

Determinants of Quality of Life in Caregivers of Children with Autism and Autism Concerns

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A dissertation

submitted in partial fulfillment of the

requirements for the degree of

Doctor of Philosophy

University of Washington

2018

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Abstract

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Given the unique demands of raising a child with autism spectrum disorder (ASD), it is necessary to understand the impact on the quality of life (QoL) of their caregivers. Though QoL is considered an important outcome in health services research (Moons et al., 2006; Oliveira, Carvalho, & Esteves 2016), there is a lack of knowledge about QoL in caregivers of children with ASD or caregivers of children for whom there are ASD concerns, but no formal diagnosis. The objectives of the current study were to (1) Examine how having a young child with ASD or ASD concerns affects caregiver QoL, relative to children with other developmental concerns and typical development; (2) Examine profiles across QoL domains within each caregiver group to determine which QoL domains were most impacted relative to other domains; (3) Examine to what extent three levels of determinants contribute to caregiver QoL: family demographic (child age, family income, caregiver employment status, number of children in the home), psychological (parenting stress), and health care (family-centered care); and 4) (Exploratory) Examine the extent to which family centered care moderates the relation between parenting stress and QoL.

The sample was drawn from a larger NIH study examining screening and referral practices for children with ASD in primary care provider (PCP) practices and early intervention (EI) agencies in Washington State. The sample was comprised of three groups: caregivers of children with ASD or ASD concerns (ASD/ASD Concerns; $n = 42$), caregivers of children with other developmental concerns (Other Concerns; $n = 34$), and caregivers of children with typical development (No Concerns; $n = 112$). Caregivers completed a measure of family demographics, parenting stress, family-centered care, and QoL at their time of entry in the study.

Results indicated that caregivers in the ASD/ASD Concerns group reported significantly lower Psychological and Social QoL than caregivers in the Other Concerns group and the No Concerns group, and significantly lower Environmental QoL and Physical QoL than caregivers in the No Concerns group (Objective 1). For caregivers in the ASD/ASD Concerns group, Social QoL was significantly lower than Environmental and Physical QoL and Psychological QoL was significantly lower than Environmental QoL (Objective 2). Income, parenting stress, and family-centered care were significant predictors for all four QoL domains, while the number of children residing in the home was a significant predictor for Physical QoL only. There was also a significant group by stress interaction for Environmental QoL, such that there was a stronger negative relationship between parenting stress and Environmental QoL for caregivers in the ASD/ASD Concerns group compared to caregivers in the No Concerns group (Objective 3). Family-centered care did not moderate the relationship between parenting stress and QoL as predicted (Objective 4). Overall, these findings suggest that future research is needed to determine how to provide additional support to all caregivers, particularly low-income families and caregivers who are experiencing high levels of parenting stress and low levels of family-centered care.

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ACKNOWLEDGMENTS

I first want to thank the families who participated in this research. Their generosity and willingness to share their experiences will help broaden our understanding of the challenges facing families of young children with ASD and ASD concerns. I want to express appreciation for my advisor, Dr. Wendy Stone, for her mentorship during graduate school. I am grateful for my committee members, Dr. Shannon Dorsey, Dr. Suzanne Kerns, Dr. Aaron Lyon, and Dr. Susan Spieker, for their support and enthusiasm for this project.

I am indebted to the READi Lab, in particular Dr. Lisa Ibañez, for her patience and innate teaching abilities, Lizzy Karp, for her ever-present enthusiasm and support, and Sarah Edmunds, for her ceaseless loyalty, kindhearted spirit, and generous support with the statistical analyses for this project.

I am immensely grateful for my clinical cohort, friends, and family for their unyielding support over the past seven years, as well as the family members who are no longer with me, but who would have been proudest of all.

DEDICATION

Dedicated to New Jersey



Introduction

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in communication and social functioning and the presence of restricted and repetitive behaviors (American Psychiatric Association [APA], 2013). According to the Centers for Disease Control and Prevention (CDC), the current prevalence rate of ASD in the United States (U.S.) is 1 in 59 children (Baio et al., 2018). This rate represents a ten-fold increase within the past 40 years, signifying a growing public health crisis, as service delivery systems struggle to meet the needs of individuals with ASD. In the U.S. the lifetime cost of caring for an individual with ASD is estimated to range from \$1.4-2.4 million, equating to a nationwide annual cost of \$61-66 billion for children and \$175-196 billion for adults (Buesche et al., 2014). These costs, attributable to special education, residential care, and loss of individual and parental productivity in the workforce, place a tremendous financial burden on caregivers and the national health care system.

Due to the heterogeneous nature of ASD, caregivers are tasked with managing the core symptoms of the disorder (e.g., impairments in social communication, repetitive behaviors, sensory interests and aversions) as well as other associated challenges, including limited adaptive skills (e.g., toileting and feeding issues), aggression and self-injurious behaviors, psychiatric comorbidities (e.g., attention deficit hyperactivity disorder [ADHD], anxiety), and/or medical conditions (e.g., seizure disorders, disrupted sleep, gastrointestinal sensitivities). As a result, children with ASD receive a variety of services including speech, occupational, physical, and intensive behavioral therapies. Additionally, caregivers are often actively involved in treatment and trained to serve as interventionists for their children (Lord & McGee, 2001). Given the high

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level of care that children with ASD require, it is not surprising that their caregivers experience higher levels of stress, increased levels of anxiety and depression, poorer physical health, reduced relationship satisfaction, and higher economic burden compared to caregivers of children with other concerns and/or caregivers of children with typical development (Allik et al., 2005; Brobst et al., 2008; Dabrowska & Pisula, 2010; Daniels et al., 2008; Estes et al., 2009; Lavelle et al., 2014; Rao & Beidel, 2009; Singer 2006; Vohra, Madhavan, Sambamoorthi, & St Peter, 2014). Given the unique and complex needs of children with ASD compared to children with other special health care needs, and the associated psychological, physical, social, and economic burden on their caregivers, it is necessary to understand the impact on caregiver quality of life (QoL) in this population.

Quality of Life (QoL)

QoL is a broad multidimensional construct defined by the World Health Organization (WHO) as “an individual’s perception about their position in life in the context of the culture and value system they live in and in relation to their objectives, expectations, standards, and concerns... it is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (WHO 1998; p. 11). QoL first emerged as a research concept in the first half of the 20th century in the fields of medicine and economics. Since the mid-1960s, QoL research has increased exponentially, and broadened its scope to include both mental health (e.g., depression, schizophrenia) and developmental disorders (e.g., cerebral palsy, Down Syndrome; Moon et al., 2006). This increased focus on QoL is attributable to modern treatment advancements, which have improved the prognosis of many diseases and

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disorders, increased treatment options, and expanded the cost-benefit factors for patients and providers to consider when selecting interventions (Moons et al., 2006).

QoL is currently recognized as a critical benchmark for evaluating the quality and outcome of health care (Moons et al., 2006), such that researchers and health care providers now consider impact on QoL when evaluating the effectiveness of new interventions, rather than only measuring symptom reduction (Oliveira, Carvalho, & Esteves 2016). QoL is used as an outcome measure in studies investigating mental health services and substance use treatment to chronic disease management (e.g., Barry & Zissi, 1997; Donovan, Mattson, Cisler, Longabaugh, & Zweben, 2005; Osoba, 2011). QoL also has important public health implications; low QoL is associated with high hospitalization rates (e.g., Mathews & May, 2007; Singh et al., 2004), high health care expenditures (Campbell, Bishu, Walker, & Egede, 2017), and low survival rates in patients with chronic illnesses (Montazeri, 2009; Steel et al., 2015). As such, QoL is considered an important component of patient-reported outcome measurement (PROM), a growing initiative influencing regulatory guidelines established by public health agencies in Europe and the United States (e.g., Food and Drug Administration [FDA]; National Health Service [NHS]; European Medicines Agency [EMA]).

Notably, the construct of QoL is not without controversy, as there is a lack of consensus both within and across fields about its definition (Felce, 1997; Gill et al., 1994; Muldoon et al., 1998; Testa & Simonson, 1996), and therefore no widely accepted conceptual framework or theoretical model of QoL unifying the research (Bakas et al., 2012). One critical issue is that researchers often use the term ‘QoL’ interchangeably with the terms ‘health status,’ ‘health utility,’ or ‘functional status’ (henceforth referred to as health status in this document for reader clarity; Moons et al., 2006). While the latter terms represent an individual’s objective condition

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(e.g., diagnoses, symptom severity, mobility), QoL represents an individual's *subjective* appraisal of their current situation (i.e., life satisfaction; Moons, 2004; Moons et al., 2006). Other researchers have opted to use the term 'health related quality of life' (HRQOL) as a compromise; however, this term is also problematic, as it overemphasizes the role of health issues on an individual's QoL and limits comparability with physically healthy individuals (Moons, 2004). Findings from empirical studies (Carr & Higginson, 2001; Garratt and Ruta, 1999; Moons et al., 2005) and a meta-analysis (Smith et al., 1999) indicate that QoL and health status are related, but distinct constructs that should not be used interchangeably (Moons, 2004).

The use of inconsistent terminology is not just an issue of semantics; it is problematic because it leads to measurement issues, as many researchers use health status measures to assess QoL. For example, the Short-Form Health Surveys (SF-12; SF-36; RAND SF-36; Hays, Sherbourne, & Mazel, 1993; Ware & Sherbourne, 1992; Ware, Kosinski, & Keller, 1996) are the most widely used QoL measures in the literature, though they were designed to be health status measures, and not direct measures of QoL. The SF Health Surveys can be contrasted with the World Health Organization's Quality of Life measure (WHOQOL-BREF; WHO 1996), which primarily assesses subjective satisfaction with functioning (e.g., "How *satisfied* [emphasis added] are you with your ability to perform your daily living activities?"), rather than objective degree of health or functioning (e.g., "How much of the time during the past four weeks did you have a lot of energy?"). Unlike the SF Health Surveys, which include only a Mental (i.e., psychological) and a Physical Component summary scale, the WHOQOL-BREF is comprised of four QoL domains, which were identified through a systematic measurement development process (WHO, 1995, 1996): Environmental QoL (e.g., living conditions, transportation),

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Physical QoL (e.g., energy, mobility), Psychological QoL (e.g., body image, self-esteem), and Social QoL (e.g., personal relationships, friendships).

Despite these issues, QoL is a construct that has been used worldwide to examine its relation to health outcomes for adults as well as children with conditions ranging from chronic medical diseases and psychiatric disorders to developmental disabilities (e.g., Chand, Mattoo, & Sharan, 2004; Gogoi, Kumar, & Deuri, 2016; Holt et al., 2010; Jennes-Coussens, Magill-Evans, & Koning, 2006; Rudolf & Watts, 2009; Vlachioti et al., 2016; Weidle, Jozefiak, Ivarsson, & Thomsen, 2014; Yamazaki et al., 2005). Given the association between QoL and other health outcomes, current research is focused on identifying factors that influence QoL, in order to improve QoL ratings in high-need clinical populations.

Determinants of QoL. Historically, there has been a poor distinction between *indicators* of QoL and *determinants* of QoL across research studies, which has only exacerbated confusion in the field (Moons et al., 2006). By definition, indicators are representations of a phenomenon; for example, an indicator of diabetes is high blood sugar. Determinants are contributing factors that influence a phenomenon (i.e., predictors); determinants of diabetes are age, race, diet, and/or family history. Many researchers use health status as an *indicator* of QoL, when in actuality, it is a potential (but not guaranteed) *determinant* of QoL (Moons, 2004). Moons and colleagues (2006) cite the example of an ‘ardent fisherman’ who is a paraplegic; despite being confined to a wheelchair, he may rate his QoL as high if he is able to go fishing. This example serves to illustrate the concept of the ‘disability paradox’ (Albrecht & Devileger, 1999). According to the disability paradox, an individual’s diagnosis or mobility status is not an automatic indicator of their QoL, nor is their income, square feet of living space, or number of friends. Instead, these variables represent potential determinants of QoL.

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Ferrans and colleagues (2005) adapted the widely-used Wilson and Cleary (1995) conceptual model of QoL (Eyler et al., 2002; McLeroy, Bibeau, Steckler, & Glanz, 1988; Wilson & Cleary, 1995) in order to better-illustrate the multidimensional nature of QoL and its determinants. The Ferrans et al. model is an ecological model of QoL, comprised of two levels of influence: individual characteristics and environmental characteristics (physical and social). Individual characteristics include demographic, psychological, and biological variables. Physical environment characteristics include variables such as crime rates, pollution, and access to outdoor space, while social environment characteristics include interactions with healthcare providers, friends, and family. The Ferrans et al. model has been used as a conceptual framework in studies examining QoL in a variety of populations, ranging from children with ASD and adolescents with solid organ transplants to adults with medical conditions (Devine et al., 2011; Faison, Burns, & Weed, 2016; Kuhlthau et al., 2014; Saban, Penckofer, Androwich, & Bryant, 2007)

Determinants of QoL that have been examined in children and adults can be categorized into the levels outlined by Ferrans et al. (2005; i.e., individual and environmental). In terms of individual characteristics, demographic (e.g., age, gender, income, and education; Klassen, Anthony, Khan, Sun, & Klaassen, 2011; McDougall & Tsonis, 2009), biological (e.g., symptom severity, co-morbidities, side-effects; Carod-Artal, Trizotto, Coral, & Moreira, 2009; Juenger et al., 2002), and psychological determinants (e.g., stress, depression, anxiety, strain/burden, coping style; Brigstocke, Donaldson, & Kalra, 2005; Friedland, Renwick & Mccoll, 2010; McCullagh; Ravens-Sieberer & Bullinger, 1998) have all been examined in the literature. With regard to environmental characteristics, both physical environment (e.g., living conditions, dangerous cross walks; Emmerink & Roeg, 2016; Rantakokko et al., 2010) and social environment

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determinants (e.g., social support; Amir, Roziner, Knoll, & Neufeld, 2005; Khanna et al., 2011) have been examined, though physical environment determinants have received less research attention than social environment determinants. Research using multivariate analyses has found that psychological variables (e.g., stress, depression) often emerge as stronger predictors of QoL than demographic or biological variables (e.g., symptom severity; Chiò et al., 2004; Jönsson et al., 2005), which is encouraging given that psychological variables are often more malleable and/or responsive to intervention than variables like income or disease stage. Additionally, though there is only emerging evidence, health care system variables at the physical environment (e.g., distance from health services; primary care facilities-to-population ratio) and social environment levels (e.g., healthcare satisfaction) are increasingly being examined as potential determinants of QoL in both children and adults (Boncinelli, Pagnotta, Riccioli, & Casini, 2015; Jia, Moriarty, & Kanarek, 2009; Ruggeri, Gater, Bisoffi, Barbui, & Tansella, 2002; Simon, Chan, & Forrest, 2008), which represents an exciting area for future QoL research.

In population-based studies of adults, demographic variables (e.g., older age, low education levels), biological variables (e.g., presence of chronic diseases), psychological variables (e.g., depression), and/or limited social networks have been identified as determinants of low QoL (Baernholdt, Hinton, Yan, Rose, & Mattos, 2012; Raggi et al., 2016). In pediatric populations, QoL can be rated both by children (i.e., self-report) and by their caregivers (i.e., parent-proxy ratings). Findings from studies examining self-reported QoL in non-clinical pediatric samples indicate that female gender, older age, low family income, limited parent education, and the presence of physical or psychological conditions are associated with poor QoL in children (Moreira et al, 2013; Ravens-Sieberer et al., 2007; Stevanovic, 2012; von Rueden, et al., 2005). Similarly, findings from studies of parent-proxy rated QoL in non-clinical

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pediatric populations indicate that low income, parent unemployment, child comorbid conditions, acute health complaints, and unmet medical needs are associated with poor QoL in children (Houben-van Herten, Bai, Hafkamp, Landgraf, & Raat, 2015; Simon, Chan, & Forrest, 2008).

Given the stressors associated with parenting children with complex physical, developmental, behavioral or emotional conditions, research has also revealed the importance of understanding QoL in caregivers of children with special healthcare needs. QoL has been extensively examined in caregivers of children with conditions ranging from cancer and ADHD to cerebral palsy and intellectual disabilities (Gogoi, Kumar, & Deuri, 2016; Malhi & Singhi, 2005; Ones, Yilmaz, Cetinkaya, & Caglar, 2005; Yamazaki et al., 2005; Xiang, Luk, & Lai, 2009). Findings indicate that caregivers of children with special healthcare needs report lower QoL than caregivers of typically developing children/healthy controls and adult population norms (e.g., Klassen et al., 2008; Lawoko & Soares, 2002; Lin et al., 2005; Lv et al., 2009; Romeo et al., 2010). In these studies, demographic variables (e.g., low income), psychological variables (e.g., high levels of parenting stress, maladaptive coping styles), and social environment variables (e.g., low levels of family-centered care) have been identified as determinants of low QoL (Davis & Gavidia-Payne, 2009; Klassen et al., 2008; Lin et al., 2009; Lowoko & Soares, 2003; Lv et al., 2009; Seliner, Latal, & Spirig, 2016) even when controlling for child symptom severity (Lowoko & Soares, 2003; Staab et al., 1998).

