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The Experiences of Individuals with a Sibling Diagnosed with an Autism Spectrum Disorder

Submitted by Hannah Huinker

May, 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

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Abstract

This study investigated the experiences of individuals with a sibling diagnosed with an autism spectrum disorder. Six siblings between the ages of eighteen and thirty-nine participated in the study. This qualitative study investigated the quality of the sibling relationship between the neuro-typical sibling and the sibling diagnosed with an autism spectrum disorder. In addition, participants were asked how having a sibling diagnosed with an autism spectrum impacted their pro-social behavior, parental treatment, career choice, self-esteem, and academic performance. The advantages and disadvantages of have a sibling diagnosed with an autism spectrum were also explored. Results indicated that participants have very close sibling relationships with their sibling diagnosed with an autism spectrum disorder but there were mixed responses to how their sibling affected their academic performance and parental treatment. The majority of participants responded that their sibling on the autism spectrum had an impact in their career choice. All of the participants believed that their sibling improved their pro-social behavior making them more compassionate and understanding of other peoples' differences.

Acknowledgements

I would like to thank my chair, Professor Keith DeRaad, for his continuous support during this past year's arduous paper writing journey. I would also like to thank my two committee members, Doug Eischens and Bridget McMahon, for the time they spent reading my paper, along with the helpful feedback they offered.

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Introduction

The frequency of Autistic Disorders in the United States today is alarming. Sears (2010) comments on the scope of autism stating, “Autism has become one of the most widespread childhood epidemics in recorded history. Except for some infectious disease epidemics of the past, no other serious condition has ever affected so many children” (p. xi). The extent to which an individual and their family’s lives are altered due to an Autistic Disorder is unimaginable. Research indicates that autism has huge implications on the way an individual functions in society. However, there has been little research on the effects autism has on the sibling of an individual with autism.

In order to research the effects of autism on the sibling relationship, two theories were applied to the study. The application of family systems theory (Minuchin, 1988) and attachment theory (Brody, 2011) were both used as a guide for research. The theories provide a framework from which to analyze the sibling relationship. The theories also assist in understanding how having an autistic sibling may have implications on that relationship (Brody, 1998; Minuchin, 1988).

The sibling relationship is a unique and influential bond (Brody, 2004; Milevsky, 2005; Padilla-Walker et al., 2010, Pike et al., 2005; Whiteman et al., 2011). Oftentimes the sibling relationship is the longest relationship an individual has during their lifetime. Several studies indicate that sibling relationships play a significant role in the enhancement of emotional understanding, social development, and self-regulation (Brody, 2004; Milevsky, 2005; Padilla-Walker et al., 2010; Pike et al., 2005; Whiteman et al., 2011). “In the past two decades, however, a growing interest in the family as an agent of change and the focus of preventative care has prompted researchers to investigate dynamic processes and problems in sibling relationships”(Brody, 1998, p. 2).

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Although there has been a growing number of studies performed on the benefits of positive sibling relationships, relatively little research has been done on the effects that autism has on sibling relationships.

Having a family member with autism has a huge impact on the ways a family functions (Corcoran & Walsh, 2009). Specifically, siblings of children with autism are put in unique positions. The distinctive characteristics of autism such as difficulties in social interaction and communication provide siblings with marked challenges in their own development of social skills, self-esteem, and emotional regulation.

Literature Review

There is an abundance of literature on the unique characteristics of autism spectrum disorders, along with research on how having a child with autism affects the caregivers. Research supports the idea that having a positive sibling relationship plays an integral role in the development of pro-social behavior, self-esteem, improved life satisfaction, and reduces the risk for depression (Brody, 1998; Milevsky, 2005; Padilla-Walker, et al., 2010; Whiteman, et al., 2011). Due to the social and communication deficits of autism, growing up with a sibling with autism can be dramatically different than growing up with a neuro-typical sibling. Researchers are just beginning to understand the implications of having a sibling with autism on the non-autistic sibling. However, many studies that exist have found conflicting information on the positive (Hastings, 2003; Kaminisky & Dewy, 2001; Macks & Reeve 2006; Rivers & Stoneman; Verte et al., 2003) and negative (Orsmond & Seltzer, 2009; Verte et al., 2003) effects of having a sibling with autism.

Autistic Disorder

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Autistic Disorder is characterized by significant impairments in social interaction, communication, and a limited range of interests and activities (Corcoran & Walsh, 2009; Guzman, 2009). Individuals with autism demonstrate characteristics of this disorder in a variety of ways depending on the developmental level and age of the individual (American Psychiatric Association [DSM-IV-TR], 2000). The Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (2000) gives a framework for the diagnostic criteria for an Autistic Disorder.

In order to meet the diagnostic requirements for a qualitative impairment in social interaction at least two of the following must be present: “(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interactions; (b) failure to develop peer relationships appropriate to developmental level; (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with others; and (d) lack of social or emotional reciprocity” (DSM-IV-TR, 2000, P. 75).

To meet the diagnostic requirements for a qualitative impairment in communication, at least one of the following must be present: “(a) delay in, or total lack of, the development of spoken language; (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others; (c) stereotyped and repetitive use of language or idiosyncratic language; and (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level” (DSM-IV-TR, 2000, p.75).

