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**AN EXAMINATION OF QUALITY OF LIFE OF PARENTS OF
ADULT CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER**

by

CHRISTINA N. MARSACK

DISSERTATION

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

2016

MAJOR: SOCIAL WORK

Approved By:

Advisor

Date

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DEDICATION

In memory of my grandmother, Geraldine Quarrella, who instilled a deep love and respect in me for older adults, specifically those caring for loved ones. I can still hear your voice echoing words of support, encouragement, and always cheering me on to do my best.

To my family, especially my parents, for providing me with such a strong example of a work ethic, compassion, and a framework to chase my dreams. Thank you for your unceasing love, support, and always encouraging me to do my best.

To my sisters, Maryann, Lisa, and Julie. I am so lucky to have each of you in my life. You each bring something unique and immensely special to my life. Thank you for supporting me on this journey.

And lastly – to the present day caregivers who have sacrificially given something of yourself for the benefit of another. May you always feel God’s blessings and hand in your lives.

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CHAPTER 1 INTRODUCTION

Autism spectrum disorder (ASD) and autism “are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors” (Autism Speaks, 2016b, para. 1). According to a study conducted by the Centers for Disease Control and Prevention (CDC; 2014), 1 in 68 children are now affected by ASD. To put this number in perspective, there were approximately 74 million children under 18 living in the U.S., according to the 2010 Population Census, which would imply that more than one million children are living with ASD (U.S. Census Bureau, 2011). Additional research supports the growth in the number of individuals diagnosed with ASD (Keyes et al., 2012, Matson & Kozlowski, 2011; Zahorodny et al., 2014). However, it is unknown whether the increase in individuals affected by this disorder is a derivation of changes in results of prior research or because of growth in the number of diagnoses from expanded causes (Brugha et al., 2011). Little is known about the actual number of adults affected by ASD (Brugha et al., 2011). Although ASD generally is considered a juvenile disorder, individuals diagnosed with ASD continue to exhibit symptomology throughout adulthood. People with this diagnosis can be expected to live into older adulthood.

As the number of children diagnosed with ASD increases, more parents are becoming caregivers, with their responsibilities growing as their children move from childhood to adolescence and then into adulthood. Caregivers are people who provide physical, mental, emotional, social, and financial care or support for other people who have chronic and serious illnesses, disabilities, or challenges that influence their ability to function independently. Research illustrated the demanding responsibilities that caregivers encounter (Phelps, Hodgson, McCammon, & Lamson, 2009). Parents of children with ASD reported greater challenges when

compared to parents of children diagnosed with other types of developmental disorders (DDs; Phelps, Hodgson et al., 2009; Sanders & Morgan, 1997; Smith et al., 2010).

Comorbidity and Behavior

The co-occurrence of ASD with another condition may add to challenges experienced by individuals with ASD and their caregivers. Comorbidity is the existence of two or more conditions simultaneously (*Merriam-Webster Dictionary*, n.d.). ASD is often a comorbid condition among both children and adults diagnosed with ASD (Fombonne, 2003; Matson & Shoemaker, 2009; Simonoff et al., 2008). Individuals with ASD commonly are found to have coexisting conditions, such as intellectual deficits, anxiety, and depression.

Challenging behaviors often are visible in childhood and adolescence/adulthood for those with ASD (Matson & Rivet, 2008; Seltzer et al., 2003; Shattuck et al., 2007). A number of maladaptive behaviors, such as aggression, often are present among this population (Shattuck et al., 2007). To add to the complexity of behaviors, 68% of children and adolescents diagnosed with ASD in one study exhibited some form of aggressive behavior toward their caregivers (Kanne & Mazurek, 2011).

Caregiving

As parents age, their caregiving duties and their personal realities can be expected to change (Schofield et al., 1999). They may be faced with caring for a debilitated spouse, parents, or other dependents. Legal issues may be present, such as challenges maneuvering the many steps required of individuals applying for guardianship or durable power of attorney for their dependent (Judicial Council of California, 2014; Sharpe & Baker, 2007). Managing these legal issues can be time consuming and expensive. Financial burdens, such as the cost of caretaking, may be problematic. These costs could include specialized therapy and treatment. Some parents

experience lost wages due to absence from work, inability to advance vocationally, and inability to maintain full-time employment. Baby boomers are expected to experience some type of disabilities and require care as they age (Fingerman, Pillemer, Silverstein, & Sutor, 2012). As they advance in age, both caregivers and adults with ASD may have increasing medical issues associated with age, such as high blood pressure, cardiovascular disease, diabetes, cognitive decline, as well as mobility issues (Hajjar & Kotchen, 2003; World Health Organization, 2011). Additionally, parents of adolescent and adult children with disabilities experienced more health symptoms, including headaches, backaches, muscle soreness, fatigue, and hot flashes when compared with parents of similarly aged nondisabled children (Smith, Greenberg, & Seltzer, 2012).

The challenges of raising a child with ASD place parents at greater risk for adverse mental health outcomes. Higher levels of depression, anxiety, worry, embarrassment, and mood alterations are associated with parenting a child with ASD (Benson, 2006). These parents also are at risk for experiencing diminished positive affect (Smith et al., 2010). Research findings suggested the presence of greater fatigue among mothers with adolescents and adults with ASD compared to mothers of nondisabled adolescents and adults (Smith et al., 2010). In addition to these adverse mental health outcomes, decreased marital satisfaction was associated with parenting a child with autism (Hartley, Barker, Baker, Seltzer, & Greenberg (2012).

Researchers (Phelps, Hodgson et al., 2009; Smith et al., 2010) asserted that parents of children with ASD experienced elevated levels of stress when compared to parents of children with other disabilities or no disability at all. Stress often comes from multiple sources, including (but not limited to) family dynamics, continuous caregiving, difficult behavior problems, and presence of co-morbidity (Kelly & Kropf, 1995).

Statement of the Problem

A plethora of literature pertains to parents of children diagnosed with ASD, with little research focusing on parents with grown children. Research that focused on caregivers of adults was more concerned with caregivers of individuals with intellectual and developmental disabilities (I/DDs; Wang & Brown, 2009). In a comprehensive review of literature on ASD in adulthood and aging published from 1990 to 2013, Wright, Brooks, D'Astous, and Grandin (2013) found only a few that mentioned parents and their roles in the lives of their adult children.

With increases in the number of children diagnosed with ASD, a need exists to understand the burdens, responsibilities, and quality of life (QOL) of parents who may continue to provide care for their adult children with ASD. Research investigating caregivers of individuals with ASD is needed in the helping professions, including social work, psychology, and nursing. The research devoted to examining elderly parental caregivers has focused primarily on caregivers of individuals with I/DDs (Wang & Brown, 2009), rather than focusing specifically on parents of adult children diagnosed with ASD. Most research on ASD has centered on parents of children with this diagnosis, but not on parents of adults (Lounds, Seltzer, Greenberg, & Shattuck, 2007). Research to investigate caregivers of adults with ASD is emerging (e.g. Cadman et al., 2012; Fairthorne, de Klerk, & Leonard, 2015; Smith et al., 2012); however, additional efforts are needed. A study of parents of adult children with ASD is important to understand how they maintain their QOL.

Considerable disagreement surrounds the definition of QOL (Felce & Perry, 1995). For purposes of this study, QOL is considered to be "... an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional

wellbeing together with the extent of personal development and purposeful activity, all weighted by a personal set of values” (Felce & Perry, 1995, p. 160, 162).

The issues that have been relevant for parents of children with ASD include: caregiver burden associated with time requirements (e.g., Krauss, Seltzer, & Jacobson, 2005), financial concerns (Altiere & von Kluge, 2009; Montes & Halterman, 2008), communication and behavioral challenges of the individual with ASD (Barker et al., 2011; Dillenburger & McKerr 2011), as well as the need for formal and informal social supports (Siklos & Kerns, 2006; Smith et al., 2012). What is not known is the relationship between these issues and the parents’ QOL. Findings can be used to gain information in this area, provide social workers with information on the experiences of parental caregivers of adult children with ASD, and to inform program development and service delivery.

Purpose of the Study

The purpose of this study was to examine effects of caring for an adult child with ASD on parents’ QOL. In addition, contributing factors to QOL, such as social support, were investigated.

Research Questions and Hypotheses

The following research questions and hypotheses were addressed in this study:

1. What is the relationship between the perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD?

H₀₁: There is not a relationship between perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD.

H_{a1}: There is a relationship between perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD.

2. What is the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?

H₀₂: There is not a relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H_{a2}: There is a relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

3. What is the relationship between living arrangement and QOL among parental caregivers of adult children with ASD?

H_{o3}: There is not a relationship between living arrangement and QOL among parental caregivers of adult children with ASD.

H_{a3}: There is a relationship between living arrangement and QOL among parental caregivers of adult children with ASD.

4. Does formal social support moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?

H_{o4}: Formal social support does not moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H_{a4}: Formal social support moderates the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

5. Does informal social support moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?

H_{o5}: Informal social support does not moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H_{a5}: Informal social support moderates the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

Methodological Design

The participants of this study include self-identified parental caregivers (50 years of age or older) of adult children (18 years of age or older) diagnosed with ASD. Parents were recruited from a number of agencies and organizations, such as the Autism Alliance of Michigan, Autism Program of Illinois, Autism Society Macomb/Saint Clair in Michigan, and Milestones Autism Resources in Ohio. It is not essential that the adult child be living at home. To investigate QOL, a quantitative study using an online questionnaire was used to collect data. The questionnaire includes portions or the entirety of four validated surveys, including the Caregiver Burden

Inventory (CBI), Caregiver Reaction Assessment (CRA), ENRICH Social Support Instrument (ESSI), and World Health Organization Quality of Life-BREF (WHOQOL-BREF), as well as a researcher created demographic survey. Chapter 4 thoroughly discusses the methodology.

The information obtained from this study can be used to investigate the QOL for parents of adult children diagnosed with ASD. Social workers, policy makers, and other ancillary service providers can begin to understand the complex stressors associated with providing care for adults diagnosed with ASD. The results of this study can be used to develop programs, services, and interventions to help parents and reduce the stress and anxiety associated with caring for their adult children diagnosed with ASD.

Statement of Relevance / Connection to Social Work

The growth in the number of individuals affected by ASD is expected to add to casework for social workers, especially in assisting caregivers who may feel overwhelmed by their continued responsibility for their adult children. Social workers could be instrumental in addressing the need for adequate services and support options for this population, as well as working with families and adults with ASD to care for individualized needs appropriately. Social workers should be supported in developing a knowledge base regarding the burdens and stressors that are affecting the QOL of parents as their children move from childhood to adolescence, and finally to adulthood. As these parents age, their lives will continue to be affected by the adjustments made to support the specific needs of their adult children with ASD. Services to both the parents and their adult children will be a challenge for social workers, requiring input into all phases of their lives. Delivering these services effectively and efficiently will necessitate an understanding of the reality of the lives of both parents and adult children, as well as background into the QOL and caregiver burden with which the parents are living.

Assumptions

A number of assumptions are made for this study. First, it is assumed that parents of adult children diagnosed with ASD continue to provide care and/or support when their children reach adulthood. Second, it is assumed that parents of adult children diagnosed with ASD have different caregiver responsibilities than parents of young children with this diagnosis. Lastly, it is assumed that the parents who respond to the survey responded honestly.

Limitations

The following limitations may affect the generalizability of the study beyond the population being studied:

- Recruitment methods relied heavily on formal support organizations to disseminate information regarding this study. As such, the results may not be generalizable to parents of adult children diagnosed with ASD who do not belong to formal support organizations.
- The self-selection may be more biased because parents who are more involved and/or more connected with organizational supports are likely to participate.
- Respondents are self-selected and therefore generalization limitations could exist related to respondent bias.
- The study is limited to parents of adult children with ASD. The results may not be applicable to parents of young children or adolescents diagnosed with ASD.
- The study utilized an online survey. Parents who did not have access to the Internet might not be able to participate in the study.

Definition of Terms

Adult children diagnosed with ASD	An individual who is 18 years of age or older and is diagnosed with ASD.
Caregiver burden	Parents' perceptions of burdens associated with providing care for their adult children diagnosed with ASD. These burdens include: time dependence, developmental, physical, social and emotional burdens (Novak & Guest, 1989). For purposes of this study, time dependence burden, developmental burden, and emotional burden was examined using a composite score for caregiver burden.
Caregiver stress	"The relationship between the person [caregiver] and the environment, which takes into account characteristics of the person on one hand, and the nature of the environmental event on the other," (Lazarus & Folkman, 1984, p. 21).
Perceived financial impact (of caregiving)	Caregivers' perceptions regarding the financial strain experienced as a result of providing care to their adult children with ASD (Given et al., 1992; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999).
Quality of life	The general subjective feelings associated with being happy, healthy, or prosperous (Merriam-Webster, n.d.)

Social support

Social resources are available or are provided to individuals in either formal or informal relationships. *Informal supports* are unpaid supports (e.g. personal network- such as family and friends). *Formal supports* are paid supports offered in the community (e.g., paid professionals- respite care, etc.; Cohen, Gottlieb, & Underwood as cited by Gottlieb & Bergin, 2010)

Organization of the Study

Chapter 1 presents the background of the study, along with the statement of the problem, purpose of the study, research questions, and significance of the study for social workers. A comprehensive review of related literature is included in Chapter 2, with the theoretical framework presented in Chapter 3. The research methods used to collect and analyze the data needed to address the research questions are included in Chapter 4. The findings of the study are presented in Chapter 5, with conclusions and recommendations found in Chapter 6.

CHAPTER 2 REVIEW OF THE LITERATURE

Introduction

This chapter incorporates caregiving literature to present an empirical foundation for the study of quality of life (QOL) among parents of adult children with autism spectrum disorder (ASD). In providing a framework for exploring QOL among this population, this literature review focuses on caregiving, geriatric realities, parental stressors, and implications for caring for a child or adult with a disability, specifically ASD.

Autism Spectrum Disorder

As of May 2013, a new categorization of “Autism” can be found in Diagnostic Statistical Manual V (DSM-5; American Psychiatric Association, 2013). ASD is characterized by five characteristics that may vary according to the level of severity.

1. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history
2. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history.
3. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
4. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
5. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level. (Autism Speaks, 2016b; para. 10, 15, 21, 22, 23)

Individuals formerly diagnosed (under the DSM-IV criteria) with having autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified (PDD-NOS), would be considered under the DSM-V criteria to meet clinical criteria as having an ASD.

Prevalence of Autism

ASD is becoming more prevalent. The Centers for Disease Control and Prevention (CDC; 2014) conducted a study that found 1 in 68 children within the investigated communities were diagnosed with a condition on the ASD. A recent study using 8-year old children at 14 Autism and Developmental Disabilities Monitoring Network (ADDMN) sites found 14.7 per 1,000 children were impacted by ASD (Baio, 2012). To confound the reported prevalence further, the CDC found that impairments associated with autism continue to increase (Singer, Biegel, & Ethridge, 2009).

Challenges of Caring for an Individual with Autism Spectrum Disorder

Comorbidity

Comorbidity refers to the presence of multiple disorders in conjunction with each other (Merriam-Webster, n.d.). Empirically, evidence exists to support an increased tendency for children with autism to experience other conditions concurrently, such as anxiety, depression, and intellectual deficits (Leyfer et al., 2006; Matson et al., 2009; Simonoff et al., 2008). The addition of other physical, intellectual, emotional, and psychiatric conditions can further confound the already complex realities that children with autism and their parents' experience. One stressor for parents is dealing with their child's atypical behavior—often exacerbated by comorbid realities.

Intellectual disability (ID) is common among individuals with ASD (Matson & Shoemaker, 2009). A study reported by La Malfa, Lassi, Bertelli, Salvini, and Placidi (2004) indicated that more than 70% of individuals with ASD also had ID. Through an extensive literature review, Matson and Shoemaker (2009) demonstrated an increased covarying presence of ID and ASD. Another study conducted by the ADDMN suggested an elevated proportion of ID in a sample of 8-year-old children with ASD (Baio, 2012). An increased prevalence of these co-existing disorders was found in females.

Simonoff et al. (2008) also reported a high frequency of psychiatric disorders among children with pervasive developmental disorder (PDD) and autism. More than 70% of participants had at least one co-morbid psychiatric disorder and 41% had at least two psychiatric disorders. Similar to other studies, their results also indicated a high frequency of attention-deficit hyperactivity disorder (ADHD), social anxiety disorder, and oppositional defiant disorder for children diagnosed with ASD (Gurney, McPheeters, & Davis, 2006; Levy et al., 2010).

Anxiety is particularly common among children diagnosed with ASD. Gilliott, Furniss, and Walter (2001) conducted a study examining general anxiety and social worry among the following three groups: neurotypicals, children with language impairments, and high-functioning children with autism. Children with autism had the highest levels of anxiety, including social and separation anxiety.

According to Leyfer et al. (2006), specific phobias are among the most common comorbid disorders, affecting approximately 44% of children in their study. Specifically, many of these children displayed phobias to loud noises. Obsessive-Compulsive Disorder (OCD) was another frequently comorbid diagnosis, affecting approximately 37% of children with autism. Additionally, compulsions were visible and added to the many demands of caregiving for parents. For example, many parents had to “perform certain daily routines and greetings and separation rituals” (Leyfer et al., 2006, p. 854). Similar to other studies, ADHD and depression also were prevalent, presenting in 31% and 10% of children with autism, respectively. Results demonstrated a concordance between OCD and major depression in 5.3% of children diagnosed with ASD.

Depression is a problem for many children diagnosed with autism. Gadow, Guttman-Steinmetz, Rieffe, & DeVincent (2012) compared “the severity of specific depression symptoms in boys with autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), or

chronic multiple tic disorder (CMTD) and typically developing boys (Controls)” (p. 1353). Mothers and teachers rated the boys’ depressive symptoms using the Child Symptom Inventory – 4 and a demographic questionnaire. When compared to the Controls, mothers and teachers reported that boys with ASD and those diagnosed with ADHD had more severe ratings for all depression symptoms and depression in total. The findings of this study were aligned with other research, indicating an increased prevalence of depression among children with ASD when compared to Controls (Gadow et al., 2012; Gilliott et al., 2001).

Kim, Szatmari, Bryson, Streiner, and Wilson (2000) found disruptive behavior to be higher among children with autism than typically developing children. When compared with typically developing children, those children with autism had higher rates of ADHD, depression, generalized anxiety, and separation anxiety. Disruptive behavior also was found to be higher among children with autism. A high positive correlation existed among anxiety and mood problems, as well as with disruptive behavior. Mood and anxiety problems adversely affected the lives of children with autism and their parents. For example, parents who were concerned about their child’s future tended to experience greater personal worry and anxiety.

Behavior Challenges

Challenging behaviors and the severity of symptoms are visible among children with autism, and often continue into adolescence and adulthood (Matson & Rivet, 2008; Seltzer et al., 2003; Shattuck et al., 2007). Whether due to a derivation of ASD or the coexistence of ASD with another disorder, children and adults with ASD often exhibit inappropriate behaviors and co-morbid symptoms. Shattuck et al. (2007) defined maladaptive behaviors as those that “interfere with everyday activities, and include self-injurious behavior, withdrawal, uncooperative behavior, aggression, and destruction of property” (p. 1736). Children with autism commonly exhibit

aggressive, repetitive, and stereotypical maladaptive behaviors (Matson & Rivet, 2008). For example, Kanne and Mazurek (2011) reported that 68% of children and adolescents with ASD exhibited some form of aggressive behavior toward their caregivers. Another study demonstrated the presence of self-injurious behavior (SIB) among children with autism (Baghdadli, Pascal, Grisi, & Aussilloux, 2003). Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein (2007) found a continuum of behaviors among children with autism, such as temper tantrums, abnormal eating, and irregular sleep patterns. Difficulties related to communication and social impairments could intensify adverse behaviors among this population.

Matson and Rivet (2008) described a study using two groups of participants ($N = 320$) living in adult residential facilities. One group ($n = 161$) was diagnosed with ID and ASD (specifically autism and PDD-NOS) and the second group ($n = 159$) diagnosed with ID only. These authors found that individuals with ASD (when compared with those with ID) had greater frequency of aggressive and destructive behaviors, such as kicking or throwing objects, taking off clothing, destroying property, and acting aggressively towards others (Matson & Rivet, 2008). Additionally, individuals with ASD had a greater frequency of stereotypy, self-injurious behavior (SIB), and disruptive behavior than participants with ID only. Self-harming by pinching, hitting, or scratching was the most common SIB. Overall, individuals with both ASD and severe ID, rather than those solely with severe ID, were found to have a higher prevalence of challenging behaviors. On a continuum ranging from ID only to autism with ID, adults with autism and ID were found to exhibit the most challenging behaviors when compared to those with ID only or participants with ID and PDD-NOS.

In another study, Shattuck et al. (2007) indicated that behavior improved for individuals with ASD as they matured. For example, maladaptive behavior diminished in adults with ASD

when compared to adolescents with ASD. Individuals who had both ASD and ID experienced greater numbers of autism symptoms and maladaptive behavior.

A cross-sectional, comparison study by Seltzer et al. (2003) examined changes in symptoms in individuals diagnosed with ASD from 10 to 21 years and 22 to 53 years across their lifespan by assessing communication; reciprocal social interaction; and restricted, repetitive behaviors and interests. The findings indicated improvements in communication, as well as diminished repetitive behavior and stereotyped interests as the individual diagnosed with ASD matured. Despite some improvements over the life course, individuals with ASD continued to display marked impairments with regard to communication and reciprocal social interaction, and in particular, restricted, repetitive behaviors and interests.

Caregiving Challenges

A review of literature provided support that caregivers encounter difficulties with providing care for their child diagnosed with ASD (Dillenburger & McKerr, 2011; Phelps, Hodgson et al., 2009; Phelps, McCammon, Wuensch, & Golden, 2009; Smith et al., 2010). Finding a specific definition for caregiving is difficult, although a general definition of a caregiver is a person who provides physical, mental, emotional, social, and financial care or support for another person who has a chronic/serious illness, disability, or challenge that influence his/her ability to function independently.

Caregiving responsibilities change over time, depending on the age of the care recipient and type of disabling condition. The challenges of caring for a spouse and/or parent, maneuvering legal issues such as guardianship, and overseeing personal medical care and concerns can be daunting tasks, especially as the parent transitions through life. Caregiving and older adulthood, in general, often is associated with additional financial burdens (Altiere & von Kluge, 2009). These

realities often confound the complexities that caregivers face in later life. Parents who are providing care for a child with a disability face different challenges than people who provide care for older adults with age-related frailties.

Parents face many challenges while caring for a child or adult diagnosed with ASD. For example, parents caring for a child with ASD face different circumstances and challenges than parents caring for children who have other disabilities or are typically developing. According to Smith et al. (2010), many stressors have been associated with raising a child with ASD. Raising a child with this disorder can be stressful and difficult, with parents facing unique responsibilities and realities (Phelps, Hodgson et al., 2009). Parental challenges typically continue, as children with ASD often remain reliant on their parents throughout adulthood (Howlin, Goode, Hutton, & Rutter, 2004).

The purpose of this review is to examine and synthesize relevant and related literature to the topic of caregivers of adult children with ASD. However, a paucity of research has been published regarding the experiences of parents with adult children with ASD. Therefore, research has been borrowed from the intellectual and developmental disabilities (I/DDs) literature.

To complicate caring for a child with a disability further, the task of caring continues into adulthood as parents continue to age themselves. Nearly two million adults with I/DDs are supported by older and middle-aged family caregivers (Yamaki, Hsieh, & Heller, 2009). Caregivers worry about the future and what may happen to their children with disabilities when they are no longer able to provide care (Dillenburger & McKerr, 2011; Murphy, Christian, Caplin, & Young, 2007; Ogston, Mackintosh, & Myers, 2011).

As caregivers reach older adulthood, challenges external to parenting a child with a disability can become problematic. For example, the presence of chronic stress and health

complications for parental caregivers may interfere with the caregiving process (Miodrag & Hodapp, 2010). Older caregivers can expect to encounter personal health problems that may interfere with their ability to provide care for grown children with disabilities. Family caregivers tend to neglect caring for their own health, and they may have difficulty accessing programs that could prove beneficial for their adult child with a disability (Yamaki et al., 2009). Due to many factors, aging caregivers may face challenges that are specific to their child's disability.

Constant caregiving. A major stressor for parents is that they never feel a sense of relief from caregiving. For many, the realization that their parental role does not cease is a harsh reality. The realization that there is no finality to their role to provide care was described as being stressful for mothers of adults with ASD (Krauss, Seltzer, & Jacobson, 2005). These mothers reported stress about their need to provide care constantly and not being able to leave their adult child with ASD at home alone (Krauss et al., 2005). According to Altieri and von Kluge (2009), an upsetting reality for parents is the recognition that their parental obligations are a 24-hour daily task. This task has many implications for parents; including fatigue (Smith et al., 2010) and diminishing the amount of time parents have available for family, friends, and their spouses (Altieri & von Kluge, 2009).

Challenges related to ASD behavior. Many challenges that adults with ASD experience can affect their parental caregivers. Individuals with ASD often lead restricted lives, have difficulty with employment, are isolated from peers, have problems accessing post-secondary education, and often place considerable challenges on their family members due to their dependency (Keogh, Bernheimer, & Guthrie, 2004; Liptak, Kennedy, & Dosa, 2011). Life challenges for both individuals with ASD and their family members may be further complicated by the presence of adverse behaviors exhibited by the person with ASD. For example, maintaining employment could

be difficult for adults diagnosed with ASD who exhibit aggressive behaviors. Recognizing the limitations that adult children with ASD often have a profound influence on parents – many of whom continue to be the primary caregivers for this population (Krauss et al., 2005). While adults with ASD often live separately from their parents, their mothers and other family members continue to be involved in their lives. This involvement provides impetus for taking a “life-span perspective” when studying families of adults diagnosed with ASD. When adult children with this disorder are unable to access employment, educational opportunities, and social networks, they often remain reliant on their parents.

Behavior problems. Behavior problems could have profound effects on parents. Dillenburger and McKerr (2011) reported that dealing with behavioral problems was one of the greatest challenges for parents of adult children with I/DDs. Barker et al. (2011) found a positive correlation between behavior problems and depressive symptoms for mothers of adolescent and adult children diagnosed with ASD. Orsmond, Seltzer, Greenberg, and Krauss (2006) indicated that increased maladaptive behavior was associated with greater strain among mothers with adolescent and adult children with autism. Empirical evidence provided support for the prevalence of behavior problems and their adverse effects on parents with adult children with ASD.

According to Benson (2006), behavior problems were associated with increased stress and had negative effects on the psychosocial well-being of the parents. Nealy, O’Hare, Powers, and Swick (2012) found that aggressive behaviors increased stress in mothers of children diagnosed with ASD. In another study, Estes et al. (2009) compared the effects of problem behavior on mothers with preschool-aged children with ASD to mothers of children with other developmental delays. Although both groups of mothers experienced high levels of parenting stress and psychological distress, those parenting children with ASD had higher levels of both stress and

distress. The authors also noted that children diagnosed with ASD exhibited a greater number of problem behaviors that could be contributing to higher rates of parenting stress and psychological distress.

Mothers of adults with ASD reported problem behaviors as a chief source of stress (Krauss et al., 2005). Consistent with previous studies, the highest stress levels were reported by mothers whose children diagnosed with ASD were “more irritable, lethargic/socially withdrawn, hyperactive/non-compliant, unable to take care of themselves, and unable to communicate or interact with others” (Shattuck et al., p. 24, 2007). Another study indicated that maternal anxiety and depression tended to be elevated when a greater number of behavior problems occurred with their children diagnosed with ASD (Barker et al., 2011). However, Shattuck et al. (2007) indicated behavioral improvements in adults with ASD over time. For example, maladaptive behavior diminished in adults with ASD when compared to adolescents with ASD.

A study by Lecavalier, Leone, and Wiltz (2006) further supported the idea that a strong correlation existed between parental stress and adverse child behaviors. Using teacher and parent ratings, respondents indicated that stress levels were associated strongly with behavior problems. Conduct problems and lack of prosocial behaviors were found to be the greatest contributors to stress for parents and teachers. Parental age, education level, and understanding of ASD or use of applied behavior analysis (ABA) were not highly correlated with stress.

Challenges in continued caregiving beyond the typical time. Although research has been published regarding stressors that parental caregivers with young children diagnosed with ASD face, a gap exists in the literature that focuses on parents of adult children diagnosed with ASD (Altiere & von Kluge, 2009; Boyd, 2002; Brobst, Clopton, & Hendrick, 2009; Estes et al., 2009). Literature illustrating the stressors and realities that parents of children with ASD encounter

is helpful in understanding the experiences of older parents. The challenges that caregivers face may not decrease as children transition to adulthood. To understand the realities of older parents caring for their adult children with disabilities, it is essential to recognize that some of the same issues and experiences from childhood may continue (Kanne & Mazurek, 2011; Shattuck et al., 2007).

At any stage in the process of parenting, parents of children diagnosed with ASD face multiple stressors. Parents of children with autism encounter unique experiences and greater challenges when compared with those of children with other developmental disabilities (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Research suggested that these parents face elevated levels of stress when compared with parents of children with other disabilities or no disability at all (Phelps, Hodgson et al., 2009; Smith et al., 2010).

Parents of children diagnosed with ASD report many stressors and elevated levels of stress (Mori, Ujiie, Smith, & Howlin, 2009). Stress comes from many sources, including constant caregiving and not being able to leave a child alone at home (Altiere & von Kluge, 2009), family dynamics, difficult behavior problems (Kim et al., 2000), the complexity of needs or disability of the child, presence of co-morbidity (Gurney et al., 2006; Levy et al., 2010), the parents' work stressors (Smith et al., 2010), financial stressors (Montes & Halterman, 2008; Sharpe & Baker, 2007), and caring for others.

Challenges related to life planning. A variety of challenges and concerns arise for parents when planning for their child's future. Parents are responsible for ensuring that the quality of care for their adult child diagnosed with ASD continues after they are gone. This planning can be time intensive and emotionally draining for parents.

A major challenge for parents of adult children diagnosed with I/DDs is the limited options available. Dillenburger and McKerr (2011) found that many parents and caregivers of adults with I/DDs experienced a lack of support and respite care options. They found that 72% of participants had not made future long-term plans for their child with disabilities, while others worried about future planning. One parent stated, “Our biggest problem... is how long we are able to go on?” (p. 34). Their research illustrated a need for support in future planning for parents of adult children with disabilities, including autism.

Many parents also worried about the adequacy of residential options for their adult children with I/DDs. Dillenburger and McKerr (2009) asserted that parents of adults with I/DDs worried about poor care and possible abuse. Parents indicated that these concerns were major hindrances in planning for their child’s future. Some parents reported that living outside of the home was not an option, as they believed that proper care would not be delivered.

