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Difference in stress in parents of children with communication disorders with or without an autism spectrum disorder

Paige Appelt

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**DIFFERENCE OF STRESS IN PARENTS OF CHILDREN WITH COMMUNICATION
DISORDERS WITH OR WITHOUT AN AUTISM SPECTRUM DISORDER**

by

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A Thesis

Submitted to the
Department of Educational Services and Leadership
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In partial fulfillment of the requirement
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at
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Thesis Chair: Terri Allen, Ph.D.

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Dedication

*I dedicate this manuscript to my parents for their constant love and support, and for
always choosing to see the potential in me.*

Acknowledgments

My sincere gratitude to Dr. Terri Allen and Dr. Roberta Dihoff, for their guidance and support throughout this research project.

Abstract

Paige Appelt

DIFFERENCE OF STRESS IN PARENTS OF CHILDREN WITH COMMUNICATION
DISORDERS WITH OR WITHOUT AN AUTISM SPECTRUM DISORDER

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Terri Allen, Ph. D.

Master of Arts in School Psychology

Children diagnosed with a communication disorder that is comorbid with an autism spectrum disorder frequently present additional symptoms to the communication deficit; the additional symptoms of an ASD could be linked to an increase of stress experienced by parents of such children (Gardiner & Iarocci, 2012). The purpose of this study is to determine if there is a difference of stress levels in parents of children with communication disorders versus parents of children with communication disorders comorbid with autism spectrum disorder. Participants included 15 parents of children with communication disorders with or without an ASD who completed The Parental Stress Scale (Berry & Jones, 1995). A non-parametric independent samples T-test was conducted for statistical analysis of collected data. Results showed that the difference of stress levels between the two groups of parents is significantly different. Implications and limitations of this study are discussed further.

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Chapter 1

Introduction

1.1 Need for Study

This study is pertinent to education, therapy, and counseling communities internationally. Communication disorders, autism spectrum disorders, and parental stress are non discriminatory and can be observed without culture, time, or space constraints. There is minimal and limited research based literature that contains measurable, repeatable, reliable and valid data on the interrelatedness of children with communication disorders, autism spectrum disorders, and the stress experienced by the parents of children with one or both of the described disorders occurring simultaneously.

1.2 Purpose

The purpose of this study is to examine the stress levels experienced by parents of children with communication disorders both with and without a comorbid autism spectrum disorder. The stress levels of the two groups of parents will be compared and statistically analyzed to determine if levels are higher in parents whose child also has a diagnosed autism spectrum disorder.

1.3 Hypothesis

The level of stress will be greater in parents of children with a communication disorder and a comorbid autism spectrum disorder when compared to the level of stress in parents of children with a communication disorder only.

1.4 Operational Definitions

ASD- autism spectrum disorder: a neurodevelopmental disorder of varying degrees of severity typically diagnosed in early childhood, although persistent throughout life; core symptoms include communication disorders, impaired social skills, and ritualistic behavior; a common overlap with intellectual disabilities greatly increases the likelihood of these individuals to pose disruptive behaviors and further psychosocial pathologies (Matson & Neal, 2009)

Communication disorder: clinical diagnosis of any child who possesses different than what is considered normal receptive, expressive, and/ or pragmatic speech, which may or may not involve a hearing disorder

PSS- Parental Stress Scale: a condensed and concise version of the Parental Stress Index; this survey is a valid and reliable generic measure of self-reported stress based on emotions and role satisfaction as reported by the parent completing the survey (Berry & Jones, 1995)

Speech Therapy: treatment of impaired articulation, oral- motor function, and/ or comprehension and/ or use of language (Sharp & Hillenbrand, 2008)

1.5 Assumptions

The first assumption is that the parents who completed the provided Parental Stress Scale understand fully what the survey was asking based on the instructions given by the investigator and the manner and language of which the questions of the survey were asked.

The second assumption is that parents answered the survey questions honestly.

The third assumption of this study is that any and all diagnosis(es) documented in the child's case file, or by parent admission, are accurate and up to date.

1.6 Limitations

A major research limitation of this study is the relatively small sample size of the population with most data being collected from the same study site. The lack of diversity of the sample does not reflect the entire population, and thus creates a limitation.

