RESOURCES AND QUALITY OF LIFE IN CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

by

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Participants were 23 caregivers of children between the ages of four to twenty-two years old who are diagnosed with autism spectrum disorder and attend the Autism Society of North Carolina (ASNC) Social Recreation program in Winterville, Wilmington, and Newport. The present study evaluated the quality of life in parents of children with autism spectrum disorder, as well as the utilization and availability of resources for their child and the family. Data was collected using an online Qualtrics survey sent out to families by email. The survey consisted of questions regarding demographics, questions from the *Questionnaire for Each Treatment* regarding the treatments their child with autism receives, and questions from the Family Quality of Life Scale by the Beach Center on Disability. Overall results revealed that parenting is the most satisfying domain of quality of life, and disability related support was the least satisfactory for the parents. Results suggest that families with disability need to identify and enroll their children in early intervention programs and recreation program that help with children's development. The government and school programs should also strive to offer educative sessions for parents and families with children with autism to enhance their contribution outside of school hours.

RESOURCES AND QUALITY OF LIFE IN CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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TABLE OF CONTENTS

TITLE PAGE i

COPYRIGHT.. ii

SIGNATURE PAGE iii

ACKNOWLEDGEMENTS iv

LIST OF TABLES vii

CHAPTER 1: INTRODUCTION………………………………………………………1

Purpose…………………………………………………………………...….1

CHAPTER 2: LITERATURE REVIEW……………………………………………….3

Theoretical Perspective……………………………………………………3

Autism Spectrum Disorder……………………………………………….3

Autism in an Ableist Society…………………………………………….....6

Autism in the Family……………………………………………………....9

Quality of Life……………………………………………………………10

Impact on Marriage………………………………………………………12

Supports to Sustain Marital Satisfaction…………………………………15

Resources for Autism and the Family……………………………………16

Limitations and Assumptions……………………………………………18

CHAPTER 3: METHODS…………………………………………………………….19

Participants…………………………………………………………………19

Instrumentation…………………………………………………………….19

Procedures………………………………………………………………….20

Data Analysis……………………………………………………………….21

CHAPTER 4: RESULTS……………………………………………………………...24

Research Question 1…………………………………...…………………...…25

Research Question 2……………………………………………………......………..26

Research Question 3……………………………………………………...………..30

Summary……………………………………………………………..………....32

CHAPTER 5: DISCUSSION……………………………………………………….………33

Implications of Study…………………………………………………..………..34

Limitations……………………………………………………………...………..…35

Recommendations………………………………………………………...…..…36

REFERENCES…………………………………………………………………………..38

APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL …………………………44

APPENDIX B: CAREGIVER SURVEY………………………………………………..46

APPENDIX C: TABLES…………………………………………………………..……59

LIST OF TABLES

1. Deficits in Social Communication and Social Interaction Across Multiple Contexts (Centers for Disease Control and Prevention, 2020)…………………………..……….4
2. Restricted, Repetitive Patterns of Behavior, Interests, or Activities (manifested by at least two of the following) (Centers for Disease Control and Prevention, 2020)…………..…...4
3. Quality of Life Depends on Experiencing Connectedness in Six Interrelated Domains: (IDEA Authors, 2009)…………………………………………………..………….12
4. Demographic Characteristics……………………………………………..…………25
5. Research Questions (Appendix C)……………………………………….………59
6. Family Quality of Life Scale Domains (Appendix C)……………………..……..……60
7. Descriptive Statistics……………………………………………………………..26
8. Thematic Analysis……………………………………………………………….27
9. ANOVA………………………………………………………………………….31

CHAPTER 1: INTRODUCTION

Autism Spectrum Disorder (ASD) is a life-long developmental disorder in which communication, behavior, and social interactions are impaired. For many people with autism spectrum disorder and their families, daily life may not be easy due to persistent symptoms and behaviors. However, finding resources and planning for the future can help families improve their quality of life. Meeting the complex needs of a person with ASD can put families under a great deal of stress—emotional, financial, and sometimes even physical. There are many studies that research the effect having a child with autism spectrum disorder has on the parents, specifically in terms of their quality of life. Several studies measure marital satisfaction in parents with children with and without ASD (Hartley et al., 2011; Hartley, et al., 2012). While some research studies show no difference in adverse effects, many found that parents of children with ASD experience stress when their child has behavior challenges which often impacted marital interactions (Hartley, et al., 2011; Hartley, et al., 2012). Stress from their child's behaviors can also create a more difficult time adapting to parenthood and showing affection toward both their children and partner/spouse (Harper, et al., 2013). The connection between the child's diagnosis in relation to the parent's quality of life can determine what resources could be put in place for families, as well as understand the factors that contribute to providing support while parenting a child with autism. Exploring resources put in place for the child's and family's needs can help us understand how they impact family's quality of life.

Purpose

This study seeks to explore the quality of life in parents of children with autism spectrum disorder, as well as the utilization and availability of resources for their child and the family. There are countless empirical research studies on the autism spectrum disorder alone - the symptoms, behaviors, and intervention treatments – however there is little research on how to assist caregivers of children on the spectrum. With the aim of parents' quality of life, the purpose is then to identify what resources are available and lacking for parents and caretakers of children with autism. This study is guided by three research question:

1. What domains of quality of life do parents of children with autism rate as being most and least satisfied?
2. What resources have been or could be helpful in supporting families of children with autism?
3. Is there a significant mean difference between the child's functioning level and the family's quality of life domains?

CHAPTER 2: LITERATURE REVIEW

Theoretical Perspective

This study utilizes Reuben Hill's 1949 Family Stress Theory to explore why some families are able to thrive in the face of stress while other families end up in crisis (Rosino, 2016). Researchers first started studying this idea during the Great Depression to better understand how families dealt with the stress associated with unemployment. Reuben Hill first introduced the family stress theory as he studied family adjustment to crisis caused by separation and reunion during wartime. With this came the creation of Hill's ABC-X model where A = stressor, B = resources, C = perception of the stressor and resources available, and X = outcome/crisis. Some families are able to cope effectively and avoid crisis, but others do not have or do not believe they have, the needed resources to work through stressful situations. Stressors are discrete life events or transitions that impact or have the potential to impact, families. Stress itself is neither positive nor negative; it becomes one or the other based on how the family perceives the situation. Resources can be both internal such as coherence, communication, shared goals, adaptation, and coping skills, and external such as social support (Smith & Hamon, 2017).

Autism Spectrum Disorder

According to the Center for Disease Control, "Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant social, communication, and behavioral challenges" (Centers for Disease Control and Prevention, 2020). The American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-5) provides standardized criteria to help diagnose ASD. To meet diagnostic criteria for ASD according to DSM-5 (American Psychiatric Association, 2013), "a child must have persistent deficits in each of three areas of social communication and interaction, plus at least two of four types of restricted, repetitive behaviors" (Centers for Disease Control and Prevention, 2020). These deficits are elaborated in both Table 1 and Table 2 below.