Parents’ fears often delay making tough decisions (Dillenburger & McKerr, 2009). Furthermore, a lack of adequate options suggests the need for the expansion of residential services and other living choices. Parents of adult children with I/DDs often fail to communicate care arrangements for their children, making it difficult for service providers to intervene when a major crisis occurs (Dillenburger & McKerr, 2009).

Variables in the Model

This section discusses each variable in the model of this study with regard to the existing relevant literature. The variables included in this section are as follows: caregiver burden, social support, perceived financial impact of caregiving, as well as QOL.

Caregiver Burden

For this study, caregiver burden was conceptualized as a composite of three domains: time dependence, developmental, and emotional burden. These three components of burden are discussed in the following sections.

Time dependence burden. Time dependence burden refers to a caregiver's burden due to restrictions of time (Novak & Guest, 1989). Due to the existing literature, which supports the notion that parents of individuals with ASD are impacted by this form of burden, time dependence burden is included in the overall composite of burden in this study. Parents of children with ASD have indicated caregiving to be burdensome and demanding of their time, many of which report caregiving as being a constant, 24-hour job (Altiere & von Kluge, 2009; Krauss et al., 2005). Since many individuals with ASD often remain reliant on a parent throughout adulthood there may be no finality to parents' role as a caregiver, adding to the stressors these parents experience (Krauss et al., 2005).

Many repercussions are associated with the demands of caring for an individual with ASD. For example, many parents reported that the amount of time devoted to caregiving diminishes the amount of time available for friends, family, and spouses, sometimes resulting in the loss of support. In addition, due to the amount of time associated with caring for their child, many parents also report feeling fatigued, having to miss work or pass up a promotion, and that they have lost their "normal" life due to the caregiving demands (Altiere & von Kluge, 2009; Cidav, Marcus, & Mandell, 2012; Montes & Halterman, 2008; Sharpe & Baker, 2007). Family supports were affected adversely as relationships were strained among extended family members. Myers, Mackintosh, Goin-Kochel (2009) stated that:

Parents told us that their children require a tremendous amount of time and energy and that this had changed life for everyone in the family. Some referred specifically to therapy. One mother wrote, "Our days consist of therapy, sensory integration, auditory treatments. PT, OT, and ST;" and another, "Our entire lives have been

devoted to him and his therapies-we do very little else.” Many listed how many therapies they juggled for their child, with therapists coming into the house or parents transporting the child to appointments. Other parents spoke of the time demands of everyday care: “My son needs constant supervision and care;” and from another, “She has to be supervised every minute of the day.” (p. 676).

Time dependence burden was included in the composite caregiver burden variable in this study.

Developmental burden. With regard to this study, the concept of developmental burden refers to the perception for parents of adult children with ASD to perceive not being aligned with other parents of an individual without disabilities. In previous studies, parents of individuals with ASD indicated that they miss their normal way of life and are described as “living in a world of their own” (Altiere & von Kluge, 2009; Woodgate, Ateah, & Secco, 2008). They experienced diminished availability to social support, which further contributed to their feelings of social isolation. Parents experienced isolation, due to feeling disconnected from family members, unsupported by the system, judged by society’s lack of understanding, and that they do not have a life (Altiere & von Kluge, 2009; Woodgate et al., 2008). Some parents reported adverse social effects (e.g., not having time for family and friends), less frequent involvement in activities and events, and feeling trapped due to parenting demands (Altiere & von Kluge, 2009; Krauss et al., 2005; Lee, Harrington, Louie, & Newschaffer, 2008). Developmental burden is included as one facet of burden to comprise a facet of the composite of caregiver burden.

Emotional burden. Emotional burden is the third domain included in the caregiver burden (composite) variable. Previous literature suggested that parents of individuals with ASD experienced a number of realities that impact what could be referred to as emotional burden, such as psychological distress and impacts on psychological health (Estes et al., 2009; Myers et al., 2009). Such impacts were substantial for some parents, resulting in depression and even suicidality among some parents of children with ASD (Myers et al., 2009). For example, mothers of children

with ASD were found to experience increased psychological distress even when compared with mothers of children with developmental disabilities (DDs; Estes et al., 2009). In addition, parents of children with ASD reported a number of adverse emotions, such as sadness, grief, depression, guilt, and blame, indicative of the presence of emotional burden (Myers et al., 2009). For some parents, the emotional burden seemed to be so significant that suicide was contemplated (Myers et al., 2009). This qualitative study provided a number of parent responses that strongly elucidated burden, such as “It is a great heartache for us and both my wife and I are fighting a constant battle with depression...” and “There is no pain like this one...” (p. 677). In the present study, perceived burdens impacting the emotional state of parents was suggested to impact QOL.

Burden related to caring. Using the National Survey of Children’s Health, Lee et al. (2008) analyzed cross-sectional parent reported data that examined parental concerns and QOL. Data from three groups of families with children (ages 3-17 years) were compared: autism, attention deficit disorder (ADD)/attention deficit hyperactive disorder (ADHD), and unaffected controls. When compared with the other two groups, parents of children with autism had significantly greater caring burden. Parents of children with autism also had significantly greater concerns (e.g. regarding their children’s achievement, self-esteem, stress-coping, etc.) than parents of unaffected children and parents of children with ADD/ADHD. According to Lee et al. (2008):

... families of children with autism reported a greater level of child caring burden, less frequent attendance to religious services, a greater likelihood to quit a job because of child care problems, more school days missed, more repeated grades, less participation in activities/events, and less involvement in community services, compared to families of children with ADD/ADHD or unaffected children. (p. 1155)

Results from this study indicated greater caring burden for parents of children with autism when compared with parents of children with ADD/ADHD and parents of children who were unaffected.

Burden related to stress. Parents of both young and adult children, diagnosed with ASD often experience stress associated with their parenting responsibilities. Estes et al. (2009) conducted a study comparing “the relative contribution of child characteristics including diagnosis, problem behavior, and adaptive functioning, to increased maternal parenting stress and psychological distress” (p. 377) among mothers of children with ASD and mothers of children with DDs. Parenting stress scores and psychological distress were higher for mothers of children with ASD than for mothers of children with DDs. Mothers of children with ASD also reported higher levels of problem behavior and lower daily living skills scores than the comparison group. A positive association was found between parenting stress and psychological distress with problem behaviors. Estes et al. (2009) indicated that this finding “provides evidence that higher levels of child problem behaviors are significantly related to increased maternal parenting stress and psychological distress for both mothers of children with ASD and children with developmental delay without autism,” (p. 383).

The degree of complexity and severity of a child’s disability often impacts stress level. Parental stress also may occur from the complexity of needs of adults with ASD. For example, individuals with ASD often face obstacles to obtain successful employment (Hendricks, 2010) and to be successful in academic settings after high school (Camarena & Sarigiani, 2009). As a result, individuals with ASD often face increased anxiety due to these challenges. Parental caregivers reported that anxiety of their adolescent child was a significant barrier to postsecondary success (Camarena & Sarigiani, 2009).

Burden related to parental health. With the physical, emotional, and socioeconomic complexities associated with having a child with ASD, parents often experience additional burdens, such as health and mental health problems. Many mothers of children diagnosed with

autism encounter multiple physical and psychological health issues, including depression, anxiety, high blood pressure, and weight changes (Altiere & von Kluge, 2009; Fletcher, Markoulakis, & Bryden, 2012). Furthermore, many parents worried about what the future holds for their child with ASD.

In another study, mothers of children with autism were found to have decreased mental, physical, and emotional health when compared with mothers of typically-developing children (Montes & Halterman, 2007). The mothers also reported difficulty in caring for their child with autism and coping with parenting demands.

Many parents of children with autism experience fatigue beyond what is normal for parents with typically-developing children. One study indicated that parents of a child with autism had less sleep and experienced poor quality of sleep when compared to parents of typically-developing children (Meltzer, 2008). Likewise, Fletcher et al. (2012) found that mothers reported excessive fatigue resulting from responsibilities associated with caring for their child diagnosed with ASD.

Burden related to marriage. Marriage can be particularly difficult for parents raising children with ASD compared to raising children with other I/DDs. One study found that mothers of children with autism had lower marital satisfaction than mothers of children with Down syndrome (Rodrigue, Morgan, & Geffken, 1990). Brobst et al. (2009) reported a negative relationship between parental stress and relationship satisfaction among couples with a child diagnosed with ASD. Relationship satisfaction was lower for couples with a child with ASD when compared to couples of normally developing children. Likewise, Fletcher et al. (2012) reported that parents experienced a range of challenges, including marital difficulties, strain, and decreased libido. One parent stated, "... I mean the toll it's taken on our marriage, I think the statistic is now 90% of marriages fail [cough] when Autism comes in. It's um a huge strain on the marriage"

(Fletcher et al., 2012, p. 62). Although the statistic quoted by this parent might not be accurate, it illustrated the degree of marital frustration that he/she experienced.

A recent study by Hartley, Barker, Baker, Seltzer, and Greenberg (2012) examined marital satisfaction across a 7-year period using a sample of 199 mothers with an adolescent or adult child diagnosed with ASD. Results indicated that closeness in mother-child relationships and household income were significant predictors of marital satisfaction. Having a second child with a disability did not have a significant effect on marital satisfaction. Behavior problems also negatively impacted mothers' marital satisfaction. "On average, on occasions when the grown child's behavior problems were higher, mothers' marital satisfaction was lower than it was at other points," (Hartley et al., 2012, p. 693). Marital satisfaction among mothers decreased during the 7-year period of this study. Statistically significant relationships were found in mothers' marital satisfaction and fluctuations in the behavior of their children diagnosed with ASD.

Another study by Hartley, Barker, Seltzer, Greenberg, and Floyd (2011) found an inverse relationship between marital satisfaction and parenting burden among parents of adolescents and adults with ASD. Specifically, parents who had lower levels of marital satisfaction were more likely to experience greater parenting burden. This study also indicated that the marital relationship was influential in helping parents deal with challenges associated with having an adolescent or adult child diagnosed with ASD.

Parenting-related stressors, such as behavior concerns, have been found to place a considerable amount of stress on the marital relationship of parents of individuals with ASD (Higgins, Bailey, & Pearce, 2005). Higgins et al. (2005) conducted a study using surveys to investigate family functioning and coping strategies among caregivers of children with ASD. Participants were comprised of both mothers (97%) and fathers (3%). A number of instruments

were used to measure family adaptability and cohesion, marital quality and marital happiness, self-esteem, and coping strategies among the primary caregiver. Based on this study's results, which illustrated that "the overall marital happiness rating for this group of primary caregivers ($M = 6.1$, $SD = 2.3$) was somewhat lower than the mean rating of 7.7 ($SD = 1.8$) obtained by the norm group of 407 married couples from four different states across America in the Norton (1983) study" (p. 131). Parents of a child with ASD had greater stress placed on their marriage because of their parenting roles (i.e., caring for a child with ASD) than parents of typically developing children (Higgins et al., 2005).

Social Support

Social support can either alleviate the number of challenges and stressors that parents of adult children with ASD experience or increase the anxiety and stress associated with caregiving. Olshevski, Katz, & Knight (1999) asserted that positive aspects of social support should be maximized, while negative social support should be minimized. The importance of social support, whether derived from a formal or informal network, for families with children with ASD, is documented in the literature (Altieri & von Kluge, 2009; Siklos & Kerns, 2006). The presence of social support can be associated with positive benefits for parents, such as diminished levels of stress and higher well-being (Boyd, 2002; Mendoza & Dickson, 2010). For many parents of a child with ASD, the tasks associated with parenting and the nature of this disorder make maintaining social support systems difficult. However, "many people who should be sources of support are, or are perceived to be, unhelpful and critical to the caregiver" (Olshevski et al., 1999, p. 11)

Gray (2003) studied coping strategies of 53 parents of children with autism and Asperger's syndrome. Using results of semistructured interviews, mothers were more likely than fathers to rely on friends and family to work through their emotions regarding having a child with autism.

The mothers indicated that support from friends was almost as important as support from family. They reported that having support from other mothers of children with autism was especially important

. . . because the mothers believed that they could more readily appreciate their problems. As one mother stated: We've cried on each other's shoulder. One of us will be having a bad time, there's usually one of us having, always one of us having a bad time. So we seem to take it in turns. And we can sit and talk to each other. You know, we can have a good cry. We can sit and laugh at the dreadful things [our children] do. We can really talk to each other. (Gray, 2003, p. 640)

Siklos and Kerns (2006) conducted a between-subjects comparison using two groups of parents, parents of children with ASD and Down Syndrome (DS). The study examined the perceptions of parents' needs and if their needs were being met using a modified version of the Child Version of the Family Needs Questionnaire. While the number of needs did not differ between the two groups of parents, the types of needs did. For example, parents in both groups indicated needing a break and needing help from other family members to take care of their child with ASD or DS. In addition, parents of children with ASD (59%) were more likely to indicate a need to discuss their feelings with parents who had a child with the same disorder than parents of children with DS (41%).

Altieri and von Kluge (2009) conducted a qualitative study with parents of a child with autism using semi-structured interviews. A number of themes emerged, including the loss of support. Results indicated that parents had less time for their loved ones (e.g., their family, friends, other children, and spouse) due to demands placed on them from parenting a child with autism. One father reported that he and his wife indicated that "you quickly find out that you don't have a life [while another stated that] we are never able to go out" (p. 146).

According to Seltzer, Floyd, Song, Greenberg, and Hong (2011), parents who are entering old age and have a child with an I/DD living with them are likely to experience less social support

than those who have a child who lives away from home. They visit less frequently with friends or relatives and are less likely to have a close personal friend who can provide social support. Yoong and Koritsas (2012) found that parents who were providing care for an adult with ID were less likely to have time to spend with friends and relatives.

Smith, Greenberg, and Seltzer (2012) investigated the quantity and quality of social support among 269 mothers of adolescents and adults with ASD over an 18-month time period. Social support was reported to influence changes in maternal well-being. The findings indicated that the number of people in the mothers' social support networks and the quality of the support (e.g., negative) were predictive of the extent of psychological well-being for the mothers in the study. Mothers who had more people in their social networks typically had fewer depressive symptoms and improved psychological well-being over time. Mothers who perceived negative social support were more likely to have higher levels of depressive symptoms and poorer psychological well-being.

Using three groups of mothers (children with autism, children with mental retardation, and normally developing children), Weiss (2002) examined the effects of social support and hardiness on mothers' level of stress. Mothers of children with autism were found to experience more negative effects of stress when compared to mothers of children with mental retardation and mothers of normally developing children. Esteem-boosting friendships and perceived social support from one's spouse were associated with positive benefits. Results of this study indicated the benefits of social support in aiding mothers' adaptation to stress.

Woodgate et al. (2008) conducted a qualitative study to understand the experiences of parents of children with autism. Results indicated that parents experienced social isolation resulting from four main sources, including: (a) parents feeling disconnected from their family, (b)

the “system” was unsupportive, (c) they missed their “normal” way of life, and (d) society lacked understanding of their child’s condition. The authors indicated that these sources of social isolation were derived mainly from external sources. Although social support had many positive benefits for parents of children with ASD, this disorder may have unique components that could isolate parents and hinder them from receiving the necessary support from which they could benefit.

Perceived Financial Impact of Caregiving

Parental caregivers of individuals with disabilities, specifically ASD, face unique financial costs that often adversely impact their financial circumstances (e.g., Altieri & von Kluge, 2009; Fletcher et al., 2012; Parish, Rose, & Swaine, 2010).

Finances. Literature provides evidence of the financial vulnerability for many parents of children with DDs (Altieri & von Kluge, 2009; Fletcher et al., 2012; Green, 2007; Parish et al., 2010); however, specific circumstances may affect finances for parents of children with autism. At or prior to diagnosis, many parents allocate additional money to care for their child with autism. Empirical evidence supports the notion that costly evaluations and treatments often are not reimbursed by insurance companies (Altieri & von Kluge, 2009; Sharpe & Baker, 2007). Altieri and von Kluge (2009) found that many middle class families with a child diagnosed with autism experienced financial consequences due to lost income and “out of pocket” expenses, such as evaluations and treatments.

The additional costs associated with caregiving can impact the extent to which parents experience caregiver burden. Cadman et al. (2012) conducted an observational study examining caregiver burden among 192 families of individuals from 14 to 24 years of age who were diagnosed with ASD or ADHD. This study deliberately investigated burden among families of adolescents or young adults as research regarding significant costs and burdens for this population have

focused on families of young children (Cadman et al., 2012). Results indicated that caregiver burden was associated with both disorders; however, caregivers of individuals with ASD experienced significantly greater burden than those with ADHD. Caregiver burden could be predicted from the presence of psychiatric comorbidities for parents of children with ASD, but not for parents of children with ADHD.

Caring for a child with ASD places considerable financial challenges on the whole family. Lost wages due to a number of reasons and the cost of specialized treatment can add to the many burdens associated with parenting a child with ASD. A number of studies provided support regarding the financial implications and challenges experienced by parents raising a child with ASD (Altiere & von Kluge, 2009; Fletcher et al., 2012; Green, 2007; Parish et al., 2010; Sharpe & Baker, 2007). Using the 2002-2008 Medical Expenditure Panel Survey, Cidav et al. (2012) investigated labor force participation, hours of work, and annual earnings of parents of children with ASD. Three groups were used for this study: parents of children with ASD, parents of children with other health concerns, and parents of children with no health limitations. Mothers of children with ASD in this study were less likely to be working when compared with mothers of children with no health limitations. Results indicated that weekly hours of work differed among the groups. “In an adjusted analysis, mothers of children with no health limitations work an average of 7 hours more per week than mothers of children with ASD” (Cidav et al., 2012, p. 621). Parental earnings also differed among mothers of children with no health limitations who were making more than mothers of children with ASD. However, differences in paternal earnings between fathers of children with no health limitations and fathers of children with ASD were not statistically significant. Parents of children with other health concerns were similar to the parents of children with ASD.

Research indicated that early intervention often is beneficial, especially for young children with autism (Green et al., 2010; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Remington et al., 2007). Many parents spend money on the most current interventions, diets, therapies, resources, and care. These expenditures do not end at the early intervention phase, but continue throughout childhood and into adulthood (Sharpe & Baker, 2007). As such, parents caring for children with ASD were faced with a number of financial challenges and realities.

The costs associated with treatment and care had major lifestyle implications for parents caring for a child with autism. Sharpe and Baker's (2007) findings suggested that overall family financial strain affected day-to-day living. Such challenges included living paycheck to paycheck and feeling the need to obtain a second job. Additionally, the loss of career was described as a major life disruption that had profound financial implications. To compound day-to-day financial concerns, some findings indicated potential difficulties for future financial security. Sharpe and Baker (2007) described how many families "shifted the value placed on the future... from saver to spender in response to autism's demands" (p. 259). For example, multiple participants discussed the need to cash out investments and retirement funds to pay for therapy and treatment. Some participants described their diminished ability to save and plan for the future, while others expressed the reality of bankruptcy due to the growth of personal debt. Some parents reported that they put the needs of their child with autism before the welfare of their family. These examples are a few of the financial realities that parents faced while raising a child diagnosed with ASD. Whether financial concerns were perceived to influence day-to-day realities or future financial prognosis, the authors described parents' comments as eliciting feelings of "deep frustration, fear, and desperation" (Sharpe & Baker, 2007, p. 259).

Montes and Halterman (2008) echoed many of the findings of Sharpe and Baker (2007). Their findings indicated that families with a child with ASD had a diminished probability of having a higher household income than parents with a child with another disability. Specifically, their results found that families with a child with ASD had an average income loss of \$6,200 annually, while families with a child with another disability experienced approximately \$1,100 loss. Overall, the treatments and cost expenditures, along with the changes in lifestyle associated with caring for a child with autism, were unique when compared to typically developing children.

Treatment and health care costs. Parents of a child with autism accrue considerable treatment and health care costs compared to those who are raising a typically-developing child. According to Sharpe and Baker (2007), behavioral interventions, speech and language therapy, neurosensory therapies, and biochemical interventions were the four main categories of autism treatment. Many of these treatments are not covered by insurance or through special education, requiring some families to pay for these needed treatments. The costs associated with such treatments could place financial burdens on families.

Three studies examined some additional costs of treatment and care for a child diagnosed with ASD. Sharpe and Baker (2007) explored the effect of caring for a child with autism on parental employment and financial status. More than half of the respondents indicated the presence of financial problems. These financial problems primarily resulted from out-of-pocket expenses, including medical interventions, prescription and non-prescription drugs, and doctor or therapy services. Other parents described their frustrations battling insurance companies to pay for therapy, while another parent described limitations of good insurance policies that did not cover relevant treatments. Additionally, one parent noted that costs incurred from a child destroying windows and home interior were not covered by insurance.

Croen, Najjar, Ray, Lotspiech, and Bernal (2006) compared health care utilization and costs for children with and without ASD. Results demonstrated that children with ASD had more doctor visits and inpatient and outpatient hospitalizations than typically-developing children. These children had substantially more prescriptions (approximately 40%). Prescription drug costs were eight times higher for children with ASD (ages 5-18). After adjusting for age and gender, the average yearly cost of health care was three times greater for those with ASD. Health care utilization and costs were significantly higher for children with ASD, particularly those with psychiatric co-morbidities.

In a qualitative study, Fletcher et al. (2012) indicated that parents felt that specialized care and treatment were needed for their children with autism. One mother reported, “There are extra costs... you can’t just hire the teenager down the street to look after your kids when one of them’s got Autism,” (Fletcher et al., 2012, p. 52). Many families reported taking out loans or money from their retirement savings to pay for treatment. Furthermore, parents reported employment-related consequences. Some mothers quit their jobs to provide care, while others felt the need to continue working to pay for treatments. Due to the caregiving challenges, one mother switched to a lower paying, more flexible, and less stressful position.

For a parent of a child with autism, the financial challenges do not subside as that child reaches adulthood. Parents of adult children with I/DDs face financial costs for their adult child – even for adult children living outside of the home (Ghosh, Greenberg, & Seltzer, 2012). In later life, many older adults provide care for elderly parents, a spouse, and an adult child with I/DDs (Ghosh et al., 2012).

Quality of Life

The existence of a child with ASD presents challenges for their parents and families that may affect their QOL. QOL is a multi-faceted dimension/construct that is examined through the use of the World Health Organization – Quality of Life – BREF (1996) that examines four domains: physical health, psychological, social relationships, and environmental factors. Myers et al. (2009) reported on a qualitative study that provided perceptions related to these QOL domains from 493 parents of children with ASD. The intent of their study was to examine parents' life and their family's life using a web-based questionnaire. The findings presented in this article were part of a larger study, but this article solely and specifically indicated responses based on the following question: "How has your child on the autism spectrum affected your life and your family's life?" (p. 672). The themes that emerged were organized into five clusters, (a) stress, (b) child's behavior and demands of care and therapy, (c) impact on parents' personal wellbeing, work lives, and marital relationships, (d) impact on the family as a whole, including siblings and extended family, and (e) social isolation. Many responses indicated stress and/or strain that having a child with ASD had on the whole family, including the parents, marriage, siblings, and family relationship

. . . both within the family and with the outside world. . . . Most of these short responses expressed distress: "ruined it;" "what life, dismal future [I'm] so unhappy;" "stressful, my son has required my undivided attention for the past 19 years;" "It has made our life very stressful and difficult; . . . financial challenges and limited activities. (p. 673).

Despite the many negative responses to this question, a few responses indicated positive effects, such as "he is a blessing! A gift from god! Helps everyone in our home spiritually!" (p. 673). Other responses to this question indicated mixed messages regarding both difficulties and gains. For example, one respondent stated, "Has put some stress on us, but has made us better because of it..." (p. 673).

Four negative and two positive themes emerged with regard to the child's behavior and demands of care and therapy. Parents expressed difficulty dealing with their child's behavior problems. For example, some parents reported that their child escaped regularly, got into things that he or she should not have, or exhibited violent behaviors. Many parents indicated that their child required constant care and supervision. Other themes that emerged included parents experiencing time demands due to the required care and therapy, sleep problems and exhaustion, as well as challenges with their child's school and other services.

In another study, Higgins et al. (2005) illustrated that parents reported difficulties in engaging in normal and spontaneous activities or even going out in general. In addition, many parents perceived that their community had little understanding of ASD, making life more challenging. In addition, parents specified that it was difficult to engage in normal and spontaneous activities or even go out in general.

Although most research findings focused on challenges and stressors associated with raising a child with autism, Myers et al. (2009) has indicated some degree of parental benefits. For example, parents of children with ASD discussed a number of benefits, including feeling joy, as well as developing patience, tolerance, and compassion (Myers et al., 2009). Many parents asserted that they understood disabilities better and felt enriched and blessed by their child. A common theme among parents was that they fully appreciated and accepted their child. Many parents also described positive elements related to their marriage, spiritual life, and benefits to the family as a whole. One mother reported numerous benefits of having a child with ASD

My son has so enriched my life that it is unbelievable. I have learned so much about living life fully, about God and the nature of man, about love. It hasn't been easy all the time, but I would not trade the experience for anything. I think regular kids are boring. You don't have to try to read their minds, expressions or mannerisms. I love him better than life itself. (Myers et al., 2009, p. 674)

Altiere and von Kluge (2009) reported parents of children diagnosed with ASD described family benefits, such as increased support from extended family and bringing the family together through adversity. Many parents expressed happiness from witnessing child improvements and spending time with their child. Results also indicated that parents had a greater appreciation for life, were less likely to take situations for granted, and felt humbled by their experiences. These parents illustrated increased levels of patience, a greater understanding for others and better coping mechanisms because of their experiences. Many parents developed new friendships through autism-related activities.

Increased spirituality was noted among parents of children with autism (Altiere & von Kluge, 2009; Meyers et al., 2009; Phelps, Hodgson et al., 2009). In one study, mothers who reported higher spirituality as a result of raising their children with autism also indicated other benefits related to self-esteem, positive affect, well-being, and life satisfaction (Ekas, Whitman, & Shivers, 2009). Higher levels of spirituality were associated with less parenting stress among mothers in this study.

Effects of Caregiving on Quality of Life

Previous research showed that caregiving for individuals with disabilities, including those with ASD, could have both positive and negative effects on parents' QOL. QOL is a multifaceted construct that has been found to have several indicators, including social well-being, physical well-being, psychological well-being, spiritual well-being, cognitive well-being, and environmental well-being (Kelley-Gillespie, 2009). Each of these indicators can be linked with caregiver burden, caregiver reaction, and social support for parents of adults diagnosed with ASD.

Caregiver burden among parents of children with severe illnesses was negatively related to parents' QOL (Salvador, Crespo, Martins, Santos, & Canavarro, 2014). Salvador et al. asserted

that the relationship between the parents' perceptions of the severity of the illness and their QOL was mediated by caregiver burden. The results showed that when children were undergoing treatment, the parents' burden of care was greater and their QOL decreased.

Health was related to QOL, with individuals who had better physical and mental health reporting higher levels of QOL. According to Lee et al. (2009), a comparison of parents of children with high functioning ASD (HFASD) and those whose children functioned normally provided evidence of the positive relationship between health and QOL. Parents of children with HFASD were more likely to have higher QOL if they perceived less stress and depression in their lives.

A study on the relationship between marital satisfaction and caregiver burden associated with having an adolescent or adult child with ASD found that marital satisfaction was an important predictor of parenting experiences (Hartley et al., 2011). The relationship was stronger for fathers when compared to mothers. Marital satisfaction was considered to be related to QOL, with Yoong and Koritsas (2012) finding that parents who were happy in their marriages had better QOL.

Caregiver reaction generally has been understood to assess the ways in which caring affects the lives of caregivers, specifically their reaction or response to providing care. Given et al. (1993) further described caregiver reaction, the manner in which caregivers' lives were affected, in the following domains: impact on schedule, caregiver's esteem, lack of family support, impact on health, and impact on finances. In a study, Given et al. (1993) examined the effect of these domains on caregiver reactions in the lives of caregivers of cancer patients. They found that caregiver reactions in terms of effects on health, scheduling, and mental health were related to depression in both the caregiver and the patient. The researchers concluded that caregiver reactions had an adverse effect on the lives of the caregivers. Lack of time for leisure activities was a source of caregiver reactions that negatively affected QOL (Yoong & Koritsas, 2012). Lack of time for

leisure activities was associated with the unavailability of respite care for the adults with ID. Caregiving also had a negative effect on the employability of the parent of a child with ID. Some parents had to quit their jobs to provide full-time care for their child, although they wanted to work. Other caregiver reactions that negatively influenced QOL included fighting for services for their adult child with ID, financial burdens, and concerns about their child's future. However, Yoong and Koritsas (2012) suggested that positive reactions to caregiving (personal satisfaction) could buffer the negative effects of providing care on the parents' QOL.

Relationship between Perceived Financial Impact (of Caregiving) and QOL

This dissertation sought to examine if a relationship exists between the perceived financial impact (of caregiving) and QOL among parents of adult children with ASD. For example, Myers et al. (2009), using a qualitative research design, reported that adverse financial realities affected family QOL among families having a child with ASD. For example, financial strain was indicated as a negative theme related to its influence on the family as a whole. Because research suggested the existence of a relationship between financial impact of caregiving for children with ASD and QOL among parents, this study anticipated this association.

According to Myers et al. (2009), parents completed a question on a survey, "How has your child in the autism spectrum affected your life and your family's life?" (p. 673). The largest number of parents had a negative tone when completing a short paragraph to answer this question, indicating that having a child with ASD had a negative effect on the parents' and family's QOL. One parent's response emphasized the strain of having to quit her job due to the inability to find childcare. Lee et al. further indicated that socioeconomic status may have an influence on health, as parents with higher income levels could afford health care for themselves, in addition to the health care that their children required. The existence of financial demands impacting parental

QOL has been suggested through a number of studies. This dissertation suggests the existence of this relationship, specifically among parents of adult children with ASD.

Relationship between Caregiver Burden and QOL

Research has suggested the existence of a relationship between caregiver burden and QOL among parents of children with ASD. This study expects to validate this association among parents of adult children with ASD. A study examined QOL among parents of children with autism, ADD/ADHD, and a typical control group (Lee et al., 2008). Parents' perceptions of their concerns for their children were assessed on five domains, including self-esteem, achievement, learning difficulty, stress-coping, and being bullied. Results indicated that caregiver burden was significantly higher among parents of children with autism when compared with the two comparison groups. Parents of children with autism had a greater number of parental concerns in all five domains than the other two groups. "Overall, families of children with autism reported a greater level of child caring burden, less frequent attendance of religious services, a greater likelihood to quit a job because of child care problems, more school days missed, more repeated grades, less participation in activities/events, and less involvement in community services, compared to families of children with ADD/ADHD or unaffected children" (p. 1155). These results illustrated that parents of children with autism experienced diminished QOL when compared with the other two groups of parents.