Each survey was intended to obtain responses from parents with regards to one child. Some parents who completed the survey have more than one child, and even more than one child with a communication disorder. Additional children in the family with or without communication disorders could have an effect on the parent's self-reported stress levels.

The children that the parents completed surveys with regards to, ranged in age from three to sixteen years. The age difference creates a limitation because the parent's reported stress levels may be higher or lower depending on the child's particular age.

1.7 Summary

There is currently not enough research available to conclude that a difference in stress levels of parents of children with an autism spectrum disorder

can be directly attributed to an underlying communication disorder, and thus the purpose of this research study.

Chapter 2

Literature Review

2.1 Communication Disorders in Children

Communication is the most important factor involved in social life and learning to the human species. Communication is much more than verbal language and written words. Communication also embodies comprehension and demonstration of body language, facial expression, and nonverbal social cues used to sustain or terminate conversation in intimate or group settings (Sharp & Hillenbrand, 2008). Language is a socially and culturally agreed upon system of symbols that when strategically placed together form words and sentences to be interpreted by a reader in written language, or by a listener in spoken language. Speech is language that is orally produced through coordination of the respiratory system and movement of articulators in the mouth, face, and throat (Sharp & Hillenbrand, 2008).

Communication disorders are any deviation from what is typically considered normal when analyzing the use of language and demonstration of speech. Communication disorders inclusive of language impairment and speech disorders are prevalent in thirty- three percent of all children between the ages of five and twelve (Semrud- Clikeman & Ellison, 2009). With such a high incidence and prevalence, the diagnosis of a speech language disorder has become a prominent issue for many children at the school entering age (Slonims & Pasco, 2009) and beyond; as more than half of children with a language impairment will still be affected by the impairment throughout adolescence and adulthood, if not properly

treated (Grizzle & Simms, 2009). The classification of speech and language disorders is not a rigid system, there are a lot of characteristics that overlap between diagnostic groups. Normal language development requires the recruitment and integration of various brain domains, each of which influence and enhance the capabilities of one another, such as: cognition, social adaptation, perceptual awareness, and motor functioning (Aneja, 1999).

2.2 Language Impairment

A language impairment is diagnosed by an identifiable difficulty in persons' ability to actively express his or her thoughts, understand the expressed thoughts of others, and/ or effectively use language in social formats (Sharp & Hillenbrand, 2008). Language disorders involve errors in semantics (the meaning of words), syntax (grammatical sentence structure), and pragmatics (social conversational language) (Matson & Neal, 2010). Language disorders have been broken down into three classification categories: expressive, mixed receptive- expressive, and higher order function. An expressive disorder is evidenced by atypical phonology, a mixed expressive- receptive disorder has characteristics of an expressive disorder but also improper syntax, and a higher order functioning disorder involves a struggle with semantic and pragmatic language.

Expressive and receptive language are highly influenced by one another. Children with an expressive disorder in infancy, will more than likely develop a secondary receptive disorder before the age of one. For example, an infant that expresses an atypical cry, will elicit an atypical response from the caregiver, thus effecting how the infant develops receptive functions (Aneja, 1999). The function of

effective receptive, expressive, and pragmatic language is a crucial element to the learning process that continues after infancy, into the school entering age, and well into adulthood.

2.3 Speech and Hearing Disorders

Speech disorders are identified when there is a deviation from what is normal in voice quality, pitch, and volume as influenced by respiration, the rate and rhythm of speech, disrupted speech patterns, and/ or movement of articulators that produce audible sound (Sharp & Hillenbrand, 2008, Matson & Neal, 2010).

Articulation impairments are not officially classified as communication disorders, due to lack of neuropsychological evidence of a disorder in children with a single diagnosis of an articulation impairment. Articulation disorders are therefore studied more through the lens of phonological or developmental disorders (Semrud- Clikeman & Ellison, 2009). However, articulation plays an integral role in speech, making these impairments just as important to understand. The four areas of articulation difficulty are articulation disorders, delays, atypical error patterns, and pronunciation inconsistencies (Semrud- Clikeman & Ellison, 2009).

Hearing impairments can also directly impact the development and acquirement of speech and language in a child. Children diagnosed with any sort of hearing impairment, would also be expected to have a speech or language disorder as hearing and speaking are highly integrated (Sharp & Hillenbrand, 2008).