Table 1

Deficits in Social Communication and Social Interaction Across Multiple Contexts *(Centers for Disease Control and Prevention, 2020).*

Deficits in social-emotional reciprocity	Reduced sharing of interests, emotions, or affect; failure to initiate or respond to social encounters; abnormal social approach and lack of normal back-and-forth conversation
Deficits in nonverbal communicative behaviors used for social interaction	Irregularities in eye contact and body language, or deficiencies in understanding and use of gestures; to a complete lack of facial emotions and nonverbal communication
Deficits in developing, maintaining, and understanding relationships	Difficulties adapting behavior to different social circumstances; difficulties sharing imaginative play or developing friends; lack of interest in peers

Table 2

Restricted, Repetitive Patterns of Behavior, Interests, or Activities (manifested by at least two of the following) *(*Centers for Disease Control and Prevention, 2020*).*

Stereotypes or repetitive motor movements	Use of objects, or speech (ex. Simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases)
Insistence on sameness	Routines that are rigidly adhered to, or ritualized patterns of verbal or nonverbal behavior (ex. Extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day)
Highly restricted, fixated interests	Intensity or attention that is abnormal (ex. Strong attachment to or preoccupation with

	unusual objects, excessively circumscribed or perseverative interests)
Hyper or Hypo reactivity to sensory input	Unusual obsession with sensory parts of the surroundings (e.g., seeming indifference to pain/temperature, negative reaction to specific noises or textures, obsessive smelling or touching of objects, visual fixation with lights or movement)

Other components of an autism spectrum disorder diagnosis include that early developmental signs must be present (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life). The symptoms of the child also produce clinically substantial impairment in social, occupational, or other areas of present functioning. Social communication should be below the expected level for the general developmental level to make comorbid diagnoses of autism spectrum disorder and intellectual disability (Centers for Disease Control and Prevention, 2020).

The autism diagnosis of a child can have a variety of effects on the entire family. Parents and caregivers may devote a large amount of time and energy to assisting their child with ASD, which may create strain on their marriage, other children, employment, finances, and personal relationships and duties (Autism Society, 2020). Parents can assist their family by telling their other children about autism and the complexities it brings, understanding and assisting siblings with the challenges they experience, and incorporating extended family members to create a network of support and understanding (Autism Society, 2020).

In a 2020 study done in Croatia, when parents were interviewed on their daily life with autism, nearly all respondents reported experiencing fulfillment caring for their child on all ends of the autism spectrum. The demands of autism were largely accepted by parents, with family life centered around the child. Parents spent a significant amount of time (and money) taking their children to a variety of private therapies, such as occupational therapy, sensory integration therapy, speech therapy, and neurofeedback therapy, in addition to implementing interventions themselves (Stošić et al., 2020). Croatian parents interviewed spoke of the mixed feelings that they experienced, wanting simply to be a parent to their child with autism, while at the same time feeling pressured to focus on maximizing development (Stošić et al., 2020). Maximizing your child's development can not only be taxing mentally, but also financially. Families with autism frequently face financial difficulties (Sharpe & Baker, 2007), and more than 70% of respondents acknowledged financial difficulties as a result of their caregiving responsibilities. For example, families in Croatia may also be paying for private therapies, educational support in the classroom, while systemic issues (e.g., applying for disability money) were a further source of difficulty. While 94% of parents experienced fulfilment caring for their child, they commonly experienced ableism within their environment. When describing their experiences of ableism, parents described how their children were excluded from social occasions such as birthday parties – "they would invite the whole class, except him...," they said – as well as bullying and abuse from other children (Stošić et al., 2020, p. 214).

Autism in an Ableist Society

Ableism is a term that refers to ideas, practices, institutions, and social connections that assume able-bodiedness and, as a result, depict people with disabilities as marginalized, oppressed, and largely invisible 'others' (Chouinard,1997). Whether deliberate or not, ableism is a way of life that takes mobility, thinking, speech, and the senses for granted, as well as a largely "unconscious" dislike to individuals and bodies that remind us that the able-bodied standard is an ideal—that we are all mortal and prone to disease and death. An ableist society, on the other hand, is one that tends to devalue its non-able-bodied individuals, despite many people's sincere intentions to regard these 'others' as equals (Chouinard, 1997).

As more genetic and neurobiology research has been done on autism spectrum disorder, some individuals with autism and their parents are dissatisfied with the increase in research on genetic susceptibility of autism rather than the quality of life and challenges they encounter (Pellicano & Stears, 2011). However, some families see this increase in scientific research as a positive in answering more questions about their child with autism and providing a "breakthrough" in not only understanding their child but the diagnosis (Pellicano & Sears, 2011). Although there is currently no genetic test for autism susceptibility, some people are concerned that rapid advances in genetics and neuroscience research could influence the development of a test to detect autism during pregnancy, allowing parents to terminate a pregnancy (Pellicano & Stears, 2011). These genetic testing breakthroughs can be impactful in these parents' marriages as well. If a couple finds out that their unborn child may have autism, that may create strain on the relationship if one partner decides they don't want that child anymore, but the other does. (Pellicano & Stears, 2011).

Social and ethical concerns of having a child with ASD are the direct consequence of a far deeper ethical divide between many researchers and members of the autistic community. These autistic self-advocates want to debunk ideas about "cure and prevention" as well as "normality and deviance" (Shapiro, 1994, as cited in Pellicano & Stears, 2011). They have promoted the concept of "neurodiversity," in which autism is viewed as one of many different cognitive styles or modes of interaction among a "diversity of minds" (Pellicano & Stears, 2011). Advocates for people with autism have also pushed for a more socially inclusive perspective of disability. This perspective recognizes that while some people may have an unusual combination of physical and/or cognitive properties that makes performing a variety of basic daily functions challenging, such challenges only result in acute "disability" if society is structured in a way that neglects to meet the needs or requirements of this community (Pellicano & Stears, 2011). Consistent with this view, the American Association on Intellectual and Developmental Disabilities insists that professionals should acknowledge both that strengths and weaknesses co-occur in cognitive disabilities, such as autism, and that the community environment shapes the capabilities of all individuals (Buntinx & Schalock, 2010). As such, efforts to "cure" or "prevent" an individual's specific configuration of physical and cognitive characteristics without their consent can be seen as discrimination. In this perspective, difficulties that individuals with autism experience are directly attributed to arising from their own "condition," rather than the changeable nature of the social world around them. Furthermore, the quest for cures and preventive measures, as well as efforts to make individuals more "normal," can be detrimental to a person's self-worth (Pellicano & Stears, 2011).

This prevalent ableism in society is challenging for not only the individual with the disability, such as autism, but also the parents and family of said individual. As parents of a child with autism, you are always advocating for them and their rights, and that can become mentally, emotionally, and physically draining. Ableism can also be seen within the family itself, whether it's organically there from the start or seeped its way from the outward society. Parents can unconsciously be ableist towards their own child, be in denial of their autism diagnosis, and/or not provide them with the interventions and accommodations they need to thrive (Chouinard, 1997).

Autism in the Family

While the typical onset of autism is around two years of age, symptoms may persist and vary throughout adolescence and adulthood (Hartley et al., 2011). Since few understand the person specific symptoms of autism as well as those living with and caring for someone daily, children and their parents share a deep connection in an interchangeably powerful way through most of their lives (Hartley et al., 2012). Depending on the child's symptoms and behaviors, there is a high probability that parents of children with ASD will experience higher stress levels and lower marital satisfaction (Harper et al., 2013). Children with autism with externalizing behaviors can consume much of his or her parents' energy (Sikora et al., 2013), and this need for constant supervision can be exhausting for some caregivers. Many parents of children with autism may not have the extra time or energy to tend to things such as their marriages or their personal hobbies, which can have a profound effect on the entire family, both positive and negative (Reichman et al., 2007). Since a lack of social communication is often prevalent in children with autism, their caretakers are found to be more stressed than caretakers of children with Down Syndrome or other developmental disabilities (Alon, 2019).

Having a child with a disability can take a toll through time and financial costs, physical and emotional demands, and logistical complexities. Impacts such as these will most likely depend on the type of condition and the severity, as well as the physical, emotional, and financial stability of the family and the resources that are available (Reichman et al., 2007). A typically or non-typically developing child's ability to adapt is influenced significantly by their parent's marital relationship and stress levels (Papp & Hartley, 2019). Therefore, it is imperative to understand the factors related to quality of life and how a child's ASD diagnosis affects these factors, so parents can receive the support they need to live happy, fulfilling lives for both themselves and their children.

