

When a Sibling Has Autism: Narrative Review of Interventions for Typically Developing Siblings

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ABSTRACT

Being a typically developing sibling to a child with autism spectrum disorder (ASD-Sib) can be associated with several behavioral and mental health problems. With this understanding, researchers are beginning to focus on sibling-oriented interventions. This review seeks to evaluate the current literature on such interventions. We searched digital databases and identified eight relevant studies. The sample ($n = 247$) had an age range of 4–16 years. The outcomes were generally positive, with improvements in different facets of ASD-Sibs. Results differed due to varied intervention styles, outcome variables, methods, and samples. Our findings highlight the potential for improvement in ASD-Sib's knowledge of autism and their psychological functioning and hence call for further research with robust methods.

Keywords: Autism spectrum disorder, typically developing siblings, Asperger's syndrome, sibling-oriented interventions

Autism Spectrum Disorders (ASD) are a set of varied groups of conditions affecting about one in every 100 children.¹ ASD includes autistic disorder,

Asperger's syndrome, and pervasive developmental disorders.² It can be identified by the early onset of impairments in social communication and repetitive, restricted, or unusual sensory-motor behaviors.^{2,3} Such behavioral repertoires a child with ASD possess can be an overwhelming experience and might impact each member of the family. This can affect various domains of their lives, including mental health, physical health, finances, housekeeping, quality of relationships, and lifestyle.^{4,5}

The behavior and caregiving load might particularly cause additional problems with the typically developing brothers and sisters. Siblings of children with any disability, including ASD, are more prone to develop emotional, adjustment, and behavioral problems than their peers.^{5–9} Barak-Levy et al. found that children who have siblings with autism have lower participation in peer activities, poor relations with friends, and poorer school performance and that such children have higher scores on measures of responsibility.¹⁰ To support their parents, the siblings often

take on additional responsibilities such as household chores.¹¹ This, however, can be a source of emotional distress.¹⁰ Moreover, the need for long-term specialized therapy makes autism costly for parents.¹² It is also likely that parents who have to care for a child with autism might not be able to spend much time with the other sibling and much of their attention is inadvertently concentrated on the child with autism.¹⁰ Thus, having a sibling with ASD can, directly and indirectly, impact the ASD-Sibs' mental health⁷ and quality of life.¹³ Consequently, the relationship between the typically developing siblings (TDS) and ASD siblings might also be strained.^{14–16} This, in turn, can also affect the prognosis and social functioning of the ASD child.

Though the siblings' role in the treatment and training process of children with ASD has been well acknowledged and evaluated in the literature,^{14,15,17} empirical literature focusing on interventions directed towards the TDS, despite their well-acknowledged need,

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is still in infancy. To our knowledge, this body of research has not been synthesized. Hence, this narrative review aimed to understand the impact of interventions directed toward ASD-Sibs.

Methods

Search Strategies

We searched PubMed and Web of Science for the 2000 to 2023 period. The keywords employed were “intervention,” “support group,” “siblings,” “brothers,” “sisters,” “children with ASD,” “children with autism,” and “children with PDD.” We included studies that (a) were empirical, (b) were published in the English language, and (c) reported interventions addressed to TDS of children with autism (or related neuro-disorders). Studies were excluded that (a) focused on TDS-mediated interventions with autism (or related disorders) or (b) were theoretical or used secondary data.

Results

Overview of Studies

Our initial search yielded 726 titles. After removing duplicates ($n = 98$), two authors (KG and VP) separately screened and reviewed abstracts ($n = 638$). The discrepancies were resolved by discussion among all three authors. After removing non-related articles ($n = 616$) that did not meet the objective of this paper, we reviewed potentially relevant articles ($n = 12$). Out of these, eight did not meet the inclusion articles. Four studies were included via manual search. Finally, we identified eight studies (Figure 1).

Included studies were published from 2005 to 2020. Five studies utilized a quasi-experimental design,¹⁸⁻²² whereas two employed an experimental design, i.e., with a control arm.^{23,24} Only one was a randomized control trial (RCT)²⁵ (Table 1).

Sample Characteristics

A total of 247 (age = 4-16) TDS, older or younger than the sibling with autism, participated in these studies. Most studies ($n = 6$) comprised only siblings, whereas two also included parents. Four studies were conducted in Europe,^{19,20,22,24} three in North America,^{21,25,26} and one was from Australia.²³ The focus broadly

was on the TDS of children with autism. Four studies kept the inclusion criteria strictly as ASD,^{19,21,24,25} though the other four studies, albeit focusing on ASD, included related disorders or co-morbidities too^{20,22,23,26} (Table 1).