Children with hearing loss are more inclined than children with normal hearing to have noticeable delays in language development, which is a known potential precursor for attention, behavior, and learning problems (Slonims & Pasco, 2009).

Pre-lingual hearing loss or congenital hearing impairment is the most detrimental to the child's development of language. Hearing loss after language has been acquired has a greater negative effect on the child's ability to understand spoken language. These children compensate for their lack of hearing with their exceptional use and understanding of nonverbal cues such as facial expressions, hand gestures, and body language, used during conversation. In children who suffer from speech impairments, there is a lack of language, but not a lack of communication (Aneja, 1999).

2.4 Evaluation of Communication Disorders

Typical development of language and communication is considerably overlooked by family members, educators, and therapists until there is an obvious communication issue demonstrated by the child, such as a significant developmental delay. It is important to understand however, that a delay in language acquisition does not always lend itself to a language disorder (Aneja, 1999). Diagnosis of a communication disorder is typically given after a comprehensive speech and language evaluation, which can include an assessment of receptive and expressive language, hearing screening, speech production, oral- motor strength and function, and swallowing efficacy (Sharp & Hillenbrand, 2008).

Pediatricians conduct the initial evaluation and determine if the delay of communication is within normal limits for the child's chronological or developmental age. Before the age of one, children begin to communicate nonverbally with the use of eye- contact, facial expressions, and gestures. Children display evidence of phonological development in the transition from crying at birth

to eventually babbling at anytime between seven and ten months of age. Between eighteen months and two years of age, children will use their limited vocabulary to create sentences, which will eventually begin to follow a grammatically correct pattern. If the delay of communication acquisition is not within normal limits, the pediatrician will refer the child to be further evaluated by a speech pathologist (Aneja, 1999). Every evaluation performed by a speech pathologist is customized to the child based on parental concerns and referrals from teachers and doctors (Sharp & Hillenbrand, 2008).

Clinical history is necessary for the speech pathologist to understand the development of the child prior to the initial meeting. Important pieces of clinical history include when and how the child began to communicate with the parent, verbally and nonverbally, if at all, and feeding history, which can hint at neuromotor developmental impairments if atypical patterns are present. Specific questions about the child's interaction and social capability within the home and between family members are asked to get an overall sense of how the child expresses oneself and relates to others (Aneja, 1999).

Physical evaluation from the speech pathologist begins upon meeting the child, noticing subtle indicators of the child's willingness to play, shyness, and use of social greetings (Sharp & Hillenbrand, 2008). The use of inner language, or talking among oneself, seen during the play observation component of the evaluation, is a good indicator of the child's standpoint in emotional and behavioral development and also typically the evaluator's first sample of spontaneous speech and language (Aneja, 1999, Sharp & Hillenbrand, 2008). Standardized tests are common practice

during a speech evaluation and are used to assess articulation, comprehension, and expressive functions of a child. Structured games and activities are used to evaluate a child's understanding of language concepts such as nouns, prepositions, and possessive forms. These activities also gauge the child's ability to understand and follow verbal directions (Sharp & Hillenbrand, 2008).

Diagnosis of impairments can occur in many areas such as expressive, receptive, written, and pragmatic language (Sharp & Hillenbrand, 2008). An important distinction needs to be made during the evaluation between articulatory problems, such as the child being unable to produce certain sounds, and phonological problems, where the child has the capability to produce the sounds but does so with substitution and omission errors (Aneja, 1999).

2.5 Comorbidity of Disorders

Communication disorders are typically seen in cases where there is a global delay of development, which affects motor, social and language skill acquisition and mastery (Aneja, 1999). The difference between groups of children with a language disorder versus children with an autism spectrum disorder that is comorbid with a language disorder, is that children with a language disorder specifically exhibit symptoms of a communication deficit only. Children with an ASD exhibit symptoms of a communication deficit, with additional deficits in domains such as social skills, rituals, and stereotypies (Matson & Neal, 2010).

