SERVICES TO HELP CAREGIVERS OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER

by

Stephanie Garcia

Liberty University

A Dissertation Presented in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Liberty University
September 2023

SERVICES TO HELP CAREGIVERS OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER

by

Stephanie Garcia

A Dissertation Presented in Partial Fulfillment
Of the Requirements for the Degree
Doctor of Philosophy
School of Behavioral Sciences

Liberty University, Lynchburg, VA
2023

APPROVED BY:

Rachel Piferi, Ph.D., Committee Chair

Natalie Hamrick, Ph.D., Committee Member

ABSTRACT

Autism spectrum disorder (ASD) is a mental health disorder for which the cause is unknown and for which there is no cure. This only exacerbates the psychological distress placed on caregivers of children diagnosed with ASD. The purpose of this qualitative study, using the phenomenological approach was to describe the services and assistance that caregivers of children diagnosed with ASD identified as most beneficial to them. Twelve participants were interviewed via phone. Each interview was audio-recorded with participants reporting the services and assistance they identified as helpful or believed would be helpful, specifically to them. Interviews were transcribed and data were analyzed. Analysis revealed details of the lived experiences of caregivers of children diagnosed with ASD, particularly related to the utilization of services, challenges to utilizing services, and their perception as to why certain services would be beneficial. The main themes of utilization included peer-parent support groups which participants stated would help to provide a sense of community, and respite care which participants stated would help to provide opportunities for self-care and improved mental health. Findings from this study may be used to establish or expand upon the services and assistance that caregivers of children with ASD identified as being helpful and/or needed. Recommendations for future research associated with this study include a larger sample size, criteria regarding the length of time a child has had a diagnosis of ASD, multiple geographic locations, and research on how the church could help fill gaps in the service needs of caregivers of children with ASD.

Keywords: Autism spectrum disorder, caregivers, children, services, assistance

Dedication

This dissertation is dedicated to my son who is truly a gift from God. Raising you has come with its fair share of challenges but I wouldn’t trade it for the world. Thank you for showing me unconditional love, teaching me more than I thought possible, and being patient with me while I was learning how to be the “best mom ever.” I love you so much, plus a billion, times a trillion!

Acknowledgments

First and foremost, I would like to acknowledge my Lord and Savior, Jesus Christ, without whom I would not be writing this. Thank you, Lord, for being with me each step of the way in raising my son. Things could have turned out so much differently, but you always make a way. Thank you also for the opportunity to earn a Ph.D. in Your honor. I would next like to thank my mother not only for the job she did raising me and introducing me to the Lord, but also for being such a strong and available support system. I will never be able to thank you for all that you have done and continue to do for me. Last, but certainly not least, I would like to thank my committee chair, Dr. Rachel Piferi, and committee member, Dr. Natalie Hamrick, for all of their support leading up to and through this process. I am truly grateful for you both!

TABLE OF CONTENTS

List of Tables

CHAPTER 1: INTRODUCTION TO THE STUDY

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder that affects approximately 1 in 44 children in the United States (Centers for Disease Control and Prevention, 2022) and about 1 in 100 children worldwide (Chen et al., 2022). ASD affects males at a rate of 4:1 compared to females (Zhang et al., 2020). Symptoms of ASD may present as early as 12 months of age; however, the disorder is not diagnosable before 18 months of age (Loubersac et al., 2021). Symptoms vary depending on the functionality of the child (e.g., low functioning to high functioning or levels 1-3). Symptoms of this spectrum disorder often include difficulties in communication, impairments in memory, emotion regulation, behavioral problems, restricted interests, thinking or behaving at a level below one's chronological age, sensory issues, sleep disturbances, incontinence, gastrointestinal disorders, feeding disorders, comorbid psychological disorders, academic difficulties, and impairments in social cognition and/or social functioning (Lai et al., 2014; Cooper et al., 2021; Elmose & Happé, 2014; Pinkham et al., 2020; Mazurek & Sohl, 2016; Williams et al., 2018; Niemczyk et al., 2019; Lord et al., 2018; Chad-Friedman et al., 2021).

Caring for a child with such symptoms has been correlated to research suggesting that caregivers of children diagnosed with ASD report high levels of stress (Likhitweerawong et al., 2020), burnout (Kütük et al., 2021), and social discrimination (Iadarola et al., 2020). Research also shows that this group of caregivers reported increased financial hardships (Drapela & Baker, 2014) and an overall lower quality of life (Ozgur et al., 2018). Additionally, caregivers of children diagnosed with ASD reported higher rates of symptoms related to anxiety and depression than caregivers of neurotypically developing children (Padden & James, 2017; Fatin et al., 2021) and caregivers of children diagnosed with other developmental disabilities (Nik

Adib et al., 2019) such as Down’s syndrome (Huang et al., 2014), attention-deficit hyperactivity disorder (ADHD), and cerebral palsy (Kütük et al., 2021).

Background

ASD is a neurodevelopmental disorder associated with impairments in communication, socialization, and behavioral issues (Burnham et al., 2019), as well as sensory issues (Williams et al., 2018), sleep disturbances (Chad-Friedman et al., 2021), hyper-specific interests (Voorspoels et al., 2018) and repetitive, stereotypical behaviors (Cooper et al., 2021). As a result of these impairments, children diagnosed with ASD often have difficulties making friends (Chamberlain et al., 2007) and may not be aware of the differences that separate them from neurotypically developing peers (Elmose & Happé, 2014).

Although symptoms of ASD present within the first two years of life, the average age of diagnosis is four years (Young et al., 2020). The exact cause of ASD is unknown, and there is no cure. However, certain medications have fared well in symptom reduction (Lai et al., 2014). Such symptom reduction has been associated with sleep disturbances, mood, physical aggression, irritability, and hyperactivity (Mazurek & Sohl, 2016). Other difficulties associated with ASD may include incontinence (Niemczyk et al., 2019), emotion regulation and processing, and social perception (Pinkham et al., 2020).

Comorbid diagnoses are common in children diagnosed with ASD, with anxiety (White et al., 2014; 2015) and ADHD being the most commonly reported (Chad-Friedman et al., 2021). Unfortunately, these comorbid disorders only exacerbate the impairments that children diagnosed with ASD experience in relation to communication and socialization.

Caregivers of children diagnosed with ASD experience varying comorbid disorders themselves. According to Chad-Friedman et al. (2021), those who care for a child diagnosed with ASD are at greater risk of experiencing psychiatric disorders such as depression and anxiety. Such disorders may coincide with the challenges this population encounters daily, including high levels of stress (Likhitweerawong et al., 2020), frustration (Watson et al., 2021), burnout (Kütük et al., 2021), social discrimination (Iadarola et al., 2020), financial hardships (Drapela & Baker, 2014), sleep disturbances (Lovell et al., 2021), impaired physical and mental health, marital conflicts, lack of familial, community, and medical support or understanding (Watson et al., 2021), and mistrust in others (Gulsrud et al., 2021) such as physicians, educators, and child care workers.

The daily challenges experienced by caregivers of children diagnosed with ASD may explain the prevalence of reports of comorbid diagnoses of anxiety and depression within this population. A study conducted by Lim et al. (2021; 2022) stated that more than half of the respondents included in their study, caregivers of children diagnosed with ASD, yielded positive screens in depression and anxiety via the Depression, Anxiety, and Stress Scales (DASS-21). Using this same scale, Lim et al. (2021; 2022) reported that many of the stressors mentioned by respondents were related to education, not feeling confident in their abilities, and a lack of therapeutic resources (especially during the pandemic).

Although the exact cause of ASD is unknown, researchers are continually collecting data that may eventually lead to an answer. Such data is being collected via scientific and biblical research. This will be important because utilizing multiple methods and areas of focus may yield data that fills gaps in existing research, expands knowledge in the field of psychology (Henriques, 2004), and simultaneously improves the lives of children diagnosed with ASD and their caregivers.

Scientific Research

Current research suggests that ASD is a prenatal disorder associated with late gestational brain overgrowth (Bonnet-Brilhault et al., 2018), known as megalencephaly (Sokol et al., 2019). Such overgrowth affects cortical and subcortical regions of the brain, including the prefrontal and temporal cortices (Jones, 2014). Additional research suggests that ASD is associated with differences in amygdala volume (Herrington et al., 2017), increased gray and white brain matter (Xiao et al., 2014), and reduced functional and coherent connectivity (Ward, 2017).

According to Nah et al. (2019), early detection of ASD yields the most successful outcomes via interventions and treatments. Studies have suggested that early diagnosis of ASD (Wan et al., 2013) and caregiver acceptance of such a diagnosis (Da Paz et al., 2018) may provide the best possible outcome for the child and caregiver. Therefore, knowing how ASD presents in infancy is imperative. This is an area of study for which additional research is necessary, as data collected may benefit children diagnosed with ASD, and their caregivers, more rapidly and comprehensively (Dinora & Bogenschutz, 2018).

Biblical Research

Similar to how scientific research explains disabilities and disorders, the same can be said for the Bible. John 9:2-3 says, “and His disciples asked Him saying Master, who did sin, this man or his parents, that he was born blind? Jesus answered, neither has this man sinned, nor his parents, but that the works of God should be made manifest in him” (King James Bible, 2015). From this, we see that disabilities have existed for centuries and provide opportunities for God’s glory to be manifested.

Although ASD was not a disorder that was explicitly mentioned in the Bible, other forms of disabilities, such as blindness, deafness, and palsy, were mentioned, along with instructions from God on how to care for those with disabilities. Biblical instructions are the same for each of these disabilities, including ASD. For example, Romans 15:1 explains that those who are strong should bear the weaknesses of those who are not strong, while 1 Corinthians 12:25 explains that there should be no division in the body of Christ and that all members should have the same care for one another (King James Bible, 2015), as demonstrated throughout the Bible by Jesus.

Children diagnosed with ASD and their caregivers should be shown the same care and love that other members of the body of Christ receive, with the biblical expectation that the strong should bear the weaknesses of these two groups. Not having the necessary support from caregivers limits the ability of the child diagnosed with ASD to succeed. Likewise, not having the necessary support from others limits the caregiver’s ability to fully support their child’s needs while exacerbating their own stress levels. As Christians, it is important to acknowledge the struggles of caregivers of children diagnosed with ASD by providing support and displaying the true love of God.

Problem Statement

Caregivers of children diagnosed with ASD experience higher levels of stress than caregivers of neurotypically developing children, as well as caregivers of children diagnosed with other disabilities such as Down’s syndrome (Huang et al., 2014), intellectual disabilities, developmental disabilities (Nik Adib et al., 2019), ADHD, and cerebral palsy (Kütük et al., 2021). Some caregivers have reported feeling stretched beyond their limits (Davis & Carter, 2008) or on the verge of crisis (Weiss & Lunsky, 2010; 2011). Perhaps this is because caregivers of children diagnosed with ASD encounter struggles that are unique to them. Such struggles include being stigmatized by other parents or caregivers (Thibodeau et al., 2017) and the inability to maintain employment due to the constant need to be accessible for the child who relies on them for care.

While research exists on the adverse effects of caring for a child with ASD, it is currently unknown what is needed to assist this population in alleviating the hardships they encounter daily. Support groups and respite care could provide temporary relief but are not offered in all areas and may have long wait lists. Additionally, services such as education programs (Milgramm et al., 2021; 2022) may provide access to other effective therapeutic options (Baykal et al., 2019) but pose an issue when child care is not available to allow caregivers the opportunity to utilize these services. Therefore, a qualitative study was proposed to examine how caregivers of children diagnosed with ASD described the services or assistance they needed to feel well-assisted and supported.

Purpose of the Study

The purpose of this qualitative study, using the phenomenological approach via interviewing, was to describe the services and assistance caregivers of children diagnosed with ASD identified as most beneficial to them.

Research Questions

RQ1: How did caregivers of children diagnosed with ASD describe their lived experiences caring for their child?

RQ 2: What services and assistance did caregivers of children diagnosed with ASD report utilizing, being needed, and reasons for not utilizing?

RQ 3: Why did caregivers of children diagnosed with ASD believe that certain services and assistance were helpful and/or needed?

Assumptions and Limitations of the Study

Assumptions associated with this study related to the depth of knowledge caregivers of children diagnosed with ASD possessed. It was assumed that these caregivers were able to provide details about what services and assistance they utilized. It was also assumed that these caregivers would know the services and assistance they needed.

Limitations associated with this study related to the small sample size and the depth of information caregivers of children diagnosed with ASD would provide. Additionally, the method of recruitment may have produced participants most engaged in the care of their child, possibly limiting data related to the perspective of those caregivers who feel the least supported.

Theoretical Foundations of the Study

This study was conducted using the interview method via a qualitative research design. Qualitative research deals with inquiry and examines a social or human problem, while interviews provide a personal, firsthand perspective. This study examined the social/human problems that caregivers of children diagnosed with ASD encounter daily, including high stress levels, social discrimination, lack of community support or understanding, and mistrust of others, as described by Wuest and Hodgins (2011). Furthermore, the services and assistance caregivers of children diagnosed with ASD reported as being needed to help cope with their daily stressors were examined.

Data collected from this study may be used to improve or create services to improve the lives of caregivers of children diagnosed with ASD. One such improvement may assist caregivers in identifying their main stressors and learning how to cope. This is consistent with Folkman and Lazarus' (1985) theory of stress which describes the process of appraising stressors. According to this theory, the appraisal of stress depends on available resources. When there are insufficient resources to handle a given stressor, an individual experiences stress. This is often the case for caregivers of children diagnosed with ASD, who frequently face stressors they do not feel adequately prepared to handle. Caregivers must then explore coping and stressbuffering skills to achieve resiliency (Walsh, 2016). This study built upon Folkman and Lazarus' (1985) theory of stress by examining how caregivers of children diagnosed with ASD appraised their stress and the resources they reported that would be beneficial in reducing their stress. These stress reducers may include having a dependable support network as well as components of resiliency such as making meaning of the situation and practicing active coping and emotional regulation (Walsh, 2016).

Definition of Terms

The following is a list of definitions of terms that were used in this study:

Autism spectrum disorder (ASD)- a set of neurodevelopmental disorders characterized by deficits in socialization, communication, emotion regulation, repetitive behaviors, insistence on sameness, fixated interests, and hyper or hypo-reactivity to sensory input (American Psychiatric Association [APA], 2013).

Chronological age- time lived since birth (Limeres et al., 2019).

Communication- verbal and non-verbal skills one uses to express their own message, as well as receive messages from others (Kristoffersson et al., 2020).

Contextual source memory- memories that involve encoding and/or retrieval (Semino et al., 2017).

Distress- a feeling of extreme worry, sadness, or pain (Dijkstra-de Neijs et al., 2020).

Emotion regulation- the ability to modify one's arousal and emotional state to promote adaptive behavior (Conner et al., 2019).

Executive functioning- cognitive processes related to behavioral goals, which may include planning, inhibitory control, and working memory (Bernier et al., 2010).

High-functioning autism spectrum disorder- a term used to describe an individual diagnosed with ASD who does not have a comorbid intellectual disability (Alvares et al., 2020).

Low-functioning autism spectrum disorder- a term used to describe an individual diagnosed with ASD who suffers from severe symptoms such as limited verbal skills and inability to function independently (Sung et al., 2022).

Megalencephaly – increased growth of cerebral structures during brain development (Sokol et al., 2019).

Neurodevelopmental disorder- a disorder related to impaired neurocognitive functioning (Shah et al., 2022).

Prospective memory- memory used to perform an expected behavior in the future (Li et al., 2021).

Restricted interests- interests of unusual focus or intensity (Carter et al., 2020).

Sensory hyperreactivity- an intense sensitivity to or avoidance of sensory input (Hohn et al., 2019).

Sensory hypo reactivity- reduced responsiveness or reaction to sensory input (Reda et al., 2021).

Sensory input- input that enters the body through one of the five senses: hearing, seeing, tasting, smelling, and feeling (Fausto-Sterling, 2021).

Single-item memory- memory involving common objects, words, or sounds without having to utilize contextual source memory (Semino et al., 2017).

Socialization- the process of understanding relationships through interactions with others (Kohn, 2019).

Stress – an internal response resulting from the unusual demands of an environment (Garrett & Hough, 2018).

Stress reactivity- individual differences in response to a stressor (Cohen & Hamrick, 2003).

Significance of the Study

Caregivers of children diagnosed with ASD play essential roles and perform crucial tasks in their children's lives. These tasks include assisting with activities of daily living (brushing teeth, bathing, toileting), preparing meals, transportation to appointments (medical, dental, therapeutic), and advocating for their child's education, inclusion, and other case-by-case needs. When these caregivers feel anxious, depressed, or overwhelmed, their physical and mental health and their child's physical and mental well-being are affected. It is, therefore, crucial that caregivers of children diagnosed with ASD feel supported and well-served, for which this research may provide a foundation.

Summary

Approximately 1 in 44 children in the United States (Centers for Disease Control and Prevention, 2022) and about 1 in 100 children worldwide (Chen et al., 2022) are diagnosed with ASD. ASD is a lifelong, neurodevelopmental disorder that impairs a person's communication skills, emotion regulation, social cognition and functioning, and ability to process sensory input (Lai et al., 2014; Cooper et al., 2021; Elmose & Happé, 2014; Pinkham et al., 2020; Mazurek & Sohl, 2016; Williams et al., 2018; Lord et al., 2018; Chad-Friedman et al., 2021).

As more is learned about ASD and how to assist children diagnosed with the disorder, it is also essential to give attention to how their caregivers may be assisted. Such assistance may come in the form of increased services or additional assistance and resources that cater to this population. Currently, there are a significant number of services and forms of assistance that exist to benefit children diagnosed with ASD. However, few services and forms of assistance exist to help their caregivers. Data collected from this study could be used to establish such services and increase support for this population.

CHAPTER 2: LITERATURE REVIEW

Overview

ASD is a neurodevelopmental disorder associated with impairments in communication, socialization, behavioral issues (Burnham et al., 2019), sensory issues (Williams et al., 2018), sleep disturbances (Chad-Friedman et al., 2021), hyper-specific interests (Voorspoels et al., 2018) and repetitive, stereotypical behaviors (Cooper et al., 2021). These impairments affect how children diagnosed with ASD present, how they are treated by neurotypically developing peers, and their ability to make friends (Chamberlain et al., 2007).

Similarly, caregivers of children diagnosed with ASD may also present differently than their adult peers. These caregivers often present anxious, depressed (Chad-Friedman et al., 2021), stressed (Likhitweerawong et al., 2020), frustrated (Watson et al., 2021), tired, and overwhelmed. Accordingly, these differences in presentation impact how others treat caregivers of children diagnosed with ASD within their own peer group.

This chapter examines the varying differences in how children diagnosed with ASD present and how they are treated by their neurotypically developing peers. The same differences in presentation and treatment are examined regarding caregivers of children diagnosed with ASD with the intention of determining ways to ease the burden experienced by these caregivers. Finally, biblical foundations via Scripture are used to demonstrate the importance of understanding one another’s differences and discerning God’s expectations on treating those who are different.

Description of Search Strategies

Scientific Databases and Delimitations

Databases used for this research were examined digitally via the Jerry Falwell Library at Liberty University. Such databases included Sage Primer, EBSCOhost, PubMed Central, PsychInfo, and ProQuest. Delimitations consisted of ASD research published within the last five years. However, significant research published more than five years ago has also been included.

Scientific Search Terms

Scientific search terms used for this research related to themes that help the vulnerable and those with unique needs. These terms included: autism, children, caregivers, services, assistance, experiences, ability, challenges, disability, inclusion, limitations, opportunities, socialization, understanding, stress, coping, struggles, and mental health.

Biblical Research and Search Terms

Biblical search strategies for this study consisted of word study and subject matter exploration via the King James Version Bible. Terms and subjects explored included: grace, compassion, kindness, children, patience, humility, loneliness, love, persecution, blindness, paralysis, perseverance, speech, self-control, and temperance.

Review of Literature

ASD is a neurodevelopmental disorder characterized by impaired communication and socialization, and restricted or repetitive behaviors (APA, 2013). Despite extensive research, an etiological cause of the disorder has not been determined, nor has a cure (Horder et al., 2018). However, research has identified symptoms of ASD to include behavioral issues (Burnham et al., 2019), sensory issues (Williams et al., 2018), sleep disturbances (Chad-Friedman et al., 2021), gastrointestinal issues (Lord et al., 2018) and incontinence (Niemczyk et al., 2019). The symptoms experienced by children diagnosed with ASD, as well as the impact of these symptoms on caregivers, differ from family to family. ASD is a spectrum disorder meaning that people diagnosed with the disorder present with varying degrees of impairment (Jensen & Spannagel, 2010; 2011), along a spectrum that may range from low functioning/level 3 (e.g.; non-verbal, requiring significant assistance in daily care) to high functioning/level 1 (e.g., limited challenges in accomplishing activities of daily living).

