caregiving as a respite, or break, from the day to day caregiving duties (Vasilopoulou & Nisbet, 2016). Additionally, work outside of the home may come with additional medical and dental benefits for the parental caregiver and also for the child with ASD (Vasilopoulou & Nisbet, 2016). Income was also similarly related, where increased household income was related to an improvement in physical health. This again, could be due to increased funds available to support better therapies for the child and better childcare for the child, resulting in respite for the parental caregiver (Vasilopoulou & Nisbet, 2016). Physical QOL was also negatively correlated with stressors, where an increase in the day to day stressors of raising a child with ASD resulted in lower physical QOL. This is consistent with the findings within the literature (Johnson et al., 2011).

Psychological QOL was positively correlated with coping self-efficacy and negatively correlated with stressors in parental caregivers of children with ASD. This shows that when parental caregivers of children with ASD had a positive self-perception of good coping strategies, they were less likely to have impacted psychological QOL, including anxiety and depression. Hsiao (2016) similarly found that parental stressors, as measured by 3 author-created questions, were correlated with mental health in parental caregivers of children with ASD.

Environmental QOL was positively correlated with household income and coping self-efficacy. This may be, in part, due to higher incomes yielding better resources and the ability to afford better therapies for the child with ASD (Pozo et al., 2014). Additionally, working outside of the home can contribute to an enhanced sense of personal and family security and can ease the uncertainty for the future (Vasilopoulou et al., 2015). Environmental QOL was also negatively correlated with stressors, where an increase in aberrant behaviors of the child is related to decreased QOL in parental caregivers of children with ASD (Baghdadli et al., 2014; Ji et al., 2014; Ooi et al., 2016; Pozo et al., 2014).

The severity of the diagnosis of ASD was also significantly associated with QOL in the physical, psychological, and environmental domains. This is similar to findings within the literature (Baghdadli et al., 2014; Ji et al., 2014; Ooi et al., 2016; Pozo et al., 2014). When the child with ASD has a diagnosis that is more severe, parental QOL is lower in these three domains. Children with a more severe diagnosis of ASD may have less independence with activities of daily living and require more care. Additionally, children with a severe diagnosis of ASD may have increased communication problems, or may even be non-verbal, and may have lower social skills when compared with children with a diagnosis of mild ASD (Baghdadli et al., 2014). This severity of ASD means that there is an increased demand on the parental caregivers

(Baghdadli et al., 2014). For example, in the physical domain, parental caregivers of children with severe ASD may have impaired sleep due to known sleep disorders of the child with ASD or the caregiver may experience fatigue and burnout due to the demands of caring for a severely disabled child (Benjak, 2011; Johnson et al., 2011; Ooi et al., 2016, Vasilopoulou & Nisbet, 2016). In the psychological domain, increased stress, depression, and burden can be worsened when caring for a child with severe ASD (Ji et al., 2014; Ooi et al., 2016; Pozo et al., 2014). In the environmental domain, parents of children with severe ASD may have a decreased personal safety due to behaviors of the child and may also have worries about future safety and security, or may have increased financial needs due to severity of behaviors including costly home repairs or cost of specialized childcare (Benjak, 2011; Hoefman et al, 2014).

Predictors of QOL. In parental caregivers of children with ASD, daily stressors, coping self-efficacy, and household income were predictors for physical QOL. Daily stressors and coping self-efficacy were predictors of psychological health. Coping-self efficacy, household income, and severity of the diagnosis of the child were predictors for environmental QOL. The domain of social health was not evaluated due to limitations of this study.

Limitations

Internal validity. There was a history threat to the internal validity of this study. History threats are environmental occurrences that are not within the researcher's control (Wood & Brink, 2012). This study was distributed to participates throughout the state of Florida on October 15, 2018. On October 11, 2018, Category 4 Hurricane Michael made landfall in the Florida panhandle and traveled through North Florida in the following days (National Weather Service [NWS], 2019). The severe weather caused substantial damage to homes and businesses (NWS, 2019). This survey was distributed throughout the state of Florida, and surveys were anonymous. For these reasons, it is unclear whether any participants of the survey were impacted by this storm. There is a potential for results of the survey, particularly stressors, coping self-efficacy strategies, and self-perceived quality of life, to be impacted by the destruction caused by the storm.

There was also an instrumentation threat to the study. Instrumentation threats are circumstances that impact the reliability and validity of an instrument (Wood & Brink, 2012). The social domain outcome of the WHOQOL-BREF normally contains three questions assessing satisfaction with sexual activity, satisfaction with personal relationships, and amount of support received from friends. Because this domain has only three questions and because the alpha coefficients for this domain were .613 for this study and .68 for previous studies (Skevington et al., 2004), it is unclear whether this instrument successfully measures social QOL in parental caregivers. Additionally, of the three questions in this domain, one question on satisfaction with sexual activity was unintentionally omitted from the survey distributed to participants. For these reasons, the decision was made to omit the social QOL outcome domain from this study.

External Validity. The platform of delivery for the survey, an online survey, may be considered as a bias to the validity of the study, where participants needed capability to access the internet to complete the survey online (Wood & Brink, 2012) This bias may have excluded some participants; however, all agencies that distributed the study used an email membership list and a website. For this reason, it was assumed that all participants would have access to the internet.

There may have been an external threat to the study with setting, where participants may have been from either rural or urban settings (Wood & Brink, 2012). This study did not include setting as a variable within the study. This variable may have impacted access to care, and therefore, possibly the environmental QOL domain. However, the study was only distributed within the state of Florida from mailing lists of CARD locations and the ASGO. All the organizations participating in distribution of the survey are located within major, urban communities throughout Florida.

Recommendations for Policy, Practice, and Future Research

While caregiver stress and quality of life in caregivers of Alzheimer's patients and oncology patients has been well studied, the population of caregivers of children with ASD is a newer area for research. After discussing the findings of the study, multiple recommendations can be made to improve QOL in parental caregivers of children with ASD. These recommendations address policy, nursing practice, and also future research.

Policy. In January 2018, the Recognize, Include, Support, and Engage (RAISE) Family Caregivers Act was passed into legislation (National Alliance for Caregiving [NAC], 2019). This policy will support caregivers through the collaboration of federal agencies, where advisors will meet to determine the needs of caregivers in the United States and will recommend national strategies to improve resources available to caregivers. While this legislation is a move in the right direction, other policies are necessary to support caregivers (NAC, 2019).

While there are policies in individual states to support paid family medical leave, there is currently no national policy to support caregivers for time taken from work to care for family members (NAC, 2019). A national policy has been proposed, the Family and Medical Insurance Leave (FAMILY) Act. This would promote physical and psychological QOL of parental caregivers of children with ASD by allowing caregivers paid time to heal when sick, to care for their child with ASD when needed, and to do so without the burden of loss of income. This legislation would provide up to 12 weeks of paid leave to caregivers throughout the United States (NAC, 2019).

There is a need for social security support for caregivers who leave the workforce to provide care for a family member (NAC, 2019). Currently, there is proposed legislation, the Social Security Caregiver Credit Act, which would apply work credit to a caregiver's social security earnings, which would impact the caregivers' future social security benefit. Similar to the FAMILY ACT, this legislation would promote psychological QOL in caregivers who would have less stress and financial burden when caring for a family member. Additionally, there is a proposed bill that would provide an increase in yearly household income. The proposed Credit for Caring Act would provide a $3000 tax credit per family for family caregivers (NAC, 2019).

Practice. There are approximately 43.5 million unpaid caregivers in the United States (U.S.) (NAC, 2019). There are currently no clinical practice guidelines for screening for physical, mental and social health in caregivers. Implications for clinical practice include that, while this study shows that QOL is impacted in parental caregivers of children with ASD, there is still a need for clinical practice guidelines. Nurses, particularly pediatric nurses caring for children with ASD, are uniquely positioned to screen parental caregivers for this decreased QOL and to recommend appropriate resources to reduce stress and improve coping. Nurses could also refer qualified families to sources of funding, such as the Medicaid Waiver program in Florida, which could increase available household income to pay for therapies for the child, respite care, and other services, which may improve QOL in parental caregivers of children with ASD. Van Tongerloo et al., (2015) in a qualitative study, found that parents of children with autism felt that one-way clinicians could improve the well-being of the caregiver was to provide practical guidelines focused on challenges in the day-to-day care of the child with ASD.

