

Relationships between Typically Developing Individuals and their Siblings with
Autism Spectrum Disorder: A Qualitative Analysis

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Spectrum Disorder: A Qualitative Analysis

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ABSTRACT

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This qualitative study is an investigation into how having a sibling with autism spectrum disorder (ASD) affects sibling relationships, specifically, how typically developing adults perceive their relationships with their siblings who have autism and the effects of autism on their relationship and their lives. Semi-structured interviews were conducted with three typically developing adults who had siblings with autism spectrum disorder. Thematic analysis of the interviews produced five themes regarding the effects of autism on sibling relationships and the typically developing siblings' lives. The findings show that the participants experienced both hardships and benefits of having a sibling with ASD. Their most frequently mentioned hardships were parents' disproportionate attention paid to their siblings with ASD and its effects on their relationship with their parents, some barriers to forming friendships, and a heightened sense of responsibility for the affected sibling. The most frequently mentioned benefits of having a sibling with autism were effects on personal development, forming friendships with others in similar situations, and valued relationships with the siblings who have autism. In addition, all participants stated having a very close relationship with their siblings with autism.

Keywords: *Autism Spectrum Disorder, Sibling Relationship*

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Introduction

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines autism spectrum disorder as a developmental disability that may cause social, communicative, and behavioral difficulties. The diagnostic criteria presented in DSM-5 indicates that a person can be diagnosed with autism if s/he has difficulties in social-emotional reciprocity; difficulties in nonverbal communicative behaviors; difficulties in developing, maintaining and understanding relationships; and/or restricted, repetitive patterns of behavior, interests, or activities. The DSM-5 also states that individuals should display these characteristics of autism spectrum disorder at an early age (American Psychiatric Association, 2013). It has been reported that the number of individuals diagnosed with autism spectrum disorder has increased rapidly in recent years (CDC, 2016).

Being associated with individuals with autism spectrum disorder affects the people around them such as immediate family members (Hesse, Danko, & Budd, 2013). In particular, because siblings spend much of their time together, indeed more time than with their parents (Rossetti & Hall, 2015; Soysal, 2016), their interactions among themselves greatly affect each one. Researchers have examined sibling relationships among individuals with autism spectrum disorder and their neuro-typical siblings. This research suggests that neuro-typical individuals experience positive and negative effects associated with having siblings with autism spectrum disorder.

Literature Review

Autism spectrum disorder (ASD) is a developmental disability that causes difficulties with regard to socialization, communication, and behavior (Angell, Meadan, & Stoner, 2012). According to the Centers for Disease Control and Prevention (CDC), the number of individuals

diagnosed with autism spectrum disorder has increased over the past 20 years. CDC data show that currently about 1 in 68 school-aged children is diagnosed with autism spectrum disorder (CDC, 2016).

As the number of people diagnosed with autism increases, the number of typically developing people with autistic siblings increase as well, and Petalas, Hastings, Nash, Loyd, and Dowey (2009) found that having a brother or sister with autism spectrum disorder is correlated with emotional and behavioral problems for the typically developing sibling. Since siblings spend a significant amount of time together, as Petalas and colleagues have stated, the interactions that take place between the sibling with autism and the typically developing sibling inevitably involve the formation of attitudes. For example, the typically developing siblings may display jealousy or rivalry toward their siblings with autism spectrum disorder.

Hesse, Danko, and Budd (2013) further report that having an individual with autism spectrum disorder in the family may affect all family members. For instance, having a person with autism in the family may result in increased emotional and economic stress for family members, and there is reason to believe that typically developing siblings are as affected as parents. However, while some researchers (e.g., Orsmond & Seltzer, 2007) suggest that having a sibling with autism negatively affects the typically developing siblings, others (e.g., Macks & Reeve, 2006) find that having a sibling with autism positively affects typically developing siblings. Such effects may be largely associated with the nature of the relationship of the neuro-typical with the autistic sibling. This paper will investigate the ways in which having a sibling with autism spectrum disorder affects the social relationship that develops between the autistic sibling and his or her typically developing sibling.

Petalas et al. (2009) conducted a study on the emotional adjustments of siblings of children with intellectual disability, with and without an additional diagnosis of autism. The findings of the study indicated that the siblings of children with both autism spectrum disorder and intellectual disability displayed more emotional problems than the siblings of children who were diagnosed only with intellectual disability. In addition, the results suggested that the relative age of the siblings impacts the emotional adjustments of the neuro-typical siblings. Typically developing siblings who are younger than the sibling with autism and intellectual disability showed more emotional problems than siblings who were older (Petalas et al., 2009). In addition, Orsmond and Seltzer (2007) conducted a study that examined adult siblings of people with either ASD or Down syndrome, and they found that the siblings of people with autism spectrum disorder were more pessimistic compared to siblings of people with Down syndrome. Moreover, siblings of people with ASD exhibited less contact with their siblings. Sage and Jetatheesan (2010), in a study examining familial influence and sibling relationships, found that typically developing siblings were less likely to maintain good relationship with their siblings with ASD when parents chose to withhold information about the children with ASD and did not involve the typically developing siblings in activities involving the autistic siblings. The study found that the typically developing siblings in this scenario avoided contact with their siblings with autism.

