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Parent/ Caregiver Burnout with Autism Due to COVID

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Parent/Caregiver Burnout with Autism due to COVID-19

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Honors Research Project

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Abstract

The purpose of this research project is to see if parents and caregivers of those with autism are experiencing more stress due to the pandemic. METHODS: We had 7 statements that related to the child with autism or the caregiver themselves. Those statements were recorded for before COVID-19 and since COVID-19, totaling to 14 statements. Each statement was related to something that factored into the amount of parent/ caregiver stress such as involvement with a support system or ability to control external stimulus for their child with Autism Spectrum Disorder (ASD). The statements were sent out in the form of an anonymous electronic survey. The group receiving this survey were parents/ caregivers of children with ASD who we were able to contact through the Autism Society of Greater Akron. The questions were answered via Likert scale by choosing from “strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, and strongly disagree.” The method allowed us to see how well each statement described the parents’/ caregivers’ experiences before and after COVID-19. RESULTS: The results showed a strong correlation between an increase in stressors for caregivers/ parents during the pandemic. The questions that were most relevant in our results were regarding personal time for the caregiver, a routing for the child, and amounts of stress for the caregiver. DISCUSSION: The results of the survey showed that the pandemic decreased the amount of personal time for the caregiver/ parent, decreased the likeliness of a routing for the child, and increased the large amounts of stress for the caregiver/ parent.

Introduction

In our honors project, we studied the burnout of parents and caregivers of individuals diagnosed with Autism Spectrum Disorder (ASD). We wanted to specifically address the stress that these caregivers experienced before COVID-19 vs during COVID-19. This was an important topic to navigate due to the relevance of the subject with COVID-19 creating a new normal for people all over the world during 2020. Additionally, this is an important topic because not much research has been done yet on the effect of COVID-19 on caregiver stress given that the pandemic began in 2020. When the COVID-19 pandemic was declared in the United States, only essential businesses were allowed to be open. Schools, workplaces, support groups, and all extra-curricular activities were cancelled to keep the spread low. Those individuals with ASD often live very routine lives. In fact, those with ASD function best when they are on a set routine and while incorporating things that they enjoy into their schedule (Stoppelbein et al., 2015). With everything shut down, their routines were turned completely upside down and were most likely unable to do the things that they regularly enjoy. Parents and caregivers were forced to help them adjust. We predicted that these caregivers experienced increased levels of stress due to COVID-19. The question this study investigated was: Have parents/caregivers of those with ASD been experiencing more stress due to the pandemic? We had predicted that parents/caregivers of children with ASD would be experiencing higher levels of stress during the pandemic than before. This study will help answer the question: Have parents/caregivers of those with autism experienced more stress due to the pandemic? Based off our survey responses, we can expand our knowledge on how to help these individuals manage their additional stress, and hopefully in the end, reduce it.

Literature Review

Autism

Autism spectrum disorder is a neuro-developmental syndrome, and it has a strong likelihood of being inherited. With ASD, there are typically impairments in the form of social and communication difficulties, and difficulty imagining others' thoughts and emotions. Individuals with ASD are commonly known to have the distinct trait of a strong attention to detail. Additionally, there are a triad of behavior domains related to poor social development commonly associated with ASD. These include difficulty with communication, repetitive behavior, and obsessive interests. Language is one of the most widely noticed social deficits in autism. It is common for there to be further deficits in receptive language skills than expressive language skills (Levinson et al., 2020). According to Levinson et al. (2020), deficits in pragmatic language are evident as well. This means that recognizing the difference between a literal or figurative phrase may be challenging. Additionally, identifying what is realistic and sensible does not come as naturally for ASD individuals. The presence of autism in an individual can also occur at various intelligence levels and is not partial to any single point in the intelligence level continuum. When identifying autism, the condition can be commonly confused with Asperger's Syndrome, which is a distinct condition included within ASD. There are several differences between ASD and Asperger's Syndrome. Individuals with autism experience a language delay such as no single word before 2 years of age while individuals with Asperger's Syndrome do not experience this delay. Asperger's Syndrome is also differentiated by an average or above intelligence level compared to the vast spectrum of intelligence levels observed with autism. Additionally, autism is characterized with a deficit to the normal process of

emphasizing which could make it difficult for children who are affected to understand the emotions of others . This deficit is relevant to the age of the individual. (Baron-Cohen, 2004).

Autism Causes

There are many different speculations about the causes of autism. Among these is the link to family genetics. Autism has a strong heritability and is thought to be passed through chromosome regions. More specifically, region 7q has been studied in the development of autism (Baron-Cohen, 2004). There are 5 genes that have been linked to the autism phenotype. The first of these is the ENZ gene that is involved in cerebral development. The gamma amino butyric acid receptor (GABR) is also thought to be affected by those with ASD. The OXTR gene is responsible for the reception of oxytocin and can be affected with individuals who have ASD. Neural migration of the developing brain can be deterred in individuals where the RELN gene is affected. The expression of happiness can be hindered by an affected SLC6A4 gene. Certain mutations of these affected genes are thought to be located on the chromosomes 2, 3, 15, 16, 17, 22 (Johnson et al., 2013).