Children with ASD Present Differently Than Peers/Treated Differently by Peers

Children diagnosed with ASD may present at various points along the spectrum. However, there are several common symptoms present in those diagnosed with ASD. Such symptoms include difficulties in communication, impairments in memory and emotion regulation, behavioral problems, restricted interests, thinking or behaving at a level below one's chronological age, sensory issues, sleep disturbances, incontinence, gastrointestinal disorders, feeding disorders, comorbid psychological disorders, academic difficulties, and impairments in social cognition and/or social functioning (Lai et al., 2014; Cooper et al., 2021; Elmose & Happé, 2014; Pinkham et al., 2020; Mazurek & Sohl, 2016; Williams et al., 2018; Niemczyk et al., 2019; Chad-Friedman et al., 2021).

Communication

Children diagnosed with ASD present with varying limitations in their ability to communicate. For example, some children diagnosed with ASD are non-verbal and remain non-verbal throughout their lives. Some are minimally verbal but eventually reach expected milestones, while some have an extensive vocabulary yet still experience difficulties communicating (Brignell et al., 2018). These difficulties often relate to the child having an intended message but being unable to communicate that message effectively to others (Rimmer et al., 2020;2021).

This can be frustrating to the child and those with whom the child is attempting to communicate, as the child may be unable to stay on topic or carry on a meaningful conversation (Yuan & Chen, 2020). In instances involving a caregiver, the caregiver may possess more patience with the child than others. However, at some point, the caregiver may begin to feel frustrated and may even begin negatively associating their caregiving abilities with being unable to understand their child.

When a child diagnosed with ASD attempts to communicate with peers and cannot do so, it could result in peer rejection (Chad-Friedman et al., 2021). Peers may not demonstrate the same level of patience as caregivers. Therefore, when the child diagnosed with ASD cannot communicate as quickly and effectively as their peers, the child may be rejected.

Memory

A study conducted by Semino et al. (2017) determined that the verbal ability of an individual diagnosed with ASD was significantly associated with memory. This was especially notable in areas related to contextual source memory. However, discrepancies with single-item memory were not noted.

Similar to communication-related frustration, children diagnosed with ASD may also feel frustrated when unable to recall specific information. In instances involving their caregivers, the children may become upset due to their inability to remember information such as their home address or telephone number. In instances involving their peers, the children may become embarrassed due to their inability to retain information in the academic setting. This may be especially true when the child is asked to recall information in front of a large group or in an instance in which the child’s memory may impact peers (e.g., prize-oriented, team study games).

Feeling frustrated, upset, or embarrassed could result in the child displaying impaired emotion regulation.

Emotion Expression and Regulation

Often in correlation with impaired communication and memory, children diagnosed with ASD have difficulties expressing emotions, expressing fewer emotions and atypical emotions compared to neurotypically developing peers. Additionally, children diagnosed with ASD demonstrate impaired emotion regulation as they are less able to self-soothe than neurotypically developing children. This is evident in the form, frequency, intensity, and duration of the emotional outbursts demonstrated by children diagnosed with ASD (Reyes et al., 2020). When children diagnosed with ASD display an emotional outburst due to impaired emotion regulation, their peers may also be affected. This often occurs in academic settings, childcare settings, and social settings. Such emotional outbursts may affect peers through distraction, annoyance, and/or safety issues.

Children diagnosed with ASD tend to demonstrate high levels of impairment when frustrated, including impaired insight, poor problem-solving skills, and low response inhibition (Conner et al., 2019). Possessing such symptoms of impaired emotion regulation is problematic not only for the child who is unable to express themselves appropriately, but for others around them. Caregivers are usually responsible for assisting children through their emotional outbursts and are also tasked with cleaning up the aftermath. This can be very stressful and embarrassing for the caregiver, especially in public settings (Zhou et al., 2018).

Behavioral Problems

Unfortunately, the form, frequency, intensity, and duration of such emotional outbursts may result in actual or perceived behavioral problems. In some ways, children diagnosed with

ASD experience the “domino effect.” These children may desire to communicate a thought, idea, or memory but be minimally or totally unable to do so. This may make them upset, embarrassed, or frustrated, resulting in emotional outbursts. These outbursts may involve shouting, injury to self or others, and/or destruction of property (Tse, 2020), which an unbeknownst person may perceive as behavioral problems.

In other cases, children diagnosed with ASD may exhibit actual behavioral problems. Such behaviors are more intentional in manner, such as rule-breaking and being disruptive (Piro-Gambetti et al., 2021), as well as pre-meditated acts of violence and/or destruction of property. Examples may include the child walking over to another child and hitting the other child for no apparent reason, tearing another child’s artwork off of the bulletin board unprovoked, and ripping it into pieces. Such behavioral problems may be associated with poor social development, which is common in children diagnosed with ASD (Tse, 2020).

At times, the behavioral problems of children diagnosed with ASD may affect the safety of their peers. For example, a child diagnosed with ASD could intentionally or unintentionally injure a peer during an emotional or behavioral outburst and may be unable to explain their behaviors. Nonetheless, this negatively impacts the child’s ability to establish friendships (Yuan & Chen, 2020).

Behavioral problems in children diagnosed with ASD pose daily challenges and are a significant source of caregiver stress (Tse, 2020). Such behavioral problems may result in the child and/or the caregiver being injured or the child being suspended from school or childcare, which requires the caregiver to explain their need to leave work abruptly, take time off from work, and lose pay, all while feeling alone, judged, and embarrassed by their child’s problematic behavior.

Restricted Interests

Restricted interests are a subtype of the restrictive and repetitive behavior symptoms associated with ASD. Such interests impede social development, negatively impact the ability to establish friendships, interfere with learning, and are clinically difficult to treat. Restricted interests are described as interests of unusual focus or intensity (Carter et al., 2020). Although the exact neural basis of development is unknown regarding restricted interests, a study by Carter et al. (2020) suggested that when the social development of communication is impaired, the functioning of specific brain systems may be altered. Such alterations may therefore promote the development of restricted interests. These restricted interests may make it difficult for others, including the caregiver, to connect with the child.

Chronological Age

Often, the restricted interests of a child diagnosed with ASD may not align with their chronological age; the time lived since birth (Limeres et al., 2019). This may lead peers to perceive the child as “odd,” negatively impacting opportunities to socialize (Smerbeck, 2019). Examples of restricted interests that may not align with chronological age include a nine-year-old boy obsessively watching a cartoon intended for children ages 5-6, or a seven-year-old girl who solely plays with toys intended for children ages 3-4. Despite efforts to engage their children in play with age-appropriate toys, caregivers may be unable to do so, which could result in others negatively judging the parenting styles of these caregivers.

Sensory Issues

Children diagnosed with ASD often experience sensory issues in conjunction with restricted interests and chronological age. Sensory issues are associated with input that enters the body through one of the five senses: sound, touch, sight, taste, or smell (Fausto-Sterling, 2021).

Sensory issues related to deficits in social skills (Kojovic et al., 2019) can negatively impact socialization opportunities. For example, neurotypically developing peers may enjoy loud noises, such as blaring music or high-pitched yelling on the playground. However, these sounds may be excruciating to a child diagnosed with ASD.

Additionally, neurotypically developing children may enjoy playing with playdough, viewing a light show, eating crunchy foods, or smelling certain aromas. However, the texture of playdough, the brightness of the lights, and the smell of certain scents may trigger a child diagnosed with ASD. In instances such as eating crunchy foods, multiple sensory issues may arise in a child diagnosed with ASD. Examples include the texture of the foods, the sound made while chewing the foods, and the actual taste of the foods, assuming that the look and smell of the foods are not initially triggering to the child.

Sleep Disturbances

According to Deliens and Peigneux (2019), sleep disturbances are another commonality among children with ASD, affecting up to 81.5% of those diagnosed with the disorder. Common sleep disturbances are often associated with circadian sleep issues or behavioral insomnia. Circadian sleep disturbances include delayed sleep onset, frequent night awakenings, and early morning waking; behavioral insomnia relates to shorter sleep duration, prolonged sleep latency, and poorer sleep efficacy, all of which are common in children diagnosed with ASD (Deliens & Peigneux, 2019). The child’s quality and quantity of sleep directly impact the caregiver’s quality and quantity of sleep, which in turn affects the caregiver’s ability to be fully functional throughout the day.

Incontinence and Gastrointestinal Disorders

Incontinence and gastrointestinal disorders are common in children diagnosed with ASD during wake and sleep cycles alike. Incontinence may present in the forms of nocturnal enuresis, daytime urinary incontinence, and fecal incontinence. Incontinence describes the involuntary excretion of urine or feces and affects children diagnosed with ASD at higher rates than neurotypically developing children. According to Niemczyk et al. (2019), nocturnal enuresis affects up to 30% of children diagnosed with ASD, while daytime urinary incontinence and fecal incontinence affect up to 55% and 12.5%, respectively. Additionally, fecal incontinence may be related to certain gastrointestinal disorders which are common among children diagnosed with ASD.

It is estimated that up to 47% of children diagnosed with ASD suffer from gastrointestinal disorders (Lord et al., 2018). Gastrointestinal disorders are one of the most common comorbid medical conditions associated with ASD. Such conditions include constipation, chronic diarrhea, abdominal cramps, gastroesophageal reflux disease, and irritable bowel syndrome (Madra et al., 2020). It is the responsibility of the caregiver to assist the child through painful experiences related to gastrointestinal disorders, clean up accidents and messes related to gastrointestinal disorders, and limit the child’s intake of foods likely to exacerbate gastrointestinal disorders.

Feeding Disorders

In addition to gastrointestinal disorders, feeding disorders are common in children diagnosed with ASD. Studies suggest that the gastrointestinal disorders common in children diagnosed with ASD may underlie their feeding disorders. Children diagnosed with ASD are up to five times more likely to experience feeding disorders than neurotypically developing children. Common feeding disorders associated with ASD include food selectivity, refusal of foods (e.g., texture/sensory-related issues), and poor nutritional intake (Madra et al., 2020).

Poor nutritional intake is directly associated with gut function and development, especially in children, and helps explain the correlation between feeding disorders and gastrointestinal problems. Madra et al. (2020) discussed the strong correlation between gastrointestinal problems and the feeding disorder known as pica. Pica is a feeding disorder that affects approximately 60% of people diagnosed with ASD at some point in their lifetime and involves consuming items not intended for consumption (e.g.; batteries, cotton balls, etc.). When consumed, these items significantly impede gut function and development. Such consumption may also result in obstructions, perforation, or poisoning and requires close monitoring of those who suffer from this feeding disorder (Madra et al., 2020). Such monitoring is yet another responsibility of caregivers of children diagnosed with ASD.

Comorbid Psychological Disorders

Similar to the comorbid medical disorders suffered by children diagnosed with ASD are the comorbid psychological disorders from which they suffer. Among commonly reported comorbid psychological disorders associated with ASD are depression (Johnston & Iarocci, 2017), ADHD, oppositional defiant disorder (ODD), and anxiety (Oerbeck et al., 2021).

Studies suggest that up to 38% of children diagnosed with ASD also reported symptoms of depression (Johnston & Iarocci, 2017). The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM–5; American Psychiatric Association, 2013) includes sadness, worthlessness, hopelessness, indecisiveness, irritability, and fatigue as common symptoms of depression. These symptoms are exacerbated in children who are diagnosed with ASD and may be unable to communicate their symptoms and/or needs adequately.

ADHD is also a frequently reported comorbid disorder associated with ASD. The *DSM-5* describes ADHD as a disorder associated with hyperactivity, carelessness, disorganization, forgetfulness, restlessness, inattentiveness, impulsivity, and loud, rapid, and intrusive speech (APA, 2013). Studies show an overlap in symptoms of ASD and ADHD and estimate that up to 80% of children diagnosed with ASD also met the criteria for ADHD (Scandurra et al., 2019). Additional studies reveal that up to 68% of children diagnosed with ASD and ADHD comorbidly, also met the criteria for ODD (Mayes et al., 2020; 2021). Symptoms of ODD include becoming easily annoyed and/or losing temper, anger, resentment, vindictiveness, disrespect toward authority, blaming others, and intentionally annoying others (APA, 2013), all of which could significantly impede the development of peer relationships.

Another commonly reported comorbid disorder associated with ASD is anxiety. Studies show that up to 84% of children diagnosed with ASD were also diagnosed with anxiety (Johnston & Iarocci, 2017). According to the *DSM-5*, anxiety symptoms include excessive worrying, inability to control such worry, restlessness, fatigue, difficulty concentrating, and irritability (APA, 2013). Many of these symptoms coincide with symptoms of other comorbid diagnoses related to ASD, such as depression, ADHD, and ODD. However, anxiety symptoms have also been proven to cause significant distress in social situations and peer acceptance (Johnston & Iarocci, 2017).

Regarding children diagnosed with ASD who present on the lower functioning end of the spectrum, anxiety symptoms usually relate to social avoidance. This is often associated with atypical presentation and externalizing behaviors. Regarding children diagnosed with ASD who present on the higher functioning end of the spectrum, anxiety symptoms usually relate to the awareness of their social deficits (Johnston & Iarocci, 2017), which can also take an emotional toll on the caregiver who wants their child to feel accepted.

Often, caregivers of children diagnosed with ASD invest so much time catering to their child's emotional and mental health that their own emotional and mental health suffers (Chad-Friedman et al., 2021). Additionally, some of the symptoms that the child experiences are also experienced by the caregiver. For example, children diagnosed with ASD often experience anxiety associated with the school setting (Hillman et al., 2020), which may also be a source of anxiety for caregivers confronted by school personnel regarding the child's behaviors.

Academic Difficulties

School may pose unique cognitive, social, and behavioral challenges for children diagnosed with ASD. Such challenges often increase the symptoms of anxiety that the children experience in the academic setting. Studies have shown that symptoms of anxiety, such as excessive worrying, fear, irritability, and difficulty concentrating, negatively impact the intellectual functioning and academic achievement of children diagnosed with ASD. These impacts could have lifelong effects, including the inability to attend college, reduced employment opportunities, financial struggles, and limited social interactions (Hillman et al., 2020).

Similarly, symptoms of other comorbid psychological disorders can exacerbate the academic difficulties experienced by children diagnosed with ASD. For example, feelings of hopelessness or worthlessness, common symptoms of depression, could significantly deter a child from learning, as could symptoms of ADHD (disorganization, forgetfulness, inattentiveness) and ODD (becoming easily annoyed or irritated, blaming others for one's decisions).

Learning disorders also significantly impact children diagnosed with ASD in the academic setting. The *DSM-5* classified learning disorders as difficulties learning and using academic skills related to inaccurate or slow reading, difficulty understanding what is read, and difficulty in spelling, written expression, numerical facts/calculations, and mathematical reasoning (APA, 2013). Li et al. (2021) described the correlation between such learning disorders on executive functioning and prospective memory. Executive functioning entails high-level cognitive processes used to produce intentional behaviors, whereas prospective memory is associated with memory used to trigger behavior performance in the future (Li et al., 2021). Because executive functioning is often impaired in children diagnosed with ASD, it may be difficult for this population to utilize prospective memory. For example, a child diagnosed with ASD may not be able to set prospective memory reminders to do homework, review for a quiz, or study for a test, often resulting in academic difficulties. These academic difficulties then impact the caregiver, who may be judged for their child's academic performance or perceived lack thereof.

Social Cognition and Social Functioning

In addition to impaired executive functioning, children diagnosed with ASD may also experience impairments related to social cognition and social functioning. Social cognition is the ability to interpret others' intentions, thoughts, emotions, and behaviors in social situations. In contrast, social functioning is defined as how an individual can function in society and engage in activities of daily living (Nijman et al., 2019). Children diagnosed with ASD are at a significant disadvantage in these areas due to "persistent deficits in social communication and social interaction across multiple contexts" (APA, 2013, p. 50), various symptoms of comorbid disorders (hopelessness, excessive worrying, inattentiveness), and chronological age. Studies have shown that the social environment and social skills of children ages 3-12 play a significant role in their overall development, including social cognition and social functioning (Derikx et al., 2021).

It is difficult for children diagnosed with ASD to improve social cognition and social functioning (Pinkham et al., 2020), often because they are unable or minimally able to engage in such efforts. For example, understanding social cues could be a way for children diagnosed with ASD to improve social cognition. However, because children diagnosed with ASD may have difficulty making direct eye contact, it would be difficult for them to interpret another person's intentions, thoughts, emotions, or behaviors. Similarly, because children diagnosed with ASD may have difficulty with social interactions, it would be difficult for them to learn and understand societal norms (Nijman et al., 2019).

Evidence of such has been shown in studies regarding parallel play. Parallel play takes place when a child plays alongside, but not with, peers. Many children diagnosed with ASD engage in parallel play instead of interactive play (Robain et al., 2021). Reasons for this may include impaired communication which could prevent the child diagnosed with ASD from communicating with peers; impaired social cognition, which could prevent the child diagnosed with ASD from connecting with peers; impaired social functioning, which may prevent the child diagnosed with ASD from understanding appropriate play, or to eliminate or reduce bullying experienced by children diagnosed with ASD.

The limited ability or inability of a child diagnosed with ASD to improve social cognition and/or social functioning may reflect on the caregiver, whom society deems responsible for the social interactions of the child. Furthermore, caregivers are also impacted when the social cues of their child are not aligned with society’s standards which could result in their child becoming the victim of bullying.

Bullying

Research indicates that over 50% of children diagnosed with ASD have been the victim of bullying, compared to 20-30% of neurotypically developing peers (Forrest et al., 2019; 2020). Children diagnosed with ASD may experience loneliness or feel demoralized when comparing themselves to neurotypically developing peers (Chamberlain et al., 2007), often due to social isolation (Cooper et al., 2021). Although all school-aged children may be bullied, the risk is elevated in children diagnosed with ASD due to their increased vulnerability and impaired communication skills (Forrest et al., 2019; 2020).

In some cases, the vulnerability of children diagnosed with ASD is exploited as they are bullied without being aware of such victimization. In other cases, children diagnosed with ASD are aware of such victimization, which has been linked to depression, anxiety, low self-esteem, self-harm, and antisocial behaviors (Forrest et al., 2019; 2020). Having a child who is the victim of bullying is challenging and painful for caregivers because they want their child to be treated with dignity and respect.

Caregivers of Children with ASD Present Differently/Treated Differently by Peers

It is not surprising that with all of the differences that set children diagnosed with ASD apart from their neurotypically developing peers, they often present differently and are treated differently by their peers. Unfortunately, caregivers of children diagnosed with ASD often present differently and are treated differently by their peers as well. Such differences relate to stress, fatigue, burnout, sleep disturbances, impaired physical and mental health, limited self-care, marital conflicts, financial hardships, social isolation and discrimination, lack of support or understanding, mistrust of others, advocating, and the need for various services and assistance. Of these issues, stress may be one of the most commonly reported issues associated with caring for a child diagnosed with ASD.

Stress and Fatigue

Studies conclude that caregivers of children diagnosed with ASD experience higher stress levels than parents of neurotypically developing children (Padden & James, 2017; Fatin et al., 2021), with over half of these caregivers experiencing clinically significant levels of stress. Compared to caregivers of neurotypically developing children, 34% of caregivers of children diagnosed with ASD met stress levels considered to be in the clinical range. In contrast, only 2% of caregivers of neurotypically developing children met such criteria (Li et al., 2017). Additional studies show that caregivers of children diagnosed with ASD report higher stress levels than caregivers of children diagnosed with other disabilities, such as Down’s syndrome (Huang et al., 2014) and cerebral palsy (Kütük et al., 2021). This could be because these disabilities are more recognizable by society, who may know little about ASD and therefore assume inept parenting is to blame.

Stress is an internal response resulting from the unusual demands of an environment (Garrett & Hough, 2018). In comparison, stress reactivity is defined as the individual differences in response to a stressor (Cohen & Hamrick, 2003). Caregivers of children diagnosed with ASD experience different stressors from one another, specific to their child (Chad-Friedman et al., 2021), with some caregivers reportedly feeling “stretched” beyond their limits and abilities (Davis & Carter, 2008).

