Stress Levels and Development: A Phenomenology of Autistic Children and Their Parents

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Abstract

Being a parent means taking on both the joys and struggles that come with it. When a parent discovers that his or her child has been diagnosed with autism spectrum disorder (ASD), the level of stress changes. It could be helpful to discover the severity of change that the stresses involved in parenting a child with ASD brings to the parent/child relationship and what effect this has on a child's physical, cognitive, emotional, and spiritual development. To attempt to answer these questions, six parents were interviewed. Findings suggested that structure in daily living improves the quality of the child/parent relationship as well as stress relief to the parent.

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Parents

A Study of Autism Spectrum Disorders

About Autism Spectrum Disorders (ASD)

Symptoms. The number of children that have been diagnosed with Autism Spectrum Disorder (ASD) has increased and is continuing to do so at a rapid rate (Pottie & Ingram, 2008). The Center for Disease Control and Prevention (CDC, 2010) currently estimates that about 1 in 110 children in the United States have an ASD. ASDs also appear to be diagnosed in at least 1 in 600 individuals, of all age, and about 1 in 200 children show at least some symptoms of it. It has been described as a social disorder in which an individual has severe and pervasive impairments in the development of social interaction (Rutgers et al., 2007). These types of disorders are also defined as a group marked by unusual communications and inappropriate responses to stimuli in the environment (Comer, 2008). Its symptoms may begin to show before the age of 3. Parents may notice their infant or young toddler exhibiting a loss of focus, lack of eye contact, repetitive behaviors, rigidity, and/or delayed motor abilities. (Boyd, McBee, Holtzclaw, Baranek, & Bodfish, 2009; Dubin & Graetz, 2009). These symptoms are what distinguish a child with autism from a neurotypical, or normally developing child (Broderick & Ne'eman, 2008). Once a parent or guardian has recognized some of these symptoms, the child is typically taken in for an assessment, which is often followed by a diagnosis.

Jenkins (2007) described autism this way:

Imagine what it's like. A person smiles at you—you're confused because you don't understand a smile. You can't get your usual breakfast cereal—your whole day is in disarray because you can't cope with your routine being upset. And someone tells you to pull your socks up. But you know you're not wearing socks, and it's very bewildering. (p.1)

Diagnoses. An ASD is usually diagnosed in individuals around the age of 3 or 4 years old and has a variety of possible diagnoses. The ASDs are autistic disorder (or autism), Asperger's syndrome, and pervasive developmental disorder.

Autistic disorder is characterized by impairments in the areas of social interaction and communication. Individuals with this disorder typically express repetitive behaviors and abnormal behavior patterns. However, individuals with Asperger's syndrome show some autistic behaviors including delayed motor abilities and very literal interpretations. However, individuals with this disorder may have an advanced vocabulary while exhibiting difficulty socially interacting with others (Dubin & Graetz, 2009). Pervasive developmental disorder is diagnosed when symptoms of autism are present but do not meet the criteria to qualify the child as having autistic disorder (King, 2009). These disorders, until recently, have always been considered to be childhood disorders. However, more recent research has found that these disorders persist through childhood, adolescence, and even adulthood (Matson & Shoemaker, 2009).

Causes. The cause of autism is currently unknown, creating controversy on the topic. Theorists initially believed that autism is caused by family dysfunction and social stress (Comer, 2008). However, research has shown that stress and dysfunction alone

cannot cause a disorder as complex as autism (HHS, 2009). There are multiple opinions regarding possible causes including vaccinations and genetics.

Vaccinations. A possible link between autism and childhood vaccinations is popular and controversial. However, scientific studies have not conclusively identified the links between autism and either thimerosal-containing vaccines or the measles, mumps, and rubella vaccine. The debate over this topic is controversial because the link between ASD and childhood vaccinations is very unclear. However, research has found the link between autism and childhood vaccinations to be correlational (Wakefield, 1999). The number of autism cases has increased over the past several decades. However, it is not clear whether or not this is due to an actual increase in the appearance of the disorder, an increase in awareness, or differences in the methods used to assess prevalence of the disorder (Miller & Reynolds, 2009).