Despite facing ableism in their environment, parents are able to view the positive side that having a child with a disability can broaden horizons, increase family members' awareness of their inner strength and their cohesion, and encourage connections to community groups (Reichman et al., 2007). Having a child with autism spectrum disorder may open parents up to new perspectives on life, such as increased sensitivity, opportunities to learn, improved family dynamics, increased confidence, and assertiveness (Myers et al., 2009). Having a child with ASD can also be a source of a parent's joy or happiness, especially in the celebration of the parental role, including celebrating the rewards of children's small gains and appreciation of the child's achievements (King et al., 2012).

Meaning-making is a central aspect of coping with adversity. A search for meaning has been found to aid the coping of families faced with medical challenges and disabilities of various kinds, and resilient families are the ones who make meaning out of adversity (Myers et al., 2009). These families had learned important lessons, including a shift in the meaning of life, making positive meaning of disability, becoming united and closer as a family, coming to appreciate small things, and experiencing a spiritual awakening or strengthening (Myers et al., 2009). Meaning-making, along with individuals own resiliency, may also be contributing factors to parents’ quality of life.

Quality of Life

Quality of life is a frequently used phrase that focuses on a person's "connectedness" in several domains (Archer, 2007 pg. 90). The traditional medical model presumes that everyone possesses their own form of quality of life, but it diminishes over the years from disease, disability, and other negative conditions (Archer, 2007). Quality of life is something that can be created or lost over time, particularly remaining actively engaged in optimizing your quality of life over the years without constraints from events or conditions you cannot otherwise control (Archer, 2007).

Family quality of life (FQOL) is defined as 'a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual- and family-level needs interact' (Zuna et al. 2010, as cited in Pozo et al., 2014, pg. 443). Bayat (2005) looked at how parental perceptions of the child's handicap affected FQOL in a study of parents of children with autism. The findings revealed that family perceptions of autism's positive benefits (e.g., autism brought the family closer and stronger) were the strongest predictors of FQOL. Both FQOL and well-being are positively correlated with a sense of coherence (SOC). Parents with a high degree of SOC are happier with their FQOL and have better psychological well-being (Pozo et al., 2014). Social support has a beneficial relationship with FQOL for both mothers and fathers. Parents who believe they have enough social support to manage the responsibilities of childcare are more likely to have a higher FQOL (Pozo et al., 2014). Receiving meaningful and suitable help in everyday life is likely to increase parents' perceptions of a better FQOL for their children with ASD. Mothers and fathers both have different relations when it comes to their FQOL and their child's severity of their disorder. The severity of the disorder typically has a negative relation to FQOL for mothers, and a positive relation for fathers (Pozo et al., 2014).

Parent well-being is conceptualized in terms of mental health, parenting stress and parenting efficacy (Kersh et al., 2006). Behavior problems in children had a high correlation with negative feelings about parenting. This is likely exacerbated by the fact that parents have less time to spend time with each other or to pursue outside hobbies. It seems to be just as important to evaluate a parent's feelings about their child and their overall happiness as it is to assess the behavioral issues (Sikora et al., 2013). The six interrelated domains of quality of life are outlined below in Table 3.

Table 3

Quality of Life Depends on Experiencing Connectedness in Six Interrelated Domains: (IDEA Authors, 2009)

Metaphysical Domain	self-esteem, self-determination, cognition, purpose, optimism, and life satisfaction.
Spiritual Domain	prayer, worship, fellowship and meaning
Biological Domain	functional capacity, physical comfort, health promotion and health maintenance.
Interpersonal Domain	social support, interpersonal dynamics and cultural dynamics.
Environmental Domain	socioeconomic status, transportation, assistive devices, safety and aesthetics.
Societal Domain	one's personal social system and the global societal system.

Impact on Marriage

Multiple sources have found that parental stress; parental resources such as the perception of coherence, control, and social support; parental adjustment including marriage quality; and the child's symptoms seem to be the overarching factors affecting marital satisfaction (Harper, et al., 2013; Papp & Hartley, 2019; Siman & Kaniel, 2010). The encyclopedia of social psychology defines marital satisfaction as "a mental state that reflects the perceived benefits and costs of marriage to a particular person" (Baumeister & Vohs, 2007, p. 541). The more costs a marriage partner inflicts on a person, the less satisfied one generally is with the marriage and with the marriage partner. Similarly, the greater the perceived benefits are, the more satisfied one is with the marriage and with the marriage partner. Several studies measured marital satisfaction in parents with children with and without ASD and found that while some results show no positive or negative difference in adverse effects, many found that parents of children with ASD experience stress from the uncertainty and level of their child's behavior problems often impacted marital interactions (Hartley et al., 2011; Hartley, et al., 2012) as well as have a more difficult time adapting and showing affection (Harper et al., 2013). Hartley et al. (2011) states that a person's spouse is typically the central source of emotional support.

Research studies have found unique variances for mothers and their marital quality in relation to parenting efficacy. While both parents experience immense stress, mothers' daily parenting stress is significantly higher than fathers', whose stress typically remains more constant (Gerstein et al., 2009). Fathers of children with ASD reported feeling less connected with their partners than fathers who had developmentally healthy children. More so, greater social support predicted increased parenting efficacy in fathers. Above and beyond socioeconomic position, child characteristics, and social support, higher marriage quality predicted reduced parenting stress and fewer depression symptoms for both mothers and fathers (Kersh et al., 2006). Reduced daily parenting stress was linked to the well-being of both mothers and fathers, as well as a healthy father-child relationship. The well-being of mothers and both parents reported marital adjustment, on the other hand, had no effect on fathers' daily parenting stress trajectory (Gerstein et al., 2009). Although individual parent qualities and high-quality dyadic connections help parents of children with disabilities develop resilience, parents can influence each other's more robust adaptations in unexpected ways (Gerstein et al., 2009).

In a 2012 study on parents of children with autism, researchers observed parents using the tag-team approach. This approach captures the change in focus of their relationship as well as the way that partners shifted their interactional patterns to meet the needs of their child (Hock et al., 2012). This tag-team approach strengthened the parenting system and increased family structure and routine. However, what really helped the parents' couple relationship was working on their deeper intimacy and commitment with each other. Parents adopted a belief that tending to their marital relationship was beneficial to their children, an example of this is working on spending alone time together (Hock et al., 2012). Parents' realizations propelled most parents to make a renewed commitment to each other as intimate partners. These changes reduced conflict and helped partners to cope with stress together rather than individually. Partners perceived that their marriage had not only survived but that parenting a child with ASD had actually strengthened their relationship, as well as confidence in the resilience of their marital relationship (Hock et al., 2012).

In a 2009 research study, parents stated that having children with autism taught them about unconditional love and made their marriage stronger than any marriage they knew (Myers, 2009). Parents mentioned that their child with ASD taught them compassion, tolerance, patience, and joy for each other. Having a child with autism has also taught parents to appreciate the smaller details in life, slow down and take each day as it comes, and not take moments for granted (Myers, 2009). Parents have learned to enjoy life a little more and shift their priorities to being happy, having fun, and appreciating each milestone. For those that are religious, almost every mention of spiritual life was a positive statement of the spiritual meaning that parents had drawn from having a child with autism; some felt that God had sent this special child to them and that they have enriched their spiritual lives in general (Myers, 2009).

Supports to Sustain Marital Satisfaction

Social support has been shown to be instrumental in helping parents adjust and adapt to the challenges that come with having a child with a disability (Alon, 2019). A strong marriage will result in both individuals feeling understood and accepted by the other, which in turn will make them feel more confident in their ability to parent effectively (Hock, R. M., Timm, T. M., & Ramisch, J. L., 2012). In order to foster that sense of control, parents must rely on others to offer support (Siman & Kaniel, 2010). Harper et al. (2013) supports the claim that external support increases marital quality. For instance, that utilizing even one additional hour of respite care per week can allow the parents to reconnect, communicate, and share common goals, which can significantly increase marital quality (Harper et al., 2013). A major way to help parents of a child with autism is through early intervention. Since parental struggle directly after diagnosis is high, early intervention can help set them up for long-term success. In addition, interventions that focus on couples' strengths, while teaching them to become more resilient, can be invaluable (Sim et al., 2019).

