

Understanding Siblings of Children with Autism



Education

KEYWORDS : Autism, Siblings of children with Autism, Awareness of Autism, Self concept

Sheila Christopher

Dean of Student Affairs & Associate Professor, Department of Rehabilitation Science, Holy Cross College, Trichy.

Cresenta Shakila

Assistant Professor, Department of Training and Placement, SASTRA University, Thanjavur

ABSTRACT

Sibling relationship is the earliest, and most enduring of all family relationships and their influence last a lifetime. This study examined the effectiveness of sibling support groups for siblings of children with autism. 25 siblings of children with autism between the ages 7 and 16 participated in the group intervention. Questionnaires examining siblings' self-concepts, knowledge of autism, and emotional reactions, feelings and concerns regarding variety of problems were administered as first group session to obtain pre-test scores and again after the last group session the post-test scores. Results indicated that siblings' self-concepts and knowledge of autism improved significantly from the beginning to the end of the sibling support group. These findings suggest that sibling support group was successful in meeting the stated goals.

Sibling relationship is the earliest and most enduring of all family relationships and their influence last a lifetime. It assumes greater meaning and significance in a family having a child with disability. Siblings exert influence over the family member with disability. Sibling relationships change over time and provide opportunities to experience sharing, companionship, rivalry, and other outcomes. (Orsmond GI et.al.2009). Some sibling pairs experience warm, supportive relationships, whereas others experience conflicts and isolation (Rivers JW and Stoneman Z.2003). The authors reported mixed results on outcomes and adjustment of typically developing siblings of individuals with ASD.

Beyer JF. (2009) reviewed the literature related to siblings' relationships when one sibling has ASD. It was found that both positive and negative factors in these siblings' relationships. Siblings claimed that they had minimal conflicts and warm relationships with their siblings with ASD (Kaminsky L, and Dewey D 2001). They also stated that they had fun with their siblings with ASD (e.g., Rivers JW and Stoneman Z (2003).

Sibling Support Groups

Sibling support groups were developed and implemented by clinicians to address the unique psychosocial needs of siblings of children with disability. They are facilitated by a group leader who is knowledgeable about the issues facing families of disabled children. The effective sibling groups are run with 12 siblings over a period of 8-10 consecutive weeks and are able to develop positive relationships with each other and the facilitators with a sense of trust and openness. It enables siblings to test out suggested coping strategies and report back to the group on their achievements. Many of the goals of these groups include providing information on disabilities to improve siblings' understanding, discussing problems and adaptive ways of coping. Despite differing methodologies, studies reported improvements in siblings' knowledge of disabilities, greater self worth, and more positive interactions between the sibling and the special child during sibling support groups. (Jones, & Mansell, 2001).

The objective of the current paper is to describe the results obtained, in our program evaluation of the sibling support groups for siblings of children with autism. The aim of the study was (1) to understand the self-concept of siblings of children with autism in the sibling support group interactions. (2) To study the knowledge and awareness of autism of these siblings and to understand the emotional reactions, feelings and concerns of the sibling who participate in the sibling support group intervention. (3) find out the impact of sibling support groups on the siblings.

Method

Participants

Participants came from families in the PRAVAAG (Transitional Center for Children with Autism and Developmental Disorders) in Trichy who have a child with autism ($n=19$). Of the 35 siblings who participated in the sibling support group, 5 did not complete the group intervention. Furthermore, 5 dropped out in the middle due to parents moving to another town. Thus, the final sample included 25 siblings of children with autism (13 sisters and 12 brothers) between the ages of 7 years and 16 years. Fourteen of the siblings were older than the child with autism and 11 were younger. Twenty-three siblings were from two-parent families, two were from single-parent families. Ten families fell into the lower socio-economic status category, 13 in the middle socio-economic status category and 2 in the upper socio-economic status category. Examination of parent responses on the Child Behavior Checklist (Achenbach, 1991) completed for 25 of the siblings prior to intervention showed that 12 siblings (48%) had borderline to clinically significant Internalizing problem behaviors and 7 (28%) had Externalizing symptoms in the borderline to clinical range. Six of these siblings (24%) had both Internalizing and Externalizing scores in the borderline to clinical range.

