

Group Intervention to Improve Quality of Life among Siblings of Children with Autism Spectrum Disorders (ASD)

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Abstract

Objective: To evaluate group intervention for siblings designed to increase siblings' Quality of life. **Methods:** Twenty well siblings (ages 8–12 years) were recruited through special schools serving children with developmental disabilities. The PedsQL parent version was used before and after the intervention. A sample of 20 families completed a 3-month follow-up to assess the maintenance of results. **Results:** After attending 6 group sessions, there was an improvement in the PedsQL scores to 88.3 (\pm 9.9), respectively (p -value $<$ 0.001). Furthermore, subjects showed significant improvement in 2 out of the 4 PedsQL subscales, namely emotional and social function (p -value $<$ 0.001) maintained at 3-month follow-up. **Conclusions:** The results support continued development and testing of family-based, early interventions to promote good Quality of life among young siblings of children with developmental disabilities.

Keywords: Sibling intervention, Quality of life, Autism spectrum

Introduction

Any form of chronic illness and disability represents a severe challenge, not only to the affected person but also to their family. Some reasons will make it challenging for the family to cope with autism. Autism is often accompanied by disruptive or inappropriate social behaviors like tantrums and self-destructive acts apart from speech problems. Because of many symptoms, receiving a correct diagnosis and suitable therapy is frequently drawn out and complicated. In contrast to other juvenile disabilities like mental retardation and Down syndrome, autism is not well known in the general population. The mental and physical demands of raising a kid with an autism spectrum condition can be overwhelming for a parent.

Moreover, it can have a disruptive impact on the wider family life. In particular, there are a variety of challenges that may be faced by other children in the family as a direct or indirect consequence of having a brother or sister with ASD result of having ASD sibling or sister (Aspect, 2013). Sibling relationships are often longer than any other relationship within the family, and self-identity, social skills, companionship, and mutual support are developed through this sibling. Research has identified the following risk areas for siblings of children with ASD (Bagenholm&Gillberg, 1991; Hastings, 2003; Ross &Cuskelly, 2006; Petalas, 2012): Loneliness, Concern about the future, Behavioral disturbances, Poor relationships with peers, Anger towards the sibling with ASD (mainly if that sibling is aggressive), Vulnerability to stress and depression, Feeling guilty and Embarrassment.

To determine how having a brother with autism spectrum disorder (ASD) has affected a child's life, The Quality of Life (QoL) of siblings of children with ASD has been assessed in this study. According to the World Health Organization, the 'quality of life' may be described as the view of a person regarding his/her place in life in the context of his/her culture and beliefs and concerning his/her aims, aspirations, and standards. A person's physical and mental well-being, degree of independence, social connections, surroundings, and personal values may all "color" their Quality of life. A child's perception of Quality of life differs from that of an adult. At this point in life, the subject's physical and mental health are less significant than the environment and economic situation since the kid is born and grows up in these conditions, which affect how they perceive their Quality of life (Eiser, 1997)

Method

Recruitment

The term sibling refers to typically developed siblings of children with ASD. All siblings of children with ASD from special schools for children with ASD in Bangalore formed the population. One hundred thirty Quality children with ASD from those schools had 79 normal siblings. The researcher met the parents of those children. Forty-seven normal siblings did not meet inclusion and exclusion criteria; the other eight sibling's parents did not want to participate in the study because of lack of time, busy work schedules, and long distance from schools, and some of them did not want to disclose the diagnosis with a typical sibling. Twenty-four normal siblings were ready to participate in the study. After

the intervention, a post-assessment was carried out. 4 study participants were excluded because they discontinued during the intervention. Thus, after excluding those participants, the number of participants for the data analysis was 20 samples selected through convenient sampling. Siblings of children with ASD were recruited adhering to the prior eligibility criteria and informed consent and assent. The study got ethical clearance from the NIMHANS ethics committee.

Evaluation Procedures

Pre- and Post- assessment

Parent evaluations were completed before, after one month, and after the third month.

Measures

Paediatric Quality of Life Inventory (J.W Varni, 1999): A modular method for assessing children and adolescents in good health and those with both acute and long-term medical issues is the PedsQL Measurement Model. The scale includes physical, emotional, social, and school functioning. It is practical and flexible. The parent was asked how much of a problem a specific situation has been for their child in the past month. Response categories for each item are 'never,' 'rarely,' 'sometimes,' 'often,' and 'almost always.' Domain scores are determined by adding all item scores within a given domain, then converted linearly to a scale of 0 to 100, where 0 represents the lowest HRQOL, and 100 is the greatest.

Group intervention

The present psychosocial group intervention program was carried out in 6 group sessions, two sessions a week for three weeks; each session took 2 hours with 15 15-minute break time. Six group sessions were held on consecutive weeks. A total of 8 groups were there (4 three-member groups and four two-member groups). The target of the intervention was two-fold. The first target was to increase sibling knowledge of the child's particular disability and, in that way, sought to improve the sibling's ability to handle his or her environment more competently. Games and other creative activities encourage participant interaction and promote the nonverbal expression of relevant feelings and themes. The researcher prepared a workbook for siblings, and each session was carried out with different workbook activities. Six parent information sheets will be handed out to parents at the end of each session, designed to foster discussion between siblings and their parents.

