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Investigating the Self-Reported Availability and Effectiveness of Parental Support for Parents of Children with Autism Spectrum Disorder Immediately Post-Diagnosis

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ABSTRACT

Autism spectrum disorder, commonly known as ASD, is one of the most well-known and recognized neurodevelopmental disorders. Parenting a child with ASD is typically more stressful than caring for other children (Boyd, 2002). Because of this stress, these parents are likely to experience caregiver burnout, which is a condition that develops when someone is overwhelmed with taking care of another person without the proper support channels (Tkatch et al., 2017). It is beneficial to utilize support services in order to alleviate caregiver stress, and there are several different types of support services. However, minimal research has been done on the benefits and availability of formal and informal support services.

This study aimed to determine which support services aimed specifically at parents of children with autism spectrum disorder are the most helpful in mitigating stress levels and how available and accessible the services are to these parents. This was accomplished by surveying parents of children with ASD, asking which services they benefitted from after their child's diagnosis and if they felt that there were services that were unavailable to them. Additionally, demographic information was collected for further exploration to determine underlying factors that could influence answers to the previous questions. Household income level, age of child at diagnosis, and total number of children of the respondent were all variables that were collected and used in the exploration of the data. Overall, respondents chose formal support as their more beneficial type of service. Formal support was always impacted by other factors, and informal services frequently were as well. About half the participants found services unavailable, and household income level did not seem to affect this availability, as an equal number of families above and below the median income experienced unavailable services. Overall, the participants tended to find formal support services more helpful, and there was not a substantial difference between the number of respondents who found services to be unavailable and those who did not.

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THESIS SUMMARY

One of the most common neurodevelopmental disorders is autism spectrum disorder, also known as ASD. Parents of children with ASD are at a high risk of developing caregiver burnout, a condition that occurs when these parents experience overwhelming stress. Having access to and utilizing external forms of support, either formal or informal, is important in order to avoid this burnout. Both are very important, but little is known about which type is more beneficial and how available the services are.

This thesis surveyed parents of children with ASD to determine which type of support service they found more helpful as they navigated their child's diagnosis, as well as the accessibility of these services. Several demographic factors were taken into consideration in order to learn how to best support different families who have children with ASD.

INTRODUCTION

Neurodevelopmental Disorders

Neurodevelopmental disorders include a large number of disorders that affect the maturation of the brain. Symptoms of neurodevelopmental disorders typically present in early childhood, and they continue to develop throughout adolescence and even into adulthood. Some of the most common types of neurodevelopmental disorders are learning disabilities, attention-deficit hyperactive disorder (ADHD), intellectual disability, cerebral palsy, and autism spectrum disorder (ASD). The causes of these disorders are still largely unknown, but it is believed that a combination of genetic, biological, psychosocial, and environmental factors all contribute to the appearance of these (Environmental Protection Agency, 2019). Therefore, there is a variety of factors that can cause the onset of any neurodevelopmental disorder.

Autism Spectrum Disorder

Autism spectrum disorder is one neurodevelopmental disorder that affects social and behavioral skills. As implied in the name, autism spectrum disorder is comprised of a range of symptoms and severity levels. While autism is present from birth, symptoms typically begin displaying within the first two years of these children's lives. These symptoms may include lack of eye contact, unresponsiveness to their name, dislike of physical contact, and difficulty understanding nonverbal cues, among many others. Additionally, behavioral symptoms that often present are the performance of routines and rituals, difficulty with coordination, and sensitivity to certain senses (Mayo Clinic, 2018). As with other neurodevelopmental disorders, there is not a single specific cause of autism spectrum disorder, but rather the combinatory effect of several factors leads to the onset of the disorder (Environmental Protection Agency, 2019). Once children begin displaying symptoms, it can be beneficial to seek medical advice for a formal diagnosis and suggestions for early intervention and treatments.

Prevalence and Family Adjustments

The number of children who are diagnosed with autism spectrum disorder (ASD) is growing each year, in part because symptoms are becoming more identifiable and medical professionals become more familiar with the disorders (McAleese et al., 2013). Despite the increase in diagnoses of these disorders, there are still many issues that arise after the diagnosis as the child begins to present more severe symptoms of the disorder. These issues can be major stressors in the lives of parents, as can the adjustment period post-diagnosis as parents learn how to navigate their new situation (Banach et al., 2010). In order to respond in a healthy way that benefits both them and their families, external support that comes from a source other than their nuclear family can very helpful. If they do not receive this necessary care, they are at high risk of experiencing burnout.

Caregiver Stress

Caregiver stress, also called caregiver burnout, occurs when those who are providing care for someone else becomes overwhelming, often due to a lack of outside resources for the caregiver to utilize (Tkatch et al., 2017). Most frequently, the caregiver is helping someone in their own family, which can greatly affect the caregiver's ability to create boundaries regarding how much time to devote to the person they are caring for. The person providing the care may feel that they cannot take any breaks or ask for help because it is their responsibility to take care of their family member all of the time. However, this mindset can be incredibly harmful, as no person is able to take care of both themselves and another person with no breaks or other help. Caregiver stress is the phenomenon that occurs when the life of a caregiver is impacted by their role. This can happen in any capacity, whether it be social, emotional, financial, or physical. Caregiver burnout can cause several health issues, such as depression, social isolation, hearth disease, and even premature death (Tkatch et al., 2017). Additionally, caregiver stress can have negative impacts on the person who is receiving the care, as having a caregiver who is feeling burned out can affect the quality of care that they receive. Those who have caregivers experiencing burnout are more likely to face physical and mental ramifications such as hospitalization and poor quality of life (Tkatch et al., 2017). Support services may help alleviate caregiver burnout. It is important that caregivers are able to receive support services in order to provide the best care possible to the person for whom they are caring.