QoL in Caregivers of Children with ASD

Despite the established relevance of QoL research and the significant impact of having a child with ASD, the QoL of caregivers of children with ASD has been relatively understudied compared to other childhood conditions. In particular, there is a lack of knowledge about the

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QoL of caregivers of young children (i.e., < 5 years old) with a diagnosis of ASD. As research indicates that children with ASD elicit different caregiving demands across their lifespan, it is important to understand how QoL may be uniquely impacted for caregivers of very young children with ASD (Russa, Matthews, & Owen-DeSchryver, 2015; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Furthermore, there is limited understanding about QoL in caregivers of young children for whom there are ASD concerns, but no formal diagnosis. The dearth of research about children with ASD concerns is concerning, given that this period is often a time of great distress for families as they navigate the service delivery system and tolerate uncertainty about their child's symptoms (Zuckerman et al., 2015). To date, only one study has examined QoL in a sample of caregivers of children with ASD concerns, and found that caregivers of adolescents and young adults with ASD symptoms but no diagnosis reported lower QoL than caregivers of adolescents and young adults with an ASD diagnosis and with typical development (McKenachie et al., 2017), suggesting that the presence of ASD symptoms without diagnostic confirmation may be particularly distressing for caregivers.

Given the limited research about QoL in caregivers of children with ASD or ASD concerns, both findings from studies that used validated QoL measures (e.g., WHOQOL-BREF) and findings from studies that used health status measures as QoL measures (e.g., SF-36) will be presented in this manuscript, in order to maximize potential understanding of QoL in this population. Of the studies that have been conducted, findings indicate that caregivers of children with ASD report lower QoL than caregivers of children with specific learning disabilities (Khan & Humtsoe, 2016), physical disabilities (Perumal et al., 2014), and typical development (Eapen et al., 2014; Ezzat et al., 2017; Lee et al., 2009; Malhotra et al., 2012; McKeachie et al., 2017;

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Perumal et al., 2014) as well as national population norms (Khanna et al., 2011; Kuhlthau et al., 2014; Rizk et al., 2011).

Determinants of QoL in caregivers of children with ASD. There is limited knowledge about determinants of QoL in caregivers of children with ASD. Studies that have been conducted have examined variables similar to studies of children with other special health care needs, including individual characteristics (demographic, biological, psychological) and environmental characteristics (social environment). These findings are presented below, by category of determinant.

Demographic determinants. Demographic variables that have been examined as determinants of QoL in caregivers of children with ASD include employment status, family income, number of children in the family, child age, caregiver education, and caregiver marital status. A majority of studies have not found an association between child age (Ji et al., 2014; Kuhlthau et al., 2014; Mahani et al., 2013; Wisessathorn et al., 2013), caregiver employment status (Favero-Nunes & Antonio dos Santos, 2010; Ji et al., 2014; Piovesan et al., 2015; Shu, 2009; Siah & Tan, 2016), caregiver education (Dardas & Ahmad, 2014a; Dardas & Ahmad, 2014c; Ji et al., 2014; Kareem et al., 2014; Kuhlthau et al., 2014; Lee et al., 2009; Mahani et al., 2013; Piovesan et al., 2015; Shu, 2009; Siah & Tan, 2016) or caregiver marital status (Favero-Nunes & Antonio dos Santos, 2010; Ji et al., 2014; Mahani et al., 2013; Piovesan et al., 2015) and caregiver QoL. Research in other caregiver populations has also found weak associations between these demographic variables and QoL, particularly when included in multivariate models (e.g., Klassen et al., 2011; Lin et al 2009; Lowoko & Soares, 2003).

Though research indicates that income is positively associated with Environmental QoL (Favero-Nunes & Antonio dos Santos 2010; Kareem et al., 2014; Mahani et al., 2013; Piovesan

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et al., 2015), its association with other QoL domains in caregivers of children with ASD is less clear. While some studies have found that income is positively associated with Physical QoL (Lee et al., 2009), Psychological QoL (Favero-Nunes & Antonio dos Santos, 2010; Lee et al., 2009; Mahani et al., 2013), and Social QoL (Favero-Nunes & Antonio dos Santos, 2010; Piovesan et al., 2015), other studies have found no association between income and Physical (Favero-Nunes & Antonio dos Santos, 2010; Mahani et al., 2013; Piovesan et al., 2015), Psychological (Piovesan et al., 2015), and Social QoL (Favero-Nunes & Antonio dos Santos, 2010; Mahani et al., 2013; Piovesan et al., 2015). Similarly, while studies of other caregiver populations have found that number of children residing in the home is negatively associated with QoL (Bellin et al., 2013; Eken & Tüzün, 2004), findings for caregivers of children with ASD are mixed, with one study finding a positive association (Lee et al., 2009), one study finding a negative association (Ji et al., 2014), and one study finding no association (Johnson et al., 2011).

Biological determinants. Biological variables that have been examined as determinants of QoL in caregivers of children with ASD include child cognitive ability and ASD symptom severity. Two studies found no association between child cognitive ability and overall QoL (Kuhlthau et al., 2014; McKechnie et al., 2017); however, the findings for ASD symptom severity are mixed. Three studies found no association between ASD symptom severity and overall QoL (Kuhlthau et al., 2014; Lee et al., 2009; Perumal et al., 2014), while other studies found that ASD symptom severity was negatively associated with overall QoL (Khanna et al., 2011) and with Physical and Psychological QoL (Ji et al., 2014). Research findings from other caregiver populations indicates that child symptom severity is not a significant determinant of caregiver QoL when included in multivariate models with other variables such as parental distress or coping style (e.g., Lowoko & Soares, 2003; Staab et al., 1998).

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Psychological determinants. Psychological variables that have been examined as determinants of QoL in caregivers of children with ASD include parenting stress, anxiety/depression, coping style, and caregiving burden/strain. A majority of research indicates that the presence of maladaptive coping styles (Dardas & Ahmad, 2014a; Dardas & Ahmad, 2014c; Khanna et al., 2011 Siah & Tan, 2016), high levels of depression (Eapen et al., 2014; Favero-Nunes & Antonio dos Santos, 2010; Piovesan et al., 2015), and high caregiver burden/strain (Ezzat et al., 2017; Ji et al., 2014; Khanna et al. 2011; Khanna et al. 2012; Marsack & Samuel, 2017) in caregivers of children with ASD are associated with low QoL. Research findings from other caregiver populations support these results (e.g., Lowoko & Soares, 2003; Staab et al., 1998; Valença et al., 2012).

Though parenting stress is one of the most widely-examined caregiver psychological variables examined in caregivers of children with ASD, its association with QoL is relatively understudied. Of the studies that have been conducted, results indicate that parenting stress is negatively associated with overall QoL (Dardas & Ahmad, 2014b; Dardas & Ahmad, 2015; Eapen et al., 2014; McKechnie et al., 2017) and negatively associated with the Environmental, Physical, Psychological, and Social QoL domains (Eapen et al., 2014; Johnson et al., 2011; Lee et al., 2009). These findings are consistent with studies that have found that parenting stress is negatively associated with QoL in other caregiver populations, including caregivers of children with other concerns (Fidika , Salewski, & Goldbeck, 2003; Wheeler, Skinner, & Bailey, 2008), psychiatric issues (Crowley & Kazdin, 1998), and medical conditions (Litzelman, Catrine, Gangnon, & Witt, 2011).

Social environment determinants. Social environment variables that have been examined as determinants of QoL in caregivers of children with ASD include social support (Johnson et

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al., Khanna et al., 2011) and family functioning (Khanna et al., 2011). Johnson et al. found that low social support (i.e., relationships that an individual can draw upon during stressful times) was associated with low Physical and Psychological QoL. However, the results for family functioning were conflicting; while Khanna et al. (2011) did not find an association between family functioning and Physical or Psychological QoL; Johnson et al. (2011) found that lower family functioning was associated with lower Physical and Psychological QoL for mothers and only with lower Psychological QoL for fathers.

Though there is some evidence about the influence of social support (i.e., interactions with friends and family) on caregiver QoL, there is a notable lack of research about the influence of caregiver interactions with healthcare providers. One variable that has been relatively unexplored in studies of QoL in caregivers of children with ASD is family-centered care. Family-centered care is similar to the concept of patient-centered care, and describes a philosophy in which caregivers are recognized as experts on their children's needs and are included in decision-making processes with their child's providers (King et al., 2004). The core principles of family centered care outlined by the American Academy of Pediatrics (AAP) are as follows: providing respectful care, honoring diversity, recognizing and building upon the strengths of the family, facilitating choice, ensuring flexibility in policy, procedures, and practices, sharing honest and unbiased information, providing formal and informal support, collaborating with families at all levels of health care, and empowering families to make their own decisions (Committee on Hospital Care, 2012). Rather than just focusing on the child, family-centered care considers the needs of the whole family (Kuo et al., 2012).

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Research indicates that high levels of family-centered care are associated with important child and family outcomes for children with and without special healthcare needs, including reduced emergency department visits (Brousseau et al., 2007), lower parenting stress (King, King, Rosenbaum, & Goffin, 1999), greater healthcare satisfaction (Carbone et al., 2012; King et al., 2004; Ngui & Flores, 2006), greater reported ease of navigating healthcare services (Ngui & Flores, 2006), better caregiver well-being (King, King, Rosenbaum, & Goffin, 1999), and improved child health (McAllister, Sherrieb, & Cooley, 2009). High levels of family-centered care are positively associated with QoL in caregivers of children with cancer (Klassen et al., 2008) and developmental disabilities (Davis & Gavidia-Payne, 2009; Seliner, Latal, & Spirig, 2016), as well as QoL in children with neurological conditions (Moore & Trute, 2009). The results of the Davis and Gavidia-Payne study (2009) are particularly relevant to the current study; results of a hierarchical regression analysis revealed that family-centered care was the strongest predictor of QoL in family members of children with developmental delays who were enrolled in early intervention programs, when entered in a model with family income, family support, and intensity of child behaviors/needs.

Though family-centered care is recognized as an important component of service provision for families of children with ASD (Gabovitch & Curtin, 2009; Homer et al., 2008), the relation between QoL and family-centered care has yet to be examined in caregivers of children with ASD. It is important to understand the association between these variables in this population, given that caregivers of children with ASD report lower levels of family-centered care compared to caregivers of children with other special health care needs (Kogan et al., 2008; Vohra, Madhavan, Sambamoorthi, & St Peter, 2014) and children with mental health conditions (Vohra et al., 2014).

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Though research indicates that family-centered care is associated with both parenting stress and caregiver QoL, there is a lack of knowledge about whether family-centered care moderates the relation between parenting stress and QoL. Understanding whether family-centered care acts as a moderator between these variables is important, as family-centered care could be an effective point of intervention for PCP practices to improve outcomes for caregivers of children with ASD or ASD concerns (King, King, Rosenbaum, & Goffin, 1999). Given the lack of research in this area, it is useful to draw upon existing research that has examined the relative influence of social support as a moderator of well-being. Like family-centered care, social support is a social environment level determinant of QoL; however, it refers to support received from friends and family, rather than support from healthcare providers. Research indicates that social support moderates the relation between depression and QoL in the elderly (Sun et al., 2017) and between symptom severity and QoL in patients with tinnitus (Murphy, 2012). This evidence of social support as a moderator is supported by the ‘buffering model’ proposed by Cohen and Wills (1985), which posits that social support protects individuals from adverse effects of stressful life events. The buffering model is contrasted with the ‘direct effect model’ which hypothesizes that social support has a beneficial influence on outcomes, regardless of the amount of stress that an individual is experiencing. Though there is some evidence to support the buffering model of social support in other clinical populations (e.g., Carpenter et al., 2010), family-centered care has yet to be examined as a moderator between parenting stress and caregiver QoL.

Current Study

While we have some knowledge about QoL in caregivers of children with ASD, many questions still remain. The current study will attempt to address some of the limitations present

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in previous QoL research. In the current study, QoL in caregivers of children with ASD or ASD concerns will be compared to those of caregivers of children with other concerns and caregivers of children with typical development. This approach allows for comparison between diverse caregiver groups, rather than relying on U.S. adult population norms. This study is also the first to examine QoL in a sample of caregivers of young children (i.e., under age five) with ASD or ASD concerns. As a majority of the sample will have yet to receive an official ASD diagnosis ($n = 10$ ASD diagnosis), we will gain an understanding of how the presence of ASD symptoms in young children may impact caregiver QoL even prior to diagnostic confirmation. Furthermore, this study will also allow us to identify which QoL domains are most affected in caregivers of children with ASD or ASD concerns. Lastly, this study will examine which family demographic, caregiver psychological, and health care variables are determinants of QoL in caregivers of children with ASD or ASD concerns, other concerns, and typical development and determine whether there are unique determinants of QoL for caregivers of children with ASD or ASD concerns. Overall, results from this study will inform our understanding of QoL in caregivers of children with ASD or ASD concerns. These findings may have implications for policy changes and interventions to provide support in this high-need population.

Objectives

The objectives of the study were to: 1) Examine how having a young child with ASD or ASD concerns affects caregiver QoL, relative to children with other concerns and typical development. Consistent with existing research for caregivers of children with ASD, it is hypothesized that caregivers of children with ASD or ASD concerns will report lower levels of QoL than children with other concerns and children with typical development across all four QoL domains; 2) Examine profiles across QoL domains within each caregiver group to

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determine which QoL domains were most impacted relative to other domains, in order to identify the areas in which caregivers may need the most support. It is hypothesized that for caregivers of children with ASD or ASD concerns, Psychological QoL will be the most impacted domain, relative to Environmental, Physical, Social QoL, given that caregivers of children with ASD consistently report higher levels of depression, anxiety, and stress than caregivers of children with other concerns and typical development. 3) Examine to what extent three levels of determinants contribute to caregiver QoL: family demographic (child age, family income, caregiver employment status, number of children in the home), caregiver psychological (parenting stress), and health care (family-centered care). By identifying the determinants of QoL, researchers and care providers can identify risk factors for low QoL, particularly in caregivers of children with ASD, who are at-risk for experiencing poor QoL compared to other caregivers. It is hypothesized that parenting stress will be the strongest predictor of QoL, given research evidence that psychological variables are stronger predictors of QoL in multivariate models than demographic or biological variables; 4) (Exploratory aim): Examine the extent to which family centered care moderates the relation between parenting stress and QoL. It is hypothesized that family centered care will moderate the relation between parenting stress and caregiver QoL, such that, in the presence of high parenting stress, caregivers who report receiving high degrees of family-centered care, will report higher QoL than caregivers who report receiving low degrees of family-centered care. It is further hypothesized that this association will be stronger for caregivers of children with ASD or ASD concerns, relative to caregivers of children with other concerns and typical development, given that the demands of raising a child with ASD are associated with increased parenting stress and a greater reliance on healthcare providers. Family-centered care may be an important area of intervention for

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healthcare systems to improve the well-being of caregivers, particularly those of children with ASD or ASD concerns.

Method

Participants

Participants in the present study were drawn from a larger NIH-funded study that aimed to examine developmental screening and referral practices in nine early intervention (EI) agencies and nine primary care provider (PCP) practices across four geographically and ethnically diverse counties in Washington State (Lewis, Skagit, Spokane, and Yakima County). In the NIH study, caregivers of children with autism spectrum disorder (ASD), ASD concerns, and other developmental concerns were recruited from both PCP practices and EI agencies, while children with typical development (i.e., no ASD or other developmental concerns) were recruited from PCP practices only. PCPs and EI providers assisted with recruitment for the larger study. PCPs distributed study flyers and permission-to-contact forms to caregivers at 18-month well-child visits and mailed flyers to all children at their practice between 16-20 months of age. EI providers posted recruitment flyers at their agencies and mailed recruitment letters and permission-to-contact forms to families of children at their agency between 16-36 months of age. Caregivers initiated contact with the research team either by using the contact information provided on the flyer or by submitting a permission-to-contact form. Research team members then completed phone screenings with caregivers in order to determine whether the family was eligible to participate in the study. Families were excluded from the larger study if their child had any severe visual, auditory, or physical impairments, and/or serious medical, genetic, or neurological disorders.

