Exploring Autism and the Caregiver Burden Relationship

Mary C. Drockton

University of Akron, mcd39@zips.uakron.edu

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Exploring Autism and the Caregiver Burden Relationship

Mary Catherine Drockton

The University of Akron Williams Honors College
Exploring Autism and the Caregiver Burden Relationship

Mary Catherine Drockton

School of Sport Science and Wellness

Honors Research Project

Submitted to

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Approved:

_________________________ Date ______

Honors Project Sponsor (signed)

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Honors Project Sponsor (printed)

_________________________ Date ______

Reader (signed)

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Reader (printed)

_________________________ Date ______

Reader (signed)

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Reader (printed)

Accepted:

_________________________ Date ______

School Director (signed)

_________________________

School Director (printed)

_________________________ Date ______

Honors Faculty Advisor (signed)

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Honors Faculty Advisor (printed)

_________________________ Date ______

Dean, Honors College
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I. Abstract

The purpose of this study was to collect qualitative data on the different stresses and burdens associated with being a caregiver for an autistic individual, and discover strategies of stress relief for caregivers. A total of four autism support group meetings were attended and observed, with documentation of the discussion between the moderator of the meeting and the caregivers in attendance. Through observation of these meetings, common themes of stress in caregivers were revealed. These include: difficulty with the diagnosis process and finding medical treatment; seeking additional information on available medical treatments; becoming a “fit” caregiver; finding the right specialized education and services; funding the care and education of their child; difficulty finding time, resources, and maintaining a schedule; special needs and considerations; and the future of his or her child. Stress relief was typically sought through social support and therapy services, but the knowledge and awareness of these resources among caregivers was limited. Support groups tended to offer some relief to stress, while therapy services, including occupational therapy, offered great value and relief to the autistic individual and the caregiver.
II. The Problem

Definition

Autism, or autism spectrum disorder (ASD) is the “neurodevelopmental disorder characterized by impairment in emotional expression and recognition, difficulty with social relationships, delayed and/or abnormal language and communication, and preoccupation with repetitive, stereotyped behaviors or interests” (Slaughter, 2016, Definition section). This disease has no clear cause, no clear treatment, and endures for the life of the patient (Slaughter, 2016). One in every sixty-eight youths are diagnosed with autism (Bagatell & Mason, 2015). Autism is the fourth most commonly diagnosed disease in children (Zima, Kokot, & Rymaszewska, 2011), and boys are at four times greater risk to develop autism (Slaughter, 2016). These statistics are particularly concerning, especially due to the lack of cure and efficacious treatment.

Autism spectrum disorder is a broad diagnosis that includes disorders of a varying level of severity. In addition to autistic disorder, Asperger syndrome and pervasive developmental disorder not otherwise specified (PDD-NOS) also fall along the spectrum of diagnosis (CDC, 2016). Historically, there is a parallel in the discovery of these diagnoses. In the 1940s, Leo Kanner and Hans Asperger both published their findings on a disorder involving social and communication deficits (Slaughter, 2016). Although working independently of one another, both described this disorder as “autism,” meaning “alone” (Slaughter, 2016). The meaning of the word autism alludes to the social isolation that is experienced by those with this disorder (Mercati & Chaste, 2015). Kanner, in his research in the United States, described “children who had impoverished social relationships from early in life, employed deviant language, and were subject to behavioral stereotypes” (Slaughter, 2016, Perspective and Prospects section). Asperger, in his research in Austria, noted his discovery of “children with normal IQs and normal language development who suffered from social and some types of communicative impairments” (Slaughter, 2016, Perspective and Prospects section). Both descriptions, though different,
describe diagnoses along the autism spectrum disorder. This demonstrates that varying symptoms of the disorder all fall under the umbrella of ASD.

Although the causes of autism are not clear, research has shown that several areas of the brain are impacted, including: the cerebral cortex, amygdala, hippocampus, basal ganglia, corpus callosum, cerebellum, and brain stem (Slaughter, 2016). Abnormalities in the structure of these areas are present in early development, and contribute to the development of this neurodevelopmental disorder (Butcher, 2015). Those diagnosed with autism typically have difficulties with social relationships, language development, and are stuck in a pattern of repetitive actions, interests, and behaviors (Slaughter, 2016). They may experience deficits in perceptual and motor development (Butcher, 2015). Changes in the brain can also impact those with autism intellectually. Three out of four children diagnosed with autism have an IQ below 70, and are considered intellectually disabled, with a profound deficit in the verbal category (Slaughter, 2016).

A diagnosis of autism is often accompanied by other disorders or diagnoses. Approximately 30% of those with ASD have attention-deficit/hyperactivity disorder (ADHD), 75% have learning disorders, and 50-70% are impacted by at least one other psychiatric disorder, the most common of which are depression, anxiety, and ADHD (Stahlberg, Nilsson, Lundstrom, & Anckarsater, 2015). Those with autism are often plagued with other medical complications. These include, but are not limited to: “gastrointestinal (GI) problems, oral health problems, increased likelihood of respiratory, food, and skin allergies, sleep disorders, and epilepsy” (Schiff & Asato, 2015, para. 1). GI problems such as constipation, diarrhea, and pain may stem from allergies and hypersensitivity associated with autism spectrum disorder (Schiff & Asato, 2015).

ASD is a lifelong developmental disability (Bagatell & Mason, 2015). Signs and symptoms of the disorder develop early on. Commonly seen in childhood, the following signs and symptoms help indicate
a possible diagnosis of autism: lack of pretend play, failure to point at objects, inability to fully relate to the emotions of others, an aversion to cuddling, repetitive movements and activities, inability to adapt to change, and echolalia (CDC, 2016). Echolalia is the parrot-like repetition of words or phrases that have been spoken, and occurs in almost 75% of those with autism (Butcher, 2015). Difficulties with social, emotional, and communication skills persist throughout the life of the individual (CDC, 2016). Impaired activities of daily living (ADLs) and life skills affect the education, and employment opportunities for those with autism (Cadman & al., 2012). These impairments hinder the children from being able to fully engage with their peers and environment (Kadar, McDonald, & Lentin, 2012). Those with autism, however, may still be able to find their niche in the workforce in a job where the environment is very structured, and the co-workers are patient and understanding. Repetitive jobs such as shelving books in a library may be well-suited to the natural tendencies of those with ASD (Slaughter, 2016).

Research in the 21st century has incorporated fMRI and PET scans to reveal brain abnormalities, particularly in the regions that are responsible for social functioning (Slaughter, 2016). The mirror neuron system, suspected to be responsible for human empathy, may have compromised structure and function in autistic individuals (Slaughter, 2016). Theories have emerged based on the deficiencies that have been recorded in perception and logic. “Weak Central Coherence” theory is concerned with the tendency of individuals with autism to fixate on details rather the comprehensive picture, and their avoidance of involvement with dynamic, abstract interaction with others (Slaughter, 2016). “Theory of Mind” references the lack of emotional intelligence, and lack of ability to see the needs and perspectives of others that is often observed in those with autism. (Slaughter, 2016). Research continues to reveal more about autism, the causes, diagnosis, and symptoms each day.
Diagnosis

The number of diagnosed cases of autism over the past several decades has increased at a profound rate. It is unclear whether the incidence of autism has increased, or the rise in numbers is due to a greater awareness of autism, and improvement in the accuracy of the diagnosis (Slaughter, 2016). When biomarkers that are indicative of autism do not appear, the diagnosis process largely depends on the recognition of signs and symptoms during the early years and development of a child (Mercati & Chaste, 2015). The Diagnostic and Statistical Manual of Mental Disorder, Fifth Edition, focuses on two categories of symptoms: “impaired social interaction and communication”, and “restricted and repetitive behavior” (Mercati & Chaste, 2015). Several different scales are used to evaluate the severity of symptoms and the likelihood of a positive diagnosis, including the Social Responsiveness Scale (SRS) which measures social deficits, the Children’s Communication Checklist (CCC) measuring language and communication deficits, the Repetitive Behavior Scale (RBS) which measures the extent of rigid and routine behavior, and the Autism Spectrum Quotient (ASQ) measuring the overall presence of autistic symptoms (Mercati & Chaste, 2015). The Autism Diagnostic Interview-Revised (ADI-R) can also be used to aid in diagnosis, and is a “semi-structured interview with the primary caregiver” (Freitag, 2015, p. 139)

