

Autism and the Family: Phenomenological Perspectives of Students with Autism

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Abstract

Autism has affected many families throughout history. There have been many studies done on both sides of the spectrum regarding the emotional, physical, and financial stress that parents, siblings, and an individual who has autism experience. Although some research disagrees, a significant number of studies suggest that autism causes harm and stress to both the parents and child. Autism has become a problem for families who experience it. A phenomenological approach was used in the present study to understand the lived experiences of an individual with autism and how those experiences impact the individual and his or her family members. The present study conducted interviews on five separate individuals to determine the lived experiences of these individuals who had a diagnosis of autism and how these experiences affected them as an individual and their family members. The present study examines autism through the lens of phenomenology. The results showed that these five individuals experienced physical, emotional, and financial effects with their autism.

Keywords: autism, family, emotional stress, physical effects, financial effects, phenomenology, qualitative study

Statement of the Problem

Autism spectrum disorder (ASD), which affects about 1% of families, is a problem in the United States because of the stress that it can bring in a family (Centers for Disease Control and Prevention, 2014; as cited in Autism Society, 2015). Some negative effects on parents of a child with autism can impact both the parents and the siblings (Sage & Jegatheesan, 2010). The behaviors associated with autism can cause increased stress levels, which can lead to the breakdown of the family. One problem that a family faces is being embarrassed by their child in public when or if the child throws a tantrum. Some children with autism have a mental capacity which causes them to act like three- or four-year-olds even when they are much older. Another problem that a family faces is their child becoming violent; some children with autism become extremely violent when they do not get their way or feel like they are not being understood. The parents and the child end up feeling frustrated much of the time. Sometimes parents feel guilty or responsible for their child having autism (Argumendes et al., 2018).

Having a child with autism spectrum disorder can be very hard on the family and place extra stress on a marriage. Very often, this stress leads to the breakdown of the family and the marriage ending in divorce (Paltrow, 2018). On the positive side, families who have

dealt with autism often come out stronger, with the parents and the siblings growing as individuals and feeling stronger because of it; families and the children receive benefits from living with one another (Krauss, 2005). Research conflicts about whether having a child with ASD in the family causes an increased occurrence of divorce. Children with developmental disabilities or special needs are more likely to see their parents' divorce than other children (Brobst et al., 2009). Regardless, autism will impact all family members (Freedman et al., 2012).

The problem with autism is that, among family members, it can sometimes cause stress for both the child, parents, and siblings. The present research will look at the lived experiences of families with an autistic child from the perspective of the autistic child.

Biblical Framework

Psalm 139:13-14 says, "For you created my inmost being; you knit me together in my mother's womb. ¹⁴I praise you because I am fearfully and wonderfully made; your works are wonderful; I know that full well" (New International Version). From a biblical perspective, this indicates that God made these children with ASD the way they are for a purpose. It also indicates that he placed these children in their specific

families for a reason. Although it is hard sometimes on the child as well as their family, it is clear that God had a plan when he made them the way that he did. It is also clear that he gave them to the specific family that he did. Children with autism are fearfully and wonderfully made by God and are viewed the same as the rest of creation. The present study chose this verse for the biblical foundation to affirm that an individual should be looked at as part of creation and should not be viewed as a problem in society. The present study also affirms that an individual with autism, as well as their family members, is an individual him or herself and is not defined by their autism.

Literature Review

Autism can affect a family in three key ways: physically, emotionally, and financially (Paltrow, 2018). These three areas play a big role in families' lives. Some families have a schedule based on their child's behavior; other families refuse to take their child out in public because of the risk of undesirable behavior. Sometimes families, mainly parents, have a mental breakdown because they feel like they cannot deal with the child or provide the proper care that he or she needs (Lofholm, 2008).

Physical Effects of Autism

Autism can affect a family physically (Paltrow, 2018). Some children with autism have episodes where they become violent and throw temper tantrums when they feel like they are not being listened to or are having trouble communicating their feelings. They can become physical with their siblings, their parents, and even their peers or teachers at school (Sage & Jegatheesan, 2010). When this happens, the question is how to restrain the child and calm him or her down. There are some parents who will get physical back with the child (Mandell et al., 2005). Getting physical, however, is not the answer because parental stress displayed in a physical way can lead to increased negative behavior in the child (Solomon & Chung, 2012). The child will most likely become more agitated and, possibly, more violent in general. It is much better for a parent to try to calm the child down or take the child to a counselor or psychologist to get treatment or medication instead of fighting the child (Green et al., 2010). Parents should remain calm. Remaining calm provides an example the child can imitate, making it easier for him or her to gain emotional control (Remington, 2007).

