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Siblings of Children with Autism: An Exploratory Study of Sibling Concerns and Coping Strategies

MARY CANHA



Mary is a senior majoring in social work with a minor in psychology. Her research was made possible with funding from a 2009 ATP summer research grant under the mentorship of Dr. Lucinda King-Frode and was presented at NCUR 2010. Mary says that the inspiration for the project came from high rates of diagnosis in autism spectrum disorders and knowing many families affected by the diagnosis.

Autism (sometimes called “classical autism”) is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASDs) and is characterized by impaired social interaction, problems with verbal and nonverbal communication, and unusual, repetitive, or severely limited activities and interests (NINDS, NIH, 2009). Other ASDs include Asperger Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder not otherwise specified (usually referred to as PDD-NOS). Experts estimate that three to six children out of every 1,000 will have autism. Males are four times more likely to have autism than females. (NINDS, NIH, 2009)

The rise in the rate of the diagnosis of Autism Spectrum Disorders makes it essential for social workers to gain insight into its impact on families including the siblings. Limitations in social interaction and empathy in a child with autism can have both positive and negative impacts on the siblings of these children. So what coping strategies do these siblings use to manage their reactions to the challenges presented by their autistic sibling? I interviewed seven siblings of autistic children to contribute to the knowledge that helps social workers better serve these families by gaining access into the siblings’ concerns and how they manage those concerns.

Background Research

While deficits in social interactions are a key issue in a child with an ASD, some studies found that a sibling relationship provides a learning environment for the development of such skills in the child with ASD. One of these studies found that children with ASD demonstrated skills in interaction with their siblings which is rarely reported with their peers and noted that an ASD child may gain positive outcomes regarding pro-social behaviors when having a typically developing sibling (Knott, Lewis, & Williams, 2007). This research by Knott, Lewis, and Williams (2007) studied six ASD sibling dyads, 10 Down’s Syndrome dyads, and utilized existing literature on typically developing sibling dyads. There has also been some research on the impact on typically developing siblings when having an ASD sibling.

Research by Dawson, Fein, Greenson, Meltzoff, and Toth (2007) noted that siblings, ages 18-27 months, of a child with ASD had lower mean receptive language, adaptive behavior, and social communication skills and used fewer

words, gestures, and responsive social smiles than comparison children without a sibling with ASD. When compared with a normative sample, siblings of children with ASD were rated as having fewer hyperactivity problems but more behavior problems (Hastings, 2007). Research by Macks and Reeve (2007) indicated that the presence of a child with ASD appears to enhance the psychosocial and emotional developments of non-disabled siblings when demographic risk factors are limited, however, the same study revealed that the presence of a child with ASD appears to have an unfavorable impact on the non-disabled sibling as demographic risk factors increase. The demographics cited as placing a child more at risk for social, emotional, and scholastic difficulties were being a male, having only one sibling, coming from a family with low socioeconomic status, and being older than the child with ASD (Macks & Reeves, 2007). Research by Orsmond and Seltzer (2007) on the effects of siblings on adult life revealed that siblings of adults with ASD had less contact with their brother or sister, reported lower levels of positive affect in the relationship, and felt more pessimistic about their brother or sister's future. It appears that as demographic risk factors increase the sibling of a child with ASD experiences more emotional and psychological stressors.

Since relationships are based on reciprocal interactions and children with ASD are typically lacking in this area, one might wonder how siblings adjust to this one way relationship. In examining the coping strategies used by siblings of children with autism, emotion-focused techniques were more often used than problem-focused techniques (Cuskelly & Ross 2006). Coping strategies refer to the specific efforts, both behavioral and psychological, that people employ to master, tolerate, reduce, or minimize stressful events. Two general coping strategies have been defined: problem-solving strategies are efforts to do something active to alleviate stressful circumstances and emotion-focused coping strategies involve efforts to regulate the emotional consequences of stressful or potential stressful events. While most people utilize both coping strategies dependent on the event or situation, often times problem-solving techniques are thought to be the healthier of the two.

Coping strategies are often measured quantitatively and with pre-determined syndrome-specific behaviors in mind, however, often in such studies, the siblings fill out scales and have been asked questions that point out behaviors associated with a child with an ASD such as; "What do you do when your brother/sister is being aggressive?" The reality is that the questions asked of the siblings are often based on underlying expectations that are behavior specific for a child with an ASD. Given the uniqueness of the diagnosis, I wondered whether the direction of these questions captured the siblings' perceptions and worries. This study didn't provide a "scale" or point out the

characteristically negative behaviors of the disabled sibling and how the subjects cope with those; I asked the sibling what they worry about and how they manage those worries. I suspected the siblings not only worry about syndrome-specific behaviors but also adult-based concerns.