Mugno, Ruta, D'Arrigo, and Mazzone (2007) conducted a study investigating QOL among 212 parents of children and adolescents with pervasive developmental disorder (PDD), mental retardation (MR), or cerebral palsy (CP), as well as 77 parents of healthy children. When compared with parents of children diagnosed with MR or CP, parents of children with PDDs exhibited

significantly decreased QOL. The differences between MR, CP, and the control group were nonsignificant.

A number of studies illustrate the presence of burden among parents of individuals with ASD, when compared to parents of typically developing children and even parents of children with other DDs (e.g., Camarena & Sarigiani, 2009; Estes et al., 2009; Lee et al., 2008; Rodrigue et al., 1990). The relationship between caregiver burden and QOL specifically has been made in the literature. A body of literature has documented the presence of burden among caregivers, including parents of children and adults with I/DDs, such as ASD (Lee et al., 2008). Research found an inverse relationship between caregiver burden and QOL. For example, a variety of international studies found relationships among caregiver burden and QOL, such as caregivers of stroke patients from Japan, Brazil, and the United Kingdom, Swedish outpatients with schizophrenia, children with autism, veterans, children and adolescents with PDD-NOS, young children with bronchopulmonary dysplasia, patients with rheumatoid arthritis, and elderly with impairments (Brouwer et al., 2004; Feeley et al., 2014; Foldemo, Gullberg, Ek, & Bogren, 2005; Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999; Lee et al., 2008; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Morimoto, Schreiner, & Asano, 2003; Mugno et al., 2007). For example, Morimoto et al. (2003) examined caregiver burden and health-related QOL among family caregivers of Japanese stroke survivors. Results suggested that caregivers of stroke victims who experienced increased burden tended to have decreased QOL related to their health. McCullagh et al. (2005) investigated caregiver burden on QOL among informal caregivers of stroke patients using a randomized control trial. The researchers reported that caregiver burden was negatively related to caregiver QOL, with burden increasing with the age of both the caregiver and care recipient.

Although a relationship between caregiver burden and QOL is indicated in the literature, this relationship has not been explored among parents of adult children with ASD. Research found that parents of children with ASD experience stressors associated with constant caregiving and feeling that they will never experience a sense of relief from their parenting and caregiving responsibilities (Altiere & Kluge, 2009; Krauss et al., 2005), which likely may result in caregiver burden that adversely impacts parental QOL. Although research indicated that much of the burden among parents of individuals with ASD resulted from constant caregiving (Altiere & Kluge, 2009; Krauss et al., 2005), no published studies specifically focused on burden and QOL among this parent population. Due to the lifelong burden that many parental caregivers experience, it is likely that a relationship exists between burden and QOL for parents of adult children with ASD. Due to a gap in the literature and salience of this topic, this dissertation explores if a relationship exists between caregiver burden and QOL among parents of adult children with ASD.

Formal Social Support as a Moderator between Caregiver Burden and QOL

The use and effects of formal social support for caregivers of a variety of care recipients are documented in the literature (Chen & Greenberg, 2004; Ryan et al., 2010). A number of studies support the role of social support among parents and families of children with disabilities, including those with ASD (e.g., Bromley, Hare, Davison, & Emerson, 2004; Mendoza & Dickson, 2010; Siklos & Kerns, 2006; Smith et al., 2012; Woodgate et al., 2008). The use of formal social support as a moderator between caregiver burden and QOL among parents of adult children with ASD has not been explored in the literature.

Although the existing literature does not explicitly examine if social support moderates the relationship between caregiver burden and QOL, it does provide evidence that social support has been a moderating variable between similar variables (Demirtepe-Saygili & Bozo, 2011). These

researchers conducted a study examining if perceived social support acted as a moderator for the relationship between caregiver well-being indicators and psychological symptoms among 100 caregivers of children with leukemia. Findings illustrated positive benefits of perceived social support as participants “were more able to satisfy their basic needs and who were more able to perform their daily activities reported lower levels of psychological symptoms if they perceived higher levels of social support” (p. 1095).

In the present study, formal social support is investigated as a moderator of the relationship between caregiver burden and QOL. Formal social support is expected to moderate the relationship between these two variables because there is a considerable amount of literature exhibiting social support as a buffer in these types of relationships. The Stress-Buffering Hypothesis justifies this relationship (Helgeson, 2003). A few studies investigated formal social support among parents of children with disabilities that indicated the importance of community and formal supports for parents of children with disabilities (Poston et al., 2003; Samuel, Hobden, & LeRoy, 2011).

Samuel et al. (2011) conducted a mixed methods study investigating community interactions using a family quality of life (FQoL) framework. The sample included 149 primary caregivers (92% mothers) of children with disabilities in the state of Michigan. Families in this study most commonly reported having a child with autism as their disability. The majority of participants (92%) were low income (\leq \$40,000) and of minority status (73%). Six dimensions of community interaction were assessed, including importance, opportunities, initiative, attainment, stability, and satisfaction. Most participants deemed that their community interaction was very important to their FQoL, with 62% of primary caregivers reporting satisfaction with their community interaction.

When asked about opportunities for community interaction, fewer than 50% reported involvement in these types of activities. “Families of children with autism reported that they had slightly fewer opportunities for community interaction than the other families, but the difference was not statistically significant” (Samuel et al., 2011, p. 65).

Findings reported by Samuel et al. (2011) indicated that families participated in four main types of activities: (a) religious involvement, (b) disability related activities, (c) social clubs, as well as (d) schools and other voluntary activities. Nearly 35% of respondents indicated they had participated in at least one of these four types of community activities, with 16% indicating involvement in at least two types of activities, and 3% in 3 or more types of community activities. The authors found that 40% of parents were taking a great deal or quite a bit of initiative to connect with community interactions.

Based on findings by Samuel et al. (2011), families with children diagnosed with ASD who were involved in their communities had high levels of FQoL. The present study anticipates that parents who have more formal social support might also experience a better QOL than parents whose formal social support is lacking.

Poston et al. (2003) conducted a qualitative study examining QOL among 187 family members of children both with and without a disability, individuals with a disability, service providers, and school administrators using individual and focus group interviews. Ten domains of family QOL were categorized as having either an individual or a family orientation. Individually-oriented domains included advocacy, emotional well-being, health, physical environment, productivity, and social well-being. Family-oriented domains included daily family life, family interaction, financial well-being, and parenting. “Across all domains, our analysis indicates that the concerns of parents of children with disabilities were more intense and generally more frequent

than the concerns expressed by parents of children without disabilities” (p. 321). When responses among parents of children with disabilities were compared with those from parents of children without disabilities, the largest discrepancy of responses was in the domain of advocacy. Although both parent groups reported that they advocated on behalf of their children, parents of children with disabilities used much stronger phraseology. For example, one parent stated, “It’s a fight, it is a battle to get anything you need for exceptional children. You fight the teacher, you fight the principal, and you fight the superintendent. It’s very frustrating to do all those battles” (p. 322). Social well-being, categorized as an individual domain of family QOL, was described as influencing both the parent and the child with a disability more adversely than parents and children without disabilities. The degree and intensity of issues experienced by families of children with disabilities surpassed those experienced by families of children without disabilities. Findings illustrated that social acceptance greatly differed between the two groups of families. In addition, families of children with disabilities indicated negative experiences and major concerns regarding their child’s acceptance. These family members also described how their children’s disabilities affected their own friendships. For example, parents asserted that their friends experienced discomfort related to their child’s disability. “Families of children with disabilities talked about needing more support to enable them to do things together as a family or to participate *in* activities with other children” (p. 324).

As previously mentioned, research specified the role of formal social support among parents of individuals with disabilities, including ASD. Bromley et al. (2004) interviewed 68 mothers of children with ASD to investigate a range of factors related to psychological well-being. Results found a number of areas of useful formal supports and areas of need. For example, many respondents reported that professional support (40%) and the school personnel (72%) were helpful,

very helpful, or extremely helpful. The mothers shared that professional support was not available (29%), not at all helpful (4%), or only sometimes helpful (28%). Although literature showed the importance of formal social supports and unmet needs associated with formal social supports, no specific published literature documented if formal social support served as a moderator in the relationship between caregiver burden and QOL. Formal social supports appear to play an important role in the lives of parents of adult children with ASD. This dissertation seeks to determine if formal social supports moderate the relationship between caregiver burden and QOL among this parent group.

Informal Social Support as a Moderator between Caregiver Burden and QOL

In the present study, informal social support is examined as a moderator of the relationship between caregiver burden and QOL. Informal social support is expected to moderate the relationship between these two variables as a body of literature supported that informal social support served as a buffer in these types of relationships (Costa, Sa, & Calheiros, 2012). Informal social supports played an integral role in the lives of parents of individuals with ASD, with interviews among mothers of children with ASD indicating a number of sources of support (Bromley et al., 2004). Mothers rated sources and helpfulness of a number of supports. Findings indicated that a number of supports were reported to be “generally helpful, very helpful or extremely helpful,” including those provided by their parents (35%), partner’s parents (20%), relatives (24%), partner’s relatives (17%), partner (69%), friends (32%), partner’s friends (12%), own children (49%), as well as other parents with autistic children (27%).

A number of other studies indicated the importance of informal social support for parents of individuals with ASD (e.g., Altieri & von Kluge, 2009; Gray, 2003; Siklos & Kerns, 2006; Weiss, 2002; Woodgate et al., 2008). Earlier, this paper noted examples pertaining to the

importance of informal social support. Specifically, mothers of children with autism and Asperger's syndrome were found to rely on friends and family to deal with their emotions surrounding having a child with a disability (Gray, 2003). In another study, parents discussed their need for a break and help from family members to watch their child with a disability (Siklos & Kerns, 2006). This study also illustrated that parents of children with ASD had a high need to discuss their feelings with parents of a child with this same disorder. Weiss (2002) found that perceived social support provided by spouses of mothers of children with various disabilities, including autism, aided in their adaptation to stress. Although no published literature supports the role of informal social support as a moderator of the relationship between caregiver burden and QOL, informal social support may serve as a moderator between caregiver burden and QOL among parents of adult children with ASD. This dissertation examines whether informal social support moderates the relationship between caregiver burden and QOL among this parent population.

Conclusion

This chapter presented research on challenges associated with caregiving for parents of individuals with ASD. Specifically these caregiving realities were discussed, including comorbidity with other physical and mental health conditions, constancy of caregiving, challenges associated with ASD behaviors, challenges of caregiving beyond the typical child rearing, and challenges related to life planning. A model for the study was developed based on literature related to caregiver burden, formal and informal social support, perceived financial impact of caregiving, and QOL. The literature on the effects of relationships between these variables, along with the moderating effects of formal and informal social support on the relationships between caregiver burden and QOL was discussed.

Research attempts were made to understand the experiences, realities, and stressors of parents of young children diagnosed with ASD. Fewer studies were found that investigated the realities of parents with adult children. With regard to adolescents and adults diagnosed with ASD, studies focused on: the trajectory of emotional well-being of mothers, the impact of residential settings on adult children, the mother-child relationship, symptoms of ASD during this phase, and the transition and change for adults and its impact on maternal well-being.

Despite the plethora of information available about parenting realities for those raising a young child with ASD, little is known about these parents in older adulthood who are caring for grown children with ASD. Current gaps in the literature exist with regard to the stressors and experiences of parents with grown children. The factors experienced by older caregivers of this population are yet to be studied and understood. The paucity of literature related to parents of adult children with ASD illustrates a need for research as this population continues to increase and require specialized services. The present study sought to explore the experiences of caregivers, specifically QOL. This information could be used to provide an understanding that can be used by social workers, public health practitioners, policy makers, and program developers.

CHAPTER 3 THEORETICAL FRAMEWORK

Research investigated caregivers' experiences with a wide variety of populations. Stress plays a role in the day-to-day activities for parents providing care for their adult children with disabilities, specifically autism spectrum disorder (ASD). Stress is noted in the literature as a reality for parental caregivers of adults with disabilities. Several different theoretical frameworks were used to investigate stress among a continuum of populations giving care, however, for purposes for this study one framework appears to provide the best lens for examining the experiences of this population. The use of Lazarus and Folkman's stress and coping framework provides a means to investigate the quality of life (QOL) of parents of adult children with ASD. This theory offers a framework for examining QOL, experiences, and circumstances among parental caregivers of adult children diagnosed with ASD.

Stress

Stress was first described by Selye (Viner, 1999) as a physiological and psychobiological reaction to a demand that is threatening or challenging. Stress could be either positive (eustress) or negative (distress). Positive stress can lead to growth and improved ability to perform a task, while negative stress can be destructive to the human body. Parents of adult children with ASD are exposed to challenging demands on a regular basis. These demands could have an accumulative effect on the emotional and physical health of the parents. While the types of demands may be variable, the parent needs to learn to cope and assess the stressor to reduce the long-term effects of stress.

Stress and Coping Model

The stress and coping theory was developed by Lazarus and Folkman (1984). They defined psychological stress as "a relationship between the person and the resources that is appraised by

the person as taxing or exceeding his or her resources and endangering his or her well-being” (p. 19). This definition extended Seyle’s assertion that stress was a singular response to a demand (Hobfoll, 1988). For purposes of this study, the stress and coping theory was used to examine parental experiences of providing caring for adult children diagnosed with ASD. Both appraisal and coping are important components of this theory (Lazarus & Folkman, 1984).

Definition of stress and coping.

To understand this stress and coping theory, the terms, stress, appraisal, and coping, need to be defined. However, these words have many definitions that need to be considered.

Stress. Reaching consensus on the definition of *stress* within the research community is difficult (Monat & Lazarus, 1985). Similar to the multi-faceted nature that must be considered when defining the term *stress*, many layers must be considered when investigating stressors among any population, including parental caregivers. For example, most aging parental caregivers have a long history of parenting a child diagnosed with ASD. They have unique stressors that may continue to evolve related to their own aging process. Stress for this population might change during their aging process, and could continue to be multi-faceted. The work of Seyle and Wolff should be considered in understanding the nature of stress. Seyle used the term, stress, in a technical way referring to an “orchestrated set of bodily defenses against any form of noxious stimulus” (Lazarus & Folkman, 1984, p. 2). Wolff’s work considered the notion that stress can be viewed as a “dynamic state.” For purposes of this paper, *stress* refers to the “relationship between the person and the environment, which takes into account characteristics of the person on one hand, and the nature of the environmental event on the other” (Lazarus & Folkman, 1984, p. 21).

According to Lazarus and Folkman (1984), stress consists of many variables and processes. Stress among parents, especially in the context of their own aging, is both multi-faceted and

complex. Stress can have both positive and negative influences on QOL. According to Lazarus and Cohen (as cited by Lazarus and Folkman, 1984), the three types of stressors are: (a) major life changes, (b) major changes affecting one or a few persons, and (c) daily hassles. These three types of stressors and their corresponding realities can affect parents of adult children with ASD.

While examining the stressful influence of caregiving is important, other stressors also should be considered. Chiriboga, Weiler, and Nielsen (1990) argued that other stressors beyond those specific to caregiving should be examined as general stressors that influence caregivers' well-being. In fact, the culmination of life stressors, such as work and family obligations, can impact caregivers' overall stress. Therefore, considering stress and coping in all areas of caregivers' lives is important.

Appraisal. Appraisal is important when looking at parental experiences. Appraisal refers to how one perceives a situation or experience (Olshevski, Katz, & Knight, 1999). Considering an individual's appraisal of a situation is important when looking at caregiver stress (Olshevski et al., 1999). For example, some caregivers report positive effects of caregiving while others report the opposite for similar situations. Appraisal, such as primary, secondary, cognitive appraisal, and reappraisal, can be influenced by many situational factors.

Primary appraisal. Lazarus and Folkman (1984) outlined three types of primary appraisal, including irrelevant, benign-positive, and stressful. When people are not invested in something or do not care about the outcome, they may experience an irrelevant primary appraisal. With this form of appraisal, the person is not invested because "nothing is to be lost or gained in the transaction" (Lazarus & Folkman, 1984, p. 32). Benign-positive appraisals exist when a person views an outcome as favorable. With this type of appraisal, positive emotions, such as joy, result. Conversely, stress appraisals are characterized as any of the following: "harm/loss, threat, and

challenge” (p. 32). For example, stress appraisals, related to harm or loss, may include a diminished sense of social or self-esteem. In this example, some form of emotional damage may take place. Having an adult child with ASD, could result in stress appraisals related to harm or loss.

When parents discover their child has a diagnosis of ASD, the outcomes can be life-altering and traumatic (Altiere & von Kluge, 2009; Hutton & Caron, 2005). In one study, many parents indicated that devastation was a major emotion when their child was diagnosed with autism (Altiere & von Kluge, 2009). Despair, sadness, denial, confusion, and anger were experienced consistently among all families in the study (Altiere & von Kluge, 2009). Likewise, for parents of adults with disabilities, worrying about the future could result in stress appraisals (Dillenburger & McKerr, 2011). Stress appraisals also can be threatening, with this form of appraisal occurring when an event has not taken place, but is expected to happen (Lazarus & Folkman, 1984). For parents of an adult with ASD, the future often is of great concern (Dillenburger & McKerr, 2011) and may present substantial threats. The benefit of threats that may take place is that they are anticipated, giving people warnings of concerns to work through (Lazarus & Folkman, 1984). Parents can plan for and work toward solutions prior to the likely event. For example, parents, in anticipating the future, may establish a special needs trust, obtain durable medical power of attorney, and/or create guardianships to protect their adult child with ASD (Sharpe & Baker, 2007).

The last type of the stress appraisal, *challenge*, is similar to a threat. Challenge requires efforts to help a person cope (Lazarus & Folkman, 1984). However, differences exist between threats and challenges. According to Lazarus and Folkman:

The main difference is that challenge appraisals focus on the potential for gain or growth inherent in an encounter and they are characterized by pleasurable emotions... whereas threat centers on the potential harms and is characterized by negative emotions such as fear. (p. 33)

Many day-to-day tasks associated with having an adult child diagnosed with ASD may be challenging, but not threatening. Challenges and threats can occur simultaneously. The difference between a person considering something to be threatening versus challenging is appraisal based on their “cognitive component [and] affective component” (p. 33). A person’s judgment (e.g., “potential harm or loss versus mastery or gain”) and types of emotions (e.g., “negative versus positive emotions”) are important factors. According to Lazarus and Folkman (1984), “Challenge, as opposed to threat, has important implications for adaptation” (p. 34). These authors asserted that morale may be better among challenged people, rather than people who are threatened, because people who are challenged are likely to have positive feelings about demanding circumstances.

Secondary appraisal. Secondary appraisal occurs when people experience difficulty and seek to manage a situation (Lazarus & Folkman, 1984). “Secondary appraisal activity is a crucial feature of every stressful encounter because the outcome depends on what, if anything, can be done, as well as what is at stake” (p. 35). According to the authors, secondary appraisal is not an intellectual exercise, but a “process that takes into account which coping options are available, the likelihood that a given coping option will accomplish what it is supposed to, and the likelihood that one can apply a particular strategy or set of strategies effectively” (p. 35).

Cognitive appraisal. According to Lazarus and Folkman (1984), the term “cognitive appraisal” refers to the process where the meaning of a particular occurrence is evaluated with regard to its personal significance. When caregivers find meaning in a stressful life event, unpleasant outcomes of a negative event can be minimized (Park & Folkman, 1997). Cognitive appraisal is important when examining the experiences of parental caregivers and their ability to cope with their adult children diagnosed with ASD. Empirical support exists for the importance of

cognitive appraisal for parents of children with ASD (Altiere & von Kluge, 2009). “It is clear that social support is beneficial for these families, but cognitive appraisal of their situation is also integral to coping” (Altiere & von Kluge, 2009, p. 142).

Reappraisal. Reappraisal is an important concept related to how a person thinks about stress. When people reconsider how they view a situation, they integrate new information to their previous thoughts and beliefs. Over the course of raising a child, parents may reconsider previous notions. Likewise, parents raising a child or adult diagnosed with ASD may change or reappraise previous notions as they find and integrate new information into their beliefs.

Defensive reappraisal is a specific type of reappraisal that “consists of any effort made to reinterpret the past more positively, or to deal with present harms and threats by viewing them in less damaging and/or threatening ways” (Lazarus & Folkman, 1984, p. 38). Defensive reappraisal is a coping mechanism and subsumed under the auspices of cognitive coping (Lazarus & Folkman, 1984). Parents of a child or adult diagnosed with ASD could benefit from many opportunities to use defensive reappraisals in coping with life and parenting stressors.

Coping

While the word “cope” has a wide range of meanings, professionals are reaching consensus on this term’s meaning (Monat & Lazarus, 1985). The term “coping” was defined as “efforts to master conditions of harm, threat, or challenge when a routine or automatic response is not readily available” (Monat & Lazarus, 1985, p. 5). Monat and Lazarus (1985) recommended that for a person to cope, environmental demands must be paired with behavioral solutions, or old solutions must be adjusted to account for current stressors. As such, coping can be viewed as process-oriented, with adjustments made to accommodate constantly changing demands and challenges (Lazarus & Folkman, 1984).

The stress and coping theory capitalizes on the importance of one's ability to cope with life's stressors. Lazarus and Folkman (1984) proposed two forms of coping, problem-focused and emotion-focused coping. Problem-focused coping accounts for attempts to enhance the problematic person-environment relationship by altering conditions (Monat & Lazarus, 1985). Among parental caregivers of adult children with ASD, *problem-focused* coping mechanisms may include seeking information by working with specialists, creating and implementing a behavior plan to diminish a child's problem behavior, and learning how best to parent a child with this disorder. Parents need to plan for their children's lives when they are no longer able to provide care (Bromley, Hare, Davison, & Emerson, 2004).

While seeking information is considered problem-focused coping, emotion-focused coping is employed to alleviate the distressing influence of stress by using thoughts and actions (Monat & Lazarus, 1985). Emotion-focused coping also is referred to as palliative coping. Emotion-focused coping may result in parental caregivers denying, being detached or distanced from the situation, or ignoring their current realities (Monat & Lazarus, 1985). Aging parental caregivers have unique circumstances, such as personal health complications, dealing with nearing the end of their own lives, and/or having an adult child diagnosed with ASD that could affect their use of emotion-focused coping further.

Overall, the ability to cope with caring for an adult child diagnosed with ASD, as well as coping with the other realities of life in the context of aging, may be greatly influenced by their ability to adapt to life's stressors. Gaining insight into the lives of parental caregivers regarding available resources, supports, and services is needed to help manage stress associated with parenting an adult child diagnosed with ASD.

Hypotheses and Theoretical Linkages

Relationship between perceived financial impact (of caregiving) and QOL

This study seeks to examine whether there is a relationship between the impact of finances and QOL among parents of adult children with ASD. A number of studies indicated the adverse impact of finances among parents of children with ASD (e.g., Altieri & von Kluge, 2009; Cadman et al., 2012; Fletcher, Markoulakis, & Bryden, 2012; Green, 2007). For example, these parents often experience extra and unique costs, such as expensive treatments, evaluations, and increased health care costs, as well as having to forego work opportunities and experience lost wages, as a result of caring for a child with ASD (Cidav, Marcus, & Mandell, 2012; Fletcher et al., 2012; Montes & Halterman, 2008). All of these factors can negatively impact family finances (Fletcher et al., 2012; Montes & Halterman, 2008).

It is likely that these financial challenges impact parents as these families have a greater likelihood to experience poverty (Lee, Harrington, Louie, Newschaffer, 2008) and financial strain affecting their day-to-day living (Sharpe & Baker, 2007). Because of the documented role of the adverse impact of finances on parents due to additional costs associated with caring for a child with ASD and additional demands that result in the loss of wages and the occurrence for parents to report tremendous financial strain, an expected relationship is anticipated. The impact of finances posed many challenges for parents that were found to affect their lives adversely. Therefore, a relationship was expected between the impact of finances and QOL for parents of adult children with ASD.

The Lazarus and Folkman's stress and coping framework can be used to examine whether finances impact QOL for parents of adult children with ASD. Due to the demanding financial realities of parenting a child with ASD, it is likely that these parents will experience greater financial challenges. Should a parent appraise his financial situation to be challenging, meaning financial liabilities exceed what he or she feels capable of (or exceed one's current financial

resources) and compromise financial security, stress may result when lacking effective coping mechanisms. As such, the presence of appraised financial challenges may impact QOL. Figure 1 (shown below) represents the conceptual model.

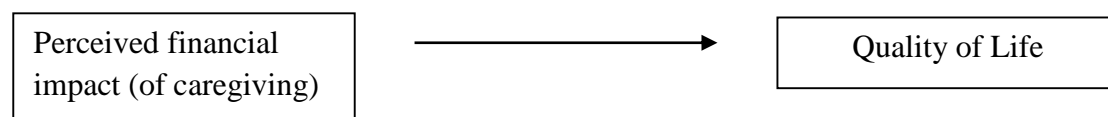


Figure 1. Conceptual model of relationship of perceived financial impact (of caregiving) and QOL

This figure represents the conceptual model indicating a relationship between perceived financial impact (of caregiving) (as the independent variable) on QOL (as the dependent variable). It was hypothesized that a parental caregiver's perceived financial impact of caregiving would impact his or her QOL.

H₀₁: There is not a relationship between perceived financial impact and QOL among parental caregivers of adult children with ASD.

H_{a1}: There is a relationship between perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD.

Relationship between Caregiver Burden and QOL

Due to the lifelong burden that many parental caregivers experience, it is likely that a relationship exists between caregiver burden and QOL for parents of adult children with ASD. Research has indicated an inverse relationship between caregiver burden and QOL. For example, a variety of international studies have found relationships among caregiver burden and QOL, such as caregivers of stroke patients from Japan, Brazil, and the United Kingdom, Swedish outpatients with schizophrenia, children with autism, veterans, children and adolescents with PDD-NOS, young children with bronchopulmonary dysplasia, patients with rheumatoid arthritis, and the elderly with impairments (Brouwer et al., 2004; Feeley et al., 2014; Foldemo, Gullberg, Ek, & Bogren, 2005; Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999; Lee et al., 2008;

McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Morimoto, Schreiner, & Asano, 2003; Mugno, Ruta, D'Arrigo, & Mazzone, 2007). For example, Morimoto et al. (2003) examined caregiver burden and health-related QOL among family caregivers of Japanese stroke survivors. Results suggested that caregivers of stroke victims who experienced increased burden tended to have decreased QOL related to their health. McCullagh et al. (2005) investigated caregiver burden on QOL among informal caregivers of stroke patients using a randomized control trial. The researchers found that caregiver burden was negatively related to caregiver QOL, with burden increasing with the age of both the caregiver and care recipient.

Although literature indicated a relationship between caregiver burden and QOL, this relationship has not been explored among parents of adult children with ASD. Research showed that parents of children with ASD experience stressors associated with constant caregiving and feeling that they will never experience a sense of relief from their parenting and caregiving responsibilities (Altiere & Kluge, 2009; Krauss, Seltzer, & Jacobson, 2005). This likely may result in caregiver burden that adversely impacts parental QOL.

Domains of Caregiver Burden

Caregiver burden, in this study, includes a composite of three domains of burden: time dependence, developmental, and emotional burden. It was expected that these three domains of burden, as a composite, would impact the QOL for parents of adult children with ASD. This expected relationship between caregiver burden, as a composite of these three burden domains, and QOL also was supported by Lazarus and Folkman's stress and coping framework.

Time dependence burden.

As it aligns with the work of Lazarus and Folkman's stress and coping framework, this study is constructed on the notion that time dependence burden likely plays a critical role in the lives of parents of adult children with ASD. Stress appears to result from the incongruity between the amount of time parents have versus what they need to perform their day-to-day needs and obligations. Time can be viewed as a resource—a resource that is lacking when compared with the daily demands in the parental caregiver's life. In this case, the definition of stress by Lazarus and Folkman (1984) as being a “relationship between the person (parent of an adult child with ASD) and the resources (time) that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p. 19) appears to embody the experiences for many in this parent population. While there is evidence to suggest that parents engage in a number of coping mechanisms, for some the demands exceed what many are capable of handling without adversely affecting their lives. Studies exist that provide support for the adverse impact of the caregiving demands on parents' lives, making it difficult to cope (Montes & Halterman, 2007). For example, many parents report missing events, diminished involvement in the community, and a higher probability of quitting a job to care for their child (Lee et al., 2008).

Developmental burden.

Likewise, this study postulates that developmental burden also plays a role in a parent's overall caregiver burden and its impact on QOL for parents of adult children with ASD. In a number of studies, parents have illustrated perceptions aligning with the notion that they are not in-line with other parents of an individual without disabilities. In fact, parents of individuals with ASD have described their experiences as "living in a world of their own" and missing their normal way of life (Altiere & von Kluge, 2009; Woodgate, Ateah, & Secco, 2008). These experiences are connected to diminished availability of social support, which further perpetuates to their feelings of isolation. It is deemed that developmental burden is critical when considering the relationship between caregiver burden and QOL. This relationship can be examined using Lazarus and Folkman's theoretical framework. For parents who feel that they are not in-line with their peers, they may experience developmental burden and detrimental impacts to their lives. For this population, it is indicated that the presence of social support is helpful. However, this population experiences feelings of social isolation and a loss of social support due to their developmental burdens, which may diminish their ability to cope.

Lazarus and Folkman's framework considers the importance of coping indicating that social support can be an effective coping mechanism to deal with life stressors. A loss of support, which is probable for parents experiencing developmental burden, could diminish parents' ability to cope with the demands in their lives. Because parents of adult children with ASD experience significant developmental burdens, this inhibits them from receiving the social support they need and from which they would benefit (Altiere & von Kluge, 2009; Woodgate et al., 2008). As a result, it was likely that parents who experience developmental burden, with a byproduct of increased feelings of social isolation, would likely experience decreased QOL.

Emotional burden.

Emotional burden, included as a domain in the overall caregiver burden variable, is expected to play a role in the overall caregiver burden for parents of adult children with ASD. According to the literature, parents of individuals with ASD experienced a number of challenges that influence what could be referred to as emotional burden, such as psychological distress and other impacts on psychological health (Estes et al., 2009; Myers, Mackintosh, Goin-Kochel., 2009). As noted earlier in this dissertation, parents of children with ASD experienced a number of adverse emotional realities, including grief, sadness, guilt, and blame (Myers et al., 2009). In such studies, perceived burdens experienced by parents of individuals with ASD appeared to affect the emotional state of parents and their overall QOL.

Lazarus and Folkman's stress and coping model serves as a viable framework when considering the impact of the role of emotional burden on QOL for parents of adult children with ASD. This model is posited on the understanding that when perceived resources outweigh what is available, an individual's well-being is endangered and may likely be impacted. For example, when a parent appraises that her resources to care for her child are insubstantial, emotional burden may ensue without the proper coping mechanisms in place. Due to the tremendously difficult circumstances that many parents experience, this framework accounts for the opportunity for emotional burdens to manifest and also considers the role of coping to adjust to and deal with the burdens in a parent's life.