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The present study included a subsample of participants ($n = 188$) from the larger NIH study. Children were classified into one of three groups based on information that caregivers provided during the eligibility screening process for the larger study: ASD/ASD Concerns ($n = 42$), Other Concerns ($n = 34$), or No Concerns ($n = 112$). Children were classified in the ASD/ASD Concerns group for one of three reasons: (1) their caregiver indicated that they had an existing diagnosis of ASD ($n = 10$); (2) they screened at-risk on an ASD screening tool in the past, their caregiver explicitly endorsed having ASD concerns, and/or their caregiver reported that a provider or another family member had concerns about ASD ($n = 25$); or (3) their caregiver reported during eligibility screening that they had concerns about how their child interacted with adults and/or peers *and* endorsed a concern about language or communication, unusual toy play, unusual body movements, and/or over- or under-responsive sensory issues ($n = 7$), given that these symptoms represent core areas of impairment for children with ASD (APA, 2013). Children with ASD concerns were combined in the same subgroup as children with ASD diagnoses, as caregiver responses during eligibility screening indicated that there was reason to believe, either through formal screening or caregiver/provider/family member observation, that these children were displaying symptoms concerning for ASD. Children were classified in the Other Concerns group if their caregiver expressed concerns about general development (e.g., delayed language or motor development, tantrums) but did not endorse any of the aforementioned criteria for the ASD/ASD Concerns group. Caregivers of children in the No Concerns group reported having no concerns about their child's development during eligibility screening.

Table 1 provides the demographic characteristics for caregivers and children in the three groups. One-way ANOVAs were used to examine group differences in caregiver age, child age,

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number of children in the home, family income, and caregiver employment status. Chi-square independence tests were used to examine group differences in child sex, caregiver race (collapsed into White vs. Non-White), and caregiver ethnicity (Hispanic vs. Non-Hispanic). Children in the No Concerns group were significantly younger than children in the ASD/ASD Concerns ($p < .01$) and the Other Concerns groups ($p < .01$) and children in the Other Concerns group were significantly younger than children in the ASD/ASD Concerns group ($p < .01$). Caregivers of children in the ASD/ASD Concerns group reported significantly lower yearly family income than caregivers of children in the Other Concerns group ($p < .01$) and the No Concerns group ($p < .01$); there were no income differences between the Other Concerns and the No Concerns groups. Caregivers of children in the ASD/ASD Concerns group were less likely to be employed than caregivers of children in the Other Concerns group ($p = .05$); there were no differences in employment status between the ASD/ASD Concerns and the No Concerns group and between the Other Concerns and the No Concerns group. There were no group differences in caregiver age, the number of children residing in the home, child sex, caregiver race, or caregiver ethnicity. A majority of caregivers in the sample were mothers ($n = 177$; 94.1%). Differences in caregiver's relationship to the child could not be compared across groups due to the low frequency of other types of caregivers in the sample ($n = 8$ fathers, $n = 3$ grandmothers).

Procedure

As part of their participation in the larger study, caregivers were mailed questionnaires every three months until their child was at least 36 months of age. The purpose of the questionnaires was to measure child social communication (i.e., language and social skills) as well as caregiver ratings of their quality of life, parenting stress and efficacy, concerns about their child's development, service enrollment, perceptions of family-centered care at their child's

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PCP practice, and attributions about their child's behavior. The present study is based on select questionnaires that caregivers completed at their time of entry into the study. Caregivers completed all questionnaires online via REDCap (Research Electronic Data Capture), a secure, web-based application designed to support data capture for research studies, hosted by the University of Washington Institute of Translational Health Sciences (Harris, Taylor, Thielke, Payne, Gonzalez, & Conde, 2009).

Measures

Predictive measures. Three different levels of predictors were examined in the current study: demographic, psychological, and health care.

Demographic predictors. Demographic predictors were measured using the *Family Demographic Information Form*. The Family Demographic Information Form is a 38-item measure that was adapted from the Baby Siblings Research Consortium (BSRC) demographic form. It assesses demographic characteristics including child and caregiver sex, age, race and ethnicity, caregiver employment status, number of children in the family, and family income. In the current study, child age, family income, and caregiver employment status, were included in all main analyses to control for group differences on these variables, in addition to the number of children residing in the home, which has been found to be a significant predictor of QoL in other studies of caregivers of children with ASD.

Psychological predictor. The psychological predictor in the present study was operationalized as parenting-related stress, and was measured using the *Parenting Stress Index-Short Form* (PSI-SF; Abidin, 1990). The PSI-SF is a 36-item self-report measure designed to assess the amount of stress that caregivers of children between one month to twelve years of age experience in their caregiving role. Abidin (1995) reported good internal consistency for each of

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the subscales ($\alpha = .80 - .87$) and for the overall measure ($\alpha = .91$). The PSI-SF was selected for use in the current study because it is a brief and psychometrically sound measure that has been used extensively in studies of parents of children with disabilities (e.g., Button, Pianta, & Marvin, 2001; Macias, Saylor, Rowe, & Bell, 2003), including ASD (e.g., Davis & Carter, 2008; Lecavalier, Leone, & Wiltz, 2006).

The PSI-SF comprises three, twelve-item subscales: Parent-Child Dysfunction (PCDI), which assesses the amount of distress that a caregiver experiences about the quality of their interactions with their child (e.g., “Most times I feel that my child does not like me and does not want to be close to me”), Difficult Child (DC), which assesses the amount of distress that a caregiver experiences about their child’s challenging behavior (e.g., “My child seems to cry or fuss more often than most children”), and Parental Distress (PD), which assesses the amount of distress that a caregiver experiences in their caregiver role (e.g., “Since having a child I feel that I am almost never able to do things I like to do”).

PSI-SF items are rated on a five point Likert scale ranging from “Strongly Disagree” (1) to “Strongly Agree” (5). Items in each subscale are summed to produce three subscale scores that range from 12 to 60. Scores for each of the three subscales are then summed to obtain a total parenting stress score ranging from 36 to 180, with higher scores indicating higher levels of parenting stress. In the current study, the PSI-SF total score was examined as a predictor of QoL in the regression analyses.

Health care predictor. The health care predictor in this study was operationalized as family-centered care, and measured using the *Measure of Processes of Care* (MPOC-20; King, King, & Rosenbaum, 2004). The MPOC-20 is a 20-item self-report measure designed to evaluate caregiver perceptions of the degree of family-centered care delivered by their child’s primary

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health care providers (e.g., doctors, nurses). The MPOC-20 was specifically designed to measure family-centered care for children with special health care needs, including chronic health conditions and disabilities, and demonstrates adequate internal consistency ($\alpha = .63 - .92$). The MPOC-20 was chosen for use in this study because of its extensive use in studies of children with disabilities (e.g., Bellin, Osteen, Heffernan, Levy, & Snyder-Vogel, 2011; Cunningham & Rosenbaum, 2013; Tessier, Hefner, & Newmeyer, 2014) including children with ASD (Carbone, Murphy, Norlin, Azor, Sheng, & Young, 2013; Hodgetts, Nicholas, Zwaigenbaum, & McConnell, 2013).

The MPOC-20 is comprised of five subscales: Enabling and Partnership (3 items), which measures the extent to which health care providers explain treatment options to caregivers and respect their decisions; Providing General Information (5 items), which measures the extent to which health care providers inform caregivers about general child development and community resources; Providing Specific Information (3 items), which measures the extent to which health care providers share individualized information with caregivers about their child's development and explain results from assessments; Coordinated and Comprehensive Care (4 items), which measures the extent to which health care providers provide comprehensive and consistent care across treatment teams; and Respectful and Supportive Care (5 items), which measures the extent to which health care providers treat caregivers as equals and create a caring atmosphere.

MPOC-20 items are rated on a seven-point scale ranging from "Never" (1) to "To a Great Extent" (7). Each item begins "To what extent do the people who work with your child...(e.g., fully explain treatment choices to you)?" Scores are computed for each subscale by calculating an average of the ratings of all of the items in each subscale; scale scores range from 1 to 7, with a higher score indicating a higher level of family-centered care. In the current study, an overall

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MPOC-20 score was calculated by averaging the mean score across all items in accord with Carbone and colleagues (2013). The MPOC-20 total score was examined as a predictor of QoL in the regression analyses.

Outcome measure. QoL was the outcome in this study, and it was measured using the *World Health Organization's Quality of Life Questionnaire* (WHOQOL-BREF; WHO 1996). The WHOQOL-BREF is a 26-item measure that examines an individual's perception of their quality of life (QoL). The WHOQOL-BREF was validated cross culturally in an international field trial, demonstrating adequate internal consistency in the United States in a sample of healthy adults and adults with physical and mental health issues ($\alpha = .69 - .87$; Skevington, Lotfy, & O'Connell, 2004). The WHOQOL-BREF was chosen for use in this study because of its extensive use in assessing QoL in caregivers of children with ASD and other disabilities in Asia, Australia, Europe, South America, and the Middle East (e.g., Dardas & Ahmad, 2014; de Souza Lima Daltro et al., 2016; Eapen et al., 2014; Manee, Ateya, & Rassafiani, 2015; Mugno et al., 2007; Piovesan et al., 2015; Shu & Lung, 2005). Notably, the WHOQOL-BREF has yet to be used to examine QoL in caregivers of young children with ASD or ASD concerns in the United States, which has prohibited cross-cultural comparisons of QoL in this population to date.

The WHOQOL-BREF is comprised of four domains: Environmental (8 items), Physical (7 items), Psychological (6 items), and Social (3 items). The Environmental domain measures satisfaction with physical environment, including items on general living conditions, personal safety, health services, and access to transportation. The Physical domain measures satisfaction with physical capacities, including items on mobility, energy, sleep, pain, and functional capabilities. The Psychological domain measures satisfaction with mental health, including items on self-esteem, body image, and presence of negative thoughts (e.g., anxiety, depression). The

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Social domain measures satisfaction with social connectedness, including items on personal relationships, friendships, and sex.

WHOQOL-BREF items are rated on a five-point scale ranging from, “Very Dissatisfied” (1) to “Very Satisfied” (5), with higher scores indicating higher QoL. The mean score of items within each domain was used to calculate each domain score; domain scores were then transformed on a scale from 0 to 100 to allow for comparison between domains with unequal numbers of items (WHOQOL-BREF, 1996). Research indicates that a score of 60 represents the cut-off in which QoL is deemed ‘neither good nor poor’ (Dardas & Ahmad, 2014c). See Appendix A for a list of the items included in each domain. In the current study, the four WHOQOL-BREF domains were examined separately as dependent variables in the regression analyses.

Data Analysis

To examine group differences in caregiver quality of life (QoL), four between-groups ANCOVAs were conducted to investigate the effect of group status on caregiver Environmental, Physical, Psychological, and Social QoL, controlling for demographic variables on which the groups differed (child age, family income, caregiver employment status) and variables that have been examined in other studies (number of children residing in the home). In order to build the most parsimonious models, only variables that were significant when initially entered in the model were included as covariates in the final models (Yoder, Watson, & Lambert, 2015).

To examine which aspects of QoL were most impacted for caregivers children with ASD/ASD concerns compared to caregivers of children with other concerns and typical development, three repeated measures ANCOVAs were conducted to investigate whether there were significant differences between QoL domains within each caregiver group, controlling for

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demographic variables (child age, family income, caregiver employment status, and the number of children residing in the home). Only demographic variables that were significant when initially entered in the models were included as covariates in the final models.

To examine the relative influence of family demographic, caregiver psychological, and health care variables on each QoL domain, four multiple linear regression models were fitted using a purposeful, stepwise process (Zhang, 2016). First, a block of four demographic variables (child age, family income, caregiver employment status, and the number of children residing in the home) was entered. Group status was then entered, after controlling for all demographic variables that were significant in the first stage. Next, the caregiver psychological variable, parenting stress, and an interaction term (group* stress) were entered, controlling for all variables from the second stage. Then, the health care variable (family-centered care) and an interaction term (group*family centered care) were entered, controlling for all variables from the third model. Lastly, two interaction terms (stress*family-centered care; group*stress*family-centered care) were entered to examine whether family-centered care moderated the relation between parenting stress and QoL and whether it differs by group. Variables that were non-significant in the stage that they were entered were removed for subsequent models. Variables for which there were planned interactions (i.e., group) were retained in the model. Once all interactions were examined, main effect variables that were non-significant were removed, such that the final models represent the most parsimonious models predicting QoL. In order to examine interactions between group (3-group categorical variable) and other predictors of interest (continuous variables), group was dummy coded as two different variables (i.e., ASD Concerns as compared to a No Concerns reference group, and Other Concerns as compared to a No Concerns reference group), which produced two different betas for each interaction (i.e., a

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beta for ASD Concerns x parenting stress and a beta for Other Concerns x parenting stress). An interaction involving group was significant if there was significant R^2 change between a model without the two interaction terms and a model that included the two interaction terms.

Results

Group Differences in Predictors

Caregivers of children in the ASD/ASD Concerns group reported significantly higher levels of parenting stress than caregivers in the Other Concerns and the No Concerns groups ($p < .01$); there were no differences between the Other Concerns and the No Concerns groups (see Table 2). There were no group differences in caregiver ratings on the MPOC-20 (see Table 2).

Group Comparisons of QoL

To address the first objective, four between-group ANCOVAs were conducted to examine the effect of group status (ASD/ASD Concerns, Other Concerns, No Concerns) on Environmental, Physical, Psychological, and Social QoL controlling for four demographic variables (child age, family income, caregiver employment status, number of children residing in the home). If covariates significantly predicted the outcome of interest, they were retained in the final model. Results indicated a significant group difference on Environmental QoL, [$F_{(2,184)} = 5.21, p < .01, \eta_p^2 = .05$], Psychological QoL, [$F_{(2,184)} = 5.13, p < .001, \eta_p^2 = .05$], and Social QoL, [$F_{(2,184)} = 9.93, p < .01, \eta_p^2 = .04$], when controlling for family income, and a significant group difference on Physical QoL, [$F_{(2,183)} = 5.28, p < .01, \eta_p^2 = .06$], when controlling for income and the number of children residing in the home (see Figure 1, Table 2). Child age and caregiver employment status were non-significant when entered in the original models and were thus not included in the final models for each domain. Post hoc comparisons using Bonferroni corrections indicated that caregivers of children in the ASD/ASD Concerns group reported significantly

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lower Psychological QoL ($M = 57.74, SD = 21.7$) than caregivers of children in the Other Concerns group ($M = 73.9, SD = 15.6$), $t(187) = 3.1, p = .01$, and caregivers of children in the No Concerns group ($M = 69.61, SD = 15.39$), $t(187) = 2.53, p = .04$, as well as significantly lower Social QoL ($M = 52.18, SD = 27.24$) than caregivers of children in the Other Concerns group ($M = 72.3, SD = 16.38$) $t(187) = 3.31, p < .01$ and in the No Concerns group ($M = 73.21, SD = 19.55$), $t(187) = 4.38, p < .01$). Caregivers of children in the ASD/ASD Concerns group reported significantly lower Environmental QoL ($M = 65.33, SD = 20.02$) than caregivers of children in the No Concerns group ($M = 79.09, SD = 13.35$), $t(187) = 3.16, p = .01$, but not caregivers of children in the Other Concerns group ($M = 75.09, SD = 17.74$). Lastly, caregivers of children in the ASD/ASD Concerns group reported significantly lower Physical QoL ($M = 62.5, SD = 21.14$) than caregivers of children in the No Concerns group ($M = 77.97, SD = 15.94$), $t(187) = 3.24, p < .01$ but not caregivers of children in the Other Concerns group ($M = 75.84, SD = 17.78$). There were no group differences between caregivers of children in the Other Concerns group and those in the No Concerns group for any of the four QoL domains.

Within-Group Differences in QoL

To address the second objective, three repeated measures ANCOVAs were conducted to determine which aspects of QoL were most impacted for caregivers of children with ASD/ASD Concerns compared to caregivers of children with Other Concerns and No Concerns. Analyses controlled for demographic variables (child age, family income, caregiver employment status, number of children residing in the home), such that demographic variables that were significant when entered in the initial model were retained in the final model as covariates. Results are provided in Figure 2 and described below.

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Results indicated that when controlling for income, there were no significant within-group differences between QoL domains for caregivers of children with Other Concerns [$F_{(3, 96)} = .08, p = .97, \eta_p^2 = .003$] or caregivers of children with No Concerns [$F_{(2.51, 275.85)} = 2.05, p = .12, \eta_p^2 = .02$]. However, there were significant within-group differences between QoL domains for caregivers of children with ASD/ASD Concerns [$F_{(3, 123)} = 10.29, p < .01, \eta_p^2 = .2$]. Post-hoc analyses revealed that for caregivers of children with ASD/ASD Concerns, Social QoL was significantly lower than Environmental and Physical QoL ($ps < .01$) and Psychological QoL was significantly lower than Environmental QoL ($p = .02$). There were no significant differences between the other domains. Demographic variables were non-significant and not included as covariates in the final model.