The presence of at least one restricted, repetitive, and stereotyped patterns of behavior, interests, and activities is necessary for a diagnosis of autism disorder (DSM-

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IV-TR, 2000). These include: “(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus; (b) apparently inflexible adherence to specific, nonfunctional routines or rituals; (c) stereotyped and repetitive motor mannerisms; and (d) persistent preoccupation with parts of objects” (DSM-IV-TR, 2000, p.75)

Prevalence. In recent years there has been a dramatic increase in the number of reported cases of autism worldwide (Corcoran & Walsh, 2009). A 2006 study by the Center for Disease Control and Prevention estimates that an average of 1 in 110 children in the United States has an autism spectrum disorder (Center for Disease Control and Prevention, 2011). The Center for Disease Control also speculates that 730,000 individuals in the United States between the ages of 0 to 21 have an autism spectrum diagnosis with the assumption that prevalence rates have stayed constant over the past two decades (Center for Disease Control and Prevention, 2011). Government statistics indicate that the percentage of autism cases will increase ten to seventeen percent annually (autismspeaks.org). The reason for the increase in cases of autism has not been established (autismspeaks.org). However, improved diagnostic criteria and some environmental influences have been considered for partial explanations (autismspeaks.org).

Benefits of Positive Sibling Relationships to an Individual’s Development

Although the research on sibling relationships is limited, most research conducted on the topic suggest that siblings play a crucial role in the lives of individuals throughout their entire lifespan (Brody, 1998; Milevsky, 2005; Padilla-Walker, et al., 2010; Whiteman, et al., 2011) The U.S Bureau of the Census (2011) reports that most children

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in the United States are living with at least one sibling. Several studies have found the roles that siblings play in each other's lives to be very significant and influential in the overall development of an individual (Brody, 1998; Milevsky, 2005; Padilla-Walker, et al., 2010; Whiteman, et al., 2011). Due to the abundance and longevity of sibling relationships several researchers have focused on the specific roles that siblings play in each others' life. Whiteman et al. (2011) researched sibling relationships in relation to attachment theory and suggest that siblings can become attachment figures during the early stages of individual's life. The ability to form a secure attachment with a sibling allows an individual to have a secure base in which to explore the world. The sibling provides emotional security and comfort in times of stress (Whiteman, et al., 2011). As siblings age and embark on adulthood, siblings that stay connected also provide each other with a sense of social support and assistance in time of need. Siblings provide companionship, someone to confide in, serve as role models, and are a source of support across the life span (Whiteman et al., 2011).

Cultivation of pro-social behaviors. Several researchers suggest that a positive sibling relationship has a significant influence on an individual's pro-social behaviors (Brody, 2004; Padilla-Walker et al., 2010; Pike et al., 2005). Pike et al. (2005) conducted a study on sibling relationships and individual adjustment, and proposed that siblings who spend more time playing together in a friendly manner may develop skills such as sharing, cooperation, and empathy which in turn helps them develop more pro-social behaviors across a lifespan (Pike et al., 2005). Researchers from Ohio State University examined the behaviors of 20,000 children around the United States and found that children with brothers or sisters had better interactions with their peers (Downey &

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Condron, 2004). Whitman et al., (2011) suggests that siblings provide an opportunity for social learning to take place through their use of social exchanges. These social exchanges can be reinforcement for both negative and positive behaviors but allow children the opportunity to learn about more acceptable social interactions through trial and error (Parke & Buriel, 2006; Whitman et al, 2011). Padilla-Walker, et al. (2010) conducted a study on sibling relationship quality while examining adolescents' self regulation as instrument through which siblings exercise their impact on adolescent outcomes. It was found that sibling affection was directly and positively related to pro-social behaviors, and negatively related to externalizing behaviors (Padilla-Walker, et al., 2010). Previous research suggests that positive sibling relationships support individuals with the framework necessary for the emergence of social skills and emotional regulation (Brody, 2004; Milevsky, 2005; Padilla-Walker et al., 2010; Pike et al., 2005).

Self -esteem. In addition, another theme found in previous research on the quality of sibling relationships is increased self-esteem in individuals with a positive sibling relationship (Milevsky, 2005; Oliva & Arranz, 2005). Milevsky (2005) conducted a study to assess whether support from siblings relates to psychological adjustment in emerging adulthood, and found a direct correlation with participants who documented high sibling support with those who scored higher on self-esteem. In a study completed by Oliva and Arranz (2005) on sibling relationships during adolescence, a correlation between a positive sibling relationship and self-esteem was found, and that for girls there was a significant correlation between self-esteem and a positive sibling adjustment.

Lower risk of depression and increased life satisfaction. Some researchers have suggested that a positive sibling relationship reduces an individual's risk for

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depression (Milevsky, 2005; Waldinger et al., 2007), and many researchers have suggested that positive sibling relationships also increase life satisfaction (Milevsky, 2005; Oliva & Arranz, 2005). Waldinger et al. (2007) conducted a study to examine the quality of childhood relationships with siblings as a predictor of major depression in adulthood, and found that a poor sibling relationship during childhood proved to be a risk factor for depression in adulthood among the participants in the study. Milevsky (2005) found that individuals receiving high sibling support scored significantly lower on depression and significantly higher in life satisfaction. Oliva and Arranz (2005) reported similar findings in a study done on sibling relationships in adolescents, and found a significant correlation between positive sibling adjustment and life satisfaction (Oliva & Arranz, 2005).

Autism Spectrum Disorder's Effects on a Neuro-Typical Sibling.

The majority of research regarding autism's effects on families is focused on child-parent relationships rather than sibling relationships. However, the recent interest in the ways sibling relationships affect an individual's development has increased researcher's curiosity on the affects autism has on the neuro-typical sibling. Due to the unique deficits of autism in communication and social skills, forming a secure sibling relationship can be difficult. People diagnosed with autism are generally unresponsive to others' emotions, have difficulties understanding different peoples' perspectives, lack reciprocity in conversation, don't seek out affection from others, and have difficulty communicating (Kaminisky & Dewy, 2001).