Methodology

This study was qualitative in nature with the aim of better understanding the concerns of siblings of children with an ASD and their coping strategies when referencing their ASD sibling. The study was exploratory and interviews were conducted to explore the experiences of being a sibling of a child with an ASD. Convenience sampling was used. Letters describing the study were mailed to area Autism Resource Centers and follow-up phone calls with these agencies followed. Announcements about my research project were produced and emailed to several of the agencies to facilitate the process given the constraints the agencies may have with HIPAA laws relative to reaching out to potential subjects/families. Several agencies generously offered to post a flyer or included my information in an e-bulletin or newsletter.

Sample

All of the siblings that participated had received my study information from a Greater Boston area Autism Resource Center's newsletter or e-bulletin. In all cases except one, the mother was the initial contact. One of the participants (a 17 yr. old) contacted me directly. Of the seven participants, six were female and one was a male. All of their disabled siblings were males between the ages of 8 – 17. Four of the participants were younger than their disabled sibling, 2 were older, and one was a twin.

The participants' ages ranged from 12 – 18. Six face-to-face interviews were conducted and one interview was conducted via email correspondence. I did not confirm any diagnosis but relied strictly on the parents' or participants' definition of their child/sibling from initial interactions; five noted Autism, one stated Aspergers, and one stated PDD-NOS. I received 10 other inquiries from parents; however, seven of the siblings were too young for the study, one sibling was too old, and in two cases the parent thought it was a good idea but the sibling did not want to participate.

Prior to the interview, the parent and participant signed an Informed Consent and an Assent form after my verbal explanation of the project including the use of a digital recorder, the sibling assurance of confidentiality, descriptions of any known risks and potential benefits, and contact information for the people involved with the study.

Interview Process

The interviews were conducted at the participant's choice of time and location. The interviews lasted an average of thirty minutes and consisted of several introductory questions aimed at getting to know the subject and learning about their siblings with an ASD. In all cases, with the exception of the one sibling who contacted me directly, just as much time was spent in discussion or interactions with the parent/guardian regarding the study and arranging a time and place that worked for the family. Six of the interviews were conducted in public spaces such as a fast food restaurant, a coffee shop, a mall, and one summer program attended by the subject.

The subjects were first asked demographic questions regarding their age, their sibling's age, and how many brothers or sisters they had. The subjects were then asked to describe their sibling and were asked what it is like to grow up with someone with autism. The subjects were then asked if they ever worried about their sibling and, if appropriate, what they worried about and what they did when they worried about those concerns. Finally, the subjects were asked how they envisioned their own future and how they envisioned their sibling's future. The questions were as follows:

How old are you?

How many brothers/sisters do you have?

How old are they?

How old is your autistic brother/sister?

Can you describe your autistic brother/sister for me?

What is it like to live with someone with autism?

Do you worry about your brother/sister?

When you worry about (.....), what do you do?

When you worry about (.....), do you talk to anyone?

How do you see your future?

Do you ever think about (name of sibling)'s future?

Do you think I should know anything else about you and what you worry about with (name of sibling)?

Findings and Discussion

When the subjects were asked to describe their sibling, the subjects responded in terms of their sibling's social vulnerabilities or their sibling's behavior. As one subject described his/her sibling "He hardly knows what to say when put into a social situation." Another described his/her sibling this way "Everywhere we go people can tell he's different. He doesn't respond to people or interact with people. If he is angry, he'll stop

wherever he is and just sit. He stims a lot too." Stimming is a form of self-stimulation and, often among autistic people; this would refer to fixating on a comforting thing or action (such as rocking or humming). Another subject mentioned that his/her sibling "gets made fun of". The subjects elaborated on their descriptions and, at times, recalled a specific event or informed me of the behaviors characteristic of their diagnosed sibling. All the subjects offered me great insight about their sibling; their descriptions showcased their awareness and understanding of their family member and their family dynamics.

After the subjects' descriptions of the siblings were complete, I asked the subjects what it like was to live with someone with autism. One subject reminded me that her sibling was "only home on Sundays" but later in the interview mentioned that "even though I'm not with him all the time, one of my favorite things to do is watch him when he is home." When asked what this subject liked to watch, the subject elaborated on his/her ASD sibling's routine of twirling a sock stuffed with items around when he was happy. The rest of the responses indicated favorable assessments of the subjects and included; "Life with (name of sibling) is a blessing mostly and a daily reminder of how lucky I am", or another respondent that simply stated "it's normal for me", and still another, "sometimes he's a pain but he helps me a lot too – he knows a lot about computers". Mostly, the answers reflected the subject's admiration towards their sibling and, at times, how inspirational their effected sibling has been in their lives; inspiring the subject to be active members of various autism advocacy groups, support groups, or research initiatives.

All of the subjects indicated that they did worry about their sibling; one of the subjects responded "yes – all the time" and another, "definitely, usually when he's out and about". When categorizing the responses to what the subjects worried about; *social concerns* and *harmful behaviors* were the two categories in which all responses could be coded. *Social concerns* included social limitations (a key characteristic of autism) as well as social vulnerabilities (i.e. "he get's teased"). *Harmful behaviors* included to the sibling risk of harming himself or harming others.