As noted previously, however, other studies have shown that having a sibling with ASD can positively affect the typically developing siblings. Walton and Reeve (2015) found that the typically developing siblings of children with ASD displayed less aggression toward their siblings compared to siblings of children without autism spectrum disorder. However, the same study showed that siblings of children with autism demonstrated less interaction with their

siblings compared to children with only typically developing siblings (Walton & Reeve, 2015). In addition, Macks and Reeve (2006) conducted a study to determine whether there were any differences between the emotional adjustments made by siblings of children with autism spectrum disorder and those made by siblings of typically developing children. Their study reported that siblings of children with autism exhibited more optimistic behavior, and were more successful at school, than children with only typically developing siblings, and maintained good relationships with their siblings with autism. The authors suggested two possible explanations for the outcomes of their study. Their first explanation is that individuals who have siblings with ASD compare themselves “favorably” with the siblings with autism. The other explanation suggests that individuals who experience life with siblings with autism spectrum disorder show higher maturity levels compared to individuals who have only typically developing siblings (Macks & Reeve, 2006).

While studying the relationships that exist between typically developing children and children with ASD, some researchers examined other factors that can affect sibling relationships. For example, Hesse, Danko and Budd (2013) found that parents’ stress levels affected sibling adjustments. In addition, the study indicated that when parents experience high levels of satisfaction, their children’s sibling relationships are positively affected. Further, Petalas et al. (2012) found that the higher the parents’ education levels, the less stress and fewer difficulties the typically developing siblings had (Petalas et al., 2012). In addition, it was found that low family income is correlated with conflict among siblings (Hesse, Danko, & Budd, 2013). Researchers have also found that the gender of the siblings affect their relationships as well. Orsmond, Kuo, and Seltzer (2009) found that women who had sisters with autism were more actively involved in their sisters’ lives than were men with sisters with autism. Petalas et al.

(2009) also found that gender affects siblings' relationships. The authors determined that siblings with sisters with autism and intellectual disability experienced fewer emotional problems compared to siblings with brothers with autism and intellectual disability.

In light of the studies that have been presented here, it is clear that numerous factors affect the relationships between the typically developing individuals and their siblings with ASD. In addition to the aforementioned factors, culture, race, religion, and environmental factors may affect sibling relationships as well. Macks and Reeve (2006) encouraged other researchers to take these factors into consideration when conducting future studies. Moreover, having an individual with ASD in the family affects not only their typically developing siblings but also their parents. Caring for the autistic offspring may result in numerous challenges and stressors for parents, and these can in turn result in conflict between parents who must share responsibilities and make decisions regarding their children with autism. As a consequence, these parents' marriages may be affected. Beyer (2009) argues that conflicts between parents may further affect siblings' relationships, and she suggests future research into all such family issues associated with having a member with ASD.

According to Orsmond, Kuo, and Seltzer (2009), sibling relationships are different from any other relationships among people because sibling relationships tend to last longer than the others. Simply by being involved in ongoing engagement in familial interactions and with one another, siblings can become mutually supportive friends. Further, one sibling can become a role model for another one. When one of the siblings has ASD, it can be expected that the neuro-typical child's relationship with that sibling will be different in some ways from a relationship between two typically developing siblings. An obvious example of this has to do with parents' expectations. The condition of individuals with ASD may mean they will require care all their

lives, and this may cause parents to expect the typically developing siblings to be responsible for their sibling with autism after the parents pass away (Orsmond & Seltzer, 2007). Such circumstances can be experienced by the typically developing siblings as a burden on their lives. The research to date on sibling relationships between typically developing individuals and their siblings with ASD suggests many issues that require further investigation. In light of the few studies in this area so far, there is still much to explore regarding this interesting topic.

The objective of the current study is to examine the relationships between typically developing siblings and their siblings with autism spectrum disorder, that is, how having a sibling with ASD affects siblings' relationships. The research question that will guide this study is: How does having a sibling with autism spectrum disorder affect sibling relationships from the perspective of the typically developing sibling?

Method

Participants

I completed this qualitative study by interviewing three typically developing adults, each of whom has a sibling with autism spectrum disorder. To recruit participants, I contacted eligible adults who were residing or studying in a city in the Midwest of the United States via email and informed them about the study. The first three participants who responded were chosen to be participants in the study. At the first meeting, the participants were asked to sign an informed consent form which described the intended study and the data collection process and provided contact information of the researcher. All of the participants agreed to sign the consent form upon explanation of the process.

Sibling Pair 1: Morgan (pseudonym) is a 21-year-old senior student at the university located in this Midwest city. She lives in a dormitory, and her family lives in the next county. Her older brother, James (pseudonym) was diagnosed with Asperger's Syndrome. According to the information Morgan provided about her brother, James was 25 years old and enrolled in the same university, where he lived in a different dormitory. During semesters, Morgan met with James once a month; however, during breaks, they spent a great deal of time with each other.

Morgan described herself as a shy person who does not make eye contact with other. However, during the two interviews, she was very active and was making eye contact for long time periods. Even though she described herself as a shy person, she did not show any signs of timidity while talking with me. After our second and last interview, she stayed longer with me to talk about daily issues such as her school and hobbies.

Sibling Pair 2: Audrey (pseudonym) was an 18-year-old high school student in this Midwest-city. Audrey had a 21-year-old sister, Bethany (pseudonym), had been diagnosed with low functioning autism spectrum disorder. According to the information Audrey provided, Audrey and Bethany attended the same high school. Because Audrey peer-tutored her sister at school, she and Bethany spent a great deal of time together both at home and school.

During the interviews, Audrey gave very clear explanations of her relationship with Bethany; however, she did not provide as much information as the other participant siblings did. Before beginning the interviews, I had talked about myself, and I asked questions to build rapport. However, she did not elaborate on her answers to my questions, and she cut the conversation short.