When, or if, the child calms down, a solution can be worked out between the child and parent; the caregiver or parent can come up with positive coping mechanisms

that can help both the child and parent in the long run. A study done by Brockman (2016) suggested ways to manage behavior problems among children with autism. Brockman demonstrated that caregivers could develop positive coping mechanisms, such as self-efficacy and social support of one another. And even if all else fails, it is still important for the parent to remain calm at all times. Rash decisions can cause harm to both the child and the parent: the child could get hurt in the process and it is not good for the parent's health to get easily upset all of the time (Meadan et al., 2010).

A study done by Sikora (2013) showed that the different behaviors children with autism display have a negative effect on family functioning. The study collected data from 136 families, whose children were divided into groups. Sikora wanted to see if there were leads to what caused the different problematic behaviors in children with ASD. Further examination led to externalizing and internalizing behaviors as a potential cause. Sikora also found that negative attitudes, marriage, and siblings were associated with the behaviors being displayed by the children with ASD. This shows that there are different factors besides the parent and child relationship that affect a child with ASD and the family as a whole. Different factors play a role in family functioning. Some families have reported that their child with autism was much harder to care for than other children the same age as their child, which then caused elevated levels of stress (Rao & Beidel, 2009). Children who have autism have more specific needs than other children without autism.

Emotional Effects of Autism

Parents can become extremely stressed and overwhelmed when dealing with their child who has autism. They can also feel guilt with this as well, feeling as if they are the ones to blame for their child having autism; they have fears of what is going to happen in the future to their child based on their limitations brought on by autism and the disapproval of others around them (Pisula & Kossokowska, 2010). They may blame each other for their child having autism. This is another reason that parents get divorced (Paltrow, 2018). They blame each other for their child having autism when they should be leaning on each other for support. Parents can also become emotionally stressed when their child acts out. In this case, they do not get physical with the child but instead experience a mental breakdown or become embarrassed by the way their child is behaving (Lofholm, 2008). When this happens, parents may fight with each other or become easily depressed because of the stress they feel from the child (Sabih, 2008). Some

parents will not take their child out in public or dread the thought of taking their child out in public because they do not want to deal with the stress of worrying about people looking at them and wondering what others may think about them when their child acts up; many parents and children experience stigma or a feeling of disgrace from being out in public (Gray, 2002). Parents may feel like everyone stares at them when their child acts up and are embarrassed about it (Davis & Carter, 2008; Hastings & Johnson, 2001).

It is never a parent's fault if their child has autism, and it is a lie to believe so. Unfortunately, many parents believe this lie, leading to divorce in families who have children with autism (Hartley et al., 2010). If parents are feeling guilty, they should seek counseling, which can help them express how they are feeling instead of bottling their emotions; mothers have expressed guilt for their children's regressive behaviors, such as verbal and nonverbal communication (Davidovitch et al., 2000). Dealing with emotions in a positive way could lead to fewer divorces among parents of children with autism. Recognizing that the autism is not their fault can help parents become less stressed and, therefore, better able to handle their child with autism and to raise their child in a normal fashion (Hastings & Johnson, 2001).

In a study done by Greenberg et al. (2006) to show the emotional effects of autism in adolescents and young adults, data was taken from 406 families with adolescents and young adults with autism. Over a period of 18 months, they found high levels of expressed emotion in a quarter of the families chosen for the study. This study showed great stress in the child because the mothers were shown to be highly critical of the children. In another study investigating effects of autism and emotional behavior, Huang et al. (2014) found that kids with autism and their caretakers showed that high parenting stress came from the conducts of the child. In this study, there were higher amounts of stress in caregivers of children with autism and bad conduct behavior than there were with caregivers of children with mild autism and behavior issues; about 86% of the caregivers were mothers.

