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Predicting and Promoting Health-Related Quality of Life for Parents of Children with Autism: A
Mixed-Methods Approach

A dissertation
presented to
the faculty of the Department of Psychology
East Tennessee State University

In partial fulfillment
of the requirements for the degree
Doctor of Philosophy in Psychology, concentration in Clinical Psychology

by
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December 2017

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ABSTRACT

Predicting and Promoting Health-Related Quality of Life for Parents of Children with Autism: A

Mixed-Methods Approach

by

Laura DeLustro

The present study used a mixed methodology approach to understand factors that predict and promote health related quality of life (HRQOL) for parents of youth with Autism Spectrum Disorders (ASD). The first component of the study used quantitative analyses to determine the extent to which study variables predict HRQOL for parents of youth with ASD ($N = 365$). Findings show that HRQOL is positively impacted by increased total annual household income, increased age of the child with ASD, male gender, and tangible support. HRQOL was negatively impacted by increased age of the parent, increased parental perceptions of burden, and use of maladaptive coping strategies. The second phase of the study incorporated qualitative methodology to describe the lived experience of parents ($N = 8$). Qualitative interviews solicited perceptions of parents regarding HRQOL. Further, qualitative analyses identified sources of parental support, how parents feel about support from varying professionals, and potential supportive interventions toward which they are amenable but cannot currently access. Directions for future research and implications for improving HRQOL for parents of youth with ASD are discussed. The results of the current study can be used to guide and inform supportive services targeted at parents of youth with ASD to improve their HRQOL.

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CHAPTER 1

INTRODUCTION

Long-term, unpaid caregivers for individuals with chronic medical and mental health diagnoses play a vital and often unrecognized role in bolstering services provided by formal, paid caregivers, including medical and mental health professionals. Long-term, unpaid caregivers have previously been identified as family members or friends who assist with activities of daily living without receiving payment (Wolff et al., 2009). Due to the aging baby boomer generation contributing to a growing population of people aged 65 or older, improvements in life expectancy following advancements in medicine and technology, and the increasing diagnostic rates of mental health conditions such as Autism Spectrum Disorders (ASD), the need for unpaid caregivers is increasing as the number of individuals with chronic conditions increases (Talley & Crews, 2007).

Unpaid caregivers provide care for these individuals with long-term conditions that would otherwise need to be administered by paid caregivers or institutional providers such as nursing homes, hospitals, or group home facilities (Family Caregiver Alliance, 2008). Although long-term caregivers provide a crucial service, this service does not come without costs to the caregivers themselves and the recipients of care. Gradual declines in the physical and psychological health of caregivers are well documented and have been linked to costly hospitalizations and institutionalization of care recipients (Essex, Seltzer, & Krauss, 1997; Horowitz, 1985; Kaye, Turner, Butler, Downey, & Cotton, 2003). By supporting caregivers in their efforts to provide long-term assistance, there can be both financial benefit to the healthcare system and an optimization of resources, such as group home placements and costly

hospitalization. The support and preservation of this network of unpaid caregivers is critically important for the continued success of America's healthcare system.

Parents of individuals with ASD are a large and growing population of individuals. Because symptoms persist across the care recipient's lifespan, individuals with ASD and other chronic conditions need long-term care (Smith, Hong, Seltzer, Greenberg, Almeida, & Bishop, 2010). ASD is a disorder with biological, social, and psychological impairments that can contribute to a daily struggle with social interactions, communication, and restrictive or repetitive patterns of behavior. It is important to remember that each person on the Autism disorder spectrum is different. Individuals who are diagnosed with ASD are unique, and their ways of interacting with the world are diverse. In 2013, the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5; American Psychiatric Association, 2013) eliminated the four subcategories of Pervasive Developmental Disorder (PDD) from the previous edition of the DSM (DSM-IV; APA 2000), which had included Autistic Disorder, Asperger Syndrome, PDD not otherwise specified, and Childhood Disintegrative Disorder, and classified these within one singular diagnosis of ASD. Currently, the diagnosis of ASD is given with symptom severity levels assigned for the two areas of diagnostic criteria: 1) social communication, and 2) restricted, repetitive patterns of behavior, interests, or activities (APA, 2013). Symptoms must appear during the period of early development and cause current impairment in major life contexts such as home, school, occupation, and/or social situations. The likelihood of being diagnosed with ASD is approximately four times higher for males than females (APA, 2013).

Research has clearly shown that parents of children with ASD experience a higher level of stress (Eisenhower et al., 2005) and report increased psychopathology, including anxiety and depression (Abbeduto et al., 2004; Dumas, Wolf, Fisman, & Culligan, 1991; Lee, 2013; Piven &

Palmer, 1999; Wolf, Noh, Fisman, & Speechley, 1989), when compared to parents of normally developing children. Mothers of children with ASD have reported feeling more stigmatized by their child's condition than mothers of children diagnosed with other severe disabilities (Gray, 1993). A lack of public understanding and knowledge of ASD and the disruptive nature of symptoms of ASD have been identified as reasons for harsh stigmatization of parents of youth with ASD (Gray, 1993). In many cases parents become both lifelong patients and providers in the sense that they are taking care of themselves as well as taking care of another with special needs. Interventions designed to improve the daily experiences of this vulnerable population need to acknowledge and incorporate this duality and build resiliency while also decreasing burden.

There are significant gender differences within the caregiving experience. Hodge, Hoffman, and Sweeney (2011) found that mothers of children with ASD are at higher risk for anxiety symptoms than fathers of children with ASD. Additionally, in a study conducted by Gray (2003), mothers were more directly affected by their child's ASD, whereas fathers reported indirect effects primarily from vicarious stress experienced through their spouse. Furthermore, Tehee et al. (2009) found that mothers of children with ASD scored higher than fathers on measures of stress, involvement, and need for external coping resources. However, there have been very few studies comparing the experience of men and women parenting children with ASD and none that have examined gender differences in predictors of HRQOL. The need for research examining gender differences in parenting a child with ASD remains substantial. Thus, this study includes both female and male parents of youth with ASD.

The rationale for studying health related quality of life (HRQOL) is two-fold. First, chronic stress contributes to several significant health problems like chronic fatigue,

hypertension, cardiovascular disease, peptic ulcers, cognitive decline, and lowered immune functioning (Sapolsky, 1998). Second, there is a reciprocal relationship between chronic stress and psychopathology in that one exacerbates the other and makes it difficult for the individual to maintain optimal psychological and physical health.

Many studies support the assertion that being a long-term caregiver puts one in a position of physiological vulnerability. According to Gallaher and colleagues (2009), parents of children with developmental disabilities were found to have weaker antibody response to the influenza vaccine than parents of typically developing children, signifying lower immune functioning. Findings from the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study show that those with high caregiver strain evidenced significantly higher rates of mortality over a 5-year period when compared to caregivers reporting moderate or no strain (Perkins et al., 2013). Factors found to be predictors of poor health in long-term caregivers include lower income (Williamson & Perkins, 2014) and level of behavioral symptoms associated with the care recipient's diagnosis (Vogan et al., 2014). For the longevity and physical health of caregivers, it is important to continue building our understanding of health effects and predictors of poor health related to caregiving.

In addition to the larger body of caregiving research, several studies have looked specifically at stress and health within the population of female caregivers of children with ASD. Tehee et al., (2009) found that mothers of children with ASD scored higher on a general perceived stress measure, stress related to caregiving measure, and measured involvement with the child with special needs relative to fathers of children with ASD. Additionally, Seltzer and colleagues (2010) found that mothers of children with ASD had poorer neuroendocrine functioning and higher resting cortisol levels in comparison with mothers with normally

developing children. These health-related vulnerabilities put mothers of children with ASD at risk for future health problems and could exacerbate current health problems, rendering them a susceptible population in need of supportive care.

The mental and physical health of caregivers is irrevocably linked to a number of outcomes for the recipient of care, including quality of life (Burgess & Gutstein, 2007), parenting efficacy (Giallo, Wood, Jellett, & Porter, 2013), and the effectiveness of child-focused interventions such as early teaching interventions to build adaptive behavior and social functioning (Osborne, McHugh, Saunders, & Reed, 2008). Thus, the rationale for being able to predict and promote caregiver health and quality of life stems from the fact that caregiver well-being affects not only the caregiver but also the recipient of care. Several factors have been identified as strongly predictive of well-being for parents. These include coping strategies, social support, perceived burden, and care recipient-related variables such as child age and level of functional impairment. For instance, Kim, Greenberg, Seltzer, and Krauss (2003) found that the use of emotional coping strategies was negatively correlated with well-being whereas problem-focused coping was positively correlated with well-being. This means that mothers of youth with intellectual disabilities who utilize problem-focused coping rated their well-being higher than mothers who used emotional coping. These findings were supported by Abbeduto and colleagues (2004), who found that emotion-focused coping predicted lower psychological health and strained mother-child relations, while problem focused coping predicted better outcomes. However, findings across studies often vary in which factors are ultimately predictive of caregiver QOL or well-being. According to research by Khanna and colleagues (2011), parents of youth with ASD had lower HRQOL than a control group of parents of normally developing children, and this deficit was influenced by the child's level of functional impairment and

presence of social support. However, no relationship was found between use of maladaptive coping strategies or feelings of perceived burden and HRQOL. Researchers called for future research increasing social support and assisting parents in developing healthy coping skills. Interestingly, while perceived burden has been used in many quantitative studies as a predictor of QOL (Khanna et al., 2011), qualitative findings suggest that mothers of children with ASD do not see themselves as “burdened” but “vigilant” (Larson, 2010), and that this vigilance contributes to fatigue, stress, poor sleep, and decreased well-being (Lee, 2013).

Along with coping, social support has also been predictive of HRQOL in parents of children with ASD (Khanna et al., 2011). Caregiving often isolates individuals from their friends and family at a time when they are most in need of social support. Differentiation is often made between informal and formal mechanisms of social support. Formal support includes structured avenues of socialization such as school or day care, clubs, agencies, professional help (e.g., medical or mental health professionals), church, and respite care (Chou, Chiao, & Fu, 2011). Informal support includes the network of people surrounding a caregiver like partners, friends, and family (Strozier, 2012). Both types of support have been found to highly influence HRQOL. Although the benefits of both formal and informal social support have been established, many parents may feel overwhelmed by the effort needed to seek out these resources. A lack of social support has been linked to a number of negative outcomes including increased feelings of hopelessness (Randall & Parker, 1999).

While previous studies have focused on maladaptive coping, lack of social support, and burden as predictors of deficits in QOL, some in the field have requested a shift in focus toward positive psychological variables such as optimism, self-efficacy, and resiliency. DePape and Lindsay (2015) conducted a meta-synthesis of qualitative studies looking at the experiences of

parents of youth with ASD and found that a common theme of benefits emerged. Oft described benefits included personal changes like increased patience and tolerance, development of coping skills, and heightened spirituality. Additionally, spousal communication and cohesion were cited as potential benefits. Unfortunately, there is still a paucity of quantitative research examining resiliency of parents of youth with ASD. One particularly large gap has been the failure to incorporate resiliency and other positive psychology variables into models that previously identified the significant impact of factors such as burden and psychopathology on HRQOL.

