

2016

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NSUWorks Citation

Ross, David B. and Salah, Elizabeth Vultaggio, "The Mystery of Autism: Parental Perspectives" (2016). *Fischler College of Education: Faculty Articles*. 243.

https://nsuworks.nova.edu/fse_facarticles/243

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The Mystery of Autism: Parental Perspectives

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Abstract

Research indicated that parents of children with autism spectrum disorder experience higher levels of stress than parents of children with other developmental disorders. Children with autism tend to exhibit problematic behaviors as a result of their inability to communicate effectively. Parents of children with autism find it challenging to determine the reasons for these behaviors. Since researchers have confirmed the presence of stress associated with caring for a child with autism, coping strategies can essentially elevate high stress levels that can lead to depression. Children with autism spectrum disorders may have multiple disabilities that can cause an even greater challenge for professionals and parents. With this said, there is no single intervention or no single best approach for assisting all children with autism spectrum disorders. While evidence-based intervention methods for children with autism spectrum disorders have been identified, the need for better understanding of how to match the most effective intervention to specific child characteristics continues to puzzle educational professionals. To accomplish this, it is essential for parents, educators, and professionals to understand how autism affects an individual and then, identify strengths and weaknesses before considering any particular

approach.

Keywords: Autism Spectrum Disorder, Family Issues, Coping Strategies, Stress, Anxiety

The Mystery of Autism: Parental Perspectives

Students with disabilities present unique challenges that require specific focus based on their educational needs. It is crucial that all stakeholders (e.g., parents, pediatricians, teachers, support groups, healthcare providers) work collaboratively to identify student's individual needs and develop an individual educational plan to improve educational results (Yell, 2012). An effective individual educational plan involves school personnel, parents, and often the student with disabilities. These individuals bring a wealth of knowledge and experience that is necessary for developing an individualized document that will help the student be involved and progress in the least restrictive environment (Yell, 2012).

Based on research and the researchers' experiences of educating children with autism spectrum disorders, there are many gaps between pediatrician's knowledge and understanding of diagnosing this neurological development disorder. The general pediatrician provides care for children with the minor childhood illnesses, to include acute and chronic health problems and growth and development concerns. In addition, a general pediatrician is not trained in certain areas as compared to a developmental pediatrician who can diagnose a child with autism spectrum disorder. A developmental pediatrician has an educational background in four years of medical school, three years of residency training in pediatrics, board certified in pediatrics, and additional professional development in developmental-behavioral pediatrics. These developmental pediatricians can better diagnosis children with developmental and behavioral issues.

Over the past few decades, psychologists, occupational and speech pathologists, and other health care professionals have implemented numerous treatment programs to address the neurological, behavioral, and developmental challenges related with autism (Skokut, Robinson,

Openden, & Jimerson, 2008). Selecting an appropriate method can be a challenge for professionals as there is no single intervention or no single best approach for supporting these children (Blubaugh & Kohlmann, 2006; Rao & Gagie, 2006).

Parents who have children with autism are not aware of many services and support for their child. These services are offered through private, public, and non-profit organizations. Some services, located in the southeast area of Florida, are The Dan Marino Foundation, University of Miami Center for Autism and Related Disabilities, and the Florida Atlantic University Center for Autism and Related Disabilities. School districts offer many services for children with autism and other disabilities; parents need to be educated and informed of the specific services. In addition, parents should be knowledgeable about the insurance coverage for a child with special needs, including autism spectrum disorder, as some insurance companies may not cover for applied behavior analysis (ABA). The student must be identified as having a disability through an individual educational plan to obtain services. Parents are unaware of the many support and therapy groups to help them cope with the diagnosis and the many challenges of raising a child with autism.

Deficiencies in the Evidence

Students with disabilities, in prekindergarten through Grade 12, are educated in the least restrictive environment or in self-contained classrooms. Students with disabilities are educated 100% of the day in a general education classroom or are placed in a self-contained classroom for *Intellectually Disabled* or *Autism Spectrum Disorders*. Placement and services are determined based on individual needs (Rothstein & Johnson, 2010; Yell, 2012). Special education services are provided through support facilitation in the general education classroom and pulled out for speech and language services. The special education teacher and general education teacher use

data to monitor patterns of learning (Rothstein & Johnson, 2010; Yell, 2012). While a school provides inclusive environments, there is a preconception that placement is a solution to academic and behavioral concerns.

The impact of proper diagnosis for children with autism spectrum disorder continues to be a topic of research in order to determine the effectiveness of understanding this neurological development disorder. Emerging research revealed that autism spectrum disorder has become more of a topic of concern and interest to uncover the challenges and successes of children who have this disorder. In 1975, 1 in every 2,500 children was diagnosed with autism; today this number has increased to 1 in every 68 children (i.e., 1 in 42 boys; 1 in 189 girls) (Center for Disease Control and Prevention, 2014). Despite the advancements of research studies regarding autism spectrum disorder, there remain limited studies regarding the perspective based on how a parent copes with the stress of having a child with autism. Most studies have focused on mothers who cope with a child with autism (King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009; Marks & Dollahite, 2001), while some studies focused on both parents (i.e., mother, father) (Agate, Zabriskie, & Eggett, 2007; Davis & Carter, 2008; Falk, Norris, & Quinn, 2014).

Purpose of the Study

The purpose of this phenomenological study was to understand parents' experiences of coping with their children with autism. Additionally, this study sought to understand the challenges, successes, and advice from parents who have children with autism from the first signs of this neurological development disorder, as well as the mystery behind the disorder. This study will provide other parents who have children with autism, family members, support groups, philanthropists and the medical workforce, as well as school personnel information useful for several purposes. Parents and other groups will become better informed how to

identify and deal with certain behaviors and characteristics of children with autism.