Determinants of QoL

Social QoL. To address the third objective, a multiple linear regression model was fitted to assess predictors of Social QoL using a systematic model building process. First, the block of four demographic variables (child age, family income, caregiver employment status, and the number of children residing in the home) were entered in the model. Income was significant and thus was retained in future models. Group was then added to the model; group was significant and was retained in future models. Next, parenting stress and a group*parenting stress interaction term were added to the model; parenting stress was significant and thus retained in future models. Family-centered care and a group*family-centered care interaction term were then added to the model; family-centered care was significant and thus retained in future models. Finally, a two-way interaction term (parenting stress*family-centered care) and a three-way interaction term (parenting stress*family-centered care*group) were added to the model. These interaction terms were not significant and thus not retained in future models. When examining the

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significant variables of interest together in the resulting model, group was no longer significant and was not included in the final model. Results from the final model are provided in Table 3.

In the final model, income significantly predicted Social QoL such that higher income was associated with higher Social QoL ($\beta = .13, p = .02$). Parenting stress predicted Social QoL, such that lower parenting stress was associated with higher Social QoL ($\beta = -.59, p < .01$). Family-centered care also predicted Social QoL, such that higher family-centered care was associated with higher Social QoL ($\beta = .17, p < .01$).

Psychological QoL. A multiple linear regression model was fitted to assess predictors of Psychological QoL using a systematic model building process. First, the block of four demographic variables (child age, family income, caregiver employment status, and the number of children residing in the home) were entered in the model. Income was significant and thus was retained in the next model. Group was then added to the model; group was significant and retained in future models. Then, parenting stress and a group*parenting stress interaction term were added to the model; parenting stress was significant and thus retained in future models. Next, family-centered care and a group*family-centered care interaction term were added to the model; family-centered care was significant and thus retained in future models. Finally, a two-way interaction term (parenting stress*family-centered care) and a three-way interaction term (parenting stress*family-centered care*group) were added to the model. These interaction terms were not significant and thus not retained in future models. When examining the significant variables of interest in the resulting model, group was no longer significant and was not included in the final model. Results from the final model are provided in Table 4 and described below.

In the final model, income significantly predicted Psychological QoL such that higher income was associated with higher Psychological QoL ($\beta = .16, p = .01$). Parenting stress

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predicted Psychological QoL, such that lower parenting stress was associated with higher Psychological QoL ($\beta = -.58, p < .01$). Family-centered care predicted Psychological QoL, such that higher family-centered care was associated with higher Psychological QoL ($\beta = .13, p = .02$).

Physical QoL. A multiple linear regression model was fitted to assess predictors of Physical QoL using a systematic model building process. First, the block of four demographic variables (child age, family income, caregiver employment status, and the number of children residing in the home) were entered in the model. Income, child age, and the number of children residing in the home were significant and thus were retained in the next model. Group was then added to the model; group was not significant but was retained in future models in order to test planned interactions. Next, parenting stress and a group*parenting stress interaction term were added to the model; parenting stress was significant and thus retained in future models. Then, family-centered care and a group*family-centered care interaction term were added to the model; family-centered care was significant and thus retained in future models. Finally, a two-way interaction term (parenting stress*family-centered care) and a three-way interaction term (parenting stress*family-centered care*group) were added to the model. These interaction terms were not significant and thus not retained in future models. When examining the significant variables of interest in the resulting model, group and child age were not significant and were thus not included in the final model. Results from the final model are provided in Table 5 and described below.

In the final model, income significantly predicted Physical QoL such that higher income was associated with higher Physical QoL ($\beta = .20, p < .01$). Number of children residing in the home predicted Physical QoL in that fewer children in the home was associated with higher

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Physical QoL ($\beta = -.14, p = .01$). Parenting stress predicted Physical QoL, such that lower parenting stress was associated with higher Physical QoL ($\beta = -.45, p < .01$). Family-centered care predicted Physical QoL, such that higher family-centered care was associated with higher Physical QoL ($\beta = .20, p < .01$).

Environmental QoL. A multiple linear regression model was fitted to assess predictors of Environmental QoL using a systematic model building process. First, the block of four demographic variables (child age, family income, caregiver employment status, and the number of children residing in the home) were entered in the model. Income and child age were significant and thus were retained in next model. Group was then added to the model. Group was significant and was retained in future models. Next, parenting stress and a group*parenting stress interaction term were added to the model; these variables were significant and thus retained in future models. Then, family-centered care and a group*family-centered care interaction term were added to the model; family-centered care was significant and thus retained in future models. Finally, a two-way interaction term (parenting stress*family-centered care) and a three-way interaction term (parenting stress*family-centered care*group) were added to the model. The two-way interaction was significant and thus retained in future models. When examining the significant variables of interest in the resulting model, child age was no longer significant and was not thus included in the final model. Results from the final model are provided in Table 6 and described below.

In the final model, income significantly predicted Environmental QoL such that higher income was associated with higher Environmental QoL ($\beta = .28, p < .01$). Parenting stress predicted Environmental QoL, such that lower parenting stress was associated with higher Environmental QoL ($\beta = -.29, p < .01$). There was also a significant interaction between

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parenting stress and group, such that lower parenting stress was associated with higher Environmental QoL overall, but this relation was only significantly different for caregivers of children with ASD/ASD Concerns compared to caregivers of children with No Concerns ($\beta = -.30, p < .01$) and not significantly different for caregivers of children with Other Concerns compared to caregivers of children with No Concerns ($\beta = -.10, p = .13$). Examination of the slopes revealed that there was a stronger negative relationship between parenting stress and Environmental QoL for caregivers of children with ASD/ASD Concerns compared to caregivers of children with No Concerns (see Figure 3). Family-centered care predicted Environmental QoL, such that higher family-centered care was associated with higher Environmental QoL ($\beta = .25, p < .01$).

Discussion

The purpose of the current study was to understand the unique topography of quality of life (QoL) in caregivers of children with autism spectrum disorder (ASD) and caregivers of children for whom there are concerns about ASD. This study builds upon previous research that examined QoL in caregivers of children with ASD; however, it is distinct in that it focused exclusively on caregivers of young children under age five, in contrast to previous research, which has primarily focused on school-aged children and/or adolescents. This study is the first to include caregivers of young children for whom ASD is suspected, providing insight into how ASD concerns may impact caregiver QoL prior to diagnostic confirmation— a distressing period of uncertainty for many families as they navigate the service delivery system to seek diagnostic clarity (Crane, Chester, Goddard, Henry, & Hill, 2016; Zuckerman et al., 2015). To date, only one study has examined QoL in caregivers of children with ASD concerns. This study found that caregivers of adolescent and young adult children with ASD symptoms and no diagnosis,

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reported lower QoL than caregivers of children with a confirmed ASD diagnosis and caregivers of children with typical development (McKechanie et al., 2017), suggesting that the presence of ASD concerns alone may have a significant impact on caregiver QoL.

The first objective of this study was to examine how having a child with ASD/ASD concerns affects caregiver QoL, relative to children with Other Concerns and typical development. Overall, results revealed that caregivers in the ASD/ASD Concerns group reported significantly lower Psychological and Social QoL than caregivers in the Other Concerns and No Concerns groups, and significantly lower Environmental and Physical QoL than caregivers in the No Concerns group. There were no group differences in QoL between caregivers in the No Concerns and Other Concerns groups. As a majority of children in the ASD sample did not yet have an official diagnosis of ASD, these results indicate that QoL may be negatively impacted in caregivers even prior to diagnostic confirmation of ASD, highlighting a potentially critical period in which additional support could be provided.

It is not surprising that caregivers in the ASD/ASD Concerns group reported significantly lower Psychological and Social QoL than caregivers in the Other Concerns and No Concerns groups, given that these domains both evaluate areas of reported impairment in caregivers of children with ASD. The Psychological QoL domain of the WHOQOL-BREF measures caregiver satisfaction with one's mental health (e.g., self-esteem, anxiety, depression) and the Social QoL domain measures caregiver satisfaction with one's social connectedness, (e.g., personal relationships, friendships). Research indicates that caregivers of children with ASD report higher levels of stress, anxiety, and depression and reduced relationship satisfaction compared to caregivers of children with other concerns and/or caregivers of children with typical development (Brobst et al., 2008; Dabrowska & Pisula, 2010; Daniels et al., 2008; Estes et al.,

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2009; Rao & Beidel, 2009; Singer, 2006), as well as high levels of perceived stigma and social isolation (Jones & Passey, 2005; Myers, Mackintosh, & Goin-Kochel, 2009; Woodgate, Ateah, & Secco, 2008).

The findings in the present study are consistent with those of other studies that have found that caregivers of children with ASD report lower Psychological and Social QoL than caregivers of children with specific learning disabilities (Khan & Humtsoe, 2016), physical disabilities (Perumal et al., 2014), and typical development (Eapen et al., 2014; Ezzat et al., 2017; Lee et al., 2008; Malhotra et al., 2012; Pisula & Porębowicz-Dörsmann, 2017). In the present study, the mean domain scores for caregivers in the No Concerns group (Psychological $M = 69.6$; Social $M = 73.2$) were comparable to WHOQOL-BREF population norms (Psychological $M = 70.6$, $SD = 14$; Social $M = 71.5$, $SD = 18.2$; Hawthorne, Herrman, & Murphy, 2006). Results also revealed that for caregivers in the ASD/ASD Concerns group the mean domain score for Psychological QoL ($M = 57.7$) was within 1 SD of the population norm mean; however, the mean domain score for Social QoL ($M = 52.2$) was 1 SD *below* the population norm mean. These findings suggest that Social QoL is impaired for caregivers in the ASD/ASD Concerns group when compared to caregivers of children with typical development *and* when compared to the population norm mean. This finding is concerning, given that research indicates that lower levels of social support predict higher levels of depression and anxiety in caregivers of children with ASD (Boyd, 2002; Dunn et al., 2001).

Results from the current study also indicate that caregivers in the ASD/ASD Concerns group reported significantly lower Environmental and Physical QoL than caregivers in the No Concerns group, but not caregivers in the Other Concerns group. The Environmental QoL domain measures satisfaction with physical environment (e.g., general living conditions,

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finances, access to health services), while the Physical QoL domain measures satisfaction with physical capacities (e.g., mobility, energy, sleep). The results of the current study are not surprising, given that research indicates that caregivers of children with ASD report greater difficulty with many of the areas that these domains directly assess, including significant unmet healthcare needs, high financial burden, poor physical health, sleep challenges, increased caregiving hours, and decreased participation in leisure activities compared to caregivers of children with other special healthcare needs and/or typical development (Crowe, 1993; Crowe & Florez, 2006; Kogan et al., 2006; LaVelle et al., 2016; Meltzer, 2008; Vohra et al., 2014). The findings in the present study are consistent with studies that have found lower Environmental (Malhotra et al., 2012; Pisula & Porębowicz-Dörsmann, 2017) and Physical QoL (Lee et al., 2008; Ezzat et al., 2017; Malhotra et al., 2012; Pisula & Porębowicz-Dörsmann, 2017) in caregivers of children with ASD compared to caregivers of children with typical development and with studies that have found *no* differences in Environmental and Physical QoL between children with ASD and children with Down Syndrome and Cerebral Palsy (Malhotra et al., 2012; Tekinarlsan et al., 2013).

In the present study, the mean domain scores for Environmental and Physical QoL for caregivers in the No Concerns group (Environmental $M = 79.1$; Physical $M = 77.9$) were slightly higher than WHOQOL-BREF population norms, but still within 1 SD (Environmental $M = 75.1$, $SD = 13.0$; Physical $M = 73.5$, $SD = 18.1$; Hawthorne, Herrman, & Murphy, 2006). Results revealed that both the Environmental QoL mean domain score ($M = 65.3$) and the Physical QoL mean domain score ($M = 62.5$) for caregivers in the ASD/ASD Concerns group were also both within 1 SD of the population norm means, suggesting that though caregivers in the ASD/ASD Concerns group reported significantly lower Environmental and Physical QoL than caregivers of

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children with typical development, their QoL ratings were still within normal ranges when compared to population norms.

The second objective of the study was to examine the profiles across QoL domains within each caregiver group to determine which QoL domains were most impacted relative to other domains. It is informative to identify the QoL domains in which caregivers of children with ASD/ASD concerns particularly struggle, in order to triage use of targeted interventions. Results revealed that there were no significant within-group differences between QoL domains for caregivers in the Other Concerns group or caregivers in the No Concerns group. However, there were significant within-group differences between QoL domains for caregivers of children with ASD/ASD concerns, such that Social QoL was significantly lower than Environmental and Physical QoL and Psychological QoL was significantly lower than Environmental QoL. These findings suggest that Psychological and Social QoL are the most impacted domains for caregivers of children with ASD/ASD concerns. To our knowledge, no other study has examined within group differences in QoL domains in caregivers of children with ASD or ASD concerns.

Research indicates that when QoL scores are linearly transformed on a scale of 0 to 100, a score of 60 represents the cut-off in which QoL is deemed 'neither good nor poor' (Dardas & Ahmad, 2014c). For caregivers of children with ASD/ASD concerns, Social and Psychological QoL were the only domains with mean scores that fell below this threshold ($M = 57.7$ Psychological QoL; $M = 52.2$ Social QoL). Notably, caregivers in the Other Concerns group and caregivers in the No Concerns group did not have any mean domain scores under 60. When comparing the means of caregivers in the ASD/ASD Concerns group to caregivers in the No Concerns group, the mean domain score for Psychological QoL in caregivers in the ASD/ASD Concerns group ($M = 57.7$) was within 1 SD of the mean for the No Concerns group ($M = 69.6$,

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$SD = 15.4$). However, the mean for Social QoL in caregivers in the ASD/ASD Concerns group ($M = 52.2$) was 1 SD below the mean for the No Concerns group ($M = 73.2$, $SD = 19.5$).

Given the high levels of stress, depression, anxiety, social isolation, and marital dissatisfaction reported by caregivers of children with ASD, these results further emphasize that caregivers of children with ASD *and* ASD concerns may benefit from interventions or support services that target psychological well-being and social connectedness. While there is emerging evidence that mindfulness-based stress reduction (MBSR) interventions lead to decreased depression and increased life satisfaction in caregivers of children with ASD (Ferraioli & Harris, 2012; Neece, 2013), research is needed to determine the types of social supports (i.e., formal, informal) that may be most beneficial for caregivers of children with ASD/ASD concerns. For example, Parent to Parent (P2P) is a formal social support program that matches parents of children with disabilities with peer mentors. Research indicates that parents in P2P report that having someone ‘to listen and understand’ is one of the largest benefits of the program (Santelli, Ginsbger, Sullivan, & Neiderhauser, 2002). Further research is needed to determine the relative influence of formal social supports on caregiver Social QoL, compared to informal supports (e.g., friends, family).

The third objective of this study was to examine determinants (i.e., predictors) of QoL in caregivers of children with ASD or ASD concerns, other concerns, and typical development. The Ferrans et al. (2005) conceptual model of QoL was applied in order to examine the extent to which two levels of determinants (individual and social environment) influenced caregiver QoL. In the Ferrans’ et al. model, individual characteristics are “demographic, developmental, psychological, and biological factors that influence health outcomes” while social-environmental-level characteristics are “interpersonal or social influences on health outcomes,

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including the influence of family, friends, and healthcare providers” (p. 337). In keeping with the model, individual characteristics included demographic variables (child age, family income, caregiver employment status, number of children in the home) and one psychological variable (parenting stress), while social environment characteristics included one health care variable (family-centered care). Ferrans et al. posited that demographic variables are immutable —though useful in helping target interventions for specific groups— while psychological and healthcare system variables may be responsive to intervention.

In the current study, all caregivers were included in the same regression models for each of the four QoL domains, with caregiver group entered as a predictor. The justification for not conducting separate models for each caregiver group was drawn from existing QoL literature, which indicates that disability status should be examined as a determinant (rather than an indicator) of QoL (Moons et al., 2006). This rationale aligns with the disability paradox, which posits that an individual’s QoL is not pre-determined by their disability (Albrecht & Devileger, 1999). Though the current study and other studies have found mean group differences across QoL domains between caregivers of children with ASD or ASD concerns and other caregiver groups, it is important to examine whether these group differences remain significant in multivariate analyses, which take into account other potentially important determinants. Analyzing all caregivers in the same models allows for a better understanding as to whether there are predictors of QoL that are unique to caregivers of children with ASD or ASD concerns. In the current study, caregiver group was not a significant predictor of QoL for three out of four QoL domains (i.e., Physical, Psychological, and Social QoL), suggesting that child’s disability status alone does not solely determine a caregiver’s QoL.

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Overall, results indicate that income, parenting stress, and family-centered care were significant predictors for all four QoL domains, while the number of children residing in the home was a significant predictor for Physical QoL only. One challenge in comparing these results with results of other studies is that a majority of existing studies that have examined predictors of QoL in caregivers of children with ASD often do not include control groups of other caregivers, and/or only examine predictors within their ASD samples. Results will thus be interpreted based on their relationship to existing research in both ASD and non-ASD samples.