Previous research has primarily focused on describing factors that predict QOL for parents of youth with ASD, stopping short of translating these findings into viable interventions. Furthermore, there has yet to be a study familiarizing researchers with level of caregiver willingness and/or interest in interventions that could provide support, address stress, or promote positive well-being. Interventions vary widely, ranging from community-based support groups to individual psychotherapy. The most common, easily accessible resource available to parents of youth with ASD is the peer-led support group. However, this population is particularly pressed for time and may feel guilty or indulgent in attending what are often lengthy support groups (Larson, 2010). According to an 8-day diary study by Smith and colleagues (2010), mothers of children with ASD spent a larger portion of their day engaged in chores and caregiving activities when compared to mothers of normally developing children. Results indicate that mothers of children with ASD compensate for this caregiving time by reducing the amount of time spent engaged in leisure activities. Brandon (2007) articulated that mothers of children with ASD simply run out of time in the day to engage in self-care and activities that could promote well-being. Additional avenues for intervention include individual psychotherapy, psychotropic medication management, and respite. Research notes that consumers can find traditional mental

health services to be hard to access, time consuming, costly, and potentially stigmatizing (Lang, 2005; Mak, Poon, Pun, & Cheung, 2007). Specifically, within a population of parents of boys with ASD, respite care was identified as contributing to burden and anxiety because mothers of children with ASD felt responsible for training or coaching the respite care provider on their child's individual needs. Additional barriers identified qualitatively included the child's reaction to being cared for by a stranger and safety concerns (Larson, 2010). Conversely, Zarit and colleagues (1998) identified respite care as decreasing stress, anger, and depression while improving well-being in the context of adult day care services for individuals with dementia.

Psychoeducation is a crucial resource for promoting caregiver efficacy and decreasing negative ramifications associated with caregiving. According to a qualitative study conducted by Hermanns and Mastel-Smith (2012), seeking knowledge was identified as a "requisite caregiver character trait" that led to more positive outcomes (p. 11). However, it is not clear that every caregiver will seek out help even when needed. Considering the increased prevalence of depression and anxiety characterizing this population, parents with the highest rates of psychopathology, lowest HRQOL, and lack of resources may be the most hesitant to seek help. Tehee and colleagues (2009) found that age of the child with ASD was related to level of support received and extent of information accessed. Specifically, parents of children ages 3-6 and 15-18 years old were identified as particularly vulnerable to lacking social support and information.

The unmet need for caregiver supportive services is exemplified by one study examining caregivers for adults with Alzheimer's disease. According to the Alzheimer's Association's (2004) study, 75% of participants identified unmet needs. Of those caregivers in need of services, only 9% had sought and utilized respite care, and only 11% had participated in support groups (Alzheimer's Association, 2004). The inconsistency between findings regarding need and

use of efficacious caregiver interventions highlights the need for further examination of the issue from new perspectives. Particularly, tailoring caregiver interventions to a specific group or need could enhance efficacy and create greater consistency. Part of this approach would require understanding the context, needs, and values of parents of youth with ASD.

Overview of Current Study

Mothers are most often identified as the primary caregiver of children with ASD and rate themselves as more involved in activities of daily living than male caregivers of children with ASD (Hastings, 2003). Research has shown that female caregivers of children with ASD experience higher rates of burden and psychopathology than male caregivers. However, within the ASD caregiver literature, there remains a lack of research evaluating the caregiving experience of men and fathers of children with ASD. Specifically, gender differences have not been analyzed under previously researched models of HRQOL for parents of youth with ASD. This study focused on the experience of both mothers and fathers of youth with ASD and conceptualized gender as a potential predictor of differences in HRQOL. Additionally, ASD is a long-term disorder that impacts individuals and their families across the lifespan; however, research has shown that parents of minors (i.e., individuals below the age of 18) self-disclose higher levels of burden and psychopathology. Previous research has shown that parents of youth between the ages of 4 and 17 with ASD report greater difficulty providing care and higher levels of frustration than parents of youth with other developmental disabilities (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Thus, the current project focuses on the experiences of parents of youth with ASD, including fathers, in order to develop a deeper understanding of predictors of HRQOL.

The overall aim of the current study was to grow the base of knowledge of factors that improve caregiver HRQOL for parents of youth with ASD while also taking an exploratory look at the subjective experiences of parents. I examined parents' perceived relationship between HRQOL and their own daily experiences. I explored barriers and facilitators towards seeking out services, resources, or support. Finally, I elicited caregiver responses to potential mechanisms of disseminating support and various types of supportive providers. Based on previous research findings, I hypothesized that the following would be predictive of higher HRQOL: (1) lower perceived burden, (2) higher perceived positive aspects of caregiving, (3) higher usage of adaptive coping strategies, (4) lower usage of maladaptive coping strategies, and (5) higher levels of social support. Due to the exploratory and qualitative nature of the second phase of the study, no hypotheses were made prior to data collection. Thematic analysis was used to identify commonalities among participant responses to semi-structured interview questions and findings were extrapolated from common themes.

Quantitative statistical analysis involved a hierarchical regression with demographic variables and care-recipient specific variables which were controlled for in the first block and main predictor variables in the second block. This methodology allowed me to see how much additional variance study variables provide in predicting HRQOL and the relative effects of predictor variables. For the second component of the study, a qualitative methodology was employed. There is a scarcity of research looking at parental attributions of HRQOL to the role of caregiving. Furthermore, no studies to date have qualitatively examined caregiver's interest in receiving supportive services from different providers and what resources or services they find desirable. According to Bauer, Sterzinger, Koepke, and Spiessl (2013), "a shift in orientation from focusing on burden to emphasizing resources is necessary" (p. 185), and Talley and Crews

(2007) wrote that “pursuing quality of life rather than simply absence of disease” should be the goal of population-based health (p. 224). Thus, the second part of this study took an exploratory look at pursuing quality of life as well as introducing approaches to bolstering quality of life such as primary care intervention. After building on the existing knowledge base of what contributes quantitatively towards HRQOL, this study incorporated the subjective experiences of parents to guide future intervention research. This study employed a pragmatic perspective in order to address a problem: parents are experiencing decreased HRQOL. These same individuals are not asking for help and are not being spontaneously offered help. A significant hurdle that health care, mental health care, and other professional care providers must overcome in improving HRQOL for parents of youth with ASD is answering the questions of “how?” and “in what form?” should help be presented. The qualitative component of this study hoped to discern barriers and facilitators toward accessing resources including understanding more about what context parents would be most comfortable having resources presented to them and what specific resources they perceive to be useful.

By using a mixed methods approach, I utilized the strengths of both quantitative and qualitative methods to broaden an understanding of what contributes to HRQOL in parents of youth with ASD. Additionally, the mixed method approach offered guidance for providers working with parents of youth with ASD on promoting better HRQOL by eliciting the experiences, preferences, and desires of parents in their own words.

CHAPTER 2

METHOD

Participants were parents of youth with ASD. To be eligible for the study, the participant must be 18 years of age or older and currently providing care to a child under the age of 18 with ASD. Parents were eligible for inclusion if their child received a medical diagnosis of any ASD [Autism, Asperger's syndrome, or pervasive developmental disorder – not otherwise specialized; (PDD-NOS)] and if they had legal custody and/or guardianship of the child.

Participants were recruited from Treatment and Education of Autistic and Communication Related Handicapped Children (TEACCH) centers operated by the University of North Carolina (UNC) at Chapel Hill. A preliminary power analysis was conducted to determine a projected sample size. It was determined that in order to identify a medium effect size (ES) of 0.15 with an alpha of .05 and power of 0.95, a sample size of approximately $N = 233$ would be needed for a multiple regression with 23 variables. The research coordinator from UNC Chapel Hill TEACCH center disseminated an online version of the survey to a broad pool of parents of agency consumers. Participants were instructed via informed consent documents that they may be contacted after completing the survey for a follow-up phone interview that would take approximately 30 minutes. Once quantitative analysis was complete and the second, qualitative phase of the study began, parents were contacted by telephone using phone numbers they had provided during phase one. Participants were invited to participate in a telephone interview. Interviews were audio recorded and transcribed in their entirety by two researchers to ensure accuracy. All procedures were voluntary, and participants were informed that they could withdraw from the study at any time without incurring any consequences.

All recruitment, survey, and informed consent procedures were reviewed and approved by the Institutional Review Board of East Tennessee State University as well as the Institutional Review Board of the University of North Carolina at Chapel Hill.

Part I: Quantitative Analysis

Participants. In total, 365 parents of youth with ASD made up the quantitative sample of this study. Survey participants were predominately female (86%), Caucasian (80%), and married (82%). Education status varied with fairly equal percentages of participants reporting completion of high school or less, completion of college, or completion of a graduate program as their highest level of educational attainment (see Table 1). Approximately one-third of the sample (31%) reported living in a rural geographical community, and the majority of participants (61%) reported living in a suburban community, with only a small percentage (8%) reporting living in an urban community at the time of the study (see Table 1). The average age of participants was 43 (SD = 8.16) and the average age of the child with ASD that parents were asked to discuss was 11 (SD = 3.99). See Table 2 for descriptive data of continuous study variables.

Table 1
Descriptive Data of Categorical Study Variables

Measure	N	Percentage (%)
Gender	366	
Male	52	14
Female	314	86
Race	364	
Majority (Caucasian)	290	80
Minority	74	20
Marital Status	362	
Single	64	18
Married	298	82

Community Type	360	
Rural	112	31
Suburban	218	61
Urban	30	8
Educational Status	366	
High school degree or less	134	37
College degree	133	36
Graduate degree	99	27

Table 2

Descriptive Data of Continuous Study Variables

Measure	N	M (SD)
Age	363	42.83 (8.16)
Child's age	365	10.75 (3.99)
Total number of children	365	2.03 (0.98)
Child's age at point of diagnosis with ASD	353	4.18 (2.59)

Data. In order to capture the subjective and often illuminating “lived experience” of parents of youth with ASD, a mixed methods approach with a sequential procedure was used. With the intention of verifying that previously identified predictors of caregiver HRQOL apply to the population being studied, the current study began with a quantitative component in the form of an online survey.

The online version of the survey was programmed to automatically discontinue if any inclusion criteria were not met, and data from discontinued surveys were not included in the final analyses. Data were analyzed using SPSS 24 for Mac. The following measures were used:

Quality of life (WHOQOL-BREF). In order to assess the outcome variable, health-related quality of life, the World Health Organization Quality of life Scale Brief (WHOQOL-BREF) was included in the study questionnaire. The WHOQOL-BREF includes 26 items scored

on a 5-point Likert Scale with 4 domains: physical health, psychological health, social relationships, and environment. The first two questions have unique phrasing with lower scores representing poor quality of life; the other 24 questions have “not at all”, “a little”, “a moderate amount”, “very much”, and “an extreme amount,” corresponding to scores of 1 to 5. For the purpose of this study, the subscale of health-related quality of life was scored for final analyses. Lower scores represent poorer HRQOL. The following questions are included in the physical health subscale: “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?”