A sense of cohesion and control is necessary for one's ability to cope with the various stressors a parent of a child with ASD may experience (Siman & Kaniel, 2010). It is important that couples have shared ideas about marriage established prior to having children since this helps couples develop strong foundations for their relationships. Research has further shown that married couples who have children with autism should share common perceptions about factors that help to keep their marriages strong, including communication and their previously established shared foundational ideas about marriage. Mothers have also identified time for self-care as both an importance for marital and parental satisfaction (Ramisch, Onaga, & Oh, 2013).

Resources for Autism and the Family

Children with disabilities may have a wide range of educational, childcare, recreational, and social needs. They may require physical, developmental, or emotional rehabilitation through early intervention programs. Specialized education programs or facilities may be required in the future. Transition programs and specialized work training can help many people with disabilities become self-sufficient in their teen and adult years, though long-term supported employment may be required (Reichman et al., 2007).

The good news is that there are a variety of services and organizations available to assist families who have children with disabilities. Respite care, psychotherapy, parent and sibling groups, and support groups for specific conditions are all resources that directly assist family members (Reichman et al., 2007). The Individuals with Disabilities Education Act (IDEA) mandates that states establish early intervention programs that provide therapeutic, educational, and case management services to children with or at risk of developmental delays from infancy to age two (Reichman et al., 2007). State departments of education, health, and human services may be in charge of these. It also mandates that school districts provide preschool programs for children with specific types of disabilities as young as three years old, as well as free and appropriate education in the "least restrictive environment" once the child enters school age (Reichman et al., 2007). The quality of services provided to children with disabilities varies by school district, and it is all too frequent to hear of families transferring to locations with better resources for their children when they are able.

Unfortunately, in order to meet their child with a disability's sometimes complex requirements, parents must work with and coordinate benefits from a range of disparate public and private agencies (Reichman et al., 2007). The amount of help available and how generous it is varies dramatically from one location to another and over time. There is no single source of information about the resources accessible to children with disabilities, who are a diverse group with varying ages, ailments, and degrees of ability (Reichman et al., 2007). Parents must be aware of the existence of each program or service, complete a program-specific application process, reapply for services or benefits on an annual basis, and frequently wait months or years to be offered services, by which time their children may be too old to receive them (Reichman et al., 2007). In addition, programs are not always carried out according to plan. On an ad hoc basis, family support services are usually offered (Reichman et al., 2007).

The findings of a research study revealed that families with children with ASD are diverse and require tailored assistance; the findings highlight the importance of undertaking regular, systematic assessments of families' psychosocial support requirements and coping mechanisms (Zaidman-Zait et al., 2018). Screening families for informal and formal social supports and coping resources may assist in identifying vulnerable families and facilitating early referral for more targeted assessment and interventions, as needed (Zaidman-Zait et al., 2018). Resilience and well-being among families of children with ASD may be improved by addressing families' psychological needs and distributing resources and support services where they are most needed. Ungar, Ghazinour, and Richter (2013) point out that neither children nor their families are "born resilient". Children and their families are "made resilient through the many different interactions with their social and physical ecologies. These aspects of their environment depended on social policies and structures to make resources available" (pp. 360-361). The findings suggest that ASD service providers have a responsibility to fulfill both parental and child needs (Zaidman-Zait et al., 2018).

Limitations and Assumptions

Limitations of studies on the quality of life in parents of children with autism spectrum disorder often include a lack of diversity in the sample in regard to race, gender, and geographic location (Hartley, et al, 2012). Self-reporting reliability and validity also becomes a limitation in many studies done (Papp & Hartley, 2019). The consistency in variables and measures used (Siman & Kaniel, 2010), as well as the determination of causal effects (Hartley, et al., 2011) is a cause for concern in many studies. In addition, a majority of research has only included families of cis straight married parents, excluding a wide range of diverse family styles. Research has stressed the need to illustrate the value of including fathers in these studies in order to get a well-rounded view of the impact having a child with ASD has on the family as a whole (Kersh, et al., 2006). Most previous studies on this topic consist of one-time self-reporting surveys and interview-style settings, thereby providing a limited view of what marriage is like over time. It is important to also recognize the sample sizes of children with autism in these studies. Symptoms of autism cannot be generalized, and boys with ASD tend to be diagnosed and researched more often than girls (Hoefman et al., 2014).

CHAPTER 3: METHODS

This study seeks to explore quality of life in parents of children with autism spectrum disorder, as well as the utilization and availability of resources for their child and the family. Utilizing a primarily quantitative design, the study reveals how having a child with autism affects caretakers' quality of life, and more specifically, the impact resources have on children and their families.

Participants

Participants were caregivers of children between the ages of four to twenty-two years old who are diagnosed with autism spectrum disorder and attend the Autism Society of North Carolina (ASNC) Social Recreation program in Winterville, Wilmington, and Newport. At the time of the study, 39 children received services at the Winterville location, 27 at the Wilmington location, and 25 at the Newport location. Therefore, surveys were sent to 91 families (some of which contain 2 parent/caregiver households) of children diagnosed with autism spectrum disorder who attend ASNC Social Recreation and Direct Care programs. The child with autism attended or received services from at least one ASNC program including summer camp, after-school care, occasional respite care, or direct care which could include in-home care. Children attending the programs had a varying range of needs and abilities and often received additional services outside of ASNC. Of the 91 families who received the survey, 28 family members attempted the survey, and 23 family members completed the survey.

Instrumentation

Using a primarily quantitative design, the online Qualtrics survey was used to measure caregivers' quality of life in relation to the resources for their child with autism. The survey is an adaptation of existing surveys and instrumentations for parents and caregivers of children with autism. The survey is broken down into three sections containing two different scales.

The first section of the survey contains 26 demographic questions about both the caregivers and their child. The second section of the survey contains 14 questions from the *Questionnaire for Each Treatment* regarding the treatments their child with autism receives. This survey was created by The Interactive Autism Network (IAN), which was established in 2006 at the Kennedy Kieger Institute to accelerate autism spectrum disorder (ASD) related research by creating a national online registry and longitudinal research database. No research was published regarding use of the use of this survey. The last section contains 25 questions from the Family Quality of Life Scale created by the Beach Center on Disability. The Beach Center Family Quality of Life Scale (FQOL Scale) assesses families' perceptions of their satisfaction with different aspects of family quality of life. The FQOL Scale contains five subscales: Family Interaction, Parenting, Emotional Well-being, Physical / Material Well-being, and Disability-Related Support. The Beach Center FQOL Scale had successfully been used in similar research studies in the past, such as a 2009 study by Werner et al. which focused on family quality of life among families with a member who has an intellectual disability. Findings highlighted the importance of examining the overall perception of FQOL and the perceptions in individual life domains.

Procedures

After receiving Institutional Review Board approval, the director of the Autism Society of North Carolina Social Recreation program in Winterville received the Qualtrics survey link by email and distributed it through email to each individual caretaker in families that receives services through the Winterville, Wilmington, and Newport Social Recreation programs. The study was accessed utilizing the Qualtrics link and could be completed by phone, tablet, or computer with an internet access. At the start of the survey, participants were instructed on the general purpose and procedure of the study before agreeing to continue with the survey. Caretakers were also asked if their partner had or would be completing the survey, as it was encouraged for both caretakers to participate in the survey. The survey questions measured caretakers' quality of life and identified what resources they did or did not use for their child with autism and the impact resources had on their life (e.g., any noticeable behavioral improvement since starting treatment).