Relationship between Caregiver Burden and QOL

It was hypothesized that caregiver burden, comprised of time dependence, developmental, and emotional burden, would impact QOL among parents of adult children with ASD. Figure 2 (shown below) presents the conceptual model.

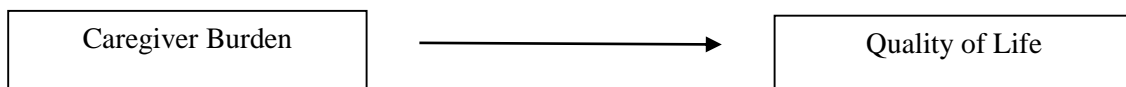


Figure 2. Conceptual model of relationship of caregiver burden and QOL

This figure represents the conceptual model indicating a relationship between caregiver burden (as the independent variable) on QOL (as the dependent variable). It was hypothesized that a parental caregiver's caregiver burden would impact his or her QOL.

H₀₂: There is not a relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H_{a2}: There is a relationship between emotional burden and QOL among parental caregivers of adult children with ASD.

Relationship between Living Arrangement and QOL

A relationship between living arrangement of the adult child with ASD and QOL of the parental caregiver is expected. Research highlighted benefits for parents of children that live outside of the home, as well as research that indicated parental strain among parents of children with ASD that co-reside with their families. For example, a number of benefits are available for mothers of children with ASD that live outside of the families' home (Krauss et al., 2005). Mothers whose children lived outside of the home reported less fatigue, more freedom, and more free time than mothers of children that lived within the families' home. Because co-residing with the family is associated with putting strain on the mother, it is likely that this type of living arrangement can adversely affect QOL for parents. Along this same line, in another study, Krauss et al. (2005) reported both benefits and struggles (e.g. stress and restriction on one's lives) for parents of adult children with ASD that live in the families' home. Parents in this study, with adult children living outside of the home, indicated decreased overall stress. A relationship between living arrangements and QOL among parental caregivers of adult children with ASD was suggested by

the decrease in overall stress reported among parents that have adult children living outside of the home (Krauss et al., 2005).

Lazarus and Folkman's stress and coping model serves as a framework for examining the relationship between living arrangement of adult children with ASD and their parents' QOL. There is literature illustrating a "push/pull" relationship with regard to living arrangement—meaning parents of children with ASD often experience both positives and negatives despite the living arrangement of their child. As such, it is indicated that parents experience a number of complex factors associated with living arrangement despite living inside the home or in another residence (Krauss et al., 2005). Despite positives and negatives, the literature indicated some benefits with regard to diminished stress levels for parents of adult children living outside of the home. It is likely that an external living arrangement (away from the family's home) serves as a coping mechanism for parents and helps to diminish many of the day-to-day stressors, such as stressors associated with behavioral challenges or providing physical care. Individuals with ASD often require a tremendous amount of routine and structure. Older parents who co-reside or have major involvement in their children's lives indicated that their own lives become regimented in their attempt to address their child's need for routine (Hines, Balandin, & Togher, 2014). In addition, feeling needed to provide around the clock care can be exhausting for parents—especially as parents age themselves. Although there are challenges and negative aspects of having an adult child in a residential facility or another placement, this form of living arrangement may help parents cope with the multitude of demands and also may shield parents from a number of stressors that would have existed should the living arrangement for their adult child be different. This relationship is shown in Figure 3.

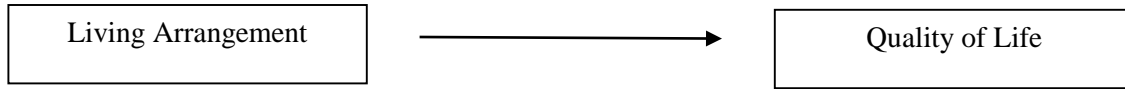


Figure 3. Conceptual model of relationship of living arrangement and QOL

This figure represents the conceptual model indicating a relationship between living arrangements (as the independent variable) on QOL (as the dependent variable). It was hypothesized that an adult child's living arrangement would impact his or her QOL.

H₀₃: There is not a relationship between living arrangement and QOL among parental caregivers of adult children with ASD.

H_{a3}: There is a relationship between emotional burden and QOL among parental caregivers of adult children with ASD.

Formal Social Support as a Moderator between Caregiver Burden and QOL

It was anticipated that formal social support could serve as a moderator between caregiver burden and QOL among parents of adult children with ASD. A number of studies suggested that formal social support is helpful in reducing stress levels, increasing feelings of perceived support, and serving as a coping mechanism for parental caregivers (Krauss, Upshur, Shonkoff, & Hauser-Cram, 1993; Luther, Canham, & Cureton, 2005). In addition, types of formal social support, such as community interaction, were found to be relevant to QOL. As previously noted, formal social supports were analyzed in a study examining community interaction among parents of children with autism and developmental disabilities (DDs). It is relevant to note that community interaction is not specifically referred to as a formal social support; however, this construct embodies many of the social support activities that are formal in nature (e.g. through the school, religious organization, etc.). Community interaction was indicated by primary caregivers of children with disabilities to be important to their QOL (Samuel, Hobden, LeRoy, 2011), which could be an instrumental coping mechanism that is discussed later in this section.

Literature suggested that battling formal supports, such as the school system, could be very stressful for parents. For example, many parents indicated the need to advocate for their child and experienced tremendous frustration when they encountered the need to advocate for their child (Poston et al, 2003). Although there is literature that suggested that formal social supports are helpful in mitigating stress for parents, it is important to consider whether or not a support is appraised to be helpful or detrimental. For example, some parents may interpret the school system to be very helpful, while others may consider it to be difficult to navigate. It is likely that the presence of benign-positive appraisals of formal social supports, rather than stressful appraisals, could play a role in the type of impact of QOL.

The role of formal social support was examined through Folkman and Lazarus' stress and coping framework. This framework is used as a model for considering the impact of formal social supports, such as community supports, as a resource to help parents cope and diminish their stress levels. This theory specifically suggested that supports might help enhance one's "well-being" and therefore positively affect QOL. For example, it is likely that formal social support, such as assistance from community organizations, could diminish parental caregivers' stressors and enhance QOL. By having an organization in which a parent could rely for help with things, such as respite care services, informational support, and financial support, stress may be greatly alleviated. For example, Factor, Perry, and Freeman (1990) reported that respite care might help mothers of children with autism cope more successfully. In addition, involvement with the community, community interaction, and use of community supports could serve as coping mechanisms for parents. Specifically, by being involved in support groups, parents might be engaged in using problem-focused and emotion-focused coping mechanisms. The presence of respite care and other resources and supports generated from community interaction (examples of

formal social support), could moderate the relationship between the burden parents experience and their overall QOL, making it more reasonable for them to maintain their day-to-day obligations with the right formal supports in place. This relationship is shown in Figure 4.

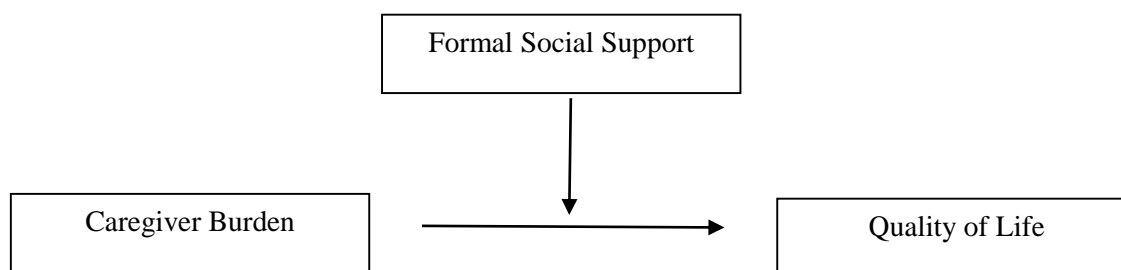


Figure 4. Conceptual model of formal social support as a moderator between caregiver burden and QOL

This figure represents the conceptual model indicating formal social support serving as a moderator between caregiver burden and QOL. It was hypothesized that formal social support could moderate the relationship between caregiver burden and QOL.

H₀₄: Formal social support does not moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H_{a4}: Formal social support moderates the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

Informal Social Support as a Moderator between Caregiver Burden and QOL

It was expected that informal social support could serve as a moderator, buffering the impact of caregiver burden on QOL, for parents of adult children with ASD. Little published literature exists to support the role of informal social support as a moderator of the relationship between caregiver burden and QOL among parents of adults with ASD. However, such a relationship is suggested by studies focusing on social support as a moderator of the relationship between the impact of autism severity on sibling adjustment among siblings of children with autism (Hastings, 2003), as well as between the effect of stress on life satisfaction and specific

behavioral variables among mothers of premature and full-term infants (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983). Because of the role of informal social support on parents' ability to manage their emotions, stress levels, and to obtain needed information (Altiere & von Kluge, 2009; Gray, 2003), the presence of positive informal social support was anticipated to impact parents of adult children with ASD favorably. As indicated, a number of studies documented that parents caring for a child with a disability rely on family members to help with their child with a disability (e.g., Bishop, Richler, Cain, & Lord, 2007; Gray, 2003; Siklos & Kerns, 2006).

The majority of studies on the topic of informal social support were conducted with parents of individuals with disabilities, typically those under 18. For example, literature indicated the importance of friends (Murphy, Christian, Caplin, & Young, 2007) and other forms of social support (Bishop et al., 2007) in reducing stress and negative impacts for parents of children with disabilities. In addition, a number of studies highlighted the importance of informal social support specifically for parents of individuals with ASD (e.g., Altieri & von Kluge, 2009; Gray, 2003; Siklos & Kerns, 2006; Weiss, 2002; Woodgate et al., 2008). For example, mothers relied on friends and family to deal with their emotions of having a child with autism or Asperger's syndrome (Gray, 2003). Parents expressed their need for a break, help from family members in caring for their child with a disability, and need to talk with other parents with similar challenges (Siklos & Kerns, 2006). Weiss (2002) in a study conducted among three groups of parents, those of children with mental retardation, autism, and no disability, found that perceived social support provided by spouses aided in parents' adaptation to stress. Informal social support was successful in reducing stress among mothers of children with disabilities, ASD, and IDs (Bishop et al., 2007; Bromley et al., 2004; Hassall, Rose, & McDonald, 2005; Murphy et al., 2007).

Lazarus and Folkman's (1984) stress and coping theory serves as the theoretical basis for this moderating relationship, the role of informal social support as a moderator between caregiver burden and QOL. According to Monat and Lazarus (1985), for a person to cope, environmental demands must be paired with behavioral solutions, or old solutions must be adjusted to account for current stressors. The presence of informal social supports may serve as a mechanism to adjust to the current stressors by allowing parents to receive a break from caregiving or an ear to hear their frustrations or offer advice. In turn, the presence of informal social support may enhance one's QOL by moderating this relationship. This suggests that the presence of informal social support likely serves as a coping mechanism for parents in adapting to life's stressors. For these parents, informal social support may provide them with the opportunity to engage in both problem-focused coping (e.g. having someone to watch their child when they need a break or to go to a function) and emotion-focused coping (e.g. having an individual listen to the frustrations of their day) to diminish their feelings of burden. The relationship between caregiver burden and QOL, as moderated by informal social support, is shown in Figure 5.

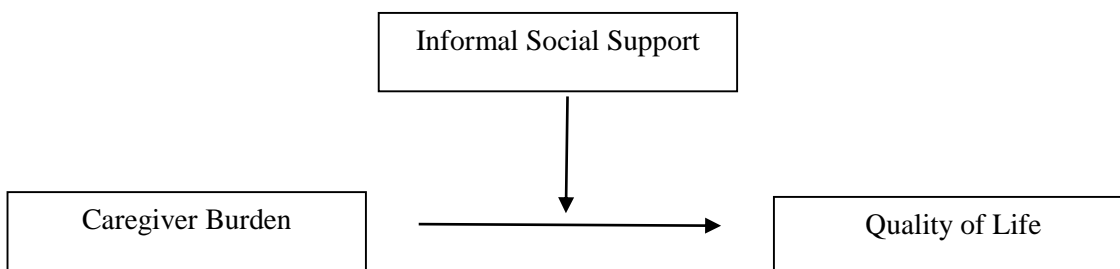


Figure 5. Conceptual model of informal social support as a moderator between caregiver burden and QOL

This figure represents the conceptual model indicating informal social support serving as a moderator between caregiver burden and QOL. It was hypothesized that informal social support would moderate the relationship between caregiver burden and QOL.

H₀₅: Informal social support does not moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H_{a5}: Informal social support moderates the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

Conclusion

This chapter discussed the stress and coping theory as a framework for investigating the experiences of parents with adult children with ASD. The stress and coping theory capitalized on the importance of one's ability to cope with life's stressors. The use of this theory provided an in-depth, theoretical explanation that was used to research QOL among this caregiving population.

When acknowledging the construct of social support, using the stress and coping theory is relevant. In looking at a parent's social network, it was an important reality that social support and navigating resources might be a source of stress for parents. For example, social support could be perceived as either an inhibitor or a promoter of stress. However, when using the stress and coping framework, considering perceptions or one's appraisal of the level of helpfulness or detriment, availability of, and access to, resources and supports was important. If these resources and supports were perceived as helpful, they could diminish one's stress level. Conversely, these resources and supports could heighten one's level of stress if they were difficult to obtain, not helpful, or even further adding to the stress in one's life. Therefore, considering parents' cognitive appraisals of supports and resources could enhance their QOL.

The literature indicated the presence of stressors for parents of children with DDs and documented greater challenges for parents of children diagnosed with ASD. These stressors could have a profound impact on the QOL of parents of adult children with ASD, as the task of parenting is not completed when their children reach adulthood. Parenting an adult child with ASD could alter the QOL of parents who are progressing through the aging process. As stress is a dynamic

state, the relationship between the person and the environment is particularly important (Lazarus & Folkman, 1984).

After reviewing a number of theoretical frameworks, the stress and coping theory was used to provide the strongest theoretical framework. Ultimately, this theoretical framework offered a basis to investigate experiences of parents of adult children with ASD, including their appraisal of stressors and coping mechanisms as it influenced their QOL.

CHAPTER 4 METHODOLOGY

Chapter 4 discusses the research methodology of this proposed study. This chapter begins with a summary of problems and then the need for this area of study. Research questions are then specified. The study design, sampling, sample participants, data collection procedures, instruments, and data analysis plan are discussed.

Restatement of the Purpose

There is a gap in the literature regarding the experiences of parents of adult children with autism spectrum disorder (ASD). Very little research has been done to investigate quality of life (QOL) among this parent population. The purpose of this study was to examine the effects of having an adult child diagnosed with ASD on older parents' QOL. Caregiver burden; a composite of developmental burden, emotional burden, and time dependence burden; impact on finances; living arrangements of the adult children with ASD; as well as formal and informal social supports were assessed as possible predictors of QOL.

Research Design

A nonexperimental, quantitative, correlational research design was used for this study. This type of research design was appropriate as the independent variables were not manipulated and no intervention or treatment was provided to the participants. The primary data collection was accomplished with the use of five survey instruments: Caregiver Burden Inventory (CBI; Novak & Guest, 1989), Caregiver Reaction Assessment (CRA; Given et al., 1992), The ENRICH Social Support Instrument (Mitchell et al., 2003), World Health Organization Quality of Life – BREF (WHO-QOL-BREF, 1996), and a short researcher-developed demographic survey.

Correlational research designs are used when the researcher is attempting to study the relationships among variables at a specific point in time. Although the findings could indicate the

existence and size of a relationship, the researcher cannot attach cause and effect to the findings (Gay, Mills, & Airasian, 2013).

Research Questions and Hypotheses

The following research questions and hypotheses were addressed in this study:

1. What is the relationship between the perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD?

H₀₁: There is not a relationship between perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD.

H_{a1}: There is a relationship between perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD.

2. What is the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?

H₀₂: There is not a relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H_{a2}: There is a relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

3. What is the relationship between living arrangement and QOL among parental caregivers of adult children with ASD?

H₀₃: There is not a relationship between living arrangement and QOL among parental caregivers of adult children with ASD.

H_{a3}: There is a relationship between living arrangement and QOL among parental caregivers of adult children with ASD.

4. Does formal social support moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?

H₀₄: Formal social support does not moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H_{a4}: Formal social support moderates the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

5. Does informal social support moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?

H₀₅: Informal social support does not moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H_{a5}: Informal social support moderates the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

Variables and Measures

The variables for this study are described in the subsections below. Each variable and the manner in which the variable is studied are described. The researcher included demographic questions to obtain information for the following variables: parent characteristics, adult child with ASD characteristics, formal social support, informal social support, and living arrangement of adult child with ASD in Table 1.

Table 1

Variables in the Study

Variable Category	Variable	Measurement
Quality of life	Physical health	World Health Organization – Quality of Life BREF
Parent Characteristics	Age Gender Ethnicity Marital Status Employment Status Educational level Annual family income Number of children in household Number of children with disabilities Number of children with ASD Parent self-reported health	Age of parent participant in years Gender of parent participant Ethnicity of parent participant Marital status as reported by parent Employment status of parent participant Highest degree of parent participant Annual family income in dollars Number of children in home Number of children with disabilities Number of children diagnosed ASD Health as reported by parent participant
Child with ASD Characteristics	Age Gender Work/school/workshop status Communication ability Behavior Peer relations Ability to perform activities of daily living	Age of child with ASD in years Gender of child with ASD Educational or employment status As reported by parent participant As reported by parent participant As reported by parent participant Assessed by rating independence level
Social Support	Social support –Formal	Type of support received based on parent report Satisfaction with support received as reported by parent participant

Variable Category	Variable	Measurement
	Social support –Informal	Social Support Index (ENRICH Scale) Type of support received based on parent report Satisfaction with support as reported by parent participant
Caregiver burden	Measured as a composite of the three sub-domains: Time dependence burden Developmental burden Emotional burden	Time dependence burden is measured by using the Caregiver Burden Inventory Developmental burden is measured by using the Caregiver Burden Inventory Emotional burden is measured by using the Caregiver Burden Inventory
Financial impact	Impact on finance	Caregiver Reaction Assessment
Living arrangement	Living arrangement of the adult child with ASD	Living arrangement of child as reported by parent participant

Variables

The variables for this study are described in the subsections below. Each variable and the manner in which the variable is studied are described. The researcher included demographic questions to obtain information for the following variables: parent characteristics, adult child with ASD characteristics, formal social support, informal social support, and living arrangement of adult child with ASD.

Quality of life. QOL is measured by the WHOQOL-BREF. The WHOQOL-100 measures 24 facets of QOL. Because the instrument with 100 items was considered too lengthy for use in research studies with other surveys or questionnaires, the World Health Organization created a short form of the WHOQOL-100, the WHOQOL-BREF. Twenty-six items were included on the WHOQOL-BREF. One item was retained from each of the 24 facets comprising the WHOQOL-100 to assess four dimensions of QOL: physical health, psychological, social relationships, and environmental. Two items from the overall QOL and general health facets of the WHOQOL-100 were included on the survey. For purposes of this study, the “psychological” domain was included

in the web-based survey. This domain included 6 items. Table 2 summarizes the “psychological” domains.

Table 2

WHOQOL-BREF Domain

Domain	Facets included within domains
Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality/Religion/Personal beliefs Thinking, learning, memory, and concentration

Note: Adapted from WHOQOL-BREF: Introduction, Administration, Scoring, and Generic Version of the Instrument, Field Trial Version, December 1996. All rights reserved by the World Health Organization (WHO), Geneva, Switzerland.

Participants were asked to rate the items on the WHOQOL-BREF using a 5-point Likert-type scale. The ratings vary depending on the specific items or dimensions. For example, the first two questions ask about life in the past two weeks and are rated using a 5-point scale ranging from 1 for not at all to 5 for completely. A 5-point scale ranging from 1 for very poor to 5 for very good is used to rate the next item, while the fourth item is rated using a scale that ranges from 1 for very dissatisfied to 5 for very satisfied. The rest of the items are rated in the same way, with changes in scaling explained at the beginning of each section.

Scoring. The researcher scored the dimensions using the protocol developed by the WHO. Specific items were recorded prior to scoring, with mean scores from each domain. Mean scores reflect the original 5-point scaling, with higher scores indicating greater QOL. Table 3 presents the scoring protocol for the “psychological” domain subscale from the WHOQOL-BREF.

Table 3

Scoring Protocol for WHOQOL-BREF

Domain	Items Included on Domain	Cronbach α^{**}
Psychological	5, 6, 7, 11, 19, 26*	.74

* Reverse coded items

** Trompenaars, Masthoff, VanHeck, Hodiamont, & DeVries, 2005

Reliability. White (2010) tested the WHOQOL-BREF with a sample of 142 African American patients diagnosed with heart failure. The alpha coefficients ranged from .73 to .82, with an alpha coefficient of .94 for the total score. According to Miller, Chan, Ferrin, Lin, & Chan (2008), the obtained Cronbach alpha coefficients for physical health on the WHOQOL-BREF ranged from .68 for social relationships to .82. The alpha coefficients for a Taiwanese sample ranged from .70 to .77 across the four domains (Yao & Wu, 2005). Yao and Wu also tested the stability of the WHOQOL-BREF, with test-retest reliability coefficients at 2-to 4-week intervals ranging from .76 to .80 for the four domains. Based on their findings, Yao and Wu asserted that the psychometric properties of WHOQOL-BREF were appropriate for use with a Taiwanese population and other cultures. These findings indicated that the WHOQOL-BREF was useful in measuring QOL among different ethnic groups.

Validity. Miller et al. (2008) used both exploratory and confirmatory factor analysis to determine the construct validity of the WHOQOL-BREF. Four domains, physical health, psychological, social relationships, and environment, emerged from the factor analysis explaining a statistically significant amount of variance in the WHOQOL-BREF. Intercorrelations between the domains on the WHOQOL-BREF and the WHOQOL-100 (the parent instrument) ranged from .89 for social relationships to .95 for physical health. Based on this finding, the WHOQOL-BREF appeared to have good convergent validity. Good discriminant validity was found on the WHOQOL-BREF. The test was able to differentiate QOL between healthy and ill patients. Based on these findings, the WHOQOL-BREF appears to be a valid measure of QOL.

Construct validity of the WHOQOL-BREF was confirmed by Dardas and Ahmad (2014) using both exploratory factor analysis and confirmatory factor analysis. The findings of their study, using 184 parents of children with ASD, supported the four dimensions of QOL (social relationship, psychological health, environment, and physical health) found in previous studies.

Parent characteristics. A number of parent characteristics were obtained using researcher-created questions. As shown in Table 1, age of the parent is measured in years. Gender, ethnicity, employment status, and marital status are measured as reported by parent participant on forced choice scales. Educational level is measured by highest level of schooling or degree obtained (e.g. “less than high school” to “doctorate / professional degree”) given a forced choice scale. The option for a narrative description is provided should a participant have further description information regarding his or her educational level. Annual family income is measured in dollars given dollar ranges using forced choice options. Based on parent report, information regarding the number of children in household, number of children with disabilities, and number of children with ASD is obtained using a forced-choice scale of “0” to “5 or more” to indicate the number of child(ren). Parent self-reported health is reported on a Likert scale.

Child with ASD characteristics. Characteristics of the child with ASD also are obtained using demographic questions on this survey. As shown in Table 1, age of the adult child with ASD is measured in years. Gender of adult child is measured as reported by parent participant on forced choice scale. Based on parent report, information regarding the employment status and educational status of the adult child with ASD is obtained using a forced choice scales. Communication ability, behavior, and peer relations of the adult child with ASD are assessed based on parent report using forced choice scales. The amount of support required by the adult child with ASD for activities of

daily living, such as dressing, are assessed using forced choice options ranging from total independence to need for total assistance.

Formal social support. Formal social support is assessed using researcher-created demographic questions from the survey. Formal social support includes paid supports (from the parent or others) and includes supports such as social work, counseling, speech therapy, and respite care as reported by the parent of an adult child with ASD. There are a total of 15 types of formal social supports asked and is measured as a count variable. The survey respondent has the option of indicating “yes” or “no” to whether or not each type of formal social support applies. In addition, respondents have the option to indicate (in text / as a narrative) any other types of formal social support that they receive.

Informal social support. Informal social support information is gathered through researcher-created demographic instrument and from a previously existing instrument, the ENRICHD scale. The researcher-created demographic instrument assesses informal social support indicated by availability of unpaid supports as reported by the parent. Specifically, this portion of the instrument examines supports such as respite care, physical assistance, financial assistance, and emotional support from a family member or friend. In addition, respondents have the option to indicate (in text / as a narrative) any other types of informal social support that they receive. For both informal and formal social support, the type of and satisfaction of the type of support is also obtained in the demographic portion of this study. The satisfaction of types of support is measured using a Likert scale ranging from “very dissatisfied” to “very satisfied.” Respondents have the option to indicate that a type of informal social support is “not applicable.”

Informal social support is measured by the Enhancing Recovery in Coronary Heart Disease (ENRICHD) Social Support Index (ESSI; Mitchell et al. 2003). The ENRICHD is a self-

administered survey with seven items that was used to “assess the availability of support from any network member plus a single item inquiring about the existence of a marital/partner” (Gottlieb & Bergen, 2010, p. 518). According to Sarason, Levine, Basham, and Sarason (1983), social support is the extent to which people who can be relied upon are available, with these people indicating that the adult diagnosed with ASD is cared about, valued, and loved. The ESSI was originally developed for use with cardiac patients who participated in the ENRICHD trial. However, the seven items on the ESSI are general questions about the availability of social support for people with a wide variety of issues.

Scoring. Participants were asked to respond to the items on the ESSI using a 5-point Likert-type response format, ranging from 1 for “none of the time” to 5 for “all of the time”. The seventh item (“Are you currently married or living with a partner?”) is answered yes or no. For the purpose of this study, this question was eliminated as this item is provided on the demographic questionnaire. The numeric responses for the six items were summed to obtain a total score that could range from 6 to 30. The total score was then be divided by 6 to create a mean score that reflected the original response unit. Higher scores indicated greater social support.

Reliability. The ESSI was tested for reliability using Cronbach alpha coefficients for the six items. Vaglio et al. (2004) reported an alpha coefficient of .88. A study of African American women provided a Cronbach alpha of .86 as a measure of internal consistency. Stability as a measure of reliability was assessed by comparing scores on the ESSI at 5 and 6 month intervals following percutaneous coronary intervention (Vaglio et al., 2004). The mean scores were compared using t-tests for dependent samples, with no difference found between scores at month 5 ($M = 27.8, SD = -1.4$) and month 6 ($M = 27.8, SD = -1.5$), $p = .98$.

Validity. Concurrent and predictive validity of the ESSi was assessed by Vaglio et al. (2004). They correlated the scores on the ESSi and the social functioning subscale and the Physical and Mental component scores on the SF-36 at start of the treatment and again at 6 months post treatment. A statistically significant, small correlation was found between the social functioning subscale and the ESSi ($r = .19, p = .002$). Statistically significant correlations were found between the scores both at baseline and 6-months post-PCI and subscales on the SF-36. These findings confirmed the concurrent and predictive validity of the ESSi as a measure of social support. The study found that depressed patients had significantly lower scores than nondepressed patients. Gottlieb and Bergen (2010) tested the ESSi for convergent validity by correlating ESSi scores with the Perceived Social Support Scale (PSSS). The resultant correlation of .62 provided support that the ESSi was measuring social support in a similar manner as the PSSS. However, the authors cautioned that the correlations were smaller for men ($r = .41$) and minorities ($r = .42$).

Caregiver burden. Caregiver burden is measured by the Caregiver Burden Inventory (CBI; Novak & Guest, 1989). The CBI is a multi-dimensional scale that measures caregivers' perceptions of burden associated with providing care for people with Alzheimer's disease (AD). Both objective burden and subjective burden concepts are included in Novak & Guest's (1989) questionnaire. The CBI includes 24-items that measures five subscales, (a) time dependence, (b) developmental, (c) physical, (d) social, and (e) emotional burden domains among caregivers. For purposes of this study, three of the five subscales are used, including those measuring time dependence, developmental, and emotional burden domains. Therefore, a total of 15-items are used from the CBI for this web-based survey. While the CBI was intended for use with caregivers of people with AD, the items are relevant for caregivers of individuals with other types of chronic

conditions, such as ASD. The researcher deems the CBI to be the most appropriate instrument available at this juncture.

Scoring. Participants were asked to rate items on the CBI using a 5-point Likert type scale, with responses ranging from 0 for “not at all descriptive” to 4 for “very descriptive”. The numeric ratings for each of the subscales were summed to obtain a total score, which then was divided by the number of items on the subscale to obtain a mean score. The use of a mean score allowed direct comparisons across the subscales and produced a score that reflected the original rating measure. Table 4 provides the subscales and items on each subscale, as well as the Cronbach alpha coefficients.

Table 4

Scoring Protocol for CBI

Domain	Scale Definition	Items Included on Domain	Cronbach α
1. Time dependence burden	Burden due to restrictions on the caregiver's time	1, 2, 3, 4, 5	.85
2. Developmental burden	Caregivers' feelings of being “off-time” in their development with respect to their peers	6, 7, 8, 9, 10	.85
3. Emotional burden	Caregivers' negative feelings toward their care receivers, which may result from the patient's unpredictable and often bizarre behavior	11, 12, 13, 14, 15	.77

Novak & Guest (1989)

Reliability. Novak and Guest (1989) tested the CBI for internal consistency as a measure of reliability. The results of their tests provided Cronbach alpha coefficients ranging from .73 for social burden to .86 for physical burden. Caserta, Lund, and Wright (1996) conducted a study using 160 primary caregivers. The results of their tests for internal consistency using Cronbach

alpha coefficients yielded similar results for time dependence (.85), development (.87), and emotional (.81).

Validity. The CBI was tested for content validity (Chou, Chu, Tseng, & Lu, 2003) and construct validity. According to Chou et al., the items on the scale were obtained from other caregiver burden instruments, which provided some assurances of the content validity. Novak and Guest (1989) used a principal components analysis with varimax rotation to test the CBI for construct validity. Five factors; time-dependence burden, developmental burden, physical burden, social burden, and emotional burden; emerged from the analysis accounting for 66% of the variance in caregiver burden. All of the factor loadings were above .50, providing support that the instrument had good construct validity.