Sibling Pair 3: Harper (Pseudonym) was a 22-year-old student at this Midwest-university. She had a typically developing older sister and a younger brother, Tom (pseudonym), who had been diagnosed with severe autism spectrum disorder. According to the information Harper provided about her brother, Tom was 18 years old and lived in another state with his parents. Therefore, Harper was able to see her brother only three or four times a year.

Harper and I had the longest interview among all the participant siblings. To every interview questions, she gave explanatory answers. She took time to think about her answers, which suggested she was very willing to answer the questions in detail. In addition, before I could ask her probing questions, she mostly clarified her answers herself, giving examples.

Research Purpose and Questions

The primary purpose of this study was to explore sibling relationships between typically developing individuals and their siblings with autism spectrum disorder. The interviews were conducted to examine typically developing siblings' perspectives on their relationships with their siblings with autism. The primary question of this study is: What are the effects of having a sibling with autism spectrum disorder on sibling relationships from the perspective of the typically developing sibling? The sub-questions are: "How did the diagnosis of autism spectrum disorder affect the siblings' relationship over the years? What was challenging about having a sibling with ASD? What were the benefits of having a sibling with ASD? How did having a sibling with autism affect the typically developing sibling's relationship with others (friends and family)? Do the typically developing siblings feel responsible for the sibling with ASD?" (Appendix A)

Data Collection

The participants were individually interviewed in face-to-face sessions in a reserved room at a university. The interviews were conducted with only the typically developing siblings. In total, five interviews were conducted; two interviews with Morgan, two interviews with Audrey, and one interview with Harper. After the interview with Harper, I considered the information she provided adequate for the study. Therefore, a second interview with Harper was not required.

The interviews were semi-structured and guided by a protocol that consisted of 25 questions (Appendix A) that elicited the interviewees' view of the relationship between typically developing individuals and their siblings with autism spectrum disorder approximately. They were scheduled to take about 45 minutes; however, some interviewees did not elaborate their answers to some of the questions. Even though they were given probing questions following the primary questions, they provided short answers. In this case the interview took as little as 20 minutes. On the other hand, some interviewees provided detailed explanations to both the primary and the probing questions and continued the discussion beyond 45 minutes. Thus there was wide variation in length among the interviews.

During the interviews, I asked probing questions (Harrell & Bradley, 2009) to get more detailed information about the sibling relationships. For example, when a participant's answer was not clear to me, I asked the participant to give an example of her answer or explain it in greater detail. To illustrate, the participants were asked to describe the challenges they had experienced. One of the participants explained how her emotional reactions changed due to spending a great deal of time with her brother with ASD. However, she did not provide any examples of how she had changed. In order to get more detailed answer, I asked the participant to explain her experience. All of the interviews were audio-recorded. Each audio-recording was

transcribed by a service available on the Internet, REV, which provides transcription, translation, and captioning.

Data Analysis

Because the aim of the study was to examine siblings' perspectives regarding their relationships with siblings with ASD, a qualitative approach was appropriate for the methodology (Merriam & Tisdell, 2015). Thematic analysis (Braun & Clarke, 2006) was employed to code the transcriptions and describe the patterns in the participants' experiences with their siblings with ASD, following Lochmiller's (2015) analysis procedures. I began with reading the transcripts and assigning generic codes to siblings' comments regarding sibling relationships. Examples of these generic codes are "future plans for sibling," "parents' support," "feeling upon diagnosis," and "developing patience."

Next, a second round of coding was undertaken to narrow the codes and eliminate nonessential information. For instance, the initial codes of "patience" and "understanding" were considered as similar categories and they were combined and coded as "sibling personality." In this process, some of the information was considered nonessential and was not included in the second round of coding. For example, one of the participants described how tall her family members were. This information was considered unrelated to sibling relationships and was not included in the coding. The second codes highlighted the typically developing siblings' perspectives on sibling relationships and the effects of having a sibling with autism spectrum disorder. Next, I created five themes by categorizing the second round of codes into broader descriptions. Finally, I underlined noteworthy expressions of participants to be excerpted in the findings section.

Findings

Table 1.

Participants

	Morgan	Audrey	Harper
Age	21	18	22
Sibling's Age	25 (James)	21 (Bethany)	18 (Tom)
Severity of Disability	High-functioning Asperger's Syndrome	Low-functioning Autism Spectrum Disorder	Low-functioning Autism Spectrum Disorder
Residency	In the same city	In the same city/home	In different states
Frequency of Interaction	Once a month	Everyday	Three or four times a year

Theme 1: Effects of Autism on Sibling Relationship

All three participants provided information about their relationships with their siblings with ASD and its effects on their relationship. While all three typically developing siblings were involved in their siblings' lives, the nature and frequency of their involvement differed. Only

Audrey saw her sister every day and spent a great deal of time with her. Even though Morgan and her brother lived in the same city, they did not see each other often. Harper, who lived in a different city from her brother, did not see him frequently. Nevertheless, all the participants stated they had good relationship with their siblings with autism, which they described as close.

The participants were asked to describe their and siblings' personalities. Morgan described her personality and James' personality. According to her, James was a funny, creative, concerned, and compassionate person. She described her brother as having two moods. He was either very calm or very angry. Morgan stated that, as a family trait, he had a short temper. She believed that James could make friends easily; however, he was always afraid that he would do something to damage the friendship. Therefore, he did not have many friends.