Autism

Autism is a complex disorder of brain development with a wide range of differences between individuals (Rao & Gagie, 2006; Tissot & Evans, 2003) that affects social interaction, communication skills (i.e., restriction in verbal and nonverbal communication), and unusual restrictive and repetitive behaviors (Mancil, 2006; Mancil & Boman, 2010; Moyson & Herbert, 2011; Robins & Dumont-Mathieu, 2006). This lifelong disorder impacts the way individuals communicate, process language, exhibit social skills, interact with others (Rao & Gagie, 2006), and the presence of repetitive and stereotyped interests (Hume, Loftin, & Lantz, 2009; Skokut, Robinson, Openden, & Jimerson, 2008).

Children with autism tend to exhibit problem behaviors due to their inability to communicate effectively (Durand, 1999; Mancil, 2006; Mancil & Boman, 2010; Moes & Frea, 2002). Hence, problem behaviors such as tantrums, screaming, and crying may be a form of communication for children with autism. Parents of children with autism find it challenging to determine the reason for problem behaviors because of communication barriers (Mancil, 2006; Mancil & Boman, 2010).

Statistics from the U.S. Centers for Disease Control and Prevention (CDC, 2013) reported that 1 in 88 American children have an Autism Spectrum Disorder; the prevalence has increased over the past 40 years. School-age children, 6-17 years of age, accounted for the increase in prevalence in or after 2008 (Blumberg, Bramlett, Kogan, Schieve, Jones, & Lu, 2013). With the alarming increase in prevalence, early detection of developmental disorders is critical to the well-being of children and their families. Autism spectrum disorder is a neurodevelopmental disorder that typically appears at three years of age and is characterized by

communication difficulties, repetitive and stereotypical patterns of behaviors, impaired social functioning, and cognitive impairments leading to life-long disability (Altiere & von Kluge, 2009; Hastings, Kovshoff, Brown, Ward, Espinosa, & Remington, 2005; Kleinman et al., 2008; Lyons, Leon, Phelps, & Dunleavy, 2010). While it is more common in males, autism spectrum disorder has affected males three times more than females at a rate of 1 out 54. In recent years, autism prevalence has increased 10% to 17% annually (Centers for Disease Control and Prevention, 2014).

Family Issues and Coping With Stress

Many families develop coping strategies as well as seek professional help and support. Individuals with autism have difficulty with the expressive language and with communicating effectively. Support services can be provided to teach children appropriate means of communication. In addition, children with autism find it difficult to develop relationships and have limited imagination particularly when it comes to playing with siblings and peers. Typically, developing siblings may not understand this aspect of autism and may feel rejected by their sibling. These emotions can hurt children's psychological state of mind.

Families face challenges raising a child with autism, and will continually throughout their life. Additionally, families experience myriad emotions with the challenges they encounter. Unless a person is a parent, sibling, or family member of an individual with autism, one cannot truly understand the quality of life of those being affected as they have daily continuous contact with the child. Families face the daunting task of forming a healthy bond and when dealing with the challenges of autism, this may feel as an impossibility.

Parental role. According to Tomeny, Barry, and Bader (2012), higher levels of maladjustment in siblings can be related to parental distress. Parenting a child with autism is an

extraordinary challenge and can be extremely stressful when dealing with outburst and/or meltdowns. The degree of the challenge may vary depending of the severity of the autism; however, the autism related issues are similar whether a child is severely impacted or has a high functioning ability. Nevertheless, parenting a child with autism can cause high levels of stress and depressions (Petalas et al., 2009). According to Smith and Elder (2010), higher stress levels in parents can be evident in typically developing siblings.

Becoming knowledgeable and proactive may help alleviate thoughts about parental competence. When parents cannot determine the need of their child with autism, this can cause frustration in both parent and child. Frustrations can lead to aggressive or self-injurious behaviors that threaten their safety and the safety of others. These challenges can be physically, mentally, and emotionally exhausting.

Research indicated that parents of children with autism experience higher levels of stress than parents of children with mental retardation, Down syndrome, and other developmental disorders (Donovan, 1988; Hasting, Kovshoff, Brown, Ward, Espinosa, & Remington, 2005; Lyons, Leon, Phelps, & Dunleavy, 2010; Mancil & Boman, 2010). Children with autism tend to exhibit problematic behaviors as a result of their inability to communicate effectively (Mancil & Boman, 2010). Parents of children with autism find it challenging to determine the reasons for problematic behaviors (i.e., tantrums, screaming, self-injurious behaviors, crying). Researchers have confirmed the presence of stress associated with caring for a child with autism (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009; Lyons et al., 2010). Coping strategies can essentially elevate high stress levels that can lead to depression (Hastings et al., 2005; Zablotsky, Bradshaw, & Stuart, 2013).

In a similar cross-sectional study, Hastings, Kovshoff, Brown, Ward, Espinosa, and

Remington (2005) examined four coping supports: (a) active avoidance coping; (b) problem-focused coping (e.g., problem-solving, seeking advice and support); (c) positive coping; and (d) religious-denial coping and found that parental coping varied with the age of the child with autism. Participants included 89 parents of preschool children (i.e., 41 male, 7 female) 37 months of age and 46 parents of school age children (i.e., 18 male, 8 female) with a mean age of 12.15 years. The procedure for data collection was different between the sample groups. Parents of school age children (Sample 1) and parents of preschool children (Sample 2) completed questionnaires of the Brief COPE and the well-being measures.

In a similar study conducted by Hastings et al. (2005), researchers indicated that families adapt successfully through the development of the child over time and/or through use of family coping strategies. According to Gray (2002), parents reported improvements in their own psychological well-being, the social experiences of immediate family members, and family relationships. A variety of factors such as increasing manageability of the child with autism, accessibility to appropriate services, and the increased coping abilities of the parents accounted for improvements (Gray, 2002). On the contrary, families with aggressive and/or violent children reported less favorable measures of psychological well-being. Higgins, Bailey, and Pearce (2005) opined that stress is attributed to the extreme antisocial and disruptive behaviors (i.e., self-injurious, tantrum, obsessive/compulsive behaviors). Gray revealed that parent perception on the level of service provisions provided was inadequate, which may have made problems worse. Under these circumstances, parents considered placing their child in a residential facility. Hastings et al. contended that the use of positive reframing of traumatic and stressful conditions might be the only effective coping supports under extreme crises.