Heritability is thought to be a cause of autism. This was seen in twin studies done on both fraternal and identical twins. The identical twins had 60-90% similarity with autistic traits. However, the fraternal twins only had 0%-10% similarity (Johnson et al., 2013). The causes of autism have also been associated with perinatal risk factors. These include reproductive technology use, cesarean birth, multiple birth, breech, preterm, and low birth weight. Although these factors are associated, the link is unknown (Johnson et al., 2013).

The environment of an individual also has an association to ASD. A high exposure to pollutants during development is linked to the development of ASD. Additionally, mothers who

have contracted a viral infection during pregnancy are thought to have increased risk of ASD as well as those who have a lot of stress during their pregnancy. The antibodies associated with a viral infection are suspected to be a factor in the occurrence of a child with ASD. However, there is no association with mothers who have received the influenza vaccine and the occurrence of children with ASD (Gyawali & Patra, 2019). This illustrates the wide spectrum of theories that lack hard evidence to support the causation of ASD. Lastly, the use of artificial insemination of ovulation inducing drugs has been linked to ASD for the children of mothers who are over 35 (Johnson et al., 2013). Regardless of the reason for a preterm delivery, there has been a link found between births before the 37th week of gestation and the diagnosis of ASD (Persson et al., 2020). This correlation was found in a study conducted by Nordic countries. The correlation between ASD and premature birth was particularly high between week 24 and 40. Although there are many probable causes, the sex of the baby was not determined to be a factor in the development of the disorder (Persson et al., 2020). An additional external factor that is associated with ASD is the mother's age at the time of the pregnancy. Women who are at the ages or 40 - 49 are at a higher risk of having a child affected by ASD than those who are ages 20-29 (Gyawali & Patra, 2019).

Diagnosing Autism

The diagnosis of autism has not always been as prevalent in the past as it is today. According to Johnson et al. (2013), in the 1980s, only the most severe and non-verbal individuals were autistic. This led to only 1 child for every 2,000 children being diagnosed. As of 2009, a wider spectrum of behaviors and phenotypes were diagnosed as ASD. This led to an increased prevalence, with 6 or 7 of every 1,000 children being diagnosed. This increased to over 1% of children being diagnosed in 2012. Of those diagnosed, there were 4-5 boys affected for every 1

girl. As the diagnosis spectrum for autism increased, so did the recognized phenotypes. These include, but are not limited to, speech delay, gastrointestinal issues, attention to detail, less social expression, and repetitive behaviors. However, one individual could show many of these signs, while another individual could show none but still have ASD. A variation in genetics and environments can contribute to the different levels of phenotypes shown with ASD (Johnson et al., 2013). Further research of genotypes and phenotypes demonstrated with ASD could potentially link certain phenotypes to genotypes. This would be helpful for both diagnosing and determining the cause of ASD.

The probable signs of ASD can be detected as early as 12 months of age. If this is suspected, further screening can be done at the age of 24 months. The most common early age of diagnoses is in preschool children at the age of 3-4 years (Miller et al., 2020). Autism may be more commonly diagnosed earlier in life, but it is still detectable in adolescence. Anxiety is a comorbidity commonly found in adolescence given the diagnosis of ASD as toddlers (Mazurek, 2017). Anxiety, as a comorbidity, can present itself in many ways depending on the age of the child. For children who are middle aged, it is most commonly presented as separation anxiety (Mazurek, 2017). Comorbidities of ASD may be more difficult to recognize and be diagnosed in adults due to masking (Hull et al., 2017). Masking is the conscious effort to disguise the symptoms of ASD to others. This begins with an effort to fit in and make connections that later becomes a habit of compensating for naturally occurring behaviors. Lastly, this compensation can leave individuals burnt out and struggling to find their self-identification (Hull et al., 2017).

Autism Treatment

Although autism is not curable, there are treatment options. The earlier that someone with autism receives intervention, the better the prognosis may be. Research has shown that early

intervention for kids with ASD in an appropriate environment at least 2 years before the start of school can be unquestionably beneficial and provide major improvement (Autism Science Foundation, 2021). There are several different forms of therapy that may provide extreme benefits to those diagnosed with autism spectrum disorder. Applied behavioral analysis (ABA), occupational therapy, speech therapy, physical therapy and pharmacological therapy are among the most effective treatments available as of now. These treatments are designed to limit the implications that come with having ASD, and to maximize the quality of life these people are able to experience.