Genetics. The study of biological causes of Autism is still under research. However, it has been found that there is an increased risk for siblings of those with ASD to also manifest the disorder (Aneja & Tierney, 2008). The National Institute of Health (HHS, 2009) suggested that the genetic link to autism is complicated and stated that, "In most cases, it's likely that each gene contributes a small amount of risk, and interacts with other genes and environmental factors to trigger the onset of the disease." (p. 1)

Cures and treatments. Although there is currently no defined cure for autism, there are many kinds of treatments available. There is a great need for intervention among children diagnosed with ASD. Although there are many interventions currently being used and developed, there is still a need for more. One type of treatment is a classroom-based antecedent intervention in which the child is given structured

opportunities to use preferred leisure activities (Sigafoos, Green, Payne, O'Reilly, & Lancioni, 2009). The symptom that is given attention by this type of treatment is obsessive-repetitive behavior. Some current therapies use evidence-based medicine. This emphasizes the areas of information processing, neural connectivity, and organization. The developers of these types of treatment believe that autism is defined as a biological disorder, with a focus on the genetics, neurochemistry and neuroanatomy areas in autism (Zimmerman, 2008). The most common treatment program used for autism is called Applied Behavior Analysis (ABA). Many families choose to use a combination of treatments with this program, including auditory integration, diet, facilitated communication, and sensory integration (Schreck & Mazur, 2008). B.F. Skinner formulated the concept of behavior analysis. The idea of positive reinforcement for a behavior is often used. The main goal of therapies for individuals with autism is to assist the autistic individual in functioning independently and in all types of environments (*Be Informed*, 2010).

Some other types of treatments that are popular today are gluten-free casein-free diet (GFCF), occupational therapy, sensory integration therapy, speech therapy, verbal behavior intervention, floor time, relationship development intervention, Picture Exchange Communication System (PECS), Social Communication/ Emotional Regulation/ Transactional Support (SCERTS), and Training and Education of Autistic Related Communication Handicapped Children (TEACCH). Floor time is when the parent or mentor meets the child where they are at physically and socially, follows his or her lead, and gets involved with the child's activities. It is as if the parent is trying to get into the child's world and understand it from his or her point of view. Those who choose

8

to put their child on a gluten-free casein-free diet keep a focus on the fiber and vitamin intake in his or her diet. Occupational therapy focuses on social play and functioning. Some of the areas of development that are given particular attention with this therapy are coping skills, fine motor skills, play skills, self-help skills, and social skills. These therapies are all techniques that are sometimes used in the assistance of a child's proper development and social advancement (Autism Speaks Inc., 2010). Research has also found that about 50 percent of children with autism use treatments including vitamin supplements, magnesium, gastrointestinal medications, antifungal agents, vitamin C, secretin, chelatoin, immunoglobins, large doses of vitamin A, antibiotics, antiviral agents, alkaline salts, withholding immunizations, auditory integration training, interactive metronome, craniosacral manipulation, and facilitated communication (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003).

Intervention for a child with autism is imperative and most effective when done as early as possible into the child's diagnosis (Goin, 2003). This has been shown to promote further progress in a child with autism. Some of the aspects of the child's development that may be positively affected by early intervention and therapy are intelligence quotient (IQ) score and improvement in cognitive, language, and adaptive behaviors. Even with such early intervention only approximately fifteen percent of individuals with ASD are self-sufficient as adults (Bopp, Mirenda, & Zumbo, 2009). It is especially difficult to find the most effective therapy for a child with autism, because there are so many available and each individual with autism is unique, having multitudes of sensory needs that are characteristic of that individual.

Areas of development

Physical. The motor skills of children with autism are unusual. Some examples of these are jumping, flapping arms, twisting hand and fingers, rocking, spinning, and making face. Children with this disorder participate in such acts because it is selfsoothing. These children grow to be dependent on these self-stimulatory behaviors. There are also self-injurious behaviors. Children use these behaviors in the same way, except that they are harmful behaviors. Examples of this behavior include banging of the head against a wall or piece of furniture, pulling of the hair, or biting of one's own self. Research has found that there may be a disturbed and contradictory pattern of reactions to stimuli in children with autism (Clark, Winkielman, & McIntosh, 2008). Reactions to different stimuli may produce dramatic results such as losing control when hearing a hum from an overhead lamp. They may start throwing objects in the area, kicking, and/or screaming. These socially inappropriate actions make it difficult for the individual to make friends, keep jobs, or try to live a normal lifestyle (Comer, 2008). An individual with an ASD may also be literal beings, which also makes it difficult to communicate in a socially appropriate manner (Dubin & Graetz, 2009).

Sensory processing patterns in children with this disorder differ from other children. Sensory processing relates to a neurological function that processes and organizes sensation from one's own body and the environment. Sensory integration is when inputs being processed in specialized areas in the brain from different sensory organs communicate in these specialized areas. Sensory integration is needed for sensory processing (Cheung & Siu, 2009). This communication is a key to clinical assessment of children with developmental disorders, such as ASD. Children with autism have a

miscommunication between these areas, affecting their sensory processing and disturbing the five senses. For example, research has shown that children with ASD are more likely to have oral sensory processing challenges including the smelling or licking of uneatable objects, olfactory hypersensitivity, and being sensitive to textures of foods (Cheung & Siu, 2009).