Families that include a child with autism spectrum disorder are some of the caregivers who benefit most from external support services. Generally, a parent is the main caregiver for a child with autism spectrum disorder, and the effects that this can have on them include emotional stress, anxiety, fear, and guilt (Samadi & Samadi, 2020). This can be damaging for all members of the family, not just the parent and the child with autism spectrum disorder. These impacts can be exacerbated if the parent has other children to care for, has a job outside the home, is a single parent, or is in a lower socioeconomic status household. Parents who are caring for a child with autism spectrum disorder may experience caregiver burnout if they are unable to access support services for themselves. Support services are essential for those who provide care and support to children who have ASD.

Autism Spectrum Disorder Caregiver Stress

Parents of children with autism spectrum disorder generally report experiencing higher levels of stress than people who are parenting children with typical development (Marsack & Samuel, 2017). Additionally, when compared to parents who have children with other developmental disabilities, such as Down Syndrome, parents of children with ASD still report higher stress levels (Boyd, 2002). While parents of children with autism spectrum disorder typically demonstrate higher levels of stress, the specific reasons for this stress after the diagnosis of their child can differ. Banach et al. (2010) states that the most common stressors of parents with a child who has autism spectrum disorder include difficulty handling their child's behavior, struggles changing their lifestyle to fit with their child's needs, and the inaccessibility of resources that could help them mitigate the stress that they are currently experiencing. The aforementioned resources provide support from people outside of the immediate family and have been found to reduce caregiver burnout and create the most positive life for their children as possible (Banach et al., 2010).

Types of Support Services

Typically, the types of support that parents receive is divided into formal and informal services. Formal support services typically include visits with a physician, therapy for the parents, and structured support groups with other parents of children with autism spectrum disorder. Contrastingly, informal support services are those that are not organized through a professional, external source. These services generally include having family members or friends babysitting, meal trains that are started by someone close to the family, or meeting up with a friend to talk about their stress and decompress somewhat regularly (Shiba et al., 2016). Both formal and informal support services can be incredibly beneficial to parents of children with autism spectrum disorder, and the amount of stress relief that a parent receives can depend on the type of service that they participate in or are provided with.

Availability of Support Services

As much as it is necessary to stress the importance of utilizing support services for parents of children with ASD, it is also important to recognize that oftentimes, these support services simply may not be available. There is a variety of reasons as to why parents cannot access the support services, some of which include distance to the services, price, and a lack of knowledge about the different service types and how they may be beneficial to the parent and the child (Antezana et al., 2017). It does not matter how much the parents wish to receive support and want to avoid caregiver burnout if the resources that could help them achieve this are not accessible to them. Ensuring that support services are widely available to parents of children with autism spectrum disorder is essential to preventing caregiver stress and creating the most beneficial environment for the parents and the children.

Literature Review

Previous literature on this subject is relatively scarce, but some studies have been done on certain aspects of this thesis, and there are adjacent studies that provide some relevant information on the topic. In a study by McCabe, data regarding the benefits of a private organization and a medical organization that both provided support services for parents of children with autism spectrum disorder was collected (2008) . Caregivers of 43 children with ASD were involved in the study who were either receiving support at the private or the medical organization. Each set of caregivers was asked open-ended questions regarding their expectations and experiences at the organization. McCabe found that despite the number of formal support services that these organizations were able to provide to the families, many parents claimed that informal conversations with other parents were highly related to how supported they felt (2008). The informal support that these parents received appeared to be just as important or outweigh the formal services from the organizations themselves.

In another study, the ways that mothers of children with autism spectrum disorder experience stress and why these mothers look for social support services were analyzed. Additionally, the effectiveness of both formal and informal social support services was determined for these mothers (Boyd, 2002). Boyd found that informal support services were typically more helpful at mitigating the stress levels of mothers of children with autism spectrum disorder. Formal support, specifically parent support groups, was still said to be effective at helping lower the mothers' stress, but generally to a lesser degree than informal support services were able to (Boyd, 2002). Boyd does also make note of the fact that while informal support is better at the time of the study, formal services can provide positive support for families and should continue to be developed in order to create more avenues for support for mothers of children with ASD (2002).

An article by Marsack and Samuel attempted to examine the impacts of both formal and informal support for parents of adult children with autism spectrum disorder (2017). Specifically, they were trying to determine if either formal or informal support was related to a lower feeling of caregiver burden, which then translates to a higher quality of life for these caregivers. Throughout the study, the authors found that informal support was better at mitigating the caregiver stress of these parents and improving their overall quality of life (Marsack & Samuel, 2017). In fact, the authors did not see any significant improvement on quality of life of these parents due to formal support services. However, the study indicates that while formal support services do not appear to be beneficial at this time, there is no reason to believe that they could never be a valid form of support for parents of children with autism spectrum disorder. The authors believe that formal support networks need to be improved in order to properly enhance the quality of life of these parents (Marsack & Samuel, 2017).