Burden. The Zarit Burden interview (ZBI) consists of 22 items on a 5-point Likert Scale with “never”, “rarely”, “sometimes”, “quite frequently”, and “nearly always,” corresponding to scores of 1 to 5. Due to the nature of this study and the participants being parents of children under the age of 18, two questions were removed after piloting the questionnaire and receiving feedback that the questions were confusing and difficult to answer. These 2 questions included the following: “Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?” and “Do you feel your relative is dependent on you?” After removing 2 questions, the final survey included 20 items for the Zarit Burden Interview. These 20 items are summed to create a total burden score, with higher scores indicating a larger subjective experience of physical, psychological, emotional, social, and financial problems related to a participant’s role as a caregiver.

Coping. The Brief COPE inventory (Carver, 1997) was used to document current coping strategies and behaviors associated with stress management using 28 items on a 4-point Likert scale: “I haven't been doing this at all,” “I've been doing this a little bit,” “I've been doing this a medium amount,” and “I've been doing this a lot” (corresponding to scores of 1 to 4 respectively). A factor analysis was conducted to look at rotated factor loading of the Brief COPE within this sample. A detailed report of the results of the factor analysis are provided in the quantitative results section. The factor analyses of the Brief COPE yielded four discrete factors differentiating between coping strategies identified as adaptive, maladaptive, help-seeking, and avoidant.

Positive Aspects of Caregiving. This study utilized the Positive Aspects of Caregiving Scale which was created to measure the tendency to positively interpret one's caregiving experience (PAC; Boerner, Shulz, & Horowitz, 2004). The PAC consists of 11 items all beginning with the prompt “Providing help to care recipient has” and followed by statements such as: “made me feel more useful,” “given more meaning to my life,” and “enabled me to develop a more positive attitude towards life.” These items are measured on a 5-point Likert scale with “disagree a lot,” “disagree a little,” “neither agree nor disagree,” “agree a little,” and “agree a lot” corresponding to scores of 1 to 5, which are summed to produce a total score with higher scores indicating a higher perception of positive aspects of caregiving.

Support. The Interpersonal Support Evaluation List-12 (ISEL-12; Cohen, Mermelstein, Kamarck, & Hoberman, 1985) was included in the study questionnaire to identify sources of support including tangible, belonging, and appraisal support. The ISEL-12 was designed as a short-form of the original 40 item questionnaire to administer with general populations to elicit perceptions of social support. Participants are asked to rate each of the 12 questionnaire items as

“definitely true,” “probably true,” “probably false,” and “definitely false.” Lower scores indicate the participant’s lower perception of social support in this category.

Caregiving variables, socio-demographic variables, and care recipient-specific variables. Participants were asked how many children under the age of 18 are currently living in their household and how many of these children have an ASD diagnosis. Socio-demographic variables assessed include gender, race, marital status, age, educational background, employment status, and total household income to gauge socio-economic status. Care recipient-specific variables include current age of the child and the age at which the child was diagnosed with ASD.

In order to identify variables that significantly predict HRQOL of parents of youth with ASD, a hierarchical regression was conducted. Independent variables hypothesized to predict HRQOL included the following: (1) perceived burden, (2) perceived positive aspects of caregiving, (3) coping strategies (adaptive, maladaptive, help-seeking, and avoidant), and (4) social support (belonging, tangible, and appraisal). The hierarchical regression allowed for the control of demographic variables and care-recipient specific variables by including them in the first step of the regression. The output of a hierarchical regression with two steps provided me with the opportunity to look at the change in R^2 in order to see how much additional variance is explained by the second step of predictor variables. I also looked at the β values within steps of the regression to examine the relative effects of different predictor variables. I chose to put the predictor variables in the second step of the hierarchical regression because the first step of demographic and care-recipient specific variables account for the overlap in variance which could have been erroneously accounted for by relationships between predictor variables. This methodology stopped the predictor variables from appearing overly influential.

Tests for multicollinearity were conducted by examining tolerance and the variance inflation factor (VIF) as well as bivariate correlations between all study variables (See Table 3). None of the study variables had a VIF over 2.5 which is considered a cut-off score for problematic inflation of variance due to correlation with other predictor variables (Field, 2009). Additionally, none of the study variables had bivariate correlations at or above .8, indicating a lack of overlap between variables and the absence of problematic multicollinearity.

Table 3

Zero Order Correlations Between Variables Included in Regression Analysis (N = 362)

Measure	D*	1	2	3	4	5	6
Health-related quality of life (D*)	--						
1. Gender (male)	.19**	--					
2. Age	.02	.18**	--				
3. Household income	.24**	.14**	.19**	--			
4. Child's age	.10	.05	.58**	.10	--		
5. Tangible social support	.38**	.08	-.001	.13*	.05	--	
6. Perceived burden	-.37**	-.004	.04	.10	.005	-.49**	--
7. Maladaptive coping	-.31**	-.06	-.10	.03	-.06	-.29**	.54**

Note. * $p < .05$; ** $p < .001$; D*: dependent variable

Part II: Qualitative Analysis

Data and Participants. A total of eight interviews were conducted with eight separate parents of youth with ASD. Once communication was established through phone calls, there was a 0% refusal rate for interviews. Three voicemail messages were left for three separate parents inviting participation in the interview component and those survey participants did not call back to participate in a phone interview. The length of interviews varied and ranged from 17.46 to 51.25 minutes ($M = 28.37$, $SD = 10.82$). Seven participants were female and one was male. Their ethnic backgrounds varied; five participants were of Caucasian decent, one was of African

American decent, one was of Hispanic decent, and one was of Asian descent. Two participants self-disclosed during the interview that they lived in rural areas, and the geographic location of the other participants is unknown.

Procedure. Participants were interviewed by a doctoral level clinician with experience in conducting semi-structured interviews. Prior to beginning a phone interview, I reviewed an informed consent document with participants and obtained verbal informed consent. The questions included in the semi-structured interview focused on caregiver attributions of their QOL, perceptions of where they get support, how they would feel getting support from various professionals, and the types of supportive interventions they would be amenable to and/or do not currently have access to. Qualitative interview questions were devised based on gaps in the current literature base and reflected the literature on predicting and promoting quality of life for parents. Questions were designed to allow participants time to elaborate on their daily experience of parenting a child with ASD as well as discuss interest in and comfort with receiving help from various sources of support. Semi-structured interview questions were used to guide the conversation; however, there were also opportunities for elaboration and discussion within each question. All phone interviews were audio-recorded and then transcribed independently by both a research assistant and myself to ensure accuracy of transcription.

In addition to myself, two clinical psychology graduate research assistants aided in the process of qualitative data analysis. Both individuals were registered as study personnel with the ETSU Institutional Review Board prior to participating in data analysis. Another research team member included the chair of my dissertation committee.

Theoretical thematic analysis was used to help describe data in rich detail through six steps articulated by Braun and Clarke (2006): 1) familiarizing oneself with the data, 2)

generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the scholarly report. As recommended by Ambert and colleagues (1995), data collection continued until coding reached saturation and themes continued to repeat themselves within new interviews. Both research assistants, my dissertation committee chair, and I determined that no new themes had emerged during the final two interviews. This solidified the decision that saturation had been reached and qualitative data collection ended.

During step one, both research assistants and I carefully read through the interview transcripts several times in an effort to familiarize ourselves with the data. Interview transcripts were then formatted for and uploaded into NVivo version 11, a qualitative analysis software package that allows for efficient and precise organization of codes, creation of themes, and observation of commonalities between textual content. Within this study, emphasis was placed on maintaining an unbiased view toward gathered data. During step two, in order to maintain an unbiased interpretation of data, two student research assistants who did not participate in the literature review or quantitative component of this study independently conducted preliminary coding of interview transcripts. Thus, their coding was not based on previously conceived hypotheses or pre-determined theoretical perspectives on the topic of caregiver quality of life.

During preliminary coding, graduate research assistants searched for data extracts (specific words or phrases) and gave these codes a descriptive identifier such as “stigma” or “formal social support.” The third step involved meeting in-person as a team with the two independent coders, my committee chair, and myself to sort through the codes, look for overlap, and identify potential themes from relationships between codes. There was almost 100% consistency between independent coders on initial overall themes. At that time, themes and sub-themes were given preliminary names and definitions for easy identification during step four.

During step four, all interview transcripts were re-coded by myself based on the agreed upon themes and subthemes. While engaging in this process, I continued to assess for the viability of themes and the ability of themes to accurately echo the viewpoints expressed within the transcripts. Additionally, I checked to see if any themes emerged that may have been missed during earlier steps. It was determined that there were no missing themes or subthemes.

During step five, themes were analyzed and discussed based on their ability to accurately reflect the story told by the data, and the bigger story emerged as part of my mixed-methods study (Braun & Clarke, 2006). During the sixth and final step, the themes were written into a conceptually concise narrative, which can be found within the results section of this paper. The results describe frequency of themes, descriptions of themes, and explanatory quotes selected from transcripts to elaborate on the theme discussed.

CHAPTER 3

RESULTS

Part I: Quantitative Analysis

Factor analysis of the Brief COPE. In order to reduce the number of subscales of the Brief COPE from 14 to a more usable number for the hierarchical regression, a principle component analysis (PCA) was conducted on 28 items with orthogonal rotation (varimax). The Kaiser-Meyer-Olkin measure of sampling adequacy was .757, at the good rating of acceptability and above the commonly recommended value of .60. Bartlett's test of sphericity $\chi^2(378) = 3966.41, p < .001$, indicated that correlations between items were sufficiently large for PCA. An initial analysis was run to obtain Eigenvalues for each component in the data. Nine components had Eigenvalues over Kaiser's criterion of 1 and in combination explained 68.68% of the variance. After removing three factors with less than 0.4 loadings, the new Kaiser-Meyer-Olkin measure of sampling adequacy was .760, still at the good rating of acceptability. Bartlett's test of sphericity $\chi^2(253) = 3339.73, p < .001$, indicated that correlations between items were sufficiently large for PCA.

The scree plot showed an inflexion justifying the retention of four components. Thus, the first four components were retained in the final analysis and in combination explained 48.03% of the variance. Table 3 shows factor loadings after rotation. The items that cluster on the same components suggest that component one represents an adaptive coping style, component two represents a maladaptive coping style, component three represents a help-seeking coping style, and component four represents an avoidance coping style. These four components of the Brief COPE had acceptably reliabilities with Cronbach's α of .79, .73, .83, and .64 respectfully (see

Table 4). These constructs identified within the Brief COPE were useful in reducing the number of subscales from fourteen to four, and in making hierarchical regression more accessible for the purpose of this study.