Measures

Achenbach Child Behavior Checklist (CBCL; Achenbach, 1991). This is a 124-item standardized parent-report questionnaire examining both Internalizing and Externalizing behaviors for children aged 4 to 18.

Piers-Harris Children's Self-Concept Scale (Piers & Harris, 1969; Piers, 1984). This is an 80-item self-report, true/false questionnaire measuring how children feel about themselves. This measure contains six specific cluster scores: Behavior, Intellectual/School, Physical Appearance and Attributes, Anxiety, Popularity, Happiness/Satisfaction and Total score.

Autism Knowledge Measure For Young Children (Perry, 1989). A 20- item measure intended to tap children's basic knowledge of the characteristics and causes of autism. The children respond "yes", "no", or "not sure" to the items. Correct answers are summed to produce Total score, higher scores greater knowledge of autism.

The self prepared questionnaire on *Emotional Reactions, Feelings and Concerns Scale* contained 12 questions on emotional reactions and 10 feelings and concerns for which answers are yes /no.

Procedure

For each participating family with the sibling, a member of the Research team met with a parent and the sibling at the family's home within three weeks of the first session of the group (pre-

test). Parental consent was obtained for siblings to participate in the sibling support group as well as the research component evaluating effectiveness. Parents were asked to complete the CBCL, siblings were concurrently asked to complete Piers-Harris Children's Self-Concept Scale, Autism Knowledge Measure, and self prepared questionnaire on "Emotional Reactions, Feelings and Concerns. For younger siblings and those exhibiting reading difficulties, the questionnaires were read aloud. Parents were later informed about the sibling support group and a date and time was fixed to conduct these activities during the weekends when most children were free. The sibling support group met weekly for six weeks.

Activities of the Sibling Support Group

Sibling support groups combine recreational and discussion based activities. The activities aimed at prevention of internalizing and externalizing behaviors in siblings. The sibling group was facilitated by the research team. This sibling group was run with 25 siblings over a period of 6 consecutive weeks. The goals of sibling support group included: increasing knowledge and understanding of autism and related developmental disorders; providing opportunity for siblings to discuss their feelings in accepting atmosphere; help siblings share ways of coping with difficulties to having a sibling with autism (e.g, through role playing); enhancing siblings' self-concepts; and encouraging siblings to have fun in supportive environment. These goals were addressed focusing on exercises, games, and activities that were fun. The first group session began with ice-break games followed by a discussion activity called Balloon Feelings. Each balloon has a label with a feeling stuck, such as happy, sad, angry, and so on. Whilst some upbeat music is playing the siblings have to keep all the balloons up in the air; when the music stops each sibling catches a balloon. Siblings were asked in turn what feeling is on their balloon and to tell the group a time when they had that feeling. Then music is played and activity continued. The purpose of this activity was to help the siblings develop a vocabulary for feelings, comfortable sharing feelings, and able to hear the experiences of other siblings. Many siblings reported that they do not get much chance to discuss sibling issues at home due to lack of time parents can give to them, but also because some parents feel they need to protect the sibling from these issues. Many siblings feel the need to protect the parent from worrying about them as well as the disabled child!

Results and Discussion

To evaluate the hypotheses regarding the sibling support groups, t tests were computed

Table 1. Results of Group Evaluation

Measures	Pre-test		Post-test		t	df	p
	M	SD	M	SD			
Self-Concept	5.48	8.61	58.87	8.96	-2.76	25	.005
Knowledge of Autism	11.43	3.49	13.23	3.04	-2.38	24	.01

Secondly, siblings' knowledge on the Knowledge of Autism Measure was significantly higher at the end of the sibling group ($p < .01$). The siblings scored at about chance on this measure prior to the group, indicating that they did not possess understanding of characteristics and causes of autism, which is consistent with other clinical studies indicating that siblings initially had little knowledge of their brother / sister's disability

but became more accurate after participating in a group (Lo-bato & Kao, 2002). Therefore, it appears that the sibling support group, in the present study have been successful in helping siblings understand more about autism, and their brother /sister's behaviors.