Demographic Determinants

Income was the only demographic factor associated with all four QoL domains (Environmental, Physical, Psychological, and Social QoL). The only other demographic determinant to predict QoL was the number of children in the home, which was associated only with Physical QoL. Child age and caregiver employment status were not associated with any of the four QoL domains.

The finding that income was positively associated with Environmental, Physical, Psychological, and Social QoL is consistent with research in populations of caregivers of children with intellectual disabilities (Lin et al., 2009; Tekinarlsan, 2013). In caregivers of children with ASD, research overwhelmingly indicates that income is positively associated with Environmental QoL (Favero-Nunes & Antonio dos Santos 2010; Kareem et al., 2014; Mahani et al., 2013; Piovesan et al., 2015). This finding makes sense, as the Environmental QoL domain includes items that ask about one's satisfaction with earnings, safety, transportation, and access to health services, which are variables that are associated with income (Vlahov et al., 2007). However, for caregivers of children with ASD, the association between income and Physical, Psychological, and Social QoL has been mixed, with some studies finding positive associations

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and others finding no associations (Favero-Nunes & Antonio dos Santos, 2010; Mahani et al., 2013; Piovesan et al., 2015). Notably, these studies often use bivariate analyses, which do not allow for examination of the relative influence of multiple variables on a given outcome. Only one study (Lee et al., 2008) used a multivariate analysis (i.e., hierarchical regression) and found that income was positively associated with both Physical and Psychological QoL. Unfortunately, Lee et al. used the SF-36, a health status measure, to examine QoL, which only includes Physical and Psychological QoL domains.

Number of children residing in the home was negatively associated with Physical QoL, such that the less children in the home, the higher the caregiver's Physical QoL. Given that the Physical QoL subscale includes items that ask caregivers to rate their satisfaction with their energy, sleep, and physical pain, it is not surprising that having less children in the home would be associated with higher caregiver QoL ratings. This finding is consistent with studies that have found a negative association between number of children in the home and Physical QoL in caregivers of children with cerebral palsy (Eken & Tüzün, 2004) and overall QoL in caregivers of children with asthma (Bellin et al., 2013). When compared with studies that have examined QoL in caregivers of children with ASD, this result is consistent with the findings of Ji et al. (2014); However, it is inconsistent with the findings of a study that found that having more children in the home was associated with *higher* caregiver Physical QoL (Lee et al., 2008) and with a study that found no association between these variables (Johnson et al., 2011). Notably, all three studies used the same health status measure (SF-36) to evaluate QoL and used multiple regression analyses to examine the relationship between variables. Ji et al. argued that having more children in the home is negative because it leads to stressful sibling conflict; however, Lee et al. hypothesized that having more children in the home is positive because it allows parents to

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delegate child-rearing tasks to older children. Cultural differences may explain the Ji et al. findings, given that the study was conducted in China, where up until 2013 it was illegal for families to have more than one child. However, it is surprising that the results of the current study are not aligned with those of Lee et al. or Johnson et al., studies which were both conducted in the U.S. and included similar mean numbers of children as the current study (approximately 2 children per family). Given that the mean age of children in the current study ranged from 19 to 26 months, while the mean age of children in the Johnson et al. and Lee et al. studies ranged from approximately 7 to 9 years-old, it could be that having more children in the family is negatively associated with Physical QoL when children are young and necessitate more physical demands from caregivers (e.g., carrying, lifting) and allow for less delegation of caregiving duties.

Parenting Stress

Results from the present study indicate that parenting stress was negatively associated with all four QoL domains. Studies of parenting stress and in other caregiver populations have also found that stress is negatively associated with QoL for caregivers of children with other concerns (Fidika, Salewski, & Goldbeck, 2003; Wheeler, Skinner, & Bailey, 2008), psychiatric issues (Crowley & Kazdin, 1998), and medical conditions (Litzelman, Catrine, Gangnon, & Witt, 2011). Though it is well-established that caregivers of children with ASD experience higher levels of stress than caregivers of children with other developmental disorders and typical development, the association between parenting stress and QoL in caregivers of children with ASD is a relatively understudied area. Nevertheless, results from the present study are consistent with previous research that has found a negative association between stress and Environmental,

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Physical, Psychological, and Social QoL for caregivers of children with ASD (Eapen et al., 2014; Johnson et al., 2011; Lee et al., 2008).

There was also a significant group by stress interaction for Environmental QoL in the present study, such that there was a stronger negative relationship between parenting stress and Environmental QoL for caregivers of children in the ASD/ASD Concerns group compared to caregivers of children in the No Concerns group. No studies to date have examined interactions between caregiver groups and parenting stress on QoL. One hypothesis as to why there was a stronger negative relationship between parenting stress and Environmental QoL for caregivers of children in the ASD/ASD Concerns group compared to caregivers of children in the No Concerns group is that parenting stress (e.g., distress about challenging behaviors, poor parent-child interactions) may serve as a proxy for child symptom severity. High levels of parenting stress may be uniquely associated with certain items in the Environmental QoL domain (e.g., “Have you enough money/information to meet your needs?”) for caregivers of children with ASD/ASD concerns due to the challenges presented by their child’s condition (e.g., intervention costs, uncertainty about navigating the service delivery system), and less inherently associated with Environmental QoL for caregivers of children with typical development. For other QoL domains (Physical, Psychological, Social) the association between parenting stress and QoL is more straightforward across caregiver groups. Overall, the results from the current study indicate that parenting stress is negatively associated with all domains of QoL for caregivers of children with ASD/ASD concerns, other concerns, *and* typical development. These results suggest that future research is needed to determine if parenting stress may be an important area of intervention to improve QoL in caregivers of young children.

Family-centered care

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Family-centered care describes a philosophy of care in which service providers share information and include caregivers in decision making-processes in an effort to promote collaboration, participation, and partnership (King et al., 2004). Results from the current study indicate that family-centered care was a significant predictor —and one of the strongest predictors — of all four QoL domains. This finding is consistent with research in other caregiver populations that indicates that family-centered care is positively associated with QoL in samples of caregivers of children with cancer (Klassen et al., 2008) and developmental disabilities (Davis & Gavidia-Payne, 2009; Seliner, Latal, & Spirig, 2016). In fact, Davis and Gavidia-Payne (2009) found that in a sample of caregivers of children with developmental delays who were enrolled in early intervention programs, family-centered care was the strongest predictor of family QoL when entered in a model with family income, family support, and intensity of child behaviors/needs. Though research indicates that caregivers of children with ASD report lower levels of family-centered care than caregivers of children with other special health care needs (Kogan et al., 2008; Vohra, Madhavan, Sambamoorthi, & St Peter, 2014), family-centered care has not yet been examined as a predictor of QoL in caregivers of children with ASD.

When considering the results of the present study, it is not surprising that family-centered care was positively associated with Environmental QoL, given that there is an item in this domain of the WHOQOL-BREF that specifically asks “How satisfied are you with your access to health services?” However, the relation between family-centered care and the other QoL domains is not as explicit. Empirical evidence indicates that family-centered care encompasses a strengths-based approach that aims to promote resiliency in families, which may explain the collateral impact of family-centered care on other QoL domains. Findings from a meta-analysis examining the influence of family-centered care in pediatric samples indicated that parent self-

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efficacy (i.e., sense of control during interactions with providers) mediated the relation between family-centered care and parent well-being, such that high degrees of family-centered care led to increases in parent self-efficacy, which in turn, led to improvements in parent well-being (Dunst & Trivette, 2009). These results suggest that provision of family-centered care may serve to empower caregivers in their interactions with health care providers. Research also indicates that caregiver empowerment may have a positive influence on child outcomes. Graves and Shelton (1999) found that caregiver empowerment, as measured by the Family Empowerment Scale (Koren, DeChillo, & Friesen, 1992; e.g., “I know what to do when problems arise with my child,” “I know the steps to take when I am concerned my child is receiving poor services”), mediated the relation between family centered-care and child outcomes, such that high levels of family centered care, led to a greater sense of parent empowerment, which ultimately led to improvements in child outcomes (Graves & Shelton, 1999). Considering that high levels of family-centered care are associated with improvements in service access, timeliness of care, service satisfaction, family functioning, and health care expenditures for children with special health care needs (Kuhlthau et al., 2011; Kuo, Bird, Tilford, 2011), provides a more helpful context for understanding the association between family-centered care and caregiver Physical, Psychological, and Social QoL in the current study.

Research indicates that children with ASD have more medical and psychological comorbidities, require more specialty care referrals, and have more frequent doctor’s appointments than children without ASD. (Brachlow, Ness, McPheeters, & Gurney, 2007; Gurney, McPheeters, & Davis, 2006). Researchers have hypothesized that the complexity of ASD, compared to other childhood disorders with clear-cut presentations and treatment courses (e.g., asthma, diabetes), makes it more challenging for pediatricians to feel confident in their

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management of children with ASD, presenting barriers to their provision of family-centered care (Levy et al., 2016; Lipstein et al., 2015). Indeed, pediatricians report that they lack knowledge about ASD treatment and available resources in the community (Levy et al., 2016) and feel less competent in treating children with ASD compared to children with neurodevelopmental conditions and chronic/complex medical conditions (Golnik, Ireland, & Borowsky, 2009). Despite these concerns, there is a lack of knowledge about interventions that promote family-centered care for families of children with ASD (Levy & Fiks, 2018), as well as very limited understanding about interventions that promote patient- and family-centered care in other clinical populations (Légaré et al., 2010; Wyatt et al., 2016).

In 2017, the AAP published guidelines for promoting shared-decision making—an important component of family-centered care—for families of children with disabilities, which included recommendations for providers to use when helping families make treatment decisions: present treatment options, review risks and benefits, check for understanding, arrange a follow-up meeting (Adams et al., 2017). Despite these concrete strategies, to date, only one study has empirically examined a family-centered care intervention for caregivers of children with ASD. In their intervention, Golnik and colleagues (2012) examined outcomes of a medical home model designed specifically for children with ASD. The model included use of a nursing and scheduling coordinator, an ASD-specific referral guide for the community (e.g., dentists), and provision of resources to support children during appointments (e.g., social stories). Results revealed that caregivers whose children received care through the medical home model reported significantly greater health care satisfaction and shared-decision making than caregivers in a control group who received standard services within the same health care system. Given movement in the field towards use of patient-centered outcome measures and adoption of the

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medical home model in primary care, it will be important for future research to determine whether increasing provision of family-centered care in primary care practices leads to direct influences on caregiver QoL, especially for caregivers of children with ASD.

The fourth and final objective of this study was to explore whether family-centered care moderated the relationship between parenting stress and QoL. Though research indicates that family-centered care is negatively associated with parenting stress (e.g., Hung, Liu, & Lin, 2015; King et al., 1995; King, King, & Rosenbaum, 2004; O'Neil, Palisano, & Westcott, 2001) and positively associated with caregiver QoL (e.g., Davis & Gavidia-Payne, 2009; Klassen et al., 2008; Seliner, Latal, & Spirig, 2016), family-centered care has never been examined as a moderator of parenting stress and QoL; therefore, this aim was considered exploratory. In the present study, family-centered care was considered a social environment characteristic, conceptualized as support from healthcare providers. Therefore, consistent with the 'buffering model' of social support posited by Cohen and Wills (1995), it was hypothesized that family-centered care would buffer the impact of parenting stress on all four QoL domains, such that in the presence of high parenting stress, caregivers who reported receiving high degrees of family-centered care, would report higher QoL than caregivers who reported receiving low degrees of family-centered care.

Results indicated that though parenting stress and family-centered care individually predicted each of the four QoL domains in the present study, family-centered care did not moderate the relationship between parenting stress and QoL as predicted. This finding is consistent with the 'direct effect model' of social support instead of the 'buffering model' (Cohen & Wills, 1995), and suggests that though family-centered care and parenting stress uniquely contribute to QoL in caregivers, family-centered care does not influence the strength of

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the relationship between stress and QoL. This finding has important practical implications, and suggests that high degrees of family-centered care are important for *all* caregivers, regardless of their amount of perceived parenting stress. Other studies have also found that social support did not moderate the relation between stress/depression and QoL in clinical populations of adults, though they found that stress/depression and social support had direct effects on QoL (Eom et al., 2013; Panayiotou & Karekla, 2013). It is important to also consider that family-centered may serve as a *mediator* between parenting stress and QoL, such that caregivers who experience high degrees of parenting stress may perceive their relationship with their child's health care providers as less family-centered, in turn leading to poor QoL. Though family-centered care has yet to be examined as a mediator, there is some evidence that social support may mediate the relation between parenting stress and psychological distress. In a study investigating the moderating and mediating effects of social support in mothers of children with hearing impairments, Quittner and colleagues (1990) found that perceived social support mediated the relation between parenting stress and depression/anxiety, such that mothers with higher stress reported lower perceptions of social support and subsequently higher levels of psychological distress. However, Quittner et al. could not find evidence to support social support as a moderator.

Limitations

This study is not without limitations. First and foremost, this study is cross-sectional and therefore it was not possible to determine the directionality of the findings. For example, though low levels of family-centered care may negatively impact caregiver QoL, caregivers who report low QoL may also be more likely to interpret their relationship with their child's primary care provider more negatively. The second limitation is that the composition of the caregiver groups

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was determined based on caregiver report and not through a formal child assessment. Children were included in the ASD/ASD Concerns group if their caregiver endorsed an explicit concern about ASD (e.g., existing diagnosis of ASD, screened at-risk on an ASD screening tool, caregiver/provider/family member endorsed having ASD concerns) *or* if their caregiver reported having concerns about a profile of symptoms indicative of ASD (e.g., concerns about social interaction issues *and* language or communication, unusual toy play, unusual body movements, and/or over- or under-responsive sensory issues). Therefore, a portion of the caregivers in the ASD/ASD Concerns group may not be aware that the concerns that they endorsed are consistent with symptoms of ASD. Regardless, this study indicates that whether caregivers have explicit concerns about ASD or are just concerned about their child's social functioning, communication, or restricted and repetitive behaviors, their QoL is negatively impacted when compared to caregivers of children with typical development and/or caregivers of children with other concerns. A third limitation of the current study was that data about child behaviors were not collected, thus it was not possible to examine how child symptom severity influenced caregiver QoL. Though research is mixed as to whether child symptom severity is associated with caregiver QoL in children with ASD (Allik et al. 2006; Ji et al., 2014; McKechnie et al., 2017; Perumal et al., 2014; Wisessathorn et al., 2013), for the purposes of this study it would have been useful to understand how child symptoms may influence caregiver QoL relative to other predictors (e.g., parenting stress, family-centered care). A fourth limitation of this study, was that the small proportion of fathers in the sample did not allow for comparison in QoL scores between mothers and fathers, or examination of whether caregiver sex predicted QoL in caregivers of children with ASD or ASD concerns. Given that research indicates that mothers and fathers of children with ASD may display different patterns of QoL results (Dardas &

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Ahmad, 2014b; Kareem & Ali, 2014; Mugno et al., 2007; Yamada et al., 2012), future research should attempt to recruit parent dyads to compare whether there are differences in QoL ratings and/or unique predictors of QoL for mothers and fathers of children with ASD or ASD concerns, compared to other caregiver populations.

Conclusion

These limitations notwithstanding, the present study provides an initial step in understanding QoL in caregivers of children with ASD or ASD concerns. Results indicated that caregivers of children with ASD/ASD concerns reported lower Social and Psychological QoL than caregivers of children with other concerns and typical development, and lower Environmental and Physical QoL than caregivers of children with typical development. Furthermore, within caregivers of children with ASD/ASD concerns, Social QoL was significantly lower than Environmental and Physical QoL, and Psychological QoL was significantly lower than Environmental QoL. When considered together, these results indicate that Social QoL (i.e., satisfaction with personal relationships and support from friends) and Psychological QoL (i.e., satisfaction with self, anxiety, depression) are particularly impaired for caregivers of children with ASD or ASD concerns. Future research is warranted to identify effect points of intervention for caregivers, potentially before children receive an official diagnosis of ASD. Furthermore, results from the current study indicate that income, parenting stress, and family-centered care were negatively associated with QoL for *all* caregivers. These findings indicate that the presence of a disability should not be used as a sole determinant of a caregiver's QoL. The only difference in predictors across caregiver groups was a significant group by stress interaction for Environmental QoL, such that there was a stronger negative relationship between parenting stress and Environmental QoL for caregivers of children with ASD/ASD concerns

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compared to caregivers of children with typical development. Future research should determine whether interventions to improve parenting stress lead to increased Environmental QoL for caregivers of children with ASD/ASD concerns, or conversely, whether improvements in Environmental QoL (e.g., safety, finances, opportunities for leisure) lead to reductions in parenting stress.