The average age of the first diagnosis of autism spectrum disorder is 3.3 years old, and is typically discovered during the pre-school years when communication challenges, lack of social responses, unusual interactions, lack of eye contact, and strictly followed routines are observed (Freitag, 2015). Signs that may lead to an early diagnosis (earlier than 2.5 years of age) using the Autism Diagnostic Observation Schedule (ADOS) are failure for the child to point or react to pointing, lack of pretend and social play, social separation, and lack of desire to hold or attend to eye contact (Freitag, 2015). This method uses clinician observation of the patient.
Typically, children with autism will remain physically and emotionally distant from their peers (Butcher, 2015). Accounts from mothers of children diagnosed with autism recall that their child did not cuddle, did not reach to be picked up, did not engage with a smile or eye contact when feeding, and did not take note of the activity of others (Butcher, 2015). These are some of the best recognized symptoms of autism (Merhoum, Mengarelli, Mottolese, Andari, & Sirigu, 2015). Reduced eye contact is considered to be one of the most accurate predictors of autism (Merhoum, Mengarelli, Mottolese, Andari, & Sirigu, 2015). Some consider this inattention to social behavior and activity to be “mind blindness” (Butcher, 2015). The mothers also noted that their children sought a consistent environment, would seek sensory stimulation, had difficulty with sleep and toilet-training, and typically had decreased intellectual ability (Butcher, 2015). The following is an example of a young child displaying the traits of autism.

Matthew is 5 years old. When he is spoken to, he turns his head away. Sometimes he mumbles unintelligibly. He is neither toilet trained nor able to feed himself. He actively resists being touched. He dislikes sounds and is uncommunicative. He cannot relate to others and avoids looking anyone in the eye. He often engages in routine manipulative activities such as dropping an object, picking it up, and dropping it again. He shows a pathological need for sameness. While seated, he often rocks back and forth in a rhythmic motion for hours. Any change in routine is highly upsetting to him. (Butcher, 2015, p. 522)

Other indicators may also prompt an evaluation for the diagnosis of autism. Socially inappropriate behavior, inability to use or read body language, and inability to understand or demonstrate empathy is characteristic of the social deficits of those with autism (Slaughter, 2016). In addition to compromised language and echolalia seen in many autistic individuals, 25-30% of those with autism never speak (Slaughter, 2016). Another typical indicator is preoccupation with restricted, repetitive behavior can lead to obsessions and stereotyped behaviors for self-stimulation. Some individuals with autism may compulsively perform actions such as hand-washing or arranging objects.
Others may take a particular interest in very limited topics such as weather patterns or TV schedules (Slaughter, 2016). In extreme cases, pica, or the eating of paper, dirt, and other inedible items may occur (Slaughter, 2016). Lastly, 80-90% of those with autism have sensory impairments that impact their quality of life (Schaaf, Benevides, Kelly, & Mailloux-Maggio, 2012). Due to their sensory needs, individuals with autism often develop repetitive, self-stimulating behaviors such as hand-flapping, rocking, self-stroking, or head-banging (Slaughter, 2016). Some of these behaviors can become harmful to the individual. Often, such behaviors and symptoms can prevent the development of relationships with peers of the same age. When alienated from others their age, depression and loneliness often follow (Slaughter, 2016).

Due to the wide spectrum of the disorder, symptoms and traits vary in each diagnosis. The two key areas used for diagnosis are impaired social interaction and communication, and restricted repetitive behavior (Mercati & Chaste, 2015). The following chart summarizes the most commonly seen criteria that are used to diagnose autism:

![Figure 3. Criteria for Autism Spectrum Disorder. (Butcher, 2015, p. 522)](image-url)
Causes

The definitive causes and risk factors for developing autism are not clear, and are a current topic of study (Butcher, 2015, p. 524). Some believe that cases of autism have developed from the measles, mumps, and the rubella vaccine that is given to children at 18 months of age (Slaughter, 2016). No evidence, however, has been discovered that leads to this conclusion. It is thought that these specific illnesses and vaccines may cause autistic symptoms that are already present to become more prevalent, and thus lead to a diagnosis shortly after exposure (Slaughter, 2016). Many different links have been found, but no single cause has been attributed to all cases of autism.

Autism is considered to be a “fundamental disturbance of the central nervous system” (Butcher, 2015). Defects found in the brain anatomy through MRI research and defective genes caused by radiation and other environmental factors may be linked to the impaired perceptual-cognitive functions of children with autism (Butcher, 2015). Defects in the amygdala have an effect on the ability to handle stressors and the way that emotions are processed (Merhoum, Mengarelli, Mottolese, Andari, & Sirigu, 2015). Enlargement of the amygdalae has also been discovered in autism patients. A positive correlation between severity on the autism spectrum and social impairment has been associated with this abnormally developed area of the brain. (Houenou & Chaste, 2015). Other risk factors that can be linked to a higher likelihood of autism are a traumatic birth, a genetic link to someone with autism, and other neurodevelopmental disorders such as ADHD and OCD (Slaughter, 2016). There is a 3-5% risk of siblings of those with autism also being diagnosed with ASD (Butcher, 2015).

It is believed that there is a strong genetic component in the development of ASD (Persico & Merelli, 2015). There are hundreds of genes that contribute to the risk for developing autism (Chaste & Devlin, 2015). Individuals with genetic condition called Fragile X Syndrome often present similar symptoms to those seen in autism, such as social avoidance and avoidance of eye contact (Gallagher,
Shen, & Anney, 2015). “Fragile X Syndrome is the most common known single gene cause of intellectual disability in boys and of ASD” (Gallagher, Shen, & Anney, 2015, p. 100). Different genetic variants can occur for many reasons and may contribute to the development of autism. Copy number variants, point mutations, irregular X chromosomes, and abnormal mitochondrial DNA are the most likely causes of the variations that are associated with ASD (Persico & Merelli, 2015).

Errors in metabolism from birth have also been determined to have a link to the development of autism (Schiff & Asato, 2015). Recent research has discovered a relationship between neurotransmitters and the development of autism. Low glutamate levels can be responsible for underdevelopment of the brain, and therefore be involved in the development of autism (Butcher, 2015). Oxytocin is another neurotransmitter that is suspected to play a role in autism. Necessary for normal functioning of the brain, oxytocin is involved in social behavior and functions (Merhoum, Mengarelli, Mottolese, Andari, & Sirigu, 2015). It is believed to be involved with the length of time that eye contact is maintained and may also allow better understanding of the facial and social cues of others. Individuals with autism have been documented to have significantly low levels of oxytocin (Merhoum, Mengarelli, Mottolese, Andari, & Sirigu, 2015).

Another field of interest is the neural component of autism. An excess of neurons, often found in those with autism, may be due to the failure of the body to appropriately perform apoptosis and synaptic pruning during development (Houenou & Chaste, 2015). With an overload of neurons present, communication and connectivity between the neurons could be poorly effected, and lead to typical symptoms seen in autism, such as challenges with sensory input (Houenou & Chaste, 2015). An overload of neurons and poor communication between the neurons increases the “noise” in neural responses that occur in autism (Behrmann & Minshew, 2015). These poor connections between the neurons occur in both the sensory and motor cortices, and offer an explanation for the sensory defensiveness and motor coordination difficulties experienced by most individuals with ASD (Behrmann & Minshew, 2015).
Lastly, the environment of a developing child, particularly during fetal development is considered to be a primary cause of autism (Persico & Merelli, 2015). When combined with an existing genetic risk for autism, environmental factors are even more impactful (Persico & Merelli, 2015). “Teratogenic drugs, and CMV (cytomegalovirus infections)” are common environmental factors that have been linked with the development of autism (Persico & Merelli, 2015, p. 115). Other factors such as exposure to air pollution or pesticides during pregnancy, use of antidepressants such as SSRIs during pregnancy, or the introduction of heavy metals such as mercury and lead to the mother’s system during fetal development all have significant links to the abnormal development of several systems in the fetus, particularly the Central Nervous System (Persico & Merelli, 2015). Environmental factors show strong evidence as a causal factor in the development of autism.