Applied Behavioral Analysis is used to change behaviors based on how we learn things. This comes from the principles associated with behavioral psychology. ABA basically encourages positive behaviors and discourages negative ones. It also teaches new skills and translates these newly learned skills to be used in new situations (Autism Science Foundation, 2021). In an article by CARD (Center for Autism and Related Disorders, 2020), they list six ways that ABA methods are used to support and benefit those with Autism. These are to increase behaviors, to teach new skills, to maintain behaviors, to transfer behaviors between different situations, to narrow conditions when interfering behaviors occur, and to reduce interfering behaviors. Another form of treatment for people with autism is occupational therapy (OT). It is helpful for sensory integration issues and improving fine motor skills. Occupational therapy can help individuals become more independent when performing their activities of daily living, like walking, sitting, going to the bathroom and any other activity involved in everyday life. It can also help to improve their overall quality of life (Autism Science Foundation, 2021). According to information published by Autism Speaks (n.d.) OT utilizes the individual's play skills,

learning strategies and self-care. The focus on these factors will help to increase the individual's autonomy.

Another treatment that people with autism may use is speech therapy. This treatment can be extremely beneficial for these individuals because it helps with their ability to communicate socially. Typically, individuals with autism have deficits in social communication, so attending speech therapy is a solid option (Autism Science Foundation, 2020). In an online article by Speech and Language Kids (2016), they name five principles of speech therapy for kids with autism. These include establishing function/spontaneous communication, provide social instruction in various settings throughout the day, target peer interactions, provide training and support to other adults, and fine tune communication skills as other areas improve. Sticking to these principles when doing speech therapy with those with autism will help these individuals to be able to communicate and function more effectively.

Physical therapy (PT) is another treatment option. PT, like Occupational Therapy (OT), is used to improve motor skills as well as sensory integration issues. Unlike OT, which focuses on fine motor skills, PT focuses on gross motor skills. A big focus with physical therapy and people with autism is their proprioception, which is feeling and being aware of your own body in space. This treatment will also help individuals when performing their activities of daily living (Autism Science Foundation, 2020). An article from the American Physical Therapy Association written by Ries (2018), states that creating individualized plans for children with autism can increase the overall quality life of children with autism. Physical therapists work in Individualized Education Plan (IEP) teams to create a strategy to help each child. This individuality helps to enhance the children's care and increase their prognosis of living with autism and functioning in daily life.

Another form of treatment for people with autism is pharmaceutical treatments. These can help to alleviate the symptoms that accompany autism, such as aggression and irritability. This treatment can also be used in combination with other treatments because they will be more effective if the symptoms of autism are dimmed by the pharmaceuticals (Autism Science Foundation, 2020). According to the National Institutes of Health (2019), there is no medication to cure Autism, but there is some research behind medications that can help with the autism symptoms. These medications are listed as potentially beneficial for those with autism: Selective serotonin re-uptake inhibitors, tricyclics, psychoactive or anti-psychotic medication, stimulants, anti-anxiety medications, anticonvulsants. Some medications will work for some individuals, and not for others. The National Institutes of Health (2019) imply the medications prescribed should be dependent on the person.

Community Support for Autism

It is easy to be overwhelmed and stressed as a parent or caregiver of a child with autism. There are support groups that families can join to help lessen the load and learn more about the disease. One organization that is helpful with this, is the Autism Society of Greater Akron (2020). Their website offers countless resources, such as: Help-Line that you can call at any time if you need help, COVID-19 preparedness and resources information, mental health and family information, and additional educational resources and information on things to do. The Autism Society also holds support groups and different events to help with the caregivers and the children themselves. The Ohio Interagency Work Group (OIWG) on Autism also has support groups based on county or residence (OIWG, n.d.). Parents and caregivers can view a map of Ohio and select the support group closest to them.

Every summer, the Autism Society of Greater Akron usually holds a walk, a bike camp, swimming lessons and more to teach the kids new things and help the parents. Due to COVID-19, none of these summer activities could legitimately happen, so they changed some things to be virtual. The pandemic did not create an easy adjustment for individuals and families living with autism. Their entire support system fell apart right in front of them. Thankfully, the Autism Society adjusted quickly to provide virtual options. Their support groups are being held via Zoom calls. The walk is still taking place, but it as well will be virtual. Although the option already existed, they still have a Facebook group that can be utilized virtually by families living with autism and others can provide solutions or support to these families. The Autism Society of Greater Akron website is also a great tool that they utilize to keep important information accessible and to spread additional information. The organization really creates a community between these families, which is essential to feel supported and thrive with this disease.