Future Research. Findings from this study suggest that interventions that positively impacts any one health domain may positively impact other domains of QOL in parental caregivers of children with ASD. Further studies on the QOL domains may be helpful to confirm these potential relationships. Additionally, studies to develop instruments specific to the population of parental caregivers of children with ASD may uncover additional relationships. For example, the social QOL domain of the WHOQOL-BREF instrument did not adequately capture data about social relationships or social resources (WHO, 1997). Additionally, the instrument was developed prior to use of the internet or social media and it is unknown how current technology affects social QOL. Additional studies using technologies such as apps to teach coping self-efficacy or use of telehealth for therapies for the child with ASD or the parental caregiver may be helpful in this population, where leaving the home to access services may be challenging.

Future studies can also focus on the population, where this study was limited to children between the ages of 3-21. Studies including toddlers at the age of diagnosis of ASD might offer a different perspective on the initial stressor of parental caregivers receiving the diagnosis of ASD for their child. Throughout the data collection process of this study, multiple parental caregivers of children with ASD over the age of 21 sent an email to the Primary Investigator to express their desire to complete the survey and to share their experience of parental caregivers of adults with ASD. There is a clear need to study this population to uncover data related to stress, coping self-efficacy, and quality of life and to determine what, if any, differences there are in parents who have been in this role over 21 years.

This study was consistent with the previous literature in that there were few fathers who participated in the study. There is a need to understand differences in caregiver roles related to gender. There is also a need to compare QOL in all domains in mothers and fathers.

Future studies can also be performed to uncover the variances not accounted for by this study. For example, this study did not address comorbidities for either the child with ASD or the parental caregiver. This study also did not address whether families lived in urban or rural areas, which may impact access to therapies and other healthcare services. Additionally, while this study addressed day-to-day stressors, future studies should include a measure for milestone stressors like a sibling moving away to college, parents' separation or divorce, the individual transitioning to a new living environment, or the death of a family member. These milestone stressors have the potential to have a significant impact on both the child and the parental caregiver of the child with ASD.

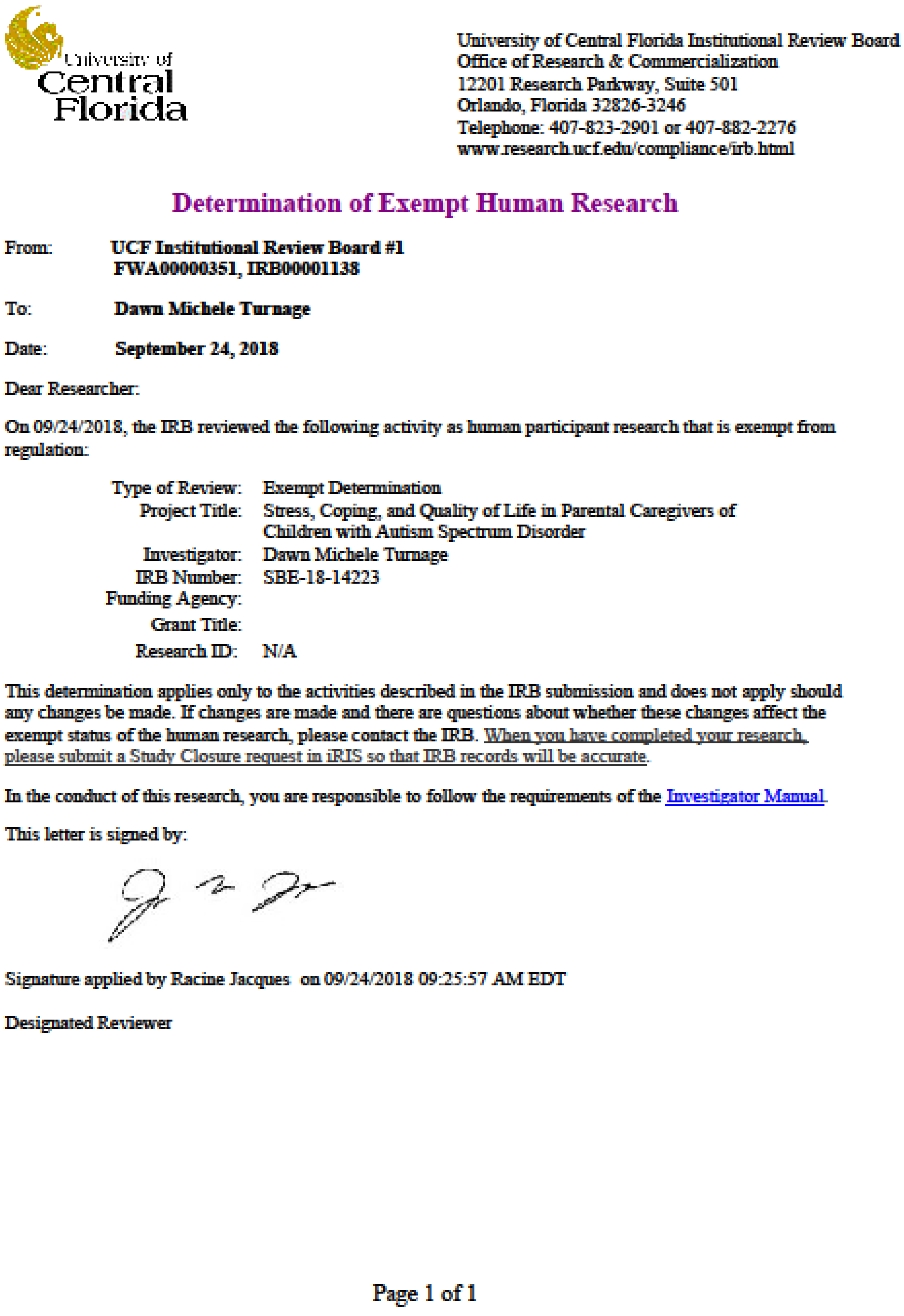
There is also a need to examine positive and negative coping strategies, differences in coping between mothers and fathers, the capability to improve upon coping skills over time, and the impact of these factors on parental QOL. This data would be beneficial to clinicians developing interventions for parental caregivers of children with ASD.

Conclusion

The findings show that coping self-efficacy and improved income can positively improve QOL, while severity of the diagnosis of ASD and daily stressors can negatively impact QOL. Clinically, nurses with a better understanding of the parental stress and coping in parents of children with ASD can better recommend tailored resources to improve QOL. Parental caregivers of children with ASD may benefit from referrals to programs that provide financial support for services. Policies to support financial help for families may also improve QOL.

Many policies are currently being considered that may have a positive impact on families of children with ASD. Future research should focus on interventions to improve coping-self efficacy. Additionally, there is a need to reevaluate instruments used to measure QOL in this population, particularly in the social QOL domain.

APPENDIX A: IRB APPROVAL



University of Central Florida

University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Determination of Exempt Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Dawn Michele Turnage**

Date: **September 24, 2018**

Dear Researcher:

On 09/24/2018, the IRB reviewed the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination
Project Title: Stress, Coping, and Quality of Life in Parental Caregivers of Children with Autism Spectrum Disorder
Investigator: Dawn Michele Turnage
IRB Number: SBE-18-14223
Funding Agency:
Grant Title:
Research ID: N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

This letter is signed by:

Signature applied by Racine Jacques on 09/24/2018 09:25:57 AM EDT

Designated Reviewer

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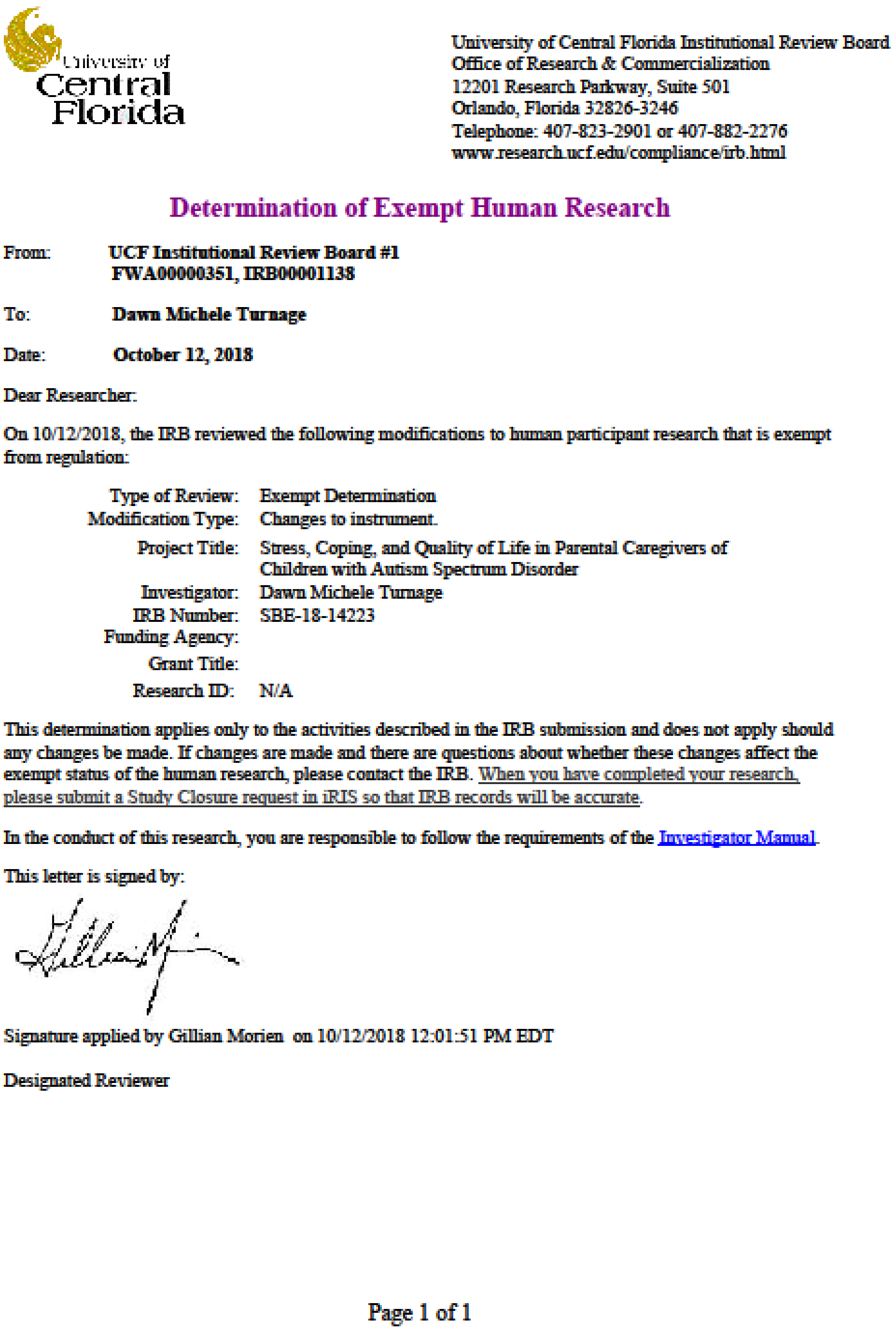
APPENDIX B: IRB INSTRUMENT MODIFICATION APPROVAL



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Determination of Exempt Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Dawn Michele Turnage**

Date: **October 12, 2018**

Dear Researcher:

On 10/12/2018, the IRB reviewed the following modifications to human participant research that is exempt from regulation:

Type of Review:	Exempt Determination
Modification Type:	Changes to instrument.
Project Title:	Stress, Coping, and Quality of Life in Parental Caregivers of Children with Autism Spectrum Disorder
Investigator:	Dawn Michele Turnage
IRB Number:	SBE-18-14223
Funding Agency:	
Grant Title:	
Research ID:	N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

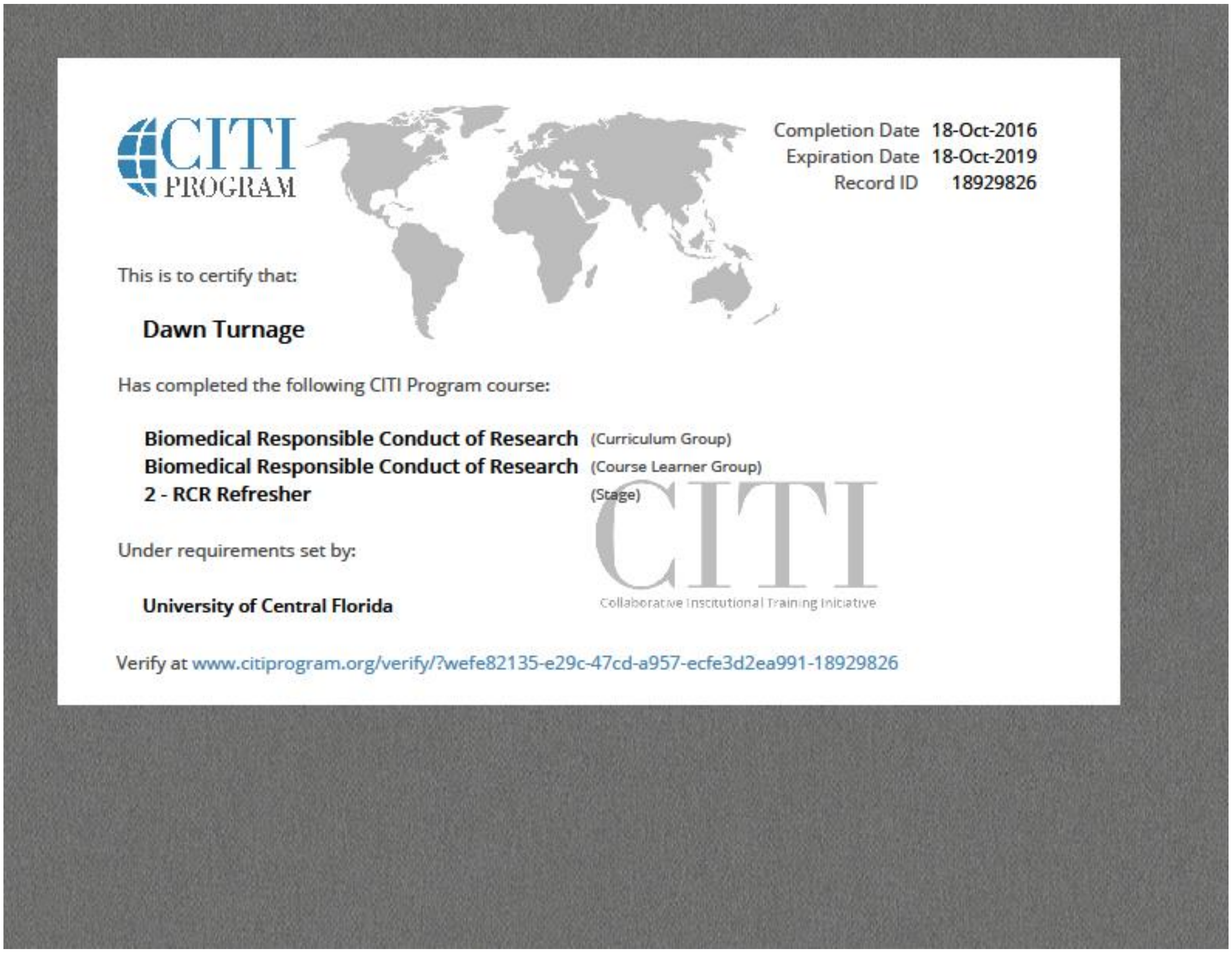
This letter is signed by:

Signature applied by Gillian Morien on 10/12/2018 12:01:51 PM EDT

Designated Reviewer

Page 1 of 1

APPENDIX C: CITI TRAINING CERTIFICATE



CITI PROGRAM

Completion Date 18-Oct-2016
Expiration Date 18-Oct-2019
Record ID 18929826

This is to certify that:

Dawn Turnage

Has completed the following CITI Program course:

Biomedical Responsible Conduct of Research (Curriculum Group)
Biomedical Responsible Conduct of Research (Course Learner Group)
2 - RCR Refresher (Stage)

Under requirements set by:

University of Central Florida

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?wefe82135-e29c-47cd-a957-ecfe3d2ea991-18929826

APPENDIX D: NON-TRADITIONAL PROPOSAL

June 6, 2018

Title of the Project

Stress, Coping, and Quality of Life in Parental Caregivers of Children with Autism Spectrum Disorder

Type of Project

This is a descriptive, cross-sectional, quantitative study.

What Is the Population/Topical Area for This Project?

The population to be studied is parental caregivers of children with Autism Spectrum Disorder (ASD).

Estimated Start Date of the Project

The estimated start date of this study is August 1, 2018.

Does This Grant Include a Co-Investigator?

No

Estimated End Date of the Project

The estimated end date of this study is July 31, 2019.

Abstract

Purpose: To describe relationships between stress, coping, and quality of life (QOL) in parental caregivers of children with ASD

Goal: To increase clinicians' understanding and awareness of parental caregivers of children with ASD.

