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Ma, What About Me?

A Study of the Mother – Child Relationship of Adolescents Having Siblings with Autism

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ABSTRACT

This study aimed at investigating the perceptions of the mother-child relationship of adolescents having siblings with autism. Adolescents having siblings with autism (n = 40) were compared with adolescents having typically developing siblings (n = 40) on how they perceived their mothers on ten dimensions. Further, an in-depth, semi structured interview was conducted on adolescents having siblings with autism (n = 10) to obtain a more detailed understanding of these adolescents' experiences and relationships with others, in light of having a sibling with autism. Preliminary analysis of the interviews has shown that adolescents having siblings with autism shared a healthy relationship with both their mothers and their autistic siblings, although some challenges were also mentioned. The joys of having an autistic sibling were also stressed upon. Analysis of the quantitative phase of the study is still underway. Future directions for research were also discussed.

Ma, What About Me?—A Study of Mother-Child Relationship of Adolescents Having Siblings with Autism

The present paper investigates the perceptions of the mother – child relationship of adolescents having siblings with autism. In this study, the adolescent's relationship with the mother was focused upon mainly because even today mothers are the primary caregivers in most Indian families (Ball, Fatima & Chakma, 2012). During adolescence, one's relationship with one's parents undergoes certain changes. Adolescents give up their child like dependency on their parents for a more mature and responsible relationship (Berk, 2009). It is due to this unique nature of the adolescent phase that the present study looks at this particular age range. Having a sibling, whether older or younger, can influence many aspects of oneself, including self-

esteem, level of life satisfaction and even one's relationship with one's mother (Gfroerer, Gfroerer, Curlette, White & Kern 2003; Sutor & Pillemer, 2007). When one's sibling has a disability, it has been shown to further alter family dynamics (Kaminsky & Dewey, 2001). For this study, the experiences of adolescents having siblings with autism were focused upon in particular because autistic individuals have been found to have a greater impact on the family than individuals with any other developmental disability. A significant amount of research has been carried out on the families of children with developmental disabilities, although most of these studies focus more on the mother and the disabled child and not on anyone else in the family. The sibling relationships have been the focus of research only recently. Petalas et al (2009) concluded that siblings of children with autism were at a higher risk of developing emotional and behavioral problems as compared

to siblings of children with other disabilities or siblings of typically developing children. Another study, by McHale and Gamble (1989) found that siblings of children with developmental disabilities perceived that their mother treated them more negatively as compared to the perceptions of children without developmental disabilities. In fact, Macks and Reeve (2007) have suggested that the reason siblings face the problems they do, is because of the increased amount of parental time, attention and energy the autistic child requires. Howlin (1988) found that the non autistic children often felt that they did not receive as much attention as their autistic sibling and that, at times, they were treated unfairly. Gupta and Singhal (2005) have stated that many siblings tend to feel that their needs are secondary and less important due to the increased time and attention parents give to the autistic child. Rivers and Stoneman (2008) examined the association between sibling temperament, differential parenting and quality of relationships between autistic children and their non autistic siblings. The study concluded that non autistic siblings who reported greater satisfaction with differential parenting also reported better sibling relationships. From the researches quoted above, it seems likely that the parent-child relationships of non autistic siblings are affected by their autistic sibling. The present paper looks into the experiences of the adolescents in terms of their relationships with their mothers, their siblings, and other aspects of their lives.

Method

Participants

The qualitative phase of the study comprised of interviews with 10 adolescents (males = 5, females = 5) all of whom had siblings with autism. These adolescents were selected through the convenience sampling technique from amongst those who had filled out the questionnaires in the first phase of the study. The participants were in the age range of 13 to 18 years of age.

Procedure

The present study followed a mixed method approach and was carried out in two phases – quantitative and qualitative. However, this paper has focused on only the second phase of the study, the qualitative one, as analysis of the quantitative phase is still underway. The qualitative phase involved in-depth, semi structured interviews that were carried out with 10 participants who had siblings with autism. The interviews were conducted on a one-on-one basis. The range of the length of the interviews was from 15 minutes to 35 minutes. Thematic analysis was used to analyze the ten interviews. The six phases of thematic analysis were duly followed in order to come up with the qualitative results – familiarization with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report (Braun & Clarke, 2006). The rigor of this study was assured through the application of three criteria – credibility, fittingness and auditability (Sandelowski, 1986).