Lastly, family-centered care did not moderate the relationship between parenting stress and QoL, suggesting that all caregivers can benefit from receiving high levels of family-centered care— not just exclusively caregivers who report high levels of parenting stress. As family-centered care was one of the strongest predictors of QoL across all four QoL domains, future research should identify interventions to improve provision of family-centered care practices, particularly for caregivers of children with ASD/ASD, who are at risk for experiencing lower levels of family-centered care than other caregiver groups. In sum, these findings suggest that future research is needed to determine how to provide additional support to all caregivers, particularly low-income families and caregivers who are experiencing high levels of parenting stress and low levels of family-centered care.

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Table 1. Demographic Characteristics of the Sample

Variable	ASD/ASD Concerns <i>n</i> = 42	Other Concerns <i>n</i> = 34	No Concerns <i>n</i> = 112	<i>p</i>
Caregiver age M (<i>SD</i>)	32.7 (8.3)	33.9 (5.7)	31.7 (4.8)	.17
Child age M (<i>SD</i>)**	26 (5.6) ^	22 (4.5) †	19.9 (1.2)	< .01
Number of children in the home M (<i>SD</i>)	2.5 (1.6)	2.3 (1.2)	2.1 (1)	.09
Child sex # (%)				.11
Male	30	20	59	
Female	12	14	53	
Caregiver race # (%)				.41
White	38 (91)	29 (85)	106 (95)	
Non-white	3 (7)	4 (12)	6 (5)	
Other/unknown	1 (2)	1 (3)	0 (0)	
Caregiver ethnicity # (%)				.26
Hispanic	6 (14)	3 (9)	7 (6)	
Non-Hispanic	35 (83)	30 (88)	105 (94)	
Unknown	1 (3)	1 (3)	0 (0)	
Family income # (%)**				< .01^

\$20,000 or less	13 (31)	4 (12)	9 (8)	
\$20,001 – 40,000	17 (41)	7 (20)	17 (15)	
\$40,001 – 60,000	5 (12)	4 (12)	30 (27)	
\$60,001 – 80,000	2 (5)	5 (15)	17 (15)	
\$80,001 – 100,000	4 (9)	4 (12)	15 (13)	
\$100,001 or greater	1 (2)	10 (29)	24 (22)	
Caregiver employment status # (%) [*]				.05 ^υ
Unemployed	25 (59)	13 (38)	50 (45)	
Part-time	7 (17)	3 (9)	27 (24)	
Full-time	10 (24)	18 (53)	35 (31)	
Caregiver relationship to child # (%) ^X				
Mother (biological, adoptive, foster)	40 (96)	32 (94)	105 (94)	
Father (biological, adoptive)	1 (2)	0 (0)	7 (6)	
Other	1 (2)	2 (6)	0 (0)	

Note. ^{*} $p < .05$, ^{**} $p < .01$

[^]ASD/ASD Concerns group significantly different than Other Concerns and No Concerns groups.

[†]ASD/ASD Concerns group significantly different than No Concerns group.

^υASD/ASD Concerns group significantly different than Other Concerns group.

^γOther Concerns group significantly different than No Concerns group.

^XUnable to calculate group differences due to low cell count in Father and Other categories.

Table 2. Group Differences on Psychosocial Measures

Variable	<i>M (SD)</i>				F	<i>p</i>	η_p^2
	Total Sample <i>n</i> = 188	ASD/ASD Concerns <i>n</i> = 42	Other Concerns 34 <i>n</i> =	No Concerns <i>n</i> = 112			
PSI-SF Total Score	67.9 (25.63)	93.05 (26.48) [^]	62.38 (20.13)	60.17 (20.46)	35.8	<.01	.28
Range	36-170	40-163	41-114	36-170			
MPOC-20 Total Score	5.43 (1.3)	5.45 (1.28)	5.84 (1.11)	5.36 (1.29)	1.8	.17	.02
Range	1.5-7	1.83-7	2.15-7	1.5-7			
Environmental QoL ^a	75.29 (16.74)	65.3 (20) [†]	75.1 (17.7)	79.1 (13.3)	5.2	.01	.05
Range	6.3-100	6.3-96.9	37.5-100	28.13-100			
Physical QoL ^b	74.13 (18.55)	62.5 (21.1) [†]	75.8 (17.8)	77.9 (15.9)	5.3	.01	.06
Range	7.1-100	7.1-100	32.1-100	21.4-100			
Psychological QoL ^a	67.73 (17.84)	57.7 (21.7) [^]	73.9 (15.6)	69.6 (15.4)	5.1	.01	.05
Range	0-100	0-91.7	25-100	15-100			
Social QoL ^a	68.35 (22.64)	52.2 (27.2) [^]	72.3 (16.4)	73.2 (19.5)	9.9	<.01	.09
Range	0-100	0-100	41.67-100	8.3-100			

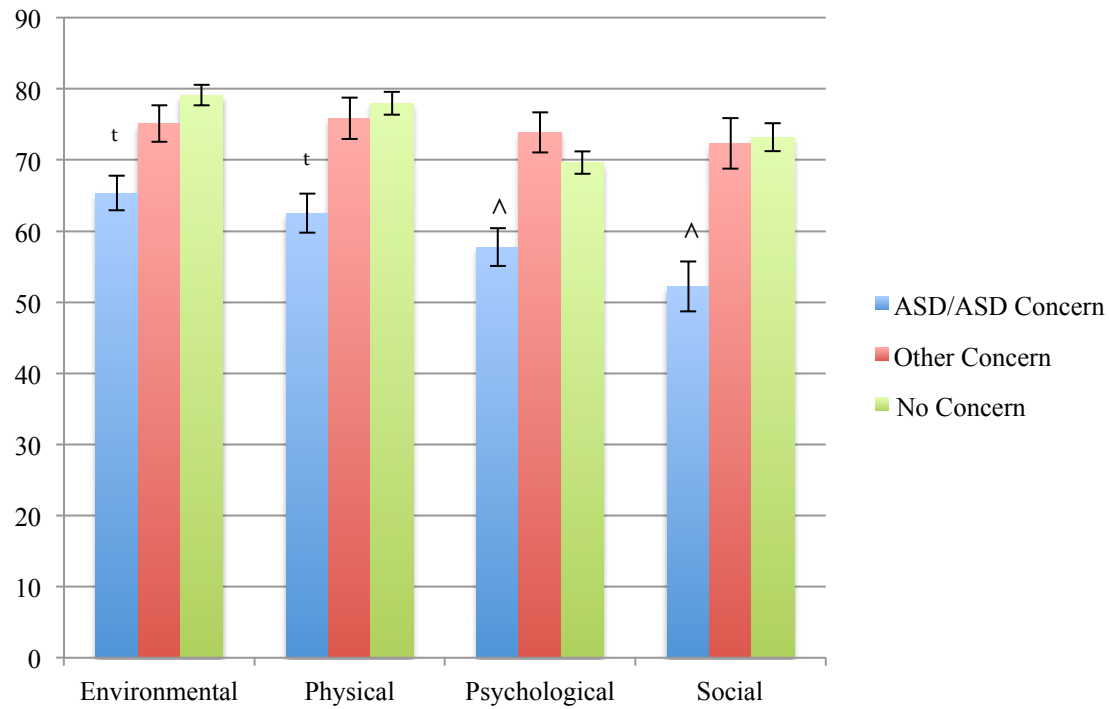
Note. PSI-SF = Parenting Stress Index- Short Form; MPOC-20 = Measure of Processes of Care;

[^]ASD/ASD Concerns group significantly different than Other Concerns and No Concerns groups.

[†]ASD/ASD Concerns group significantly different than No Concerns group.

^aControlling for income, ^bControlling for income and number of children in the home.

Figure 1. Quality of Life domains by group

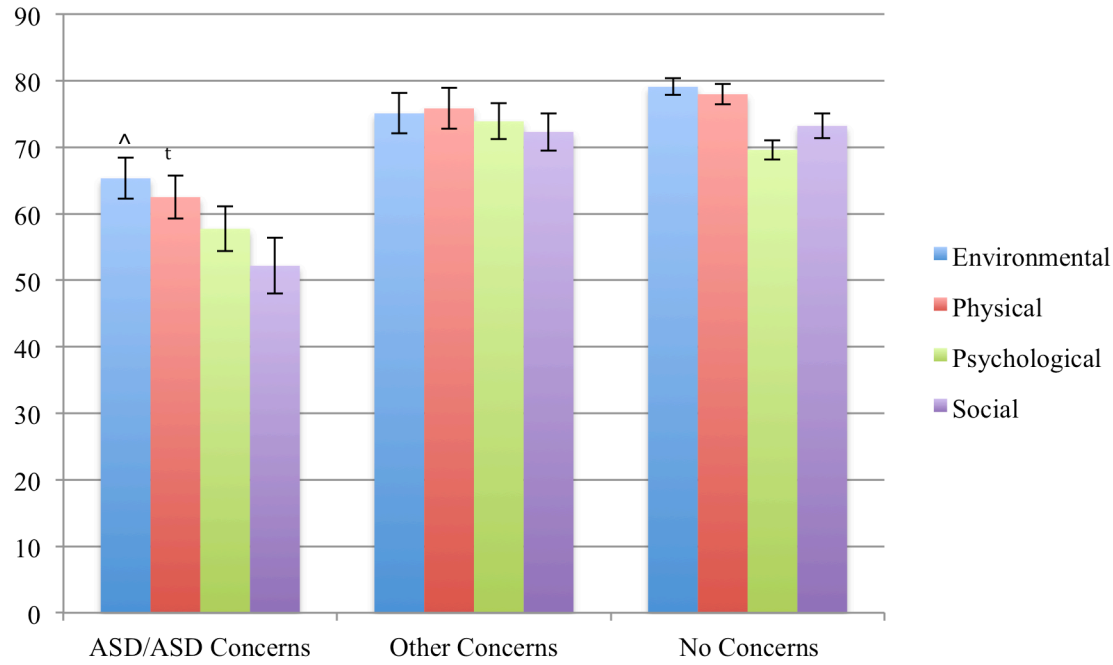


Environmental and Psychological controlled for income, Physical and Social controlled for income and number of children in the home.

^t ASD/ASD Concerns group significantly different than No Concerns group.

[^] ASD/ASD Concerns group significantly different than Other Concerns and No Concerns groups.

Figure 2. Within-group differences in Quality of Life domains



Other Concerns and No Concerns groups controlled for income.

[^] Significantly higher than Social and Psychological QoL.

[†] Significantly higher than Social QoL.

Table 3. Final Hierarchical Regression Model for Social Quality of Life

Predictors	B	SE B	β	t (<i>p</i>)	R^2	Adjusted R^2	$R^2 \Delta$
Intercept	63.1						
Family demographic					.09	.09**	.09
Family income	1.46	.64	.13	2.29 (.02)			
Caregiver Psychological					.44	.43**	.35
Parenting stress	-.52	.05	-.59	-10.23 (<.01)			
Health care					.47	.46**	.03
Family-centered care	2.97	.97	.17	3.06 (<.01)			

** $p < .01$.

Table 4. Final Hierarchical Regression Model for Psychological Quality of Life

Predictors	B	SE B	β	t (p)	R ²	Adjusted R ²	R ² Δ
Intercept	62.6						
Family demographic					.11	.11**	.11
Family income	1.43	.5	.16	2.83 (.01)			
Caregiver psychological					.44	.44**	.33
Parenting stress	-.4	.04	-.58	-10.02 (<.01)			
Health care					.46	.45*	.02
Family-centered care	1.88	.77	.13	2.44 (.02)			

* $p < .05$.

** $p < .01$.

Table 5. Final Hierarchical Regression Model for Physical Quality of Life

Predictors	B	SE B	β	t (p)	R ²	Adjusted R ²	R ² Δ
Intercept	72.3						
Family demographic					.16	.15**	.16
Family income	1.83	.55	.2	3.32 (<.01)			
Number of children	-2.16	.87	-.14	-2.47 (.01)			
Caregiver psychological					.37	.36**	.22
Parenting stress	-.33	.04	-.45	-7.47 (<.01)			
Health care					.41	.4**	.04
Family-centered care	2.96	.84	.2	3.54 (<.01)			

**p < .01.

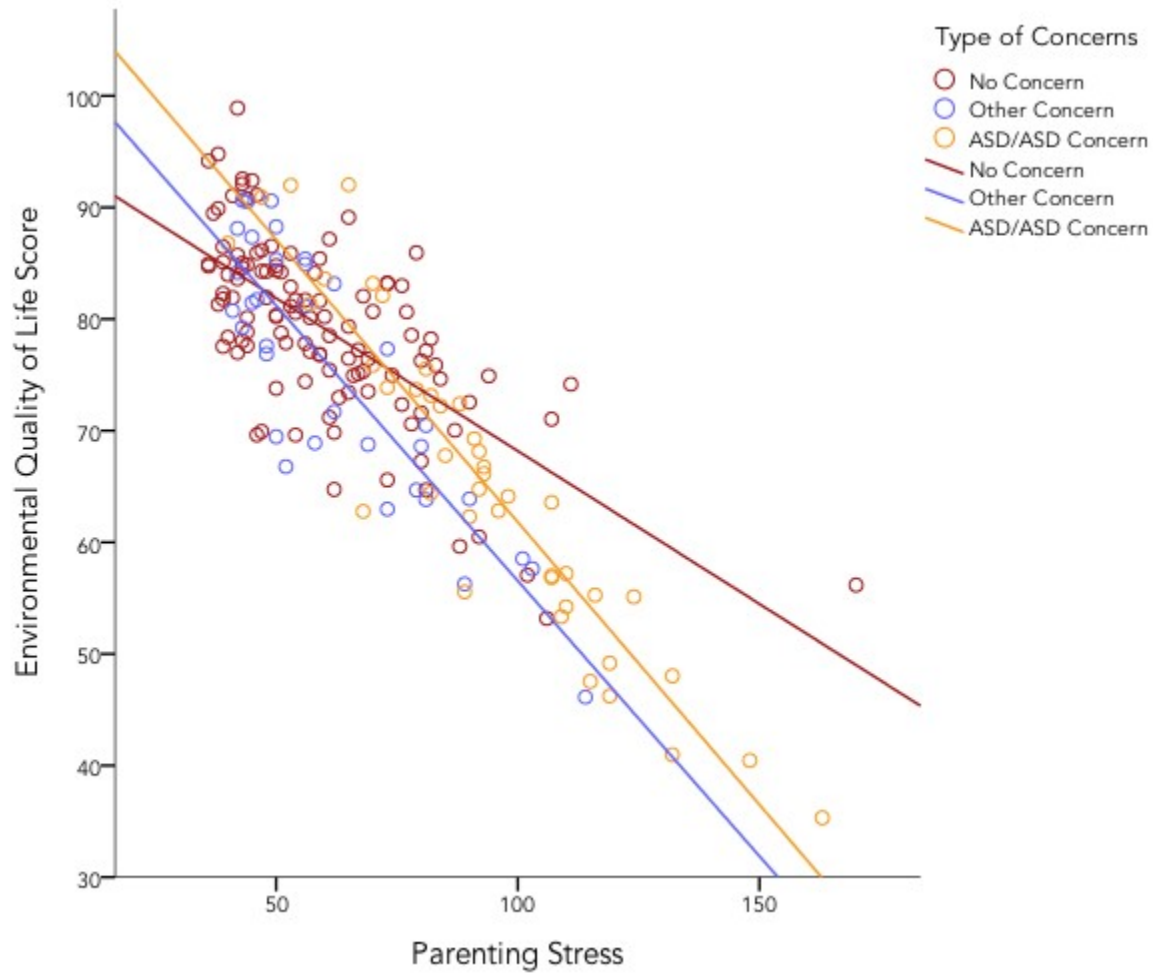
Table 6. Final Hierarchical Regression Model for Environmental Quality of Life

Predictors	B	SE B	β	t (p)	R ²	Adjusted R ²	R ² Δ
Intercept	68.91						
Family demographic					.17	.16**	.17
Family income	2.28	.48	.28	4.81 (<.01)			
Group [‡]					.21	.2**	.05
ASD/ASD Concerns	3.6	2.9	.09	1.23 (.22)			
Other Concerns	-6.22	2.51	-.14	-2.48 (.01)			
Caregiver psychological					.44	.42**	.23
Parenting stress	-.19	.06	-.29	-3.26 (<.01)			
Parenting stress*ASD/ASD Concerns	-.31	.09	-.3	-3.32 (<.01)			
Parenting stress*Developmental Concerns	-.18	.12	-.1	-1.53 (.13)			
Health care					.5	.48**	.06
Family-centered care	3.34	.73	.25	4.6 (<.01)			

** $p < .01$.

[‡] Reference group is the No Concerns Group.

Figure 3. Relation between PSI and Environmental Quality of Life by Group



APPENDIX A.