When Morgan was asked to describe her personality, she stated she was a shy person. She said: "I like to be around people but I do not want to be involved." She also stated that she did not often approach people to make friends. Later in the interview, she mentioned that she had a difficult time making eye contact with people.

Audrey stated that her sister Bethany does not adhere to a strict pattern; however, she is generally an easy going, happy, and loving person. She rarely gets upset. As for her own personality, Audrey said she was not an ambitious person. She described herself as an outgoing and blunt person.

Harper described her brother as a very positive person. She added that people around them called her brother "Joy Boy" and "Gentle Giant" because he is very tall. She stated that unlike many people with autism spectrum disorder, Tom did not show any aggressive tendencies.

When discussing her own personality, Harper described herself as a patient and understanding person. She added that these characteristics stemmed from her relationship with her brother.

For Morgan and Audrey, who were younger than their siblings with ASD, the diagnosis occurred before they were old enough to comprehend what it meant. However, Harper, the older sibling, stated she witnessed her brother, Tom, changing and showing autistic characteristics when she was between the ages of six and eight. She expressed that she found it very difficult to adjust to the reality of her brother's ASD and her own loss of the "playmate" she had known. On the other hand, both Morgan and Harper stated that they did not have any negative memories regarding the realization of their siblings' autism. Morgan expressed it this way: "I have like a specific memory of like – we are outside playing and I remember thinking like- oh yeah, he has autism."

The siblings spoke of the activities they did with their siblings when they were younger, which included playing on playgrounds, swinging, swimming, and playing with puppets. When asked, "What activities did you usually do with your brother/sister when you were children?" Morgan and Harper described the activities they did with their siblings with autism in detail and smiled often as they remembered these experiences. However, Audrey did not provide as much detail about her activities with her sister. She gave only a few examples, such as swimming and "hanging out" together. She explained: "She is a very low functioning, so we could not do any great activities... There are not many things we can do together."

Among the activities the participants presently did with their ASD siblings were watching TV series or cartoons that the sibling with autism likes, tutoring at school, trying new food, and trying new activities such as going to the cinema. However, because Harper and Morgan did not see their siblings with autism often, these activities occurred infrequently. With some

excitement, Harper explained she encourages her brother, Tom, to try new experiences, such as foods and activities. For instance, Tom used to be afraid of dark rooms so he could not go to the cinema, but she helped him overcome his fear. Harper stated that when she meets her brother, she encourages him to do things he could not do before. On the other hand, although Audrey spends a great deal more time with her sibling, Bethany, than the other participants do, she only mentioned tutoring her sister at school and just spending time together because her sister was low functioning.

Some of the participants also spoke of the conflicts they had with their siblings with autism spectrum disorder. Audrey reported having minor conflicts with her sister with autism, who used to chew on her toys and books when she was younger. When Audrey was asked if she got angry with her sister because of her chewing behavior, she said: “Not really. I might go up to her and be like ‘This is mine, do not do that please. That is mine.’ but she does not really care... She lives in her own little world. She does not care.”

According to Audrey, since Bethany did not care when she was asked to stop chewing something of Audrey’s, they got over the conflicts between them quickly. She also expressed that she did not dwell on such conflicts, suggesting that she accepted the futility of arguing with her sibling with autism.

However, Morgan expressed having some conflicts with her brother with autism due to his frequent tantrums. She also added having problems with her brother because of family issues:

My parents told me why they were getting divorced. I knew everything that was going on and he just knew they were splitting up....He was not happy about it but he did not understand what was going on. I was angry at our father and did not

want anything to do with him. James did not understand that and he would get mad at me....I would get so frustrated with him because he just did not understand....It was horrible because he was so mad at me.... (Morgan, personal communication, March 2017).

Morgan stated that in order to resolve the conflicts with her brother, she considered herself responsible for taking the first step and explaining the problem to him. Similar to Audrey's comments, Morgan also stated her brother with autism would not make any attempts to help solve the problem. Harper, on the other hand, did not report any conflicts with her brother with autism.

Among sibling participants, only Morgan reported sharing personal issues with her sibling with autism because his autism is not as severe as that of the others' siblings. The other participants agreed that because their siblings with autism were low functioning, they would not comprehend a conversation about personal issues.

When asked to explain the effects of autism spectrum disorder on their relationship with their siblings, all the participants identified the effects as positive.

Morgan explained:

...We definitely appreciate each other a lot in a way that you just do not think when you are really small because people are just there...We understand our relationship and that it is different from most people's, and I think we have come to embrace it... (Morgan, personal communication, March 2017).

Audrey reflected:

...I think we are closer because there is this unconditional bond and I cannot really be mad at her for whatever she does. I do not like to use the word but I find her very adorable. In spite of the fact that she is older than me because she has autism, it is very much like I am the older sister so it did change that dynamic there (Audrey, personal communication, March 2017).

Finally Harper commented:

I know that he will not understand it but I cannot thank him enough for the life lessons that he has taught me and just always being there for me even though he does not even really know it. On the days where I needed him most, he was just there saying “Tickle my neck.” So, he has small phrases that he can use. Like, “Juice please.” or “Tickle me.”...The connection we have is like nothing I have ever seen (Harper, personal communication, March 2017).

Even though they differed in their interactions, the participants indicated having very close relationships with their siblings with autism. Referring to autism, Audrey said: “I think it did bring us closer.” Morgan and Harper stated that due to their close relationships with their brothers with autism, they could understand their siblings better than their parents could.