2.6 Autism Spectrum Disorders

Previous research has concluded a significant overlap between symptoms of communication disorders and autism spectrum disorders (Matson, Fodstad &

Mahan, 2009). Classic identifiers of an autism spectrum disorder include odd social behaviors, ritualistic behaviors, and communication impairments (Matson & Neal, 2010). However, the presenting characteristic of autism, is a delay in language development, or a regression of early language development (Aneja, 1999). Children with autism in particular, have the most difficulty with expressive language and using verbal communication skills (Chiang & Lin, 2008). Autistic children are known to be socially impaired and typically play alone unimaginatively, do not respond when being called, and lack the ability to communicate with, or comprehend facial expressions and gestures (Aneja, 1999).

Both communication disorders and autism spectrum disorders are persistent throughout life and directly affect the child's interactional capability directly related to language communication (Matson & Neal, 2010). It is typical for children with autism to also have disruptive behavior disorders. The most definitive explanation for the cause of these comorbid behavior disorders stems from the original presence of the underlying communication disorder (Murphy et al., 2005). The presence of symptoms such as communication disorders seen in autism, suggests that the behavior disorders associated with communication disorders will also persist throughout the lifetime and become a chronic condition in these individuals. A longitudinal study conducted with participants with intellectual disabilities such as autism suggested that at an early age, better language skills were associated with overall better behavior (Murphy et al., 2005). Other characteristics of autism such as routines, rituals, and resistance to change, were not related to language skills (Murphy et al., 2005).

With the increase of social impairments common in autism, comes an increase in behavior disorders with an increased likelihood of self-injury, stereotypies, and resistance behaviors (Murphy et al., 2005). The most common challenging behaviors of autistic children are problems eating and sleeping, as well as inattention and impulsivity, and most frequently, tantrum and conduct disorders (Matson, Fodstad & Mahan, 2009). Behavioral interventions intended to reduce challenging behaviors in such individuals use functional communication training techniques (Carr et al., 1994).

2.7 Implications

Such examples of behavior disorders present parents with stressful challenges both in public and private family life (Murphy, et al., 2005). Parents of children with autism have reported spending less time socially engaged with adult peers because most of their time was spent focusing their attention on their child. Parents also reported feeling self-conscious in a sense, about people outside of the immediate family not understanding their child's disorder and disruptive behaviors with such examples as self-injury, rituals, strict schedules, and tantrums (Fox et al, 2002).

A study conducted regarding Family Quality of Life had indicated that the severity of a child's intellectual disability is inversely proportionate to the perceived overall family quality of life. A direct explanation of this could be attributed to the fact that as the severity of an intellectual disability (such as an ASD) increases, so does the occurrence of behavior problems, which negatively impacts the family quality of life (Gardiner & Iarocci, 2012). Families of children with autism, in

particular, are shown to have greater levels of stress, depression, decreased marital satisfaction, and overall less family bonding when compared to families of typically developing children or families of children with other developmental disorders (Gardiner & Iarocci, 2012). The decreased family quality of life in families of children with autism is more than likely due to the behavioral problems associated with the disorder (Lee et al., 2008), which as previously stated, stems from the communication disorders also present in autism spectrum disorders.

Raising a child with special needs is linked to greater over all stress and less time for parents to take care of their own needs. Compared to the parents of typically developing children, parents of children with autism are more likely to experience greater physical and psychological stress, also reporting greater instances experiencing family burden because of their child's disorder (Bouma & Schweitzer, 1990). The level of stress experienced by the parent(s) is directly proportional to the child's level of outward demonstration of challenging behavior, and inversely proportional to the child's ability to effectively communicate (Lee et al., 2008). Thus, in summation, with increased communication difficulties, comes increased behavioral issues, and increased parental stress.

Chapter 3

Methodology

3.1 Participants

Participants of this study included 15 parents of children currently enrolled in a speech therapy program. 10 of the parents surveyed had children diagnosed with communication disorders and 5 of the parents surveyed had children diagnosed with both a communication disorder and an ASD. Parents were recruited from a speech therapy office of which their child is a client, and other parents were recruited for reasons being that their child currently receives speech therapy, or had received speech therapy in the past that was provided by their school district or through a separate agency. To be included in the study, participants also needed to sign the informed consent. Respondents did not receive an incentive or compensation for their participation in the study.

