2016

Examining Maternal Psychological Recollections of Children Diagnosed With Autism Spectrum Disorders

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Dissertation Submitted in Partial Fulfillment

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Abstract

Mothers of children diagnosed with autism spectrum disorders (ASDs) experience symptoms of depression, anxiety, stress, and despair stemming from the challenges of raising offspring with behavioral, communicative, and socioemotional impairments. Researchers have shown that children diagnosed with ASDs exhibit symptoms within the first year of life (early-onset), while some exhibit normal development until the second year (regressive-onset), and some exhibit normal development until the second year but display abnormalities in the first year (mixed-onset). Despite the wealth of research on ASDs, there are few examinations of ASD symptom onset groups and the impact of those onset groups on parental psychological experiences: stress, impact on family, and future hopes. This research compared the retrospective parent reports of 31 mothers across ASD onset groups (early-onset, $n = 16$, regressive-onset, $n = 8$, and mixed-onset, $n = 7$) with psychological experiences using Impact on Family Scale, the Vicarious Futurity Scale, and the Parent Stress Inventory. A one-way multivariate analysis of variance assessed the relationship between maternal groups and psychological experiences. No significant differences were found between the groups. However, significant correlations were found between stress, family impact, and perceived hope for the future. Mothers reporting high levels of stress also reported high levels of family impact and low levels of perceived hope for the future. There is a need for increased emotional support for mothers of children diagnosed with ASDs. It should be a standard practice for clinicians, upon diagnosing children with ASDs, to refer mothers and caregivers to therapy or support groups. This may alleviate key aspects of family stressors.

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Dedication

This body of work is dedicated to my son, Anthony, who not only educates but inspires me to help families affected by Autism Spectrum Disorders. Maybe, in his lifetime, a cure will be found.

Acknowledgments

I would like to first thank my children, Anthony, Giavanna, and Jianni, for allowing me their incredible patience and understanding in order to complete this dissertation. Second, my parents, Rita and John Losinno, for giving me enormous support and an abundance of free babysitting while I took on this task. This dissertation is as much as their accomplishment as it is mine. Third, The Center for Discovery, especially Drs. Theresa Hamlin, Rune Simeonsson, and Johanna Lantz, for providing never-ending guidance and allowing me to access the families they serve. Fourth, the mothers of children diagnosed with autism spectrum disorders who took the time out of their busy schedules to participate in my study. I truly appreciate the way you answered difficult questions about your children, families, and experiences in order to help out this old college student! Last, but certainly not least, my wonderful dissertation committee, Drs. Brian Ragsdale, Chet Lesniak, and Frederica Hendricks-Noble for their invaluable feedback and advisement. Dr. Ragsdale provided me not only direction, but a big shoulder to cry on when I needed it. Rest in peace, Dr. Trocchio, and thank you!

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Chapter 1: Introduction to the Study

Most families in this United States are affected by autism, either by having a member diagnosed or knowing someone who has the diagnosis. Researchers have indicated that the number of children diagnosed with autism is increasing. Forty years ago, one in 10,000 individuals were diagnosed with autism; five years ago, one in 150 were diagnosed (Cave, 2008). Now it is believed that one out of 68 individuals is diagnosed with an autism spectrum disorder (Center for Disease Control and Prevention [CDC], 2014). Autism is more likely to develop in boys (one out of 42) than girls (one out of 189) (CDC, 2014). Although there is no known cause, it has been speculated that the disorder stems from an interaction between genetics and the environment (Twoy, Connolly, & Novack, 2007). In the United States alone, 1.5 million individuals have autism; it is estimated that this number will increase to 4 million in 10 years (Twoy et al., 2007). Despite this growth, according to the research, there is no known cure (CDC, 2010; Twoy et al., 2007). The CDC has called autism a growing medical concern (2011). Other researchers have declared it an epidemic (Cave, 2008).

What is Autism?

According to the Diagnostic Statistical Manual of Mental Disorders (DSM-IV-TR), autism is labeled *autistic disorder* and is classified as one of the pervasive developmental disorders (PDD) (American Psychiatric Association [APA], 2000). The APA categorizes five separate disorders under the umbrella term PDD (2000): autistic disorder, Asperger's Disorder, Rett's Disorder, childhood disintegrative disorder, and

PDD-not otherwise specified (PDD-NOS). Autistic disorder, Asperger's Disorder, and PDD-NOS are more commonly known as autism spectrum disorders (ASDs) (Kleinman et al., 2008). The common symptoms of ASDs include impaired verbal and nonverbal communication, socialization, and narrow but preservative interests and behaviors during the first few years of life (APA, 2000).

History of Autism

The first child to receive a diagnosis of autism was a little boy named Donald Gray Triplett by Austrian child psychiatrist Leo Kanner at Johns Hopkins University in 1938 (Donvan & Zucker, 2010). According to Donald's parents, Oliver and Mary Triplett, he seemed intelligent: he could memorize passages of the bible and could recite the alphabet in reverse order (Donvan & Zucker, 2010). However, Donald's parents described him as disconnected from the world as he preferred to be alone; he also exhibited restricted interests and eating habits and often played with objects by spinning them (Donvan & Zucker, 2010). Because there was no evidence of hallucinations, a diagnosis of child schizophrenia was ruled out (Donvan & Zucker, 2010). Dr. Kanner did not have a diagnosis to give at that time, but several years later contacted Mary Triplett after meeting 10 other children like Donald (Donvan & Zucker, 2010; Sanders, 2009).

Dr. Kanner's original work was based on eight boys and three girls between the ages of two and eight years (Neumarker, 2003); he labeled his patients' condition *early-infantile autism*; it was also known as Kanner's Syndrome (Jacobsen, 2010):

> Many of these children were brought to us primarily with the assumption that they were so severely feeble-minded or with the question of auditory impairment. Psychometric test performances yielded indeed very low quotients, and often enough absent or inadequate responses to sounds of any kind gave good reason for the suspicion of deafness. But careful examination showed very soon that the children's cognitive potentialities were only masked by the basic affective disorder…in all instances it could be established that hearing as such was not defective. The common denominator in all-these patients is their disability to relate themselves in the ordinary way to people and situations…disregards, ignores, shuts out anything that to the child from the outside. (Kanner, 1944, p. 211).

The same year that Dr. Kanner developed his work on infantile autism, another Austrian psychiatrist named Hans Asperger published similar research in Vienna after assessing four boys between 7 and 11 years of age (Lyons & Fitzgerald, 2007; Neumarker, 2003; Sanders, 2009); however, Dr. Asperger published his work in German (his native tongue), while Dr. Kanner published his work in English (Lyons & Fitzgerald, 2007; Neumarker, 2003). Asperger's research did not get published in the United States until 37 years after it was written (Sanders, 2009). It was debatable which Austrian psychiatrist first discovered autism; however, neither was the first to use the term *autistic*. Dr. Bleuler, a psychiatrist from Switzerland, was the first person to use the term when describing people afflicted with schizophrenia (Lyons & Fitzgerald, 2007). In

fact, autism was originally thought to be a type of (or precursor to) child schizophrenia (Sanders, 2009). Both Drs. Kanner and Asperger differentiated autism and Asperger's Disorder from schizophrenia in that children afflicted with the latter disorder usually exhibit normal development, whereas the former disorders are often present since birth (Sanders, 2009). Nonetheless, the original DSM and DSM-II did not list autism as a disorder by itself, but as a subcategory of schizophrenia (Neumarker, 2003; Sanders, 2009); in 1980, the DSM-III was the first version to include PDDs as its own category (Jacobsen, 2010).

Austrian psychologist Bruno Bettelheim, a concentration camp survivor during World War II, immigrated to the United States and eventually became the head of a residential school for children with emotional disorders (Baker, 2010). In the 1950s, Dr. Bettelheim worked with children diagnosed with ASDs; he compared them to concentration camp survivors (Baker, 2010; Lyons & Fitzgerald, 2010). In 1956, Dr. Bettelheim wrote about one of his patients diagnosed with autism named Joey; Dr. Bettelheim asserted that his patient's condition was a result of poor parenting (Baker, 2010); Dr. Kanner was the first psychiatrist to use the term *refrigerator moms* to describe mothers who reportedly caused their children's autism by not loving them enough (Park, 1998). Drs. Kanner and Bettelheim, along with many other professionals during that period, believed that autism stemmed from parents (mainly mothers) who were cold, unreachable, and who did not want their children. This tendency to blame the parents for

their children's disorders was pervasive in the 1950s and 1960s until parents started challenging this belief (Baker, 2010).

Parents of children diagnosed with autism rallied against the misconception that they were to blame and brought further awareness of the disorder to the field of psychology. Dr. Bernard Rimland discovered that his toddler son, Mark, had autism by researching the disorder after doctors were unable to render a diagnosis (Edelson, 2009). Dr. Rimland refuted the previous theory that parents of children diagnosed with autism are cold and detached and proposed the now popular theory that autism is caused by genetic and environmental factors; he asserted that autistic twins are almost always identical and rarely fraternal, suggesting that genetics play a role in the etiology of the disorder (Edelson, 2009). Dr. Rimland also founded the Institute for Child Behavior Research in 1967 to study childhood autism (Edelson, 2009).

Clara Claiborne Parks, an English professor, also increased autism awareness by writing about her daughter, Jessica, who was diagnosed with an ASD (Hays, 2007). In1967, Parks wrote about her daughter's life in The Siege: The First Eight Years of an Autistic Child; when Jessica became an adult, Parks followed up with Exiting Nirvana: A Daughter's Life with Autism (Hays, 2007). Dr. Eric Schopler, clinical psychologist, became fascinated with autism as a college student and visit Dr. Bettelheim's school in Chicago; he dedicated his doctoral research to autism (Mesibov, 2007). Dr. Schopler cofounded a method of teaching children diagnosed with ASDs that is still used today, which is the Treatment and Education of Autistic and related Communication-

handicapped Children (TEACCH) (Mesibov, 2007). Dr. Lorna Wing, a physician and mother of a daughter with autism, developed the term *autistic spectrum disorders* to refer to children who did not meet the criteria for autistic disorder in 1996 (Drifte & Vize, 2010).

No Two Individuals With ASDs Are the Same

Dr. Stephen Shore, who is diagnosed with an ASD, stated "When you've met one person with autism--you've met one person with autism" (2011, "Infinitec," para 1). In other words, individuals diagnosed with ASDs have varying behavior and cognitive levels and may not closely resemble each other (Askshoomoff, 2006; CDC, 2011). However, there has been varying research on individuals diagnosed with ASDs and cognitive impairments. Newschaffer (2007) purported that ASDs are comorbid with intellectual disabilities in 70-75% of the time. In contrast, Felce, Perry, Lowe, and Jones (2011) contended that the prevalence of individuals diagnosed with ASDs and intellectual disabilities was 30%. Bryson, Bradley, Thompson, and Wainwright (2008), posited that ASDs are more likely to coincide with mild intellectual disabilities, as opposed to severe. Despite conflicting research as to the frequency of ASDs and intellectual disabilities, there is a clear distinction between high and low-functioning ASDs in terms of intellect and symptom severity.

Low-Functioning Versus High-Functioning ASDs

Researchers often use the term *high-functioning* to describe individuals diagnosed

with ASDs who do not have intellectual disabilities (i.e., intelligence quotients at or above 70 on standardized tests or estimated intelligence quotients at or above 70) (Koyama, Tachimori, Osada, Takeda, & Kurita, 2007). Conversely, the term *low-functioning* is used to describe individuals diagnosed with ASDs who have intellectual disabilities (i.e., intelligence quotients below 70 on standardized tests or estimated intelligence quotients below 70). In addition, low-functioning individuals are more likely to have severe ASDs instead of mild or moderate ASDs (Goldstein et al., 2008; Volkmar et al., 2009). Due to ASD symptoms worsening with the severity of the disorder (Felce et al., 2011; Madsen, Wilkins, & Macken, 2009), individuals with severe ASDs exhibit more aggression, self-injury, tantrums, and elopement compared to individuals with mild or moderate ASDs.