Data Analysis

The survey consisted of 67 questions including descriptive questions that required in-depth answers and questions with scalable answers (See Appendix B). Therefore, the study used a primarily quantitative design. Data analysis involved a combination of descriptive and inferential statistics to analyze parent's quality of life and resources.

The survey consisted of demographic questions focused on gender, ethnicity, age, education, and relationship status. The survey also included two different questionnaires, which assessed the child's treatments, the caretaker's view on treatments, and the overall family quality of life. After initial reading and re-reading of the non-scalable survey questions, the researcher did manual coding to categorize information into themes for interpretation and analysis. This included identifying and placing emerging data, themes, and ideas into groups. Significant data, themes, and ideas correlated directly to the research questions. A second graduate student reviewer examined and discussed themes then confirmed categories.

The primary coder reviewed initial coding for the research questions with the secondary coder to confirm the manual coded data and themes. Using SPSS and the Beach Center Family Quality of Life Scale, the primary coder used descriptive statistics to analyze and measure the subscales of family quality of life to determine what domains were most and least satisfied.

Manual coding was used to identify the most prevalent themes in the survey questions and the occurrence and frequency of the themes in the responses to identify the most popular replies. A one-way ANOVA test was utilized to determine if there were statistically significant differences between the quality-of-life domains and the three types of a child's functioning level. When reading the answers to the Family Quality of Life questions, the researcher used the Beach Center FQOL scoring scale. The FQOL Scale used satisfaction as the primary response format. The items were rated on a 5-point Likert scale, where 1 = very dissatisfied, 3 = neither satisfied nor dissatisfied, and 5 = very satisfied. Specific groups of data, themes, and ideas were developed into a descriptive narrative. The researcher then interpreted and analyzed this to determine the meanings and implications for having a child with autism and how that impacted a caretakers' quality of life, as well as the resources acquired, or lack thereof impact the quality of life of caretakers for children with autism. In addition, when reviewing caretakers' surveys, the researcher analyzed and matched subscales and compared means when reviewing the family's quality of life domains. Once these questions were reviewed, the researcher compiled a short list of the highest dissatisfied questions to share with the director of the Winterville ASNC Social Recreation program who could use this information to determine what available resources could be provided to the families to assist in these areas of dissatisfaction, along with the author's list of possible resources.

In order to determine areas of dissatisfaction within families, the researcher examined each of the three survey subscales through Qualtrics separately and analyzed which areas and questions resulted in the highest rate of dissatisfaction. The family quality of life domains and subscales were analyzed by reviewing the statistical means of these domains and determining if there was a statistical significance. Once the areas of dissatisfaction were analyzed, the researcher divided sections into categories of high need (very dissatisfied), moderate need (dissatisfied), and low need (low dissatisfied) to then identify areas where parents may need more resources.

CHAPTER 4: RESULTS

The primary aim of the study was to investigate the family quality of life when they have a child with autism spectrum disorder and the utilization and availability of resources for the child and their family. The results section presents the study findings and interpretation of findings based on the obtained data set. The section is organized based on the formulated research questions, as shown below.

From a sample size of 23 respondents who completed the study, majority of the respondents, 91.3% (n=21), were females, while 8.7% (n=2) were males. The respondents were also from different ethnic groups, majority, 60.9% (n=14) were white, 34.8% (n=8) were black or African American, and 4.3% (n=1) were from other ethnic origins. The participants were distributed across different age groups with the majority, 56.5% (n=13) within the age range of 35-44 years, 26.1% (n=6) were 45-54 years, 13% (n=3) were 25-34 years, and only one respondent (4.3%) was aged between 65-74 years.

Based on their education levels, the majority of the study respondents had a four-year degree 34.8%(n=8), followed by 30.4 % (n=7) with a two-year degree and 17.4% (n=4) with a professional degree. Two of the study respondents had some college education (without culminating in a degree); there was one respondent with a high school graduate education level and one had a doctorate level degree. Out of 23 parents that participated in the study, the majority were married 78.3% (n=18), 8.7% (n=2) were divorced, 4.3% (n=1) was separated, 4.3% (n=1) in a committed relationship, and 4.3% (n=1) was single. The descriptive statistics showed that the study population was not randomly or evenly distributed across respondents from different ethnicities, gender, education level and marital status which decreases the generalizability and reliability of the study findings. The demographic characteristics are outlined below in Table 4, as well as the breakdown of research questions and their perspective survey questions and analysis in Table 5 in Appendix B.

Table 4
Demographic Characteristics

		Frequency	Percent
Gender	Female	21	91.3
	Male	2	8.7
Ethnicity	White	14	60.9
	Black or African American	8	34.8
	Other	1	4.3
Age	25 - 34	3	13
	35 - 44	13	56.5
	45 - 54	6	26.1
	65 - 74	1	4.3
Highest level of education	High school graduate	1	4.3
	Some college	2	8.7
	Two-year degree	7	30.4
	Four-year degree	8	34.8
	Professional degree	4	17.4
	Doctorate	1	4.3
Relationship status	Married	18	78.3
	Divorced	2	8.7
	Separated	1	4.3
	In a committed relationship	1	4.3
	Single	1	4.3

Research Question 1: What domains of quality of life do parents of children with autism rate as being most and least satisfied?

The survey instrument assessed quality of life based on five domains, family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support (See Table 6 in Appendix B). Descriptive statistics were utilized to analyze these variables. A high mean score indicated high degree of agreement or satisfaction.

Family interaction (mean = 26.09, std. deviation = 4.08, range = 17-30) was rated high and most satisfactory by the parents on the quality-of-life domain scale. While, emotional wellbeing was considered least satisfactory (mean = 12.74, std. deviation= 4.54, range = 4-20). Table 7 enlists the descriptive statistics for each of the sub-scales.

Table 7
Descriptive Statistics

Domain	Question No	Mean	Range	Std. Deviation
Family interaction	43,49,52,53,54,60	26.09	[17-30]	4.08
Parenting	44,47,50,56,59,61	24.30	[11-30]	4.67
Emotional well-being	45,46,51,55	12.74	[4-20]	4.54
Physical/Material well-being	48,62,57,58,63	21.70	[10-25]	4.09
Disability- Related Support	64,65,66,67	16.61	[8-20]	3.65

Research Question 2: What resources have been or could be helpful in supporting families of children with autism?

Research question 2 sought to identify resources that have been or could be helpful in supporting families of children with autism. Based on thematic analysis, the researcher identified the occurrence and frequency of the themes to identify the most popular responses. There were a total of 21 responses given to open-ended question, “What resources have been most beneficial to support you as a family?”, and 23 responses to the open-ended question “What additional resources do you feel would be beneficial to support you as a family?” The most common responses for resources that were beneficial to support families of children with autism were early intervention 17.4% (n=4) and recreation program 43.5% (n=10). On the other hand, the themes that had most popular responses when identifying resources parents feel would be beneficial to support their family included resources to help with transition to adulthood 21.7% (n=5) and the need for more staff 30.4% (n=7). Below, the thematic analysis Table 8 outlines the two themes identified for both beneficial resources and additional resources recommended.

Table 8
Thematic Analysis

Most Beneficial Resources

Themes	Subthemes	N= (%)	Example
Early intervention	early speech and OT services ABA therapy, speech therapy, and occupational therapy	4 (17.4%)	“Early speech and OT services through Vidant proved to be the most helpful in progression of behaviors ….” (Respondent 3)
Recreation program	Winterville Social Rec program	10 (43.5%)	“Winterville Social Rec program is a blessing….” (Respondent 7)
Additional Resources recommended			

Resources for transition to adulthood	Respite care and transition care	5 (21.7%)	“Respite care, more options for behavioral therapy…” (respondent 19)
More staff	Accessibility of care to all patients	7 (30.4%)	“More staffing and numbers so my other daughter could receive services.” (respondent 11)

The study findings revealed that, over the years, early intervention measures provided the most beneficial support to the family of children with autism. Some of the early interventions highlighted include early speech therapy and occupational therapy services through the local hospital, which proved to be the most helpful in the progression of behaviors. Applied Behavioral Analysis therapy was also shown to be beneficial. When asked about the resources that were most beneficial to support the family, one mother of a 10-year-old boy, revealed that the "Winterville Social Rec program is a blessing. Without this after school option, either myself or my husband would not be able to work full time", six participants supported the effectiveness of the Winterville Recreation Autism Society by identifying it as the most beneficial resource for their children with autism. One mother of an 11-year-old boy added, "Autism Society Social Recreation! We love their after-school program and their summer camps. The school has a good relationship with my whole family (adults and kids), so communication is clear."