In a qualitative longitudinal study of family coping and autism, Gray (2006) found that

copied supports changed from the time of the initial study (a decade ago), as fewer parents coped through reliance on service providers, family support, social withdrawal and individualism and religious, and other emotion-focused strategies. The sample group included 35 parents (i.e., 25 mothers, 10 fathers) and their children with autism (i.e., ages 4 to 19 years). The number of children with autism was 24 and included 16 males and 8 females, all of which lived at home except for two who had residential placements. Results of the study revealed that the number of coping strategies employed by parents declined and a shift toward higher emotion-focused means of coping developed over time.

Altiere and von Kluge (2009) reported higher levels of stress, which was attributed to a deterioration of social support. Research suggested that social supports are imperative for families with children with autism and is an integral piece of the coping milieu (Altiere & von Kluge, 2009; Gray, 2002). Mothers of children with autism reported more depression symptoms compared to fathers, which in turn contributed to increased levels of spousal problems (Altiere & von Kluge, 2009; Hastings et al., 2005). Furthermore, Altieri and von Kluge, and Hastings et al. (2005) reported that there are limited studies involving fathers, as they only account for 1% of the assessed population compared to 48% of mothers. According to Altieri and von Kluge, both mothers and fathers reported comparable scores for cohesion, adaptability, and satisfaction with family functioning, and family coping supports. On the contrary, mothers reported a high risk for somatic problems and depressive symptoms compared to fathers (Altiere & von Kluge, 2009). Likewise, mothers reported high levels of stress and psychological distress (Altiere & von Kluge, 2009; Estes et al., 2009). Mothers perceived more social support from family and friends compared to fathers. Altieri and von Kluge reported that fathers who participated in groups reduced their level of depression. In addition, it helped fathers mitigate use of avoidance

and withdrawal coping supports.

In addition, Lyons, Leon, Phelps, and Dunleavy (2010) reported on three coping supports: (a) task-oriented coping, (b) emotion-oriented coping, and (c) avoidance-oriented coping, which include social diversions and distraction, as well as four types of stress listed as (a) parent and family problems, (b) pessimism, (c) child characteristics, and (d) physical incapacity. Researchers suggested that task-oriented coping predicted lower physical incapacity scores, and emotion-oriented coping predicted more psychological distress and significantly less personal growth when autism symptoms were severe (Lyons, Leon, Phelps, & Dunleavy, 2010). Furthermore, problem-solving coping was associated with less psychological parental distress (Hastings et al., 2005; Lyons, Leon, Phelps, & Dunleavy, 2010).

Hastings et al. (2005) reported gender differences between mothers and fathers coping supports in association between coping supports and parental stress and mental health problems. According to Hastings et al., families coping supports vary, as family conditions are not homogeneous. Likewise, the frequency or intensities of using coping supports and parental stress varied between mothers and fathers. Mothers used more problem-focused coping supports and social supports compared to fathers. Researchers suggested that maternal stress levels were higher than fathers (Hastings et al., 2005). Positive coping was associated with lower levels of depression in both parents; in contrast, active avoidance coping produced stress or mental health problems, supporting the research of Altieri and von Kluge (2009). Furthermore, researchers suggested that religious coping might play a role in the adaptation of families of children with autism; however, more research is needed to support this finding (Hastings et al., 2005).

Higgins, Bailey, and Pearce (2005) surveyed parents in relation to general demographics, characteristics and behavioral characteristics of their child and support services available for

children with autism spectrum disorder and their families. This study investigated their perception about support services available for children with autism spectrum disorder and their families. The sample included 55 parents (i.e., 97% mothers, 3% fathers) of children with high functioning autism spectrum disorder exhibiting particular behaviors (e.g., fascinations with topics, people, or objects; repetitive behaviors; aggressive behaviors; repetitive talking about a topic; lack of eye contact in communication). Parents reported lower marital happiness, family adaptability and family cohesion, and that coping styles did not help with adjustment (Higgins, Bailey, & Pearce, 2005). Researchers suggested that emotional disturbance experienced by parents can cause psychological problems (e.g., depression, anxiety), higher divorce rate, and a sense of social isolation, as well as impacting families' lives in respect to recreational activities, finances, domestic responsibilities, emotional and mental health of parents, sibling relations, and relationships with extended family and friends.

According to Zablotsky, Bradshaw, and Stuart (2013), the presence of maternal and resilient coping supports reduced risks of poor mental health and high stress levels. Researchers suggested high stress levels could potentially cause emotional and psychological distress weakening the family unit (Zablotsky, Bradshaw, & Stuart, 2013). Participants included children with autism between the ages of 3 to 17 and mothers. The total sample size comprised of 56,547 individuals that included 1,014 individuals diagnosed with an autism spectrum disorder, 667 individuals who received a more current diagnosis, and their mothers. Zablotsky, Bradshaw, and Stuart (2013) found that lower socio-economic families and mothers of Black children reported higher levels of stress and mental health risks. In contrast, mothers of high socio-economic status reported low levels of stress and mental health risks. Furthermore, maternal mental health problems and high stress levels were attributed to an increase of autism complications

(Zablotsky, Bradshaw, & Stuart, 2013). Researchers supported the use of effective coping supports, and emotional and neighborhood social supports, which lowered the risk for stress and mental health problems, especially for mothers who had children with the greatest impairments (Zablotsky, Bradshaw, & Stuart, 2013). In this cross-sectional study, researchers reported that the severity of the autism was a strong predictor of stress for parents and the ability to deal with high stress relied on the effectiveness and quantity of coping strategies employed by parents (Estes et al., 2009; Lyons, Leon, Phelps, & Dunleavy, 2010; Zablotsky, Bradshaw, & Stuart, 2013).