Caregivers/Parents Burnout with Autism

Parents and caregivers of those with autism endure numerous challenges and face a magnitude of stressors. It is likely that they experience burnout, especially since the pandemic began. People lost their entire routine when COVID-19 became prevalent in our country. Schools shut down, businesses closed, and just about everything went virtual. People with autism function best when on a routine that they have input in and are able to do things they enjoy. COVID-19 changed everyone's routine and this was especially difficult for those with autism and their caregivers. People were forced to quarantine and stay at home which is a big change in routine. Those with autism no longer were going to school so their parents or caregivers were spending more time than normal with them. This can result in burnout. There are several

influences that contribute to this burnout, which can include employment status, marital status and age. (Alnazly & Abojedi, 2019).

Diamant (2009) discussed published research in her online Disability Scoop article that found “Autism moms have stress similar to combat soldiers.” This conclusion was determined because the moms and the soldiers found a hormone associated with stress that was very similar between the two groups. The amount of stress that these parents experience has caused their hormones to change, which is a result of the daily stress associated with being a mom of a child with autism. Stress management and learning different ways to cope with stress is an important part of managing caregiver burnout. Research suggests that mindfulness-based stress reduction is beneficial in these cases. Additionally, positive psychology has been effective in reducing many aspects of caregiver burnout including, but not limited to, lack of sleep, anxiety, and depression (Shenoi, 2020).

According to Sarris (2017) of the Interactive Autism Network, parents of children with autism experience more stress than parents of kids with Down Syndrome, and more than parents of children that are developing normally. A quote from this online article was, “And those stresses don't necessarily end on a child's 18th or 21st birthday. Just ask Marilyn Cox of Missouri. ‘I can't say the stress is any less now than it was when my son was 3 years old,’ she sighs. That was four decades ago. Her son is 47, works, and lives at home.” (Sarris, 2017). This statement shows that these parents can suffer from chronic stress. Life caring for a child with autism can be hard and stressful, and it doesn't stop as they go through adulthood. They still will need their parent or caregiver's help, even as they become an adult, because they still suffer from the difficulties of having ASD.

COVID-19 Effect on Autism

In March of 2020, our way of life in the United States shifted. People were forced to stay at home to slow the spread of the coronavirus. Students went from attending school in person, to having to log on to their classes virtually via zoom or some other video conferencing platform. All in person activities were halted due to social distancing requirements. Everyone's routine changed dramatically, and that can be harder for some people than others. People with autism function best on a regular schedule that includes their favorite activities.

When the country began quarantine, everyone was staying home for the most part. Children went from attending school for 6+ hours a day, to attending virtual school from home all day. Like those with autism, kids in general also function best on a routine. According to The Marcus Autism Center (2021), "All children learn best from repetition, and children with autism spectrum disorder (ASD) especially appreciate predictability and patterns. Establishing routines at home can promote positive bonds between children and caregivers and ease the unpredictability of everyday life for young children." COVID-19 took away most of the people's daily routine and flipped it upside down. This would cause stress to the average person, but it would also create a particularly immense amount of stress for those who have autism and their caregivers. In this research study, we aimed to identify the effect the coronavirus had on parent/caregiver stress and burnout of those who care for individuals with ASD.

Methods

The basic design of this study was a survey distributed via a convenience sample. The survey instrument contained seven (7) questions containing various quality of life indicators for their child pre-pandemic compared to during COVID-19, for a total of fourteen (14) questions. The survey was created using Qualtrics, (Provo, UT) which is a survey software licensed by The University of Akron. The study population included parents/caregivers of those with autism who

were involved in the Autism Society of Greater Akron. After obtaining approval from The University of Akron's Institutional Research Board to conduct the research, the survey and introduction email/informed consent, seen in Appendix A, was sent to Lisa Thompson, Director of Programs for the Autism Society of Greater Akron. She distributed the email/link to our survey via digital newsletter and Facebook to families registered with their organization. The survey was set up such that each participant could only take the survey once and their identity was kept anonymous when submitting their responses. The survey was distributed via an online newsletter on March 31st of 2021 and on the Autism Society of Greater Akron's Facebook page on April 6th. A reminder to take the survey was sent again via the online newsletter on April 6th and 12th. The data was analyzed using Qualtrics (Provo, UT) reporting tools. The survey was closed on April 18th, 2021 at 7:30 pm.

Results

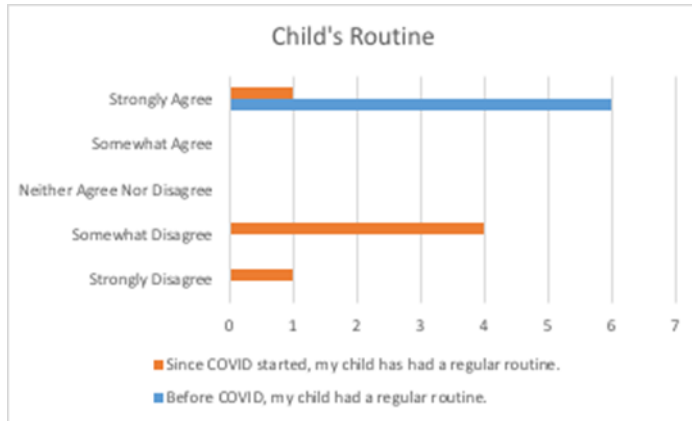
There were 6 people who completed the survey. Qualtrics (Provo, UT) recorded the responses to each question which are listed below. The same questions were asked, but in relation to before COVID-19 and since COVID-19. Therefore questions 1 and 2 are comparable, and 3 and 4, and 5 and 6, and so on.