Finally, the participants discussed being curious about how their relationships with their siblings would be if they did not have autism spectrum disorder. All the participants stated that they loved their siblings with autism and appreciated the relationship they shared. Morgan and Harper also expressed their curiosity about the person their siblings might have become if they did not have autism spectrum disorder, while Audrey recalled once wishing she had a neuro-typical older sister: “I wished I had that big sister I could just depend on every now and then. I

do not think about it much anymore. I am very happy with the way she is but as a kid, I definitely thought about that.”

Theme 2: Effects of Autism on Typically Developing Siblings’ Relationships with Parents

All the participants stated that having a sibling with autism spectrum disorder affected their relationships with their parents. The most mentioned factor affecting their relationship with their parents was the attention given to the sibling with ASD. All the participant siblings reported memories of being upset and frustrated because their siblings with autism were getting most of their parents’ attention. Audrey and Harper reported being jealous of the attention their siblings receiving. Harper explained how she felt when her parents could not attend her sporting events or take her to places she wanted to go, which led to her wanting to be self-sufficient:

Just deciphering and choosing, picking your battles essentially. Do I really want to fight with my parents over being able to go do this or whatever? That is why getting my drivers’ license was huge. Because I could take myself somewhere (Harper, personal communication, March 2017).

Harper also described how her father would support and advise her when she was having a difficult time coping with her parents and her brother with autism:

...if I am upset about something, he (her father) would just say, “What can you control?” And the response always would be, “Myself.” and my dad would say “You cannot control that Tom has autism....You can only control how you react to it and that is it.” (Harper, personal communication, March 2017).

Despite the amount of parental attention their siblings with autism spectrum received, the participant siblings were not upset with them. They all discussed having arguments with their

parents but not with their siblings. In addition, all the participants expressed being understanding towards the attention their siblings were receiving because their siblings needed more attention. Nevertheless, because of the frustration they felt, they talked and argued with their parents. Morgan stated that talking to her mother made her closer to her. Audrey and Harper reported that even though their siblings with autism spectrum disorder were receiving most of the attention from their parents, they were aware of the necessity of the situation.

The second most mentioned factor that affected the relationship between the participants and their parents was their parents' attitudes toward their siblings with autism spectrum disorder. Morgan reported having a bad relationship with her father because of how he treated her brother and her feelings about it:

...My dad wrote him off because...He thinks he is broken...I was the kid who did all of the things he wanted me to do because he would put me into sports that he wanted me to play and drag me to conventions that he wanted me to go to. It was like being the little trophy that you put in front while you kind of brush the other child to the side. Which on the one hand was awful because I love my brother quite a bit and that, I thought, was awful...It is weird, I guess, that made my relationship with my mom so much better and [she] completely did the opposite thing with him (referring to the father) (Morgan, personal communication, March 2017).

On the other hand, Harper reported having a bad relationship not with her parents but with her older sister. She stated the diagnosis of her brother put a strain on her relationship with her older typically developing sister because her older sister had a negative reaction toward their sibling with autism:

We took completely different paths of reactions to it. I think I took it in a positive way, “All right, this is the new life. We have got to keep moving forward. We have got to live it.” And hers was, “My life is a tragedy.” ...so I think it caused a rift in our relationship because of the way that she took it (Harper, personal communication, March 2017).

Theme 3: Effects of Autism on Typically Developing Sibling’s Relationship with Others

The participants discussed the impact that having a family member with autism spectrum disorder had on how they evaluated people when they were first getting to know them. All the participant siblings reported that how acquaintances treated people with autism was a decisive factor in whether they could become friends. Participant siblings did not want to be friends with people who treated people with autism spectrum disorder or any disability poorly.

Harper explained:

Having a brother who is autistic caused me to look at the views and values that others had, and if they did not share the same values that I shared when it comes to people with autism, I did not really care for them. So, that caused me to have less friends (Harper, personal communication, March 2017).

Audrey stated that she did not want to be friends with people who did not have positive attitudes toward her sister with autism. On the other hand, Morgan explained how she made friends through a common experience with autism:

A couple of times though I actually became friends with people on the grounds that [we both had similar experiences]. It just was like a passing moment in conversation

that we had an autistic sibling. Then it was like there was kind of a connection (Morgan, personal communication, March 2017).

Morgan believed that having a brother with autism spectrum disorder gave her the opportunity to teach people:

I feel like it is a good way to teach people because we are like “Oh, well my brother has autism...My brother has very high functioning autism so it just means this specifically, but I have a friend who has a brother who has autism and is in a wheelchair and all of these are different things.” It is kind of like an opportunity to educate (Morgan, personal communication, March 2017).

On the other hand, Harper stated that her parents did not allow her friends to come to her house because her mother did not want to have any incidents due to her brother with autism. She reported that her mother’s decision restricted her from having many friends. However, Harper did not complain about having fewer friends because of her brother’s autism.

Finally, Audrey and Harper both expressed concerns regarding finding a life partner who would accept their siblings with autism. They expected to be responsible for their siblings with autism at some time in the future, which would have an impact on their relationship with a possible romantic partner. Harper explained: “I got my first boyfriend and literally on our first date my question to him was “What do you think about people with autism?”

Theme 4: Sense of Responsibility

It was found that the participants had a strong sense of responsibility for their siblings with ASD, which, they explained, came from within themselves as well as the expectations of

their parents. Audrey and Morgan stated feeling like an older sibling and even a mother although they were younger than their ASD siblings.