Because high and low-functioning children diagnosed with ASDs have varying or perceived varying levels of cognitive ability and symptom severity, their prognoses differ as well. Many high-functioning children diagnosed with ASDs are able to be educated in regular or inclusionary classrooms, live at home with their families, and eventually go to college or trade schools. Many low-functioning children diagnosed with ASDs may need continual supervision and support and often need to be educated in special schools apart from typical peers. Some of these children may need to live away from their families in residential settings, where 24-hour support is available (CDC, 2006).

Early-Onset Versus Regressive-Onset

Most children who are diagnosed with ASDs, regardless of being high or low-functioning, are known as having early-onset or early-infantile, where they display symptoms of the disorders somewhere within the first year (Luyster et al., 2005; Ozonoff, Heung, Byrd, Hansen, & Hertz-Picciotto, 2008; Stefanatos, 2008). Children diagnosed with ASDs and having early-onset initially exhibit normal growth and then plateau (Stefanatos, 2008). Regressive ASDs were reported 30 years after Dr. Kanner's description of early-infantile autism (Ozonoff et al., 2008). Ozonoff et al. (2008) posited that children diagnosed with ASDs and having regressive-onset display a decrease of skills and an increase in symptoms somewhere within the second year of life. Some parents report a gradual regression in their children (Ozonoff et al., 2008), while others report rapid loss (Stefanatos, 2008). Regression usually occurs in the area of speech, but children may regress in other areas as well (Luyster et al., 2005). Like with early-onset ASDs, the etiology of regressive-onset ASDs is unknown; however, early-onset ASDs has better prognosis than regressive autism (Ozonoff et al., 2008). Therefore, more high-functioning children diagnosed with ASDs have early-onset symptoms than low-functioning children.

Some researchers describe another type of onset, known as mixed-onset, where individuals display some abnormalities before actual regression (Ozonoff et al., 2008; Stefanatos, 2008). However, parents may not perceive these as abnormalities (Stefanatos, 2008). The researcher stated that some children can slowly regain what is lost, but most deficits last. It is questionable whether children diagnosed with ASDs and

present with either early-onset or regressive-onset symptoms should be classified as having the same disorder or different variants.

Regressive ASDs Versus Childhood Disintegrative Disorder

It is a common occurrence to mistake regressive-onset ASDs for child disintegrative disorder (CDD). For an individual to be diagnosed with CDD, the individual would have to exhibit normal development for at least two years before regression takes place; most children diagnosed with CDD actually develop typically until the ages of three or four (Fombonne, 2002; Stefanatos, 2008). Although children who are diagnosed with ASDs can also regress after a period of normal development, this often occurs before age two; and, in some cases, these children exhibit some developmental oddities prior to the actual regression (Fombonne, 2002). For children diagnosed with CDD, loss of intellect is extreme, and usually marked with loss of social, communicative, and overall functioning—including continence, motor skills, self-help competence, and socioemotional skills (Stefanatos, 2008).

How Are ASDs Diagnosed?

Autism spectrum disorders do not show up on cat scans, magnetic resonance images, or blood tests; they are diagnosed purely through behavioral observation (Newschaffer, 2007). Diagnoses are usually made by psychologists, psychiatrists, neurologists, and developmental pediatricians; however, ASDs diagnoses can also be rendered by general practitioners and licensed social workers. There are many assessments that measure autism symptomology, such as the autism diagnostic

observation schedule (ADOS), the autism diagnostic interview (ADI-R), childhood autism rating scale (CARS) (Kleinman et al., 2008), which can assist practitioners in the diagnosis.

How ASDs Affect Families

A baby is born with four limbs, 10 fingers, and 10 toes. The baby has properly working organs and normal facial features. The baby's respiratory, digestive, and excretory systems appear to be intact. All tests are normal. The baby cries, eats, and sleeps when he/she should. The doctor assures the parents that they gave birth to a perfectly healthy baby and they feel overjoyed. They look at their sleeping baby and dream five, 10, 15, and maybe even 20 years into the future. They imagine their baby walking, talking, going to school, playing sports, going to the prom, driving, graduating, going to college/learning a trade, and maybe even getting married. They imagine, at the very least, their baby will be happy. They document their baby's development as he/she rolls over, sits up, and walks. They may even videotape their baby's first word.

Then one day, their beautiful, normal baby suddenly seems frighteningly abnormal. Their baby stopped talking, playing, and behaving the way he/she used to. Maybe the baby stopped making eye contact or wanting to be held. Maybe the baby fails to progress, saying the same 10 words for months and learning new skills very slowly compared to other children. Perhaps the baby seems lost or deaf to the outside world. Maybe the baby starts to hit other children, bangs his/her head against the floor, and bites

his/her hand. Soon the parents cannot bear to take their baby out in public or around other children for fear of what other people will think of them.

The parents turn to their baby's pediatrician, out of desperation. Perhaps the pediatrician does not know or assures the parents that the baby is fine. Maybe the pediatrician refers the family to a specialist, like a developmental pediatrician or child neurologist. The specialist does an examination, asks the parents questions, plays with the baby, or watches the baby play. The specialist then sits the parents down and says the word "autism." Maybe the parents already knew, but maybe not. Although the specialist rambles on about treatments, research, education, and services, the parents cannot hear past "autism." The parents may associate other words with "autism"—behavior, medication, intellectual disability, lifelong, genetic, and maybe even institution. After hearing the word "autism," the hopes and dreams the parents had for their baby disappear one by one. With one word, their lives change forever.

Parents with children diagnosed with developmental disabilities, such as intellectual disability, cerebral palsy, and ASDs face lifelong prognoses (Kuhn & Carter, 2006). However, unlike intellectual disability and cerebral palsy, low-functioning individuals diagnosed with ASDs often engage in harmful or disturbing behavior. Parents of children diagnosed with ASDs also have more responsibilities than other parents. They not only manage their children's maladaptive behavior daily, they also have to be strong advocates—ensuring that their children receive proper education, supports, and therapies (Mount & Gayle, 2014).

How ASD Onset Affects Parents From Seeking Help

Stefanatos (2008) claimed that parents of children diagnosed with ASDs and having regressive-onset symptoms take longer to seek help than parents of children diagnosed with ASDs and having early-onset autism symptoms; this may be due to parents believing that the regression is a phase that the children will soon outgrow. Mitchell and Holdt (2014) also echoed the statement that parents often wait to seek help because they believe their children's odd behavior is a phase. Stefanatos proposed that parents may seek professional help when loss is restricted to language skills, rather than social abilities. This may be due to the communication loss being easier to identify than social abilities.

How Healthcare Professionals Fail To Service Parents

Although healthcare professionals offer therapeutic services to children diagnosed with ASDs, not many extend these services to family members (Kuhn & Carter, 2006). Low-functioning children diagnosed with ASDs can exhibit behaviors so intense that their parents often cannot leave their homes, which can lead to severe isolation from society (Kuhn & Carter, 2006). As more children are getting diagnosed with ASDs across the world, more parents are dealing with stress of round-the-clock care for their children (Kuhn & Carter, 2006; Mount & Gayle, 2014). Mount and Gayle (2014) purported that some professionals fail to provide accurate diagnoses for children because the professionals are not properly trained in detecting ASDs and do not want to render inaccurate diagnoses. Parents of children diagnosed with ASDs often report feeling

stressed, anxious, and even depressed (Mitchell & Holdt, 2014; Mount & Gayle, 2014; Pozo, Sarria, & Brioso, 2014).

When diagnoses are made, professionals usually offer the parents information regarding treatment and intervention methods for their children. However, very little support is offered to the parents (Blackledge, 2006) or even a forewarning of what they may be feeling—now or in the future: denial, shock, trauma, anger, fear, guilt, relief, worry, or maybe a combination of the above (Mitchell & Holdt, 2014).

Hingley-Jones (2005) argued that professionals often do not recognize or appreciate the trauma that parents go through and, subsequently, cannot be an adequate resource. Both parents and professionals go through a phase, where they look for something or someone to blame for their children's ASDs (Hingley-Jones, 2005). She purported that parents blame themselves for their children's disorders. Klauber (1998) asserted that many doctors do not adequately support the parents once they render this life-changing diagnosis. Klauber (1998) posited that doctors do not schedule additional appointments with the parents to go over resources, services, therapy, medications, education, and possibly residential placement.

Background of the Study

Parents, particularly mothers, of children diagnosed with ASDs can experience various psychological states—depression, stress, grief, guilt, trauma, anger, poor self-worth, decreased psychological well-being or functioning. There is an abundance of literature conducted on the psychological states of families of children diagnosed with

ASDs. Researchers have investigated associations between parents of children diagnosed with ASDs and stress (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Mitchell & Holdt, 2014; Mount & Gayle, 2014; Pozo et al., 2014; Tomanik, Harris, & Hawkins 2004), depression (Benson, 2006; Ingersoll & Hambric, 2010; Mitchell & Holdt, 2014; Mount & Gayle, 2014; Pozo et al., 2014); coping (Hutton & Caron, 2005; Ingersoll & Hambrick, 2010; Pozo et al., 2014; Twoy, Connolly, & Novack 2007), anxiety (Cohen, 2006; Lee, 2009; Pozo et al., 2014), quality of life and satisfaction (Allik, Larson, & Smedje, 2006; Higgins, Bailey, & Pearce, 2005; Pozo et al., 2014), and competence (Kuhn & Carter, 2006).

There is also an abundance of research carried out on the difference between children diagnosed with ASDs and presenting with early-onset or regressive-onset symptoms, as well as parents' abilities to report early-onset or regressive-onset indicators (Ozonoff, Williams, & Landa, 2005; Werner & Dawson, 2005). Researchers have also examined parents' beliefs regarding the etiology of their children's ASDs (i.e., genetics, environment, immunizations, etc.) (Goin-Kochel & Myers, 2005; Hilton, Hunt, & Petticrew, 2007), parents' experiences after receiving their children's diagnoses (Gaspar de Alba & Bodfish, 2011), as well as parents' perceptions of their children's ASD onset (i.e., early-onset, regressive-onset, mixed-onset, etc.) (Goin-Kochel & Myers, 2005; Goldberg, 2003; Werner & Dawson, 2005). Full descriptions of the literature are detailed in Chapter 2 of this dissertation. However, there is a gap in the current research. There is little research regarding whether mothers of children diagnosed with ASDs who present

with early-onset symptoms experience different psychological recollections than mothers of children diagnosed with ASDs who present with regressive-onset symptoms. Although studies have been conducted regarding the accuracy of parental recall of the onset of their children's ASDs, as well as studies regarding the effects of the mothers' psychological states, there have been no comparisons between ASD onset and past parental psychological experiences.

Problem Statement

Mothers of children diagnosed with ASDs are reported to experience greater stress (Blackledge, 2006; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Mitchell & Holdt, 2014; Mount & Gayle, 2014; Pozo et al., 2014; Rao & Beidel, 2009), depression (Benson, 2009; Ingersoll & Hambric, 2010 Mitchell & Holdt, 2014; Mount & Gayle, 2014; Pozo et al., 2014;), less coping (Ingersoll & Hambrick, 2010; Pottie & Ingram, 2008), and less life satisfaction (Allik, Larson, & Smedje, 2006; Montes & Haltermen, 2007), compared to mothers of typical children or mothers of children diagnosed with other developmental disorders such as Down's Syndrome or intellectual disabilities. Children diagnosed with ASDs typically display either early-onset symptoms or regressive-onset (Bernabei, Cerquiglini, Cortesi, & D'Ardia, 2007; Hansen et al., 2008). However, comparing the past psychological experiences of mothers of children diagnosed with ASDs and having early-onset symptoms and mothers of children diagnosed with ASDs and having regressive-onset symptoms has not presently been explored.

