

Apr 19th, 8:30 AM - 9:45 AM

Autism & Cancer: Interventions and Interpersonal Communications

Patricia Northcutt

Kevin Holland

Follow this and additional works at: <https://digitalcommons.collin.edu/ccuisrc>

Northcutt, Patricia and Holland, Kevin, "Autism & Cancer: Interventions and Interpersonal Communications" (2018). *Collin College Undergraduate Interdisciplinary Student Research Conference*. 5.
<https://digitalcommons.collin.edu/ccuisrc/2018/thursday/5>

This Panel is brought to you for free and open access by DigitalCommons@Collin. It has been accepted for inclusion in Collin College Undergraduate Interdisciplinary Student Research Conference by an authorized administrator of DigitalCommons@Collin. For more information, please contact mtomlin@collin.edu.

How Neuro-typical Adults with Autistic Siblings Disclose their Siblings with Friends

Patricia Northcutt

Collin College

SPCH.1318

The purpose of this study is to examine how neuro-typical adults with autistic siblings disclose their siblings with their friends, and to discover any trends that may occur during the disclosure process. In most cases, the research on neuro-typical adults with autistic siblings is widely overlooked and rarely studied. My conation for this study is to bring attention to this topic in order to educate the public, support those who are able to relate to the topic, and provide my personal insight to the topic.

While autism is widely known, there is still an existing barrier between the knowledge and understanding of it within the public. A study was conducted by Abousaadah, Alsehem, Sairafi, and Jan (2017) on the public's awareness of autism, and their results concluded that public awareness of autism is limited and needs improvement (Abousaadah et al., 2017). With limited knowledge on autism, it is difficult for the neuro-typical siblings of autistic individuals to disclose the topic of their autistic siblings and their home-life with friends, since there are commonly believed misconceptions on autism. The relationship between neuro-typical siblings and their autistic siblings is extremely complex, so the study on disclosure with friends is vital in order to discover how people can understand autism, and also improve the relationships between these adult siblings and their friends.

Method

Participants

In order to be included in this study, participants needed to be over the age of 18 and have at least one sibling with a diagnosed autism spectrum disorder. I only surveyed the neuro-typical sibling to ensure I received the proper information needed for this study. Sex was not a subjective matter while gathering participants. As a result of these criteria, participants included six females and four male individuals. The ages of the participants ranged from 18 to 45 years

old at the time the survey was completed. Of these 10 participants, nine had one sibling with autism, and one had two siblings with autism. Age and gender of the autistic siblings was not significant to the study.

Procedures and Instrumentation

Data collection occurred during week 12 of a 16-week semester. The survey given to all 10 participants included four open-ended questions. These four open-ended questions related to what methods the participants use to disclose their autistic siblings, the chronemics involved during disclosure, and what the common reaction is after the initial disclosure. At the end of the survey, the participants were asked to answer three demographic questions such as their age, gender, and the number of autistic siblings each participant has. These questions were optional, but they served as support for the research.

Six out of the 10 surveys completed were handwritten onto the paper survey I presented to the participants, and four surveys were sent over email and text messages due to long distance communication. I was not present during the completion of the surveys, but one survey was given to a close relative.

Data Analysis

After receiving 10 completed surveys, similar responses were grouped together and written on sticky notes. Each group of answers was placed onto a white board broken up into four sections, one for each question, and then organized by response. A total of 64 sticky notes were used in this process. For example, question one had two similar answers that were placed under two categories, six participants answered “as soon as possible” and three answered “far into the relationship,” with a lone participant answer of “never.” Question two had two categories that had five participants answers “far into detail” and five answer “not too much

detail.” Each question had a multitude of answers that resulted in numerous categories, with some categories only containing one answer.

Results

Question one asked the siblings how far into the relationship they wait to disclose the topic of their autistic sibling(s). Two themes were identified from the responses, including as soon as possible and far into the relationship. Six out of the 10 participants answered with the former response, with the intention of honesty and trust within the relationship. Participant three answered, “How is the relationship supposed to be successful if it is built on a lie? I want my friends to know who I am from the very beginning to avoid any confusion.” These six participants were analogous with their answers. The other four participants who answered far into the relationship elaborated by using code words such as “privacy” and “none of their business.” Participant five answered, “[my sibling] and my family is a private matter. If I don’t fully trust the person yet, or it is too early into the relationship, I don’t want them to know about my private life. That’s none of their business.” Participant two answered “never” which was its own category without any similar responses.

Question two asked the siblings what detail they go into while discussing the topic of their autistic siblings(s). Only two categories were identified from the responses. Five participants answered far into detail and five answered not too much detail. The five that answered far into detail had a theme in their responses of assisting the friend to understand what autism is in order to create a strong foundation in the relationship. Participant eight answered, “I find its best to go into great detail while discussing my sibling so that way my friend will know what to expect when they meet my family.” Participant seven had a similar answer, “I let my friends know the good, the bad, and the ugly. That’s why we are such good friends.” The oldest

participant, participant 10, is 45 years old and gave more insight into how the older generations perceive autism during disclosure, “Before my brother was diagnosed, autism was not well known. Many people have misconceptions and lack a point of reference. Details provide background and serve as educational opportunities.” The other five participants had a coherent theme in their answers as well. One coherent idea was that not too much detail is best as to not scare off any potential relationships. Participant five answered similarly stating, “No one really wants to know what is going on at home. If they say they do then they’re lying to you.”