Another study researched the effects of one specific type of formal support for parents of children with autism spectrum disorder (McAleese et al., 2013). This formal service was a course for parents that was meant to increase the understanding around their child's cognitive and behavioral deficits resulting from their ASD diagnosis. The authors surveyed the parents both before and after to determine the effectiveness of it and whether the parents felt more confident in their ability to relate to their child after the course was completed (McAleese et al., 2013). Overall, the study found that when the parents consistently attended the course, they were able to better relate to their child and comprehend the behavioral and cognitive tendencies that their child was displaying (McAleese et al., 2013). While this article is not directly related to the thesis topic, it lends credibility to the impacts of one type of formal support service, which had previously not been indicated to be as helpful as informal support services in other studies.

Thesis Statement

In general, research indicates that caregiver support is important for both the caregiver's health and the functioning of the family. However, the research that is currently available is limited on the accessibility and effectiveness of formal and informal support services. This thesis aims to determine which types of parental support are most helpful for parents of children with autism spectrum disorder immediately after receiving their child's diagnosis and which services mitigated their stress levels surrounding the diagnosis and their new role as a caregiver; specifically, what the perceived benefit from formal and informal support services was. Additionally, I examined the availability of these support services to find if there were specific types that parents would have utilized if the services were available to them at the time of their child's diagnosis. The main research questions to be answered were: What support services are available to families of children with autism spectrum disorder? Were formal or informal support services typically reported to be more beneficial for these families in adjusting to their child's diagnosis? and Are there support services that are found to be unavailable to these families, but may have been utilized if offered? To do this, I surveyed parents of children with autism spectrum disorder to learn more about their experience post-diagnosis of their child and understand through which services they felt the most supported, as well as if there were gaps in the availability of the services that they feel would have been beneficial to them.

METHODOLOGY

Participants

The study included 21 responses from parents of children formally diagnosed with autism spectrum disorder. Of these respondents, 19 were mothers of the child, and two were the father. The average age of the children of the respondents at diagnosis was 3.81 years, while the average age of the parent when their child was diagnosed was 31.19 years. Six of the participants in the study only had one child, while 12 had two children, one had three children, and two had four children. The total household income of 13 of the respondents was under the national median household income level, and eight participants were above the median household income level.

Procedures

A survey was created on Google Forms. This survey asked demographic information about the parents, age of diagnosis of the children, questions about the stress levels of the parents after their child's diagnosis, types of support services utilized and most beneficial support types, as well as other questions relating to the topic of support systems. Questions on the survey about support services were based upon the gaps in knowledge determined during review of the literature. After creating the survey, approval from Institutional Review Board (IRB) was obtained by writing a protocol that included the specific aims of the project, background information, the research design, information on the protection of the human subjects, references, and a copy of the survey. Once IRB approval was obtained, participants were recruited to this study using a flyer with details on the study and a link to the survey itself that was distributed by the South Carolina Autism Society. Unfortunately, approximately a month and a half after initially distributing the flyer, there were no submissions of the survey completed by these families. Due to this, a second group of families was needed, and the flyer was sent to the families on the listserv of the director of this thesis project, Dr. Jessica Bradshaw. This distribution of the survey yielded 39 responses within five weeks. Two participants in the study were randomly selected to win a $50 Amazon gift card. After approximately five weeks of receiving submissions, the survey was closed with a total of 39 results, and the submissions were downloaded into a Microsoft Excel csv file.

Measures

Upon the studying of the survey results, it was determined that there were groups of several responses that were invalid and likely were submitted by the same person or a few individuals. These results were therefore removed from further exploration of the data. The results that were removed were determined to be false due to identical sentences in the free response questions, including phrases such as “Self-stimulation is a right that people with autism spectrum disorders have regained after negative and punitive interventions took it away” and “The Novel Coronavirus keeps my child exposed to fewer things, making him sicker”. These phrases and others with remarkable similarity were each repeated in several responses, and the submissions with phrases like these were typically submitted minutes apart, indicating that each group of responses was likely completed by a single individual one after the other. Upon removing these submissions, 21 results were used in the final examination process. The data was broken down, and graphs were created, using several questions as a guide. These questions were:

- Do families find formal or informal support to be more beneficial?
- Did families find that some type of support service was unavailable to them?
- Does age of diagnosis affect which type of support (formal or informal) is most beneficial?
- Does household income level affect which type of support is most beneficial?
- Does number of total children affect which type of support is most beneficial?
- Does household income level affect the availability of support services?

For questions regarding age of diagnosis and household income levels, the answers were split into two groups based on the average age of diagnosis for autism spectrum disorder—approximately 4.5 years old—and the average household income in the United States, which is a little under $70,000. Therefore, answers for these questions were separated into "above the average age of diagnosis" and "below the average age of diagnosis" or "above the average household income level" or "below the average household income level" and compared against each other. The choices for the questions asking which type of support were most beneficial were "formal support" and "informal support", and those about support availability asked if there were support services that the parents found to be inaccessible, with answer choices of "yes" or "no". The answers for each of these questions were collected, and graphs were made with the results for a visual representation.