WHOQOL-BREF Items by Domain

Domain	Items
Environmental	How safe do you feel in your daily life? How healthy is your physical environment? Have you enough money to meet your needs? How available to you is the information that you need in your daily-to-day life? To what extent do you have the opportunity for leisure activities? How satisfied are you with the condition of your living place? How satisfied are you with your access to health services? How satisfied are you with your transport?
Physical	To what extent do you feel that physical pain prevents you from doing what you need to do? How much do you need any medical treatment to function in your daily life? Do you have enough energy for everyday life? How well are you able to get around? How satisfied are you with your sleep How satisfied are you with your ability to perform your daily living activities? How satisfied are you with your capacity for work?
Psychological	How much do you enjoy life? To what extent do you feel your life to be meaningful? How well are you able to concentrate? Are you able to accept your bodily appearance? How satisfied are you with yourself? How often do you have negative feelings such as blue mood, despair, anxiety, depression?
Social	How satisfied are you with your personal relationships? How satisfied are you with your sex life? How satisfied are with the support you get from your friends?

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Community Fellow, University of Washington

Awards and Honors:

- 2016 University of Washington Travel Award, Nathaniel Wagner Memorial Endowment Fund
- 2015 University of Washington Psychology Department Scholar Award
- 2015 Autism Science Foundation, International Meeting For Autism Research Travel Award
- 2015 International Meeting For Autism Research Student Travel Award
- 2014 International Meeting For Autism Research Student Travel Award
- 2013 UCLA PEERS® Research Training Scholarship
- 2013 University of Washington Travel Award, Nathaniel Wagner Memorial Endowment Fund

Research Experience:

- 2016-present Dissertation Project
Study: Predictors of Quality of Life in Caregivers of Children with Autism Concerns
Description: The objective of this study is to examine factors that predict quality of life in caregivers of children with autism concerns using the World Health Organization’s abbreviated quality of life measure (WHOQOL-BREF). Results will be compared to caregivers of children with Other Concerns and typically developing children.
- 2014-17 University of Washington Research in Early Autism Detection and Intervention (READi) Laboratory, Seattle, WA
Study: Screen-Refer-Treat (SRT) Study
Principal Investigator: Wendy Stone, Ph.D.
Role: Graduate Student Research Associate
Description: The SRT study is a five-year, NIH-funded study, which aims to implement and evaluate an innovative service delivery model designed to promote earlier access to specialized ASD intervention in geographically and ethnically diverse communities throughout Washington State. Led Reciprocal Imitation Training (RIT) workshops for birth-to-three providers, assisted with the development and selection of study measures including organizational and implementation climate measures, and helped conceptualize how to provide performance feedback to primary care practices.
- 2015 University of Washington Child Health Institute, Seattle, WA
Study: Brief Intervention for School Clinicians (BRISC): A Modularized, Evidence-Informed Mental Health Treatment for Use by School Clinicians Working with High School Students
Principal Investigators: Elizabeth McCauley, Ph.D. & Eric Bruns, Ph.D.
Role: Behavioral Coder
Description: This three-year study examined the feasibility of implementing the BRISC intervention in school based mental health centers in high schools throughout Washington. Coded therapist adherence to the BRISC intervention during therapy sessions and provided feedback to study team members about session quality.
- 2014 Masters Thesis
Study: The Relation between Maternal Behavior and Social Smiling in Infants at High Risk for Autism Spectrum Disorder

Description: This study examined how parenting style at 9 months predicted growth in infant social engagement (i.e., social smiling) between 9 and 18 months during a free-play interaction in infants at high (HR-infants) and low (LR-infants) familial risk for Autism Spectrum Disorder (ASD). Results indicated that across all infants, higher levels of maternal responsiveness were concurrently associated with higher levels of social smiling, while higher levels of maternal directiveness predicted slower growth in social smiling. When accounting for maternal directiveness, which was higher in mothers of HR-infants, HR-infants exhibited greater growth in social smiling than LR-infants.

- 2013-15 University of Washington Research in Early Autism Detection and Intervention (READi) Laboratory, Seattle, WA
Study: National Children's Study
Principal Investigator (site): Wendy Stone, Ph.D.
Role: Graduate Student Research Associate
Description: NCS was a longitudinal, multisite study that aimed to develop and evaluate a streamlined method for ASD diagnostic assessment for NCS staff. Administered assessments for the study including the Screening Tool for Autism in Toddlers (STAT) and a DSM-5 caregiver interview. Coded STAT fidelity at other study sites and provided administration feedback to other NCS staff.
- 2012-14 University of Washington Research in Early Autism Detection and Intervention (READi) Laboratory, Seattle, WA
Study: ASAP! Project
Principal Investigator: Wendy Stone, Ph.D.
Role: Graduate Student Research Associate
Description: The ASAP! Project was a two-year grant funded by the Washington State Attorney General's Office. The aim of the project was to train early intervention providers in the use of a validated screening tool (Screening Tool for Autism in Toddlers [STAT]) and an evidence-based ASD intervention (Reciprocal Imitation Training [RIT]). Developed and led RIT trainings at early intervention and Early Head Start agencies throughout the state. Developed and led a five-week RIT training for fathers, assisted with the development of our study measures, and reviewed RIT administration and provided feedback to providers.
- 2012-14 University of Washington Research in Early Autism Detection and Intervention (READi) Laboratory, Seattle, WA
Study: Early Detection of Pervasive Developmental Disorders
Principal Investigators: Wendy Stone, Ph.D., Deborah Fein, Ph.D., & Zachary Warren, Ph.D.
Role: Graduate Student Research Associate
Description: The aim of this multisite study was to examine the efficacy of the revised Modified Checklist for Autism in Toddlers (M-CHAT) in detecting autism in younger siblings of children with autism. Administered diagnostic assessments including the Mullen Scales of Early Learning and the ADOS.
- 2012-14 University of Washington Research in Early Autism Detection and Intervention (READi) Laboratory, Seattle, WA
Study: Social-Emotional Development of Infants at Risk for Autism

Principal Investigators: Wendy Stone, Ph.D., Daniel Messinger, Ph.D., & Zachary Warren, Ph.D.

Role: Graduate Student Research Associate

Description: The objective of this longitudinal, multisite study was to examine the early development of social attention, affect, and joint attention and their relation to later autism symptomatology. Administered assessments with study participants including the Mullen Scales of Early Learning, the Screening Tool for Autism in Toddlers (STAT), and the Vineland Adaptive Behavior Scales.

2008-11

University of Pennsylvania, Center for Mental Health Policy & Services Research

Study: Philadelphia Autism Instructional Methods Study (AIMS)

Principal Investigator: David Mandell, Sc.D.

Role: Research Specialist

Description: Philly AIMS was the largest randomized controlled trial to date of a school-based intervention for children with ASD. The objective of the study was to compare the Strategies for Teaching based on Autism Research (STAR) program to the Structured Teaching program in K-2 Autism Support Classrooms throughout the School District of Philadelphia. Recruited over 400 families, teachers, and classroom staff members, performed monthly fidelity videotaping and coding in 22 classrooms, and administered more than 200 ADOS as part of the student assessment battery. Coordinated the pre and post evaluations and organized teams of psychologists and graduate student assessors. Presented at parent advocacy and school district meetings and maintained IRB documentation for four regulatory offices, including the University of Pennsylvania, the Children's Hospital of Philadelphia, the City of Philadelphia, and the School District of Philadelphia.

Clinical Experience:

2017

UCLA Child OCD Intensive Outpatient Program (IOP), Los Angeles, CA

Role: Clinical Psychology Intern

Supervisors: Lindsey Bergman, Ph.D. and Michelle Rozenman, Ph.D.

Description: Co-led treatment groups and provided individual therapy for children ages 5-17 with severe obsessive-compulsive disorder in an IOP treatment setting.

2017

UCLA Resnick Neuropsychiatric Hospital Child and Adolescent Inpatient Unit, Los Angeles, CA

Role: Clinical Psychology Intern

Supervisors: Michael Strober Ph.D., Rhonda Sena, Ph.D., and Mark DeAntonio, MD

Description: Worked on a multidisciplinary care team to provide individual and family therapy and case management for youth with complex psychopathology.

2017

UCLA Child and Adult Neurodevelopmental (CAN) Clinic, Los Angeles, CA

Role: Clinical Psychology Intern

Supervisors: Enjey Lin, Ph.D., BCBA-D and Mina Park, Ph.D., BCBA-D

Description: Conducted comprehensive diagnostic evaluations and provided treatment consultations individual therapy to individuals with autism spectrum disorder and other neurodevelopmental disabilities.

2017

UCLA Pediatric Consultation-Liaison Service, Los Angeles, CA

Supervisors: Brenda Bursch, Ph.D. and Jena Lee, MD

Role: Clinical Psychology Intern

Description: Provided psychiatric consultation services for children and adolescents with serious and complex medical needs who also have behavioral, emotional, and family problems that are complicating their medical care.

2017

UCLA PEERS[®] Social Skills Program for Young Adults, Los Angeles, CA

Role: Clinical Psychology Intern

Supervisors: Elizabeth Laugeson, Psy.D.

Description: Led groups and served as a behavioral coach for the PEERS[®] Program for young adults with ASD and other social challenges.

2017

PEERS[®] Social Skills Program for Young Adults, Seattle, WA

Role: Young Adult Group Co-Leader

Supervisors: Andrew Fleming, Ph.D.

Description: Co-led the PEERS[®] Program for a group of young adults with ASD, ADHD, social anxiety disorder, and depression. Conducted screening phone calls and intakes with young adults and their caregivers. Taught developmentally appropriate skills for making friends and dating.

2016-17

University of Washington Psychological Services & Training Clinic

Role: Clinic TA and Intake Coordinator

Supervisor: Corey Fagan, Ph.D. and Julie Quamma, Ph.D.

Description: Co-led weekly group supervision with second year graduate students, provided clinical consultation to graduate students, and managed crisis situations in the clinic. Provided information about referral resources to outside providers and callers. Screened and scheduled clients for the main treatment clinic and for the assessment clinic, which offers comprehensive evaluations for learning disabilities and ADHD.

2016

University of Washington Psychological Services & Training Clinic

Role: Clinical supervisor

Supervisor: Corey Fagan, Ph.D.

Description: Provided hour-for-hour individual supervision to clinical psychology graduate students, supervised by Dr. Fagan.

2015-17

Advanced Outpatient Practicum, The Seattle Clinic

Role: Practicum Therapist

Supervisors: Julia Hitch, Ph.D. & Andrew Fleming, Ph.D.

Description: Trained to deliver evidence-based treatments to children, adolescents, and families in an outpatient setting. The practicum included one hour per week of didactics and supervision, one hour of observation of therapy sessions conducted by Dr. Fleming or Dr. Hitch, and two sessions with live phone supervision and consultation. Clinical cases included an adolescent female with a specific phobia, an adolescent female with social anxiety, three OCD assessment cases, and a behavioral parent training case. Independently conducted in-vivo exposure sessions in schools, homes, and other community settings and provided behavioral parent training.

- 2015-16 Parent Child Clinic, University of Washington, Seattle, WA
Role: Behavioral Parent Training Practicum Therapist
Supervisor: Neil Kirkpatrick, Ph.D.
Description: The Parent-Child Clinic (PCC) is a specialty clinic within the UW Psychological Services and Training Clinic. The PCC provides direct service and training in the assessment of children and families and the delivery of Behavioral Parent Training (in both child and adolescent versions). The practicum included 8 hours per week of didactics, group and individual supervision, and live observation of Dr. Kirkpatrick's sessions. Maintained a caseload of three clients (two adolescent cases and one child case). Conducted classroom observations and provided consultation to staff.
- 2016 PEERS[®] Social Skills Program, Seattle, WA
Role: Parent Group Leader
Supervisor: Andrew Fleming, Ph.D.
Description: The PEERS[®] Program is an evidence-based social skills intervention for adolescents with social challenges (e.g., ASD, ADHD, anxiety). Led the parent group portion of the intervention, meeting weekly with parents for 14-weeks to teach the PEERS[®] skills (e.g., handling bullying, entering group conversations), train them to act as social coaches for their teens, and troubleshoot challenging situations.
- 2014-16 PEERS[®] Social Skills Program, Seattle, WA
Role: Behavioral Coach and Parent Group Co-Leader
Supervisors: Karen Barnes, Ph.D. & Andrew Fleming, Ph.D.
Description: Served as a behavioral coach, which involves modeling skills for teens, providing behavioral support and in-vivo coaching to teens during group, and meeting with teens after group to review homework assignments, set individual goals, and troubleshoot homework completion issues.
- 2015 Emotion Regulation Group, Seattle Children's Hospital Autism Center, Seattle, WA
Role: Co-Leader
Supervisor: Emily Rastall, Ph.D.
Description: Co-led a weekly emotion regulation group for school-aged children with ASD and emotion regulation difficulties. Taught children coping skills based on strategies from Dialectical Behavioral Therapy (DBT) and provided behavioral support during the group.
- 2015 Seattle Children's Hospital Autism Center, Seattle, WA
Role: Assessor
Supervisors: Karen Barnes, Ph.D. & James Mancini, M.S., CCC-SLP
Description: Conducted weekly team-based diagnostic evaluations using the ADOS and a clinical interview under the supervision of a clinical psychologist and a licensed speech and language pathologist. Participated in feedback sessions with the families and assisted with report writing.
- 2014-15 Pediatric Feeding Program, Seattle Children's Hospital Autism Center, Seattle, WA
Role: Practicum Therapist
Supervisor: Danielle Dolezal, Ph.D., BCBA-D

Description: Led therapy sessions and co-led intakes for children and adolescents with developmental and genetic disorders (e.g., ASD, Down Syndrome, Cystic Fibrosis) with Avoidant/Restrictive Food Intake Disorder using principles of Applied Behavior Analysis and Cognitive Behavioral Therapy for anxiety. Collected data and tracked feeding progress. Met with parents to provide adjunctive coaching. Attended weekly rounds with a multidisciplinary feeding team comprised of a psychologist, nutritionist, occupational therapist, practitioner, and two behavioral technicians.

2014-15

University of Washington Autism Center, Seattle, WA

Role: Staff Therapist

Supervisor: Kelly Johnson, Ph.D.,

Description: Conducted individual therapy with young adult male with ASD, anxiety, and depression using principles of CBT and Behavioral Activation. Conducted individual therapy with an adolescent female with anxiety using CBT principles.

2014-15

University of Washington Autism Center, Seattle, WA

Role: Assessor

Supervisor: Kelly Johnson, Ph.D. & Ella Vanderbilt-Adriance, Ph.D. *Description:*

Conducted ASD diagnostic assessments with toddlers, school-aged children, and adolescents. Assessments included clinical interviews with parents, Autism Diagnostic Observation Schedule, Vineland Adaptive Behavior Scales-II Parent Interview, Wechsler Intelligence Scale for Children, 4th edition, and Mullen Scales of Early Learning. Consulted with teachers, wrote reports, and participated in feedback sessions.

2013- 15

LEARN Clinic, University of Washington, Seattle, WA

Role: Assessor

Supervisor: Julie Quamma, Ph.D.

Description: Conducted initial intakes and administered cognitive (e.g., WISC-IV, WAIS-IV), academic achievement (e.g., Woodcock-Johnson Tests of Achievement – Third Edition), reading and language (e.g., TOWRE-2, CTOPP-2), and neuropsychological (e.g., WRAML-II) tests to adults and children with learning disabilities. Conducted ADHD evaluations using the measures such as the CAARS, BRIEF, and Conners-3. Scored and interpreted measures, wrote reports, developed recommendations, consulted with teachers, and co-led feedback sessions with clients and their families. Received direct supervision on test administration, report writing, and providing recommendations.

2013-14

University of Washington Psychological Services & Training Clinic, Seattle, WA

Role: Advanced graduate student mentor

Description: Served as a mentor to second year clinical graduate students who were beginning their clinical training; role-played clinical scenarios and provided feedback.

2013-14

Preschool Social Skills Group, University of Washington Autism Center, Seattle, WA

Role: Co-Leader

Supervisors: Annette Estes, Ph.D., Rachel Lowy, M.S., CF-SLP, Jo Ristow, M.S., CF-SLP

Description: Co-led a social skills group for preschool children with ASD using the

Social Thinking and the Stop and Think! social skills curricula. Provided behavioral support during the group and led activities.