Another important aspect of physical development is nutrition. Many individuals with autism have restricted diets as a result of their obsessive behavior and desire for routine. This is described as repetitive food choice. The most popular diet plan used for individuals with autism is a Gluten-Free Casein-Free (GFCF) diet. Gluten is found in wheat and other grass-related grains and cereals and Casein is found in dairy products. GFCF diets have been found to improve development in individuals with autism (Knivsberg, Reichelt, Hoien, & Nodland, 2002). However, another study found that the GFCF diet neither negatively affects one's nutrient intake nor does it significantly improve it (Cornish, 2002).

Cognitive. Some individuals with an ASD have delayed cognitive development. However, the 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) shows that there is no clinically significant delay in cognitive development in those with Asperger's Syndrome. Research does suggest that symptoms of this disorder may relate to an abnormality in cognitive development (Dubin & Graetz, 2009).

One major inhibiting symptom of autism is its tendency to be coupled with obsessive-compulsive behaviors. One example of this type of behavior is the obsessive rearrangement of furniture or objects (Sigafoos, Green, Payne, O'Reilly, & Lancioni, 2009). Individuals with autism spectrum disorder have difficulty focusing or

concentrating on relevant activities or people. It is easy for an autistic individual to be distracted. This can take a toll on their social life as well as their academic career. Research has found that such inattentiveness may possibly result in delayed language development over time (Bopp, Mirenda, & Zumbo, 2009). One study stated that about half of all cases of this disorder fail to speak or develop language skills at all (Comer, 2008). However, another study (Attwood, 1998) found that individuals with Asperger's syndrome are able to develop speech and speak fluently by the age of five.

Although some individuals may eventually develop phonology and grammar similar to neurotypical children, they may still struggle with language pragmatics (Tager-Flusberg et al., 2005). A common language disability in these children is echolalia, when a person repeats exacts words and tones spoken by others. However, there is generally no understanding of the words. Dubin (2009) described echolalia as a form of scripting for some individuals with an ASD. It may be used in order to have control over the flow of conversation in an attempt to avoid spontaneous interaction, which may in turn alleviate some anxiety for him or her. There is special difficulty in naming objects, using abstract language, using the proper tone when talking, speaking spontaneously, using language for conversations, and understanding speech (Siller, 2008). This makes it especially difficult for children with autism to make friends.

Emotional. Children with autism have a lack of social competence (Brim, Townsend, DeQuinzio, Poulson, 2009), which affects many areas of the child's life, including social and cognitive learning. Social referencing is another ability that children with autism lack. Social referencing is defined by Brim (2009) as a form of nonverbal communication that seeks out discriminative stimuli provided by others. Another social

problem among children with autism is that of repetitive behaviors that range from lower order behaviors such as stereotypy and self-injury, to higher order behaviors such as compulsions, rituals/sameness, and restricted interests (Boyd, McBee, Holtzclaw, Baranek, Bodfish, 2009).

Another social deficit has been defined as socially unresponsive behavior. This is what one research referred to as a decreased capacity either to initiate or respond to social and/or emotional exchanges by other people and is one of the hallmarks of autism spectrum disorder (Bopp, Mirenda, & Zumbo, 2009). Some of these socially unresponsive behaviors include failure to smile in response to others, avoidance of eye contact, and failure to respond to verbal or physical actions. (Bopp, Mirenda, & Zumbo, 2009).

Bopp, Mirenda, and Zumbo (2009) defined acting-out behavior as behaviors that cause harm or damage to the child himself/herself, to another person, and/or to the environment. It is not uncommon to see individuals with autism act out in tantrums or aggressive behaviors. They may bite or hit themselves, as well as other people.

Impulsivity is a characteristic of an individual with autism and can result in dangerous behaviors when they get frustrated or go into sensory overload. Sensory overload is when one feels overwhelmed by many of the five senses and it causes a loss of concentration in the current task (Schmahmann, Weilburg, & Sherman, 2007).

Spiritual. Human beings by nature have a yearning for peace, acceptance, and understanding. Spiritual life may also be linked to a sense of ego development and health (Dubin & Graetz, 2009). Many individuals, both neurotypical and those with ASD, may

use religion or spirituality as mean of coping with life's events, both positive and negative (Dubin & Graetz).

It is also difficult for individuals with autism to understand the mental states of others, due to the lack of social understanding (Deeley, 2009). The mental states include beliefs, desires, and intentions. This type of understanding is typically necessary in order for one to understand the concept of religion. Deeley also discussed Theory of Mind, which is comprised of mentalization and perspective taking and which includes an ability to interpret the perspective of others as they relate to the mental states mentioned previously. This may be necessary for an individual to delve deeper into theology. It also takes a certain level of social skill to be able to understand Theory of Mind. Theory of mind is comprised of one's life experiences, interpretations, and relationships with others. It is the belief about the thinking of self and others (Dubin & Graetz, 2009).