Features of Intervention

Table 2 summarizes the key characteristics of the interventions and critical analysis in terms of the outcomes. Support groups were the most common type of intervention utilized,^{18,19,21-23,25} whereas one used psychoeducation.²⁴ The main foci of the studies selected were: enhancing knowledge and/or understanding of autism,^{18,19,21,24,27,28} improving mental health, managing symptoms of anxiety and depression,^{21,23,25} and managing emotional/behavioral problems.^{24,25} A few studies also focused on improving the siblings' coping, adjustment, and problem-solving skills.^{18,22,24,25} The least focused variables were self-concept,¹⁸ social support,²² and improving sibling relationships.²⁰

The sessions varied from 6 to 10, lasting 1 to 2 hours weekly.^{19,21-24,26,27} All the interventions were delivered in person^{19,21-27} and one utilized the audio conferencing mode.²²

Outcome Measures

The interventions in the reviewed articles focused on various psychosocial variables such as knowledge about autism, social support, coping, adjustment, self-concept, depression, and anxiety (Table 3). Some studies also employed qualitative measures. For example, in the study of Cooke and Semmens (2011), the siblings were asked to make a poster listing everything they knew about autism (and/or Asperger syndrome). In another study, a semi-structured questionnaire concerning the sibling's views was used to elicit information regarding participants' concerns about the siblings' behavior, their consequences, and participants' expectation from the intervention.²² Four studies also evaluated the experiences of the participants via qualitative feedback.^{19,22,26,27}

Summary of Findings

All included studies employed a pre-and-post design. Smith and Perry²⁶ evaluated the effectiveness of a support group on 26 siblings of children with autism. The self-concept of the siblings ($P < 0.005$) and their knowledge regarding autism ($P < 0.01$) improved significantly. However,

FIGURE 1.

Flow Diagram Displaying the Selection of Articles.

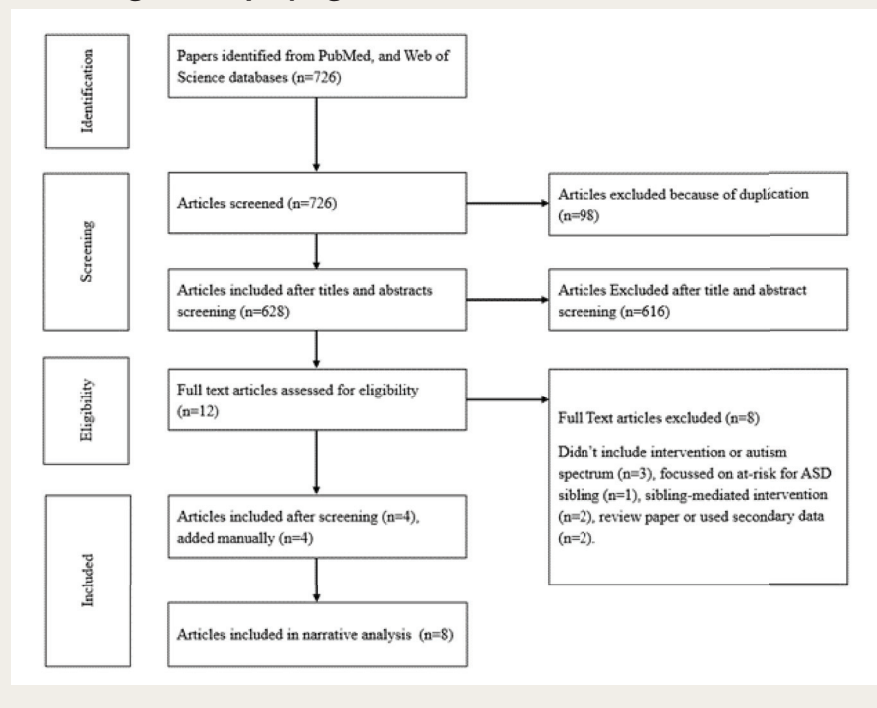


TABLE 1.

Findings Regarding Research Design and Study Population.