In recent years there has been an increase in research on the adjustment of siblings of children with different kinds of disabilities, including autism. However, the findings

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have shown very conflicting results. Some studies suggest that having a sibling with autism negatively effects the non autistic sibling (Orsmond & Seltzer, 2009; Verte et al., 2003) while others propose positive effects (Hastings, 2003; Kaminisky & Dewy, 2001; Macks & Reeve 2006; Rivers & Stoneman; Verte et al., 2003).

Pro-social behavior/ social competence. Some research studies suggest that siblings of children with autism report less pro-social behavior when compared to siblings of non-disabled children (Hastings, 2003; Kaminisky & Dewy, 2003). A study by Hastings (2003) surveyed mothers of a child with autism and a non-disabled child, in which the mother had to rate the adjustment of the sibling closest in age to their child with autism. Hastings (2003) found that siblings of a child with autism had lower levels of pro-social behavior when compared to a normative sample of children. Kaminisky and Dewy (2003) had similar conclusions with regards to pro-social behavior. They investigated sibling relationships of children with autism compared to children with Down syndrome and siblings of normally developing children, and found that siblings of children with autism reported less pro-social behavior (Kaminisky & Dewy, 2003).

While some researchers suggest that siblings of children with autism report less pro-social behavior, other researchers suggest the opposite (Verte et al., 2003). Verte et al (2003) conducted a study investigating the psychological adjustment of siblings of children with High Functioning Autism (HFA) to a comparison group of siblings of normally developing children, and found that sisters of children with HFA showed higher social competence than sisters of the control group (Verte et al, 2003).

Self-esteem/self concept. In addition, many researchers have also examined self-esteem and self concept in siblings of children with autism, and found that siblings of

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children with autism have a higher self-concept (Macks & Reeve, 2006; Verte et al., 2003). Macks and Reeve (2006) conducted a study in the adjustment of non-disabled siblings of children with autism, and found that siblings of children with autism scored significantly higher than the norms on the self-report measures of self-concept (Macks & Reeve 2006). Verte et al. (2003) conducted a study on self-concept in siblings of children with high-functioning autism (HFA), and found that sisters of children with HFA have a more positive self-concept when compared to sisters of normal developing siblings.

Depression. Some researchers have found more depressive symptoms in siblings of children with autism. Orsmond and Seltzer (2009) conducted a study on adolescent siblings of individuals with an autism spectrum disorder and found that having a family history of autism spectrum disorders was associated with more depressive symptoms. Interestingly, sisters reported higher levels of depressive symptoms when compared to brothers (Orsmond & Seltzer, 2009)

However, some researchers have found that siblings of children with autism scored significantly better on measures of depression when compared to siblings of non-disabled children (Macks & Reeve, 2006). Macks and Reeve (2006) conducted a study on the adjustment of non-disabled siblings of children with autism, and found that siblings of children with autism scored much lower on symptoms of depression when compared with siblings of non-disabled children.

Quality of Sibling Relationship Between a Neuro-typical sibling and ASD Sibling

A small amount of research has been done on the quality of the sibling relationship between an autistic sibling and a neuro-typical sibling, from the perspective

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of the neuro-typical sibling. However, the research that exists is very conflicting on whether or not having a sibling with autism affects the quality of the sibling relationship. Kaminsky and Dewey (2001) investigated sibling relationships of children with autism compared to children with Down syndrome and siblings of neuro-typical children. The researchers surveyed 90 siblings and found that sibling relationships in families with a child with autism were less intimate and nurturing when compared to children with normal developing children or Down syndrome (Kaminsky & Dewey, 2001). However, Rivers and Stoneman (2003) conducted a study on sibling relationships in 50 families with a child with autism and illustrate different findings. Rivers and Stoneman (2003) found that typically developing siblings were positive in their ratings of their sibling relationship.

Future Research

The experiences of siblings of autistic children are relatively unexplored, and there is a limited amount of research on the advantages and disadvantages of having a sibling with autism (Kaminsky & Dewey, 2001). The studies that are available are inconsistent and contradictory in their findings (Verte et al., 2003), and there is very little known about how siblings of children diagnosed with an autism spectrum disorder adjust over the life course (Orsmond & Seltzer, 2009).

Despite research suggesting the importance of a secure sibling relationship, little is known about the experiences of individuals who have had a sibling with an autism spectrum disorder. Given the communication and social deficits that appear in children with an autism spectrum disorder, it is possible to conclude that normal developing siblings experience a different kind of sibling relationship when compared to normal

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developing sibling dyads. Due to the lack of research pertaining to the experiences of siblings of children on the autism spectrum, the proposed research question is: What are the experiences of individuals with a sibling diagnosed with autism spectrum disorder?

The purpose of this study is to explore the experiences of siblings with a sibling with an autism spectrum disorder. This will be done by first, exploring their views on the quality of their sibling relationship and then having them speculate on how they think their life would be different in having had their sibling be a non-disabled sibling? Finally, they will be asked how having a sibling with autism affected their self-esteem, pro-social behaviors, academic performance, and their choice of an occupation?

Conceptual Framework

Theoretical Frameworks

The goal of the current study is to investigate the experiences of siblings with a sibling diagnosed with an autism spectrum disorder. In order to analyze the sibling relationship, specific theories were used to guide the study. Two different theories were chosen to direct the research; the family systems theory and attachment theory.