Nature of the Study

For mothers of children diagnosed with ASDs and having early-onset symptoms, the signs of the disorders were likely present from early infancy (Goin-Kochel & Myers, 2005). If they are first-time mothers, they may not even recognize their children's behavior as unusual because of a lack of comparison to other children. Many of these mothers believe their children were born exhibiting ASD symptoms (Goin-Kochel & Myers, 2005). However, mothers of children diagnosed with ASDs and having regressive-onset have much different experiences. They witness their children growing normally until approximately the second year of life (sometimes longer) (Ozonoff et al., 2008). Then, gradually or suddenly, these mothers watch their children lose communicative, social, and play skills. These mothers can usually remember how old their children were when they started to regress and sometimes can even pinpoint events prior to the loss (e.g., after an immunization, family trauma, or illness). In some cases of regressive-onset, mothers may blame themselves for indirectly causing the ASDs in their children by unknowingly exposing the children to environmental toxins (Hilton, Hunt, & Petticrew, 2007; Mercer, Creighton, Holden, & Lewis, 2006) or allowing the pediatricians to assure them that their children are fine and will grow out of the phase (Mitchell & Holdt, 2014).

The research questions posed by this dissertation are as follows: (a) Do mothers of children diagnosed with ASDs and having regressive-onset symptoms experience different psychological recollections compared to mothers of children diagnosed with

ASDs and having early-onset symptoms? (b) Do mothers of children diagnosed with ASDs and having regressive-onset symptoms experience different psychological recollections compared to mothers of children diagnosed with ASDs and having mixed-onset symptoms? (c) Do mothers of children diagnosed with ASDs and having early-onset symptoms experience different psychological recollections compared to mothers of children diagnosed with ASDs and having mixed-onset symptoms?

This researcher hypothesized that mothers of children diagnosed with ASDs and having regressive-onset symptoms will report more symptoms of stress and decreased psychological well-being than mothers of children diagnosed with ASDs and having early-onset symptoms. This researcher also hypothesized that mothers of children diagnosed with ASDs and having regressive-onset symptoms will report more symptoms of stress and decreased psychological well-being than mothers of children diagnosed with ASDs and having mixed-onset symptoms. This researcher further hypothesized that mothers of children diagnosed with ASDs and having mixed-onset symptoms will report more symptoms of stress and decreased psychological well-being than mothers of children diagnosed with ASDs and having early-onset symptoms. The details of these research questions will be described in Chapter 3 of this dissertation.

Purpose of Study

Researchers have found that parents whose children lose the ability to talk and relate to others while simultaneously engaging in self-stimulatory, aggressive, or self-injurious behavior will experience greater symptoms of stress and decreased

psychological well-being compared to having a child who did not progress and possessed ASD symptoms in the first year of life. This researcher suspected that watching one's child suddenly regress and develop ASD symptoms will result in greater symptoms of stress and decreased psychological well-being compared to watching a child regress after noting developmental abnormalities. The purpose of this study is to investigate whether a relationship exists between ASD onset and maternal psychological experiences upon diagnosis.

Theoretical Base

Wong and Heriot (2007) defined vicarious futurity as the dreams and disappointments families have for each other. Wong and Heriot posited that parents of children diagnosed with ASDs lose their goals and expectations for their children. Klauber (1998) studied the trauma associated with parents of children diagnosed with ASDs. Klauber asserted that parents of children diagnosed with ASDs can suffer from posttraumatic stress disorder (PTSD) twice: first when they discover the abnormalities in their children compared to same-aged peers and then again when the doctors formally diagnose their children with ASDs. He stated that what intensifies the trauma is parental realization that the hopes and dreams they have for their children are no longer reality.

Mitchell and Holdt (2014) discussed parents experiencing three phases when their children are diagnosed with ASDs: prediagnosis, diagnosis, and postdiagnosis. Mitchell and Holdt described the prediagnostic phase as parents worrying about their children's autism symptoms and justifying their odd behavior as phases. According to Mitchell and

Holdt (2014), the diagnostic phase is when parents are given ASD diagnoses for their children and feeling relieved that their children's odd behavior has a name. Mitchell and Holdt explain that, during the post-diagnostic phase, parents initially experience denial, sadness, stress, anger, and grief, but eventually accept and deal with their children's disorder.

Klauber (1998) purported that parents understandably want to know how their children became autistic. Often parents with children diagnosed with ASDs and having early-onset symptoms attribute genetics as the cause of the disorders (Goin-Kochel & Myers, 2005). In essence, their children's ASDs could not have been foreseen or prevented. However, parents with children diagnosed with ASDs and having regressive-onset symptoms attribute the environment as the cause of the disorders—often the measles/mumps/rubella vaccine (Goin-Kochel & Myers, 2005; Madsen et al., 2002; Madsen et al., 2003; Parker, Schwartz, Todd, & Pickering, 2004; Uchiyama, Kurosawa, & Inaba, 2007). Many parents believe their children's ASDs could have been prevented if they did not allow their children to be vaccinated, despite their pediatricians' insistence that the shots are necessary to prevent disease (Madsen et al., 2002; Madsen et al., 2003; Mercer et al., 2006; Parker, Schwartz, Todd, & Pickering, 2004; Uchiyama, Kurosawa, & Inaba, 2007).

Definition of Terms

Autism Spectrum Disorders (ASDs): for the purpose of this dissertation, ASDs include individuals diagnosed with autistic disorder, Asperger's Disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS).

Early-onset ASDs: refers to symptomology occurring during the first year of life, where children do not regress but fail to progress.

Mixed-onset ASDs: refers to the symptomology occurring during the second year of life after noted developmental abnormalities.

Regressive-onset ASDs: refers to symptomology occurring during the second year of life and after normal development. Regression can include speech-language deficits, socialization impairments, or lack of appropriate play.

Assumptions

One assumption of this dissertation is that the measure used to assess mothers' perceptions of whether loss of skills took place will correctly do so. Another assumption is that mothers' recall of loss of skills is precise. A third assumption is that the ASD diagnoses of the children are accurate. A final assumption is that, to be considered having regressive ASDs, individuals will have delays in at least one area: speech-language, social, or play skills.

Limitations

One limitation to this dissertation is selection bias. The participants in this study will be selected based on having a child diagnosed with an ASD. There will be no random sampling and the participants will be mothers of children at a pediatric

educational program and residential facility or volunteers from the community. Another potential limitation is that this study is only focusing on mothers and not fathers of children diagnosed with ASDs. This can possibly affect the generalizability of this study. Also, based on past research, mothers who are Caucasian, educated, and middle to upper class tend to participate more than mothers from other races and socioeconomic status. This can also affect the generalizability of this study. Another limitation is that mothers who participate in this study may have pre-existing mental health issues, which may skew the results. It is important to note that this study will not be designed to show causation; this study is intended to discover if there is a correlation between ASD onset and parental psychological recollections. In addition, this study is requiring the mothers to go back in time and think of when their children were first diagnosed with ASDs before filling out assessments. This will give the researcher information about their past psychological states upon learning of their children's ASDs. For some mothers, this means recalling how they were feeling 10-15 years ago. It is possible that the mothers will have difficulty with this type of recall. A final possible limitation to this study is sample size, as the number of mothers who perceive their children as having early-onset ASDs may be quite lower or higher than the number of mothers who perceive their children as having regressive-onset or mixed-onset ASDs.

Delimitations

This study only includes mothers who have biological children diagnosed with ASDs. This study is only using mothers of children diagnosed with ASDs as participants and not fathers, siblings, grandparents, or other extended family.

Significance of the Study

This study is the only one conducted on ASD onset and maternal psychological recollections. The study will be able to use its results to reach out to mothers of newly-diagnosed children so they can get help for themselves, in addition to their children, as soon as possible. This may change the way professionals evaluate and share findings with mothers. Professionals may be more equipped to provide therapeutic resources for the mothers, allowing them to be more sensitive to the mothers' needs. As the frequency of ASD diagnoses increase, even more mothers will be in need of mental health services. Being able to offer mental health services to parents, siblings, and extended family upon the child's ASD diagnoses may prevent symptoms of stress, decreased psychological well-being, depression, anxiety, stress, loss of functioning, loss of life satisfaction, grief, anger, and guilt. Having mental health practitioners become more sensitive to mothers of children diagnosed with ASDs, and knowledgeable about the trauma associated with regressive ASDs, can result in a positive social change in the way families of children diagnosed with ASDs are treated.

Summary

Mothers of children diagnosed with ASDs are in need of mental health services. Mothers of children having regressive-onset symptoms may need even more services due to the suspected trauma associated with experiencing their children's deterioration. These mothers may feel stressed, depressed, anger, guilt, or grief. Chapter 2 of this dissertation focuses on the literature conducted on parents of children diagnosed with ASDs. Chapter 3 outlines the proposed study. Chapter 4 reviews the results of the completed study and Chapter 5 concludes the dissertation.

Chapter 2: Literature Review

Introduction

The following body of work describes the research conducted on the psychological states of parents with children diagnosed with ASDs and their ability to cope with their children's ASDs. This body of work discusses the types of ASD onset, the significance of ASD onset in terms of language and social delays, and accuracy of parent recall.

ASDs and Parental Stress

Given that parenting a child with special needs require additional services, individualized support, parental advocacy, and specialized healthcare visits, researchers have conducted studies that investigate the association between parents of children diagnosed with disabilities and parental stress levels. It has been asserted that parents of children diagnosed with ASDs experience more stress than parents of children diagnosed with any other disorder (Blackledge & Hayes, 2006; Mitchell & Holdt, 2014; Mount & Gayle; 2014; Pozo et al., 2014). Benson (2006) further argued that parenting a child

diagnosed with an ASD is stressful due to the child's behavior, financial hardship, marital problems, withdrawal from society, and catering to the child's needs.

Schieve, Blumberg, Rice, Visser, and Boyle (2006) and Hamlyn-Wright, Draghi-Lorenz, and Ellis (2007) took the above positions one step further by comparing stress levels of parents with children diagnosed with ASDs and parents with children diagnosed with other developmental disabilities, as well as parents of typical children. Both studies found that parents of children diagnosed with ASDs reported more stress than parents of children diagnosed with other developmental disabilities, as well as parents of typical peers.

Although the above studies compared parents of children diagnosed with ASDs to parents of children diagnosed with other disabilities, there has been research conducted on how the behavior of children diagnosed with ASDs affect parental stress. Lecavalier, Leone, and Wiltz (2006) recruited 293 parents of children diagnosed with ASDs and gave them questionnaires assessing parental stress and child socioemotinal difficulties. The researchers found a positive relationship between parental stress and child behavior.

Although the above research investigated parental stress and child behavior, there has also been research conducted on parental stress and supports. Pottie, Cohen, and Ingram (2009) hypothesized that parents of children diagnosed with ASDs will feel less stressed with more support. The researchers recruited 93 parents (60 moms, 33 dads) of children with diagnosed with ASDs and mailed them questionnaires on a biweekly basis, assessing daily stress and support. The researchers found that both stress and perceived

support affected parental mood. The researchers revealed that the mothers reported having a more negative mood than fathers.