Caregiver reaction. Caregiver reaction is measured by the Caregiver Reaction Assessment (CRA; Given et al., 1992). The CRA was used to determine the reactions of caregivers regarding the effects of providing care for their adult children diagnosed with ASD. The 24 items on the CRA measure five domains associated with caregiving: (a) caregiver's self-esteem, (b) lack of family support, (c) impact on finances, (d) impact on schedule, and (e) impact on health. Caregiver's self-esteem is used to assess positive aspects of caregiving, while the other four domains focus on negative outcomes of providing care. For purposes of this study, one subscale, impact on finances, was used to examine the impact of this domain on QOL among this parent population. This subscale includes three items from the CRA measure. The scale has been translated into several languages and used worldwide to examine caregivers' reactions to providing care for family and friends with a variety of chronic illnesses. For the purpose of the present study, one domain, impact on finances, was used. For purposes of this study, perceived financial impact (of caregiving) was assessed using the impact of finances subscale.

Scoring. The CRA enabled participants to respond based on a five-point Likert scale. The numeric responses for each item ranged from 1 to 5, with 1 indicating “strongly disagree” and 5 “strongly agree.” A mean score was obtained by summing the numeric responses and then dividing by the number of items on the domain. The mean scores then reflected the original 5-point scale. Higher scores indicated a stronger positive or negative influence on caregiving. A total sum score was not used as numerous dimensions were obtained from the use of the CRA. Table 5 presents the scoring protocol for the CRA.

Table 5

Scoring Protocol for CRA

Domain	Scale Definition	Items Included on Domain	Cronbach α
Impact on Finances	Measures the financial strain on the caregiver	1*, 2, 3	.62

*Reversed item

Nijboer, Triemstra, Tempelaar, Sanderman, and van den Bos (1999)

Reliability. All the domains of the CRA were tested for internal consistency as a measure of reliability using Cronbach alpha coefficients. Nijboer et al. (1999) indicated that the alpha coefficients ranged from .62 for the domain, impact on finances, to .83 for the domain, lack of family support. Visser-Meilly, Post, Riphagen, and Lindeman (2004) reported alpha coefficients for the five domains on the CRA which ranged between .80 and .90 for a study of caregivers of stroke patients. Given et al. (1992) found alpha coefficients ranging from .80 for impact on health to .90 for caregiver self-esteem in a study of caregivers of patients diagnosed with chronic physical and mental health impairments. Grant, Bartolucci, Elliot, and Giger (2000) conducted a pilot test to determine the stability of the CRA. The r -value of .81 provided support that the CRA had good test-retest reliability.

Validity. The validity of the CRA was examined by Given et al. (1992) using a sample of 377 caregivers of elderly patients with chronic physical and mental health problems. To test for construct validity, the researchers used both exploratory and confirmatory factor analysis. The results indicated that the five-domain outcome maximized the amount of explained variance. The eigenvalues associated with each domain ranged from 1.47 to 6.60, providing additional support that each domain was accounting for significant amounts of variation in the latent variable, caregiver reaction. Additional tests for the construct validity were conducted by correlating the five domains of the CRA with the number of patient dependencies in activities of daily living and caregivers' depression levels as measured by the CES-D depression scale (Given et al., 1992). The correlations between the number of dependencies and the five domains on the CRA were in the expected direction, with caregiver self-esteem having a negative correlation and the other domains having positive correlations. Similar outcomes were obtained for the relationships between the five domains of the CRA and the depression scores. According to Given et al., "the correlations between the CRA subscales and depression are consistent with the notion that specific caregiver burdens may result in overall caregiver depression" (p. 282).

Living arrangement. Living arrangement is assessed as a single question on the researcher-created demographic portion of this survey. Choices referring to living arrangement included the following: "live independently," "live independently with support," "live in a group home," "live with you," or "other" with a text box available to provide information. Living arrangement was assessed by the parent of the adult child with ASD.

Data Collection Procedures

Development of Online Survey Tool

An online survey software platform (Qualtrics) was used to combine all instruments or portions of instruments into one online survey. The web-based survey was comprised of the following: the (a) researcher-created demographic survey, (b) ESSI, (c) three subscales from the CBI (time dependence, developmental, and emotional burden domains), (d) one subscale CRA (impact on finance subscale), and (e) one domain from the WHOQOL-BREF (“psychological” domain only). All of these scales were combined to create the Qualtrics survey. The survey was uploaded to Qualtrics online survey software.

In designing the survey for use on the Qualtrics website, consideration was given to the number of items that should be included on each page (Dillman, Smyth, & Christian, 2014). One of the benefits of using multiple pages was that responses were saved as they were entered. If a person chose not to complete all of the items, his/her responses were saved to the point of leaving the website. Breaking the survey into separate pages also reduced the ennui that could result from having the items in a continuous stream (Dillman et al., 2014). The questions were placed purposefully by grouping like items together, instead of sporadically throughout the survey. This placement was intended to reduce erroneous connections across survey items that were not intended to be inferred by the participants.

The informed consent form was included on the Qualtrics website. Appendix A provides an information sheet with the consent following this information that was included prior to the actual Qualtrics survey. Participants were required to read the consent form and then answer yes if they wanted to participate or no if they did not want to participate. If they answered yes, they were directed to the survey. If they answered no, they were thanked for their time and then exited from the survey. An informational section was included on Qualtrics providing information about the study. For purposes of this study, participants were asked to refer to their oldest child with

ASD (if they have more than one adult child with ASD). The survey was estimated to take about 20-25 minutes to complete. At the end of the survey, information regarding community resources was provided should participants feel the need to connect with such resources (Appendix B).

After combining the five surveys into a single document and uploading it to Qualtrics, eight experts were asked to review it for content validity. The online survey was tested through distribution to professionals in the area of ASD and Developmental Disabilities (DDs). Eight professionals were given the survey and asked for their critical feedback, suggestions, and how long the survey took to complete. Professionals included a special education teacher, a school psychologist, three teacher consultants, a speech and language therapist, a transition coordinator, and a school social worker. Based on professional feedback, it was estimated that the survey would take approximately 15 to 20 minutes to complete. They offered suggestions to improve the readability of some items and clarify ambiguous statements. Improvements were made to the phraseology of sentences, as well as deletions of irrelevant and/or redundant portions. Additions were made to the survey to gather comprehensive information (e.g., formal services parents received to support their adult child with ASD). After making suggested changes, the survey was considered to have content validity.

To protect their anonymity, participants did not have to place their name on the survey. In addition, all information obtained for this study was secured on a password-protected computer. At the end of the survey, participants were asked if they wanted to participate in a drawing to win a \$25 gift card. When a participant indicated, yes (that they would like to participate in a drawing), they were routed to another screen so that their name could not be connected to their actual survey. Three gift cards were distributed to participants whose names were drawn after indicating that they

were interested in the raffle and providing contact information. Any contact information obtained was kept only until raffle winners were randomly selected.

Recruitment

Sample

Older parents of adult children diagnosed with ASD comprised the population for this study. To be included in the population, parents met the following inclusion criteria:

- self-identified parental caregiver at least 50 years of age,
- caregiver must be caring for an adult child (18 years of age or older) diagnosed with ASD, and
- the parent must be able to read and comprehend English.

However, the adult child did *not* need to be living in the home. (For example, the child might be living in the home, residential facility/group home, or semi-independent living (SIL) facility).

Recruitment Process

The researcher applied to the Wayne State University Institutional Review Board (IRB) to obtain permission to conduct the study. After receiving IRB approval, the researcher contacted organizations that provide support and services to parents and individuals with ASD to obtain permission to place survey links on their websites, in their newsletters, and through email to encourage their members to participate in the study. The link was forwarded to the organizations that had agreed to publish it on their website, in their newsletters, and via email.

A variety of recruitment methods were used to disseminate information regarding this study and obtain participants for this study as described below. Four modes of recruitment were used, including (a) recruitment using organizations that interfaced with the eligible population, (b)

face-to-face efforts on the researcher's behalf, (c) contacting professionals, and (d) snowball sampling – particularly through the use of parents of adult children with ASD.

Recruitment through autism and/or developmental disability organizations.

Recruitment for this study consisted primarily of purposive sampling (Teddlie & Yu, 2007) by recruiting parents who met the criteria for inclusion from a number of organizations that work with parents and individuals diagnosed with ASD. Recruitment efforts targeted organizations, resources, and programs designed for adults diagnosed with ASD and parents of individuals with ASD. These organizations included: (a) Autism Alliance of Michigan, (b) Autism Society of Macomb/Saint Clair (Michigan), (c) Autism Society of Oakland County (Michigan), (d) Autism Society of Wisconsin, (e) Judson Center (Michigan), (f) Milestones Autism Resources (Ohio), (g) Shelby County Regional Special Education PTA (Tennessee), (h) SRVS (Tennessee), and (i) the Autism Program of Illinois. These strategies ranged from sending information and the study link via email to organizations' contacts, and posting in organizations' newsletters, websites, and on their social media. In April 2015, flyers were distributed at an Autism Awareness walk (through the Autism Society of Oakland County – Michigan). Individual study flyers were placed in participant bags and were distributed to approximately 500 participants.

Flyers were posted in agencies, passed out, and posted in emails, newsletters, and on agency websites. [See Appendix C and D for the recruitment flyers.] Appendix E includes the email template that was sent to organizations and points of contact to help in the recruitment process. A number of support groups and autism organizations were contacted via email to communicate details of this study. Many of these groups and organizations offered to distribute information about the study to their participants via word of mouth (e.g. at parent support group meetings), email, or social media. In addition, Appendix F provides the email for organizations

that agreed to send a follow up reminder via email regarding this study to potential participants.

Table 6 below indicates the specific recruitment strategies for each organization.

Table 6

Recruitment through Autism and/or Disability Organizations

Organization / Source of Recruitment	Strategies for Recruitment
Autism Alliance of Michigan	Put information regarding study and link to study on website and in newsletter. Put information on organization's Facebook site. Emailed information regarding study to members.
Autism Society of Macomb/Saint Clair (Michigan)	Disseminated information to members by putting information and a link to this study on organization's website and in newsletter. Emailed information regarding the study to organization's members.
Autism Society of Oakland County (ASOC) (Michigan)	Flyers distributed at the ASOC's Autism Awareness walk. Individual study flyers were placed in participant bags and were distributed to approximately 500 participants.
Autism Society of Wisconsin	Emailed information regarding this study to their organization's listserv that includes 1,000 people. Sent a follow up email to listserv as a reminder about the study.
Judson Center (Michigan)	Assisted with the recruitment of participants by making information about this study available to families at Autism Connections Program at their two service centers (Royal Oak and Washtenaw). Flyers posted and flyers provided in our service center waiting areas /lobby with information about this study and how families can become involved in the study. Information regarding this study put on organization's website and Facebook site.
Milestones Autism Resources (Ohio)	Study information included in organization's newsletter that goes to all contacts.

Organization / Source of Recruitment	Strategies for Recruitment
Shelby County Regional Special Education PTA (SEPTA) (Tennessee)	<p>The Shelby County Regional Special Education PTA (SEPTA) helped in the recruitment process by providing information about this study to their members.</p> <p>Information and a link to study put on SEPTA's website and in their newsletter.</p> <p>Information regarding this study sent via email to its members.</p> <p>Information specifically sent to the following organizations: Representatives from the Shelby Residential Vocational Services (SRVS), Arc of the Midsouth and the SEPTA Board of Directors. SRVS and Arc have families with adults with special needs, hundreds in the greater Memphis area.</p>
SRVS (Tennessee)	<p>Information and link to study put in SRVS' newsletter.</p> <p>Study information (information and link) put in their newsletter.</p>
The Autism Program of Illinois (TAP)	<p>Forwarded information about the study throughout TAP's service network.</p> <p>Specifically, forwarded information about the study and contact information for clients to participate to each of their service network partners and encouraged them to make it available to their clients.</p>

Recruitment through researcher face-to-face measures. A second mode of recruitment consisted of face-to-face efforts by the researcher. Specifically, information about the study was distributed at venues (in Michigan) where parents or relevant professionals were likely to be present, including Autism Alliance of Michigan's annual meeting / conference, Autism Society of Macomb / Saint Clair's PAC meeting, Oakland County Transition Association's monthly meeting, as well as Parent Advisory Council's (PAC) meeting through Troy School District. At each of these meetings, the researcher provided flyers with study information. In addition, the researcher distributed information orally and passed out flyers at the PAC meetings through Troy School District, as well as the Autism Society of Macomb and Saint Clair. Participants were given the opportunity to ask questions about the study. Table 7 below indicates the specific strategies that the researcher used to recruit participants for this study.

Table 7

Recruitment through Face-to-Face Measures

Source of Recruitment	Strategies for Recruitment
Autism Alliance of Michigan annual conference	<p>The researcher attended this day-long conference and was placed at a booth in the area where vendors were available to provide information regarding their services.</p> <p>Communicated study information to parents, professionals, vendors, and organizations. The researcher talked to each of the vendors about this study and provided those of interest with flyers.</p> <p>Flyers were distributed and the study was explained orally.</p> <p>For individuals interested in learning more and/or having information sent directly to them, a contact log was available to include their information.</p> <p>The researcher followed up via email or telephone and provided study details to each parent and professional that left their name and contact information.</p>
Autism Society of Macomb/Saint Clair PAC meeting (Michigan)	<p>The researcher explained the purpose and nature of the present study.</p> <p>Flyers were passed out indicating information about this study to members at the PAC meeting.</p> <p>Participants were given the opportunity to ask questions about the study.</p>
Oakland County Transition Association (Michigan)	<p>The researcher presented the purpose and existence of the present study to approximately 50 transition coordinators throughout the public school districts in Oakland County.</p> <p>Flyers were disseminated to the association's members.</p> <p>Members' questions pertaining to the study were answered.</p>
Troy School District PAC meeting (Michigan)	<p>The researcher explained the purpose and nature of the present study.</p> <p>Flyers were passed out indicating information about this study to members at the PAC meeting.</p> <p>Participants were given the opportunity to ask questions about the study.</p>

Recruitment through professional contacts. The researcher relied on a wide community of professional, support group, and parent contacts to disseminate information about this study. The researcher communicated with Autism Society chapters throughout the United States about

the present study. Many Autism Society chapters communicated their willingness to email their members and/or post information regarding this study on their social media.

Table 8

Recruitment through Communication with Professional Contacts

Source of Recruitment	Strategies for Recruitment
Communication of study to the Autism Society chapters throughout the United States	<p>Communicated study information with link and study flyer to Autism Society chapters throughout the United States.</p> <p>Follow up communication was made when questions regarding the study arose or when more information was requested.</p>
Communication of study to professional contacts	<p>The researcher contacted known professional contacts to disseminate information regarding this study and its corresponding flyer.</p> <p>Known professional contacts included public school teachers, teacher consultants, transition coordinators, school social workers, school administrators, one vocational specialist, and one school psychologist.</p> <p>These contacts were encouraged to pass along the information and flyer about this study.</p> <p>Many professionals communicated their willingness to forward this information along to their parent and professional contacts.</p> <p>Many professionals communicated contact and organization names that the researcher followed up with to disseminate study information.</p>
Communication of study to known parents	<p>The researcher disseminated study information via email and word of mouth with her parent contacts.</p> <p>Many of these parents stated their willingness to pass along this information to their contacts.</p>
Communication of study to support groups throughout the United States	<p>Via email the researcher communicated with Autism and Asperger's support groups throughout the United States.</p> <p>Study information and the study flyer were sent.</p> <p>Many support group leaders offered to forward this information along to their support group and contacts.</p>

This mode of communication appeared to help to fuel the snowball sampling recruitment measures.

Snowball sampling. Due to the close community among many parents of children and adults with ASD and because many parents may not be connected with formal support networks (e.g. organizations and agencies), snowball sampling was used as a secondary means of recruitment.

Snowball sampling can achieve broader coverage because respondents, including those who do not attend public venues, are reached through their social networks. In snowball sampling, the researcher recruits a few eligible individuals who are then asked to bring in other potential respondents or provide references (contact details) for other potential respondents. (Abdul-Quader, 2006, p. 460)

The use of snowball sampling enabled the researcher to recruit individuals from other participants. A particularly useful strategy involved including parents of an adult child with ASD in the recruitment process by spreading information about the study via email, word of mouth, and social media. For parents that participated in the qualitative follow up interviews, they were asked by the researcher if they knew of any other parents that might be interested in participating in the study. Many of these parents knew of other parents and offered to contact their contacts, such as other friends that were parental caregivers, classroom teachers, and support group leaders.

Sample Size

To determine the appropriate sample size for this study, a power analysis using G*Power 3.1 (Faul, Erdfelder, Buchner, & Lang, 2009), was conducted. For a multiple regression analysis with 6 independent variables, using blocks, an alpha level of .05, and a power of .80, a sample of 242 participants is needed.

Data Analysis

The data collected from Qualtrics were transferred to an IBM-SPSS ver. 22 data file for analysis. The statistical analyses consisted of three phases. The first phase used frequency distributions and measures of central tendency and dispersion to provide a description of the participants and their children diagnosed with ASD. All of the variables shown in Table 1 were used to provide information regarding sample characteristics based on information obtained from participants in the study. Descriptive statistics were used to provide baseline information on the scaled variables included in the study. As part of the preliminary analysis, the scaled variables (QOL, formal social support, informal social support, time dependence burden, developmental burden, emotional burden, composite score for caregiver burden, and impact on finance) were compared between parents whose adult child with ASD lives at home with them or lives independently or in a group home using one-way multivariate analysis of variance (MANOVA), one-way analysis of variance (ANOVA), or t-tests for independent samples. Separate MANOVA analyses were used to compare the two types of social support (formal and informal), and the three subscales measuring caregiver burden (time dependence burden, developmental burden, and emotional burden). A composite score for caregiver burden was compared between parents of adult children with ASD who lived in their homes and parents whose adult children with ASD lived outside of the home. QOL and impact on finance were compared using separate one-way ANOVAs. The third section of the data analysis used inferential statistical analyses to address the research questions. The inferential statistical analyses included multiple linear regression analysis and moderation analysis. All decisions on the statistical significance of the findings were made using a criterion alpha level of .05. Table 9 presents the statistical analyses that were used to test each research question.

Table 9

Statistical Analyses

Block	Research Question and Hypothesis	Statistical Analysis Independent Variables Predicting QOL (Block arrangement for hierarchical linear regression)
1		Insert health of parent (Independent Variable) into block 1.
2	<p>1. What is the relationship between the perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD?</p> <p>H₀₁: There is not a relationship between perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD.</p> <p>H_{a1}: There is a relationship between perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD.</p>	Insert health of parent and financial impact (of caregiving) into block 2.
3	<p>2. What is the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?</p> <p>H₀₂: There is not a relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.</p> <p>H_{a2}: There is a relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.</p>	Insert health of parent, financial impact, caregiver burden into block 3.
4	<p>3. What is the relationship between living arrangement and QOL among parental caregivers of adult children with ASD?</p> <p>H₀₃: There is not a relationship between living arrangement and QOL among parental caregivers of adult children with ASD.</p> <p>H_{a3}: There is a relationship between living arrangement and QOL among parental caregivers of adult children with ASD.</p>	Insert health of parent, financial impact, caregiver burden, and living arrangement into block 4.
5	<p>4. Does formal social support moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?</p> <p>H₄: Formal social support moderates the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.</p> <p>H₀₄: Formal social support does not moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.</p>	Insert health of parent, financial impact (of caregiving), living arrangement, caregiver burden X formal social support into block 5.

Block	Research Question and Hypothesis	Statistical Analysis Independent Variables Predicting QOL (Block arrangement for hierarchical linear regression)
6	<p>5. Does informal social support moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?</p> <p>H₅: Informal social support moderates the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.</p> <p>H₀₅: Informal social support does not moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.</p>	<p>Insert health of parent, financial impact (of caregiving), caregiver burden, living arrangement, caregiver burden X formal social support, and caregiver burden X informal social support into block 6.</p>

For purposes of this study, the statistical analyses included a hierarchical linear regression using 6 blocks. Block 1 included the control variable, health of the parent. The blocks are displayed (above) in Table 9. Block 2 added the impact of finances. Next, caregiver burden as a composite of time dependence burden, developmental burden, and emotional burden was inserted in block 3. Block 4 added living arrangement (of the adult child with ASD). Block 5 includes the interaction between caregiver burden and formal social support. Lastly, in block 6, the interaction between caregiver burden and informal social support was added. Blocks 5 and 6 were not included as part of the multiple linear regression as part of the power analysis, but were included for exploratory purposes.

Missing Data

The data cleaning process included handling missing data. A total of 33 surveys were deleted. Specifically, one survey was deleted as it was blank, one case was deleted because the adult child was the brother of the respondent (rather than a parental caregiver), nine additional surveys were deleted as respondents did not meet the inclusion criteria (they were under the age of 50), and 22 surveys were removed as they were substantially incomplete. The 22 surveys that

were eliminated had responded to fewer than half of the survey items, with some only answering 1 or 2 items.

A missing values analysis was used to determine the extent to which the study variables had missing values. Various methods can be used to replace missing values in a data set, including replacement of the missing value with the mean score for the variable (Howell, 2012). According to Mertler and Vannatta (2010), any variable that has less than 5% of the values missing can be replaced with the mean score for that variable. The results of the missing values analysis are presented in Table 10.

Table 10

Missing Values Analysis: Study Variables

Study Variable	Number of Missing Values	Percent of Missing Values
Quality of life	3	0.9
Time dependence burden	1	0.3
Developmental burden	1	0.3
Emotional burden	1	0.3
Impact on finances	5	1.6
Informal social support	3	0.9
Formal social support	0	0.0
Time dependence x formal social support	1	0.3
Developmental burden x formal social support	1	0.3
Emotional burden x formal social support	1	0.3
Time dependence x informal social support	4	1.3
Developmental burden x informal social support	4	1.3
Emotional burden x informal social support	4	1.3

The greatest number of missing values was for impact on finances ($n = 5$, 1.6%), with no missing values for formal social supports. Because of the few variables with missing values, the decision was made to replace the missing value with the mean for the variable.

Qualitative Follow Up

Although this dissertation is mainly quantitative in nature, involving a web-based survey, a qualitative portion was conducted to supplement this dissertation's findings. At the end of the web-based survey, respondents were asked if they would like to participate in a follow up interview. Interested individuals had the option of providing their contact information to be part of a follow up interview. An email was sent to these participants to let them know the researcher would be contacting them to set an appointment for their interview (See Appendix G). The qualitative portion involved conducting 51 face-to-face and/or phone based semistructured interviews with parents of adult children with ASD. Individuals participating in a one-on-one interview received a \$20 gift card as a token of appreciation for their time and for sharing their experiences. The interviews ranged in length; however, most took approximately one hour. Individuals were provided information about the follow up interview. Prior to the start of the interviews, participants were made aware that they had the option of not having their interview recorded by the researcher, as well as having the recorder turned off at any point throughout the interview. All participants consented to allowing his or her interview to be recorded.

An interview script (See Appendix H) with corresponding questions is included in Appendix I. Questions sought to learn more about participants' QOL and experiences of caring for an adult child with ASD, including learning about how participants felt about caring for their adult child with ASD. The interview attempted to gain an understanding of the types of organizations that provide support to parents and their satisfaction with organizations. The interview questions

also sought to know if and how having an adult child with ASD had affected parents' finances and personal health. In addition, this qualitative portion attempted to explore the rewards and challenges associated with caring for an adult child with ASD. Appendix J contains an information sheet for participants. All information collected about the participants during the course of this study was maintained without any identifiers.

Interviews were transcribed by an experienced transcriber. Any identifying information in the recordings was deleted from the transcripts. The typed interviews were proofread by the researcher with any corrections made to check for accuracy. The transcribed interviews were analyzed using Atlas.ti 7 software using grounded theory and coded using line-by-line analysis to determine present themes. To ensure the validity of the interviews, member checking was completed. Each participant was emailed information from their interview indicating findings, such as codes and themes, after the researcher conducted analysis. Participants were asked to make corrections to any errors and add to the information where appropriate. The researcher asked participants to return the analysis from the interviews within five working days.

Four factors are needed to determine the trustworthiness of qualitative research (Lincoln & Guba, 1985). These four factors include: credibility (internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity). *Credibility* is used to determine the internal validity of the study and provides an accurate picture of the phenomenon under investigation. *Transferability* is similar to external validity of a quantitative study and is used to determine if the study can be used in different contexts, as well as the extent to which the present study is similar to other studies on the same topic. The findings of this study may be useful in designing studies of caregivers of adults with other types of developmental disabilities who may be experiencing similar circumstances. *Dependability* is similar to reliability and typically is

determined after replicating the study using the same methodology. This factor can only be determined if another study using the same methodology is conducted and the findings are similar to the present study. *Confirmability* is used to assure that the findings of the study are from the collected data and not from researcher biases. Confirmability was verified by determining that findings were presented objectively and did not include researcher biases. The completed interviews were analyzed using these four factors associated with trustworthiness.

CHAPTER 5 RESULTS

This chapter describes the demographic and health characteristics of the sample, describes the relationship between burden and living arrangement, and presents the results of the hypotheses for this study. The first section uses descriptive statistics to describe the study sample. The second section presents a bivariate analysis of the burden measures by living arrangement. The third section presents results from the inferential statistical analyses that were used to address the research questions and test the hypotheses.

The purpose of this study is to examine effects of caring for an adult child with ASD on parents' QOL. In addition, contributing factors to QOL, such as social support, were investigated.

Study Enrollment

A total of 353 surveys were submitted on Qualtrics website. Of this number, 22 were eliminated because of incomplete responses, 9 were deleted because participants did not meet the inclusion criteria of being over 50 years of age, 1 was deleted because the respondent was not the parent of the adult child with ASD, and 1 was deleted as it was blank. As a result, the number of responses that were included in the final analyses was 320.

Sample Characteristics

The parents of adult children with ASD were asked to respond to items regarding their demographic characteristics. Their responses were summarized using frequency distributions. Table 11 presents results of this analysis.

Table 11

Frequency Distributions: Parents' Demographics (N = 320)

Parents' Demographics	n	%
Parents' age		
50 to 59	212	66.3
60 to 69	95	29.7
70 and over	13	4.1
Gender of parent completing survey		
Male	57	18.0
Female	259	82.0
Missing 4		
Ethnicity		
African American/Black	5	1.6
American Indian/Alaskan Native	1	0.3
Caucasian/White	289	90.9
Hispanic	12	3.8
Multiethnic	6	1.9
Other	5	1.5
Missing 2		
Marital status		
Single, never married	6	1.9
Married	252	79.2
Divorced	41	12.9
Widowed	11	3.5
Co-habiting	2	0.6
Separated	6	1.9
Missing 2		
Employment status		
Employed full-time	116	36.9
Employed part-time	79	24.7
Retired	49	15.3
Unemployed, looking for work	9	2.8
Unemployed, not looking for work	5	1.6
Disabled and unable to work	9	2.8
Homemaker	40	12.5
Self-employed	7	2.2
Other	4	1.3
Educational level of respondent		
Less than high school	1	0.3
High school/GED	10	3.1
Some college	42	13.1
Associates degree/technical school	44	13.8
Bachelor's degree	100	31.3
Master's degree	90	28.1
Doctorate/professional degree	33	10.3

Parents' Demographics	n	%
Educational Level of Other Parent		
Less than high school	1	0.3
High school/GED	21	6.6
Some college	47	14.8
Associates degree/technical school	20	6.3
Bachelor's degree	96	30.3
Master's degree	63	19.9
Doctorate/professional degree	38	12.0
Not applicable	31	9.8
Missing	3	
Annual Family Income		
Less than \$20,000	14	4.5
\$20,001 to \$40,000	24	7.7
\$40,001 to \$60,000	42	13.4
\$60,001 to \$80,000	45	14.4
\$80,001 to \$100,000	37	11.8
More than \$100,000	103	32.9
I would prefer not to respond	48	15.3
Missing	7	

The majority of the responding parents were from 50 to 59 years of age ($n = 212$, 66.3%), and female ($n = 259$, 82.0%). The greatest number of parents reported their ethnicity as Caucasian/White ($n = 289$, 90.0%). The majority of parents were married ($n = 252$, 79.2%) and working either full-time ($n = 116$, 36.9%) or part-time ($n = 79$, 24.7%). Forty-nine (15.3%) parents were retired and 40 (12.5%) reported their employment status as homemaker. Most of the parents had bachelor's degree ($n = 100$, 31.3%), master's degrees ($n = 90$, 28.1%), or doctorate/professional degrees ($n = 33$, 10.3%). The other parent had completed a bachelor's degree ($n = 96$, 30.3%), master's degree ($n = 63$, 19.9%), or a doctorate/professional degree ($n = 38$, 12.0%). Annual family income levels varied from less than \$20,000 ($n = 14$, 4.5%) to more than \$100,000 ($n = 103$, 32.9%). The largest group of parents ($n = 103$, 32.9%) reported income levels in excess of \$100,000, followed by \$60,001 to \$80,000 ($n = 45$, 14.4%). Forty-eight (15.3%) reported that they preferred not to respond in regard to their annual family income.

The parents were asked to provide information about their children in their household who were under or over 18 years of age. The responses to these items were summarized using frequency distributions for presentation in Table 12.

Table 12

Frequency Distributions: Children in the Household

Number of children in household	N	%	M	SD
Number of children in household under 18			0.25	.58
0	256	81.0		
1	43	13.6		
2	14	4.4		
3	3	1.0		
Missing 4				
Number of children in household over 18 including child with ASD			1.55	1.03
0	33	10.4		
1	149	47.0		
2	85	26.8		
3	30	9.5		
4	18	5.7		
5 or more	2	0.6		
Missing 3				
Number of children under 18 with disabilities other than ASD			0.06	.27
0	297	94.3		
1	16	5.1		
2	2	0.6		
Missing 5				
Number of children other than child with ASD over 18			0.16	.43
0	271	86.6		
1	34	10.9		
2	8	2.6		
Missing 7				
Number of children with ASD under 18			0.03	.16
0	301	97.4		
1	8	2.6		
Missing 11				
Number of children with ASD over 18			0.98	.43
0	29	9.2		
1	266	84.2		
2	20	6.3		
4	1	0.3		
Missing 4				

The mean number of children in the household under 18 years of age was 0.25 (SD = .58), with most of the parents ($n = 256$, 81.0%) indicating they had no children under 18 years of age living in their homes. In contrast, most of the parents ($n = 149$, 89.6%) had at least one child, including the adult child with ASD, over 18 years of age living at home. The number of adult children in the household ranged from 1 to 5 or more. The mean number of children in the household over 18 years including the child with ASD was 1.55 (SD = 1.03). The mean number of children under 18 years with a disability other than ASD was 0.06 (SD = .27), with 16 (5.1%) parents having one child under 18 years of age with a disability other than ASD and 2 (0.6%) having two children with disabilities other than ASD. The mean number of children over 18 years in the household other than the adult child with ASD was 0.16 (SD = .43). Thirty-four (10.9%) parents indicated they had one child over 18 years who did not have ASD living at home, with 8 (2.6%) parents reporting they had two children over 18 years who did not have ASD living in their homes. Eight (2.6%) parents reported one child with ASD who was under 18 years of age. The majority of the parents ($n = 266$, 84.2%) reported they had one child over 18 years of age with ASD, with 20 (6.3%) parents reporting two children over 18 years of age with ASD, and 1 (0.3%) parent indicating he/she had four children over 18 years of age with ASD.