Financial Effects of Autism

Having a child with autism can be expensive and can lead to stress among parents (Järbrink et al., 2003). Parents become stressed if they feel like they cannot support the child or cannot pay other bills because of paying expenses related to treating their child with autism. This financial strain can lead to the parents fighting with each other over how to pay for the expenses that come with raising a child with autism; providing

social support such as respite care can cause high stress and financial strain on a family (Harper et al., 2013). According to a study by Freedman et al. (2012), behavioral challenges, as well as other difficulties associated with the social and communication deficits inherent to ASD, are often associated with increased financial burden on the entire family system. Financial burdens can involve the welfare of the child, insurance, and medication. Certain medications can be effective, but they can be very expensive as well, which can put stress on a family (Järbrink et al., 2003).

It is important for parents to seek help if they are struggling with their finances (Järbrink et al., 2003). They could approach another family member or an organization that helps families in need, or they could even ask their church for help instead of just trying to handle it on their own. Handling it on their own will only cause problems, chaos, and fights. It will cause these things because parents will get stressed from their job, their bills, and their other kids. There have been programs or interventions to help parents cope with daily stress they feel from their child who has autism (Gupta & Singhal, 2005). If the father loses his job, the church can step in and help the family out, but, if the family remains silent about the situation, then that is like putting gasoline on the fire, it will guarantee a fight between both parents (Valicenti-McDermott et al., 2015).

A study which was conducted by Sharpe and Baker (2007) to determine all the financial struggles associated with raising a child with autism involved 423 parents or caregivers of children with autism between July of 2003 and May of 2004. It was found that most of these parents or caregivers who had an income of only \$40,000 dollars were more likely to have financial troubles than families who had an income of \$60,000 dollars. Financial troubles were present among families because parents were caught off guard by the world, they had stepped into by having the child with autism. Also, the medical demands of autism stripped the resources of the parent and they had no money left over for themselves or their other bills. Looking at how big an impact financial stress can have on a family with a child of autism, Saunders et al. (2015) conducted a study which showed that 52% of the caregivers or parents involved in the study admitted to having to quit their job in order to care for their child with autism. Over half of these caregivers or parents reported some sort of financial difficulty meeting their child's autism needs.

Methods

This study used phenomenology as a theoretical perspective or lens in which to understand the lived

experiences of families who have children with autism and the impacts on the family. Phenomenology was first introduced by Edmund Husserl and is the study of the structures of experience and consciousness experienced from a first-person point of view (Smith, 2018). The nature of a family is for its members to be intensely connected emotionally. Phenomenology's major ideas are to study the experiences and the consciousness of an individual. Phenomenology relates to autism because this study is based on the participant's own experiences with autism and their family relationships.

There have been studies that examine the experiences of autism using phenomenology as a theoretical perspective (Turner-Brown, 2011; Remington, 2007). Turner-Brown conducted a study using the phenomenology to test IQ's of children who have high functioning ASD. Turner-Brown found that there was strong internal consistency between the two groups. In another study using phenomenological approach, Martins et al. (2013) looked at the father's perception in raising a child with ASD. Martins et al. found that there were personal experiences, challenges, and coping strategies among the participants. It was also found that participants, mainly the fathers, were overwhelmed with the idea of their child having autism or some form of learning disability. There has not been much research done on the topic of autism (Remington, 2007). This approach of studying the lived experiences of autism on both parents and child was used in the current research to bring a new perspective on having and living with autism.

This study involved the qualitative lens of phenomenology to understand the lived experiences of a person with autism and to show how they effect that individual and his or her family. This study involved interviews with open-ended questions on a random sample of students. Since the goal of this study was to study the lived experiences of a child with autism and to show how that affects the individual and his or her family, using phenomenology as a theoretical approach was an adequate method. Through five interviews, the study gained data from lived experiences of people with autism. Each participant was asked questions about their personal experience with autism and how it has affected them and their family members. According to Cridland et al. (2015), interviews are a good way to collect data because they can provide reflections in the qualitative process and they make observations on the individual with autism based on their own experiences. The results were coded to ascertain themes of experiences and effects of autism on the family unit. The dependent variable of the present study was the final results of the study itself.