The application of the family systems theory (Minuchin,1988) provides a framework from which to analyze the sibling relationship (Brody, 1998). Brody (1998), states “According to this perspective, family members are part of an interactive, interdependent network in which behavior in one individual or subsystem affects the others. As applied to the study of sibling relationship quality, characteristics of individual family members or dynamics within family subsystems can contribute to sibling attitudes toward and interactions with one another” (p.3).

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The second theory used to analyze the sibling perspective was the attachment theory (Bowlby, 1969). This theory highlights the early bond between infants and their caregivers (Whiteman et al., 2011). This theory suggests that a secure attachment between caregiver and infant is crucial in the full development of a child (Whiteman et al., 2011). Whiteman et al. (2011) state, “Equally important from an attachment perspective is that, in addition, to their primary caregiver, children can form attachments to a range of familiar others in their social worlds...Siblings can become objects of attachment” (p. 125). If there is a secure attachment formed with a sibling or caregiver, these figures become the base from which children can explore the world (Whiteman et al., 2011). If children have a secure base from which to explore the world, this leads to close and trusting relationships with others. They will also be able to seek the attachment figure as a source of comfort in stressful situations, as well as social supports (Whiteman et al., 2011).

Professional Lenses

The researcher was first introduced to the autistic population through working at a non-profit that supported adults with disabilities in finding career opportunities. The researcher worked with adults that were on the autism spectrum and gained firsthand experience on how autism can affect a family. After working at the non-profit for three years, the researcher began an internship for an organization for children on the autism spectrum. The researcher is currently providing therapy for children on the autism spectrum in both group and individual settings.

As a result of the researcher’s professional experiences with clients on the autism spectrum, the current research project was constructed. The researcher has had the

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chance to observe the effects autism has on individuals and their families. Due to the lack of research on the effects of autism on the sibling relationship, the researcher thought it necessary to explore the experiences of the normal developing siblings'.

A professional bias of the researcher is that autism has huge implications for the family system. The researcher has observed the unique characteristics of individuals diagnosed with autism. In the opinion of the researcher, the unique characteristics of autism make it difficult to share intimate relationships with people diagnosed with autism.

Methods

Purpose and Design

This is a qualitative study and was conducted through six interviews. The interview questions were developed by the researcher, based on data from previous research. The interview questions were written prior to the interviews taking place. The purpose of the study was to gain a better understanding of the experiences of individuals who have a sibling diagnosed with autism.

Sample

The interviewees were between the ages of 18-39 years old and all of the interviewees had at least one sibling diagnosed with an autism spectrum disorder. All of the interviewees were their own legal guardian. Interviewees were found using the snowballing strategy. The snowball strategy required the researcher to first identify several people with the necessary or applicable characteristics and then interview them. At the end of the interview the subject was asked for names of other people who have the same unique characteristics (Berg, 2009).

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The board of directors of an agency working with individuals diagnosed with an autism spectrum disorder and their families was contacted to start the snowballing strategy. One of the board members was asked to forward the email and information to possible subjects for the study. The email that was sent to the board of directors is attached as appendix A. Once at least two subjects were found, the process of snowballing began by asking the subjects if they are aware of anyone else who fit the criteria for this study.

Data Collection

The interviews lasted anywhere between 15 minutes up to 30 minutes and were recorded to provide accurate information for the data analysis. There were approximately sixteen questions used in the interview. The interview questions are attached as appendix C. To guarantee the interview questions were appropriate, they were approved by the IRB before the interview. The questionnaire was a series of questions pertaining to the respondent's experiences in having a sibling diagnosed with an autism spectrum disorder. The questions were open and close-ended in order to gain more detailed insight into the experiences of the interviewees. The questions were based off of previous research covered in the literature review. The first questions pertained to the respondent's view of the quality of their sibling relationship with their sibling diagnosed with an autism spectrum disorder. For example, "how would you rate the quality of your relationship, on a scale of one to five, five being very high in quality and one being very low in quality?". The next series of questions were asked to gain a better understanding of the effects of having a sibling with an autism spectrum disorder on their pro-social skills, self-esteem, emotional well-being, career path, equal treatment by parents, and academic

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performance. For example, “how did having a sibling with an autism spectrum disorder effect your pro-social behaviors?”. The remainder of the questions pertained to how they think their life might be different if their sibling had not been diagnosed with an autism spectrum disorder. For example, “How do you think your life would have been different if your sibling had not been diagnosed with an autism spectrum disorder?”. The entire interviews were transcribed in order to analyze the data for the partner reliability exercise. The interview questions that were used are attached as Appendix C.

Setting

The interviews took place in a quiet, calm, and confidential setting. The interviewees were asked if there was a setting they preferred for the interview for their convenience. Many of the interviews were face to face and some were recorded over the phone.

Analysis Technique

Data from the interview was analyzed using the grounded theory research methodology. Grounded theory is a type of research methodology in which a theory is developed by allowing it to materialize from the data gathered (Monette et al., 2011). Monette et al (2011) states, “With this method, there is a continual interplay between data collection, data analysis, and theory development” (p.225). Codes and themes were identified using the transcript from the interviews. For accuracy purposes, a partner was used for a reliability check after the interviews took place. A partner, working on a similar type of research method, was selected to assist in coding data from the interview transcripts. The partner was given the details on the research question.

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Protection of Participants

The respondents had the option of agreeing to do the interview or declining to do the interview on the terms outlined in the consent form. The agreement included an audio recording of the interview, ambiguity of respondent, and the understanding of the destruction of the recording and field notes on June 1, 2012. A consent form was given to the respondent before the interview to ensure the subject's protection and privacy and to obtain written consent. The consent form is attached as Appendix B. The consent form was approved by the University of St. Thomas/ St. Catherine University Institutional Review Board in addition to complying with the Protection of Human Subject requirements.