Research Design: Descriptive, cross-sectional survey

Methods: Participants will be parental caregivers of children with ASD. An electronic survey will be distributed to participants to evaluate stress, coping, and QOL. Data will be analyzed using multiple regression to identify predictors of QOL as defined by the World Health Organization (WHO) as overall health, overall satisfaction with health, physical health, psychosocial health, social health, and environmental health in parental caregivers of children with ASD.

Purpose Statement

Parental caregivers of individuals with Autism Spectrum Disorder (ASD) have increased levels of stress and caregiver burden (Autism Society of America [ASA], 2018). Chronic exposure to stress can negatively impact an individual's health and quality of life (QOL) (Family Caregiving Alliance [FCA], 2018). ASD is a lifelong disorder, that requires care indefinitely (ASA, 2018). The needs of a newly diagnosed toddler, a school aged child, an adolescent, and an adult with ASD vary greatly. Likewise, stressors faced by parental caregivers throughout an individual with ASD's different developmental stages may vary greatly and parents' coping mechanisms may vary. Additionally, the variability of the spectrum of autism means that severity of the diagnosis and of associated behaviors can differ between children of ASD. QOL is defined by the World Health Organization (WHO) using the variables of overall health, overall satisfaction with health, physical health, psychosocial health, social health and environmental health (WHO, 1997). The purpose of this study is to determine whether demographic factors, stress, coping, self-efficacy, and severity of ASD can be used to predict parental caregiver QOL. Results of this study may be used to increase clinicians' understanding and awareness of parental caregivers of children with ASD.

List 3-5 Objectives for Your Proposal

1. To determine whether the following demographic factors: Age of the parent; gender of the parent; education level of the parent; marital status; household income; number of

hours worked outside of the home; age of the child with ASD; and gender of the child, with ASD predicts overall health, overall satisfaction with health, physical health, psychosocial health, social health or environmental health in parental caregivers of children with ASD.

2. To determine whether severity of ASD predicts overall health, overall satisfaction with health, physical health, psychosocial health, social health or environmental health in parental caregivers of children with ASD.
3. To determine whether parental stress predicts overall health, overall satisfaction with health, physical health, psychosocial health, social health, or environmental health in parental caregivers of children with ASD.
4. To determine whether coping self-efficacy predicts overall health, overall satisfaction with health, physical health, psychosocial health, social health, or environmental health in parental caregivers of children with ASD.
5. To identify a subset of two or more variables (demographic factors, stress, coping self-efficacy, and severity of diagnosis) that can be used to predict overall health, overall satisfaction with health, physical health, psychosocial health, social health or environmental health in parental caregivers of children with ASD.

Background and Significance

Autism Spectrum Disorder. The American Psychiatric Association (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-V) lists three diagnoses under the ASD umbrella: autism, Asperger's syndrome, and pervasive developmental disorder-not otherwise specified (PDD-NOS) (American Psychiatric Association [APA], 2013). The term "spectrum" is used to describe the variability of autism, where symptoms of the diagnosis range from mild to severe. Symptoms of ASD include communication problems, social impairment, behavioral problems, sleep disturbances, and repetitive behaviors (APA, 2013; National Institute of Mental Health [NIMH], 2018; Centers for Disease Control and Prevention [CDC], 2018). Individuals with ASD may also have mental or behavioral disorders, or other comorbidities, adding to the overall severity of symptoms (APA, 2013).

Prevalence. The Centers for Disease Control and Prevention (CDC) estimate that one in 59 children are diagnosed with ASD (CDC, 2018). A recent 2015 National Health Interview Survey (NHIS) conducted by the United States Census Bureau indicates that the prevalence of ASD may be higher and found that one in 45 children in the U.S. has a diagnosis of ASD (CDC, 2018). This increased incidence and prevalence of ASD in children means that there is also an increase in the parents who care for these individuals.

Economic Impact. The average lifetime cost of care for one child with ASD is over $3 million (Ganz, 2007). Costs include medical care, therapy costs, in-home nursing and respite services, missed time from work, and costs related to special needs education. In 2011, the estimated yearly total cost of care for all individuals with ASD was estimated to be between 11-61 billion dollars (CDC, 2018). The average yearly cost for medical services was $4,000-6,000 per year higher for children with ASD versus children without ASD (CDC, 2018). Additionally, the average yearly cost paid by Medicaid for a child with ASD was six times greater that the yearly Medicaid cost for a child without ASD (CDC, 2018). Costs related to care of a child with ASD can also be felt at the level of the family. Some parents are unable to work outside of the home because of high out-of-pocket costs of specialized childcare or severe behaviors of the child with ASD (Ganz, 2007).

Quality of Life. There is a potential for lower QOL for parents of children with ASD because of the initial diagnosis and additional stressors and burdens faced daily. Additional stressors include daily care, coordinating medical care and therapies, behavioral problems of the child, missed time from work, financial strain, and the potential need for lifelong care (FCA, 2018). This build-up of stress over time can have a negative impact on parental QOL. For example, caregivers have greater risk for depression, cardiovascular disorders, and chronic illnesses (FCA, 2018). Additionally, caregivers have little time to focus on health promotion activities to keep themselves healthy, which may lead to a decrease in QOL. Studies to analyze QOL in parents of children with ASD are necessary improve QOL in parents, which might prevent chronic illnesses and depression. Improved QOL in parental caregivers may also improve the health and QOL of the child with ASD.

Literature Review

The concept of caregiver burden is prevalent within the nursing literature oncology and dementia research; however, there have been very few studies to date where the focus is parental caregivers of ASD. This unique population has unique challenges.

The Pearlin Caregiver Stress Process is a framework that helps to define the phenomenon of caregiver burden (Pearlin, Mullin, Semple & Skaff, 1990). This framework has been widely studied in the caregiver literature (Pearlin et al., 1990). The components of the framework are the background and context, primary and additional stressors, mediators, and QOL. The Pearlin Caregiver Stress Process model (1990) was originally proposed to define caregiver burden in individuals caring for a family member with dementia. The model describes the stressors faced by the caregiver as a changing process, where the primary stressor is the care recipient and the recipient's disability. Additional stressors, or life events, can further impact the caregiver's stress. Additional stressors can include small things like assisting the care recipient with daily care, or larger obstacles like a death in the family or a financial hardship. Moderators can also affect the outcome of the caregiver. Moderators can be informal or formal social support, or the mechanisms used by the caregiver to cope with stressors. This process alters the caregiver's self-concept and, dependent on moderators, can have a positive or negative outcome.

Background and context include demographic data. Factors including family income, higher level of parent education, and parents' ability to work outside of the home were found to be associated with improved parental QOL (Benjak, 2011; Favero-Nunes & dos Santos, 2010; Vasilopoulou & Nisbet, 2016). Likewise, lower income was associated with decreased QOL (Hoefman, Payakachat, van Exel, Kuhlthau, Kovacs, Pyne & Tilford, 2014; Pozo, Sarria & Brioso, 2014).

Stressors can include the primary diagnosis of ASD. Additional stressors include aberrant behaviors of the child, comorbidities like seizures or cognitive delay, and a higher level of day-to-day care (Baghdadli, Pry, Michelson & Rattaz, 2014; Benjak, 2011; Cappe, Wolff, Bobet & Adrien, 2011; Hall, 2012; Hoefman et al., 2014; Hsiao, 2015, Ji, Zhao, Turner, Sun, Yi & Tang, 2014; Ooi, Ong, Jacob & Khan, 2016; Pozo et al., 2014; van Tongerloo, van Wijngaarden & Lagro-Janssen, 2015).

Coping in this population includes the need to adapt to the day-to-day stressors faced when caring for a child with ASD (Ooi et al., 2016). While coping and stress are widely discussed together (Lazarus & Folkman, 1984), coping is only minimally addressed within the literature related to caregivers of parents of children with ASD.

Although the existing literature is limited, the small number of studies examining this population are consistent in reporting that parental caregivers experience decreased psychological health, including, depression, depressive symptoms, stress and burden at a greater rate than non-caregivers (Benjak, 2011; Hoefman et al., 2014; Johnson, Frenn, Feetham & Simpson, 2011; Ooi et al., 2016; Van Tongerloo et al., 2015 & Vasilopoulo & Nisbet, 2016).

There are no studies to identify factors predictive of QOL in parental caregivers of individuals with ASD. Studies in this area would be helpful to examine the effects of build-up of stressors, and differences in parents caring for toddlers, school-aged children, adolescents, and young adults. Additionally, there is no literature to address coping in this population, specifically, whether parental caregivers learn improved coping skills over time and how this impacts parental QOL. A better understanding of the burden faced by parental caregivers of children with ASD may help to increase awareness of the need for additional research, resources, and policies to support this population.