When participants were asked what responsibilities related to their siblings' autism they had to assume when they were younger, they described taking the sibling with autism to places such as to the occupational therapist, preparing meals, helping them socialize, watching over the sibling when the parents could not, and cleaning the sibling such as changing their diapers and bathing the sibling. Audrey reported being angry at her mother when she was younger but never at her sister because of the responsibilities she had. Morgan also described her feeling about the responsibilities she had in the past: "It is like stressful because I also was just a child...It is kind of scary sometimes to be that little and have that much responsibility for another child."

Next, the participant siblings were asked to discuss their present responsibilities for their siblings with autism. Because Morgan's brother was high functioning, she did not consider herself responsible for the same things that Audrey and Harper described. For instance, Morgan saw herself responsible mainly for making sure her brother did not meet the wrong people and for encouraging him to do things he is capable of. In these matters, she took her responsibilities seriously: "If something is not going well, I feel particularly responsible for – oh, I did not do my job."

On the other hand, Audrey and Harper felt that their responsibilities had not changed since when they were younger. They also expressed their concerns regarding the future of their siblings with autism. Audrey reported mixed feelings about her responsibilities for her sister when they are both adults:

I would love to just have Bethany with me but I know it is not always going to be a possibility. I do not want to put her in a home, but I get concerned about how it is going to be when I am an adult and she is an adult (Audrey, personal communication, March 2017).

Harper also expressed her concerns regarding the future with her brother with autism. However, unlike Audrey, Harper is very certain that she wants to assume full responsibility for the care of her brother when her parents pass away. After her parents stipulated in their will that Harper was to live with her brother with autism once they had passed away, she realized she would have to prepare herself for that future:

I will not be able to take care of my brother if I cannot take care of myself. So I really need to mentally prepare for that, physically prepare for that...It is a little scary because “knock on wood and say all the prayers” but if my parents were in a car accident and passed away tomorrow, my brother becomes mine. And that is kind of scary, so obviously, I do not want that to happen. But right now, I am just preparing for that by staying in school, doing my best, going to graduate school (Harper, personal communication, March 2017).

Thus, knowing that she would eventually be responsible for the sibling with autism spectrum disorder was affecting Harper’s life decisions and chosen career path, as she explained she was studying to become an occupational therapist and considering going to the graduate school in order to provide her brother better support options in the future. Morgan also expressed her concerns for the future even though she would not have to assume full responsibility for her brother:

The thing that freaks me out is that I want to move away and I feel kind of morally obligated to not but I really want to, and for the career path that I want to follow, it is not feasible for me to stay here. I do not want to leave him here...I know I have the right and that I can leave and I can do whatever I want but I do not know if that is good or kind or fair (Morgan, personal communication, March 2017).

Theme 5: Personal Development

The participants also discussed ways in which having a sibling with autism spectrum disorder could affect the personal development of the typically developing siblings. This theme emerged from participant siblings' responses to the questions "What was challenging about having a brother/sister with ASD?" and "What were the benefits of having a sibling with ASD?" The answers varied among the participants. Although all the ways in which having a sibling with autism spectrum disorder affected their personalities over the years, Harper and Morgan gave more detailed responses to these questions.

Both Morgan and Audrey reported being more compassionate to people with autism spectrum disorder. Morgan stated:

I think definitely it made me more compassionate, I guess. Especially when I was younger and kids can be very mean....There were a couple of kids in my class who reminded me so much of my brother, and my brother is just a person who is a little bit different, and then people would be so mean to those boys and it freaked me out because if people were being mean to them ... [it meant] somebody was being mean to my brother probably. I did not like the thought of that very much at

all. I just would try to teach people (Morgan, personal communication, March 2017).

Morgan also explained that she had become very protective of people with autism and people with disabilities. Harper explained that she had developed a life goal to help others:

I am not living my life for me anymore. I am living it to help my brother and to help others. I would describe it as I lived my life growing up to help my brother, which stemmed me to now I live my life to help others (Harper, personal communication, March 2017).

Audrey and Harper both mentioned becoming more understanding since they have a sibling with autism spectrum disorder. Audrey explained: "I think it does give me a different insight into it [having a disability] and makes me more prone to understanding and being able to help."

Harper especially emphasized learning to be more patient because of her brother with autism. She also said that she did not like to use expressions such as "tolerate," which suggested sacrifice, when she talked about her relationship with her brother: "...like "tolerating" and "dealing with" -- it has such a bad, negative connotation. I am not "dealing with" my brother. I am exerting patience because I love him and I want him to be happy."

According to Harper, being patient and understanding toward her brother affected her interactions with other people as well. She reported getting less angry with people; instead, knowing that her anger would not resolve an issue, she chose to discuss problems with others and resolve them amicably. However, she acknowledged that she had to get used to adjusting to situations in her life. For instance, she had to adjust herself to being okay when her parents were

not there or when she could not get what she wanted: “Just growing up and learning to be unselfish with things and really distinguishing between what do I want and what do I need.”

When participants were asked to describe the negative effects on their personality development of having a sibling with autism spectrum disorder, Harper and Audrey reported having no negative effects. However, Morgan mentioned some effects which she considered negative. She explained that she had become desensitized to situations about which others would have emotional responses. For instance, because she had gotten used to things that would make many others panic, she often did not react in ways others would consider normal. In addition, she stated her belief that even though she did not have autism spectrum disorder, she had started to show some of the characteristics of autism because she spent a great deal of time with her brother with autism:

I have noticed that I actually am very bad at making eye contact when I talk to people, even though I am not autistic and I do not have Asperger’s or anything. I wonder if that is because I talked to him so much when I was little, because he does not make eye contact with people very much and so I wonder if I learned that from him and now it is hard to break (Morgan, personal communication, March 2017).