Author and Year	Design and Related Variables	N (Finally Analysed)	Age Range (Years)	Target Condition
Smith & Perry, 2005	Design: Quasi-experiment Data collection points: two (pre- and post-intervention) Follow-up period: two weeks	26 siblings (14 girls) (older and younger); Responses from parents were also utilized	6-16 (M = 10.63, SD = 2.13)	Autism or a related disorder (PDD, Rett Disorder, developmental delay)
Cooke & Semmens, 2011	Design: Quasi-experiment, Data collection points: two (pre and post-intervention). Follow-up period: two weeks	12 (8 girls) (younger and older) Responses from parents were also utilized	8-12	Autism or Asperger Syndrome
Granat et al., 2011	Design: Quasi-experiment design, Data collection points: two (pre and post-intervention) Follow-up period: two weeks	54 (33 girls) (younger and older)	8-12	Autism, Aspergers, ADHD, physically disability, intellectually disabled,
Kryzak et al., 2014	Design: Quasi-experiment design, Data collection points: two (pre and post-intervention)	15 (6 girls)	4-14	ASD (PDD not otherwise specified, autism, Asperger's, or autism spectrum diagnoses)
Gettings et al., 2015	Design: Quasi Exp/ Longitudinal Data collection points: two (pre and post-intervention) Follow-up period: three to six months	6 (5 girls) (younger) Responses from parents were also included	8-13	ASD (as well as comorbidities in the ASD-affected siblings such as ADHD, mood disorder, OCD, Down Syndrome, ODD, enuresis, visual impairment, harmful use of cannabis, anxiety disorder/phobia)
Roberts et al., 2015	Design: Experimental Data collection points: three (baseline, post-intervention, and follow-up) Follow-up period: three months	42 (25 girls) (older and younger)	7.5-12.5 (M = 9.3, SD = 1.38)	ASD (however, some had Angelman's Syndrome, Down Syndrome, Phelan-McDermid Syndrome, Global Developmental Delay, PDD, ID, and Optic Nerve Hypoplasia)
Bruzous et al, 2017	Design: Experimental (with control arm) Data collection points: two (pre and post-intervention)	38	Age 6-15 (M = 10.75)	ASD
Jones et al., 2020	Design: RCT Data collection points: two (pre and post-intervention)	54 (control arm = 34, support group = 24) (30 girls)	5-14	Autism

ADHD, Attention Deficit Hyperactivity Disorder; ASD, autism spectrum disorder; ID, intellectual disability; M, mean; OCD, obsessive compulsive disorder; ODD, oppositional defiant disorder; PDD, pervasive developmental disorder; RCT, randomized controlled trial; SD, standard deviation.

TABLE 2.

Characteristics of Interventions and Outcomes.

Study: Author, Year	Intervention Details	Outcomes	Strengths and Limitations
Smith & Perry, 2005	Intervention type: Support Group. Number of Sessions: eight (weekly) Main components: increasing knowledge about autism and related developmental disorders, enhancing coping skills, enhancing self-concept, Mode: In-person	Greater knowledge of siblings of autism; improvement in overall self-concept following group participation; no significant difference was observed in the siblings' feelings of anger/resentment (coping measure)	Strengths: Qualitative data indicated that the participating children enjoyed their experience. Limitation: Small sample size, lack of control group, no follow-up assessment was done.
Cooke & Semmens, 2011	Intervention type: Support Group Number of sessions: eight, two hours (weekly) (last two sessions were kept as outings) Main components: knowledge of ASD, Mode: In-person	Enhanced knowledge of autism	Strengths: In-depth data provides quite rich insight into the understanding and experiences of children regarding ASD. Limitations: Small sample size lack of control group; the outcome measures could not ascertain the increase or decrease reliably

(Table 2 continued)

(Table 2 continued)