3.2 Materials

Items used for data analysis include completed self- report surveys of the distributed Parental Stress Scale. The *Parental Stress Scale* contains eighteen items to be rated on a five- point scale: 1) strongly disagree, 2) disagree, 3) undecided, 4) agree, 5) strongly agree. The items are representative of both positive and negative themes of parenting. Positive themes of the scale include emotional benefit and self-enrichment, and negative themes include demand of resources and opportunity restrictions. The positive items of the scale are reverse scored and therefore higher scores on the scale are indicative of higher stress with a possible range of the scores between 18-90.

The Parental Stress Scale shows convergent validity with various measures of sources of stress, emotions, and family/marital role satisfaction. The scale shows satisfactory internal reliability (.83) and test- retest reliability (.81). The scale also demonstrated the ability to discriminate between parents of typically developing children and parents of children with developmental and behavioral disorders (Berry & Jones, 1995).

Client charts of Speech Pathology Solutions were also reviewed for confirmation of diagnosed disorders when appropriate.

3.3 Design

This quasi- experimental, correlational study compares the means of two pre-determined groups. The first group contains parents of children with communication disorders currently enrolled in a speech therapy program. The second group contains parents of children with communication disorders as well as an autism spectrum disorder currently enrolled in a speech therapy program. Both groups completed the same survey. The levels of parental stress determined by the self- report Parental Stress Scale were compared between the two groups.

3.4 Procedure

The two groups of the parents were predetermined based on prior knowledge of their child's diagnoses. Knowledge of diagnosis was acquired through patient files containing pediatrician notes located in the speech therapy office, or through parent admission. Once the two groups were determined, the groups were separated by the pen ink color used to complete the survey. Group 1, the parents of children with communication disorders were provided with blue pens to complete

the survey with. Group 2, the parents of children with communication disorders and an ASD were provided with black pens to complete the survey with. This allowed investigators to maintain group separation along with participant anonymity.

After a verbal explanation of the study and successful parent recruitment, participants had read the provided adult informed consent, which can be found in the Appendix, questioned the investigator if necessary, and lastly, signed and returned the final page of the adult informed consent to the collecting investigator. Parents were then provided with the Parental Stress Scale, a black or blue pen dependent on the group, and a blank and empty envelope. Once the Parental Stress Scale was completed, participants were instructed to then return it to the investigator in the sealed blank envelope. All returned envelopes were stored in a basket with only investigator access.

Once all participant surveys were collected and scored accordingly, data was analyzed using a nonparametric independent samples t-test. This statistical analysis compared the difference of mean parental stress scores between the two groups.

Chapter 4

Results

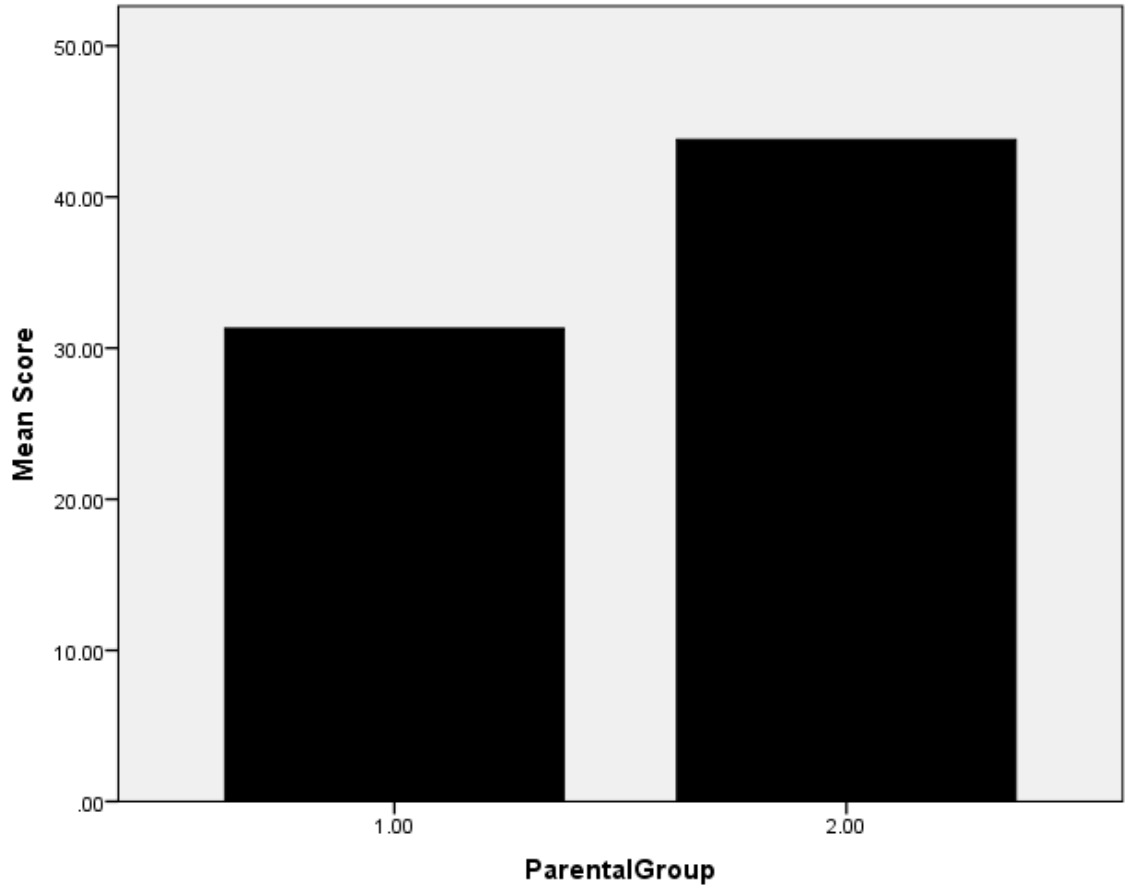
This study analyzed the correlation of parental stress levels between two groups of parents. Group 1 contained parents of children with communication disorders, and Group 2 contained parents of children with communication disorders and an autism spectrum disorder.