Religion typically includes many symbolic thoughts and abstract thinking, which can be complicated for both children and adults with types of autism. Therefore, it is debatable whether or not these individuals can have a meaningful, fully reflected and understood relationship with God. Research has been conducted on the topic of spiritual life in those diagnosed with ASD (Deeley, 2009; Dubin & Graetz, 2009). A link has been found between health and spiritual life. A spiritual life has been found to be both therapeutic and healing for many disorders and therefore it could be presumed that spirituality would do the same for those with ASD (Lewis, 2009). Dubin and Graetz reported that individuals with Asperger's syndrome do in most cases believe in a greater power, even if it may be difficult for a neurotypical individual to understand. It is suggested that this is due to his or her desire for order and predictability. Individuals with

ASD yearn for consistency and religion can usually provide this sense of continuity. However, once they determine what it is they believe, it is often difficult for them to shift from it. Their thinking is inflexible and will typically be resistant to change. Overall, spirituality has been found to be beneficial for those with an ASD, because of it provides structure, a feeling of connectedness, contribution to self-esteem, and the opportunity to develop better social skills (Dubin & Graetz).

There is evidence in the Bible of God's purpose for individuals who have Autism, or any other disorder. God especially loves those who are sick, oppressed, and outcast. He reaches out in compassion for these types of individuals, considered to be the least of these, and commands everyone else to do so as well (Matthew 25:31-46, New International Version). However, the major obstacle in spiritual development for these individuals could be in the area of communication. It is especially difficult to discuss spiritual development in those with autism when they are children. Being a child in itself can make an obstacle in the full understanding of a deep topic.

Parenting

Relationship building. Some traits that are typical of most children, such as attachment, identification, and empathy can influence the child-parent relationship and, are often missing in an autistic child (Hoppes & Harris, 1990). This missing factor, which may be labeled as the lack of social responsiveness, is one of the most unsettling traits within a parent and their autistic child's relationship (Hoppes & Harris, 1990). This social deficit has been found to be related to parental stress, parent-child relationship problems, and distress for mothers and fathers (Davis & Carter, 2008). Attachment is also important in the parent-child relationship (Hoppes & Harris, 1990). Children with autism do not

typically express interest in sharing events or object with other people. This idea can be applied to the concept of a child's attachment to a parent. If an autistic child is not willing to share events or objects, then it seems inevitable that there would be difficulty in the parent-child relationship (Kasari & Sigman, 1997). Because children with Autism Spectrum Disorder (ASD) have severe and pervasive impairments in the development of social interaction, the attachment relationship with their parents can be affected (Rutgers et al., 2007).

Stress and coping. Having a child with autism does create some extra stress-related factors for a parent. In a study conducted by Kasari and Sigman (1997), participants were parents of children with forms of autism, neurotypical children, children with mental retardation, and children with Down syndrome. The parents were presented a Parenting Stress Index, which included information on the parents' perceptions of the difficulty in their children's characteristics. An important finding of the study was that parents who reported their children as being more difficult and having a less responsive nature in social interaction had higher levels of stress.

Many parents of children with this disorder find it difficult to attain educational provision or help with their children compared to those who have children with other disabilities. Some studies show that over 50% of parents of children with ASD are unhappy with their child's current school placement. As a result of the difficult in dealing with the day-to-day obstacles that come with autism, more anxiety is placed on the parents as well as pressure to find a suitable education for their child. (Parsons, Lewis, & Ellins, 2009). One study found that 81.9% of parents of children with autism reported that they were sometimes stretched beyond their limits. This percentage was further

broken down into 52.2% feeling unable to cope, 13.3% feelings anxious or stressed, 9.9% feelings depressed, 3% feeling isolated and lonely, 1.5% blame themselves, and .5% reported feeling awful. These results are just one of the many studies that find such related evidence (Sharpley, Bitsika, Efremidis, 2007).

Parents in a study by Altiere (2009) reported that they had spent time trying to find services for their child with autism. This can become frustrating, stressful, and discouraging to a family. A child can recognize this and possibly regress. Parents complained about lack of support groups, financial help, inadequate research, unhelpful and unqualified schools, doctors, and clinicians (Altiere).

Parents of children with ASD typically report higher levels of parenting stress and higher affective symptoms when compared to parents of typically developing children and parents of children with other disabilities (Davis & Carter, 2008). It would make sense that any parent would have a higher level of stress when dealing with a child that requires more than the usual amount of attention.