Significance of the Problem to Nurse Practitioners

Because the population of ASD children has now increased to one in 59 (CDC, 2018), the population of parents caring for ASD children is also increased. This rapidly increasing population of parents of children with ASD is at risk for decreased QOL. The results of this review demonstrate that parents of individuals with ASD have lower QOL in the physical, psychological, social, environmental, and spiritual domains, and particularly in mental and physical health; however, predictive factors of QOL are not known. Clinicians with a better understanding and awareness of the factors that affect QOL of parental caregivers of children with ASD may be able to recommend tailored resources to optimize QOL in this population.

Project/Study Description

Research Design. The research design is descriptive, non-experimental and a cross-sectional approach will be used.

Sample. The sample will include parental caregivers of children, age 3-21, with ASD living in Florida. Participants for this study will be recruited from 18 organizations supporting individuals and families living with autism in Florida. Participants must be able to read and answer questions in English and must be able to access a computer to complete the electronic survey. Using G Power 3.1 ® software, an alpha = 0.05, and power = 0.80, the estimated sample size needed is N = 194. Therefore, the proposed sample size of this study (*N* = 225) will adequately meet the statistical needs of this study while allowing for potential attrition due to incomplete surveys.

Data Collection. No personal identifying data, including name, address, date of birth, or other identifying information, will be asked on the electronic survey. Each participant's data will be assigned a random code number. Data collected will be kept on a password-protected computer. All data will be collected via electronic survey using Qualtrics® software. The participating autism support organizations will distribute a survey link to their members. A participant cover letter will describe the purpose of the study and potential risks and benefits. The only risk related to this study is the potential for stress related to answering questions. The benefit to completing the study may be that there will be a better understanding of health-related quality of life in parental caregivers of individuals with ASD. The participating autism organizations will also send potential participants a series of three emailed reminders to complete the survey, approximately one week apart. The survey will remain open for thirty days. Participants' completion and submission of the survey will serve as an acceptance of informed consent. Upon completion of the survey, participants will have the option to give an email address to receive a $10 incentive gift card for participating in completing the survey. All data will be downloaded from Qualtrics® to a Microsoft® Excel® spreadsheet to create datasets for analysis.

Research Questions and Data Analysis. The primary investigator will analyze data with the assistance of a statistician. IBM®SPSS® Student Version 24 software will be used for all statistical analyses.

Independent and Dependent Variables. Independent variables are: Age of the parent; gender of the parent; education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; and coping self-efficacy. Dependent variables are: Overall health, overall satisfaction with health, physical health, psychosocial health, social health; and environmental health in parental caregivers of children with ASD.

Demographic Factors. Frequency tables will be analyzed to determine whether data are sufficient, and some categories may be combined, if necessary. Demographic data will be analyzed using descriptive statistics with count and percentage for categorical variables and mean and SD for continuous variables (see Table 1).

Multiple Regression Model with Preliminary Correlation Matrix. The main statistical test to be used in this study is multiple regression. A correlation matrix will be performed as a preliminary component of this analysis. For the purpose of clarity in presenting each research question and the corresponding statistical analysis, the correlation matrix is discussed in questions 1-3; however, this preliminary component will only be performed once.

Research Questions.

1. What, if any, relationships are present between the dependent variables: Overall health, overall satisfaction with health, physical health, psychosocial health, social health; and environmental health in parental caregivers of children with ASD?
    a. A correlation matrix will be used to determine whether any relationships exist between variables. Relationships will be reported as Pearson's correlation coefficient, *r*. Appropriate non-parametric testing will follow to determine strength and direction of relationship. A $p = 0.05$ will be used to determine statistical significance.
2. What, if any, relationships are present between the independent variables: Age of the parent; gender of the parent; education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; and coping self-efficacy?
    a. A correlation matrix will be used to determine whether any relationships exist between variables. Relationships will be reported as Pearson's correlation coefficient, *r*. Appropriate non-parametric testing will follow to determine strength and direction of relationship. A $p = 0.05$ will be used to determine statistical significance.
3. What, if any, relationships are present between independent and dependent variables: Age of the parent; gender of the parent; education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; coping self-efficacy; Overall health, overall satisfaction with health, physical health, psychosocial

health, social health; and environmental health in parental caregivers of children with ASD.

   a. A correlation matrix will be used to determine whether any relationships exist between variables. Relationships will be reported as Pearson's correlation coefficient, *r*. Appropriate non-parametric testing will follow to determine strength and direction of relationship. A p = 0.05 will be used to determine statistical significance.
   b. Graphic representation of the data will be presented, using boxplots and scatterplots, to identify functional relationships between independent and dependent variables, to uncover any outliers, and to determine if any changes to categorical data need to be made.

4. Do any of the independent variables: Age of the parent; gender of the parent; education level of the parent; marital status; household income; number of hours worked outside of the home; age of the child with ASD; gender of the child with ASD; severity of ASD; parental stress; and coping self-efficacy, either alone or in a subset, predict the following dependent variables: Overall health, overall satisfaction with health, physical health, psychosocial health, social health; and environmental health in parental caregivers of children with ASD?
   a. Relationships uncovered in Questions 1-3 will be further analyzed to identify predictors of QOL (dependent variables) using multiple regression. A $p = 0.05$ will be considered statistically significant.

Operationalizing Concepts

The Pearlin Caregiver Stress Process defined four concepts within the caregiver stress process model: Background and context, stressors, mediators, and outcomes (Pearlin, Mullen, Semple & Skaff, 1990). In this study, the background and context will be measured by demographic factors. Stressors faced by parents will be measured using the Autism Parenting Stress Index (APSI). Because severity of the ASD diagnosis may also contribute to parental stress, this will be measured using the Gilliam Autism Rating Scale (GARS). Mediators are the mechanism that parents use to deal with these stressors and will be measured using the Coping Self-Efficacy Scale (CSES). The outcomes for this study are QOL as measured by the WHOQOL-BREF using the following variables: overall health, overall satisfaction with health, physical health, psychosocial health, social health, and environmental health (WHO, 1997).

Instruments

Demographic Questionnaire. A demographic questionnaire will be included to assess characteristics of the child with ASD and of the parental caregiver. No names, dates of birth, or any other identifying data will be collected. The demographic questionnaire will include the following: Age of the parent; gender of the parent; education level of the parent; number of hours of paid work outside the home; marital status; household income; age of the child with ASD; and gender of the child with ASD.

Gilliam Autism Rating Scale (GARS). This scale has 56 items and uses a four-point Likert-type scale. This scale is appropriate for children and adolescents with ASD and can be completed by caregivers. The scale assesses behaviors of the child with ASD, including stereotyped autism behaviors, communication, and social interaction. The scale has one total score that reports the severity of ASD, where a higher score (on a scale of 1-60) indicates a more severe diagnosis. Cronbach's alpha was 0.87 (Lecavalier, 2005).

Autism Parenting Stress Index (APSI). This scale has 13 items and uses a five point, Likert-type scale. The scale assesses stressors specific to the ASD parent, including sleep, toileting, communication, and concerns about the future. The scale also has one total score that reports the parental level of stress, with a higher number indicating a higher level of stress. The total score has been validated with an acceptable internal consistency and good test-retest validity for parents of children with ASD, as well as parents of children with other developmental disabilities (Silva & Shalock, 2013). Cronbach's alpha was 0.827 (Silva & Shalock, 2012). The specific variable to be used to measure stressors is the overall stress index score.

Coping Self-Efficacy Scale (CSES). This scale measures coping self-efficacy and has 26 items. The scale assesses an individual's ability to cope with stressors. The scale has one total score that reports overall CSES. The total score has been validated testing internal consistency, test-retest validity, and concurrent validity. Cronbach's alpha was 0.91 (Chesney et al., 2006).

World Health Organization Quality of Life BREF Scale (WHOQOL-BREF). This scale has 26 items and uses a five point, Likert-type scale. This is an abbreviated version of the WHOQOL-100 scale. Two questions assess general quality of life and the remaining 24 questions assess QOL in 4 domains: physical, psychological, social, and environmental health. This instrument has been widely developed and used. Reliability of the 4 measured domains falls in the acceptable to good range, as measured using Cronbach's alpha: physical health = 0.79; psychological health = 0.78; social relationships = 0.76; environment = 0.87 (Fu et al., 2013). This instrument has also shown good content validity, criterion-related validity, and construct validity (Fu et al., 2013; Fons et al., 2005). Specific variables used to measure health outcomes are the overall QOL assessment and 4 domains of the WHOQOL-BRIEF instrument. These 6 variables are: overall health, overall satisfaction with health, physical health, psychosocial health, social health, and environmental health.