Study: Author, Year	Intervention Details	Outcomes	Strengths and Limitations
Granat et al., 2011	Intervention type: Group Intervention. Number of sessions: six (two hours) (weekly) Main components: enhancing knowledge, problem-solving skills Delivered by: Clinical Staff from the outpatient rehabilitation centre Mode: In-person	Significant improvement in TD siblings' correct denomination of their sibling's disability; improvement in explanation of the sibling's disorder which; there was no marked improvement in problem-solving strategies in the siblings of children with ASD.	Strengths: Comparison with siblings of children with other disabilities throw light on the similarities and dissimilarities in their experiences. Limitations: self-selected sample; lack of randomization
Kryzak et al., 2014	Intervention type: Support Group Number of sessions: 7 (2 hours) Main components: Delivered by: licensed and credentialed professionals (special education) psychology doctoral fellows, and student volunteers (undergraduate and masters from related fields). Mode: In-person	Improvement in siblings' self-reported depression and anxiety; improvement in siblings' adjustment and peer network	Strengths: Focus on the mental health of siblings. Limitations: Lack of randomization, small sample size
Gettings et al., 2015	Intervention type: Support Group Number of sessions: 8 sessions (1 hour) Main components: group cohesion, psychoeducation, problem-solving, and instillation of hope Mode: Audio-conferencing	The intervention showed improved communication among family members, as well as improvement in siblings' social networks.	Strengths: Use of audio-conferencing; high attendance (indicative of good engagement) Limitations: Extremely small sample size
Roberts et al., 2015	Intervention type: Manual-based Cognitive Behavioural Support Group Number of sessions: 6 weekly, 2 hour Main components: Siblings' perceived social support, problem-solving skills, self-esteem, adaptive coping skills, and sibling relationships Delivered by: Provisionally registered clinical psychologist (supervised by a clinical psychologist) Mode: In-person	The treatment group showed improvement in emotional and behavioural difficulties, improved self-esteem	Strengths: The presence of a control arm, Limitations: Lack of randomization
Bruzous et al, 2017	Intervention type: Psychoeducational Group Sessions Number of sessions: 8 /wk (90 mins) Main components: psychoeducation, emotional education, cognitive restructuring, relaxation techniques, problem-solving, social skills training, and self-acceptance Mode: In-person	Significant increase in knowledge about autism post-intervention; significant reduction in adjustment difficulties and emotional or/and behavioural difficulties post-intervention	Strengths: the presence of a control arm; enrolled participants spanning a wide age range included in the intervention groups, thus making it possible to take into consideration developmental issues when evaluating the group's efficacy. Limitations: lack of randomization
Jones et al., 2020	Intervention type: Support group Number of sessions: 10 weekly (2 hours) Main components: learning about the group and each other, sharing feelings and, education, helping and problem-solving, and reflection. Delivered by: masters and Ph.D. students (trained and supervised by authors) in psychology with a background in implementing social skills intervention for children with ASD Mode: In-person	Marked improvements in coping skills and externalizing behavior in the intervention group were observed	Strengths: use of randomization Limitations: A lot of baseline questionnaires were not returned to the team, hence generating a lot of missing data. Though, the missing data were random.

ASD, autism spectrum disorder; PhD, Doctor of Philosophy; Wk, Week.

there was no improvement in feelings of resentment or anger. A noted limitation was the lack of a control group.²⁶ Cooke and Semmens¹⁹ utilized an 8-session workshop-based support group on 12 siblings of children with ASD to assess

the improvement in knowledge of the autism spectrum. The findings suggested improved knowledge; however, the study lacked a control group. Also, quantitative results have not been reported. Cooke and Semmens¹⁹ and Kryzak et al.²¹ developed

and evaluated a 7-week Support and Skills Program on 15 siblings from 14 families. The study observed a marked improvement in the depression and anxiety levels of the siblings. Moreover, the peer networks of the siblings also improved.²¹

TABLE 3.

Measurement Instrument Used in the Studies.

Domain	Instrument (Abbreviation)	Study
Knowledge about autism	Sibling Knowledge Interview (SKI)	Granat et al., 2011
	Autism sibling knowledge	Kryzak et al., 2015
	Knowledge of autism syndrome	Brouzos et al., 2017
Mental health, behavioral, and emotional problems	Achenbach child behavior checklist	Jones et al., 2020; Smith & Perry, 2005
	The strengths and difficulties questionnaire (SDQ)	Brouzos et al., 2017; Gettings et al., 2015
	The strengths and difficulties questionnaire—Parent Version	Roberts et al., 2015
	Child behavior checklist (filled by a parent).	Jones et al., 2020
	The brief developmental behaviour checklist	Roberts et al., 2015
	Children's depression inventory (CDI)	Jones et al., 2020; Kryzak et al., 2015
	Revised children's manifest anxiety scale	Jones et al., 2020; Kryzak et al., 2015
	Profile of neuropsychiatric symptoms	Gettings et al., 2015
	Autism severity	Childhood Autism Rating Scale (CARS)
Self-esteem and concept	Piers-Harris children's self-concept scale	Smith & Perry, 2005
	The Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1989).	Roberts et al., 2015
Sibling relationship	The Sibling Relationship Questionnaire (SRQ)	Granat et al., 2011; Roberts et al., 2015
Quality of life	Paediatric Quality of Life Inventory	Gettings et al., 2015
Support	The Social Support Scale for Children (SSSC)	Roberts et al., 2015
	Support (self-developed questions).	Jones et al., 2020
Coping	The Self-report Coping Scale (SRCS)	Roberts et al., 2015
	Coping/adjustment scale	Brouzos et al., 2017; Smith & Perry, 2005
	Children's coping strategies checklist	Jones et al., 2020