Parenthood is a major life change in itself without even considering the trials and tribulations of raising a child with autism spectrum disorder. Dealing with the diagnosis of autism spectrum disorder may be one of the most difficult challenges for parents, siblings, and families (Higgins, Bailey, & Pearce, 2005). The road to an autism diagnosis can be a long process, which in turn, can be extremely stressful for many parents (Gray, 2002). Due to the variations of the symptoms exhibited in children with autism, the diagnosis presents unique challenges and stressors for the family because of the ambiguity of the diagnosis, duration of the disorder, problems with the low social functioning, and severity of autism (Altiere & von Kluge, 2009). The degree of which children are affected varies greatly, as no two children are the same.

Parenting children with autism poses high levels of stress on parents. Researchers reported that there are limited studies on the types of coping supports parents use (Hastings et al., 2005; Lyons, Leon, Phelps, & Dunleavy, 2010). Research on the severity of the autism was a strong predictor of stress for parents and psychological well-being (Lyons, Leon, Phelps, & Dunleavy, 2010). There is much debate on whether symptoms of autism or behaviors problems accounts for high levels of stress in parents of children with autism. According to Lyons, Leon,

Phelps, and Dunleavy (2010), emotion-oriented coping supports contributed to parent and family problems, which impacted family functioning, as well as to parental pessimism when autism symptoms were high. Higgins, Bailey, and Pearce (2005) suggested that disabilities have a negative impact on families and family functioning. Hence, children autism symptoms and behaviors are strong predictors of parental stress and the use of specific coping supports effect stress levels.

Increasing parent knowledge of the coping supports through educational programs can impact parental perceptions of their emotional well-being and family functioning (Samadi, McConkey, & Kelly, 2013). In addition, researchers reported on the impact of social supports on the emotional and mental well-being of parents with children with autism (Altiere & von Kluge, 2009; Gray, 2002; Hastings et al., 2005; Samadi, McConkey, & Kelly, 2013; Zablotzky, Bradshaw, & Stuart, 2013). Hastings et al. (2005) contended that social supports affect the development of effective coping strategies in parents of children with autism. In contrast, Samadi, McConkey, and Kelly (2012) found no correlation, indicating that there was not an associated decrease in parents' use of emotional coping strategies. Researchers found that the ability to deal with high stress levels lies in the effectiveness and quantity of the coping strategies that parents use for stress management (Zablotzky, Bradshaw, & Stuart, 2013).

Siblings role. Many times friends and acquaintances may not know the circumstances families endure and a feeling of embarrassment may set in. Unpredictable and unexplainable outbursts may cause embarrassment and stress for the typically developing sibling. However, typically developing siblings of children with autism are the furthest things from typical. These children are likely to be more compassionate, mature, and wiser than their age, given the multiple challenges they endure both socially and emotionally. There is growing recognition that

siblings play potentially important roles in contributing to each other's social, emotional, and cognitive development (Kaminsky & Dewey, 2001). Growing up with a sibling with autism or other special needs requires adjustment and can be an overwhelming experience (Hastings, 2003). Researchers reported in regard to sibling relationships and experiences of children with autism, the effects of autism on typically developing siblings, as well as support for siblings. Orsmond and Seltzer (2007) mentioned that there is no research on siblings of adults with autism; however, there is research on siblings of young children with autism.

Kaminsky and Dewey (2001) reported that typically developing siblings of children with autism were less nurturing than siblings of normally developing children. In addition, siblings of children with autism reported less quarreling, intimacy, competition, and prosocial behavior compared to normally developing children (Kaminsky & Dewey, 2001). Patalas, Hastings, Nash, Lloyd, and Dowey (2009) stated that siblings of children with autism are likely to present more psychological problems and an increased risk for externalizing problems and internalizing problems compared to siblings of children with other disabilities or individuals of typically developing siblings. Furthermore, it is common for these children to experience emotions, such as feeling isolated from friends and family members, confusion, fear, embarrassment, and anger.

Typically developing siblings experience a wide range of emotions and in turn, become affected both negatively and positively (Aksoy, 2008; Brewton, Nowell, Lasala, & Goin-Kochel, 2012; Hastings, 2003; Patalas, Hastings, Nash, Lloyd, & Dowey, 2009; Orsmond & Seltzer, 2007). Acknowledging that these emotions are normal can help alleviate negative thoughts and behaviors in non-disabled siblings (Aksoy, 2008; Tomeny, Barry, & Bader, 2012). However, this is not the norm. Families may require other strategies for improving the relationship among their children.

In respect to children with autism, visibility of this disorder is difficult to observe making this more difficult for a non-disabled peer to cope. Non-disabled siblings may find it challenging to understand their differences and may feel responsible for their sibling as well as they may feel neglected by their parents (Aksoy, 2008). It is essential for typically developing children of siblings with autism to get appropriate support in order to help them overcome these challenges. Appropriate interventions can provide children the essential tools for improving social interaction. Children with autism benefit from an environment that accepts them for who they are and that is supportive. Furthermore, most children with autism will require significant lifelong support in everyday activities.

Smith and Elder (2010) felt that sibling of children with autism exhibit a variety of adjustment and coping difficulties, as well as impaired intimate relationships with their sibling. Smith and Elder reported positive results when siblings taught their younger sibling with autism. The findings resulted in fewer behavior problems of the typically developing siblings. Emotional and psychological wellbeing of these typically developing siblings also improved as reported in research (Petalas, Hastings, Nash, Lloyd, & Dowey, 2009; Smith & Elder, 2010).