We used these data to determine the effect that COVID-19 had on parent and caregiver burnout. We analyzed trends to determine the most detrimental areas that have been affected since the sample size was too small to run statistical analyses.

Statement 1 said, "Before COVID-19, my child had a regular routine." All 6 responses strongly agreed with that statement. Statement 2 said, "Since COVID-19 started, my child has had a regular routine." Four of the respondents picked "somewhat disagree," with 1 choosing "strongly disagree," and 1 choosing "strongly agree" (Figure 1).

Figure 1

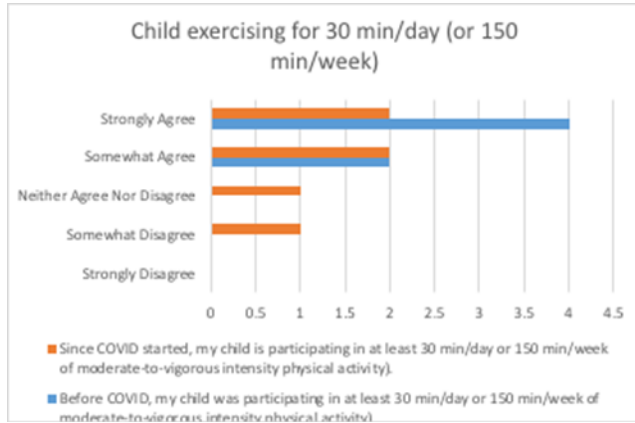
Questions 1 and 2 - Child's routine before and since COVID-19



Statement 3 said, “Before COVID-19, my child was participating in at least 30 min/day or 150 min/week of moderate-to-vigorous intensity physical activity.” Everyone agreed, with 4 of them strongly agreeing and 2 of them somewhat agreeing. Statement 4 said, “Since COVID-19 started, my child is participating in at least 30 min/day or 150 min/week of moderate-to-vigorous intensity physical activity.” The responses included 2 strongly agreeing, 2 somewhat agreeing, 1 neither agreeing or disagreeing, and 1 somewhat disagreeing (Figure 2).

Figure 2.

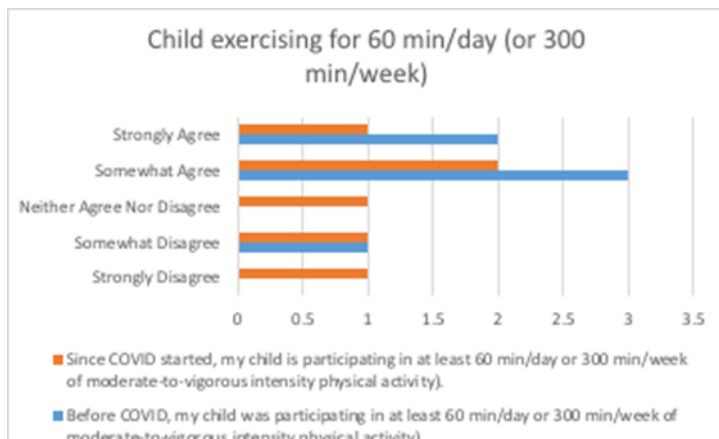
Questions 3 and 4 - Child participating in 30 min of physical activity a day before and since COVID-19.



Statement 5 said, “Before COVID-19, my child was participating in at least 60 min/day or 300 min/week of moderate-to-vigorous intensity physical activity.” The majority, with 3 responses, somewhat agreed, while 2 strongly agreed and one somewhat disagreed. Statement 6 said, “Since COVID-19 started, my child is participating in at least 60 min/day or 300 min/week of moderate-to-vigorous intensity physical activity.” Two respondents somewhat agreed, while 1 person strongly agreed, 1 neither agreed nor disagreed, 1 somewhat disagreed, and 1 strongly disagreed (Figure 3).

Figure 3.