Population and Human Subjects Protection

Ethical principles for the protection of human subjects will be used and all attempts will be made to proceed with the highest level of ethical rigor. Any ethical dilemmas will immediately be brought to the attention of the UCF IRB. Participants' access of the survey will assume consent to participate. Transparency in reporting risks and benefits of the study will be explained to participants in a letter prior to beginning the study. Participants may be encouraged to know that this research is being done to increase understanding and awareness of stress, coping, and quality of life in parental caregivers of individuals with ASD. The risk involved is minimal and includes that participants may experience emotional distress when answering questions. The electronic participant cover letter will include the web address of the Family Caregiving Alliance, a national organization supporting caregivers of various disabilities which includes a feature to search for local resources. Study participants will be informed that they can contact the Primary Investigator to obtain results of the study.

While participants in this study are parental caregivers of individuals with ASD, the primary investigator will also make every effort to protect the individual with ASD. All personal information from participants, including information about participants and individuals with ASD, will be de-identified. No names, addresses, or other personal identifying information will be collected.

To ensure respect of the participant's time taken to complete the survey, all efforts will be made to give an accurate estimate of the time needed to complete the study. Additionally, participants will be informed that they are not obligated to complete the study and that they may stop their participation at any time during the study. To prevent respondent fatigue, the number of questions used will be the minimum number of survey questions to answer the aims of the study. Participants will be eligible to receive a $10 incentive gift card upon completion of the study.

Expected Outcome and Impact

The expected outcome of the study is that results will generate a better understanding and awareness of stress, coping self-efficacy, severity of diagnosis of ASD and QOL in parental caregivers. Predictive factors of QOL may be used by clinicians to recommend tailored resources to improve parental caregiver QOL.

Please List Two or Three Key Words or Tags

Autism, caregiving, quality of life

What is the budget amount requested, up to $2,500?

The requested amount is $2,500. See Appendix A for budget and justification.

WHO

APPENDIX E: WHOQOL-BREF

[Questionnaire]

The following questions ask how you feel about your quality of life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one (The numbers after responses indicates the scores of the responses).

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks (The overall quality of life and general health facet).

1. How would you rate your quality of life?

Very poor: 1

Poor: 2

Neither poor nor good: 3

Good: 4

Very good: 5

2. How satisfied are you with your health?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

The following questions ask about how much you have experienced certain things in the last four weeks.

3. To what extent do you feel that physical pain prevents you from doing what you need to do?

Not at all: 5

A little: 4

A moderate amount: 3

Very much: 2

An extreme amount: 1

4. How much do you need any medical treatment to function in your daily life?

Not at all: 5

A little: 4

A moderate amount: 3

Very much: 2

An extreme amount: 1

5. How much do you enjoy life?

Not at all: 5

A little: 4

A moderate amount: 3

Very much: 2

An extreme amount: 1

6. To what extent do you feel your life to be meaningful?

Not at all: 5

A little: 4

A moderate amount: 3

Very much: 2

An extreme amount: 1

7. How well are you able to concentrate?

Not at all: 1

A little: 2

A moderate amount: 3

Very much: 4

Extremely: 5

8. How safe do you feel in your daily life?

Not at all: 1

A little: 2

A moderate amount: 3

Very much: 4

Extremely: 5

9. How healthy is your physical environment?

Not at all: 1

A little: 2

A moderate amount: 3

Very much: 4

Extremely: 5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

10. Do you have enough energy for everyday life?

Not at all: 1

A little: 2

Moderately: 3

Mostly: 4

Completely: 5

11. Are you able to accept your bodily appearance?

Not at all: 1

A little: 2

Moderately: 3

Mostly: 4

Completely: 5

12. Have you enough money to meet your needs?

Not at all: 1

A little: 2

Moderately: 3

Mostly: 4

Completely: 5

13. How available to you is the information that you need in your day-to-day life?

Not at all: 1

A little: 2

Moderately: 3

Mostly: 4

Completely: 5

14. To what extent do you have the opportunity for leisure activities?

Not at all: 1

A little: 2

Moderately: 3

Mostly: 4

Completely: 5

15. How well are you able to get around?

Very poor: 1

Poor: 2

Neither poor nor good: 3

Good: 4

Very good: 5

16. How satisfied are you with your sleep?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

17. How satisfied are you with your ability to perform your daily living activities?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

18. How satisfied are you with your capacity for work?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

19. How satisfied are you with yourself?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

20. How satisfied are you with your personal relationships?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

21. How satisfied are you with the support you get from your friends?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

22. How satisfied are you with the conditions of your living place?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

23. How satisfied are you with your access to health services?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

24. How satisfied are you with your transport?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

25. How often do you have negative feelings such as blue mood, despair, anxiety, depression?

Never: 5

Seldom: 4

Quite often: 3

Very often: 2

Always: 1

[Scoring method]

Equations for computing domain raw scores:

Domain 1 (physical) score = Q3 + Q4 + Q10 + Q15 + Q16 + Q17 + Q18

Domain 2 (psychological) score = Q5 + Q6 + Q7 + Q11 + Q19 + Q25

Domain 3 (social) score =Q20 + Q21

Domain 4 (environmental) score = Q8 + Q9 + Q12 + Q13 + Q14 + Q22 + Q23 + Q24

Transformed scores were estimated using the following tables for standardizing scores from 0-100 with the lowest score of zero and the highest score of 100. (See Reference 20 for additional information)

APPENDIX F: COPING-SELF EFFICACY SCALE

Coping Self-Efficacy Scale v. 06-08-10

When things aren't going well for you, or when you're having problems, how confident or certain are you that you can do the following:

Cannot do at all					**Moderately certain can do**					**Certain can do**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

For each of the following items, write a number from 0 - 10, using the scale above.

When things aren't going well for you, how confident are you that you can:

1. Keep from getting down in the dumps. ____ 99

2. Talk positively to yourself. ____ 99

3. Sort out what can be changed, and what can not be changed. ____ 99

4. Get emotional support from friends and family. ____ 99

5. Find solutions to your most difficult problems. ____ 99

---

6. Break an upsetting problem down into smaller parts. ____ 99

7. Leave options open when things get stressful. ____ 99

8. Make a plan of action and follow it when confronted with a problem. ____ 99

9. Develop new hobbies or recreations. ____ 99

10. Take your mind off unpleasant thoughts. ____ 99

---

11. Look for something good in a negative situation. ____ 99

12. Keep from feeling sad. ____ 99

13. See things from the other person's point of view during a heated argument. ____ 99

14. Try other solutions to your problems if your first solutions don't work. ____ 99

15. Stop yourself from being upset by unpleasant thoughts. ____ 99

please go on to next page ➲

When things aren't going well for you, or when you're having problems, how confident or certain are you that you can do the following:

Cannot do at all					**Moderately certain can do**					**Certain can do**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

When things aren't going well for you, how confident are you that you can:

16. Make new friends. _____ 99

17. Get friends to help you with the things you need. _____ 99

18. Do something positive for yourself when you are feeling discouraged. _____ 99

19. Make unpleasant thoughts go away. _____ 99

20. Think about one part of the problem at a time. _____ 99

---

21. Visualize a pleasant activity or place. _____ 99

22. Keep yourself from feeling lonely. _____ 99

23. Pray or meditate. _____ 99

24. Get emotional support from community organizations or resources. _____ 99

25. Stand your ground and fight for what you want. _____ 99

26. Resist the impulse to act hastily when under pressure. _____ 99

Chesney MA, Neilands TB, Chambers DB, Taylor JM, Folkman S. A validity and reliability study of the coping self-efficacy scale. Br J Health Psychol 2006 Sep; 11(3): 421-37. http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1602207.

We appreciate copies of manuscripts or conference presentations generated from the use of this scale to help us stay current with its use and to assess its validity and reliability in other populations.

Please address correspondence to Margaret A. Chesney, PhD, Director, Osher Center for Integrative Medicine, Box 1726, University of California San Francisco, San Francisco, CA 94143-17262, USA (e-mail: chesneym@ocim.ucsf.edu).