RESULTS

Most Beneficial Support Services

Figure 1 (shown below) shows the support type found to be more beneficial by all of the responses. Respondents had the option to choose from formal support, informal support, or both. Out of the 21 responses to the survey, 11 people said that they found formal support to be more beneficial for their families, eight respondents claimed informal support services were more helpful, and two parents said that both services were equally beneficial. This means that 52.83% of participants found formal support to be more useful, 39.1% chose informal support services, and 9.52% benefitted from both types equally. Overall, nearly one and a half times as many respondents felt that formal support benefitted themselves more than informal support did. Also, it is clear that parents did find one type to be better than the other, rather than thinking both are equally helpful.

Shown below, Figure 2 depicts the breakdown of which support type was more beneficial by household income level. The line for above or below the median income level was dependent on the national median income for the United States, which is just under $70,000, as not all respondents were presumed to be from the state of South Carolina (Shrider et al., 2020). For the 11 people who chose formal support as more beneficial, eight of them (72.7%) were under the national median income, and three (27.3%) were above it. Of the eight participants who selected informal support, four (50%) were under the income line and four (50%) were above it. There were two respondents who claimed both support services were equally beneficial, and one (50%) was under the median income, while one (50%) was above it. From this graph, it is clear that formal support services being chosen as more beneficial was impacted by whether the respondent was under or over the median income level, but informal support and both were not.

Figure 3, displayed at the end of the section, displays which category of support services was more beneficial for families whose children were diagnosed with autism spectrum disorder either over or under the age of five years. Five years of age was chosen as the cutoff because the average age of diagnosis of autism spectrum disorder is approximately 4.3 years, so this would provide an estimation of those diagnosed before the average age and after the average diagnosis age. Out of the 11 respondents who selected formal support as more beneficial, seven (63.6%) had children who were diagnosed under the age of five years, and four (36.4%) had children diagnosed over the age of five years. From the eight participants who chose informal support services as more beneficial, six (75%) had a child diagnosed under five years old, and two (25%) had a child diagnosed over the age of five. Both of the respondents who claimed that formal and informal support were beneficial to them had a child diagnosed under the age of five years. This result indicates that formal and informal support services being more beneficial were both impacted by the age of the child at diagnosis, as more people with a child diagnosed under five years chose either of those options than did participants with a child over the age of five at diagnosis.

Figure 4, displayed below, provides information on which form of support service was more beneficial for families depending on how many total children they have. These families were split into groups of one child and two or more children, as the average number of children per household in the United States is 1.93 (Statista, 2021). Of the 11 respondents who stated formal support was more beneficial for them, three (27.3%) had only one child, and eight (73.7%) of them had two or more children. There were eight participants who selected informal support, and three (37.5%) of them had one child, while five (62.5%) had two or more children. Both of the people who selected both had two or more children. This suggests that the number of children that a family has impacts if they found formal support to be more beneficial, as more families with two or more children found formal support better than did families with just one child. This is also true for informal services, since more families with two or more children chose informal support as more helpful than families with one child.

Overall, these results indicated that formal support was a more beneficial service for these families. The household income of a family appeared to be a factor in who selected formal support, as far more respondents who were under the median income level said that formal support services were more beneficial than did respondents who were above the median income level. However, the amount of people who benefitted more from informal support was not affected by household income level, as there was an even number of people who benefitted more from informal support who were under the median income than those above the median income. Finding formal and informal support services more beneficial also seemed to be affected by the age of diagnosis of the respondent's child, as there were more people with a child diagnosed under the age of five years for both formal support and informal support. Both formal and informal support services were chosen to be more beneficial by a higher number of participants who had two or more children than those with only one child.

Availability of Support Services

One question on the survey asked about parents' experience with the overall availability of services. The parent responding to the survey could choose "Yes" or "No" in regards to whether or not they felt that some services were unavailable to them, for any reason. Of the 21 respondents, ten (47.6%) said that they experienced some level of unavailability of support services, while eleven people (52.4%) said that they did not find any support services to be inaccessible to them. There was not a large difference overall in whether or not respondents had experienced some service being unavailable to them.

Figure 5, depicted below, shows the availability of support services based on the household income levels of each of the respondents. The cutoff was at the national median household income in the United States, which is approximately $70,000 per year. Of the 10 respondents who said that they did find some services to be unavailable, five (50%) were under the median income and five (50%) were above the median income. There were 11 participants who did not experience any services being unavailable, and eight of the 11 (72.7%) were under the median income, while three (27.3%) were above the median household income level. This result indicates that families who found services to be unavailable did not experience this to be due to their income level.