Findings

Demographics of Participants

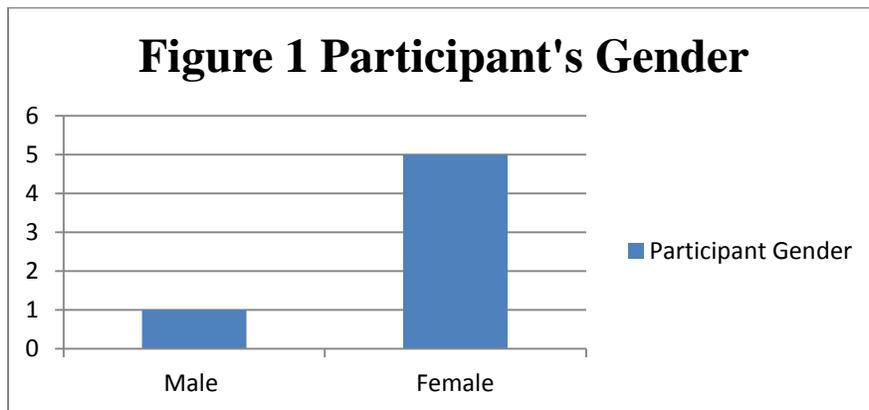
There were a total of six people that participated in this study. The participants' ages ranged from eighteen to thirty-nine years. The majority, four out of the six participants, were under the age of twenty-eight. In regards to the participants' gender, five of the participants were female, while only one was male (see Figure 1). The number of siblings the participants had ranged from one to five. Three of the participants had only one sibling, being their sibling with an autism spectrum disorder. A large number of participants lived with their sibling with an autism spectrum disorder for at least fourteen years. Four of the participants had been living with their sibling with an autism spectrum disorder within the last ten years. In regards to closeness in age, most of the participants were within five years of their sibling with an autism spectrum disorder. Only two participants had a gap of over ten years in age difference. Almost all of the

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participants were older than their sibling diagnosed with an autism spectrum disorder.

Only one participant was younger than their sibling with an autism spectrum disorder.

The majority of the siblings diagnosed with an autism disorder were males. Only one sibling diagnosed with an autism spectrum disorder was a female.



Quality of the Sibling Relationship

The participants were asked to rate their sibling relationship on a scale of one to five, five being very close and one being the least close. Four of the interviewees rated their relationship a five on the scale. Of the participants that rated their relationship a five, they also noted that their sibling relationship with their sibling diagnosed with an autism spectrum disorder was a closer relationship when compared to their sibling relationships with their neuro-typical siblings.

Only two participants gave their sibling relationship with their sibling diagnosed with an autism spectrum disorder a score less than five. One participant noted that her relationship with her brother has improved since they have gotten older. She gave her relationship with her brother three scores, one for their elementary years, one for her high school years, and one for their most current relationship. This participant gave her current

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relationship with her brother a 3.5 on the scale. The other participant gave her relationship a score of four on the scale. She gave a relationship a four because she and her sibling live far apart and they only talk on the phone occasionally.

Pro-Social Behavior

All six of the interviewees suggested that having a sibling with an autism spectrum disorder improved their pro-social behaviors. All of the participants pointed out that they are more understanding and accepting of people's differences because of their experience with their sibling with an autism spectrum disorder. Most participants noted that making friends was fairly easy for them. One participant thought that having a sibling diagnosed with an autism spectrum disorder helped her communications skills and patience with other people because of the ways she had to learn to communicate and be patient with her sibling.

Another participant noted there were some social difficulties she experienced due to her brother's diagnosis. She suggested that due to her brother's diagnosis it was hard to bring friends over to her house because he could become deregulated easily. She noted that she would rarely have friends over to her home unless her parents had made special arrangements for her brother.

Self-Esteem

Five of the participants felt like their self-esteem was not affected by their sibling with an autism spectrum disorder. Only one participant thought that it had a positive effect on her self-esteem. This participant thought that the caretaking role she had with her brother gave her more confidence.

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Academic Performance

There were mixed responses to how academic performance was affected. However, three of the respondents felt like their performance could have been somewhat negatively affected by their sibling with autism, while one thought it had a positive effect, and only two thought it had no effect.