The *social concerns* the subjects reported can be reflected better in their own responses which included a response referring to the subjects 16 year old brother "When he's out on his own I don't know how he's going to do. He'll have a hard time getting a job." Another respondent claimed "I worry when he's not with the family and when he is alone; what he'll say to people or how people will react to him." While one subject praised her younger sibling's attitude and personality, she worried that he might not find any friends. Still another responded "Yes,

I worry. I feel bad for him because he is different and people don't like him".

Two of the subjects responded with *harmful behavior* concerns. One subject said "He's tall and bigger than everyone (in the family) and sometimes he's hard to control. I'm afraid he'll hurt mom because she's around the most." This subject's sibling was earlier referred to as low-functioning and residing in a residential facility. This subject also had concerns about hurting himself because "others (referring to the residential program) might not understand him and sometimes he'll just run in the street or something". The second subject worried about his/her sibling's harmful behavior to others. "He can't control his anger and he'll throw stuff and swear...I worry that if he's at someone else's house, he'll do something to hurt others but he doesn't mean it."

I began the research wondering what siblings of children with autism worried about and how they handled those worries. My next question asked the subjects how they handled the worries they had just confided to me. In response to *social concerns* the siblings had concrete task oriented replies such as "I facilitate his conversations with other children his age" or "I try to instruct him if something new comes up." as well as "I talk to him (the sibling) about it and ask him what he thinks." The respondents appeared to use problem-focused coping when addressing the worry they had expressed to me.

In addressing *harmful behaviors* one of the two subjects responded, "We (referring to the family) constantly tell him not to do those things. We have to be patient." The second subject who expressed worry about harmful behaviors admitted "I can't do anything. I just get dad because he's the only one who can do anything." Again, in responses to what the subject worried about and how they handled those worries, these two responses also suggest a more problem-focused technique that is action oriented (even if in the slightest way or having to rely on other family members for support). While the literature might suggest emotion-focused coping strategies predominate among siblings of children with autism, when asked about a behavior-specific question, this small research sample expressed problem focused coping techniques when addressing the concerns reported by them; *social concerns* and *harmful behaviors*.

Since my literature review on the older siblings of children with autism showed that siblings of children with autism are less likely involved in their sibling's lives as they age, I wondered if younger siblings ever considered their autistic sibling's future. I asked these siblings 1) how they envisioned their own future and 2) how they envisioned their sibling's future. When asked about their own future five of the respondents shared their

work, school, or career aspirations while two of the respondents included plans for their autistic sibling as part of their own futures. For example, one respondent who is younger than his/her autistic sibling said "I'll have a good job to be able to take care of (names autistic sibling)" and the other said of his/her severe autistic sibling "I plan on taking care of my brother because he can only stay at (names residential facility) until he is 22 and then we (referring to the family) are going to have to find somewhere else and I know someday my parents won't be able to take care of him because they'll have to take care of themselves so I plan on taking care of him; not necessarily live with him but making sure I live nearby in case he needs anything". The respondent in this case is fourteen years old.

Four out of the seven respondents revealed that when considering their siblings future they felt as though their sibling would still be living with a family member such as themselves or their parent/guardian. This response was from a twelve year old subject, "He'll always be with me." "When he's older, he'll probably be with my parents or me" was another response in addition to, "We (the family) are always going to be checking on him and close by and support him all through his life." Two of the subjects had high aspirations for their sibling such as being a mathematician or being a sports announcer. These two siblings were earlier described as high functioning and both of the subjects had indicated to me that their autistic siblings were great with numbers and had remarkable memorization skills. The last subject, whose sixteen year old sibling resides in a residential program, stated "Yeah, I think about his future. I plan on putting him somewhere nice but somewhere that will take him at his age". The particular residential program his/her sibling attends can only accept people up until 22 years of age. This subject is only sixteen and clearly has concerns about his/her siblings' future, as did most of the respondents.

This study was exploratory in nature with the hopes of better understanding the concerns of siblings of children with autism and how they handled those concerns. The subjects in this study had concerns with their autistic sibling's social limitations and harmful behaviors. When asked how the respondents handling those concerns, the subjects responded with problem solving techniques as opposed to emotional regulation strategies. In addition to these findings, the subjects also reported having concerns with their autistic siblings' future and affirmed that they themselves would likely be involved in the caregiving of their autistic sibling. Unfortunately, research has revealed that siblings of adults with ASD had less contact with their brother or sister and were less likely to be involved in the adult care of their sibling when comparative groups were used (Orsmond and Seltzer 2007).

The findings highlight the autistic sibling relationship and the many concerns typically developing siblings express regarding their autistic sibling. Understanding the siblings of a family with an autistic member helps professionals understand the dynamics of the family and this particular dyad.

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