Research shows that families who have moderate levels of cohesion and adaptability have higher levels of positive coping (Altiere, 2009). It is important for a family to spend time together and allow such bonding to help them through emotional, physical, and spiritual challenges. For a case including a child with autism, this is especially important. Family functioning plays a critical role in the development of any child. Again, this is critical for a child diagnosed with autism. Social support is beneficial to family functioning and development in a child with autism (Altiere).

Altiere (2009) maintained that women more often report depression symptoms.

Having social support gives an individual confidence and can give him or her the

perception of a low-stress lifestyle. He found that mothers were more likely to report that her family seeks social support during times of crisis than fathers. It also found that mothers perceived significantly more social support from their friends and family than fathers. Mothers who perceive much social support are also less likely to feel stressed and to become depressed.

Both parents and children experience anxiety. Children with autism may especially develop anxiety. In fact, children with autism spectrum disorder are at an increased risk for developing clinical anxiety symptoms. These symptoms can have an effect on many aspects of his or her life such as school performance, peer relationships, and family functioning (Reaven, 2009).

There are some therapies available to help children with ASD deal with these anxiety symptoms. Research has shown that modified cognitive behavioral therapy is fairly effective in reducing anxiety in these children (Reaven, 2009). Anxiety can affect anyone's lifestyle from sleeping habits, school or work performance, to physical health. It is important for parents to understand and recognize signs of anxiety in their child. Signs of anxiety in a child with ASD may appear differently from those in a typically developing individual. Research has indicated that anxiety disorders are the most common psychiatric conditions that are present during childhood and that may co-habit with attention, mood, conduct, and/or development disorders. A study of children with autism and anxiety discovered that those individuals with developmental disabilities, such as autism spectrum disorder, are at a higher risk of developing one of these co-occurring mental health conditions compared to typically developing children (Reaven).

Many parents of children with this disorder find it difficult to get educational provision or help with their children compared to those who have children with other disabilities. Some studies show that over 50 percent of parents of children with ASD are unhappy with their child's current school placement, placing more anxiety on parents for getting their child a suitable education (Parsons, Lewis, & Ellins, 2009).

Life after childhood. About 80 percent of all cases of ASD occur in males and about 90 percent of children with this disorder remain severely disabled into adulthood (Comer, 2008). In adulthood, individuals with this disorder have a difficult time trying to get and keep a job. Overall, those with this disorder may have a significant amount of difficultly in leading an independent life.

Purpose of the Study

After reviewing the literature, the following research questions were developed:

Does the level of parental involvement impact the physical, cognitive, emotional, and spiritual development of a child with Autism? Does having a child with Autism increase parents' stress levels? In order to answer these questions, a qualitative study was conducted.

Method

The approach used for this study was the phenomenological research method. The main goal and purpose of phenomenology is to identify and describe the subjective everyday experiences of individuals (Schwandt, 2001). Phenomenology rejects scientific realism and the accompanying view that the empirical sciences have a privileged position in identifying and explaining features of a mind-independent world. Phenomenology insists on careful descriptions of ordinary conscious experiences of everyday life and

looks towards the nature of certain behaviors or philosophies as opposed to its meaning or scientific value. It turns from critical evaluation of forms of social life to a subjective interpretation or description of lived experience (Schwandt, 2001).

The two major variants of phenomenology that are manifested in contemporary qualitative methodologies are the hermeneutic and existential (Schwandt, 2001). A hermeneutic approach is an interpretation of lived experience, whereas an existential approach is a description of lived experience (Van Manen, 1990). The hermeneutic approach was used in this study, as it focused on the perspectives and experiences of the participants and made an attempt to interpret the findings in a subjective manner.

Participants

There were a total of six participants in this study. The participants were parents of children who have been diagnosed with Autism Spectrum Disorder (ASD) and who were recruited through an autism support group at a Christian organization using convenience and snowballing techniques. Participation was voluntary. The mother was the parent that volunteered initially, so each participant in this study is female. The age of the participants ranged from 18-65 years and the children's ages ranged from four to 16 years. Six of the children were male and one was a female. Three of the children are homeschooled, two attend public school, and one attends a non-religious private school. All participants were from the same geographic area.

Materials

After attaining approval from the Institutional Review Board (IRB), an informal structured interview was conducted. The participants were asked to answer a series of questions relating the quality of their relationship with their autistic child, life stressors,

and the progress their child has made. The interview guide (Appendix B), viewed only by the principle researcher, was a set of open-ended questions presented to the participants in a conversational manner. The research questions guided the questions asked in the interviews.

Each question included one or two prompts to keep the conversation on track when necessary. Also included in the interview guide were rating scales concerning stress level and social connectedness. Participants were asked to rate their average daily stress level using a ten-point scale (a score of one representing not being stressed at all and a score of 10 being stressed.) The ability to connect with their child was also reported using a ten-point scale (a score of one being unconnected and a score of 10 being connected) using these ten-point rating scales.