APPENDIX G: AUTISM PARENTING STRESS INDEX

Date: __________ Name of child: __________________________ Person completing checklist:________________

Autism Parenting Stress Index

	Stress Ratings				
Please rate the following aspects of your child's health according to how much stress it causes you and/or your family by placing an X in the box that best describes your situation.	**Not stressful**	**Sometimes creates stress**	**Often creates stress**	**Very stressful on a daily basis**	**So stressful sometimes we feel we can't cope**
Your child's social development	0	1	2	3	5
Your child's ability to communicate	0	1	2	3	5
Tantrums/meltdowns	0	1	2	3	5
Aggressive behavior (siblings, peers)	0	1	2	3	5
Self-injurious behavior	0	1	2	3	5
Difficulty making transitions from one activity to another	0	1	2	3	5
Sleep problems	0	1	2	3	5
Your child's diet	0	1	2	3	5
Bowel problems (diarrhea, constipation)	0	1	2	3	5
Potty training	0	1	2	3	5
Not feeling close to your child	0	1	2	3	5
Concern for the future of your child being accepted by others	0	1	2	3	5
Concern for the future of your child living independently	0	1	2	3	5
Subtotal					
Total					

APPENDIX H: COPYRIGHT PERMISSION FOR PEARLIN ALZHEIMER'S CAREGIVER STRESS PROCESS MODEL

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Institution name
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Expected presentation date
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Portions
Figure 1 A Conceptual model of Alzheimer's caregiver's stress.
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APPENDIX I: COPYRIGHT PERMISSION FOR COPING SELF-EFFICACY SCALE

Dear Ms. Turnage,

Thank you for your interest in using the Coping Self Efficacy scale (CSE). You mentioned that you will be using the scale in your PhD dissertation in which you are studying stress, coping, and quality of life among parents of children with autism. As you may be aware, the scale has been given to assess coping self-efficacy of parents of children with other challenges and it seems to be capturing something that is helpful.]]

I recommend that you use the full scale and I have attached a copy. The full 26-item scale will give you the most reliable measure and the one that other investigators are using. By using the full scale you also have the total scores and have the option of using the full scale or the subscales, which are described in the attached paper on the reliability and validity of the scale. Using the full scale is important because we built the subscales on our studies with HIV patients and your population will be different. The CSE as a full scale is being used with many different populations, young and old, with a full range of stressful conditions, including psychological and physical. I'm attaching general scoring instructions and if you have any problems, just let me know.

I am also including an article that I wrote with my colleagues that describes the reliability and validity of the CSE and provides information about the subscales. I can provide additional information, if you have questions.

I've also attached a copy of the first paper that my colleagues and I wrote which showed how coping self-efficacy was helpful in evaluating a coping intervention and mediated the effect of the intervention on outcomes.

In agreeing to use the scale for research purposes, I also ask that you keep me informed of what you find. I have created a log of all the scientists, such as yourself who are using the scale and will let everyone on the log know when there are developments as well as the results found by others who are using the scale. For the log, could you send me your best e-mailing address, or any other identifying information.

I look forward to hearing from you,

Margaret

Margaret A. Chesney, Ph.D.
Professor of Medicine
UCSF
415-613-7343

Margaret A. Chesney, PhD

APPENDIX J: CURRICULUM VITAE

Dawn M. Turnage, DNP, APRN, FNP-BC

University of Central Florida College of Nursing
12201 Research Parkway Suite 300
Orlando, FL 32826
(407) 404-6153—Office
(407) 823-5675—Fax
Dawn.turnage@ucf.edu

EDUCATION

Year	Degree	Institution	Clinical Major	Role Preparation
	PhD	University of Central Florida, Orlando, FL	Nursing	Research
2018	Post-Masters	University of Central Florida, Orlando, FL	Nursing	Education
2015	DNP	University of Central Florida, Orlando, FL	Nursing	Leadership
2013	MSN	University of Central Florida, Orlando, FL	FNP	Family Practice
2011	BSN	University of Central Florida, Orlando, FL	Nursing	General
2009	AA	Valencia Community College, Orlando, FL	General	General
2008	AS	Valencia Community College, Orlando, FL	Nursing	Registered Nurse
1994	LPN	Orlando Tech, Orlando, FL	Nursing	Practical Nurse

LICENSURE/CERTIFICATION

RN/APRN	Florida, 9288079
FNP-BC	

EMPLOYMENT

ACADEMIC APPOINTMENTS:

*Graduate Faculty Status

7/15-present	**Lecturer***, University of Central Florida College of Nursing, Orlando, FL
08/13-7/15	**Instructor,** University of Central Florida College of Nursing, Orlando, FL
01/12-7/13	**Adjunct Instructor,** University of Central Florida College of Nursing, Orlando, FL

CLINICAL APPOINTMENTS:

08/2008-07/2012	**Staff/Charge**, Surgical Oncology, MD Anderson Cancer Ctr., Orlando, FL
08/2007-08/2008	**Staff Nurse,** Emergency Department**,** Orlando Health, Orlando, FL
2002-2007	**Staff Nurse,** Med/Surg Dermatology, Knipe & Moskowitz, Orlando, FL
2000-2002	**Staff Nurse/Weekend Supervisor,** Winter Park Towers, Winter Park, FL
1999-2000	**Staff Nurse**, Visiting Nurses Association, Orlando, FL
1995-1999	**Staff Nurse**, Internal Med Outpatient Clinic, Orlando Health, Orlando, FL
1994-1995	**Staff Nurse**, Sunbelt Healthcare, Orlando, FL

PUBLICATIONS

REFEREED JOURNALS***:*** (# data-based)

Woodmansee, R., **Turnage, D**., & Loerzel, V. (2018). Nurse Practitioner student knowledge and attitudes towards skin cancer assessments. *The Nurse Practitioner*, 44(3), 14-18. Reproduced with permission from the *Journal of the Dermatology Nurse's Association. #*

Woodmansee, R., **Turnage, D**., & Loerzel, V. (2018). Nurse Practitioner student knowledge and attitudes towards skin cancer assessments. *Journal of the Dermatology Nurse's Association. #*

***BOOK CHAPTERS*: (**# Refereed)

Turnage, D. (2014). Rash. In J. Waldrop (Ed.). *Pediatric case studies to develop diagnostic reasoning* (1st ed., pp.). #

RESEARCH AND GRANTS

Date	*Role*	*Title*	*Agency*	*Type*	*Amount*

2018	PI	Social Determinants of Health in Caregivers: Implications for Practice, Policy, and Research	University of Central Florida, Graduate Studies, Travel Fellowship Grant	Intramural	$500
2017	PI	A State of the Science Review of the Quality of Life of Parental Caregivers of Children with Autism Spectrum Disorder	University of Central Florida, Graduate Studies, Travel Fellowship Grant	Intramural	$300
2017	PI	Quality of Life of Parental Caregivers of Children with Autism Spectrum Disorder	American Academy of Nurse Practitioners	Intramural	Unfunded $2500
2015	PI	An Implementation Project to Improve Provider Review and Recommendation of Immunizations in Adult Patients with Psoriasis Receiving Biologic Therapy	University of Central Florida, College of Nursing, Waldrop DNP Grant	Intramural	$816
2015	PI	An Implementation Project to Improve Provider Review and Recommendation of Immunizations in Adult Patients with Psoriasis Receiving Biologic Therapy	Sigma Theta Tau International, Theta Epsilon Chapter	Intramural	$750

NATIONAL AND INTERNATIONAL PRESENTATIONS

Date	Type	Title/Authors	Conference Title, City/State	Refereed/ Invited
8/2018	Poster	Social Determinants of Health in Caregivers: Implications for Practice, Policy, and Research	Sigma Theta Tau Leadership Conference Indianapolis, Indiana	Invited
07/2018	Poster	A State of the Science Review of the Quality of Life of Parental Caregivers of Children with Autism Spectrum Disorder	Sigma Theta Tau International 29th Research Congress, Melbourne, Australia	Refereed
02/2018	Poster	Social Determinants of Health in Caregivers: Implications for Practice, Policy, and Research	American Academy of Colleges of Nursing Graduate Student Nurses Association Atlanta, GA	Refereed
07/2015	Poster	An Implementation Project to Improve Provider Review and Recommendation of Immunizations in Adult Patients with Psoriasis Receiving Biologic Therapy	Sigma Theta Tau International 26th Research Congress, San Juan, PR	Refereed