The complex and mostly unknown etiology of autism makes it difficult to identify effective treatments and early prevention strategies; because of the influence of genetic heritage, environmental exposure, and differences in brain development and plasticity, interindividual differences are very significant. (Pallanti, Bencini, Cantisani, & Hollander, 2015, p. 152)

**Treatment and Occupational Therapy**

There is no cure for autism, and no single treatment that can fully compensate for the complications associated with ASD. For this reason, several types of treatment are typically used for those with autism, including behavior modification, social skills training, changes in diet, speech therapy, music therapy, and occupational therapy (Slaughter, 2016). Behavior modification is focused on increasing social interaction and awareness while reducing socially inappropriate behaviors (Slaughter, 2016). While this treatment reinforces positive behavior with a reward, it has been questioned due to its inclusion of punishment for poor behavior (Slaughter, 2016). Social skills training has the goal of improving conversation skills and social literacy (Slaughter, 2016). Dietary changes have been found to
relieve some symptoms of autism, speech therapy focuses on improving communication and social skills, and music therapy works to help those with autism realize and express their emotions (Slaughter, 2016). Occupational therapy has a holistic approach towards the mental, physical, and emotional health of the patient and family, and has many benefits. New treatments for autism are under constant investigation. Research has even shown the potential for a video game/virtual reality based treatment. This appears to be a motivating method of treatment for the patient, and it can be developed to address the specific needs of each patient (Butcher, 2015). However, while this method may be promising to maintain the attention of a child receiving treatment, there is concern that the patient may become addicted to playing/using virtual games (Butcher, 2015).

Use of medication has seen some limited success for the treatment of autism. Its use is typically to lessen the severity of symptoms experienced by those with ASD (Pallanti, Bencini, Cantisani, & Hollander, 2015). Stimulants have been used to increase attentiveness, tranquilizers have been administered to patients that suffer from extreme OCD, antidepressants are given to patients to increase emotional reactions and provide emotional stability, and anti-seizure medications are given to over one-third of children with autism who experience seizures (Slaughter, 2016). As referenced earlier, there appears to be a connection between levels of oxytocin and autistic symptoms. New research has shown that supplementing oxytocin in patients with autism can decrease anxiety and increase the eye contact maintained by the patient (Merhoum, Mengarelli, Mottolese, Andari, & Sirigu, 2015). Production of a drug to supplement oxytocin is still in development (Pallanti, Bencini, Cantisani, & Hollander, 2015). No single medication has proven to be universally effective, or the solution to the symptoms of autism, and the controversial side-effects and limitations of medication has sparked an ethical debate amongst caregivers and medical professionals. Unless a child with autism has severe aggression that cannot be otherwise managed, medication does not appear to be the most effective treatment (Butcher, 2015).
Early behavioral intervention is a slight variation of behavior modification that emphasizes positive reinforcement. It has been shown to be effective in reducing self-injury (Butcher, 2015), and is best implemented for young children with ASD (Freitag, 2015). This treatment has the best results when it is done in the home of the patient, and is typically done for forty hours a week over a span of two to four years (Butcher, 2015). Some may see an improvement in cognitive ability and language skills after a few years of treatment (Freitag, 2015). Due to the inability of individuals with autism to generalize learned skills and behaviors to novel situations that arise, this treatment has its limitations (Butcher, 2015). Less than 25% of the children who receive behavioral treatment show life-long improvements (Butcher, 2015), and outcomes from this treatment vary significantly (Freitag, 2015).

Occupational therapy is one of the most common treatments for individuals with ASD (Bagatell & Mason, 2015). OT is a cornerstone for the treatment of autism. It works to address all aspects of autism, including emotional expression, communication, mental health, and activities of daily living essential to the independent function (Slaughter, 2016). Occupational therapy treatment for a child with autism begins by assessing the needs of the child and family. A multitude of methods are used to gauge

![Figure 4. Future Learning Priorities. (Ashburner, Rodger, Ziviani, & Jones, 2013, p. 117)](image-url)
these needs, including tools such as the Sensory Profile, Self-Care Checklist, Test of Visual-Motor Integration, Gross and Fine Motor Skills Assessment, Handwriting Speed Test, and Peabody Developmental Motor Scales (Kadar, McDonald, & Lentin, 2012). The following diagram illustrates the prevalence of various treatments and frames of references that may be used after an assessment of the patient has been completed. Based on the needs of the patient, the areas of focus for treatment are determined and typically include, but are not limited to: self-care, development of social skills, decreasing sensory defensiveness, preparation for school, and improving physical function, play skills, and communication skills (Freitag, 2015).

OTs use various methods and frames of reference to treat their patients with autism. The most common frames of reference include: sensory integration, early intervention, sensory diet, environmental modification (Kadar, McDonald, & Lentin, 2012), picture exchange communication, the Wilbarger Therapressure protocol, family and client centered treatment, visual schedules, task adaptation, and play therapy (Ashburner, Rodger, Ziviani, & Jones, 2013). Of these treatments, sensory integration currently plays one of the biggest roles in Occupational Therapy. Sensory Integration is the “neurological process that organizes sensations from one’s body and from the environment and makes it possible to use the body effectively in the environment” (Schaaf, Benevides, Kelly, & Mailloux-Maggio, 2012, p. 322). When used in therapy, sensory integration can to help the child better understand the sensory information gathered by the body, which allows the child to adapt to these stimuli (Schaaf, Benevides, Kelly, & Mailloux-Maggio, 2012).

Occupational Therapists introduce new sensory stimuli through play and child-centered methods. They use “scaffolding” to slowly increase the challenge for the child in order to provide the appropriate level of difficulty for the child to develop and adapt from these encounters (Schaaf, Benevides, Kelly, & Mailloux-Maggio, 2012). The OT will develop goals for the child in order to develop sensory adaptation to improve attention and behavior control, as well as to integrate sensory input in
order to improve motor function. Achievement of these goals will allow for greater involvement in social settings, and improvement in school, play, and ADLs (Schaaf, Benevides, Kelly, & Mailloux-Maggio, 2012). While sensory integration can improve many symptoms of autism, it is not intended to be a comprehensive treatment for ASD. Instead, it is intended to be used in conjunction with other interventions (Schaaf, Benevides, Kelly, & Mailloux-Maggio, 2012).

Regardless of the intervention method, it has become clear that a highly-structured environment encourages the patient to follow cues and directions, and is beneficial in ASD treatment (Freitag, 2015). The person directing the intervention must also have an extensive knowledge of the typical development of language, social skills, and play in children (Freitag, 2015). For these reasons, Occupational Therapy is a great tool for addressing the needs of autistic patient. OT meets these needs, and offers the ability to individualize treatment for the needs of each patient and their family.

**Caregiver Burden and Occupational Therapy**

In addition to the effects on the patient, autism has a great effect on the family and caregivers of the individual. The unique challenges of caring for someone with autism typically lead to a high level of stress for the caregiver. This physical, emotional, and mental strain is known as “caregiver burden.” The caregiver, typically the parent or guardian of the child, provides the most direct day-to-day care for the individual with autism. Research shows that mothers and women are more likely to become the primary caregiver than fathers and men in the lives of the patient (Khanna, et al., 2012). Caregiver burden has a direct correlation to predicting the mental health of the caregiver (Khanna, et al., 2012). In caring for individuals with autism, the role of caregiver can become an additional full-time responsibility. This holds true long-term, particularly when 96% of patients continue to have autism through their adult lives (Mao, 2012). These individuals are not eligible for school services after the age of twenty-one, so
recent legislature in the IDEA law has required transitional planning for adult life, beginning at the age of fourteen years old (Mao, 2012).

While the caregiver takes on many extra responsibilities of caring for a child with autism, this full-time job comes without pay, and often without respite (Khanna, et al., 2012). The behavior and needs of the child often make it challenging to find a substitute caregiver (Mao, 2012). Research has shown that levels of stress and burden tend to be higher in caregivers responsible for someone with autism, compared to those who care for an individual with ADHD (Mao, 2012), or Down syndrome (Zima, Kokot, & Rymaszewska, 2011). Parents of children with autism are likely to score higher in aggravation and frustration compared to caregivers for individuals with other diseases (Mao, 2012). In addition, mothers have been shown to have a higher level of burden than fathers when acting as the caregiver (Mandleco, Freeborn, & Dyches, 2014). Caregivers face the daily challenge of trying to understand their child, his or her needs, trying to provide the best care, and searching for new treatments, resources, and medical providers (Butcher, 2015). In general, caring for children with autism can be trying, stressful, and financially challenging (Butcher, 2015).