Procedure

Participants signed an Informed Consent Form (Appendix A) created by the researcher, indicating that the participant understood the risks and benefits of the study as well as the purpose of the study. A series of interview questions were given to each participant in a private, individual manner. The same questions were given to each participant, based on an interview guide created by the researcher. The length of each interview ranged from 30 minutes to a one hour. Handwritten notes were taken during the interviews and then stored in a secure location. Only the participant and the researcher were present during each interview. No identifying information was presented on the notes other than the pseudo-names created by the researcher. The list of participants' name and their corresponding pseudo-names were kept and will be kept in a secure location to protect to confidentiality of the participants. The names of the children were

never, and will never be, disclosed. Information from each interview was organized into four areas of development: physical, cognitive, emotional, and spiritual. The stress of the parents and social connectedness between parents and their autistic children were also reported. These data were read and re-read by the researcher in an attempt to understand and explore the participants' experiences. With the information gathered, the research endeavored to answer the principle research questions.

Findings

Overview

Brief descriptions of each participant are presented in order to provide a background for the findings of the amount of time a parent invests in his or her child, in addition to ability of the parent to manage his or her stress levels, can improve the quality of the child-parent relationships as well as the progress of the overall development of the child.

Jane. Jane is a stay at home mom with two children. The oldest child, who is 8 years of age, has been diagnosed with autism, obsessive-compulsive disorder (ODC), and sensory processing disorder. Jane is married and her husband lives in the home. She has a five-year-old neurotypical child as well.

Amanda. Amanda is a single mother with one child that has been diagnosed with mild autism at three years of age. Amanda's mother lives in the home and assists with her child's autism. Amanda works a full-time job. Her autistic child attends a public school.

Barbara. Barbara has three children, two of whom have been diagnosed with autism. The children with autism are ages 10 and 16. The 10-year-old was given the diagnosis of mild autism as well as gastrointestinal disorder. The 16-year-old was

initially given the diagnosis of PDD but is now under severe autism and also has gastrointestinal disorder. Barbara is a stay-at-home mother. She is married and her husband lives in the home. One of her autistic children attends a public school and the other is taught within the home.

Diane. Diane works full-time. She is married and her husband lives in the home. She has three children of the ages of eight, 10, and 16. The 10-year-old was diagnosed with severe auditory processing disorder, visual dyslexia, and PDD. Diane homeschools her 10-year-old. Her two other children attend a private school.

Erica. Erica owns a business and works in the home full-time. She is married and her husband lives in the home. She has two children, a neurotypical child of six years old and a nine-year-old child with autism. Doctors originally thought that her child had Asperger's syndrome. He was then diagnosed with mild autism. There has also been discussion of diagnosing him with PDD. Her child also struggles with gastrointestinal problems. Both of her children are homeschooled.

Hillary. Hillary also owns a business and works in her home full-time. She is married and her husband lives in the home. She has two children, ages eight and 10. The eight-year-old was initially diagnosed with severe autism but is now under moderate autism. He is also diagnosed with OCD and a pediatric autoimmune disorder. Hillary homeschools her autistic child. However, her oldest child, who is neurotypical, attends a private school. The child with autism attends a therapy center on a regular basis, including occupational therapy and speech therapy.

Hours of Parental Involvement

Participants were asked to give the average time they or their spouses spend with the child individually each day. The number of hours reported ranged from one to eight hours a day. Barbara explained the variation of hours: "The hours vary. Some days it is more and some days it is less. Some of the time is broken up. There are even some days when he just says, 'Leave me alone." The amount of parental involvement also varied based upon the type of schooling the child received. Three parents out of the six total homeschool their child, making the hours of parental involvement relatively higher than those who were not taught in the home. Hillary, who homeschools her child, stated: "I spend almost eight hours a day with him." Two of the parents have their child in a public school. One of these parents, Amanda, reported: "I try to spend as much time with him after school as I can. He especially has trouble with homework. I try to help him with it." Only one parent, Diane, has their child in a private school. She described the amount of time she gets to spend with her child: "We spend about two to three hours alone each day during the week. We have no time on the weekend."

Stress and Social Connectedness

Included in each interview, the participants were asked to rate the social connectedness they feel with their autistic child. This included means of communication and emotional connectedness. Diane gave a score of seven and commented with "It's getting better." Amanda gave a score of 10 and commented with "He is the best child I could ask for." Erica gave a score of 10 and commented with "Can I put eleven?" Hillary gave two scores of eight and 10, which was averaged to a score of nine for the purpose of the study. Her comments explained the two numbers: "When we are at home, a 10.