According to Whitmore (2016), the stress of parenting a child diagnosed with ASD is comparable to the stress experienced by combat soldiers. In addition to caring for themselves and other family members, caregivers of children diagnosed with ASD must also cater to their child's unique needs regarding communication barriers, impaired emotion regulation, often leading to tantrums, property damage, self-aggression, aggression toward others, and the child being sent home from school or daycare as a result of such behavior. For caregivers who work outside of the home, this means having to leave work, lose pay, risk being let go from their job, and increased financial worries.

Caregivers of children diagnosed with ASD also face challenges related to their child being mistreated or bullied, catering to their child's sensory issues (avoiding loud/ triggering noises, bright lights, etc.), sleep disturbances (often resulting in sleep disturbances for the caregiver as well), incontinence and gastrointestinal disorders (cleaning up the aftermath), and symptoms of comorbid disorders to include irritability, impulsivity, and anger. Additionally, caregivers of children diagnosed with ASD must fill in educational gaps for their child, advocate for all of their child's needs (educational, medical, emotional, etc.), and help their child improve social cognition and social functioning (Waheed et al., 2020). Many caregivers feel overwhelmed by the responsibilities placed on them, often surpassing symptoms of stress and fatigue, resulting in burnout.

Burnout

Parental burnout is an exhaustion syndrome that occurs when the demands of parenting outweigh available resources (Mikolajczak et al., 2021). Studies show that the strongest predictors of parental burnout include caring for a child with special needs, not feeling supported by others, and lack of involvement in leisure activities, all of which are characteristic of caregivers of children diagnosed with ASD. Parental burnout often leaves parents and caregivers feeling like they are on "auto-pilot." This means that aside from the primary responsibilities of parenting (e.g., providing food, safety, and shelter), parents and caregivers experiencing burnout no longer feel invested in the relationship with their child, no longer enjoy being with their child, and lack fulfillment in their parental role (Mikolajczak et al., 2021).

Parental burnout affects the parent/caregiver and negatively impacts the child, often with lifelong consequences. Studies show that children associated with parental burnout were more likely to be victims of domestic violence and/or neglect. Such violence and neglect were directly correlated to parental burnout symptoms, including somatic complaints, suicidal ideations, and sleep disturbances (Mikolajczak et al., 2021).

Sleep Disturbances

Studies show that sleep disturbances, defined as sleep-wake disruptions or altered sleep patterns (Ortiz-Rubio et al., 2021), affect caregivers of children diagnosed with ASD at higher rates than caregivers of neurotypically developing children (Chad-Friedman et al., 2021). Such sleep disturbances related to the frequency of waking after sleep onset (waking more than six times after initially falling asleep), sleep latency (attempts at falling asleep that last more than 20 minutes), sleep duration (sleeping less than seven hours a night), sleep efficiency of less than 80% (Ortiz-Rubio et al., 2021), and overall sleep quality (Lovell et al., 2021).

Sleep disturbances in caregivers of children diagnosed with ASD are often the result of overwhelming caregiver burdens or expectations, unmanageable responsibilities (Ortiz-Rubio et al., 2021), stress, fatigue, burnout, or symptoms of comorbid psychiatric disorders (Chad-Friedman et al., 2021). Some studies presume that by alleviating such factors, sleep disturbances in this population could significantly decrease. This is especially important as sleep disturbances among caregivers of children diagnosed with ASD are linked to impairments in both their physical and mental health (Lovell et al., 2021).

Impaired Physical and Mental Health

Caring for a child diagnosed with ASD has been shown to have negative physiological and psychological consequences on the caregiver (Chad-Friedman et al., 2021). According to Lovell et al. (2021), caregivers of children diagnosed with ASD are at higher risk of experiencing physical health problems than caregivers of neurotypically developing children. Reasons for this may relate to the extreme stress, fatigue, and burnout experienced by this population, which, if left untreated, could lead to issues with the endocrine system, immunity (Lovell et al., 2021), and microbiome imbalance (Dijkstra-de Neijs et al., 2020). These issues may include changes in appetite, food intake, body weight, and fat storage (Li et al., 2017). Studies show that these issues render caregivers of children diagnosed with ASD more vulnerable to the common cold, aches and pains (Lovell et al., 2021), obesity, heart disease, diabetes, gastrointestinal problems, asthma (Li et al., 2017), and even cancer (Dijkstra-de Neijs et al., 2020).

Additional studies show that caring for a child diagnosed with ASD also increases the caregivers' vulnerability to psychiatric disorders such as depression and anxiety (Chad-Friedman et al., 2021). According to the *DSM-5*, symptoms of depression are categorized either by depressed mood or loss of interest in previously pleasurable activities. Related symptoms include insomnia, fatigue, suicidal ideations, and significant distress in critical areas of functioning, such as social and occupational (APA, 2013), all of which have been linked to caregivers of children diagnosed with ASD (Mikolajczak et al., 2021).

Studies show that caregivers of children diagnosed with ASD also reported significant symptoms of anxiety which include excessive worrying, inability to control such worry, fatigue, difficulty concentrating, shame, guilt, inadequacy (Zhou et al., 2018), and distress in social situations (Johnston & Iarocci, 2017). Dijkstra-de Neijs et al. (2020) pointed out that caregivers of children diagnosed with ASD are twice as likely to utilize mental health facilities than caregivers of neurotypically developing children. This may be because of the overwhelming symptoms of depression and anxiety frequently reported by this population, as well as limited engagement in activities related to self-care.

Limited Self-Care

Self-care involves engaging in activities that may be of personal benefit to an individual when faced with uncontrollable aspects of a situation (Haakonsen-Smith et al., 2017; 2018). Caregivers of children diagnosed with ASD experience these uncontrollable aspects daily regarding their child's behaviors. For example, these caregivers may have a positive outlook on the day at 7:45 a.m. but be called out of work at 8:45 a.m. to pick up their child from school or daycare due to the child's aggressive behaviors. Aside from the embarrassment of leaving work within an hour of arrival and the loss of pay (which could have more significant, long-lasting effects), the caregiver may be confined to the home with the child. If neither has successfully managed their emotions, being confined together in the home could worsen the situation.

Many caregivers of children diagnosed with ASD report that they do not often engage in self-care activities for various reasons. Some of these include lack of time, lack of energy or sleep, financial restraints, fluctuating mood (Riegel et al., 2021; 2019), and feeling guilty for doing so (Haakonsen-Smith et al., 2017; 2018). Of the caregivers who reported engaging in self-care, mindfulness activities such as yoga and adult coloring books were common. However, less healthy activities were also reported, such as consuming alcoholic beverages each night when their child went to bed (Chad-Friedman et al., 2021).

Studies show that caregivers of children diagnosed with ASD who reported not engaging in self-care were also more likely to report lower self-worth and quality of life (Waheed et al., 2020). With the many responsibilities associated with caring for a child diagnosed with ASD, caregivers often overlook the importance of caring for themselves. However, some studies show that caregivers are starting to understand the importance of caring for themselves and “not just” (Haakonsen-Smith et al., 2017; 2018, p. 257) for their children.

Marital Conflicts

Aside from the strain caring for a child diagnosed with ASD puts on the caregiver; the same can be true of the caregiver’s marriage. Caregivers of children diagnosed with ASD are more likely to experience divorce than caregivers of neurotypically developing children (Chad-Friedman et al., 2021). Some studies estimate the divorce rate among caregivers of children diagnosed with ASD to be as high as 80% (Lashewicz et al., 2018).

Cited marital conflicts leading to divorce among caregivers of children diagnosed with ASD were often related to disagreements on how to help the child, or not fully understanding the child’s diagnosis or how to navigate it (Chad-Friedman et al., 2021). Some studies suggest that up to 47% of caregivers denied that their child displayed symptoms of ASD (Tathgur & Kang, 2021), which delayed services and worsened the marital relationship. Other marital conflicts reportedly leading to divorce among caregivers of children diagnosed with ASD related to a lack of intimate time spent together, financial hardships, and caregiver struggles associated with symptoms of anxiety, depression, and stress (Tathgur & Kang, 2021).

Financial Hardships

Studies show that caregivers of children diagnosed with ASD experience unique financial hardships and are economically disadvantaged compared to caregivers of neurotypically developing children (Waheed et al., 2020). Such hardships and disadvantages relate to the extensive needs of the child, which often include physical and mental healthcare expenses, specialty schooling, childcare, and tutoring (Chad-Friedman et al., 2021; Benevides et al., 2019). However, the most significant financial hardships seem to be associated with employment.

Studies show that caregivers of children diagnosed with ASD earn 28% less than caregivers of neurotypically developing children (Benevides et al., 2019). These findings are likely linked to this population's unemployment and underemployment rates. Many caregivers of children diagnosed with ASD are forced to make difficult decisions regarding employment. For example, the overwhelming demands of caring for a child diagnosed with ASD lead some caregivers to leave the workforce, remain in the workforce to a limited capacity, or voluntarily accept positions of underemployment (Marsack-Topolewski et al., 2021). In instances regarding underemployment, caregivers may accept work in fields such as retail, fast food, or day labor in exchange for more flexible work hours and/or disposable positions. In other instances, caregivers may feel pressured to stay at their current place of employment to avoid losing necessary health care or insurance benefits for their child (Watson et al., 2021). This is especially difficult for caregivers who must frequently leave work to pick up their child from school or daycare due to behavioral issues (Chad-Friedman et al., 2021) and may be on the verge of losing their job, income, insurance, and opportunity to socialize outside of the home.

Social Isolation and Discrimination

As a result of limited opportunities for socialization and feeling unaccepted by others when such opportunities do present themselves, many caregivers of children diagnosed with ASD reported feeling socially isolated or discriminated against (Johnston & Iarocci, 2017). Such isolation (e.g., inability to go on typical family vacations) and discrimination (e.g., being the only family in the neighborhood not invited to a block party) negatively impacts these caregivers' personalities, social and emotional functioning (Waheed et al., 2020), and physiological health. For example, studies show that socially isolated individuals are at greater risk of heart attacks, coronary artery disease, and stroke (Piferi, 2001).

Unlike caregivers of neurotypically developing children, caregivers of children diagnosed with ASD also report feeling stigmatized by others (Thibodeau et al., 2017). Such stigmatization often presents in the forms of insensitive comments, hostile stares, and even aggressive confrontations with members of the public, often because these members of the public witness the child's undesirable behaviors and deem the situation to be "bad" parenting. Unfortunately, caregivers of children diagnosed with ASD also report similar stigmatization by their friends and family (Lovell & Wetherell, 2019).

Lack of Support or Understanding/Mistrust of Others

Caregivers of children diagnosed with ASD express particular concern with such stigmatization and lack of support from friends and family members, whom the caregivers expect to provide hope and positivity. Instead, some caregivers of children diagnosed with ASD reported that their friends and family members have laughed at their child, made disparaging comments regarding the child's future, including marital status or lack thereof, and in some cases, even blamed the caregiver for the child's diagnosis. For example, one caregiver stated that a family member blamed her son's diagnosis on her past sins (Tathgur & Kang, 2021). Other caregivers (specifically mothers) may be labeled "refrigerator mothers," an outdated, disproven term used to describe cold, uncaring mothers thought to be the cause of their child's ASD diagnosis (Fasano & Hill, 2017).

The stigmatization and lack of support experienced by caregivers of children diagnosed with ASD often lead to mistrust of others, including primary care providers. Such mistrust may result from feeling judged by providers, not feeling understood by providers, and lacking confidence in providers. According to a study by Al-Mazidi and Al-Ayadhi (2021), primary healthcare providers show deficits in the early detection of ASD symptoms. The study indicates that of the 62% of children diagnosed with ASD by age 3, 66% of those diagnoses were not initiated by the child’s primary care provider. Such deficits in diagnosis could significantly hinder the child’s optimal improvement, prolong and exacerbate the stress experienced by caregivers, and leave caregivers with the duty of advocating for their child, though often untrained and unprepared to do so.

Advocating

For caregivers of children diagnosed with ASD, advocating may include uncomfortable and, sometimes, confrontational conversations with educators, insurance companies, and healthcare teams to ensure their child receives the best care possible (Drapela & Baker, 2014). Typical roles associated with advocating for a child diagnosed with ASD include negotiator, monitor, supporter, and case manager. Studies suggest that over time, caregivers of children diagnosed with ASD grow into their role as negotiators once they understand their child’s needs. This is common in matters such as drafting the child’s individualized education plan (IEP), which also helps the caregiver monitor the quality and content of their child’s education while providing support strategies that could be used to help the child and educator alike. Studies show that many caregivers of children diagnosed with ASD believe that if they did not support their child, no one else would, worsening their child’s disengagement and rendering their child less social, with more challenging behaviors and more significant mental health issues (O’Hare et al., 2021).

In their role as case managers, caregivers of children diagnosed with ASD spend countless hours making phone calls, sending text messages and emails, attending meetings, conducting research, and sharing information. These tasks are necessary to be the self-proclaimed “warriors” for which some caregivers describe themselves. Many caregivers report being labeled a “difficult parent,” not being believed about their child’s issues, having their concerns ignored, and being talked down to by others who had less practical experience than them. Such stigmatization leads some caregivers to feel as if they are going into battle each day (O’Hare et al., 2021).

Caring for a child diagnosed with ASD presents additional pressures to live up to societal standards. Not only are these caregivers expected to remain the primary caregiver throughout the child’s life, but they are also expected to naturally possess the qualities and abilities necessary to care for the child and prioritize the child’s needs above their own. Additionally, these caregivers may be expected to display a facade of social normalcy, as if their role as a caregiver is no more complex than that of caregivers of neurotypically developing children (O’Hare et al., 2021). This is a challenging task due to the limited services and assistance explicitly established to help this population.

Services and Assistance

A 2019 study conducted by Nik Adib et al. concluded that over 90% of caregivers of children diagnosed with ASD felt that at some point over the last month, they could not cope with all the things they had to do. The study also concluded that over the same period, 92% of these caregivers had become angered because of things that were out of their control, and over

82% felt that difficulties in their lives were piled up so high that they could not overcome them. Such data indicates a need for services and assistance specifically for caregivers of children diagnosed with ASD, with less than 10% reportedly receiving proper psychological care for themselves (Al-Mazidi & Al-Ayadhi, 2021).

Although an abundance of data has proven the need for services and assistance designed specifically for caregivers of children diagnosed with ASD, no such abundance exists to explain the specific types of services and assistance this population desires and deems necessary. However, existing data does show methods that many caregivers have used to cope with their struggles. Some of these methods have included utilizing services such as respite care (Cooke et al., 2020) and medical homes (Al-Mazidi & Al-Ayadhi, 2021) as an opportunity to engage in self-care activities, while others included attending church services (Ekas et al., 2008; 2009), and engaging in religious and spiritual activities to inspire meaning and purpose outside of caregiving (Cook-Cottone & Guyker, 2018).

Biblical Foundations of the Study

Research shows that mothers of children diagnosed with ASD often use religion and spirituality as coping mechanisms (Ekas 2008; 2009). However, some report not feeling fully welcomed by church congregations (Brock, 2021). This may be because ASD was not a known disorder in biblical days (Macaskill, 2018), and therefore limits the ability of churchgoers to understand the disorder from a biblical perspective (Macaskill, 2021).

According to Macaskill (2020), ASD is often viewed as a functional deficit, measured against the standard that society deems “normal.” In terms of including all children in church services (not just those labeled as “normal”), Stranske (2007) pointed out that Jesus invited all children to come to Him and even corrected His disciples, who attempted to prevent the children from gathering around Him. It is, therefore, important for church leaders to do the same by inviting and incorporating all of God's children into church services and activities (Thompson, 2019), despite the possible discomfort in doing so on both sides (Waldock & Forrester-Jones, 2020).

Research conducted by Ault et al. (2021) suggests that people with disabilities participate in their communities of faith less often than their neurotypically developing peers. This is concerning because the same study demonstrated an increase in the quality of life of those with disabilities who were involved in their communities of faith. Inclusion of those with disabilities in all areas of life, including religion, faith, and spirituality, has long been a goal of many disability advocacy groups. However, even within particular churches, the perception of such inclusion differs depending on who is asked (Ault et al., 2021). For example, Ault et al. (2021) stated that although many church leaders reported welcoming and including people with disabilities, this perception was not shared by the caregivers of those with disabilities within the church.

Similarly, research conducted by McMahon-Panther and Bornman (2020) suggests that limited attention is given to the persistent obstacles that people with disabilities and their caregivers encounter related to faith-based inclusion. Via the use of three focus groups (people with disabilities, caregivers of people with disabilities, and church leaders who have members of their congregation with disabilities), McMahon-Panther and Bornman (2020) concluded that not feeling understood, being treated differently, and being aware of such differential treatment were all factors that hindered those with disabilities (especially children with disabilities) from participating in religious and/or faith-based activities.

Excluding people and treating them differently goes against biblical instruction. Perhaps one of the most well-known biblical examples may be found in Luke 10:30-35, in which a man had been robbed, beaten, and left for dead on the roadside. A priest passed by and did not help the man. A Levite passed by and did not help the man, yet a Samaritan who was different from the man did stop. Not only did the Samaritan save the man's life, but he also arranged and paid for a safe place for the man to recover from the injuries he had sustained. Later, in Hebrews 6:10, it was explained that God sees and does not forget good works and will repay those who do good deeds (King James Bible, 2015).

The Bible's instructions on how to treat one another are clear. However, special attention was placed on helping the vulnerable. There came a time when Moses was vulnerable. Exodus 17:12 explains how Moses' hands became heavy. Seeing his vulnerability, Hur and Aaron helped Moses hold up his hands, allowing the Israelites to prevail in battle (King James Bible, 2015).

Additional verses, such as Colossians 3:12, point out the importance of being humble, meek, and kind, while Proverbs 31:8 points out the importance of speaking for those who cannot speak for themselves. In Matthew 25:40, Jesus reminded everyone that "inasmuch as you have done it to one of the least of these brethren, you have done it to Me" (King James Bible, 2015).

Finally, and perhaps the most easily understood biblical instruction regarding how to treat vulnerable people is stated in Galatians 6:2. It reads, "Bear you one another's burdens, and so fulfill the law of Christ" (King James Bible, 2015). A tremendous burden is placed on those with disabilities such as ASD, as well as their caregivers. God's instruction on how to treat those who bear such burdens is clear. He expects His followers to bear burdens alongside one another. This requires taking the time to understand the burdens of others and put forth the effort to fulfill their needs; and, in doing so, fulfill the law of Christ.

Summary

God does not make mistakes, and this includes children diagnosed with ASD. The Bible explains that those with disabilities were not born as such due to the wrongdoing of the individual or the individual’s parents. Instead, so that the works of God could be made manifest in that individual (King James Bible, 2015). It is estimated that up to 2% of the population suffers from ASD (Horder et al., 2018), with symptoms including difficulties in communication, impaired memory and emotion regulation, behavioral problems, restricted interests, thinking or behaving at a level below one’s chronological age, sensory issues, sleep disturbances, incontinence, and gastrointestinal disorders, feeding disorders, comorbid psychological disorders, academic difficulties, and impairments in social cognition and/or social functioning (Lai et al., 2014; Cooper et al., 2021; Elmose & Happé, 2014; Pinkham et al., 2020; Mazurek & Sohl, 2016; Williams et al., 2018; Niemczyk et al., 2019; Chad-Friedman et al., 2021), many of whom experience bullying (Forrest et al., 2019; 2020).

For each child diagnosed with ASD, there exists at least one caregiver. Caregivers of children diagnosed with ASD present with their own symptoms, which include stress and fatigue (Padden & James, 2017; Fatin et al., 2021), burnout (Mikolajczak et al., 2021), sleep disturbances (Ortiz-Rubio et al., 2021), impaired physical and mental health (Chad-Friedman et al., 2021), limited opportunities for self-care (Riegel et al., 2021; 2019), marital conflicts (Chad-Friedman et al., 2021), financial hardships (Waheed et al., 2020), lack of support/understanding from others (Tathgur & Kang, 2021), mistrust of others (Al-Mazidi & Al-Ayadhi, 2021), and social isolation and discrimination (Johnston & Iarocci, 2017) similar to that experienced by their child. The key difference between children diagnosed with ASD and their caregivers is that a plethora of services and assistance exist to help the children, but not their caregivers.