Many researchers studying parental stress and ASDs noticed differences between mother and father participants. Rao & Beidel (2009) and Phelps, McCammon, Wuensch, and Golden (2009) both noted that mothers tend to fill out their questionnaires more than fathers. It is possible that mothers of children diagnosed with ASDs experience more stress than fathers because they generally do more caretaking. There have been many studies that solely focused on maternal stress in raising children diagnosed with ASDs. Tomanik, Harris, and Hawkins (2004) hypothesized that there was a positive relationship between child behavior and maternal stress. After sampling 60 mothers of children diagnosed with ASDs and administering parental stress rating scales, the findings confirmed their hypothesis (Tomanik et al., 2004). The researchers concluded that raising children diagnosed with ASDs causes maternal stress due to their taxing behaviors, as well as their need for significant assistance.

Hastings et al. (2005) was interested in comparing the stress levels of mothers and fathers of children diagnosed with ASDs. The researchers asserted that mothers experience more stress associated with their children's behavior then fathers. The researchers recruited mothers and fathers of preschool children who were diagnosed with ASDs. Mothers were found to have more stress than fathers in relation to their children's behavior (Hastings et al., 2005). Yamada et al. (2007) conducted a similar study with comparable findings-- mothers of children diagnosed with ASDs were more stressed then

fathers of children diagnosed with ASDs.

Parental Coping With Children's ASDs

Research has been done to investigate how the parents of children diagnosed with ASDs cope with their children's diagnosis, as well as the daily caregiving. Pottie and Ingram (2008) posited that, as time passes, parents grow accustomed to their children's diagnoses and their overall coping skills improve. Hutton and Caron (2005) found that most caregivers accept the diagnoses, despite feeling overwhelmed or stressed. The researchers also contended that siblings of children diagnosed with ASDs also have trouble coping. Hutton and Caron (2005) found that parents help their typical children by educating them about their siblings' ASDs, offering to take them to therapy, or spending extra time with them. The researchers also discovered that the parents coped with their children's ASDs by seeking out support groups, educating themselves, leaning on family, and restructuring the household. Like the above research, Ingersoll and Hambrick (2010) also investigated parental coping skills of children diagnosed with ASDs but with one difference: the parents also had symptoms of ASDs, which the researchers labeled as "Broader Autism Phenotype" or BAP. The researchers found that parents with high BAP reported less ability to cope compared to parents with low BAP.

Researchers have also investigated the associated of parent gender and the ability to cope with children diagnosed with ASDs. Twoy, Connolly, and Novack (2007) sampled married mothers and fathers. The researchers found similar levels of coping between parents, but the fathers' coping was higher than the mothers' coping.

The researchers acknowledged that all participants were married, which may lead to better coping as opposed to single parents who are forced to cope with their children's disorder on their own.

Mount and Gayle (2014) were interested in looking at the experiences and coping strategies of parents of children diagnosed with ASDs. The researchers interviewed nine parents of children diagnosed with ASDs in England and found that parents had both positive and negative methods of coping with their children's ASDs. The researchers found that both mothers and fathers had difficulty coping with their children's ASDs and both genders reported marriage difficulties, feelings of guilt, and worry for the future.

ASDs and Parental Depression

In addition to research being done on parental stress and coping, there has also been an abundance of research conducted on parental depression. Hamlyn-Wright, Draghi-Lorenz, and Ellis (2007) compared symptoms of depression in parents with children diagnosed with ASDs and parents with children diagnosed with Down's Syndrome, as well as parents with typical children. The researchers found that parents of children diagnosed with ASDs reported more symptoms of depression than parents of children diagnosed with Down's Syndrome and parents of children without disabilities. Lee (2009) also compared depression in parents of children diagnosed with ASDs to parents of typical children. The researcher predicted that parents of children with high-functioning ASDs will report more depressive symptoms compared to parents of typical

children. As predicted, Lee found that parents of children diagnosed with ASDs reported more symptoms of depression compared to parents of typical peers.

Past research has found that mothers of children diagnosed with ASDs exhibit more stress and less ability to cope, but are there gender differences in terms of depression? Cohen (2006) investigated the relationship between mothers and fathers of children diagnosed with ASDs and parental depression. Cohen found that mothers reported more symptoms of depression than fathers. Lee (2009) and Hastings et al. (2005) both conducted research comparing depression levels in mothers and fathers of children diagnosed with ASDs. Both Lee and Hastings et al. found that mothers of children diagnosed with ASDs reported more depression than the fathers.

Barker et al. (2011) conducted longitudinal research on mothers of children diagnosed with ASDs and depression. The researchers hypothesized that symptoms of depression will dissipate with the passage of time and that older mothers will report less symptoms than younger mothers. The researchers collected data via questionnaires five times throughout a decade, which assessed symptoms of depression. The researchers found that depressive symptoms did not decrease over the decade. Nonetheless, older mothers reported less symptoms of depression compared to younger mothers (Barker et al., 2011).

Most research on parental depression with parents of children with ASDs, but there is also research carried out with other family members. Macks and Reeve (2007) investigated siblings of children with autistic disorder in terms of depression. The

researchers administered questionnaires to the participants, measuring sibling depression. Macks and Reeve reported that the siblings of children diagnosed with autistic disorder demonstrated higher depressive symptoms compared to siblings of children without the diagnoses.

ASDs and Parental Well-Being

In addition to parental stress, coping, and depression, there has been some research done on the association between parents of children diagnosed with ASDs and well-being. Higgins, Bailey, and Pearce (2005) investigated family well-being and marital happiness between parents of children diagnosed with ASDs in Australia and a control group in the United States. Participants were administered measures assessing family cohesion and marriage satisfaction (Higgins et al., 2005). The researchers found that family functioning and marital happiness was greater in parents of typical children, compared to parents of children diagnosed with ASDs.

As with past research on parental stress, coping, and parental depression, research has been done to assess mothers' and fathers' sense of family well-being and having children with ASDs. Allik, Larson, and Smedje (2006) investigated the quality of life parents with children who were diagnosed with high-functioning ASDs. The participants were given questionnaires measuring quality of life and autism symptomology (Allik et al., 2006). The researchers discovered that the mothers were more affected by their children's behavior than fathers. Montes and Haltermen (2007) compared the well-being of mothers of children diagnosed with ASDs and mothers of typical children. The

researchers interviewed 61,772 mothers over the telephone and asked questions regarding the children's ASDs and parental well-being. The mothers of children diagnosed with ASDs exhibited less well-being compared to mothers of typical children (Montes & Haltermen, 2007).

More recently, Pozo et al. (2014) conducted research on family quality of life in parents of children diagnosed with ASDs. The researchers gave 118 parents in Spain a Family Quality of Life questionnaire. The researchers found that an indirect relationship between the children's behavior and the parents' reported family quality of life and ability to cope.

Parental Perceptions Regarding Etiology and Guilt

The research outlined in Chapter 2 of this dissertation discussed psychological states of parents of children diagnosed with ASDs, as well as the significance of symptom onset on parent reporting, loss of skills, and parent recall. However, there has also been an abundance of research on parent perceptions regarding the etiology of their children's ASDs. There have also been some studies regarding parent guilt surrounding their perceived contributions toward their children's ASDs. Since so little is known about the cause of ASDs, many professionals and parents develop their own hypotheses on etiology—which usually encompasses either genetic or environmental causes. In their study, Goin-Kochel and Myers (2005) revealed that 40% of the parent participants reported believing their children's ASDs were caused by either genetic or environmental causes, while 26% did not know the cause.

Popular beliefs of environmental causes of ASDs are vaccinations, lead, aluminum, microwave, and manganese exposure (Seitler, 2010). The most controversial environmental cause are vaccinations, particularly the Measles/Mumps/Rubella (MMR) shot, which previously contained the mercury-based preservative thimerosal (Madsen et al., 2003). Although a growing number of studies refute the notion that thimerosal plays a role in children developing ASDs (Madsen et al., 2002; Madsen et al., 2003; Parker, Schwartz, Todd, & Pickering, 2004; Uchiyama, Kurosawa, & Inaba, 2007), many parents hold onto the belief that their children were healthy and normal before the vaccination was administered, usually around 12 months of age. However, ASD symptoms often manifest around 12-18 months of age. In the cases of children diagnosed with ASDs, would they have developed the disorders even if the MMR shot was not administered?

Hilton, Hunt, and Petticrew (2007) carried out research on whether parents of children diagnosed with ASDs believed the MMR vaccination caused the disorders. The researchers reported that parents who believed that the MMR shot contributed to their children's ASDs also felt guilty for allowing the vaccinations to be given. These parents also questioned whether their younger children should receive the MMR shot.

Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean (2010) also studied parental beliefs regarding their children's ASDs. Eight-nine families were given either hard or electronic copies of questionnaires assessing etiology (Al Anbar et al., 2010). Parents who reported that their children's ASDs were caused by environmental, and not

genetic, factors were less likely to seek help professional help and were more likely to seek interventions that are holistic and detoxing (Al Anbar et al., 2010).

Mercer, Creighton, Holden, and Lewis (2006) also investigated parental perceptions of causation of ASDs in their children. Participants were recruited online between 2003-2004 in the United States and Canada (Mercer et al., 2006). The researchers administered questionnaires measuring parental perceptions of cause (genes, pregnancy, shots, diets, etc.). The participants most frequently reported that they believed their children's ASDs were caused by genetics or immunizations (Mercer et al., 2006). Although past research linked parent guilt to environmental causes, Mercer et al.'s study found that parents who believe their genes contributed to their children's ASDs also felt guilty.

ASDs and Vicarious Futurity

Parents of children diagnosed with ASDs display higher symptoms of stress and depression, as well as lower coping skills and sense of well-being. Do they also exhibit more despair and less hope for their children's future? Wong and Heriot (2007) posited that parents of children diagnosed with ASDs lose the goals and expectations they originally have for their children. They defined *vicarious futurity* as the hope and dreams that people have for loved ones. The researchers examined vicarious futurity and vicarious despair in parents of children diagnosed with ASDs and childhood dementia; they hypothesized that parents of children diagnosed with ASDs will have more vicarious despair and less vicarious futurity than those with childhood dementia.

The researchers conducted anonymous questionnaires with the parents. Wong and Heriot (2007) found that 80% of parents of children diagnosed with ASDs reported decreased hope and increased despair, while 71% of parents of children diagnosed with dementia reported decreased hope and increased despair. Wong and Heriot (2007) found no significant difference in their participants' despair. This suggested that parents of children with ASDs and parents of children with dementia both grieve the hopes and dreams they initially had for their children.

ASDs and Early-Onset vs. Regressive-Onset

The above-mentioned studies targeted the psychological states of parents of children diagnosed with ASDs. However, there has also been quite a bit of research conducted on ASD symptom onset. Goin-Kochel and Myers (2005) recruited 327 parents of children diagnosed with ASDs living in the United States and Canada. The participants filled out online questionnaires regarding the onset of their children's ASDs (Goin-Kochel & Myers, 2005). The researchers reported that 50% of the participants indicated that their children exhibited early-onset ASDs and 50% exhibited regressive-onset ASDs.

Since regressive-onset ASDs involve loss of already-acquired skills, many researchers chose to examine only regressive-onset ASDs in their studies. Wiggins, Rice, and Baio (2009) recruited 285 children diagnosed with ASDs. Out of this sample, 28% of these children exhibited regression (Wiggins et al., 2009). The researchers revealed that 78% of those children regressed in language, while 12% regressed in social skills.

The researchers reported that 49% of those who regressed exhibited abnormalities prior to the actual regression. It was unclear why some children with regressive-onset ASDs only lose communication skills, while some only lose social skills, and while some exhibit abnormalities prior to the regression.