LOCAL/STATE AND REGIONAL PRESENTATIONS

Date	Type	Title/Authors	Conference Title, City/State	Refereed/ Invited
4/2017	Poster	A State of the Science Review of the Quality of Life of Parental Caregivers of Children with Autism Spectrum Disorder	Sigma Theta Tau, Theta Epsilon Chapter, Research Conference, Orlando, FL	Refereed
4/2017	Poster	A State of the Science Review of the Quality of Life of Parental Caregivers of Children with Autism Spectrum Disorder	University of Central Florida, Graduate Research Forum, Orlando, FL	Refereed

Date	Type	Title/Authors	Conference Title, City/State	Refereed/ Invited
04/2015	Advisory Panel	Advancing the Science of Public Health and Safety	Sigma Theta Tau, Theta Epsilon Chapter, Research Conference, Orlando, FL	Invited
04/2015	Podium	An Implementation Project to Improve Provider Review and Recommendation of Immunizations in Adult Patients with Psoriasis Receiving Biologic Therapy	Sigma Theta Tau, Theta Epsilon Chapter, Research Conference, Orlando, FL	Refereed
03/2015	Poster	An Implementation Project to Improve Provider Review and Recommendation of Immunizations in Adult Patients with Psoriasis Receiving Biologic Therapy	University of Central Florida, Graduate Research Forum, Orlando, FL	Refereed
03/2014	Poster	Does Oxytocin Improve Social Cognition in Individuals With Autism Spectrum Disorder?	University of Central Florida, Graduate Research Forum, Orlando, FL	Refereed

HONORS AND AWARDS

Date	Award	Organization/Group
8/2018	Rising Stars of Research and Scholarship	Sigma Theta Tau International
5/2017	Nursing Scholarship	Jean Kijek
5/2017	Nursing Scholarship	Linda Hennig
01/2017	Nursing Scholarship	UCF Knightingale Society
01/2017	Nursing Scholarship	Sam Realista
01/2016	Nursing Scholarship	Hugh F. and Jeanette McKeon Endowed Scholarship / University of Central Florida, College of Nursing
05/2013	Nursing Grant	Gertrude Skelly Fund / University of Central Florida, College of Nursing
09/2012	Graduate Nursing Fellowship	University of Central Florida, College of Nursing

05/2012	Graduate Nursing Fellowship	University of Central Florida, College of Nursing
01/2012	Graduate Nursing Fellowship	University of Central Florida, College of Nursing
2012	Nursing Scholarship	Winter Park Memorial Hospital Auxiliary
09/2011	Graduate Nursing Fellowship	University of Central Florida, College of Nursing
2008	Nursing Scholarship	Gerontological Society of America

PROFESSIONAL ACTIVITIES AND COMMUNITY SERVICE

Date	**Organization**	**Role**
2019	Theta Epsilon Chapter, Sigma Theta Tau Annual Scholarship Day	Abstract Reviewer
2019	Theta Epsilon Chapter, Sigma Theta Tau Annual Scholarship Day	Poster Judge
2016-2017	Southern Nursing Research Society	Student Member
2018	Theta Epsilon Chapter, Sigma Theta Tau Annual Scholarship Day	Abstract Reviewer
2018	Theta Epsilon Chapter, Sigma Theta Tau Annual Scholarship Day	Poster Judge
2017-2019	Theta Epsilon Chapter, Sigma Theta Tau	Board Member, Vice President
2015-2017	Theta Epsilon Chapter, Sigma Theta Tau	Board Member, Succession Planning Committee
2013-2014	Theta Epsilon Chapter, Sigma Theta Tau	Member
2011-Present	Delta Epsilon Iota, Academic Honor Society	Member
2011-Present	American Academy of Nurse Practitioners	Member
2002-2007	Dermatology Nurses’ Association	Member
1994-Present	Health Occupations Students of America	Member

PUBLICATION AND EDITORIAL BOARDS AND REVIEW:

Date	**Journal or Publisher**	**Role**
2019	Journal of Autism and Related Disorders	Reviewer

COMMUNITY SERVICE

Date	Organization	Role
2013 - 2015	Scott Coopersmith Stroke Awareness Foundation	Board Member
2007-Present	Autism Society of Greater Orlando	Member

UNIVERSITY SERVICE

Date	Level	Committee	Role
2018-2019	College	Undergraduate Curriculum Committee	Member
2017-2018	College	DNP Taskforce	Member
2017-2018	University	Non-tenure Earning Research Community	Member
2016-2017	University	Instructor/Lecturer Excellence Program	Member
2018-2019	College	PhD Curriculum Committee	Student-Representative
2017-2018	College	PhD Curriculum Committee	Student Representative
2016-2017	College	PhD Curriculum Committee	Student Representative
2015-2016	College	PhD Curriculum Committee	Student Representative
2018-2019	College	Valencia-College/UCF Concurrent Faculty Committee	Member, UCF Representative
2017-2018	College	Valencia College/UCF Concurrent Faculty Committee	Member, UCF Representative
2016-2017	College	Valencia College/UCF Concurrent Faculty Committee	Member, UCF Representative
2015-2016	College	Valencia College/UCF Concurrent Faculty Committee	Member, UCF Representative
2018-2019	College	Valencia Nursing Advisory Council	Member, UCF Representative
2017-2018	College	Valencia Nursing Advisory Council	Member, UCF Representative
2016-2017	College	Valencia Nursing Advisory Council	Member, UCF Representative

2015-2016	College	Valencia Nursing Advisory Council	Member, UCF Representative
2017-2018	College	Admission, Progression, Graduation Committee	Member
2016-2017	College	Admission, Progression, Graduation Committee	Member
2015-2016	College	Admission, Progression, Graduation Committee	Member
2014-2015	College	Admission, Progression, Graduation Committee	Member
2013-2014	College	Admission, Progression, Graduation Committee	Member
2017-2019	College	Organization of Doctoral Student Nurses	President
2012- 2019	College	Organization of Doctoral Student Nurses	Student Member

DISSERTATION/THESIS/RESEARCH PROJECT ADVISING:

Date	Student	Title	Level	Role
2019	Sarah Sakala	In progress	DNP	Committee Member
2019	Samantha Day	Communication Tools for Parents of Pediatric Patients	HIM BSN	Committee Member
2018	Ariana Ruiz Aguilar	The Effect of Race on Parents' Intent to Vaccinate Their Children Against Human Papillomavirus	HIM BSN	Committee Member
2017	Ryan Woodmansee	Practitioner Student Knowledge and Attitudes Towards Skin Cancer Assessments	HIM BSN	Committee Member
2017	Amanda Wimmersberg-Schultz	Exploring the Relationship Between Symptom Management and Distress in Pediatric Oncology Nurses	HIM BSN	Committee Member
2016	Nicole Licata	Exercise and quality of life in breast cancer survivors	HIM BSN	Committee Members
2016	Samantha Normand	Therapy Options for Winged Scapula Patients	HIM BSN	Committee Member

COURSES TAUGHT:

Date	**Level**	**Committee**	**Role**
2018-2019	College	Undergraduate Curriculum Committee	Member
2017-2018	College	DNP Taskforce	Member
2017-2018	University	Non-tenure Earning Research Community	Member
2016-2017	University	Instructor/Lecturer Excellence Program	Member
2018-2019	College	PhD Curriculum Committee	Student-Representative
2017-2018	College	PhD Curriculum Committee	Student Representative
2016-2017	College	PhD Curriculum Committee	Student Representative
2015-2016	College	PhD Curriculum Committee	Student Representative
2018-2019	College	Valencia-College/UCF Concurrent Faculty Committee	Member, UCF Representative
2017-2018	College	Valencia College/UCF Concurrent Faculty Committee	Member, UCF Representative
2016-2017	College	Valencia College/UCF Concurrent Faculty Committee	Member, UCF Representative
2015-2016	College	Valencia College/UCF Concurrent Faculty Committee	Member, UCF Representative
2018-2019	College	Valencia Nursing Advisory Council	Member, UCF Representative
2017-2018	College	Valencia Nursing Advisory Council	Member, UCF Representative
2016-2017	College	Valencia Nursing Advisory Council	Member, UCF Representative
2015-2016	College	Valencia Nursing Advisory Council	Member, UCF Representative
2017-2018	College	Admission, Progression, Graduation Committee	Member
2016-2017	College	Admission, Progression, Graduation Committee	Member
2015-2016	College	Admission, Progression, Graduation Committee	Member
2014-2015	College	Admission, Progression, Graduation Committee	Member
2013-2014	College	Admission, Progression, Graduation Committee	Member

2017-2019	College	Organization of Doctoral Student Nurses	President
2012- 2019	College	Organization of Doctoral Student Nurses	Student Member

REFERENCES

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