According to Osmond, Kuo, and Seltzer (2009), females of siblings reported more positive affect in their sibling relationship when their sibling had fewer behavioral problems. In the account given by Coyle (2010), there was evidence that her sibling had a positive effect on her life as an adult. In addition, Osmond et al. reported that adults accepted their sibling's disability more so as adults than as children; this was the case for Coyle. Osmond et al. claimed that adult siblings who used more problem-focused coping strategies reported a closer relationship with their sibling with autism. It is plausible that this may have been a coping strategy utilized by Coyle.

Hodapp and Urbano (2007) reported that siblings of adults with autism displayed less contacts and less close relationships with siblings 45 years and older. Additionally, closer sibling relationships were evident in siblings who had more frequent contacts and with siblings who were capable of maintaining friendships and who had lower levels of behavioral and emotional problems, and with siblings who felt more rewarded for having a sibling with autism (Hodapp & Urbano, 2007).

According to Hodapp and Urbano (2007), age and interaction between siblings made an influence on their relationship. These variables as well as others can influence relationships between siblings. Tomeny et al. (2012) declared that siblings may exhibit problems with low prosocial behaviors, peer problems, and increased internalizing and externalizing behaviors. There is no doubt that autism places family members at higher risk for psychological difficulties. The impact of autism on typically developing siblings has not been explored as far as the relation to psychosocial and emotional adjustment on siblings (Macks & Reeve, 2007; Smith & Elder, 2010). According to Macks and Reeve (2007), there were inconsistencies in research. For example, in two studies, Mates (1990) and Ferrari (1984) reported that typically developing siblings are well-adjusted, with positive self-concepts, and good social competences.

The impact on the sibling of a child with autism has been well documented by the researchers aforementioned. According to Aksoy (2008), the type of disability played a major role in attitudes and the concept of self in the typical siblings as well as the degree of disability had significance in attitudes. Although siblings have a lifelong relationship, developmental changes were reported in the research conducted by Aksoy. Problems with social interaction may arise; siblings may experience a vast range of emotions such as anger, hostility, jealousy, guilt, anxiety, fear, shame distress and rejection, and depression. Being that children with

siblings with autism are vulnerable, children will benefit from support services. In addition, the challenges they face will carry on in the life course.

With the growing recognition that siblings play potentially important roles in contributing to each other's social, emotional, and cognitive development, sibling relations carry over in the course of life after their parents are unable to care for them (Kaminsky & Dewey, 2001). Growing up with a sibling with autism requires adjustment and can take a toll on their psychological and emotional wellbeing (Hastings, 2003). With the number of challenges faced by families, it is clear that support is essential and must be implemented early on. Siblings are an important part of the family and further research must be done to investigate this topic further (Hastings, 2003).

Tsao and Davenport (2012) opined there is limited empirical research on support provided by typically developing siblings; however, siblings can help improve positive and mutually satisfying relationships. Tsao and Davenport reported that by observing siblings' communication with one another, they could learn about social interaction and relationships. In addition, typically developing siblings have the ability to influence children with autism making them effective intervention partners.

In education, early intervention is paramount to success and implementation of strategies which can potentially yield great benefits for siblings with autism and typically developing siblings. Maintaining positive relationships can benefit both typically developing siblings and individuals with autism. Kaminsky and Dewey (2001) specified this can provide an individual with social support that can lower behavioral problems, loneliness, and higher self-worth.

Having a child with autism can affect the emotional well-being of family members. Parents must utilize support services and training before reaching high level of frustration or

other negative feeling. Support services can provide parents the tools for enhancing children's social competencies. Tsao and Davenport (2012) commented that supports enhance children chances of growing into emotionally and psychologically healthy adults.

Methodology

The constructivist worldview is associated with qualitative research to understand a phenomenon by developing themes and patterns, and finally, a theory. Basic elements of constructivism are understanding, multiple participant meanings, social and historical construction, and theory generation. Creswell (2014) explained this worldview helps people seek understanding in their environment and the meaning of their experiences. An example for this worldview is quite simple and actually a great method to gain peoples' experiences and meanings with consideration of social and historical aspects of the problem to construct explanations of the phenomenon under study. The researchers conducted a phenomenological study by developing a group of questions for the participants to share their experiences. After transcribing the interview, the researchers conducted a second interview with the participants to review their interview, and then were asked a closing question to obtain the meaning of their experiences. This final question asked what advice they would give another person who experienced similar events.

Phenomenological Method

This qualitative study examined the experiences that parents encountered while raising a child with autism. Using a phenomenological approach and design, the researchers wanted to gain a better understanding how the participants managed their sometimes conflicting, sometimes overlapping, and sometimes unique experiences as parents who have children with autism. According to many methodologists, this type of design can explain to researchers on the

central phenomena that are being studied (Creswell, Hanson, Plano Clark, & Morales, 2007; Lester, 1999; Moustakas, 1994; Smith, Flowers, & Larkin, 2012). The participants were interviewed and recorded via a digital recorder; the data was transcribed verbatim and verified using member checks. The researchers coded the transcripts and synthesized identified themes and shared experiences from the collection. By looking at the unique perspective these individuals brought to the body of research, the researchers hoped to understand their experiences and advice-recommendations they may offer to other parents who have children with autism, as well as other researchers. The researchers also wanted to gain the positive and negative aspects of their experiences, and the growing traits and characteristics of children who are diagnosed with autism spectrum disorder.

Sample Strategy

In this study, the researchers gained an insight to parents' experiences with raising a child with autism spectrum disorder as well as understood the coping strategies used by parents. The target population of parents resulted from networking at conferences and workshops who shared a commonality of attending professional development opportunities and continuing learning about Autism Spectrum Disorder. The selection of the six participants was important to consider in the data collection process. The preliminary stage of selecting the parents focused on understanding the participants' perceptions about *Autism Spectrum Disorder*. The participants provided insight to uncover the phenomenon of being a parent to a child with autism spectrum disorder through delving into their experiences (see table). Glesne (2011) described the sampling selection as, "The strategy of participant selection in qualitative inquiry rests on the multiple purposes of illuminating, interpreting, and understanding-and on your own imagination and judgment" (p. 46).