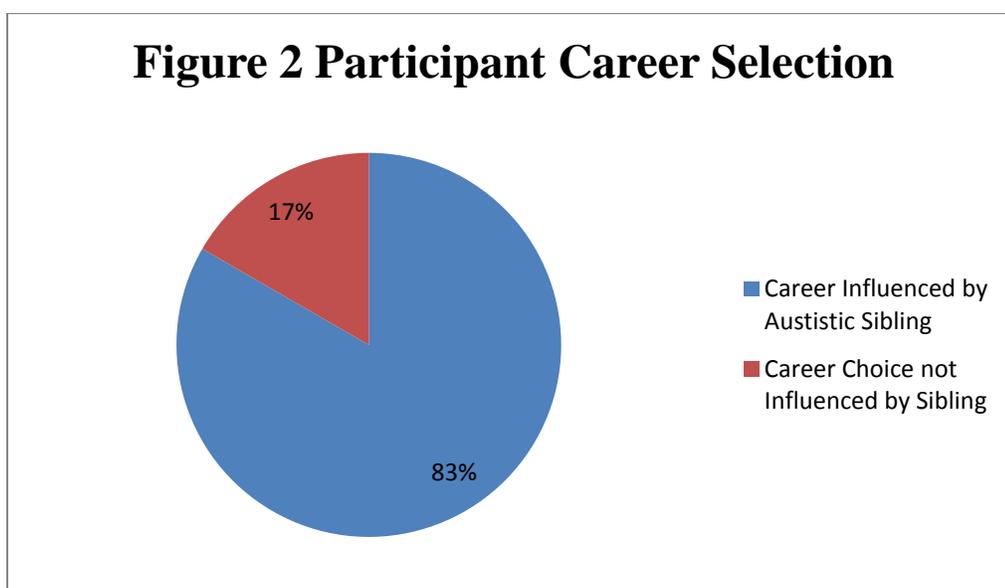
The participants that felt like their sibling may have had a negative impact on their academic performance all had different responses to why there may have been an impact. One participant thought that it was possible she did not finish her four year degree due to her brother's diagnosis. The participant said that she had always been conscious of money because having a sibling with a special need was very expensive. Instead she decided to go to a two year college instead, to reduce her college expense. Another participant suggested that she did well in school but due to her brother's diagnosis, school was very difficult for her. She noted that it was difficult because the way teachers viewed her due to her brother's behavior in school. The next participant suggested that she had difficulty completing homework due to her brother's diagnosis. She noted that she never saw her older brother (sibling with an autism spectrum disorder) do homework so she felt like she shouldn't have to either.

One participant thought that having a sibling diagnosed with an autism spectrum disorder may have had a more positive effect on his academic performance. He suggested that having a sibling diagnosed with an autism spectrum disorder taught him more responsibility, which he carried over to school.

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Career Choice

Five out of the six participants suggested that their career choice was decided based on the experiences they had had with their sibling diagnosed with an autism spectrum disorder (see Figure 2). This quote illustrates how a participant's career choice was affected, "Absolutely, I think my sister had everything to do with this career path. If it wasn't for her diagnosis, I wouldn't have known what a social worker was and what it is that they do. She was definitely a factor in choosing my career path."

**Parental Treatment**

Many of the participants had mixed feelings about the ways in which they were treated by their parents in comparison to their sibling diagnosed with an autism spectrum disorder. Two of the participants felt like they were treated differently than their sibling diagnosed with an autism spectrum disorder, while the other four felt like there was not a difference. Most of the participants that felt like they weren't treated differently suggested that their age gap had something to do with their particular experience. One

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participant suggested that she and her sibling weren't treated differently. However, she felt somewhat confused when she was an adolescent because her mom couldn't make it to all her extracurricular activities because she needed to stay home with her brother diagnosed with an autism spectrum disorder. The other participants acknowledged that they were treated differently. One of the participants felt confusion when she was an adolescent and she would have consequences for things that her brother didn't. Another participant said that her brother would get attention that she wished she had had. This quote illustrates how one participant felt about parental treatment, "I was the perfect child verses the problem child. I received a lot of positive praise and attention and he receive a lot of the negative attention ...But at the same time I resent that he got more attention for that. Everything was very dramatic for him. He did get some of the attention that I wish I had had."

Advantages of Having a Sibling Diagnosed with an Autism Spectrum Disorder

Many of the participants reflected on their relationship with their sibling diagnosed with an autism spectrum disorder with many positive experiences and life lessons. All of the participants commented on how they are more understanding of people's differences. Many participants expressed having more compassion for people that have differences.

Disadvantages of Having a Sibling Diagnosed with an Autism Spectrum Disorder

All of the participants suggested many of the same disadvantages. Four out of the six participants commented on how it was difficult to watch their siblings deal with challenges surrounding school and their peers. These participants also discussed issues associated with watching or hearing about their sibling being bullied or seeing that some

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teachers didn't seem to work constructively with their sibling. Two participants also added that they often feel worried about their sibling and feel the need to protect them. One participant stated, "The disadvantages, as I had said before, I felt like I was my brother's keeper and feeling the need to protect him..... It was really hard growing up with people laughing at my brother..what's wrong with him? Why doesn't he understand? Why does he act that way? And that was really hard for me and it can still be hard for me but he does act strange in a lot of social situations." Another participant commented on how difficult it was to see the way some teachers worked with her sibling. She stated, "I have seen teachers who have completely disregarded him and didn't change how they taught to work well with him."

Discussion

The experiences of individuals with a sibling diagnosed with an autism spectrum disorder are relatively unexplored (Kaminsky & Dewey, 2001). The research that does exist on the experiences of individuals with a sibling diagnosed with an autism spectrum disorder is not consistent (Verte et al., 2003). It is still somewhat unclear why some studies report more positive findings while others have found negative implications to having a sibling diagnosed with an autism spectrum disorder (Orsmond & Seltze, 2009). The current study's findings are more consistent with the research that indicates positive experiences for individuals that have a sibling diagnosed with an autism spectrum disorder. For example many participants reported increased pro-social behavior and a more positive relationship with their sibling diagnosed with an autism disorder. While many of the participants had positive experiences growing up with their sibling, many

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participants reported increased challenges in the areas of academic performance and parental treatment.

In regards to the quality of the sibling relationship from the perspective of the neuro-typical sibling, there was a limited amount of research. However, the research that exists is conflicting. The results of the current study in the area of the quality of the sibling relationship are consistent with a study by Rivers and Stoneman (2003). Rivers and Stoneman (2001) found that typically developing siblings were positive in their ratings of their sibling relationship. In the current study, most of the participants rated their relationship at the highest quality level. The findings conflict with a study conducted by Kaminsky and Dewey (2001), who found that sibling relationships with a child diagnosed on the autism spectrum were less nurturing and intimate when compared to normal developing sibling dyads.