Results and Discussion

The analysis of the data gathered through the interviews brought out a number of themes through which the adolescents' perceptions about their relationship with their mothers and their autistic siblings can be understood.

Perceptions of the Mother-Child Relationship

Certain aspects of the adolescent-mother child relationship emerged clearly. The subthemes below deal with how much time the adolescents spent with their mothers, how close they were to their mothers and their relationships with their mothers as compared to their siblings' and friends' mother – child relationships. This section also illuminates how the mothers enabled the participants to deal with fact that they had a sibling with autism.

Time. Most participants said that they spent a significant amount of time with their mothers. The estimates provided by the

adolescents ranged from seven to fifteen hours in a week, generally after they returned from school. While all the participants said that some of their mother-child quality time was spent in the company of their sibling, a few mentioned that they had specific days assigned where the participant and the mother went out by themselves.

When asked if they were satisfied with the amount of time they spent with their mothers, most said they were and would not like to change it in anyway. However, three out of the ten participants did say that they would like to spend more time with their mothers. Lack of time was blamed on the adolescents having to focus most of their time on academics or on mothers being busy and working long hours. However, none of the participants cited the sibling as a reason behind the inadequate amount of quality time with their mothers. This contradicts what Satterwhite(1998) found – that adolescent siblings of children with developmental disabilities feel that there need are put behind those of their disabled sibling.

Appreciation. Each participant was asked what they appreciated most about their mother. The respondents spoke of a number of qualities such as their mothers being practical, independent, strong, caring, alert, being good listeners, understanding their children and being a source of encouragement. As one seventeen year old boy eloquently put it, “...she never made us feel like we were a dysfunctional family. My brother and I have got the best, when it comes to education, when it comes to anything. ..She’s just always been there for us.” Several participants mentioned that they appreciated their mother for how much she cared for their autistic sibling. The fact that their mothers helped, understood and accepted their siblings was a source of great pride, respect and appreciation towards their mothers. One thirteen year old girl, talking about both her parents, said, “My parents are very nice and they’ve taken such good care of my brother. Most parents would have found a boarding school for my brother and dumped him there and not cared any more. But my parents aren’t like that.” Some participants expressed that having an

autistic child had enabled their parents to better raise their children. A fourteen year old boy said, “I think mothers of children with autism have higher values and instill these values in their non autistic children, that they need people to have if they want a stable environment for their autistic child.”

Relationship vis-a-vis sibling. The participants were asked about how their relationship with their mother was different from their siblings’ relationships with her. Four out of ten participants said that there was no difference at all between their mothers’ relationships with them and with their siblings. They said their mothers loved them both equally and reacted the same way to the achievements of both the siblings. Several said that the relationships differed because their siblings were given a lot more attention and care than they were. As one thirteen year old participant put it “...She (mother) is with him (brother) a lot and knows a lot about him...She knows what’s going on in his school and things like that.” However, most of these participants were quick to clarify that they knew that being autistic, their sibling required more attention and therefore they did not feel negatively about it or pay too much heed to these differences. A seventeen year old participant was able to aptly express the differences between the relationships and his feelings towards it. He said, “The fact that he (brother) is autistic obviously means that he needs a little more attention than I do and he’s more dependent on my mother than I am. ...And obviously, she can have an intelligent conversation with me and not with my brother. So that slightly affects our equation with each other. But the obvious differences that are supposed to be there are there and nothing out of the ordinary.”

In terms of their mothers’ reactions to their achievements as well, most participants expressed that achievements were defined differently for them than their siblings. While what would be considered an achievement for their autistic sibling, the same would not necessarily be considered an achievement for them. The adolescents were quite accepting of this difference. This has been more clearly

verbalized in the following thirteen year old girl's response, "...Though I don't know if I had done the same thing that my brother gets praised for, I don't know if I'd get so much praise. But then he's autistic and I'm not, so it makes sense. I've come to terms with it."

These findings were in line with previous literature which clearly stated that adolescents acknowledged their parents attempts to treat all children equally, even though they were not always able to do so (Cate & Loots, 1999)

Perceptions of Sibling with Autism

The interviews were also analyzed with regard to how the participants perceived their siblings, how close they felt to them and how much time they spent with them. Each of the subthemes below looks at a different aspect of the sibling relationship. It also looks into the reactions the participants get from those around them when they are with their siblings.