CHAPTER 3: RESEARCH METHOD

Overview

The purpose of this qualitative study, using the phenomenological approach via interviewing, was to describe the services and assistance caregivers of children diagnosed with ASD identified as most beneficial to them. To determine what services and assistance caregivers of children diagnosed with ASD utilize, desire, and find helpful, this chapter explored such research questions by directly asking members of this population. Using a qualitative research method via the interview design, the participants, procedure, and instruments/measurements involved in this study (e.g.; concepts related to reliability, validity, credibility, transferability, dependability, and confirmability) were discussed. Additionally, data were analyzed, and delimitations, assumptions, and limitations were explored.

Research Questions

RQ1: How did caregivers of children diagnosed with ASD describe their lived experiences caring for their child?

RQ 2: What services and assistance did caregivers of children diagnosed with ASD report utilizing, being needed, and reasons for not utilizing?

RQ 3: Why did caregivers of children diagnosed with ASD believe that certain services and assistance are helpful and/or needed?

Research Design

To answer these research questions, a qualitative research study was conducted using a phenomenological approach via interviews to collect data. Because caregivers of children diagnosed with ASD are the subject matter experts regarding the services and assistance they use, need, and find beneficial, it was best to collect data from them directly to fulfill the purpose of this study.

Participants

To conduct this study, 12 caregivers of children diagnosed with varying levels of ASD participated. Participants were comprised of full-time caregivers, age 18 or older, who have assisted in the day-to-day care of the child diagnosed with ASD over the last 12 consecutive months. Participants came from various backgrounds, including race, gender, disability status, geographic location, socioeconomic status, ethnicity, and level of education.

Study Procedures

I recruited participants via one of two methods (one direct and one indirect). The direct method involved contacting potential participants with whom I had prior knowledge to be caregivers of children diagnosed with ASD, as I too am a caregiver of a child diagnosed with ASD. The indirect method for which I recruited potential participants was via “snowball sampling.” This involved asking individuals who may know a potential participant to have the potential participant contact me if they were interested in participating in this study. During initial contact with potential participants, I introduced myself, described the purpose of the study, and verified potential participants’ eligibility to participate in this study. If the potential participant was eligible and wished to participate in the study, I provided the participant with an informed consent (Appendix A). Once the informed consent was signed and returned, a time and date were scheduled for the interview to be conducted. For transcription purposes, the interviews were audio-recorded with options to be conducted in person, virtually via Zoom, or via telephone. Once an interview was transcribed, I emailed a copy to the respective participant to be approved and/or revised if necessary.

Instrumentation and Measurement

At the beginning of the interview, I identified myself as a fellow caregiver of a child diagnosed with ASD in an effort to build rapport and reduce tension or feelings of judgment. Using Appendix B, I collected demographic information from the participants such as age, race, education, and ASD diagnosis information. Using Appendix C, I asked the participants to describe their experience caring for a child diagnosed with ASD, as well as the services or assistance (if any) used by the caregiver that has helped in caring for their child. I also asked the participants what services and assistance (related to self-care, improved interactions with their child, and learning techniques) would be helpful in caring for their child diagnosed with ASD. I then asked participants why they believed these services and assistance would be beneficial. Finally, I asked the participants if there was anything else they would like to share about their experience caring for a child diagnosed with ASD. I concluded the interview by thanking the participant for their time and assuring them that they were in my prayers.

Reliability/Dependability/Confirmability

In qualitative research, reliability, which is sometimes referred to as “dependability” or “confirmability” (Coleman, 2021), describes the likelihood that data collected from various sources will be similar. Therefore, it was likely that this study would be proven reliable/dependable/confirmable, as the data collected from multiple sources (participants) related to similar experiences and would likely provide similar responses to the research questions asked.

Validity/Credibility

Validity, sometimes referred to as “credibility” (Coleman, 2021), refers to the degree to which the data collected from a study answered what it set out to answer; essentially, the correctness of its conclusion. To ensure the validity/credibility of this study, I obtained data solely and specifically from the population for which the research questions and inventory questions were created.

Transferability/Replicability

Data collected from this study may be easily transferred and used in other studies. Similarly, it may be replicated by other researchers to explore concepts related to reliability and validity or for other desired purposes. To ensure the transferability/replicability of this study, I provided the research questions, inventory questions, and coding strategies used to conduct this study.

Data Analysis

Responses from the interviews were coded by the services and assistance currently being utilized, services and assistance reported as being needed, and justification as to why reported services and assistance are or would be beneficial. In coding such responses, data may be used to prioritize, expand, and/or create services and assistance to help caregivers of children diagnosed with ASD.

Delimitations, Assumptions, and Limitations

Delimitations

Delimitations placed on this study required that participants were 18 years or older, and had actively assisted in the day-to-day care of a child diagnosed with ASD for the last 12 consecutive months. This was to ensure that participants were familiar with the day-to-day challenges of caregivers of children diagnosed with ASD, and that they were able to provide knowledgeable responses and accurate data associated with the research questions, as well as the inventory questions.

Assumptions

Assumptions associated with this study related to the depth of knowledge caregivers of children diagnosed with ASD possessed. It was assumed that these caregivers were able to provide details about what services and assistance they utilize. It was also assumed that these caregivers would know the services and assistance they need and be able to describe the benefits of these services and assistance.

Limitations

Limitations associated with this study related to the small sample size and the depth of information caregivers of children diagnosed with ASD would provide. Additionally, the methods of recruiting participants may have produced those participants who were most engaged in the care of their child, possibly limiting data related to the perspective of those caregivers who feel the least supported.

Summary

As more is learned about ASD and how to assist children diagnosed with the disorder, it is also important to give attention to how the caregivers of these children may be assisted. Such assistance may come in the form of increased services and/or additional services that cater to this population. Currently, there is a significant number of services and assistance for children diagnosed with ASD, but not their caregivers. Data collected from this study could change that.

CHAPTER 4: RESULTS

Overview

The purpose of this qualitative, phenomenological study was to describe the services and assistance caregivers of children diagnosed with ASD identified as being most beneficial to them. A semi-structured interview protocol was used to include the use of an audio-recording device. The interviews were then transcribed and a copy of each transcription was emailed to the respective participant for approval. None of the transcriptions required revisions, as all were approved the first time I sent them to the participants.

After receiving transcription approval, I then began searching for common codes and themes amongst all of the participants' responses. These responses were directly associated with the following research questions:

RQ1: How did caregivers of children diagnosed with ASD describe their lived experiences caring for their child?

RQ 2: What services and assistance did caregivers of children diagnosed with ASD report utilizing, being needed, and reasons for not utilizing?

RQ 3: Why did caregivers of children diagnosed with ASD believe that certain services and assistance are helpful and/or needed?

This chapter discusses the results of the interviews as they relate to the research questions, as well as the discovered codes and themes associated with these research questions.

Descriptive Results

At the beginning of each interview, I collected demographic information from all 12 of the participants. It was determined that the participants ranged in age from 25-59 years old with a mean age of 41.75 and a standard deviation of 9.25. Data was collected from two men and ten women of various educational backgrounds (less than a high school diploma through doctoral degree). Participants also varied in marital status (single, married, common-law marriage), race/ethnicity (Caucasian, African-American, Latino), child's age at diagnosis/current age of the child, and the level of care required of the child (low, moderate, significant).

Table 1

Participant Demographics

Participants	Age/ Gender	Race/ Ethnicity	Education	Marital Status	Age of Child at Diagnosis/Current	Level of Care Required of Child
P1	39/F	Caucasian	Masters	Married	6/8	Moderate
P2	25/F	Caucasian	Associates	Married	3/3	Low
P3	50/M	Caucasian	Doctorate	Married	6/8	Low
P4	46/F	Caucasian	Bachelors	Married	5/11	Low
P5	59/F	Caucasian	Masters	Common-law-marriage	2.5/12.5	Moderate
P6	49/F	African-American	12th Grade	Married	23/31	Low
P7	42/F	Caucasian	Masters	Married	3/15	Moderate
P8	32/M	African-American	Bachelors	Married	5/5	Low

P9	35/F	African-American	Bachelors	Married	4/5	Moderate
P10	36/F	Caucasian	12th Grade	Single	12/15	Significant
P11	48/F	Of Latino Descent	10th Grade	Married	1.5/9	Moderate
P12	40/F	Caucasian	Associates	Single	4/6	Low

Study Findings

After receiving transcription approval from each participant, I analyzed the data by identifying and studying the various codes and themes associated with the participants' responses to the research questions. Eighteen codes were identified and are defined below.

Code 1: Personal Education

The code of *Personal Education* emerged when participants described either possessing knowledge prior to their child's diagnosis, 17%, or intentionally seeking it subsequent to their child's diagnosis, 83%. Regardless of whether participants possessed knowledge prior to or subsequent to their child's diagnosis, all reported such knowledge as being helpful. For example, Participant 3 stated, "During my undergraduate degrees, the requirements for those degrees required, you know, some child development courses, which I'm really glad I was able to take as electives and, um, that all has helped in, uh, helping [my child] develop." Participant 7 described the knowledge she obtained via "trial and error and perseverance" on her part as being "instrumental in guiding" her.

Code 2: Peer-Parent Support Groups

The code of *Peer Parent Support Groups* emerged as participants described their desire to connect with others who are going through similar experiences. Only 8% of participants reported having access to and participating in peer-parent support groups while the other 92% did not. Participant 2 explained her experience, saying “The kid gets a lot of services, but the mom does not, and I have not been able to find like a support group, or you know, somewhere we can go.” All participants of this study reported their primary source of support as being friends or family members despite these individuals not being able to fully relate to the challenges of caring for a child with ASD.

Code 3: Occupational Therapy (OT)

The code of *Occupational Therapy* was identified by 34% of participants as a service that helped them learn how to assist their child in a more effective manner. Participant 11 demonstrated this by saying,

> I definitely love that he takes uh, occupational therapy. I wish that it was more than once a week, but I love that he takes occupational therapy because they do things with him and they show me how to do things with him to help him maybe the way they teach him to do it.

An additional 17% of participants reported that occupational therapy is a service they desire for their child. Participant 1 demonstrated this by saying, “if she had the occupational therapy, I think that would help.”

Code 4: Speech Therapy

The code of *Speech Therapy* was identified by 34% of participants as a service that helped them communicate with their child in a more effective manner. Participant 12 demonstrated this by saying,

> Um yes, um, speech therapy was a big one because he wasn't speaking um, for a long time and I couldn't communicate with him because he would just get frustrated and angry and mad because I didn't understand what he was saying, and I would have to say, "say it again, repeat it again," and he would just get angry and it caused a lot of tension between him and I because I, I didn't know what he wanted or um, you know, what he was trying to say, what he meant by what he said, so speech therapy was definitely a huge uh (pause) service that helped me with him.

Code 5: Applied Behavior Analysis (ABA) Therapy

The code of *ABA Therapy* was identified by 42% of participants as a service that helped them teach their child to be more structured and behave in a more socially appropriate manner, with an additional 9% identifying it as a service they desire for their child. For example, Participant 4 described how ABA therapy helped her in recognizing her child's triggers, reducing anger outbursts, and teaching self-soothing techniques. Participant 4 stated, "They taught us, they sat with us and met with us, and, they provided more structure and then for us to learn and teach him," while Participant 12 reported that her child "has a lot of like behavioral issues, and he definitely would benefit from ABA therapy."

Code 6: Services Not Offered in All Areas

The code of services not being offered in all areas emerged as participants described not having certain services available to them in close proximity to where they live, and/or not being able to utilize services in the setting which they deemed most necessary. For example, Participant 5 explained, "They don't do ABA out in the community or in schools, or in settings where, you know, his life is getting, I guess, wider and more expansive in school and in the community." Participant 4 explained her situation by saying, "I couldn't use some of the services like Trillium and all that. I wasn’t offered that, unless you know, I was able to drive like an hour out of the area.”

Participants reported ABA therapy, occupational therapy, and speech therapy as the three most inaccessible services, with 25% reporting they did not have easy access to any of these services. Fifty percent of the participants reported having access to one of the services, 17% reported having access to two of the services, and only 8% reported having access to all three services.

Code 7: Income Stipulations

The code of *Income Stipulations* was identified by 34% of participants who stated that their family was denied services such as ABA therapy, education assistance, and respite care due to the household income being above assistance guidelines. Participant 3 explained his experience by saying, “So basically in my opinion they’re protecting their budgets and making it hard for people like us to get that funding.” Participant 4 stated, “I had to fight for some [services] because people said I made too much,” whereas Participant 5 reported “funding the gap” for therapies for her child which cost the family approximately $1,000 a month out-of-pocket.

Code 8: Child Does Not Meet Diagnosis Requirements

The code of the child not meeting diagnosis requirements was identified by 17% of participants who experienced difficulty in getting their child assistance such as disability and educational services because the child’s level of diagnosis did not meet the granting entity’s requirements. Participant 1 described her experience with a state disability insurance agency saying, “They don’t seem to want to help those who are higher functioning, even though it’s an ASD 2 diagnosis.” Participant 3 discussed his frustration with the education system saying, One of the arguments that the schools and the funding source requirements gives for not funding her, which they didn’t even interview her, it's like the autism diagnosis is, they feel like, well, she’s exceptional, she doesn’t need this money. And well, she does because even though she’s twice exceptional because of the autism, she’s you know, lacking in a lot of the social, um, areas, and um, those areas that are lacking because of the autism, so they tend to disregard that, so, um (laughs) there we are.

Code 9: Lack of Trust in Others

The code of *Lack of Trust in Others* was exemplified by 25% of the participants who described their lack of trust in others’ (laypersons and professionals) ability to comprehend the symptoms and special needs of their child. Participant 1 stated that her child has a comorbid diagnosis of “social separation anxiety” and that she “couldn’t just have a random person” help with her child. Participant 6 confided that she and her husband noticed that “something wasn’t right” with their child at age 4 but that it took until the age of 23, after almost two decades of begging for their child to be retested and reevaluated, that their child finally received an autism diagnosis. Participant 7 voiced her concern that an ABA therapist may have “emotionally abused” her child.

Code 10: No State/Federal Funding

The code of not having state or federal funding was discussed by 17% of participants whose children were unable to receive certain services and/or assistance related to their ASD diagnosis as a result of no initial state or federal funding, or a depletion of state or federal funding. Participant 6 recalled such frustration, saying, “She was approved, but um, they didn’t have enough funding, so once again, she was back on the list for having a mentor.”

Code 11: Family Does Not Meet Insurance Requirements

The code of the family not meeting insurance requirements was described by 25% of participants whose children were deemed ineligible for services or assistance because of the insurance requirements of certain agencies and entities. Participant 5 described an experience with her insurance company's refusal to cover her child's speech therapy services. Participant 1 described her child not being able to receive ABA therapy or occupational therapy due to issues related to copay, and Participant 7 described the "fantastic resources" offered by a local managed care company for which her child was found ineligible due to not being a Medicaid recipient.

Code 12: Caregiver Schedules

The code of *Caregiver Schedules* was discussed to some extent, by all of the participants. Participants described difficulties they encountered in their children's utilization of certain services and assistance due to scheduling conflicts with their own schedules. Participant 2 laughed as she described time being an issue, saying she has "a lot of stuff going on." Participant 11 described her obligation to care for other family members saying, "It's a little bit harder for me to only concentrate on his services," while Participants 4, 10, and 12 discussed the scheduling conflicts associated with being a single parent.

Code 13: Not Knowing What Services Exist

The code of *Not Knowing What Services Exist* was also discussed, to some extent, by all of the participants. Either at present or immediately following the diagnosis of their child, all participants recalled not knowing what services their child may qualify for because they did not know what services existed. When asked if there were services or assistance that she has not utilized but thinks would be helpful, Participant 9 replied, "None that I know about." Participant 10 had a similar response and said,

> I guess if I figured out what the services were um, (pause) and if it was something that I knew could help him, um, then maybe I would look into it, um, but I'm not really sure what, what services they would be.

Code 14: Not Knowing Where or How to Start

The code of *Not Knowing Where or How to Start* was reported by all participants as they recalled not knowing what to do or where to go for help immediately following their child's ASD diagnosis. Participant 7 stated, "They hand you that diagnosis, but then it's like your kid's autistic, good luck (laughs) you know, there's no like okay, you may want to call this person, this is where you want to get started." Participant 9 stated, "I really had to figure this out on my own honestly." Participant 4 stated that "there could have been more help in the beginning," while Participant 1 stated, "information just has to be more accessible because when you first get the diagnosis, it's like ok, here's your diagnosis, now what?"

Code 15: Respite Care

The code of *Respite Care* emerged as 50% of the participants reported it as a highly desired service that would allow them time to complete tasks such as grocery shopping, engaging in self-care, and attending their own medical appointments. Only one of the twelve participants reported utilizing any form of respite care. Participant 10 stated that she uses the time that her child engages in ABA therapy as her time of respite.

Code 16: Child Sense of Community

The code of *Child Sense of Community* emerged as 34% of participants described the need for a sense of inclusion and sameness among other children diagnosed with ASD. Participant 10 agreed saying, "just to be around their peers and kids like them," while Participant 11 stated, "I would love some kind of, you know, group, maybe with children like him, to get them interacting more with each other and just seeing, you know, just seeing the differences in the spectrum, I'll say on the spectrum."

Code 17: Impact on Caregiver Mental Health

The code *Impact on Caregiver Mental Health* was explored by participants who described the impact that being the caregiver of a child with autism has on their own mental health. Fifty percent of the participants, especially those who are currently single or were single during much of the child's life, described symptoms of stress and anxiety. However, Participant 1 most boldly confessed, "I did get on some medication for anxiety."

Code 18: Feeling Unrelatable

The code *Feeling Unrelatable* was described by 50% of participants who felt that their role as a caregiver of a child with ASD rendered them unrelatable to caregivers of neurotypically developing children. Participant 1 stated, "I would say that it affected me socially, you know I kinda shied away from social situations." Similarly, Participant 2 described her attempts to socialize, saying that her child

> Didn't want to socially interact with other children so he kinda kept running off, so then, it was hard for me to socialize with other moms, but I would say from first perspective to try to, you know, push through that, deal with that to make sure you're not getting isolated.

In addition to the eighteen codes that emerged from this study, thirteen themes emerged as well: riding an emotional roller coaster, feeling alone, lack of caregiver services, services that have indirectly helped caregivers, peer-parent support groups, respite care, uniform school/state funding, activities and facilities specifically designed for children with ASD, challenges to utilizing services, sense of community for caregiver, sense of community for child, reduction in out-of-pocket costs, and confidence in navigating the system with the help of a professional. These themes are examined further within the research questions later in this section. Furthermore, these themes also proved helpful in terms of the validity and reliability of this study.

Evidence of Trustworthiness

Validity/Credibility

According to Coleman (2021), the terms "validity" and "credibility" describe the correctness of a given conclusion. This study proved its validity/credibility by accurately portraying the experiences and opinions of the specific population (caregivers of children diagnosed with ASD who have been actively involved in the day-to-day care of the child for the last 12 consecutive months, and are 18 years or older) for which the research questions and inventory questions were created.

Transferability/Replicability

By providing the research questions, inventory questions, and coding strategies used to conduct this study, I ensured that the study could be replicated by other researchers. This also allowed for the transferability of data which could be used to compare and contrast replicated studies, especially with regard to reliability and validity.

Reliability/Dependability/Confirmability

According to Coleman (2021), the terms "reliability," "dependability," and "confirmability" are interchangeable. These terms describe the likelihood that data collected from multiple sources will be similar. In this study, the referenced "multiple sources" were the research participants. This study proved to be reliable/dependable/confirmable as participants reported similar experiences and provided similar responses to the research questions.

Research Question 1: How did caregivers of children diagnosed with ASD describe their lived experiences caring for their child?

Two themes emerged as salient in caregivers' discussion of their experience caring for their child with ASD. Caregivers repeatedly discussed feeling as if they were riding an emotional roller coaster and described feeling alone. Each is described below.

Theme: Riding an Emotional Roller Coaster

Twenty-five percent of the participants in this study described their experiences in caring for their child as a "roller coaster." Participant 4 reported, "Uh, sometimes it's a roller coaster (laughs), but, um, he teaches me stuff, and I teach him stuff." Similarly, Participant 7 discussed the many "highs and lows" she has experienced in caring for her child with ASD. Participant 1 elaborated by describing her child's frequent "meltdowns" and varying emotions leading to such meltdowns.

In discussing the emotional roller coaster of caring for a child with ASD, several caregivers described how these meltdowns often led to their own feelings of being emotionally drained and uncertain about what to do. Participant 12 said, "I don't know how to correct his behavior because it's not typical." Participant 1 expanded by describing how she has to be conscious of where and how she directs her own energy.