Question three asked the siblings what the common reaction they receive is when they initially disclose their sibling(s) to their friends. Three themes were identified in the answers, including friendly and supportive, uninterested, and anecdotal stories. Five participants answered friendly and supportive, three answered uninterested, and two answered anecdotal. The participants that answered friendly and supportive had coherently positive reactions and remarks towards their friends. Participant one stated, “If my new friend seems supportive towards my life situation, then I feel good about the choice I made for having them as a friend.” A similar answer was given by participant three, “Not only do I know my friend is supporting me, but they are also supporting [my sibling] and the rest of my family as well.” For the three participants that answered uninterested, disappointment and discouragement was a common reaction in their responses. Participant six stated, “When I realize they don’t care about my sibling having autism, I assume they don’t care about me as well.” One participant from this category answered differently stating, “I once had someone tell me they didn’t care my sibling has autism since they see everyone as equal. It made me feel good about my relationship with them.” The two participants who answered in the third category expanded their responses by discussing times they interacted with friends who believe false rumors or misconceptions on autism. Participant

10 stated, “Anecdotal stories are what I commonly hear. Questions like ‘Were your siblings vaccinated’ or ‘Maybe it’s their diet that made them autistic.’”

Finally, question four asked the siblings how far into the relationship they wait to have their friends meet their autistic sibling(s). Only two themes emerged from their responses, including soon after the relationship initiation and later into the relationship. Three participants answers were placed into the first category, while the other seven answers were placed in the second category. One participant gave a specific time range of three to four months, another gave one to two months, and the other gave up to six months. Participant nine stated, “I once waited a week before having my new friend meet my autistic sibling. It didn’t end well since they were not prepared for how my sibling acts around new people.” Participants nine and three similarly answered that they talk to their autistic sibling(s) about meeting their new friend before having the formal meeting. The other seven participants set a long wait period between relationship initiation and the meeting, including any time between six months to a year. Participant five answered, “I will usually wait to have my new friends meet my sibling as an attempt to stop them from getting scared off.”

Discussion

The purpose of this study was to understand the complex nature of how neuro-typical adult siblings discuss their autistic siblings with their friends. This study extends the limited research conducted on the topic of neuro-typical siblings, and the results have the possibility of changing any previous misconceptions on autism by educating the public. The results from this study indicate that relationship initiation varies, as well as the maintenance of these relationships with the disclosure of autistic siblings. Two overall themes were present in this study, one including those who are comfortable with sharing with their friends the topic of their autistic sibling(s)

with the intention of relationship maintenance and trust, and also educating their friends and the public. And two, those who choose not to discuss with their friends the topic of their autistic sibling(s) in order to maintain privacy and boundaries in the relationship, or to protect their friends or autistic siblings from any possible harm or confusion. A similar study was done by Angell, Meadan, and Stoner (2012) to determine how young neuro-typical siblings discuss their autistic siblings with friends. The results of the study concluded that neuro-typical individuals seek out relationships with people in order to fulfil their supportive needs. According to the study, “Our participants wanted time for themselves when situations were stressful, and they benefitted from talking with others who understood their situation, educating others about ASDs, and implementing techniques to assist their siblings with ASDs” (Angell et al., 2012). The findings of my study concluded similar ideas that when discussing their autistic siblings, neuro-typical individuals seek out relationships with people who will be supportive and understanding of their situation.

The findings of this study can be beneficial to scholars and doctors alike since it covers the gaps of previously conducted studies, and gives recognition to the neuro-typical adults that may struggle with discussing their autistic siblings with friends. Previous studies have mainly focused on the relationship between the neuro-typical siblings and their autistic siblings, instead of how the neuro-typical siblings interact with those outside of the family. A study was done last year by Ben-Itzhak, Zukerman, and Zachor (2016) to find out if having an older neuro-typical sibling helps autistic siblings have less severe social interactions. Their findings concluded that there is in fact a strong correlation between having an older neuro-typical sibling and exhibiting less severe social interactions with others. The study states, “Having sibling/s may offer opportunities for the child with ASD to experience social interactions with children and to

acquire communication skills” (Ben-Itzhak et al., 2016). Another study was also conducted to determine how neuro-typical children discuss their autistic sibling with their parents. The authors of the study state, “Siblings of children with autism are often described as the ‘forgotten child.’ This is because the child with autism is often in the centre of the family due to his or her complex needs” (Chang & Goh, 2014). This idea of neuro-typical siblings being forgotten or less supported is similar to the study done by Angell on how the siblings seek out a support system in order to deal with their home-life. Friendships are a vital tool in assisting neuro-typical siblings to be heard and understood by others, and this study I conducted will hopefully aid in this continuous study.

It is apparent in this study that the public’s awareness is extremely limited when it comes to understanding autism and the siblings who live with autistic individuals. To further this research, more neuro-typical siblings with autistic siblings would need to be surveyed, and the viewpoints from the friends of the adult, neuro-typical siblings should be enacted to truly determine the results of this study. Another question should be added to the survey to determine the participants knowledge on autism. With the research conducted, this study builds on interpersonal communications skills and methods used by neuro-typical adult siblings, and also allows for improvement in these skills and methods. With this study, I hope to educate the public on who the people are that are affected physically and emotional due to autistic siblings, and also the friends who may be a support system for the neuro-typical siblings.

References

- Abousaadah MM, Alsehemi MA, Jan MM, Sairafi RA. (2017). Public awareness of autism spectrum disorder. *Neurosciences*, 22, 213-215.
- Angell, M. E., Meadan, H., Stoner, J. B. (2012). Experiences of siblings of individuals with autism spectrum disorders. *Autism Research and Treatment*, 2012, 1-12.
- Ben-Itzhak, E., Zukerman, G. & Zachor, D. A. (2016). Having older siblings is associated with less severe social communication symptoms in young children with autism spectrum disorder. *Journal of Abnormal Child Psychology*, 44, 1613-1620.
- Chang, G. W., & Goh, E. C. (2014). My parents told us that they will always treat my brother differently because he is autistic- are siblings of autistic children the forgotten ones? *Journal of Social Work Practice*, 28, 155-171.