- 2012-16 University of Washington Psychological Services & Training Clinic, Seattle, WA
Role: Therapist
Supervisors: Fransing Daisy, Ph.D., Lisa Emerson, Ph.D., James Keyes, Ph.D., Neil Kirkpatrick, Ph.D., Elizabeth McCauley, Ph.D., ABPP, Robert Kohlenberg, Ph.D.
Description: Clinical experience included treatment of children, adolescents, and young adults with generalized anxiety disorder, social anxiety disorder, depression, ADHD, and avoidant/restrictive food intake disorder using evidence-based treatments such as CBT and Mindfulness Based Cognitive Therapy. Clients were from diverse ethnic, religious, and socio-economic backgrounds. Received hour-for-hour supervision from licensed clinical psychologists in the community. Used standardized measures to aid in case formulation and ongoing weekly assessment using the OWL Outcomes for routine outcome monitoring.
- 2012 Individual and Supportive Group Therapy (IGST), Collaborative Adolescent Research on Emotion and Suicide (CARES) Study, Seattle, WA
Supervisors: Gretchen Gudmundsen, Ph.D. & Molly Adrian, Ph.D.
Role: Assistant Leader
Description: The CARES study compared Dialectical Behavioral Therapy (DBT) to Supportive Therapy for adolescents with emotion regulation difficulties. Assisted with a weekly activity group for adolescents receiving Supportive Therapy, during which teens socialized, made art projects, and engaged in other self-care activities.
- 2011 University of Pennsylvania Adult Social Learning Disorders Program, Social Skills Seminar, Philadelphia, PA
Supervisor: Carol Moog, Ph.D.
Roles: Social Coach Coordinator
Description: This program was developed to assist adults with social challenges including ADHD, ASD, and social anxiety disorder. The program comprised two hours of didactics and one hour of practice with social coach. Recruited and supervised social coaches, developed the social coaching curriculum (e.g., speed conversations, mock job interviews, dating panels), planned social activities in the community (e.g., trivia night), and matched coaches with mentees.
- 2009-10 University of Pennsylvania Adult Social Learning Disorders Program, Social Skills Seminar, Philadelphia, PA
Supervisor: Carol Moog, Ph.D.
Roles: Social Coach
Description: Acted as a social coach for several individuals with social challenges. Helped mentees set individual goals for overcoming social challenges and accompanied them to social events in the community while providing in-vivo feedback.
- 2009 Children's Hospital of Philadelphia Center for Autism Research
Social Skills Group, Philadelphia, PA
Role: Assistant Leader

Supervisor: Sarah Woldoff, Ph.D.

Description: This social skills group was developed for school-aged males with ASD. Provided behavioral support and coaching during practice activities.

Specialized Clinical Training:

General Assessment

2012 *Structured Clinical Interview for DSM-IV-TR (SCID-II)*
Lori Zoellner, Ph.D., University of Washington (10 hours)

Internalizing Disorders

2015 *Obsessive Compulsive Disorder (OCD)*
Neil Kirkpatrick, Ph.D., Hope Sparks (8 hours)

2013 *Trauma Focused Cognitive Behavioral Therapy (TFCBT)*
Georganna Sedlar, Ph.D., University of Washington (30 hours)

Externalizing Disorders

2015-16 *Behavioral Parent Training*
Neil Kirkpatrick, Ph.D., University of Washington (120 hours)

2013 *Helping the Non-Compliant Child*
Suzanne Kerns, Ph.D., University of Washington (30 hours)

Developmental Disorders

2015 *Down Syndrome (36th Annual Duncan Seminar)*
Seattle Children's Hospital (8 hours)

2015 *Fetal Alcohol Spectrum Disorders*
Susan Astley, Ph.D. (1 hour)

2014 *Autism Diagnostic Observation Schedule (ADOS-2) research reliability training*
Valeria Nanclares-Nogués, Psy.D., Advocate Medical Group (24 hours)

2013 *Reciprocal Imitation Training (RIT)*
Brooke Ingersoll, Ph.D., University of Washington (8 hours)

2013 *Screening Tool for Autism in Toddlers (STAT)*
Wendy Stone, Ph.D., University of Washington (16 hours)

2009 *Autism Diagnostic Observation Schedule (ADOS) research reliability training*
Sarah Woldoff, Ph.D., Children's Hospital of Philadelphia (24 hours)

Suicide

2013 *Suicide Assessment*
Marsha Linehan, Ph.D. (20 hours)

Personality

2012 *Clinical Personality Assessment: MMPI-2*

Ronald Smith, Ph.D., at the University of Washington (24 hours)

Professional Affiliations:

International Society for Autism Research (INSAR)
Society for Implementation Research Collaboration (SIRC)

Service:

2015-16

Society for Implementation Research Collaboration (SIRC)

Role: Student Officer

Description: Assisted with recruiting SIRC student members and managing the Student Network of Expertise (NoE). Responsibilities included attending twice monthly officer meetings, reviewing applications for the Student NoE, matching Student NoE members with implementation science mentors in the New Investigator NoE, planning social and networking events for students at SIRC conferences, and advising SIRC officers about how to effectively support SIRC student members.

Reviews and Editorial Experience:

2014

Ad hoc Reviewer: Autism: The International Journal of Research and Practice

2016

Ad hoc Reviewer: Journal of Autism and Developmental Disorders

Teaching:

2014- 17

HuskyMOSSAIC: Mentoring, Organization and Social Support for Autism Inclusion on Campus

Role: Affiliate Instructor

Teaching Assistantships:

Graduate courses:

1 quarter

Clinical Methods

Instructor: Corey Fagan, Ph.D. & Danny O'Rourke, Ph.D.

Role: Provided teaching assistance to the Clinic Director, Dr. Fagan, for the initial course of the clinical training sequence for first year clinical psychology doctoral students. Demonstrated intake sessions for live observation, modeled clinical interviewing skills, supervised student role plays and provided feedback, and met individually with students to practice skills.

1 quarter

Ethics

Instructor: Corey Fagan, Ph.D.

Role: Provided teaching assistance to Dr. Fagan, including filling in as a substitute instructor and selecting and preparing course materials. Course was focused on teaching students about the American Psychological Association's Ethical Standards for Psychologists and helping them develop an awareness of state-specific laws. Time in class was focused on discussions about ethical dilemmas.

1 quarter

Practicum: Assessment of Intelligence (1 quarter)

Instructor: David Breiger, Ph.D.

Role: Trained and supervised first year graduate students in their administration of the Wechsler Abbreviated Scale of Intelligence (WASI) and the Wechsler Intelligence Scale

for Children, 5th edition (WISC-5). Provided feedback on test administration.

1 quarter Assessment of Intelligence
Instructor: David Breiger, Ph.D.
Role: Provided feedback on WASI and WISC-5 reports and scoring exercises for first year graduate students.

Undergraduate courses:

5 quarters Abnormal Psychology
Instructor: Deborah Chun, Ph.D.

4 quarters Developmental Psychology
Instructors: Betty Repacholi, Ph.D. (2011-13) & Katherine Monahan, Ph.D. (2016)

6 quarters Undergraduate Psychology Writing Center
Instructor: Patti Loesche, Ph.D.

1 quarter Introduction to Psychology
Instructor: Jonathon Brown, Ph.D.

Lectures by Invitation:

August 6, 2015 *Child Psychopathology*, Clinical Psychology, University of Washington

July 10, 2015 *Introduction to Autism*, Child & Adolescent Behavior Disorders, University of Washington

May 26, 2015 *Child Psychopathology*, Clinical Psychology, University of Washington

May 26, 2015 *Child Psychopathology*, Clinical Psychology, University of Washington

Sept. 15, 2014 *ASAP! Project*, Implementation Science Seminar, University of Washington

Oct. 10, 2013 *Introduction to Autism*, Child & Adolescent Behavior Disorders, University of Washington

May 10, 2013 *Introduction to Autism*, Seattle Health Services Advisory Committee

Trainings and Workshops Presented:

April 19, 2017 *Reciprocal Imitation Training Workshop*; Children's Village, Yakima, WA

March 28, 2017 *Peer Mentoring for UW Students with ASD*; University of Washington, Seattle, WA

Feb. 11, 2017 *Reciprocal Imitation Training Workshop*; Center for Pediatric Therapy, Spokane, WA

Oct. 6, 2016 *Peer Mentoring for UW Students with ASD*; University of Washington, Seattle, WA

Sept. 7, 2016 *Reciprocal Imitation Training Workshop*; Northwest Center, Seattle, WA

January 5, 2016 *Peer Mentoring for UW Students with ASD*; University of Washington, Seattle, WA

Sept. 8, 2014 *Reciprocal Imitation Training Workshop*; Oak Harbor School District, Island County, WA

March 2014 *Group-Based Reciprocal Imitation Training*; Kinderling Center, Bellevue, WA

Nov. 16, 2013 *Reciprocal Imitation Training Workshop*; Dynamic Partners, Kent, WA

Nov. 4, 2013 *Reciprocal Imitation Training Workshop*; Lower Elwha Early Head Start, Port Angeles, WA

Sept. 11, 2013 *Reciprocal Imitation Training Workshop* Neighborhood House Early Head Start, Seattle, WA

August 16, 2013 *Reciprocal Imitation Training Workshop*; Children's Village, Yakima, WA

June 7, 2013 *Reciprocal Imitation Training Workshop*; Wonderland Developmental Center, Shoreline, WA

Bibliography:

Research Publications, peer reviewed:

1. Locke, J., Wolk, C. B., **Harker, C. M.**, Olsen, A., Shingledecker, T., Barg, F., Mandell, D. S., Beidas R (2016). Pebbles, rocks, and boulders: The implementation of a school-based social engagement intervention for children with autism. *Autism*.
2. **Harker, C. M.**, Karp, E. A., Edmunds, S. R., Ibañez, L. V., & Stone, W. L. (2016). Predicting the use of an evidence-based intervention for autism in birth-to-three programs. Proceedings of the 3rd biennial conference of the Society for Implementation Research Collaboration (SIRC) 2015: Advancing efficient methodologies through community partnerships and team science. *Implementation Science*, 11, (Suppl 1): A38.
3. Locke, J., Wolk, C. B., **Harker, C. M.**, Olsen, A., Shingledecker, T., Barg, F., Mandell, D. S., Beidas, R. (2016). Proceedings of the 3rd biennial conference of the Society for Implementation Research Collaboration (SIRC) 2015: Advancing efficient methodologies through community partnerships and team science. *Implementation Science*, 11, (Suppl 1): A28.
4. **Harker, C. M.**, Ibañez, L. V., Nguyen, T. P., Messinger, D. M., & Stone, W. L. (2016). The effect of parenting style on social smiling in infants at high and low risk for ASD. *Journal of Autism and Developmental Disorders*, 46(7), 2399-407, doi: 10.1007/s10803-016-2772-y.
5. Locke, J., Rotheram-Fuller, E., Xie, M., **Harker, C.M.**, Mandell, D.S. (2013). Correlation of cognitive and social outcomes among children with autism spectrum disorder in a randomized trial of behavioral intervention. *Autism*, 18(3), doi: 10.1177/1362361313479181.

Research Publications, non-peer reviewed:

1. **Harker, C.M.** & Stone, W.S. (2014). Comparison of the diagnostic criteria for autism spectrum disorder across DSM-5, DSM-IV-TR, and the Individuals with Disabilities Act (IDEA) definition of autism. Document prepared for the IRIS Center, Vanderbilt University:
<http://iris.peabody.vanderbilt.edu/wp-content/uploads/2014/09/ASD-Comparison-092214.pdf>

Abstracts:

1. **Harker, C. M.**, Ibañez, L. V., Edmunds, S. R., Karp, E. A., & Stone, W. L. *What happens after the workshop? Factors associated with sustained use of an evidence-based intervention for children with ASD in community practice.* International Meeting for Autism Research, Baltimore, MD. May 12, 2016. Poster.
2. Karp, E. A., Ibañez, L.V., Edmunds, S.R., **Harker, C.M.**, & Stone, W.L. *Service providers perspectives of obstacles to ASD-specialized services.* International Meeting for Autism Research, Baltimore, MD. May 12, 2016. Oral Presentation.
3. **Harker, C. M.**, Karp, E. A., Edmunds, S. R., Ibañez, L. V., & Stone, W. L. *Predicting the use of an evidence-based intervention for autism in birth-to-three programs.* Society for Implementation Research Collaboration Conference, Seattle, WA. September 25, 2015. Poster.
4. Locke, J., Wolk, C.B., **Harker, C.M.**, Olsen, A., Shingledecker, T., Barg, F., Mandell, D.S., Beidas, R. *Pebbles, rocks, and boulders: The implementation of a school-based social engagement intervention for children with autism.* Society for Implementation Research Collaboration Conference, Seattle, WA. September 25, 2015. Oral presentation.
5. Berends, V.N., Dolezal, D.N., Persons, A., **Harker, C.M.** *Evaluation of a multielement assessment and behavioral training for pill-swallowing difficulties.* Association for Behavioral Analysis International, San Antonio, TX. May 25, 2015. Poster.
6. Ibañez, L.V., **Harker, C.M.**, & Stone, W.L. *A screen-refer-treat model to promote earlier access to ASD intervention.* International Meeting for Autism Research, Salt Lake City, May 16, 2015. Oral presentation.
7. **Harker, C.M.**, Edmunds, S.R., Ibañez, L.V., Froehlig, C., Karp, E. Nanda, S., & Stone, W.L. *Factors associated with intervention uptake in community practice: Acceptability, feasibility, and implementation climate.* International Meeting for Autism Research, Salt Lake City, UT. May 16, 2015. Oral presentation.

8. Karp, E., Ibañez, L.V., Edmunds, S.R., **Harker, C.M.**, & Stone, W.L. *Parental and child characteristics that contribute to parental concerns in toddlers at high risk for autism spectrum disorder over time*. International Meeting for Autism Research, Salt Lake City, May 14, 2015. Poster.
9. Edmunds, S.R., Ibañez, L.V., **Harker, C.M.**, Karp, E., & Stone, W.L. *Sex and ASD risk status predict both 3-year expressive language and expressive language growth from 1 to 3 years in children at high and low risk for ASD*. International Meeting for Autism Research, Salt Lake City, May 14, 2015. Poster.
10. **Harker, C. M.**, Nguyen, T. P., Ibañez, L. V., Nanda, S., Karp, E., Messinger, D. S., & Stone, W. L. (2014). *The relation between infant social engagement and maternal behavior in infants at high-risk for autism spectrum disorder*. International Meeting for Autism Research, Atlanta, GA. May 16, 2014. Poster.
11. Ibañez, L.V., Edmunds, S.R., **Harker, C.M.**, Karp, E.A., & Stone, W.L. (2014). *Evaluating the impact of statewide community-based training for early intervention providers*. International Meeting for Autism Research, Atlanta, GA. May 15, 2014. Poster.
12. **Harker, C. M.**, Nguyen, T. P., Ibañez, L. V., & Stone, W. L. (2013). *Maternal behavior during free play with infants at high vs. low risk for autism spectrum disorder*. American Psychological Association's Annual Convention, Honolulu, HI. July 31, 2013. Poster.
13. **Harker, C. M.**, Reisinger, E. M., Shin, S., & Mandell, D. S. *Using the ADOS severity metric to evaluate the trajectory of students with ASD in a large public school district*. International Meeting for Autism Research, San Diego, CA. May 12, 2011. Poster.
14. **Harker, C. M.**, Reisinger, E. M., Sherman, A. D, Xie, M., Shin, S., & Mandell, D. S. (2010). *Using the revised ADOS algorithm to evaluate a behavioral intervention in a large public school district*. Penn State National Autism Conference, State College, PA. August 2010. Poster.
15. Sherman, A. D, Shin, S., **Harker, C. M.**, Reisinger, E. M., & Mandell, D. S. (2010). *Stress in 1 parent and 2 parent households with children with autism*. International Meeting for Autism Research, Philadelphia, PA. May 22, 2010. Poster.
16. Reisinger, E. R, Xie, M., Mandell, D. S, Shin, S., Sherman, A. D, & **Harker, C. M.** (2010). *Parent teacher concordance on the social responsiveness scale for children with a putative diagnosis of ASD*. International Meeting for Autism Research, Philadelphia, PA. May 21, 2010. Poster.
17. **Harker, C. M.**, Reisinger, E. M, Sherman, A. D, Xie, M., Shin, S., & Mandell, D. S. (2010). *Using the ADOS severity metric to evaluate a behavioral intervention in a large public school district*. International Meeting for Autism Research, Philadelphia, PA. May 21, 2010. Poster.

Editorials, Reviews, Chapters, including participation in committee reports:

1. Locke, J. & **Harker, C. M.** (2017). Using typically developing peers as support for social inclusion of children and adolescents with autism in school settings. In C. Little (Ed.), *Social inclusion and students with ASD*. New York, NY: Routledge.
2. Locke, J., **Harker, C. M.**, Karp, E. A., & Kratz, H. E. (2017). Autism Spectrum Disorders in childhood. In T. P. Gullotta & G. M. Blau (Eds.), *Handbook of childhood behavioral issues: Evidence-based approaches to prevention and treatment* (2nd Ed.). New York, NY: Routledge.