The parents were asked to respond to the following items based on their eldest child diagnosed with ASD. Frequency distributions were used to summarize their responses. Table 13 presents results of this analysis.

Table 13

Frequency Distributions: Demographic Characteristics of the Adult Child with ASD (N = 320)

Adult Child's (with ASD) Demographics / Characteristics	<i>n</i>	%
Age of adult child with ASD ($M = 25.14, SD = 7.09$)		
18 to 20	71	25.0
21 to 25	119	41.9
26 to 30	52	18.3
31 to 35	16	5.6
36 to 40	11	3.9
41 and over	15	5.3
Gender of adult child with ASD		
Male	257	80.3
Female	63	19.7
Living arrangement of adult child with ASD		
Live independently	16	5.0
Live independently with support	35	10.9
Live in a group home	11	3.4
Live with parents	248	77.5
College	6	1.9
Other	4	1.3
Employment status of adult child with ASD		
Employed full time	21	6.6
Employed part time	59	18.5
Working with a job coach	41	12.9
Employed in a sheltered workshop	13	4.1
College	16	5.0
High school / post-secondary program	52	16.3
Unemployed	53	16.6
Unable to work	58	18.2
Other	6	1.9
Missing 1		
Educational status of adult child with ASD at time of study		
Attending university or college	31	10.0
Attending community college	24	7.8
Attending vocational training program	14	4.5
Attending public school (extended program for students 18-26)	86	27.9
Unable to attend educational program	27	8.7
Aged out of public school	59	19.1
College graduate	45	14.6
Dropped out of college/left college	6	1.9
Other	17	5.5
Missing 11		
Communication ability of adult child with ASD		
Communicates a wide variety of topics in a meaningful way	124	38.8
Communicates in a limited range of topics in a meaningful way	112	35.0
Communicates needs and wants in some meaningful way	29	9.1
Communicates basic needs and wants	33	10.3
Very little meaningful communication	17	5.3

Adult Child's (with ASD) Demographics / Characteristics	<i>n</i>	%
Communicates with a device	4	1.3
Other	1	0.3
Behavior of adult child with ASD		
Typical, age appropriate adult behavior	14	4.4
Requires minimal prompting, direction, or redirection	160	50.3
Requires substantial prompting, direction, or redirection	108	34.0
Engages in self-injurious behavior and/or dangerous / aggressive behavior	19	6.0
Requires 24 hour supervision to manage behavior	16	5.0
Other	1	0.3
Missing 2		
Social behavior of adult child with ASD		
Has a group of friends, goes out with others in the community	43	13.4
Is part of a social group	88	27.5
Would like friendships, but has no friends	73	22.8
Is not able to make friends	32	10.0
Socializes with family only	82	25.6
Other	2	0.6

The majority of the adult children with ASD were male ($n = 257$, 80.3%). The mean age of the adult child diagnosed with ASD was 25.14 ($SD = 7.09$) years. The adult children with ASD ranged in age from 18 to 62, with a median of 23 years. The largest group of adult children with ASD were between 21 and 25 years of age ($n = 119$, 41.9%), with 15 (5.3%) of the adult children with ASD 41 years of age and older. Most of these children were living with parents, with 21 (6.6%) employed full-time and 59 (18.5%) employed part-time. Thirty-one (10.0%) of the adult children were attending university or college, while 86 (27.9%) were attending public schools' extended programs for students 18 to 26. The largest group of adult children ($n = 124$, 38.8%) were able to communicate a wide variety of topics in a meaningful way, with 112 (35.0%) able to communicate in a limited range of topics in a meaningful way. Seventeen (5.3%) had very little meaningful communication and 4 (1.3%) could communicate only with a device. The majority of adult children ($n = 160$, 50.3%) required minimal prompting, direction, or redirection for their behavior, with 14 (4.4%) having typical age appropriate adult behavior. Nineteen (6.0%) parents indicated that their adult with ASD engaged in self-injurious behavior and/or dangerous/aggressive

behavior and 16 (5.0%) parents reported their adult child required 24-hour supervision to manage behavior. Eighty-two (25.6%) parents reported that their adult child with ASD socialized only with family, while 88 (27.5%) indicated that their adult child was part of a social group. Forty-three (13.4%) parents reported that their adult child with ASD had a group of friends and went out with others in the community.

The parents were asked to indicate the amount of support their adult children required for activities of daily living. Their responses to the items were summarized using frequency distributions for presentation in Table 14.

Table 14

Frequency Distributions: Amount of Support Required for Activities of Daily Living (N = 320)

Support Required for Activities of Daily Living	<i>n</i>	%
Bathing / Showering		
Able to perform task independently	230	71.9
Requires minimal assistance to perform task	37	11.6
Requires moderate assistance to perform task	33	10.3
Requires total assistance to perform task	20	6.3
Dressing		
Able to perform task independently	246	77.1
Requires minimal assistance to perform task	48	15.0
Requires moderate assistance to perform task	19	6.0
Requires total assistance to perform task	6	1.9
Missing 1		
Eating / Feeding		
Able to perform task independently	258	80.6
Requires minimal assistance to perform task	46	14.4
Requires moderate assistance to perform task	13	4.1
Requires total assistance to perform task	3	0.9
Functional mobility (moving around safely from one place to another)		
Able to perform task independently	265	82.8
Requires minimal assistance to perform task	33	10.3
Requires moderate assistance to perform task	15	4.7
Requires total assistance to perform task	7	2.2
Personal hygiene and grooming		
Able to perform task independently	163	50.9
Requires minimal assistance to perform task	89	27.8

Support Required for Activities of Daily Living	<i>n</i>	%
Requires moderate assistance to perform task	48	15.0
Requires total assistance to perform task	20	6.3
Community-based activities for child with ASD		
Able to perform task independently	116	38.7
Requires minimal assistance to perform task	74	24.7
Requires moderate assistance to perform task	70	23.3
Requires total assistance to perform task	40	13.3
Missing 20		
Toileting		
Able to perform task independently	263	82.2
Requires minimal assistance to perform task	31	9.7
Requires moderate assistance to perform task	21	6.6
Requires total assistance to perform task	5	1.6
Making bed / cleaning room		
Able to perform task independently	128	40.1
Requires minimal assistance to perform task	90	28.2
Requires moderate assistance to perform task	72	22.6
Requires total assistance to perform task	29	9.1
Missing 1		
Cooking simple meals		
Able to perform task independently	103	32.3
Requires minimal assistance to perform task	82	25.7
Requires moderate assistance to perform task	66	20.7
Requires total assistance to perform task	68	21.3
Missing 1		
Managing money		
Able to perform task independently	53	16.6
Requires minimal assistance to perform task	57	17.8
Requires moderate assistance to perform task	72	22.5
Requires total assistance to perform task	137	42.8
Missing 1		
Taking public transportation		
Able to perform task independently	79	25.5
Requires minimal assistance to perform task	44	14.2
Requires moderate assistance to perform task	46	14.8
Requires total assistance to perform task	141	45.5
Missing 10		

The majority of parents reported that their adult children with ASD were able to do most activities of daily living independently or with minimal assistance. However, in activities that were related to managing money, 137 (42.8%) required total assistance to perform the task and 141 (45.5%) required total assistance to take public transportation.

The parents of adult children with ASD were asked to self-report their own health status using a 5-point scale ranging from 1 for poor to 5 for excellent. Their responses were summarized using frequency distributions for presentation in Table 15.

Table 15

Descriptive Statistics: Caregiver Self-rating of Health and Health-related Items

Health-related Items	N	M	SD	Median	Range	
					Minimum	Maximum
Parents' self-reported health	313	3.56	1.00	4.00	1	5
Extent to which participant enjoys life	317	3.27	.85	3.00	1	5
Extent to which life is meaningful	316	3.61	.95	4.00	1	5
Ability to concentrate	317	3.36	.75	3.00	1	5
Accept bodily appearance	313	3.47	1.03	4.00	1	5
Satisfied with self	315	3.48	.98	4.00	1	5
Frequency of negative feelings*	312	3.37	.80	3.00	1	5

*Reversed scored

The mean score for self-reported health of the parents was 3.56 ($SD = 1.00$), with a median of 4.00. The scores ranged from 1 (poor) to 5 (excellent). The extent to which the participant enjoyed life had a mean score of 3.27 ($SD = .85$), with a median of 3.00. The scores ranged from 1 for not at all to 5 for extremely. The range of scores for the item, extent to which life is meaningful, was from 1 for not at all to 5 for extremely. The mean score was 3.61 ($SD = .95$), with a median of 4.00. The mean score for ability to concentrate was 3.36 ($SD = .75$), with a median of 3.00. The range of scores for this subscale was from 1 (slightly) to 5 (extremely). The item, accept bodily appearance, had a mean score of 3.47 ($SD = 1.03$), with a median of 4.00. The range of responses on this item was from 1 for not at all to 5 for completely.

The scores for satisfied with self ranged from 1 for very dissatisfied to 5 for very satisfied. The mean score for satisfied with self was 1 for very dissatisfied to 5 for very satisfied. The mean score for negative feelings, after reverse scoring to reflect positive feelings, was 3.37 ($SD = .80$), with a median of 3.00. The responses on this item ranged from 1 for never to 5 for always.

The parents were provided with a list of formal and informal social supports that were available to them. They were asked to indicate the supports that they received. Descriptive statistics were used to summarize the number of formal and informal social supports. Table 16 presents results of this analysis.

Table 16

Descriptive Statistics: Formal and Informal Social Supports

Social Support	N	M	SD	Median	Range	
					Minimum	Maximum
Formal	320	3.02	2.33	3.00	0	12
Informal	320	1.94	1.50	2.00	0	6

The mean number of formal social supports used was 3.02 ($SD = 2.33$), with a median of 3 types of formal social supports. The number of possible formal social supports ranged from 0 to 12. Parents reported receiving an average of 1.94 ($SD = 1.50$) informal social supports with a median of 2 informal social supports. The range of informal social supports was from 0 to 6. Table 17 presents types of formal and informal social supports to which parents of adult children with ASD have access. The numbers and percentages represent positive responses. As parents were asked to indicate all that apply, the number of responses exceeded the number of participants.

Table 17

Frequency Distributions: Use of Formal and Informal Social Supports for Parent of Adult Child with ASD (N = 320)

Social Supports	N	%
Formal Social Supports		
Psychiatric services	156	48.8
Financial support from private or public organizations / services	154	48.1
Counseling	133	41.6
Autism support groups	88	27.5
Respite care (paid by parent or through another source)	82	25.6
Social Work	75	23.4
Care for a chronic condition	70	21.9
Community Mental Health	69	21.6
Community support groups for caregivers (regardless of disability)	52	16.3
State organizations for caregivers of adults with autism	41	12.8
Speech therapy	34	10.6
Occupational therapy	30	9.4
Vocational/Employment supports/Educational supports	19	5.9
Adult day care	18	5.6
Physical therapy	13	4.1
National organizations for caregivers of adults with autism	9	2.8
Social groups/Recreational	6	1.9
Paid caregivers	6	1.9
Other	4	1.3
Informal Social Supports		
Informal emotional support	221	69.5
Informal informational support	168	52.5
Informal physical assistance	74	23.1
Informal respite care	70	22.0
Informal help with chores / household activities	45	14.3
Informal financial assistance	42	13.1
Other	8	2.5

Psychiatric services were the most frequently used formal social support ($n = 156, 48.8\%$). Financial support from private or public organizations/services ($n = 154, 48.1\%$) was the second most used formal social support, followed by counseling ($n = 133, 41.6\%$). Emotional support ($n = 221, 69.5\%$) was the most frequently used informal social support. A total of 168 (52.5%) participants reported that they received informal informational support. Seventy-four (23.1%) of the participants indicated that they used informal physical assistance.

The parents of adult children with ASD were asked to respond to a list of people to whom they were providing care in addition to the adult child with ASD. The positive responses for this list are presented in Table 18.

Table 18

Frequency Distributions: Provision of Care (N = 320)

Provision of Care	N	% of yes response
Provide care for others beside child with ASD	110	34.8
Care for another child	65	20.3
Care for parents	30	9.4
Care for spouse	26	8.1
Care for other relatives	7	2.2
Care for anyone else in the home	1	0.3
Care for friends	1	0.3

The largest group of parents ($n = 110, 34.8\%$) were providing care for others besides their adult child with ASD. Those parents who were providing care were asked to indicate for whom they were providing care. They were presented with a list of six possible responses and asked to specify all that apply. As a result, the number of responses for whom they were providing care exceeded the number of participants who indicated they were providing care for another person.

Of the 110 parents who were providing care for another person other than their adult child with ASD, 65 (20.3%) were providing care for another child, 30 (9.4%) were caring for parents, and 26 (8.1%) were caring for their spouses.

Univariate Analysis of Dependent Variables

The items measuring the dependent variables were summed and divided by the number of items on the scales to obtain mean scores that reflected the original unit of measure. The individual items were scored so that a high score represented a high burden. Descriptive statistics were obtained for the five dependent variables in the study to provide baseline data. Table 19 presents results of these analyses.

Table 19

Descriptive Statistics: Dependent Variables (N = 320)

Dependent Variables	<i>M</i>	<i>SD</i>	Median	Actual Range of Scores	
				Minimum	Maximum
Burden					
Time dependence burden	2.88	1.01	2.80	1.00	5.00
Developmental burden	2.92	1.05	3.00	1.00	5.00
Emotional burden	1.84	.76	1.60	1.00	5.00
Composite caregiving burden	2.55	.73	2.53	1.00	4.60
Social Support					
Informal social support	3.37	.98	3.37	1.00	5.00
Number of formal social supports	3.02	2.33	3.00	0.00	12.00
Impact on finances	2.78	1.12	2.67	1.00	5.00
Quality of life	3.43	.68	3.50	1.17	5.00

Time dependence burden. Time dependence burden was measured using five items from the Caregiver Burden Index (CBI). Time dependence burden is burden due to restrictions on the

caregiver's time. Each of the items were rated using a 5 point scale ranging from 1 for never to 5 for nearly always as the item applied to their situation with their adult child with ASD. The mean score for the scale was 2.88 ($SD = 1.01$), with a median of 2.80. The range of actual scores was from 1 to 5, with higher scores indicating greater time dependence burden.

Developmental burden. Five items from the CBI were included on this scale. Developmental burden indicates caregivers' feelings of being "off-time" in their development with respect to their peers. The mean score for developmental burden was 2.92 ($SD = 1.05$), with a median of 3.00. The actual score on this subscale ranged from 1 to 5, with higher scores indicating greater developmental burden.

Emotional burden. Emotional burden was measured using five items from the CBI. This subscale measures caregivers' negative feelings toward their care receivers, which may result from the adult child's unpredictable and often bizarre behavior. The mean score for emotional burden was 1.84 ($SD = .76$), with a median score of 1.60. The responses from the parents on emotional burden ranged from 1 to 5, with higher scores indicating greater emotional burden.

Caregiver burden (composite score). The scores for the three types of burden (time dependence, developmental, and emotional burden) were used to create a composite score for caregiver burden. The mean score for caregiver burden was 2.55 ($SD = .73$), with a median score of 2.53. The range of actual scores was from 1.00 to 4.60, with higher scores indicating greater caregiver burden.

Informal social support. Six items on the ENRICHD Social Support Instrument (ESSI) measure the perceived availability of informal social support from one's network. The items were rated using a 5 point scale with a 1 specifying none of the time and 5 indicating all of the time.

The mean score for this scale was 3.37 ($SD = .98$), with a median of 3.37. The range of scores on this scale was from 1.00 to 5.00, with higher scores indicating greater informal social support.

Formal social support. Fifteen types of formal social support were listed on the survey. The parents of adult children with ASD were asked to indicate all that were used by their child with ASD or themselves. The number of selected items was counted to obtain a score for formal social support. The mean number of items was 3.02 ($SD = 2.33$), with a median of 3.00 items. The range of number of formal social support items ranged from 0.00 to 12.00, with higher numbers indicating greater use of formal social support.

Impact on finances. Three items from the Caregiver Reaction Scale were used to measure impact on finances. Impact on finances measures the financial strain on the caregiver. The three items were rated by parents using a five point scale ranging from 1 for strongly disagree to 5 for strongly agree. The mean score for this scale was 2.78 ($SD = 1.12$), with a median of 2.67. The range of scores on this scale was from 1 to 5, with higher scores indicating a greater impact on finances from having an adult child diagnosed with ASD.

Quality of life. Six items were used to measure QOL. This subscale was adapted from the World Health Organization Quality of Life – BREF Scale (WHOQOL-BREF). For purposes of this study, the “psychological” domain from this scale was used to measure the following facets of this domain: bodily image and appearance, negative feelings, positive feelings, self-esteem, spirituality/religion/personal beliefs, and thinking, learning, memory, and concentration. The items were rated using a 5-point scale with a 1 representing negative attitudes and 5 specifying positive attitudes about the items contributing to QOL. The mean score for this scale was 3.43 ($SD = .68$), with a median of 3.50. The actual scores ranged from 1.17 to 5.00, with higher scores indicating more positive perceptions regarding the parents’ QOL.

Bivariate Statistical Analyses of Burden by Living Arrangement

A multivariate analysis of variance (MANOVA) was used to determine if caregiver burden; as measured by time dependence burden, developmental burden, and emotional burden; differed by adult children's living arrangements. Parents of adult children with ASD may experience all three types of caregiving burden depending on whether their adult child lives with them or lives outside of the home. Parents may experience differential types of burden, with parents whose adult children living at home requiring more time, and parents whose adult children live outside of the home causing the parents greater emotional burden as they worry about their welfare (Hines, Balandin, & Togher, 2014). Parents of adult children with ASD typically are concerned about their adult children's development.

Before using the multivariate analysis of variance, the assumptions for MANOVA were reviewed to verify that the data were valid for this type of analysis (French, Macedo, Poulsen, Waterson, & Yu, 2002). The first assumption is that the data were normally distributed. Using the explore command, the data met this assumption with skewness and kurtosis between zero and 1.00 for each of the three variables. The second assumption was linearity, with linear relationships assumed among the pairs of dependent variables.

Pearson product moment correlations were used to test the relationships among the three variables measuring burden. The results of these analyses showed that developmental burden was significantly related to emotional burden ($r = .57, p < .001$) and time dependence burden ($r = .47, p < .001$). The relationship between emotional burden and time dependence burden ($r = .16, p = .004$) also was statistically significant. These analyses provided support that the assumption of linear relationships among the pairs of variables was supported.

Homogeneity of variance, the third assumption was supported with nonsignificant results on Levene's test of equality of error variances for time dependence burden ($F [1, 318] = .34, p = .558$), developmental burden ($F [1, 318] = .89, p = .346$), and emotional burden ($F [1, 318] = .84, p = .359$). The results of the Box's test of equality of covariance matrices ($F = .86, p = .526$) provided support that the assumption of homogeneity of variance and covariances was met. Living arrangements were dichotomized into two groups: lives with parents and lives outside of parents' home. The three subscales measuring caregiver burden were used as the dependent variables in this analysis. Table 20 presents results of this analysis.

Table 20

Means and Standard Deviations: Caregiver Burden by Adult Child's Living Arrangements (N = 320)

Caregiver Burden	Lives with Parents (n = 248)		Lives outside of parents' home (n = 72)	
	Mean	SD	Mean	SD
Time Dependence burden	2.99	.99	2.50	.97
Developmental burden	2.97	1.03	2.75	1.10
Emotional burden	1.82	.74	1.93	.82

The results of the MANOVA and between subjects effects are presented in Table 21.

Table 21

Multivariate Analysis of Variance and Between Subjects Effects for Caregiver Burden by Adult Child's Living Arrangements (N = 320)

MANOVA*			Between Subjects Effects								
			Time Dependence Burden			Developmental Burden			Emotional Burden		
F	p	η^2	F	P	η^2	F	P	η^2	F	P	η^2
5.96	.001	.05	13.96	<.001	.04	2.55	.111	.01	1.09	.298	.01

*F ratio is an approximation of Wilks Lambda.

The MANOVA comparing the three subscales measuring caregiver burden was statistically significant, $F(3, 316) = .946, p = .001, \eta^2 = .05$. Although the results were statistically significant, the small effect size illustrated that the result has little practical significance. One statistically significant result was obtained for time dependence burden, $F(1, 318) = 13.68, p < .001, \eta^2 = .04$. Time dependence burden was significantly higher for parents whose adult child with ASD lived in their home ($M = 2.99, SD = .99$) than for those who lived outside of their parents' homes ($M = 2.50, SD = .97$). While the between subjects effect was significant, the effect size of .04 was small, providing evidence that the result had little practical significance. The remaining two subscales, developmental burden and emotional burden, did not differ between the parents whose adult child with ASD lived with them and those whose adult child lived outside of the home.

The comparison of the three types of caregiver burden was statistically significant when taken as a whole in the MANOVA, but when analyzed separately, only the time dependence burden differed between parents of adult children with ASD who lived in the parents' homes or lived outside of their homes. A composite score for burden was used to include the three measures of burden as a way to provide a holistic representation of burden associated with providing care for an adult child with ASD.

A t-test for two independent samples was used to determine if the composite score for caregiver burden differed between adult children with ASD who lived at home with their parents or those who lived outside of their parents' homes. The scores for the three types of burden (time dependence, developmental, and emotional burden) were used to create the composite score for caregiver burden. The results of this analysis are presented in Table 22.

Table 22

t-Test for Two Independent Samples: Caregiver Burden (composite score) by Adult Child's Living Arrangements (N = 320)

Living Arrangements	<i>N</i>	<i>M</i>	<i>SD</i>	<i>DF</i>	<i>t</i> -Value	<i>p</i>
At home with parents	248	2.59	.71	318	2.09	.038
Live outside of parents' homes	72	2.39	.78			

The comparison of the composite scores for caregiver burden between adult children with ASD who lived at home with their parents ($M = 2.59$, $SD = .71$) and those who lived outside of parents' homes ($M = 2.39$, $SD = .78$) was statistically significant, $t(318) = 2.09$, $p = .038$. Based on this finding, it appears that parents whose adult child lives at home with them have higher levels of caregiver burden than those who lived outside of their parents' homes.

A MANOVA was completed using formal and informal social supports as the dependent variables and living arrangements of the adult child with ASD as the independent variable. Table 23 presents results of the descriptive statistics for this analysis.

Table 23

Means and Standard Deviations: Informal and Formal Social Support by Adult Child's Living Arrangements (N = 320)

Social Support	<u>Lives with Parents (n = 248)</u>		<u>Lives outside of parents' home (n = 72)</u>	
	Mean	SD	Mean	SD
Informal	3.30	.98	3.62	.97
Formal	2.94	2.31	3.26	2.42

The results of the MANOVA for formal and informal social support are presented in Table 24.

Table 24

Multivariate Analysis of Variance and Between Subjects Effects for Informal and Formal Social Support by Adult Child's Living Arrangements (N = 320)

MANOVA*			<u>Between Subjects Effects</u>					
			Informal Social Support			Formal Social Support		
F	p	η^2	F	p	η^2	F	P	η^2
3.82	.023	.02	6.04	.014	.02	1.05	.306	<.01

*F ratio is an approximation of Wilks Lambda.

The comparison of formal and informal social support by living arrangements of adult child with ASD was statistically significant, $F(2, 317) = 3.82, p = .023, \eta^2 = .02$. While the comparison of informal and formal social support was statistically significant, the effect size of .02 showed that the result had little practical significance. The between subjects analysis was statistically significant for informal social support, $F(1, 318) = 6.04, p = .014, \eta^2 = .02$. The difference, although statistically significant, had little practical significance as evidenced by the low effect size of .02. Parents whose adult children with ASD lived outside of their home ($M = 3.62, SD = .97$) had higher scores for informal social support than parents whose adult children with ASD lived in their homes ($M = 3.30, SD = .98$). The comparison of formal social support did not differ significantly between parents whose adult children with ASD lived outside of their homes ($M = 3.26, SD = 2.42$) and those whose adult children with ASD lived outside of their homes ($M = 2.94, SD = 2.31$).

A one-way analysis of variance (ANOVA) was used to determine if a difference existed between impact on finances differed between parents whose adult children with ASD lived in their homes or outside of their homes. The results of this analysis are presented in Table 25.

Table 25

One-way Analysis of Variance – Impact on Finances by Living Arrangements of Adult Child with ASD (N = 320)

Living Arrangements	M	SD	DF	F	Sig	η^2
Lives at home with parents	2.75	1.10	1, 318	.89	.346	<.01
Lives outside of home	2.89	1.19				

The comparison of the impact on finances by living arrangements of the adult child with ASD was not statistically significant, $F(1, 318) = .89, p = .346, \eta^2 < .01$. Parents whose adult children with ASD lived outside of the home ($M = 2.89, SD = 1.19$) had higher scores for the impact on finances than parents whose adult children with ASD lived in their homes ($M = 2.75, SD = 1.10$), although this difference was not statistically significant.

The parents' QOL was compared by the living arrangements for their adult children with ASD using a one-way ANOVA. The QOL was used as the dependent variable, with living arrangements used as the independent variable. Table 26 presents results of this analysis.

Table 26

One-way Analysis of Variance – Quality of Life by Living Arrangements of Adult Child with ASD (N = 320)

Living Arrangements	M	SD	DF	F	Sig	η^2
Lives at home with parents	3.38	.69	1, 318	5.78	.017	.02
Lives outside of home	3.60	.64				

The comparison of QOL between parents whose adult children with ASD were living at home and those whose children were living outside of the home was statistically significant, $F(1, 318) = 5.78, p = .017, \eta^2 = .02$. Although the finding of the ANOVA was statistically significant, the effect size of .02 was low, indicating the result has little practical significance. Parents whose

children lived outside of their homes ($M = 3.60$, $SD = .64$) had higher QOL than parents whose children lived in their homes ($M = 3.38$, $SD = .69$).

Research Questions and Hypotheses

Prior to beginning the multiple linear regression analysis that would be used to address the research questions and test the hypotheses, interaction variables were created. The interaction variables were developed by multiplying two independent variables to create a third variable. The interaction of caregiver burden and formal social support was obtained by multiplying the score for caregiver burden by the mean score for formal social support. The same process was used to create the interaction between caregiver burden and informal social support.

All variables, including independent variables, the dependent variable, and interaction terms, were tested for skewness and kurtosis. The independent variables were tested for skewness using the Explore command in IBM SPSS. None of the variables had skewness greater than 1.00 and did not require any transformations.

An intercorrelation matrix using Pearson product moment correlations was obtained among the dependent variable and the independent variables, including those that had been transformed. Table 27 presents results of this analysis.

Table 27

Intercorrelation between Quality of Life and Independent Variables

	QOL	1	2	3	4	5	6	7
QOL	—							
1. Caregiver self-rating of health	.41**	—						
2. Caregiver burden	-.52**	-.26**	—					
3. Informal social support	.53**	.26**	-.37**	—				
4. Formal social support	-.06	-.05	.32**	-.09	—			
5. Impact on finances	.38**	.30**	-.48**	.36**	-.17**	—		
6. Burden X Informal social support	-.01	-.02	.55**	.54**	.18**	-.14*	—	
7. Burden X Formal social support	-.21**	-.09	.57**	-.19**	.93**	-.28**	.31**	—

*p < .05; **p < .01

Statistically significant correlations were obtained between QOL and each of the independent variables, with the exception of formal social support and the interaction between emotional burden and informal social support. The positive correlation between QOL and caregiver self-rating of health ($r = .41$, $p < .001$), informal social support ($r = .53$, $p < .001$), and impact on finances ($r = .38$, $p < .001$) suggested that higher levels of QOL were associated with higher values on these independent variables. The negative correlations were between QOL and caregiver burden ($r = -.52$, $p < .001$) and the interaction between burden and formal social support ($r = -.21$, $p < .001$). These results indicated that higher scores for QOL were associated with lower caregiver burden and lower scores on the interaction between burden and formal social support. The correlations among the independent variables were high, with most statistically significant.

A multiple regression analysis was completed using QOL as the dependent variable and the independent variables entered in blocks. On the first block, caregiver self-reported health was entered, and the impact on finances was added on the second block. Caregiver burden (composite

of time dependence burden, developmental burden, and emotional burden) was added on the third block, and living arrangements of the adult child with ASD was included on the fourth block. The interactions between formal social support and the composite score for burden was entered in the fifth block, with the interactions between informal social support and the composite score for burden entered on the sixth block. Table 28 presents results the variance explained at each block and cumulatively.

Table 28

Multiple Linear Regression Analysis – Quality of Life

Step and Predictor Variable	Total R ²	ΔR ²
Step 1		
Parents' self-reported health	.17**	
Step 2		
Impact on finances	.25**	.08**
Step 3		
Burden	.37**	.12**
Step 4		
Living arrangement of adult child with ASD	.37**	<.01
Step 5		
Interaction between burden and formal social support	.38**	.01
Step 6		
Interaction between burden and informal social support	.45**	.07**

*p < .05; **p < .001

On the first step of the multiple linear regression analysis, parents' self-reported health accounted for 17% of the variance in QOL, $r^2 = .17$, $F(1, 311) = 62.85$, $p < .001$. Higher scores on self-reported health were associated with better QOL outcomes. The positive relationship between parents' self-reported health and QOL indicated that parents who self-reported their health as better were more likely to have a better QOL.

Impact on finances was entered on the second step of the multiple linear regression analysis, explaining an additional 8% of the variance in QOL for a total variance explained of 25%, $r^2 = .08$, $F(2, 310) = 50.62$, $p < .001$. The relationship between impact on finances and QOL was in a positive direction, providing evidence that parents who reported greater impact on finances tended to have lower QOL.

Caregiver burden, a composite of time dependence burden, developmental burden, and emotional burden, was entered on the third step of the multiple linear regression analysis. This predictor variable accounted for an additional 12% of the variance in QOL for a total variance explained of 37%, $r^2 = .12$, $F(3, 309) = 59.65$, $p < .001$. The negative relationship between burden and QOL was indicative that higher levels of burden among older parents of adult children with ASD were associated with lower QOL.

On the fourth step of the multiple linear regression analysis, the living arrangement of the adult child with ASD added less than 1% to the explained variance in QOL for a total variance explained of 37%, $r^2 < .01$, $F(1, 311) = 45.19$, $p < .001$. Although the regression equation remained statistically significant, the living arrangement of the adult child with ASD was not a statistically significant predictor of QOL when considered in a regression with other predictors.