More than one-third of mothers of autistic children have levels of depression that are above the clinical cut-off for diagnosis (Khanna, et al., 2012). However, these challenges do not diminish the level of love and affection these caretakers have for their children. Over 90% of mothers have high levels of affection for their children (Khanna, et al., 2012). The challenges and stresses of caring for a child with autism arise from many different symptoms of the disease. These symptoms include maladaptive behavior, social and communicative impairments, restricted and repetitive behaviors, and medical complications involving the G.I. system, sleep, and many other areas of health. Sleep problems have been recorded in 50-80% of ASD patients, and have proven to increase family stress (Schiff & Asato, 2015). Sensory impairments can keep the individual with ASD and their caregiver from participating fully in daily activities, work, and social opportunities (Schaaf, Benevides, Kelly, & Mailloux-Maggio, 2012).
Depending on the severity of symptoms, caregivers and families may feel social isolation with the compromised social functioning of individuals with autism (Khanna, et al., 2012). Greater severity in symptoms and behavioral problems in the child with autism are typically accompanied by low levels of emotional support and poor ability to cope in the caregiver. This leads to high levels of strain and low quality of life in the caregiver (Khanna, et al., 2012). On the other hand, when the caregiver experiences strong social support from family and friends, levels of stress and burden are reduced (Khanna, et al., 2012).

Caregiver burden results from various stresses associated with raising a child with a disease or disability. In the case of autism, a stressful family routine, financial difficulties, and heightened emotions often play a leading factor in causing stress. The current lack of knowledge about the causes and treatments for autism are a great source of doubt and uncertainty (Zima, Kokot, & Rymaszewska, 2011). Exhaustion, lack of energy, and inability to control their child’s health is a common source of frustration for the caregiver (Zima, Kokot, & Rymaszewska, 2011). An autistic child often does not have a healthy sense of self-preservation, and this is a source of constant worry for the caregiver. Doubts about their ability to care for their child, ability to financially provide for medical treatment, capability to care for their family in addition to their autistic child, or maintaining friendships and staying involved socially plague the mind of caregivers (Zima, Kokot, & Rymaszewska, 2011). Inevitably, the time caregivers spend with friends in social situations declines, which in turn compromises the network of support for emotional coping (Stuart & McGrew, 2009). After surveying caregivers, their biggest concern was for the future of the child, his or her own care, and the child’s livelihood (Khanna, et al., 2012). Accompanying concern for the child’s future, the caregiver’s life plans and goals are often postponed in the wake of the current demands for constant attention and care of the child (Zima, Kokot, & Rymaszewska, 2011).

These stresses as a caregiver compound with the typical stresses of a day to day life. Marital stress often builds under the stress of caring for children with autism (Stuart & McGrew, 2009). Spouses
often experience more negatives and less positives in their relationship (Mandleco, Freeborn, & Dyches, 2014). Other responsibilities involved with caring for a family and social commitments can pile up and increase anxiety in caregivers (Stuart & McGrew, 2009). However, resolving these stressors may not be the priority in light of the pressing responsibilities of caring for a child with autism. This underlying stress, combined with the challenge of caring for a child with autism, can cultivate high levels of strain and poor ability to cope with emotions (Stuart & McGrew, 2009). The most reliable predictors of caregiver burden are high levels of symptom severity, negative societal views towards the child, low levels of social support, and poor coping, including passive avoidant strategies (Stuart & McGrew, 2009). Even the path to diagnosis of autism in the individual can affect the degree of burden in the caregiver (Stuart & McGrew, 2009).

One of the biggest challenges for caregivers in dealing with this burden is identifying an effective strategy for managing stress and emotions associated with caring for an individual with autism. In the instance of caregivers, problem-solving strategies may not provide relief (Khanna, et al., 2012). While the cure for autism remains unidentified, autism provides a challenge that the child and their caretaker must face throughout their lives. This makes problem-solving a less efficacious method of managing stress. A more advantageous strategy has been seen in younger caregivers that use a more pro-active problem-focused approach, such as seeking support (Lovell & Wetherell, 2015). Seeking solutions for health-related co-morbidities in the individual with autism can reduce stress in the family and caretaker, as well as potentially improve symptoms of autism (Schiff & Asato, 2015). Caregivers can use this pro-active, problem-focused approach to identify the behaviors and symptoms that are causing the most stress, and seek support and intervention for these needs (Khanna, et al., 2012).

Support from those with the same stressors has also been shown to be helpful by providing a sense of community (Stuart & McGrew, 2009). This type of community is what an autism support group intends to foster. When caregivers feel they need extra support and encouragement, they often seek
out such groups (Mandell & Salzer, 2007). A group setting can be beneficial by providing a network of resources and information, and often has more information to offer than a one-on-one meeting (Mandell & Salzer, 2007). A survey of caregivers for individuals with ASD showed that two-thirds of caregivers had been involved in an autism support group at one time (Mandell & Salzer, 2007). Eighty-six percent of attendees were mothers, seven percent fathers, and the majority of attendees were in the middle-income class and had obtained some form of higher-level education (Mandell & Salzer, 2007). Approximately fifty percent of those that were current members of a support group felt as though they were benefitting from attending meetings (Mandell & Salzer, 2007).

Caregivers of children struggling with self-harming behaviors, abnormal sleep patterns, and significant language impairment, as well as those who were having difficulty paying for medical services or finding feasible and available practitioners often turn to a support group for help (Mandell & Salzer, 2007). With the lack of a “coordinated care system” for those with autism, clinicians may refer caregivers to a support group to find support and advice from other caregivers with the same challenges (Mandell & Salzer, 2007). Overall, autism support groups offer the chance for caregivers to lessen their burden through social comparison by gathering in a community with those who face the same challenges (Mandell & Salzer, 2007). These groups may provide caregivers with a sense of belonging, reduce social isolation, and allow them to learn and improve their caretaking abilities based off the advice and experience of others (Mandell & Salzer, 2007).

Occupational Therapy is another resource available that integrates the needs of the individual with autism and the needs of the family and caretaker. Historically, there has been a focus on not only the patient, but also on improving the parent-child relationship (Slaughter, 2016). In the past, Occupational Therapists evaluated if a home situation was healthy, and would help remove a child from the situation if they determined it unsuitable, until it could be remedied (Slaughter, 2016). Since then, Occupational Therapy has evolved to include a wide variety of treatments that target various symptoms
and complications associated with autism. These treatments not only help the patient, but also have a positive impact on the caregiver.

OT addresses various symptoms and needs of the patient. Environmental modification is one method that can be used to help patients become more successful with activities of daily living, and helps families meet the needs of their children. This helps to reduce behavior problems in those with ASD, and increases the successful completion of routines and ADLs. This, in turn, decreases stress in caregivers (Kadar, McDonald, & Lentin, 2012). Occupational Therapy seeks to provide the most complete and effective treatment for their patients, and typically involves the caretaker in the assessment and creation of goals for the patient (Kadar, McDonald, & Lentin, 2012). This is referred to as family/client-centered therapy, and considered to be an essential practice in Occupational Therapy (Ashburner, Rodger, Ziviani, & Jones, 2013). Seventy-four percent of practitioners state that they always work with the caretaker. This kind of collaboration ensures that the greatest needs of the child as an individual and as part of a family are met, thereby helping to reduce the high levels of stress found in caregivers (Kadar, McDonald, & Lentin, 2012). This attests to the goal of Occupational Therapy to help all people achieve complete health physically, mentally, and emotionally.

Occupational Therapy also includes Sensory Integration (SI) as a treatment for patients with autism. This intervention is a safe, feasible method of treatment for patients, and caretakers are often asked to carry the treatment over into daily activities at home. Caretakers show satisfaction with the progress associated with Sensory Integration, and one-hundred percent of parents surveyed attested to the positive impact SI has had on their ability to handle challenges that arise in day-to-day care for their child (Schaaf, Benevides, Kelly, & Mailloux-Maggio, 2012).