Table 4

Results of Brief COPE Factor Analysis with Rotated Factor Loading

Item	Adaptive Coping	Maladaptive Coping	Help-Seeking Coping	Avoidance Coping
I've been turning to work or other activities to take my mind off things	-.02	.49	.09	-.04
I've been concentrating my efforts on doing something about my child's Autism	.70	-.09	.06	.185
I've been saying to myself "this isn't real"	.10	.09	-.01	.81
I've been using alcohol or other drugs to make myself feel better	.06	.66	-.15	-.05
I've been getting emotional support from others	.18	-.13	.68	.04
I've been giving up trying to deal with it	-.27	.55	.02	.18
I've been taking action to try to make my child's situation better	.65	-.23	.17	.11
I've been refusing to believe that it has happened	.04	.04	.11	.76
I've been getting help and advice from other people	.32	-.07	.70	-.02
I've been using alcohol or other drugs to help me get by	.05	.66	-.11	-.07
I've been trying to see it in a different light, to make it seem more positive	.47	.11	.36	-.01
I've been criticizing myself	.22	.61	-.18	.18
I've been trying to come up with a strategy about what to do	.69	.17	.14	-.03
I've been getting comfort and understanding from someone	.27	-.11	.71	-.06
I've been giving up the attempt to cope	-.05	.42	-.04	.52
I've been looking for something good in what is happening	.61	.04	.32	-.09
I've been making jokes about it	-.07	.49	.05	.02
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	.11	.56	.07	.16

I've been accepting the reality of the fact that it has happened	.40	.22	.09	-.44
I've been trying to get advice or help from other people about what to do	.43	-.08	.63	.02
I've been learning to live with it	.53	.13	.12	-.17
I've been thinking hard about what steps to take	.80	.07	.08	.09
I've been blaming myself for things that happened	.21	.48	-.13	.44
I've been praying or meditating	.40	-.36	.09	.24
I've been making fun of the situation	-.16	.46	.46	.08
Eigenvalues	3.82	3.30	2.73	2.16
% of variance	15.30	13.18	10.93	8.62
α	.79	.73	.83	.64

Predictors of health-related quality of life for parents of a child with ASD. I

hypothesized that parenting-related variables, including tangible social support, belonging social support, appraisal social support, positive perceptions of caregiving, perceived burden related to caregiving, adaptive coping, maladaptive coping, help-seeking coping, and avoidance coping would predict HRQOL above and beyond demographic variables. After running a preliminary regression including all variables regressed onto HRQOL, the following variables were not significantly related to the outcome variable and thus were excluded from final analyses: belonging social support, appraisal social support, positive perceptions of caregiving, adaptive coping, help-seeking coping, avoidance coping, education status, relationship status, number of children under the age of 18 living in the household, and number of children under the age of 18 living in the household with an ASD diagnosis. In order to test the study hypothesis a hierarchical regression with two steps was conducted. The first step included control variables: gender, total annual household income, age of parent, and age of the child with an ASD diagnosis. The second step involved variables that emphasize specific reactions to and aspects of

parenting a child with ASD, including tangible social support, perceived burden related to role as a caregiver, and utilization of a maladaptive coping style.

Results showed that the first model (i.e., regression of HRQOL on gender, total annual household income, age of parent, age of child with ASD) was significant in explaining variance in level of HRQOL ($F(4, 348) = 8.65, p < .001$). Gender, total annual household income, age of parents, and age of child with ASD explain 9% of variance in HRQOL ($\Delta R^2 = .09$). Within the first model, gender significantly explained variance in HRQOL ($b = .15, SE = .39, p = .004$), where gender is coded as 0 = Female and 1 = Male. Age of parent significantly explained variance in HRQOL ($b = -.13, SE = .02, p = .043$) indicating that with a standard deviation increase in age, HRQOL in parents of youth with ASD decreases by a .04 standard deviation ($\beta = -.04$). Age of child with ASD significantly explained variance in HRQOL ($b = .14, SE = .04, p = .023$) indicating that with a standard deviation increase in child's age, HRQOL in parents of a child with ASD increases by a .09 standard deviation ($\beta = .09$). Total annual household income significantly explained variance in HRQOL ($b = .23, SE = .04, p < .001$) indicating that with a standard deviation increase in annual household income, HRQOL in parents of a child with ASD increases by a .17 standard deviation ($\beta = .17$). The standardized regression coefficients indicate that total annual household income has the largest influence on HRQOL, gender is the second most influential predictor, child's age is the third most influential predictor, and parent's age is the fourth most influential predictor of HRQOL (see Table 5).

Table 5

Hierarchical Regression Analysis Summary for Health-Related Quality of Life for Parents of a Child with ASD Regressed on Gender, Age, Total Annual Household Income, Child's Age, Tangible Social Support, Perceived Burden, and Maladaptive Coping (N = 365)

Variable	<i>b</i>	<i>SE</i>	β	R^2	ΔR^2
<i>Model 1</i>				.09	.09
Gender (male)	1.13*	.39	.15		
Age	-.04*	.02	-.13		
Household income	.17**	.04	.23		
Child's age	.09*	.04	.14		
<i>Model 2</i>				.28	.19
Gender (male)	.94*	.35	.13		
Age	-.04*	.02	-.12		
Household income	.18**	.04	.23		
Child's age	.08*	.04	.12		
Tangible Social Support	.17**	.05	.19		
Burden	-.05**	.01	-.23		
Maladaptive coping	-.08*	.03	-.13		

Note. * $p < .05$. ** $p < .001$

Results showed that the second model (i.e., regression of HRQOL on tangible social support, perceived burden, and maladaptive coping style) was significant in explaining additional variance in HRQOL above and beyond the variance explained by the first model ($F(7, 345) = 19.41, p < .001$). These second model predictor variables account for an additional 19.2% of variance in level of HRQOL ($\Delta R^2 = .19$). Within the second model, tangible social support significantly explained variance in HRQOL ($b = .19, SE = .05, p < .001$) indicating that with a standard deviation increase in tangible social support, HRQOL for parents of a child with ASD increased by a .17 standard deviation ($\beta = .17$). Perceived burden significantly explained variance in HRQOL ($b = -.23, SE = .01, p < .001$) indicating that with a standard deviation increase in perception of burden related to caregiving, HRQOL for parents of a child with ASD decreases by a .05 standard deviation ($\beta = -.05$). Maladaptive coping style significantly explained variance in HRQOL ($b = -.13, SE = .03, p = .016$) indicating that with a standard deviation

increase in use of maladaptive coping, HRQOL for parents' decreases by a .08 standard deviation ($\beta = -.08$). The standardized regression coefficients indicate that perceived burden has the largest influence on HRQOL, tangible social support is the second largest predictor, and maladaptive coping is the third largest predictor (see Table 5).

Part II: Qualitative Analysis

Main themes identified through thematic analysis included social and community support, resources, lack of understanding about ASD demonstrated by others, experiences of the caregiver, caregiver coping strategies, and process of reaching a diagnosis of ASD. These themes and their associated sub-themes are described in further detail in Table 6. For the purposes of this study, I have chosen to focus discussion on the themes most relevant to this study's aims of predicting and promoting health related quality of life for parents of youth with ASD. Thus, the theme of *process of reaching diagnosis of ASD* was identified and defined within Table 6 but will not be discussed further within this manuscript.

Table 6
Qualitative Themes, Subthemes, and Definitions (N = 8)

Theme and Subthemes	Definition
Experience of the caregivers	
Emotional/mental health	This theme refers to the caregiver's experience of stress, frustration, exhaustion or other perceived tolls on mental health and emotional functioning.
Strain on relationships	This theme refers to the perceived strain on relationships as the result of the child's diagnosis, behavior, or others' expectations of them and the child. May also include statements indicating frustration with other parents or lack of "getting it" about their child and therefore distancing themselves.
Sacrifices	This theme refers to sacrifices the parents have made for their child, including financial strain, pressure in relationships, loss of a job, sacrificed time, etc.

Successes and child progress	This theme refers to the parent's perception of the child's progress, satisfaction associated with the child improving in one or more domains, and feelings of pride and accomplishment associated with their child's success.
Challenges for their child	This theme refers to the parent's awareness of specific challenges the child faces and their struggle with addressing these challenges on a daily basis.
Social & community support	
Formal sources of support	This theme describes support received from those expected, as a part of their profession, to give support to the child and family as well as the perceived or real lack of support from formal sources. This may include teachers, physicians, therapists, school administrators, etc.
Informal sources of support	This theme describes support received from family, friends, community members, etc.; as well as the perceived or real lack of support from formal sources.
Resources	
Autism-Specific	This theme refers to specific organizations or people that have provided information about ASD. There may be a range in how large vs. local the organization's reach. This subtheme can also be reflective of a subculture used to trade information or secure information about available resources.
Pragmatic Concerns	This theme refers to concerns regarding cost, insurance, and time required for treatment, travel, or other necessities.
Medical or Other Providers	This theme references any discussion of availability of providers, including range of providers available, relationship with providers, and providers' knowledge.
Dissatisfaction with resources	This theme includes expressions of limited resources, overt dissatisfaction with resources, or unwillingness to seek resources. May also include disparaging comments about treatment providers or other caregivers.
Lack of understanding about ASD demonstrated by others	
Lack of understanding	This sub-theme refers to expressions of others' lack of understanding or knowledge about Autism. This may also include the parents' experience of others stating inaccurate information (e.g., vaccines cause Autism).
Misperceptions/hostility	This sub-theme references expectations or misperceptions about the child or their behavior. This may also include comments that are critical, hostile, or judgmental regarding the child, family, or diagnosis.

Stigma	This sub-theme refers to the parent’s experience of being stigmatized or treated differently as the result of their child’s diagnosis or behavior.
Caregiver coping strategies	
Self-care	This theme refers to anything a caregiver might have done to take care of themselves, including therapy, taking breaks, or other strategies that show concern for self.
Relying on personal characteristics or traits	This theme refers to use of individual personality traits, such as having a positive attitude, using humor, “going with the flow,” or other personality features that help them cope.
Acceptance and adaptability	This theme refers to making adaptive changes over time that helped them ultimately reach where they are today. Also includes acceptance of diagnosis, child’s capabilities, or other features related to caregiving.
Research and education	This theme refers to a caregiver actively doing research or seeking information about their child’s diagnosis, prognosis, or available resources and sources of support.
Process of reaching diagnosis of ASD	
First indications of the diagnosis	This theme refers to either early symptoms that were first noticed, or who may have first suggested the presence of a diagnosis.
Differential diagnosis	This theme refers to the process of identifying other potential diagnoses along the way of making the diagnosis of Autism, as well as specific diagnoses that were most likely considered.
Use of medication/supplements	This theme refers to the use of medications, supplement, or dietary changes to complement their child’s treatment.
Co-morbidities	This theme refers to the presence of medical or other mental health comorbidities, as well as the presence of significant physical or behavioral symptoms.