When we are in a situation that is unfamiliar, an eight." Barbara gave a score of 10 for her ten-year-old son and a five to six for her sixteen-year-old son. However, she did comment that her sixteen-year-old son "used to be a 10, until he hit puberty." A theme that appeared through the process of interviewing was routine. Parents found it more difficult to communicate with their children when they were in an unfamiliar environment, or not following their typical schedule.

In addition to the social connected scale, participants were asked to rate the level of stress they felt after a typical day in their homes. The typically reported score was that of a five. However, situational stress was a common theme. Many parents reported their stress levels being lower when they are on routine and schedule, in agreement with the findings from the social connectedness scale. Hillary described her stress this way:

It depends on the day. I wouldn't say I am overly stressed [on a typical day] because we have a schedule to follow. But when we are off of our routine, I am more stressed.

Jane found that her stress levels are lower when she is participating in a Bible study on a regular basis. She also explained that she becomes frustrated with her children when she begins to become "too busy with birthday parties, bills, and other life necessary tasks."

Discussion

Explanation of Results

The findings of this study indicated that while the lack of social connectedness with a child may be a burden on a parent, they might find ways to handle the stress in a healthy manner. Several parents reported their means of coping with stress. For Jane,

being involved in a Bible study assisted her in developing patience and stress management. In agreement with this idea, Hillary mentioned that God is what helps her deal with the obstacles that come with autism and in the healing of her child: "We pray over him all the time. That God will heal him... I know that he will be healed either in this lifetime or another."

The amount of parental involvement in the child's life was found to have an effect on the child's physical, cognitive, emotional, and spiritual development. However, the stress scale submitted by the participants and the number of hours they reported spending individually with their child did not suggest that more time spent with the child either improved or diminished the level of stress in the parent. It appears to vary depending of the diagnoses of the child and the difficultly of communication the child experiences. Hillary explained her and her child's struggle with communication:

I cannot always meet his needs, because I cannot always know what it is he needs.

I can guess what it is, but cannot know for sure. Although he tries hard to make
me understand some how, I find myself playing the guessing game on what it is
he wants.

Hillary described why it is so beneficial for any child, special needs or not, to have a stay at home mother and to be homeschooled. "I think always being able to have someone who can facilitate his needs improves his quality of life. It's nice to have your mom home."

Jane put in words the most effective technique in the improvement of both her relationship with her child and his physical, cognitive, emotional, and social development.

By decreasing stress, I allow him to trust. When he trusts, he relaxes his shoulders and really lets me in his space. He trusts when I stop being pushy and I am more flexible with him. I can't expect him to be flexible with me yet.

An especially stressful task for Diane was the ability to manage her household and all three of her children. She explained that her child "needs structure." "She needs constant one-on-one time. She is not independent at all." Diane answered this as her biggest struggle with her autistic child in her day-to-day living. As one can see, structure appears to be a common theme among the findings and an important matter to all of the parents. It can be concluded that structure and routine play a major role in both the development of the child, the child-parent relationships, and the parent's stress levels. It is suggested that further research be conducted on the relationship between structured routine and parental stress levels.

Limitations to the Study

One limitation to the study is the types of autism of the children of the parents that were interviewed. It is possible that different kinds of autism can cause different levels of stress in parents. Further research in needed in this area. It would be beneficial to expand the study to a larger population.

Participants in this study were recruited through a support group run by a Christian organization. The Christian organization was a support group, which the participants had chosen to attend, most likely in an attempt to find Christian support and interact with others in a Christian setting. Therefore, it could be concluded that the participants in this study were seeking a way to relieve their stress and cope with the struggles that autism carries. This could possibly skew the outcome of the study, because

it is limited to those who are taking the initiative in support seeking. Stress levels for those that are not receiving such may have different levels of stress. It is also difficult to know the true amount of the stress the parent is feeling. The participant could possibly be unaware of some of the stressors that are impacting them and their children.

A significant limitation in studying autism is the fact that it is such a detailed, unique, and uncharted territory. Autism is difficult to pinpoint, because it is an evergrowing issue with so much variation. Therefore, developing a phenomenology on ASD is difficult. As indicated in the review of literature for this study, autism is growing quickly (Pottie & Ingram, 2008). The causes of autism are unknown and still under research, and it is likely that autism will continue to be a complex issue. More research is needed on why autism exists.