Because autism has no cure, parents and caregivers tend to search for alternative treatments and medical interventions to help with the symptoms associated with autism (Pallanti, Bencini,
Cantisani, & Hollander, 2015). Caregivers, particularly those for an individual with autism, are likely to have additional burdens associated with these extra responsibilities, and feel pressure to provide the best care possible. While most of the focus is typically on the need for services and treatment for the individual with autism, the caregiver’s needs cannot be forgotten. Several resources, such as support groups and Occupational Therapy, are available. These resources can decrease the burden associated with being a caregiver. Occupational Therapy can help provide relief from frustration and depression often associated with the social isolation experienced by caretakers (Slaughter, 2016). Caring for the mental, physical, and emotional needs of the caregiver will in turn allow them to provide the best care for their child.
III. Methods

Support Group Meetings

A well-known autism society in the Midwest region of the United States provides many services and resources to the autism community. They are a group that is dedicated to promoting the well-being of all those who are impacted by autism. Their goal is to ensure that every individual is respected, and has the opportunity to reach their highest potential. One of the services that they provide is a network of support group meetings throughout the Midwest region of the United States. These meetings are led by a volunteer peer facilitator that has personally navigated the journey of caring for someone with autism. The peer facilitator has been trained in active listening, group dynamics, and has been shown how to access resources with information about autism.

There are several groups that meet in each county of the state in which the support group is located. Each group is led by a different peer facilitator, and meet in a different location. The meetings at each location are held on the same day each month. Between the different groups, there is a variety of options for days of the week and meetings times. The meetings are open to anyone that has been touched or affected by autism, and there is a public calendar that lists the dates and times of all the meetings on the society’s website. Individuals can get involved in these groups by contacting the autism support group, or by attending a meeting and receiving more information.

Procedures

I began to research local support group meetings, and found meetings advertised on a major autism society’s website, located in the Midwest region of the United States. I submitted an online request form in which the requester had to provide personal contact information, what support group meeting they would like to join, the current county in which they reside, what they are seeking in a support group, their personal connection to autism, the age of the autistic individual that they know, and if they would like to receive email newsletters from the autism society. I completed this form to join
three different meeting groups in two adjoining counties. In the section that asked what I was seeking in a support group, I indicated that I was a student who was going to be attending Occupational Therapy school. I noted that I was interested in working with the pediatric population, and wanted to learn more about autism and caregiver burden, in order to be able to fully understand the disorder and be able to provide the best care possible.

Several days later, I received a phone call from the resource specialist with the autism society. She had received my request, but wanted to know why I was interested in attending support group meetings, because I indicated that I did not have a personal connection to autism outside of my future as an autism service provider. We had a long discussion, and I explained my desire to learn firsthand about the needs of caregivers, and to better learn how I, as a future Occupational Therapist, could help to meet these needs. At the end of our conversation, she told me she would check with the moderators of each support group to see if they would be comfortable with my presence. A few days later, I received a call letting me know that I was free to attend meetings at all of the locations I had requested. Due to the sensitive nature of the support group meetings, the approval process to allow a student such as myself to sit in on meetings was very delicate, and there was much hesitation in the approval of my request. During this process, it was explained that no identifying factors would be revealed or discussed in my research.

The goal of attending the support group meetings was to gather qualitative data regarding the various struggles and burdens associated with being a caregiver for an individual with autism, and the methods through which these caregivers relieve this stress and find support. Over the next four months, I attended four meetings. Three of these meetings were in two different locations of one county, and the fourth meeting was located in an adjoining county. I arrived fifteen minutes early for each meeting, introduced myself to the moderator, and explained what I was hoping to learn from the meetings. I brought a small notebook and a pen to the meeting to take informal notes, but I had to be very discreet
in doing so, due to the sensitive subjects and emotions that were being discussed. Each meeting was held in a meeting room in a public library, and ran for two hours. The meetings were very informal, and seemed to be social gatherings to share current struggles, emotions, and ask for advice from other caregivers. Each meeting was unique, and the attendees communicated in very different ways. Some meetings consisted of the peer facilitator sharing their personal struggles, burdens, and solutions, while other meetings were mainly run by the caregivers in attendance by sharing their own personal struggles and asking for advice.
IV. Results

After attending four support group meetings, the notes were reviewed and compiled. An analysis of the notes was done to find trends of typical stressors and burdens in autism caregivers, as well as reveal any strategies to relieve stress and find social support. Upon completion of observing the support groups, all field notes were transcribed and were evaluated for emerging themes (Appendix A). Using the inductive approach, the data was analyzed with little or no predetermined assumptions. I used the process of thematic content analysis to evaluate the data and searched for themes within the text. Many common themes can be revealed through an analysis of the notes taken at these meetings. Caregivers for autistic individuals face many common stressors, and struggle to find a source of relief. Five major themes of stress in caregivers emerged from the observations: the autism diagnosis process, filling the role of a “fit caregiver,” navigating treatment options, time management, considering how to accommodate for the physiological symptoms of autism, and finding healthy and appropriate social situations for themselves and their child.

The Diagnosis

From the very beginning of their journey with autism, these caregivers struggled with the diagnosis process for their child. Various testimonies shared that the whole diagnosis process took five to seven months, and they often did not receive a diagnosis until the child was past the age of three years old. Some shared stories of other caregivers whose children had not yet been diagnosed with autism, but instead were being labeled as “emotionally disturbed” and as a “sexual deviant” after having undressed in school because they had urinated on themselves. The caregivers’ frustration with the labels assigned to their children and the lack of understanding while waiting on receiving a diagnosis was evident. Even after receiving a diagnosis, they still experienced frustration at the lack of information provided in the medical records they received about their child. Caregivers’ negative feelings towards
the diagnosis process also extended to some of the practitioners that they worked with. Many expressed they felt as though some doctors “practice with a chip on their shoulder” and don’t want to work to their fullest ability to help the child. While this was a common complaint among caregivers, there was a lack of concrete examples discussed at the meetings. However, it seemed as though this frustration and negativity towards the practitioner prevented a good relationship between the caregiver and the healthcare provider. This, in turn, seemed as though it could be one reason for a compromise in the quality of care received by the individual with autism.

“Fit Caregiver”

Once caregivers were able to get a diagnosis for their child, they found it very difficult to navigate the different medical treatments and options. Without a clearly effective treatment available, caregivers are left to search for their own information and solutions. While some think medication may be beneficial, many parents are concerned that medication suppresses the emotional and social development of their child. No cure has been found for autism, but medical tests can help analyze and correct imbalances in the body or clear toxins that do not naturally dissipate. One caregiver shared that she had found supplementation of Vitamin B12 helped improve certain functions in her son that associated with neurotransmitter activity. This mother also felt that she had found more success with Western medicine in caring for her child. In general, caregivers agreed that after their child received a diagnosis of autism, they felt that other people put up boundaries for their children that limited their success and progress.

After receiving a diagnosis, caregivers face the challenge of constantly searching for more information on autism and the latest treatment. Many feel a great pressure to be a “fit” caregiver for their child. One father was attending the support group meetings to seek more information about autism and its potential treatments in order to be looked upon as a “fit” caregiver through the court
system in the custody battle for his son that he was currently involved in. This stress to be a “fit”
caregiver for a child with autism was expressed by the majority of caregivers, and was noted in addition
to the stress of many personal challenges and demands a caregiver may face in his or her lifetime. The
same father involved with the custody case was also struggling with many personal battles including
alcoholism, his religious conviction, various moral dilemmas, and several financial problems.

The moderator of the meeting sympathized with these struggles and gave suggestions as to how
caregivers could find new information. She recommended attending an annual Autism Summit
conference hosted locally. The Autism Summit offered many resources, lectures, and information on
current research being done in the autism field. She also suggested some strategies, such as Applied
Behavioral Analysis (ABA) to help minimize improper behavior and increase good behavior. A third
resource that she recommended was research done through the Autism Research Institute (ARI) that
networks with caregivers to find out what strategies have been tried and tested with autistic individuals.
Overall, the moderator stressed the importance of being open to new solutions and resources during
the journey as a caregiver.

