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Understanding sibling experiences in autism spectrum disorder families: The role of disability severity and gender

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Abstract

This article explores the adjustment experiences of siblings living with a brother or sister with Autism Spectrum Disorder (ASD), focusing on how the autistic child's characteristics influence the sibling relationship. Derived from a comprehensive doctoral study, this analysis centers on three key areas: the general effect of ASD on sibling adjustment, how this adjustment varies with the severity of autism, and the role of sibling gender in this dynamic. Employing a mixed-methods approach, data were gathered from 52 siblings and their parents using tailored scales and in-depth case studies. Findings indicate that while a majority of siblings report low levels of adjustment difficulties, those with siblings in the severe ASD category face more challenges, particularly in the social domain. Furthermore, a clear gender dynamic emerged, with female siblings demonstrating significantly higher levels of adjustment and nurturing compared to their male counterparts. The study underscores the need for targeted support programs that consider the severity of autism and the gender of the typically developing sibling to foster resilient and positive family ecosystems.

Keywords: Autism; Sibling Adjustment; ASD Categories; Gender Differences; Family Systems; Psycho-Social Impact

1. Introduction

The family system is a complex web of interrelationships where each member influences and is influenced by the others. When a child has autism spectrum disorder (ASD), the ripple effects touch every family member, with siblings being particularly significant yet often overlooked stakeholders. While prior research has extensively documented the challenges faced by parents, the adjustment journey of typically developing siblings warrants deeper exploration, especially concerning specific contextual variables.

This article addresses this gap by focusing on three critical dimensions derived from my doctoral research: understanding the overall impact of an autistic child on their sibling's adjustment; examining how this adjustment varies with the severity of the autism; and investigating the role of sibling gender in this dynamic. Understanding how the severity of a child's autism and the gender of their sibling shape their mutual adjustment is crucial for developing nuanced support systems. This paper presents a detailed analysis of these themes, blending quantitative findings with qualitative case narratives to provide a holistic view of the sibling experience.

2. Methodology

The study adopted a descriptive research design, utilizing a mixed-methods approach to capture both the breadth and depth of sibling adjustment experiences.

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2.1. Participants

The study involved 52 typically developing siblings of children with ASD. These participants were purposively sampled from eight special schools in Jaipur, India. The autistic children in the study were categorized as Mild (n=24), Moderate (n=16), and Severe (n=11). The sibling group comprised 30 boys and 22 girls.

2.2. Data Collection Tools

- **Adjustment Difficulties Scale (for Siblings):** A self-developed 30-item Likert-scale tool measuring difficulties across three domains: Personal, Family, and Social Adjustment. Reliability was established at 0.79 via the test-retest method.
- **Psycho-Social Effect Scale (for Parents):** A 30-item tool used to gather parent perspectives on the influence of siblings on the autistic child's social and adaptive skills.
- **Case Studies:** In-depth narratives from 10 families were collected to provide contextual, qualitative insights into the quantitative data.

2.3. Data Analysis

Quantitative data were analyzed using descriptive statistics (frequencies and percentages) to identify patterns in adjustment difficulties relative to autism category and sibling gender. Qualitative data from case studies were analyzed thematically to illustrate and explain the statistical trends.

3. Data Analysis and Findings

3.1. Quantitative Findings

3.1.1. Overall Sibling Adjustment

Analysis of the Adjustment Difficulties Scale revealed that a significant majority of siblings experienced low levels of difficulty (scores of 0-10 on a 60-point scale).

- Personal Domain: 100% of siblings reported low-level difficulties.
- Family Domain: 90.39% reported low-level difficulties.
- Social Domain: 84.62% reported low-level difficulties.

This indicates a generally positive adjustment, though the social domain presents the greatest challenge, with 15.38% of siblings reporting moderate levels of difficulty, citing embarrassment in public and dealing with peers' reactions.

3.2. Adjustment by ASD Category

The severity of the autistic child's condition had a measurable impact on their sibling's adjustment, particularly in the family and social domains.

- Personal Domain: Adjustments remained high across all categories. Only one sibling of a child with severe ASD reported moderate difficulties.
- Family Domain: Difficulties were more pronounced. Siblings of children with moderate and severe ASD reported more moderate-level problems related to family time and parental attention.
- Social Domain: This area showed the most significant variation. Siblings of moderate and severe ASD children reported moderate adjustment difficulties, relating to social stigma and managing public behavior.

