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Risk Factors Affecting the Adjustment of Siblings of Children with Autism Spectrum Disorder: A Brief Review

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ABSTRACT

The aim of this systematic review was to evaluate the extend of adjustment difficulties encountered by siblings of children with Autism spectrum disorder. In addition, it attempts to get a better understanding of previous research carried out in this area. Methods: the 32 articles relevant to the topic were critically appraised using electronic databases. Results: this study looked at variables such as: cultural influences, social embarrassment, parental stress and depression, behaviour problems of the child with ASD, symptom severity, broader autism phenotype, and birth order. Conclusion: in order to properly test study efficacy, larger samples and randomised design studies are needed to conduct more rigorous empirical research in this area.

Keywords: Autism, Siblings, Adjustment

Introduction

With a prevalence of 1 in 57, autism spectrum disorder (ASD) is a concern of immence global significance due to the extent to which it can affect individuals and families around the word [1] and [2]. For children with ASD, families have acquired the value of being a basic resource, and this resourse is widely acknowledged in the clinical field. In fact, each family member of a child with ASD faces unique challenges. As the diagnostic rates of ASD increases, researchers' interest in the lived experiences of typically developing (TD) siblings of children with ASD rises as well, though not at the same rate. In a recent meta - analysis [3] it was found that TD siblings of children with ASD had significantly more negative outcomes than comparison groups, including siblings of individuals with other intellectual and developmental disabilities. This suggests that the unique difficulties facing families of individuals with ASD also extend to individual outcomes among siblings. However, there have been equivocal results regarding the adjustment of TD siblings. Although living with a sibling who has ASD does not necessarily have negative outcomes, it's crucial to identify TD siblings that are probably prone to adjustment difficulties and may need intervention programs [4].

Mixed results may also reflect the complexity of the set of factors that interact in influencing sibling adjustment.

Several variables were used in the literature to quantify adjustment among TD siblings of children with ASD. In many cases researchers use the term adjustment to refer to more specific outcomes, such as emotional and behavioral problems [5] to [8] or depression and anxiety symptoms [9] to [11]. For other studies, however, adjustment relates to the way TD siblings operate in their environment, such as at school or at home. For example, the Child and Adolescent Survey of Experiences [12], relies on individuals' interpretation of their life experiences over the previous 12 months, and whether they percieve them negatively or positively. Similarly, the Stress Response Scale [13] measures how children typically respond to stress, an outcome different from coping mechanisms. Within the sibling literature, adjustment is a term that is somewhat imprecise, but can be used to measure variance in sibling outcome beyond more traditional measures of behavioral problems or psychological symptomatology [3].

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A better understanding of risk factors for the adjustment of siblings of children with ASD is an important step in the development of future interventions to prevent maladjustment in this group. This narrative review was conducted to determine what factors can affect the adjustment of siblings of children with ASD. This information is crucial for research on the adjustment of siblings of children with ASD, policy development, and program and service planning.

Methods

This narrative review used a wide variety of electronic databases including Science Direct, PubMed, and Web of Science. Search terms included siblings, adjustment, and autism spectrum disorder. Criteria included English language and articles that examined sibling adjustment. Articles solely about children with ASD, intervention studies, and short reports were excluded. Articles published from 2000 to 2014 were collected on the basis of objectives and variables of the study.

Results

This article reviewed 32 published papers which met the selection criteria. A wide variety of variables which affect sibling adjustment were found in this literature. These factors can be grouped into six domains:; cultural influences; social embarrasment; parental stress and depression; behaviour problems of the child with ASD; symptom severity; broader autism phenotype, and birth order**.**

Cultural influences

Few studies have explored the influence of cultural factors on sibling experience [14] to [16]. Cultural beliefs potentially could affect TD siblings' adjustment. For example, in a study [17] about sibling experience in two cultural context, it was proven that cultural context may have a significant impact on the responses of the family members. As found in the mentioned study, additional roles and responsibilities for caring for autistic siblings may be the norm in some cultures as opposed to Western or more individual cultures.

Social embarrassment

In a qualitative research [10] Several TD siblings reported that they rarely shared information about their ASD sibling with peers. They noted that they often avoid going out in public with their ASD sibilings due to unpredictable behavioral outbursts that may cause shame or embarrassment. Heightened states of anxiety and hypervigilance were noted in TD siblings both at home and out in public. There was also evidence in another narrative review [18] that most siblings felt anxious or hesitant about how others would perceive their autistic sibling, and some of these fears would persist into adulthood.

Parental stress and depression

The potential negative effects of parental stress and negative parenting practices are believed to affect siblings of children with ASD. It seems possible that poor child adjustment related to poor family functioning may generalize across settings, as Mandleco, Olsen, Dyches, and Marshall [19] found a relationship between parent-reported family conflict and teacher-reported externalizing behaviors in sibling groups of children with developmental disabilities and control groups. Similarly, other studies [20] and [21] have highlighted that parental stress, which leads to emotional dysregulation and poor social modelling, may be strongly linked to children's adjustment difficulties.