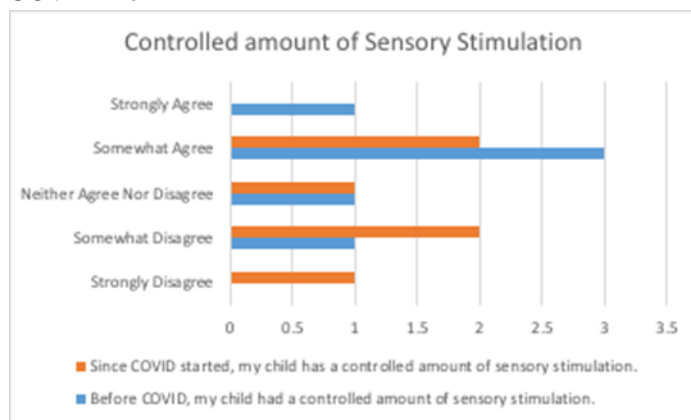
Questions 5 and 6 – Child participating in 60 min of physical activity a day before and since COVID-19.



Statement 7 said, “Before COVID-19, my child had a controlled amount of sensory stimulation.” Three respondents somewhat agree, while 1 strongly agreed, 1 neither agreed nor disagreed, and 1 somewhat disagreed. Statement 8 said, “Since COVID-19 started, my child has a controlled amount of sensory stimulation.” Two respondents somewhat agreed, while 2 also somewhat disagreed. One respondent chose “strongly disagree” and the last one chose “neither agree nor disagree” (Figure 4).

Figure 4.

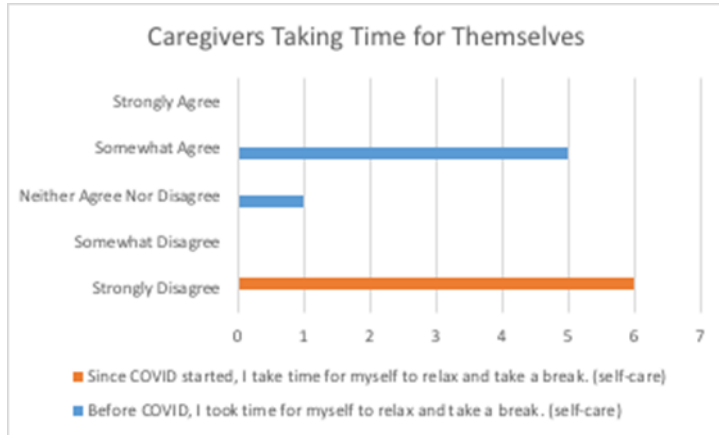
Questions 7 and 8 – Child had a controlled amount of sensory stimulation before and since COVID-19.



Statement 9 said, “Before COVID-19, I took time for myself to relax and take a break. (self-care).” Five respondents somewhat agreed, while 1 neither agreed nor disagreed. Statement 10 said, “Since COVID-19 started, I take time for myself to relax and take a break. (self-care)” All 6 responses were recorded as “strongly disagree” (Figure 5).

Figure 5.

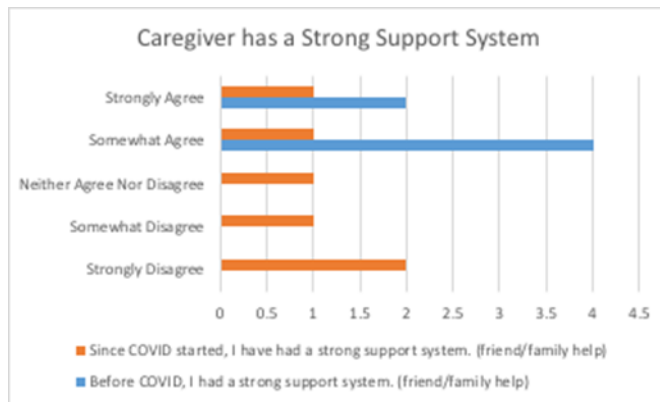
Questions 9 and 10 - Caregivers take time for themselves before and since COVID-19.



Statement 11 said, “Before COVID-19, I had a strong support system. (friend/family help)” They all agreed, with 4 of them somewhat agreeing and 2 of them strongly agreeing. Statement 12 said, “Since COVID-19 started, I have had a strong support system. (friend/family help)” The answers varied with 2 strongly disagreeing, 1 somewhat disagreeing, 1 neither agreeing or disagreeing, 1 somewhat agreeing, and 1 strongly agreeing (Figure 6).

Figure 6.

Questions 11 and 12 - Caregiver has a strong support system before and since COVID-19.

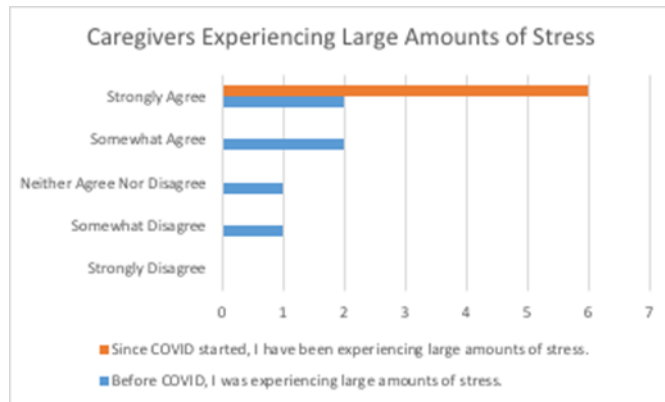


Statement 13 said, “Before COVID-19, I was experiencing large amounts of stress.” Two respondents strongly agreed, 2 somewhat agreed, 1 neither agreed nor disagreed, and 1 somewhat disagreed. Lastly, statement 14 said, “Since COVID-19 started, I have been

experiencing large amounts of stress.” All 6 responses were unanimous for strongly agreeing (Figure 7).