Dynamics of relationship. Saxena and Sharma(2000) found that the relationship between the two siblings was quite comfortable and that the adolescents appeared to be well adjusted in their sibling role, accepting the disabled child as an integral part of their lives. The present study echoed the same. Half of the participants said they spent a significant amount of time with their siblings. The other half said that they did not spend a great deal of time with their siblings. Explaining why, a thirteen year old girl said, "I don't really spend much time with him. I can't possibly tell him what happened to me in school. And we don't play any games together. It was never like that. ...The most I can do is smile at him." However, some participants said that their siblings were more comfortable with them than with anyone else. Quoting one fifteen year old female participant, "...Even though I sometimes get annoyed with him and scream at him, he won't go complain to my mother. He'll come complaining to me. And sometimes, when my parents are out, I babysit him so he's all over the house. He's better with me than he is with my parents. With my parents, he tries to get a lot of attention and says stuff he's

not supposed to say, but with me he's fine." A few participants said that they did not generally tell people about their siblings' autism. The participants said that their close friends knew that their siblings had autism and got along well with their siblings. When asked how they tell their friends about their siblings' autism, one fifteen year old participant put it quite simply, "I say, 'He's a little different, that's all.'"

Gains and losses. The participants were asked about what they liked and disliked about having a sibling with autism. In terms of the benefits or the joys, a lot of responses revolved around how, because they weren't 'normal' siblings, they did not engage in normal sibling rivalry or fights. They shared a relatively peaceful relationship with their siblings. One 13 year old girl said, "Well, I've heard from my friends who have brothers without autism, whether they are older than them or younger than them, that brothers are a menace and that they have a cat-dog relationship and they keep fighting and punching and kicking and arguing. They make life hell for each other. That never happens with my brother." One of the benefits that one of the thirteen year old participants was able to verbalize very clearly has been quoted as well. She said, "...Because my parents are already there to make most of my decisions, but if I had a normal brother, being much older than me, would become like a third parent. Considering that I am allowing my friends to become the centre of my life now, I don't think I'd want a third parent." Another benefit of having a sibling with autism seemed to be that it changed the lives of the participants for the better. Most of them said that they were better human beings because of their siblings. They said it made them more responsible, caring, understanding and perceptive about the world around them. In the words of one seventeen year old, male participant, "Because I have someone like him (brother) at home, who is a little offbeat, to say the least, it makes it a lot easier for me to accept people's oddities, people's weird little habits and accept them for the people they are, and I find it a lot easier than others do." This was in line with what Grossman (1972) found, where about 45% of the

participants reported that they had benefited from having a disabled sibling.

The challenges the participants faced revolved around the unpredictability of their siblings' temper tantrums, the need to look after the minute details of their lives and not being able to share 'normal' sibling moments. About sharing 'normal' sibling moments, a thirteen year old girl said, "There are some things I can't tell my parents, that I could probably ask my brother, having more experience and being a sort of go-between between my parents and me. Acting as somebody to make the peace between me and my parents." Another sixteen year old girl talked about how taking her autistic brother out of the house posed a problem, saying, "Sometimes controlling him in a public place is difficult when he gets hyper. I still can't take him anywhere alone, without Mom or Dad. Because if he gets hyper, I won't be able to handle it."

Expectations

Previous research had cited that because a lot of the parents' time is spent with the autistic child, the siblings are often expected to take on more household responsibilities and physically care for their autistic sibling (Randal & Parker, 1999). However, most participants in the present study had few responsibilities when it came to household duties which mainly involved keeping their room clean and doing what their mothers would tell them to do. Some had no household duties at all. Listing out the household duties he was expected to do, one seventeen year old participant said, "I'm supposed to do what she asks me to do. So, if she asks me to make her a cup of coffee, I'm supposed to do it; if she asks me to clean up my room or clean up my closet, clean up my table, I'm supposed to do it. ..But, yeah I mean, household duties, she pretty much takes care of everything. The little little things that every child is supposed to do, I'm supposed to do. That's all." The pressure and expectations with regard to academics seemed to be significantly higher. Most participants said their mothers tell them to do the best they can while a few said their mothers tell them to get the top grades.