Table

Demographics of Parents and Their Children

Parent(s)	Race	Age	Child	Age	Grade level
Mother/father	White	37/36	Boy	11	6th
Mother	White	42	Boy	8	2nd
Mother	White	49	Boy	16	10th
Father	White	34	Boy	7	2nd
Mother	Latin	34	Boy	7	2nd
Mother	White	51	Boy	17	12th

The purpose of the study was to look at individual's experience with personal insight as a parent with a child diagnosed with autism spectrum disorder; thus, leading to a purposive sampling strategy (Creswell, 2013; Edmonds & Kennedy, 2013; Glesne, 2011). The target population was composed of a purposive homogeneous sample (Glesne, 2011; Smith, Flowers, & Larkin, 2012). The individuals were selected based on past involvement with professional development and familiarity with the researcher. Having selected participants who have a relationship with the researchers, Holstein and Gubrium (2003) stated "if participants come to trust in the sincerity and the motivation of the interviewer, they may be prepared to share in-depth insights into their private and social worlds" (p. 251). The homogeneity of the population consisted of parents who have children with autism spectrum disorder. Since the contact information was obtained through professional contacts and conferences, a *snowball sampling* (i.e., directly recruiting for the study) found participants beyond the existing social network of

parents who have children with autism.

Design

A qualitative study is an appropriate research design to study participants' experiences of having children with autism spectrum disorder, and examine common themes from the data. To better delve into the lived experiences of the participants and to hone in on the essence of children who are diagnosed with autism spectrum disorder is most appropriate. From the qualitative method approach, the researchers conducted personal interviews with individual parents to explore "the meaning, composition, and core of the lived experience of specific phenomena" (Edmonds & Kennedy, 2013, p. 136). The significance of the lived experiences is to develop an understanding about the phenomenon of children diagnosed with autism spectrum disorder (Creswell, 2014). This information was collected and analyzed to find the challenges and issues parents face with their autistic children.

Procedures and Trustworthiness

The procedures for this study were to gather qualitative data from interviews of parents who have children diagnosed with autism spectrum disorder. For this qualitative research project, it was vital that the researchers validated the data. One process that these researchers conducted was to include a panel of experts to review the interview protocol questions. The selection of this panel was based on their experiences of teaching, mentoring, and advising parents about autism spectrum disorder. The interview protocol of six open-ended questions was given to this panel of experts in the field of autism spectrum disorder to review and verify the questions. After the panel felt the line of questions elicited parents' lived experiences of having children with autism spectrum disorder, they determined there was no reason to make changes. Once the panel of experts agreed upon the questions, the interview protocol was pilot tested by

the researchers. Member checking was conducted to confirm the interview data. The interview data, once transcribed was given to participants to review to make additions and/or deletions. Glesne (2011) commented that member checking allows the researcher “to look for accuracy in the representation of the participants’ ideas and beliefs during the interviews” (p. 15).

Data Collection

The collection of the data consisted of gathering qualitative one-on-one interview data from parents who have children with autism spectrum disorder using the interview protocol questions that explored their perceptions regarding their child’s behaviors. The interview protocol gathered perceptual data from the participants by asking six open-ended questions about their experiences of having children with autism spectrum disorder. The researchers selected an unstructured open-ended interview approach so that the participants could “best voice their experiences unconstrained by any perspectives of the researcher or past research findings” (Creswell, 2012, p. 218). Additionally, the researchers employed a one-on-one type of interview, a popular approach in educational research in which the researchers “asks questions to and records answers from only one participant in a study at a time” as they will “articulate,” “not hesitant to speak,” and “can share ideas comfortably” (Creswell, 2012, p. 218). To conduct the interview with the parents, the researchers identified interviewees which would be parents who are eligible to participate in the study using homogeneous purposive sampling strategy. Specifically, only parents who have children with autism spectrum disorder will be participants in this study.

Findings

The findings that occurred for this research was based on the researchers’ initial examination in which themes were developed for each parent who had a child with autism. After

analyzing these individual themes for these parents, the researchers then begin developing themes from a collective perspective. There is not one correct manner in which an interpretive phenomenological analysis should be conducted (Smith, Flower, & Larkin, 2012). Therefore, the researchers decided to look at each individual parent and before discussing emergent themes across the group of participants. The following interview protocol questions assisted the researchers to obtain experiences and meanings of having a child with autism spectrum disorder:

1. Would you please take a little time to share your personal thoughts on autism?
2. How would you describe your experiences as a parent who has a child with autism?
3. Can you talk about your experiences with the “challenges” you encounter as a parent?
4. There is a lot of research and medical opinion of a child with autism; what do you feel is the “mystery” of how children are diagnosed with autism.
5. Based on your personal experiences, if you were going to give advice to another parent who has a child with autism, what would you say?
6. Is there anything that I did not ask you that you would like to share with me?

After a careful analysis was conducted across participant responses, a total of 5 emergent themes were identified. The following is a breakdown of emergent themes for each of the research questions.

Research Question 1. What are some challenges for parents who have children with autism spectrum disorder? Some of the themes and challenges that parents had were the thought of their child being bullied and evidence that their child would face experiences of bullying at school and in the neighborhood. Another common theme that 5 out of 6 parents mentioned was how other people did not know how to communicate with the children who were diagnosed with autism spectrum disorder as well as their negative perception of the diagnosis. Whereas, a 2 out

of 6 of parents reported that their children prefer engaging in conversations with adults. These children would engage in deep conversations about their special interests (e.g., Minecraft).

Three out of six parents reported that keeping family members in the loop, so to speak, either helped their situation or hurt it. The parents, whose family members were not receptive of the diagnosis, found it challenging to communicate their needs as well as expressed their fears openly as family member had no understanding of their child's disability and passed judgment on their parenting skills.