The thematic analysis table also identifies two themes from respondents' recommendations on additional resources that would be beneficial to support families with children with autism. The main themes identified were the need for resources to help the children transition from childhood to adulthood and more staffing, as explained below. The resources that were recommended to support the family and children with autism included the provision of resources to help them navigate through their transition to adulthood. One married mother revealed that she would recommend "Respite care, more options for the behavioral therapy and more support as children grow into teenage years and adulthood. An option for a developmental doctor." This recommendation was also supported by a mother of an 8-year-old boy and a mother of an 11-year-old boy who revealed that "transition care of adults with disabilities would be helpful" and provision of "future financing for when the children become adults/job market," respectively.

Respondents also revealed that there was a need to enhance resources to help them communicate and relate with their children with autism after the school and community programs. For instance, a married white mother of three with one child with autism (respondent 15) revealed, "Ideas for helping my son at home. He gets support at school and at the after-school program, but I do not know if I am supposed to be doing anything at home". This claim was also supported by a mother of two with a 10-year-old boy with autism who recommended that, “maybe some sort of class that would help us learn to communicate with our son more for times when he chooses to be nonverbal."

Moreover, the study respondents revealed there was a need for more staffing to ensure all children receive the necessary attention. Resources for families without Medicaid insurance were also recommended to ensure every child has access to services without paying high insurance premiums, deductibles and co-pays.

Research Question 3: Is there a significant statistical mean difference between the child's functioning level and the family quality of life domains?

To investigate the relationship between children's functioning level and the family quality of life domains (family interaction, parenting, emotional wellbeing, physical/mental wellbeing, disability support), a one-way ANOVA was performed. The question under investigation was; Do the quality of life domains differ based on three types of a child's autism functioning level, which include (high functioning autism, moderate functioning autism and low functioning autism). Findings from the ANOVA table revealed there were no significant mean differences in the children's functioning levels and the quality of life domains; family interaction (F (2,20)=0.525, sig. = 0.600 >0.05), parenting (F(2,20)=0.049, sig. 0.953 > 0.05), emotional wellbeing (F(2,20)=2.246, sig.= 0.132 >0.05), disability support (F(2,20)=0.832, sig. 0.450 > 0.05), physical and mental wellbeing (F(2,20)=0.426, sig. = 0.659 > 0.05). The results imply that all children with autism whether it is high, medium or low functioning level, have the same impact on the quality of life of the family. The results in Table 9 below also indicate that the quality of life of families of children with autism may be affected by other factors not included in study model.

Table 9

ANOVA

FQOL Domains	Measure	Sum of Squares	df	Mean Square	F	Sig.
Family Interaction	Between Groups	18.244	2	9.122	.525	.600
	Within Groups	347.582	20	17.379		
	Total	365.826	22			
Parenting	Between Groups	2.324	2	1.162	.049	.953
	Within Groups	476.545	20	23.827		
	Total	478.870	22			
Emotional wellbeing	Between Groups	83.353	2	41.676	2.246	.132
	Within Groups	371.082	20	18.554		
	Total	454.435	22			
Disability support	Between Groups	22.533	2	11.266	.832	.450
	Within Groups	270.945	20	13.547		
	Total	293.478	22			
Physical/Material wellbeing	Between Groups	15.088	2	7.544	.426	.659

Within Groups	353.782	20	17.689
Total	368.870	22	

Summary

The results section has identified various areas of quality of life that are considered satisfactory and less satisfactory by parents of children with autism, the resources that have been working in support of the families, and recommendations that could be helpful in supporting the family children of autism. The study findings also reveal that there were no mean differences in the child’s functioning level and the family quality of life domains. That is, all children with autism have the same effect on the quality of life of the family.

CHAPTER 5: DISCUSSION

The study findings revealed that parenting is the most satisfying domain of quality of life. Parenting is comprised of the ability of family members to help with children with autism, the ability of adult family members to instill proper decision-making skills, and the skills to learn how to take care of the children independently. On the other hand, disability related support was the least satisfactory for the parents. Children with disability did not receive support to make progress at home, school, and workplace. Parents were also dissatisfied with the claim that family and service providers of people who have a disability have a good relationship. These findings are consistent with Bayat (2005) and Pozo et al. (2014) who state that a sense of coherence (SOC) from parents and families make them happier and enhance their psychological wellbeing.

The study findings also revealed that, in supporting the families of children with autism, early intervention measures such as introduction of speech therapy, Applied Behavioral Analysis therapy, and occupational therapy, and implementation of recreational programs for children with autism were beneficial. This study's findings are consistent with the Individuals with Disabilities Education Act (IDEA) mandates that states establish early intervention programs that provide therapeutic, educational, and case management services to children with or at risk of developmental delays from infancy to age two (Reichman et al., 2007). The study respondents also recommended implementation of additional resources to help children as they transition to adulthood, and increased staff to ensure all children receive the needed level of care. The study findings support the claims by Reichman et al., 2007 who explained that the transition programs and specialized work training can help many people with disabilities become self-sufficient in their teen and adult years, though long-term supported employment may be required. Reichman et al. (2007) added that, despite the need for additional resources and the associated benefit for children with autism, parents had to coordinate with a wide range of both public and private agencies. Resources also varied across different locations. As such, parents need to be aware of the available resources, reapply for the services annually and often wait for years to receive them which may not be beneficial to the children. The study findings revealed that, while different resources may benefit children with autism, parents need to invest their time to secure the resources for their children.

The third research question revealed there were no mean differences between the child's functioning level and the family quality of life domains. That is, all children with autism have a similar effect on the quality of life for the family. This implies that irrespective of the child's functioning levels, involved institutions, government policies and resources should be equally distributed among all families who have children with autism.

Implications of Study

The study findings provided a basis for examining the suitable resources for families with children with disability. However, the study findings had practical implications. Families with disability need to identify and enroll their children in early intervention programs and recreation program that help with children's development. Available intervention programs are mostly therapeutic and should focus on developing children's speech and coordination. Family members can also benefit from a wide range of services, including respite care, psychotherapy groups, parent and sibling support groups, condition-specific support groups, and national clearinghouses that provide information on various treatment choices (Reichman et al., 2007). Therefore, children with or at risk of developmental delays from infancy to age two must be served through early intervention programs mandated by the Individuals with Disabilities Education Act (IDEA) (Reichman et al., 2007).

The study results have implications for government and school policies. These powerful structures need to develop strategies to help students with disabilities. This can be done by implementing policies that support allocation of resources and staff sufficient for all students with disabilities. The education, health, and human services departments of the state may oversee these. For children with certain types of disabilities as young as three years old, the law demands that school districts provide preschool programs and free and appropriate education in the "least restrictive environment" once the child reaches school age (Reichman et al., 2007). Therefore, the study findings matter for they provide a basis for care for children with autism.

Moreover, results from the third research question imply that the quality of life for families with children with autism was affected by other factors apart from the child's functioning level. Some of the factors that may contribute to the quality of life for families include family perceptions of autism (Bayat, 2005), a family a sense of coherence (SOC) (Pozo et al., 2014), social support (Pozo et al., 2014), and behavior problems in children (Kersh et al., 2006).