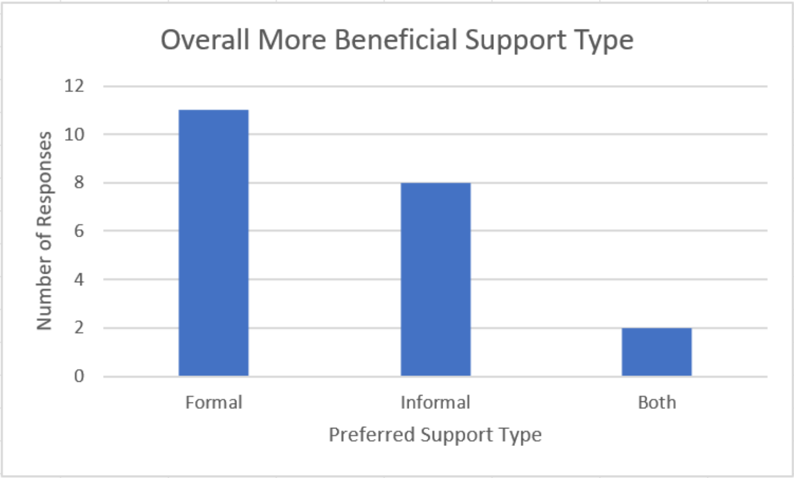

Figure 1

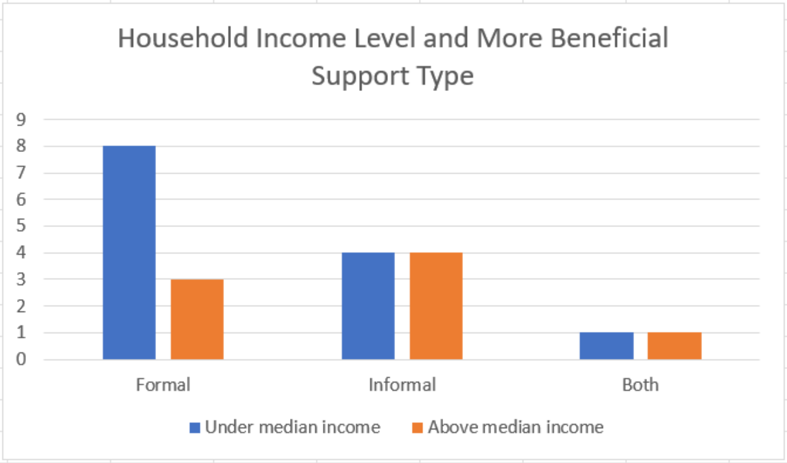

Figure 2

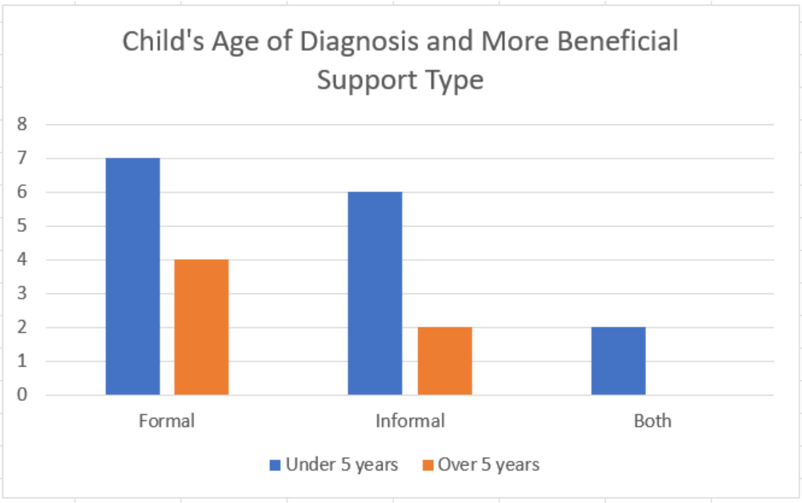

Figure 3

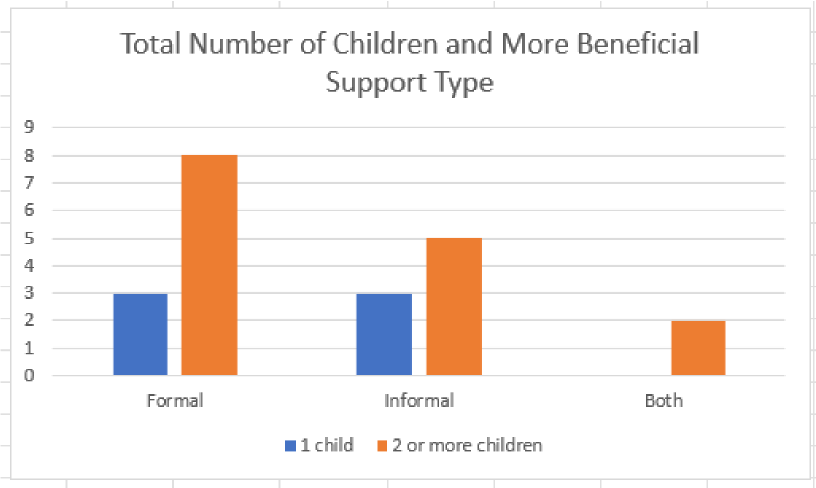

Figure 4

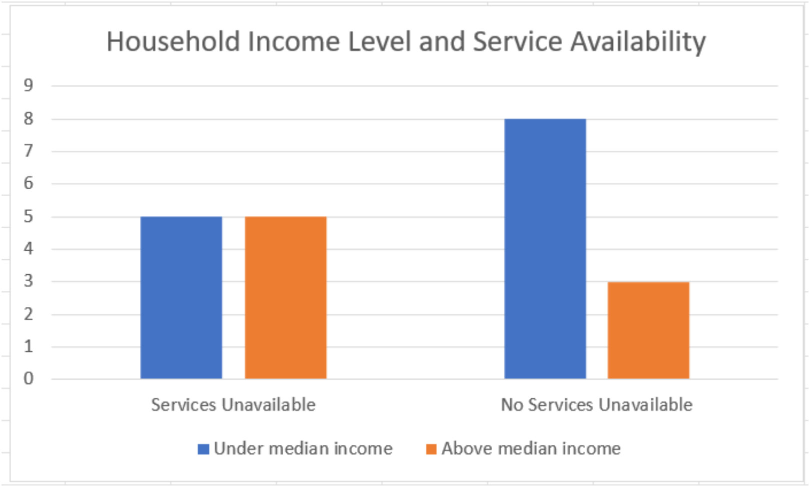

Figure 5

DISCUSSION

The results of this survey displayed the different types of support services that parents of children with autism spectrum disorder benefitted from more after receiving their child's diagnosis of ASD, as well as how accessible they felt that the services were to them at that time. As mentioned previously, formal support services generally include visits with a physician, therapy for parents, and structured support groups with other parents of children with autism spectrum disorder. Informal support services are those that are not organized through a professional, external source and often include having family members or friends babysitting, meal trains that are started by someone close to the family, or meeting up with a friend to talk about their stress and decompress somewhat regularly (Shiba et al., 2016).

More Beneficial Support Services

Overall, respondents of the survey reported formal support to be more beneficial in supporting them after their child's diagnosis of autism spectrum disorder. This breakdown of the results was done with no parameters and only looked at which support service was more helpful for these parents. However, it is important to understand that there may be factors that influence which type of support service parents found to be more beneficial for them, and it is necessary to consider them while exploring the responses. Some of these factors include household income level, the child's age when they received a diagnosis of autism spectrum disorder, and the total number of children that the family currently has. To begin, the relationship between household income level and more beneficial support type was determined. It was found that for those who felt formal support was more helpful, the household income level was a factor, as far more families under the median income level chose formal support than did families above the median income level. This was unexpected because it was thought that more respondents who chose formal support as more effective would be above the median income level than below it. However, this could be due to a variety of reasons. One possibility of the responses is that families who make less money may only have one parent working, so a second parent may be at home during the day and would have more time and flexibility of schedule to travel somewhere for this formal support, such as a therapy appointment or a parent support group. A second reason could be that families who make less money are more likely to have a lower education level than those in higher income brackets. Formal support could be more beneficial to these parents because those who provide formal services are able to close a larger gap of knowledge for families who have less of an understanding of what autism spectrum disorder is and how to parent a child with it. For informal support, there were equal numbers of families below and above the median income level. This result was also unexpected, but one reason for this outcome could be that informal support services such as neighbors or family members do not require payment and are therefore not influenced by the household income level of the respondent. Although these results were somewhat unexpected, they are very helpful in learning more about which services are most beneficial for parents of children with ASD.