The interaction effects of burden; as a composite of time dependence burden, developmental burden, and emotional burden; with formal social support was entered on the fifth step of the multiple linear regression analysis, added 1% to the explained variance in QOL for a total variance explained of 38%, $r^2 = .05$, $F(1, 311) = 31.34$, $p < .001$.

On the sixth step of the analysis, the interaction effects of the composite of the three burden scales with informal social support accounting for an additional 5% of the variance in QOL for a

total variance explained of 45%, $r^2 = .09$, $F(1, 311) = 30.94$, $p < .001$. The results of the final model of the regression analysis are presented in Table 29.

Table 29

Multiple Linear Regression Analysis – Final Model with All Predictor Variables

Variable	b	SE _b	B	t	Sig
Caregiver self-rating of health	.16	.03	.23	5.02	<.001
Impact of caregiving on finances	.04	.03	.07	1.39	.166
Caregiver burden as a composite	-.63	.06	-.67	-9.97	<.001
Living arrangements revised	.06	.07	.04	.83	.409
Interaction between caregiver burden and formal social support	.01	.01	.11	2.03	.043
Interaction between caregiver burden and informal social support	.08	.01	.34	6.44	<.001
Multiple R	.67				
Multiple R ²	.45				
F Ratio	41.98				
DF	6, 306				
Sig	<.001				

The multiple linear regression equation for the final model was statistically significant, accounting for 45% of the variance in QOL, $R^2 = .45$, $F(6, 306) = 41.98$, $p < .001$. Therefore, the following statements can be made in reference to the research questions and hypotheses.

RQ 1. What is the relationship between the perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD?

H₁: There is a relationship between perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD.

H₀₁: There is not a relationship between perceived financial impact (of caregiving) and QOL among parental caregivers of adult children with ASD.

The results of the multiple linear regression equation provided evidence that the financial impact of caregiving was not a statistically significant predictor of QOL, $\beta = .07$, $t = 1.39$, $p = .166$. Based on this finding the first null hypothesis was retained.

RQ 2. What is the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?

H₂: There is a relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H₀₂: There is not a relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

Caregiver burden, as a composite of time dependence burden, developmental burden, and emotional burden, was a statistically significant predictor of QOL, $\beta = -.67$, $t = -9.97$, $p < .001$. The negative relationship between caregiver burden and QOL indicated that older parents of adult children with ASD were more likely to have higher QOL if they reported less caregiver burden. These findings provided support for rejection of the null hypothesis.

RQ 3. What is the relationship between living arrangement and QOL among parental caregivers of adult children with ASD?

H₃: There is a relationship between living arrangement and QOL among parental caregivers of adult children with ASD.

H₀₃: There is not a relationship between living arrangement and QOL among parental caregivers of adult children with ASD.

The relationship between living arrangement and QOL was not statistically significant, $\beta = .04$, $t = .83$, $p = .409$. This finding indicated that where the adult child lived (at home or away

from their parents' homes) was not related to their QOL. Based on this finding, the null hypothesis of no relationship was retained.

RQ 4. Does formal social support moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?

H₄: Formal social support moderates the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H₀₄: Formal social support does not moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

The interaction between formal social support and caregiver burden was a statistically significant predictor of QOL, $\beta = .11$, $t = 2.03$, $p = .043$. Based on this finding, the null hypothesis of no relationship was rejected.

RQ 5. Does informal social support moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD?

H₅: Informal social support moderates the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

H₀₅: Informal social support does not moderate the relationship between caregiver burden and QOL among parental caregivers of adult children with ASD.

The relationship between the interaction of informal social support and caregiver burden was significantly related to QOL, $\beta = .34$, $t = 6.44$, $p < .001$. Based on this finding, the null hypothesis of no relationship was rejected.

Three of the five hypotheses were rejected in the multiple linear regression analysis. Caregiver burden was the strongest predictor of QOL, but in a negative direction, indicating that higher caregiver burden was associated with lower QOL. The second strongest predictor of QOL

was the interaction between caregiver burden and informal social support. The interaction between caregiver burden and informal social support was a statistically significant predictor of QOL. The impact of caregiving on finances and living arrangements of the adult child with ASD were not statistically significant predictors of QOL.

Additional Findings

Caregiver burden was a statistically significant predictor of QOL. Caregiver burden has been associated with impact on finances, including income (Altiere & von Kluge, 2009; Fletcher, Markoulakis, & Bryden, 2012; Green, 2007; Sharpe & Baker, 2007), as well as social support (Boyd, 2012; Grey, 2003; Mendoza & Dickson, 2010; Olshevski, Katz, & Knight, 1999). Additional analyses were used to determine which of the selected variables could be explaining or predicting caregiver burden. A multiple linear regression analysis was used to determine if four variables, annual family income, impact of caregiving on finances, informal social supports, and number of formal social support, were explaining a significant amount of variance in caregiver burden. The results of this analysis are presented in Table 30.

Table 30

Multiple Linear Regression Analysis – Caregiver Burden

Variable	b	SE _b	B	t	Sig
Annual family income	-.01	.03	-.02	-.37	.715
Impact of caregiving on finances	-.23	.04	-.36	-6.38	<.001
Informal social support	-.16	.04	-.22	-3.86	<.001
Number of formal social supports	.07	.02	.21	4.11	<.001
Multiple R	.57				
Multiple R ²	.32				
F Ratio	31.36				
DF	4, 260				
Sig	<.001				

Three of the four variables in the multiple linear regression analysis were statistically significant predictors of caregiver burden accounting for 32% of the variance in caregiver burden, $F(4, 260) = 31.36, p < .001$. Impact of caregiving on finances was a significant predictor of caregiver burden in a negative direction, $\beta = -.36, t = -6.38, p < .001$. The negative relationship between these variables provided support that as caregiver burden decreased the impact of caregiving on finances increased. Informal social support was a negative predictor of caregiver burden, $\beta = -.22, t = -3.86, p < .001$. Based on this finding, as caregiver burden increased, the perceptions of informal social support were decreasing. The number of formal social supports was related significantly to caregiver burden in a positive direction, $\beta = .21, t = 4.11, p < .001$. This finding provided evidence that as the number of social supports increased, caregiver burden decreased. An interesting finding was that annual family income was not significantly related to caregiver burden.

The scores for caregiver burden, informal social support, and formal social support were dichotomized using median splits to form groups reflecting high and low caregiver burden, and high and low informal and formal social support. The mean scores for QOL were calculated for each of the four combinations included in the interaction (low caregiver burden/low informal social support; low caregiver burden/high informal social support; high caregiver burden/low informal social support; and high caregiver burden/high informal social support). The mean scores for the interaction effects for QOL by caregiver burden and informal social support are presented in Table 31.

Table 31

Interaction Effect for Quality of Life by Caregiver Burden and Informal Social Support

Caregiver Burden	Social Support					
	Low Informal Social Support			High Informal Social Support		
	N	M	SD	N	M	SD
Low Caregiver Burden	54	3.42	.52	102	3.92	.49
High Caregiver Burden	108	2.99	.64	56	3.40	.59

The participants with low informal social support and high caregiver burden had the lowest scores for QOL ($M = 2.99$, $SD = .64$). In contrast, older parents who had low caregiver burden and high informal social support had the highest scores for QOL ($M = 3.92$, $SD = .49$). The inclusion of high levels of informal social support with low caregiver burden had a positive influence on QOL. Older parents of adult children with ASD were more likely to have lower levels of QOL if they were experiencing greater burden and less informal social support. The interaction effect is presented in Figure 6.

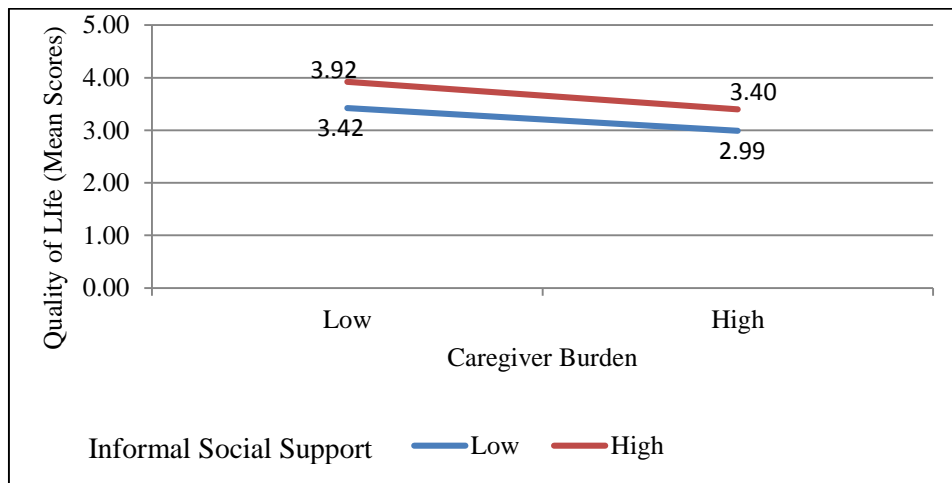


Figure 6: Interaction of Caregiver Burden and Informal Social Support on Quality of Life

The mean scores for the interaction effects for QOL by caregiver burden and formal social support are presented in Table 32.

Table 32

Interaction Effect for Quality of Life by Caregiver Burden and Formal Social Support

Caregiver Burden	Social Support					
	Low Formal Social Support			High Formal Social Support		
	N	M	SD	N	M	SD
Low Caregiver Burden	114	3.74	.55	42	3.77	.57
High Caregiver Burden	90	3.05	.60	74	3.22	.71

Older parents of adult children with ASD were likely to have similar levels of QOL if they had low caregiver burden, regardless of whether they had high formal social support ($M = 3.75$, $SD = .55$) or low formal social support ($M = 3.77$, $SD = .57$). In contrast, older parents of adult children with ASD with high caregiver burden and high formal social support ($M = 3.22$, $SD = .71$) had higher scores for QOL than those with high caregiver burden and low formal social support ($M = 3.05$, $SD = .60$). Figure 7 presents a graphical representation of the interaction effect between caregiver burden and formal social support on QOL.

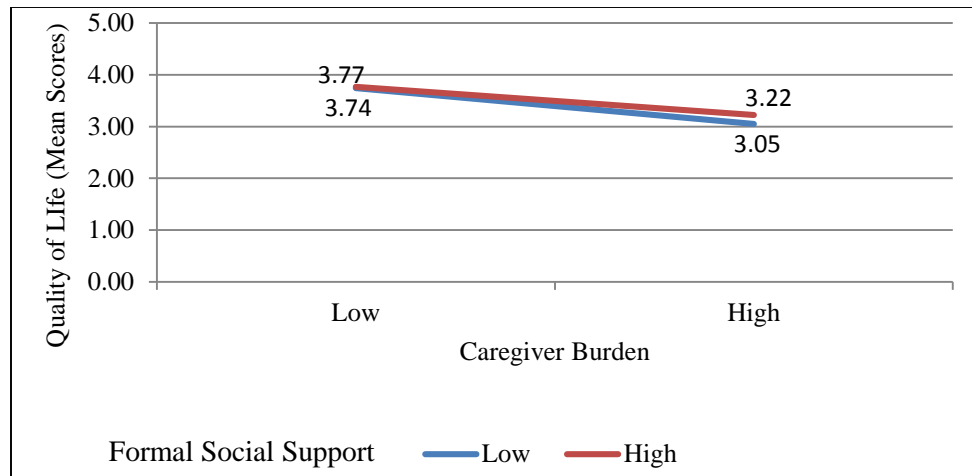


Figure 7: Interaction of Caregiver Burden and Formal Social Support on Quality of Life

When looking at the effects of informal and formal social support and caregiver burden on QOL, older parents of adult children with ASD who experienced low caregiver burden were more likely to have higher QOL, especially with higher levels of informal and formal social support. Informal social support may be a more important contributor to QOL than formal social support.

CHAPTER 6 CHAPTER DISCUSSION

With increases in the number of children diagnosed with Autism Spectrum Disorder (ASD), a need exists to understand the effect of caregiving burdens and responsibilities on the quality of life (QOL) of parents who continue to provide care for their adult children with ASD. Research investigating caregivers of adults with ASD is emerging; however, further efforts are needed. A study of parents of adult children with ASD is important to understand how they maintain their QOL as they continue to age. This study defines QOL as "... an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional wellbeing together with the extent of personal development and purposeful activity, all weighted by a personal set of values" (Felce & Perry, 1995, p. 160, 162). The purpose of this study was to examine effects of perceived financial impact, caregiver burden, living arrangement of the adult child with ASD on QOL among parents of adult children with ASD. In addition, contributing factors to QOL, such as social support, were investigated.

Summary of Findings

A total of 320 parents of adult children diagnosed with ASD participated in the study by completing a web-based survey. The parents were at least 50 years of age and had at least one child with ASD who was 18 years of age or older. The majority of the parents who responded were female, Caucasian/White, married, and working full or part-time. The greatest number of parents had completed at least a bachelor's degree and had family incomes in excess of \$80,000. Most adult children with ASD were male and living with their parents.

The mean age of the adult children with ASD was 25.14 (SD = 7.09) years, ranging from 18 to 62 years. Some adult children with ASD were working full (6.6%) or part-time (18.5%), some were in college (9.2%), many were either unemployed (16.6%) or unable to work (18.2%).

The largest group of adult children (n = 124, 38.8%) were able to communicate a wide variety of topics in a meaningful way, with 112 (35.0%) able to communicate in a limited range of topics in a meaningful way. Seventeen (5.3%) had very little meaningful communication and 4 (1.3%) could communicate only with a device. Most of the adult children with ASD required either minimal or substantial prompting, direction or redirection. Few of the adult children with ASD were unable to socialize or socialized with family only. Most of the adult children with ASD were able to complete activities of daily living either independently or with minimal assistance, with the exception of managing money and taking public transportation. Regarding living arrangements, the majority (n = 248, 77.5%) of adult children with ASD lived with their parents in this study. Less than a quarter (n = 72, 22.5%) of adult children with ASD lived outside of their parents' homes.

The caregivers were asked to answer questions regarding their health and health-related items. Most parents self-reported their health from fair to good. The parents were asked to indicate the types of formal social supports they received for themselves or their adult children with ASD. The greatest number of parents indicated their children received psychiatric services (n = 156, 48.8%). The second most commonly indicated formal social support was financial support from private or public organizations (n = 133, 41.6%), followed by counseling (n = 133, 41.6%). Informal social support most commonly included informal emotional support (n = 221, 69.5%), followed by informal informational support (n = 168, 52.5%). To a lesser extent, some parents reported they received informal physical assistance (n = 74, 23.1%) and informal respite care (n = 70, 22.0%).

The first hypothesis, concerning the relationship between financial impact of caregiving and caregivers' QOL, was not supported. In contrast, the second hypothesis was supported in terms

of a significant relationship between caregiver burden and QOL. The third hypothesis, suggesting a relationship between living arrangements of the adult child with ASD and QOL, was not supported in terms of a statistically significant relationship. The relationship between the interaction of caregiver burden and formal social support and QOL, suggested in the fourth hypothesis, was supported, indicating that formal social support was a statistically significant moderator of the relationship between caregiver burden and QOL. In contrast, the fifth hypothesis stating that informal social support was a significant moderator of the relationship between caregiver burden and QOL was supported. This finding provided support that informal social support moderated the relationship between caregiver burden and QOL.

Three of the five hypotheses were supported in terms of statistically significant predictors of QOL as shown in the multiple linear regression analysis. Caregiver burden was the strongest predictor of QOL, but in a negative direction, indicating that higher caregiver burden was associated with lower QOL. The second strongest predictor of QOL was the interaction between caregiver burden and informal social support. The interaction between caregiver burden and formal social support also was a statistically significant predictor of QOL. The impact of caregiving on finances and living arrangements of the adult child with ASD were not statistically significant predictors of QOL.

Implications of Study Results

A convenience sample was used to recruit participants for the study. The older parents in the sample were well educated and had middle to upper middle incomes. While they may not have been representative of older parents of adult children with ASD, they may have been more connected in the ASD community and more aware of the need for research on this topic. The

primary recruitment efforts for this study targeted individuals associated with disability organizations and/or support groups across the nation.

Most parents in this study self-reported their health as good to excellent. While no previous research directly addressed the health of older parents of adult children with ASD, studies on parents of younger children were likely to report physical and psychological health issues, such as elevated levels of fatigue, depression, and anxiety (Altiere & von Kluge, 2009; Benson, 2006; Smith et al., 2010). Parents of adult children with developmental disabilities (DDs) also reported poor health outcomes, such as fatigue and headaches, when compared with parents of similarly aged adult non-disabled children (Smith, Greenberg, & Seltzer, 2012). The findings of the present study were inconsistent with previous research. In the present study, parents indicated that their lives had meaning, satisfaction with selves, and enjoyment in life on the psychological domain of the WHOQOL-BREF. As children with ASD grow and mature into their adult years, they might require less time, attention, and energy from their parental caregivers. It also is possible that their parents learned to cope more effectively and had levels of resiliency that mitigated some of the adverse mental health realities/outcomes that many parents of younger children experience. While the findings of the present study were compared to prior studies of parents of young children with ASD or parents of adult with DDs, the findings were dissimilar, possibly because of differences among the participants in the past and present studies.

In contrast to prior research (Altiere & von Kluge, 2009; Montes & Halterman, 2008), the first hypothesis found that financial impact of caregiving for parents of adult children with ASD was not a statistically significant predictor of QOL. This finding was not surprising because the majority of older parents in the study had annual incomes in excess of \$60,000. One possible explanation was that the costs associated with parenting an individual with ASD became a norm

for these parents, perhaps without even realizing the continued costs associated with caregiving. In addition, the literature supported the high costs of parenting a child with ASD, including for those who sought early intervention services for their child. As children matured into adulthood, many of the formal social services and supports might have changed and could have been phased out (e.g., services like Applied Behavioral Analysis that were typically used for younger children). Another possible explanation was that parents reported less financial burden, when compared with previous studies (Altiere & von Kluge, 2009; Fletcher, Markoulakis, & Bryden, 2012; Montes & Halterman, 2008; Parish, Rose, & Swaine, 2010; Sharpe & Baker, 2007), as adults with ASD may receive some financial support, such as income provided through Supplemental Security Income. As children with ASD enter adulthood, parents might experience less financial burden associated with medical insurance. Adults with ASD might qualify for either Medicaid or their own personal health insurance instead of their parents' medical insurance.

The findings for the second hypothesis supported previous research findings (e.g. Lee, Harrington, Louie, & Newschaffer, 2008), suggesting an inverse relationship between caregiver burden and QOL for parents of adult children with ASD. An inverse relationship between caregiver burden and QOL among caregivers is supported in the literature worldwide. For example, a number of international studies indicated an inverse relationship exhibited by caregivers, including those caring for stroke patients, individuals with schizophrenia, children with autism, and veterans (Brouwer et al., 2014; Feeley et al., 2014; Foldemo, Gullberg, Ek, Bogren, 2005; Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999; Lee et al., 2008; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Morimoto, Schreiner, & Asano, 2003; Mugno, Ruta, D'Arrigo, & Mazzone, 2007). The present study's findings were consistent with the results of earlier research in which parents

of adult children with ASD were more likely to have higher QOL when they reported less caregiver burden.

In contrast with previous literature that provided support for a number of benefits for parents of children with ASD (Krauss, Seltzer, & Jacobson, 2005) and for parents of adults with ASD (Krauss et al., 2005) who lived outside of their families' homes, living arrangements were not a statistically significant predictor of parents' QOL for the third hypothesis. However, parents of adult children with ASD who were living at their homes had higher mean scores for time dependence burden than parents of adult children living outside of their homes. One possible reason for this finding was that adult children with ASD residing in their parents' homes might have greater impairments that require more parental involvement and care, with more time devoted to caregiving/parenting duties. When the adult child lived outside of the home, many tasks associated with parenting an adult child with ASD might not be required. For example, an adult child with ASD living in a group home or another form of supported living arrangement might receive assistance and supervision from someone other than their parent, alleviating some of the time required of his or her parent. Another possible explanation is that some adult children with ASD who are able to live almost or entirely independently outside of their homes may require less assistance. Parents of adult children with ASD who live outside of their homes may feel comfortable that their children's needs are being met.

In explaining caregiver burden, particularly time dependence burden; social behavior, communication deficits, as well as the need for behavioral prompting and redirection of adult children with ASD should be considered. In the present study, few adult children with ASD socialized with anyone outside of their homes (e.g. > 25% socialized with family only, > 10% were not able to make friends). The communication ability of adult children with ASD ranged from

being able to communicate on a wide variety of topics in meaningful ways to needing a device to communicate or having very little meaningful communication. Most adult children with ASD required minimal to substantial prompting, direction, or redirection to manage or control behavior. This lack of independence could place additional time demands on caregiver burden for their aging parental caregivers who were responsible for the day-to-day care of their adult children with ASD.

The fourth hypothesis supported the finding that the interaction between formal social support and caregiver burden was a statistically significant predictor of QOL among parents of adult children with ASD. This finding was consistent with previous literature, indicating the importance of social supports for parents of children diagnosed with ASD (Altiere & von Kluge, 2009; Boyd, 2002; Mendoza & Dickson, 2010; Siklos & Kerns, 2006). Formal social supports appear to play an important role in the lives of parents of adult children with ASD. Having a keen understanding of the benefits of formal social supports and the extent to which these supports were used by parents of adult children with ASD may provide a framework for the development and refinement of services. The importance of formal social supports and unmet needs associated with these supports were demonstrated in the literature (Poston et al., 2003; Samuel, Hobden, & LeRoy, 2011), although no specific published literature documented the use of formal social support as a moderator between caregiver burden and QOL.

The moderating effects of social support on the relationship between caregiver burden and QOL were tested. Caregiver burden and formal and informal social support were categorized into four groups using median splits. The four groups were low caregiver burden and low formal/informal social support, low caregiver burden and high formal/informal social support, high caregiver burden and low formal/informal social support, and high caregiver burden and high formal/informal social support. The mean scores for QOL were obtained for each of the groups.

To explore this finding further, post hoc analyses were conducted to determine the interaction effect between caregiver burden and formal social support were used as independent variables to determine their effect on QOL. When the mean scores for QOL were compared by high and low caregiver burden and high and low formal social support, the findings provided support that parents of adult children with ASD were more likely to have higher QOL if they had low caregiver burden and high formal social support. Parents with high caregiver burden and low formal social support had the lowest levels of QOL. Based on these results, parents of adult children with ASD benefitted from formal social support, but only if they had lower levels of caregiver burden.

The level of informal social support on parents' ability to manage their emotions, stress, and to obtain needed information (Altiere & von Kluge, 2009; Gray, 2003) could impact the QOL for parents of adult children with ASD favorably. The findings of the fifth hypothesis that informal social support moderates the relationship between caregiver burden and QOL provided support that parents who had an informal social support network experienced lower levels of caregiver burden and higher levels of QOL. The levels of QOL were compared between high and low caregiver burden and high and low informal social support. Parents of adult children with ASD had the highest levels of QOL if they had low caregiver burden and high informal social support. In contrast, parents who had high caregiver burden and low informal social support had the lowest levels of caregiver burden. These findings provided additional support that QOL was moderated by the levels of caregiver burden and informal social support.

A post hoc multiple linear regression analysis was used to determine which independent variables, annual family income, impact of caregiving on finances, informal social support, and number of formal social supports, could be used to predict level of caregiver burden. Three variables, impact of caregiving on finances, informal social support, and number of formal social

supports, were statistically significant predictors of caregiver burden. Impact of caregiving on finances and informal social support were negatively related to caregiver burden. Parents of adult children with ASD who had lower levels of caregiver burden tended to report less impact of caregiving on finances and higher levels of informal social supports. In contrast, parents of adult children with ASD who indicated they had used a higher number of formal social supports were more likely to have higher caregiver burden. A possible explanation for this relationship was that adult children who had greater needs from their ASD were likely to use available formal social supports. The parents of these adult children would likely have greater caregiver burden because of their adult children's continuing needs.

Implications for Practice

The results of this study provided information on the need for the development of social work policies and programs to help parents of adult children with ASD. These policies should address the need for both formal and informal social supports, as well as ways for social workers to inform parents of available programs that could relieve some of the burden they encounter while caring for their adult children with ASD. In addition, social workers should be instrumental in supporting the efforts of other disciplines/interdisciplinary teams to assist individuals with ASD and their caregivers. For example, collaborative efforts with professionals in the public health and medical fields are warranted as ASD is a social issue needing social work attention. At this time, public health programs through organizations, such as National Association of City and County Health Officials (NAACHO), could be instrumental in developing focused and deliberate efforts to address the needs of individuals affected by ASD with emergency preparedness and health promotion programming. Specifically, health promotion programming should concentrate on the

needs of both individuals with ASD and their parental caregivers to enhance their physical health and QOL.

Social workers need to be aware that parents of adult children diagnosed with ASD could benefit from specialized social support services that might help improve their QOL. Many parents whose adult children were diagnosed as young children might have thought that services received while in school were no longer available after they aged out of school-based services. As many participants in the present study were drawn from support groups and were considered well educated, with moderately high incomes, representation from parents with low incomes who may have experienced greater caregiver burden was not available. These parents might need information regarding formal social supports that could be used with their children. For example, vocational rehabilitation services could help adults with ASD to find employment and employment support. Having their adult children working, even in entry-level jobs requiring few skills, could help adult children with ASD feel more independent and provide a sense of well-being for the parents.

Educating the public about ASD and the range of needs associated with this disorder is vital as the prevalence of ASD continues to grow. Social workers could be instrumental in providing accurate information to the public and advocating for support and services for both children and adults with ASD and their families. Through the efforts of social workers, greater awareness and increased understanding of ASD could result in the public becoming more accepting of individuals with ASD. Through this acceptance, parents and their adult children with ASD could obtain formal and informal social supports needed to enhance their QOL.

National, state, and local policies, programs, and interventions to help alleviate some of the time dependence burden need to be developed. Parents of adult children diagnosed with ASD who

lived at home experienced more time dependence burden than parents of adult children with ASD who lived outside of the home. While this finding was not surprising, social workers and other professionals should be cognizant of the acute needs of older parents who are providing care to adult children with ASD. The policies, interventions, and services need to be tailored to provide support for these caregivers. For example, formal social supports need to be individualized to accommodate the myriad of behaviors, characteristics, and idiosyncrasies of the adult child with ASD. The diagnosis of ASD is on a continuum, with no two individuals exhibiting the same set of traits, making a “one size fits all” approach ineffective.

The importance of informal social supports was confirmed in this study and other studies (Siklos & Kerns, 2006; Smith et al., 2012). While most of these supports are provided by relatives and friends, social workers should help nurture and foster the development of informal social support networks for older parents. These parents are experiencing the normal stages associated with aging, in addition to maintaining care for their adult children with ASD, and need support to enhance their QOL. Through the development of informal social support networks, parents of adult children with ASD could obtain short-term help with care and have someone to talk to about the demands associated with caring for their adult children.

Due to the broad continuum of needs for individuals with ASD, national awareness of the causes and treatment for ASD in adulthood is lacking. Programs and services are primarily targeted to address the needs of young children and adolescents with ASD and their caregivers. Individuals with ASD in adulthood appear to be a hidden population, as if this disorder affects only young children and adolescents. Few social policies and program focus on supporting this group and their caregivers. Micro and macro level efforts, such as notifying parents of adult children with ASD of programs and services as they are developed, are needed to support this growing population.

Parents have a variety of needs, likely contingent on the severity and characteristics of their adult child's ASD, as well as their own age. The social work profession needs to focus on advocacy and educational efforts to inform the public on ASD and the needs of families. A growing number of children continue to be diagnosed with this disorder. As these children age out of public education, family networks and formal social supports may become more important in alleviating the demands associated with caregiver burden by parents. In addition, due to the countless needs of both adult children with ASD and their parental caregivers in supporting their adult children, a central place for comprehensive and individualized services is warranted. A central place to obtain services may likely alleviate some of the burdens for parents, such as time dependence burden, associated with finding, obtaining, and navigating supportive services for their adult children with ASD.

Limitations of the Study

There are several limitations to this study that should be noted. First, this study primarily recruited participants who were members of many ASD support groups and national organizations. Although snowball sampling was used in an attempt to recruit additional participants, the sample may not have included parents of adult children diagnosed with ASD who were not part of such groups. In addition, some organizations may not have been included and/or represented in the recruitment efforts.

A second limitation of this study was the lack of information using a formal measure regarding the severity and degree of ASD for the adult children. In the present study, information from the parent assessing the degree or severity, such as severe, moderate, mild) of a parent's adult child with ASD might have provided pertinent information to determine the impact of severity of disability on a parent's QOL. This information might have been helpful in providing a framework

and profile of adult children with ASD, while potentially providing additional information as to how severity/manifestation of ASD influenced domains (e.g. burden, QOL) in parents' lives.

A third limitation concerns the lack of information regarding the age of the adult child with ASD at diagnosis. Parents of children with ASD who were diagnosed at an early age may have different perceptions of burden than children with ASD who were diagnosed when older. Because of the inclusion criteria of the study (e.g., adult children with ASD who are over 18 years of age), the type of diagnosis and timing of the diagnosis may have been different.

A fourth was the over-representation in this study of people who had higher family incomes and who were more highly educated than the average American. Approximately 39% of participants had annual family incomes over \$100,000, with a median income between \$80,000 and \$100,000, which was higher than the median income of \$53,657 (DeNavas-Walt & Proctor, U.S. Census Bureau, 2014). According to the 2014 U.S. Census Bureau's findings, 32.5% of the general population (including individuals at least 25 years of age) reported having earned at least a bachelor's degree. In the present study, over 62% of the population reported having earned at least a bachelor's degree. The participants in the present study may have been more aware of ASD and might have been better able to address the issues associated with caregiver burden and might not have experienced some of the same financial burdens as people who had lower socioeconomic levels.

The sample was primarily comprised of White parents (90.9%), with a small percentage of minorities, Black (1.6%) and Hispanic (3.8%) participating. In comparison, the 2014 U.S. Census Bureau's racial composition data indicated that the majority of the population was White (62.8%), with Blacks (12.2%) and Hispanics (16.9%) comprising the next largest groups (DeNavas-Walt &

Proctor, U.S. Census Bureau, 2014). This comparison provides support that minorities were underrepresented in the sample.

The measure of formal and informal social supports and the effectiveness of these supports might have been a limitation of the study. In the present study, formal social supports were a count of how many formal social supports were used, while informal social supports were assessed using five items using a Likert scale on helpfulness. Consistency is needed in measuring both the number and effectiveness of both formal and informal social supports for families of children with ASD.