Limitations

This study was limited by the sample size. 91 respondents were recruited in the study, with 23 respondents successfully completing the research. Although this is a fairly high response rate, the limited sample size interferes with the generalization of the study to a larger population which calls for further research to validate the study findings. The power of a study is reduced and the margin of error increased when the sample size is too small. In a study with a low statistical power, it is commonly understood that a statistically significant result is less likely to reflect a true effect than a study with a high statistical power. In addition, the small sample size did not include a diverse population, with white women being the majority of participants.

Moreover, the study is limited to Eastern North Carolina which limits the scope of the study to a specific region. Additionally, there may have been sample size selection bias for respondents that were self-selecting to participate, which may lead to under-representation of specific populations. Concentrating the research to a specific area also limits the generalization of results, since different geographical locations have varied characteristics and individuals may be affected by other factors that may not align with the study setting. Therefore, it is vital for further studies to increase the scope of the research by covering a larger population and diversifying the study to various geographical settings.

Recommendations

For further research, scholars should utilize a larger sample size to investigate the resources and quality of life for caregivers of children with autism spectrum disorder. Moreover, the study should implement mixed method research with specific hypothesis to determine factors that influence the quality of life for caregivers of children with autism spectrum disorder.

The study findings revealed that there is limited staffing to care for children with autism, and lack of knowledge to help in the transition from childhood to adulthood are crucial causes of concern. Further research should strive to investigate how different resources affect the quality of care for autism children and identify measures to curb the problem.

The study findings revealed the need to implement early interventions such as respite care, speech therapy and state related therapies to help children develop the relevant skills. Therefore, the government and schools should strive to implement measures and policies to enhance the availability of the resources and facilitate their distribution to every setting with children with autism spectrum disorder.

The government and school programs should also strive to offer educative sessions for parents and families with children with autism to enhance their contribution outside of school hours. Respite care, more options for behavioral therapy and increased support as children transition into teenage years and adulthood should also be implemented to enhance quality of life for families for children with autism.

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APPENDIX A: IRB APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
4N-64 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · **rede.ecu.edu/umcirb/**

Notification of Exempt Certification

From: Social/Behavioral IRB
To: Tiana Cypher
CC: Sheresa Blanchard
Date: 3/8/2022
Re: UMCIRB 21-002764
Resources and Quality of Life of Parents of Children with Autism

I am pleased to inform you that your research submission has been certified as exempt on 3/7/2022. This study is eligible for Exempt Certification under category # 2a.

It is your responsibility to ensure that this research is conducted in the manner reported in your application and/or protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

Document	Description
Cypher.Thesis_Proposal 2022 tcc.docx(0.01)	Study Protocol or Grant Application
Survey Consent Paragraph for Exempt Research 2 20 20 (2).doc(0.01)	Consent Forms
Thesis Email Rectruitment.doc(0.01)	Recruitment Documents/Scripts
thesis survey questions.docx(0.01)	Surveys and Questionnaires

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

APPENDIX B: CAREGIVER SURVEY

Demographics

1. Your Gender
    a. Male
    b. Female
    c. Non-binary
    d. Prefer not to say
2. Your ethnicity
    a. White
    b. Black or African American
    c. Hispanic and Latino
    d. Asian
    e. Native American and Alaska Native
    f. Native Hawaiian and Other Pacific Islander
    g. Two or more races
3. Your age
4. Your highest level of education
    a. Less than high school
    b. High school diploma/GED
    c. Associates degree
    d. Bachelor's degree
    e. Master's degree
    f. PhD or Doctoral degree
5. Your relationship to the child
    a. Mother
    b. Father
    c. Other relative:___________
    d. Guardian

6. Relationship status
    a. Married or living with partner
    b. In a committed relationship
    c. Single
    d. Divorced or separated
7. Are you the primary or main caregiver to this child
    a. Yes
    b. No
8. How many days out of the week is this child is in your care?
9. Number of adult caregivers in your home
10. Number of children in your home
11. Number of children diagnosed with autism in the home
12. Your child's gender
    a. Male
    b. Female
    c. Non-binary
    d. Prefer not to say
13. Your child's current age
14. How old was your child when you recognized that he or she might have autism?
15. Your child's age when diagnosed with autism spectrum disorder
16. How many years/months has it been since your child's diagnosis?
17. From your perspective which of the following statements best describes your child?
    a. My child has high functioning autism
    b. My child has moderate functioning autism
    c. My child has low functioning autism
18. Have you had any training related to parenting your child with autism?
    a. Yes
    b. No

19. If so, name or briefly describe any other training
20. Do you use any of the methods you learned from this training with your child with autism?
    a. Yes
    b. No
    c. Not applicable
21. Has your child with autism participated in any behavioral treatment programs?
    a. Yes
    b. No
22. If so, what is the length of time your child has participated in behavioral treatment programs?
23. If your child is currently in a behavioral treatment program, about how many hours a week does your child receive services?
24. How satisfied are you with the number of hours of behavioral services your child has been receiving?
    a. Not at all satisfied
    b. Slightly satisfied
    c. Somewhat satisfied
    d. Mostly satisfied
    e. Completely satisfied
25. How satisfied are you with the behavioral services your child has received up to now?
    a. Not at all satisfied
    b. Slightly satisfied
    c. Somewhat satisfied
    d. Mostly satisfied
    e. Completely satisfied
26. Does your child receive support services at school?
    a. Yes
    b. No
27. If so, how satisfied are you with the support services your child receives at school?

a. Not at all satisfied
b. Slightly satisfied
c. Somewhat satisfied
d. Mostly satisfied
e. Completely satisfied

Child Treatment Questionnaire

The ***Questionnaire for Each Treatment*** *asks parents of children with an ASD for more information about each treatment or therapy their child currently receives.*

28. Who or what most influenced your decision to start your child on therapy/treatment?
    a. Pediatrician
    b. Primary care doctor or family doctor (other than a pediatrician)
    c. Psychiatrist
    d. Clinical Psychologist
    e. School Psychologist
    f. Neurologist
    g. Team of professionals
    h. Teacher
    i. Speech Pathologist
    j. Occupational Therapist
    k. Behavioral Therapist
    l. Another parent
    m. Friend
    n. Internet research/web article(s)
    o. Print material/article(s)
    p. Other
29. Does your child's treatment/therapy REQUIRE a prescription by a medical professional?
    a. Yes
    b. No
30. If so, what type of professional prescribed this treatment/therapy?

   a. Primary care pediatrician
   b. Primary care doctor or family doctor (other than a pediatrician)
   c. Developmental Pediatrician
   d. General pediatrician that focuses on treating children with autism
   e. Subspecialist pediatrician (such as an allergist/immunologist or gastroenterologist)
   f. Psychiatrist
   g. Neurologist
   h. Osteopathic doctor
   i. Other

31. Is your child's treatment/therapy provided by or funded by the public school system, a state early childhood program, or other source of public funding (excluding Medicaid)?
   a. Funded by and provided in the public school system
   b. Funded by the public school system, but provided in another setting (at home, in a private school, or other community location)
   c. Funded by State early childhood program
   d. Other source of public funding (excluding Medicaid)
   e. None of the above

32. Sometimes obtaining a treatment/therapy can be very difficult. Did you have to do any of the following to obtain treatment/therapy for your child?
   a. Move to another state
   b. Move within a state but to another county
   c. Place your child into a different school
   d. Travel more than 100 miles to see a professional or therapist
   e. Enroll in a research study to obtain this treatment/therapy
   f. Pursue legal action in any way to obtain this treatment/therapy
   g. Go to a new doctor (specialist) just to get this treatment/therapy
   h. Quit job (or significantly reduce hours) to either take child to treatment/therapy or to do treatment/therapy at home

33. Were you satisfied with the evaluation/work-up your child received prior to starting treatment/therapy?

   a. Yes - satisfied with the evaluation/work-up
   b. No - not satisfied with the evaluation/work-up
   c. Not Applicable