Treatment Options

The next challenge that is typically experienced in the journey as a caregiver is the search for
specialized education and services for their child. Children with autism often struggle in various
academic subjects due to their tendency to think in one particular manner. Higher level math can prove
to be a challenge because it involves many different methods for solving problems, which don’t always
align with the thinking of the individual with autism. Caregivers at the meeting expressed that they
believe that the focus in education is shifting to speed and execution, as opposed to understanding.
Many caregivers shared their concern that this sort of focus may compromise the ability of their child to
succeed academically. Some schools may offer a life-skills classroom and a standard classroom for
children with special needs. However, caregivers are uncertain which classroom would be of more benefit, and often seem to seek a compromise of the two classrooms. Some caregivers have particularly strong feeling about the schools their children attend and the services they provide. They said that “special education is worthless” and that “schools haven’t progressed to accept the diagnosis of autism, and do not offer therapy services.”

One mother relocated to seek a better education for her child, while another mother shared her story of hiring an attorney to take her child out of their local public schools and relocate to send her to the Lerner School for Autism in Cleveland, Ohio. Some specialized schools can offer more therapy services to the children, and provide a comfortable environment with a stable routine that is beneficial to the happiness of the child. However, options such as the Lerner School for Autism do not come without a high price. The mother estimated the annual cost for tuition was $62,000 a year. The challenge of finding a program that offers what they feel their child needs, and being able to afford the services if they look outside the public-school systems, is a large burden that caregivers face.

**Time Management**

Caregivers shared their difficulties in maintaining a schedule. At multiple support group meetings, caregivers arrived thirty or more minutes late, and talked about the challenge they faced finding the time and resources to be able to attend the meetings. Finding a babysitter that is capable and competent of caring for their child and his or her additional needs is often stressful and burdensome. This can prevent caregivers from attending support group meetings or social events. Certain events or meetings hosted by the local autism society, including the Autism Summit, provide free childcare. This relieves a great burden from the caregiver, and allows them to attend more events without the worry of finding someone to care for their child during the time they are gone.
One mother also shared her difficulty in balancing a job that requires her to travel around the state during the week. This interrupts the routine that she has for her daughter. However, she is unable to quit the job because she needs a steady income to pay for her daughter’s care and education at the Lerner School for Autism. Another caregiver asked “how do you work and earn a living while being a full-time caregiver?” Unfortunately, the balance between earning a living and providing care is not easy to find, and the moderator was not able to give him much advice. She did, however, suggest that parents living in Ohio should consider using a STABLE (Savings to Achieve a Better Life Experience) account that is offered in the state. This account allows a caregiver to invest for the future care of a child, and offers the benefit of investing tax-free when the money is used for appropriate disability purchases. Other states around the country may have similar programs.

**Physiological Symptoms**

Caregivers have many special considerations when it comes to the health and needs of their child. Many times, an individual with autism will experience Gastrointestinal Issues, and the caregiver may need to consider testing for food sensitivities and allergies. A question under current consideration is the possibility for a nutritional influence on individuals with autism. One mother noticed that her son’s speech and eye contact had decreased. She put her son on a special gluten-free, dairy-free, egg white-free diet, and said she saw his eye contact return with the elimination of dairy products, and his speech return with the elimination of gluten. When these changes are called for, caregivers must alter their cooking and meal preparation to meet the needs of their child.

Other medical complications may also be present in individuals with autism. One caregiver’s son had vision problems, including an astigmatism and near-sightedness. Other caregivers talked about complications with sensitive skin and hypersensitivity to sounds, lighting, and sensory input. There are even with administration of treatments for autism that require additional consideration, such as
evaluating how the chemical effects of medicine intended for adults may impact children. Day to day activities also may require extra attention and effort from the caregiver. A twelve-year old girl with autism is currently struggling with toilet-training, and the process is especially difficult because she does not understand incentives. She also struggles with insomnia and sleepless nights, averaging five out of seven nights with less than four hours of sleep. Once she is awake, her mother has to keep an eye on her, and this means less sleep for her, as well. Her mother made a comment that her daughter “may physically be twelve, but she is not mentally twelve.” When the daughter had her first menstrual period, she was unable to understand the pain she was experiencing and what was happening to her body. Due to her inability to fully comprehend what was happening and her lack of toilet-training, her mother started her on medication to prevent menstruation. Another caregiver discussed her 15-year old son who also experiences insomnia. She noted that he has a very difficult time sleeping in stormy weather. During storms, he wakes up and spends all night looking at a mobile weather app on his mother’s phone. He also struggles with showering, and is sensitive to soap near his eyes and face due to his sensory defensiveness.

Social Situations

Caregivers also worry about the social situations that their child is in. Children with autism may not understand the consequences to their actions, or be able to understand the commands given to them by someone else. This goes hand in hand with the restricted, repetitive nature of many autistic individuals. Typically, an individual with autism may experience anxiety in new social situations, and may take time to adjust to a new home, school, or environment. One moderator’s son came to the meeting, and made himself comfortable by occupying himself with coloring for two hours. He colored with the same few colors in a very linear pattern and echoed his mother’s comment that his coloring was
“pretty.” By the end of the meeting, Nathan was a more comfortable with my presence, and gave me some of his artwork!

While often harmless, some limited interests can be a cause of concern for caregivers. One father shared that his son took a strong interest in fire, so the father had to take care to get rid of all lighters and matches in the house to prevent him from unintentionally harming himself or the house.

Overall, the caregivers in attendance at each meeting agreed that their largest concern was what the future of their child looked like. They felt uncertain how they could help their child succeed and find his or her vocation. Some spoke of concerns that their child may end up homeless, while others
worried about the high suicide rate in autistic individuals. One mother shared concern over her son’s loneliness after he had asked, “why don’t I have any friends?” Some caregivers shared stories of success, such as a son who earned his Associate’s degree, while others worried if their child would become self-sufficient and if they will be able to care for themselves when they are older. If there is a concern that the child will not be able to care for himself or herself, the caregiver may wonder if the child will end up in assisted living later in life. In general, caregivers worry about the success of their children, wonder where the future will take them, and constantly search for ways to help ensure a safe and healthy life.

Caregivers are required to handle many additional burdens and stressors when caring for a child with autism. One of the best ways to help relieve this stress is by finding social and emotional support. With sporadic outbursts and disregard for social expectations from the individual with autism, caregivers shared that they often felt the need to apologize for their child’s behavior. With very different struggles than other parents, caregivers often feel that there are boundaries that emotionally separate them from others who do not share in the same experiences and difficulties. Many of the caregivers and moderators in the support groups had made it a personal goal to provide support to others by listening to the challenges and burdens that others are experiencing. They felt that as fellow caregivers, they were the best channel for supporting others in their journey with autism. They encouraged a focus on connecting with the emotions and experiences of other caregivers so that they could laugh, smile, and cry together.

Support meetings are just one channel of support for caregivers. They can also find relief through other channels such as therapy services or medical treatment for their child and themselves, as well as counseling services to find healthy solutions for emotional burdens. Caregivers testified to the large impact that therapy services had on their child and themselves. They were able to turn to another source for help, and were able to watch their child progress, which effectively relieved stress. One caregiver talked about the improvement in her daughter’s communication after receiving speech
therapy. This improvement helped her daughter, but also improved social interactions within her family and relieved burdens associated with impaired communication. Another caregiver spoke about the occupational therapy her child received and the positive impact it had on Nathan’s interactions, activities of daily living, and sensory experiences. The improvement associated with these complications allowed Nathan to interact more fully with his family and peers, and relieved a great deal of his mother’s concern about his social interaction with others. Overall, caregivers agreed that therapy services are of great value to the mental, physical, and emotional health of themselves and their child.
V. Discussion

Caregivers for autistic individuals undergo many additional physical, emotional, and social stresses compared to traditional caregivers and caregivers for children with other disorders. From observing the conversations at support group meetings, themes of stress in caregivers for autistic individuals typically include: difficulty with the diagnosis process and finding medical treatment; seeking additional information on available medical treatments; becoming a “fit” caregiver; finding the right specialized education and services; funding the care and education of their child; difficulty finding time, resources, and maintaining a schedule; special needs and considerations; and the future of his or her child. These additional burdens require strategies to relieve stress. The two most common strategies for doing so were seeking social support through support group meetings or counseling, and seeking help for their child through therapy services.