There has been speculation among autism researchers whether there is an association between different types of ASDs (e.g., autistic disorder, Asperger's Disorder, and PDD-NOS) and symptom onset. Siperstein and Volkmar (2004) recruited 436 parents of children diagnosed with ASDs and gave them questionnaires to fill out, assessing their children's developmental history and ASD symptomology. The researchers found that parents of children diagnosed with autistic disorder reported more regression than parents of children diagnosed with PDD-NOS and Asperger's Disorder. However, there were no significant differences found in regards to the children's autism symptomology. Siperstein and Volkmar (2004) acknowledged that it was difficult to determine whether parents reported actual regression (e.g., regressive-onset) or lack of progression (e.g., early-onset) and suggested that future research should define regression better.

Although the study carried out by Siperstein and Volkmar (2004) differentiated between the different subtypes of ASDs, many researchers collapse the subtypes together and focus on symptom onset and child development. Ozonoff, Williams, and Landa (2005) compared the development of children with early-onset ASDs with regressive-onset ASDs, via parent report. The researchers sampled 60 parents of children diagnosed

with ASDs in two states across the country from each other. Parent participants were divided up into one of three categories: Early-Onset (symptoms developing before 12 months), Regressive-Onset I (symptoms developing before 2.5 years and lasting for at least six months), or Regressive-Onset II (abnormalities noted before actual regression or symptoms lasting less than six months) (Ozonoff et al., 2005).

The researchers stated that the Regressive-Onset I group reported that their children lost both verbal and social skills by 18 months of age, while the Regressive-Onset II group either revealed either a loss of verbal or social skills (but not both) before 18 months. The Early-Onset group indicated that their children exhibited more autistic symptoms at 18 months than either regressive group (Ozonoff et al., 2005). The researchers also claimed that the Regressive-Onset I group displayed more typical behaviors than the Early-Onset group prior to 18 months of age.

Like the study conducted by Ozonoff et al. (2005), Hansen et al. (2008) also chose to investigate ASD onset and loss of developmental skills. The former research group divided their sample based on age of ASD onset, length of regression, and presence of abnormalities before regression; the latter group divided their sample based on age of ASD onset as well as type of skills lost. After recruiting 333 children diagnosed with ASDs, the participants were divided into three groups: (a) Early-Onset Group, (b) Regressive-Onset Group with loss of language and social skills, (c) Regressive-Onset Group with loss of language or social skills (Hansen et al., 2008). The researchers reported that 15% of the participants displayed both language and social regression while

41% displayed either. The researchers indicated that 82% of the entire regression sample lost social skills, while 54% lost language alone.

Lord, Shulman, and DiLavore (2004) studied communication regression in children diagnosed with ASDs, other developmental disabilities, as well as typical peers. The researchers interviewed parents of children who were being evaluated for ASDs, parents of children referred for other delays, and typical children. One quarter of children diagnosed with ASDs used to have spontaneous, functional speech after their first birthday, which was not the case with the children diagnosed with other disabilities or even with typical children (Lord et al., 2004). The researchers also found that the children diagnosed with ASDs who lost speech-language skills also lost socialization abilities as well. They reported that the children diagnosed with ASDs who lost speech-language skills reached a plateau and they did not gain any words before stopping communicating all together prior to 18 months. Some children diagnosed with ASDs actually re-learned some language, while others never regained it (Lord et al., 2004). The researchers indicated that the severity of the children's ASDs did not matter in terms of whether speech-language and social regression took place. It was unclear why some children were able to re-learn skills, while others were not.

Most of the above-mentioned studies relied on parent reporting to gather early developmental information and skill acquisition/regression. Studies which rely on parent reporting are susceptible to inaccuracies, as memories of events and developmental milestones may be false. Werner and Dawson (2005) examined parent recall by

supplementing parental reports with home videotapes. The researchers divided their participants into three groups: Early-Onset Autism (symptoms exhibited before one year of age), Regressive-Onset Autism (loss of skills before age 3), and Typical children (no autism symptoms). Raters, blind to the children's diagnoses, watched the home videos and coded the children's communication and social skills on their first and second birthdays (Werner & Dawson, 2005). Interviews were also conducted with the parents to gain a full developmental history.

The researchers found that, at one year of age, the Regressive-Onset and Typical groups exhibited similar and better communication and social skills compared to the Early-Onset group. In fact, the Regressive-Onset group exhibited superior verbal skills to the Typical group (Werner & Dawson, 2005). At two years of age, the researchers found that the Typical group exhibited superior social and communication skills compared to both the Early-Onset and Regressive-Onset groups. The parent interviews revealed similar results (Werner & Dawson, 2005); this suggested that these participants displayed accurate recall.

Werner and Dawson (2005) were not the only researchers to use home videos to confirm child regression. Goldberg (2003) used home videos and reports of parents of children diagnosed with ASDs to assess child regression. During the interview, if the parents reported that their children exhibited regression in any area (i.e., speech-language, social skills, play, motor skills, etc.), then the parents were given an assessment measuring the length of regression, age observed, the skills re-learned, illness, or

significant event in the child's life (Goldberg, 2003). Goldberg interviewed the parents of 44 children diagnosed with ASDs. Their parents' reports were compared to home videos of the children; these videos were taken from 6-18 months of age (Goldberg, 2003).

Goldberg defined regression was having a skill for at least three months before losing it for at least three months. The parents who reported regression in their children were divided up into categories. The Language Only Regression (LOR) group consisted of children who lost expressive communication before the age of three (i.e., single words, short phrases); the Other Skills Regression (OSR) group included children who skills other than language (i.e., social and play skills) before the age of three. The Full Regression group (FR) consisted of children who lost every skill before the age of three (Goldberg, 2003).

Goldberg divided the FR group into subcategories: simultaneous--children who lost all skills at once for three months and other—children who lost all skills longer than three months. Goldberg found that 33% of the children exhibited regression, which was confirmed by parent reports as well as home videos. Most parents reported that their children regressed in both language and social skills, such as eye contact, joint attention, name response, and reciprocal play; the regression was noted after 12 months of age and for the most part came on gradually (Goldberg, 2003). Goldberg reported that some of the children re-learned the skills a few years later. Like with past studies, it was unclear why some of the children re-learned the skills and some did not.

Maestro et al. (2006) was also interested in comparing the development of children diagnosed with ASDs and having early and regressive-onset symptoms. Like the above research, Maestro et al. (2006) used home videos to gather developmental data. However, unlike the above research, Maestro et al. (2006) included a control group and primarily focused on social and not language skills. The researchers divided their child participants into three groups: Early-Onset, Regressive-Onset, and Typical peers and used blind raters to look at videos at six-month intervals, between birth to 18-months of age.

The researchers found a difference in the presence of social abnormalities for the Early-Onset and Regressive-Onset groups. While the Early-Onset Group exhibited social abnormalities during the first six months of life, the Regressive-Onset Group displayed social abnormalities by 18 months of life (Maestro et al., 2006). Nonetheless, the researchers reported that the Typical Group had more social skills than the Regressive-Onset Group at 12 months and at 18 months. The researchers concluded that there seems to be two types of children diagnosed with ASDs: those who always have social deficits and those who slowly acquire social deficits.

Like the research conducted by Maestro et al. (2006), Bernabei, Cerquiglini, Cortesi, and D'Ardia (2007) also examined the differences in development between children with early-onset and regressive-onset ASDs using home videos, but focused on an older age group of two to six years. Participants were diagnosed with ASDs (15 with regressive-onset, 10 with early-onset) (Bernabei et al., 2007). To be classified as a regressive-onset participant, children had to lose at least five words, as well as gestures,

eye contact, and object manipulation for a minimum of three months (Bernabei et al., 2007). The researchers reviewed home videos and created their own questionnaires which assessed receptive and expressive communication, play skills, and requesting. The researchers reported that the regressive-onset group was developmentally behind the early-onset group; the children in the regressive-onset group, on average, loss skills by 20.6 months.

Goldberg, Thorsen, Osann, and Spence (2008) asserted that parents of children with autistic disorder appear to have better recall when reporting a loss of communication skills as opposed to a loss of other abilities (e.g., social skill, motor skills, etc.). Fifty-six parents of children diagnosed with autistic disorder with regressive and early-onset and 14 parents of typical peers participated in the study; all participants volunteered their home videotapes for review (Goldberg et al., 2008). The parents were also interviewed and their reports were compared to the home videotapes. The researchers found that parent reports corroborated with the home videotapes as far as communication, but less accurate with other types of loss. They concluded their study by stressing that professionals and researchers should rely on parental reports more often because they are fairly accurate.

Summary

This chapter reviewed the symptoms of parent stress and depression associated with raising children diagnosed with ASDs, due to dealing with daily severe behavior, feeling isolated from friends and family, advocating for educational placement and

therapeutic services, and caring for other children. The research suggested that parents of children diagnosed with ASDs cope differently, particularly if they have support systems in place and have been coping with the ASDs for a long period of time; however, fathers appeared to cope better than mothers which may be due to the tendency for mothers to generally do more of the caregiving than fathers. Similarly, fathers of children diagnosed with ASDs tended to report a higher sense of well-being than mothers. Past research purported that some parents of children diagnosed with ASDs report feeling guilty for indirectly contributing to their children's disorders, either passing on certain genes which caused the ASDs or exposing them to environmental toxins. Past research also suggested that parents of children diagnosed with ASDs experience more despair and less hope compared to other parents, due to expectations in regards to their future. The main difference in ASD onset is early-onset and regressive-onset, which determines when autistic symptoms of loss of skills occur. Although there was research on parental psychological states and research on differences in ASD onset, there is no research comparing ASD onset to past parent psychological states upon diagnosis.

Chapter 3: Research Method

Introduction

This chapter is divided into five subsections. First, the research design and approach is described. Second, the participants and setting of the study is discussed. Third, the intended instruments are explained. Fourth, research procedures are outlined. Fifth, the data analysis is reviewed.

Research Design and Approach

This quantitative study compared differences in the psychological recollections among mothers of low-functioning children diagnosed with ASDs whose histories reflect early-onset, mixed-onset, and regressive-onset symptoms. The design was quasi-experimental, since mothers cannot be randomly assigned to early-onset, mixed-onset, or regressive-onset groups. The independent variable was onset of symptoms of ASD, with three levels: early-onset, mixed-onset, and regressive-onset. The dependent variables were past psychological states of the mothers upon learning of their children's diagnoses. The mothers were instructed to go back in time and think of when their children were first diagnosed with ASDs before filling out assessments measuring psychological states. For complete detailed information on how the mothers filled out the assessments, see the Procedures section.

The past psychological states assessed in this study were stress, sense of well-being, and vicarious futurity. Stress was measured using the Parenting Stress Index, fourth edition (PSI-IV) (PAR, 2013). Parental well-being was measured using the Impact on Family Scale (IOFS) (Stein & Riessman, 1980). Vicarious futurity was defined as the dreams and aspirations people have when thinking about their loved ones' future (Wong & Heriot, 2007). Vicarious futurity was examined using the Vicarious Futurity Scale (VFS) (Wong, Heriot, Dossetor, & Nunn, 2011). The onset of the ASD symptomology was measured by the Regression Supplement Form (RSF) (Goldman et al., 2003).

Based on the results of the RSF, the participants were divided into onset groups: early-onset, mixed-onset, and regressive-onset. Based on previous definitions of ASD onset (Ozonoff et al., 2005), the following criteria was used to divide the participants into onset groups: early-onset--children exhibiting symptoms of ASDs within the first year of life, having no regression in speech, social, or play skills, and failing to progress; mixed-onset—children exhibiting symptoms of ASDs within the second year of life, having regressed in speech, social, or play skills, but displaying some developmental abnormalities before regression; regressive-onset—children exhibiting symptoms of ASDs within the second year of life, having regressed in speech, social, or play skills, with normal development prior to regression.