4.1 Hypothesis

The level of self reported stress as determined by the Parental Stress Scale will be greater in parents of children with a communication disorder and a comorbid autism spectrum disorder than the level of stress in parents of children with a communication disorder only.

The self- reported levels of stress in parents of children with a single diagnosis communication disorder and in those comorbid with autism spectrum disorder, were compared using an independent samples t-test. This revealed that the mean total stress score of parents of children with comorbid ASD (M= 43.80, SD= 6.017) was significantly higher than the mean for the stress level score reported by parents of children diagnosed with communication disorders without comorbid ASD (M= 31.30, SD= 8.895) ($t (.008) = -3.973, p = 3.893$).

Figure one demonstrates a side-by-side visual comparison of the mean scores of the two groups of parents.



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Figure 1. Parental Group and Mean Scores of Reported Stress Levels

Chapter 5

Discussion

5.1 Summary

Parental Stress Scale scores determined stress levels in both groups of parents and results of the study demonstrated significantly higher levels of stress in parents of children with communication disorders comorbid with an autism spectrum disorder compared to parents of children with communication disorders only. Increased stress levels in parents of children with a communication disorder comorbid with an autism spectrum disorder could be attributed to a multitude of reasons. One of those reasons being the stereotypic behaviors common in ASDs.

Stereotypies may be verbal or nonverbal behaviors that are often observably repetitive, rigid, inappropriate, and invariant (Cunningham & Shreibman, 2008). Stereotypies are stigmatizing and create undesirable social consequences for both the parents and child; such as uncomfortable experiences in public, limited interactions with peers, and restricted educational settings (Cunningham & Shreibman, 2008). Children with verbal stereotypies however, tend to have a more optimistic prognosis for learning (Sherer & Shreibman, 2005). Hypothesis suggests that verbal stereotypies mimic infant babbling, the prerequisite for language acquisition, and a direct sign of the ability to produce speech (Cunningham & Shreibman, 2008).

Speech therapy targeted for children with autism spectrum disorder specifically, places emphasis on behavioral and developmental skills. Speech therapists can work with the child to enhance both receptive and expressive

language, working on how the child comprehends what others are saying and helping the child to learn how to put thought into words for effective communication. Perhaps the most important aspect of speech therapy for these children is the aspect of learning pragmatics. The speech therapist can teach the child how to socially communicate by asking and answering questions, reciting conversational dialogue, and even cover nonverbal communication such as appropriate eye contact, less egocentric turn-taking, and maintaining personal space barriers (Pantano, 2015).