Theme: Feeling Alone

Twenty-five percent of participants also reported feeling alone. Code 18 previously stated that 50% of the participants reported feeling unrelatable, specifically to caregivers of neurotypically developing children, however, the theme of feeling alone is more general. Participant 1 expressed this by saying, "It's kind of lonely." Participant 2 described how her child's social deficits impact her own ability to socialize, saying, "They're very, you know, rigid to their schedule. Sometimes it can be very hard to get out." It was not surprising, therefore, that much of the data collected from the next research question related to caregivers' desires to get out of the house more often.

Research Question 2: What services and assistance did caregivers of children diagnosed with ASD report utilizing, being needed, and reasons for not utilizing?

When asked to discuss the services and assistance that they utilized, caregivers of children diagnosed with ASD reported seven themes (lack of caregiver services, services that have indirectly helped caregivers, peer-parent support groups, respite care, uniform school/state funding, activities and facilities specifically designed for children with ASD, and challenges to utilizing services). Each of these themes is described below.

Theme: Lack of Caregiver Services

The most notable theme that emerged as caregivers were asked to describe the services that have helped them, was that 84% could not identify any services that have helped them directly. For example, Participant 3 credited his "years of education" and "advanced degrees" as being personally helpful. Only one of the twelve participants reported access to and attendance of a peer-parent support group, and only one of the twelve participants reported access to (limited) respite care. Participant 6 stated that although her child has been diagnosed with ASD for 8 years, but presented symptoms for far longer, she only recently found an online peer-parent support group that meets via Zoom. Participant 10, whose child has co-morbid diagnoses, reported that she utilizes a limited form of respite care during the time that her child receives services from the Autism Society saying, "Uh, the Autism Society, um, he gets a therapist twice a week to come out and kinda hang out with him and they'll do different activities so that kinda gives myself a break."

Theme: Services that Have Indirectly Helped Caregivers

The second theme that emerged regarding services that help caregivers involved services directed at helping their child. Four of the participants reported that the ABA therapy services that their child received indirectly helped them as well. Participant 7 described ABA therapy as being “a God-send in many different ways.” Four of the twelve participants reported that the speech therapy services that their child received indirectly helped them, with Participant 8 saying that speech therapy, “helped us to uh, communicate uh, with him better and understand how he’s feeling, what he’s feeling, you know, different triggers.” Three of the twelve participants reported that the occupational therapy services that their child received indirectly helped them. Participant 11 stated, “I love that he takes occupational therapy because they do things with him and they show me how to do things with him to help him.”

Theme: Peer-parent Support Groups

After addressing the direct and indirect services that helped the participants, I then asked about the services desired by these caregivers. Peer-parent support groups were reported by 50% of participants as a resource that could minimize feelings of being alone and increase a sense of community. For example, Participant 2 described her desire to “socialize with other moms,” whereas Participant 8 described his desire for a support group in which others are “familiar with what’s going on.” Participant 6 stated that she “just recently” found such a support group, explaining, “I do the peer-parent support meeting, and by us getting on their Zoom meetings, we’re meeting other parents that are facing challenges like we are.”

Code 2 previously described peer-parent support groups as one of the most desired services reported by participants of this study. This differs from the theme of peer-parent support groups in that the theme focuses more on why the service is so heavily desired.

Theme: Respite Care

Similarly, Code 15 previously described respite care as another highly desired service reported by participants. This differs from the theme of respite care in that the theme focuses more on why the service is so heavily desired by participants.

Respite care was reported by 50% of participants as a highly desired service, as it would allow caregivers the opportunity to accomplish day-to-day tasks such as cleaning the house, getting a haircut, or going grocery shopping. Participant 1 stated, “I would love to be able to get some kind of a respite because taking a break can make all the difference.” Participant 7 stated,

> If they could find somebody that could help me babysit my son and give me a minute to go get my hair done, I would love you know, I would take that you know, in a heartbeat. That would answer my self-care problem.

Theme: Uniform School/State Funding

The desire for uniform school and state funding was mentioned by 17% of the participants who were frustrated that their child was not able to receive services or assistance due to variations in the ways that states and schools disburse funds for children diagnosed with ASD. Participant 1 elaborated on her desire that monies be awarded based on diagnosis as opposed to the severity of the diagnosis. Participant 3 provided similar feedback stating,

> There’s a lot of barriers, uh, hurdles that basically are discouraging parents in our situation from acquiring that funding. It’s my understanding that you know, they, they have a certain amount of money that they have for the children that they educate, and when children like [mine] come along, it pulls some of their available funding out of their system.

This theme differs from Code 10 which discussed not having an initial source of federal/state funding or depletion of such funding, whereas this theme relates to the availability of school/state funding that is not uniformly disbursed. This issue was reported most commonly by participants whose children required a lower level of care.

Theme: Activities and Facilities Specifically Designed for Children with ASD

The last commonly desired service reported by 50% of participants was activities and facilities specifically designed for children with ASD. Participant 11 stated, “I would love some kind of, you know, group, maybe with children like him,” while Participant 8 stated, “I think there needs to be more activities around the city for the kids.” Participant 10 echoed by saying,

> I do believe there needs to be more, um, care available, like a camp, um, not necessarily a summer camp, or, just somewhere that we can take them to drop them off, um, just to be around their peers and kids like them, or adults like them, and we know that they’re safe, um, (pause) but I do think they need to have more, more options.

Theme: Challenges to Utilizing Services

The final theme that emerged when discussing services available to caregivers of children diagnosed with ASD was the challenges of utilizing services. Not having options or services offered in their area was a challenge to utilizing services reported by 25% of participants. This was demonstrated by Participant 4 who said, “I think it’s hard for people to try to get services because they’re not in your area,” while Participant 5 described certain services not being offered in the specific area or environment needed (e.g.; school and community settings).

Participants also reported income stipulations, 34%, and caregiver schedules, 100%, as challenges to utilizing services. Participant 3 stated, “With our upper to middle-class income status, uh, we’re basically turned away from any funding.” Participant 4 also recalled being told that she "made too much." Participant 4 went on to explain that she only recently got married and had been a single parent for the majority of her child's life. She described how her schedule also presented a challenge to utilizing services. Similarly, Participant 2 also reported a lack of time in her own schedule as a challenge to utilizing services.

Additional challenges to utilizing services reported by participants included a lack of trust in others, 25%, and no state or federal funding, 17%. Participant 1 described a personal lack of trust in others regarding having someone look after her child, saying "I couldn't just have a random person [babysit her]." Participant 6 voiced a professional lack of trust in others, namely those who delayed her child's ASD diagnosis saying,

> It has been difficult. Um, why I say that is because we noticed from the age of four until she was 15 that it was just something different, but her doctors were always, would tell us, that you know, it's just her. I have patients that's way worser than her but do so much better than her and I was like something, something's not clicking. Something's just not right. Anytime you constantly put your clothes inside out, or you put your shoes on the wrong feet, I'm like, you know, somethings, something's not right. And we talked to doctors for years for her to, you know, be reevaluated and retested, and it was like we was up against a brick wall. So, it wasn't until she was 23 when the doctors out of Greenville, my husband's doctors, recommended her to a specialist. So, it has been a difficult, long, frustrating journal, I mean journey, and now we're just starting to see a little bit of the light at the end of the tunnel.

Participant 6 went on to explain her frustrations with a lack of state/federal funding that has resulted in her child being left on lengthy waiting lists for services. Participant 5 voiced similar frustrations, stating that a lack of state/federal funding left her family paying one thousand dollars a month out-of-pocket for the services that her child needs. This problem can be exacerbated when families do not meet certain insurance requirements as reported by 25% of participants, or when the child does not meet certain diagnosis requirements as reported by 17% of participants. On one end of the spectrum, Participant 5 had to fill in the financial gap between not meeting certain insurance requirements and lack of state/federal funding, while Participant 7 reported not being given such an opportunity because of the insurance requirements associated with her family's government/military insurance.

Perhaps more frustrating than a family not meeting certain insurance requirements for services, was discussed by participants who reported that the level of their child's ASD diagnosis did not meet certain requirements. For example, Participant 12 voiced her frustration regarding her child's clinical diagnosis and her ability to obtain certain services for her child. Participant 3 discussed his child's low acuity diagnosis saying, "So basically, in my opinion, they're protecting their budgets and making it hard for people like us." Similarly, Participant 1 stated, "They don't seem to want to help those who are higher functioning."

The final two challenges to utilizing services, each reported by 100% of participants, are closely related. The first was not knowing what services exist, and the second was not knowing where or how to start after their child received an ASD diagnosis. Participant 8 has a child who was newly diagnosed with ASD. When asked about challenges to utilizing services, he said in a questionable manner, "I'm thinking that he is getting every service that's available to him." Participants 9 and 10 also have children newly diagnosed with ASD. When asked about challenges to utilizing services, Participant 9 responded by saying, "None that I know about," while Participant 10 said,

> I don't know. I guess if I figured out what the services were um, (pause) and if it was something that I knew could help him, um, then maybe I would look into it, um, but I'm not really sure what, what services they would be.

Participant 11 has a child who has had an ASD diagnosis for many years. However, she still reported not feeling confident in knowing the services available to her. She responded by saying, "I don't know of any other services that I would be able to use and that's why I haven't used any services, but um, I'm willing to, like, I'm willing to look into different services."

Other participants who have children who have had an ASD diagnosis for many years, were able to recall their experiences of not knowing where or how to start their search for services for their child. For example, Participant 5 described "additional, unexpected duties and learning," requirements in relation to medical appointments, completing and maintaining various insurance and educational documents, and becoming an advocate for all of her child's needs. Participant 4 made statements such as, "It was difficult at first because I couldn't find services," and "I still feel that he could have had more help in the beginning than what he did." Participant 1 stated, "It's much harder to get access to resources than I thought," while Participant 7 summed it up by saying,

> They hand you that diagnosis, but then it's like your kid's autistic, good luck (laughs), you know, there's no like, okay, you may want to call this person, this is where you want to get started. It was all trial and error and perseverance on my part.

Research Question 3: Why did caregivers of children diagnosed with ASD believe that certain services and assistance are helpful and/or needed?

After asking about the services and assistance that the participants utilized and/or thought would be helpful, I then asked participants why they perceived these services to be helpful. Four themes emerged from this final research question. These themes related to a sense of community for the caregiver, a sense of community for the child, a reduction in out-of-pocket costs, and confidence in navigating the system with the help of a professional.

Theme: Sense of Community for the Caregiver

The theme of a sense of community for the caregiver emerged as participants described the benefit of being able to interact with other caregivers of children diagnosed with ASD. Participants 2, 8, and 9 voiced their perceptions of how a sense of community for caregivers is essential. Participant 2 described the importance of being reminded that “you’re not alone,” while Participant 8 pointed out the benefits of being around “other people who are familiar with what’s going on during a day-to-day basis.” Similarly, Participant 9 discussed the benefit of knowing what other caregivers are experiencing. This theme, which focused on the benefit of a sense of community among participants, differed from Code 18 which discussed participants’ feelings of being unrelatable to caregivers of neurotypically developing children.

Theme: Sense of Community for the Child

Participants 6, 10, and 11 voiced their perceptions of how a sense of community for their children is important, with ABA therapy being a prime example. Regarding services that allow her child to interact with others on the spectrum, Participant 6 said, “Now that she see other peers as her, then maybe that will help her just to be able to cope better.” Participant 10 described the potential benefit for children with ASD “just to be around their peers and kids like them,” whereas Participant 11 stated that interaction with other children on the spectrum “would maybe help him understand himself a little bit better.” This theme, which focused on the benefit of a sense of community for children with ASD, differed from Code 16 which discussed the need for a sense of inclusion and sameness among children with ASD.

Theme: Reduction in Out-of-Pocket Costs

The perceived helpfulness of services related to a reduction in out-of-pocket costs was shared by participants who discussed the high costs that their family paid out-of-pocket to cover certain services and assistance related to their child's diagnosis of ASD. Participants 1, 3, and 5 elaborated with Participant 1 discussing her desire to not have "so much information behind paywalls." Similarly, Participant 3 described the importance of initial funding as it relates to out-of-pocket costs, saying, " Uh, it increases the uh, the funding, the uh money source that I need to uh, to pay for the services and the materials that she needs for her, uh, for her autism."

Participant 5 discussed insurance covering a small portion of her child's needs, adding "So um, and even then with that coverage, you know, I would say, on a monthly basis, out-of-pocket was about a thousand dollars a month." While a reduction in out-of-pocket costs is an overall theme that participants reported would be helpful, Codes 7, 8, and 11 identified obstacles to such a reduction (Code 7- income stipulations, Code 8- child does not meet diagnosis requirements, and Code 11- family does not meet insurance requirements).

Theme: Confidence in Navigating the System with the Help of a Professional

Finally, the perceived helpfulness of confidently navigating the system with the help of a professional was shared by Participants 4, 5, 6, 7, and 12. When asked how having the help of a professional to navigate the system would be beneficial, Participant 4 stated, "I think maybe he wouldn't have had a rougher time once we figured out his diagnosis and what was going on." When asked the same question, Participant 5 said, "Government services are very complicated to understand and to know what my rights are." Participant 6 stated, "I think it would be helpful because they could do way more than what we can do as a parent." Participant 7 reported that having the help of a professional to navigate the system would open up " an abundance of resources," while Participant 12 stated, "It would give me the tools that I need to be better with him, to help with his behavior, to get him on a good track." The overall theme of having confidence in navigating the system with the help of a professional was especially relatable to Code 13- not knowing what services exist, and Code 14- not knowing where or how to start looking for services.

Table 2

Summary of Codes and Themes

Themes and Codes	Reported by Percentage of Participants
Theme: Riding an Emotional Roller Coaster	25%
Code 17: Impact on Caregiver Mental Health	50%
Theme: Feeling Alone	25%
Code 18: Feeling Unrelatable	50%
Theme: Lack of Caregiver Services	84%
Code 1: Personal Education	100%
Code 2: Peer-Parent Support Groups	8%
Code 15: Respite Care	50%
Theme: Services that Have Indirectly Helped Caregivers	92%
Code 3: Occupational Therapy (OT)	34%

Code 4: Speech Therapy	34%
Code 5: Applied Behavior Analysis (ABA) Therapy	42%
Theme: Peer-Parent Support Groups	50%
Code 13: Not Knowing What Services Exist	100%
Code 14: Not Knowing Where or How to Start	100%
Code 18: Feeling Unrelatable	50%
Theme: Respite Care	50%
Code 17: Impact on Caregiver Mental Health	50%
Theme: Uniform State/School Funding	17%
Code 8: Child Does Not Meet Diagnosis Requirements	17%
Code 10: No State/Federal Funding	17%
Theme: Activities and Facilities Specifically Designed for Children with ASD	50%
Code 16: Child Sense of Community	34%
Theme: Challenges to Utilizing Services	25%
Code 6: Services Not Offered in Area	Up to 25%
Code 7: Income Stipulations	34%
Code 8: Child Does Not Meet Diagnosis Requirements	17%
Code 9: Lack of Trust in Others	25%

Code 10: No State/Federal Funding	17%
Code 11: Family Does Not Meet Insurance Requirements	25%
Code 12: Caregiver Schedules	100%
Code 13: Not Knowing What Services Exist	100%
Code 14: Not Knowing Where or How to Start	100%
Theme: Sense of Community for the Caregiver	25%
Code 2: Peer-Parent Support Groups	8%
Theme: Sense of Community for the Child	25%
Code 5: Applied Behavior Analysis (ABA) Therapy	42%
Theme: Reduction in Out-of-Pocket Costs	25%
Code 7: Income Stipulations	34%
Code 8: Child Does Not Meet Diagnosis Requirements	17%
Code 10: No State/Federal Funding	17%
Code 11: Family Does Not Meet Insurance Requirements	25%
Theme: Confidence in Navigating the System with the Help of a Professional	42%
Code 6: Services Not Offered in Area	Up to 25%
Code 9: Lack of Trust in Others	25%
Code 13: Not Knowing What Services Exist	100%

Code 14: Not Knowing Where or How to Start	100%

Summary

Data collected from this qualitative study provides insight into the services and assistance that caregivers of children diagnosed with ASD identify as most beneficial to them. Twelve audio-recorded interviews were conducted in which participants described their lived experiences in caring for a child diagnosed with ASD. Data was collected via three research questions that yielded 18 codes and 13 themes (see Table 2). In the next chapter, an overview, summary of findings, discussion of findings, implications, limitations, and recommendations for future research will be provided.

CHAPTER 5: DISCUSSION

Overview

The purpose of this qualitative study, using the phenomenological approach via interviewing, was to describe the services and assistance caregivers of children diagnosed with ASD identified as most beneficial to them. This chapter will include a summary of the findings and will explain how these findings compare to the previously discussed research literature and biblical foundations. Furthermore, implications of the study, limitations of the study, and recommendations for future research will also be presented in this chapter.

Summary of Findings

Data collected from this study yielded 18 codes and 13 themes that coincided with the three research questions. The first research question allowed data to be collected regarding the lived experiences of caregivers of children diagnosed with ASD. The second research question collected data related to the services and assistance that these caregivers reported utilizing, being needed, and reasons for not utilizing. The final research question collected data related to the reasons why caregivers believe that certain services and assistance are helpful and/or needed.

Lived Experiences of Caregivers

As caregivers described their lived experiences in caring for a child with ASD, two main themes emerged. The first was the feeling of riding an emotional roller coaster. Some of the caregivers described how their mood fluctuated dependent on the mood of their child. The moods of both the child and the caregiver could drastically change in a matter of seconds, often related to the child having a meltdown. Many of the caregivers reported feeling alone as a result of these meltdowns and sudden, drastic changes in mood which usually limit the caregivers' ability to socialize.

Utilization, Need, and Reasons for Not Using Services

Regarding utilization, need, and reasons for not using services, seven main themes emerged. The most significant theme was the lack of caregiver services, as the majority of participants could not identify a single service that has directly helped them. However, in discussing the other themes (services that have indirectly helped caregivers, peer-parent support groups, respite care, uniform school/state funding, activities and facilities specifically designed for children with ASD, and challenges to utilizing services), participants produced more in-depth responses.

Why Certain Services and Assistance Are Helpful and/or Needed

When caregivers were asked why certain services and assistance are helpful and/or needed, four themes emerged. These themes related to caregiver sense of community, child sense of community, reduction in out-of-pocket costs, and confidence in navigating the system with the help of a professional. These themes allowed for interesting data collection as each of the participants provided a different perspective when discussing the helpfulness and/or need of the same services.

Discussion of Findings

Lived Experiences of Caregivers

Riding an Emotional Roller Coaster

Several participants in this study described caring for their child with ASD as riding an emotional roller coaster. This statement aligns with much of the research literature that associates impaired emotion regulation and tantrums with children diagnosed with ASD. One minute the child may be calm and quiet, and the next minute, for no apparent reason at times, can become upset, inconsolable, and screaming at the top of his lungs. According to Chad-Friedman et al.

(2021), caring for a child diagnosed with ASD is shown to have negative physiological and psychological consequences on the caregiver, while Waheed et al. (2020) specifically point out the negative impact that caring for a child with ASD can have on the caregiver's emotional functioning. Often, caregivers of children with ASD are left feeling isolated and unrelatable, as mentioned by participants of this study.

Feeling Alone

In particular, a participant in this study recalled feeling lonely and unrelatable. She stated that even when opportunities to socialize presented themselves, the needs, actions, and behaviors of her child prevented such interaction from occurring. This demonstrates the point made by Johnston & Iarocci (2017), that as a result of limited opportunities and failed attempts at socialization many caregivers of children diagnosed with ASD reported feeling socially isolated themselves.

Utilization, Need, and Reasons for Not Using Services

Lack of Caregiver Services

Challenges related to emotion regulation, feeling isolated, and engaging in self-care are only a few of the issues that caregivers of children diagnosed with ASD encounter. In a study conducted by Nik Adib et al. (2019), it was determined that 82% of these caregivers felt unable to overcome the difficulties they encountered in raising a child with ASD. This was exacerbated by not having the necessary services available to them. Of the twelve participants interviewed for this research study, ten could not identify a single service that has been directly helpful to them. They were, however, able to identify services established for their children which have indirectly been helpful to them.