Experiences of the caregiver. During interviews, parents frequently discussed their experiences as a caregiver. In conversation about their experiences, parents linked their personal experience to their emotional functioning and mental health, strain in interpersonal relationships, sacrifices, successes of their child, and challenges of their child.

Emotional functioning/mental health. In describing their experiences as a parent of a child with ASD, all participants emphasized their emotional experience even without being specifically asked about this topic. Parents utilized a large spectrum of words to describe their negative emotional functioning and the state of their mental health, including depressed, anxious, stressed, desperate, socially isolated, nervous, guilty, sad, confused, pressured, frustrated, mad, angry, aggravated, and exhausted. One parent said “we’re getting by but [...] I’m tired. I’m tired all the time. I’m tired. Sometimes I just feel like I need a break” (P6), another said “I’m kind of sad sometimes, but I feel like I can cope with it. You know, because I’m worried, but I feel like I can cope” (P7), and one mother said “we were just ... it was out of desperation really, you know it will make you do, um, funny things” (P8). Another parent described a type of hyper-vigilance about ASD-symptoms that negatively impacted his overall emotional well-being. He said “you think you got it knocked but you can never relax and let it be. It just...it’s always there” (P4).

Some parents linked their negative emotional experiences to the discrepancy between hopes and expectations that they have for their child in terms of level of functioning or potential progress through treatment, and how things were actually going or how they worried things would be in the future. For example, one parent said “Well, it makes me sad. Because he doesn’t reach full potential. But beyond that...that’s based on what my judgment of full potential is. Right? [...] I have to be careful not to judge his success by my standards. [...] I only find myself disappointed when I fail to accommodate his difference” (P4). One mother expressed her desire to tell others how their treatment of her daughter impacts their home life in order to build the awareness of others. Specifically, she said that she’d like to express “how it impacts not only my daughter but, as an extension...you know, our home life” (P8).

Positive emotional experiences were also described by participants, and these included excitement, determination, hope, pride, acceptance, feeling loved, and feeling supported. What will be described later under the theme *caregiver coping strategies* is the process of moving towards acceptance and adapting. The process is aided by the presence of these positive emotions. One woman reflected on the trials and tribulations that she has experienced while helping her son said, “while it was hard in the beginning...I wouldn’t change anything” (P2).

Strain in interpersonal relationships. In over half of the interviews, participants described strain on their ability to have quality interpersonal relationships with family and/or friends as a negative consequence related to their child’s ASD diagnosis or care. Some explained that the strain stemmed from a lack of time and trying to allocate emotional and social resources. One parent described feeling stretched thin between parenting both of her children equally: “Having [...] more than one kid there’s always that feeling of ‘am I giving them all equal time?’, ‘Do they feel equally loved?’ But when you have a special needs kid, there’s a lot of ramp up for me because I started with zero knowledge and so I spent a lot more than half my time on my son and less than half on my daughter” (P2).

Many examples of strain in interpersonal relationships stemmed from a mismatch or discrepancy between coping strategies and perceptions about ASD of the parent and another individual. Thus, there was significant overlap between this subtheme and the subthemes of *stigma* and *personal traits*. For instance, one parent said “I think that there are people who are just self-absorbed” (P8). Interestingly, this same parent also acknowledged that they struggled with talking about their child’s ASD and other concerns: “I didn’t feel I had a right to talk about my problems” (P8). Another participant said “To be blunt, it was a strain on the marriage early on because I, my personality is, this is the situation, I need to read and educate myself as much as

humanly possible to understand how I can support him. And talk to as many people as possible so that I am okay. I'm doing what I can to make things easier for him. My husband's way of dealing with it was 'they're lying,' 'That's not true,' 'Why are you agreeing with them?', 'I don't want to talk about it'" (P2). Finally, a participant said "There is a lot of problems with Autism and, because of the lot of problems that you have, you cannot really have a normal social life. Maybe other people can, but in my case, I didn't find that my family was understanding" (P5).

Sacrifices. Every participant had an example of at least one sacrifice they had made in order to improve outcomes for their child. Some were very obvious sacrifices, such as one mother who stopped working in order to stay at home with her child. She said the following: "We decided that I was going to be a stay-at-home mom. Because of what you have to pay for daycare. [...] So, what happened to me is that I basically became my son's therapist. I was his therapist, I was his chauffeur, I was his everything" (P5). This participant was very blunt in saying that, when you have a child with ASD, "you don't have a normal life" (P5). This sentiment was parroted by another participant who said something similar: "we don't do what you would consider to be normal or main-stream activities" (P4). Participants also had examples of sacrificing time at home to facilitate their child's progress in intervention services. For instance, parents talked about working on strategies their child was learning in ABA, OT, school, etc. One parent said, "His motivation is kind of low so you know, we have to work on that to be able to teach him things" (P7). Some sacrifices were subtler, such as sacrificing spontaneity because of their child's preference for routine. One parent described dealing with a situation in which she and her husband had planned a vacation, used social scripts to prepare their child for the stops they were making on vacation, and then found that some of those stops were closed.

Even after preparing and making sacrifices, parents of youth with ASD often encounter situations in which they are challenged to remain patient and resilient.

Successes of their child. A majority (six out of eight) of the parents interviewed talked about successes that their child has had or progress that their child has made towards success. As seen in these example; oftentimes, successes of the child are linked to specific efforts on the part of the parents: “Overall, my daughter is an early intervention success. Um, she is you know...she is high functioning. Most people who meet her don’t realize that she has Autism. They think that she takes the time to choose her words carefully. [...] I guess if I would say what my successes as a parent is, getting her the resources that have been able to get her to that place” (P8). “I’m actually working at my son’s school. So I’m super involved in whatever happens to him. So this was the first year that we got an IEP” (P5). Because the descriptions of success were so often linked to efforts on the part of the parent, this subtheme often coincides with examples of the theme of *caregiver coping strategies*.

Challenges for their child. Many of the experiences that parents talked about reflected a need to coping with challenges for their child, and all the parents interviewed at some point discussed challenges their child has encountered. These challenges related to activities of daily living such as eating (e.g. “When you go to the park, and you see I don’t know, an 18-month old eating little chunks of sugar or little chunks of grapes, you know your son is unable to swallow and therefore he eats baby food. And he’s 3,” P5), speech and language challenges (e.g. “He has his own language but he not really communicating what he wants, and he is not really listening,” P7; “She was extremely grammatically challenged....I could only understand about half of what she said,” P1), seemingly spontaneous meltdowns (e.g. “He looks normal, and then he completely flips out,” P6; “She was just having these wild...wild like outbursts,” P1), and social and emotional

difficulties (e.g. “I think this past year in school she thought she had friends but they really just kind of tolerated her,” P8). It is important to note that many parents voiced dealing with, not just one challenge, but a combination of some or all of these challenges.

Social and community support. All participants talked about social and community support. This topic emerged in several ways, including the perception of the presence of formal and/or informal sources of social support as well as a perception of the lack of presence of formal and/or informal social support.

Formal social support. This theme describes support received from those expected, as a part of their profession, to give support to the child and family as well as the perception that formal social support is lacking. Formal social support professionals may include teachers, physicians, therapists, school administrators, etc. Several key points emerged from discussions with participants about formal social support. The first was that the main facilitator to accessing formal social support was getting information about services. Once a parent knew where or to whom to go, they then had to overcome any pragmatic or logistical barriers to attend sessions or appointments. Due to the relationship between formal social support and the above barriers and facilitators, this subtheme is closely related to the content represented in the subthemes of *research and education, medical and other providers, and pragmatic concerns*.

The quality and accessibility of formal social support was closely linked to overall quality of life. For instance, one parent said, “Life has gotten so much better since then because there’s so many, um, so many things available here” (P6). This parent went on to cite a specific source of formal social support as particularly impactful when she said, “The Autism specialist at the school has been a fantastic support for us and for him” (P6). It is important to note the usage of the “us” and “him” because it shows the impact that formal social support has not only on the

child who functions as the provider's client in this case, but also on the parents of the child. In this sense, providers often play a larger role in the lives of families than they may realize. One parent pointed out that she did not feel as though professionals in her child's life listened to her and/or valued her opinion. She expressed the hope that "in the future, professionals are more open to hear and listen to what we say and consider the stuff we say" (P5).

Formal social support, while cited by all participants as an overall positive impact on their lives and the lives of their child, can also have drawbacks, such as the frequent and pervasive presence of providers within the family's schedule and lives. For example, one participant said, "What does it do to everybody else's life? We have a visitor in our home every night" (P4), and another said, "She did not go more than 24 hours without some sort of intervention" (P8).

Having a child who was of moderate functioning (rather than severe or mild) was noted as an issue in accessing formal social support by two participants. These participants claimed that their child's level of functioning placed him/her in a limbo zone between accessible services. One mother said, "When you have a kid in-between, you have no resources. You have no help. You have a bunch of help when you're in the low functioning but not when you're in the higher functioning stage. You don't have anything" (P5). Efforts should be taken to ensure that there are no gaps in services and that barriers to accessing services and receiving formal social support are remedied.

Informal social support. Many participants had an intimate family circle that provided emotional support and tangible support in the form of child care and breaks. For instance, one participant lived with her mother for a period of time and said that she did not need to reach out for help when she needed it because her mother was "right there" (P3). Another caregiver said, "I

live with my husband and my daughter. And they're really great" (P1). Apart from immediate family, many participants also talked about having a strong informal social support network of friends and members of their community that provided them with emotional support and tangible support in the form of information and referrals. For instance, one mother said the following about a group of women she met at an Autism society event: "They actually gave me more information than the pediatricians" (P5).

However, parents who lacked social support experienced disadvantages in several areas. For instance, one mother reported that "there're just no possibilities of, you know 'oh my God, I've been in a car wreck and I have to pick your child up too. Would you pick mine up?' That's not, you know, impossible to happen. Very silo-ed" (P3). Another parent mentioned the difference between making friends when you have a typically developing child and when you have a child with ASD: "She doesn't have any friends, and you know, my husband and I, our social circle, as she's gotten older, has gotten smaller because as a parent, that's how you make a lot of your friends. It's whoever is a parent of your kid's friends" (P8). Another mother, who described herself as "very isolated," also said, "I have a loving husband and I have very supportive parents and in-laws. And I have two wonderful kids" (P8). Thus, the potential negative impact of social isolation was buffered by having a strong intimate social circle of family.