Parents feeling of despair and helplessness and not having the proper care needed to help their child live a meaningful life was a common theme shared by 4 out of 6 parents. The majority of the parents (i.e., 5 out of 6) felt that support groups were the best outlets to cope with these challenges and to learn more about the disorder itself. These support groups would not just be a platform to discuss personal issues; it was more of an informative gathering because people were sharing research, strategies, and techniques to assist the child with daily functioning skills.

Parents felt that support groups opened many doors providing opportunities to children and families; something that parents felt they did not have access too on their own. Networking was a common theme parents were in search of.

Parents reported that they were not receiving the correct information or the proper care so they took it upon themselves to individually research this disorder. A common theme was that all parents (i.e., 6 out of 6) resorted to their own research subsequently when they attended these support groups made of parents of children with autism; they too were experts. This resulted in support groups as being a pseudo professional seminar. Five out of six parents reported the lack of information given by their health care practitioner. Parents did not know what interventions were available to them, which ultimately increased stress levels in some parents. Some parents

even admitted to being on medication to help them cope with the daily stresses of raising a child with autism.

Four out of six parents felt that the schools were not providing proper interventions to meet their child's needs. Parents understand that because of the lack of funds in public school education programs, their children were given the minimal service based on their Individual Education Program (IEP). A few parents reported that schools were not accepting a diagnosis from their medical doctors (e.g., neurologists). One parent reported that she felt like they "didn't want to hear it." She recounted the conversation she had with the Exceptional Student Education coordinator who stated, "we really don't tend to a diagnosis, we tend to the symptoms." This parent explained that her child was initially identified as Developmentally Delay. Once he turned 6 years of age, the diagnosis went away; however, his behaviors continued to impede learning. The parent explained that he no longer had an IEP and was waiting on a psychological evaluation, which "takes a long time for someone to come in and do an evaluation."

Safety was a major concern and challenge for a 3 out of 6 parents. One parent described how her child left the home early one morning, at age two, and was found walking down the road away from their home. One of the biggest challenges one parent expressed was her son being misunderstood and judged, as she stated, "nobody really understand what Asperger's is." A couple of parents expressed that they did not see eye to eye with their ex-spouse. One parent explained how the child's father refused to meet with the teachers to explain their son's "challenges and diagnosis." This parent claimed that the child's father was in denial. This was also a common theme shared by two other parents.

Research Question 2. What is the mystery behind children who are diagnosed with autism spectrum disorder? A major theme that evolved was parents not knowing initially what

“was wrong” with their child. Parents were unaware their child had autism; however, they knew something was different about their child. One theme that transpired was the feeling parents had receiving incorrect or no diagnosis. Three out of six parents expressed their concern after receiving a diagnosis for their children and stated it was out of their control (i.e., overwhelmed with a sense of helplessness) because they trusted the expertise of the doctors. This alone, caused stress and anxiety in the families, as most doctors disregarded parents’ concerns and felt that their child was developing like any other child. One parent claimed “it would be easy if we could go to a doctor, draw blood, and come up with a diagnosis. It wasn’t that easy.” Five out of six parents reported that doctors felt the parents were overreacting and that they should wait and see before placing a label on their child.

Three parents reported that life would be easier if they had the answers to their child’s mystery and why they showed unusual behaviors compared to siblings and peers. Another theme was the sense of urgency in getting the proper diagnosis as parents felt stress and strain on the family dynamics. Parents reported that doctors who lacked awareness of the neurological disorder would dismiss their concerns and see that nothing was wrong with the child. One parent reported that she felt it could stem from vaccinations, as infants are administered “six shots in a row when he was a half-year-old.” To give you a scientific reason why we have autism, one parent claimed she could not. Her primary concern was to “focus my time on what to do about it.” One parent felt that autism stemmed from “your genetic line, something in the food, and the environment.” “Things are getting worse,” as one parent attested. Three parents felt that something in the water could be causing autism or an herbicide that is being sprayed on vegetables causing a rise in autism.

A question that was raised was “why are more boys being affected with autism than girls

and why does it happen multiple times in some families.” Some parents felt that things were being added to food and vaccinations and that today’s children are being given more vaccinations than before and big companies are pumping money into vaccinations. Another theme that evolved was how parents would do anything to get their child the help they needed; however, felt the strain while looking for answers and a diagnosis, and felt that they were fighting a battle on their own. Parents reported that the diagnosis was essential piece to initiate healthcare services for their child. Four parents reported that as long as they get a diagnosis, they would take the necessary actions needed for seeking appropriate care for their child with autism. Four parents expressed the following theme, “give me a diagnosis and I will do whatever it takes to get my child the help he needs.” Parents trusted their instinct and went from doctor to doctor until they found one that would listen to their concerns and refer their child to appropriate specialists for diagnosis.

Three parents reported that compared to a few years ago, pediatricians were unfamiliar with diagnosing autism and sometimes dismissed their concerns, delaying diagnosis and the opportunity for early intervention therapies. Today, there seems to be a better understanding of autism compared to 15 years ago. Another theme was the need to raise awareness of early signs among physicians. Four of the six parents reported when children are screened for developmental milestones during routine well visits their voices should be heard. Most times pediatrician dismissed parents’ concerns making it out as if they were overreacting; a trait new parents display. Because of this, parents felt that the doctor should listen more and refer the child to a developmental pediatrician who specializes in evaluations and early intervention.

Some parents reported that at first they put all the trust in their children’s doctor; however, when issues worsened, parents would take matters into their own hands to seek help

from other healthcare practitioners such as psychologists, speech and language pathologists, and occupational therapists. Autism is a brain development disorder, as one parent explained. Autism affects children differently; they can range from mild to severe. With a heightened awareness compared to 10 years ago; autism is being identified sooner than later, both privately and in the academic setting. This could be the reason for more children being diagnosed. Nevertheless, there are also changes in our environment and foods we consume that could comprise children's overall health including brain development. Although through the interviews there seems to be common themes of the challenges that parents face. The reason that the researchers determined this was based on the responses of the parents claiming that there is some sort of mystery behind this disorder. Along with the challenges, regardless of their understanding of a diagnosis, the mystery is more of an overwhelming experience.