Thirdly, emotional reactions of siblings were looked closely by Mathew et. al. (2007) they pointed out that in the early childhood stages, siblings understand that there is something different about their brother or sister in comparison with themselves, but still have relationship and interactions. Siblings may have misconceptions about how the disability developed, and in some cases fear "catching" the disability. There are specific concerns for siblings that have emerged out of this research during the pre-test. Being bullied at school about their brother/ sister's condition (88%), wondering why their brother/sister attends a special school (82%). When asked if they feel sad/pity about their sibling 54% answered in the affirmative. Only 22% said that it was easy to accept their sibling and 55% said that their peers know that they have a special sibling. It was astonishing to note that 77% thought their popularity has waned because of their sibling 82% were anxious about being teased or bullied about their sibling. Only 42% felt comfortable when the special sibling is around them and only 43% felt that they could protect and be with their sibling till the end of their life. Having said all this, yet 71% did say that they liked their sibling. An astounding 84% have thought they should have had a normal sibling. 76% said that they cried, thinking of their sibling.

With regard to concerns and feelings expressed by siblings of disabled children, more than half of the siblings were unable to explain their brother/sister's disability, and one-third said they could only talk with someone outside their family about their brother/sister's condition. They also reported problems with destructive behavior in their brother/sister, and were concerned about their future (68%). However siblings should be encouraged to express all of their feelings, or the feelings may intensify; e.g. unexpressed embarrassment may lead to guilt and then shame. 76% expressed that they were guilty of having hurt their sibling. Only 48% said they wished that their sibling was not born. 57% had negative thoughts and feelings while 79% worried Autism is contagious. Majority 89% of siblings were anxious whether their child may be autistic, and 69% felt something might be wrong with them. Only 32% felt like running away from home, while 54% felt embarrassed taking their sibling in public. When asked if they were anxious about their spouse accepting their brother/sister, 77% answered affirmatively. There was substantial reduction in scores after involvement of the siblings in the sibling support group sessions. Children participated in the program wished to have more sessions because they enjoyed. Opportunity was given to discuss their experiences, express their feelings, solve problem, learn about autism in a supportive environment, and to have fun.

Conclusion

This group of siblings reported greater knowledge of autism and better self concepts following group participation. The Sibling Support Group provided a relaxing environment and opened the doors of communication between parents and children about the joys and concerns of living in a family with a child with autism. Since Sibling Support groups are both recreational and therapeutic, they are an effective way to help sibling's emotional and personal needs.

REFERENCE

Ⓜ Achenbach, T.M. (1991). Manual for the Child Behavior Checklist/4-18 and 1991 Profile. Burlington, VT: University of Vermont Department of Psychiatry. | Ⓜ Beyer JF. Autism spectrum disorders and sibling relationships: research and strategies. Education and Training in Developmental Disabilities. 2009; 44(4):444-452. | Ⓜ Kaminsky L, Dewey D. Sibling's relationships of children with autism. Journal of Autism and Developmental Disorders. 2001; 31(4):399-410. | Ⓜ improve sibling knowledge and adjustment to chronic illness and disability. Journal of Pediatric Psychology, 27, 711-716. | Ⓜ Mathew, J, Leong, S., & Whit, S. (Retrieved 2007). Helping siblings understand and | encouraging positive relationships. Society for Treatment of Autism, www.staab.com/siblings.pdf | Ⓜ Orsmond GI, Seltzer MM, (2007). Siblings of individuals with autism spectrum disorders across the life course. Ment Retard Dev Disabil Res Rev. 13(4):313-20. | Ⓜ Perry, A. (1989). Autism knowledge measure for young children. Unpublished, Toronto; | Ⓜ Piers, E. V. (1984). Piers-Harris Children's Self-Concept Scale, Revised Manual. Western Psychological Services, Los Angeles. | Ⓜ Rivers JW, Stone-man Z. Sibling relationships when a child has autism: marital stress and support coping. Journal of Autism and Developmental Disorders. 2003; 33(4):383-394. |