Another factor that may impact which support service is better for families is the age of their child with ASD at the time of diagnosis. These responses were separated based on the average age of diagnosis of autism spectrum disorder, which is four years and four months (CDC). The results indicated that for formal support, more families with a child diagnosed under the age of five years found formal services to be beneficial than participants with a child diagnosed after five years. This could be because children who are diagnosed earlier may present with more severe symptoms, which could require more formal services for the parents to learn how to cope with their child’s diagnosis. For informal services, more families with a child diagnosed under the age of five found the services to be beneficial as well when compared to participants with a child diagnosed after the age of five. This could be due to the fact that parents cannot take time away from their child if they have the more severe symptoms that children diagnosed under the age of five may present. These parents could find informal support services more beneficial because they are more readily available to them. It did appear that more families with children who were diagnosed under five years utilized support services than did families with children diagnosed at an older age.

The third variable that was explored in relation to which type of support was more beneficial was the total number of children that the respondents had. The average number of children per household in the United States is 1.93 (Statista, 2021), so the data was divided into families with one child and those with two or more. More families found formal support services beneficial when they had multiple children than when they had just one. For the families above the average number of children, it is possible that formal support was beneficial for more families because their informal support systems may not have been able to support larger families. For example, it is more time, effort, and money for a friend to cook a meal for five people than for three, or for a family member to babysit three children instead of just one. For informal support services, the number of children did not have a drastic impact on the results, as they were relatively similar, with a higher number of families with multiple children finding informal services more beneficial than families with one child. It is possible that families with multiple children simply require more support than do parents of only child. There is likely less stress that comes with parenting one child with autism spectrum disorder than there is with parenting one child with autism spectrum disorder and one or more typically developing children. Although these are possible explanations for the differences in the effectiveness of support types, further research would be necessary to determine the exact reasons that certain families favored different types of support services.

Availability of Support Services

The second aspect of support services for families with a child with ASD that was looked at was the availability of these services. In general, approximately equal numbers of respondents appeared to find services to be unavailable as those who did not experience any unavailable services. To find potential reasons for the availability, or lack thereof, of services, the household income level of the participants was considered.