Services that Have Indirectly Helped Caregivers

Impaired communication and socialization (APA, 2013), behavioral issues (Burnham et al., 2019), and sensory issues (Williams et al., 2018) are common in children with ASD. In regards to the benefit to caregivers, several participants involved in this study indicated that the speech therapy services that their child received helped them communicate better with their child. Additionally, occupational therapy was reported as being helpful in understanding and assisting their child with sensory issues, whereas ABA therapy was reported as being helpful in areas related to behavior problems, expression and regulation of emotions, and social and cognitive functioning.

Peer-Parent Support Groups

In determining the services that caregivers of children with ASD desired for themselves, common challenges such as stress (Fatin et al., 2021), parental burnout (Mikolajczak et al., 2021), sleep disturbances, lack of support, impaired physical and mental health (Chad-Friedman et al., 2021), and social isolation (Johnston & Iarocci, 2017) were explored. Aligning with the research to common challenges of caregivers of children with ASD, participants of this study reported their desire to have peer-parent support groups and respite care more readily available. Participants of this study determined that peer-parent support groups would provide a non-judgmental platform to speak candidly to others who can empathize with them, be supportive, and give guidance. Although peer-parent support groups are in high demand by caregivers of children with ASD, they are low in supply. Only one of the twelve participants of this study was involved with such a group.

Respite Care

Similar to the high demand and low supply for peer-parent support groups, the same applies to respite care. The intent of respite care is to provide temporary relief to the main caregiver of a child with special needs (Cooke et al., 2020). The crucial need for respite care for caregivers of children with ASD was solidified by studies indicating that caregivers of children diagnosed with ASD are twice as likely to utilize mental health facilities than caregivers of neurotypically developing children (Dijkstra-de Neijs et al., 2020) and that the stress of parenting a child diagnosed with ASD is comparable to the stress experienced by combat soldiers (Whitmore, 2016). Despite the overwhelming need for such a service, accessing respite care is a daunting process (Cooke et al., 2020) that does not always lead to fruition, as demonstrated in this study, with only one participant reporting the utilization of such services (on a limited basis).

Uniform School/State Funding

ASD is a spectrum disorder meaning that people diagnosed with the disorder present with varying degrees of impairment (Jensen & Spannagel, 2010; 2011). For example, some may be non-verbal while others possess an extensive vocabulary. Some may require significant assistance with activities of daily living, while others require minimal assistance, and some may visibly struggle in social settings while others are able to mask such struggles. Participants of this study reported having children across the entirety of the autism spectrum. However, the degree of school and state funding that the children received was not uniform. Participants of this study reported frustrations particularly related to children with higher functioning ASD diagnoses receiving less funding, and children diagnosed with ASD residing in homes that surpassed income guidelines not receiving funding at all.

Activities and Facilities Specifically Designed for Children with ASD

The vast differences that set children with ASD apart from their neurotypically developing peers are significant. For example, when a child diagnosed with ASD attempts to interact or communicate with peers and cannot do so, it could result in peer rejection (Chad-

Friedman et al., 2021). Such rejection could lead to bullying, which has been linked to depression, anxiety, low self-esteem, self-harm, and antisocial behaviors (Forrest et al., 2019; 2020). Participants of this study voiced the need for more activities and facilities specifically designed for children with ASD, providing opportunities for socialization, understanding, and inclusion.

Challenges to Utilizing Services

Participants of this study reported similar challenges to utilizing the services that could directly benefit them in caring for their child with ASD. Such challenges included lack of time, lack of energy, and lack of support or mistrust of others.

In particular, participants stated that the amount of time they spent advocating for their child significantly impacted the amount of available time they had to engage in non-related activities. According to O’Hare et al. (2021), advocating for a child with ASD involves acting as a negotiator, monitor, supporter, and case manager, and includes duties such as frequent attendance of school meetings and medical appointments, making phone calls, sending text messages and emails, and self-educating, all of which were common tasks acknowledged by participants of this study.

Participants of this study also reported that lack of energy was a challenge that prevented them from utilizing services that could directly benefit them in caring for their child with ASD. Studies show that caregivers of children diagnosed with ASD reported higher levels of stress and fatigue than caregivers of neurotypically developing children (Li et al., 2017), as well as children diagnosed with other disorders such as Down’s syndrome (Huang et al., 2014) and cerebral palsy (Kütük et al., 2021). Participants of this study acknowledged that the level of stress, fatigue, and burnout they experience directly impacts their utilization of services.

Similarly, participants of this study also reported a lack of support from others, or mistrust of others, as challenges that impact their utilization of services, namely a lack of support from friends, family, and community members, or mistrust in providers such as educators, medical professionals, and the childcare industry. Participants reporting at least one of these issues identified them as challenges to utilizing services that could directly assist them in caring for their child with ASD.

Why Certain Services and Assistance Are Helpful and/or Needed

When asked why certain services and assistance are helpful and/or needed, each participant of this study provided their perspective, especially in the areas related to a sense of community for the caregiver, a sense of community for their child, a reduction in out-of-pocket costs, and confidence in navigating the system with the help of a professional.

Sense of Community for Caregiver

On a more frequent basis than caregivers of neurotypically developing children, caregivers of children with ASD experience stress, fatigue, burnout, sleep disturbances, impaired physical and mental health, limited self-care, marital conflicts, financial hardships, social isolation and discrimination, lack of support or understanding, and mistrust of others. For example, a study conducted by Li et al. (2017) revealed that only 2% of caregivers of neurotypically developing children met stress levels in the clinical range, compared to 34% of caregivers of children diagnosed with ASD.

A study conducted by Al-Mazidi and Al-Ayadhi (2021) determined that less than 10% of caregivers of children with ASD reported receiving proper psychological care for themselves, with caregivers reportedly feeling “stretched” beyond their limits and abilities (Davis & Carter, 2008). This was a common feeling reported by participants of this study as well, however, several stated that they did not believe they could open up to others about their struggles because others could not relate. All twelve participants of this study agreed that a sense of community for caregivers of children with ASD is necessary and could be beneficial in providing support, understanding, and inclusion.

Sense of Community for Child

Similarly, a sense of community for children with ASD is important as well. Common issues associated with ASD include difficulties in communication and emotion regulation, behavioral problems, restricted interests, thinking or behaving at a level below one's chronological age, sensory issues, sleep disturbances, incontinence, gastrointestinal disorders, comorbid psychological disorders, academic difficulties, and impairments in social cognition and functioning. Often, these issues impede the child's ability to make friends and increase the likelihood that they will be bullied. Research indicates that over 50% of children diagnosed with ASD have been the victim of bullying, compared to 20-30% of neurotypically developing peers (Forrest et al., 2019; 2020). Children diagnosed with ASD may experience loneliness or feel demoralized when comparing themselves to their neurotypically developing peers (Chamberlain et al., 2007), often due to social isolation (Cooper et al., 2021). Participants of this study agreed that a sense of community for their child was equally as important to them as their own sense of community.

Reduction in Out-of-Pocket Costs

Regarding a reduction in out-of-pocket costs, Waheed et al. (2020) discussed the unique financial hardships and economic disadvantages of caregivers of children with ASD. Examples of such hardships include earning statistically less than caregivers of neurotypically developing children, struggles related to employment including unemployment and underemployment, and the need to take more time off from work than caregivers of neurotypically developing children. Participants of this study identified with these concepts and described their perception of how a reduction in the out-of-pocket costs associated with caring for their child with ASD is needed, particularly in areas related to education, childcare, and medical care. Participants of this study discussed how expenses related to special education, tutoring, specialized child care, therapies, medications, and time and travel to appointments add up quickly. All twelve participants of this study, even those who identified as "upper-middle class," agreed that a reduction in out-of-pocket costs would benefit their household.

Confidence in Navigating the System with the Help of a Professional

Lastly, participants of this study described their perception of how having the confidence of navigating the system with the help of a professional could benefit them. Similar to studies conducted by Al-Mazidi and Al-Ayadhi (2021) and O'Hare et al. (2021), areas in which participants reported the most significant benefit were related to interactions with medical professionals, insurance companies, and the education system. These three entities are commonly reported as being intimidating to caregivers of children with ASD, with one participant from this study describing her feelings of being overwhelmed and lacking knowledge about her basic legal rights in advocating for her child. Other participants of this study described how navigating the system with the help of a professional could help reduce clerical errors in documentation ultimately shortening the time spent on waiting lists, be a source of guidance, knowledge, and clarity, and provide them access to resources they had not previously been aware of to help their child.

Biblical Foundations

Studies have shown that not feeling understood, being treated differently, and being aware of such differential treatment were all factors that hindered those with disabilities from participating in religious and/or faith-based activities (McMahon-Panther & Bornman, 2020). Although none of the participants of this research study explicitly discussed this matter, the information they provided did align with the general concept.

In biblical days, ASD was not a known disorder (Macaskill, 2018), but is viewed today as a functional deficit, measured against the standard that society deems “normal” (Macaskill, 2020). Children with ASD and their caregivers bear daily burdens that surpass what may be deemed “normal” by society. Nonetheless, biblical instruction orders followers of Christ to bear the burdens of one another. Unfortunately, issues reported by participants of this study such as feeling alone, significant lack of services, and extreme challenges to utilizing existing services, suggest that this population’s burdens are not being shared by others.

Based on these findings, it appears the church has a unique opportunity to assist those who care for children with ASD. In planning programs and developing outreach, the church should consider ways to help those who carry unique caregiving burdens, such as caregivers of children with ASD. The community of believers that is the church can help alleviate some of the hardships described by the participants of this study.

Implications

Findings from this study should be used by the scientific, psychological, and religious communities to broaden the services and assistance that caregivers of children diagnosed with ASD identify as being most needed and beneficial. The scientific community, for example, could further examine data collected from this study, especially in areas related to sleep disturbances (e.g.; sleep studies) and impaired physical and mental health (e.g.; pharmaceuticals) to identify services and assistance that may be beneficial to caregivers of children with ASD. Similarly, since less than 10% of caregivers of children with ASD reported receiving proper psychological care for themselves (Al-Mazidi & Al-Ayadhi, 2021), those in the psychological community could use the findings of this study to improve upon practices and policies which may be beneficial to this population, especially in areas such as lack of support, lack of understanding, and mistrust of others, which could be improved upon in counseling sessions. Finally, those in the religious community could use the findings of this study to create and expand upon services to help this population, particularly in areas related to self-care and financial hardships by offering programs such as “Mom’s Morning Out” and church offerings or no-interest, loan repayment options.

Limitations

Previously stated limitations of this study related to the small sample size, the depth of information caregivers of children diagnosed with ASD would provide, and that recruitment methods may have produced participants most engaged in the care of their child, possibly limiting data related to the perspective of those caregivers who feel least supported. An additional limitation discovered while conducting this study was that some caregivers had not yet gone through certain experiences and were therefore unable to provide significant data.

Recommendations for Future Research

It is my recommendation that similar studies be conducted in the future using a larger sample population. This will allow the collection of more rich data, especially in terms of statistical data. Also, in an effort to minimize limitations, it is recommended that participants meet requirements such as having a child who has been diagnosed with ASD for at least three years, as this will increase the likelihood that the participant is able to provide significant data regarding a variety of lived experiences. Another recommendation for future research would be to conduct this study in multiple geographic locations to compare and contrast data (e.g.; caregivers living in rural areas versus caregivers living in urban areas). A final recommendation would be to include research on how the church could help fill in the gaps in the service needs reported by participants of this study.

Summary

The purpose of this qualitative study, using the phenomenological approach via interviewing, was to describe the services and assistance caregivers of children diagnosed with ASD identified as most beneficial to them. The results of this study identified the strong need for more readily available services and assistance for these caregivers, particularly in areas such as self-care, support or understanding, and mistrust of others.

Unless an individual has lived the life of a caregiver of a child diagnosed with ASD, he or she will not be able to fully understand the physical, social, and emotional effects placed on this population. Caregivers of children with ASD are more likely to suffer from stress (Padden & James, 2017; Fatin et al., 2021), burnout (Mikolajczk et al., 2021), sleep disturbances (Chad-Friedman et al., 2021), physiological problems such as obesity, heart disease, diabetes, and gastrointestinal issues (Li et al., 2017), and psychiatric disorders such anxiety and depression (Chad-Friedman et al., 2021) than caregivers of neurotypically developing children.

Furthermore, this population experiences a higher divorce rate (up to 80%) than caregivers of neurotypically developing children (Lashewicz et al., 2018), and experiences more financial hardships (earning 28% less when able to maintain employment) than caregivers of children with neurotypically developing children (Benevides et al., 2019). Reports of feeling stigmatized (Thibodeau et al., 2017), discriminated against, and socially isolated (Johnston &

Iarocci, 2017) are also more common among caregivers of children with ASD, with some reporting that they do not even feel fully welcomed by church congregations (Brock, 2021).

It is important to remember that God does not make mistakes. Children diagnosed with ASD were born as such so that the works of God could be made manifest in them (King James Bible, 2015). Caregivers of these children encounter unique struggles that could be improved upon by religious, scientific, and psychological communities alike, as indicated by this study. Although caregivers of children with ASD are faced with challenges, and delegated responsibilities that may be incomprehensible to some, there is comfort in knowing that with God, all things are possible (King James Bible, 2015).

References

Al-Mazidi, S. H., & Al-Ayadhi, L. Y. (2021). National profile of caregivers' perspectives on autism spectrum disorder screening and care in primary health care: The need for autism medical home. *International Journal of Environmental Research and Public Health, 18*(24), 13043. https://doi.org/10.3390/ijerph182413043

Alvares, G. A., Bebbington, K., Cleary, D., Evans, K., Glasson, E. J., Maybery, M. T., Pillar, S., Uljarević, M., Varcin, K., Wray, J., & Whitehouse, A. J. (2020). The misnomer of 'high functioning autism': Intelligence is an imprecise predictor of functional abilities at diagnosis. *Autism: The International Journal of Research and Practice, 24*(1), 221-232. https://doi.org/10.1177/1362361319852831

American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC: Author.

Argumedes, M., Lanovaz, M. J., & Larivée, S. (2018). Brief report: Impact of challenging behavior on parenting stress in mothers and fathers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 48*(7), 2585-2589. https://doi.org/10.1007/s10803-018-3513-1

Ault, M. J., Slocum, V., Collins, B. C., Leahy, M. M., & Miller, V. P. (2021). Perceptions of faith leaders on the inclusion and participation of individuals with disabilities in their communities. *Journal of Disability & Religion*, ahead of print, 1-22. https://doi.org/10.1080/23312521.2021.1932691

Baykal, S., Karakurt, M. N., Çakır, M., & Karabekiroğlu, K. (2018;2019;). An examination of the relations between symptom distributions in children diagnosed with autism and caregiver burden, anxiety and depression levels. *Community Mental Health Journal, 55*(2), 311-317. https://doi.org/10.1007/s10597-018-0343-8

Benevides, T. W., Lee, J., Nwosu, N. A. O., & Franks, J. (2019). Understanding the family impact of autism spectrum disorder in a racially and ethnically diverse sample: Findings from the national survey of children with special health care needs. *Maternal and Child Health Journal*, *23*(7), 951-960. https://doi.org/10.1007/s10995-018-02724-x

Bernier, A., Carlson, S. M., & Whipple, N. (2010). From external regulation to self-regulation: Early parenting precursors of young children's executive functioning. *Child Development, 81*(1), 326-339. https://doi.org/10.1111/j.1467-8624.2009.01397.x

Bonnet-Brilhault, F., Rajerison, T. A., Paillet, C., Guimard-Brunault, M., Saby, A., Ponson, L., Tripi, G., Malvy, J., & Roux, S. (2018). Autism is a prenatal disorder: Evidence from late gestation brain overgrowth. *Autism Research, 11*(12), 1635-1642. https://doi.org/10.1002/aur.2036

Brignell, A., Chenausky, K. V., Song, H., Zhu, J., Suo, C., Morgan, A. T., & Song, H. (2018). Communication interventions for autism spectrum disorder in minimally verbal children. *Cochrane Database of Systematic Reviews*, *2018*(11), CD012324-CD012324. https://doi.org/10.1002/14651858.CD012324.pub2

Brock, B. (2021). Autism and the image of god: On becoming a mobile and reproductive church. *Cultural Encounters*, *16*(2), 5-20.

Burnham Riosa, P., Khan, M., & Weiss, J. A. (2019). Measuring therapeutic alliance in children with autism during cognitive behavior therapy. *Clinical Psychology and Psychotherapy, 26*(6), 761-767. https://doi.org/10.1002/cpp.2404

Carter, R. M., Jung, H., Reaven, J., Blakeley-Smith, A., & Dichter, G. S. (2020). A nexus model of restricted interests in autism spectrum disorder. *Frontiers in Human Neuroscience, 14*, 212-212. https://doi.org/10.3389/fnhum.2020.00212

Centers for Disease Control and Prevention. (2022). *Data and statistics on autism spectrum disorder*. https://www.cdc.gov/ncbddd/autism/data/html

Chad-Friedman, E., Kuhlthau, K. A., Millstein, R. A., Perez, G. K., Luberto, C. M., Traeger, L., Proszynski, J., & Park, E. (2021). Characteristics and experiences of parents of children with learning and attention disabilities and autism spectrum disorder: A mixed methods study. *The Family Journal (Alexandria, Va.),* 106648072110523. https://doi.org/10.1177/10664807211052304

Chamberlain, B., Kasari, C., & Rotheram-Fuller, E. (2007). Involvement or isolation? the social networks of children with autism in regular classrooms. *Journal of Autism and Developmental Disorders, 37*(2), 230-242. https://doi.org/10.1007/s10803-006-0164-4

Chen, Y., Zhou, Z., Cao, M., Liu, M., Lin, Z., Yang, W., Yang, X., Dhaidhai, D., & Xiong, P. (2022). Extended reality (XR) and telehealth interventions for children or adolescents with autism spectrum disorder: Systematic review of qualitative and quantitative studies. *Neuroscience and Biobehavioral Reviews, 138,* 104683-104683. https://doi.org/10.1016/j.neubiorev.2022.104683

Cohen, S., & Hamrick, N. (2003). *Stable individual differences in physiological response to stressors: Implications for stress-elicited changes in immune related health*. Elsevier Inc. https://doi.org/10.1016/S0889-1591(03)00110-7

Coleman, P. (2021). Validity and reliability within qualitative research in the caring sciences. *International Journal of Caring Sciences, 14*(3), 2041-2045.