In summary, the themes that were discussed above showed that the participant siblings experienced both the hardships and the benefits of having a sibling with autism spectrum disorder. The participants explained that they went through the hardships when they were younger, most frequently the difficulty of accepting their parents’ greater attention toward their siblings with autism spectrum disorder and its effects on their relationship with their parents, although as they matured they understood the necessity of

the situation. The second most frequently mentioned hardship was related to friendship. The participants discussed that people's attitudes toward individuals with autism determined whether they would be acceptable as friends, which limited the participants' number of friendships. Another hardship mentioned was the responsibility they assumed for their siblings with autism spectrum disorder both in the present and for the future, which was reported by all three participants though they described different kinds of responsibilities. Despite the difference in their assumed responsibilities, the participants indicated that the responsibilities concerned them and had certain implications for their lives.

Nevertheless, the participant siblings reported experiencing greater benefits of having a sibling with autism spectrum disorder. The most frequent mentioned benefit was the effect on their own personal development. All three participants claimed that having a sibling with autism helped them have more understanding, sympathy, and patience. In addition, the participants reported even though there were some negative effects on friendships, they also found friends among people who shared similar experiences. They explained that meeting someone who had a sibling with autism resulted in almost immediate friendship due to the bond they shared. Finally, the participants stated that autism spectrum disorder made their relationship with their siblings closer.

Discussion

The present study examines three typically developing adults' perspectives, elicited through semi-structured interviews, on their relationships with their siblings who have autism spectrum disorder. The main finding of this study is that having a sibling with autism spectrum disorder has both negative and positive effects on the typically developing siblings' lives and

their relationships with the siblings who have autism. The findings of the current study concur with the other studies that examined the relationship between the typically developing siblings and siblings with autism spectrum disorder. Five themes emerged from the interviews that reflect typically developing individuals' interpretations of the experience of having a sibling with autism.

All three participants reported having very few conflicts with their siblings with autism and expressed resolving conflicts that did arise very quickly. Walton & Ingersoll (2015) indicated in their study that siblings of individuals with autism show less aggression in their relationship with their siblings compared to siblings of typically developing individuals. The results of the current study suggests an explanation for this outcome, which is that because of the social characteristics of the sibling with autism, typically developing siblings are likely to accept responsibility for taking the first step to resolve minor conflicts. Orsmond et al. (2009) and Petalas et al. (2012) suggest that problem behavior on the part of the sibling with autism has a negative effect on the sibling relationship. However, these results were not confirmed by the findings of this study, which indicate that the problem behavior of the sibling with autism did not increase conflict between siblings.

Orsmond and Seltzer (2007) stated in their study that having a sibling with autism spectrum disorder may have effects on the relationship between the typically developing sibling and their parents and that these effects are generally positive, in particular on the relationship between the mother and the typically developing children. The current study also indicated that the relationship between the typically developing siblings and parents is affected by the sibling with autism. However, participants of this study reported having more negative effects than positive, largely due to the disproportionate amount of parental attention given to the sibling with

autism spectrum disorder, in response to which the participants reported experiencing frustration and jealousy. However, despite these negative emotions, the typically developing siblings showed understanding of the need to give extra attention to their siblings with autism. The results also indicated that the attitudes of other family members toward the child with autism have an impact on the parent-typically developing child relationship. It was found that the negative attitude of one of the parents or other siblings toward the sibling with autism negatively affected the sibling-parent relationship.

Although neither supporting nor opposing literature was found, the current study showed that having a sibling with autism spectrum disorder influences typically developing siblings' friendships both positively and negatively. People's attitudes toward individuals with autism can be an indicator of the acceptability of a friendship for typically developing siblings. In addition, according to the reported experiences of the participant siblings, it was found that people who have siblings with autism spectrum disorder form immediate friendships among themselves due to their similar experiences.

It was found that the participant siblings assumed responsibility for their siblings with autism both in the present and for the future. Orsmond and Seltzer (2007) found that the typically developing siblings assume additional responsibility when their parents pass away. This finding is consistent with the results of the current study, which show that although the assumed responsibilities vary from helping with homework to providing lifetime care, typically developing siblings have concerns regarding the future of their siblings with autism and their own future lives. Rossetti and Hall (2015) found that siblings of people with severe disabilities experience stress and frustration due to the responsibilities they assume. Hesse et al. (2013) also reported that typically developing siblings of individuals with autism have emotional and

economic stress in their lives. The findings of this study showed that these siblings were concerned with the pressures of needing to provide for both their siblings with autism in the future and their own personal well-being. The siblings reported needing to prepare themselves mentally, physically, and economically to be able to thrive in the future.

The results of this study indicate that having a sibling with autism spectrum disorder has some impacts on typically developing siblings' personal development. These findings concur with Macks and Reeve's (2006) study, which reported that typically developing siblings of individuals with autism consider the effects on their personal development as positive, such as encouraging them to have more optimistic attitudes than peers. As stated above, the participants of this study reported developing more understanding, sympathy, and patience due to their relationships with their siblings with autism. It was also found that having a sibling with autism inspired a desire to help other people. Walton and Ingersoll (2015) also indicated that typically developing siblings of individuals with autism spectrum disorder may display high levels of tendency to help others.