Behavior problems of the child with autism

In several studies, behavioural problems among siblings with ASD have negatively affected TD siblings [22] to [25], including self-reported depression [11] and anxiety [26].

Symptom severity

In some studies, symptom severity has been found to relate to TD sibling adjustment, both concurrently and over time [22], [27] to [29]. In another research [20], it was noted that TD siblings of children with ASD with less developed verbal skills had more behavioural problems and less social skills. However, Jones et al. [30] did not find an association between ASD symptom severity and internalizing difficulties broadly, or depressive symptomatology specifically. In addition, Iannuzzi et al [10] found that TD siblings expressed more levels of frustration or annoyance with ASD-siblings who were verbal and higher functioning, as compared to those participants who had siblings with more functional limitations.

Broader autism phenotype

Bauminger and Yirmiya [31] proposed a diathesis-stress model and suggested that it is the interplay between genetic and environmental risk factors that impact sibling adjustment. Specifically, the study suggests that the genetic basis of autism may place siblings at increased risk for developing subthreshold symptoms of the disorder (often called broad autism phenotype [BAP]) which, under stressful circumstances, such as the presence of behavioural problems in the child with autism or adverse family circumstances, may result in sibling adjustment problems. BAP comprises a spectrum of cognitive, neuropsychological, neurolinguistic, social, communicative and behavioral difficulties similar to those observed in individuals with ASD but less severe.

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Orsmond and Seltzer [9] found that BAP characteristics in adolescent sisters of children with ASD interacted with adverse life events to predict symptoms of depression and anxiety. These results suggest that BAP can be an important risk factor for adjustment difficulties among siblings of children with ASD. McGrail [32] also pointed out that TD siblings of children with ASD, as a result of their genetic liability, are at greater risk for poor psychological adjustment. Other studies have found similar results, which prove that siblings of children with ASD who exhibit a greater number of BAP characteristics may be more likely to have adjustment difficulties [33] and [34].

Birth order

Tomeny, Barry, and Bader [7] found that children with ASD and higher levels of behavior problems had older TD siblings with higher levels of behavior problems, which aligns with another study suggesting that children born after their sibling with an ASD may be at greater risk for maladjustment [35]. However, Walton and Ingersoll [8] noted that older brothers of children with ASD are more likely to have emotional or behavioral difficulties. Even so, Orozco [36] found no significant differences in younger siblings compared to older siblings of children with ASD.

Discussion

Thirty-two studies were identified that described risk factors (factors that were far more prevalent among siblings of children with ASD compared to control groups). A small number of factors repeatedly emerged as signifcant: cultural influences; social embarrasment; parental stress and depression; behaviour problems of the child with ASD; symptom severity; broader autism phenotype, and birth order. The prevalence of these risk factors is signifcantly higher than one would expect to see in these communities, perhaps confirming the impression that different intervention strategies may be necessary in this group. Most of the studies reviewed in this article had numerous methodological limitations, such as a small sample size, multiple diagnoses, a broad age range, etc. All these gaps point to the difficulty of generalizing results and the importance of future research in this field with the control of confounding variables. Including children and youth in a single study to assess different variables such as adjustment and adaptation will not yield actual results. Siblings of children with ASD in childhood may not understand the behaviours of their siblings due to the invisible nature of ASD, which will affect their relationship. Siblings in their adolescence may experience social embarrassment due to their understanding of the disease and friendship. It is therefore important that the two groups be considered independently.

The findings cited in this review recognize that there are not two identical families or circumstances. A need has been identified for more robust empirical research in this area which incorporates larger samples and uses randomized control studies to test the effectiveness of the intervention in an appropriate manner.

Conclusion

This paper reports on the adjustment research of siblings of children with ASD. The 32 studies included a number of factors that influence the adjustment of siblings. There is, however, a limited amount of evidence related to the strength of each factor because of issues involving sample size, types of disabilities studied, varying comparison/control measures, and changing perceptions of ASD over time. Despite the current lack of specificity of the pathways, the weight of evidence is that there are effects on the adjustment of siblings. Most but not all of these effects are negative, and the difficulty of pinpointing causes is likely because of complex interactions of the characteristics of the child with the ASD and family and environmental factors. More in-depth research, particularly in the larger population and longitudinal and life-course research, is needed to help unravel these effects. However, to be effective, both future research and policy, and practice should account for the effects of the complexity of these interactions in the lives of families with children with ASD.

Better understanding of the experiences and perceived needs of siblings with ASD can lead to the development of an effective support system that is based on those needs. Practitioners should have a clear understanding of the social, emotional and behavioural adjustment of siblings to provide effective support.

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