Setting and Participants

Participants for this study were obtained from various settings, a private school called The Center for Discovery, a support group center called Action Toward

Independence, an online Facebook group "My Life is Affected by Autism," and various independent volunteers. The Center for Discovery was a private school for children with developmental disabilities in rural southern New York. The participants at The Center for Discovery were mothers of children diagnosed with ASDs, who attend either a day or residential program at the school. Action Toward Independence was a support center for children with ASDs, as well as their parents, in Sullivan County, New York. *My Life is Affected by Autism* was an online parent support group on Facebook. Independent volunteers contacted the researcher through word of mouth and asked to participate in the study. All participants were mothers who had biological children diagnosed with ASDs by those professionals who are licensed to make such a diagnosis.

In order to determine the proper sample size, a power analysis was conducted using G*Power 3 (Erfelder, Faul, & Buchner, 1996). According to Pallant (2010), ideal power should be .80 and effect sizes can be measured using the partial eta squared statistic. An average partial eta squared was taken from past autism literature using MANOVA and the average effect size was .25. Given an alpha level of $p < .05$, the sample size needed for each group was determined to be 11 ($n = 11$). Total sample size needed to achieve power was 33 ($N = 33$).

Instruments

The assessment packets contained the following assessments: (a) demographic questionnaire, (b) RSF, (c) PSI-IV, (d) IOFS, and (e) VFS. The participants completed each measure independently. The demographic questionnaire gathered information

regarding parent marital status, race, ethnicity, socioeconomic status, religious affiliation, age, level of education, number of biological children, number of biological children with disabilities, birth order of child diagnosed with ASD, and age of children. The following paragraphs give descriptions the RSF, BDI-II, NAS-PI, and VFS:

Regression Supplement Form

The RSF was a self-administered questionnaire assessing child regression in the areas of communication, socialization, and play (Goldman et al., 2003). The RSF included 18 different categories, yes/no checklist for concurrent events, and two open-ended questions about when the rater noticed lost/gains (Goldberg et al., 2003). The 18 categories measured verbal and nonverbal communication and social skills, as well as the age when the loss took place, whether the loss was slow or fast, and whether the skills were ever re-learned (Goldberg et al., 2003). The yes/no checklist assessed whether the loss of skills coincided with other events, such as an illness, family crisis, vaccinations, medication change, death of a loved one, or major transition (Goldberg et al., 2003).

Another yes/no checklist measured whether the gain of skills coincided with the same major life events. The two open-ended questions were fill-in answers so participants have an opportunity to voice their own beliefs regarding why communicative or social losses/gains took place (Goldberg et al., 2003). Scores were be coded by dividing the responses into two categories (i.e., loss of skills, no loss of skills). The loss of skill category represented regressive symptoms and no loss of skills will represent early-onset symptoms. Sample items from the RSF ascertained whether the participants'

children lost one-two words, lost social smiles, and lost direct eye gaze (Goldman et al., 2003). According to the authors, the RSF was normed on 44 parents; the reliability and validity was 91%.

Parenting Stress Index, fourth edition

The PSI-IV was a self-administered assessment, consisting of 120 questions that measure sources of stress such as child characteristics, parental characteristics, and environmental conditions (PAR, 2013). According to the publishing company, the PSI-IV was normed on over 1000 mothers and fathers. The reliability for this measure was over 96%, with subscale reliability coefficients ranging from ranging from .75 to .88 (PAR, 2013). The measure's validity was examined in research involving both child and adult mental illness, addiction, and developmental disorders (PAR, 2013).

Impact on Family Scale

The IOFS was a self-administered questionnaire, measuring the effects of long-term childhood illnesses on parents and siblings (Stein & Jessop, 2003). According to the authors, the IOFS was a 15-item questionnaire focusing the financial, familial, social, and physical strains of raising a child with a chronic disability. The IOFS yielded a Total Score, which is based on four scales: General Negative Impact, Disruption of Social Relations, Coping, and Financial Impact (Stein & Riessman, 1980). Sample items from the IOFS were as follows: 1) Fatigue is a problem for me because of my child's condition, 2) I don't have much time left over for other family members after caring for my child, and 3) I live from day-to-day and don't plan for the future (Stein & Riessman,

1980). The IOFS was normed on over 1000 parents of children with chronic illnesses (Stein & Jessop, 2003). The reliability coefficient for the Total Score was .97 and the construct validity ranged from .327 to .470 (Stein & Jessop, 2003).

Vicarious Futurity Scale

The VFS was a 20-item, self-administered measure assessing the hopes or disappointments parents have in regards to their children's future (Wong et al., submitted). The VFS contained two subscales, Vicarious Hope and Vicarious Despair, which are calculated in the Global Vicarious Hopefulness score (Wong et al., submitted). Sample items from the VFS were as follows: (a) I will look back on my child's life and be satisfied, (b) I often fear that the rest of my child's life will not be worthwhile (Wong et al., submitted). According to the authors, the VFS was normed on 318 parents of children ages five-12. The test reliability was 76% for Vicarious Despair and 63% for Vicarious Hope (cronbach alpha = .83) and the validity was .83 (Wong et al., 2011).

Procedures

The researcher sent invitation letters to The Center for Discovery and Action Toward Independence, inviting participants to join her study. The researcher also posted on the My Life is Affected By Autism Facebook site, inviting participants to join her study. The invitation letters outlined the criteria for participation. Participants were mothers of biological children between the ages of 5 and 21 years and who have ASDs as their primary diagnoses; the diagnoses were rendered by licensed professionals qualified to render such diagnoses. The mothers were listed as the primary caregivers (as opposed

to children being raised by their fathers, grandparents, or other guardians). The Center for Discovery and Action Toward Independence screened their students'/residents'/ clients' records and identified appropriate candidates, using the criteria listed above.

The Center for Discovery and Action Toward Independence forwarded the researcher's invitation letter to mothers in their agencies who fit the above-mentioned criteria to participate in the study. The invitation letters were either mailed to the mothers' homes or emailed to them. All invitation letters contained the researcher's email. Interested mothers were instructed to email the researcher directly. The researcher posted the invitation letter to My Life is Affected by Autism website on Facebook. Interested mothers were instructed to email the researcher directly. Word of mouth of the study brought additional volunteers, who contacted the researcher via email.

Once the researcher received emails from interested mothers, she mailed them two copies of the informed consent forms for them to review and sign. They were instructed to keep one copy for themselves and mail another copy back to the researcher. By signing the informed consent forms, the mothers agreed to participate in the study and provide verification of their children's ASD diagnoses.

Once the informed consent forms were received by the researcher, the researcher mailed the participants assessment packets. The researcher stuffed and labeled the assessment packets and mailed them to the participants with self-addressed, stamped envelopes. No identifiable information was listed on the assessments. The measurements that asked for identifiable information were blacked out. All assessments

were coded for privacy. The codes used were specific to the onset of the children's ASDs (R = Regression, EO = Early Onset, MO = Mixed Onset). The codes also included numerical numbers so the researcher could keep the different assessments together (R1, R2, EO1, EO2, etc.). Although the researcher knew which study group the parent is in (Regression Group, Early Onset Group, Mixed Onset Group), the researcher did not know which specific parent filled out an assessment.

Each packet contained a demographic information questionnaire, as well as an informed consent form. The packets also included letters of instruction to the participants on how to fill out the assessments. The letters explained that the participants should not fill out the assessments in their current state of mind. Rather, they needed to go back in time and think of when their children were first diagnosed with ASDs before filling out the assessments. Finally, each packet contained the following assessments: RSF, PSI-IV, VFS, and IOFS.

Packets were mailed back to the researcher, who then tallied and analyzed the data via SPSS. After the data was analyzed and the results were written, the researcher generated a one-page summary of the research findings and emailed it to the participants (regardless of whether the actually returned assessments). The researcher also emailed the one-page summary of the research findings to the stakeholders. The researcher will keep all assessments and relevant paperwork in a locked cabinet for five years before being destroyed.

Analyses

The research question proposed in this study addressed whether ASD onset is related to past psychological states in mothers upon diagnosis. The null hypothesis predicted no difference in the past psychological states of mothers of children diagnosed with ASDs whose histories reflect either early-onset, regressive-onset, or mixed-onset symptoms, as measured by the PSI-IV, IOFS, and VFS. The alternative hypothesis predicted that mothers of children diagnosed with ASDs with regressive-onset symptoms will report increased symptoms of stress and decreased sense of well-being compared to mothers of children diagnosed with ASDs with early-onset or mixed-onset symptoms as measured by the PSI-IV, IOFS, and VFS. The alternative hypothesis also predicted that mothers of children diagnosed with ASDs with mixed-onset symptoms will report more symptoms of stress and decreased well-being compared to mothers of children diagnosed with ASDs with early-onset symptoms as measured by the PSI-IV, IOFS, and VFS.

A one-way multivariate analysis of variance (MANOVA) was used to assess the past psychological states of the three groups of mothers to determine if there is a significant difference. Since the dependent variables had large correlations, multicollinearity checks were conducted to determine the level of correlation between the variables (Pallant, 2010). Univariate outliers were identified via data entry into the SPSS computer system by examining the Histogram and Boxplot (Pallant, 2010). After ascertaining that the outliers are real and not the result of erroneous data entry, the 5% trimmed mean was examined and extreme values was removed from the study while less-extreme values remained. Multivariate outliers were checked using Mahalanobis

distance (Pallant, 2010). If the multivariate outliers were extreme, they were removed from the study.

In order to calculate the effect size, the sum of squares between groups was divided by the total sum of squares (Pallant, 2010). According to Pallant (2010), Cohen's specifications for eta squared can be applied to determine the strength of partial eta squared. Cohen (1988) outlined the size of the effect of eta squared as: .01 small, .06 medium, and .14 large. If any of the one-way MANOVA tests produced significant F scores, post-hoc between group comparisons were carried out using univariate analyses to determine where the significant differences lie.

Summary

Chapter three outlined the research methods for this quantitative study, including the recruitment of participants, rationale for statistical analysis, proposed effect and sample sizes, and intended testing measures. This chapter also entailed participant protection and confidentiality, as well as the proposed data collection process. Chapter 4 discusses the results of the study, while Chapter 5 applies these findings to positive social change as well as recommendations for future research.

Chapter 4: Results

Introduction

Chapter four describes the result section of this research, which investigated the psychological recollections of mothers of children diagnosed with ASDs and to determine whether ASD onset affected maternal experiences. This chapter discusses the research sample, the research questions, and the data analysis.

Descriptive Statistics

Characteristics of Sample

Table 1 outlined descriptive statistics for the 31 mothers of children diagnosed with ASDs who participated in the study. Twenty two mothers were married (71%), while six were divorced or separated (19%), and three were never married (10%). The majority of mothers identified as Caucasian (77%), while the remaining 13% of mothers identified themselves as African American, Latina, or "Other." Seventy two percent of the sample revealed their faith as Christian, while the remaining 28% of mothers revealed their faith as Jewish or "Other." One mother identified as an atheist.

In terms of education, 13 mothers earned graduate degrees (42%), one completed "some graduate school" (3%), nine earned undergraduate/vocational degrees (29%), four completed "some college" (13%), and four were high school graduates (13%). The majority of mothers reported a family income of over $100,000.00 (52%), while seven mothers reported a family income between $60-100,000.00 (23%), and six mothers reported a family income between $20-60,000.00 (19%). One mother reported a family income between $10-20,000.00 (3%) and one mother reported a family income of less than $10,000.00 (3%).

The majority of mothers in the sample had two children (61%), 20% had between three and four children, 13% had one child, and 6% had more than five children. followed by one child (13%). When asked how many children they had diagnosed with disabilities, the majority of mothers (74%) reported having one child, 19% reported having two children, and seven percent reported having between three to four children with disabilities. Finally, the mothers revealed the order of birth of their children with

ASDs. Sixteen mothers (52%) reported that their children with ASDs were the oldest, eight (26%) mothers reported that their children with ASDs were in the middle, and seven (22%) mothers reported that their children with ASDs were the youngest.