Household income level did appear to be an influencing factor for those families who found services to be unavailable. Of the 10 respondents who experienced unavailable services, five of them were below the median income level and five were above it. This likely means that there are multiple factors as to why services would be unavailable. For those who are under the median income level, it could be that services are too expensive, and they do not have the extra money for the services themselves or for the insurance that could possibly cover the services. For the people who are above the median household income level, services could be unavailable for a reason that is not financial. This could be due to a lack of time in their schedule, perhaps due to a busier work schedule that is the reason they are above the median income level. For both those under and above the median income level, services could be unavailable due to a lack of a support network or awareness about the services until after they no longer needed them. For the families who did not experience unavailable services, there were more families under the median income than above it. This result could be because for families who are lower income, it is possible that there is only one parent working, which could provide a larger time frame during the day to utilize services. It is also possible that families who make less money qualify for aid that covers some of the expenses of formal support services. However, as mentioned previously, more research could be done on the specific reasons why some families found services to be unavailable while others did not.

Throughout this study, it is possible that errors were made, altering the results of the survey. For example, the questions of the survey could have been worded unclearly, causing confusion in how to respond. This would result in a variety of responses that may not accurately reflect the participants' true experiences on this subject. Additionally, there is the possibility that respondents were not entirely honest in their answers to the survey questions. This would provide inaccurate answers and would affect the validity of the responses. Finally, there were some survey responses that were removed from the final data set due to clear falsifying of answers. These responses included repeated unique phrases that often did not make sense in the context of the question, as well as being submitted within minutes of the other responses with these phrases. Although these seemed to be blatantly false, it is possible that some responses were truthful and inaccurately removed. There also may have been responses that should have been removed that were not, and this would have distorted the responses as well.

To further this research, it would be important to collect a larger sample size of respondents. Also, the study could be improved in the future by asking more specific questions that allow the participant to reflect and expand on their answers to previous questions. The study could also provide more useful results by determining which types of support may have been unavailable to parents and why they were. In general, the study yielded very interesting results that could be used to better help parents who have a child with autism spectrum disorder in mitigating their stress levels and avoiding caregiver burnout.

CONCLUSION

This study indicated a need for more research to be done on how parents of a child with autism spectrum disorder are able to handle their stress levels. The results provided intriguing data as to what type of support services are most available and beneficial for parents with children with ASD. Determining what factors contribute to the benefits and availability of different support services allows those who know people who have a child with autism spectrum disorder to best help them, whether they are a professional or a member of the family's informal support system. The results can also help create an individualized support plan for families who have a child with ASD, assisting them in avoiding caregiver burnout and overwhelming levels of stress regarding their child's diagnosis. Overall, this study provided direction for future research related to this topic, as well as results that can begin to help support systems care for these families.

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APPENDIX

IRB Protocol

Study Title: Investigating the Availability and Effectiveness of Parental Support for Parents of Children with Autism Spectrum Disorder Post-Diagnosis

Principal Investigator Name: Maria Striebich

Faculty Mentor: Dr. Jessica Bradshaw

A. Specific Aims

The overall goal of the study is to determine the most available and effective types of parental support for parents of children with ASD shortly after receiving the initial diagnosis of ASD. A survey will be used to determine demographics of the families being surveyed, as well as their stress levels at the time of diagnosis. Additionally, the survey will measure which services were most available and helpful to these parents in mitigating their stress levels. The survey will be used to find if there are any barriers to or trends in accessing certain types of parental support in response to stress related to their child's ASD diagnosis.

Aim 1: Aim 1 is to explore the demographics of the caregivers being surveyed, including education level, income level, race, gender, and age of both the caregiver and child.

Aim 2: Aim 2 will determine the stress levels of these parents or caregivers shortly after a diagnosis of ASD for their child, as well as the different types of parental support that they felt were accessible and effective for them when utilized. We will compare demographic information and stress levels to the types of support that were available and helpful. We hypothesize that there will be differences across socioeconomic status in regard to which types of support were most effectively utilized.

B. Background and Significance

It is a relatively standard assumption that parents of children with a diagnosis of ASD experience higher levels of stress than most other parents. In fact, according to a literature review by Boyd, parents of children with autism spectrum disorder experience the most stress related to their child's diagnosis compared to parents of children with other disabilities. One of the main reasons that Boyd lists as a factor of stress for parents is the lack of support that the parents receive after their child's diagnosis (Boyd, 2011). Boyd goes on to discuss the effects that lack of support has on parental stress, as well as the benefits of receiving social support for these parents. This study specifically looked at other studies that investigated the lack of spousal support, the lack of social support, and the lack of formal support as a way to determine the effects that inaccessibility of support have on stress levels (Boyd, 2011). Additionally, Boyd examines benefits of both formal and informal supports. At the end of this review, Boyd concludes that stress levels are higher when support is unavailable, and they are lower when social support is available and utilized. These results indicate that support is important in mitigating parental stress associated with a child's ASD diagnosis.