Conner, C. M., White, S. W., Beck, K. B., Golt, J., Smith, I. C., & Mazefsky, C. A. (2019). Improving emotion regulation ability in autism: The emotional awareness and skills enhancement (EASE) program. *Autism: The International Journal of Research and Practice, 23*(5), 1273-1287. https://doi.org/10.1177/1362361318810709

Cooke, E., Smith, V., & Brenner, M. (2020). Parents' experiences of accessing respite care for children with autism spectrum disorder (ASD) at the acute and primary care interface: A systematic review. *BMC Pediatrics, 20*(1), 244-244. https://doi.org/10.1186/s12887-020-02045-5

Cooper, R., Cooper, K., Russell, A. J., & Smith, L. G. E. (2021). “I’m proud to be a little bit different”: The effects of autistic individuals’ perceptions of autism and autism social identity on their collective self-esteem. *Journal of Autism and Developmental Disorders, 51*(2), 704-714. https://doi.org/10.1007/s10803-020-04575-4

Cook-Cottone, C. P., & Guyker, W. M. (2018). The development and validation of the mindful self-care scale (MSCS): An assessment of practices that support positive embodiment. *Mindfulness, 9*(1), 161-175. https://doi.org/10.1007/s12671-017-0759-1

Daniels, A. M., Como, A., Hergüner, S., Kostadinova, K., Stosic, J., & Shih, A. (2017). Autism in southeast europe: A survey of caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 47*(8), 2314-2325. https://doi.org/10.1007/s10803-017-3145-x

Da Paz, N. S., Siegel, B., Coccia, M. A., & Epel, E. S. (2018). Acceptance or despair? maternal adjustment to having a child diagnosed with autism. *Journal of Autism and Developmental Disorders, 48*(6), 1971-1981. https://doi.org/10.1007/s10803-017-3450-4

Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*(7), 1278-1291. https://doi.org/10.1007/s10803-007-0512-z

Deliens, G., & Peigneux, P. (2019). Sleep–behaviour relationship in children with autism spectrum disorder: Methodological pitfalls and insights from cognition and sensory processing. *Developmental Medicine and Child Neurology*, *61*(12), 1368-1376. https://doi.org/10.1111/dmcn.14235

Derikx, Dagmar F. A. A, Houwen, S., Meijers, V., Schoemaker, M. M., & Hartman, E. (2021). The relationship between social environmental factors and motor performance in 3- to 12-year-old typically developing children: A systematic review. *International Journal of Environmental Research and Public Health*, *18*(14), 7516. https://doi.org/10.3390/ijerph18147516

Dijkstra-de Neijs, L., Leenen, P. J. M., Hays, J. P., van der Valk, E. S, Kraaij, R., van Rossum, E. F. C, & Ester, W. A. (2020). Biological consequences of psychological distress in caregivers of children with autism spectrum disorder and its potential relevance to other chronic diseases including cancer. *Current Epidemiology Reports, 7*(3), 139-148. https://doi.org/10.1007/s40471-020-00237-2

Dinora, P., & Bogenschutz, M. (2018). Narratives on the factors that influence family decision making for young children with autism spectrum disorder. *Journal of Early Intervention*, *40*(3), 195-211. https://doi.org/10.1177/1053815118760313

Drapela, L. A., & Baker, D. L. (2014). Policy awareness, financial hardship, and work impact: Correlates of negative experiences with health care providers and health care insurers among caregivers of children with autism spectrum disorder. *SAGE Open*, *4*(3), 215824401455321. https://doi.org/10.1177/2158244014553212

Ekas, N. V., Whitman, T. L., & Shivers, C. (2008;2009;). Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 39*(5), 706-719. https://doi.org/10.1007/s10803-008-0673-4

Elmose, M., & Happé, F. (2014). Being aware of own performance: How accurately do children with autism spectrum disorder judge own memory performance? *Autism Research, 7*(6), 712-719. https://doi.org/10.1002/aur.1421

Falk, N. H., Norris, K., & Quinn, M. G. (2014). The factors predicting stress, anxiety and depression in the parents of children with autism. *Journal of Autism and Developmental Disorders, 44*(12), 3185-3203. https://doi.org/10.1007/s10803-014-2189-4

Fasano, A., & Hill, I. (2017). Serum zonulin, gut permeability, and the pathogenesis of autism spectrum disorders: Cause, effect, or an epiphenomenon? *The Journal of Pediatrics, 188,* 15-17. https://doi.org/10.1016/j.jpeds.2017.05.038

Fatin, Samsul, D., Mohammad, C. M., Zubir, Y. M., Rozanizam, Z., & Amilin, H. N. (2021). Prevalence of depression, anxiety, stress symptoms and the related factors among caregivers of children with autism spectrum disorder in kuantan, pahang. *Malaysian Family Physician*, *16*, 33-34.

Fausto-Sterling, A. (2021). A dynamic systems framework for Gender/Sex development: From sensory input in infancy to subjective certainty in toddlerhood. *Frontiers in Human Neuroscience, 15,* 613789-613789. https://doi.org/10.3389/fnhum.2021.613789

Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology, 48*(1), 150-170. https://doi.org/10.1037/0022-3514.48.1.150

Forrest, D. L., Kroeger, R. A., & Stroope, S. (2019; 2020). Autism spectrum disorder symptoms and bullying victimization among children with autism in the united states. *Journal of Autism and Developmental Disorders, 50*(2), 560-571. https://doi.org/10.1007/s10803-019-04282-9

Garrett, B., & Hough, G. (2018). *Brain and behavior: An introduction to behavioral neuroscience*, 5th ed. Sage. ISBN: 978-1-5063-4920-6

Gulsrud, A., Lee, H. S., Hassrick, E. M., Iadarola, S., Pellecchia, M., Shih, W., Vejnoska, S., Morgan, E. H., Hochheimer, S., Crabbe, S., Li, J., Hauptman, L., Castellon, F., Nuske, H., Garcia, C., King, R., Luelmo, P., Carley, K., Smith, T., . . . Stahmer, A. C. (2021). It's who you know: Caregiver social networks predict service use among under-resourced children with autism. *Research in Autism Spectrum Disorders, 88,* 101843. https://doi.org/10.1016/j.rasd.2021.101843

Haakonsen-Smith, C., Turbitt, E., Muschelli, J., Leonard, L., Lewis, K. L., Freedman, B., Muratori, M., & Biesecker, B. B. (2017;2018;). Feasibility of coping effectiveness training for caregivers of children with autism spectrum disorder: A genetic counseling intervention. *Journal of Genetic Counseling, 27*(1), 252-262. https://doi.org/10.1007/s10897-017-0144-1

Henriques, G. R. (2004). Psychology defined. *Journal of Clinical Psychology, 60*(12), 1207-1221. https://doi.org/10.1002/jclp.20061

Herrington, J. D., Maddox, B. B., Kerns, C. M., Rump, K., Worley, J. A., Bush, J. C., McVey, A. J., Schultz, R. T., & Miller, J. S. (2017). Amygdala volume differences in autism spectrum disorder are related to anxiety. *Journal of Autism and Developmental Disorders, 47*(12), 3682-3691. https://doi.org/10.1007/s10803-017- 3206-1

Hillman, K., Dix, K., Ahmed, K., Lietz, P., Trevitt, J., O'Grady, E., Uljarevic, M., Vivanti, G., & Hedley, D. (2020). Interventions for anxiety in mainstream school-aged children with autism spectrum disorder: A systematic review. *Campbell Systematic Review, 16*(2), n/a. https://doi.org/10.1002/cl2.1086

Hohn, V. D., de Veld, Danielle M J, Mataw, K. J. S., van Someren, Eus J W, & Begeer, S. (2019). Insomnia severity in adults with autism spectrum disorder is associated with sensory hyper-reactivity and social skill impairment. *Journal of Autism and Developmental Disorders, 49*(5), 2146-2155. https://doi.org/10.1007/s10803-019-03891-8

Horder, J., Petrinovic, M. M., Mendez, M. A., Bruns, A., Takumi, T., Spooren, W., Barker, G. J., Künnecke, B., & Murphy, D. G. (2018). Glutamate and GABA in autism spectrum disorder-a translational magnetic resonance spectroscopy study in man and rodent models. *Translational Psychiatry, 8*(1), 106-11. https://doi.org/10.1038/s41398-018-0155-1

Huang, C., Huang, C., Yen, H., Yen, H., Tseng, M., Tseng, M., Tung, L., Tung, L., Chen, Y., Chen, Y., Chen, K., & Chen, K. (2013; 2014). Impacts of autistic behaviors, emotional and behavioral problems on parenting stress in caregivers of children with autism. *Journal of Autism and Developmental Disorders, 44*(6), 1383-1390. https://doi.org/10.1007/s10803-013-2000-y

Iadarola, S., Pellecchia, M., Stahmer, A., Lee, H. S., Hauptman, L., Hassrick, E. M., Crabbe, S., Vejnoska, S., Morgan, E., Nuske, H., Luelmo, P., Friedman, C., Kasari, C., Gulsrud, A., Mandell, D., & Smith, T. (2020). Mind the gap: An intervention to support caregivers with a new autism spectrum disorder diagnosis is feasible and acceptable. *Pilot and Feasibility Studies, 6*(1), 124-124. https://doi.org/10.1186/s40814-020-00662-6

Ismail, M. F., Safii, R., Saimon, R., & Rahman, M. M. (2021;2022;). Quality of life among malaysian parents with autism spectrum disorder child: The double ABCX model approach. *Journal of Autism and Developmental Disorders, 52*(1), 113-123. https://doi.org/10.1007/s10803-021-04929-6

Jamison, J.M., Fourie, E., Siper, P.M., Trelles, M.P., George-Jones, J., Buxbaum Grice, A.,…Kolevzon, A. (2017). Examining the efficacy of a family peer advocate model for black and hispanic caregivers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(5), 314-1322. Doi: 10.1007/s10803-017-3045-0

Jensen, V. K., & Spannagel, S. C. (2010;2011;). The spectrum of autism spectrum disorder: A spectrum of needs, services, and challenges. *Journal of Contemporary Psychotherapy, 41*(1), 1-9. https://doi.org/10.1007/s10879-010-9161-1

Ji, L., Zhao, Q., Gu, H., Chen, Y., Zhao, J., Jiang, X., & Wu, L. (2021). Effect of executive function on event-based prospective memory for different forms of learning disabilities. *Frontiers in Psychology, 12,* 528883-528883. https://doi.org/10.3389/fpsyg.2021.528883

Johnston, K. H. S., & Iarocci, G. (2017). Are generalized anxiety and depression symptoms associated with social competence in children with and without autism spectrum disorder? *Journal of Autism and Developmental Disorders, 47*(12), 3778-3788. https://doi.org/10.1007/s10803-017-3056-x

Jones, B. (2014). Human genetics: Autism - clues from brains and protein domains. *Nature Reviews. Genetics, 15*(5), 287-287. https://doi.org/10.1038/nrg3715

King James Bible. (2015). Whitaker House Publishing. (Original work published 2001).

Kohn, G.M. (2019). How social systems persist: Learning to build a social network in an uncertain world. *Animal Behaviour, 154,* 1-6. https://doi.org/10.1016/j.anbehav.2019.06.006

Kojovic, N., Ben Hadid, L., Franchini, M., & Schaer, M. (2019). Sensory processing issues and their association with social difficulties in children with autism spectrum disorders. *Journal of Clinical Medicine, 8*(10), 1508. https://doi.org/10.3390/jcm8101508

Kristoffersson, E., Dahlgren Sandberg, A., Holck, P., Göteborgs universitet, Gothenburg University, Samhällsvetenskapliga fakulteten, Psykologiska institutionen, Department of Psychology, & Faculty of Social Sciences. (2020). Communication ability and communication methods in children with cerebral palsy. *Developmental Medicine and Child Neurology, 62*(8), 933-938. https://doi.org/10.1111/dmcn.14546

Kütük, M. Ö., Tufan, A. E., Kılıçaslan, F., Güler, G., Çelik, F., Altıntaş, E., Gökçen, C., Karadağ, M., Yektaş, Ç., Mutluer, T., Kandemir, H., Büber, A., Topal, Z., Acikbas, U., Giray, A., & Kütük, Ö. (2021). High depression symptoms and burnout levels among parents of children with autism spectrum disorders: A multi-center, cross-sectional, Case–Control study. *Journal of Autism and Developmental Disorders, 51*(11), 4086-4099. https://doi.org/10.1007/s10803-021-04874-4

Li, X. S., Pinto-Martin, J. A., Thompson, A., Chittams, J., & Kral, T. V. E. (2018). Weight status, diet quality, perceived stress, and functional health of caregivers of children with autism spectrum disorder. *Journal for Specialists in Pediatric Nursing, 23*(1), e12205-n/a. https://doi.org/10.1111/jspn.12205

Lai, M., Lombardo, M. V., & Baron-Cohen, S. (2014). Autism. *The Lancet (British Edition), 383*(9920), 896-910. https://doi.org/10.1016/S0140-6736(13)61539-1

Lashewicz, B., Boettcher, N., Lo, A., Shipton, L., & Parrott, B. (2018). Fathers raising children with autism spectrum disorder: Stories of marital stability as key to parenting success. *Issues in Mental Health Nursing, 39*(9), 786-794. https://doi.org/10.1080/01612840.2018.1466943

Lei, X., & Kantor, J. (2021). Social support and family functioning in chinese families of children with autism spectrum disorder. *International Journal of Environmental Research and Public Health, 18*(7), 3504. https://doi.org/10.3390/ijerph18073504

Likhitweerawong, N., Boonchooduang, N., & Louthrenoo, O. (2020). Parenting styles, parental stress, and quality of life among caregivers of thai children with autism. *International Journal of Disability, Development, and Education,* 1-14. https://doi.org/10.1080/1034912X.2020.1837354

Lim, T. S. H., Tan, M. Y., Aishworiya, R., Kang, Y. Q., Koh, M. Y., Shen, L., & Chong, S. C. (2021;2022;). Factors contributing to psychological ill-effects and resilience of caregivers of children with developmental disabilities during a nation-wide lockdown during the COVID-19 pandemic. *Journal of Autism and Developmental Disorders, 52*(7), 3015-3025. https://doi.org/10.1007/s10803-021-05180-9

Limeres, J., Diz, P., Abeleira, M. T., Outumuro, M., Fernández-Feijoo, J., Diniz-Freitas, M., & García-Caballero, L. (2019). Brief report: Estimating the dental age of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 49*(6), 2612-2617. https://doi.org/10.1007/s10803-019-04007-y

Lin, H., Bourque, J., Zeanah, P., & McFatter, R. (2018). Perceptions of stress and enrichment in caregivers of children with autism spectrum disorder: Implications for community support. *Societies (Basel, Switzerland), 8*(3), 88. https://doi.org/10.3390/soc8030088

Lord, C., Elsabbagh, M., Baird, G., & Veenstra-Vanderweele, J. (2018). Autism spectrum disorder. *The Lancet (British Edition), 392*(10146), 508-520. https://doi.org/10.1016/S0140-6736(18)31129-2

Loubersac, J., Michelon, C., Ferrando, L., Picot, M., & Baghdadli, A. (2021). Predictors of an earlier diagnosis of autism spectrum disorder in children and adolescents: A systematic review (1987-2017). *European Child & Adolescent Psychiatry,* https://doi.org/10.1007/s00787-021-01792-9

Lovell, B., Elder, G. J., & Wetherell, M. A. (2021). Sleep disturbances and physical health problems in caregivers of children with ASD. *Research in Developmental Disabilities, 113*, 103932-103932. https://doi.org/10.1016/j.ridd.2021.103932

Lovell, B., & Wetherell, M.A. (2019). Affiliate stigma, perceived social support and perceived stress in caregivers of children with autism spectrum disorder: A multiple mediation study. *Archives of Psychiatric Nursing, 33*(5), 31-35. https://doi.org/10.1016/j.apnu.2019.08.012

Macaskill, G. (2018). Autism spectrum disorders and the new testament: Preliminary reflections. *Journal of Disability & Religion, 22*(1), 15-41. https://doi.org/10.1080/23312521.2017.1373613

Macaskill, G. (2020). Joy and autism: Biblical, theological and practical perspectives. *Journal of Disability & Religion, 24*(3), 268-280. https://doi.org/10.1080/23312521.2020.1750535

Macaskill, G. (2021). The bible, autism and other profound developmental conditions: Regulating hermeneutics. *Journal of Disability &* Religion, ahead of print, 1-25. https://doi.org/10.1080/23312521.2021.1881024

Madra, M., Ringel, R., & Margolis, K. G. (2020). Gastrointestinal issues and autism spectrum disorder. *Child and Adolescent Psychiatric Clinics of North America, 29*(3), 501-513. https://doi.org/10.1016/j.chc.2020.02.005

Marsack-Topolewski, C. N., Samuel, P. S., & Tarraf, W. (2021). Empirical evaluation of the association between daily living skills of adults with autism and parental caregiver burden. *PloS One*, *16*(1), e0244844-e0244844. https://doi.org/10.1371/journal.pone.0244844

Mayes, S. D., Calhoun, S. L., Baweja, R., & Waschbusch, D. A. (2020;2021;). Relative frequency of psychiatric, neurodevelopmental, and somatic symptoms as reported by mothers of children with autism compared with ADHD and typical samples. *Journal of Autism and Developmental Disorders, 51*(7), 2297-2307. https://doi.org/10.1007/s10803-020-04697-9

Mazurek, M.O., Sohl, K. (2016). Sleep and behavioral problems in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(6), 1906-1915. doi: 10.1007/s10803-016-2723-7

McMahon-Panther, G., & Bornman, J. (2021). The perceptions of persons with disabilities, primary caregivers and church leaders regarding barriers and facilitators to participation in a methodist congregation. *Journal of Disability & Religion*, ahead of print, 1-47. https://doi.org/10.1080/23312521.2020.1859040

Mikolajczak, M., Gross, J. J., & Roskam, I. (2021). Beyond job burnout: Parental burnout. *Trends in Cognitive Sciences, 25*(5), 333-336. https://doi.org/10.1016/j.tics.2021.01.012

Milgramm, A., Corona, L. L., Janicki-Menzie, C., & Christodulu, K. V. (2021;2022;). Community-based parent education for caregivers of children newly diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 52*(3), 1200-1210. https://doi.org/10.1007/s10803-021-05025-5

Nah, Y., Young, R.L., & Brewer, N. (2019). Development of a brief version of the autism detection in early childhood. *Autism: The International Journal of Research and Practice, 23*(2), 494-502. Doi: 10.1177/1362361318757563

Niemczyk, J., Fischer, R., Wagner, C., Burau, A., Link, T., & von Gontard, A. (2019). Detailed assessment of incontinence, psychological problems and parental stress in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 49*(5), 1966-1975. https://doi.org/10.1007/s10803-019-03885-6

Nijman, S., Veling, W., Greaves-Lord, K., Vermeer, R., Vos, M., Zandee, C., Zandstra, D., Geraets, C., & Pijnenborg, G. (2019). Dynamic interactive social cognition training in virtual reality (DiSCoVR) for social cognition and social functioning in people with a psychotic disorder: Study protocol for a multicenter randomized controlled trial. *BMC Psychiatry, 19*(1), 272-272. https://doi.org/10.1186/s12888-019-2250-0

Nik Adib, N. A., Ibrahim, M. I., Ab Rahman, A., Bakar, R. S., Yahaya, N. A., Hussin, S., & Wan Mansor, Wan Nor Arifin. (2019). Perceived stress among caregivers of children with autism spectrum disorder: A state-wide study. *International Journal of Environmental Research and Public Health*, *16*(8), 1468. https://doi.org/10.3390/ijerph16081468

Oerbeck, B., Overgaard, K. R., Attwood, T., & Bjaastad, J. F. (2021). “Less stress”: A pilot study on a cognitive behavioral treatment program for anxiety in children with autism spectrum disorders. *Scandinavian Journal of Child and Adolescent Psychiatry and Psychology*, *9*(1), 30-40. https://doi.org/10.21307/sjcapp-2021-005

O'Hare, A., Saggers, B., Mazzucchelli, T., Gill, C., Hass, K., Shochet, I., Orr, J., Wurfl, A., & Carrington, S. (2021). 'he is my job': Autism, school connectedness, and mothers' roles. *Disability &* Society, ahead of print, 1-22. https://doi.org/10.1080/09687599.2021.1976110

Ortiz-Rubio, A., Torres-Sánchez, I., Cabrera-Martos, I., Rodríguez-Torres, J., López-López, L., Prados-Román, E., & Valenza, M. C. (2021). The caregiver burden inventory as a sleep disturbance screening tool for parents of children with autism spectrum disorder. *Journal of Pediatric Nursing*, *61*, 166-172. https://doi.org/10.1016/j.pedn.2021.05.013

Ozgur, B., Aksu, H., & Eser, E. (2018). Factors affecting quality of life of caregivers of children diagnosed with autism spectrum disorder. *Indian Journal of Psychiatry*, *60*(3), 278-285. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_300_17

Padden, C., & James, J. E. (2017). Stress among parents of children with and without autism spectrum disorder: A comparison involving physiological indicators and parent self-reports. *Journal of Developmental and Physical Disabilities*, *29*(4), 567-586. https://doi.org/10.1007/s10882-017-9547-z

Piferi, R. L. (2001). *Giving social support to others: Psychological and ambulatory blood pressure correlates* [Doctoral dissertation, University of Tennessee-Knoxville]. ProQuest Dissertations Publishing.