There was ambivalence within this sample on the helpfulness of social support groups to improve access to informal social support. There were examples from parents who enjoyed and got a lot out of support groups and some that did not, while others were ambivalent. For instance, one parent spoke about attending a parents' meeting at the Autism Society and said, "It really, definitely made me feel less alone. [...] It gave me that strength to overcome being upset over

the situation and it really made me come to appreciate who he is” (P6). Another felt as though hearing about other people’s struggles made her feel worse: “I feel like I’m not gaining too much, [...] all the people have issues and I have issues and sometimes it makes it harder. I mean, that’s from my personal opinion. I see other people’s problems and I feel sad too then” (P7). Another parent did not feel comfortable sharing because her child had high functioning ASD and she “couldn’t relate to the other participants’ challenges” (P8). A male participant found himself in a parents’ meeting at the Autism Society because his wife wanted to go and he said the following about his experience: “You know it’s a room full of people sitting around talking about...kinda like AA...where you know ‘oh woe is me.’ And ‘the kid’s doing this’ and ‘oh yeah, I had that problem and this is what I did’” (P4). Finally, a participant living in a rural area said, “To my knowledge there isn’t one [in reference to a support group] and, if there is, I don’t know about it” (P3).

Obviously there is no one-size-fits-all parent support group that will attract and meet the needs of every caregiver of a child with ASD. Thus, further efforts are needed to address this issue further and conceptualize various options that could take into account the pragmatic issues with attendance (time in the meeting, time of day that the meeting is held, and distance from where attendees live or work) as well as personal issues (groups high in emotionality and emotional support versus psycho-educational groups, groups aimed at parents of youth with mild, moderate, or severe ASD).

Resources. During interviews, parents frequently discussed accessibility of or barriers in accessing tangible resources. Parent participants elaborated on their experiences utilizing resources, including encounters with Autism-specific resources, pragmatic concerns about

accessing resources, interactions with medical or other providers, and dissatisfaction with resources. These topics are presented as subthemes.

Autism-Specific. All participants interviewed discussed ASD-specific resources that they had utilized or would want to utilize if available. This theme refers to specific organizations or people that have provided information to parents about ASD or provide intervention to children with ASD. This subtheme was also reflective of a subculture used to trade information or secure information about available resources.

ASD-specific, interdisciplinary programs that were housed in a child's school were cited by parents as both effective and convenient. For instance, one parent said, "They're a real private program. But they work within the schools, and the one that she was in was a class specifically for Autism. And they specialize in and they use ABA strategies in the classroom, and it was a miracle" (P1). And another parent reported, "He's actually getting services in school and, with the Autism specialist at the school, has been a fantastic support for us and for him" (P6). It appears that having access to these ASD-specific resources positively impacted the quality of life of the child with ASD as well as his or her parents. One parent noted, "I've been blessed with some really great teacher support, and the Autism Society has also been really great about pointing me in different directions" (P2), and another said, "The CAP waiver that he has is outstanding. I'm glad we have it. I would never have sought it. Right. But it's there and it works and halleluiah!" (P4). This sub-theme co-occurs often with the sub-theme of *emotional functioning and mental health*. This connection emphasizes the importance of providers helping families connect to ASD-specific resources and supporting them in overcoming barriers to access in an effort to improve their quality of life.

Many parents recognized that ASD-specific interventions often made things worse before they made things better. For example, a parent reported that “at home, at first it kinda... at first it kinda got worse because there’s a lot of, you know, pressure at school to focus.” (P1)

Interestingly, within this sample, there was no evidence that the possible stress of this transition into treatment was enough to prematurely terminate. However, the fact that this pattern (things getting worse before they get better) emerged across several interviews necessitates the discussion of potential avenues for better informed consent prior to initiation of treatment. Providers can prepare parents prior to initiating treatment to potentially inoculate them against the negative impact of this pattern.

Pragmatic Concerns. All participants noted barriers that had prevented or temporarily blocked them from accessing services. The main pragmatic concerns revolved around time spent in intervention, time spent out of work transporting to intervention, distance to services, access to services, financial concerns, and issues related to insurance. For example, when describing the time spent attending intervention one mother said, “It was just hardcore every single day. She never went...she did not go more than 24 hours without some sort of intervention” (P8). When speaking about the distance travelled to see providers, one parent became frustrated and said, “How many people using Medicaid can go to Wilmington every 6 months for their younguns’ teeth? I mean it’s just mind bogglingly stupid” (P3), and another expressed similar sentiment when she said, “Just having all these bills plus the hassle of dealing with everything. And like having to travel and me going a distance to get services” (P6). The two participants who self-disclosed as living in rural areas placed a particular emphasis on the lack of resources in their area. For example, one parent noted that, “We live in a rural area. [...] drive for a day, and that is a lot. That is a lot of time” (P5).

Specific concerns about insurance coverage included worries about getting reimbursed after paying for services out of pocket, navigating long waiting lists to see providers that are in-network, finding providers that are in-network and providing the services needed, and fears about changes in insurance coverage. One parent noted, “I speak with teachers about the Medicaid coverage [...] they said that he is eligible, he’s approved, so you know, it make me feel good. But I’m worried that, you know I hear that news that Medicaid is cutting and stuff like that so it is on my mind. [...] I’m worried about like he will not get the services that he needs” (P7). This quote highlights the fact that, even after a professional had attempted to alleviate her concern about her child’s insurance coverage, this parent was still experiencing chronic worry. Interventions aimed at improving HRQOL of parents of youth with ASD need to be assessed for efficacy via continued follow ups.

Medical or Other Providers. This subtheme references any discussion of availability of providers, including range of providers available, relationship with providers, and providers’ knowledge. Within this sample, participants placed a premium on providers who had personal experience with ASD or advanced training in working with patients with ASD. One parent said, “We actually started traveling to see her, three hours. And she’s a medical doctor whose son has Autism” (P5), and another described a parent advocate at the Autism Society by saying, “She has a son who is also Asperger’s [...] And so that’s...that’s a great person to talk to, to get some advice from” (P2). Concrete suggestions and advice were also perceived as highly valuable. One parent said, “Snapology [...] she started giving us...uhh...like concrete suggestions on what...how to manage things. And tips for things that might help and resources that we should follow up on. And so that was really helpful” (P6). Another parent said, “His physician [...] he’s contacted therapies, he used that information, and gave me some advice that would work for us

and for him [referring to her son]” (P7). In addition to advice, parents also expressed value in the relationships that their child formed with his/her providers. For instance, one parent said, “I feel like he’s caring. [...] He does care about him [referring to her son] so much” (P7).

Dissatisfaction with resources. All participants interviewed expressed dissatisfaction with resources; however, there was an equal amount of satisfaction expressed. Thus, the following description is meant to serve as an identification of areas of weakness within the ASD service delivery model. Dissatisfaction was expressed towards school systems, particularly regarding the size of classrooms and the impact this had on a teacher’s ability to provide individualized attention, competence of medical and mental health care providers when working with both parents and the child with ASD, and politicians in charge of passing legislature that improves access to ASD resources. Several parents described dissatisfaction with mental health professionals. For instance, one mother said the following: “Honestly, I feel like therapy is one of those things where it could be a wonderful thing if you find the right person. And it could be a lackluster thing if you don’t really, you know, don’t really find the right person. It could be a really awful thing if you find the very much wrong person.” The same participant felt as though her primary care provider did not understand her needs either: “My primary care at the time she just was like, ‘Well, you’re just pressured. Here’s some pills. Well, you don’t have any energy. Here’s some pills. Oh this, well, here’s some pills.’ And I’m not a pill person” (P2).

Many parents expressed both frustration with previous pediatricians they had worked with as well as gratitude and relief for finding better pediatricians. Their frustration and dissatisfaction often came from a lack of information about ASD on the part of the pediatrician or the pediatrician’s failure to share information with the parent. For instance, one parent said, “The pediatrician didn’t provide any information about it or any suggestion about it. And he

started having diarrhea. And he didn't say why. So on the day when I reach out to these women, I didn't care at all about what the pediatrician has to say. Because he didn't help me at all before" (P5). Another mother said, "My child's pediatrician [...], she retired a few years ago. I thought she was fantastic for the run of the mill pediatric medical issues. But she had no idea about Autism...none. [...] Pediatricians are pretty useless when it comes to Autism" (P8). Another parent described her child's pediatrician laughing at her during an appointment: "'She passed the screen test, she doesn't have Autism.' And I was like, 'if it's all the same to you, I think I'm going to have her tested anyhow.' And then she laughed at me and I was like 'Alright, I'm out of here'" (P1). These anecdotes demonstrate the continued need for advanced training for medical and other professionals in working with children and families of children with neurodevelopmental disorders such as ASD.

The main purpose behind utilizing a qualitative methodology for the current project was to elaborate on gaps in current interventions and gain an understanding of what parents' desire in terms of getting their needs addressed. Thus, parents were asked what it would look like if a pediatrician offered more helpful feedback and one parent said the following: "They [referring to the pediatrician] would talk about the benefits in the good and the bad about medication that he's on. Talk about dietary changes. Talk about, you know, the things that we could do that's more pro-active. That maybe, you know, that I wouldn't be aware of. Because I'm not aware of all things, you know. There's always stuff going on that you could learn from. You know, letting me know of any kind of clubs, meetings, conferences, lectures, anything like that. That's what it would look like. It would be much more of a partnership as opposed to 'Okay it's your one year look. You've grown this much, you weigh this much, great job. Okay take your vitamin D. Good job. Get good grades in school'." (P2)

Lack of understanding about ASD demonstrated by others.

Lack of understanding. Most participants noted that they had experienced a lack of understanding about ASD demonstrated by others, directed at either themselves or their child. For instance, one parent said, “The first grade teacher blew it off; it wasn’t a big deal.” (P6) The idea that others did not understand ASD and thus, did not take it seriously enough, occurred several times. Another parent commented her frustration when her daughter’s pediatrician made this mistake: “She had no idea about Autism...none. I mean she obviously knew what it was but she, you know, like after we had switched...well maybe a year or two...we walked into the office for my daughter’s annual visit. And the doctor said, ‘Oh my goodness, she’s practically normal.’ And I was thinking to myself, ‘You’re an idiot. You have no idea what you’re looking at’” (P8). Sometimes the lack of understanding was due to the age of the bystander in question. For instance, another parent noticed that her daughter’s friends demonstrated an unconscious lack of understanding [e.g. “At her age, the little girls want to talk a lot and she’s just not a really big talker” (P1)].