Although it was not the aim of this study to examine the effects of the characteristics displayed by autistic siblings on their typically developing siblings, the findings suggest that growing up with siblings who have autism may result in the typically developing siblings assuming some of the characteristics of autism. The phenomenon of relatives of individuals with autism spectrum disorder displaying characteristics of autism is called broader autism phenotype (BAP) (Scheeren & Stauder, 2008). Research on the incidence of BAP in families with individuals with ASD indicates that there is a high likelihood that family members will display autistic characteristics when they have an individual with ASD in the family (Cribb, Olaithe, Di Lorenzo, Dunlop, & Maybery, 2016).

The literature shows that younger typically developing siblings have more emotional problems compared to older typically developing siblings (Petalas et al., 2009), a finding that was not supported by this study. The findings showed that the participants had similar emotional problems despite differences in their birth order in relation to the sibling with ASD. The literature also indicates that female typically developing siblings are more involved in the lives of their siblings with autism lives and show fewer emotional problems (Orsmond et al., 2009, Petalas et al., 2009). However, the current study did not indicate gender effects on the siblings' relationship because all participants were female, and the gender of the sibling with autism did not suggest any significant differences among the participants' relationships with their siblings with autism.

At the beginning of this study, it was expected that participants who have siblings with low functioning autism spectrum would report more negative than positive effects of the presence of autism. However, it was found that having a sibling with autism spectrum disorder had more positive effects than negative. All three participants reported being very close with their siblings with autism. Despite being very close to their siblings and positive effects mentioned above, typically developing siblings also expressed concerns due the responsibilities they assumed and would continue to assume for their siblings with autism.

Implications and Limitations

In the present research, there are several limitations. First, the study consisted only of female typically developing siblings' experiences with their siblings with autism. Also all three of the participants were Caucasian. Therefore, other ethnic groups and genders were not represented in the study. The results of this study emerged from only interviews. Because most of the participants lived apart from their siblings with autism, observation of their current

relationships was not possible. Therefore, there are no data to support the reliability of the typically developing siblings' interpretations of their relationships with their siblings who have autism. Thus, because this study involved only three Caucasian female typically developing participants from middle-class backgrounds living in a Midwest city, the results cannot be generalized to a larger group.

The results of this study have several implications for future research. First, age, ethnic group, social class, and gender effects on the sibling relationship should be further investigated. Second, future studies are needed to examine the coping strategies of the typically developing siblings. Third, researchers should focus on ways to provide information and support groups for parents and typically developing siblings.

Conclusion

The purpose of this study was to examine sibling relationships between typically developing individuals and their siblings with autism spectrum disorder. For this study, three typically developing individuals who had siblings with autism spectrum disorder were participants. Two of the participants were older than their siblings with ASD. Although they grew up together, only one of the participants reported spending a great deal of time with her sister with ASD. In total five face-to-face semi-structured interviews were conducted with the participant siblings. Interviews took from 20 to 45 minutes. Twenty-five interview questions and probing questions were asked to examine the perspectives of the participant siblings on their relationship with their siblings who had ASD. Following Lochmiller's (2015) analytic procedures, thematic analysis was used and five themes were defined, which reflect the effects of autism on sibling relationships and the typically developing siblings' lives.

The participant siblings explained their experiences with their siblings who had ASD. All participants stated having a close relationship with their siblings even though the frequency of their interaction differed. The participants agreed that having a sibling with ASD affected their relationships with their parents and friends. People's attitudes toward the sibling with ASD determined their quality of the relationship with the participants. Also, the participant siblings agreed that they experienced stress and frustration due to the parents' attention given to the sibling with ASD. All the participants discussed the issue of assuming responsibility for their siblings. They stated that they expected to be responsible for their sibling when their parents passed away. Finally, the participants stated that having a sibling with ASD helped them develop understanding, sympathy, and patience. As this study elucidates only three typically developing participants' experiences with their siblings with ASD, more research is needed to broadly understand the possible effects of having a sibling with ASD on the sibling relationship.

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Appendix A

Interview Questions

1. Can you describe your family?
2. How often do you see your brother/sister?
3. How did you find about your brother/sister's disability?
4. What activities did you usually do with your brother/sister when you were children?
5. What activities do you do with your brother/sister?
6. How did you feel when you were informed about your brother/sister's disability?
7. Did the diagnosis affect your relationship with your brother/sister? Were there any changes in your relationship after you learned about the diagnosis?
8. What was challenging about having a brother/sister with ASD?
9. What were the benefits of having a sibling with ASD??
10. Between you and your sibling, who was getting most of the attention from your parents/guardians when you were younger? How about as you got older?
11. Have you ever felt jealous of your brother/sister?
12. What happened that made you jealous of your brother/sister?
13. Have you ever had any conflicts between you and your brother/sister? How did you solve these conflicts?
14. Have you ever considered your brother/sister as your rival? Why?

15. What were your responsibilities for your sibling when you were a child?
16. How did you feel about your responsibilities in the past?
17. Do you feel particularly responsible for your brother/sister? If so, in what ways?
18. How did autism affect your relationship with your parents?
19. How did autism affect your relationship with your friends?
20. Does your sibling ever make you angry/frustrated? In what ways?
21. What do you think about your brother/sister's future?
22. Do you share personal issues with your brother/sister?
23. How did your relationship change over the years?
24. How do you manage your frustration which is caused because of your brother/sister?
25. Have you ever felt that your relationship would have been better if your brother/sister did not have autism spectrum disorder?

Curriculum Vitae

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