3.3. Gender-Wise Effects

A striking pattern emerged regarding gender. Female siblings consistently demonstrated better adjustment and a more positive influence.

- **Girls as Siblings:** A large majority of parents reported a high level of positive psycho-social impact on the ASD child from a female sibling.
- **Boys as Siblings:** While still positive, a slightly different dynamic was observed, with a key difference in the quality of interaction and adjustment.

3.3.1. Further analysis of adjustment difficulties by gender revealed

- **Siblings of Autistic Boys:** Most brother-boy and sister-boy dyads showed low adjustment problems. However, a small percentage of brothers reported high problems, whereas no sisters did.
- **Siblings of Autistic Girls:** The contrast was starker. A vast majority of sister-girl dyads showed low problems, compared to a much lower percentage of brother-girl dyads. Conversely, a notable proportion of brothers reported high problems with their autistic sisters, while no sisters reported this level of difficulty

3.4. Qualitative Findings: Case Study Insights

The case studies brought these numbers to life, illustrating the "why" behind the statistics.

3.4.1. Theme 1: The Protective and Nurturing Role of Sisters

Several cases highlighted sisters who were patient, nurturing, and acted as natural therapists. For example, one case described an 18-year-old sister who patiently managed her brother's tantrums, explained the world to him, and provided care that allowed their mother respite. This aligns with the quantitative data showing girls' superior adaptability.

3.4.2. Theme 2: Frustration and Withdrawal in Brothers

Other cases illustrated the struggles of male siblings. One case involved an elder sister who was resentful and detached from her autistic sister, expressing embarrassment and feeling neglected. Another case described a brother who, while understanding, faced significant disruptions to his studies and personal time, leading to adjustment stress. This echoes the finding that boys are more vulnerable to experiencing moderate-to-high adjustment difficulties.

3.4.3. Theme 3: The Compounding Effect of Severe ASD

One case provided a poignant example of how severe autism, coupled with comorbid challenges like inverted sleep cycles, could lead to significant family isolation and strain on the sibling's social life, supporting the data that severity exacerbates difficulties, especially socially.

4. Discussion

The findings paint a detailed picture of sibling adjustment. Contrary to a deficit-based perspective, the study reveals that most siblings in this cohort are remarkably resilient, reporting low levels of adjustment difficulties. This resilience, however, is not uniform and is significantly tested by two key factors.

First, the category of ASD is a critical determinant. As the severity of autism increases, so do the demands on the sibling, particularly in social situations outside the protective home environment. Siblings of children with severe ASD must navigate more complex behavioral challenges, which can lead to greater social isolation or stress.

Second, gender plays a profound role. The consistent trend of female siblings exhibiting better adjustment and a more nurturing influence can be attributed to complex interplays of socialization and inherent coping styles. Society often encourages nurturing roles in girls from a young age, which may equip them with a different emotional toolkit for handling the challenges of a sibling with ASD. The higher reported frustration and withdrawal among male siblings suggest a need for tailored support to help them process their emotions and develop effective coping strategies.

5. Conclusion and Implications

This study demonstrates that sibling adjustment to autism is not a monolithic experience but is finely shaped by the autistic child's level of need and the sibling's own gender. Recognizing this complexity is the first step toward effective intervention.

Implications for Practice and Policy

- **Targeted Support Groups:** Sibling support programs should not be one-size-fits-all. Separate groups for siblings of children with severe ASD could provide a space to share specific challenges. Similarly, groups for young male siblings could help them build emotional literacy and resilience.
- **Family Counseling:** Therapists and counselors should proactively engage with siblings, especially brothers and those in families with a severely affected child, to help them navigate their unique emotional landscape.

- **School-Based Awareness:** Inclusive education programs should include modules that foster empathy and understanding among peers, which can reduce the social stigma that siblings often report and help create a more supportive environment for the entire family.

In conclusion, by acknowledging and addressing the specific influences of ASD category and sibling gender, we can move beyond merely recognizing siblings as part of the family unit to actively empowering them as individuals on their own unique journeys of adjustment and growth.

Compliance with ethical standards

Disclosure of conflict of interest

No conflict of interest to be disclosed.

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