Table 1

Demographics for Sample (N = 31)

Variable	n	%
Marital Status		
Married	22	71
Divorced/Separated	6	19
Never Married	3	10
Race		
African American	1	3
Caucasian	24	77
Latina	3	10
Other	3	10
Religion		
Christian	22	71
Jewish	6	19
Atheist	1	3

(*table continues*)

Variable	n	%
Other	2	7
Education		
High School Degree	4	13
Some College	4	13
Undergraduate/Vocational Degree	9	29
Some Graduate School	1	3
Graduate Degree	13	42
Family Income		

Less Than $10,000	1	3
$10-20,000	1	3
$20-40,000	2	6.5
$40-60,000	4	13
$60-80,000	5	16
$80-100,000	2	6.5
$100-150,000	8	26
>$150,000	8	26

Demographics for Sample (N = 31)

Variable	n	%
Number of Children		
1	4	13
2	19	61
3	3	10
4	3	10
5	1	3
8	1	3
Number of Children Diagnosed with Disabilities		
1	23	74
2	6	19
3	1	3.5
4	1	3.5
Rank of Children Diagnosed with ASDs		
Oldest	16	52

(table continues)

Variable	n	%
Middle	8	26
Youngest	7	22

Age of Onset

As stated in Chapter 3, mothers were given the Regression Supplement Form (RSF) to determine the age their children exhibited symptoms of ASDs. Sixteen mothers (52%) reported Early Onset (symptoms of ASDs exhibited within the first 12 months of life), eight mothers (26%) reported Regressive Onset (symptoms of ASDs exhibited after 12 months of life), and seven mothers (23%) reported Mixed Onset (symptoms of ASDs exhibited after 12 months of life with abnormalities observed before). Table 2 outlines the age of onset for this sample.

Table 2

Age of Onset of Autism Spectrum Disorders (N = 31)

Variable	n	%
Early Onset	16	52
Regressive	8	26
Mixed	7	23

Data Collection

Recruitment Process and Response Rates

Participants were mailed assessment packets after contacting the researcher expressing interest in joining the study. As mentioned in Chapter 3, a power analysis for sample size was conducted and a sample size of 33 was recommended. In a 12 month period, over 50 participants were recruited but 19 eventually dropped out of the study. The reasons given for this were other family stressors, time constraints, or the

participants simply stopped communicating with the researcher. It was ultimately decided by the researcher to run the data analyses with 31 participants. However, this number dropped to 30 due to partial data completion.

Preliminary Analyses

As stated in Chapter 3, univariate outliers were identified via data entry into the SPSS computer system by examining the Histogram and Boxplot graphs (Pallant, 2010). After reviewing the Histogram and Boxplot graphs for the data on the Impact on Family Scale and double checked the data for errors, the 5% trimmed mean was examined. No extreme values needed to be removed. The Boxplot graph for the Parenting Stress Inventory reported one outlier, but it did not extend more than 1.5 box lengths from the edge of the box (Pallant, 2010). After double checking the data for errors, the 5% trimmed mean was examined. No extreme values needed to be removed. The Boxplot graph for the Vicarious Futurity Scale reported one outlier, but it did not extend more than 1.5 box lengths from the edge of the box (Pallant, 2010). After double checking the data for errors, the 5% trimmed mean was examined. No extreme values needed to be removed.

Analyses were conducted to assess the normality of each dependent variable in order to ascertain the skewness and kurtosis of the distribution (Pallant, 2010). After reviewing the histogram for the Vicarious Futurity Scale and Test of Normality table in the SPSS output, the value of the Kolmogorov-Smirnov statistic was .20 which indicates normality (Pallant, 2010). After reviewing the histogram for the Parenting Stress

Inventory and Test of Normality table in the SPSS output, the value of the Kolmogorov-Smirnov statistic was .20 which indicates normality (Pallant, 2010). After reviewing the histogram for the Impact on Family Scale and Test of Normality table in the SPSS output, the value of the Kolmogorov-Smirnov statistic was .20 which indicates normality (Pallant, 2010).

Correlational analyses were conducted on each dependent variable (perceived hope for the future, perceived stress, and perceived family impact). The perceived impact of the child's autism spectrum disorder (ASD) on the family and perceived hope of the future was measured by the Impact on Family Scale and the Vicarious Futurity Scale ; the relationship between the perceived impact of the child's ASD on the family and the perceived hope of the future was investigated using Pearson product-moment correlation coefficient. There was a large, negative correlation between perceived impact on family and perceived hope of the future, $r = -.62$, $n = 30$, $p < .0005$. Specifically, high levels of perceived impact on family were associated with lower levels of perceived hope of the future.

The perceived level of stress was measured by the Parenting Stress Index; the relationship between perceived impact of the child's ASD on the family and the perceived stress was investigated using Pearson product-moment correlation coefficient. There was a large, positive correlation between perceived impact on family and perceived stress, $r = .62$, $n = 30$, $p < .0005$. Specifically, high levels of perceived impact on family were associated with high levels of perceived stress. The relationship between perceived

hope of the future and perceived level of stress was investigated using Pearson product-moment correlation coefficient. There was a large, negative correlation between perceived hope of the future and perceived stress, $r = -.67$, $n = 31$, $p < .0005$. Specifically, high levels of perceived stress were associated with low levels of perceived hope of the future.

Since the dependent variables had large correlations, multicollinearity checks were conducted to determine the level of correlation between the variables (Pallant, 2010). It has been suggested that correlations around .8-.9 are concerning (Pallant, 2010), but the correlations in this study were not higher than .67. Therefore, none of the dependent variables needed to be removed from the study.

Research Questions:

There were three research questions tested in this research:

RQ1: Do mothers of children diagnosed with ASDs and having regressive-onset symptoms experience different psychological recollections compared to mothers of children diagnosed with ASDs and having early-onset symptoms?

$H_0$1: There are no significant differences in the psychological recollections of mothers of children diagnosed with ASDs between mothers whose children exhibited early-onset symptoms and those who exhibited regressive-onset symptoms.

$H_1$1: There are significant differences in the psychological recollections of mothers of children diagnosed with ASDs between mothers whose children exhibited early-onset symptoms and those who exhibited regressive-onset symptoms.

RQ2: Do mothers of children diagnosed with ASDs and having regressive-onset symptoms experience different psychological recollections compared to mothers of children diagnosed with ASDs and having mixed-onset symptoms?

$H_0$1: There are no significant differences in the psychological recollections of mothers of children diagnosed with ASDs between mothers whose children exhibited regressive-onset symptoms and mixed-onset symptoms.

$H_1$1: There are no significant differences in the psychological recollections of mothers of children diagnosed with ASDs between mothers whose children exhibited regressive-onset symptoms and mixed-onset symptoms.

RQ3) Do mothers of children diagnosed with ASDs and having early-onset symptoms experience different psychological recollections compared to mothers of children diagnosed with ASDs and having mixed-onset symptoms?

$H_0$1: There are no significant differences in the psychological recollections of mothers of children diagnosed with ASDs between mothers whose children exhibited early-onset symptoms and mixed-onset symptoms.

$H_1$1: There are no significant differences in the psychological recollections of mothers of children diagnosed with ASDs between mothers whose children exhibited early-onset symptoms and mixed-onset symptoms.

Data Analysis

As stated in Chapter 3, a one-way multivariate analysis of variance (MANOVA) was used to assess the past psychological states of the three groups of mothers to

determine if there is a significant difference. Since the dependent variables had large correlations, multicollinearity checks were conducted to determine the level of correlation between the variables (Pallant, 2010). Univariate outliers were identified via data entry into the SPSS computer system by examining the Histogram and Boxplot (Pallant, 2010). After ascertaining that the outliers are real and not the result of erroneous data entry, the 5% trimmed mean was examined and extreme values was removed from the study while less-extreme values remained. Multivariate outliers were checked using Mahalanobis distance (Pallant, 2010). If the multivariate outliers were extreme, they were removed from the study.

In order to calculate the effect size, the sum of squares between groups was divided by the total sum of squares (Pallant, 2010). According to Pallant (2010), Cohen's specifications for eta squared can be applied to determine the strength of partial eta squared. Cohen (1988) outlined the size of the effect of eta squared as: .01 small, .06 medium, and .14 large. If any of the one-way MANOVA tests produced significant F scores, post-hoc between group comparisons were carried out using univariate analyses to determine where the significant differences lie.

Results

A one-way between-groups multivariate analysis of variance (MANOVA) was conducted to examine the differences of child onset of autism spectrum disorder (ASD) in maternal perceived family impact, perceived hope, and perceived family stress. Preliminary analyses were conducted to ascertain whether any assumptions of normality,

linearity, outliers, homogeneity of variance, and multicollinearity were violated. No major violations were found. No statistically significant differences were found between child onset of ASD and maternal perceived family impact, perceived hope, and perceived family stress, F (6, 50) = .85, p = .54. Wilks Lambda = .82, partial eta squared = .09. The null hypotheses were not rejected.

Summary

This chapter discussed the data analysis that was undertaken. Thirty one biological mothers of children diagnosed with ASDs participated in this study. The majority of mothers were married, Caucasian, Christian, educated, and affluent. Most of the mothers had two children and most reported having one child diagnosed with an ASD. Many of the children diagnosed with ASDs were the oldest in birth order and most exhibited early onset symptoms, as opposed to regressive or mixed onset symptoms.

Although a power analysis was conducted and indicated that at least 33 participants would be needed for this study, only 31 participants were recruited. One participant had to be removed from the data analysis, due to incomplete data. Preliminary analyses were conducted to ascertain normality of each dependent variable and identify any outliers. Histogram and Box Plot graphs were used for each dependent variable and no significant outliers were found. No extreme values were removed. Correlation analyses were conducted on each dependent variable, which showed moderate correlations. Multicollinearity checks were conducted to determine the level of

correlations between the dependent variables. Since none were higher than .67, no dependent variables needed to be removed.

There were three research questions posited for this study: (a) Do mothers of children diagnosed with ASDs and having regressive-onset symptoms experience different psychological recollections compared to mothers of children diagnosed with ASDs and having early-onset symptoms? (b) Do mothers of children diagnosed with ASDs and having regressive-onset symptoms experience different psychological recollections compared to mothers of children diagnosed with ASDs and having mixed-onset symptoms? (c) Do mothers of children diagnosed with ASDs and having early-onset symptoms experience different psychological recollections compared to mothers of children diagnosed with ASDs and having mixed-onset symptoms?

A one-way MANOVA was used to determine if the null hypotheses could be rejected for the three research questions. However, the one-way MANOVA did not produce significant findings and the null hypotheses for each research question could not be rejected. Chapter 5 talks about the implications to this study beyond the data.

Chapter 5: Discussion

Overview

This chapter interprets findings of this study in relation to the hypotheses made by this researcher in Chapter 1. This chapter also discusses the study's limitations and implications for social change. Lastly, this chapter talks about some recommendations for future research.