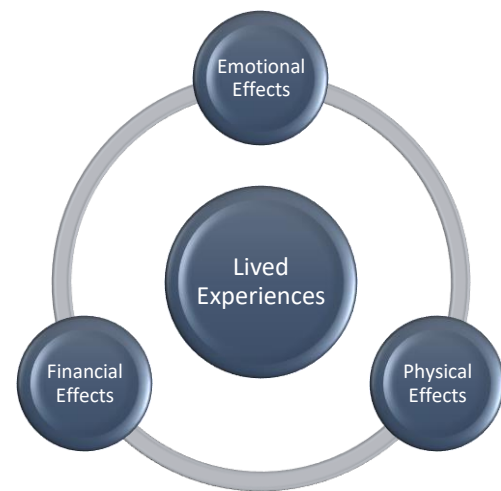
The independent variable included students, gender, and class.

Research Question

What are the lived experiences of a person with autism and how do they effect that individual and his or her family?

Conceptual Framework

The diagram below show a graphical representation of this study using the phenomenological approach to help share the experiences of students who have autism. The experiences shared tell the stories of the students with autism and the emotional, financial and physical effects.



Target Population

The target population for this study will be individuals who have autism themselves. This study performed qualitative measures to develop its data results. Five separate individuals were interviewed on how autism has affected their family based on their own experiences. The participants were chosen from other knowledge that they had autism. The goal of this study was to provide the lived experiences of an individual with autism and to show how these experiences effected the individual and his or her family. Participants included four male students and one female student; one participant was a high school student, three were college juniors, and one was a college graduate.

Four males and one female were interviewed. Two of the males are juniors at the Georgia Institute of Technology (Georgia Tech). They are not the same age. One of the males interviewed is also a junior in college. The female interviewed is a civil engineer and a photographer who has graduated from Georgia Tech. The

other male interviewed loves the military and also loves to fish. He is a junior in high school.

No personal information was received from the participants, and their interview answers were not shared with anyone on Truett McConnell's home campus. The interviewer assured the participants involved in the study that nothing said during the interviews would be released and asked for their permission before they took part in the study. Names and gender of the participants involved in the study were kept anonymous (fictitious names will be used throughout this study).

Data Collection, Analysis and Instrumentation

The participants of this study were interviewed by telephone. The interviews took no more than 5-10 minutes a person. There were six questions in the interview. An example question was "Do you feel bad about having autism and have you ever lashed out at the people around you including your family members due to frustrations with autism?" (see Appendix A). Each of the five individuals chosen for the research were interviewed, and the answers to the questions were recorded. Once the interviews had taken place, the information was transcribed to a document and the results will be coded based on common themes found in the research. The literature supports that autism causes physical, emotional, and financial struggles for families and individuals who experience it. In the interviews, all of the participants were found to have at least one of these types of struggles or experiences, consistent with the literature (see Appendices B-F).

Results

Emotional Stress

The first highlighted theme was that three participants discussed having emotional struggles with their autism. Participants stated,

"I feel upset at some points in my life, but I do not feel upset all of the time."

"Yeah, sometimes because it makes me different and it makes it difficult to communicate with other family members and it puts stress on everyone in the family in general."

"My family does not fight; in fact, they are actually happy about me having autism. However, they sometimes get stressed about my autism."

Another participant shared that his parents were emotionally stressed by autism. This theme of emotional stress was found in three of the five interviews.

Research conducted by Ashwin et al. (2006) supports that autism causes emotional harm in people. "Fear and anger have been characterized in autism spectrum conditions in individuals who have damaged their amygdala or the almond shaped gray matter that is inside each of the individual's cerebral hemispheres" (p.349). Participants in the study mentioned fear and anger. One participant stated that "yeah, sometimes because it makes me different and it makes it difficult to communicate with other family members, and it puts stress on everyone in the family in general", when asked does autism make you sad.

Physical Effects of Autism on Family Members

The second highlighted theme was that two of the participants discussed having physical struggles with their autism. Participants stated,

"No, I have never gotten physical with any of my family members, but I have thought about doing it."

"Yes, I have lashed out at the people around me and my family due to my autism because it sometimes makes it hard to communicate with each other."

This theme of physical stress was found in two of the five interviews. Research supports that autism brings potential problems such as unpredictable behavior for families who are raising a child with autism (Norton & Drew, 1994). Physical effects of autism can cause people to lash out as demonstrated by Elizabeth, who stated, "yes, I have lashed out at the people around me and my family due to my autism because it sometimes makes it hard to communicate with each other".