Recommendations for Further Study

This study should be replicated using a larger, more heterogeneous sample that includes a greater representation of older adults of adult children diagnosed with ASD (age 50 and above). This sample should have representation from all racial groups in proportion to their prevalence in the population. To assure that Blacks and Hispanics are represented, these groups should be oversampled. People from all income groups and educational levels should be represented. The increased heterogeneity could result in findings that could be generalized to the population of interest, older parents of adult children diagnosed with ASD.

The present study included only parents whose adult children had been formally diagnosed with ASD. Some parents may have been excluded because their adult children lacked this diagnosis. A study including older parents of adult children who had formal and informal diagnoses of ASD should be used to determine if caregiving burdens, formal and informal social supports, and financial burden were similar between the two groups.

The present study did not obtain the age of the adult child with ASD at the time of his/her diagnosis. As the children in this study were adults, some may have been diagnosed at a later age, potentially affecting social, financial, and educational challenges for both the child and his/her

parents. Other adult children with ASD and their families may have encountered biased responses due to stigma associated with ASD, particularly among older cohorts. Additional research is needed to determine differences in caregiver burden and QOL based on the age at the initial diagnosis and generational cohort.

A study of the types of formal and informal social supports available and used by older parents is needed. The parents should be asked to indicate the types of social supports they used and then rate the ones used based on both satisfaction with the support and the effectiveness of the services provided. The results of this study could provide implications for the need for services and ways to improve their delivery to families of adults with ASD.

Future studies on adults with ASD should include the healthcare or educational professional who initially diagnosed the ASD. For a number of reasons it would have practical relevance to know the derivation of the diagnoses. This may prove beneficial when reaching out to families affected by ASD.

The severity of ASD should be assessed in future work. ASD is on a continuum and can range from mild to severe. The severity of ASD might impact caregiver stress due to different levels of an adult child's independence and functional capabilities. It is relevant to have an understanding of the severity of this disorder and how severity might impact caregiver burden and reported QOL. The results of the present study may have yielded interesting results if the severity of the ASD had been known.

State services and programs vary throughout the United States, with little being known about the needs in different geographic localities. It might prove beneficial to conduct an assessment by state of adults diagnosed with ASD to provide information regarding available services for these individuals. Future research attention should be devoted to understanding the

needs of adults with ASD and their supporting parental caregivers by state. An analysis of state-level policies regarding education, support, and social services for individuals with ASD and their parents/caregivers is needed to determine differences and similarities in services available nationwide. Additional research by state needs to be conducted using individuals with ASD and their parents/caregivers as participants to understand individuals' needs throughout the United States better and develop systematic services and programs based on these needs.

APPENDIX A
SURVEY INSTRUMENT

RESEARCH INFORMATION SHEET

Title of Study: An Examination of Quality of Life of Parents of Adult Children Diagnosed with Autism Spectrum Disorder

Principal Investigator (PI): Christina Marsack, School of Social Work,

Purpose: You are being asked to participate in a research study that seeks to examine the effects of caring for an adult child with Autism Spectrum Disorder (ASD) on parents' quality of life. This study is being conducted at Wayne State University.

Study Procedures: In order to be eligible to participate in this study, you must be at least 50 years of age. Your adult child must be at least 18 years old and be diagnosed with ASD. If you take part in the study, you will be asked to complete a web-based survey, including a demographic portion. You will be asked about your social support, health, finances, and feelings of burden. If you have more than one adult child with ASD, please refer to your oldest child with ASD. The survey and demographic questionnaire will take approximately 15 minutes to complete. At the end of the survey, you will be asked whether you would like to participate in a one-on-one interview to answer more questions regarding your experiences of caring for an adult child with ASD.

Benefits: As a participant in this research study, there will be no direct benefit for you; however, information from this study may benefit other people now or in the future.

Risks: You may experience some emotional discomfort while completing items on the survey. Emotional discomfort may include negative feelings such as sadness, anger, or anxiety.

Costs: There will be no costs to you for participation in this research study.

Compensation: You will not be paid for taking part in this study. Participants that would like to be included drawing may be selected to receive one of three \$25 gift cards.

Confidentiality: All information collected about you during the course of this study will be kept without any identifiers.

Voluntary Participation/Withdrawal: Taking part in this study is voluntary. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with Wayne State University or its affiliates.

Questions: If you have any questions about this study now or in the future, you may contact Christina Marsack at the following phone number: . If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313)

577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

Participation: Please indicate if you would like to participate in the survey.

- Yes (4)
- No (5)

If Yes Is Selected, Then Skip To What is your age? If No Is Selected, Then Skip To End of Survey

Q1 What is your age?

- Under 50 years (1)
- 50-59 (2)
- 60-69 (3)
- 70 and older (4)

Q2 What is the age of your oldest child with ASD?

- under 18 years (1)
- 18 years or older (2)

Q3 What is your gender?

- Male (1)
- Female (2)

Q4 What is your ethnicity?

- African American / Black (1)
- American Indian / Alaskan Native (2)
- Caucasian / White (3)
- Hispanic (4)
- Middle Eastern (5)
- Multi-ethnic (6)
- Other (7) _____

Q5 What is your marital status?

- Single, never married (1)
- Married (2)
- Separated (7)
- Divorced (3)
- Widowed (4)
- Cohabiting (5)
- Other (6) _____

Q6 What is your employment status that best describes you?

- Employed full-time (1)
- Employed part-time (2)
- Homemaker (8)
- Retired (3)
- Unemployed, looking for work (4)
- Unemployed, not looking for work (5)
- Disabled and unable to work (6)
- Other (7) _____

Q7 What is your level of education?

- Less than high school (1)
- High school / GED (2)
- Some college (3)
- Associate's degree / Technical School (4)
- Bachelor's degree (5)
- Master's degree (6)
- Doctorate / Professional Degree (7)
- Other (8) _____
- Not Applicable (9)

Q8 If there is a second parent involved with your adult child with ASD, what is his/her level of education?

- Less than high school (1)
- High school / GED (2)
- Some college (3)
- Associate's degree / Technical School (4)
- Bachelor's degree (5)
- Master's degree (6)
- Doctorate / Professional Degree (7)
- Other (8) _____
- Not Applicable- Please specify why it is not applicable. (9) _____

Q9 Please indicate the correct response for the items below.

	0 (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 or more (6)
Number of children in household (under 18 years) (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Total number of adult (18 and older) children in household, including the individual with ASD (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Number of children with disabilities other than ASD (under 18 years) (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Number of children with disabilities other than ASD (18 and older) (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Number of children with ASD (under 18 years) (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Number of children with ASD (18 and older) (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q10 Age of oldest child with ASD (in years)

Q11 Gender of adult child with ASD

- Male (1)
- Female (2)

Q12 Does your adult child with ASD:

- Live independently (1)
- Live independently with support (2)
- Live in a group home (3)
- Live with you (4)
- Other (5) _____

Q13 Please describe the employment status of your adult child with ASD:

- Employed full-time (1)
- Employed part-time (2)
- Working with a job coach (3)
- Employed in a sheltered workshop (4)
- Unable to work (11)
- Other (12) _____

Q14 Please describe the educational status of your adult child with ASD:

- Attending university or college (1)
- Attending community college (2)
- Attending a vocational training program (3)
- Attending public school (extended program for students 18 to 26 years) (4)
- Unable to attend educational program (5)
- Other (6) _____

Q15 Please rate your adult child's communication ability.

- Communicates a wide variety of topics in a meaningful way (1)
- Communicates within a limited range of topics in a meaningful way (2)
- Communicates needs and wants in some meaningful way (3)
- Communicates basic needs and wants (4)
- Very little meaningful communication (5)
- Communicates with a device (6)
- Other (7) _____

Q16 Please rate your adult child's behavior.

- Typical, age appropriate adult behavior (1)
- Requires minimal prompting, direction, or redirection (2)
- Requires substantial prompting, direction, or redirection (3)
- Engages in self-injurious behavior and/or dangerous, aggressive behavior (4)
- Requires 24 hour supervision to manage behavior (5)
- Other (6) _____

Q17 Please rate your adult child's behavior.

- Has a group of friends / Goes out with others from the community (1)
- Is part of a social group (2)
- Would like friendships, but does not have any friendships (3)
- Is not able to make friends (4)
- Socializes with family only (5)
- Other (6) _____

Q18 Please rate your adult child's activities of daily living. Please indicate which option reflects the amount of support that your adult child with ASD requires for the following activities of daily living.

	Able to perform the task independently (1)	Requires minimal assistance to perform the task (2)	Requires moderate assistance to perform the task (3)	Requires total assistance to perform the task (4)
Bathing / showering (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dressing (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating / Feeding (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Functional mobility (moving around safely from one place to another) (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal hygiene and grooming (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community-based activities for child with ASD (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Toileting (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Making bed / cleaning room (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cooking simple meals (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Managing money (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking public transportation (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q19 Do you provide care for anyone else other than your adult child with ASD? (e.g. spouse, parent, another child or dependent)?

- Yes (1)
 No (2)

Q20 If yes, please indicate the person(s).

- Parent (1)
- Spouse (2)
- Anyone else in the home (3)
- Other child(ren) (4)
- Other relative (5)
- Friend (6)
- Other (7) _____

Q21 Do you or your adult child with ASD receive formal social supports (e.g. supports paid by you or others) from any of the following? Indicate all that apply.

	Yes (1)	No (2)
Social work (2)	<input type="radio"/>	<input type="radio"/>
Counseling (9)	<input type="radio"/>	<input type="radio"/>
Speech therapy (8)	<input type="radio"/>	<input type="radio"/>
Occupational therapy (12)	<input type="radio"/>	<input type="radio"/>
Physical therapy (13)	<input type="radio"/>	<input type="radio"/>
Adult day care (10)	<input type="radio"/>	<input type="radio"/>
Psychiatric services (11)	<input type="radio"/>	<input type="radio"/>
Care for a chronic condition (21)	<input type="radio"/>	<input type="radio"/>
Financial support from private or public organizations / sources (14)	<input type="radio"/>	<input type="radio"/>
National organizations for caregivers of adult with autism (3)	<input type="radio"/>	<input type="radio"/>
State organizations for caregivers of adults with autism (4)	<input type="radio"/>	<input type="radio"/>
Autism support groups (1)	<input type="radio"/>	<input type="radio"/>
Community support groups for caregivers (regardless of disability) (5)	<input type="radio"/>	<input type="radio"/>
Respite Care (paid by you or through another source) (6)	<input type="radio"/>	<input type="radio"/>
Community Mental Health (7)	<input type="radio"/>	<input type="radio"/>

Q22 Please indicate if there are any other types of formal social support that you receive.

Q23 Do you or your adult child with ASD receive informal social supports (e.g. unpaid supports) from any of the following? Indicate all that apply.

	Yes (1)	No (2)
Respite care (e.g. from a family member or friend) (1)	<input type="radio"/>	<input type="radio"/>
Friends or family that you can rely on for physical assistance (2)	<input type="radio"/>	<input type="radio"/>
Friends or family that you can rely on for financial assistance (3)	<input type="radio"/>	<input type="radio"/>
Friends or family that you can rely on for emotional support (4)	<input type="radio"/>	<input type="radio"/>
Help with chores / household activities (5)	<input type="radio"/>	<input type="radio"/>
Informational support (e.g. from a social contact, family member, or friend) (6)	<input type="radio"/>	<input type="radio"/>

Q24 Please indicate if there are any other informal social support that you receive.

Q25 Please indicate the type of support (e.g. formal, informal, both or neither) that you receive for each of the categories below.

	I receive formal support (e.g. paid). (1)	I receive informal support (e.g. unpaid). (2)	I receive both formal and informal supports. (3)	I don't receive help in this way from any source. (4)
Emotional support (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Informational support (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial support (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical relief from caregiving (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Housing support (e.g. group home) (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation services (e.g. for medical care) (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community-based activities for adult child with ASD (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community mental health services, such as respite care, etc. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q26 How satisfied are you with each type of support? Place a check mark in the column that reflects your level of satisfaction with each of the following types of support.

	Not applicable (1)	Very Dissatisfied (2)	Dissatisfied (3)	Satisfied (4)	Very Satisfied (5)
Emotional support (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Informational support (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial support (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical relief from caregiving (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Housing support (e.g. group home) (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation services (e.g. for medical care) (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community-based activities for adult child with ASD (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community mental health services, such as respite care, etc. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q27 Please answer the following questions that describes your feelings about your adult child with ASD.

	Never (1)	Rarely (2)	Sometimes (3)	Quite Frequently (4)	Nearly Always (5)
He/she needs my help to perform many daily tasks (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
He/she is dependent on me (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have to watch him/her with many basic functions (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have to help him/her with many basic functions (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't have a minute's break from his/her chores (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that I am missing out on life (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wish I could escape from this situation (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My social life has suffered (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel emotionally drained due to caring for him/her (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expected that things would be different at this point in my life (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never (1)	Rarely (2)	Sometimes (3)	Quite Frequently (4)	Nearly Always (5)
I feel embarrassed over his/her behavior (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel ashamed of him/her (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I resent him/her (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel uncomfortable when I have friends over (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel angry about my interactions with him/her (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q28 Choose the option that best represents how often the statement describes your feelings.

	None of the time (1)	A little of the time (2)	Some of the time (3)	Most of the time (4)	All of the time (5)
Is there someone available to whom you can count on to listen to you when you need to talk? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is there someone available to you to give you good advice about a problem? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is there someone available to you who shows you love and affection? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is there someone available to help with daily chores? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	None of the time (1)	A little of the time (2)	Some of the time (3)	Most of the time (4)	All of the time (5)
Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide in? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q29 Choose the option that best represents how often the statements describes your feelings.

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)
I will never be able to do enough caregiving to repay my adult child with ASD. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial resources are adequate. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is difficult to pay for my adult child with ASD. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caring for my adult child with ASD puts a financial strain on me. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q30 Would you say your health is:

- Excellent (1)
- Very Good (2)
- Good (3)
- Fair (4)
- Poor (5)

Q31 The following questions ask about how much you have experienced certain things in the last two weeks.

	Not at all (1)	A little (2)	A moderate amount (3)	Very much (4)	An extreme amount (5)
How much do you enjoy life? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To what extent do you feel your life to be meaningful? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q32 The following question asks about how much you have experienced certain things in the last two weeks.

	Not at all (1)	Slightly (2)	A moderate amount (3)	Very much (4)	Extremely (5)
How well are you able to concentrate? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q33 The following question asks about how completely you experience or were able to do certain things in the last two weeks. Are you able to accept your bodily appearance?

- Not at all (1)
- A little (2)
- Moderately (3)
- Mostly (4)
- Completely (5)

Q34 The following question asks you to say how good or satisfied you have felt about an aspect of your life over the last two weeks. How satisfied are you with yourself?

- Very Dissatisfied (1)
- Dissatisfied (2)
- Neither satisfied nor dissatisfied (3)
- Satisfied (4)
- Very Satisfied (5)

Q35 The following question refers to how often you have felt or experienced certain things in the last two weeks. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?

- Never (1)
- Seldom (2)
- Quite often (3)
- Very often (4)
- Always (5)

Q36 Annual Family Income

- Less than \$20,000 (1)
- \$20,001 to \$40,000 (2)
- \$40,001 to \$60,000 (3)
- \$60,001 to \$80,000 (4)
- \$80,001 to \$100,000 (5)
- More than \$100,000 (6)
- I would prefer not to respond (7)

Q37 A follow up interview will be conducted either over the phone or locally with any participants interested in sharing more information regarding their experiences. Should you be interested in sharing

more information, please indicate "yes" and you will be asked to leave your name and contact information.

- Yes (1)
- No (2)

Answer If A follow up interview will be conducted either over the phone or locally with any participants in... Yes Is Selected

Q38 Please provide the following information:

- Name (1)
- Primary email address (3)
- Secondary email address (5)
- Phone Number 1 (4)
- Phone number 2 (6)

Q39 As a thank you for your participation you may take advantage of entering to be included in a drawing for a \$25 gift card. Three participants will be chosen in the drawing to win a gift card.

If you provide your contact information it will not be connected to the responses in your survey. Your contact information will not be included in the analysis of the data. Please provide your name and email address below if you would like to take advantage of these incentives:

- Yes (1)
- No (2)

Q40 Please provide the following information to be included in the drawing for a gift card:

- Name (1)
- Primary email address (4)
- Secondary email address (5)
- Phone Number 1 (3)
- Phone Number 2 (6)

Q41 Because you might have experienced emotional discomfort while completing survey items, the following sources of support are offered as suggestions: If you feel that you are in need of support, you could contact the National Autism Association at 877.622.2884 (<http://nationalautismassociation.org/>) or your local Autism support network / organization. In addition, a number of possible hotlines are available through the following website: <http://www.healthyplace.com/other-info/resources/mental->

health-hotline-numbers-and-referral-resources/#Hotline Thanks for taking the Survey. Please click Submit to finish your Survey.

APPENDIX B**COMMUNITY RESOURCES**

Because you might have experienced emotional discomfort while responding to interview questions, the following sources of support are offered as suggestions: If you feel that you are in need of support, you could contact the National Autism Association at 877.622.2884 (<http://nationalautismassociation.org/>) or your local Autism support network / organization. In addition, a number of possible hotlines are available through the following website: <http://www.healthyplace.com/other-info/resources/mental-health-hotline-numbers-and-referral-resources/#Hotline>

APPENDIX C

RECRUITMENT FLYER

Quality of life among parents of adult children with autism spectrum disorder

Be a part of a research study investigating quality of life among parents of adult children with autism spectrum disorder (ASD). The purpose of this study is to examine the effects of caring for an adult child with ASD on parents' quality of life. Contributing factors, such as social support and burden, will be investigated. To be included, you must

be at least 50 years old

have an adult child (18 years of age or older) diagnosed with ASD

If you have answered yes to these questions, you are eligible to participate in this study. Interested participants will be entered into a raffle to receive a \$25 gift card. The study will be conducted using an online survey. For interested participants, a follow up interview may be conducted over the phone or in-person to gather more information regarding parental quality of life.



If you are interested in participating, please
Visit the following link: <https://bitly.com/1wkSy0p>

Or contact:

Christina Marsack, Doctoral Candidate
AL9887@wayne.edu

APPENDIX D

RECRUITMENT FLYER- WITH TEAR OFF INFORMATION AREA

Quality of life among parents of adult children with autism spectrum disorder

Be a part of a research study investigating quality of life among parents of adult children with autism spectrum disorder (ASD). The purpose of this study is to examine the effects of caring for an adult child with ASD on parents' quality of life. Contributing factors, such as social support and burden, will be investigated. To be included, you must

be at least 50 years old

have an adult child (18 years of age or older) diagnosed with ASD

If you have answered yes to these questions, you are eligible to participate in this study. Interested participants will be entered into a raffle to receive a \$25 gift card. The study will be conducted using an online survey. For interested participants, a follow up interview may be conducted over the phone or in-person to gather more information regarding parental quality of life.



If you are interested in participating, please
Visit the following link: <https://bitly.com/1wkSy0p>

Or contact:

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Study link: https://bitly.com/1wkSy	Study link: https://bitly.com/1wkSy	Study link: https://bitly.com/1wkSy	Study link: https://bitly.com/1wkSy	Study link: https://bitly.com/1wkSy	Study link: https://bitly.com/1wkSy	Study link: https://bitly.com/1wkSy	Study link: https://bitly.com/1wkSy	Study link: https://bitly.com/1wkSy	Study link: https://bitly.com/1wkSy

APPENDIX E

EMAIL TO PARTICIPATING ORGANIZATIONS, AGENCIES, AND PROFESSIONAL CONTACTS DURING THE RECRUITMENT PROCESS

Dear _____ (insert name of point of contact or organization),

Thank you for agreeing to help in the recruitment process. I am conducting a study, which has been approved through Wayne State University's Institutional Review Board, to examine the quality of life among parents of adult children with Autism Spectrum Disorder (ASD). In order to be eligible for participation, parents must be at least 50 years old and have an adult child diagnosed with ASD (18 years or older). I appreciate you helping to recruit participants for this study. Attached you will find two recruitment letters to post or pass out to potential participants. In addition, I appreciate any help in the dissemination of material through email, in newsletters, by word of mouth, and on your website. For your convenience, below you will find drafted study information that can be sent to potential participants and contacts.

Please do not hesitate to contact me via email (al9887@wayne.edu) or phone should you have questions.

Thank you so much. Your help is greatly appreciated!

Best,

Christina Marsack
Doctoral Candidate

Sample information for email, newsletters, and/or website:

Hello,

Christina Marsack, doctoral candidate at Wayne State University, is conducting a study for parents of adult children diagnosed with Autism Spectrum Disorder (ASD). If you are interested, please see the information below.

Thank you,

_____ (organization / name)

Quality of life among parents of adult children with autism spectrum disorder

Be a part of a research study investigating quality of life among parents of adult children with autism spectrum disorder (ASD). The purpose of this study is to examine the effects of caring for an adult child with ASD on parents' quality of life. Contributing factors, such as social support and burden, will be investigated. To be included, you must

be at least 50 years old

have an adult child (18 years of age or older) diagnosed with ASD

If you have answered yes to these questions, you are eligible to participate in this study. Interested participants will be entered into a raffle to receive a \$25 gift card. The study will be conducted using an online survey. For interested participants, a follow up interview may be conducted over the phone or in-person to gather more information regarding parental quality of life.



If you are interested in participating, please
Visit the following link: <https://bitly.com/1wkSy0p>
Or contact:
Christina Marsack, Doctoral Candidate
al9887@wayne.edu

APPENDIX F

REMINDER EMAIL TO PARTICIPATING ORGANIZATIONS, AGENCIES, AND PROFESSIONAL CONTACTS DURING THE RECRUITMENT PROCESS

Dear _____ (insert name of point of contact or organization),

Thank you for your help in the recruitment process. I am trying to encourage participation of your membership by asking you to post a reminder email that is attached. I appreciate all of your help in disseminating the information about my survey through your email, in newsletters, by word of mouth, and on your website.

Please feel free to contact me via email (al9887@wayne.edu) or by phone _____ if you have any questions.

Thank you for your help.

Christina N. Marsack
Doctoral Candidate

Sample reminder email information for email, newsletters, and/or website:

Hello,

I would like to take this time to thank everyone who has completed my survey for parents of adult children diagnosed with Autism Spectrum Disorder (ASD). I appreciate your help with my research.

I would like to encourage anyone who has an adult child diagnosed with ASD to take a few minutes to complete the survey online. The link to the survey is:

<https://bitly.com/1wkSy0p>

If you would prefer to complete a paper copy of the survey, please feel free to contact me at _____ or by email at al9887@wayne.edu. I will be happy to send you a copy along with a postage-paid, preaddressed envelope for confidential return of the survey.

Your help is appreciated in this important research study.

Christina Marsack
Doctoral Candidate

APPENDIX G**EMAIL TO PARTICIPANTS WHO INDICATE INTEREST
IN QUALITATIVE INTERVIEW**

Dear _____,

Thank you for your interest in participating in a one-on-one interview. You recently indicated that you would be willing to answer a few questions about caring for your adult child with ASD. Interviews will be conducted either in person or over the phone. It is optional for me to record your responses for use in my research. Should you agree to an interview, please let me know if you do not want me to record your responses. In addition, I want to make you aware that at any time throughout the interview process, the recorder can be stopped. Let me know if you would like me to stop the recorder. All identifying information will be taken out of my records. As soon as the dissertation is approved, I will erase all of your comments. Be assured that none of the people who agree to be interviewed will be identifiable in the final paper.

I will contact you to set up a time to conduct the interview. Should you have questions, please feel free to contact me via email (AL9887@wayne.edu) or phone .

Thank you so much,
Christina Marsack
Wayne State University

APPENDIX H**INTERVIEW SCRIPT**

Hello _____

My name is Christina Marsack. You indicated that you would be willing to answer a few questions about caring for your adult child with ASD. I appreciate your help in my research. It is optional for me to record your responses for use in my research. Please let me know if you do not want me to record your responses. In addition, I want to make you aware that at any time throughout this interview, I can stop the recorder. Let me know if you would like me to stop the recorder. As soon as the dissertation is approved, I will erase all of your comments. Be assured that none of the people who agree to be interviewed will be identifiable in the final paper.

APPENDIX I**INTERVIEW QUESTIONS**

1. What types of organizations provide support for you to assist in caring for your adult child with ASD?
2. What types of support do you receive from each of these organizations? (e.g., financial, help with physical care of the adult, respite care, etc.)
3. Are you satisfied with the help you are receiving? If no, what is lacking and how can it be improved?
4. How does caring for your adult child with ASD affect your personal health?
5. Where does your adult child with ASD live?
 - a. How has having an adult child with ASD living with you affected your quality of life? Or
 - b. How has having an adult child with ASD living (independently or in a group home) affected your quality of life?
6. What is the most challenging aspect of caring for your adult child with ASD?
7. What is the most rewarding aspect of caring for your adult child with ASD?
8. How has having an adult child with ASD affected your finances now and in the future?
9. Do you have any additional comments about caring for an adult child with ASD?

APPENDIX J

INTERVIEW INFORMATION SHEET

Title of Study: An Examination of Quality of Life of Parents of Adult Children Diagnosed with Autism Spectrum Disorder

Principal Investigator (PI): Christina Marsack, School of Social Work,

Purpose:

The purpose of the one-on-one interviews is to gain supplemental information (in addition to the information obtained from the surveys). The interviews seek to gain information regarding your experiences of caring for an adult child with Autism Spectrum Disorder (ASD). This study is being conducted at Wayne State University.

Study Procedures:

In order to be eligible to participate in this study, you must be at least 50 years of age. Your adult child must be at least 18 years old and be diagnosed with ASD. If you take part in the interview portion of this study, you will be asked questions about your social support, organizational support, health, finances, and the living arrangement of your child with ASD. In addition, you will be asked about the challenging and rewarding aspects of caring for your adult child with ASD. As in the survey, if you have more than one adult child with ASD, please refer to your oldest child with ASD. The interview will take approximately one hour to complete.

Benefits:

As a participant in this research study, there will be no direct benefit for you; however, information from this study may benefit other people now or in the future.

Risks:

You may experience some emotional discomfort during the interview or after answering interview questions. Emotional discomfort may include negative feelings such as sadness, anger, or anxiety. A list of community resources to help you cope with emotional discomfort or other concerns will be provided.

Costs:

There will be no costs to you for participation in this research study.

Compensation:

Interview participants will receive a \$20 gift card as a “thank you” for their time and participation.

Confidentiality:

All information collected about you during the course of this study will be kept confidential. Recorded interviews will be transcribed and identifying information will be taken out.

Voluntary Participation /Withdrawal:

Taking part in this study is voluntary. You are free to not answer any questions or ask to stop the interview at any time. Your decision will not change any present or future relationships with Wayne State University or its affiliates. By completing the interview you are agreeing to participate in this study.

Questions:

If you have any questions about this study now or in the future, you may contact Christina Marsack at the following phone number: . If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

APPENDIX K

WAYNE STATE UNIVERSITY INSTITUTIONAL REVIEW BOARD APPROVAL

WAYNE STATE
UNIVERSITY

IRB Administration Office
87 East Canfield, Second Floor
Detroit, Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
<http://irb.wayne.edu>

CONCURRENCE OF EXEMPTION

To: Christina Marsack
Social Work Instruction Un
4756 Cass Avenue

From: Dr. Deborah Ellis C. Tientacosta
Chairperson, Behavioral Institutional Review Board (B3)

Date: February 10, 2015

RE: IRB #: 012615B3X

Protocol Title: An Examination of Quality of Life of Parents of Adult Children Diagnosed with Autism Spectrum Disorder

Sponsor: Graduate School Social Work Instruction Un

Protocol #: 1501013701

The above-referenced protocol has been reviewed and found to qualify for **Exemption** according to paragraph #2 of the Department of Health and Human Services Code of Federal Regulations [45 CFR 46.101(b)].

- Revised Social/Behavioral/Education Exempt Protocol Summary Form (received in the IRB Office 2/10/2015)
- Revised Protocol (received in the IRB Office 2/10/2015)
- Research Information Sheet - Online Survey (dated 2/7/2015)
- Interview Information Sheet (dated 2/7/2015)
- Email to Participating Organizations, Agencies, and Points of Contact during the Recruitment Process
- Study Flyer
- Study Flyer with Tear-Aways
- Email to Participants that indicate interest in Qualitative Interview
- Community Resources
- Interview Script for Qualitative Interview
- Data Collection Tools: Interview Questions for Qualitative Interviews and Online Survey

This proposal has not been evaluated for scientific merit, except to weigh the risk to the human subjects in relation to the potential benefits.

-
- Exempt protocols do not require annual review by the IRB.
 - All changes or amendments to the above-referenced protocol require review and approval by the IRB **BEFORE** implementation.
 - Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the IRB Administration Office Policy (<http://irb.wayne.edu/policies-human-research.php>).

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Increasing autism prevalence in metropolitan New Jersey. *Autism, 18*(2), 117-126. doi:

10.1177/1362361312463977

ABSTRACT**AN EXAMINATION OF QUALITY OF LIFE OF PARENTS OF
ADULT CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER**

by

CHRISTINA N. MARSACK**May 2016****Advisor:** Dr. Faith Hopp**Major:** Social Work**Degree:** Doctor of Philosophy

Previous research on parental caregivers has focused primarily on caregivers of individuals with intellectual and developmental disabilities, rather than focusing specifically on parents of adult children diagnosed with autism spectrum disorder (ASD). Most research on ASD has centered on parents of young children with this diagnosis, but not on parents of adult children with ASD. Understanding the experiences of parents caring for adult children with ASD is important given the increase in the prevalence of individuals with ASD and the lack of information regarding parents of adult children with ASD.

A nonexperimental, quantitative, correlational design was used to examine effects of caring for an adult child with ASD on parents' quality of life (QOL; $n = 320$). To be included in the sample, participants had to be at least 50 years of age and have an adult child diagnosed with ASD. Participants completed a web-based survey, including a demographic questionnaire and five measures examining burden, financial impact, health, and formal and informal social support. In addition to the online portion, 51 parents also participated in an individual interview focused on their experiences of caring for an adult child with ASD.

Overall, the findings emphasized the negative relationship between burdens that parents experience and their QOL. Social workers can use these findings to develop services, service delivery models, and interventions that acknowledge the needs (including burdens, QOL), realities, and experiences of parents of adult children with ASD.

The growth in the prevalence of individuals affected by ASD is expected to add to casework for social workers, who are expected to play an increasingly important role in assisting parents who may feel overwhelmed by their continued responsibility for their adult children. As these parents age, their lives will continue to be affected by their efforts to support their adult children with ASD. To deliver services effectively, social workers need to understand the reality of the lives of both parents and adult children with ASD, as well as understanding the QOL and caregiver burden with which the parents are living.

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Grand Blanc Community Schools, Grand Blanc, MI Special Education Teacher	2006 - 2007

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Hartford Geriatric Fellowship, University of Michigan	2005 - 2006

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