Implications for Future Research

This study revealed the need for research to be conducted on the spiritual development of individuals with ASD. Although there is research showing that those with ASD are able to have a spiritual life, research on the details of their relationships with God is scarce. Autism is an issue that still needs much exploration. It is hoped that adding more information regarding autism to the body of literature will give society a better ability to gain knowledge of the thoughts, feelings and motivations those with autism. Dubin & Graetz (2009) put it this way: "By understanding more about their world, we increase our knowledge about our own." (p. 37)

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Tiffany Wiggs, Principal Investigator

Appendix A

Informed Consent Form

Project title: The Effects of Child-Parent Relationships on Parent's Stress Levels and Child's Development: A Phenomenology of Autistic Children and Their Parents

Undergraduate, Honors Student
Liberty University

I, _______, agree to be interviewed as a participant in a research project entitled: "The Effects of Child-Parent Relationships on Parent's Stress Levels and Ch

entitled: "The Effects of Child-Parent Relationships on Parent's Stress Levels and Child's Development: A Phenomenology of Autistic Children and Their Parents" being conducted by Tiffany Wiggs as an authorized part of the Senior Honors Thesis through the Honors department of Liberty University.

Purpose: The purpose of this study is to answer research questions regarding children with autism and the level of parental involvement, stress, levels, and development.

Risks and Benefits: It is possible that the interview might produce emotions since the topic is personal experience as a parent of an Autistic child. I will endeavor to be a supportive listener in this instance. You will also be able to use this experience to think through how you handle challenges with Autism and possibly make a change in the relationship you have with their Autistic child. This study will also be beneficial in adding to the body of literature. Risks are no more than the stress experienced in daily living.

Procedure: If you agree to be in this study, we would ask that you answer some questions regarding the daily struggles you may face and what your average day looks life. You, as a participant, will first be asked to sign an Informed Consent Form, stating that you understand the risks and benefits of the study and the purpose behind it. A series of interview questions will be given to you in a private, one-on-one manner. The location of the interview will be at Thomas Road Baptist Church in Lynchburg, Virginia. The same questions will be given to each participant. The length of each interview will be approximately 1 hour. Once these data are collected, I, the principle investigator, will analyze it. Notes will be taken during the interview and then stored in a secure location. There will be no identifying information on the notes. The research questions will be answered in an effective way until the Honors Thesis is complete and turned in by April 1, 2009.

Consent/Confidentiality: Your answers from the interview will be kept private by using pseudo-names, or fake names. This is to protect the confidentiality of your information. Research records and data will be stored in a private, secure place that is only accessible to the researcher. The list of pseudo-names, real names, and interview notes will all three be store in separate, secure locations as to protect the participant. All data will be kept for

Please check one of the following:

at least three years from the time it is collected. This will be no earlier than February 2013.

Voluntary Nature: The participants in this study are interviewed on a voluntary basis and have the choice to withdraw from the interview or study at any time. If this were to happen, all information recorded will be destroyed immediately.

Questions: I understand that information given to me along with any questions I might have had related to this study have be satisfactorily answered. I also know that if I have any additional questions about this research project, I may contact: Tiffany Wiggs – (757) 285-7827 or by email at trwiggs@liberty.edu

I also understand that should I have questions regarding my rights as a participant in this research, I may contact:

Tiffany Wiggs – (757) 285-7827 or by email at trwiggs@liberty.edu Dr. Janet Brown, Assistant Professor of Psychology – (434) 592-4035 or by email at jmbrown@liberty.edu

By signing this form I certify that I am 18 years of age or older.

I give my permission to be interv I do not give my permission to be	
Participant Signature	Date
Researcher: I certify that the informed have answered any questions from the	consent procedure has been followed and that l participant as completely as possible.
Researcher Signature	Date

Appendix B

Interview Guide

1. Tell me about yourself, your job/work, what you do.

Prompts:

Are you married, divorced, etc.?

Does your spouse or significant other live at home?

What is his or her job/work?

- 2. How many children do you have?
- 3. Which of these children has an Autism Spectrum Disorder (ASD)?
- 4. Describe a "typical" day in your home.
- 5. After a "typical" day in your home, how stressed do you feel (on a scale of 1 to 10, 1 being not stressed at all and 10 being extremely stressed)?

Prompts:

What are some things you do to relieve your stress?

- 6. What do you feel are the biggest struggles with your child in your day-to-day living?
- 7. Tell me what your child is like?

Prompts:

What is his or her personality like?

8. On a scale of 1 to 10, how socially connected do you feel with your child overall?

(1 being not connected at all and 10 being extremely connected).

Prompts:

Do you find it difficult to connect with your child? What are some reasons why you think this is the case?

- 9. Approximately how many hours each day do you (or the child's other parent) spend one-on-one time with your child?
- 10. How do you feel that your relationships with your child has improves his or her cognitive, behavioral, and/or social development?
- 11. Is there anything else significant to this topic that you would like to share?
- 12. If you have any questions or concerns following this interview, please remember that you may contact:

The principle investigator/Interviewer: Tiffany Wiggs – (757) 285-7827 or by email at trwiggs@liberty.edu

The faculty sponsor: Dr. Janet Brown, Assistant Professor of Psychology – (434) 592-4035 or by email at jmbrown@liberty.edu