A second study by Marsack and Samuel also investigated the types of support that are most beneficial for parents of children with ASD, as well as their stress levels. They found that informal support appeared to work better than formal support, but the study lacked demographic information that could have impacted it (Marsack and Samuel, 2017). A third study by Papgeorgiou and Kalyva discusses the specific reasons as to why parents of children with ASD experience stress, as well as any demographic information that could contribute to the stress, and how/if support groups can help to manage these stress levels. They determined that demographics have an influence on the types of stress and support that parents have and receive but did not have as much information on what specific types were most beneficial (Papgeorgiou and Kalyva, 2010). Two other studies by Banach et al. (2010) and McAleese et al. (2013) researched the ability of parent classes to minimize stress and help parents learn how to raise their children. These studies all provide different aspects of parental stress and types of support, but our study will seek to understand the relationship between parental stress, support types, and any demographic information that could influence this relationship.

C. Preliminary Studies

No preliminary studies were performed.

D. Research Design and Methods and Data Analysis

LOCATION:

Aim 1: The survey will be created using Google Forms and posted on a Facebook and Instagram, as well as sent to members of a support group, all of which support families of children with ASD.

Aim 2: The same survey will be used for both aims; therefore, the location is the same.

SURVEYS:

Aim 1: The purpose of Aim 1 is to determine demographic information about the caregivers for the child with ASD, including socioeconomic status, race, and gender. The survey will ask questions about the child's age, caregiver age, income and education levels, race, gender, and number of children in the household. These questions are meant to determine if there are any factors that may contribute to differences in outcomes of Aim 2.

Aim 2: The purpose of Aim 2 is to assess the level of stress that parents felt after receiving a diagnosis of ASD for their child, as well as the different types, availability, and effectiveness of support systems for parents of children with ASD. This is the second part of the same survey used for Aim 1, and it will include questions about their level of stress post-diagnosis, their feelings about formal versus informal support, types of support they felt was not available, and if COVID-19 had an impact on their stress supports, among others. This part of the survey will be used to measure support systems available to caregivers of children with ASD.

DATA ANALYSIS:

Aim 1. Demographic information will be collected and analyzed in conjunction with data from the part of the survey geared towards Aim 2.

Aim 2. Parental support system data will be collected and analyzed based on the types of support that were utilized most often, what kind was most helpful, and what was felt to be unavailable, with analysis also focusing on the demographic information collected in the part of the survey for Aim 1.

E. Protection of Human Subjects

1. TARGET POPULATION:

Aim 1. The target population of Aim one is people who have a child with ASD and live in the state of South Carolina. Fifty to seventy-five participants are desired.

Aim 2. The target population of Aim two is again people who have a child with ASD and live in the state of South Carolina. Fifty to seventy-five participants are desired.

2. RECRUITMENT PLANS:

Aim 1. Participants will be recruited for Aim 1 through ASD Facebook and Instagram groups, as well as a support group for families of children with ASD in South Carolina. A recruitment letter will be posted with the link to the study (see Appendix A).

Aim 2. Participants will be recruited for Aim 1 through ASD Facebook and Instagram groups, as well as a support group for families of children with ASD. A recruitment letter will be posted with the link to the study (see Appendix A).

3. EXISTING DATA/SAMPLES:

n/a

4. CONSENT/ASSENT:

A consent form will be presented at the beginning of the survey. This form will describe the protocol, risks, and benefits of participating in the study. The participant will be able to email the researcher with any questions. If the participant would like the participate in the study, they will check the “I agree” box before being allowed to continue to the next page and completing the study.

5. POTENTIAL RISKS:

The possible risks or discomforts of the study are minimal. The participants may feel a little uncomfortable answering sensitive questions about their behavior.

6. POTENTIAL BENEFITS:

The information obtained from this study may not impact the participants directly. It will help researchers understand the relationship between knowledge and acceptance with autism spectrum disorder.

7. CONFIDENTIALITY:

All collected data will be completely anonymous. The survey answers will be sent to a link at GoogleForms.com where data will be stored in a password protected electronic format. Google Forms does not collect identifying information such as name, email address, or IP address. Therefore, responses will remain anonymous. No one will be able to identify the participant or their answers, and no one will know whether or not the participants participated in the study.

8. COMPENSATION:

Participants will have the option of entering two separate drawings to win a $50 amazon gift card. In order to be entered in the drawing, they will provide their email address. Their email address will not be connected to their responses in the survey.

9. WITHDRAWAL:

Participants may voluntarily withdraw from the study at any time after enrollment without any negative consequences.

F. References/Literature Citations

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G. Appendix

APPENDIX A:

Recruitment Letter for Caregiver of Child with ASD Support Survey

Hello, my name is Maria Striebich, and I am an undergraduate student at the University of South Carolina in Columbia. I am conducting research to explore the different types of support that are available and beneficial to parents of children with ASD shortly after diagnosis. To do this, I have created an anonymous survey that asks for demographic information about your family, perceived stress levels right after diagnosis, and the different support systems that were either available or unavailable. The questions ask about how these different support systems helped you to mitigate your stress after receiving your child’s diagnosis of ASD. If you are willing to participate, please click on the link below. If you complete the survey, you will be

entered to win a $50 Amazon Gift Card. If you have any questions, feel free to reach out to me at striebim@email.sc.edu.
Thank you so much!
Maria Striebich

Survey Questions

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