Figure 7.

Questions 13 and 14 - Caregiver experiencing large amounts of stress before and since COVID-19.



Discussion

Although statistical analyses were not performed due to that small sample size, trends were clear. The statements, 1 and 2 on the survey, that mentioned the child having a regular routine before and since COVID-19 were most striking. Before COVID-19, all 6 responses strongly agreed that their child had a regular routine. Since COVID-19, 5 of those responses shifted to disagree strongly or somewhat. This suggests that COVID-19 turned these families' lives upside down and upset their children's' normal routines. Studies have shown that individuals with autism function best on a routine grounded on regularity. Without a regular routine, due to COVID-19, these families were forced to adjust which can be challenging to say the least.

The statements, 9 and 10 on the survey, regarded if the caregivers take personal time for themselves, and participate in some sort of self-care. Before COVID-19, 5 respondents selected

an agreeing category, meaning they do practice self-care. Since COVID-19, all 6 responses strongly disagreed, meaning none of them take time for themselves. COVID-19 has completely disrupted their lifestyle in a way that perhaps eliminates the ability to relieve stress in their lives. The requirements of caring for their child with autism has taken precedence over caring for themselves.

The statements, 11 and 12 on the survey, discussed if the caregiver experiences large amounts of stress before and since COVID-19. Before COVID-19, the responses were pretty spread out between the choices. Since COVID-19, all 6 responses indicated that they strongly agree that they are experiencing large amounts of stress due to COVID-19.

Statements 3 through 6 on the survey all related to physical activity trends and guidelines. Statements 3 and 4 were related to the child getting 30 minutes/day (or 150 minutes/week) of moderate-to-vigorous physical activity. Before COVID-19, all 6 responses were in the agreeing sections, either somewhat or strongly. Since COVID-19, the responses have varied across the board, ranging from strongly agree to somewhat disagree. This shows that the children may not be meeting their recommended physical activity guidelines because COVID-19 has caused on these families' lives. Statements 5 and 6 on the survey mentioned the child getting 60 minutes/day (or 300 minutes/week) of moderate-to-vigorous physical activity. Before and since COVID-19, the 6 responses varied in their responses. Before COVID-19, most of the responses agreed, either somewhat or strongly, while 1 response somewhat disagreed. Since COVID-19, all the responses varied from strongly agree to strongly disagree, and everything in between. This shows that not all children have been able to include sufficient exercise in their routines, especially with the pandemic being around.

The implications from this study showed a direct relationship between the COVID-19 pandemic and caregiver stress. The presence of COVID-19 raised caregiver stress in multiple instances. This rise in caregiver stress was related to the impact that COVID-19 had on multiple determining factors in the lives of caregivers and their children with ASD. Some of these include a lack of exercise time, a lack of personal time for the caregiver, and a smaller personal support group. The pandemic greatly decreased these tools for stress management due to social isolation that was produced through quarantine. Other factors that may have greatly increased stress levels were the decrease in control of stimulation and the change in routine for children with ASD. We have learned that children with ASD rely strongly on a daily routine, and we can imply through these survey findings that the change in their routines has produced more outbursts and higher stress levels for caregivers. We can also imply from these findings that caregivers rely heavily on social support and personal time to manage their stress.

We faced several limitations when completing this project. It took us multiple months to receive approval from the Institutional Review Board (IRB). Since that process took such an extended amount of time, we did not have much time to actually have to survey open to the participants. This drastically cut into our data collection time and kept our sample size quite small.

Another limitation we faced was that we did not control when or how often the survey got sent to those within the ASGA community. The survey link was sent to the director of programs for ASGA, and she took care of sending it out to possible respondents. It was also sent out in their weekly newsletter and was posted to their Facebook page. The researchers were assured that a reminder was sent as well. Not being able to take the time to complete this survey may speak volumes to the dedication of the caregivers.