Pinkham, A.E., Morrison, K.E., Penn, D.L., Harvey, P.D., Kelsven, S., Kelsey, L., & Sasson, N.J. (2020). Comprehensive comparison of social cognitive performance in autism spectrum disorder and schizophrenia. *Psychological Medicine, 50*(15), 2557-2565. http://dx.doi.org/ezproxy.liberty.edu/10.1017/S0033291719002708

Piro-Gambetti, B., Rodriguez, G., Papp, L. M., Greenlee, J. L., & Hartley, S. L. (2021). Parent couple conflict and emotional and behavioral problems in youth with autism: Longitudinal investigation of bidirectional effects. *Development and Psychopathology,* 1-11. https://doi.org/10.1017/S0954579421000596

Recio, P., Molero, F., García-Ael, C., & Pérez-Garín, D. (2020). Perceived discrimination and self-esteem among family caregivers of children with autism spectrum disorders (ASD) and children with intellectual disabilities (ID) in spain: The mediational role of affiliate stigma and social support. *Research in Developmental Disabilities, 105*, 103737-103737. https://doi.org/10.1016/j.ridd.2020.103737

Reda, M., Meguid, N. A., Eid, O. M., Hussein, F., & Elalfy, D. Y. (2021). Study of sensory processing deficits in autism spectrum disorder symptom triad: An egyptian sample. *Middle East Current Psychiatry (Cairo), 28*(1), 1-9. https://doi.org/10.1186/s43045-020-00082-5

Riegel, B., Dunbar, S. B., Fitzsimons, D., Freedland, K. E., Lee, C. S., Middleton, S., Stromberg, A., Vellone, E., Webber, D. E., & Jaarsma, T. (2021;2019;). Self-care research: Where are we now? where are we going? *International Journal of Nursing Studies, 116*, 103402-103402. https://doi.org/10.1016/j.ijnurstu.2019.103402

Reyes, N. M., Factor, R., & Scarpa, A. (2020). Emotion regulation, emotionality, and expression of emotions: A link between social skills, behavior, and emotion problems in children with ASD and their peers. *Research in Developmental Disabilities, 106*, 103770-103770. https://doi.org/10.1016/j.ridd.2020.103770

Rimmer, J., Lawrence, C., & Mahon, L. (2020;2021;). 'I can't understand a word he says': A personal exploration of autistic dysfluency in film. *Disability & Society, 36*(2), 332-336. https://doi.org/10.1080/09687599.2020.1838262

Robain, F., Kojovic, N., Solazzo, S., Glaser, B., Franchini, M., & Schaer, M. (2021). The impact of social complexity on the visual exploration of others' actions in preschoolers with autism spectrum disorder. *BMC Psychology, 9*(1), 50-50. https://doi.org/10.1186/s40359-021-00553-2

Salomone, E., Leadbitter, K., Aldred, C., Barrett, B., Byford, S., Charman, T., Howlin, P., Green, J., Le Couteur, A., McConachie, H., Parr, J. R., Pickles, A., Slonims, V., PACT Consortium, & The PACT Consortium. (2017;2018;). The association between child and family characteristics and the mental health and wellbeing of caregivers of children with autism in mid-childhood. *Journal of Autism and Developmental Disorders, 48*(4), 1189-1198. https://doi.org/10.1007/s10803-017-3392-x

Salunkhe, G., Weissbrodt, K., Feige, B., Saville, C. W. N., Berger, A., Dundon, N. M., Bender, S., Smyrnis, N., Beauducel, A., Biscaldi, M., & Klein, C. (2021;2018;). Examining the overlap between ADHD and autism spectrum disorder (ASD) using candidate endophenotypes of ADHD. *Journal of Attention Disorders, 25*(2), 217-232. https://doi.org/10.1177/1087054718778114

Scandurra, V., Emberti Gialloreti, L., Barbanera, F., Scordo, M. R., Pierini, A., & Canitano, R. (2019). Neurodevelopmental disorders and adaptive functions: A study of children with autism spectrum disorders (ASD) and/or attention deficit and hyperactivity disorder (ADHD). *Frontiers in Psychiatry, 10*, 673-673. https://doi.org/10.3389/fpsyt.2019.00673

Semino, S., Ring, M., Bowler, D. M., & Gaigg, S. B. (2017;2018;). The influence of task demands, verbal ability and executive functions on item and source memory in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(1), 184-197. https://doi.org/10.1007/s10803-017-3299-6

Shah, P. J., Boilson, M., Rutherford, M., Prior, S., Johnston, L., Maciver, D., & Forsyth, K. (2022). Neurodevelopmental disorders and neurodiversity: Definition of terms from scotland's national autism implementation team. *British Journal of Psychiatry,* 1-3. https://doi.org/10.1192/bjp.2022.43

Sokol, D. K., Maloney, B., Westmark, C. J., & Lahiri, D. K. (2019). Novel contribution of secreted amyloid-β precursor protein to white matter brain enlargement in autism spectrum disorder. *Frontiers in Psychiatry, 10*, 165-165. https://doi.org/10.3389/fpsyt.2019.00165

Smerbeck, A. (2019). The survey of favorite interests and activities: Assessing and understanding restricted interests in children with autism spectrum disorder. *Autism: The International Journal of Research and Practice, 23*(1), 247-259. https://doi.org/10.1177/1362361317742140

Stranske, T. (2007). Let all the children come to me: A practical guide to including children with disabilities in your church ministries/Autism and your church: Nurturing the spiritual growth of people with autism spectrum disorders. *Christian Education Journal, 4*(1), 170.

Sung, K., Glazer, H., O'Grady, J., McEntee, M. L., Bosley, L., Reich, D. B., & Gordon, B. (2022). Measuring visual electrophysiological responses in individuals with low-functioning autism: A feasibility and pilot study. *Pilot and Feasibility Studies, 8*(1), 7-7. https://doi.org/10.1186/s40814-021-00960-7

Tathgur, M. K., & Kang, H. K. (2021). Challenges of the caregivers in managing a child with autism spectrum disorder— A qualitative analysis. *Indian Journal of Psychological Medicine, 43*(5), 416-421. https://doi.org/10.1177/02537176211000769

Thibodeau, R., Thibodeau, R., Finley, J.R., & Finley, J.R. (2017). On associative stigma: Implicit and explicit evaluations of a mother of a child with autism spectrum disorder. *Journal of Child and Family Studies, 26*(3), 843-850. Doi: 10.1007/s10826-016-0615-2

Thompson, J. D. (2019). Children with autism and congregations: Leader’s assessments of knowledge, programming, and potentialities. *Social Work and Christianity, 46*(4), 39-66. https://doi.org/10.34043/swc.v46i4.102

Tse, A. C. Y. (2020). Brief report: Impact of a physical exercise intervention on emotion regulation and behavioral functioning in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 50*(11), 4191-4198. https://doi.org/10.1007/s10803-020-04418-2

Voorspoels, W., Voorspoels, W., Rutten, I., Rutten, I., Bartlema, A., Bartlema, A., Tuerlinckx, F., Tuerlinckx, F., Vanpaemel, W., & Vanpaemel, W. (2018). Sensitivity to the prototype in children with high-functioning autism spectrum disorder: An example of bayesian cognitive psychometrics. *Psychonomic Bulletin & Review, 25*(1), 271-285. https://doi.org/10.3758/s13423-017-1245-4

Waheed, A., Khan, M. J., & Khurshid, M. (2020). Effect of behavioral problems of children with autism on their mother’s quality of life. *Pakistan Armed Forces Medical Journal, 70*(6), 1666-70. https://doi.org/10.51253/pafmj.v70i6.3386

Waldock, K. E., & Forrester-Jones, R. (2020). An exploratory study of attitudes toward autism amongst church-going christians in the south east of england, united kingdom. *Journal of Disability & Religion, 24*(4), 349-370. https://doi.org/10.1080/23312521.2020.1776667

Walsh, F. (2016). Applying a family resilience framework in training, practice, and research: Mastering the art of the possible. *Family Process, 55*(4), 616-632. https://doi.org/10.1111/famp.12260

Wan, M. W., Green, J., Elsabbagh, M., Johnson, M., Charman, T., Plummer, F., & BASIS Team. (2013). Quality of interaction between at-risk infants and caregiver at 12-15 months is associated with 3-year autism outcome. *Journal of Child Psychology and Psychiatry, 54*(7), 763-771. https://doi.org/10.1111/jcpp.12032

Ward, J. (2017). The student’s guide to social neuroscience (2nd ed.). New York, NY: Taylor and Francis. ISBN: 9781138908628

Watson, S. L., Stine, F., Tumin, D., & Stiles, K. M. (2021). Employment and well-being among caregivers of children with autism spectrum disorder. *Children's Health Care, 50*(1), 16-27. https://doi.org/10.1080/02739615.2020.1810576

Weiss, J. A., & Lunsky, Y. (2010;2011;). The brief family distress scale: A measure of crisis in caregivers of individuals with autism spectrum disorders. *Journal of Child and Family Studies, 20*(4), 521-528. https://doi.org/10.1007/s10826-010-9419-y

White, S.W., Lerner, M.D., McLeod, B.D., Wood, J.J., Ginsburg, G.S., Kerns, C.,…Compton, S. (2014;2015;). Anxiety in youth with and without autism spectrum disorder: Examination of factorial equivalence. *Behavior Therapy, 46*(1), 40-53. Doi: 10.1016/j.beth.2014.05.005

Whitmore, K. E. (2016). Respite care and stress among caregivers of children with autism spectrum disorder: An integrative review. *Journal of Pediatric Nursing, 31*(6), 630-652. https://doi.org/10.1016/j.pedn.2016.07.009

Williams, Z. J., Failla, M. D., Gotham, K. O., Woynaroski, T. G., & Cascio, C. (2018). Psychometric evaluation of the short sensory profile in youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(12), 4231-4249. https://doi.org/10.1007/s10803-018-3678-7

Wuest, J., & Hodgins, M. J. (2011). Reflections on methodological approaches and conceptual contributions in a program of caregiving research: Development and testing of Wuest's theory of family caregiving. *Qualitative Health Research, 21*(2), 151-161. https://doi.org/10.1177/1049732310385010

Xiao, Z., Qiu, T., Ke, X., Xiao, X., Xiao, T., Liang, F., Zou, B., Huang, H., Fang, H., Chu, K., Zhang, J., & Liu, Y. (2014). Autism spectrum disorder as early neurodevelopmental disorder: Evidence from the brain imaging abnormalities in 2–3 Years old toddlers. *Journal of Autism and Developmental Disorders, 44*(7), 1633-1640. https://doi.org/10.1007/s10803-014-2033x

Young, G.S., Constantino, J.N., Dvorak, S., Belding, A., Gangi, D., Hill, A.,…Ozonoff, S. (2020). A video-based measure to identify autism risk in infancy. *Journal of Child Psychology and Psychiatry, 61*(1), 88-94. Doi: 10.1111/jcpp.13105

Yuan, C., & Chen, L. (2020). Improving reciprocal conversation and social preference of children with autism. *Exceptional Children, 87*(1), 113-132. https://doi.org/10.1177/0014402920926460

Zhang, Y., Li, N., Li, C., Zhang, Z., Teng, H., Wang, Y., Zhao, T., Shi, L., Zhang, K., Xia, K., Li, J., & Sun, Z. (2020). Genetic evidence of gender difference in autism spectrum disorder supports the female-protective effect. *Translational Psychiatry, 10*(1), 4-4. https://doi.org/10.1038/s41398-020-0699-8

Zhou, T., Wang, Y., & Yi, C. (2018). Affiliate stigma and depression in caregivers of children with autism spectrum disorders in china: Effects of self-esteem, shame and family functioning. *Psychiatry Research*, *264*, 260-265. https://doi.org/10.1016/j.psychres.2018.03.071

APPENDIX A

Informed Consent

Services to Help Caregivers of Children Diagnosed with Autism Spectrum Disorder

Principal Investigator: Stephanie Garcia, Doctoral Student, Psychology Department, Liberty University, MS, MA, DBS, NCC, BCCC, LCMHC

Invitation to be part of a Research Study

You are invited to participate in a research study. To participate, you must be 18 years or older, and a caregiver of a child diagnosed with autism who has been caring for the child over the last 12 consecutive months. Taking part in this research project is voluntary. Please read this entire form and ask questions before deciding whether to participate in this research.

What is the study about, and why is it being done?

The study aims to find out what services and assistance caregivers of children diagnosed with autism use or would use if available. This study will also ask why these services and assistance are or would be helpful.

What will happen if you take part in this study?

If you agree to be in this study, I will ask you to do the following:

1. Participate in a short interview (in person, virtually through Zoom, or via telephone). This interview should take no longer than 20 minutes and will be audio-recorded.
2. After your interview, a written transcript (word-for-word copy of our conversation) will be emailed to you. Please respond by emailing the word “approved” or list anything that

needs to be changed. If you request changes, a new transcript will be emailed to you, and at that time, you may respond by emailing the word "approved."

How could you or others benefit from this study?

Participants should not expect a direct benefit from participating in this study. However, benefits to society include education on the needs of caregivers of children diagnosed with autism.

What risks might you experience from being in this study?

The risks involved in this study are minimal, which means they are equal to the risks you would encounter in everyday life. However, please note that if you divulge information regarding child abuse, child neglect, or intent to harm yourself or others, this researcher is a mandated reporter, and a report will be made.

How will personal information be protected?

The records of this study will be kept private. Research records will be stored securely, and only the researcher will have access to the records. If data collected from you is shared, any information that could identify you, if applicable, will be removed before the data is shared.

- Participant responses will be kept confidential through the use of codes. Interviews will be conducted in a location where others will not easily overhear the conversation.
- Data will be stored on a password-locked computer and may be used in future presentations. After three years, all electronic records will be deleted, and hard copies shredded.
- Interviews will be recorded and transcribed. Recordings will be stored on a password-locked computer for three years and then erased. Only the researcher will have access to these recordings.

Is study participation voluntary?

Participation in this study is voluntary. Your decision on whether or not to participate will not affect your current or future relations with Liberty University. If you decide to participate, you are free not to answer any questions or withdraw at any time without affecting those relationships.

What should you do if you decide to withdraw from the study?

If you choose to withdraw from the study, please contact the researcher at the email address included in the next paragraph. Should you decide to withdraw, data collected from you will be destroyed immediately and will not be included in this study.

Whom do you contact if you have questions or concerns about the study?

The researcher conducting this study is Stephanie Garcia. You may ask any questions you have now. If you have questions later, you are encouraged to contact her at: [email address retracted]. You may also contact the researcher's faculty sponsor, Rachel Piferi, at rpiferi@liberty.edu.

Whom do you contact if you have questions about your rights as a research participant?

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, you are encouraged to contact the Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA 24515, or email at **irb@liberty.edu.**

Disclaimer: The Institutional Review Board (IRB) is tasked with ensuring that human subjects research will be conducted in an ethical manner as defined and required by federal regulations. The topics covered and viewpoints expressed or alluded to by student and faculty researchers are those of the researchers and do not necessarily reflect the official policies or positions of Liberty University.

Your Consent

By signing this document, you agree to be in this study. Make sure you understand what the study is about before you sign. You will be given a copy of this document for your records. The researcher will keep a copy as well, with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

☐ The researcher has my permission to audio-record me as part of my participation in this study.

____

Printed Subject Name

____

Signature & Date

Appendix B

Demographic Information (of Participant)   Your Age: _____

Marital Status (Circle one): Single   Married   Divorced Widow/er Prefer not to answer

Race (Circle one):	African-American	Asian	Native American
	Caucasian	Other	Prefer not to answer

Highest Level of Education (Circle one):

High School/GED	Associate or Technical degree	Bachelor degree
Master's degree	Doctoral degree	Prefer not to answer

What was the age of your child when they were diagnosed with ASD? ___________

What is the age of your child now? _____

How many hours a week do you spend caregiving for your child with ASD? ______

Number of other children in the household: _____

Are there any other diagnoses in the household that require regular care? _____

If yes, please describe to your level of comfortability____________________________

____

Where on the spectrum is your child's ASD diagnosis? Place an X on the line below.

____

High functioning   Low functioning

APPENDIX C

Interview Format and Questions

Hello, today I would like to speak to you as a fellow caregiver of a child diagnosed with Autism. I will be collecting data about caregiver experiences. I will also ask about the services and assistance you have found helpful or think would be helpful to you personally in caring for your child. Let’s get started.

1. First, can you tell me a little about your experience caring for your child with Autism?
2. Are there any services or assistance that have helped you personally in caring for your child with Autism, particularly those related to self-care, improved interactions with your child, and learning techniques?
3. Are there any services or assistance that you have not used but think would be personally helpful in caring for your child with Autism? Why haven’t you used these services?
4. Why do you think these services or assistance would be helpful?
5. Is there anything else you would like to share about what may be helpful to caregivers of children with Autism?

This concludes our interview. I want to thank you for your time, input, and participation. Once I transcribe this interview, I will email you a copy. If everything looks good, please respond, “approved.” If anything needs to be changed, please e-mail the revisions to me. Once I make those revisions, I will e-mail you a revised transcript for approval. Thank you again, and please know that I am praying for you!

APPENDIX D

Services to Help Caregivers of Children Diagnosed with Autism Spectrum Disorder (ASD)

- Are you 18 years or older?
- For the last 12 consecutive months, have you been actively involved in the day-to-day care of a child diagnosed with ASD?
- Would you like to provide input regarding the types of services and assistance that would be helpful to you, specifically as a caregiver, in caring for a child with ASD?

If you answered **yes** to these questions, you may be eligible to participate in a study aimed at increasing public knowledge of ASD, and possibly even establishing or improving upon services and forms of assistance that may help caregivers of children diagnosed with ASD.

The purpose of this study is to describe the services and forms of assistance that caregivers of children diagnosed with ASD identify as being most beneficial to them.

Participants will be asked to take part in an interview. In an effort to accommodate each participant's demanding schedule, this interview may be conducted at the time and location of the participant's choice, including in-person, virtual, and telephonic meeting options.

Stephanie Garcia, a doctoral candidate in the Psychology Department at Liberty University, is conducting this study.

Please contact Stephanie Garcia at: [email address retracted] for more information.

Liberty University IRB – 1971 University Blvd., Green Hall 2845, Lynchburg, VA 24515

APPENDIX E

Screening Questions

1) Are you 18 years or older?
2) Are you a caregiver of a child diagnosed with Autism Spectrum Disorder (ASD)?
3) Have you been actively involved in the day-to-day care of the child for the last 12 consecutive months?
4) Are you interested in volunteering to participate in a research study for which the information you provide may be used to help establish or improve upon existing services and forms of assistance that are aimed at helping reduce the stress of caring for a child diagnosed with ASD, and improving the quality of life for caregivers such as yourself?

APPENDIX F

Recruitment Letter (Verbal)

Hello Potential Participant,

As a graduate student in the School of Behavioral Sciences at Liberty University, I am conducting research as part of the requirements for a doctoral degree. The purpose of my research is to identify the services and forms of assistance that are most beneficial to caregivers of children diagnosed with Autism Spectrum Disorder (ASD). If you meet my participant criteria and are interested, I would like to invite you to join my study.

Participants must be 18 years of age or older and caregivers of a child diagnosed with ASD who have actively participated in the day-to-day care of the child for the last 12 consecutive months. Participants will be asked to participate in an audio-recorded interview, answering questions and providing information regarding their experiences in caring for a child with ASD. This interview should take approximately 20 minutes.

Following the interview, a transcribed copy will be emailed to you for approval. Names and other identifying information will be requested as part of this study, but the information will remain confidential. Interviews may be conducted at a time and location convenient to you and may be conducted in person, virtually, or via telephone.

Would you like to participate?

Yes: Great, could I get your email address so we can set up a time for an interview?

No: I understand. Thank you for your time.

A consent document will be given to you prior to or at the time of the interview. The consent document contains additional information about my research. If you choose to participate, you will need to sign the consent document and return it to me prior to the start of the interview. After you have read, signed, and dated the consent form, please return it to me in person (if applicable) or via email at [email address retracted]. Doing so will indicate that you would like to take part in the study.

Thank you for your time. Do you have any questions?

APPENDIX G

Recruitment Letter (E-mail)

Dear Potential Participant,

As a graduate student in the School of Behavioral Sciences at Liberty University, I am conducting research as part of the requirements for a doctoral degree. The purpose of my research is to identify the services and forms of assistance that are most beneficial to caregivers of children diagnosed with Autism Spectrum Disorder (ASD). If you meet my participant criteria and are interested, I would like to invite you to join my study. Participants must be 18 years of age or older and caregivers of a child diagnosed with ASD who have actively participated in the day-to-day care of the child for the last 12 consecutive months. Participants will be asked to participate in an audio-recorded interview, answering questions and providing information regarding their experiences in caring for a child with ASD. This interview should take approximately 20 minutes. Following the interview, a transcribed copy will be emailed to you for approval. Names and other identifying information will be requested as part of this study, but the information will remain confidential.

To participate, please contact me at [email address retracted] to schedule an interview. Interviews may be conducted at a time and location convenient to you and may be conducted in person, virtually, or via telephone. A consent document will be given to you prior to or at the time of the interview. The consent document contains additional information about my research. If you choose to participate, you will need to sign the consent document and return it to me prior to the start of the interview. After you have read, signed, and dated the consent form, please return it to me in person (if applicable) or via email: [email address retracted]. Doing so will indicate that you would like to take part in the study.

Sincerely,

Stephanie Garcia

Doctoral Student