In their hybrid intervention, Gettings et al.²² administered four face-to-face and four telemedicine sessions to six siblings and their parents. The authors developed support group sessions that improved communication between the siblings and with other family members as well. Additionally their knowledge improved with psychoeducation, reducing their concerns regarding their siblings, and coping mechanisms improved, too. The main strengths of the study were qualitative inquiry as well as the use of audio-conferencing. However, the results are not generalizable, given the small size.²² Roberts et al.²³ used an experimental design to evaluate the *SibwokrS* program, i.e., a manual-based cognitive-

behavioral program that spanned six weeks. The authors administered the intervention to 36 siblings of children with various disabilities, particularly autism and other related disorders such as attention deficit hyperactivity disorder (ADHD), global developmental delay, etc. Findings revealed fewer behavioral and emotional difficulties in the siblings' group receiving the intervention. The positive results were sustained at three-month follow-up.²³

Brouzos et al.²⁴ developed and examined the effectiveness of a psychoeducational intervention on 38 siblings of children with ASD, intending to improve their psychosocial adjustment/coping and knowledge about autism.

The eight-week program, encompassing components such as emotional education, cognitive restructuring, psychoeducation, relaxation, problem-solving, and self-acceptance, yielded positive results. Findings revealed marked improvement in knowledge of autism and a significant reduction in adjustment difficulties in the experimental group.²⁴ In their RCT, Jones et al.²⁵ assigned 98 participants to a support group and an attention-only group to improve the mental health of the TDS. The support group (n = 24) was administered a 10-week intervention. The findings showed significant improvement in the coping skills and management of externalizing symptoms in the intervention group as compared to the control.²⁵

Discussion

ASD in a child can significantly and detrimentally affect family members, particularly the other siblings.^{4,5,13-15} While some literature demonstrates positive experiences of ASD-Sibs,²⁹ they might also face adverse outcomes such as decreased parental attention¹⁰; increase in negative life events (e.g., parents divorcing)³⁰; having to handle repetitive, unpredictable, and aggressive behaviors of siblings, and elevated responsibilities.²⁹ These issues can increase stress and mental health issues, including greater emotional and/or behavioral problems and symptoms of anxiety and depression.^{21,29} Despite these well-documented potential risks for the siblings, there is limited evidence-based literature focusing on ameliorating these adverse outcomes. This review synthesized the current literature^{19,21-27} focusing on the interventions for TDS of children with ASD. The commonly studied interventions are support groups and psychoeducation. Most studies comprised only siblings, while a few studies also included parents for the intervention. Support groups aimed at providing the siblings social support, along with psychoeducation to improve the knowledge of disability. Though most interventions were delivered face to face, Gettings et al.²² found audioconferencing an acceptable, feasible, and effective method of facilitating sibling support groups. The findings were generally positive, and most studies

showed marked improvement in knowledge of autism followed by various facets such as adjustment, coping, emotional difficulties, problem-solving, self-concepts, and sibling relationships and in managing mental health issues. Similar intervention studies focusing on supporting siblings of children with various disabilities such as pediatric cancer, diabetes, ADHD, and meningitis have also shown promising potential.^{31,32} Providing interventions in such a population may help identify those who require additional support and offer clinical care in case of significant mental health problems.

Nevertheless, these findings should be interpreted cautiously, given the small number of studies conducted and the weak methodologies, namely lack of control groups, lack of sufficient power (i.e., small sample-size), and varied inclusion criteria in terms of including multiple disorders. Interventions in such populations should be family-centered, and thus, parents and/or caretakers can be involved, which was lacking in most studies. Studies were also lacking in the use of measures to assess the impact of interventions that are reliable, valid, and sensitive to change. Besides, the studies were from developed and high-income countries, making the findings somewhat less generalizable for developing and under-developed countries. Nonetheless, the review highlights the potential and direction that might be useful to consider. The limitations of this paper are that we restricted our search to English language articles and also did not include grey literature. Hence, we might have missed some insights.

Conclusion

In the last few decades, there have been considerable advancements in the scientific knowledge regarding ASD. Though there is agreement that ASD in a child can have negative outcomes for the siblings, there is a gap when it comes to scientific interventions around it. Considering that this review highlights the potential for improvement in wellbeing, mental health, problem-solving, and communication among the siblings as well as the family members, we conclude with a clear call for more robust research in this direc-

tion. Future researchers can employ more robust methodologies and focus on variables such as socioeconomic status and educational levels, which might have an additional burden on the families. There is also a need to address the intensity of symptoms of the child to ascertain the type of intervention required, even if it is for the sibling. Such insights might warrant tailor-made therapy. Lastly, there is an urgent need for such intervention studies in low and middle-income countries, and further interventions can be developed based on the needs of siblings with ASD.

Declaration of Conflicting Interests

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