Statistical analysis

The Shapiro-Wilk W test was used to evaluate the normality assumption, and for the majority of the variables, no significant deviation was discovered. Repeated measures ANOVAs were conducted to assess the main effects of time (before, after one month, and three months after treatment).

Results

Sibling Characteristics

The sample comprised 20 healthy siblings (9 boys and 11 girls). The siblings ranged in age from 8 to 12 years (M age = 9.8 years). The children with ASD ranged in age from 4 to 16 years (Mage = 11.5 years). Most siblings were female children (55%), and most belonged to the Hindu religion (70%). Most of them were younger (65%) than children with ASD. 95% of participants appeared to have regular health status, and only one child had Asthma. Table 1 shows the distribution of the number of participants, birth order, and gender across the sibling groups.

Table 1 Participants' details

Variables		N	%
Gender	Girl	11	55
	Boy	9	45
Religion	Hindu	14	70.0
	Christian	5	25.0
	Muslim	1	5.0
Age in years	8	4	20.0
	9	4	20.0
	10	6	30.0
	11	3	15.0
	12	3	15.0
Health status	Normal	19	95.0
	Asthma	1	5.0
Birth order	Elder	7	35.0

	Younger	13	65.0
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Changes in Quality of Life with group intervention

Siblings of children with ASD had a mean PedsQL total score of 75.0 out of 100 (± 10.3) before group intervention. After attending 6 group sessions, there was an improvement in the PedsQL scores to 88.3 (± 9.9), respectively (p -value < 0.001). Furthermore, subjects showed significant improvement in 2 out of the 4PedsQL subscales, namely emotional and social function (p -value < 0.001) (Table 2).

Table 2 Total Quality of Life Scale Scores by Group and Time of Measurement

Domains	Baseline Mean (SE)	Post 1 Mean (SE)	Post 2 Mean (SE)	RMANOVA
Emotional problems	46.88 (5.55)	76.11 (7.1)	72.40 (1.18)	<0.001
Social problems	56.88 (4.25)	82.0 (8.21)	80.10 (7.48)	<0.001
Physical function	89.22 (8.51)	89.51 (9.0)	89.35 (9.3)	0.015
School function score	88.25 (8.47)	88.47 (8.50)	88.49 (8.55)	0.009
Total score	75.0 (10.3)	88.3 (9.9)	86.95 (9.0)	<0.001

The Pediatric Quality of Life Inventory (PedsQL™) is reverse scored and linearly transformed to a 0–100 scale score, with higher scores corresponding to higher Quality of life.

Discussion

Most of the typically developing siblings who attended the study were younger ($n=13$) than children with ASD. Parents were worried about the future of the child with ASD and were concerned about their bringing in their absence. Hence, Quality rents who participated in the study preferred a second child. Global research literature focused on families of children with developmental disabilities has often been designed to consider evidence that those parents and siblings might be at increased risk for psychological problems as a result of the presence of a child with disabilities (Dodd, 2004). In particular, there are a variety of challenges that may be faced by other children in the family as a direct or indirect result of having an ASD sibling. This includes isolation or resentment, loneliness, confusion, distress, or Embarrassment at how ASD manifests itself in the affected sibling. Numerous research studies have shown that siblings of kids with ASD are more likely to experience internalizing behavior issues, and the psychosocial well-being of a sibling can be impacted if they are affected by any behavioral problems (Benson & Karlof, 2008; Ross & Cuskelly, 2006).

Research involving siblings of children with impairments has provided evidence for the possible benefits of sibling support groups. (Burke & Montgomery, 2000; Dodd, 2004). However, a detailed review of the literature helped to identify that there is a paucity of controlled evidence based on Indian research on psychosocial issues of siblings of children with ASD. In this empirical context, the current study was conceptualized and formulated to respond to a few of the challenging issues of siblings of children with ASD.

Current study results show that Siblings' emotional (46.88%) and social functioning (56.88%) were poor in baseline. This finding was based on previous results. Hastings (2003) showed that siblings of children with autism reported more behavioral issues in a sample of school-aged children (four to sixteen years old) and more prosocial behaviors than children in the normative samples. Older siblings also demonstrated increased rates of both internalized and externalized behavior problems (Rodrigue et al., 1993). These studies highlight the possible dangers for siblings of children with extensive developmental problems.

The current study's findings demonstrated notable modifications in the siblings' emotional and social functioning scores post-assessments after attending group intervention. Emotional and social functioning scores increased. These scores were maintained during three months follow-ups. It may be due to siblings utilizing and maintaining new behavioral techniques. Therefore, the sibling support group in the present study may have been successful in helping siblings to adjust and cope with their brother or sister's condition. This finding was based on previous results (Lobato & Kao, 2002), which compared pre- and post-assessments. It showed that parental reports of global behavior problems decreased, and both internalizing and externalizing behaviors were significantly decreased. However, only the externalizing behavior decreased during the three-month follow-up, while the internalizing behavior stabilized.

Limitations

One potential limitation of this study is that it is challenging to make any conclusive statements on the feasibility of this sibling support group without a control group. The participants were recruited as volunteers, thus yielding a convenience sample that needs accurate population representation. The periodic follow-up assessment could not be conducted after six months and a year, which would otherwise show the intervention's sustained effect over time.

Conclusion

The results of this study are encouraging for future research utilizing a more diverse participant sample and randomized control groups. Although preliminary, the results support continued development and testing of family-based, early interventions to promote good Quality of life among young siblings of children with developmental disabilities.

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