Oftentimes, lack of understanding leads to unwanted or unhelpful advice, such as was the case for the mother that said this: “I had, you know, friends and family, like, I love my mom. It’s ridiculous, but sometimes she’ll say stupid things. Like, ‘Do you really need therapy? He needs an exorcist.’ I’m like, he doesn’t need a freaking exorcist! He’s on the spectrum. He’s fine. He has his moments. Leave him alone.” (P6) The same mother also reported that “When we’re out in public and he looks normal, and then he completely flips out...so we’ve gotten unwanted advice from passersby and sometimes some family and friends.” (P6) Another example of this lack of helpfulness was described by this mother who said, “My daddy and his wife. They love him and they would want to, but their help is not good. And they kinda can’t.” (P3)

Within the interviews there was a common thread of frustration felt towards other parents, medical providers, other professionals (e.g., teachers), and bystanders who lack understanding about ASD. One parent noted that “The most helpful thing anybody can do for a parent of a child on the spectrum is to behave compassionately and reserve judgment. And I don’t think people who have neuro-typical children, who kind of breeze through childhood, have any idea what it’s like.” (P8)

Misperceptions/hostility. This sub-theme references expectations or misperceptions about the child or their behavior. This may also include comments that are critical, hostile, or judgmental regarding the child, family, or diagnosis. Seven of eight participants talked about this subtheme during their interview. Some reported instances of misperceptions or hostility were obvious and intentional, such as the many parents who talked about the “wow, you’re a really bad parent” (P6) look. In most cases, parents received this blatant, negative, and typically non-verbal feedback when their child was exhibiting behaviors consistent with ASD, like externalizing behaviors, melt-downs, and/or behavior related to their developmental delay. Reactions to this negative feedback ranged from anger to humor, and parents said that they took these encounters more personally and felt stigmatized more when their child was younger. Interestingly, many participants now reportedly approach these encounters as an opportunity to provide others with information about ASD to minimize the potential of future misperceptions or hostility. For example, one parent said that she used to feel nervous when her child first started soliciting unwanted attention from others, then she began to feel annoyed, and now she is able to laugh it off and said that she “might make a comment like ‘Don’t mind us, we’re just spreading a little Autism awareness over here’” (P1).

There were also several occasions during which parents received “unwanted advice from passersby and sometimes some family and friends” (P6) that was interpreted as hostile and contributed to feeling stigmatized. One participant described strangers giving advice and said, “They think they need to have an opinion and feel the need to crap on you, and then some parents take that to heart and display that by getting angry at their child for not quite acting normal” (P2). This advice often involved other people’s belief that immunizations cause ASD, and that the child’s ASD could have been prevented if they had not vaccinated them. Examples of this included the following: one parent was told, “Hey, if you got your kid vaccinated, maybe you should stop doing vaccinations. Because your kid has Autism” (P1), and another reported that his “brother accused me of causing the Asperger’s; it was my fault. And him and his then wife, second wife, accused me of it because I...I think it was the immunizations that we know that he has which apparently was all my fault” (P2). Sometimes the behavior of others is justified by saying that “everyone tries to be helpful in their own way” (P1) or that no advice is bad. Another mother explained that children who treated her daughter differently at school had trouble being compassionate because they were “too insecure,” and she hoped at some point she would “have an opportunity to like explain mother-to-mother what this means” (P8).

Some instances of reported misperceptions or hostility are exchanges in which the perpetrator of the misperception or hostility may have been attempting to sound encouraging or supportive, but his or her efforts were perceived in a negative way by the parent of the child with ASD. One mother noted several instances in which people assumed her child’s ASD was under control or very mild, such as when her child’s pediatrician said, “Oh my goodness, she’s practically normal,” and her sister-in-law said, “Oh she’s doing so great, you would never know” (P8). She described these experiences as frustrating and invalidating.

Stigma. This sub-theme refers to the parent's experience of being stigmatized or treated differently as the result of their child's diagnosis or behavior. Six of eight participants reported experiencing stigma or discussed stigma during their interview. Some parents were impacted by perceived stigma to the point that it affected their daily experiences and patterns of interaction with others. One mother said, "We weren't going out as much because, you know, we couldn't go anywhere and not get looks" (P6). Another parent also described interacting less often with friends and family because of the assumptions they make about her. She said, "Number one, you are always the crazy woman. You are the crazy woman that is the one talking about the subjects that nobody wants to hear" (P5).

On the other hand, some parents are able to deflect perceived stigma and protect themselves from the potential negative impact. One participant interviewed indicated using his own personality traits to combat against the perception of stigma. When describing his reaction to other people's unwanted or unhelpful advice, he said, "I don't get uncomfortable with things like that. I accept them, or I reject them. I know we're back to arrogance with that but, if I don't like it, I don't do it. Regardless of anyone else's opinion" (P4).

Caregiver coping strategies.

Self-care. While the parents interviewed focused primarily on strategies they had used to help their child succeed, they all, at some point, also identified self-care strategies for themselves. Oftentimes these self-care strategies involved seeing a psychotherapist, engaging in activities outside of their role as a parent such as hobbies or work, and becoming active in their community. One parent noted, "I have hobbies I enjoy" (P3), and another said, "Honestly, like, most Monday mornings, I come to work, and it's, like 'Yes! It's Monday, I've survived the weekend.' And it's back to work. And I don't have to think about...I don't have to think about

the kids for a few hours. It's great. So work is a big help too 'cause it's stimulating and it's, you know, it's not about them" (P6). Although not common, there was one example of using political engagement as a type of self-care strategy: "It was extremely exciting going to the building, you know, the Senate building. I went to the House of Representatives; it was really exciting. Really, really exciting. I was ready you know, after three years of writing to these people, finally they listened. So, it was really exciting. We [referring to her husband and herself] felt really proud of ourselves" (P5).

Relying on personal traits or characteristics. This theme was identified in all eight interviews and refers to the use of individual personality traits, such as having a positive attitude, using humor, "going with the flow," or other personality features that help participants cope with stressors. It was clear during these interviews that having a child with ASD presents a unique set of challenges and stressors, regardless of the child's level of functioning. One participant said, "Autism is a tragedy. [...] Your life is never going to be the same" (P5). That same participant, like many other participants, also said that she would not change her child or take away ASD if she could and recognized that coping with her child's ASD had improved her overall quality of life. Specifically, she said, "I was not going to let Autism screw my life. So for me, Autism has made me a better person, a better parent, a better everything for me in my experience" (P5).

Other unique personality traits and characteristics identified were self-reliance (e.g. "I've learned to be very self-reliant," P8; "I try to figure out how to resolve an issue and then we figure out a plan. And execute it and sometimes it works and sometimes it doesn't. But I don't believe in asking for help," P4), the ability to regulate one's emotions (e.g. "I just try to cope myself. Like, 'all things are going to be okay'," P7), and being defensive or dismissive about the impact of others (e.g. "These people don't know me. I don't really care. They're never going to see you

again. I don't even know you. You don't even know me. So that doesn't really play a big role in my life, but, you know, it still hurts your feelings," P2).

When asked what he was least comfortable with about getting help, one participant responded with a summary of personality characteristics that presented a barrier for him in accepting help or asking for help: "It's...I don't know whether it's...you could chalk it up to arrogance or chalk it up to a belief in self-reliance. Maybe those are two angles of the same situation. I don't know. I like to do things for myself" (P4). Of note, the same participant relied heavily on his wife to seek out resources and, when talking about going to ASD-related events and meetings, he commented that "This was all my wife making this happen. I mean, it wasn't me doing it. I get dragged into meetings and I participated. But I wouldn't have gone on my own" (P4). This dynamic emphasizes the importance of social support, and even though this participant did not prefer to seek out resources, he did exhibit a willingness to attend meetings and engage with providers at appointments. The impact of personality traits on outcomes is related to context and other variables.

Acceptance and adaptability. In all of the interviews, there was evidence that these parents had shifted toward adopting an attitude of adaptability and acceptance about their child's ASD or about life in general. Within one mother's interview, the process of moving towards acceptance emerged as she spoke about her thoughts and feelings at various points over the past few years. She started out by saying the following: "At that point, I was seeing a psychologist myself because I was trying to finish grad school and dealing with all this stuff that was going on with him. And fell apart myself and, um, but after the diagnosis, things of course got worse instead of better at first." Then she continued with the following: "You know, within a year it got to be that we weren't cringing at some of the things anymore. We were, I guess, sort of accepting

that he was different. Um, that he just had different ways of expressing himself and of doing things. And of, um, just started to manage things a little bit better.” Finally, she said the following: “We’ve come miles. We have miles to go but things are so much better than they were.” (P6)

This mother’s ability to articulate these varying experiences was helpful in identifying potential phases of acceptance that parents may go through. Phases indicated included a period in which one’s situation may feel more overwhelming before or after diagnosis, a period when one has begun to accept the reality of their child’s ASD, and finally a reflection on how far one has come and feeling satisfaction with one’s progress. It is important to remember that there are many variations of this progression towards adaptability and acceptance, and the above description is included as one such example. Other examples of the process of moving toward acceptance are provided in the following interview excerpts:

- “You have to be able to understand that you cannot control everything anymore. And all those experiences, sooner or later, are going to let you change. If you, if you, don’t follow by the rules, then I don’t know how the adult is going to survive. Because Autism is a tragedy. If you have a severe autistic kid, it’s a tragedy. Your life is never going to be the same.” (P5)
- “My husband, was like tremendously nervous. I was tremendously nervous. And we really felt like we had no alternative. Um you know to...it was our child. And we’re just going to do what we needed to do to get her the help that she needed. So you know I did it.” (P8)
- “I used to be so self-conscious about it at first but over the years I kind of stop noticing it. ‘Cause it’s like whatever. It is what it is.” (P1)

Research and education. Almost all participants (seven of eight) described using research and education as a coping strategy. This research was done both online and in-person with community members who were familiar with ASD resources. For instance, this parent described both methods when she said, “I just put it in Google and Googled and Googled it. Start talking to people, and then I kept Googling” (P1). Successful use of research and education was often linked to success as a parent. For example, one participant said, “I guess if I would say what my successes as a parent is, getting her the resources that have been able to get her to that place” (P8). Use of research and education was linked to better relationships with providers and access to formal and informal social support. One parent reported the following about her relationship with her son’s pediatrician: “My relationship with my doctor is a little bit from colleague to colleague. So when I go to her, I do not ask naïve questions. I ask questions based on something that I already read. I already searched. I already studied” (P5). In this example, there is pride associated with asking good questions.

The tenacity and determination needed to engage in research and educational pursuits seems to stem from personality characteristics of the parent present prior to their child’s diagnosis with ASD. For example, one mother said, “I, my personality is, ‘This is the situation.’ I need to read and educate myself as much as humanly possible to understand how I can support him. And talk to as many people as possible so that I am okay. I’m doing what I can to make things easier for him” (P2). Of all the coping strategies discussed within this project (including self-care, adaptability, and reliance on personality traits), research and education are the most directly related to other themes, including *resources* and *social and community support*. This relationship and overlap with other themes highlights the importance of research and education for families of youth with ASD.

CHAPTER 4

DISCUSSION

A growing body of research attempts to understand the experience of caregivers of those with lifelong disorders. The current study investigates parents of youth with ASD from the perspective of predicting and promoting caregiver HRQOL. Results demonstrate that HRQOL was significantly predicted by several demographic variables, including total annual household income, age of parent, and age of child with ASD. HRQOL is likely to increase when total annual household income increases, decrease when age of parent increases, and increase when age of the child diagnosed with ASD increases.