Some children with autism spectrum disorders have not acquired or do not use spoken language to communicate, and instead rely on Augmentative and Alternative Communication devices. More pre-school aged children (<6 years of age) use AAC to communicate than school-aged children (≥ 6 years of age), and within the pre-school aged children, more severely autistic children use AAC than do mild or moderately autistic children (Chiang & Lin, 2007). Speech therapists can use multimodal communication systems such as AAC devices, picture cards, or gestures to more effectively develop communication in these children (Pantano, 2015).

Most stereotypies stem from the child seeking environmental feedback, with the stereotypies being sensory reinforced (Rincover, 1978). Sensory extinction can be used as an effective treatment strategy for eliminating stereotypic behaviors (Rincover, Cook, Peoples, & Packard, 1979) and the speech therapist can use sensory integration techniques to help these children cope with sensory input disintegration issues (Pantano, 2015).

This leads to the conclusive assumption of the study that children with communication disorders specifically comorbid with autism spectrum disorders who participate in speech and language therapy will have reduced stereotypic behaviors, increased learning, and less inappropriate behaviors stemming from frustration of their lack of communication. The reduction of undesirable behaviors demonstrated by the child, will in-turn reduce the amount of stress experienced by the parents of these children.

5.2 Limitations

A major research limitation of this study is the relatively small sample size of the population with most data being collected from the same study site. The lack of diversity of the sample does not reflect the entire population of this study's two groups of parents, and thus creates a limitation.

Each survey was intended to obtain responses from parents with regards to one child. Some parents who completed the survey have more than one child, and even more than one child with a communication disorder. Additional children in the family with or without communication disorders could have an effect on the parents self-reported stress levels.

The children that the parents completed the surveys with regards to, ranged in age from three to sixteen years. The age difference creates a limitation because the parents reported stress levels may be higher or lower depending on their child's particular age. Different ages and developmental stages present different stressors to parents with varying severity thus directly impacting their survey responses.

Azad et al. (2013) found that maternal stress tended to decline during the middle childhood years.

This was a non- parametric study with unequal group sizes with total participant sample being majority maternal. There is also a risk of self- report bias and participants minimizing or overgeneralizing their responses to the survey, which would undoubtedly affect the reliability of collected data. Taking into account the specific limitations of the study, results can still be seen as valid and meaningful data.

5.3 Future Direction

It would be a disservice to the community, parents, children, and professionals to not continue to research this subject matter further. The research of this study creates a foundation for future studies to expand knowledge already gained on this specific topic while avoiding certain limitations and may even pave the path for effective parental stress interventions.

Points to consider for successful future studies would be to increase the overall sample size, recruit participants from multiple settings, have equal size parent groups, and limit the study to parents of children with communication disorders with and without an ASD within a set age category. Conducting multiples of the same study with only child age differing between each study would allow researchers to compare 1) overall stress levels in parents dependent on the child age and, 2) the stress levels between both groups of parents within each child age. The information gained could lead to establishing proactive interventions for parents of children with communication disorders both with and without a

comorbid ASD during the most at risk time period of increased stress as determined by the studies previously suggested. Another study could similarly be conducted analyzing a difference in stress levels experienced by mothers versus fathers. It could be suggested that potential future studies incorporate some additional or alternative interview- based data collection. The interview- based data collection has the potential to eliminate self- report bias as the researcher would be the one to determine the level of stress the parent is experiencing and possibly even allow the researcher to pinpoint the exact target of stress.

Future studies related to this analysis should be conducted that could potentially further support the results found in this study and expand on the knowledge already gained.

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Appendix

Adult Consent Form

CONSENT TO TAKE PART IN A RESEARCH STUDY

TITLE OF STUDY: Difference of Stress in Parents of Children with Communication Disorders with or without an Autism Spectrum Disorder

Principal Investigator: Dr. Terri Allen

This consent form is part of an informed consent process for a research study and it will provide information that will help you to decide whether you wish to volunteer for this research study. It will help you to understand what the study is about and what will happen in the course of the study.

If you have questions at any time during the research study, you should feel free to ask them and should expect to be given answers that you completely understand.

After all of your questions have been answered, if you still wish to take part in the study, you will be asked to sign this informed consent form.