With regard to sibling related duties, most participants said that the main things were left to their parents. The only duty they had was keeping their sibling company or keeping them entertained. One fifteen year old participant spoke of her duties saying, "I have to entertain him, because my parents don't want him to get bored, though he doesn't get bored when I'm at home. So, I have to make him sit and watch TV or do something with him and if he's feeling bad, I just have to talk him out of it and stuff. Usually, he likes to be by himself so he just lies around and if he's too stressed, I just put on music for him." When asked how they felt about these duties, most of them said they did not see them as duties and liked spending time with their siblings. When asked how they felt about the other expectations their mothers had, they said they seemed reasonable most of the time. One sixteen year old boy, however, said, "I think that she is, kind of, never satisfied. No matter what you do, there is some shortcoming that she finds and likes to point out."

Concerns and Worries

The participants were asked whether they had any concerns and worries regarding the future. Three categories were found – worries about self, worries about sibling and worries about mother. In terms of worries about self, participants were concerned about their academics, getting into a good college and eventually getting a good job, mainly so that they would be able to care for their siblings. Explaining her concerns, one thirteen year old said, "The only thing is I haven't decided what I'll be when I grow up. I need to decide that. When there are two siblings, both of them can earn a livelihood and care for their parents in their old age. My brother earning a living is out of the question. He needs to be cared for. So, looks like I'm the only one who is going to grow up and have a job and earn money. And I better be good at it because I now have to look after my mother and my father and also my brother. That thought might have scared me earlier on but I don't worry about it anymore." Concerns regarding the sibling centered on worrying about

how they would manage once they grew up. Some said their siblings were still children and so could be controlled but that it would be very difficult to handle them after they had grown up. One sixteen year old girl said, "It's just that my brother's getting bigger by the day. I worry about what will happen if he gets too hyper or out of control. He's almost as big as my dad now. I don't know what will happen when he gets so big that they can't control him." They were also concerned about what would happen after their parents were no more. Vocalising this thought, one seventeen year old male participant said, "Obviously, whether my brother will be able to sustain himself after mom's gone, because she's not going to be there forever. And my immediate concern is what after mom?" Participants were also asked if they worried about their mothers. Most of them said that they did, the reason for their worry being that their mothers seemed to have too much on their plate and were very busy or stressed out. One of the participants, a sixteen year old girl said, "Mom's always worrying about my brother and what will happen to him in the future, how will he survive and face the world. So, I tend to worry about her, hoping she doesn't take on too much stress and that nothing serious will happen because of all her stress." Another participant, an eighteen year old male said, "Sometimes when my brother gets violent, it's been two and a half years since he last fought with Mom, but when he did, he punched and broke her nose. The only thing that concerns me is that nothing like that should happen which may turn fatal."

Conclusion

Hastings (2003) suggested that the effects on the non autistic sibling were moderated by the severity of the child's autism and the availability of a formal social support system. Therefore, the researcher must admit that the results of the current study cannot be generalized to all adolescent siblings of children with autism, as severity of the autism was not controlled for. It is possible that the adolescents interviewed for this study appeared to be behaviorally and emotionally well adjusted because of the social support their family receives. Due to the fact that

the sample was taken from special schools and early intervention centers, the assumption is that these families have reached out for assistance and have received it. The researcher accepts that there is a possibility that, if families that have not enrolled their autistic children in special schools or have not sought out therapy for their children, had been approached; the findings may have been different. Such a step would be a useful direction towards future research.

Through the findings of the present study, the researcher is careful not to imply that all is well in the lives of such adolescents and that they do not require assistance, intervention or social support. The researcher is reiterating that it is possible that social support and early intervention (either by the parents or external sources) is what led to these adolescents being as understanding as they are. However, further research will have to be undertaken before one can concretely identify the benefits of having a sibling intervention programme.

The current findings may also be explained by considering the age range that is being studied. Adolescents are known to move away from their families and be more involved in their own lives and the lives of their peers. It is possible that, because of the lowered importance issued to their own families, the presence of an autistic sibling does not affect them much. They may be spending more of their time worrying about friend related and school related problems as opposed to problems at home.

To conclude, the study has found, that on a whole, adolescents having autistic siblings are quite satisfied with their relationships, with both their mothers and their siblings. As previous literature has suggested, their siblings are an integral part of their lives and they have learnt to accept their sibling, and their family, the way it is.

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