We recommend that caregivers take time to themselves at all times, especially during the COVID-19 pandemic. While being home all day, it is still important to have a designated self-care time to unwind and decompress. It is especially important to schedule this time routinely and to value the importance of self-care to manage stress. This could be in the form of a hobby, reading, exercising, or just relaxing. Regardless of what the aid is, alone time is crucial for caregivers to decompress from the day. Additionally, we encourage that caregivers find a new routine for their children with ASD that is like their daily lives before the pandemic. If the children had been in day care or at school for regular number of hours, we recommend that caregivers use that time for structured activities and other types of stimulation. This will also help caregivers to have a greater control on the external factors of stimulation. Increasing the amounts of physical activity for both the caregivers and children should be a priority. Physical activity is a stress relieving activity that also helps to manage symptoms of ASD. This is even more important during the pandemic due to the large amount of time people are spending in their homes being sedentary. Lastly, we are not underestimating the importance of a social support system. We recommend using other tools for social support such as facetime or online support groups to ensure that caregivers can still have that support without needing to be in person.

The Autism Society of Greater Akron already offers many opportunities for the families in their community. They have a Help-Line that caregivers can call if they are in need of a support system that will listen to their issues and help to solve them. They also have support group meetings called “Coffee, Tea and Autism,” where parents and caregivers can informally meet with each other and discuss among each other. The ASGA also has an event calendar, where they organize and post different events that those within their community can participate in. Another program that the ASGA has, and I helped with, is called “Movin & Groovin with

Erin.” I helped make it last summer during my internship and the purpose of it was to provide ways to stay active during COVID-19. I made several workout videos at different levels, beginner, intermediate and advanced. The Autism Society of Greater Akron offers so much to their members and I hope they do utilize the resources they are offered. A recommendation we would give to the ASGA to increase their support for the caregivers even more would be to hold self-care events for them. Maybe a spa day or painting event, just something that is fun and relaxing for them. They work so hard to care for their child with ASD and sometimes they are not able to relax or take time for themselves. Having an event designed to help them relax would be amazing for them.

For me, Erin Babcock, this project frustrated me. We worked so hard and to only get 6 responses was kind of disappointing. When I interned at the Autism Society of Greater Akron, Lisa mentioned to me that they struggled getting the ‘clicks’ on their newsletter and social media, meaning people actually clicking on the links and other content they post. I think this survey could have reached more people, and in turn, benefitted more people. Overall, the research process has been a learning experience for me. I have written research papers and completed projects, but this is the first time I have ever done anything like this. I am going to graduate school in the Fall, so I think that this process benefitted me and will prepare me for similar assignments in the future.

This project was a great learning experience for me, Leah Recker. I have not completed this extensive of a research project before, and I am appreciative for the opportunity. At times, this project was very frustrating. The process of getting our IRB approved was probably the most frustrating part. I believe that this part could have negatively influenced our ability to get responses. We put a lot of work and thought into the survey, so I had higher hopes of it being

able to reach more people and to in turn show data on a larger scale. However, we were still able to analyze the 6 responses we did get and learn from them. We were also able to form recommendations from this data that I hope could help those who wish to read them. Although this project did not end up how I thought it would, I do think this was a very productive experience and I will take the skills I have learned into research that I complete in the future.

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Appendix A

Email to be sent to parents/caregiver network through Autism Society of Greater Akron

Dear parents/caregivers,

Hi, my name is Erin Babcock, and I interned with the Autism Society of Greater Akron this past Summer in 2020. We made a program called “Movin and Groovin with Erin” which is still located on the ASGA website if you’d like to take a look and get some exercise! I am a Senior at the University of Akron and I partnered with my classmate, Leah Recker, for a research project. We created a short survey to find out if COVID-19 has caused increased stress for those who are a parent or caregiver of someone with autism. If you could please take 5-10 minutes to complete this survey, we would be very grateful! Thank you so much and I hope you all have a happy and healthy year!! :)

Informed consent statement:

You are invited to participate in a research project being conducted by Erin Babcock and Leah Recker, two undergraduate students in the School of Exercise & Nutrition Sciences at The University of Akron. The purpose of this research is to find out if parents/caregivers of those with autism are experiencing more stress due to COVID-19.

If you decide to participate, you will be asked to complete an anonymous web-based survey. The survey should take no more than 10 minutes and we hope to recruit 50 participants. If at any time during the survey you do not wish to continue, you can stop and the survey will not be counted. Additionally, there are no risks or guaranteed benefits associated with the completion of this survey.

The survey will not collect any identifiable information, and no one will be able to connect your responses to you. Your anonymity is further protected by not asking you to sign and return a consent form. Beginning the survey will serve as your consent. Please print this introduction for future reference.

If you have any questions about this study, you may call Erin Babcock at 513-356-5450, or Leah Recker at 567-525-6837, or our advisor, Melissa Smith, at 330-972-4905. This project has been reviewed and approved by The University of Akron Institutional Review Board. If you have any questions about your rights as a research participant, you may call the IRB at (330) 972-7666.

Please click on the link below to access the survey. Thank you.

https://akron.qualtrics.com/jfe/form/SV_3rDU0UHMVF4MM1E