Support group meetings vary in their effectiveness and the way they are run. In my observation, the meetings through the local autism society were run by volunteer moderators who had a personal connection with autism. Some of the meetings offered a great deal of concrete advice, examples, and active listening, while other meetings lacked a positive outlook, and had destructive conversation instead of constructive interactions. While all the moderators received training in active listening, group dynamics, and were shown how to access resources, they had very different styles of presenting information and addressing the concerns of those at the meetings.

As the sole researcher in this project, my background as a student preparing to become an Occupational Therapist should be noted. I acknowledge that as an attendee to these meetings, I may have pre-conceived perceptions and opinions about the various topics that were discussed. While my goal as a researcher is to eliminate bias and collect and evaluate data with objectivity, my background as a student in a medical profession may influence my interpretation of data and cause unintentional
subjectivity. Due to this fact, there is the possibility for the presence of researcher bias in the conclusions that were drawn from the data.

A thought for future improvement of support groups may be to have a medical professional lead the group. This would provide a resource to ask questions about the diagnosis process, treatment options, and avenues for support from a trained professional. It may also prove to be beneficial in steering the conversation in a positive direction when complications or frustrations are being discussed. In my observation, there were instances where the community style discussion led to a negative attitude about many resources based on one personal encounter. With the addition of a trained professional to run the meeting, conversations and meetings may be able to provide a more constructive environment for solving problems.

This study is limited in its scope of observation. A small sample size of convenience was chosen in two counties of a state in the Midwest United States, and the meetings observed were all sponsored by the same organization. A total of four meetings were attended. The information gathered was limited to the individuals that were able to attend each meeting based on the date, time, and location of the meeting. The information was further limited to the topics that were of current relevance to the caregivers at the meetings based on the age, health, and education of their child. The meetings were all held in areas of a similar middle-level socioeconomic class, and were relatively close in geographic terms. This may limit the information and experiences of the caregivers in terms of medical care and education due to limited access to a select few local schools and local hospital systems. Another major flaw to this study is data collection through observation. As a stranger attending the support group meetings, my obtrusiveness may have changed the dynamics of the environment. This may have caused conscious or subconscious variations in the typical discussion at support group meetings.
Much research is being done about the diagnosis and treatment of autism, but the burden that is placed on the caregiver needs more attention. A child is dependent on his or her caregiver. Without a mentally, emotionally, and physically healthy caregiver, the quality of care that a child receives is compromised. Future research should not only focus on the fore-mentioned areas of stress in caring for an individual with autism, but also on the most effective ways of relieving stress and finding social support for caregivers. Specific areas for future research include the relieving effects of therapy services on the caregiver, and the efficacy of support groups run by volunteers versus the efficacy of support groups run by trained professionals in the medical field.
References


VI. Appendix A

Field Notes

Saturday October 29, 2016: 11am-1pm

• I was the first person to arrive to the meeting
• The moderator arrived with her son who has autism, and I introduced myself and explained that I am a student going into Occupational Therapy school who wanted to learn more about the stresses and burdens associated with being a caregiver
• We talked and she began to tell me about her journey with being a caregiver for her son, Nathan* (fictitious name used) until a man arrived to the meeting approximately half an hour after the scheduled start time, and told us about his difficulty in finding the time and resources to be able to attend the meeting
• Regressive autism: a normally developing child begins to lose speech and social skills between 15 months and 3 years old vs. autism beginning at birth: signs and indications; Nathan has regressive autism
• Signs began to appear around 2 ½ years old, but the diagnosis process took 7 months, and Nathan was 3 years old at this point
• There was a lot of crying, prayers, and phone calls
• Nathan now attends school at the Center for Autism, but it costs $62,000 a year
• They turned to therapy services for help, and found much relief and progress
• Staying on schedule is very difficult
• Nathan has a special diet to try to improve symptoms of autism and help with G.I. issues: gluten-free, dairy free, no egg-whites
• Nathan’s immune system is weak, and he often has ear infections and fevers
• I sat next to Nathan in the meeting. He was a very sweet boy, and was occupying himself with coloring
• He had very repetitive patterns in his coloring, often using one color to fill an entire sheet of paper, and colored in the same direction so all his lines were parallel
• He echoed his mother’s comment of “pretty” in regards to his coloring for the entirety of the two hour meeting, but often said it in the tone of a question and would look in my direction for affirmation
• 30 minutes after the start of the meeting, a man arrived out of breath, stressed, and looking for information to become a more “fit” parent to win a custody case for his child
• He shared about his personal struggles in significant detail; he was working to start up a business, and was working to try to overturn a previous custody ruling for his child
• Currently not working, trying to start up a business of renting houses
• Wanted to know more about nutritional influence on autism- can additives to food cause autism?
• The diagnostic process for his boy took a very long time; 5 months of counseling occurred before he could get a diagnosis
• The dad was overwhelmed and said he felt “brain dead”
• He wanted to know how people could work and earn a living while being a full-time caregiver for a child with autism
• He also wanted to know if there were food sensitivity or allergy testing available
• Nathan’s mom took milk out of his diet, and noticed that his eye contact came back
• Nathan also regressed to being mute, but after his mom removed wheat from his diet, his sounds and basic capabilities of speech were regained
• She has modified her cooking to account for these needs, and his allergies, including peanuts
• Eastern vs. Western medicine has very different views on treatments for autism and its symptoms; she has found more success with Western medicine
• She sees a great value in therapy-based services, including Physical Therapy, Occupational Therapy, Speech Therapy, Equine Therapy, Aquatic Therapy, Art therapy, and Social Skills Therapy
• Nathan also has very sensitive skin
• The dad that arrived to the meeting expressed his frustration at the medical records he has been receiving, and said that the only information on it is that his son was recommended for diagnosis of autism
• His child is primarily with the mother right now, but he does not agree with or follow her plan of care, so he is trying to learn about his 6-year-old son to be more suited to have custody
• Nathan’s mom helped explain the fight or flight response, and Nathan’s hypersensitivity to sensory stimuli, particularly fluorescent lights and the sound they make
• Nathan has astigmatism and near-sightedness, and his mom went to great lengths to find a special-needs optometrist
• She also commented to the dad at the meeting that regardless of the custody battle, the best thing for his son was to establish a routine
• She explained that the parrot-like repetition of “pretty” that Nathan was demonstrating was echolalia
• At this point, she asked me to explain what kind of treatment and goals are addressed in Occupational Therapy to the dad
• At this point, the dad began to talk about everything he was battling: alcoholism, finding a religion, trying to start a real-estate business, a middle-school drop-out, and struggling to find funds, so he lied to the bank, and was trying to get funding by using his parents to get a mortgage; he also spun-off onto a topic of struggling with lying to the bank and if it was moral/ethical, because “all lies are from the devil” and was asking for our input
• We refrained from commenting on his religious inquiries
• Nathan’s mom re-assured him and told him that this life and all the struggles in it are a journey and not something that can be fixed or addressed overnight; she stressed the need for support and that circumstances are not the final product of the person
• She told him about the upcoming Autism Summit and the movie called “Life” that was going to be on exposition
• She also told him about some strategies, such as ABA (applied behavioral analysis) to help minimize bad behavior and increase good behavior
• She commented that some people are upset and resistant when parents push them to work; “some practitioners practice with a chip on their shoulder” and have to lower themselves and understand that a parent is looking out for a child’s best interest and only want them to do their job to the best of their ability
• The facilitator was patient and listened to the emotional “venting” of the dad, just nodded, listened, and understood to try to relieve some of his stress
• The dad also voiced his concerns about his 15-year-old son’s outburst, breaking social cues, and constantly feeling that he needs to apologize to others for his behavior; the son’s self-esteem was low, and wants to know how to help him find his vocation
• His son has a dual diagnosis of a cognitive delay and on the autism spectrum
• Is medication for autism the solution? Nathan’s mom thinks it suppresses the personality of the child
• As a parent with an autistic child, she feels that she is a channel for supporting others
• Two people attended this meeting besides myself; both arrived late
• Nathan demonstrated little to no eye contact, but kissed his mom and told his mom “I love you”
• She was glowing with joy and said “it’s like Christmas to me!”