Financial Effects of Autism on the Family

The third highlighted theme was that the participants discussed having financial struggles with their autism. Participants stated,

"Yes, autism has cost my family a lot of money to pay for my needs like college and financial aid."

"Yes, there have been many high costs in my family due to autism."

"Yeah, it has a little. When I was younger, my parents bought a book on how autism works."

“Yes, in some ways. When I was younger, me and my family could go on a lot of vacations and like ride in airplanes and stuff like that, and now we cannot do that because we do not have enough money.”

“Yes, at some points it has cost my family money.”

This common theme of financial stress was found among all the interviews. Research supports that autism brings financial problems to families: “Costs of autism can peak during the periods when a diagnosis is being assessed and when treatments are being administered” (Horlin et al., 2014, p. 1). Financial effects of autism were mentioned by all the interviewees based on their responses.

Conclusion

Different circumstances from being diagnosed to developing at an early age can influence autism’s effects on the individual and his or her family members. Autism can cause many struggles among individuals and their families. A study done by Williams (2004) discussed a phenomenological analysis of ten individuals who had Asperger’s syndrome. Some findings of the study were that four of the teenagers expressed having difficulties relating to the people around them and finding coping strategies to address these issues. The present study found that the interviewed participants did have at least one of the three main effects of autism. All five participants expressed having financial struggles with autism. The current research did, in fact, conclude autism has a negative effect on individuals and family members.

It is important to understand all aspects of autism and the steps families must take to live peacefully with each other. Learning about autism and the treatment options for it can be vital for both the individual and his or her family. According to further research, music therapy can help families, mostly mothers, gain confidence in raising and engaging with their child with autism, as well as provide rare opportunities for both mother and child enjoyment (Thompson, 2017). By focusing on lived experiences, the present study affirmed that the individuals interviewed experienced emotional, physical, and financial effects with their autism. These experiences also impacted the lives of their family members. This research could be beneficial for the future understanding of autism and the effects it has on an individual and family who experience it.

Limitations in the Research

A significant limitation within the study is the lack of dialogue about treatment options offered to families who have children with autism. Music therapy has been shown as a beneficial treatment option for children with autism. Wigram and Gold (2006) found that children and adolescents with autism spectrum disorder respond well to music therapy (Wigram & Gold, 2006). The need for Christian counseling is beneficial, understanding the place of faith in the lives of individuals who have autism gives them a voice (Liu et al., 2014). Psalm 139:13-16 tells the readers that they have a purpose on this earth and that God saw what they were before they were even born. Counseling based on biblical principles of worth are essential as noted by Crabb (1977); it helps individuals to understand that they have already been declared acceptable by God. In addition, Parker (2008) points out that the Holy Spirit allows individuals to see themselves the way that God sees them. Although the interview questions did not discuss treatment options or counseling, these components are lacking in my research. More research is needed to determine the benefits of Christian counseling for people on the autism spectrum.

Another limitation within this study was the over representation of males compared to their female counterparts. Women should be represented for future studies of autism to provide a different perspective of autism. Women who have autism have been shown to have different experiences than men (Bargiela, 2015). According to Bargiela, young women with an autism spectrum disorder are prone to abusive relationships. More research is needed on the lived experiences of females who experience autism to describe those experiences and compare them to their male counterparts.

Lastly, this study was limited to high school and college students. The research did not have access to children to gauge their emotional and psychological effects of having autism. More research using the phenomenological lens is needed to learn about children’s experiences. A phenomenological approach facilitates an individual’s experiences of autism and provides a more holistic view of the characteristics of the individual’s autism (Carrington et al., 2003). For future studies, a phenomenological approach could be used to determine the lived experiences of an individual with autism and the exact characteristics of that particular autism. In addition, the qualitative nature of the study should broaden to incorporate quantitative approaches to provide statistical analysis and assessment of the greater autism community.

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Appendix A
Instrumentalization

1. Do you feel bad about having autism?

2. Do you feel sad about having autism because your family fights?

3. Have you lashed out at the others around you, including your family due to frustrations with autism?

4. Have you gotten physical with your family due to symptoms of autism?

5. Does autism make you feel like a financial burden to your family?

6. Has autism been costly for your family?