These findings are consistent with previous research showing that household income improves access to resources for the child with ASD as well as the larger family. Also, as parents age, they are more likely to experience personal age-related health problems, so it is reasonable to assume that increasing age will predict decreasing HRQOL in ways perhaps independent of child's diagnostic status and needs. Previous research has demonstrated that as children with ASD grow older, their externalizing behaviors decrease or lessen in intensity (Shattuck et al., 2007). Thus, as a child's behavioral difficulties decrease, the improved HRQOL of the parent reflects the lessening of demands of intervening with overt behaviors. Furthermore, as documented in the qualitative component of this study under the theme of *stigma*, stigmatization that parents experience often originates from bystander reactions to their child's externalizing behavior. As their child grows older, it is possible that parents perceive decreased stigma, and this relief from perceived stigma has a positive impact on their HRQOL. Interventions aimed at improving parental health and well-being should focus on parents most at risk for lower

HRQOL. This means reaching out to older parents, parents of young children, and families with fewer socio-economic resources.

Additionally, being male (rather than female) was predictive of higher HRQOL. This finding is consistent with previous research showing that mothers of children with ASD experience more stress, feel more involved in their child's activities of daily living, and feel the need for more resources than fathers of children with ASD (Tehee et al., 2009). The finding that being male predicts better HRQOL is a new finding that adds to the conversation about what impact gender has on parental well-being.

Results also demonstrated that the following study variables were significantly predictive of HRQOL: perceived burden, tangible support, and maladaptive coping. HRQOL is likely to increase when parents have lower levels of perceived burden, higher levels of tangible support, and lower levels of maladaptive coping. Parents who utilized a maladaptive coping style (e.g., turning to alcohol or drugs, giving up, denying the current situation, self-critical or self-deprecating internal and external dialogue, and/or blaming oneself) had lower HRQOL. Providers can assess for coping strategies and potentially offer psycho-education about adaptive coping strategies, such as problem-focused coping, if it would be helpful and appropriate within the context of the interaction.

Participants who perceived that they were burdened by their role as a caregiver of a special needs child were at greater risk of having lower HRQOL. These individuals reported experiencing physical, psychological, emotional, social, and/or financial problems related to parenting a child with ASD. The relationship between burden and QOL was not found to be significant in a previous study (Khanna et al., 2011). Thus, the impact of perceived burden on HRQOL in this study is an important advancement in clarifying the potential variables

contributing to HRQOL as opposed to overall QOL. As noted earlier, burden has been found to have a direct and negative impact on health (Sapolsky, 1998), and this study supports that link within this specific subsample of parents of youth with ASD.

The quantitative finding that perceived burden predicts decreased HRQOL juxtaposes findings of the qualitative component of this study, which found that caring for a child with ASD has an impact on emotional functioning, contributes to strain in relationships, and can raise pragmatic concerns (e.g. concerns related to time, money, scheduling, and insurance). These findings make sense considering the daily accommodations that need to be made when adapting to the needs of a child with special needs, as well as the often unavoidable financial burden placed on families who want to engage their child in efficacious interventions. These findings should be used as a reminder that parental perception of burden can contribute to their HRQOL. Providers can assess for perceived burden as an indication of larger concerns and the potential need for a referral to specialty mental health services or supportive community services.

There were several important points in which the qualitative and quantitative data converged to emphasize a particular variable as highly important in the lives of parents of youth with ASD. One such example is the identification of tangible support in the quantitative analysis and the subsequent discussion within the qualitative component of *resources*. Tangible support refers to the type of social support that solves problems and offers concrete sources of assistance in times of need. For instance, getting a ride when your car is broken down or being able to ask a friend for a ride to the airport are examples of tangible social support. Within this study it was shown that tangible social support not only offers daily experiences of accommodation and aid but is also predictive of increased HRQOL. The knowledge that one will be supported in times of need had a positive overall impact on HRQOL.

As identified through the qualitative portion of this study, raising a child with ASD can be both extremely challenging and also extremely rewarding. Several parents said that if they could take away their child's diagnosis, they would not. Some themes that captured this positivity include *successes of child*, *self-care*, *relying on personal characteristics or traits*, *acceptance and adaptability*, and *research and education*. These findings support the idea that the ability to take action through research or education, use self-care strategies, seek out support, adapt to rather than resist change, and/or look at the “something good” can have a direct impact on the daily lived experience of a parent of a child with ASD.

While these findings were identified through qualitative analysis, only one variable (tangible support) was found to have a significantly positive impact on HRQOL in the quantitative analysis. These positive psychological concepts were purportedly represented in the study questionnaire with the inclusion of the following variables: positive aspects of caregiving, adaptive coping style, help-seeking coping style, tangible support, belonging support, and appraisal support. The discrepancy between the qualitative and quantitative analysis with regards to positive psychology-related variables could indicate that the experiences of parents are not being captured through quantitative questionnaires alone. Another potential reason for the discrepancy could be that the outcome variable, HRQOL, is affected by tangible support but is not as impacted by the other variables. Other outcome variables, such as psychological quality of life or general quality of life, may be more closely impacted by the positive experiences of parents. Future studies should expand the range of outcome variables when studying QOL for parents of youth with ASD while continuing to include positive psychology variables. Additionally, efforts should be made to ensure that questionnaires reflect the language used by parents to talk about these variables so that findings are representative of their actual

experiences. This integration between the narrative experience of parents and the language used to word items within questionnaires will necessitate the use of further qualitative research with parents of youth with ASD.

In addition to positive variables, many barriers to promoting HRQOL were identified in the qualitative component. These barriers are demonstrated within the following themes: *misperceptions and hostility, lack of information about ASD on the part of others, sacrifices, stigma, dissatisfaction with resources, pragmatic issues related to resources, lack of informal and/or formal social support, strain on relationships, and challenges for the child.* It is apparent that the experience of parenting a child with ASD can have an impact on one's mental health and emotional functioning, schedule, relationship with others, daily interactions with strangers, and many other things in a way that others likely do not consider or may simply take for granted. It is important for healthcare providers and other sources of formal support such as teachers and day care or respite care providers to incorporate validation and positive reinforcement of parents into interventions, even if the intervention is predominately aimed toward the child. Based on previous findings that compare the mental health of the parent with the success of the child (Giallo et al. 2013; Osborne et al., 2008), it is apparent that these small efforts to boost morale and resiliency of caregivers will benefit the efficacy of interventions with the child.

It is important to remember that parents described feeling stigmatized in several ways, including a lack of information about ASD on the part of others, misperceptions made by others, and hostility directed toward them. These actions and attitudes were perpetrated by close others (e.g., family members, friends, spouses, and providers) as well as bystanders or strangers. It is more straightforward to discuss how the results of this study can be used to guide and inform the actions and attitudes of professionals who work with parents of youth with ASD. However,

having an empirically-based conversation about changing the actions and attitudes of the larger community to increase knowledge and decrease misperceptions and hostility is also a valid and vital pursuit that could be initiated in response to this study.

Major benefits of including both quantitative and qualitative methods within this study are breadth and depth. I was able to engage a large sample of caregivers of youth with ASD in the overall research project through the quantitative component, while also expanding the depth of understanding about the lived experience of caregivers in their own words through the qualitative component. Of note, there were limitations of this study that I would also like to address. Firstly, a self-selection bias exists within this sample. Participants self-selected to be included in the UNC-TEACCH database that was used for solicitation. In addition to that initial self-selection, they also self-selected to participate in this particular study when the solicitation email was sent to them. Thus, those parents sampled may not be representative of all parents of youth with ASD.

Generalizability may be further limited because the sample is not representative of the entire population of parents of youth with ASD. This study's sample over-represented Caucasian caregivers (80% of total sample) and parents of older children (with the average age of child being 10.8 years old). Also, all participants were living in the state of North Carolina at the time of their child's diagnosis of ASD through the UNC-TEACCH center. Thus, there are many state-specific references made in the qualitative interviews that may not generalize to other states. In a general sense, the lack of consistency across states in terms of ASD-specific resources available is a limitation.

Secondly, the original intention for data collection was to include a standardized adaptive behavior score as a control variable. However, when participants completed the online survey, it

became apparent that in the majority of cases in which parents left blank the answer to this question, they simply did not recall this number and/or did not have ready access to their child's comprehensive diagnostic report to obtain it. Hopefully future researchers will have access to the medical history of the child with ASD, thus mitigating this limitation. This study could be replicated with the inclusion of an adaptive behavior score in order to determine the predictive power of adding it to existing variables.

Thirdly, the primary investigator of this study was the singular interviewer of participants for the qualitative component. The consistency of utilizing a semi-structured interview guide with a singular interviewer is a strength of this approach and decrease the likelihood of inter-interviewer differences confounding thematic analysis results. However, the individual variables of the interviewer such as tone, speech volume and speed, and style (such as such of silence and reflection of participant's answers) could also be seen as a limitation in that they are not perfectly replicable, and another interviewer may have elicited different responses from interview participants.

Finally, while the regression model accounted for 28% of variance in HRQOL, there is still room to further explore and predict variables that contribute to HRQOL of parents of youth with ASD. Finally, this study lacks a control group of parents of children without an ASD diagnosis. My hope is that, through my contextualization of these findings within the existing empirical literature base, I have moved in a helpful direction towards this study's purpose of predicting and promoting HRQOL of parents of youth with ASD while also describing their experiences in depth. However, future researchers could compare these findings to other groups, including a control group, in order to exhaustively document the varying presentations of parental HRQOL across conditions.

In spite of the limitations, the results of the quantitative component of this study deepen the understanding of how to predict HRQOL in parents of youth with ASD, and the results of the qualitative component deepen the understand of how to promote HRQOL in parents of youth with ASD. In conclusion, this study found that HRQOL, an important domain in quality of life, can be predicted by measuring burden, maladaptive coping skills, and tangible support. These findings provide support for caregiver interventions that screen for perceived burden and current coping strategies and offer increased access to tangible support. Taken together, the findings of this study demonstrate the impact that raising a child with ASD can have on the lives of parents as well as the continued need to innovate and expand the offerings of supportive services available to parents of youth with ASD.

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APPENDICES

Appendix A

Semi-Structured Interview Guide

“What has your experience been like as a parent of a child with Autism?”

“What have some successes been?”

“What have some difficulties been?”

“What contributes to your quality of life?”

“If you feel as though you need help, would you reach out for it?”

“Who would you most likely turn to?”

“What kind of help would you feel most comfortable with?”

“What help would you feel least comfortable with?”

“Have you ever been to a support group?”

“What would it be like going to a support group?”

“Have you ever been to a therapist?”

“What would it be like going to a therapist?”

“Have you ever been offered help by your primary care provider?”

“What would it be like if your primary care provider offered help?”

“Have you ever been offered help by your child’s pediatrician?”

“What would it be like if your child’s pediatrician offered help?”

“Is there anything I haven’t asked you about yet that feels as though it’s important for me to know?”

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