Saturday November 12, 2016: 11am-1pm

• This meeting also began with just myself and the moderator (Nathan’s mother)
• She told me that many fears of parents include worries that the child does not have the mental capacity to succeed, and may end up homeless; they are also concerned about the high suicide rate in autistic individuals
• She stressed that it is important to be open to new solutions, and suggested that going to the “Provider Fair” is a good place to look for a solution
• Nathan’s mom talked about giving Nathan Vitamin B12 injections to increase the neurotransmitter activity; this has helped Nathan with his talking and pointing
• There is potential damage in Nathan’s Ileum, but the B12 helps
• “Solving autism is like solving a puzzle”
• There is no cure, but different medical tests can analyze and help correct imbalances in the body to help improve function
• Sometimes the body can’t clear toxins or correct imbalances on its own
• The brain is intact in autism, but Nathan’s mom describes it as having damaged networks, and the mind must work through these damaged networks
• There is a STABLE account in Ohio that allows parents to make investments for their child’s care later in life
• “Autism is its own universe”
• Autism Research Institute (ARI) tries to network with parents and find out what parents have tried with their children, what works, and what doesn’t
• When going through periods of extended mental effort, autistic individuals need a break to reset and recharge
• Autistic individuals tend to avoid certain subjects/problems like math because their minds usually solve problems in one certain way, and trying to understand differently can be very challenging
• Unfortunately, school now-a-days is more focused on speed/execution that on understanding, which makes it more challenging for students with autism
• Nathan has an incredible memory; he knows when he needs shots, and memorizes his math problems
• Executive Functioning: a cognitive process that allows us to control actions; functions with emotional control, inhibition, goal-setting, initiative, working memory, and shifting
• Challenges with autism: set patterns, repetitive behavior, restricted interest
• One dad at the meeting talked about his boy who had a particular interest in fire, and the dad had to get rid of all lighters/matches
• A friend of this same little boy was labeled as “emotionally disturbed” and was not able to get a diagnosis of autism
• This friend undressed at school because he urinated on himself and was uncomfortable, but was written up as being a sexual deviant
• “School systems have not progressed to accept the diagnosis of autism, and often offer no therapy services”
• This friend was found running away in the woods two different times at school
• His mom moved to Beachwood so he could receive a better education, but he didn’t even receive an IEP at his new school
• The public doesn’t want to accept mental illness
• Nathan had meltdowns at first when he would see lab coats, crying babies, or shots
• There are a great many challenges, including saving money and investing money for later care for a child with autism
• Nation is high on emotional intelligence, and tries to aid and comfort another child when they cry
• Nathan is lower on the IQ scale than some individuals, but compensates in other areas
• Cultures are different around the world; people in London show less disappointment when their child is diagnosed with autism
• One father in the meeting shared that he had to let go of idealistic thoughts of raising a child, otherwise he would always find himself being disappointed, and had to find joy and happiness in his current situation
• The Autism Summit event offers free child care, which is a big deal! Finding child care can be stressful and burdensome to find a sitter who is going to be capable and competent when caring for a child with special needs

Monday November 14, 2016: 7-9pm

• Three other people attended this meeting
• The group was led by a mother of four children; her oldest son has Asperger’s syndrome, and was diagnosed at 8 years old
• He was able to work through difficulties and earn an Associate’s degree
• She cared about connecting with the emotions and experiences that others are challenged with in their journey as a caregiver
• Two of the parents shared that their main concern was that their child become self-sufficient, and be able to care for themselves as they grow older
• There are two types of classroom settings in school: a standard classroom setting and a life-skills classroom setting; One parent was asking for advice on what kind of classroom his son should be in
• Another parent shared that his son was in a standard classroom in order to pursue the best education, but he had concerns that the life-skills classroom might offer benefits for his son that are unavailable in the standard classroom.
• This group shared a lot of stories and experiences they had been through, but their experiences brought them together, and they were able to bond over similar stories; they certainly shared several laughs, and were able to reduce stress by sharing stories and taking a step back from their own struggles to listen to others.
• There was a wide range of emotions that were shared at this meeting; they changed from confusion, sadness, and serious concerns, to joyful, light-hearted laughter.
• They all seemed to agree that they felt other people put up boundaries that limited the success and progress of their child, and these boundaries were created out of assumptions, based on their diagnosis.
• They also feel that there are boundaries that separate themselves from other parents and friends, because they can’t emotionally connect over the same life events and challenges.
• The last point of the meeting was the moderator sharing her advice on finding different support networks as a parent of a child with autism; she named several resources, including the support group meeting they were at, therapy services, medical treatment and intervention, and counseling.

Thursday January 12, 2017: 6-8pm

• Moderator’s daughter was diagnosed at 3 years old.
• Right now, she is 12 years old, and her current challenge is toilet training; it proves to be especially challenging, because she doesn’t understand incentives.
• Approximately five nights out of the week are “sleepless nights” where she sleeps 4 hours or less.
• At age twelve, she got her first menstrual period, but was put on medication to prevent her cycle from occurring while she is not bathroom trained.
• A middle-aged man with autism (fictitious name: John) joined the meeting; the moderator did not greet him as he shyly entered, and he didn’t speak for the first 15 minutes of the meeting.
• He was very anxious about being at the meeting, and the first thing he asked was “Is it OK that I’m here?”
• He intently listened to the symptoms of the little girl, and began to make suggestions; his suggestion for the sleepless nights and skewed perception of time was to change the clocks in the house to display the time that would encourage proper sleeping hours.
• The little girl just began school at the Learner School for Autism; up until this point, she had been denied Occupational Therapy services in her public school.
• Another mom shared that her 15-year-old son was also dealing with Insomnia; she said that he would wake up in the middle of the night to a storm, and would stay awake to watch the AccuWeather app on her phone all night.
• Her son is high-functioning and just started in an Early College program.
• He recently started asking his mom “why don’t I have any friends?”
• During these conversations, John remained quite shy, and struggled with a stutter and spasmodic tics; the moderator and other mother at the meeting were personal friends, and shared smirks, condescending looks, and laughter at his behavior
• I felt quite uncomfortable during all of this and thought to myself that these two women have children with the same diagnosis as this man, but do not show empathy or understanding for his behavior
• The moderator’s daughter is receiving speech therapy, and is currently non-verbal, and the speech therapist wants her to get an IPad 2 for her communication, and would like the mom to begin implementing this at home
• John suggested some of the difficulties she is having with implementation at home may stem from her familiarity with her current communication with her mother, and she may not understand the need to change her routine, especially if the mom doesn’t implement regularly
• The mom struggles with this, because she works for the state and travels around the state for her job
• Her daughter woke up at 4am the morning of the meeting, and took the initiative to go use the restroom on her own for the first time!
• One of her biggest concerns down the road is what the future holds for her daughter; will she end up in assisted living when she is older?
• John voiced concern that if this is the case, they must be careful to ensure a roommate doesn’t take advantage of her
• The moderator’s daughter has a special talent for puzzles, and just completed a 1500 piece puzzle
• She is unable to read and understand that a directive sentence is a command to her; however, she can understand oral commands
• John suggested that she pair the written commands with the action to help her make the association
• The little girl seems to be genuinely happy now that she has entered her new school, her needs are being met, and she is currently receiving medication; she seems to be very comfortable with her new environment
• John commented that coming to this meeting was a great challenge for him, and took a lot of courage to come into a new environment
• The young girl doesn’t know the consequences to her actions, struggles with ADLs, and must keep all the objects on her desk in a perfect line
• John chimed in the little girl may physically be twelve, but she is not mentally at that age; people shouldn’t be shamed for acting other than their physical age
• Showering is a struggle for the little girl, and John remarked that he always hated showering because of the soap getting into his eyes
• The moderator talked about her journey, and the need to get an attorney to fight the local school to transfer her daughter to the Learner School
• John commented that “special education is worthless”
• The mothers at the meeting seemed to think that public schools didn’t properly address the needs of their children, and instead only focused on their academic education
John wrapped up the meeting by warning the mother that he thinks the little girl’s medication may be causing complications in her behavior; he also said that in his opinion, very few doctors understand the chemistry behind the medication, and how adult medications affect children.