Interpretation of Findings

Past research purported that parents of children diagnosed with ASDs experience more stress than parents of children without ASDs, due to the daily rigors of caring for children with behavioral issues and decreased safety awareness (Blackledge & Hayes, 2006; Benson, 2006; Hamlyn-Wright et al., 2007; Mitchell & Holdt; 2014; Mount & Gayle, 2014; Schieve et al., 2006). Past research demonstrated that parents of children diagnosed with ASDs report less happiness, less marital satisfaction, and decreased family functioning compared to parents of children without ASDs (Higgins et al., 2005; Montes & Haltermen, 2007; Pozo et al., 2014). Past research also revealed that parents of children diagnosed with ASDs experience less hope for the future compared to parents

of children without ASDs (Wong & Heriot, 2007; Mount & Gayle; 2014). In addition, research looked at genetic versus environmental causes of ASDs (Al Anbar et al., 2010), as well as ASD onset (Ozonoff et al., 2008; Stefanatos, 2008; Luyster et al., 2005). Some studies have found that parents of children diagnosed with ASDs and exhibiting regressive onset symptoms believed that the ASDs could have been prevented because the disorders were assumed to be caused by environmental factors (Madsen et al., 2000; Madsen et al., 2003; Mercer et al., 2006; Parker, et al., 2004; Uchymama et al., 2007). The gap in current research was that there were no examinations of ASD symptom onset and parent psychological experiences.

This study investigated the psychological recollections of 30 mothers of children diagnosed with ASDs in order to determine if mothers of children who experienced regression differed in their recollections compared to mothers of children who did not experience regression. There was one independent variable, onset of ASDs, with three levels: Early-Onset, Regressive-Onset, and Mixed-Onset. Three dependent variables comprised the psychological recollections of the mothers: perceived stress, perceived family impact, and perceived future hope. After preliminary analyses were conducted, one-way MANOVA was used to determine if significant differences existed between the three groups.

The first research question posed whether mothers of children diagnosed with ASDs who experiences Early-Onset symptoms differed in their psychological

recollections as opposed to mothers of children diagnosed with ASDs who experiences Regressive-Onset symptoms. This researcher hypothesized those mothers of children with Regressive-Onset symptoms would report psychological recollections that included increased stress, increased negative family impact, and decreased future hope compared to mothers of children with Early-Onset symptoms. It was hypothesized that mothers of children with Regressive-Onset symptoms would have more negative recollections than mothers of children with Early-Onset symptoms due to the maternal trauma of helplessly watching their children lose their communicative and social skills in early childhood. However, there was no significant statistical difference between mothers whose children regressed and mothers whose children did not regress. The null hypothesis for this research question could not be rejected.

The second research question posed whether mothers of children diagnosed with ASDs who experiences Regressive-Onset symptoms differed in their psychological recollections as opposed to mothers of children diagnosed with ASDs who experiences Mixed-Onset symptoms. This researcher hypothesized those mothers of children with Regressive-Onset symptoms would have more negative recollections than mothers of children with Mixed-Onset symptoms due to the maternal trauma of helplessly watching their children lose their communicative and social skills in early childhood. However, there was no significant statistical difference between mothers whose children regressed and mothers whose children did not regress but exhibited social abnormalities

before exhibited ASD symptoms. The null hypothesis for this research question could not be rejected.

The third research question posed whether mothers of children diagnosed with ASDs who experiences Mixed-Onset symptoms differed in their psychological recollections as opposed to mothers of children diagnosed with ASDs who experiences Early-Onset symptoms. This researcher hypothesized those mothers of children with Mixed-Onset symptoms would have more negative recollections than mothers of children with Early-Onset symptoms due to the maternal stress of watching their children suddenly exhibit social abnormalities which precede symptoms of ASD in early childhood. However, there was no significant statistical difference between mothers whose children with sudden social abnormalities and mothers whose children exhibited ASD symptoms since early infancy. The null hypothesis for this research question could not be rejected.

It was hypothesized that mothers of children diagnosed with ASDs would experience more stress, less future hope, and more negative family impact if their children displayed Regressive-Onset symptoms than Early-Onset symptoms or Mixed-Onset symptoms, due to the belief that their children's ASDs were caused by the environment and could have been prevented. These findings were not observed with this sample. Mothers of children diagnosed with ASDs with Early-Onset symptoms did not report different psychological recollections than mothers of children with Regressive or Mixed-Onset symptoms. In other words, these mothers may have felt stress, decreased

hope, and negative family impact from raising children diagnosed with ASDs but the onset of their children's symptoms did not appear to play a role in their experiences. This study's findings support past research that mothers of children diagnosed with ASDs are stressed (Blackledge & Hayes, 2006; Mitchell & Holdt, 2014; Mount & Gayle; 2014; Pozo et al., 2014), have less future hope (Mount & Gayle, 2014; Wong & Heriot, 2007), and less well being (Allik et al., 2006; Higgins et al., 2005; Montes & Haltermen, 2007; Pozo et al., 2014). The study does not support that there is a difference between ASD onset and these recollections. There has not been research on the topic of ASD onset and parent psychological recollections so these findings may not be surprising.

Limitations

One major limitation to this study was its small sample size. Although this researcher originally recruited 50 participants, there was a significant drop out rate. The target N after the power analysis was conducted was 33. This researcher could recruit only 31 participants from multiple agencies (private school, county-wide parent support group, and Facebook parent support blog). Out of 31 participants, one participant was excluded from the data analysis due to incomplete data. As a result of the small sample size, the study lacked power. Correlation analyses were run to determine the relationship between the three dependent variables. The correlation analyses for all three dependent variables yielded moderate correlations. It is suspected that if the sample size was larger, the MANOVA may have yielded statistically significant results.

Although significant drop out rates are a potential hazard to any research, possible

reasons for drop outs in this study speaks to why the study was originally conducted. Not all mothers who dropped out of this study gave the researcher reasons for not participating; they simply stopped communicating with the researcher and never returned the test materials. However, some mothers explained that their lives were simply too busy/stressful to take on another responsibility. Other mothers shared that the content of the assessment packets the researcher had sent was too painful to revisit. In other words, revisiting when their children were diagnosed with ASDs and the impact it had on their families brought up feelings that they did not want to remember or relive again. Although having these mothers drop out of the study was disappointing, it also justified why this research should be conducted. Most mothers lead busy, stressful lives, but mothers of children with disabilities, especially ASDs, often juggle work, other children, spouses, and the everyday rigors and challenges of dealing with their autistic children's needs.

Another substantial limitation to this research was the lack of diversity of the sample size. According to the participants' demographics, most mothers were Caucasian, middle to upper class, well educated, Christian, and married. This sample was not the most representative of all mothers of children diagnosed with ASDs in New York State. The researcher attempted to reach out to more diverse resource pools (e.g., local school districts, etc.), there was not enough interest to generate participation. It was possible that mothers who were more educated, affluent, and had spouses/significant others had

more free time to participate in this study compared to mothers who were less educated, less affluent, or single.

A final limitation to this research was the study did not differentiate between the children's level of functioning. Participants who were recruited from The Center for Discovery had children who were low-functioning and were either residents of the school or attended the day program. This program is only reserved for low-functioning children, as higher functioning children could be serviced in public education settings. It was unknown if the participants who were recruited from the physical and online parent support groups were mothers of children with high or low functioning ASDs because the assessments given did not measure overall functioning. This could be important information because lower functioning children diagnosed with ASDs may be more behavioral, less independent, less aware of safety, and overall harder to care for compared to higher functioning children. Therefore, maternal psychological recollections may be very different for mothers of low-functioning children than mothers of high-functioning children.

Implications for Social Change

Although this study did not produce significant findings, there continues to be a need for emotional support for mothers of children diagnosed with ASDs (Blackledge & Hayes, 2006; Kuhn & Carter, 2006; Klauber, 1998; Mitchell & Holdt, 2014; Mount &Gayle, 2014). Depending on the severity of the children's needs, many mothers find themselves needing to provide round-the-clock care for their children; sometimes their

children's behaviors are so aggressive, destructive, or self-injurious that the family cannot leave the home (Kuhn & Carter, 2006).

When children are initially diagnosed with ASDs and potential services are being discussed by educators, therapists, or doctors, it should be mandated that the professionals offer the mothers referrals for their own psychotherapists. It appears that the mothers' needs are ignored during this process; professionals fail to appreciate the magnitude of parental trauma upon rendering ASD diagnoses to their children (Hingley-Jones, 2005). Even though the experience of hearing their children are being diagnosed with ASDs may be painful and overwhelming, the referrals for psychotherapy could be filed away to be reviewed at a later date—after the shock of the diagnoses has sunk in if not accepted. Even if the mothers refuse the referrals for psychotherapy, it should be offered. After all, services for the children are recommended upon diagnoses. Services for the mothers should not be neglected for overall well-being. Referrals for psychotherapy, whether it is individual, group support, or family therapy, may prevent mothers from undergoing unnecessary stress, feelings of isolation, and helplessness. Instead they may feel empowered knowing they are not alone and their feelings about their children and the world around them are normal (Mitchell & Holdt, 2014). This may have positive effects on their parenting, spousal relationships, health, and overall well-being.

Recommendations for Future Research

It would be the most advisable to redo this study with more participants in order to gain adequate power, which may produce significant findings. It is also recommended that future researchers attempt to include participants with more diverse demographics in terms of race, marital status, religion, economic level, and education. It is possible that mothers from diverse backgrounds and cultures perceive their lives and the outside world differently, which may produce different findings. This study used participants from one private school, one parent support blog, and one agency for social skills for children with ASDs. Recruiting participants from multiple schools, parent support blogs, and agencies for families of children with ASDs may produce more interest and may provide a more diverse participant pool.

Another factor to be considered for future research is the functioning level of the children. This study did not address functioning level of the children. Research has shown that low-functioning children diagnosed with ASDs may have more behavioral difficulties, and may require more therapy and care, then high-functioning children diagnosed with ASDs. It might be worthwhile to differentiate this in future research. Mothers of children diagnosed with low-functioning ASDs may report different psychological recollections compared with mothers of children diagnosed high-functioning ASDs.

This research targeted mothers of children diagnosed with ASDs who were aged 5-21 years. This range was chosen because 5-21 years is considered “school age” in a

special education setting. Also, by five years of age, ASD diagnoses are usually rendered and a mother of a child older than 21 may not fully recall what her life was like upon her child's diagnosis. However, a longitudinal analysis may be worthwhile to investigate a mother's experiences upon her child's ASD diagnosis, upon her child reaching school age, adolescence, young adulthood, and adulthood. Data from each time period could be compared to see if her psychological experiences change as her child ages. As children learn new skills, their needs change. For children with ASDs, their behavior can change as they acquire skills in academic settings, reach puberty, and develop more mature interests.

Lastly, this research only focused on biological mothers of children diagnosed with ASDs. This brought some criticism from interested fathers of children diagnosed with ASDs, who were the primary caregivers in the family and had wanted to join the study. The decision to include only mothers in this study was due to practicality. Most research on parents of children diagnosed with ASDs includes mothers because they are most likely the primary caregivers and can correctly recall early development information for their children. In addition, mothers of children diagnosed with ASDs are usually more available to participate. If the parents are divorced, the children often reside with the mothers which make them more accessible. However, if an appropriately-sized participant pool allows, it would be worthwhile to compare maternal and paternal psychological recollections for future research.

Concluding Statement

This body of research was intended to shed light on the psychological experiences of mothers of children diagnosed with ASDs, as the researcher proposed that these mothers are an under-serviced population. It is already known that children diagnosed with ASDs have behavioral, social, and communicative challenges that are indicative of their diagnoses. It is also known that therapies, such as occupational therapy, speech therapy, and behavior therapy, coupled with specialized and individualized education, most often produces skill and behavior improvement—which is why immediate therapy, special education programs are recommended to families upon their children's diagnoses. If this is a widely accepted practice by professionals in the field, it should also be an accepted practice to offer therapies for the parents and siblings of the children diagnosed with ASDs. Families of children diagnosed with ASDs need just as much emotional support as their family members who have the ASDs. This researcher hopes that this body of work, even though it did not produce significant findings, can bring society one step closer in recognizing the needs of this under-serviced population and help facilitate social change.

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