Research Question 3. What advice would other parents gain from the experiences of parents who have children with autism spectrum disorder? Several parents shared some miscellaneous thoughts regarding their relations with their child with autism spectrum disorder. They felt that they would never change the characteristics, mannerism, and "quirkiness" to have a "normal child" and to "love them for who they are and not for what you decide they should be." Most parents are in denial and want to change their kids and still having a difficult time with this. The parents felt that their children were little scientist, savants, and they would not trade their child in. For those children who had typical siblings, some had functional relationships while some did not. Not all children with autism had siblings, whereas some did. Although parents stated that some of their children had differences growing up with their siblings, even in a normal functioning families, parents advised that it was a family effort to provide support to the child with autism and not alienate the child from their siblings. Typical

developing siblings also go through emotional distress and coping patterns. They have difficulty communicate with their sibling with autism and this alone warrants family counseling and support services. Modeling positive, supportive behaviors is vital for sibling to see reported one mother. Children will notice parents' emotions and it is how parents cope with stressors as it can have a negative or positive impact on the family dynamics.

Some of the mothers reported how they coped differently compared to the fathers of the children with autism. One father credited his spouse for handling daily "ups and downs" of their child's explosive behaviors. He felt that he had difficulty with handling the behaviors and that she seemed more effective with defusing the behaviors. He resorted to removing himself at times, which was his coping mechanism. Understanding autism and talking to other parents to share experiences is advice that most parents provided. Five of the parents seemed in tuned to their child, as most were younger. On the other hand, one of the parents explained how at times he did not understand his son's autism due to the fact how it varied. Five of the parents seemed heavily involved with their child and getting the help they required. One parent was not involved in getting the help for their child with autism. He relied on his spouse for making appointments to see a trained psychologist. This was the only family in the study whose child was aggressive and had severe behaviors.

Most parents advised parents to do their own research to educate you and loved ones. Two parents stressed the importance of taking care of yourself if you are the parent of a child with autism, as raising a child with autism can be taxing on one's mental health. "Be patient, find people in your life to support you whether it is a spouse, friend, parent, other child, or any other support group. Parents need an outlet, someone to talk to." One mother admitted to not telling her family and friends of his son's diagnosis. She did not want people to cast judgment

on him and felt a need to protect him from people's negative perspective on autism. She felt that from her experience, she did not want people to put her son's diagnosis before him and say that it is the autism that is making him the way he is (i.e., aggressive, noncompliant). Five of the six parents advised other parents that they should take advantage of any services that they can receive for their child and not attempt to hide the diagnosis from friends and family. Talking to other parents and learning about services was another common theme that was established by all parents in this study.

Recommendations and Conclusion

Researchers may contemplate on replicating this study worldwide and within different cultures as this phenomenon of autism spectrum disorder occurs in more nation-states, not only in the United States. Therefore, additional exploration into the background that assists parents and others who have children with autism spectrum disorder merits study. As a result of the findings of this study, there are several recommendations to be made regarding best practices and considerations to parents on learn how to cope with stress and build a stronger family unit and assist with meeting the needs of their child who is diagnosed with autism spectrum disorder. These recommendations are made in hopes to enlighten parents and other stakeholders to what can be done to initiate positive changes and outcomes and how to positively confront this diagnosis of autism spectrum disorder.

The findings of this study supported the following recommendations for future research: (a) the need for both parents to become involved with counseling, study groups, support groups, and self-help therapy; (b) to be open minded to listening to many people, doctors, psychologists, and other parents; (c) the need for parents to talk with their child with ASD and their other children; (d) the need to learn, just like any situation occurring with a family, and not be

blindsided by the diagnosis; (e) do not hide this disorder from your family and friends; (f) seek professional and family support to make the family dynamics work to reduce stress; and (g) learn how to cope with family stressors.

Other recommendations would be to (a) utilize other qualitative methodologies to conduct case studies or another phenomenological approach, but with the siblings of children with ASD; (b) administer quantitative surveys regarding the divorce rate among parents who have children with ASD; (c) research studies regarding environmental impacts; (d) analyze how men and women differ in handling stress; (e) analyze diverse families of children with ASD; and (f) research how to improve relationships for families who are involved with children with ASD.

Two of the six parents did have a concern for their child's future when they planned to attend college. The parents felt that their children would not adjust to college life easily as well as living on their own. They expressed multiple fears of (a) their child not advocating for themselves at the college level, (b) not making friends or being accepted in social groups, (c) being alienated academically, and (d) not having the wittiness to ask for help when needed or who to ask for help. While attending a conference regarding qualitative research, the topic of self-determination was discussed as students who have intellectual disabilities have a need for independence, interconnectedness, and internal locus of control. In Wiorkowski's (2015) phenomenological study, eight questions were asked of the participants who attended higher education. These questions asked the experiences of students with ASD in higher education; the questions were asked to describe their social and academic experiences as well as their interactions with employees of the university. Based on Wiorkowski's study, a suggestion for future study would be a longitudinal study to follow a child with ASD from high school through college.

One thing that can be determined is that parents who have children with ASD are trying to learn about the disorder, help their child, develop a cohesive family, reduce stress, and educate the public to include family and friends. This challenge becomes greater when there are unanswered questions and not enough research. No matter the situation, parents need not give up the fight to find the cure of autism spectrum disorder. In order to achieve this, everyone must reflect regarding what is working and what is not for ASD. It begins by listening to the medical experts, the researchers, the parents, and other contributors when making critical decisions regarding autism spectrum disorder.

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