34. Which of the following symptoms was your child's treatment/therapy meant to address?
   a. Social interaction (examples: eye contact, peer relationships, sharing interests with others, participation in social play or games)
   b. Communication (examples:spoken language, augmentative communication, conversations with others, gestures)
   c. Stereotypical behaviors and restrictive interests (examples: inflexible adherence to routines, repetitive body movements, compulsions and rituals, unusual preoccupations)
   d. Maladaptive behaviors (examples: aggression, irritability, hyperactivity, tantrums, self-injurious behavior)
   e. Executive functioning (examples: inattention, impulsivity, poor planning and/or organizational skills, transitioning issues)
   f. Gastrointestinal (examples: constipation, diarrhea, vomiting, stomach pain, reflux)
   g. Neurological (examples: sleep disturbances, headaches, motor deficits, sensory issues, seizures)
   h. Allergic and/or Immunological (examples: eczema, asthma, ear or sinus infections, frequent colds)
   i. Other

35. On a scale of 1 to 5, how much improvement did you expect treatment/therapy to have in treating the targeted symptoms? Think back to when your child first began treatment/therapy. Try not to choose your answer based on things that happened after starting.
   a. I expected no improvement
   b. I expected a minimal level of improvement
   c. I expected a moderate level of improvement
   d. I expected a high level of improvement
   e. I expected a very high level of improvement

36. On a scale of 1 to 5, what was your impression of the potential risks associated with treatment/therapy? Think back to when your child first began treatment/therapy. Try not to choose your answer based on things that happened after starting.

a. I thought there would be no risk

b. I thought there would be minimal risk

c. I thought there would be moderate risk

d. I thought there would be high risk

e. I thought there would be very high risk

37. On a scale of 1 to 5, how difficult or burdensome did you anticipate it would be to use treatment/therapy? Think back to when your child first began treatment/therapy. Try not to choose your answer based on things that happened after starting.

    a. I thought there would be no burden

    b. I thought there would be a minimal level of burden

    c. I thought there would be a moderate level of burden

    d. I thought there would be a high level of burden

    e. I thought there would be a very high level of burden

38. What has your experience been to date? Has your child's treatment/therapy improved the targeted symptoms?

    a. Yes - My child's symptoms have improved

    b. No - My child's symptoms have worsened

    c. No - There has been no change in my child's symptoms

39. (If symptoms have improved) On a scale of 1 to 4, how much have the targeted symptoms improved following treatment/therapy?

    a. There has been a minimal level of improvement of symptoms

    b. There has been a moderate level of improvement of symptoms

    c. There has been a high level of improvement of symptoms

    d. There has been a very high level of improvement of symptoms

40. (If symptoms have worsened) On a scale of 1 to 4, how much have the targeted symptoms worsened following treatment/therapy?

    a. There has been a minimal level of worsening of symptoms

    b. There has been a moderate level of worsening of symptoms

    c. There has been a high level of worsening of symptoms

    d. There has been a very high level of worsening of symptoms

41. Is the cost of any or all of your child's treatment/therapy covered by private health insurance or by Medicaid?
    a. No
    b. Yes, private insurance only
    c. Yes, Medicaid only
    d. Yes, both private insurance and Medicaid
42. On average (in US dollars), how much do you pay for your child's treatment/therapy each month? How much are you still left responsible to pay after any insurance payment, educational subsidies, or public agency funding? (We understand that month-to-month payments may vary for a variety of reasons, so please give your best estimate of the monthly average.)

Family Quality of Life Survey

How satisfied am I that...

43. My family enjoys spending time together
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
44. My family members help the children learn to be independent
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
45. My family has the support we need to relieve stress
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied

    e. Very satisfied

46. My family members have friends or others who provide support
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
47. My family members help the children with schoolwork and activities
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
48. My family members have transportation to get to the places they need to be
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
49. My family members talk openly with each other
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
50. My family members teach the children how to get along with others
    a. Very dissatisfied
    b. Dissatisfied

   c. Neither
   d. Satisfied
   e. Very satisfied

51. My family members have some time to pursue our own interests
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
52. Our family solves problems together
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
53. My family members support each other to accomplish goals
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
54. My family members show that they love and care for each other
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
55. My family has outside help available to us to take care of special needs of all family members

    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied

56. Adults in our family teach the children to make good decisions
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied

57. My family gets medical care when needed
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied

58. My family has a way to take care of our expenses
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied

59. Adults in my family know other people in the children's lives (friends, teachers, etc.)
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied

    e. Very satisfied

60. My family is able to handle life's ups and downs
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
61. Adults in my family have time to take care of the individual needs of every child
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
62. My family gets dental care when needed
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
63. My family feels safe at home, work, school, and in our neighborhood
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
64. My family member with a disability has support to accomplish goals at school or at workplace
    a. Very dissatisfied
    b. Dissatisfied

    c. Neither
    d. Satisfied
    e. Very satisfied

65. My family members with a disability has support to accomplish goals at home
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
66. My family member with a disability has support to make friends
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
67. My family has good relationships with the service providers who provide services and support to our family member with a disability
    a. Very dissatisfied
    b. Dissatisfied
    c. Neither
    d. Satisfied
    e. Very satisfied
68. What resources have been most beneficial to support you as family?

69. What additional resources do you feel would be beneficial to support you as family?

APPENDIX C: TABLES

Table 5: Research Questions

Research Question	Survey Questions	Statistical Test	Rationale
What domains of quality of life do parents of children with autism rate as being most and least satisfied?	Family interaction (43, 49, 52, 53, 54, 60). Parenting (44, 47, 50, 56, 59, 61). Emotional wellbeing (45, 46, 51, 55). Physical/maternal wellbeing (Q48,57,58,62,63) Disability support (64,65,66,67)	Descriptive statistics	Responses will identify the domain of quality of life that was considered to be more satisfactory and one that was least satisfactory.
What resources have been or could be helpful in supporting families' of children with autism?	Open-ended questions 68 and 69	Thematic analysis	Responses will tell us what specific resources have been helpful for families, as well as what resources may bridge the gap between dissatisfaction and satisfaction
Is there a significant statistical mean	Q17 Child's Functioning Level		Responses will tell us how the child's

difference between the child’s functioning level and the family quality of life domains?	Family Quality of Life Domains	functioning level may affect and or correlate with their family quality of life

Table 6: Family Quality of Life Scale Domains

Family Interaction	
Q43	My family enjoys spending time together
Q49	My family members talk openly with each other
Q52	Our solves problems together
Q53	My family members support each other to accomplish goals
Q54	My family members show that they love and care for each other
Q60	My family is able to handle life’s ups and downs
Parenting	
Q44	Family members help the children learn to be independent
Q47	Family members help the children with schoolwork and activities
Q50	Family members teach the children how to get along with others
Q56	Adults in my family teach the children to make good decisions
Q59	Adults in my family know other people in the children’s lives (i.e. friends, teachers)
Q61	Adults in my family have time to take care of the individual needs of every child
Emotional Wellbeing	
Q45	My family members has the support we need to relieve stress

Q46	My family members have friends or others who provide support
Q51	My family members have some time to pursue their own interests
Q55	My family has outside help available to us to take care of special needs of all family members
Physical/Material Wellbeing	
Q48	My family members have transportation to get to the places they need to be
Q62	My family gets dental care when needed
Q57	My family gets medical care when needed
Q58	My family has a way to take care of our expenses
Q63	My family feels safe at home, work, school, and in our neighborhood
Disability Support	
Q64	My family member with a disability has support to accomplish goals at school or at workplace
Q65	My family members with a disability has support to accomplish goals at home
Q66	My family member with a disability has support to make friends
Q67	My family has good relationships with the service providers who provide services and support to our family member with a disability