Dr. Terri Allen or another member of the study team will also be asked to sign this informed consent. You will be given a copy of the signed consent form to keep.

You are not giving up any of your legal rights by volunteering for this research study or by signing this consent form.

SPONSOR/S OF THIS STUDY: Speech Pathology Solutions, LLC

Frequently Asked Questions

Why is this study being done?

This study is being conducted for the purpose of a Master's Thesis in the School Psychology M.A./ Ed. S. at Rowan University. The data collected during this study will help determine if stress levels of parents of children with a communication disorder and an Autism Spectrum Disorder are greater than the stress levels of parents of children with communication disorders.

Why have I been asked to take part in this study?

You have been asked to participate in this study for the sole reason that you are a parent or guardian of a child who is a client at Speech Pathology Solutions.

Who may take part in this study? And who may not?

Only parents or guardians of children with communication disorders with or without an ASD may participate in this study.

How long will my participation in this study take?

Participation in this study involves completion of one short survey. Completion of the survey takes approximately 10 minutes. The survey involved is the Parental Stress Survey, which is a general survey intended to gather information about parental stress levels from the scope of the parent taking the survey.

Where will the study take place?

The survey will be distributed at the Speech Pathology Solutions office where you may complete it while waiting for your child during the scheduled therapy session.

What will I be asked to do if I take part in this research study?

The only participation necessary for involvement in this study is completion of the provided survey.

Are there any benefits for me if I choose to take part in this research study?

Your participation may help us understand if there is a difference of stress levels in parents of children with communication disorders with or without an ASD. This has potential to benefit you directly, and further data analysis may be able to benefit parents of such children in the future.

What are my alternatives if I don't want to take part in this study?

The alternative is to not take part in this study.

How will I know if new information is learned that may affect whether I am willing to stay in this research study?

During the course of the study, you will be updated about any new information that may affect whether you are willing to continue taking part in the study. If new information is learned that may affect you, you will be contacted directly and immediately by an investigator of this study.

Will there be any cost to me to take part in this study?

There will be no cost to participate in this study.

Will I be paid to take part in this study?

You will not be paid for your participation in this research study. All participation is completely voluntary.

How will information about me and my child be kept private or confidential?

It is of utmost importance that all efforts will be made to keep your personal information provided in your research record confidential. To ensure confidentiality, we will abide by HIPAA protocol. Presentations and publications to the public and at scientific conferences and meetings **will not** use yours or your child's name or other personal information. Information provided by you will only be seen by the Principle Investigator of this study and myself as the Co- Investigator. All completed surveys will be stored in a sealed and protected folder with only private access.

What will happen if I am injured during this study?

There is minimal to zero chance of injury due to participation in this study.

What will happen if I do not wish to take part in the study or if I later decide not to stay in the study?

Participation in this study is voluntary. You may choose not to participate or you may change your mind at any time.

If you do not wish to enter the study or decide to stop participating, your relationship with the study staff will not change, and you may withdraw without penalty and without loss of benefits to which you are otherwise entitled.

You may also withdraw your consent for the use of data already collected about you, but you must do this in writing to (Dr. Terri Allen, allente@rowan.edu)

If you decide to withdraw from the study for any reason, you may be asked to participate in one meeting with the Principal Investigator.

Who can you call if you have any questions?

If you have any questions about taking part in this study or if you feel you may have suffered a research related injury, you can call the study doctor:

Dr. Terri Allen
School Psychology
856-256-4500 extension 3110

If you have any questions about your rights as a research subject, you can call:

Office of Research
(856) 256-5150 – Glassboro

What are my rights if I decide to take part in this research study?

You have the right to ask questions about any part of the study at any time. You should not sign this form unless you have had a chance to ask questions and have been given answers to all of your questions.

AGREEMENT TO PARTICIPATE

I have read this entire form, or it has been read to me, and I believe that I understand what has been discussed. All of my questions about this form or this study have been answered.

Subject Name: _____

Subject Signature: _____ Date: _____

Signature of Investigator/Individual Obtaining Consent:

To the best of my ability, I have explained and discussed the full contents of the study including all of the information contained in this consent form. All questions of the research subject and those of his/her parent or legal guardian have been accurately answered.

Investigator/Person Obtaining Consent: _____

Signature: _____ Date: _____