In the area of pro-social behavior, previous research has shown conflicting findings. The current study found that participants believed their sibling with an autism spectrum disorder to have a positive effect on their pro-social behavior. This finding is consistent with Verte et al (2003), who found that sisters of children with high functioning autism showed higher social competence than sisters of neuro-typical dyads. However, research by Hastings (2003) and Kaminisky and Dewey (2003) have discovered lower levels of pro-social behavior when compared to a normative sample of children.

Implications

Social Work Practice

Many families are faced with the challenges associated with raising a child with special needs. Due to the progressively rising number of families affected by an autism spectrum disorder, it is important to understand how each individual in the family system may be affected by the diagnosis. The amount of research on the experiences of individuals with a sibling with an autism disorder is lacking. The current research gives social workers a greater understanding of the experiences of individuals that have a sibling diagnosed with an autism spectrum disorder. A better understanding of the challenges and strengths associated with this diagnosis will support social workers in being more effective in their work with these families.

In this study the majority of participants indicated challenges surrounding peers, teachers, and academics. Many participants discussed how difficult it was to watch their sister or brother being bullied or teased at school. This is an area where social workers should be aware of how challenging it can be for the neuro-typical child to deal with teasing from peers. School social workers may want to start a group for neuro-typical siblings on ways to handle teasing from peers and positive ways they can intervene if they see it happening.

Some participants even brought up how difficult it was to see the way some teachers chose to work with their sibling on the autism spectrum. Social workers could offer teachers educational sessions on ways to best support a child diagnosed with an autism spectrum disorder. Another major challenge that came up with participants was feeling as though they had to be constantly worried about their sibling, some participants

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even discussed feeling like their siblings' keeper at times. This is another area where a support group, in or out of school, lead by a social worker who is aware of the challenges, could be beneficial for these children or adolescents. Lastly, some participants discussed parental treatment. While many participants felt like their parents had treated them equally, some felt some confusion around parental treatment. It would be important for social workers to educate parents on strategies to help their neuro-typical child understand the differences in treatment and find ways to limit differential treatment.

Policy

Additional research in the area of the experiences of individuals with a sibling diagnosed with an autism spectrum disorder helps social workers identify the needs of these specific families. Discovering the needs of these families can help social workers advocate for policies that will best support the people affected by an autism spectrum diagnosis. The results of this study show fairly positive results for the neuro-typical sibling, but there were still challenges associated with their sibling's diagnosis. Many of the participants commented on how difficult it was to see their sibling diagnosed with an autism spectrum disorder being bullied or teased. It would be important for social workers to advocate for programs that help educate school age children on being accepting of people's differences.

Another challenge mentioned by participants was the issue surrounding teachers that did not have effective strategies for working with their sibling diagnosed with an autism spectrum disorder. Additional education for teachers on specific strategies for working with children with an autism spectrum disorder might help reduce the challenges associated with school, for both the neuro-typical sibling and the sibling diagnosed with

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an autism spectrum disorder. Also, early detection of an autism spectrum disorder could help neuro-typical siblings understand why a sibling is acting like they are and help educators to be more effective in their educational plans. This additional education for teachers could be in the form of staff development opportunities that would be mandatory for all educators in order to increase autism awareness and knowledge of autism spectrum disorder. Furthermore, teachers should be required to attend regular meetings involving their students with an autism spectrum disorder, case managers, and parents to create more effective individual educational plans. The increased involvement of the teachers would allow for more consistent support and treatment across all settings for the student diagnosed with an autism spectrum disorder.

Also, many participants mentioned that the one disadvantage of having a sibling diagnosed with an autism spectrum disorder is watching them get teased or being constantly worried about them and feeling as though they are their sibling's caretaker. For these specific challenges it would be helpful to have support groups for adults or children with a sibling diagnosed with an autism spectrum disorder. Support groups would give these individuals a place to discuss their concerns and fears with people that are going through similar challenges. A school would be a great setting for a support group for younger kids who have a sibling diagnosed with an autism spectrum disorder. Also, education programs for parents on the experiences of the neuro-typical sibling would help parents reduce the challenges and stress associated with having a sibling diagnosed on the autism spectrum.

Research

There is a limited amount of research on the experiences of individuals with a sibling diagnosed with an autism spectrum disorder (Kaminsky & Dewey, 2001). In addition, studies that have been done are inconsistent with one another (Verte et al., 2003). Future research will help identify the areas where these siblings are truly facing challenges. Focusing on the experience of the neuro-typical sibling will help researchers gain more insight on the needs of this population. Further research on this topic may also want to look into the specific diagnoses on the autism spectrum to help determine which diagnoses are most challenging for the neuro-typical sibling. Additional research should look into the experiences of the siblings that are currently living with their sibling diagnosed with an autism spectrum disorder. The challenges associated with the diagnosis would be fresh in their minds compared to the participants that were used for the current study. Lastly, future research may want to look into how same sex dyads are affected by the autism spectrum diagnosis verses opposite sex dyads.

Strengths and Limitations

Currently, there is an overall lack of research in the area of sibling relationships and autism (Hastings, 2003; Kaminisky & Dewy, 2001; Macks & Reeve 2006; Orsmond & Seltzer, 2009; Rivers & Stoneman, 2003; Roeyers & Buysse 2003; Verte et al., 2003). Additionally, previous research has indicated a lack of documented information from the perspective of the adult non-autistic sibling (Kaminsky & Dewey, 2001). Therefore, a strength of this study is gaining the perspective of the sibling relationship based on the neuro-typical sibling's perspective. This study offers more insight to the challenges faced by this population. Also, most of the participants were relatively close in age to

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their sibling with an autism spectrum diagnosis and they lived with them for most of their childhood. Due to the fact that most of the participants have spent so much time with their special needs sibling, they were able to offer more in-depth and reliable experiences to the study. In addition, most of the participant had lived with their sibling with autism within the last ten years so their experiences with their sibling were relatively fresh in their minds.

There are some limitations to the current study. The first limitation was the short time frame in which it was implemented. There were only six people who participated in this study. It would have been more helpful to have had a larger sample size to gain a broader understanding of the experiences of individuals with a sibling diagnosed with an autism spectrum disorder. Another limitation to the study was the lack of variation of subjects participating in the study. There were six people who participated in the study; five of the total participants were female. The study only included one male, so the experiences of male individuals with a sibling diagnosed with an autism spectrum disorder may not be fully portrayed in this study. Also, most of the siblings of the participants were males. The study only included one sister dyad. Therefore, the experiences of sister dyads may not be truly reflected in this study. It might be helpful for future research to look into how same sex dyads are affected by the autism spectrum diagnosis verses opposite sex dyads.

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Appendix A

Dear Board of Directors:

My name is Hannah Huinker and I am currently a Master's student at St. Thomas/St. Catherine's School of Social Work. I am working on a research project that is looking into the experiences of individuals with siblings diagnosed with autism. I am interested in interviewing these individuals to gain a better understanding of their experiences, along with identifying areas where they may have needed extra support. I am hoping that you can assist me in finding individuals who have siblings with autism that are at least 18 years of age and are their own guardians. Participants willing to participate in this study will be kept confidential.

The interview will consist of approximately sixteen open and close ended questions. The participants will have the option of answering as many of the questions as they feel comfortable answering. Participation in this study is completely voluntary and they are allowed to stop the interview at any time. Participants will have the opportunity to decide where they would like the interview to take place to ensure confidentiality.

If you are aware of anyone who would fit the criteria for this study, and would be willing to participate, please have them contact me by email or phone.

I will attach the interview questions to this email, so that you can pass them along to any individuals you think would be willing to participate. Thank you for your time and consideration.

Sincerely,

Hannah Huinker

Appendix B

CONSENT FORM**UNIVERSITY OF ST. THOMAS****The Experiences of Individuals with Siblings Diagnosed with Autism**

I am conducting a study on the experiences of siblings with siblings diagnosed with autism . I invite you to participate in this research. You were selected as a possible participant because you have a sibling diagnosed with autism. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Hannah Huinker, supervised by Keith DeRaad, for the School of Social Work.

Background Information:

The purpose of this study is: to gain a better understanding of the experiences of siblings diagnosed with autism. There has been little research done on the effects of autism on the sibling relationship from the perspective of the non-disabled sibling. This research could lead to a greater understanding of the ways in which an autistic brother or sister effects their sibling's development and the quality of the sibling relationship.

Procedures:

If you agree to be in this study, I will ask you to do the following things : participate in an interview session, where you will be asked 10-12 questions about your experiences with your sibling with autism and what you believe to be advantages or disadvantages of having a sibling diagnosed with autism. The interview will take approximately 30 minutes. During the interview field notes along with an audio recording will be gathered

Risks and Benefits of Being in the Study:

The study has some risks. First, participants may not feel comfortable answering all of the questions. Secondly, some of the interview questions may be too personal or evoke emotions that are unwanted by the participants. In order to minimize the risks, participants will be reminded that they can stop the interview at any time. Participants are not required to answer all of the questions and can decide whether or not they want to respond to particular questions

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The direct benefits you will receive for participating are: furthering the research in the area of sibling relationships and autism.

Confidentiality:

The records of this study will be kept confidential. The types of records I will create include field notes, audio recording, and the final research paper. The research paper will be handed in to my professor and two committee members for review. The audio tape and field notes will be destroyed by June 30, 2012.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of St. Thomas. If you decide to participate, you are free to withdraw at any time.

Contacts and Questions

My name is Hannah Huinker. You may ask any questions you have now. If you have questions later, you may contact me. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I consent to an audio recording of the interview.

Signature of Study Participant

Date

Print Name of Study Participant

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Signature of Researcher

Date

Appendix C

Qualitative Research Topic: The experiences of individuals who have a sibling diagnosed with an autism spectrum disorder.

Research Question: What are the experiences of individuals who have a sibling diagnosed with autism?

Interview Questions

1. How old are you?
2. How many siblings do you have?
3. How old is your sibling with autism?
4. How long did you live with your sibling with autism?
5. How long has it been since you lived with your sibling with autism?
6. What are your experiences of having a sibling diagnosed with autism?
7. What do you think are the advantages and disadvantages of having a sibling with autism?
8. How do you think your life would have been different if your sibling was not diagnosed with autism?

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9. How do you think your sibling with autism affected your performance in academics?
10. How do you think your sibling with autism affected your pro-social behavior (sharing, cooperation with peers, and how well you played with your peers)?
11. How do you think your sibling with autism affected your self-esteem?
12. On a scale of 1 to 5, how would you rate the quality of your sibling relationship (1 being the lowest and 5 being the highest)? If you have other siblings how would you rate those relationships? Are they different?
13. What career path have you chosen? Do you think your career choice had anything to do with growing up with a sibling with autism?
14. Do you feel like you were treated the same by your parents? If not, how was it different?
15. How do you think having a sibling with autism has impacted you emotionally?
16. Do you have anything else you would like to add?